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Jonelle Ward, B.A., M.Sc.

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AUTHOR: Jonelle Ward, B.A. (York University), M.Sc. (The College of New Rochelle)

SUPERVISOR: Dr. Meridith Griffin, PhD

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Lay Abstract

This dissertation explores the lived experiences of young adult caregivers (YACs) caring for an older adult with Alzheimer’s Disease or a Related Dementia. Research on this group of caregivers is limited, particularly YACs (ages 18-25) who provide substantial (unpaid) caregiving for an older adult affected by Alzheimer’s or a Related Dementia. Therefore, a key aim of this research is to generate awareness and shed light on the nature of caregiving as experienced by this overlooked population of caregivers. As such, this dissertation aims to understand how young caregivers give meaning to, interpret and make sense of their caregiving experience. To understand the caregiving experience of YACs, I conducted interviews with 12 YACs from Canada and the United States and analyzed their perspectives in detail. The findings shed light on the many factors that shape the caregiving experiences. In addition, the findings show that more research is needed to understand the differences amongst young caregivers to better support their needs. In general, the research can contribute to existing knowledge on young adult caregivers, as well as relevant programs and policies.

Abstract

In the literature, the experience of 'care' and 'caregiving' has been well documented and widely researched. Caregivers are recognized as people (family and friends) who provide unpaid substantial care for family members. Over time, research has increased awareness of caregivers as a distinct social group and has also contributed to caregiving being a widely recognized social issue. However, despite this increased awareness and continued concern for caregivers, much of the literature focuses on adult caregivers. As a result, the experiences of other caregiving populations, such as the youth and young adults, continues to be overlooked and underrepresented. Therefore, there is a need to explore and understand the unique experience of this population and how they give meaning to their experiences.

Young caregivers (YCs) are children (5-18) and young adults (18-25) who provide substantial (unpaid) care for a family member who has an illness or disability (Stamatopoulos, 2016). Research on this population is scant and there exists many notable gaps in the literature in terms of diversity, age-based differences, programming and best practices for intervention. More specifically, there is a gap in understanding the experiences of young caregivers who are affected by progressive and incurable chronic brain diseases such as Alzheimer's Disease or a Related Dementia. As such, this dissertation explores the experiences of YACs affected by ADRD, in terms of their personal experiences with ADRD (knowledge, dementia care and care practices), perceptions of their caregiving role and how they navigate the caregiving role. It builds on scholarship on young caregivers to broaden existing knowledge by using a phenomenological approach, known as Interpretive Phenomenological Analysis, to explore their caregiving experiences and the meaning they give to these experiences in-depth (n=12). It also aims to challenge the dominant assumptions about young caregivers by giving voice to this population by situating the young caregivers as the experts in their own lives. Findings indicate that the caregiving experience for YACs is complex, and situated within a larger socio-political context, which impacts the overall experience of care. Overall, the findings contribute to knowledge on the experiences of care among YACs and highlight the need for more inclusive research and practices on addressing caregiving among this group.

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I dedicate this work to my late Grandmother Hannah Thomas, whose second act in life inspired my first.

List of Figures, Tables and Appendices

Figures and Tables:

Chapter Three: Methods

Chapter Four: The Experience of Navigating the Impact of ADRD

Chapter Five: Me, Myself and Us

Chapter Six: Turning Points (Dealing with Adversity)

Appendices:

Chapter Three:

Abbreviations

AD	Alzheimer’s Disease
ADRD	Alzheimer’s Disease and Related Dementias
EO	Early-Onset Dementia
FTD	Frontotemporal Dementia
IPA	Interpretative Phenomenological Analysis
PDD	Parkinson’s Disease Dementia
PWD	Person with dementia
YAC	Young Adult Caregiver
YC	Young Carer

Table of Contents

Chapter 1: Introduction

Overview of the Project

This project explores the experiences of young adult caregivers (ages 18-25) of people with Alzheimer's Disease or a Related Dementia (ADRD). Young caregivers, as described in the literature, are widely recognized as a hidden and neglected population. A handful of researchers have drawn attention to prevalence of young caregivers, and the trends in their experiences (Aldridge & Becker, 1993; Becker, 2007). However, given that research on young caregivers is still in its adolescent stages in terms of the global level of awareness, often this group is assumed to have a common experience purely on the basis of age. Therefore, this study seeks to address the factors that contribute to young caregivers being framed as a monolithic group. In particular, the aim of this project is to explicitly focus on the experiences of young caregivers affected by ADRD (ages 18-25). The study aims to bring together two distinct social issues that arguably intersect- ADRD and young caregivers- to shed light on how they might inform each other. Overall, this project will complement the current studies on young caregivers (Aldridge & Becker, 2003, Charles et al., 2010; Hendricks, Kavanaugh & Bakitas, 2021; Newman & Bookey-Bassett, 2021; Stamatopoulos, 2016; Wang & Wang, 2019) and show the diversity across their experiences as well as contribute to relevant research, practice, and policies.

Origins of the Thesis and Positionality

Prior to entering this PhD program, I worked at the Alzheimer's Association in Westchester County, New York. The Alzheimer's Association is a non-profit organization that is dedicated to Alzheimer's care, research and support. During my time with the chapter, there were several goals all geared towards improving support for PWD and their caregivers, with a focus on expanding our reach to disadvantaged and hard-to-reach caregiving populations. In my role, I served as the Director of Outreach, where I developed community initiatives, participated in advocacy efforts and provided direct support to caregivers and PWD in the form of care consultations. My final initiative was geared towards supporting young caregivers from the inner cities of Westchester County. I was quite astonished by the response and the high level of engagement from young caregivers who came forth to participate in the initiative. They expressed concerns about the lack of awareness about programs and services, and the barriers to access to health and social care in the inner city. I also identified that their concerns were connected to the broader socioeconomic and racial divisions in Westchester County, which contributed to inequities and disparities for family caregivers.

As the project progressed, I became intrigued with the stories shared by the participants at community events. The level of transparency and intricate details of their caregiving experience transcended the theoretical views I had come across in the literature**.** Their stories presented a disconnect between their caregiving reality and the dominant narratives presented in political discourse pertaining to policy supports for caregivers. Furthermore, I got to know many of the families on a very personal level, which contributed to my interest in ensuring the programs I led were sustainable. In my professional role, I felt like an insider because the person with dementia and their caregivers invited into their world. At the same time, I felt somewhat like an outsider because I did not have the same type of lived caregiving experience. This was evident in the support groups and events that I led where I demonstrated the professional competencies, knowledge and skills to facilitate the core programs, however, I soon realized that our constituents were the true caregiving and dementia experts. This motivated me to desire more of an ‘insider perspective’ to further understand the experiences of young caregivers beyond the scope of my professional role. I was content being a gatekeeper and an advocate and found this role to be quite meaningful. However, I wanted to make more of an impact and amplify the voices of young people caregivers. Overall, it was the absence of these voices, and the resultant lack of knowledge in the professional field, that inspired the motivations for this PhD.

Together, my professional background and personal experience guide my motivations for this dissertation. As a life-long learner, with a non-traditional educational path, my initial plan was to pursue a PhD in my ‘third act of life’ (Mira, 2019). However, my professional experience, specifically my interactions with caregivers, encouraged me to ask critical questions after identifying the limitations of my work-related projects. While I had practical experiences, I wanted more knowledge on the origins, developments and responses to young caregivers as an emergent social issue.

After moving back to Canada, furthering my education was the next best step towards this aim. During my time as a PhD student, I became aware of the importance of continuing to challenge the dominant assumptions associated with ADRD and caregiving. For example, one common assumption is that the majority of caregivers of PWD are middle aged adults. Second, is the assumption that only older adults over age 65 are diagnosed with ADRD. Finally, I also acknowledged the limitations of non-government organizations in their ability to provide long-term and sustainable solutions for caregiving populations that are often overlooked. I now question if such dominant assumptions impact caregivers, as well as the many young caregivers who are or will be caregivers at some point in their young adult life. As research continues to grow on the subject of young caregivers, I hope to build upon the work of other scholars who have made a significant contribution to this area of research. Following this PhD, I plan to return to my work in the sector to work with young caregivers and their families.

Background

Defining Informal Care and Aging

Historically, care and caregiving have been commonplace in the social fabric of society. While caregiving is certainly not a new phenomenon, there are many misconceptions about the meanings of caregiving and care work. In the literature, in the context of aging, informal care has generally been understood to mean: "*the unpaid care provided to older and dependent persons by a person with whom they have a social relationship, such as a spouse, parent, child, other relative, neighbor, friend or other non-kin*" (Triantafilou, 2010). While caregiving is necessary for societies to function, it is often overlooked and considered to be a form of free and invisible labor. In the literature, this has been a contentious view and has been made more complex with shifting political discourses emphasizing social exchange, reciprocity and civic responsibility (Barret et al., 2013; Hollander, 2007). The rise of the aging demographic has necessitated the need for informal caregivers. Research suggests that the aging of the Baby Boomers, also known as the "2030 problem" or "aging tsunami" will be a major public health concern placing a major economic burden on society worldwide (Henderson, Maniam & Leavell, 2017, Duffy, 2022). As a result, there have been many international efforts to increase awareness and support for informal caregivers. These campaigns and initiatives are centered around elevating the recognition of caregivers, financial support, work and education, health and well-being, financial support, and shaping policies and practices (International Association of Caregivers, 2021). This has led to increased awareness of the rights and responsibilities of informal caregivers, which has contributed to an increase in awareness about the need for enhanced supports and resources to improve their competence and capacity to mitigate the risks related to caregiving.

ADRD and Informal Care

Alzheimer's Disease and Related Dementias (ADRD) is widely known as a major public health challenge of the 21st century. Despite scientific advances in understanding the mechanisms of ADRD, there is no cure to delay or slow its progression (Desai & Grossberg, 2005). Reports show that in 2015 the number of people living with dementia worldwide was 74.47 million and this number will reach 75.63 million in 2030 (World Health Organization, 2018). In the context of an aging society, with life expectancy increasing and more people living with long-term conditions, it is well-documented that as rates of ADRD continue to rise, care will continue to be provided by family members (Sinha, 2012). As such, these concerns have prompted an increase in programs, services, and policies to support individuals and families affected by ADRD. In particular, these initiatives focus on the quality of life and well-being of those affected, rather than only medical intervention, therefore confirming ADRD as a social issue.

As the location of care continues to shift to the community, the care of people with ADRD will continue to fall upon family caregivers. Research on informal caregivers and ADRD has drawn attention to the risks, burden and consequences of caregiving (Bauer & Sousa-Poza, 2015, Hellis & Mukaetova-Ladinska, 2023) as well as the benefits (Cohen, Gold & Shilman, 1994, Quinn & Toms, 2019). Research has shown that informal caregivers affected by ADRD experience a range of challenges that are more complex compared to non-dementia caregivers, including emotional, physical, and financial losses (Ory, Hoffman, Yee, Tennstedt & Schulz, 1999, Parker, Fabius, Rivers & Taylor, 2022). Providing care for people with ADRD is particularly demanding as the needs for care escalate with the progression of the disease (Ory et al., 1999). Furthermore, often informal caregivers do not have the specific skills and knowledge required to respond to the care needs of a PWD which can complicate the experience of caregiving leading to adverse consequences (Manthrope, IIiffe & Eden 2003). Therefore, it is not feasible to assume that informal caregivers who have limited training and skills can care for persons with ADRD without some difficulty.

As rates of dementia continue to increase, combined with the emphasis on home and community care, it is important that informal carers are factored into prospective caregiving policies. Current policymakers are beginning to recognize ADRD as a social issue, thus prioritizing improving the quality of life for persons with dementia and their caregivers. For instance, in 2016, the World Health Organization initiated a global strategy for dementia-friendly communities, which encourages the full participation for people with ADRD in their communities (World Health Organization, 2016). While these initiatives encourage the independence of PWD, at the same time they heavily rely on informal caregivers. This raises questions about the role of the social and economic system in supporting informal caregivers, as well as the potential of these systems to significantly reduce the burden for families in caregiving roles.

Who are Young caregivers?

In the literature, young caregivers (ages 5-25), also known as ‘invisible children’ are recognized as a hidden and understudied population who assume caregiving responsibilities in their communities (Hendricks et al. 2021; Levine et al., 2005). While defining young caregivers has been a challenge for researchers, they have drawn attention to the pathways to caregiving for this population, as well as highlighting the level and type of care provided and for whom, the impact of caring on the well-being of young caregivers, the potential risks (Aldridge & Becker, 1993; Becker, 2007, Becker & Sempick, 2019) and benefits (Fives et al, 2013; Gough & Gulliford, 2020). Research shows that young caregivers are negatively impacted by caregiving responsibilities and have an increased risk of loneliness, depression, low self-esteem, social isolation, restricted social networks, and compromised educational careers (Becker & Sempik, 2019; Chalmers, 2011; Charles, Stainton, & Marshall, 2008; Stamatopoulos, 2015; Toporas, 2003). Further complicating this issue are the long-term consequences of caregiving which extend well into adulthood. Several researchers (Cree, 2003; Lackey, 2001; Shifren & Kackohreck, 2003, Rolling, Falkson, Hellmers & Metzing, 2020; Szafran et al. 2016) have conducted retrospective studies on the experiences of former young caregivers and found their social development was seriously impacted given that they are not always prepared for a caregiving role.

Significance of the Research

In 2008, initial research by Dearden and Becker was the first to identify young caregivers as a hidden population. Arguably, with increased awareness, there is still a need to explore young carer populations that are overlooked to account for contextual factors that implicate caregiving (Black, Groce & Harmon, 2017). In doing so, research can address sub-groups of young caregivers that have been vastly under-researched, such as the experiences of young adult carers (ages 18-25) affected by ADRD. This can provide helpful insights into the social issues that might perpetuate the issue of hidden caregivers, including structural and social barriers. Given that little is known about how young adult carers navigate a complex caregiving role, there is much to be explored about this ‘hidden’ population to better understand the phenomenon of being a young adult caregiver, particularly in the context of ADRD.

Further, given that research on young caregivers is in its infancy, there is still also a need to address the diversity amongst young caregivers. It is frequently assumed that young caregivers are a homogenous group and have equivalent levels of responsibility, suggesting that the provision of care and the care needs of the recipient are of the same intensity. In addition, there are other contextual factors that implicate caregiving which are often neglected in research, such as class, race, geographic location, and access to social and health services. Given that current theorizing may overlook the variation of experiences for young caregivers, this is an essential consideration for the aim of this dissertation- to explore the nature of caregiving for a neglected population emphasizing the context of each participant.

Moreover, a significant gap in the research is the lack of concern for age-based differences amongst the young caregiver population. Current research tends to consider young caregivers to be a homogenous group, although quite recently has differentiated between ‘young caregivers (11-25) and ‘young adult caregivers’ (18-25). The main reason for this is due to legislation in the United Kingdom (UK) that differentiates the groups on the basis of funding and the differing needs between the groups. As such**,** this suggests that the experiences of young adults are different from those of young caregivers. This is a view that has been emphasized by theories on social development, which classify this life stage (ages 18-25) as emerging adulthood. For Arnett (2007), this stage is associated with significant changes in social relationships, identity and overall life trajectory. In the context of dementia care, the experiences of this group of young caregivers are heavily neglected. Given that young adult caregivers are at a critical developmental stage, it can be assumed that this will make for a different experience compared to child (aged 11-18) and adult (aged 25+) caregivers. This challenges the assumption that the experiences of young adult caregivers can be merged with those of children and middle aged adults, given that there are differences in social and emotional development (Jurkovic, 1997).

Given these gaps combined with my practical experience, this dissertation aims to amplify the voices of young adult caregivers affected by ADRD. Arguably, this is a way to extend understanding about a population that has been underrepresented in the literature on young caregivers. In doing so, I hope that this dissertation will offer a more careful consideration of the nature of caregiving for this population. Overall, I hope to build on current research and revisit existing dialogues informing research on informal caregivers and ADRD.

Research Questions

As discussed above, this dissertation uses an IPA method to understand the experiences of young caregivers affected by ADRD. While caregiving research has drawn attention to the issue of young caregivers, it has neglected to emphasize the diversity within their experiences. Therefore, this study will address a gap in current knowledge and practice, which is to understand what the experience of caregiving is like for young adult caregivers caring for an older person with ADRD. As such, the central research question that guides this research is: what is the nature or essence of being a young adult caregiver (ages 18-25) for an older adult with Alzheimer's Disease or a Related Dementia? This will be answered by the following research questions:

- How do young adult caregivers describe their experience of caring for a relative with ADRD?
- How do young adult caregivers make sense of their caregiving experience?

- What would young adult caregivers share about navigating the role of caregiver, while also maintaining their own lives?

The Rationale for Interpretative Phenomenological Analysis

I have chosen to utilize a phenomenological approach, known as IPA, to gather an in-depth understanding of caregiving as lived by young adults (Smith, Flowers, and Larkin, 2009). This approach is fitting given the focus of this study, which is to understand the nature of caregiving for young caregivers affected by ADRD. In effect, IPA is concerned with the 'particular,' specifically how a particular person makes sense of a particular experience at a particular point in time (Smith, Flowers & Larkin, 2009). Further, it employs a double-hermeneutic approach, which allows for a shared knowledge production between the researcher and the participant. These features are critical to my aim in this study, which is to explore, as closely as possible, how young adult caregivers in a particular context make sense of their caregiving experience.

IPA is underpinned by three theoretical approaches which are suitable for this study. First, IPA is a phenomenological method with roots in psychology, which means that its aim is to study subjective experience. In this study, I aim to "to go back to things themselves" (Smith, Flowers & Larkin, 2009, p. 12) by focusing on the particular experience on its own terms, in order to understand a particular experience apart from the natural attitude (bias, presuppositions) or dominant views presented on caregiving. Second, IPA employs an idiographic approach, which is concerned with a detailed "micro-analysis" of each participant in earnest, which provides an "insider's view" not always feasible with an empirical study. Here, 'the particular' is again emphasized in order to situate participants in their particular contexts to provide a detailed understanding of the phenomenon under investigation (Smith, Flowers & Larkin, 2009). The third and final theoretical underpinning, hermeneutics, emphasizes the double-hermeneutic approach, which is concerned with the co-production of knowledge between the researcher and the participant. To this end, it aims to ‘give voice’ by situating the young caregivers as the experts in their own lives.

The selection of IPA is not to negate the relevance of other qualitative approaches that could have been considered for this study. There are a handful of qualitative approaches that have contributed to understandings of informal caregiving and, to some extent, young caregivers. For example, discourse analysis would be helpful for analyzing how young caregivers talk about caregiving**.** Similarly, narrative analysis is helpful in understanding how young caregivers construct their story of caregiving and how their story of caregiving unfolds. Studies employing this method (Blake-Holmes, 2020; Keighbher et al., 2005; Nap et al., 2020) also emphasize meaning-making and amplifying the voices of caregivers. In addition, while grounded theory has been helpful to generate potential theories (Grant & Robinson, 2009; Metzing & Schnepp, 2008; McDonald, Cumming & Drew, 2009), these studies have largely focused on young child caregivers. However, given the exploratory nature of this study, I am not aiming to generate plausible theoretical-level accounts. Overall, these approaches have been helpful in contextualizing and theorizing care and care work; however, they would not be suitable for the goals of this study as they emphasize finding patterns across a group sample, as opposed to each individual case.

Overview of the Dissertation

The dissertation consists of seven chapters, including this introduction. *Chapter Two* provides a review of the literature across three inter-related literature areas that are central to this dissertation: informal care, young caregivers and ADRD. For each literature area, I highlight the key developments and ideologies that contributed to the emergence of each as a social issue, as well as research gaps. *Chapter Three* presents an overview and rationale of the methodological approach, IPA, its theoretical underpinnings, as well as critiques and limitations. In the second part of this chapter, I outline the recruitment and data collection processes, and how I analyzed the data. Then, I discuss my efforts to maintain trustworthiness of the research findings. *Chapters Four to Six* present the findings of the study highlighting the superordinate and, if relevant, the subordinate themes that I identified. Following the analysis in each chapter is a discussion where I integrate the findings with extant literature and interpret the meaning of the results in relation to the research question. The dissertation ends with *Chapter Seven*, where I synthesize the findings and consider the strengths and limitations of the study. It concludes with recommendations for future research, practice and policy development.

Chapter 2: Literature Review

The purpose of this research study is to explore the lived experiences of young adult caregivers affected by Alzheimer's disease or a related dementia (ADRD). This research builds on the literature on 'young caregivers (ages 5-25) by adding a small voice to the current research on young caregivers (see appendix B for search strategy). Although a handful of studies have explored issues related to young adult caregivers (Aldridge & Becker, 1993; 1999, 2003; Becker, 1995; Becker, Aldridge & Dearden, 1998; Bjorgvinsdottir & Halldorsdottir, 2014; Cass, Smith, Hill, Blaxland, & Hamilton, 2009; Charles, 2011; Levine et al., 2005; Stamatopoulos, 2015, Hendricks et al. 2021), studies exploring young adult carers (ages 18-25) affected by dementia are limited. A large majority of studies explore 'young caregivers' as a homogeneous group (Aldridge, 2003; Cree, 2004; Dearden, 2004; Dearden & Becker 2003; Kavanaugh & Stamatopoulos, 2021; Rose, 2010). Given the paucity of literature in this area, I aim to shed light on the perspectives of young adult caregivers affected by ADRD.

As discussed earlier, my research question explores the phenomenon of caregiving for an older person with dementia from the perspectives of young adults. There are three dominant literature areas which inform the research question: *1) young caregivers; 2) informal care; and 3) dementia and ADRD*. While each literature field has increased public awareness and stands alone as a social movement, taken together they allow for a focused exploration into critical issues concerning a seemingly neglected social group. To prepare for exploring each of these literature fields, this chapter begins by exploring definitions, meanings, and constructions of informal care as well as the shifting context of caregiving throughout history. This is followed by a discussion on the social responses and dialogues about young caregivers. What follows is an exploration of ADRD alongside relevant socio-political issues, including a discussion on the shifting discourses which shape public responses to ADRD.

Given that research on ‘young caregivers’ is still in its infancy, and that young caregivers in general are often considered as a homogenous group, in this thesis, I hope to express the voices of young adults who are in a critical stage of their lives while balancing caregiving responsibilities. This work is a contribution to the current research base by exploring a neglected group of young caregivers. This study is thus an opportunity to explore an issue that is often overlooked in young carer literature and provides insights into new ways of understanding this hidden, but vital population.

Caregiver Research

To set the stage for the discussion on the three literature areas, a discussion on caregiver research is necessary for understanding past, current and future trends. Prior to the 1970s, caregiver research was virtually non-existent, and caregivers were unrecognized as a distinct social group (Bytheway & Johnson, 1998). From a Western perspective, the emergence of ‘care’ and ‘caregiving’ as a social issue and a valuable infrastructure was necessitated by shifting values about community and family care needs. A pioneering text, which brought attention to the needs of caregivers, is Townsend’s “The Family Life of Old People” (1957). In it, he highlighted the importance of the family as central to social organization. Townsend (1957) also discussed aspects of kinship, as well as the shifting responsibilities for provision of care for older people from the family to the State. Ultimately, the text challenged conventional assumptions about isolated and disadvantaged older adults by emphasizing the critical role families play in preventing institutionalization of older adults.

Subsequently, a number of impactful social movements accelerated research on caregivers and care work. The feminist movement, probably the most influential, shed light on how caregiving is a taken-for-granted aspect of women's work which often exploits women. Many feminist scholars continue to argue against the gendered provisioning of care and highlight how this gendered construction has translated into policy and practice (Armstrong & Armstrong 2004; Connelly & Armstrong, 1992; Hooyman, 1999; Neysmith, Reitsma-Street, Collins & Porter, 2004). While the impact of feminism drew attention to the multiple caregiving roles that women assume, the disability movement strengthened the awareness of the inadequacies of the welfare state (Scotch, 1989). A key argument here is that the welfare state creates a system of dependence which victimizes people with disabilities (Keith & Morris, 1995, Oliver, 1990; Morris; Oliver & Barnes, 1998).

These ideas are also mirrored by a handful of scholars in relation to research on young caregivers (Davis, 1995; Fives, 2013; Keith & Morris, 1995). Here, the argument is that the welfare state does not address the factors contributing to why young people (involuntarily or voluntarily) are increasingly assuming caregiving roles (Fives, 2013). Each of these social movements emphasizes the shortcomings of the social and economic system which promote youth-based caregiving, yet questions remain about whether or how the system actually supports the needs of caregivers. In addition to the influence of social movements, the general consensus in the literature suggests that caregiver research has also increased due to several social trends: 1) an aging population resulting in an increased demand for caregivers (Novak et al., 2012); (2) deinstitutionalization and the shift towards community care (Novak et al., 2012); 3) efforts to increase funding for caregiver research and programs (Rose et al., 2015); 4) global recognition and awareness of caregivers as a crucial part of the health care system (Aldridge & Becker, 1993); and 5) the increasing involvement of young caregivers in research and political efforts (Stamatopoulos, 2016). Such shifting trends have informed caregiver research and practices as well as the location of care which continues to grow and expand into new territories.

From a western perspective, caregiver research has also expanded alongside significant shifts in social and health care models. Early care models and discourses on care commenced with views informed by the medical model, which emphasizes concepts such as burden, strain and stress in relation to caregiving (Cantor, 1983; George & Gwyther, 1986; Todd & Zarit, 1986). The assumptions of the medical model omit critical features of caregiver needs and typically pathologize the care-recipient through assessments which confirm a diagnosis. This is evident in common discourse used to describe patients which emphasize the deficits of an individual (i.e., wheelchair bound, noncompliant with care, exhibits compromising behaviours, etc.) (Haegele & Hodge, 2016). Further, research informed by the medical model emphasizes the correlation between caregiving, risk factors and burnout while downplaying potential positive impacts (Wang, Yang & Feng, 2009). The abundance of research informed by the medical model further constructs care-recipients as dependent on informal caregivers. In addition, it also frames informal caregivers as a population who is overwhelmed by caregiving and in need of support.

The medical model of care has increasingly been supplemented by the social model of disability. The social model emphasizes the relationship between the person and their environment (i.e., barriers and access), personal autonomy, and capabilities rather than loss and deficits (Clarke, 2004; Oliver, 2013). The social model also explores structural barriers to accessibility, inclusion, and social and civic participation. For instance, Clarke (2004) asserts that "dominant constructions of caregiving informed by the medical model result in an oversimplified discourse, where media, popular culture, service providers and policy leaders reduce the complex social problems and multifaceted circumstances of ‘vulnerable’ populations” (p.24). This narrow view of caregiving is what the social model seeks to alleviate by making room for a more nuanced and subjective understanding of caregiving. Quite recently, caregiver research has embraced issues of diversity, inequity, and differential impacts of caregiving (Dilworth- Anderson, Moon & Aranda, 2020), as well as other understudied topics. New approaches in caregiver research go beyond the traditionally theoretical frameworks of ‘burnout and burden’ to include sociodemographic, sociocultural environment and ecological factors which are often neglected.

The problematization of caregivers within the literature is noteworthy. Dominant themes within caregiver research construct caregivers as ill-prepared, burdened and isolated. Schultz (2016) suggests that the problematization of caregivers is mostly political given that caregivers who were once deemed capable of managing the complex caregiving tasks are now analyzed on the basis of their preparedness, availability and skill level. This view is supported by others (Gonzales et al., 2011; Luecken & Lemery, 2004; Lynch & Lobo, 2012) who claim that caregiving has been re-conceptualized as a ‘risky’ social endeavour. These risks are multi-faceted, and include physical, emotional, psychological risks - all of which have been shown to have negative consequences. Framing caregiving as *risky* exposes a complex relationship between caregivers and broader social systems by revealing a notable contradiction - it over-emphasizes the burden and toll of the role of the caregivers by suggesting that are in need of support, while at the same time minimizing the structural factors which perpetuate caregiver burden and dependency.

The problematization of caregivers is also shaped by various political trends and agendas.

Since the 1970s, research on the conceptualization of informal caregivers emphasizes how discourses have shifted alongside shifts towards deinstitutionalization (Bytheway & Johnson, 1998). Similar to Schultz (2016), Barret, Hale and Butler (2014) suggest that through an increased political gaze of informal caregivers were made more visible which shifted them from a 'hidden' to a more revered social group. Following this, the visibility of informal caregivers was further heightened by political agendas that emphasized individual and familial responsibility, citizenship and obligation (Fine, 2018). As such, the new social role ascribed to caregivers became embedded with public expectations of doing one's part for society and a part of one's civic duty.

There are contradicting perspectives about the role of caregivers in contemporary society. On one hand, the care role has been normalized such that the conceptualization of caregivers is grounded in a functionalist view, whereby the family is deemed vital for the provision of care, which is ultimately necessary for social stability. On the other hand, this conceptualization of caregiving has overshadowed the responsibility of the welfare state. For Barret et al. (2014), the relationship between the state and caregivers is complex because increased welfare provision would relieve families from caregiving duties but also ultimately compromise their role as caregivers. This raises questions about whether or how caregivers might be expected to take on care in greater amounts depending on shifting political agendas. It might be assumed that the visibility of caregivers will be increased if they continue to have a critical social and economic role. However, for Twigg and Atkin (1989) and Fine (2018), caregivers in contemporary society are no longer the focus of social policy and, as such, their visibility remains questionable. The debate continues to be shaped by shifting discourses and social forces which accentuate or weaken the position of informal caregivers in society.

Caregiver Research, Construction of Care and the Elderly

By and large, caregiver research further contributes to the construction of caregivers as a distinct social category of people. According to Bytheway and Johnson (1998), the construction of caregivers also produces new classifications and contrast between the ‘types of caregivers.’ The types of caregivers mainly fit into two categories - informal caregivers and formal caregivers. Arguably, what separates these two classifications are a professional social status, fee for service and the social location within the broader health care system. Twigg and Atkin (1994) maintain that formal caregivers function within the health care system and informal caregivers function on the periphery of the health care system. Here, the position of formal caregivers is defined by their relationship to clients in the system and the position of informal caregivers is defined by their relationship to the care-recipient.

Theoretically, Bytheway and Johnson (1998) describe this relationship between two people as uni-directional where person A (caregiver) cares for person B (care-recipient). When this relationship is uni-directional, the focus is on the direction of care from the caregiver to the care-recipient which exists with a limited focus on reciprocity (Lyons, Zarit & Whitlatch, 2002). Specifically, in the context of dementia, research on this relationship tends to under-emphasize the perspectives of the care recipient and emphasize how they contribute to informal caregiver stress (Lyons, Zarit & Whitlach 2002). This has been seen as problematic because when the person with dementia is objectified, very little is learned about the complete dyadic process. In the context of caregiving, research on the dyadic process has expanded to be more inclusive of both the caregiver and care-recipient perspectives (Lohfeld & Willison, 2007; Moon & Adams, 2013; Pristavec, 2019; Revenson et al., 2016). This has allowed for a greater understanding of the caregiver dyad as a unit (person A *and* person B) rather solely focusing on individuals in the dyad as units that exist separately (A *cares for* person B).

Formal caregivers exist within the health care system as paid professionals (i.e., nurses, personal support workers and occupational therapists) working in long-term care and community-based settings. In general, the regulation of the caregiving profession creates a different set of expectations for professional caregivers through which they are expected to adhere to strict guidelines and a professional code of ethics. In addition, the oversight of a regulatory body maintains a professional standard for client and working relationships as a direct paid employee within the broader health care system (Verma Broers, Paterson, Schroder, Medves & Morrison, 2009). Compared to informal caregivers, caregivers receive specialized training to equip them to function within long-term care, community-based and residential settings (Wilson, Rochon, Mihalidis & Leonard, 2012). Although the comprehensiveness of such training may differ, the overall aim is for formal caregivers to be able to effectively handle complex situations as well as chronic and social needs.

Within the literature, there is a general consensus that the role of caregivers is maintained by the care needs of older people. In an aging context, the meaning of care is informed by the dominant narratives of aging which medicalize age and are consistent with notions of structured dependence and decline (Atchley & Barusch, 2004). For Estes and Binmey (1989) the medicalization of age positions older adults under the control of biomedicine which impacts social policies and practices. Such discourses categorize older people into cohorts and categories which further perpetuate dominant age-based narratives~~.~~ This not only informs social norms and care practices, but also the nature of the relationship between older people and informal caregivers (which is often framed as uni-directional). Arguably, when this relationship is predicated by age-constructions, it further frames informal caregivers as critical players on the periphery of the healthcare system.

Informal Care

To illustrate the development of informal care, I will discuss a series of social trends which led to its emergence. During the 1990s, literature emerging from Great Britain was probably the first to set the stage for shifting trends in informal care for older adults (Hirst, 2002). It is widely acknowledged that a key trend was the effects of urbanization which not only generated a shift towards industrialization but also reinforced the need for informal care. With the increased proportion of older adults in society, the relationship between aging and care shifted dramatically. Hareven (1996) explains that pre-industrial societies did not make clear distinctions of having any specialized functions of each age group. However, with modernity came more prescribed and formal stages between older adults, categorizing them into groups depending on functionality, mobility and dependence (Silva, 2008). Several scholars (Katz, 1995) suggest that such distinct stages have informed long-term care policies and legitimized the type of care that older adults are permitted to receive, as well as the location (community or institution). As such, older adults tend to be placed between policy definitions of needing care in the community or the institution depending on their levels of physical decline and incapacity.

A second significant social trend is women participating in workforce in greater proportions compared to previous eras. It is widely acknowledged that the increase of women in the labour market shifted family structures as women who traditionally occupied the role in the home performed fewer domestic tasks (Brannen, 1998; Drew, Emerek, Mahon & Walby, 1998). While there is a general consensus that the increase of women and paid work have contributed to social policies to support caregivers in the modern world, there is mixed debate on how the process of caregiving changed for working women in the modern world compared to women of previous generations who were less attached to the labour market (Johnson & Sasso, 2006). Irrespective of the increase of women's employment, women still tend to be the primary caregivers for their families, particularly for older adults, and are balancing work and caregiving responsibilities (Lee & Tank, 2015). It is apparent that in the modern world women are still challenged by reconciling their work and caregiving obligations.

A third significant trend is globalization which has rapidly shifted how caregiving is situated and the structure and organization of families (Bengston, 2004). Powell (2014) suggests that globalization has increased social integration across populations, mobility, access and advanced technology and innovation. In the context of aging, Horn and Scheppe (2016) suggest that globalization has situated aging within a trans-national context shifting aging from a local issue to a global concern. Here, trans-national not only refers to the geographic expansion of aging but also how related ideologies, institutions and policies are implicated by renewed definitions of aging (ibid, 2016). In turn, this view has also shifted meanings of informal care from a traditional and 'local' view to a more contemporary view which has been theorized as "*global aging"* whereby caregivers are living apart from their aging family members (Bengston, 2018; Kinsella & Philips, 2005). Ultimately, global aging has created new systems and networks of caregiving to maintain the exchange of care and support in families.

The concept of informal care is commonplace in lay and academic discourse. Definitions of informal care have been re-conceptualized over time and informed by various disciplines. Early definitions of informal care were dominated by feminist literature, and still relevant today, emphasize how capitalist and patriarchal systems take a disproportionate toll on women in caregiving roles (Folbre, 2017). In general, within sociological literature, informal care is explored alongside social and structural change and the interactive relationships between individuals and communities. From a political-economy perspective, informal care is often generally discussed in terms of the economic value of unpaid work. Each of these conceptualizations of care broaden and enhance understandings of the complexities and dimensions of care.

A clear definition of informal care is necessary for understanding this dissertation's key focus. Across most sectors, informal care is recognized as an unpaid form of care that encompasses assistance provided by individuals to other individuals outside of civic or voluntary organizations (Zukewich, 2002). A widely applied definition in care literature is *'the unpaid care provided to older and dependent persons by a person with whom they have a social relationship, such as a spouse, child, parent, child, other relative, neighbour, friend or other non-kin*" (Triantafilou, 2010). I will be using this definition in this dissertation because it focuses on three key concepts that I consider to be significant to the research study: 'informal care,' 'unpaid care,' and 'aspects of kinship,' specifically when relating to the care of an older person.

While the aforementioned definition is widely applied, there is actually no universal definition of unpaid care. Antonopoulos and Hirway (2010) suggest that unpaid work includes unpaid work activities which depend on class, age, family structure, and that such work activities might be offset by access to adequate health and social services. However, feminist scholars have made efforts to expand definitions of unpaid care to include domestic activity (i.e., cooking, housekeeping, shopping) as these are the tasks often associated with informal care in the literature (Werner, Vosko, & Devea, 2018). Yet, Werner, Vosko and Devea (2018) also suggest that unpaid care extends beyond these domestic tasks and is actually similar to paid occupations requiring the same level of skill as formal caregivers.

The normative assumptions about caregiving are laden with ideas of tasks and performance. Historically, care has been measured by the performance of tasks required to provide physical necessities to those who need support (Hayward, Amaratunga, Colman, Kiceniuk & Neumann, 2002). However, within definitions of informal care there is a distinction of what it means to care 'for' and care 'about' someone (Baines, Evens & Neysmith, 1999). Ranjnovish, Keefe, and Fast (2005) provide a definition which attempts to further understand of both ideas: *"Caring about refers to the mental, emotional, and physical effort involved in looking after, responding to, and supporting others…while [caring for] caregiving work includes tasks such as personal care, homemaking, errands, monitoring, decision making, and medical care* (p.11). This distinction has informed new understandings of the caregiving role beyond tasks, but also in terms of companionship and emotional support.

It is apparent that the literature frames informal care as positive or negative depending on shifting public and political narratives. On the other hand, studies which support the needs and awareness of caregiving tend to highlight the negative aspects. A number of pioneering studies highlight burden and emotional strain as the primary consequence of caregiving (Cantor, 1983; George & Gwther, 1986; Todd & Zarit, 1986) and others explore financial strain (Arling & McAuley, 1983; Scharlach, Sobel & Roberts 1991) and disruptions to plans and lifestyles (Braithwaite, 1992; Moen et al. 1995). In contrast, literature focusing on the positive aspects of caregiving emphasize resilience, finding meaning, conflict resolution, developing personal strength and experiencing older person's full life (Hogstel, Curry, & Walker, 2005; Koerner, Kenyon, & Shirai, 2009; Henry et al., 2018). For adult informal caregivers, some documented benefits include personal mastery, self-efficacy, and coping style (Harnell et al., 2011). In the context of young caregivers, benefits include maturity, resilience and, in some cases, improved well-being (Wepf, Joseph & Leu, 2021). More specifically, research on benefit-finding has only emerged quite recently in the literature. It has been found that young caregivers experience benefits in the caregiving role in spite of competing demands or age - as young as age 10 experienced benefits (Cassidy & Giles, 2014; Pakenham, Chiu, Bursnall & Cannon, 2011). As such, one can see that the social development of young caregivers is negatively impacted, and they can simultaneously or not find benefits in the caregiving process.

As alluded to, there is a marked difference between the roles and expectations of informal caregivers and formal caregivers. The main conceptual difference is mostly governed by whether the caregiver is paid or unpaid, professionalization and location within the broader social and health care system. The relationship between informal caregivers and formal caregivers have been described as linked, but also fluctuating and tense (Barrett, 2014). A key tension that exists is the marginalization of informal caregivers in comparison to formal caregivers. As aforementioned, this is largely due to the location of informal caregivers existing on the periphery or "out-there" compared to formal caregivers (Twigg, 1989). While this view might be considered outdated given the recent awareness and inclusion of informal caregivers' voices in policy and practice, the exploitation of informal caregivers is still a theme in contemporary caregiver literature. Barret et al. (2013) describe caregiving labour as a cheap whereby family care is a free resource to compensate for deficiencies in a publicly funded system. Hollander (2007) adds to this concern by acknowledging that funding available for caregivers is not sufficient and is only made available when family care is ineffective or unavailable.

In a social context, informal care is located within the context of social networks and the broader care system. This fluctuating relationship has placed emphasis on the role care in the community, alongside the broader health care system. Studies show that people utilize the formal system only after the informal system is no longer deemed adequate (Bookman and Harrington 2007, as cited in Gonyea, 2009). Alongside this, the push for community care further emphasised the role of informal caregivers. From a historical point of view, community care has come to mean not only care in the community but care by the community Bayley (1973, as cited in Spicker, 1992). Here, care *in* the community includes care that is not in an institution (care in social housing, shelters etc.) and care *by* the community is broadly understood as care delivered by informal caregivers (Spiker, 1989). While there are a range of perspectives on the motivations for the shift towards community care, it is certain that the renewed new ethos of care further emphasizes the role of family members as care providers in the community and sources of support and care.

One of the earliest frameworks attempting to explain the role of informal caregivers, as viewed from the perspective of social care agencies, is Twigg, Perring and Atkin's typology (1989). Twigg, Perring and Atkin's typology has remained a widely revisited framework to understand the role that caregivers assume in contemporary society. Here, they describe three roles for caregivers: caregiver as a resource; caregiver as a co-worker; caregiver as a co-client, each with distinct but interrelated aspects. In describing caregivers as resources, the role is presented as a resource to fill in the gaps of the healthcare system. This is the most common view of caregivers portrayed in different studies portraying caregivers to be resourceful, skilled and knowledgeable to fulfill their role (Giberman & Mahea 2002). When depicting a caregiver as a co-worker, they are portrayed as working in tandem with health care professionals as equal players in the caregiver process. We can see this idea employed in the various models of care which integrate the caregiver as having an active voice in the care-recipient's care-planning (Guberman & Mahea, 2002). Lastly, when depicting caregivers as a co-client, they are portrayed as in need of care themselves to cope with their situations optimally and seeking support (Ward-Griffin & McKeever, 2020). Many studies acknowledged the dimensions of work where care work cannot neatly fit within these three categories (Law, Ormel, Babinkski, Kuluski & Quesnel-Valle 2021), such as the role of a care-coordinator which involve navigating complex care systems without support from a care team and other tasks which fall in 'gray areas.'

Young Caregivers

Introduction

This section of the literature review will review how the topic of young caregivers is explored within the academic literature. I begin by discussing the origins of the young carer movement, followed by discussing meanings and definitions as well as the social constructions. Then, since this dissertation focuses on adult young caregivers (ages 18-25) who have been or are caring for an older adult with ADRD. I explore literature relevant to this sub-group. This is followed by a discussion on the status of young carer research internationally and social policy considerations. This section will conclude with a discussion on key debates and critiques central to this area of research.

The Origins of the Young Carer Movement

The young carer movement began in the 1990s in the United Kingdom (U.K.) when Aldridge and Becker (1993) first identified young children and adults (ages 5-25) as a distinct, but hidden group, followed by several other European countries (Becker, 1995). These efforts increased attention around ‘young carer’ research in the U.K. and garnered the interest of policymakers, researchers and advocates (Aldridge & Becker, 1993). The efforts of researchers gave voice to young caregivers through qualitative studies which emphasized their opinions and motivations, perceived benefits and challenges, and how early caregiving experiences impact adulthood (Andrew & Becker, 2000).   From an international perspective, young caregivers have been identified in studies in Australian, Africa, Asian countries, U.S. and Canada, and European countries to assess prevalence, characteristics, contributions and support needs for this population.

Compared to other countries, research in the United States and Canada is seen as preliminary (Becker, 2007). The British Columbia Young caregivers Study was the first retrospective study to fill a gap in knowledge in Canada regarding the prevalence of young caregivers **(**Charles, Marshall & Stainton, 2010). In Ontario, the origins of the young carer movement emerged from the work of frontline workers and community organizations advocating for the unmet needs of youth in vulnerable families (Stamatopoulos, 2016; Szafran & Duerksen, 2012; Waugh, Szafran, Duerksen, Torti, Charles & Shankar, 2015). The seminal paper by Stamatopoulos (2018), and also the first qualitative study in the Niagara and Toronto regions, describes the ‘young-carer penalty’ as being the impediments to leisure and education that young caregivers face as a result of ongoing care provision. This penalty is often higher for disadvantaged young people who face limited educational, leisure, and employment opportunities (Stamatopoulos, 2018). Several smaller studies have shed light on the educational experiences of young caregivers (Lakman, Chalmers & Sexton, 2017), young caregivers of immigrant families (Charles, Stainton & Marshall, 2009)**,** and first steps to caring for young caregivers (Chadi & Stamatopoulos, 2017). Despite some national attention, research remains scant and has not translated into significant progress in young carer policies.

Similarly, the United States has been lagging behind more advanced countries in recognition of young caregivers. In September 2003, the National Alliance on Caregiving conducted the first national survey of child caregivers in the United states. The survey had three aims: determine the prevalence of caregiving among children nationwide; learn what role children play in care; learn how the caregiving role impacts children (National Alliance for Caregiving, 2005). Recommendations from the survey affirm that young caregivers have experiences that are different from their non-caregiving peers, experience both positive and negative impacts, and that social service agencies should be aware of the needs of vulnerable caregivers. Further, following some modest research in the United States, a scoping review by Kavanaugh, Stamatopoulos, Cohen and Zhnag (2021) highlights the overall lack of attention paid to young caregivers. Since that time, young carer research in the U.S. has somewhat plateaued.

Meaning and Definitions: A Challenge for Researchers

A common refrain in the literature is that there is no universal definition of a young carer. While young caregivers are commonly identified by age and by task(s) performed, there is some debate about the role (primary or secondary) that young caregivers play in their families. There is also a lack of clarity on what constitutes going beyond the norm of what would be socially, culturally, and developmentally expected of young people (Aldridge & Becker, 1999; Charles, Marshall & Stainton, 2012). In addition, the term ‘young carer’ continues to be redefined and expanded internationally. In the U.K., the definition of young caregivers is broad and includes varying levels of responsibility depending on the varied needs of the care-recipient (Becker, 2001). In Norway, children who are ‘next of kin’ are assumed to be young caregivers (Leu &

Becker, 2014). In Australia, Canada, and the U.S., young caregivers tend to be defined as people (family or friends) under age 25 who provide unpaid care and support for family members or friends with a disability, a physical or mental illness or who are aged (Stamatopoulos, 2016; Kavanaugh, Kalipeni & Stamatopoulos, 2016). For such reasons it remains difficult to assess the prevalence, incidence, and growth of young caregivers across countries (Joseph, Sempik, Leu & Becker, 2019).

It appears that young carer definitions may be context-dependent and are developed based on the intended needs of service providers, policymakers, and funding agencies. In general, the term young carer is widely accepted as a person between the ages of 11-25 who provides substantial care to a family or friend with a disability or chronic illness (Stamatopoulos, 2018). Quite recently, an important distinction was made between child carers (under the age of 18) and young adult carers (ages 18-25) because of the vast developmental differences between each group (Dearden & Becker, 2004). This distinction has implications for the level of physical and emotional responsibility assumed by young caregivers, as well as the types of services and interventions implemented (ibid, 2004).

Further, given that the experiences of young caregivers are diverse, conceptualizations of care occur across several dimensions. Some researchers assert that young caregivers should be assessed in terms of three elements: amount of care, significance of the care to the young person and family, and the impact of care work (Dearden & Becker, 2001; Szafran & Duerksen, 2012). Other noted dimensions include intensity, household dynamics, needs of care-recipient, and the caregiver-care recipient dyad (as seen in Dearden, Aldridge & Becker, 2001). While each of these dimensions is important, they can all be understood in the context of whether a young carer is in a primary or secondary caregiving role. Arguably, this is a dimension that could potentially enhance our understanding of how the role that young caregivers play in their families impacts care work. This is an important consideration because while it is assumed that young caregivers are in a secondary care role (i.e., supporting middle-aged parents caring for persons with dementia), they may actually be (in many cases) performing primary care tasks (Dearden & Becker, 2004). Given that most data sources rely on information provided by primary caregivers, the experiences of young caregivers in a secondary role are largely omitted, therefore limiting a complete understanding of their experiences.

With the emergence of new approaches to defining young caregivers, there has been a recent shift from activity-based definitions to definitions which explain the social, emotional, and financial impact that caregiving has on young caregivers (Newman, 2002). This shift suggests that previous research employed a positivist lens, thereby reducing the caregiving load to measurements: activities performed, tasks and hours. Current definitions of young caregivers offer subjective accounts and are constructed to include the impacts on psychosocial development. For instance, current research shows that young caregivers are likely to experience restricted social networks, compromised educational achievement, school absences, depression, anxiety, fear of immediate and future losses, and financial hardships due to unanticipated caregiving costs (Stamatopoulos, 2018). Therefore, the expansion of definitions to include environmental and social circumstances invites new opportunities to view this issue from a psychosocial perspective.

Young caregivers: Naming & Framing

The recognition of young caregivers as a distinct group and increasing awareness of their needs is not without its problems. A common concern is that the increased attention on young caregivers has led to the pathologizing of this social group. According to Joseph et al. (2020), the terms ‘young carer’ and ‘young adult carer’ are controversial as it contributes to the labeling, naming and framing of children and young adults. Olsen (2000) agrees with this view and has called for greater sociological understanding of how the term ‘young carer’ is a social construction that problematizes childhood, as well as excludes those who are extremely hidden. In addition, the identification and legitimization of young caregivers has dramatically informed the self-perception of this group (Gough & Gulliford, 2020; Rose & Cohen, 2010; Boddy, 2016). A study on the self-perceptions of young caregivers highlights how popular discourse can become internalized and result in young caregivers perceiving themselves to be deficient or inadequate in some aspects of the caregiving role (O’Dell, Crafter, de Abrua & Cline, 2009). This raises questions about whether or how the framing of young caregivers and associated labels impacts one’s individual identity and to what extent.

The Westernized Child & Social Capital

Literature on the ‘westernized ideas of childhood’ emphasizes the impact of child labor and education reforms in shifting the social roles and expectations of children. This new regime was facilitated by a new morale which was state regulated to save children from parental neglect and inadequacy, as well as inappropriate child labor within the home (Brockliss, 2016). As such, the removal of children from adult society extended the period of childhood which contributed to a new ‘behaviorist’ view of the child emerging in psychological research (Heywoon, 2001). Kaufman (2010) and Furlong (2013) argue that behaviorism, as the underpinning philosophy of capitalism, emphasizes the efficiency, production and utility of the child. Taken together, this new approach to the relationship between children and labor resulted in changing meanings and values of children in the West.

Evidently, capitalist regimes promote a renewed conception of childhood which is rooted in productivity and control. This renewed social system, primarily based on ownership and labour, also extends to the issue of young caregivers. Olsen (2000) highlights the parallels between the young caregivers debate and the transformation of childhood in the late nineteenth century. In as much as Olsen (2000) recognizes the importance of enhancing policy efforts on behalf of young caregivers, he argues that research on young caregivers is limited as it does not offer a historical perspective to account for broader political forces that limit parental access to resources. In addition, Olsen (2000) argues that a detailed examination into the reasons young people fall into caregiving roles needs to be explored. A second consideration, as discussed by Newman (2002) and Olsen (2002) includes the assumption that parents of young caregivers are either chronically ill or disabled, and therefore lack the capacity to be good parents (this will be further discussed below).

There is some consensus that the capitalist regime that has taken hold over the last century is not appropriate for young caregivers. Barry (2011) argues that from a social capital perspective analyzing young caregivers with adult frameworks is problematic. For most of history children have not fit neatly into definitions of social capital which are based on citizen power, reciprocity and social exchange. For Fukuyama (2001), social capital is an informal network that promotes cooperation between two or more individuals, who are assumed to be adults. Therefore, Fukuyama (2001) argues that such models are not designed for young people who are under the authority of parental figures and presumably have less power and capital. Arguably, new definitions which incorporate young people into models of social reciprocity, exchange, social and political participation are needed to fully make sense of the role of young people as caregivers in modern society.

Social Policy & Young Carer Rights

Burgeoning attention on young caregivers raises questions about children's rights and welfare in situations where they were providing care for an adult. A primary concern, as described by Lloyd (2006), is whether or not the level of care that some young people provide is "inappropriate" for their age depending on the type and level of care provided. Another key concern is that very few studies question whether the connection between the level of care provided by young caregivers is related to the experience of financial and material deprivation (Gays, 2000). Although there has been modest progress towards the rights and protection of young caregivers, this concern is often overlooked because their caregiving responsibilities are widely encouraged and promoted. The concern for young carer rights mirrors early declarations emphasizing the rights of children to a normal upbringing and the right not to be exploited. For instance, a policy brief written by the Canadian Caregiver (2015) asserts that the human rights of caregivers, including young caregivers, is being denied. In general, they suggest that young people should have more rights and the autonomy to choose the amount and type of care they provide.

Dearden and Becker (2022) trace relevant legislation between 1970 and 2022 aimed to support young caregivers. In 1995, the development of a whole-family approach was implemented in policy with the aim to enhance the provision of care to young caregivers through coordinated efforts on a local level. A whole family support approach seeks to address the needs of at-risk families who rely on young caregivers, rather than focusing solely on the needs of the young caregiver in isolation (Becker et al., 1998). This approach has been highlighted for being more inclusive of other actors informing the lives of young caregivers, particularly social and health care professionals.

In 2014, The UK enacted The Children and Families act which created rights for young caregivers who provide care or support to an adult. The renewed rights largely focus on assessments, information and support for transitions into adulthood while encouraging the whole-family approach (Dearden et al. 2010). As mentioned, it also focuses on the local authorities' role in properly identifying, assessing and supporting young caregivers and their families and working alongside other local organizations to improve care coordination for young caregivers (Dearden, 2004). Specifically, Section 96 of the act emphasizes the duty of local authorities to protect the well-being of young caregivers by providing information and services, including an assessment. It says that '*the duty of local authorities to assess whether a young carer in their area needs support and what those needs are if: it appears to the Local Authority that a young carer may have need for support; the Local Authority receive a request from a young carer or a parent of a young carer to assess the young carer's need for support; or an assessment has been carried out, but the circumstances of the young person or person being cared for have changed.'* While the need for improved assessments and better care-coordination (not working in silos) is widely discussed in the literature, very few countries have adopted such a stringent form of assessments for young caregivers. However, there is a general consensus that early intervention and identification is necessary to adequately support this population.

Beyond Recognition: Financial Support for the Unpaid

Social policy relevant to informal caregivers is embedded within notions of civic responsibility. While policies aim to support caregivers through community support, financial assistance, and work accommodations, they are not substantial enough to rid them of caregiving responsibilities all together. Many countries have introduced caregiver strategies that act as a “policy umbrella” to develop and coordinate support for caregivers on an individual level (Leu & Becker, 2017). The U.K., for example, through recent legislation, have formalized the recognition of caregivers’ vital roles through their national caregiver strategies (Dearden, 2004). In the UK, The National Strategy for Carers was initiated in 1999, along with three separate acts of parliament: The Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act (2000) and the Carers Equal Opportunities Act of 2004. These efforts were mirrored in Australia and New Zealand, and also informed efforts in other countries.

Compared to the UK and Australia, other countries have less focused policies and legislation, and tend to focus on awareness building efforts**.** In other countries, specifically the U.S. and Canada, researchers suggest that the recognition of young caregivers lags behind other countries and is in a preliminary position in terms of level of awareness (Becker, 2007). This lower response level is influenced by a range of factors, including advocacy, proper identification of young caregivers, and data-driven research to drive policy change (Joseph, 2016). However, there have been some changes in legislation to increase awareness and recognition of informal caregivers. For example, in Canada, Manitoba introduced the first Caregiver Recognition Act in in 2011, which was followed by Ontario in 2018 (Funk, 2021). The act broadly emphasizes that the health, social and economic well-being of caregivers should be supported (Funk, 2021). Beyond general awareness of their contributions and needs, the Act has not explicitly contributed to the development of sustainable caregiver related policies or legal rights.

In Canada, informal caregivers are supported through employment insurance policies that offer tax benefits and tax credits. The compassionate care benefit is one of the most common benefits available to caregivers. However, this benefit is available to caregivers caring for someone at the end of life, which omits caregivers engaged in other stages of care (Osborne, Margo, & Margo, 2005). In addition, Canada also offers caregiver tax credits, however these forms of financial assistance are reserved for caregivers who are earning sufficient income, meaning only a small few are eligible (Sinha, 2012). In addition, existing tax relief does little to support age-related caregiving needs, such as long-term chronic illness, including ADRD **(**Sinha, 2016). It has been documented that while employment insurance programs present an option to alleviate the financial burden experienced by informal caregivers, more governmental support is needed to safeguard their well-being (Chadi & Stamatopoulos, 2017).

Further, national and provincial legislation to support young caregivers is largely absent in Canada. This is mainly due to the lack of continuity between provincial jurisdictions with regards to dedicated policies acknowledging the unmet needs of young caregivers (Stamatopoulos, 2018). Some provinces have made efforts to increase awareness of the role that young caregivers play in their families. For instance, in 2017, the first young carer forum was held in Ontario which included policy recommendations from stakeholders and young caregivers (The Change Foundation, 2020). Such efforts demonstrate the growing awareness and support of young caregivers on a local level, despite the absence of national and provincial legislation.

In the United States, there are some state-wide programs and legislation to support family caregivers. However, these are not universal, but vary from state to state (Family Alliance on Caregiving, 2021). Research shows that current policies supporting caregivers do little to protect the financial and health security of caregivers beyond workplace benefits/leave and temporary paid family care, and unemployment insurance (Kavanaugh, Stamatopoulos & Cohen, 2016). In addition, many caregivers may not quality for certain programs if they do not meet the eligibility criteria, specifically for dementia related services (ibid, 2016). Quite recently, The Raise Family

Caregivers Act, a proposal to develop a national family caregiving strategy, was implemented to better support family caregivers (National Alliance on Caregiving, 2018). The recommendations include a focus on resources, awareness and support, with some focus on workplace and financial security issues, work/life balance, and financial education and planning (National Alliance on Caregiving, 2018). Also, the CARE act, a state-by-state law, seeks to address a gap between health care providers and the needs of caregivers in hospital settings, emphasizing the need to improve the discharge, transfer and transitions of patients from the hospital to home settings (Coleman, 2016).

Although there are vast differences between the health and social systems in Canada and the United States, both countries recognize that the increased demand for family caregivers is necessitated by an aging population. In fact, in both Canada and the United States, the methods to prioritize the needs of informal caregivers are quite similar. In general, these priorities reflect service gaps in the health and social care system which contribute to the unmet needs of caregivers. Many policies emphasize increasing awareness and supports for family caregivers through collaboration between agencies, enhanced care coordination, equitable policies and financial support.

Young caregivers: Theory, Debates, Gaps, and Methodological Challenges

Theoretical Approaches to Advance Young Carer Research

While early caregiver burden models do not explicitly consider young caregivers, they have been useful in understanding the informal care role. Child parentification, a dominant theoretical approach, is a process of role-reversal whereby a young person takes on adult responsibilities and are seen as substitute parental figures (Earley & Cushway, 2002). Second, Pearlin’s stress and coping model likens caregiving to a long-term stressor mediated by contextual factors (Pearlin, Mullan, Semple, & Skaff, 1999). Third, attachment theory considers how weakened social bonds can lead to feelings of ambivalence and anxiety (Bretherton, 1992; Bowlby, 1988). Applying such psychological perspectives to care work can be helpful to theorize the experiences of young caregivers who are subject to the challenges of early caregiving.

Research on young caregivers also draws on theoretical approaches from the discipline of social psychology, such as Erickson's stages of psychosocial development (Erickson, 1963 as cited in Gross, 2020) and Bowlby's attachment theory (Bowlby, 1979). Erickson's developmental theory helps to expand conceptualizations of caregiving by demonstrating how the stages of psychosocial development impact attitudes and responses to caring for a dependent relative. For instance, in this context, young adults who experience the nuances of caregiving may have a compromised sense of self, social bonding issues, and defer personal aspirations (Kahana et al., 1994). A second approach, role theory, considers the expectations associated with social roles and assumes that role overload arises when caregivers lack sufficient time, access, and resources (Bastawround, 2013; Biddle, 1986; Kramer & Kipnes, 1995).

There is some debate that research on young caregivers ought to be more theoretically driven. While there are challenges with using adult-based theories to understand the experiences of young caregivers, each of these theories holds promise in helping to contextualize and understand the experiences of young caregivers. Given that young carer research is a relatively new point of discussion in Canadian public discourse, research in this area may uncover new ways to theorize young caregivers affected by ADRD. Furthermore, conducting the proposed investigation using a phenomenological lens may contribute to a deeper understanding of the psychosocial outcomes and developmental implications of young caregivers affected by ADRD.

Methodological Challenges

Since the initial research by Aldridge and Becker in the 1990s, there has been some growth in research focusing on young caregivers. To explore this issue, current research includes a range of research methods, including, quantitative demographic surveys, mixed methods and qualitative research. Previous research on young caregivers has largely been exploratory providing data on prevalence and incidence of young caregivers. Beyond this, research has also explored characteristics, demographics, and caregiving activities and experiences (Charles, 2011, Charles, Leu & Becker, 2017; Marshall & Stainton, 2010; Stamatopoulos, 2016). Since the early 2000s, research on young caregivers has expanded to gather more interpretive accounts through the use of thematic analysis, focus groups, semi-structured interviews, grounded theory and phenomenology. The handful of studies on young caregivers affected by dementia have utilized much of these same approaches. Overall, these efforts have sought to address the lack of depth and personal narratives in research on younger caregivers

There are a few methodological concerns which are well-documented in the literature. One of the first methodological challenges is that there is no universal definition of what constitutes a young carer and no baseline for what constitutes a young carer role (Olsen, 2000). Young caregivers are often defined broadly as children who provide ‘a substantial amount of care on a regular basis without support from welfare agencies/services’ (Carers National Association, 1992). Young caregivers have also been identified by their age, and over time the definition has expanded beyond a young carer who is under age 18 to include young adult caregivers ages 18-25 (Becker, 1995). Although young carer research has had some momentum, it has been acknowledged that without a single definition, it is difficult to assess prevalence, properly identify young caregivers and the overall extent of the issue (Joseph, 2012). A study by Fives et al. (2013) questioned if the term ‘young carer’ should continue to be used and it was eventually concluded that the concept is still emerging and is therefore needed to continue to increase awareness and address knowledge gaps.

Young caregivers are also recognized as a hard-to-reach population which makes sampling difficult. Within the literature, young caregivers are commonly referred to as a hidden and neglected population due to the complexities associated with proper identification. In some cases, where issues of class and poverty are concerned, young caregivers are considered to be even more obscure (Dearden, Aldridge & Horwath, 2010). As such, sample sizes are quite small, particularly for studies which attempt to explore meaning and experience. Further, many studies rely on samples that come from already existing networks which support young caregivers or certain geographical areas which can lead to sample bias (Keenan, Fives & Canavan, 2012). These factors contribute to concerns with attrition and identification which have also limited the opportunity for longitudinal studies to understand the long-term and residual impacts for young caregivers (Shifren & Kachorek, 2003).

Another issue is that the research neglects to capture the heterogeneity of young caregivers, (i.e., gender, diversity, racialized groups, class, socio-economic status, etc.) particularly for people affected by dementia. Current knowledge on such contextual factors which shape a young adults’ caregiving experience of such populations to and with caregiving is limited. These vital contextual factors can illuminate important insights into the details of the caregiving experience compared to a broad understanding. Although research shows that the role of young caregivers is similar regardless of the country or continent, the details and nuances of these roles are limited in the research (Joseph, 2012). This is particularly true for research on young adult caregivers of older adults with dementia. As such, future research could expand on the diversity among young caregivers to enhance understanding of the variation that exists in the caregiving experience.

Another methodological challenge is that before 2014 there was no validated scale to adequately measure perceived stress in young caregivers. In the literature, this has presented a major obstacle in the efforts to clearly identity the impact of competing demands on the development of young caregivers (Early, Cushway & Cassidy, 2006). The majority of scales to address the stress are informed by earlier scales which assess stress in informal caregivers is specific to adult caregivers (Robinson, Zarit Reever & Bach-Peterson, 1980). Even though these scales have been developed with dementia populations in mind, the focus remains on adult caregivers (Bigen & Schilz, 1999). Further, other scales that might focus on specific populations such as siblings, spouses exclude the young carer population (Carpenter & Sahler, 1991). Quite recently, Early, Cushway and Cassidy (2006) developed the Young caregivers perceived Stress Scale (YCPPS) in an attempt to adequately assess stress in young caregivers . This 50-item scale focuses on key stressors related to the young carer role (i.e., social restrictions, school-caring conflict, victimization) as well as positive aspects of caregiving (Early et al., 2006).

Key Debates

There are two central and long-standing debates within the young carer literature which are centered around two approaches: the disability rights approach and the children’s rights approach. Olsen (1997) first challenged the research proposed by Aldridge and Becker (1999) by suggesting that the construction of young caregivers has had negative consequences on the public perceptions of people with disabilities. The first debate centers around the disability rights perspective which seeks to humanize people with disabilities (Olsen, 2000). In the context of young caregivers, proponents of the disability rights movement suggest that the scholars on young caregivers have implied that people with disabilities are dependent and are therefore unfit to be parents (Newman, 2002; Olsen, 2000). These exaggerated claims have largely contributed to a negatively charged portrayal of families where children are taking on caregiving roles (Fives et al., 2013). Morris (1993) suggests that this narrative has theorized young children as parentified (i.e., a role-reversal) where a child takes on the roles of a parent prematurely for their age.

In contrast, the second debate is centred around children's rights. The children's rights approach maintains that research on young caregivers has contributed to a greater awareness and the recognition of young cares as a distinct welfare category (Fives et al., 2013). Here, the assumption is that young caregivers will no longer be hidden and can be properly identified, assessed and supported (Fives et al., 2013). As a challenge to proponents of the disability rights movement, Fives et al. (2013) suggests that a broader and critical question needs to be asked, which is, "why do young children become caregivers in the first place?" This critical question seeks to address the structural factors that perpetuate the young carer role. According to some researchers (Lakman & Chalmers, 2019; Levine, 2005), the impacts on young caregivers, and arguably people with disabilities, will no longer be separated from structural and systemic concerns, all of which contribute to systems of structured dependency.

While the tensions between both debates have been made clear, they both address the unintended consequences of young carer research. In addition, they question whether or how the welfare state is responsible for the basic security of people with disabilities and/or children. By focusing on only individual and behavioral factors and downplaying systemic factors, those deemed vulnerable will continue to be framed as deficient. This is a point of contention which may not dissolve any time soon, particularly due to there being less focus on structured dependency in the literature.

Alzheimer’s Disease and Related Dementia: Origins, Definitions, and other Considerations

Origins of Dementia

A brief historical account of the emergence of dementia as a classified disease may help to set the stage for understanding how the past has implicated future trends and conceptualizations of dementia and dementia care. Early ontological and epistemological assumptions about AD were informed by dualistic perspectives of the mind and body. This informed the meanings of old age, which were often regarded as a stage of ‘senescence’ with an emphasis on the degenerating mind (Yang, Kim, Lee & Young, 2016). However, opposing views suggested that dementia was not an inevitable consequence of aging (Cicero, 1923). Further, from a religious standpoint, early conceptualizations regard dementia as senility or a type of mental illness) and a punishment of man’s original sin (Albert & Mildworf, 1989). As a result, people who were assumed to have this condition were shamed and ultimately removed from society (Albert & Mildworf, 1989).

Following the first reported case of dementia in the 18th century, dementia was still mostly associated with a mental illness. However, the first diagnosed case was transformative because it separated senility from mental illness, and thus created a new category called dementia (Berchtold & Cotman, 1998; Holstein, 1997; Vatanabe, Maanzine & Cominette, 2020). Following this, dementia research expanded and became increasingly framed as a growing problem, which contributed to an increase in research, assessments and diagnosis of older people. Holstein (2000) confirms that this led the institutionalization of older adults who were diagnosed with dementia as well as older people who were no longer considered functional and independent.

As such, the medicalization of dementia contributed to a re-framing of dementia as a major medical problem in the 21st century. Although this broad re-framing of dementia was clearly positive in raising awareness and funding for research, it had some problematic aspects that should be considered. First, the growing medicalization of ADRD influences political discourses and the wider views of society. Medina (2014) calls this a political conundrum suggesting that the growing importance of dementia has served to create a fear of the illness within the general public. Second, for Katz (1996) the negative portrayal of PWD has also contributed to fearmongering, but in this case the motivations are to promote a narrative that dementia is not an inevitable part of aging to justify the search for a cure. For Ballenger (2006), the medicalization of dementia has made caregiving came to seem less important than research aimed at a cure and the stigma surrounding dementia has only increased.

Defining Dementia

The term dementia derives from the Latin root *demens*, which means being out of one's mind. In general, clinical interpretations of dementia are aligned with mental deterioration or cognitive losses or deficits. A widely applied, but simple, definition that is commonplace in the social services sphere is that "dementia is an umbrella term for an individual's changes in memory, thinking or reasoning and affects their ability to perform daily tasks" (Alzheimer's Association, 2021). Public opinion tends to assume that dementia is a specific disease, however it is an umbrella term for a collection of symptoms that can be caused by a number of disorders that affect the brain (Alzheimer's Association, 2021). The literature makes a clear distinction between dementia and Alzheimer's disease, and highlights that they are often used interchangeably (Markoa et al., 2005; Mehta & Schneider, 2002; Sestakova & Plichtova, 2020).

The Diagnostic and Statistical Manual of Mental Disorders (The DSM-5) defines dementia as a neurological disorder – and the umbrella term for a number of neurological conditions of which the major symptom is decline in brain function due to physical changes to the brain (Rabins & McIntyre, 2009). It specifically defines Alzheimer's disease as the development of cognitive deficits manifested by both memory impairment or cognitive disturbance which cause significant impairment to social and occupational functioning and a gradual decline (p. 9). A key role of the DSM is to inform practice guidelines for people with dementia, including treatment recommendations, disease management, as well as education and support for families (Bell, 1994). Overall, the DSM, as a principal authority in diagnosis, has enhanced the legitimacy of dementia as a neurological condition and has an important influence on the way dementia is diagnosed, treated and perceived by the public.

The Changing Discourses of Dementia: Biomedical and Sociological Considerations

The medical model contributes to an understanding of assessing, diagnosing and treating dementia. Although such clinical modalities are useful in managing ADRD, it underscores how the consequences of the biomedical approach can be overlooked. The impact of the medicalization of ADRD induces an over-medicalization and over-diagnosis of the disease (Conrad, 2008). As a result, the current ADRD narrative stresses the importance of preventing and delaying ADRD altogether, despite the fact that scientific literature agrees there is no cure (Desai & Grossberg, 2005). For Poveda (2003) medical discourse reinforces the medical model of disease whereby people are framed according to their limitations and or impairments. The increase in the medical management of the disease reinforces that a person with dementia is vulnerable and dependent and should preferably be institutionalized in the later stages of the disease.

Arguably, ADRD disease is often discussed with a central focus on mortality and morbidity. Popular discourse highlights that ADRD is a leading cause of death among other chronic conditions. In a report on the global status report on the response to dementia, the World Health Organization states that dementia is the sixth leading cause of death (World Health Organization, 2021). The focus on ADRD morbidity and mortality rates further increases concern about the future implications of the disease. Over time, there has been awareness that trends in dementia mortality are related to a range of contributing factors including pre-existing health conditions, lifestyle and behavioural factors, as well as social determinants (Shirai & Iso, 2020). However, perspectives on the future of dementia are contradictory - suggesting that there will be effective preventive techniques, while at the same time estimating an increased prevalence due to the absence of medical breakthroughs (Reuben & Wolff, 2021). Taken together, despite trends that there has been some decline in dementia-related mortality rates, global efforts to prevent the disease are still quite pervasive.

The biomedical influence surrounding ADRD has necessitated the quest for a cure. The quest for a cure is promoted as necessary to prevent the amount of people who will be affected in the future, which is estimated to increase to 155.5 million people worldwide by 2050 (World Health Organization, 2021). In 2013, the G8 political forum initiated a global response to dementia to identify a cure or disease-modifying drug by 2025 (Cummings, 2016). In addition, the National Alzheimer’s Project Act, signed into law in 2011, also aims to prevent and effectively treat ADRD by 2025 (Batsch & Mittleman, 2012). While such plans address issues of access, service provision and advocacy, the majority of the plan emphasizes finding a cure and treatment (Batsh & Mittleman, 2012). Although the cure for ADRD is nowhere near, the efforts to cure the disease have not been derailed and continue to be robust.

The Social Perspective

In addition to the medical and political constructions of dementia, the social perspective has influenced how dementia is constructed and perceived. Literature informed by this view highlights the problematic nature of the medical perspective which can be negatively charged. Research suggests a biomedical view can poorly impact how people with dementia and the general public perceive themselves and the illness (de Boer et al., 2007). Typically, in the context of dementia, stigma is seen in three ways; a) public stigma – the attitudes and beliefs of the general public; b) self or personal stigma- when people internalize these public attitudes; and c) the emotions and behaviours towards family and professionals involved with the person with dementia (Goffman 1963 as cited in Harper, Dobbs, Stities & Sajatovic, 2019). Broadly, the medicalization of dementia frames PWD as deficient and lacking independence. Clare (2003) suggests that such negative stereotypes ascribed to people with dementia puts emphasis on production, independence and the contribution of citizens. This in turn impacts the level of significant and importance that people with dementia receive in society.

Literature on the social perspective emphasizes the social needs of PWD which are often obscured by the medical model. While the medical model emphasizes clinical interactions and interventions, the social model emphasizes relational and person-centred approaches. The fundamental idea is that knowing the person is just as important as understanding the disease, in fact they will inform one another (Epstein, 2000). As such, the person-centred model rejects the medical model for neglecting to understand the subjective experiences of people with dementia

(Kitwood, 1997). Here, the concern is on the perceptions of the disease, individual experience and emotional experiences in relation to how they understand and make meaning of the disease and disease process. For Mezzich et al. (2010), the goal should be to focus on separating the person from labels and the disease to a focus on the individual nature of the person. Here, the experience of the PWD is contextualized to enhance understanding of how they exist in their environment and social settings, which can inform patient care and interaction.

The efforts to humanize PWD has led to some significant changes in legislation and policy. This shift has been largely informed by research from the social sciences and humanities, both which address dementia and its social implications. Proponents of this view suggest that dementia research should move from ‘cure to care’ due to the lack of effective disease-modifying therapies (Wong & Knapp, 2020). The emphasis on ‘care’ has led to a significant shift from a unidirectional approach to a bi-directional approach to account for what dementia means for both the PWD and the caregiver (Rippon, Quinn, Martyr & Morris, 2020). There has also been a notable shift in dementia discourses from dependence to active citizenship (Brit et al., 2017). Both shifts (more so the latter) have informed dementia legislation to equally recognize the roles of both the caregiver and the care-recipient. This is clearly articulated in the World Health Organization’s Global Action Plan in which action areas 4 and 5 aim to empower and maintain the quality of life of people living with dementia and caregivers (World Health Organization, 2017). These recommendations are reflected in other dementia strategies worldwide and they continue to emphasize the social and relational aspect of dementia.

Collaboration of Two Distinct Approaches

While there are some tensions between the medical model and the social model as two distinct approaches, there have been efforts to find a middle ground to provide a clearer understanding of dementia. A number of psychological approaches have informed understandings of dementia through various approaches, including behavioural and cognitive approaches. Such approaches are often are used in combination with the medial model to provide a more holistic understanding of dementia. For example, the biopsychosocial model provides a theoretical framework for approaching care in dementia in a holistic way by emphasizing the interactions between social factors. According to Spector and Orrel (2010), the biopsychosocial model emphasizes how the person with dementia is situated in biological influence (genetic makeup, brain structure), psychological influences (response to stress, thinking patterns) and socio-cultural influence (cultural expectations, stigma, abuse).

This biopsychosocial model has also informed the types of interventions and therapies available to people with dementia. Quite recently, non-pharmacological approaches including psychodynamic, cognitive and validation therapies have been found to be quite effective for PWD (Douglas & Ballard, 2004; D'Onofrio, Sancarol, Seripa & Riccardi, 2016). A systematic review by Meyer and O'Keefe (2018) found that music therapy, validation therapies and sensory stimulation were effective in reducing emotional disorders and challenging behaviours in people with dementia. Such therapies are used independent of, or sometimes along with pharmacological therapies, offering a blended approach for PWD (Stewart, 1994; Shadowsky, 2021; Cohen-Mansfield, 2001).

For the purposes of this dissertation, ADRD will be conceptualized as a social issue related to psychological, economic, physical and emotional concerns. This is mostly based on the recognition of the value of focusing on improving the quality of life and well-being of people affected by dementia given that medical interventions may limited and there is no cure for the disease. I also acknowledge how the new conceptualization have played a role in shaping how dementia and caregiving are perceived and understood. This, in turn, has broadened the literature to explore the meanings, attitudes and beliefs surrounding dementia and dementia care practices. The result has led to a greater appreciation for the voices of those affected rather than solely relying on the narratives of medical experts.

ADRD: A Social Problem & A Social Movement

The development of dementia as a global social problem is a complex process shaped by historical, political, and cultural forces as well as existing empirical knowledge. Within recent years, dementia has been problematized and framed as "a public health challenge" or the "most feared problem of the 21st century," mostly by medical and political authorities. However, to further understand this problematization, it will be helpful to define a social problem. An early definition by Fille and Myers (1941) describes a social problem: *"a social problem is a condition which is defined by a considerable number of persons…and every social problem consists of an objective condition and a subjective definition. …social problems are what people think they are, and if conditions are not defined as social problems by the people involved in them, they are not problems to those people, although they may be problems to outsiders or to scientists* (p.3). Below I will discuss how this might be applicable in the context of my research endeavour.

The earlier review on the origins of ADRD indicates that ADRD did not emerge out of a vacuum, but exists within a complex web of interest groups, medial and political authorities and power dynamics. In their work 'Dementia as Zeitgeist,' Parker, Cutler and Heaslip (2020) trace the phenomenon of dementia as a social problem through various phases cementing its construction. The phases identify the various turns in how dementia has been understood, ranging from being constructed through the lens of normal aging, the medical turn and the biopsychosocial approach. This mirrors what other scholars have suggested about the construction of dementia as a social problem. For instance, Knifton and Yates (2019) suggest that the way dementia has been problematized in a variety of ways is mostly biomedical in nature. On the other hand, others emphasize seeing "beyond the disease" which aligns with person centered trends that emphasize how socio-political forces contribute to the construction of the disease (Gilleard et al. 2005; Thomas & Milligan, 2015). Overall, these perspectives can enhance one's understanding of how the problematization of dementia has been perpetuated through discourses and biomedical and political motivations.

The predominant beliefs about ADRD as a social problem have a profound effect on the formulation of social policies and the design of social programs. ADRD social policies tend to be organized around neoliberal ideologies which focus on the responsibility of the individual and less so on systemic issues. This view contributes to social welfare policies that address matters of the individual by focusing on their quality of life and well-being. For example, Chow et al. (2018), in a summary of national dementia strategies, emphasize the promotion of individual lifestyle, dementia-friendly communities, education and training, access to support, dementia campaigns, and educating professionals. While each of these domains is widely promoted, there is an assumption that the solutions to this issue will rely on change at an individual level with limited consideration for time constraints, financial factors and accessibility concerns which impact whether or how caregivers seek out resources.

However, social problems do not exist in isolation as many neoliberal frameworks might assume. Identifying the root causes of ADRD as a social problem have been well researched

(Cantly et al., 2004; Canady, 2022; Majoka, 2021). Only quite recently have connections between ADRD and issues of racism, poverty and inequality been discussed. Here, literature focuses on disadvantaged groups (Biggs, Carr & Haapala, 2019) and other social determinants which contribute to the manifestation of ADRD. Hulko (2004) argues that the personal identities and social relations of people with dementia exist in interlocking power relations: factors such as sex, ethnicity, class and age determine one's social location and thus the experiences of dementia in a socio-cultural context. In addition, research shows that many of the risk factors associated with dementia cluster in lower socio-economic groups that experience material deprivation (Winbald et al., 2016).

Since the beginnings of the ADRD social movement, there have been many shifts, trends and priorities. However, questions remain about if ADRD as a social movement has brought about social change and any permanent solutions to the constructed problems. Significant changes have occurred in public understandings of dementia, social responses to those affected with dementia and community-level interventions and policy efforts. However, it is apparent that there have also been many structural lags in finding effective solutions to dementia as a social problem given that policies responding to caregivers have not changed all that much since the 1970s. Nevertheless, the problematization of dementia has resulted in increased awareness which has shaped the direction of the ADRD social movement.

Informal Care & ADRD

Within the context of dementia, the literature suggests that informal caregivers are a much-needed group, in fact they are recognized as the cornerstone of the health care system. In the context of dementia, family caregivers of people with dementia are often called the invisible second patients (Sanders, 2016), demonstrating the importance of their care needs. In the literature, the effects of being a caregiver are discussed both negatively and positively. Informal care literature explores the adverse effects of caregiving through discussions on burden, psychological and emotional factors, social isolation, physical ill-health, and financial hardship (Bauer & Sousa-Poza, 2015) It is suggested that these social factors, when ameliorated, can make the caregiving experience quite positive. Positive impacts of caregiving include resilience, relationship with PWD and meaning-making (Cohen, Gold & Shilman, 1994). These factors have informed the literature on the competence and capacity of informal caregivers in the context of dementia.

A large majority of support program for informal caregivers focus on strengthening and building the capacity of caregivers. Here, the definition of capacity building is consistent with health promotion and public health frameworks that "improve or promote individual skill, abilities and competencies…through training courses and skill acquisition programmes" (Eade & Ligteringen, 2004, p.325). In the context of caregivers, the literature highlights that enhancing one's capacity is often done through the distribution of information and resources, training (Aksoydan et al., 2019), respite (Vandepitte et al., 2001) and financial support in the form of paid leave form work and tax credits (Keefe & Rajinovich, 2007). In the context of dementia, typically, informal caregivers utilize training for dealing with challenging behaviour and communication, which have been shown to be the necessary skills needed to care for a loved one with dementia (Haberstroh et al., 2011). With regards to information and resources, research shows that this is mostly made available through available community-support programs and in-person or virtual networks and (Goodhead & McDOnald, 2007).

Numerous studies report that informal caregivers are in need of support because caring for a person with dementia is more stressful than caring for a person with a other chronic conditions (Ory et al., 1999; Schulz et al., 1990). Compared to other chronic conditions, dementia is more progressive, and without a cure, can result in a longer duration of caregiving (Ory et al., 1999). Literature emphasizes that caregivers of people with dementia are often burdened because there are few disease modifying treatments (Ory et al., 1999). In addition, given recent shifts to community-based care, in the home setting family caregivers are confronted with multiple tasks that evolve throughout the disease process (Adams, 2006). In addition, as dementia progresses the level of support expands beyond support for instrumental activities of daily living to include almost constant supervision (Brodaty et al., 1990). Overall, the ability to provide sound care requires the informal caregiver to have special skills, understanding of the cognitive progression and how dementia impacts the person beyond cognition alone.

Dementia & Young caregivers: The Experiences of Young caregivers affected by ADRD

Since the emergence of young caregivers as a distinct group, the experiences of this group have been explored by a handful of researchers. While the literature on young caregivers affected by ADRD is scant, there are a handful of studies which explore this group's subjective experiences. Research shows that young caregivers affected by ADRD experience several emotional challenges, including grief and emotional detachment (Nichols, Fam, Cook & Pearce, 2013; Hutchinson, Roberts, Kurrle & Daly, 2016). For example, one pioneering study interviewed 14 adolescent children aged 15-27 about their experiences of providing care and found that they had difficulties managing multiple responsibilities and expressed concerns about their future (Millenaar, Vilet, Bakker Vernooji-Dassen, Koopmans, Verhey & de Vugt, 2014). Hamil (2012) found the grandchildren provided more help to grandparents with dementia when parents were involved. Also, a study exploring the effects of frontal temporal dementia on young caregivers found they needed more support from professionals to manage their role (Nichols, Fam, Cook, Pearce, Elliot, Baado, Rockwoon & Chow, 2013).

The research has led to some new approaches in identifying and supporting young caregivers. To better support young caregivers, research suggests moving from individualistic interventions towards a whole family approach (Frank & Slatcher, 2010). In practice, the whole family approach considers the needs of all family members, as well as the family dynamic. This approach is underpinned by the social model of disability perspective which suggests that the failure and shortcomings of the welfare state are responsible for a disabled or ill parent involving their child in the provision of care (Aldridge & Becker, 1999; Hutchinson, Roberts, Daly, Bulsura & Kurrle, 2016). In cases where a parent has dementia, this perspective has contributed to greater awareness of clinical dementia-care environments that undermine the needs of the family, which in turn, further marginalize young caregivers (Hutchinson et al., 2015). Through these examples, one can see that the research is beginning to address the heterogeneous nature of young caregivers as well as specific contextual factors shaping their experience.

Conclusion

This chapter provides a synthesis of literature related to informal care, young caregivers, and ADRD. The literature synthesized here conveys the current state of knowledge in each literature area to identify overall trends, key debates, and gaps in the literature. This will help to inform a deeper understanding of the research topic and set the stage for the subsequent chapters by providing a critical exploration, including development and limitations of each literature area. Taken together, the integration of the literature areas provides some context and justification for my research topic.

Chapter 3: Methodology

The aim of this chapter is to outline the methodology used to explore the phenomenon of interest. The chapter begins by introducing the research design and underpinning epistemological and ontological positions. What follows is a brief discussion on qualitative approaches and human science methods. Due to the emphasis on lived experience within this dissertation, a detailed rationale for selecting interpretative phenomenological analysis (IPA) will be discussed as well as critiques and limitations. This chapter includes a discussion of my role as the researcher, participant recruitment and data collection.

Research Design

The purpose of this research is to investigate the phenomenon of caregiving from the perspective of young adults. More specifically, the aim is to gain an in-depth understanding of the experiences and perceptions of young adults caring for an older adult with Alzheimer's Disease or a Related Dementia (ADRD). Given that this study aims to explore a detailed examination of a particular phenomenon (the phenomenon of caregiving from the perspective of young adult caregivers ages 18-25), it utilizes a phenomenological approach. Key features of phenomenology are to describe an experience as lived, illuminate the 'essence' of the experience, and illuminate how people make sense of their lived experiences (Creswell & Poth, 2018). Dahlberg (2006) describes 'essence' as a structure of essential meanings that explicates a phenomenon of interest. Here, 'structure' refers to the emotions, thoughts, perceptions and reflections that are experienced in a particular (natural) setting (Kaufer & Chemero, 2016). As such, phenomenology seeks to describe and/or interpret an experience as lived from a first-person point of view.

As this research is focused on a detailed examination of a phenomenon, I am approaching this research from a qualitative point of view. One assumption of qualitative research is that the process of qualitative research is inductive, which emphasizes that knowledge is developed and observed, rather than tested and confirmed. As Denzin and Lincoln (2011, p.3) suggest, "qualitative research is a situated activity which locates the observed in the world…attempting to make sense of and interpret phenomena in terms of the meanings people bring to them." Accordingly, knowledge is gained through understanding the process, context and meaning of an experience.

Guba and Lincoln (2011) outline 4 competing paradigms that guide qualitative inquiry: positivism, post-positivism, critical theory, and constructivism/interpretivism. A paradigm, as described by Kuhn, refers to a "disciplinary matrix"- commitments, beliefs, values, methods and outlooks shared across a discipline (Kuhn, in Schwandt, 1997). More broadly, "a paradigm is a set of beliefs or a worldview and defines (for its holder) the individual's place in the world, and the range of possible relationships to that world and its parts" (Denzin & Lincoln, 1994, p.107). A fundamental question when discussing questions of truth is *what* is known about reality (ontology) and *how* is it known (epistemology). Mantzoukas (2004) proposes that the four research paradigms converge in the understanding of the distinction between a singular truth/objectivist epistemology and multiple truths (relativism). Willig (2013) proposes that when reality is viewed as relative, instead of 'out there,' there is room for truth to be understood through context, situations and intrinsic positions.

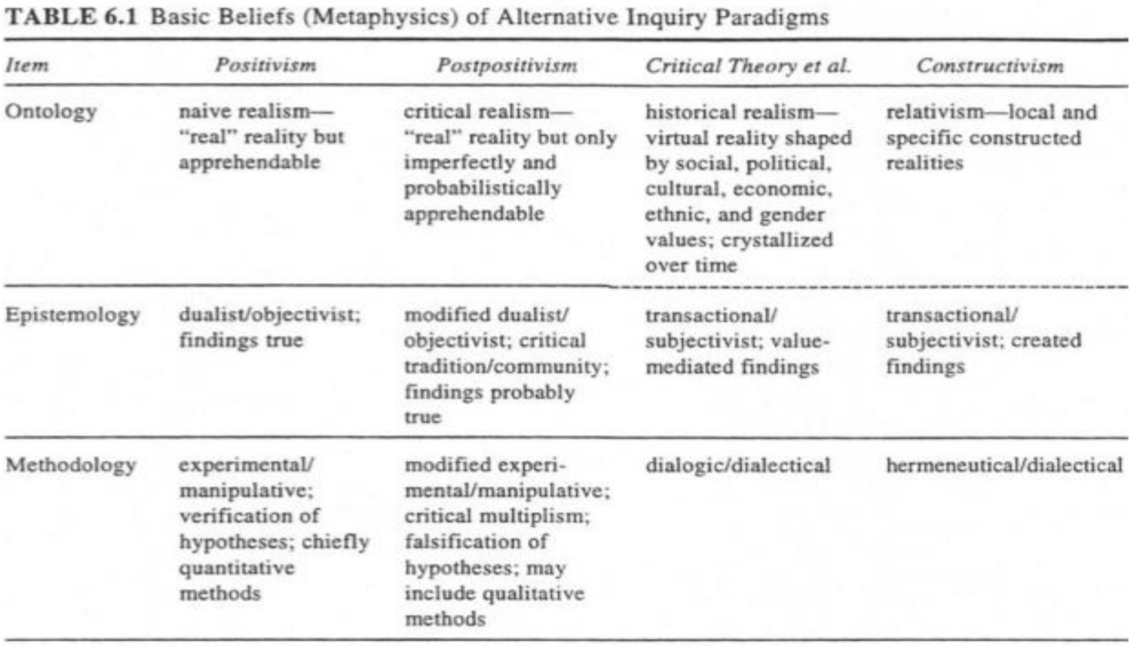

TABLE 6.1 Basic Beliefs (Metaphysics) of Alternative Inquiry Paradigms

Item	*Positivism*	*Postpositivism*	*Critical Theory et al.*	*Constructivism*
Ontology	naive realism—"real" reality but apprehendable	critical realism—"real" reality but only imperfectly and probabilistically apprehendable	historical realism—virtual reality shaped by social, political, cultural, economic, ethnic, and gender values; crystallized over time	relativism—local and specific constructed realities
Epistemology	dualist/objectivist; findings true	modified dualist/objectivist; critical tradition/community; findings probably true	transactional/subjectivist; value-mediated findings	transactional/subjectivist; created findings
Methodology	experimental/manipulative; verification of hypotheses; chiefly quantitative methods	modified experimental/manipulative; critical multiplism; falsification of hypotheses; may include qualitative methods	dialogic/dialectical	hermeneutical/dialectical

Figure 1: Basic Paradigms from Guba and Lincoln, 2011, p.109

Ontological and Epistemological Position

Given that this study aims to understand the phenomenon of caregiving from a subjective standpoint, it aligns with an interpretivist/constructivist paradigm. Mertens (2019) suggests that *"The ontological belief associated with constructivism assumes that there is no singular truth, rather multiple truths; each constructed by the individual's subjective response to their experience and the sense made of that experience. The epistemological assumption is that 'data', interpretation and outcomes are rooted in contexts and persons apart from the researchers"* (p.19). In contrast, in a positivist view, there is a marked difference between the role of the researcher and the participant during the research process. Here, the researcher is seen as an expert who is in a position of authority and is separate from the participant. In comparison, for Karniell-Miller, Strier and Pessach (2009), the interpretivist paradigm can create an atmosphere of power equality, encouraging disclosure and authenticity, and potentially minimize problematic boundaries. Here, research is seen as a collaborative and engaging act which serves a key purpose in building a shared knowledge base (Wassler & Bresler, 1996). Overall, my aim for aligning with this research paradigm is three-fold: i) to encourage a redistribution of power in order to facilitate the co-production of knowledge between the researcher and the participant; ii) to shed new light on a phenomenon that has been underrepresented in the literature; iii) to reflect on and reach collaborative ways of understanding a phenomenon.

Research Questions

The research questions were born out of an inquiry to address a gap in the literature concerning young caregivers. After taking an interest in this population in my former professional work, I took notice that there were very few studies that explored whether or how young caregivers are affected by ADRD. Given the exploratory nature of this study, the questions did not include any a priori testing of a hypothesis related to particular findings of previous research or existing theory. The central research question that guides this research is: what is the nature or essence of being a young adult caregiver (ages 18-25) for an older adult with Alzheimer's Disease or a Related Dementia? This will be answered by the following research questions: 1) how do young caregivers describe their experience of caring for a relative with ADRD; 2) How do young caregivers make sense of their caregiving experience? and 3) What would young adult caregivers share about navigating the role of caregiver, while also maintaining their own lives?

Phenomenology & Human Sciences Methods

A discussion on human science methods may be useful when it comes to further justifying the methodology of the study. While there is no unified definition of the human sciences in historical literature, early definitions suggest that the human sciences are an effort to describe and explain individual human behaviour (Dilthey, 1991). Proponents of the human sciences reject positivist approaches to knowledge suggesting that they are too “mechanistic and reductionist, limiting understanding to causal relationships and relationships between variables” (Kincheloe & Tobin, 2009, p. 518). Compared to the natural sciences, the human sciences do not employ deductive methods to confirm or refute a hypothesis or theory. Rather, inferences made in the human sciences make an attempt to assess patterns through a wide range of possibilities. This approach can be beneficial for understanding specific aspects of human life.

Phenomenological philosophy has been recognized as a basis for human science methods. For Husserl (as cited in Smith, Flowers and Larkin, 2009, p.12), human science inquiry emphasizes “intentionality” or the study of an individual’s consciousness towards the lived experience of something. This method includes precise description through a series of steps: description, bracketing (*epoche)* all previous knowledge, assuming the transcendental phenomenological attitude (reduction), and free imaginative variation (Kaufer & Chemero, 2016). From this point of view, the object of phenomenological description is achieved solely through grasping the essential structure of the phenomenon as it appears in consciousness.

Following in the footsteps of Dilthey and Husserl, Giorgi (2014) agrees that the human sciences is a more appropriate approach for understanding lived experience as it transcends dominant positivist approaches to human understanding. Similar to Husserl, Giorgi’s methodology is descriptive, not interpretive; unlike Husserl, Giorgi’s method is pre-transcendental and not transcendental (Giorgi, 2012). Here, the aim is to arrive at the structure (a psychological researcher seeks psychological essences, not philosophical ones (Giorgi, 2009, p.100) of an experience through phenomenological reduction, however his method is more empirical and practical rather than philosophical (Shakalis, 2014, p.14) Contemporary psychologists (Giorgi, Moustakas, Colazzi) employ the same methods outlined in Husserl's philosophical method (description, reduction and structure), however the steps are modified to meet criteria for psychological research (Giorgi, 2017). Here, the aim is to move from philosophy to empirical work and establish a general structure of an experience, also known as the essence, which is descriptive in nature.

Heidegger built on the work of Husserl to include a hermeneutic approach which includes description and interpretation (the what and the how). For Heidegger (as described by Giorgi, 2007) we cannot bracket our understanding of the world because we are always in the world with others in circumstances of existence. This is what Heidegger calls 'dasein,' which ultimately means 'beings-in-the-world' emphasizing that a human being cannot be taken into account except as a being existing in the world among other things (Hornsby, 2012). The central argument here is that a description may aim to capture the lived experience (i.e., an aspect of the lifeworld) conceptually and/or theoretically, but somehow fail to elucidate the lived meaning of that experience (Hornsby, 2007). In other words, Heidegger is concerned about how prior theoretical commitments might skew the description of a phenomenon (Kaufer & Chemreo, 2015).

For van Manen (1990), there is a difference between the theory of phenomenology and 'doing phenomenology.' From his view, "doing phenomenology" is an attitude…a way of seeing, thinking and expressing insights about events in the existential world (Van Den Berg, 1972, p. 77 as cited in van Manen 1990). This attitude requires an effort of being strict in one's commitment to understand experience as lived while withholding their own theoretical presuppositions. He suggests that researchers that employ this approach must strive "to abstain from theoretical, polemical and suppositional intoxications" (van Manen, 2014, p. 26). In order to achieve this, he suggests that the methodological structure of human science research be seen as the interplay between 6 research activities: 1) turning to the nature of lived experience; 2) investigating experience as we live it; 3) reflecting on essential themes; 4) writing and re-writing; 5) maintaining a strong and oriented relation; 6) balancing the parts with the whole (van Manen, 1990, p.27). These steps illustrate that pursuing phenomenological research is an involved endeavour, where a researcher must explore the category of lived experience in all aspects.

Phenomenology: From Description to Interpretation

To ensure that my methodological choice is appropriate for what I am to accomplish for this dissertation, I considered the different types of phenomenological methods and the overall purpose of phenomenological research. First, I understand that phenomenology differs substantially from other qualitative methods given its effort to bracket one's assumptions, if possible. In general, it is widely acknowledged that there are two main philosophies a researcher can choose from when employing a phenomenological method: Husserl's transcendental phenomenology or Heidegger's hermeneutic phenomenology. I chose the latter because I mostly agree with Heidegger that we cannot fully bracket our experiences completely as we are always in a relational experience with the world and with others.

Second, phenomenological research is strictly aimed at understanding experiences that are lived. In essence, not just the initial reaction to such experiences, but how it is that they are lived (Munhall, 2007). As such meaning-making, interpretation and reflection are essential phenomenological inquiry. For instance, phenomenology allows for a more in- depth type of question to be asked, such as "What is it like to experience a certain phenomenon" or "what is the lived experience of caregiving among millennials? or "how do individual make sense of being angry?" Such research questions explicitly focus on the phenomenon of experience as lived from a particular or shared point of view.

Interpretative Phenomenological Analysis

As this dissertation is focused on gathering an in-depth understanding of caregiving as lived by young adults, I am employing a phenomenological approach known as interpretative phenomenological analysis (IPA) (Smith, Flowers, & Larkin, 2009). The method emerged out of discontent with the hyper-emphasis on quantitative methods in psychological research (Smith, 1996). While health psychology is IPA's home discipline, the approach has been widely applied to other disciplines, including social science research (Wagstaff & Williams, 2014). The aim of IPA is to explore in detail a participant's perception of a topic under investigation (Smith, Jarman, & Osborn, 1999). To this end, it aims to 'give voice' by explaining how a person makes sense of a particular phenomenon.

It is widely known that IPA is not only a phenomenological activity, but also an interpretive activity. As such, it is concerned with two key facets which can be quite complex: a) how a person makes sense of a particular experience; and b) how the researcher makes sense of the experience (Smith, Flowers, & Larkin 2009). This is also known as the "double-hermeneutic approach" whereby the researcher is making sense of the participant making sense of a phenomenon (Smith, Flowers & Larkin, 2009). The aforementioned complexity is largely due to the intersubjectivity between the researcher and the participant. In essence, the researcher is interpreting the phenomenon against the backdrop of their own conceptions in order to make sense of the participant's personal world.

Although IPA shares commonalities with other qualitative approaches, it differs in its commitment to understanding layers of cognition. For IPA, cognition lies at the heart of the phenomenological project as cognition is “dynamic, multi-dimensional, affective, embodied, and intricately connected with our engagement with the world (Smith et al., 2009, p. 191). Here, cognition refers to the ‘thinking, feeling, and beliefs’ about a topic under investigation (Smith et al., 1999). Further, IPA is concerned with the spaces in-between language and thought forms which are not transparently available from a transcript (Smith et al., 1999). These spaces are represented by body-language, tone, eye contact, mood and other non-textual elements. As such, IPA emphasizes multi-dimensional aspects of communication; including communication of different forms (beyond text) which might include thought forms originating through and from the body.

Traditional qualitative approaches emphasize finding patterns across a group sample; however, IPA is concerned with a more detailed “micro-analysis.” This level of analysis is referred to as an idiographic, which refers to the in-depth and detailed analysis of a particular phenomenon. Here, the analysis is layered and factors in three levels of exploratory comments: descriptive, linguistic, and conceptual (to be explained below) (Smith, Flowers & Larkin, 2009). Further, IPA engages in a case-by-case analysis, identifying emergent patterns, prior to a group-level analysis (Pringle, Drummond, McLafferty & Hendry, 2011; Smith et al., 2009). The analysis of each individual case aims to explore key themes and nuances that emerge at an individual level. This idiographic approach is key to IPA and contributes to obtaining an “insider’s view” which is not always feasible in quantitative research.

Theoretical Underpinnings of IPA

Central to IPA are three theoretical underpinnings: phenomenology, hermeneutics, and idiographic (Smith, 2011). While each has its own distinct philosophical approach, together they strengthen the detailed examination of each case through a process of description, interpretation, and an individual micro-analysis. I will now discuss each commitment in some detail.

Phenomenology

While phenomenology is considered a philosophy and a method, within IPA it is considered a mode of analysis (Smith, Flowers & Larkin, 2009). As a philosophy, phenomenology is a particular way of approaching the world and apprehending lived experience (Merleau-Ponty, 1962). For phenomenologists, experience is the ultimate source of meaning and should be examined in the way it occurs. In Husserl's view, this refers to stepping back from the natural attitude (i.e., the appearance of the things or the object-world) in order that we "get back to things themselves" (Shinebourne, 2011, p.17). To achieve this, 'a phenomenological attitude is adopted which involves a certain degree of reflexivity whereby one's presuppositions are bracketed' (Smith, Flowers & Larkin, p. 99). When applied to IPA, the purpose of phenomenology is to describe the lived experience *without* assigning meaning, and to reflect on the phenomenon itself rather than exploring how experiences can fit with a pre-defined criterion.

IPA is also influenced by the perspectives of Heidegger and Merleau-Ponty who emphasize the embodied nature of experience. They agree that the body is lived and is intertwined in historical, social and cultural contexts, so there is no separation between the lived body and the object body (Dreyfus, 1996). When experience is embodied it makes it even more difficult to separate from one's preconceived notions. In Heidegger's view, "every interpretation is founded essentially upon the fore-having, fore-sight, and fore-conception" (Heidegger, 1962, p.191 as cited in Shineboure 2011). For these reasons, it is argued that suspending all prior assumptions in order to achieve ‘epoche’ is not possible as all experience is grounded in prior knowledge (Shinbourne, 2011). Here, the aim is to replace ‘epoche’ with reflexivity and self-awareness to be aware of how the researcher influences the research process (Peat et al., 2018).

REFLEXIVE BOX
I agree with Heidegger’s views on bracketing and the importance of reflexivity. In my view, complete epoche/bracketing would be difficult for me to do because of my previous experiences as a former professional working with people with dementia and their caregivers and a social gerontology graduate student. I attempted to ‘set aside’ my past knowledge in these areas by documenting my biases and preconceived notions in a reflexivity journal (see Appendix E) which you will see throughout this thesis represented by ‘reflexivity boxes.’

Compared to other qualitative approaches, IPA is a pre-reflective and pre-theoretical endeavour. In general, a reasonable starting point for any research project is to begin with theory to inform the phenomenon under study. From my prior-knowledge, applicable caregiver theories informing this study come from a wide range of disciplines, including social psychology, social sciences and the human sciences. Earlier theories include Erickson’s theory on human development (Kahana et al., 1994), Bowlby’s (1979) attachment theory and role theory (Bastawrous, 2013; Biddle, 1986; Kramer & Kipnes, 1995;) which helped to add to conceptualizations of caregiving being linked to one’s social development and /or stage of life. Many caregiver theories are linked to dominant constructs of stress and burden, including caregiver identity theory (Montgomery & Kosloski, 2009). A more contemporary theory is child parentification which emphasizes the role reversal that young caregivers experience when they take on tasks of a parent prematurely (Earley & Cushway, 2002) Rather than fully bracket prior knowledge, I opted to “hold on lightly” to former theoretical and conceptual knowledge regarding this phenomenon.

Hermeneutics

Hermeneutics is the theory and practice of interpretation and meaning of texts (Landridge, 2007). Theoretically, it is the study of how life is understood through language, while in practice it is concerned with efforts to understand written communication (Zimmerman, 2015). Byrne (1998, 2001) suggests that there are two assumptions of hermeneutics: 1. Humans experience the world through language; and 2) this language provides both understanding and knowledge. For Schleiermacher, the interpretation of text is both linguistic (grammar, poetic) and psychological analysis (what is said and how it is said) (Smith, 2007). This relates to Heidegger’s views on language whereby it is inseparable from one’s ‘being-ness.’ For Heidegger, it is through language that beings are brought into the open and how beings are ‘shown’ (Meservy, 2014). To illustrate this Meservy (2014) uses the example of saying *“I love you”* to demonstrate how language can elicit bodily phenomena, as saying I love you can cause your heart to race and palms to sweat. In a sense, by exploring the meaning we give to words, our interactions with others are given greater meaning and allow a critical exploration of language beyond linguistic analysis.

Within IPA, hermeneutics emphasizes that sense-making is a fusion of participant and researcher perspectives or “horizons”. Here, the fusion of horizons refers to the point where the worldviews of the participant/researcher intersect. This relationship, according to Willig (as cited in Shinebourne, 2011) is inseparable because the researcher brings a frame of reference to the data and during the process of analysis. Within IPA, while the participant is an experimental expert, the researcher assists in meaning making through the hermeneutic circle. This involves a cyclical and iterative process moving between the part (smaller units of meaning) and the whole (larger unit of meaning) (Schwandt, 1997). For example, Smith (2011) suggests that what counts as the part can be a word, a sentence or an interview, and what counts as the whole can be a sentence, a transcript or the whole corpus. From this view, shifting between the part and the whole gives a greater sense of the experience for the participants.

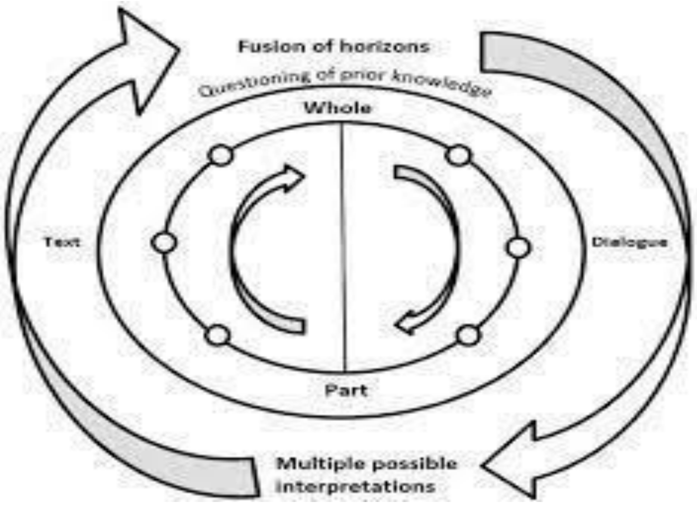

Figure 2: The Hermeneutic Circle in IPA from Peat, Rodrigues & Smith, 2019, p. 5

Within IPA, there are 3 layers of exploration used to interpret the text of a transcript: descriptive, linguistic and conceptual (Smith et al., 2009). This exploratory process begins with descriptive coding, whereby the content of the data is described to hone in on particular words or phrases and emotional responses that stand out in the text. This is what Smith et al. (2006) refer to as the close line-by-line analysis of experiential claims, concerns and understandings of each participant (i.e., things that matter, events, relationships, concepts). This is followed by the next level of analysis, linguistic coding, which includes a deeper examination of descriptive comments, specifically the “how” along with the “what.” Here, particular attention is given to elements of speech (pause, repetition, pronouns use, pauses, laughter), as well as figurative language (i.e., metaphors, similes) used to describe experiences (Smith, 2009). The final stage of analysis, conceptual coding, moves away from the “explicit claims of the participant” towards sense-making and contextualizing expressed concerns (Smith et al., 2009, p. 88) This level of coding allows the researcher to draw upon their own experiential and professional knowledge to interpret the data.

Idiography

Idiography is the third theoretical underpinning of IPA. The aim of idiography is to capture an in-depth and detailed analysis on the particular. The particular operates at two levels: detailed and first-person accounts (Smith, Flowers & Larkin, 2009). In other words, this is described as focusing on a *particular* phenomenon as experienced by *particular* people in a *particular* context (Smith et al., 2009). Idiographic methods emphasize behavioural patterns across a sequence of experiences or situations. In contrast to nomothetic knowledge, which generalizes claims to broader populations, in idiographic approaches special attention is given to ‘the single case’ or a small group of cases.

Given the idiographic nature of IPA, there is caution with generalizing results and transferability of findings. Here, the focus is not on generalizing findings to all settings, but rather the perceptions of a particular group within their settings. (Smith et al., 2009) suggests that IPA ought to be considered in terms of theoretical generalisability rather than empirical generalisability. It is well documented (Carminati, 2018; Davids & Dodd, 2002; Delmar, 2010) that ‘generalizability’ in the qualitative domain can be thought of as analytical, theoretical, situational (case-to-case), contextual and shared. Further exploration of the motivations and methodology of a study can help inform the relevance of generalizability. Overall, it appears that ‘partial’ generalizability is appropriate for studies that are pre-theoretical and exploratory.

Pathos

Although pathos is not included as one of the theoretical underpinnings of IPA, the literature does suggest that it strongly informs IPA, specifically phenomenology. There is consensus that pathos - the emotional experience of a phenomenon- is the aim of phenomenology (Fink & Grugan, 1972; Oele, 2012; Van Manen, 2016). In particular, Heidegger incorporates the notion of pathos in his notion of ‘dasien’ by suggesting that one’s emotions or mood is what helps them navigate the world *or* attune to the world (Gross, 2006) For Heidegger, “mood is ontological and takes into account the pre-intelligible background necessary for us to make sense of, experience, and interact in the world” (Gross, 2006, p. 146).

The relationship between pathos and research has been somewhat unclear. Arguably, in a dominant positivist paradigm, the relationship between pathos and research need not exist. Further, within some disciplines, there has been some reluctance to discuss how emotion implicates the research process and researchers themselves (Widdowfield, 2000). However, there has been a fair attempt to close the gap between research and emotion. McLaughlin (2003) suggests there is false polarity between reason and emotion and suggests that reason and emotion are inextricably linked in the research process. As such, there has been a reassessment of the role of pathos in academic studies. Many scholars have highlighted the connection between emotion and research which helps to explore taken for granted assumptions, draw closer to participant experiences, and assist with researching sensitive topics (Dickson-Swift et al., 2009; Johnson, 2009; Kitty, 2014; Leitch & Day, 2002).

In his seminal book, Phenomenology *of Practice,* Van Manen (2007)) suggests that phenomenology helps to grasp the world 'pathically' (a felt sense of being in the world). More specifically, he suggests that "theory *thinks* the world and practice *grasps* the world" (Van Manen, 2007, p. 20). An effort to grasp the world in such a way is less detached and objective than in quantitative approaches. For Van Manen (2007) grasping the world in such a way encourages enhanced relational understandings which include empathizing with someone and also understanding from the other persons point of view. Smith (1999) proposes that this understanding is not only "gnostic, cognitive and intellectual, but also relational, situational, corporeal, temporal and actional" (p.20). From this view, the entire being (body and mind) can be seen as a source of knowledge.

The Case for IPA

Now that I have explained phenomenology as a philosophy and a method, I will discuss why IPA has been chosen as the method for this study. First, it is consistent with the epistemological position of the research questions, which aims to explore how young adults describe and interpret being a caregiver for someone with ADRD. In addition, the theoretical underpinnings of IPA are well-suited to explore the research questions in depth. Further, the application of the three exploratory layers of analysis (i.e., conceptual, exploratory, linguistic) will allow for a micro-level analysis and assist with uncovering the nuances and meanings at an individual and group level.

I also value that IPA is not only concerned with personal lived experience, but with the notion of "experience close and experience far" (Smith, Flowers & Larkin, 2009). As such, it is an approach for the researcher to attempt to get as close as possible to the meaning of experiences for participants (experience near) while at the same time recognizing the difference in experience and understanding between two people (experience far). Yet at the same time, through inter-subjectivity, a participant's relationship to a phenomenon can be closely accessed only via interpretation (Finlay, 2011). Therefore, I am adopting IPA to shed light on a phenomenon that has lacked detailed exploration in the literature. Further, IPA is an approach which supports my aim to provide an in-depth exploration of the lived experience of young caregivers affected by dementia and highlight the heterogeneity amongst caregiving populations.

Although this dissertation is a complex endeavour, my aim is to give meaning to a phenomenon through a deeper understanding of it. I assume that this can be achieved by 'doing phenomenology' and adopting a strong phenomenological lens and attitude. As such, this approach will assist me to capture the subtle nuances, affect, and emotion which is often concealed with other methodological approaches, and more broadly within scholarship itself. Given that this dissertation explores the views of an underrepresented population, capturing the essence of caregiving as lived for young adults will highlight taken for granted assumptions and diverse insights which can offer new ways of understanding this phenomenon.

Critiques & Limitation of IPA

While the benefits of IPA have been widely recognized, there are some strong criticisms which are noteworthy. Critics of IPA suggest that it is ambiguous, lacks standardization, and is mostly descriptive without sufficient interpretation (Dennison, 2019). On one hand, the lack of a defined and prescribed way to conduct IPA has been touted to have many advantages, including flexible decision-making throughout the research process (Smith, Flowers, & Larkin, 2009). On the other hand, critics have suggested that this can actually make it challenging to capture and analyze participant experiences and meanings of these experiences accurately (Dennison, 2019). As a result, IPA has been criticized for research that can result in lower levels of validity and reliability (Sousa, 2014).

Consistent with most qualitative approaches, IPA embraces diversity and pluralism. However, there is some concern that the emphasis on subjectivity encourages "fast and loose;" in other words, irresponsible research methods (Sullivan, as cited in in Dennison 2009, p.3). Further, IPA relies on a complex chain of connection between talking, thinking, and emotional state to describe experience. Willig (2013) expresses concern these theoretical commitments may implicate the reliability and validity (this will be discussed below) of the IPA approach. She suggests that because IPA relies on language, participants may not be able to fully articulate their experiences and meanings of such experiences, as well as any complexities (Willig, 2013).

The role of the researcher in IPA has been criticized for being too active or influential. Since the researcher has such an active role in the process of analysis, it has been argued that interpretations are constrained by the researcher's own ability to interpret, reflect and make sense of the data (Brocki & Wearden, 2006). In IPA, the researcher needs to be particularly skilled in reflexivity, praxis, and the ability to extract interpretations beyond description, but also on conceptual and linguistic levels. Alongside this, some novice IPA researchers (Wagstaff et al., 2014) have expressed concerns with implementing the double hermeneutic approach as well as making decisions on whether or how to bracket prior knowledge.

To address these limitations and critiques I ensured that I followed the steps in the analysis to maintain standardization. Second, I took into consideration that IPA relies on language to convey the meaning of one's ideas, which can be problematic if interpreted poorly. Given that the role of language contributes to meaning making, I ensured that I was attentive to the language participants used (in the form of metaphors, narratives and discourse) to adequately gain insight into experience. Further, the interview guide was constructed to allow for a dialogue with participants and, beyond this, I made an effort to probe and build rapport and trust with each participant to allow for the collection of rich and in-depth data (i.e., to bridge the gap between 'researcher' and 'participant'). In addition, I addressed my multiple roles (i.e., researcher, interviewer, writer, recorder, interpreter) by maintaining reflexivity through a journal (see Appendix E). I also attended training and workshops to enhance my research and analysis techniques relevant to IPA. I plan to return to these limitations and critique in the discussion section below.

Population

The population examined in this study are young adult caregivers (also known as 'young adult carers') (ages 18-25) caring for an older adult with ADRD age 60 or older. Young caregivers are defined as children and adolescents under the age of 18 who provide care, assistance or support for one or more chronically ill family members (Dearden & Becker, 2004). I decided to explore the views of young adult carers (ages 18-25) because they are an underrepresented population in the literature. Most studies homogenize young caregivers, which minimizes differences in age, care type, and pathways to caregiving. The young carer population fits within the broader population of informal/unpaid family caregivers, which has historically been an 'invisible' and 'hidden' population (Hendricks et al. 2021; Stamatopoulos, 2015).

Recruitment and Sampling

The initial phase of recruitment involved outreach by email to relevant stakeholders (community organizations, caregiver organizations, social media networks). Each point of contact at relevant recruitment sites received the recruitment poster and brochure electronically and was asked to share these materials where appropriate (i.e., website, email, social media platforms). I also shared the recruitment materials on my social media platforms (Facebook, Twitter and Instagram). The majority of recruitment took place in the months of June, July and August 2021. I reached out to ‘followers’ who expressed interest in the social media platform and/or content. Once contact was established, I then shared more information about the study and asked if the participant might be interested in sharing more about their experiences. If interest was expressed, I followed up with an email including the letter of intent and a potential time to conduct the interview. Young caregivers are considered a hard-to-reach group and are often referred to as “hidden” (Stamatopoulos, 2015). This is often because there is still limited awareness on the prevalence and characteristics of this population, which often contributes to a lack of proper identification (Stamatopoulos, 2016). For such reasons, many studies on young caregivers rely on recruiting from community agencies and already existing programs (Stamatopoulos, 2016.) The community agencies I reached out to were not responsive, so I relied on social media to recruit participants.

Within IPA, sampling is consistent with other qualitative paradigms. I employed purposive and snowball sampling techniques to locate participants that met the selection criteria. Participants were included in the study if they met the following criteria: they are or have been a young carer (ages 18-25), living in North America, and have been or are providing some level of care (no minimum definition) for an adult over the age of 60 with ADRD. I applied purposive sampling to select participants on the basis that they could provide rich data. Snowball sampling occurred when participants were recruited directly or from acquaintances (Clarke & Braun, 2013). I employed purposive sampling when I contacted individuals who expressed an interest in the social media platforms and content. I also employed snowball sampling when participants were contacted via referral or through a community gatekeeper. I recruited participants using social media and by sending emails to community agencies and various clubs at colleges and universities. As aforementioned, the latter recruitment strategy was ineffective as I had no responses. Recruiting on social media, primarily Instagram, was much more effective. My social media posts included content which reflected facts and figures, caregiving trends and animated invitations to participate in the study. There was a screening process where I asked participants the following questions: What is your age? What is the length of time you have been a caregiver? Who are you caring for? What type of dementia do they have? What is the age of the care-recipient?

Between the months of May 2021 and November 2021, 14 participants came forward. Of the 14 interested participants, I had to turn 2 away because one was a paid formal caregiver in a memory care unit with no family relation to an older adult with ADRD and the other was age 50. Two participants, YC10 and YC11, were over age 25 when they were providing care (YC10 was age 29 and YC11 was age 39); however, they both self-identify as young caregivers. As such, they are considered exceptions in this study. Within IPA, participants are selected on the basis that they can grant access to a particular perspective rather than a population (Smith, Flowers & Larkin, 2009). While there is no right answer to the question of sample size, the recommendation is to focus on a small number of cases. Further, the sample is usually homogeneous, and the extent of this homogeneity will vary depending on the study (Smith, Flowers & Larkin, 2009). As such, between three to six participants are recommended for graduate student projects, although anywhere between 1 and 15 is common (Smith, Flowers & Larkin, 2009). I will be treating young caregivers as a homogenous group who share the experience of caring for an older adult with ADRD. As the study progressed, I chose to take a pragmatic approach and expand inclusion criteria beyond Canada to include other geographic locations. This study was approved by the University ethics board (see Appendix C), and the adjustments made to recruitment location were approved by amendment to the same. Several factors informed this decision including recruitment barriers, access to young adults affected by ADRD, and the COVID-19 pandemic changing the research process in terms of minimizing opportunities for recruitment and in-person interviews.

Participants

The initial aim was to recruit 15 participants to allow for attrition. However, 12 participants were ultimately recruited, and none dropped out. The sample was homogenous to the extent that a) the participants shared the same experience of a particular event (Smith, Flowers & Larkin, 2009), which is that they have been or are caring for an older adult with ADRD b) live in North America c) and are or have been a young carer). The majority were between the ages of 18 and 25 at the time they were caring in keeping with my recruitment plan, however, because of difficulties with recruitment and also recognizing the debates over the definition of young caregivers, I included two participants who began caregiving younger, and two who began older, than this age range. I discuss this decision further in the section on Limitations (Section 7.7). The majority of the participants were women, with the exception of two men. All of the participants either attended university or college, but not all completed their degrees. Of the participants, 4 were married, 3 were single, and 5 were in a relationship. There was also variation in the type of dementia the care-recipient was diagnosed with, their ethnic background and the length of time of providing care.

Table 3: Demographic Profile of Participants

Participant identifier	Male/ Female	Age	Ethnicity	Professional/ Educational Background	Country of Residence	Cares For /Cared For	Care-Recipient Age	Type of Alzheimer's Disease or Related Dementia (ADRD)	Age when caregiving began
YC 1	M	30	Caucasian	Some college	Canada	Mother	Deceased	AD	24
YC 2	F	22	South Asian	University student	Canada	Father	86-87	ES	21
YC 3	F	31	Caucasian	College Educated and Working Professional	US	Mother	31	Primary progressive aphasia (under FTD umbrella)	25
YC 4	F	30	African American	Working Professional	USA	Mother	72	AD	24
YC 5	F	24	South Asian	College Educated, Employed	CAN	Grand-mother	88	AD	18
YC 6	F	32	Caucasian	Some College; Unemployed	US	Father	Deceased	ES	12
*YC 7	F	33	Caucasian	College Educated and Working Professional/ Entrepreneur	US	Mother	68	ES + FTD	29
YC 8	F	30	South Asian	Working Professional and mother	CAN	Father	Deceased	EO	12
YC 9	F	29	South Asian	College Educated and Working Professional	US	Mother	Deceased	Parkinson's Disease Dementia (PDD)	20
YC 10	F	33	Caucasian	College Educated and Working Professional	US	Father	Deceased	EO	25.5
*YC 11	F	43	Caucasian	College Educated and Working Professional	US	Mother	67	AD	39
YC 12	M	20	South Asian	University Student	CAN	Grand-mother	74	AD	17

Data Collection

I used semi-structured interviews to collect data for this study. This allowed me to probe interesting areas that arose and follow the respondent's interests/concerns. In IPA, the aim is to elicit detailed stories, thoughts and feelings from the participant (Smith et al., 2009). Semi-structured interviews encourage the participant to speak freely and openly and ensure that the areas relevant to the research questions are covered (Smith et al., 2009). Using a 'Gadamerian' approach, I attempted to make the interviews conversational and dialogical with more focus on the participant while limiting my personal views. Within IPA, it is recommended to approach research questions 'sideways' focusing on facilitating discussion of relevant topics which allows the research questions to be answered during the analysis (Smith et al., 2009). While this was not explicitly decided upon from the outset, the interview guide did lend itself towards this by breaking down the broad area of focus into three distinct parts to follow the chronology of the research questions.

Each participant interview took place 1-3 weeks after confirmation (between the months of May 2021 and November 2021). Due to the COVID-19 pandemic, each interview took place via zoom. Within IPA, multiple interviews are quite common. The initial aim was to have three interviews; each subsequent interview informing the next to distill down to the essence of the phenomenon. In the beginning stage of recruitment, I encountered several barriers, which were mainly due to time constraints experienced by the target population. I addressed these barriers by reducing the number of interviews from three to one or two, keeping the second interview as an "open door" to discuss any emerging points of focus that could be further explored. Two participants expressed interest in participating in a second interview where we were able to discuss points of emphasis that emerged from the initial interview.

The purpose of the interview(s) was to gain an in-depth understanding of the participants' experiences. I focused on the three areas informing the central research question, which emphasized descriptive, interpretive and conceptual elements. The interviews ranged from 45 minutes to 2 hours depending on how much participants wanted to share. I kept a journal (see Appendix E) where I took notes during and after the interview to reflect on what was discussed and how I felt during the interview. The interviews were audio-recorded and transcribed (and video-recorded when consent was provided) and saved to the zoom cloud, and then transferred to a password-protected cloud storage account on the MacDrive.

The interview schedule (see appendix A) was devised to be flexible to help guide the interviews. The interview questions aligned to answer the research questions in the study (see page 24). The interview guide was not always followed in sequence and not all of the questions were asked. This is because the interview guide followed a Gadamerian approach to make the interview more conversational and flow with the thought-process of the participant. The beginning of the schedule focused on 'get to know you' questions such as "tell me about yourself" and "how would you describe yourself" as well as demographic questions. This is recommended to facilitate rapport to make the participant comfortable, which tends to produce richer data (Smith & Shinebourne, 2012). Also, the interview guide was utilized during the interviews to allow for rapport building with participants. When crafting the schedule, I was able to think about how certain questions might be phrased and sequenced, while giving attention to conceptual and perceptual topics. Additional prompting and probing questions were devised to encourage participants to talk more in depth and elaborate on further points. Within IPA, it is recommended that questions be open and expansive and consist of a combination of descriptive, narrative, structural, evaluative, circular questions, as well as probes and prompts (Smith et al., 2009). I also made efforts to avoid leading, over-empathic, and closed questions (Smith et al., 2009). The questions were discussed with my supervisor which was helpful to omit unnecessary questions and rethink some of the problematic and redundant questions.

Analysis

Smith, Flowers and Larkin (2009) describe IPA as an iterative and inductive cycle moving between ‘the part and the whole’ or the ‘particular to the shared’ and the descriptive and the interpretive (p.79). In addition, they do caution that the IPA analytical process may not always be linear and that the experience can be complex. From their view, there is no right or wrong way in doing the analysis and allow room for innovation and flexibility. The IPA analysis (see table 4) includes the following steps: (1) reading and re-reading (2) initial noting (3) developing emergent themes (4) searching for connections across emergent themes (5) moving to the next case (6) looking for patterns across cases. Below I provide a table of the main steps of the analytical process, followed by a table of how I engaged in each step.

TABLE 4 – Main steps of the IPA analytical process
1.Reading and re-reading
2. Initial noting (descriptive, linguistic and conceptual comments)
3. Developing emergent themes
4. Searching for connections across emergent themes
5. Moving to the next case
6. Looking for patterns across cases

TABLE 4: Main Steps of the IPA Analytical Process adapted from Smith, Flowers and Larkin, 2017

TABLE 5- Main Steps in the IPA Analytical Process

Reading and **Re-reading**	Each transcript was read 2-3 times to allow for full immersion in the original data. Re-reading allows for active engagement with the data and allows for a structure to develop (Smith, Flowers & Larkin 2009). Here, structure refers to chronology of events, life history and explanations which shift from the general to the specific. I also listened to the videorecording once on its own, and a second time while reading the transcript. By watching the videorecording, I was able to take note of non-verbal communication patterns which I included in my exploratory notes. During this step, I carefully checked and corrected the transcript by listening to the recording and reading through the transcript. I accounted for patterns of repetition, filler words, tone, and other elements of speech. To do this effectively, I would pause the recording and re-listen and re-watch parts of the audio-recording.
Initial Noting	This step of the analysis includes semantic content and language use on a very exploratory level (Smith, Flowers & Larkin, 2009). I aimed to create a comprehensive set of detailed notes and comments on the data to engage in a close analysis. This process includes 3 levels of exploratory comments: descriptive, linguistic and conceptual which I coded in different colours throughout the transcript. As I moved through the transcript, I commented on the ideas shared by the participant. I organized this by using the review function to input the initial exploratory notes on the right-hand side, which were colour coded to represent linguistic (blue), conceptual (green) and descriptive (purple) notes that I was making. I also included emergent themes within the transcript on the left. Following this, I attempted to employ a suggestion by Smith, Larkin and Flowers (2009) of decontextualization which is to bring the detailed focus to the participants' words and meanings. I did this by reading sentences backwards to stay as close to the explicit meaning expressed by the participant.
Developing **Emergent** **Themes**	In this step I looked for emergent themes through a process of reduction. My aim was to reduce the volume of detail (Smith, Flowers & Larkin, 2009). I analyzed the exploratory comments to identify emergent themes by focusing on discrete chunks of the transcript. The themes took the form of short phrases (i.e., loss of self, reflections on childhood; feeling disconnected from a parent) which speak to the psychological essence of that piece of the transcript. The themes represent the hermeneutic circle, where I am taking into account what the participant is saying, but also my interpretation.

	I listed the emergent themes from the first transcript into an excel spreadsheet and clustered the key themes. Each theme was accompanied by short verbatim extract from the transcript. I then reduced the themes by distilling them down into superordinate themes and subordinate themes. I repeated this process for the remaining interview transcripts. I then created a comprehensive master list (roll up) of superordinate and subordinate themes for all the transcripts.
Searching for connections across themes	In this step, themes were drawn together based on abstraction (similar themes put together), polarization (opposite themes) and subsumption (a subtheme taking the place of a superordinate theme). There are 2 ways to look for connections. I followed the first way. I typed all of the themes in a chronological order into a list. I eyeballed the list and moved themes around to form clusters of related themes. Some themes naturally went together, others repelled, and some fell away.
Moving to the next case	The next step involved moving to the next participant transcript and repeating the process. I attempted to treat each case on its own terms to allow new themes to be developed and maintain a commitment to the idiographic approach.
Looking for patterns across cases	This stage involves looking for patterns across cases. I typed out the list of superordinate themes and cut each one out, so it stood alone. I then laid them out on a table to see what connections could be made across cases. Subordinate themes were drawn together, and this resulted in a number of superordinate themes for the group. Superordinate themes that were not recurrent in the majority of the transcripts were discarded. The final result is presented in a master list (Appendix G) of illustrating themes for each participant nested within superordinate themes.

Trustworthiness, Validity and Quality

To ensure trustworthiness, I relied on Lucy Yardley's (2000) four principles for assessing the quality of qualitative research. Yardley presents the four principles as: sensitivity to context, commitment to rigour, transparency and coherence, and impact and importance. Next, I will discuss how I engaged with each of these principles.

The first principal, *sensitivity to context,* is centered upon close engagement with the accounts of one's lived experience. In addition, this principle takes into consideration the time period of the research study as well existing literature on the research area. I made several efforts to ensure that I was sensitive to maintain an idiographic focus throughout the study. I also engaged with literature on this topic area to draw upon what was currently done and address gaps to see where my study could be situated. Sensitivity to context is also demonstrated in the relationship between the researcher (myself) and the participants by demonstrating empathy, negotiating the power relationship dynamic, and giving voice to the participant. I demonstrated this by acknowledging my research position and attempting to maintain a double-hermeneutic approach throughout the interview process and the analysis stage to fully immerse myself in the data. Smith, Flowers and Larkin (2009) suggest that the decision to employ IPA as a methodology demonstrates sensitivity to context due to such a close engagement with the material at an idiographic level. Overall, I maintained efforts to remain sensitive to the data collection and analysans and the participants individual accounts.

The second principle, *commitment and rigour,* was demonstrated by giving special attention to each participant during data collection. There is also a considerable amount of personal commitment and investment by the researcher to ensure the participant is comfortable during the data collection process. I attended a training hosted by John Smith, the founder of IPA, to acquire the necessary skills to conduct IPA research at a high-level. A segment of the training included an interactive component where we practiced playing the role of the researcher and the participant during the interview process. Also, there was an effort to keep a balance of separateness and closeness throughout the interviews (Smith et al., 2009). As I developed a comfortable research persona for myself, I learned to find a balance between listening, probing and picking up on verbal and non-verbal cues from the participant. Rigour was also maintained by selecting a reasonable homogenous sample which matched the research question. I also maintained rigour by conducting a thorough analysis attempting to move from the particular to the shared and from description to interpretation. The analysis led to three major themes present for each participant. I attempted to include excerpts from all participants to illustrate each theme but given the size of the sample I gave priority to the most poignant excerpts that could best emphasize the theme being discussed.

The third principle, *transparency and coherence,* was demonstrated by offering detailed accounts of the study procedures, including how participants were selected, construction of the interview guide, and steps used in the analysis. I also used tables to provide more detail on these features. I also maintained transparency by logging my reflections and progress during the research process in a research journal (see Appendix E). I then integrated portions of the research journal throughout the thesis, as represented by reflexive boxes, to demonstrate my thoughts and ideas throughout.

The fourth and final principle, *impact and importance*, addresses whether the research tells the reader something interesting, important or useful (Smith et al., 2009). Often this is evaluated based on how the information is disseminated to the public. As the project progressed, there were (and will continue) to be opportunities to share the project findings with international IPA networks. I also intend to the leverage the results of this research to inform practices and policies regarding young caregivers, specifically young caregivers affected by ADRD by publishing the findings from my doctoral dissertation in relevant academic journals. In addition, I plan to engage in knowledge mobilization activities to share my findings with professionals working in the sector, the participants of the study, and other communities who may find this work of interest. Such activities will include developing an executive report, presenting at young caregiver conferences, and developing relevant content for the Instagram page.

Limitations

First, and probably the most significant limitation, is that this research took place during the COVID-19 pandemic. Many of the initial plans were revised in order to locate and recruit participants. As mentioned, I utilized social media to recruit participants rather than in-person interviews (as initially planned). Given that the interviews took place on Zoom, there were barriers to true ‘interpersonal’ connection and communication that one would hope for in qualitative interviews. More specifically, there were limitations in building in-person rapport and reading body language at a high level. At the same time, this method did save time and was more convenient for participants, and they were more likely to participate, because they did not have to leave home.

A second limitation were the time constraints and competing demands that caregivers experienced. This implicated the study as I was unable to complete multiple interviews I initially planned. The majority of caregivers informed me that subsequent interviews would not be conducive for them. As such, I was unable to obtain some of the advantages of conducting follow-up interviews that phenomenological studies offer, such as addressing gaps in data and or gather additional data that may not be expressed in the initial interview. This would have added depth and richness to the study and a layer of exploration that has not previously been done in young carer research. The need to respect the time constraints of the participants also impacted my ability to do quality checks/member checks throughout the research process. However, the majority of the participants are interested in a report of the findings once the study is complete.

Another limitation is being the sole researcher on a qualitative research project. In IPA, researchers have many roles- reporter, recorder, interpreter, writer, interviewer. Given that the expectation of an IPA researcher is to engage in multiple roles, the process is one that demands reflexivity and authenticity. Maintaining a double-hermeneutic approach alongside bracketing my own experience demands a high-level of skill. Further, engaging with the data at an individual level and across each case is a thoughtful and demanding process because you want to provide/gather a rich account. The process of interpretation of any kind will be subject to limitations as we will always have some form of bias to put aside. There were instances where my naivete as a novice researcher challenged me, but also made it easier to remain objective throughout the process.

As aforementioned, a critique of IPA is that the results are not generalizable to the wider population. Although this is not my intent given the aim of the study, I acknowledge that a study of this nature will be subject to limitations and perhaps reach. At most the study can help to inform theoretical and contextual understandings of young caregivers affected by ADRD given that it highlights the individual nature of the participants experiences and individual needs. Also, the sample was selected based on the participant’s capacity to provide data. The majority of participants had an active voice on social media and were therefore not considered completely hidden. (Stamatopoulos, 2015)

Findings

The following three chapters present an overview of the three superordinate themes that I identified in this study. The superordinate themes were identified as occurring with the greatest frequency across cases, which means they were present in at least 50-75% of the cases (see chapter 3, page 26). The first superordinate theme is **The Experience of Managing the Impact of ADRD**. This theme highlights how ADRD and caregiving impacts the lives of YACs and how the ways YACs described the impact of ADRD. Related subthemes include *Coping: I'm alright, I'll manage; Caregiving and Systems Collide: They Don't Understand, The Missed, and They are Still Somebody.* The second superordinate theme is **Caregiving: Me, Myself and Us**. Broadly, this superordinate theme addresses the relationship between the participant's personal identity, caregiving identity, and maintaining personhood. The sub-themes include *Who Am I? I Need Support Too, How Do I Make Sense of This: Learning as I go,* and *I am my Mother/Father's Keeper*. Finally, the third superordinate theme is **Turning Points: Dealing with Adversity.** This theme highlights the ways participants made sense of adversity and responded to hardship or disruption in their lives. Related sub-themes include *Life Interrupted, I Feel Broken, and Caregiving in Silence: A Lonely Road.* Within this superordinate theme, there was one subordinate theme that I identified, **Polarity in Caregiving: A Devastating Gift**, which draws attention to the juxtaposition in emotions described by participants when describing psychological and emotional challenges.

The superordinate themes inform the study phenomenon and answer the research questions (see chapter 3, p. 4) most closely, while the subordinate theme helps to look at the phenomenon "sideways" (Smith, Flowers & Larkin, 2009). In other words, the subordinate theme is germane to the study phenomenon and does have a bearing; albeit is loosely connected. Table 1 provides a visual representation of each superordinate theme and related subthemes, as well as subordinate themes if identified. (The master list provides a representation of the prevalence of the superordinate and subordinate themes across all 12 cases). Each of the findings chapters will be phenomenological (experiences of YACs) and interpretative (the meaning of the data through my own awareness) in what I hope will be a comprehensive overview of the data.

Table 6: Superordinate Themes, Sub-themes and Subordinate Themes

Superordinate Theme	Subthemes	Subordinate Theme
1. The Experience of Managing the Impact of ADRD	Coping: "I'm alright, I'll manage"	
	Caregiving and Systems Collide: They Don't Understand	
	"The Missed"	
	"They are still somebody"	
2. Caregiving- "Me, Myself and Us"	"Who am I? "	
	"I Need Support Too"	
	"How Do I Make Sense of This? Learning as I go"	
	"I am my Mother/Father's Keeper"	
3. Turning Points: Dealing with Adversity	"Life interrupted"	
	"I Feel Broken"	Polarity in Caregiving: "A devastating gift"
	Caregiving in Silence: A Lonely Road	

Chapter 4: The Experience of Managing the Impact of ADRD

4.1 Overview of Chapter

As mentioned, the purpose of this research study is to amplify the voices of young adult carers (YACs) affected by Alzheimer's disease and related dementias (ADRD) by examining their descriptions, meanings, and attitudes about caregiving and ADRD. As such, the aim of this chapter is to present a descriptive account of the first superordinate theme that I identified: **The Experience of Managing the Impact of ADRD**. This theme includes the following sub-themes: *Coping: "I'm alright, I'll manage," "Caregiving and Systems Collide: They don't understand," "The Missed,"* and *'They are Still Somebody."* These sub-themes will be discussed individually using illustrative quotes from participants. I have also included reflexive commentary throughout in the form of reflexive boxes to demonstrate my thinking process, reactions and reflections. Finally, a summary of the main points, with attention to their relevance to the research questions, is provided at the conclusion of the chapter.

4.2 Table 7: Superordinate Theme 1 and Related Subthemes

Superordinate Theme: The Experience of Managing the Impact of ADRD	Subthemes
	Coping: "I'm alright, I'll manage"
	Caregiving and Systems Collide: They Don't Understand

	“The Missed”
	“They are still somebody”

4.3 Superordinate Theme 1: The Experience of Managing the Impact of ADRD

The first superordinate theme reviews how YACs discuss managing the impact of ADRD. YACs address their perceived challenges and benefits associated with their caregiving role and how ADRD has impacted their lives across several dimensions. The meanings of the four sub-themes which I identified (i.e., Coping: *“I’m alright, I’ll manage,” “Caregiving and Systems Collide: They Don’t Understand,” “The Missed,”* and *‘They are Still Somebody*) are discussed in detail to highlight the many ways YACs respond to the impact of ADRD. Taken together, the sub-themes interconnect to create a particular experience of caregiving for YACs. Overall, this superordinate theme suggests that there are significant interactions with the public (people and spaces) and societal systems that implicate the nature of caregiving for someone with ADRD.

4.3.1 Coping: “I’m alright, I’ll manage”

Participants underscored the importance of coping while caring for the care-recipient with ADRD. In this context, coping was often described in terms of planning, negotiating one’s own life alongside caregiving responsibilities, and various communication techniques to respond to the needs of the care-recipient. There was a great deal of variation in coping techniques described by participants, which were often due to the specific stage of ADRD experienced by the PWD. Participants also discussed the strategies and techniques they developed, as well as the techniques they learned from others. For some, learning to find balance in life was one of the many ways that coping was described:

"I try really hard to find the balance, and I have the luxury of not being the primary caregiver so if I have a couple of weeks where my role in helping them is like super maxed out, then I can just say like I'm not going out for a week, I just live in my space. A little bit like you know boundary setting, I guess. It's been hard for me. Because there was a time where I would – no matter where I was, [no] matter what I was doing – I would pick up a phone call from my dad and…. assume that there was a problem. And so, you know he now will text me, 'no emergency." [YC3]

For YC3, coping was expressed in terms of learning to set boundaries, although difficult at first. Other participants expressed that learning to find balance included pausing certain aspects of their life. This was particularly true for YC6, who experienced challenges with having time to manage her own life. Here, YC6 emphasizes having to put her life 'on pause':

"So just trying to find a balance with taking care of the important stuff. Making sure the bills are getting paid. Finding the balance between managing life and caregiving. And then you know, it's tough because I know for me and my brother our life was kind of like on a pause. You know, during a time where you're going out, where you're figuring your own stuff out and you kind of don't have the time to do that because you have the responsibility of caring for somebody that is just declining." [YC6]

In this context, coping with ADRD includes finding the balance through boundary setting, and learning to manage one's own life while responding to competing demands. This is true irrespective of whether the YAC is in the primary or secondary caregiving role. For YAC3, she views being the secondary caregiver as a luxury because she can set boundaries, although found that to be difficult at first. On the other hand, for YAC6, she is expressing that the demands of the caregiving role are so significant that she had to put her own life on hold.

Some participants described the importance of storytelling as a method of coping. Here, storytelling was a way of entering into the reality of the care-recipient and also served as a helpful technique to mediate the impact of ADRD in their own lives. Participants discussed storytelling as valuable in three ways: 1. as a method of managing or preventing disruptive behaviours, which also includes; 2. playing along in the PWD's reality or lifeworld and; 3. to navigate situations or convince themselves that things are going to be okay. For example, YC7 describes her experience with this:

"She was on long term disability after that and my mom would constantly ask, 'why am I not going back to school?' 'Why am I not teaching?' And I had to sort of make up stories for her like, 'oh you retired early' or 'they let you retire early' or 'summer break started early.' It was always kind of a different story. But you know when somebody repeats the same question with dementia, you just try to redirect them; try not to prove them wrong. Just create a positive space of interaction. You know changing the subject and eventually she just forgot that she needed to go back and teach." [YC7]

In contrast, YC7, who lived abroad for many years, also described that storytelling can be counterproductive in some ways. She described that the stories she told herself contributed to naivete and mismanaged expectations. In this particular example, she says how her stories contributed to unrealistic expectations that her mother could travel safely internationally and unattended. She says:

"I feel like you just you make situations up in your head that you think will work out, but in reality, it's like completely the wrong thing to do. So, she flew through Amsterdam and I think she had misplaced time and events and she thought that she was an art teacher, and she did a travel abroad trip with them [students]. She was trying to corral students to get on the plane, she might have seen like a group of kids and like thought they were her students. That should have never happened. She should have never gotten on [the plane] in the first place. So, I think being this young caregiver I was naive, definitely naïve. Just like 'oh yeah, this will go according to plan' and I kind of made these expectations like 'oh yeah, she'll just land in Amsterdam.' 'She'll call me from the airport, she's capable of using her phone,' and it all backfired. [Y7]

While YC7 emphasizes the counter-productive nature of storytelling, YC10, for example, describes how she used storytelling to respond to challenging behaviours. When asked to elaborate on this experience, she highlights how in difficult caregiving moments, storytelling was a helpful technique to respond to moments of agitation in the PWD. In this example, she used storytelling to calm her father down during a critical moment before being institutionalized:

"Here's the story that we told him- we were going to put a chair in on the stairs so that he didn't have to deal with the stairs because he was getting so angry and frustrated with the stairs and scared on them and it was so hard to go up and down, especially by the end of the day. So, we told him there was going to be a lot of construction, so we needed to go someplace. So, this place is going to be flat there's going to be no stairs. But that was really hard, and, in some ways, turned out to be true." [YC10]

Some participants described how they would enter the care-recipients' reality through storytelling. This seemed to be particularly helpful with managing difficult or challenging behaviour. YC10, for example, conveys that she found it helpful not to resist her father's reality. She says:

> "I think there was like a couple of other dementia types in there, but it [the center] was really for Alzheimer's individuals. And there were men there, because so many places have a lot of women, it was just it was great for him. He called it his work and it was great for us because they serve lunch there." [YC10]

YC11 also discusses her experience with entering her mother's lifeworld. When asked to elaborate on this experience, she describes how existing in two realities (hers and her mother's) was confusing at first. Here, she says:

> "It's very easy to fall into the world of the person experiencing Alzheimer's. So, with my mom we don't correct [her] like we don't tell her things 'like remember?' or 'No mom like we're here now' we don't say it in a scolding type of way. We instead just softly let her know what's going on, but it is easy in that you know once you're in someone's world with Alzheimer's to also get a little confused yourself and it's funny because I will notice that happening to me every so often." [YC11]

The perceptions of YACs who utilized storytelling emphasize that there is value in non-medical caregiving approaches. The participants in this study largely felt that storytelling was a useful technique to respond to the impact of ADRD. Here, stories were constructed by the YACs to regulate the PWDs emotions and respond to their challenging behaviours. Participants emphasized the importance of non-interference (i.e., not resisting and not correcting), but rather entering into the story or reality of the care-recipient. This also served as an approach to reduce agitation and other disruptive episodes from the PWD. While in some cases, participants emphasized non-interference, in others, they actively interfered by offering a fabricated reality (as in the case of YC10 using a story to avoid agitating her father prior to being institutionalized). In most cases, this was not a technique that was innate to the YAC's, but rather something that was developed throughout the process of caregiving.

Overall, the young adult caregivers I interviewed for this study described their experiences in terms of *coping*. Coping involved finding ways to set boundaries around their caregiving responsibilities. At times it also involved ‘telling stories,’ or finding ways to enter into the cared-for person’s reality, in order to ease agitation and distress. In their descriptions of ways of coping, participants highlighted one aspect of the nature or essence of caregiving, which is the persistent efforts to minimize burden of caregiving in their own lives.

4.3.2 Caregiving and Systems Collide: They don’t Understand

Participants described that they managed ADRD by navigating through external or societal systems. These systems, as I interpreted them, consist of three interrelated levels (i.e., micro, meso, macro) which include the public, the workplace, and social and medical systems as well as broader social policies. The ability to navigate through societal systems depended on the participants’ previous exposure to health and social care systems. As such, there was a range of competency levels when navigating these systems which are reflected in the following quotes. YC5, a caregiver for her mother, who did not have previous experience navigating through the medical system, described her experience with bureaucratic challenges:

“I’d say a bit of a struggle because you're going through loops. You're going through a lot of [red] tape to get to get something done. Even when she [her mother] was in the hospital…. that was also an emotional strain on the whole family. But luckily, everything at the end panned out well and are able to get everything situated.” [YC5]

Relatedly, YACs discussed the limits of medical knowledge in the context of dementia care. These limiting factors interactions impacted how YACs interpreted and utilized advice and information provided by medical professionals. Here, YC2 discusses an experience with questioning the recommendations of medical authority:

“For example, I will mention [that] he's had hallucinations here and there. But they'll just be like okay we might have to consider putting him on like anti psychotics and then they'll go into the side effects of that, but we'll just kind of be sitting there- like is it really at that stage? Because they don't communicate that to us.” [YC2]

YC2 then went on to discuss the relationship with the care provider and being confused about their prognosis and evaluation. She says:

“I want to say it's a good relationship, but also, I feel like half the time I’m also kept in the dark. Sometimes they won't really tell me what's going on, but then I’ll get a call every now and they'll give me an update and I’ll be kind of confused as to how much do I really know? And then I’ll see my dad's condition and it's like, well now, how much *should* they know? And it just gets really confusing because they don't really tell us where he is at. Like we tell him, we've seen him have like hallucinations and all of a sudden, it's jumped to antipsychotics and, from what I know antipsychotics are given when it's much further down. And I’m just sitting there thinking-but I don't think he's there.” [YC2]

For YC2, barriers to understanding or comprehending medical knowledge were at times tied to the complex communication with medical professionals. Alongside these interpersonal interactions, some participants discussed their perceptions of engaging with the broader health and social system as a caregiver. YC12, a university student of South Asian descent, for example, discusses his perceptions of navigating institutions such as in long-term care and retirement homes.

“I mean just look at retirement homes- no compassion no patience. My mother and I, we visited some retirement homes just to take a look and see what the options were. We were both disgusted what was available. First of all, the place was so dark and gloomy and not suitable for living. [It] looked like a prison more than a home. But also, the way she [the manager] was dealing with people- like with other residents- just showed exactly the kind of care that was being offered there. Just not caring like, this is the money business, not the patient’s business. We don't have time for patience or compassion it's just a money-based capitalist society.” [YC12]

The perceptions of YC12 emphasize that there is a need to revisit the taken-for-granted assumptions about institutionalization for people with dementia. Often, it is assumed that people with dementia, and often in the later stages, should be placed in a memory care unit or a nursing home. However, YC12 rejected the notion of institutionalization and described it to be part of a capitalist regime. In fact, the majority of the participants opted to provide care for the PWD at home, rather than institutionalize them (with the exception of YC10 when caregiving responsibilities became too great). For participants, the decision to institutionalize was informed by a range of factors, including access, cost, family values, culture and the relationship to the care-recipient.

For some participants, issues of access, inequality and equity were also emphasized. For example, YC4 discusses how inequitable public systems implicate opportunities for social engagement for persons with dementia, as well as her experience dealing with inequity as a caregiver in ‘small and big ways.’ For YC4, her experiences were especially challenged by the fact that many public spaces, such as sports arenas, were not accessible for her and her mother:

“My season tickets are in the very front row. So, any building should be accessible, regardless of whether you're in a wheelchair. Because of [COVID] protocols, we cannot use the elevator to get down to the floor to get to our seats and there is no family restroom in this arena. When my mom has a bathroom accident, I’m now at a public restroom having to walk through as quietly as possible, using the bathroom and change her underwear. But when you're thinking about it, you should have a family restroom on every corner regardless, because you don't know what people need” [YC4]

YC4 went on to describe how the language of policies can be exclusionary. She shared a story of advocating for herself as a caregiver during an interaction with an employee at the sports arena:

“So, even in the language of how we write policies, you're including and excluding people. Well, I bring a diaper bag, I have to explain that I don't have a child with me, this is my mom. You don't have any close parking that's not handicap. So, I can't bring my mom, she can't walk up. I technically cannot bring a diaper bag, unless I get a clear bag and now [there’s] the dignity of preserving all of her stuff. Anyway, it's a really specific example, it happens in small and big ways all the time. It's just infuriating. It's like if people learn the power of more inclusive language, we could be on top of people's ignorance. I just need for people to be more aware of other people beyond their able-bodied perspectives and lives. That’d be helpful.” [YC4]

Other participants also discussed their views on navigating public spaces, such as restaurants. The descriptions of their experiences affirm that their views on the public (people and places) have changed since becoming a caregiver and encountering stigma and feelings of embarrassment. Here, YC6 explains her experience:

“We went on vacations together, we tried to keep it as normal as possible. My dad liked to go to restaurants, so we try to do that. So, we would either go to have breakfast at IHOP because he liked having breakfast at IHOP and then there was Japanese hibachi. He loved it. If he was kind of staring, we would just let the people in the vicinity no he has Alzheimer's. So, if he's just staring at, he's not you know trying to do any ill will and to not feel embarrassed about it because it's his experience." [YC6].

Similarly, YC10 discussed her experience with navigating public spaces. In this context, she draws a comparison between how members of the public tend to perceive her father and her perceptions of her father as his caregiver. It appears that her feelings of angst are associated with the public's inability to truly grasp the realities of her caregiving role.

"So sometimes it's taken seriously, but it's not taken seriously. So, for a while we would go out to things and people say oh your dad seems okay. It seems all right, but you didn't see him like put the coffee mug in the microwave, put those like little plates on top of it, and then try to pull it out later with the thing on and have it spill all over. You don't see some of these little things that go on because *-he just never looked sick*. He never looked like something is wrong and to hear people be like "well, he seems okay." And you're like. "are you kidding me!?" [YC10]

For these participants, navigating the public as a caregiver brought upon new social interactions and encounters. The social responses and public stigma generated feelings of embarrassment, and in some cases, indifference. The participants emphasized that the public only sees one dimension of the care-recipient's reality and not the complete caregiving dynamic that occurs *"behind closed doors."* It is evident that when YACs perceive their personal caregiving reality as 'hidden' it can strongly impact how they engage with the general public.

Another system that YACs also expressed concern about navigating was the workplace. Here, the main concern is that there is a general lack of understanding, compassion and empathy from employers and other authorities in the workplace for young caregivers. Further, their concern raises questions about how YACs' needs compare to other prioritized populations in the workplace (i.e., pregnant women, employees on long term disability, middle aged caregivers). From the perspective of YC3, young caregivers are reprimanded more harshly than middle-aged caregivers in the workplace:

“I think that the implications in terms of employment is that younger caregivers are more likely to have negative consequences if they have to miss work or they'll be reprimanded or even later lose a job because it's less expected to be a caregiver when you're so young. So employers don't have the same understanding as they do for maternity leave or, if you are older and caring for a parent or caring for a spouse.” [YC3]

YC3 went on to explain a specific example of perceived neglect in the workplace. She says:

“I’ve been at my job for four years and my supervisors really have no idea. And it's not that I wouldn't share that but, they don't think of us as humans. They don't care about people's personal lives. And, so it's just been, I’ll just take a day off and I’ll take them [care-recipient] to an appointment, but they don’t know the extent of it. So yeah, I guess that that’s, for all young caregivers, probably one of the biggest challenges.” [YC3]

When describing their experience of navigating systems, participants emphasized their frustrations and concerns when such systems were less inclusive for caregivers and people with dementia. They described navigating systems to include issues of access, stigma, lack of empathy in the workplace and interactions with medical and care institutions, many of which created challenges for them in their caregiving role. These descriptions highlight that the nature of caregiving for someone with ADRD is often challenged by the overlapping of structural systems which create limitations to social participation, and constraints and barriers for caregivers.

4.3.3. “The Missed”

Participant interviews highlighted that YACs were challenged by their perceptions of what they had missed while managing the impact of ADRD. In this context, ‘the missed’ refers to missing out on opportunities, missing their loved one, and also missing early cues and warning signs while navigating the effects of ADRD. For some participants, ‘the missed’ referred to mismanaged expectations, which contributed to feelings of unpreparedness. YC5, for example, describes how intense the process of caregiving has become:

"I wasn't expecting when it when it got really difficult. I wasn't expecting how intense it would be or how it would really impact the whole family. At the beginning, she did get symptoms, when it got really bad, of hallucinations and a difficulty connecting certain things. So that took a heavier toll on the family. That that was very [intense] because at that moment when they're developing the symptoms, you're also trying to connect to what this person is, how their personality is and what is being affected by this illness. That was our difficulty- trying to navigate through and overcoming that." [YC5]

Other participants described 'the missed' as missing out on social and educational opportunities. When asked to elaborate on how she missed out on work and school-related opportunities YC2, a college student, expressed concern with time constraints, which limited her opportunity to take work placements that were out of town:

"I couldn't take on opportunities because of my parents or I got rejected from those [said opportunities] when I mentioned the background of my parents and why I wouldn't be able to move." [YC2]

For other participants, it was difficult to see their peers engaging in age-appropriate activities and opportunities. YC5, for example, acknowledges that while caregiving is gratifying, she did experience challenges with putting the needs of the care-recipient first. During the interview, she emphasized, quite emotionally, the urgency and despair she felt when met with social opportunities that she could not accept. The statement, *"there's no one to take care of dad"* was repeated multiple times which emphasized that her caregiving role needed to be prioritized over social opportunities. Here, YC5 explains this:

"I feel like I sometimes I put people's needs before my own a lot of the time and that's really hard. I feel like being a young caregiver I see my friends doing things and going out and living their lives and stuff like that, and I just feel like I've kind of missed out a little bit on like my early 20s." [YC5]

YC5 went to describe an example of how she experienced social constraints. She emphasized that although the social activities might be considered normal or ordinary, they are very meaningful for her:

"Right after class my friends would be like 'hey like let's go grab a bite to eat on campus' or 'hey you want to stay after school and study?' And I'm like 'no guys like I gotta go home and take care of dad, there's no one there.' So definitely missing out on stuff like that. And then like overnight trips when my girlfriends go or something, like, ‘hey, let’s go here.’ I’m like, well there’s no one to take care of dad.” [YC5]

In contrast, for some participants ‘the missed’ was expressed in terms of being ill-prepared for the responsibilities of caregiving. They described missing early cues and warning signs associated with ADRD, which led to underestimating or overestimating the capabilities of the PWD. For example, YC7 acknowledges her naivety, and in some cases, lack of competence, which contributed to neglect of her mother’s condition:

“Because I didn't want to live at home, and I don't live with her and I was being a stubborn millennial right. She had a car and I told her to come to my apartment and meet me for lunch. She drove and, I remember, I saw her outside and she drove past my house and then she drove past again. I was getting so frustrated because I kept yelling ‘Mom, I live here!’ I called her on her cell phone, and she didn't answer. And I look back at that day, I think ‘she should not have been driving.’ I only lived in that place for three months and then I moved back home with her.” [YC7]

Similarly, YC10 mentions that, in hindsight, she might have been somewhat naïve during her caregiving process which led to feelings of disappointment. Here, she acknowledges that she experienced feelings of ambiguity and uncertainty which contributed to compromised judgement:

“At this point he had been prescribed some Ativan to help with his anxiety and agitation. I will say, looking back on some videos, I can see where he was absent-minded. Maybe that's something that should have been done earlier. But I think when you're in it you don't realize what's going on. You’re like, ‘maybe that's why he was behaving that way’ or ‘maybe that's why he was flicking at his shorts’. We didn't pick up on it, and that has been very hard to think about because you tried to do so much and you're disappointed in yourself that you didn't realize it. But you're in the midst of it and you're trying to go through life.” [YC10]

Overall, participants described their caregiving experience in terms of missing something or someone. Here, missing something refers to a lack of competence, awareness of early warning signs, skills or school-related or professional opportunities. On the other hand, missing someone refers to social connections with peers or the relationship with the care-recipient. This speaks to the immediate and anticipated feelings of loss or lack that can occur for YACs, which can contribute to feeling of loneliness and incompetence. As such, this theme emphasizes that, for YACs, there are conditions needed to feel connected and competent in their caregiving role. Overall, this theme highlights that the nature of caregiving involves navigating through and learning to overcome perceived individual shortcomings and adapt to a lack of meaningful peer interactions.

Reflection:
I was slightly apprehensive when I was discussing the idea of missed cues and early warning signs. While I wanted to probe further, I got the sense that this was very challenging for young caregivers to discuss. I wanted to know more about how/if they course-corrected, any potential impact on the relationship with care-recipient, and how they dealt with feelings of disappointment and perceived incompetence. I was conscious that I did not want to 'add insult to injury' so I tempered my probing in these instances.

4.3.4 They Are Still Somebody

All of the participants described the significance of maintaining the dignity of the care-recipient while managing the impact of ADRD. This was a very significant sub-theme as they emphasized the importance of maintaining their loved one's independence, preferences and identity. In doing so, they formed renewed and, in some cases, more intimate connections with their loved one although they had cognitive limitations. YC11, for example, shares her perspective on how she learned to view her mother and 'the disease' as two separate entities.

> "It was kind of muddled between me understanding her versus the disease. That separation has just gotten easier with time because I understand her better; I understand the disease better. But, overall, I just see it as something that's happening to her, it's not her. I think that's the thing that so many people have an issue with." [YC11]

For some participants, maintaining personhood was grounded in the ability to provide meaningful instrumental care. This was centered around maintaining their loved one's independence and identity by performing certain tasks. These tasks included being attentive to the preferences of the care-recipient, such as meals and activities. For example, YC12, a college student of South Asian descent, provides a compelling description on how he maintains the dignity of his grandmother through cultural care practices and what his perception of what excellent care looks like:

> “It looks like trying to do everything so that my grandmother's happy. That's what it looks like. So instead of feeding my grandmother cheerios, we'll feed her this very large breakfast that she's familiar with right. We're not feeding her cheerios- what she's unfamiliar with -no I will never give her something that is not related to her culture and our upbringing. It is being gentle whether it's not yelling at her or screaming at her or hitting her…it is being patient, even when she yells at us. You’re being kind [and] giving her good words. It's staying up late with her until she falls asleep. It’s dying her hair when no one will ever see her hair - that's what it looks like” [YC12].

The example of ‘cheerios’ suggests that sustaining care for PWD and their well-being includes being attentive to daily routines, particularly meals. In addition, it is tied to the notion of personalized and meaningful care practices, whether in public or in private settings. In this context, care practices are tied the broader meanings of culture, particularly South Asian heritage, family values and tradition given that past cultural traditions were connected to maintain the well-being of the PWD.

Similarly, YC4 emphasizes that the notion of dignity is important in her experience of caring for her mother. When asked about her thoughts on caregiving, she perceives that caregiving takes place at the front-end (what others can see) and not only in the back-end (behind closed doors). Here, the outward (public perceptions and attitudes) are a reflection of how well her mother is cared for:

> “However, caregiving is like- are you willing to be selfless enough and actually take care of and preserve the dignity of your mom [says name in first person]. Are you? Well, the answer is caregiving for me has been like- how do we make sure she gets everything she needs to be comfortable and safe? It has been like- how do I make sure that like other people know she's okay? Like actually a lot of caregiving on the front end of this was almost hiding, but it's like, no, my mom is eating, she has clean and fresh clothes, like I’m here. I might be flying every other week, but I am here because I think caregiving is also making sure that she is being cared for and not neglected.” [YC6]

The young adult caregivers I interviewed for this study propose that the experience of caregiving is related to *maintaining personhood.* Maintaining personhood involved caregiving in public and private settings, the ability to separate the 'person' from the disease and preserving the dignity of the care-recipient. They achieved this through instrumental tasks and activities that were personalized and meaningful to the care-recipient, even when cognitive losses and functional decline were present. The aim to preserve the remaining capacities of the PWD through personalized approaches indicates that YACs found value in the non-medical approaches to caregiving. Their efforts suggest that there is a need to challenge the dominant assumptions concerning people with dementia commonly associated with dependence, deficits and decline. In their descriptions of maintaining personhood, participants highlighted one aspect of the nature or essence of caregiving, which is the commitment to personalizing care practices, which focus on dignity and compassion, to maintain the well-being and quality of life for the PWD.

4.4 Discussion

The aim of this section is to consider the research findings in relation to extant literature in this research area. By engaging in a dialogue between the research findings and the existing literature, I discuss how my research can illuminate, counter or go beyond what other studies have found. By placing my work in a wider context, new insights emerge which will advance current understandings of research on young caregivers.

The first superordinate theme, ***The Experience of Managing the Impact of ADRD***, refers to not only managing the disease through instrumental tasks and activities of daily living, but also managing the impact of the disease as a caregiver. Typically, within the literature, the impact of ADRD is associated with costs or harms (Aoun, 2005; Bastawrous 2013; Earle & Heymann, 2012; Hoffman;

1998; Turcotte, 2013). Specifically, these costs include the economic, social, physical, and psychological consequences associated with caregiving. On the other hand, beneficial impacts of caregiving include resilience, maturity and an enhanced relationship with the care-recipient (Henry et al. 2018; Hogstel, Curry & Walker, 2005; Koerner, Kenyon & Shirai, 2009). While the findings of this study broadly echo the consequences and benefits in the literature, the depth of the accounts reveal unique details of how YACs manage the impact of ADRD.

4.4.1 Coping: "I'm Alright, I'll Manage"

Coping is a saturated theme, since all participants referred to some form of coping with managing ADRD as a young carer (see section 4.3.1). Previous caregiving research also presents coping as an important theme for caregivers managing different disease types. This research is largely informed by Lazarus and Folkman's theory of stress and coping, where coping is explained as a phenomenon that involves both cognitive and behavioural responses that individuals use in an attempt to manage internal and/or external stressors perceived to exceed their personal resources (Lazarus & Folkman, in Biggs, Brough & Drummond 2017). There are a handful of studies which have applied this model to assess stress and coping in young caregivers (Earley, Cushway & Cassidy, 2007; Lindgren, Pass, & Sime, 1990; Rose & Cohen, 2010). A common finding is that young caregivers cope by finding ways to self-regulate through listening to music or cooking a meal which helps to manage perceived burnout and caregiver strain (Earley, Cushway & Cassidy, 2015; Areguy et al., 2019; Gough & Gillford, 2020). In addition, young caregivers tend to utilize coping strategies informed by positive psychology, including social support, sense-making (finding meaning), emotion-focused coping, and mindfulness (Gough & Guillford, 2020; Pakenham, Chiu & Bursnall, 2007; McDougall & O'Conner, 2018).). Given that the coping literature considers young caregivers as a homogenous group, it is unclear if how young caregivers of persons with dementia cope differently compared to caregivers of non-dementia persons.

The participants in this study emphasized finding the balance as a key part of their coping strategies. Here, balance appears to mean finding balance between one's caregiving roles and their other identities. One participant, however, was explicit about making the sacrifice to accept that balance will not be found. Ultimately, this meant 'putting her life on pause' and emphasizing that she needs to adjust to the 'roller-coaster' of caregiving. Others discussed balancing their own life (i.e., social, work, partnerships) with the pressures and demands of caregiving. While the notion of balance is not thoroughly discussed in existing young carer studies, "finding balance" in family caregiving for older adults has been conceptualized through a "Finding a Balance Point" framework (Shyu, 2017). When this framework (Figure 3) was used to explore the balance trajectories of family caregivers of people with dementia, it was found that caregivers with a poor sense of balance experienced more significant emotional and physical challenges compared to caregivers with a good sense of balance (Liu et al., 2021). Here, balance points are referred to as 'recognizing competing needs (reactional or planning ahead), weighing competing needs (simulation, principle or dominance weighing) and taking balance strategies (i.e., preparedness, modify environment, managing behaviours, collaboration, altering schedule, engaging in self-care activities)' (Liu er al., 2021).

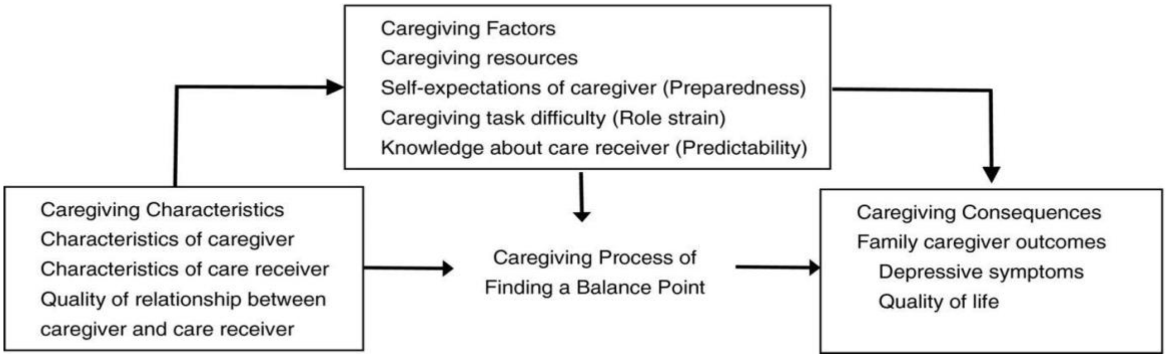

Figure 3- Finding the balance framework adapted from Shyu, 2017, p.3

YACs made efforts to find their "balance point" by recognizing and weighing competing needs. The majority of the YACs had no previous experience with caregiving which compromised their preparedness and capacity for weighing demands which ultimately lead to reactional planning and feelings of strain. YACs also emphasized that they learned to find balance by implementing balance strategies throughout the caregiving process. There was considerable variation in the degree of balancing strategies among the participants. Some were more flexible in their approach employing multiple strategies, while others applied fixed strategies depending on the needs of the care-recipient.

Storytelling was another coping strategy utilized by YACs in this study. YAC's reported using storytelling in two ways: a) initiating stories as a way of reducing disruptive behaviours and agitation in the care-recipient; and b) playing along in the realities/stories initiated by the care-recipient. Playing along in patients' realities is widely accepted and promoted as a contemporary non-pharmacological caregiving approach, particularly in dementia care. This form of therapy is known as 'Feil's Validation method' and was initially developed for people with cognitive impairments but has since informed interventions for people with a diagnosis of dementia. The therapy is based on the general principle of validation and the acceptance of the reality of another person's experience (Feil, 2014). This method has been widely used in the context of dementia focusing less on what is factually correct and more on validating the person's feelings and emotions (Feil, 2014; Grasel, Wiltfang & Kornhuber, 2003; Morton & Bleathman, 1999; Neal & Wright, 2003). While validation therapy has attracted a good deal of criticism for its potential shortcomings and tedious nature (Harper, 2017), such approaches have been found to be effective in enhancing the quality of life and decreasing the intensity of dementia-related behaviours (Neal & Wright, 2003; Logson, McCurry & Teri, 2007; Wager, 2017).

Most YACs were unaware that their storytelling techniques are widely recognized as validation therapy. In other words, most YACs incorporated validation therapy on their own with very little coaching and support. They described that not correcting their loved one or shaming them for their dementia-related realities was useful to manage difficult behaviours and agitation, particularly in instances where the PWD is feeling threatened or experiencing tension. For example, YC11 spoke about how confusing it can be to enter her mother's lifeworld as a caregiver. Similarly, YC 10 spoke about maintaining her father's independence by engaging in his life world. In both cases, the realities of the PWD were validated, particularly in moments of confusion or distress.

In the literature, this dementia-related reality is often described as the lifeworld of the PWD (McFadden, Frank & Dysert, 2008). Here, making sense of a person with dementia's lifeworld is to understand how they see the world around them and their point of view. Ashworth and Ashworth (2015) argue that aspects of one's lifeworld include selfhood, sociality, embodiment, temporality, spatiality, project, discourse, and moodedness. Given that dementia interrupts and slows down cognitive processes, each of the aforementioned dimensions will be impacted. In turn, this will create a new reality/lifeworld which is subject to misperceptions, hallucinations, misidentification and delusions. Arguably, by engaging in a PWDs new reality/lifeworld, it can shed light on how dementia alters a persons' sense of self, place, cognitive process, time and mood.

Ashworth and Ashworth (2003) suggest that the PWD's lifeworld is one which used to be denied and medicalized with limited opportunity for interpretation and validation. This is evident in the shift from a biomedical approach to a whole-person approach (and other humanistic approaches) in community and long-term care settings. Based on the participant's accounts, it seems that YACs are exposed to more contemporary and renewed conceptualizations of dementia care practices which emphasize personhood, citizenship and holism. For some participants, a holistic approach made the task of caregiving more bearable and satisfying. Rather than perceiving the PWD as deficient or lacking capacity, they embraced that engaging in the PWD's lifeworld prompted a new level of discovery and interaction during the caregiving process.

Reflection:

In reading Ashworth and Ashworth (2003), I was quite captivated by their suggestion that the caregiver becomes a phenomenologist of a kind, attempting to set aside their own presuppositions and suspend knowledge to enter their world objectively and with compassion. This parallels my objective as a researcher employing a double-hermeneutic approach- how I (the researcher) make sense of the caregiver/participant making sense of the phenomenon. In my view, observing the caregiver as a phenomenologist in their own right enhances the shared horizon between the researcher and the participant.

4.4.2 Caregiving and Systems Collide: They Don't Understand

Navigating systems is another saturated theme, as all participants expressed some difficulty navigating health and social systems alongside caregiving. In addition, they also expressed difficulty with navigating micro-level systems (i.e., family, intrapersonal) and meso-level systems, including the public and institutional settings. They discussed how such systems created barriers and obstacles which influenced their caregiving capacity and outcomes. This was reinforced by their perception of the broader neoliberal ideologies which inform caregiving policies and practices. Overall, the participants considered such policies to produce and reproduce individual barriers and largely underrepresent the concerns of young caregivers.

YACs discussed their problematic encounters with the public. Here, the public is defined as interactions with individuals, communities and groups in social and public settings. Arguably, this would align with a straightforward definition by Ford (2012)- *"the world outside the home."* YACs emphasized that their interactions in public with the PWD were often met with stigma and discrimination. Here, most of the stigmatised judgement of outsiders is consistent with the dominant stereotypes associated with ADRD, including a lack of understanding about the disease and misleading assumptions about the disease process. YACs concur that these dominant constructions of dementia have informed policies and practices which contribute to the lack of accessibility and social exclusion of people with dementia.

The YACs also emphasized the importance of making communities more accessible for people with dementia. The literature on accessibility in public spaces for people with dementia emphasize environmental barriers and the broader issue of social exclusion (Brorsson et al., 2011, Forbes et al., 2011). Several recent initiatives, such as age-friendly communities and dementia-friendly communities, are an attempt to address these issues by adapting the built environment to be conducive to everyday practices of care outside of the home (Brittan & Degnen, 2022). The majority of YACs discussed motivations for accessing dementia-friendly public spaces (i.e., zoos, restaurants, and sports stadiums) as necessary to provide adequate care as they perceived it. In most instances, the access to dementia-friendly public spaces/places positively impacted the relationship between the YAC and their loved one.

Beyond the public, institutions such as the workplace were difficult for YACs to navigate. While this issue has been discussed in extant literature, to date more emphasis has been on middle-aged adults and work-life-balance (Barr, Johnson, Nobel et al., 2019; Warshaw, 1992). Where discussions do include young caregivers and the workplace, the emphasis is on future career plans or trajectories and how caregiving might impede these plans or contribute to employment disadvantage (Hamilton & Adamson, 2013; Hill et al., 2011; Stamatopoulos, 2019). The participants expressed that there is a considerable lack of awareness in the workplace about the unmet needs of young caregivers compared to other groups. In many cases, employers were unaware that these young adults needed time off or other accommodations to attend to caregiving responsibilities.

Alongside this, YACs discussed challenges with navigating social and health care systems. A large majority of YACs discussed the bureaucratic nature (i.e., red tape) of the health care system as well as their encounters with medical authority. This is not unique to this group of YACs, as much of the literature speaks to how the medical-industrial complex can be challenging for caregivers to navigate (Estes, 1993; 2001). Further, the participants also discussed their views on institutionalization and the decision-making process guiding institutionalization. There are few studies which discuss this decision-making process from the perspective of young caregivers, however the literature does broadly highlight that the decision to institutionalize a person with dementia (PWD) is often complex and involves interaction between PWD and caregiver factors, as well as contextual factors relating to the caregiving situation (Caron, Ducharme & Griffith, 2006; Tew et al., 2010; Vandepitte, 2018). For most YACs, this was their first experience with long-term care or end-of-life decision making. While most YACs saw institutionalization as a last resort, YACs who identified as South Asian or African American resisted institutionalization. This is consistent with literature on filial piety and cultural perceptions of institutionalization which generally received familial disapproval (Chen, 2011; McLaughlin & Braun, 1998). For such groups, there is a cultural expectation that children have a duty to care for their family member at home. Although cultural care practices are not a new phenomenon, the cultural aspect of YACs affected by dementia is largely underexplored. Typically, studies exploring cultural aspects of young caregivers explore the differences in care practices between western and collectivist societies (Charles et al., 2010; Shahoo & Damodar, 2010).

YACs discussed their perceptions of the influence of capitalism and neoliberalism on caregiving. They discussed how these broader ideologies create systems which promote an individualistic approach to caregiving. For Wren and Waller (2017) the neoliberal culture encourages caregivers to abandon their autonomy and the cared for to lose their autonomy. In other words, under a neoliberal regime, personal responsibility is emphasized and the distance between individuals is heightened (Wren & Waller, 2017). Given that interdependence and care are essential to human life, neoliberalism may be considered antithetical to care (Wren & Waller, 2017). This view is reinforced in the literature which suggests that neoliberalism undermines the relational values of care - for example, attentiveness, nurturance, responsibility, compassion, meeting others needs by promoting care as a commodity (as purchased services) rather than a process (Koggel, 1998; Nedelsky, 2008; Tronto, 2010). To remedy this, Gilligan (1982, as cited in Okano 2016) suggests an alternative paradigm to care – an ethics of care- which builds a sense of collective responsibility that neoliberalism discourages. Ultimately, this raises questions about the ethical responsibility to and for citizens who are taking over the responsibilities of the state by providing free labour in the form of caregiving to those in need.

4.4.3 "The Missed"

It is well documented that young caregivers perceive that they miss out on opportunities due to caregiving demands (see above, section 4.3.3). The most prominent finding in this context is that young caregivers feel that they have missed out on their childhoods as a result of caregiving, growing up too fast or accelerated childhood (O'Dell et al., 2010; Charles, Stainton & Marshall, 2009; Wady, 2015; Stamatopoulos, 2018). For YACs specifically, the notion of "missing out" goes beyond a lost childhood, but extends to missing out on adult milestones, employment opportunities, academic opportunities, and partnerships or relationships (Stamatopoulos, 2018).

The findings from this study suggest that YACs for PWD appear to encounter similar concerns with missing out on social life and caregiving derailing potential future aspirations. The participants discussed being unable to entertain extracurricular activities or opportunities that might contribute to academic advancement. Several participants specifically mentioned being unable to take a work promotion or feeling conflicted about this decision. Although there is paucity of literature focused on how young caregivers function in the workplace, there are a handful of studies which explore the educational lives of YACs. An empirical case study by Day (2021) found that YACs in higher education experienced challenges with engaging/investing in educational activities due to the competing demands of caregiving. Similarly, a study by Kettell (2018) found that young caregivers often drop out of higher education, do not complete their studies and experience barriers and challenges to learning. Also, a scoping review by Runacres et al. (2021) found that universities often have stringent rules and policies which do not suit the needs of student carers.

The views of participants are thus somewhat consistent with the literature on educational engagement. While participants did not explicitly mention which areas of higher education they did or did not participate in, the YACs who were students did discuss challenges with split-decision making and restrictions to social and educational participation. In addition, some YACS made the decision to drop out of school to fulfill caregiving duties full time. In this case, YACS who withdrew from university decided to take alternative programs, whether hybrid or fully online, to manage their caregiving responsibilities. Although the participants did not mention how policies in higher education might change to better support young caregivers, there were recommendations for enhanced employment supports and policies to better accommodate young caregivers.

The views of the YACs are also consistent with literature on theoretical models on human development, young adult transitions into adulthood, and bounded agency. Theories on human development emphasize that the developmental stage of early adulthood (ages 18-25) are important as it sets the stage for later life (Erikson & Arnett, 2012; Lenz, 2001; Scales et al., 2016). Arnett et al. (2001) suggest that this life stage, which he coined ‘emerging adulthood,’ is critical to shaping one’s identity as it represents a time of life where young adults reach for independence and autonomy and make significant life choices. Further, within this process are many transitions which also shape the lives of young adults. In the context of caregiving, these transitions include ‘critical moments’, such as the initial diagnosis, institutionalization or death of a loved one. Such transitions are recognized as turning points providing opportunities for re-evaluation, change and identity formation (Furlong, 2009; Scales et al., 2016). While it can be assumed that this process of emerging adulthood can be compromised for young caregivers, several studies suggest that the process might also be enhanced by caregiving responsibilities. (Hillman & Rowe, 2014). For instance, young caregivers often feel a sense of accomplishment or purpose which contributes to a positive sense of self (Becker, 2007). Also, it has been found that young caregivers often develop effective coping strategies and mature faster compared to their non-caregiver peers (Becker, 2007; Newman, 2002) and tend to be highly independent (Banks, et al., 2001). While my findings somewhat echo the literature on benefit- finding, most YACs in my study had ambivalent feelings about the benefits to some extent.

In addition, personal agency for young adult carers is a noteworthy factor in the caregiving literature. The literature suggests that agency emerges from a process of reflection, compromise and negotiation (Tomanovic, 2012). When this process is interrupted it is referred to as bounded agency or “structured” agency, which refers to the ways personal agency is shaped, constrained and embedded by societal forces (Evans, 2002; Shanahan, 2000). Research shows that the personal agency of young caregivers can be shaped or constrained by their personal contexts (Blake-Holmes, 2020; Boumans & Dorant, 2014; Evans, 2002, Hamilton & Adamson, 2012;). In other words, the attempt to exercise agency and control in one's life is constrained by the demands of caregiving (i.e., family expectations, the care-recipient's illness, duration of care, etc.) and broader societal factors such as social policies, class and care settings. For Evans (2002), bounded agency is more than an individual's ability to be resilient, but it is a socially constructed process. Here, the relationship between agency and structure is inexplicably linked and quite complex in situations where social structures might create barriers for YACs. The findings did suggest that YACs, although resilient, were bounded within broader social systems and structures. Here, YACs described personal agency to exist within the constraints of employment, family, and other socio-political institutions. They indicated that these interrelated barriers (i.e., societal, institutional) constrained their personal agency and ability to navigate through the caregiving process.

4.4.4. They Are Still Somebody

All of the participants expressed the importance of preserving the dignity and trust of the care recipient (see above, section 4.3.4). In the literature, this is often referred as personhood (person-centered care) or a whole-person approach (Brooker, 2003). In the context of dementia, the definition of personhood includes the notion of *"keeping what remains"* or focusing on the capacities of the individual and not their deficits (Higgs & Gilleard, 2016). Tom Kitwood (1997) proposed that in dementia care, personhood aims to maintain aspects of the affected person as the disease progresses, focusing on what is concealed rather than what is lost. Kitwood (1997) also emphasized that dementia is best understood 'in context' which includes the interplay between neurological impairment and psychosocial factors. This renewed conceptualization of dementia care (i.e., The Kitwood Shift) has transformed dementia care practices and conceptualizations of dementia by aiming to maintain aspects of the affected person as the disease progresses. Nolan et al. (2002) highlight that this has preserved the autonomy, power and agency of the person with dementia by recognizing their intrinsic value and ability to make societal contributions.

Preserving personhood is embedded in broader models of person-centered care. Kogan, Wilber and Mosqueda (2016) found that person-centred care includes six dominant domains: (a) holistic or person-centered care, (b) respect and value, (c) choice, (d) dignity, (e) self-determination, and (f) purposeful living. The participants in this study emphasized that they made a consistent effort to address and maintain the dignity of the PWD by incorporating many of the aforementioned domains in their care practices. They did this by acknowledging the PWDs preferences (new or old), making efforts to maintain their independence during decline, and learning how to separate the person from the disease. For example, YC6 discusses maintaining dignity through *"front-end" and "back-end" caregiving"*. Here, the front-end refers to what the public sees, and the 'back-end' refers to the more intimate moments. Similarly, YC12 shares that maintaining dignity is dying his grandmother's hair even though the public will not see it. From these examples, we learn that YACs prioritized the needs of the PWD in private and in public settings. Each of these interpretations highlight that the YACs focused on the PWDs remaining capacities (rather than losses) and preserved their identity by helping them continue to participate in meaningful interactions which preserved a sense of self.

The YACs also discussed how the dominant assumptions about PWD shape policies which reinforce negative stereotypes. It is well-documented that social policies often create structured dependency for older adults, often framing them as frail and dependent (Bond, 1976; Townsend, 1981; Katz, 1996). This is reinforced for people with dementia as many dementia -related policies infantilize PWD or frame them as incapable of participating in society or interacting with the world. Participants acknowledged that they were ill-prepared for the lack of acceptance for PWD in society and social settings. This is consistent with the literature which connects person-centred care to the broader conversation of PWD citizenship and rights. The literature acknowledges the abjection of agency for PWD in the traditional paradigm of clinical and social care (Gilleard & Higgs, 2011). Here, the behaviour of PWD is pathologized and their behaviours are subject to being controlled and contained.

Newer models of citizenship for people with dementia encourage the full participation of PWD in social life (Bartlettt & O'Conner, 2007; Kontos et al., 2017; Nolan et al., 2002). Such models continue to inform policies and practice guidelines for family caregivers and people with dementia. Recent frameworks are informed by broader international agreements (i.e., the Convention on the Rights of Persons with Disabilities and the Canadian Charter of Rights and Freedoms) which aim to protect the rights and freedoms of all citizens (Sabbata, 2020). Examples of such frameworks include: A charter of rights for people living with dementia (Mann, 2020), and the WHO international human rights framework (World Health Organization, 2017), and PANEL; the acronym stands for participation, accountability, non-discrimination, empowerment, legality (World Health Organization, 2015). Each of these examples represents a human-rights approach to improve public perceptions of PWD, reduce stigma and support their full participation in society. While several of the participants were actively engaged in advocacy, all of the participants made efforts to maintain the dignity and citizenship of the care-recipient. This was demonstrated by managing public perceptions, maintaining personhood, and encouraging social participation for the PWD.

4.5 Conclusion

This chapter has reported on the first superordinate theme – **The Experience of Managing the Impact of ADRD-** through the most dominant sub-themes (i.e., Coping: *"I'm alright, I'll manage," "Caregiving and Systems Collide: They Don't Understand," "The Missed," and 'They Are Still Somebody*.) The findings provide valuable insights on how ADRD influences the attitudes, beliefs and behaviours of YACs. Further, the findings demonstrate how co-ordinating care for a PWD implicates the experience of caregiving and is impactful on many levels – education, interpersonal, relationships, and to the care-recipient. Participants emphasized that managing the impact of ADRD is multi-dimensional and impacted by broader social factors (place, built environment, social ideologies). The effort and willingness to manage the impact of ADRD through consistent learning and reflection was apparent through descriptions offered by the participants. The YACs also demonstrated a great deal of reflexivity by addressing how they managed their individual shortcomings throughout the caregiving process. It is apparent that YACs managed the impact of ADRD through different techniques that were innate, learned or acquired throughout the caregiving process. Despite being faced with perceived individual and broader structural barriers, the YACs appeared to put the needs of the PWD first by focusing on their well-being despite perceived challenges.

Chapter 5: Caregiving: Me, Myself and Us

5.1 Overview of Chapter

The aim of this chapter is to present a descriptive account of the second superordinate theme that I identified from the research findings: "**Caregiving: Me, Myself and Us.**" The meanings of the four sub-themes which I identified (i.e., *"Who am I," "I Need Support Too," "How Do I Make Sense of This: Learning as I go,"* and *'I am my Mother/Father's Keepe*r') are discussed in detail. I have also included reflexive commentary throughout in the form of reflexive boxes to demonstrate my thinking process, reactions and reflections. Finally, I will discuss the findings of this chapter in relation to extant literature, followed by a conclusion to summarize the main points of this chapter drawing attention to the research question.

5.2 Superordinate Theme 2- Caregiving- Me, Myself and Us

The second superordinate theme reviews how YAC's discuss caregiving in terms of relations to self and others and society. The meanings of the four sub-themes which I identified (i.e., the self and identify, the utilization of supports and networks, sense making through professional and academic knowledge, and relationship to the care recipient) are discussed in detail to highlight how participants describe the nature of caring for someone with ADRD. Broadly, this superordinate theme addresses the relationship between the participant's personal identity and their caregiving identity, and their relationship to the care-recipient. Overall, the participants' descriptions capture the distinct, but also interrelated, identities which represent the connections between the self and others throughout the caregiving process.

Table 8 - Superordinate Theme 2 and Related Sub-themes

Superordinate Theme- **Caregiving: Me, Myself and Us**	**Sub-Themes**
	“Who am I?”
	“I Need Support Too”
	“How Do I Make Sense of This? Learning as I go”
	“I am my Mother/Father’s keeper”

5.2.1 Who Am I?

The participants described whether or how they identified with the role of caregiver. YACs did identify with primary, secondary (or both) caregiving roles or a full-time or part-time caregiving status. This largely depended on the position of the YAC in their family unit as well as the tasks associated with their caregiving role. Several participants also emphasized that their identity was so engulfed by caregiving that they had concerns about how their identity would shift once caregiving responsibilities ceased. Here, YAC6 explains how she perceives her identity as caregiver and describes a typical day:

Jonelle Ward: How would you describe your caregiving role?

YC6: I am a full-time caregiver. No one else. I would say I am I am the primary caregiver for her and myself.

Jonelle Ward: What's a typical day look like, for you as the primary full-time caregiver.

“Yeah so, a typical day, right now in June 2021 is I get up at about six forty-five, seven and in that time it's my chance to kind of get my bearings together...Currently, or recently that has looked like getting her [mother] up and changing her bed linens because she has incontinence issues now. After that, we put her in the shower, and by put her in the shower we go through the showering process, get out, figure out her new clothes, change and put new clothes on. We have a breakfast routine. I do her breakfast, do her medications and then I say- you can watch TV and eat your breakfast which is what we do every day.” [YC6]

YC6 also discusses what caregiving looks like towards the end of her day. She describes how towards the end of the day caregiving includes engaging in activities and instrumental tasks with her mother:

“We usually do a walk around the neighborhood because she's been tired. Then it's porch sitting time, so we sit on the porch and just watch the cars go by, listen to the birds. Then, I try to do dinner where it's - we do something together. So, she will help me prep dinner, which often is just standing and overseeing the things, and then we'll eat dinner together. And then again do another activity which is often a 15-piece puzzle. It's very easy, but it's challenging to her every single time. Then evenings are usually something to tire her out, so I usually either say folding clothes for the evening time and then we'll sit up and talk and then I try to get her like tired by about 1030-11 and then she’ll the lay down watching TV and fall asleep.” (YC6).

The description by YC6 describes her view on her role as a primary full-time caregiver. Other participants shared similar experiences but stated that they were in a secondary role. For these participants, their caregiving status (full-time, part-time, primary or secondary) was determined by their position in the family and distance from the family geographically. Here, YC1 discusses being in a secondary role as a caregiver because he does not live with his mother, although he mentions performing tasks associated with being in the primary role:

“I guess, by definition, it will be secondary. By definition secondary because I didn’t live in the house, but primary in other aspects or at nighttime when I knew that things will start to roll and you'd have to do things at night. So, I think, by definition, I’m secondary, so I didn't live in the house, but I took her everywhere, especially every weekend I would take her out during the week.” (YC1)

Most participants described their role and caregiving status in relationship to the care-recipient. However, other participants discussed their caregiving role in relation to other caregivers. In this case, several YACs were providing care alongside their other parent (who was not ill). YC9, for example, discusses identifying with being in a secondary caregiving role alongside her father who is the primary caregiver:

> “I would say secondary. I feel my father overall being the spouse and also, he really wanted to be there, almost all the time. I also did, but with my other things that I was carrying at that time, I think he carried more of the weight of taking care of her. I’d say I’d be a support, a caring support- a supportive role also with for my father and the rest of the family. I was helping them whenever they need, they did have their opportunities to care for my mother, but sometimes it was a little difficult for them emotionally I saw. I was there to be a support for them.” [YC9]

Other participants viewed their role as blended or mixed. This was often tied to the relationship with another caregiver (most often a parent). For YC2 the perceptions of her role depended on a range of factors, including the health condition of her mother. When asked about how she would describe her caregiving role, she describes it as mixed and overlapping:

> “I would say it transitions from primary to secondary depending on the day. For example, when my mom's dealing with her health conditions. So, about a month ago she broke her arm, so I had to take over full time on doing all the cooking all the cleaning all the dishes and helping to get my mom a shower and then also trying to convince my dad to go take a shower as well. He, for whatever reason, really does not like taking a shower so I’d have to like to bring a bucket of water and try it and, like to a sponge bath while still maintaining his dignity.” [YC2].

Participants described that there was little separation between their personal identity and their caregiving identity. Here, they described that they often felt their identify was defined by their caregiving role. This was tied to length of time being a caregiver, the extent of the role, and the relationship with the care-recipient. For example, YC3 explains feelings of uncertainty about her identity when caregiving responsibilities ceased:

> “I was very involved in her care and since she's had the condition for so long. It's been almost eight or nine years. And so, I do consider myself to have my role as a caregiver such a big part of my identity. And so I don't really think much about life post-caregiving because I don't know if that'll ever--, it just

feels like such a faraway thing. And, in some ways that's scary ‘cause I think it's become such a big part of my identity that it's almost like- what else did I have you know? [YC3]

Similarly, YC10, also discusses how the caregiving role can be all-encompassing. She suggests that there is no separation between her personal identity and her caregiving identity. She describes how her identity has been integrated into her other roles beyond caregiving directly:

‘It’s just kind of who I am, who I’ve become, I feel like it's almost like this weird natural process, natural thing to happen. I mean I’m the oldest in my immediate family, I don't know, it's I mean it's also kind of a role of just always has been around for me whether I was like a babysitter, for my family cousins you know, whatever. Even at one point, like I lived with my Nana for two summers and just you know, being around that and helping take care of her, so I feel like it's almost like a role that's just been around. Also being like a speech therapist like that's a caring position as well, like it's just like- it might be part of my DNA, maybe right? (YC10)

There were many participants who had ambivalent feelings about caregiving and expressed initial resistance to accepting this new identity. These participants described a desire for a sense of control over their own lives, which for them meant personal freedom and balance. When asked if she identifies with being a young carer, YC5, a college student of South Asian descent, explains how she negotiated initial feelings of resistance:

“I think now I do. I think I have accepted the role as a young caregiver and now I’m very proud of it, but that wasn't always the case when I was younger. I didn't really identify as a young caregiver, even though it was kind of pushed on to me. I was kind of just, like, doing my duty as a daughter, and as a granddaughter and caring and stuff. And it was really frustrating at the time because there were times when I didn't really want to be a young caregiver. I wanted to just live my life normally and I definitely didn't want to have that title at that time, I guess. But now as I’ve grown and evolved I definitely, yes, I definitely do think of myself as that.” [YC5]

Similarly, YC6 discussed initial feelings of ambivalence with taking up the role of caregiver. Here, she shares that she eventually learned to balance her caregiving role, alongside others:

YC6: “You give yourself and just be true to who you are. Just because you're a caregiver doesn't mean you have to lose who you were before you started caring, it can be a part of who you are. I mean, it's definitely become a part of who I am. You know there's a way to create space for you as a caregiver, and you as the person you were before you were caring and pursue your passions. It doesn't mean that you have to stop caring. There's a way to balance both.

Jonelle Ward: A way to balance both. Ok, you've definitely found that balance, I think.

YC6: Yeah, and I didn't do it well at first. But I think because I failed, not failed. But like I was saying, I grew from it, and that gives me, hopefully, the wisdom to share with others.

In contrast, other participants described the importance of not identifying with the caregiving role completely. This was motivated by observations of patient care in clinical settings which were deemed to be insensitive. For example, YC2 explains her reasons for not letting the caregiver role become her entire identity. Here she explains the significance of remaining her parent's daughter first to ensure that she is emotionally available for them:

YC2: "I've learned it's really important for caregiving to not make it your identity."

Jonelle Ward: "Would you say that you identify with being a caregiver?"

YC2: "It's a part of me and it's played a big part of my life, but I wouldn't let it fully take over my identity. When it comes to my parents, I want to be their daughter first and then their caregiver because I find that, for example, if we were to look senior homes, some of the caregivers that will come in, who are paid, it just felt like they were emotionally distant from whoever it was that they're caring for, which makes sense, like they care for a lot of people. It's a lot of emotional burden– well not burden-it's just it's taxing. So, I just overall I don't want to emotionally distance myself completely from my parents and lose that I sense of empathy. I don't want to treat them like this is the full-on patient."

There was one participant, YC12, whose views on being a young carer were informed by his family values. He described how he felt indifferent about identifying with being a caregiver initially, but overcame this indifference by affirming his sense of responsibility. When asked if he identifies with being a young caregiver, he differentiated between societal and family definitions of caregiving:

"If on a societal level, you asked me that question, I would say yes, I do identify as a young carer. But if you asked me on the family level - no I'm just part of a family and just doing what is right. Even going above and beyond, it's just doing what I need to do, doing what is expected of me to do. It's not like I need to be given an award here or pat on the back, like good job. No, it's just my responsibility as a member of this family, and this is how it is and I can do that either positively or I can huff and puff and make everyone make everyone angry, including myself." [YC12]

Following this, YC12 described his views on the distinct categorization of young caregivers which contributed to their perceived social status. When asked his views on being a young carer, YC12 disagreed with the social construction of young caregivers being framed as a distinct group:

> “I don't think it means anything, to be honest. I don't think being young makes any difference. I think that to be quite frank, I think that making young caretakers feel any different than regular caretakers just makes them feel entitled or like oh we're more important, my mental health as a young person is more important than anyone else’s mental health. You know, at the end of the day, it's just an Alzheimer’s patient that needs care. Whether you're young or old, you need to take care of them, preferably in a good way.” [YC12].

Reflection
The comments from YC12 made me critically think about the meanings of being a young carer for participants. His views suggest that by society making ‘young caregivers’ a distinct category can lead to feelings of entitlement. While this a subjective view, it reinforced the importance of considering taking for granted assumptions in this context. I suppose I assumed that all participants would identify or relate with the role of young carer because they self-identified with this title at the beginning of the study. The views of YC12 reinforces that self-identification does not mean they agree with the pre-scribed role of ‘young carer’ that society makes distinct.

What was evident from these interviews is the way in which the participants feel their sense of identity is undermined or reconstructed by their caregiving role. Their descriptions also emphasize that they engaged in a process of considerable reflection towards acceptance of their caregiving role or a complete re-configuration of their personal identity. Here, the construct of self/identity involved differentiating between a primary or secondary role, as well as accounting for the tasks performed independently or alongside another caregiver. In their descriptions of self/identity, participants highlighted one aspect of the nature or essence of caregiving, which is that the caregiving role can invade on one’s sense of self and requires the ability to negotiate and find balance among one’s personal and caregiving identities and embracing where they might overlap.

5.2.2 "I Need Support Too"

Participants discussed their views on social support, whether it be from family and/or friends, support groups, professional or online networks. In addition, participants discussed their motivations for soliciting or disengaging from social support, which were often tied to a personal or unmet need. Most participants confirmed that their motivations for reaching out to support networks were to connect with others going through similar circumstances. Two participants, YC3 and YC7, discussed their positive experiences with support networks:

You know I have through Young Professional Alzheimer's Council (YPAC), for example, come to become close with many caregivers and I don't particularly find support groups to be helpful just in the experience I've had. But this is like a version of that without being a support group - there's just like a network of people who get it." [YC3]

"I connected with the Alzheimer's Association early on because I live in a bigger city. I am very grateful because I've talked to clients who don't have [support]. I was able to find a group called Young Caregivers. The young adults or young adult caregivers of people with early onset Alzheimer's. It was once a month and it was the first time that I sat around a table of people that were around my age, give or take, older, younger and they had parents in their late 50s and their 60s, some in their 70s who were diagnosed with early onset Alzheimer's and they were saying, well, my mom is doing this, and my mom is my parent is doing that and I thought, oh my gosh I can relate so much.' [YC7]

Participants underscored the importance of feeling a sense of connection with people who could identify with their experiences. Most participants took the initiative to reach out to local community agencies to find support, specifically in the form of a young caregiver network. YC5, for example, discussed her need for connection with other young caregivers; the absence of it motivating her to create her own online network to connect with other young caregivers. Here she describes her experience reaching out to her local Alzheimer's Association for support, who gave her the contact of another young carer:

"So, I just asked them like, can I be in contact with other young caregivers. Is there a group or something? And they're like, no we don't have many other young caregivers. So, they gave me her contact with her permission and vice versa. Then we were texting for a bit, and then it kind of just fell through a little bit. But then I decided to like to create my own blog on social media about Alzheimer's and spreading awareness and honestly doing that, by myself, I have been connected to so many more young caregivers through social media than through like the Alzheimer society of British Columbia." (YC5)

In addition to the need to connect with young caregivers specifically, other participants highlighted additional aspects that were important in terms of support. This was often associated with inclusion, representation and diversity. For some participants, the lack of representation of minority or racialized groups in the young carer community contributed to perceived challenges. YC4, an African American caregiver for her mother, describes how the lack of representation among the young carer community contributed to difficult feelings:

'I actually just want to talk to someone else who's 33 years old and it's like I see you right now, you know? I didn't ask this, but I get another like thing on top of a young caregiver, like being a young caregiver that's a figure of colour. There's actually very few young caregivers of colour telling their stories. You know again great books on Instagram but like it's a small handful of them that I know are impacted by this. It's the lacking community or connection that makes it really hard…but I just thought of it, like the I think there's like the desire for community and connection from people who get it' (YC4).

Other participants had mixed feelings about support groups. In these cases, the support group may not have been the right fit, although they did offer reasonable resources and information. When asked about her experience with the adult child support group, YC10, describes her experience as mixed:

"There were actually a lot of individuals who had parents with frontotemporal dementia. I did appreciate that they were talking about starting to plan and doing your research and they kept emphasizing safety, which was something that more recently talked about even some financial planning, because it did seem like some of the people there, maybe they didn't have, like the other parent available. So, trying to work through those types of things and then, just like talking through the feelings of guilt of frustration. There's a big vent session that would just be like this what's happening this week and I'm just really frustrated, and you guys have any suggestions on how I handle x y & z?" [YC10]

For participants, in-person support groups and networks were not the only utilized form of support. Some participants underscored the importance of online support groups and networks as an alternative to in-person groups. They described that online support networks provided them with a broader support network and global community. In their view, the online networks were helpful because members shared insights that can help with the nuances of caregiving that might be obscure. For example, YC3 and YC9, described their thoughts on the online networks and forums:

> “I like that if there's something random going on, you can search and more likely than not someone has posted a question or comment about that same issue somewhere. So, it has that effect making you feel less alone, but also, it's great to learn what to do. I find that to be more helpful than websites that have pamphlets because they tend to dish out more generic things. Someone who's gone through it is going to know exactly what to do first.” [YC3]

YC9, whose mother had Parkinson’s disease dementia, also discussed utilizing online networks for support:

> “I’ve definitely used Reddit. That was definitely very supportive and helpful with Parkinson’s. There are people who have Parkinson’s or carers or people in the family or have someone who was diagnosed with Parkinson’s- they post about their stories that they’ve gone through or any issues they might have, not only from a perspective of medical help. It's also you know, in relation to, “my father my mother's going through something and I don't know how to cope with this, what can I do?” So, it's seeking out other carers and other people who have experienced. It’s pretty much a support system and a very supportive community” [YC9]

Barriers to achieving support in-person were tied to the perceived limitations of in-person support groups. For these participants, in-person support groups were too generic or only offered medical help. These perceived deficits motivated many young caregivers to find online communities or create their own online networks, in the form of blogs and other social media platforms. In addition, the digital space was perceived to be less restrictive, which allowed for broader and more global connections to caregivers who had similar experiences. Ultimately, the online support networks contributed to participants feeling less alone and learning specific techniques from other caregivers.

Overall, this sub-theme highlights how support (or lack thereof) is interpreted by YACs that I interviewed for the study. YACs described their experience of support by engaging with caregivers independently or in the form of peer support network, either online or in-person. This theme suggests that the participants' experience of peer support (or lack thereof) was characterized to a considerable extent by representation of other YACs in the support networks, demographic background and age of group participants and the discussions that took place in the group networks. Participants seemed to be willing to disclose sensitive information and reach out for help regarding their caregiving experience when they felt comfortable. This suggests that participants' receptivity to the support networks that they choose to engage in can impact how connected and supported YACs feel, which, in turn, can inform the effectiveness of their care practices. Further, through peer support networks YACs are able to receive and give support from others going through similar experiences. However, YACs felt disconnected when peer support networks were considered to be restrictive or lacking in some way.

5.2.3 How Do I Make Sense of This? Learning as I Go

Participants described how they utilized academic and professional knowledge to support them in their caregiving role. This often took the form of school-related classes, training and professional core competencies. Here YC2 discusses taking academic courses to educate herself in order to better care for her parents:

> "I ended up going into kinesiology mainly because of my parents. I want to be able to better support them in their health and just have more knowledge on it. I don't want to be contributing to their health issues or their situation. I just try and focus on preventative measures and making sure that their condition doesn't get worse. A lot of the times I like informing them as to like how to improve themselves. I've taken a few health and aging courses to also better educate myself on how to take care of them. I like to use my psychology courses because it (caregiving) takes a lot of patience." [YC2]

Other participants were also motivated to major in disciplines that were relevant to their caregiving experience for a PWD. YC12, for example, described that he was inspired to study neuroscience and mental health due to his experiences as a caregiver for his grandmother. When asked if he utilizes formal education, he described an animation he saw in school which helped him to understand the lived experience of dementia, which ultimately informed his perspectives on caregiving:

“I saw great animation that showed Alzheimer’s as just everything as foggy. They’re lost right and the moment they see someone they love, it's like person that can guide them, which is why they're always so clingy and shadowing people. I would say that remember that they are, lost, they need help like young children (they) need (you) to grab them by the hand and lead (them) to a good place. In the same sense, you can figuratively grab the hand of this Alzheimer’s patient and lead them to this good place, you completely can just as well lead them to a bad place, which is essentially just neglect and lack of care. Or you can take them to the good place, show them care (and) respect.” (YC12).

Participants described the value of professional knowledge in the process of caregiving. Two participants, both speech therapists, described the value of their professional experience in the caregiving process. They relied on their professional background and core competencies when providing care for their parents. YC10, for example, describes that her professional skills were helpful with communicating with her father when he was in the mid-stages of dementia:

“In New Jersey, I am a speech therapist, I work primarily with the little guys. But I will say that that it did come in handy the past couple of years, with my dad in terms of communication and just helping him us navigate you know that entire area.” [YC10].

Similarly, YC3 described that her professional skills enhanced her capacity for caregiving. When asked about her experiences with dementia, YC3, described how her professional experience as a speech-therapist helped with specific understandings of language and cognition:

“I guess mine is a little bit unique because I’m a speech pathologist. I was working right after my mom had her initial diagnosis, I got a job in sub-acute rehab and I was working in a skilled nursing facility, so I worked professionally with people in dementia care units.

I have a lot of understanding specifically [with] the cognition and language. And then also I have the caregiver side, where I see it, impacting my mom and it's a much more personal experience and has more emotion attached to it. I have, I think, a very unique lens that I look at it through, because a professional on the personal side I guess.” [YC3].

Other participants also acknowledged the intermingling of their personal and professional life. One participant, YC7, was motivated to become a dementia coach while providing care for her mother. Her motivations were tied to wanting to help others learn appropriate caregiving techniques and approaches. She discussed how her training has informed her views on providing care that is not counterproductive. Her knowledge has not only informed her caregiving techniques, but she also shares this knowledge with her clients. Her training has allowed her to make sense of the realities of having dementia and reasonable caregiving techniques:

> ‘Everybody who has Alzheimer's has something left. There's always something left and a lot of people are using their energy and their time, their resources on the wrong things, you know they're trying to get their parent …well, my parent can't do crossword puzzles anymore, so I brought them a crossword puzzle with larger letters. I think it's really hard for them to like process that and find words, and they probably can't do that anymore. And I'm not trying to say, I'm not trying to like to downplay their capabilities, but I kind of am because you have to be realistic about it. So, let's look at pictures and let's do some sort of game and let's look at photo albums and let's listen to music. So, like when I think about Alzheimer's, we need to just look at our interactions with those who have Alzheimer's differently you know, and it's hard because we have somebody who they could… they could do this all their life like why can't they do it now? (YC7)

Overall, this sub-theme suggests that academic and professional knowledge helped to facilitate the caregiving process for participants. Sense-making through academic and professional knowledge includes intentionally selecting age-related disciplines or courses, attending formal educational seminars, applying professional core competencies, and engaging in dementia-related training to enhance their skills to better meet the needs of the care-recipient. In many instances, these efforts also helped participants to feel more competent and capable in their caregiving role. This highlights that the nature of caregiving is not always innate or straightforward, but it can consist of taking initiative to fill in knowledge gaps that are identified that might challenge or complicate the caregiving process.

5.2.4. I Am My Mother/Father's Keeper

The relationship to the care-recipient was an important sub-theme for participants. All participants discussed the perceived nature of their relationship to the care-recipient. In their descriptions, YACs commented on the relationship to the care-recipient before, during and (when applicable) after caregiving responsibilities had ceased. Specifically, the majority of participants emphasized that their relationship to the care-recipient had become stronger during the caregiving process. Here, YC1 describes his willingness to care for his mother:

> "I would have done this, without even asking, so it's very voluntary. I would have done it a million times over. In fact, there's no one else here for me so it's just like the willingness to care for mother. I have no one else to care for you know what I mean, other than myself right? That like my God, to put it this way, to live a life that everyone just kind of like leaves or dies, and you had this like last person? My God, for anyone else in the world and it wouldn't even be a question, it would be voluntary hundred percent you know what I mean? (YC1)

In a similar vein when asked about their relationship with the care recipient, two participants discuss being their parent's protector:

> "It's very strong. My mother knows even on days when she doesn't know my name or know who I am, that I am the person that she sees, I'm like her safety net, her protection, her person who's going to look out for her. So, I think that it's a strong relationship, I think, even in the midst of all of this, she can still say like that's [uses first person]. That [uses first person] she's something else she's pretty awesome and like rattle off random achievements." [YC4]

> "Even the simple task of taking her for a walk or pushing her through a wheelchair, I was like I'll take care of you. I'm going to dodge these sketchy sidewalks or I'll find a way to get into this building. But just seeing it's (the relationship) closer. We're more tight. I'm pretty much there to you know, protect her from anything that might cause any difficulty." (YC9)

YC9 went on the describe the changing nature of the relationship with her mother. She emphasized how power dynamics shifted while caring for her mother. Here, she describes how caregiving created an equalizing effect within her and her mother's relationship:

"With my mother in the relationship, we did become closer. We were almost as equal planes 'cause I think growing up, we have the idea that the parent as an authority figure and the son or daughter is lower, like I'm going to follow the rules stuff. But when you're in that a tough situation it's -I'm going to have to carry you. It's kind of like coming to terms- coming to the truth. But at the end of day, this is what it is and we're going to be close and strong together on the same page." (YC9)

Other participants also found the transition to caring for a parent to be challenging. YC4, for example describes that she was ill-prepared for caring for her mother. She also suggests that caregiving was intensified because her mother had younger-onset ADRD. Here, she describes the impact of becoming a caregiver prematurely:

"Nothing prepared me for my mother, the person who provided for me cared for me to no longer be able to care for herself and like step into being the parent of my parent. That is very different, and not saying no worse, but just it's just different if it was my mom taking care of her mom or I watched the toll of my grandparent -it's not the same. I think it's magnified - it's my mom- magnified in like all the worst ways. I think it's hard because the transition happens pretty quickly. There was no preparation, I had to figure all of that out on my own." [YC4]

For these participants, caregiving led to a shift in the authoritative position between a parent and a child, which can also be referred to as a role-reversal. Navigating how to trade places with a parent, while perceived as challenging, was often met with resilience. For some participants, this shift was represented by the notion of protection, which symbolized a new way of relating to the PWD. The nuances of this shift are often influenced by the relationship dynamic between the parent and child prior to caregiving. For these participants, the notion of protection and safety were grounded in the positive relationship they had with the PWD.

Some participants regretted that they did not have the opportunity to have an adult friendship with their parent who had ADRD. For these participants, this relationship was just emerging prior to their parent being diagnosed with ADRD. This resulted in disengaging from meaningful activities that they shared with the PWD prior to becoming their caregiver. YC10, for example, describes her inability to go running, the meaningful activity she shared with her father, prior to his diagnosis:

> "In my early to mid 20s like I also started running with him, and that is something that we did together. I had a conversation with my boyfriend being like, "how am I ever going to do the broad street race? Because that was our first big race that we did together. And him introducing me to like the types of shoes you should wear or going to buy Nike's at the sporting goods store. That friendship, that more adult friendship was really starting to blossom before he was diagnosed. That has been very hard for me. I'm not going to be having that anymore. (tears) [YC10]

For YC10, running is a symbol of bonding and connection with her father. Running was at the center of their 'blossoming' adult friendship prior to her father being diagnosed with ADRD. The significance of this interaction went beyond running but was also related to the activities that YC shared with her father through running (i.e., shopping for shoes). For YC 10, running, particularly participating in the annual race, will not have the same meaning without the presence of her father.

From the above descriptions, one can assume that the feelings young caregivers had towards the PWD influenced their perspectives on caregiving. YC11, for example, describes the fond memories of her mother which contributed to her views on caregiving and also influenced the nature of the caregiving relationship. Here, she describes the notion of reciprocity and caregiving as a full circle moment:

> "We were really close. I mean I'm the only daughter and you know? She always gave me the best possible life that she could. It's really loving and it (caregiving) was out of respect and duty to my family really. It's so funny that some of the things that she taught me are the things that keep me the most grounded now. It's just so cool to see it come full circle. She also gave me some not-so-great traits that I get to work with you know!" (laughs).

Overall, this theme highlights that the relationship between a caregiver and a care-recipient is an important feature in how the process of caregiving unfolds. For participants in this study, their relationship with the care-recipient informed their attitudes and beliefs about their caregiving role. The relationship to the care recipient involved reflections on perceived closeness and the quality of the relationship with the care-recipient before, during and after caregiving. More specifically, it involved feelings of reciprocity, altruism and selflessness, which were all motivating factors for caregiving. This theme highlights how the nature of caregiving is not fixed but contributes to the development and quality of the ongoing relationship between the caregiver and care-recipient over-time.

5.3 Discussion

5.3.1 Who Am I?

The ‘self’ and identity are saturated themes in this study and examples of how this was expressed can be found above in section 5.2.1. To summarize this sub-theme, YACs discussed how their identity was shaped by and through the process of caregiving. They also discussed the various ways that they negotiated and navigated their caregiving role, which was met with varying levels of acceptance. The majority of YACs embraced their new caregiving identity, while others resisted it at first or completely. By and large, the level of acceptance varied according to each individual caregiving journey and at different stages of the ADRD disease process. This is significant to the context of caregiving, particularly for young caregivers whose personal and adult identities are still emerging. In many cases, it was quite common for the identity of the YAC and the care recipient (mostly parents) to become integrated with the caregiving role. This was evident in the language the YACs used to describe their identity in relation to caregiving. For instance, phrases such as in “it defines me” and “I am her caregiver” or “I don’t know who I am apart from caregiving” all reveal how the YACs identity became integrated with the care-giving role.

A central discussion point regarding caregiver identity is to begin with how such identities are constructed in society. Here, I am referring to Boddy's (2016) work, which suggests that a caregiver's identity is socially and individually constructed through global awareness which subsequently informs the self-perceptions of young caregivers. Most YACs were aware of the concept of a young carer and the majority identified with this title, although with varying levels of acceptance. In these cases, the title of 'caregiver' was self-prescribed, but also reinforced through familial and social systems that the participants were a part of. In the literature, L'Odell et al. (2009) suggest that the status of 'young carer' can be a public marker of the role one plays in society. While this public status guarantees certain social privileges and recognition, at the same time, the limited political visibility also obscures one's identity which exacerbates the hidden nature of YACs (Becker, 2007; Stamatopoulos, 2016). YACs expressed challenges negotiating their personal identity and their caregiving identity, and in most cases they did overlap. Overall, their identities were maintained and reinforced by interactions with family, the public and the broader social systems that promote the young carer as a distinct status.

In most cases, YACs had adopted a positively charged identity as a caregiver. By positively charged, I am referring to a sense of pride, ownership and strong interest in their caregiving role. The literature on benefit-finding suggests that young caregivers who see their role in a positive light experience benefits such as maturity, resilience and improved well-being in some cases (Wepf et al., 2021). There were also instances where a caregiver's identity was somewhat integrated into their personal reality and other roles (as described by YC6 and YC10). In this context, some YACs expressed uncertainty over what their future identity will be once their caregiving role had ceased (i.e., what to do now?). Here, YACs found usefulness in self-identification and a strong sense of meaning and purpose. The literature suggests that caregivers often experience challenges learning to live again once caregiving responsibilities have ceased (Corey, 2018). This what Corey and McCurrey (2016) refer to as the post-caregiving process, characterized by initial uncertainty about how to proceed in life and a reluctance to relinquish caregiving after years of identifying with the caregiver role (p. 91). This was particularly evident for YACs in my sample whose caregiving responsibilities had come to an end. They expressed a sense of relief to some extent, but also feelings of uncertainty and ambivalence with the direction of their life post-caregiving.

In other instances, the experience of identifying with the caregiving role was negatively charged. Here, YACs felt challenged because of the limitations and constraints they experienced due to their caregiving role. For instance, many discussed not wanting the caregiving role to define them, feelings of ambivalence, or feelings that their personal identity was undermined by their caregiving role. This mirrors the findings from a study by Skaff (1992) that found that the 'loss of self' in child caregivers for a relative with ADRD was caused by being completely engulfed in the caregiving role. For Becker et al. (2000), such limitations negatively impact the social development of young caregivers, particularly in the areas of relationships, identity development and emotional health.

YACs made clear distinctions between identifying as being a primary or secondary caregiver. For YACs, there was some overlap between the interpretations of the primary and secondary role. Many YACs saw their role as primary if caregiving fulltime and secondary if providing ancillary support. In most cases, their role was described as secondary or semi-primary if they were supporting the spouse of the care-recipient. Although there was certainty with the understanding of their role and expectations of this role, there was some overlap and contradictions between their perceived role and the tasks performed. For example, many of the YACs were in a secondary care role but performed primary care tasks. This is consistent with the literature on difficulty defining the role, tasks and dimensions of caregiving in young carer studies (Joseph, 2020). While there is some variation in the limits and depth of the caregiving role, all participants perceived that being a young carer and the expectations alongside the role were atypical. For the most part, the majority of YACs experienced challenges with their caregiving role irrespective of the level of familial obligation.

This is quite different from findings which emphasize the caregiving role for young caregivers becomes normalized over time (Smyth, Blaxland & Cass, 2011). This is significant because such assumptions will overlook experiences that are counter to these claims, which contributes to young caregivers remaining a hidden population.

For YAC's, the notion of their identity was embedded, constructed and reinforced through the relationship to the care-recipient. This can be seen in the language YACs used to describe relating to the care recipient. As noted in the excerpts, YC4 describes herself as a 'safety net' and YC9 says that "I am her protector." From a sociological perspective (Mead, 1913), for YACs, their "me" (the social self) and the "I" (the individual self) were reinforced, conflicted, integrated or reconstructed in their attempts to navigate the caregiving role, which suggest a blurring of identities given the multiple roles they assume. This is consistent with the literature (Karner & Bobbit-Zeher, 2005) that describes caregiving as a process whereby one's personal identity is transformed with a limited chance of returning to the personal identity one had before becoming a caregiver.

5.3.2 "I Need Support Too"

As demonstrated above with examples (see section 5.2.2), all participants agreed that receiving some level of support was necessary to function as a caregiver. For some YACs, support meant connecting and relying on family and friends who had interacted with the care-recipient on a regular basis. For others, support meant reaching out to local and online networks. There was a general consensus among all YACs that connecting with other young caregivers was a key aspect of feeling supported. This finding is consistent with previous research emphasizing that young caregivers feel supported when connecting with others who are going through a similar circumstance (Stamatopoulos, 2016). Overall, support was perceived differently and there was great variation regarding support preferences, response to the support, and overall motivations for long-term use of these supports (or lack thereof).

YACs place significant importance on the support that they needed. The majority of YACs in this study entertained the idea of engaging in support groups at some point in their caregiving journey. These groups took the form of professional networks or clubs or general support groups offered through local community organizations. For those that engaged in a support group, there were mixed perceptions of the utility of the group. YACs who considered the group to be effective did so because they learned about available resources. Overall, the value of the support group was based on the opportunity to connect with others going through a similar experience, receive mutual support, and feel a sense of belonging. These qualities have been shown to be critical factors that influence the well-being of young caregivers (Barry, 2011; Moore, McArthur & Morrow, 2009; Phelps, 2021). For YACs, it is not only about talking and sharing one's thoughts about caregiving, but also being heard, validated and feeling included. The need for inclusion was particularly necessary for YACs who felt there was a lack of representation and diversity of young caregivers in support groups.

In contrast, YACs who found support groups to be ineffective expressed concern with the commiserating of group members which was perceived as discouraging. They also expressed feelings of concern with the age-range of the attendees and the discussion/aim of the group. Many YACs made attempts to access supports but found there were very few accessible or conducive programs to meet their needs, which resulted in general non-use of support groups. To rectify this, some YACs resorted to online networks or professional support groups to better meet their needs. They utilized online platforms to raise questions, connect and build community with others, and for help-seeking. The reasons that YACs preferred online networks align with research on online peer support for caregivers, which shows that online support networks are beneficial for caregivers because they provide information exchange and emotional support (Friedman, 2018).

YACs did not utilize much support from social service professions or community services. They engaged with respite, in-home caregivers, and palliative care to some extent, however their views on the effectiveness of these services were mixed depending on the level of unmet need or cultural preference. Mostly, the external services were considered to be of poor quality or inaccessible which resulted in them caring independently with limited outside support. This is consistent with literature on reasons why young caregivers tend to not access support, which include service issues, service promotion issues, accessibility, and resistance to outside help or delayed institutionalization (McArthur, 2007). However, the reasons participants did not solicit external services were not consistent with the findings specific to young caregivers in the literature. The literature shows that young caregivers who are children do not solicit outside help due to a fear of unwanted scrutiny, a lack of identification with the young carer status and a lack of general awareness (McArthur, 2007). Given that the age of the participants in this study was older (18-25) than young child carers (11-18), their lack of motivation for soliciting outside help was quite different. Here, YACs were less concerned with their caregiving role being made public, and more concerned with the conduciveness and accessibility of outside help, as well as the structural and systemic barriers that impacted caregiving.

The lack of accessible programming for young caregivers is part of a wider problem identified in the literature, particularly in North America. Given the preliminary positions of these countries with regards to awareness, it is not a surprise that programming is virtually non-existent (Becker, 2007; Stamatopoulos, 2016). Previous studies exploring young-carer programming suggest it is under-funded or not sustainable due to budgetary constraints (Stamatopoulos, 2016). Further, such programming is obsolete in geographic areas where young caregivers may need it most, as alluded to by Morris (1997) and Becker (2005) who assert that marginalized and disadvantaged families with care needs not met by the system are often where young caregivers exist. When this lack of programming is connected to the broader systemic issue of resource allocation and federal priorities, one can see how the lack of state provision can compromise the role of young caregivers and families in need.

5.3.3 How Do I Make Sense of This? Learning as I Go

Making sense of caregiving in the context of dementia can present a great challenge, especially for young caregivers. Although there are very few studies on how young caregivers engage with dementia care, broadly, questions of how informal caregivers perceive, make sense of, and engage in dementia care are widely addressed in the literature (Harper et al., 2021; Lindeza et al., 2020). As mentioned in sub-theme 2 (the utilization of support and networks/lack thereof), young caregivers made efforts to reach out to and engage with community agencies, support groups and online networks for support (to help make sense of their role, dementia diagnosis, and related care practices). However, given that dementia is a complex disease, there is often a disconnect between theorizing dementia and being a caregiver in practice (Fleming & Farquhar, 2016). This view was accurate in this context, as most YACs spoke about being ill-prepared for the role of caregiving, particularly for an older adult with dementia. The disconnect was apparent in the ways that, for example, YC2 questioned the recommendations and role of medical professionals who did not have direct caregiving experience. In addition, from her experiences, YC11 discussed the ways caregiving techniques are counterproductive in practice (i.e., the use of wordsearches for people with cognitive deficits).

For YACs, making sense of their caregiving role includes understanding dementia as a medical condition and aging with dementia. Research has found that aging with dementia can pose a different set of challenges/experiences, such as longer durations of caregiving and increasing challenges due to the lack of disease modifying treatments or a cure (Hubbard et al., 2003, Ory et al., 1999). For YACs, sense-making went beyond traditional help seeking and information-seeking, which studies show is often used by young caregivers as a means of coping (Daniels et al., 2007). Here, sense-making was represented by the application or fusion of academic and/or professional knowledge with their personal life (see section 5.2.3). This is markedly different from what is suggested within the literature on young caregivers which focuses on the vulnerability and dependency of children, and this being undermined by caregiving role (Szafran & Duerksen, 2012). Given that the literature on young caregivers focuses on challenges in school performance and missing school, there is very little focus on how school informs the caregiving process (Stamatopoulos, 2016). Comparatively, in this study, the participants were working professionals, self-educated, college graduates or in college full-time or part-time. The participants were explicit in how they used their knowledge to make sense of dementia and/or their caregiving role. For example, many YACs were motivated to major in health and aging disciplines to enhance their understanding of dementia and age-related concerns. Others embarked on professional journeys to become trained coaches to support other caregivers affected by dementia. Moreover, participants in specialized fields (i.e., speech therapy) relied on their cognitive-communication skills to provide care.

The professional application of knowledge proved to be different among the participants. While most YACs agreed that their professional and academic knowledge supported them in their role as a caregiver, it did not necessarily reduce the perceived psychological challenges to a great extent. Where the knowledge was useful was in establishing feelings of competence, having realistic expectations, and with handling tasks or behavioural challenges related to dementia. For the professionally trained YACs, they felt they had a "head start" given their professional backgrounds and specialized training. In other instances, YACs applied their education to theorize or make sense of various stages of the disease (i.e., death and dying). Overall, the application of academic and professional knowledge helped many YACs to feel more empowered and enhance feelings of self-efficacy. This is consistent with the literature on how knowledge can enhance techniques to deal with dementia-related problems and also increase a caregiver's sense of control in unpredictable circumstances, thus acting as a protective factor against perceived helplessness (Broadate et al., 1994; Coen et al., 1999; Lyman, 1993; Williams, Morrison & Robinson, 2013; Lyman, 1993). In addition, increasing carer knowledge is beneficial and can lead to decreased levels of depression and feelings of competence (Graham, Lackey & Gates, 2001; Nichols et al., 2013; Ballard & Sham, 1999; Brodaty et al., 1994; Coen et al., 1999).

The literature widely explores the role of medical knowledge for informal caregivers and suggests that acquiring knowledge can inform emotional responses, help to make sense of various situations, and create meaning in caregiving and resilience through information (Cherry, Salmon, Dickon, Powerrl & Ablett, 2013). Medical knowledge is also helpful to manage the disease and the caregiving relationship (Dunham & Cannon, 2007). However, the literature also has found that caregivers express concern with the limits of medical knowledge and resistance to some aspects of medical control (Dunham & Cannon, 2008). In this instance, the limits of the participants' medical knowledge motivated them to improve their knowledge of ADRD and health and aging. This was discussed by YC2 and YC12 on their motivations for pursuing degrees in aging and neuroscience. In turn, this helped them to be more compassionate and empathetic in their role as a caregiver. For example, YC2 indicated that she perceives her education in health and aging will help her be more prepared and competent in her caregiving role. Also, she indicated that the applies the skills she learned in psychology class to be more patient with her father. In addition, YC12 was also inspired to learn more about mental health and neuroscience after becoming a caregiver for his grandmother. Through these efforts, YC12 demonstrated greater empathy and compassion for his grandmother, which motivated him to be extremely involved in her care.

5.3.4 I Am My Mother/Father's Keeper

The relationship between the YACs and the care-recipient was a significant sub-theme for the participants (see section 5.2.4). The participants agreed that the quality of the relationship with the care-recipient was an integral component of caregiving. In the literature, this relationship is known as the care-giver dyad which emphasizes that the caregiver and care-receiver exist as a unit (Lyons et al., 2002). Traditionally, this dyadic process is uni-directional, but research has emphasized that a limitation within this process is that the perspectives of the care-recipient are neglected (Lyons et al., 2002). Studies exploring the care-giver dyad often explore the perspectives of both parties- the caregiver and the care-recipient. Given that this study only interviews caregivers, my aim here is to show how YACs make sense of this dyadic relationship from their point of view. In addition, there is very little research on the dyadic process for young caregivers in the context of dementia. Most research on the dyadic process focuses on couples and spouses (Braun, Scholz, Bailey, Perren, Hornugh & Martin, 2007) or middle-aged adult children (Nelis, Clare & Whitaker, 2012).

However, this is not to suggest that the dyadic process is always favorable and harmonious. While the majority of YACs would agree that their identity was embedded in the dyadic process, there was some concern about the implications of this. A central discussion point was the role-reversal that takes place (or what participants described as having to be ‘a parent to their parent). Theoretically, this role-reversal has been described as the process of parentification whereby children take on the role of an adult prematurely (Morris, 1993). The ramifications of parentification have been explored in several young carer studies and the findings suggest that identity and interpersonal relationships and personality are impacted (Early & Cushway, 2002). Studies show that the impacts of parentification are mixed and can include difficulty functioning in adult relationships (Armas, 2022). YACs discussed how parentification resulted in them having to be a ‘parent to their parent’, but less so about how this impacted their adult development. What was consistent with the literature is that there is polarity (ambivalent yet rewarding feelings) that occurs as a result of parentification.

Not all participants agreed that the dyad process was always disruptive. Many participants were able to reach a level of compromise throughout the caregiving process. They embraced finding new ways to relate to the care-recipient and find meaning in the caregiving-process. In the context of caregiving, meaning has primarily been used to describe ‘finding a redeeming value in loss” (Folkman, 1997, p.125). A study by Quinn, Clare and Woods (2012) found that caregivers of people with dementia find meaning when they are intrinsically motivated, feel competent, feel not engulfed by the caregiving role and hold strong religious beliefs. Despite its relevance in understanding meaning-making for dementia caregivers, there has been little research exploring the role of finding meaning in dementia caregiving for young caregivers. However, broadly, studies on young caregivers' perceptions of meaning-making emphasize the importance of variation and multiple views on meaning and how meaning can be co-constructed (Turner, 2016). In addition, for young caregivers meaning is often associated with benefit-finding, particularly relational benefits (becoming closer with the care-recipient) and social recognition (Areguy, Mock, Breen, Rhijn, Wolson & Lero, 2019; Cassidy et al., 2014).

5.4 Conclusion

This chapter reported on the second superordinate theme, **Caregiving "Me, Myself and Us."** Here, the most dominant sub-themes that I identified were *"Who am I?' 'I Need Support Too' "How Do I Make Sense of This: Learning as I Go' and "I Am My Mother/Father's Keeper.* Taken together, these sub-themes emphasize that the nature of caregiving is not only instrumental and transactional, but it is inherently a relational and social process. This is apparent in the ways participants sought out supports and networks, took initiative to fill in knowledge gaps, and made significant efforts to step into an authoritative role, which in many ways, confirmed and reinforced their caregiving identity.

Further, YACs emphasized that the nature of their shifting identities impacted the perceptions of their caregiving role and interactions with others. This is evident in the ways participants described their evolving intrapersonal and interpersonal relationships. This contributed to the need to relate to and connect with other caregivers who had a shared identity. It also contributed to the ways YACs interacted with the care-recipient and the shifting nature of this relationship before, during and after caregiving. In most cases, the nature of the relationship before caregiving implicated the process and meanings of care for YACs. This process includes the changing expressions of one's caregiving identity, as well as the process of role-reversal between the caregiver and the care-recipient. Overall, this process is informed by meanings of culture, education, professional life, and family values, which, for YACs, exist alongside and contribute to the nature of caregiving for someone with PWD.

Chapter 6: Turning Points (Dealing with Adversity)

6.1 Overview of Chapter

In this chapter, I will present a descriptive account of the third superordinate theme, which I identified as ***Turning Points: Dealing with Adversity***. In analysing the interview data, YACs described adversity as dealing with hardship or a disruption to their lives in some way. There were three sub-themes (*'Life Interrupted,' 'Feeling Broken,'* and *"I Feel Alone: Caregiving in Silence')* and one subordinate theme (*Polarity in Caregiving: A Devastating Gift*) that I identified. In this chapter, my goal is to capture how participants experienced and made sense of adversity while in a caregiving role. Similar to the previous chapters outlining findings (chapters 4 & 5), this chapter will be phenomenological and interpretive, and include personal reflections.

Table 9: Superordinate Theme 3 and Related Sub-themes

Superordinate Theme: Turning Points: Dealing with Adversity	Sub-Theme	Subordinate theme
	Life Interrupted	
	Feeling Broken	Polarity in Caregiving: A Devastating Gift
	Caregiving in Silence: I Feel Alone	

6.2.1 Life Interrupted

One of the ways YACs described their lives being interrupted was in the form of lost or accelerated childhood. For these YACs, their childhood was disrupted by caregiving at an early age. YACs expressed that they often had to grow up more quickly than their peers which resulted in them being more mature for their age. Here, YC2 describes her views on this:

"I had to mature in order to take care of my parents. I didn't get that opportunity to be a kid, I didn't get to go out to parties. I went to my first party in first year and like that was it. It wasn't anything special for me, just a lot of people, but it was just like those stereotypical little like high school or experiences, I never end up getting or even being able to go on vacation." [YC2]

Similarly, YC8, who at age 8 began caring for her father in India, describes her views on growing up too fast due to feeling responsible for her parents as a child. She says:

"Once dementia set in and I lost that again, so I had to grow up soon, I did not have the freedom of enjoying life, like any other teenager would, life was all about responsibilities for me…. I started driving very early in India…I did not want my mom to drive because it's very stressful to drive in India and she already had enough stress…because she's been so busy caring for my dad. So, I thought it was my responsibility to care for her while she cared for my dad so I never let her drive…and then that's how I grew up too soon I literally straightaway jumped into adulthood… and because of that, I feel I burnt out way too early See you know with the emotions, with the physical stuff with the mental stuff like. I was spent and completely spent by the time my dad passed away." [YC8]

A second way YACs described disruption was to their social and peer relationships. For example, YC7 explained how much her relationships - both romantic and otherwise - had been impacted by her caregiving responsibilities for her mother.

"I gave up a lot. I forfeited a lot, you know, living abroad. I had a relationship that really fizzled away because I was so stressed out caring for my mom. My younger brother like moved away to be with his wife and her family, because he was already married.
You know my older brother was in dental school and I felt like Oh well, your things are more important than my things, right?" [YC7]

Similarly, YC3, discussed being apprehensive about entering new relationships and how caregiving limited opportunities for social interaction.

“It’s impacted my life in my relationship. I had a five-year relationship that ended, and I do think that one of the reasons is ended is because he couldn't really deal with how big of a part of my life that was. So now that's like a really big thing, as I enter relationships and date.
You know that this is just like a non-negotiable, but it stinks that it has impacted you know that sort of stuff.” [YC3]

As YC4 summed up, “I think relationships very much do suffer….I have been too exhausted at times when I'm not texting people back, I'm not responding, I'm not showing up to stuff and that does take a toll on current and potential future relationships."

Participants lamented that caregiving limited their opportunities (and energy) for social interaction and were very conscious that their relationships were impacted by the competing demands of their caregiving role. Here, there is a sense of being unable to sustain relationships with others, but also experiencing challenges to the relationship with oneself in terms of one’s development (i.e., having to mature too fast). This was particularly the case for participants who were in romantic relationships or anticipating the negative impact of caregiving on their future romantic relationships. In a sense, the participant’s personal life was somewhat downplayed compared to the relational needs of the care-recipient. This is evident in the ways participants intentionally or inadvertently allowed caregiving to be prioritized over their personal relationships. Overall, the disruptions to intrapersonal and interpersonal relationships lead to relational discord, difficulty navigating relationships and limited social interactions.

YACs also described disruption in terms of the financial cost of ADRD. Here, affordability of care for dementia resulted in YACs being in a long-term caregiving role, which contributed to social constraints and a lack of financial flexibility. YACs were also cognizant of existing social inequalities for people with dementia and their caregivers which can limit access to optimal care, services and supports. YC8, who at age 8 began caring for her father in India, describes her views on the expensive disease. She says:

"It was a nightmare for us, and dementia is a very expensive neurodegenerative disease. It's not for the poor at all, not at all for the poor, we don't have any support financially or emotionally, or in any way in India. So, whatever my mom would earn would all go into his medication, his daycare, his care person, his travel just in those things. So, one thing I learned that it's a very, very expensive disease, but we tried to sail through. That broke us down many times." [YC8]

Similarly, YC5, a university student and caregiver for her father, discusses how the inability to afford a full-time caregiver resulted in social constraints:

"Also like financially, it was really hard for us at that time to afford a full-time caregiver and so like right after class, my friends would be like hey like let's go grab a bite to eat on campus or hey you want to stay after school and study and I'm like no guys like I gotta go home and take care of dad, there's no one there" [YC5]

In comparison, some YCs had the support of a parent (who was not ill) who contributed to the care of the care-recipient. YC10 comments on anticipating future caregiving costs and being involved in financial decision making:

"So, it's my mom and I because she is his spouse…so one of the things that we discussed and then that she acted upon was just making a lot of financial decisions in terms of speaking to an elder care lawyer, making sure, everything is kind of consolidated…it's thinking like long term planning. I know for him to go into a memory care facility nursing homes facility or that type of thing, you know, financially like, what the cost will be down the line. I don't know." [YC10]

While YC10 did not have to shoulder financial decisions or planning on their own, being involved with such conversations alongside other caregivers was still disruptive in that the anticipation of future costs related to long-term care planning, specifically institutionalization, in the later stages of the disease.

As these examples demonstrate, the YACs I interviewed for this study described their experiences in terms of their lives being interrupted. They described this in terms of disruption or lost or accelerated childhood, disruption to social relationships or partnership, and financial challenges (inability to pay for care or anticipating future costs). The ways that YCs described disruption draws attention to the many ways caregivers can experience hardship while in a caregiving role. Taken together, the many forms of disruption do intersect which can compound the disruptions associated with caregiving producing a range of effects. Through expressing their views on disruption, participants highlight one aspect of the nature of caregiving, which is that it can widely vary depending on economic factors which will impact access to adequate care, services and supports.

6.2.2 Feeling Broken

All of the participants discussed experiencing feeling broken in some way, specifically in terms of psychological and emotional challenges. They perceived psychological and emotional challenges to be wide-ranging and complicated. These feelings included a range of emotions, such as fear, sadness, grief and anger, which were contextualized differently by participants. Two of the participants, YC1 and YC8, expressed their concerns with inheriting ADRD. They questioned how they would potentially deal with having a genetic risk of ADRD and the issue of memory loss. When asked about his concerns of genetic risk, YC1 expressed that, in hindsight, he would have had a genetic test earlier given the unabated expectation that he might inherit ADRD. YC1, then went on to describe feelings of anticipation and anxiety generated by the fear of inheriting ADRD and not wanting to be a burden to somebody else.

Similarly, YC8 discusses how instances of minor forgetfulness contributes to her fear of being diagnosed with ADRD. While these ‘forgetful moments’ might be normal; they become exaggerated for her given her family history. Here, she explains her fear:

> “Now, the only fear that I have is that in my generation we shouldn't start showing signs in our 30s right? It's possible to show symptoms when you're 30. It may not be early 30s, but maybe late 30s but that's a possibility, so I’m shit scared. Sorry, to use that word. If I forget one thing in the day, my day is done. I’m so scared.” [YC8]

YC8 also discusses feeling broken emotionally with multiple attempts to treat or cure ADRD and having to deal with feeling heartbroken when expectations were not met.

“It breaks you emotionally … so there were a lot of things that broke us down, sometimes we hoped for results, we tried every test under the sky, every single thing that could help us either you know slow down the process of dementia, or even cure. We tried every single day, and after each one of those we would be heartbroken that it didn't work and we were just hoping and then every time there was a new medication it will take a toll on him either he would get violent or he has severe tummy issues or temper issues or muscle pain, every time a medication was added or removed, or a dose changed.” [YC8].

Yet, not all experiences of psychological and emotional challenges were centered around fear.

Here, YC6, a caregiver for her father, discusses anger, frustration and uncertainty in her experience with caregiving:

“I mean, they still don't have any type of true prevention, so it's just kind of having to figure it out afterwards, like what do we do? There's so many feelings and emotions. You're frustrated. You're angry, you know, angry at the situation, like man, why is this happening?” [YC6]

Similarly, YC3, expressed feelings of anger because some aspects of her life have been drastically impacted by caregiving. During the interview, YC3 was quite impassioned when describing that she felt her life was being ‘taken away:’

“The things that it robs you of and the time and the energy and the money and the emotional toll that it takes on the caregivers, so that other side is really unfair. Then, I get into thinking and how our whole health care system is built on the backs of caregivers and its expected that someone is going to step up and do this work without society having the resources made available to make it easier. Pretty criminal I know.” [YC3]

For YC3, ‘being robbed’ is a metaphor for aspects of her life that were taken away. Further, this emphasizes the social and material deprivation that resulted from being a caregiver. The significance of this infers that there are both tangible and intangible consequences associated with caregiving. Over time, these consequences can accumulate or multiply which further compounding the effects of caregiving.

In contrast, YC10 discusses feelings of sadness, victimhood and despair. When recollecting the difficult choice to institutionalize her father, she shared how she felt as though she was failing him:

> “So, I took him by the hand and I escorted him in…and we can hear him very upset this is not my room, I want to go home he's incredibly agitated and that was awful…But as the person who's been taking care of him for so long and just having that relationship that was awful to hear, it was a very hard thing to go through, because it just felt like you were setting him up for just failure.” [YC10]

She went on to discuss feeling like a victim and questioning why she is often in a caregiving role:

> **“**In terms of [uses first person pronoun] still probably going to be a caregiver in some way, shape or form because it just seems to keep happening. I talked to my mom about that, and I was just like, why does, why am I always in this situation…and not trying to make light of it but it's just like why me and like, why does this keep happening?” [YC10]

This sub-theme highlights how participants described their experiences in terms of psychological and emotional challenges. Such challenges included feelings of fear, grief, guilt, victim, and anger and frustration and uncertainty. From their descriptions, we learn that the negative feelings are often associated with some aspect of caregiving- fear of forgetting, caregiving, failed attempts to treat or cure ADRD, and feeling like a victim. Their descriptions of psychological and emotional challenges highlight that the nature of caregiving for someone with ADRD includes navigating through personal feelings and emotions, which are often the result of broader social relations and processes.

6.2.3 Polarity in Caregiving: A Devastating Gift

A subordinate theme that I identified from the participants’ descriptions is the *polarity in caregiving*. In other words, all of the participants spoke about contrast, in one sense or the other. While all participants had corresponding feelings of psychological and emotional challenges, that can be described as negative, these were countered and existed alongside positive feelings. Such positive feelings include feelings of joy, grace, opportunity, growth and relief. The juxtapositions of feelings described by participants in this study highlight the polarity that exists for YACs when caregiving for someone with ADRD. The following table includes the language YACs used to discuss the polarity in caregiving for someone with ADRD.

Table 10: Polarity in Caregiving: A Devastating Gift

YC4 YC11	Shame	Pride/empowerment
YC4 YC11	Victim	Victor
YC1 YC2 YC5 YC12	Acceptance	Reluctance
YC1 YC2 YC6 YC9 YC11	Blessing	Tough/Burden
YC9	Roll with it	Exhausted
YC8	Growth	Lost/accelerated childhood

YC1 YC2 YC3 YC10 YC11	Relief	Grief/Regret
YC4 YC12	Joy	Undesired feelings
YC11 YC4	Fear	Fun
YC11	Light	Shadow
YC11	Logic	Emotion
YC11	Cannot wait to provide care	Scared as hell to provide care
YC11	Happening	fading
YC4 YC6 YC8 YC9	Opportunity	Burden/Disruption

Reflection
It is quite interesting that the majority of participants all described feelings of duality or polarity when describing the psychological impact of caregiving. From their descriptions, I can understand the challenge of holding two contrasting/polarizing views together. In my experience professionally, I was trained on the importance of this in conflict resolution or mediation, particularly when working with caregivers and their families. Beyond this, their stories made me think of times in my life where I was challenged by feelings of tension in a relationship or another experience. From their experiences, I can understand how the polarizing feelings can take shape differently and can have an

effect on caregiving but can potentially make the process of caregiving challenging (i.e., I am angry, but there is joy too…I feel guilty because I should not be angry because this will end soon, but I also need to acknowledge my feelings of anger…but is this important considering my loved one is going through a serious health challenge?)

After discussing their experiences with grief, YC10 discussed the contrast between grief and relief. Here, feelings of grief also extended into ideas about excitement and freedom about no longer having having caregiving responsibilities. At the same time, there was some uncertainty about life after caregiving. Here, she says:

> "So, I think Alzheimer's is, now I don't want to be a broken record, I do think it is a gift in terms of what it can provide the family unit, but I also think it is a devastatingly difficult disease to go through in terms of just being in a constant state of grief watching someone slowly, you know dwindle." [YC11]

She went on to describe how caregiving for someone with ADRD is a fleeting experience; the temporary nature of caregiving making it more tolerable:

> "Also, the other thing that I like to preach like so often is that everything is temporary so like one day I will miss giving my mom showers, even though I cannot stand that task…it's all going away, you know it's all happening and fading. If you can lend the understanding of impermanence to caretaking it can sincerely change the entire situation. It provides you with relief, knowing as a caretaker that this is not what you're going to be doing for the rest of your life. And it also makes everything feel so much sweeter and just you just want to be so much more present and aware, because it is going to go away." [YC11]

Relatedly, YC4 described her experiences with both anger and joy while caring for her mother. After discussing her feelings of anger due to being ill-prepared for caring for her mother with younger-onset dementia, she then discusses how she found great comfort in the joy of caregiving:

> "There's still so much joy in Alzheimer's…I think it's like taking the time to savor the moment where you like see the laughs you see the moments of connection. You see them go down memory lane, they're looking at photos… I'm never like forcing them – like no don't ask that question, "do you remember me? Do you remember this?" No, no, no, no if they knew they would tell you right, just like go with them, wherever they are, and live in that space …that's where you'll find the joy in all of this in this really scary disease." [YC4]

The YACs descriptions of conflicting emotions in caregiving draws attention to the tensions that exist when caring for someone with ADRD. The participant accounts emphasize the nature of caregiving for someone with ADRD involves managing polarizing emotions and feelings. In their descriptions of the polarity in caregiving, participants highlight that the nature of caregiving involves the process of navigating through emotional polarization which can complicate caregiving, but also offer a renewed perspective which can minimize or ameliorate negative feelings.

6.3. Feeling Alone: Caregiving in Silence

Another way that participants described social isolation as another source of adversity. The majority of participants described experiencing feelings of social isolation and loneliness, which often stemmed from social constraints, being engulfed with the caregiving role, being misunderstood and a lack of connectedness. Also, although there was overlap, there is a distinction between loneliness and social isolation for YACs. Here, social isolation appeared to be associated with social restrictions and a lack of engagement, while loneliness was associated with a lack of understanding from peers and stigma. Demonstrating the latter, YC6 discusses feeling disconnected from her peers given they could not understand or identify with her reality. She says:

“I think the thing that’s also been hard is that while your friends have empathy, while they like are like let me know anything you need it, you still don’t feel like people get it. There’s a sense of like deep loneliness actually I would say now that I’m well into this, like all those things don’t hit me at once, but I’m hyper aware of that now more than anything.” [YC6]

The theme of social isolation was also discussed by YC8 who, together with her mother, cares for her father. She not only highlights the challenges with feeling disconnected from her peer group, but also how social stigma and assumptions about young caregivers contributed to feelings of loneliness.

“It’s the loneliest place you can be because no one in your age group can understand that. No one could comprehend what I was going through. I couldn’t share it with any of my friends, because they never understood they didn't know why I was acting the way I was. You're very alone when you're a young caregiver, and people older than me- I have to share all this with them and they have stigma they don't even want to come talk to you right. For the few who did speak to me, they connected more with my mother because of that age right…they would connect more with my mom so no one ever thought that a child can be impacted." [YC8]

For YC8, this interaction serves of an example of the ways young caregivers can be overlooked in public settings, specifically their needs, roles, and perspectives. In this interaction, the taken for granted assumptions demonstrated by the public about young people in caregiving roles contributed to stigma and general oversights about how children and young adults are impacted by caregiving. Here, loneliness not only manifests due to feeling disconnected from one's peer group, but also feeling dismissed or overlooked by others in public settings.

Some participants were very guarded about their caregiving role YC5, for example, was initially very discreet about her caregiving role because she felt her friends would not be able to empathize. This led her to withholding her feelings of grief from friends. She says:

> "So, for the longest time I never spoke to anyone about my father's diagnosis, I didn't even tell my best friends till like five or six years into when my dad was being diagnosed simply because I just didn't think anyone would understand, and so I never talked about it and then one day like, and I would grieve so much over my dad's diagnosis." [YC5]

The theme of social isolation was also discussed by YC9 who not only highlights that the position of being a caregiver comes with social restrictions, which contribute to feelings of social isolation and loneliness. She says:

> "Sometimes it is a little isolating, a little different just because you see everyone else on Instagram or on social media, but I have this position where I can't always do that and it's the same with certain events. It feels alone and I think that's another reason why I really like my Instagram page helping people because you know it's like I said at the beginning it's an epidemic, yet you can feel completely alone in this disease." [YC9]

The participants in this study described their experiences in terms of **Feeling Alone: Caregiving in Silence,** which involved feelings of loneliness, being misunderstood, dealing with stigma, and not wanting to disclose the care-recipients diagnosis or their caregiving status/identity. At the same time, feelings of loneliness and isolation are increased by withholding and being discreet about their status and caregiving role. From these descriptions, it is clear that the need for validation from those who will empathize is important for YACs. In their descriptions of social isolation, participants highlighted that the lack of social supports in the form of mutually satisfying connections contributes to social isolation which can impact the nature of caregiving.

6.4 Discussion

6.4.1 Life Interrupted

When one's life is interrupted or disrupted, in the context of young caregivers, it can result in psychological and emotional consequences (Aldridge & Becker, 2003). All participants discussed some form of interruption to their lives while being in a caregiving role (section 6.2.1). Here, disruption appeared to mean a 'break' or 'pause' in their life or some aspect of their life. YACs spoke about interruption or disruption to childhood, relationships, professional work trajectory, social life, education, and personal freedom. Each of these themes echoes the literature with respect to the known impacts on young caregivers, some of which include psychological and emotional challenges, social exclusion and financial hardship well-being, social stigma and exclusion and financial hardship (Hutchinson et al., 2016; Stamatopoulos, 2016). However, given that YACs in this study were of an older age (18-25), the meanings associated with disruption were different from the meanings expressed by young caregivers (age 11-18) in the literature. The participants in this study were explicit in their concerns about the impacts of caregiving on romantic relationships and their education (specifically college) as a way of improving their life chances and career trajectory. Taken together, this suggests a need to understand how young adults may interpret an interruption to their lives differently from other caregiver populations. In doing so, we can learn whether or how their experiences are different or similar to what is considered a ‘normal’ disruption in the literature.

Young adult caregivers are considered to be at risk for accelerated or lost childhood (Charles et al., 2009) and child parentification (Hendricks et al., 2021). This was relevant to participants in this study who took on caregiving roles and tasks prematurely. This was also true for participants who felt the need to protect their parent who had ADRD and preserve the health of their other parent (spouse of the care-recipient). Participant views broadly echoed the literature highlighting the tensions that young caregivers experience from lost or accelerated childhood which have been connected to positive outcomes, such as maturity and resilience (Nichols et al., 2014) and negative outcomes, including resentment and compromised development (Svanberg et al., 2016). However, a key difference for participants is their perceived meanings of being a “parent to their parent.” For child carers, this role is demonstrated by the provision of support and instrumental tasks; for young adult caregivers it included additional responsibilities in terms of advocacy, financial planning, and long-term care planning. In this way, the findings largely echo the literature that shows how young caregivers perceived having a lost or accelerated childhood when they have to mature before their time and when they take on age-inappropriate responsibilities (Charles, Stainton & Marshall, 2009) or when they miss out on age-appropriate activities due to the demands of providing family care (Jurkovic, 1997; Noble-Carr, 2002).

Some scholars have challenged research on young caregivers because of the narrow definitions applied and the negative portrayal of children (Smyth, Blaxland & Cass, 2011). For example, Smyth et al. (2011) suggests that a large majority of literature assumes that caregiving stops once young caregivers reach age 18. However, as YACS highlighted in this study, many times caregiving continues past the age of 18 and into adulthood. When this is the case, young cares can become ‘imprisoned by caregiving' throughout their life course which impacts their transition into adulthood (Stevens, 2002). The notion of imprisonment is highlight in participant descriptions when they emphasized the social restrictions, constraints and barriers caused by caregiving.

In addition, some scholars have challenged how the role of children is portrayed in young carer studies, particularly in a western context (Gays, 1998; O'Dell, 2010). For example, Gays (1998) asserts that the normative assumptions about childhood are constructed to emphasize their utility and accelerated transition into adulthood which contributes to their maturity and resiliency. However, Gays (1998) also says that this construction neglects to acknowledge the factors contributing to young caregivers remaining in a long-term caregiving role. Participant views acknowledged both assertions in their descriptions on caregiving – first, how they identified with the construction of young carer as a self-prescribed public marker and second, in their descriptions on the socio-economic factors related to ADRD, which contributed to social constraints and a lack of financial flexibility positioning them in a long-term caregiving role.

The YACs discussed that they dealt with interruption or disruption to their education and career opportunities. However, the findings were somewhat dissimilar to the dominant literature on young caregivers. The literature on young caregivers emphasizes a disruption to school, but mainly discusses restrictions to educational progress in the form of punctuality, absences, homework challenges, low attainment, anxiety and fatigue (Dearden & Becker, 2002, Reibelt, 1998). Overall, these findings conclude that, for young caregivers, the most impactful aspect of caregiving is the inability of the child to attain the educational standard that would otherwise be expected. Comparatively, in this study, YACS were of college age which made for a different view on how they perceived disruption to their education. Here, they faced disruption to completing college, experienced limited opportunities to pursue academic opportunities, and an overall disruption to their long-term academic and professional plans (4.4.3 'The missed').

YACs also discussed disruption in terms of financial difficulties. This finding has been discussed in young carer literature to an extent (Thompson, 2011; Harding, 1994), but less so about how young caregivers contribute financially or manage finances in their caregiving role. In many families, the research shows that the parent (i.e., spouse) takes on the majority of financial decisions or more paid work (Allen, 2009). This was true for participants who perceived themselves to be in a secondary role with support of the parent. With regards to finances, the literature mostly discusses the affordability of dementia care and how a family's financial future is disrupted by caregiving obligations, which in turn, impacts young caregivers (Hutchinson, 2016). This was true for participants who discussed being unable to social constraints or pay for extra support as a result of caregiving. ADRD being expensive was one factor contributing to young caregivers taking up the role.

In addition, given that research shows a large proportion of young caregivers come from disadvantaged households, this also raises questions about the structural factors that contribute to the financial challenges for young caregivers (Olsen et al., 2011). In this study, YACS were responsible for all financial decisions if they were the primary caregiver. In contrast, YACs were responsible for collaborating in financial decision making if they were in a support role alongside another primary caregiver (in most cases the other parent/spouse of the care-recipient). The general consensus of the participants was that the level of financial disruption they experienced was in relation to their social location. Further, all YACs agreed that caring for someone with dementia is costly, and the lack of affordability contributed to them being in a caregiving role long-term.

Overall, the forms of interruption described by YACs are related to the disparities in caregiving. The most commonly cited factors underlying social inequalities in caregiving and dementia care include working conditions, educational attainment, political constraints, and a lack of access to state provisions (Tough et al., 2020). This extends to literature by Newman (2002) and Sahoo (2009) that connects the issue of disparities in caregiving that young caregivers experience to broader issue of social justice, whereby the compromised role of young caregivers is related to poverty, social exclusion, and the lack of attention in social policy. This also connects to one of the central debates in young carer literature which questions the role of state provision in supporting families of young caregivers. Participants emphasized the limitations of adequate government supports (4.3.2 'Caregiving and Systems Collide: They don't Understand) as well as financial challenges associated with dementia care costs, and the lack of recognition in social policy. Such disparities contribute to financial challenges, which lead to having to be in a caregiving role.

6.4.2 Feeling Broken

The emergence of child psychology (and positive psychology) has informed a large proportion of literature on young caregivers and greater awareness of social development, identity formation, benefits and risks (Gough & Guilliford, 2020). However, the contribution of psychology has had unintended consequences in terms of pathologizing young caregivers emphasizing that they are at risk for psychological and emotional challenges. Nevertheless, the findings largely echo this literature that suggests that young caregivers are impacted by a range of psychological and emotional challenges which disrupt their normal social development, particularly as young caregivers transition into adulthood (Cass et al., 2011). Likewise, participants discussed a range of emotional and psychological experiences caused by their caregiving experience. The language used to describe their emotions includes fear, anger, sadness, resentment, depression, anxiety and uncertainty and confusion, among others. YACs spoke about the fear of getting the ADRD and the day-to-day fear associated with casual forgetting, confusion and uncertainty about decision making and ADRD itself, as well as feelings of depression and helplessness.

One of the more dominant emotions described by participants was grief. In a caregiving context, grief are emotional feelings related to loss, which can be complicated, ambiguous and often occurs in stages (Boerner and Schulz, 2009). In the literature, grief is also a dominant emotion associated with young caregivers (Bjorgvinsdottir & Halldorsdottir, 2014; Hamil et al., 2017; Lackey & Gates 2001; Moore & McArthur, 2007)). This emotion stood out for the participants in their descriptions of psychological challenges and caregiving. Here, grief was defined as unresolved, which included grieving the person who is still alive or grieving who the person once was (i.e., the loss of personhood). In the literature this is referred to as anticipatory grief, which is defined as grief that takes place while a loved one is still alive, not only when caregiving responsibilities have ceased or following the death of a loved one (Doka, 1999; 2013; Walker et al., 1995).

The psychological challenges experienced by YACs emphasize the experience of ambiguous loss, which is a loss where loved ones are absent and present at the same time, such as the case with dementia where someone is physically present by psychologically absent (Boss, 1999; 2010). Ambiguous loss is unclear, lacks finality, and often has no predictable ending (Pauline & Boss, 2016). For participants in this study, caring for someone with ADRD did contribute to feelings of ambiguous loss. YACs discussed feelings of anxiety and tension due to the multiple losses they experienced in their personal life, as well as the personal, functional and cognitive losses experienced by the care recipient (4.3.4 They are Still Somebody). Here, the losses can be viewed as symbolic (e.g., as in the case of Y5 losing the opportunity to run with her father) in that they are not explicitly related to death, but related to one's role, identity, or relationship to another person.

Overall, caregiving has contributed to the mental health risk of young caregivers, which has also necessitated the need for professional assessments and intervention. (Cree, 2003; Gray et al., 2008; Janes et al., 2022; McAndre et al., 2012; Shifren & Kachorek, 2003). This was true for participants as exemplified in their discussions on the various interventions they used to cope (section 4.3.1). Further, young caregivers all described feelings consistent with other young caregivers in the literature, such as feelings of shame, hopelessness, embarrassment and social isolation when caring for a parent with dementia (Allen et al., 2000; Luscombe et al., 1998; Thompson, 2012). These feelings were further compounded by the multiple losses associated with the progressive nature of dementia (Ory et al., 1999). In addition, a study by Schleicher (2011) which situates young caregivers in the mental health system, has found that navigating the social and health system can increase psychological challenges for young caregivers. This held true for participants in terms of navigating through bureaucratic healthcare processes and interactions with medical authority (4.4.2 Caregiving and Systems Collide: They Don't Understand). Overall, the attention to psychological and emotional challenges associated with caregiving has led to significant efforts to protect and the mental health of young people in caring roles through the form of professional therapies and interventions.

6.4.3. Polarity in Caregiving: A Devastating Gift

A subordinate theme identified when analyzing the psychological and emotional challenges is the ***Polarity in Caregiving: A Devastating Gift***. The participants described caregiving with stark contrast through the language that they used. In this context, I understand polarity to be similar to a paradoxical situation with two dissimilar and often opposite experiences/forces occurring simultaneously. In many instances, YACs would describe the contrast in opposing statements, such as “relief, yet grief” or “acceptance and reluctance” or “victim and victor”. This is what YC6 describes as the “roller-coaster of emotion” given the conflicting experiences occurring simultaneously. While polarity in caregiving is not explicitly focused on in the literature, researchers do highlight the ambiguous nature of caregiving and show contrast through studies exploring the advantages in the form of opportunities and disadvantages in the form of consequences.

Participant descriptions are consistent with the literature that normalizes the tensions that young adults experience in a caregiving role. Research on tensions in caregiving have contributed to more contemporary caregiving models normalizing the contrast that exists. For example, in his model on the stages of caregiving, Pfeiffer (1999) emphasizes that there is a disconnect between the fixed clinical stages of ADRD used in clinical practice and the stages described by caregivers themselves. In particular, in stage 6, ‘the death of the patient: grief and relief,’ he highlights that,

> *“Although a large amount of anticipatory grief has already occurred, the actual death of the patient triggers new and profound grief reactions for the caregiver….in addition to the sense of renewed grief, the caregiver may also experience a sense of relief, although some caregivers fault themselves for their sense of relief and experience unwarranted guilt”* (p. 127).

This view certainly holds true for participants in the way that it draws attention to the cyclical and fluid nature of emotions associated with caregiving that are polarizing and complicated when providing care for someone with ADRD. This was made clear by some participants in their descriptions on feeling a sense of grief and relief when the care-recipient passed away. Overall, this emphasizes that the process of grieving is not straightforward or linear but is more often ambiguous and prolonged.

6.4.4. Feeling Alone: Caregiving in Silence

YACs discussed disruption in terms of social isolation and loneliness, referring broadly to social connectedness (Lee & Robbins, 1995). Although sometimes used interchangeably, the participants in this differentiated between meanings of social isolation and loneliness. Here, social isolation refers to reduced social engagement and participation with peers as a result of caregiving, while loneliness refers to feeling misunderstood and others not being able to identify.

The findings of this study related to the literature which describes the pathways leading to social isolation for young caregivers. First, social isolation is a manifestation of being invalidated stemming from a lack of connection with other young caregivers (Charles, 2011; Charles et al., 2010; Hamilton & Adamson, 2013; Rose & Cohen, 2010). Second, social isolation is caused by stigma, unawareness, unmet needs and feelings of alienation (Butler & Astbury, 2005; Dearden, Aldridge & Horwath, 2010). On the contrary, other scholars emphasize that geographic location, disadvantage, lack of access and poverty can also contribute to feelings of social isolation for young caregivers (Aldridge & Becker, 1993). The view of participants also reflects similar findings. Participants in my research experience stigma in social settings which contributed to feelings of being invalidated, unseen and isolated. Also, participants discussed feeling disconnected and alienated from their peer groups who could not relate to their experience, which led them to desire connections with other young caregivers. Lastly, YACs discusses how social isolation can also be caused by a lack of access to programs, services and external support.

In drawing on these views together, for YACs, we learn that social isolation is caused by a multitude of factors, can be both subjective and objective, and often perpetuated by broader socio-political factors**.** The literature also distinguishes between the two concepts suggesting that social isolation is an objective and subjective experience as it refers to both the absence of social interactions and relationships and also a displeasure with the quality or quantity of social contact (De Jong, 2003). The literature also distinguishes between loneliness and social isolation. De Jong (2015) defines loneliness as a discrepancy between the desired and achieved networks of relationships or when a person's network is perceived as deficient in some way, either quantitively or qualitatively.

Similarly, literature on young adults and loneliness theorizes loneliness as distinct from social isolation and a feeling associated with the experience of perceived social relationships as inadequate, either quantitatively or qualitatively (Ó'Súilleabháin, Burns, McMahon, Summerville, & Creaven, 2021). This is relevant for the participants in my study given their age (18-25) and transitional life stage. Kirwin et al. (2021) suggests that this stage of emerging adulthood (18-25) is a distinct developmental stage which may make the experience of loneliness different for young adults. Participants identified with findings in the literature which show that this stage represents a transitional life stage from adolescence to adulthood which is characterized by instability, possibilities, identity exploration, self-focus, and feeling in-between (Arnett & Mitra, 2018)

Based on the literature, young adult caregivers are considered to be at risk for social isolation and or loneliness (Wood et al., 2018). Emerging adulthood is a stage of life that scholars have described as "transitional, ambiguous and explorative" (Arnett & Mitra, 2018). This certainly held true for participants within this study who experienced a lack of perceived social connectedness, ambiguous loss, and complicated transitions in one's personal life and relationships. For instance, many YACs expressed that they felt lonely because their peers could not identify or relate to their lived experience. Others indicated that they were unable to attend social events or engage socially with peers due to time constraints. For YACs who did attend social events, some expressed concern with the lack of access for people with dementia which demotivated them from attending in the future (see chapter 4.3.2.

Caregiving and Systems Collide: They don't understand). At times, the lack of empathy from peers also contributed to feelings of loneliness for YACs. In this way, the findings largely echo the literature that outlines how social isolation for YACs can be understood as an act and a process, whereby feelings of social isolation and loneliness are increased by social and relational factors, which in turn, leads YACs to further withdraw from peers and society.

There was some overlap between the study findings and extant literature in terms of recommendations to mitigate social isolation for young caregivers. For example, there is a general consensus that social isolation can be mitigated by young caregivers connecting with others going through similar circumstances (Aldridge & Becker, 1993). The premise here is that such individual-level interventions will improve feelings of connectedness. To an extent, this is true for participants given that the absence of conducive support led them to form their own support networks. Moreover, some scholars suggest that the main way to address social isolation is with a whole family approach (Frank & Slatcher, 2009). This approach strives to meet the needs of the entire family with the support of professional services, rather than employing individualist approaches to support young caregivers (Frank & Slatcher, 2009). However, YACs did not mention that they felt the parenting of the care recipient was or had been deficient in any way. This could be because the whole family approach tends to focus on young children and not young adults. For YACs some categories that might be more critical to YACs of this life stage are less individual and more structural, such as work and educational constraints and financial hardships. This potentially highlights the critical role of life stage for young caregivers and it is plausible that structural factors play an equal, or more critical role, than individual level interventions in the experience of loneliness and social isolation.

6.5 Conclusion

This chapter has provided valuable insight into the ways YACs make sense of and experience **Turning Points (Dealing with Adversity)** in their lives. The three sub-themes (*i.e., Life Interrupted, Feeling Broken, I Feel Alone: Caregiving in Silence)* and one subordinate theme (*i.e., Polarity in Caregiving: A Devastating Gift*) draw attention to how adversity is interpreted by YACs. While each theme exists independently and has a profound effect on the impact of caregiving, they do overlap to contribute to the experience of adversity for YACs. Further, YACs emphasize that navigating through psychological and emotional challenges can be difficult, but also offer a renewed perspective on their circumstances. Here, we learn that the experiences of adversity are not isolated but can be engendered by broader social issues such as stigma, lack of awareness and structural barriers. From this vantage point, I argue that to more fully understand this experience of adversity, further investigation on how YACs manage, interpret, and give meaning to these tensions will be valuable for future research.

Chapter 7: Conclusion

In this dissertation I used IPA to investigate the nature of caregiving from the perspectives of young adult caregivers. In what follows, I summarize the findings of my research, consider strengths and limitations and possible areas for future research. First, I will reflect on the process of the dissertation by summarizing the findings that I identified from the study and reflecting on the care-practices of a sub-group of the sample. Then, I will discuss the strengths and limitations of the study. This will be followed by recommendations for research, policy and practice which will be helpful to further improve knowledge on young caregivers. Finally, I conclude with a discussion on my final thoughts about the research process.

7.1 Summary of Key Findings

The purpose of this dissertation is to explore the nature of caregiving as lived by young adult caregivers affected by ADRD. As such, I began by making the case for this research study by bringing together three relevant literature areas (informal care, young caregivers and ADRD), where I highlighted the origins and development of each area. In particular, I wanted to emphasize the vital, but often hidden, status of informal caregivers, factors contributing to youth-based caregiving and the socio-political implications of ADRD. More specifically, I wanted to emphasize that there are gaps in the understanding of the experiences of young adults in caregiving roles for an older adult with ADRD. Taken together, the literature review helps to set the stage for this thesis by linking broader societal change, including the rise of an aging demographic, to the emergence of each as a social issue.

The study aims to address this omission by increasing knowledge about the caregiving experiences of young adults affected by ADRD**.** Based on my data, the individual and group analysis lead to 3 significant findings, represented by the following superordinate themes: First, **The**

Experience of Managing the Impact of ADRD highlights how YACs describe and respond to the impact of ADRD in terms of coping, navigating through systems and their relationship to the care-recipient. Second, **Caregiving: Me, Myself and Us** describes the relationship between a YACs personal identity, caregiving identity and relationship to the care-recipient and whether or how these interactions are facilitated by external supports. Third, **Turning Points: Dealing with Adversity**, highlights the ways participants made sense of adversity and responded to perceived hardship in their lives as a caregiver. This superordinate theme includes one subordinate theme, **Polarity in Caregiving: A Devastating Gift,** which draws attention to the juxtaposition in emotions described by participants when describing their caregiving experience. I will now expand on these findings by returning to the overarching research questions and sub-questions that guided this study.

Overarching question: What is the nature or essence of being a young adult caregiver (ages 18-25) for an older adult with Alzheimer's Disease or a Related Dementia?

This project allowed us to see that the lived experiences for YACs varied and followed many pathways. While each of the participants' experiences were unique, there was some overlap in terms of personal identity, support (or lack thereof), belonging, and polarizing emotions. As echoed in the literature (Barr et al., 2019; Shannon et al., 2019), the nature of caregiving does not only include responding to the disease, and the ever-changing needs of the PWD, but also responding to one's own individual needs and interactions with the public and various institutions. As such, the nature of caregiving does not exist in isolation or in the "back-end" (YC4) and it is certainly not separate from broader structural and macro-level factors. This project allowed us to see that there are many assumptions about the nature of caregiving related to young caregivers, including that caregiving stops after age 18. However, this is not the case for YACs who began caregiving as children, which ultimately shaped their life trajectory and overall sense of identity. This helps us to understand how

YACs often had to redefine their lives before, during and after the caregiving journey, as well negotiate between cyclical feelings of ambiguity, resistance, and acceptance. Overall, the lived caregiving experiences of YACs is complex, nuanced, and not linear.

i) How do young caregivers describe their experience of caring for a relative with ADRD?

This study enhances our understanding of how participants describe the experience of caregiving in various ways conceptually and figuratively. They described caring for someone with ADRD as a challenging process, adjusting to each stage as the disease progressed (i.e., "It is a unique process that takes a lot of patience"- YC3). They described the experience in terms of instrumental tasks, companionship and reciprocity, all of which are quite common for informal caregivers. Similar to the literature, almost all participants alluded to the changing nature of the relationship between a parent and child in instances where role-reversal occurred (Earley & Cushway, 2002). They often described caregiving as a journey with both negative and positive aspects. In a way this can help us to understand the labels they gave themselves had positive connotations, such as "protector" or "safety net," as well as seeing the caregiving experience as a blessing and an opportunity, while others have more negative associations which related to self-neglect, sacrifice and trauma.

Although previously understudied, in this study, the meanings given to ADRD by the YACs in this study through the use of figurative language were prominent. Through the use of figurative language, the phenomenon of caregiving was illuminated or "brought out into the open" (Meservy, 2014). Participants described ADRD in various ways, through the use of metaphors, such as "swiss cheese brain" or as a "block" or "puzzle pieces" where everyday a 'piece' is taken away; each alluding to the symbolic losses, deficits and brain atrophy that occurs with ADRD. When describing what caring for a family member with ADRD is like, the process was compared to "being hit by a truck" or "a ton of bricks" which emphasizes the weight of the caregiving role and also the uncertainty that comes along with caregiving. Given the progressive nature of ADRD, and that there is no cure, it was often described as "the long goodbye," when participants witness the slow progression of the disease.

ii) How do young caregivers make sense of their caregiving experience?

This study allows us to see that an important insight of the research are the ways that young adults navigate caregiving in the contemporary world. There have been many social changes and historical events since the emergence of caregiving as a social issue in the 1980s. One of these changes has been the increase in technological advancements which has situated care and caregiving in the digital space. For young adults in caregiving roles, this has transformed the caregiving experience by providing increased access to supports and resources in more accessible ways. The emphasis on access can help us to understand the value of the digital space for caregiving. This was evident in chapter 5 (section 5.2.2- I Need Support Too) where participants mentioned the uptake of online supports, as well as building their own online networks in the absence of conducive supports. This helps us to understand that the experiences of young adult caregivers are influenced by the technological changes that have occurred as a result of globalization, which has shifted caregiving a "transnational activity," whereby caregivers connect wider and further to establish supportive connections" (Horn & Scheppe, 2020). The shifting global context that impacts young caregivers is an important consideration to understand how information technology implicates the views of young adults in caregiving roles, facilitating new understandings compared to historical and more traditional representations.

The participants in this student did not speak about biomedical interventions or potential cures for ADRD. All of the participants rejected the traditional view of ADRD which subjects people with dementia to a 'medical gaze,' suggesting that ADRD is an individual problem (Davis, 2004).

Participants aligned with social models of care which emphasize personhood – seeing the person beyond the disease (Gilleard et al., 2015). More specifically, they expressed concerns about social barriers, including the lack of service provision, discrimination and lack of access to public spaces (see section 4.3.2). This view informed their care practices, motivations, relationships with the care-recipient and, to some extent, their worldview. As such, they placed less demand on biomedical interventions and institutionalization (unless necessary at the end of life), but rather incorporated social interventions in their treatment and care approaches.

Participants also felt ill-prepared for the immediate and long-term effects of caring for an older adult with ADRD. Feeling ill-prepared contributed to feelings of incompetence and inadequacy, which led participants to find ways to enhance their skills through education and training. For participants, being ill-prepared for caregiving also led to the mismanaging of expectations and missed cues in terms of identifying the early warning signs of dementia, which also, in some cases, contributed to the intensity of the caregiving experience (see section 4.3.3). Also, the participants had the capacity to understand how their social location impacted the experience of caregiving. Overall, the availability of welfare state provision (or lack thereof) also contributed to the experience of caregiving, in terms of feeling supported or let down.

iii) What would young adult caregivers share about navigating the role of caregiver, while also maintaining their own lives?

This study allows us to see how participants navigated the role of caregiver while maintaining their own life was complex and challenging. In many cases, their caregiving role and personal identity became merged or overlapped. In addition, there were concerns with the process of role-reversal and being a "parent to their parent" (YC2). In general, participants learned to "find the balance" (YC6), which sometimes meant putting their lives "on pause" (YC6). Some participants responded to navigating this new terrain by reaching out and soliciting advice through support groups, online networks, or creating their own networks in the absence of conducive supports and to mitigate feelings of isolation. These supports became central to their sense of belonging fostering a sense of connection with other young caregivers going through similar experiences. In this study, participants also shared experiences of navigating the complexities of the education system, workplace, and health and social care system, as well as public spaces. In particular, they described learning to navigate their way through public stigma, labels and dominant assumptions related to ADRD and caregiving. Additionally, the majority of the participants shared their views on navigating life post-caregiving once responsibilities had ceased, ultimately reflecting the meaning of their identity and personal futures. Overall, the general advice for other young caregivers includes acceptance, self-compassion, “going with the flow” and patience for one’s self and the care-recipient and the overall journey of caregiving.

7.2 Reflections on the Sample

In this section, I will reflect on the sample by highlighting characteristics that I consider to be relevant to the study findings. Specifically, I will reflect on age, gender, cultural background and the socio-economic status of the participants. While there are more characteristics to consider that should not be underestimated, such as ability, geographic location or sexual orientation, I have chosen to reflect on the four aforementioned characteristics to highlight the importance of recognizing the social location of participants.

The average age of the participants when they began caregiving was 22 years old. At the time caregiving began, 4 participants would have been considered young caregivers and 8 participants would be considered young adult caregivers. This distinction is significant because while the two groups are at different developmental stages, they were both subject to role-reversal or parentification.

When this is the case, participants forsake age-appropriate developmental activities and take on adult responsibilities prematurely. Further, when caregiving begins at an earlier age, participants expressed that not many people can identify with this position and they experience challenges finding age-appropriate support due to the dominant assumptions about the age of caregivers. Specifically, for YACs, the age of the participants is significant because they experience more complex educational, professional and personal penalties. For many YACs, their educational plans were disrupted due to caregiving responsibilities. In addition, they also experienced difficulties navigating the workplace and qualifying for support.

There were 10 female participants and 2 male participants in this study. This is consistent with literature which suggests that more women are socialized into caregiving roles as compared to men (Carmichael & Charles, 2003; Esplen & Brighton, 2009). For the most part, the type of care work done by participants did not differ significantly across male and female participants. As such, there was not a significant difference in the approaches to care in terms of roles, tasks and other caregiving responsibilities as one might assume. One significant feature is that the men in this study were caring for aging women with dementia, they both had no siblings, and were from different cultural backgrounds. YC1, from Canada, who shared the caregiving responsibility with his stepfather, emphasized the power dynamics that emerge when two men are in a joint caregiving role. Here, he was in a primary caregiving role, yet in the shadows of another male who was the head of the household. For YC11, who is of South Asian descent, it was important to teach men how to be compassionate when in caregiving roles given that men in his culture are ‘emotionless.’ Overall, for participants in this study, tradition and cultural rituals contributed to some differences in caregiving responsibilities, specifically end of life practices. Also, for both genders, it appears that they took on caregiving roles if they were the eldest child or the only child, and not always on the basis of gender.

The participants in this study varied in terms of cultural background (see table 3- demographic profile). The response and engagement from South-Asian participants was an unexpected outcome of this study. Of the twelve participants in this study, almost half identified as South Asian (YC2, YC5, YC8, YC9 and YC12). During the recruitment process, I identified that this sub-group expressed great interest in the study. For example, they were the only participants who took interest in participating in a follow-up interview to expand further on their caregiving experience. In addition, they also took an interest in sharing the study findings with their networks.

One theme this sub-group highlighted was gender norms. Both YC2 and YC8. Both participants discussed the gender norms associated with caregiving which contributed to women and children having a subordinate role in the home and in the community. In particular, this impacts how men are perceived when they have ADRD; often being perceived as weak and powerless. Both Y2 and YC8, described their efforts to preserve the independence and autonomy of their fathers. However, compared to other non-south Asian participants, these efforts were complicated by resistance to some aspects of their caregiving role. For example, YC8 shared how culturally, women are included in caregiving practices, but excluded from conducting end-of-life rituals. Given that her father did not have a son, she was adamant about organizing the end-of-life rituals, which was resisted by the wider community. This was a very significant event, which represented a shift in perceptions of the rights of women in end-of life practices, which ultimately inspired the wider community of women to take on a more active role in end-of-life rituals. Overall, her experience suggests that South Asian young adult caregivers, more often females, experience challenges balancing cultural norms and tradition and more contemporary approaches in caregiving.

Cultural and linguistic barriers were also a central concern for South Asian participants. This impacted whether or how participants and their families navigated the health care system successfully.

For instance, they discussed the lack of representation in the medical field which contributed to medical mistrust and limited access to health care services (section 4.3.3). To mitigate such language barriers, YACs discussed the value of social programming and translation services in Urdu, the official language of South Asia. In many cases, these participants also served as the gatekeeper or translator between parents and medical authorities. Overall, given the shift to dementia care taking place in the community, their views reinforce the need for culturally inclusive programs and services.

YC2 and YC8 also described how ADRD is viewed in South Asian culture and in their families and wider communities. They explained that the overall awareness about dementia is absent, limited, or mixed, and mostly underpinned by a negative connotation. This was true whether care took place in their native country, India, or in Canada or the United States. It is apparent that there is a strong resistance to getting a diagnosis due to the dominant public responses and related stigma. This notion was particularly true for the older generations who viewed asking for help as negative, which was particularly significant for men who would be perceived as weak if they are affected by ADRD. This view contributed to the accepted locations of care, and the preference for care taking place in the home rather than in institutions. In addition, these cultural perceptions impacted whether or how young caregivers reached out for external support, their feelings of duty or obligation and perceived burden. Compared to other participants, their responses were more emotionally charged due to the fear of potential vitriol from the wider community about inadequately caring for their parents, reinforcing the role of cultural expectations in the caregiving process.

Reflective Box
I was quite surprised by the level of interest demonstrated by this group of caregivers. After engaging in the interviews with this group, they informed me that there is a broader South Asian millennial caregiving community online. They informed me of their motivations for joining forces with this robust community; one being to amplify their own voices and shed light on their perspectives. With each interview, my interest in this population grew and more questions were raised along the intersections of race, class, age, and generational tradition. Specifically, how they

negotiate living in the western world, with much different ideological foundations, while in caregiving roles that are influence by strong family traditions.

While income data was not collected in this study, many of the participants did allude to their socio-economic position. For many participants, the pathways to caregiving were due to being from a single-parent household or a low-income household. The lack of financial flexibility within these contexts resulted in caregivers un-enrolling from college to contribute to the household financially, delaying institutionalization of the care-recipient and lack of access to adequate care support. On the other hand, participants who came from two parent households and had multiple family members financially contributing to care provision had more flexibility with their decision-making. For all participants, the anticipation of future costs and affordability of ADRD were greatly considered.

Reflecting on various characteristics of the sample can help us understand how the participant's social location can impact their caregiving experience. We learn how the characteristics such as age, gender and cultural background can intersect and overlap to create a unique experience of caregiving. This was clear in the ways the age of young caregivers is often overlooked compared to more dominant caregiving groups, how gender can exclude women from certain aspects of caregiving such as end-of life practice, how South Asian YACs experience language and cultural barriers and how socio-economic status can lead to the social participation and access to services for both caregivers and the care-recipients. As such, while there are many similarities across participants, it is important to acknowledge the differences and how caregiving varied by social location. Where there is a lack of attention to the heterogeneity of young caregivers it impacts who is included in research studies, how participants are recruited, the provision of care supports, as well as the stories about young caregivers that are told.

7.3 Recommendations for Future Research

This study works as a starting point for further research and raising critical questions about the experiences of young caregivers. As mentioned in the introduction, my intent for this research is to explore, learn and amplify the voices of young caregivers who are ‘hidden’ and ‘invisible.’ Although there has been an increase in awareness, there have been very modest practical and limited political changes since the early research on young caregivers began in the 1990s. As such, young carer research is still holding a ‘preliminary’ position in both the U.S. and Canada. However, this does not negate the potential power of young caregivers as key informants to provide information on the process of caregiving. The continued and integrated involvement of young caregivers can shed light on the implications of the constructions of young caregivers as a distinct group, their role in research, and the programs and policies designed to support them. The following discussion will make recommendations for theory, policy and practice based on the descriptions from the participants.

7.4 Theoretical Reflections and Contributions

Throughout this dissertation, I have mentioned that scholars have acknowledged the conceptual and theoretical limitations in young carer research (Section 3.3) More specifically, how these limitations contribute to this population remaining hidden, the potential overestimation or underestimation or complete omission of some groups, which in turn, excludes critical knowledge about young caregivers. These are two shortcomings that encourage scholars to push the boundaries of research to include new conceptual and theoretical considerations, and also revisit current ones. This may assist with continuing to understand the lived experience of young caregivers, adding a new space for dialogue, particular when considering groups that may be neglected.

Given these theoretical and conceptual limitations, very little is known about this age group (ages 18-25) of caregivers. This view is supported by scholars, who indicate that this group has been widely neglected (with the exception of retrospective studies) and that there are very few studies which help to understand this demographic of caregivers **(**Levine, 2005). As such, scholars draw upon established caregiver theories and frameworks to conceptualize informal caregiving. A more contemporary theory, and probably the most dominant in young carer research, child parentification, has also been helpful to conceptualize young caregivers in terms of understanding of how young caregivers take up the caregiving role prematurely (Hendricks et al., 2021). However, a limitation of such current theories is that they tend to homogenize young caregivers neglecting to account for age-based differences and other contextual factors. In other words, they do not account for when caregiving takes place across an individual's life course, for young adults, as can be the case with ADRD. Most studies take a cross-section of a homogenized group failing to account for broader contextual factors that implicate care for this age group. This also raises questions about how adequately the literature has explored differences between young caregivers and young adult caregivers in terms of life stage, social development and overall care practices.

Moreover, with such paucity of data, very little can be said with confidence about the many dimensions of care for this population, particularly the caregiving position. In the literature, there are very few studies which explore the caregiving position of young adult caregivers in terms of primary or secondary role or a full- time or part-time role. In particular, research shows that young adults are not typically counted as the primary caregiver**,** which is defined as the caregiver who provides most or all of the care recipient's care (Levine, 2005). Many of the participants in this study described themselves as the primary caregiver, meaning that they take on full-time caregiving responsibilities. For some participants, even when they considered themselves to be in a secondary role, they still took on primary care tasks. As such, the participants of this study drew attention to how current understandings of the caregiver role may need to be re-framed, or at least further understood in terms of one's caregiver position for young adults caring for an older adult with dementia.

Another dimension which can be overlooked is the length of time spent in a caregiving role. As mentioned, most young carer studies take a cross section of the data and do not consider the time variation in the context of ADRD. By only focusing on a point in time, less is understood about the long-term impacts of caregiving. Further, many young adults began caregiving as young teenagers or children which is not factored into cross-sectional studies. In addition, in many cases, research makes assumptions about the length of time caring for someone with ADRD and, in young carer studies, assumes that it is of the same level and intensity of other chronic conditions. However, the findings of this study are consistent with research on ADRD which shows that a PWD can live for 20 years or more (Olazaran et al., 2010). Therefore, the experience of caring for someone with a chronic condition, such as ADRD, will be much different than providing care for an older adult with a less prolonged condition (for example, 6-12 months), in terms of life-altering implications for these long-term caregiving situations.

In this study, I have attempted to draw attention to the life stage of this group to highlight how they are dissimilar to young caregivers and middle-aged adults. For example, social development theories link age to one's developmental stage, suggesting appropriate roles, identity concerns, attachments and conflicts that typically occur (Montgomery & Kosloski, 2000). For example, young adults between ages 18-25 are considered to be in a stage of "emerging adulthood" (Arnett et al. 2001), which will ultimately inform their worldview, and in turn, their outlook on caregiving (Arnett et al., 2001; Early, 2002; Furlong, 2009; Scales et al., 2016). The more widely applied theory in young carer research, child parentification, has been helpful to understand implications when taking up care roles occurs prematurely (Early, 2002). However, this theory is limited as it is only applied to young caregivers under the age of 18 to assess how caregiving as a child impacts adult functioning (Early, 2002). Young adult caregivers also do not fit neatly with current theories on informal caregivers which categorize them as adults because they are over the age of eighteen. However, the findings of this study confirm that the caregiving experience for YACs is quite unique in terms of psychological and developmental factors. Given that the experience of caregiving has not been adequately told from their view, further investigation is needed to help bridge the gap between research on young caregivers , more specifically differences between young adult carers and middle-aged caregivers.

7.5. Methodological Reflections and Contributions

This study aimed to address a limitation in young carer research, which is how political and structural factors contribute to young caregivers remaining a hidden population. I addressed this omission by attempting to identify young caregivers who are ‘hidden’ by exploring a population that is often neglected. While research has made the case for increasing the diversity among young caregivers, I do acknowledge that many of these methodological concerns are attached to broader socio-political factors. Therefore, while I do agree that methodological approaches need to expand in order to increase the awareness of young caregivers, evidently broader policy changes are needed to properly identify young caregivers.

This dissertation has made the case for IPA as a suitable method to investigate the phenomenon of caregiving from the perspectives of young adults. To the best of my knowledge, this study is the first to utilize IPA to explore young caregivers affected solely by ADRD, which allowed for a more nuanced understanding of individual level cases. One of the reasons for this choice of method is because of the methodological limitations identified in research on young caregivers. For example, current studies attempting to learn about young adults employ retrospective methods which limit understanding in real time (Lackey & Gates, 2001). Others employ methods which explore group level themes which overshadow individual cases (see Literature Review, section 2.8.7). A method such as IPA, which assesses individual cases rather than only group themes, provides an opportunity to learn about contextual differences within this population. This can potentially challenge the dominant assumptions about informal caregiving for this group, which often merge their experiences with young caregivers and middle-aged adults.

There have been some attempts to engage young caregivers in the research process through participatory-based approaches. It has been recommended that, because participatory based approaches in young carer research are rare, going forward these approaches will allow for young caregivers to be at the forefront of the research process (Raanaas et al., 2018). In addition, such approaches can also be helpful to conduct more culturally informed research to shed light on how cultural affiliation mediates caregiving. Overall, this will allow young caregivers to have an authoritative role in the research process and take on an “expert frame of reference” (Joseph et al., 2020). For example, two young carer studies included participatory-based approaches (through cafes and photographic drawings) which prevented young caregivers from being victimized, but rather positioned them as “competent social actors” (Skovdal et al., 2009; McAndrew, 2012).

There is also value in the implementation of longitudinal studies in the context of ADRD. The findings indicate that young caregivers of PWD can be in caregiving roles for a significant amount of time (3-18 years). For Hendericks et al. (2021), longitudinal studies can correct for limitations in cross-sectional research by enhancing understandings of care over one's life course in terms of long-term effects and benefits and risks sustained by early caregiving. By tracking the same young caregivers over time, more can be learned about how caregiving impacts YACs social development, educational and employment opportunities, decision-making, and life plans (Hendricks et al., 2021). For adults who began caring as children or teenagers, this will be helpful to understand how they transition into adulthood or age out of services (i.e., when caregiving extends beyond age 18). Further, longitudinal studies will be helpful to understand these factors in the context of ADRD, to further understand care practices that take place at each stage as the disease progresses.

7.6 Practice and Policy

Current research on young caregivers has acknowledged that there is a need for improved programs and services for young caregivers. Based on the recommendations of previous scholars, there is a general consensus that the recommendations should fall into three areas: awareness, legislation and programmatic expansion (Charles et al., 2010; Dearden & Becker; 2002; Stamatopoulos, 2016). The findings of this study also emphasize the need for increased awareness of young caregivers and ADRD and relevant programs and services. Further, there is a connection between policy and relevant young carer programming that cannot be separated, meaning that programs are often connected to the availability of funding and political priorities. Overall, more research can inform best practices and policies on how to best develop and maintain services for young caregivers.

For many participants from my study, caregiving took place during their college or university years. The majority of participants indicated that due to the competing demands of caregiving, they were unable to balance caregiving and their education. Ultimately, this resulted in these participants having to unenroll from college or enroll in an online program. Many countries recognize education as a fundamental right for all children, but educational policies for young caregivers are limited. The UK, for example, is one of the few countries to recognize the educational impact that caregiving can have on children and offer a variety of policies to support young caregivers in their education. For example, in elementary school and high school, ID cards have been developed for young caregivers to inform authorities of their status, in addition to the right to request deadlines and flexibility in terms of school absences (Dearden & Becker, 2000). These opportunities should also be made available to young adult caregivers in college settings who feel they need to choose between caregiving responsibilities and their education. At the college level, mechanisms (i.e., identifiers, support groups, awareness campaigns, etc.) can be put in place, or accommodations made to ensure that education can be continued to some extent. This will potentially limit educational disadvantage, and problematic transitions into adulthood and the labour market (also called “knock-on effects") in the future (Dearden & Becker, 2000).

There is a need to enhance support for young caregivers in the workplace and those who leave the workplace to commit to caregiving full time. A first step would be to enhance awareness of young caregivers in the workplace given that this population is often overlooked, and it is assumed by employers that they are not in caregiving roles. Beyond this, there is a need for employment policies to be more inclusive and understanding of young caregivers’ needs and requests for time off, leave, or accommodations in the workplace, such as flexible work hours or remote work options. Further, based on the findings, because young adults rely on their care-recipient’s assets as well as their personal incomes to support the care-recipient, there is a need for more flexible work arrangements and family leave options that can alleviate the financial burden. This is particularly true for chronic conditions, such as ADRD, where caregiving can outlast the PWD’s assets. While current tax credits and leave are options, many young caregivers do not qualify for these options if they do not make above a certain income (Chadi & Stamatopoulos, 2017). Therefore, this excludes a large majority of young caregivers, particularly those who are low-income earners or subject to precarious employment.

It is apparent that the expansion of young carer programs is attached to political efforts and priorities. By and large, federal funding schemes are responsible for both health care and social services in Canada and the U.S. In general, federal programming for young caregivers is integrated with broader informal caregiver policies which are grounded in neoliberal ideologies prioritizing individual behavior change (Chadi & Stathopoulos, 2017). I suppose a question here which may limit the expansion of federal funding for young caregivers is – how do you justify expanding funding for this group compared to other populations who are considered to be 'vulnerable?' This is potentially why most young carer programs are not sustainable to demonstrate a long-term impact and why they are often a part of already existing programs. Therefore, a necessary consideration is the ongoing evaluation of federal policies to ensure that policies relevant for young caregivers are actually impactful and to determine their long-term effects. According to Rye (2005), the evaluation should not take into account the multiple effects of young carer policies (i.e., behavioural change and awareness), without considerations for the limitations of structural changes. This can potentially help to filter through policies which have more symbolic change (attitudes and aspirations) from those with tangible and permanent changes.

There is also a need for enhanced home care options and institutional support for young caregivers. For many participants, in addition to the aforementioned factors, the lack of adequate home care and institutionalized care led them to personally take on caregiving responsibilities. In the Western world, home care is part of the long-term care system, which as mentioned, is connected to federal funding schemes responsible for both health care and social service. In many cases, ADRD education and training may not be adequate, and combined with inadequate compensation, limited quality assurances measures, and the overall motivation and attention of formal caregivers and personal support workers has been shown to be poor (Breen, Orange & Kothari, 2021; Zeytinoglu, Denton, Brookman & Plenderleith, 2014). In addition, there are limits in terms of the assessments offered in home care settings; at times focusing on the care-recipient only and neglecting the needs for the caregiver. Therefore, homecare services and assessment could benefit from a whole family approach which will not undermine the parenting abilities of the care-recipient (i.e., parent), while at the same time not victimizing young caregivers (Becker et al., 1998).

A key consideration for young caregivers affected by ADRD is access to and the promotion of dementia-friendly programming. These programs provide inclusive spaces which promote and enhance participation opportunities in society for PWD. A key concern of the participants was the challenge of navigating public spaces due to limitations in the built environment. Research has shown that the benefits of dementia-friendly communities has enhanced the reduction in stigma, discrimination and enhanced engagement of PWD in their communities (Shannon, Bail & Neville, 2019; World Health Organization, 2021). More specifically, such programs promote citizenship of PWD which contributes to a reduction in social stigma and negative stereotypes associated with this population. This reinforces the importance of meaningful engagement opportunities for PWD to limit social exclusion, which ought to be considered by policy makers and city planners.

Overall, the implications for research, practice and policy are connected to broader systemic factors. In order to make substantial legislative changes, there is still a need to correctly quantify young caregivers, in terms of prevalence and incidence, but also gain more knowledge on the lived experiences of caregivers to ensure that policies and programmes reflect the actual needs of those affected. The efforts of scholars to increase awareness are providing a sound knowledge base, which have led to some significant program and policy changes in specific areas (i.e., U.K.). However, to further improve resources for young caregivers, there is still a need to address the heterogeneous nature of young caregivers and address the political factors which limit or halt substantial progress.

7.7. Strengths and Limitations

There were several strengths of this study which contributed to much needed insight into the understudied realities of young caregivers. First, employing IPA provided a great breadth and depth of detailed data which would otherwise not be available through other qualitative methods. Specifically, the focus on a microanalysis, which includes a focus on ‘the particular,’ sets IPA apart from other methods due to its emphasis on individual level cases (Smith, Flowers & Larkin, 2012). In hindsight, I believe this was a beneficial approach as it helped me to address the main goals of the study and provide more detailed analysis to contribute to the findings. In addition, this approach supported my aim of balancing the power dynamic between researcher and participants, therefore providing an opportunity for participants to be the experts in their own lives.

A second benefit of this study is that similar to the participants, I too identify with being part of the millennial demographic. Therefore, I greatly identified with many of the broad concerns and experiences that affected this age group in terms of social development. This contributed to my ability to easily build rapport and relate to the participants through a “shared horizon” (Smith, Flowers & Larkin, 2012). I recall several impromptu discussions that took place during the interview about popular culture and shared interests, as well as instances where our personal lives did relate. More specifically, I also identified with many of the experiences relevant to South Asian caregivers. In particular, my parents are also immigrants and I am also a first-generation college graduate. Overall, the ability to connect with the participants on many levels contributed to the depth and insights in the data which shed light on an understudied group of young caregivers.

Now that I have discussed the strengths of the study, it is important to also consider the limitations. First, and most significant, there were serious limitations to recruitment given the social restrictions caused by the pandemic. This impacted the nature of the interviews, opportunities for follow-up interviews and the quality of interaction between me, as the researcher, and the participants. I attempted to compensate for this by reviewing the exploratory notes multiple times, as well as listening to and watching the recordings several times to account for para-verbal communication.

Second, while the sample was homogenous, it is limited because the participants are from two different countries- Canada and the United States. Due to the pandemic, I chose to expand recruitment beyond Canada to also include the United States. My initial plan was to conduct research only in Canada in order to build upon young carer research in the Canadian context. I believe this is important given that there are no studies in Canada (or the United States) that focus on young caregivers affected by ADRD using an IPA approach. Recruitment from the two countries is a limitation of this research given the vast differences in social, healthcare and political systems, combined with the existing complexities of young carer research. Overall, I attempted to compensate for this by being conscious of contextualising experiences within different health and policy environments. Future research could explore the particular cross-national similarities and differences from the perspectives of young caregivers that has been largely overlooked in the literature to shed light on the conditions of care that are connected to broader policy and service responses.

Third, the sample is also limited because there are 2 participants (YC7 and YC11) who began caring older than the age range (18-25) and two participants who began careging younger than this age range (YC8 and YC12). I consider these participants to be exceptions because they self-identify as young caregivers but were not between the ages of 18-25 at the time of caregiving. Another reason for including these participants is because young caregivers have been identified as a hard-to-reach population (Stamatopoulos, 2016) which led me not to turn away participants who self-identify. I was challenged by having limited access to data given that this population is considered hidden and invisible and also because of the lack of response from various community agencies and academic institutions following my recruitment efforts. Further, the participants have emphasized that the concept of young caregivers, as defined in the literature, is often used interchangeably with lay language such as millennial caregivers, young caregivers and youth-carers. As such, this further adds to the challenges of recruitment due to the limitations to proper identification of this population (Stamatopoulos, 2016). This also raises questions regarding differences between constructed definitions of young caregivers compared to how young caregivers actually self-identify. Future research can explore whether or how one's caregiving identity is related to the discrepancies between one's chronological age and their subjective age.

Fourth, given the exploratory nature of the study, the intent of the study was to find meaning for a particular group of caregivers. As such, the findings are not generalizable to the broader population of informal caregivers. At most, the study can lend itself towards theoretical generalizability which can further enhance knowledge and understanding of young caregivers. Theoretical generalizability, which is often also referred to as transferability, can allow researchers and young caregivers to make connections between elements of the study and their own experiences (Curtis and Fossey, 2007). As Tracy (2010) highlights, 'transferability is invited by gathering direct testimony, providing rich description and writing accessibly and invitationally (p.845). As such, it is through storytelling where generalizations can be made between the lived experiences of individuals to see where they might transfer these findings to their own circumstances. However, scholars suggest that this can be a challenge for participants because it depends on them having strong knowledge on the research topic in order to draw comparisons and similarities (Curtis and Fossey, 2007).

7.8. Concluding Remarks

Through this investigation, I provided a detailed analysis of the nature of caregiving for young caregivers affected by ADRD. Based on their descriptions, YACs were challenged by caregiving and made sense of the process in various ways. They shed light on the ideological, familial, and societal factors and influences that shape their experience of caregiving. By and large, the experience was polarizing, in that it was empowering, but also disempowering in terms of limits to personal autonomy and the constraints of neoliberal policies. Despite these factors, the process of caregiving allowed for new insights and levels of awareness about their identity, broader social issues, and provided opportunities for growth that they would not have had otherwise. It is my hope that policy makers, researchers and other authorities involved will promote the involvement of young caregivers in critical processes which can guide knowledge and services for young adults in caregiving roles.

FINAL REFLECTION
As earlier stated in my introduction, my motivations for this dissertation were informed by my personal and professional work experiences. Throughout the research process, my hesitations, concerns and insecurities of conducting research were modestly calmed by the level of engagement and interest of the participants, which I do not take for granted. Similar to many of the participants, this research process was a new endeavour for me. I am not suggesting that research is anything like caregiving, however similar to the participants, this experience did require me to learn new skills and competencies. Overall, this process has been incredibly rewarding, especially given the many challenges and disruptions caused by COVID-19. I have learned to embrace research as a process, and I look forward to building upon this foundation to ask and potentially answer more critical questions. I hope those reading this work will find their own meanings and think critically about this research focus in new ways. Specifically, for young caregivers, I hope they will be able to see themselves in these stories and be inspired to share their stories. In doing so, they can continue to position themselves as the ‘experts’ in their own lives.

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DATE: July 18, 2020

Appendix A

Student investigator: Jonelle Ward
Faculty Supervisor: Meredith Griffin
Department of Health, Aging and Society
McMaster University
A Study about The Lived Experience of Young Adults Caring for an Older Adult with Alzheimer's Disease or a Related Dementia

Information about these interview questions: The following questions serve as a guide to the types of questions that will be asked during the interview. Interview will be one-to-one and will be open-ended (not just "yes or no" answers). Because of this, the exact wording may change somewhat. Sometimes I will use other short questions to make sure I understand what you told me or if I need more information when we are talking such as: "*So, you are saying that …?*), to get more information ("*Please tell me more?"),* or to learn what you think or feel about something ("*Why do you think that is…?").* At any time during the interview please feel free to ask for clarification or offer any additional information that you think is relevant.

The following questions will guide the first interview. True to a phenomenological approach, subsequent interviews will be guided by questions that emerge out of directions taken in the first interview and analysis of that interview data, and as such are not possible to predict from the outset. That said, they will cover similar thematic areas about the lived experience of caregiving.

Other Information:

- Length of time being a caregiver?
- Age of care-recipient?

Interview Guide

Introduction

Thank you for agreeing to talk with me about your experiences as a young carer. As you are aware, we will be discussing your experiences with ADRD, perceptions of caregiving, and how you navigate being a caregiver while managing your own life. There is no fixed time limit for the interview, so feel free to share as much information as you want to. Let us begin with a couple introductory questions…

Get to Know You/Rapport/Warm Up

1. Tell me about yourself

2. How would you describe yourself as a person?

Experiences with ADRD

1. How you would describe ADRD?

2. I'd like to know more about your experiences with ADRD. Tell me about your experience with ADRD.

3. Did you know anything about ADRD before becoming a caregiver?

4. What do you think about ADRD?

   [Alternative: When you think of ADRD, what comes to your mind OR what does ADRD mean to you?]

5. In your view, what is having a family member with ADRD feel like?

6. Do you/have you seek/sought support/formal education about the disease and caregiving?

Perceptions of caregiving role

1. How would you describe caregiving?

2. Can you please tell me how long you have been a caregiver and describe how you came to that role?

   [Alternate: Tell me about how you came to caregiving]

3. What are your thoughts about caregiving?

4. Tell me what it is like being a caregiver while so young?

   [Alternate: What has being a young carer/caregiver been like for you?]

5. How would you describe your caregiving role? (Primary, Secondary, support role?)

6. Tell me about what a typical caregiving day looks like.

7. Does being a caregiver impact any particular areas of your life? If so, which areas?

8. Do you have any particular caregiving needs?

9. Has your role of carer affected your life choices/options?

10. Are there activities you do or have done for yourself alongside caregiving to take care of yourself?
    - What kinds of activities?
    - Have they been helpful?

11. Describe your relationship with the care-recipient? (i.e., mother, grandmother, grandfather, etc.)

12. Has ADRD has impacted your ____ (i.e., the care-recipient)? If so, how?

13. How exactly do you care for the care-recipient?

14. Do you make decisions and plan on behalf of the care-recipient?

- If so, what types of decisions? Do you talk to anyone about these decisions?

15. Do you utilize any social/community supports (statuary – home, nursing, domestic help, support person, respite/ non-statuary- meal delivery, day centers) alongside caregiving?

16. Are there any challenges/opportunities you have experiences as a result of caregiving?

17. Describe how you manage your own life while caregiving.

18. How do you feel about being a young carer?

    [Alternate: What does being a young carer mean to you?]

19. What are your thoughts about the future? (i.e., probe depending on responses)

Sharing experience about navigating the caregiving role

20. What would you like other young caregivers to know?

21. Do you feel there is anything young adults should know before they become a caregiver?

22. Do you feel there are challenges/opportunities for young caregivers who identify with the role?

23. Do you have any recommendations for young caregivers in need of support?

24. What advice would you give to young caregivers in a similar position?

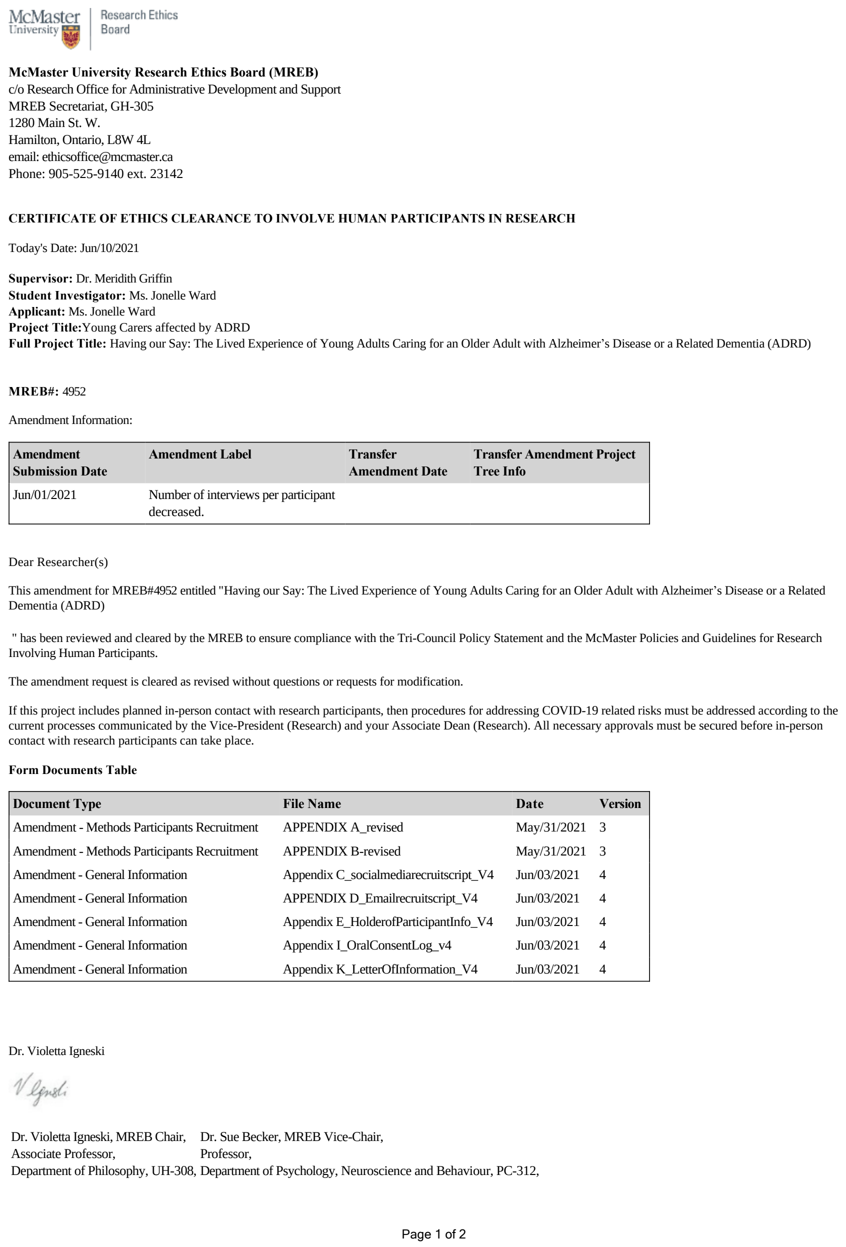
- About ADRD?
- About caregiving?

END: Is there anything you would like to add?

APPENDIX B

The search strategy for the literature review included articles from 5 databases, including: Google Scholar, PubMed, Ageline, PsychInFo and ScienceDirect and used the following key words: young career, young caregiver, young adult caregiver, elder, older adult, gerontology, caregiver, care, caregiving, dementia, Alzheimer’s, informal care, and care work.

APPENDIX C:



McMaster University | Research Ethics Board

McMaster University Research Ethics Board (MREB)
c/o Research Office for Administrative Development and Support
MREB Secretariat, GH-305
1280 Main St. W.
Hamilton, Ontario, L8W 4L
email: ethicsoffice@mcmaster.ca
Phone: 905-525-9140 ext. 23142

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Today's Date: Jun/10/2021

Supervisor: Dr. Meridith Griffin
Student Investigator: Ms. Jonelle Ward
Applicant: Ms. Jonelle Ward
Project Title: Young Carers affected by ADRD
Full Project Title: Having our Say: The Lived Experience of Young Adults Caring for an Older Adult with Alzheimer's Disease or a Related Dementia (ADRD)

MREB#: 4952

Amendment Information:

Amendment Submission Date	Amendment Label	Transfer Amendment Date	Transfer Amendment Project Tree Info
Jun/01/2021	Number of interviews per participant decreased.		

Dear Researcher(s)

This amendment for MREB#4952 entitled "Having our Say: The Lived Experience of Young Adults Caring for an Older Adult with Alzheimer's Disease or a Related Dementia (ADRD)

" has been reviewed and cleared by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster Policies and Guidelines for Research Involving Human Participants.

The amendment request is cleared as revised without questions or requests for modification.

If this project includes planned in-person contact with research participants, then procedures for addressing COVID-19 related risks must be addressed according to the current processes communicated by the Vice-President (Research) and your Associate Dean (Research). All necessary approvals must be secured before in-person contact with research participants can take place.

Form Documents Table

Document Type	File Name	Date	Version
Amendment - Methods Participants Recruitment	APPENDIX A_revised	May/31/2021	3
Amendment - Methods Participants Recruitment	APPENDIX B-revised	May/31/2021	3
Amendment - General Information	Appendix C_socialmediarecruitscript_V4	Jun/03/2021	4
Amendment - General Information	APPENDIX D_Emailrecruitscript_V4	Jun/03/2021	4
Amendment - General Information	Appendix E_HolderofParticipantInfo_V4	Jun/03/2021	4
Amendment - General Information	Appendix I_OralConsentLog_v4	Jun/03/2021	4
Amendment - General Information	Appendix K_LetterOfInformation_V4	Jun/03/2021	4

Dr. Violetta Igneski

Dr. Violetta Igneski, MREB Chair, Associate Professor, Department of Philosophy, UH-308,	Dr. Sue Becker, MREB Vice-Chair, Professor, Department of Psychology, Neuroscience and Behaviour, PC-312,

APPENDIX D: Example of Initial Exploratory Comments, Codings and Emergent Themes with Transcript 1

Initial noting/exploratory comments
DC -descriptive comments
LC – related to language spoken; linguistics
CC- interpretive comments

1
00:00:02.550 --> 00:00:04.110
Jonelle Ward: So yeah tell me a little bit about.

2
00:00:06.600 --> 00:00:07.049
YC1: myself.

3
00:00:07.350 --> 00:00:07.680
yeah.

4
00:00:09.360 --> 00:00:12.389
YC1: yeah um I was born in Montreal.

5
00:00:13.950 --> 00:00:16.109
YC1: To to my parents.

6
00:00:17.850 --> 00:00:19.110
YC1: My dad left very early.

7
00:00:20.280 --> 00:00:26.100
YC1: Left when I was like about five or six he tried to re enter my life, later on, and it just didn't work i'm. ambivalence, absent father in childhood

8
00:00:27.210 --> 00:00:33.900
YC1: Very in control of like who I am and i'm not very easily swayed by people trying to trick me or something like that you know to me[an] Autonomy, self-control,

9
00:00:35.940 --> 00:00:46.410
YC1: And so, for most of my life was just it was just like me my mom doing our thing, she was ~~bracing a month~~ a great single mom, we traveled the world one of her best friends.

10
00:00:48.690 --> 00:00:56.340
YC1: had invested in IBM early, and so I, as a young kid I frequently travel between here in Paris, where they lived. (well travelled as a child)

11
00:00:57.930 --> 00:01:01.110
YC1: And so I always kind of thought that was like my second home in some way.

12
00:01:02.460 --> 00:01:22.770

YC1: And just surrounded by like like nice people who weren't even necessary my family but I call them auntie and uncle, and all this kind of stuff because I was, I was, I was just me my mom I was a single kid and um yeah I just kind of like had always been a kind of like a troublemaker kid. (reflections on childhood- trouble maker kid)

13
00:01:24.360 --> 00:01:25.170
YC1: I just kind of.

14
00:01:26.250 --> 00:01:32.580
YC1: I would, I would always get in trouble, but like I was always just trying to do the right thing I don't know I just never came out.

15
00:01:33.180 --> 00:01:40.650
YC1: The way people perceive it right, and so I would like just kind of go through life as saying like no i'm single kid will tell me like I like i'm.

16
00:01:41.160 --> 00:01:48.240
YC1: i'm spoiled I don't have a **single kids ~~sing~~ syndrome** and like i've never gotten anything in my life, like my mom was like more or less poor my dad left or poor type thing right.
(naming & framing: single- kid syndrome, financial hardship/poverty growing up)
17
00:01:49.740 --> 00:01:50.400
YC1: And so.

18
00:01:51.960 --> 00:01:57.540
YC1: People are always telling me that, like oh i'm this i'm that and and I kind of just like would live my life as as.

19
00:01:58.830 --> 00:02:04.110
YC1: Look confused I guess right knowing who I was but confused because I walk out the door, and it was like oh like. (confusion about self-identity)

20
00:02:04.290 --> 00:02:09.990
YC1: you're this you're that and they'd be like Oh, you have everything, so we don't need to spend any time with you when I was always I was always weird my.

21
00:02:10.290 --> 00:02:18.810
YC1: I was always bouncing around different schools, and so I was always meeting new people until I landed here until my mom met my step dad. (moving a lot)

22
00:02:20.160 --> 00:02:26.940
YC1: Here in Toronto and basically that was that was it was a life I I live with them, so I was about 17 and then I left I left home. (left home at 17)

23
00:02:29.340 --> 00:02:36.000
YC1: And I kind of just did did my own thing from then, and then I had a lot of people around me mentors and mentors but. (mentors & mentorship)

24
00:02:36.720 --> 00:02:43.440
YC1: Older people that could take me in and, just like the part like be part of my life type thing and something that they can like send me out like they taught me a lot of good.

25
00:02:44.970 --> 00:02:52.620
YC1: things about life so much that i'm after school didn't know what I need to do, but one of my coaches in ~~score~~ [school] gym teacher in school, he was.

26
00:02:53.310 --> 00:03:02.040
YC1: He was part of like volleyball team for Canada and he said that like you could probably do this for school, so I got a scholarship to university of Michigan and I did that.

27
00:03:03.150 --> 00:03:04.530
YC1: Then I thought it was hot shit.

28
00:03:05.790 --> 00:03:17.970
YC1: I know skipping with the whole thing but that's just school and high school went on that, but then I did that and I bought a motorcycle on a crash that so I lost my scholarship had to come back, I was as a whole thing.

29
00:03:19.320 --> 00:03:22.260
Jonelle Ward: you'd like- sorry, you were playing volleyball in Michigan.

30
00:03:22.650 --> 00:03:23.940
Jonelle Ward: Yes, Nice.

31
00:03:24.270 --> 00:03:37.110
YC1: And then I it's but, but then it was it was it was very, very, very quickly, I screwed that up, it was all my fault and obviously they can't pay for a scholarship you're not actually doing what they need you to do so, then I came back.

32
00:03:38.370 --> 00:03:41.940
YC1: At which point I I came back, and I was living in Toronto.

33
00:03:43.500 --> 00:03:47.640
YC1: And so now i'm like going to school at sheridan college.

34
00:03:49.230 --> 00:03:51.930
YC1: And this is shared in college in brampton.

35
00:03:53.070 --> 00:04:04.560
YC1: Is the best yeah brampton so I, so I did that architecture, whatever i'm one week into like finishing everything and I got lucky and I went to go start a firm and.

36
00:04:05.520 --> 00:04:18.300
YC1: I met a guy in a bar and i'm just like and i'm never drink i'm not I don't even drink now I haven't drank for having to jump in two years and that's, not because I was a drinker just one day i'm just like i'm not I just don't want alcohol my body, so I just stopped.

37
00:04:20.280 --> 00:04:25.560
YC1: At this bar and I would be at this bar and there's a guy beside me, and he.

38
00:04:27.540 --> 00:04:34.350
YC1: You know, we talk, every day we watch watch hockey and everything and I asked him one day said, like What do you do that, you can like sit at this bar every single day, and he looked like just.

39
00:04:34.830 --> 00:04:42.840
YC1: grumpy old man I love like old grumpy men I don't know I just have an affinity for these people and he said he was a locksmith and so with.

40
00:04:43.500 --> 00:04:48.870
YC1: Amazon was supposed to start a architecture firm which would be very good for me, I like an.

41
00:04:49.710 --> 00:04:55.710
YC1: architecture that would set me up for life, everything will be all good and I met this guy and he was a locksmith and I found that so interesting I was like.

42
00:04:56.160 --> 00:05:03.720
YC1: I didn't know that was a job, I was like this doesn't make sense, I went home that night and I googled I was like locksmith what like okay last I get it doors I get it.

43
00:05:04.230 --> 00:05:07.860
YC1: And i'm starting to learn about like what locksmith thing is and kind of learn like okay what.

44
00:05:08.670 --> 00:05:16.740
YC1: it's like the old one of the world's professions that in prostitution and i'm going like this is the weirdest thing right and I basically like showed up at his office, the next day.

45
00:05:17.490 --> 00:05:20.490
YC1: He gave me his card I show biz OPS next day, and I was like hey man, are you hiring.

46
00:05:21.150 --> 00:05:26.010
YC1: And he's like yeah and I was, and I was you know, he said he wasn't hiring but he's willing to take me on and I just like.

47
00:05:26.400 --> 00:05:38.520
YC1: quit like everything that I had done for the last like three years and all the money for the scholarship and all this stuff and I just became a locksmith and I was living in Toronto and ran this locksmith shop and basically I started my own locksmithing shop.

48
00:05:39.720 --> 00:05:56.010
YC1: jumping off from what he was doing, and we had a business out in Toronto, and at that time my grandmother got sick, so I moved them to Oakville, and so I moved to just be closer to her and she had a couple heart attacks like that her house was in Oakville. (care for grandmother)

49
00:05:57.960 --> 00:06:08.190
YC1: I her husband my grandfather had already passed from Alzheimer's and that was he had about five six years of struggling with that, when I was a little younger, which I knew what was happening, but. (early exposure to ADRD as a child)

50
00:06:09.270 --> 00:06:23.520
YC1: You know there's there's adults here that are taking care of it right, so I didn't really affect me and I didn't know really whether they were trying to protect me out of this like kind of gross and like hard thing to deal with kind of thing right. (caregiving for grandmother)

51
00:06:24.630 --> 00:06:24.930
YC1: But.

52
00:06:25.980 --> 00:06:29.100
YC1: So I mean don't feel i'm gonna take care of my grandmother who's a fantastic woman, the best.

53
00:06:30.300 --> 00:06:47.670
YC1: And she eventually passed and I didn't need to be an open anymore, and just kind of moved to Toronto, and I had been here, ever since since okay so i've just been living at Humber base and since I spend about six years so after six seven know six years and then yeah I basically. (death & dying)

54
00:06:48.840 --> 00:06:54.240
YC1: almost immediately, the first time I got here, obviously I had I had things that we're definitely going awry. (falling apart; awry due to loss)

55
00:06:55.530 --> 00:07:02.400
YC1: I had mentioned to you like, I had brought things to my my my step parents like hey like-Alzheimer's stuff like that right and. (brought educational materials)

56
00:07:03.720 --> 00:07:05.790
YC1: yeah it it.

57
00:07:07.200 --> 00:07:10.830
YC1: It kind of happened right away, it was just like things are things are going wrong i'm just living in Toronto.

58
00:07:11.130 --> 00:07:21.030
YC1: And, slowly but surely i'm just living my life as a security professional and working in all these places doing my thing and and life kind of catches up to you and that's it I don't know I got in this now now i'm here so yeah.

59
00:07:21.570 --> 00:07:24.720
Jonelle Ward: OK cool Thank you how would you describe yourself as a person.

60
00:07:25.950 --> 00:07:27.870
YC1: i'm i'm like.

61
00:07:29.760 --> 00:07:42.360
YC1: I I don't think I suffer from anxiety, but I do think, I do believe that sometimes i'm a burden which is not, which is not a mental health issue it's it's more of like a. (self-proclaimed burden; anxiety..)

62
00:07:43.440 --> 00:07:56.580
YC1: I have a lot to say, and I might require I think people sometimes call it love language or something I may require like a lot of time, because how on earth you ever going to really grasp, who I am without spending the time right. (introspective/introspection)

63
00:07:57.750 --> 00:08:03.300
YC1: And so, when i'm with people I kind of have this thing, where I go, you know, like.

64
00:08:03.990 --> 00:08:09.540
YC1: I already know how much time will have with this person i'll go with myself like you'll never you'll never know what i'm trying to say because.

65
00:08:09.750 --> 00:08:18.030
YC1: i'm never just gonna be like this is, who I am let's move on right like it's, it is a part of the story, as part of like who, I am as a person, all the experiences i've had up to this point and combination right. Perspectives on identity

66
00:08:19.200 --> 00:08:26.010
YC1: Whereas I think I think like tick tock tick tock or [clubhouse] right would be like this is, who I am and i'm supposed to take that as.

67
00:08:27.330 --> 00:08:28.080
YC1: i'm like okay.

68
00:08:29.280 --> 00:08:34.260
YC1: Okay, like and let's move on, but like I think a lot of people miss what it takes to like.

69
00:08:34.890 --> 00:08:43.620
YC1: Be who you are, you know to mean and so like it takes a lot, it takes it literally is a ~~combination~~ [culmination] , I always joke that, like the like who you are is like **[ugh].**

70
00:08:44.160 --> 00:08:58.830
YC1: Which is like basically the last sound you're gonna make before you die and so like I kind of practice this thought, where I I don't see myself retiring because i'm I met a guy once, when I was in Thailand, who said.

71
00:09:00.300 --> 00:09:03.510
YC1: He is building a house it's going to take him his whole life to build.

72
00:09:05.160 --> 00:09:07.470
YC1: And if he if he finishes it too early.

73
00:09:08.760 --> 00:09:20.760
YC1: Then, then he then he will have wasted his time and so like I just think I just think of it as like like like like who I am is has yet to be experienced, but like. (a work in progress, the individual)

APPENDIX E: JOURNAL ENTRIES

YC1 Interview

-first interview; learning how to balance the discussion- letting participant talk and also bringing the interview back into focus. I don't want to steer things too much because I might miss important ideas from their stream of consciousness.
-tried to balance bracketing….'holding on lightly' to previous knowledge was helpful. Some of my assumptions about support groups and educational supports were challenged in this interview- NOT ALWAYS HELPFUL and various reasons why.
-Male perspective- protector, masculinity references
-set up 2nd interview, might want to discuss the idea of 'masculinity' further and caring for a mother…
-saw support groups as harmful for various reasons- a unique perspective …is this something common. I might have assumed otherwise.
- participant wants to help others from his experience through outreach and knowledge sharing.
-EKR- stages of grief

YC2 Interview

-second interview; less probing as participant was very descriptive!
-raised attention to cultural sensitivity/competence; South Asian perspective - if appropriate, in second interview discuss these issues further
-similar to first participant- saw support groups as lacking in some way (in this context culture rather than facilitation expertise was the issue)
-filial piety and expectations another theme
--application-based caregiving, interesting how participant seeking education to support her in the role (rather than vice versa)- choosing educational preferences to meet a need.
-bracketing- still holding on lightly to previous knowledge, although it is helpful to understand the meaning-making of participant and illuminate key ideas

YC3 Interview

-third interview, given professionalism of participant there was an enhanced intersubjectivity in this interview. My former professional knowledge, theoretical knowledge helped to bridge the gap and allowed me to make sense of her making sense of the phenomenon.
-U.S. perspective- might want to further discuss the systemic/structural barriers- although not the key aim here.
-participant preferred having camera off, some of the paraverbal communication was lost as a result, but core ideas maintained
-common theme emerging so far- support groups are unhelpful.
- common theme: the interviews provided an opportunity for YC to talk about things they have not in a long tome "I haven't actually talked about this" which may be an indication of the quality of phenomenological questions that were being asked.

Appendix F: Participant Profiles

Participant	Profile
YC 1	30-year Caucasian old male. Went to college on a scholarship, but the experience was halted due to an injury. Became a caregiver for his mother at 24. Shares the role of caregiver responsibility with his stepfather, which has led to tensions and a power struggle between them. Some previous mental health challenges. Currently in a relationship.
YC 2	22-year-old female of South Asian descent. Born in the US and moved to Canada with her parents for her mother to pursue higher education. Observing her mother's educational path has motivated her to pursue a master's in clinical psychology. Became a caregiver for father at 6 years old. Considers herself to be a gatekeeper for both of her parents. Concerned with issues of diversity and inclusion. Currently in a relationship and she lives with her parents.
YC 3	31-year-old Caucasian female from Westchester County, U.S; now living in NJ. Became a caregiver for her mother who has PDD at 25. Shares the caregiving responsibility with her father, but often takes the lead primary role. Works as a speech pathologist and has some experience working in skilled nursing facilities.
YC 4	25-year-old female of South Asian descent living in the U.S. Is a caregiver for father and grandmother. Assuming the role was an Involuntary decision; feels as though she is 'doing what is expected." Has hopes of moving out one day to begin living independently.
YC 5	30 years old African-American female living in Virginia, U.S. An only child to her mother. Identifies strongly as her mother's only child. College educated. Cares deeply about advocacy and education and social justice. Works in a non-profit with the goal of providing educational

	equity. Unmarried, well-travelled and considers herself to be fiercely independent. Created an Instagram page to increase awareness about young caregivers
YC 6	30-year-old of Hispanic female living in Florida, U.S. Caregiver for her father along with her siblings, although in the primary role. Stopped attending college due to caregiving responsibilities. Not currently engaged in work or study. Caregiving led to participation in advocacy efforts, which included efforts to get the Older Americans Act reauthorized.
YC 7	33-year-old Caucasian female. Lived abroad (Germany) for many years and moved back to Seattle to care for mother. Complicated relationship with mother and siblings. Parents are divorced. Feels that caregiving ‘fell on her shoulders’ because brothers had more ‘important’ roles (i.e., law school and doctor). Former professional work experience in advocacy. Caregiving led to her becoming an entrepreneur to support and teach other young caregivers. Married with 2 children.
YC 8	36-year-old female of South Asian descent. Caregiving began in India, caring for father at age 8. Marriage and employment led to relocating to Canada. Following this, became a distance caregiver travelling often between India and Canada. Identifies with being a trailblazer in her family for taking on ‘male’ dominated roles in caregiving, including end-of life care and rituals for her father. Suggests that her father raised her ‘like a boy.’ Works for a non-profit and has 1 child. Suggests that her father raised her ‘like a boy.’
YC 9	25 years old South Asian female. Lives in Rockland County, NY. College student, however, college was interrupted by caregiving. Currently, single, an only child and shares caregiving responsibilities with father. Lives with her parents. Developed an Instagram page to make connections with other young caregivers.

YC 10	33-year-old Caucasian female. The eldest of 3 children. Became a caregiver for her father at age 25. Very close to her parents and shared the caregiving role with her mother. A speech language therapist. Played an active role in end-of-life care for her father.
YC 11	43-year-old Caucasian female. Identifies as an older millennial at the time caregiving began. Has a partner who was influential in her decision to become a caregiver for her mother. Takes a very spiritual lens on caregiving which helps her navigate her role. College educated and currently working for a realtor. Started a social media page as an outlet when caregiving began.
YC 12	22-year-old South Asian male University student studying neuroscience; his choice of major informed by his grandmother's diagnosis. Shares the caregiving responsibilities with his mother. Had some initial resistance to caregiving but has a more positive perspective on his role. Motivations for caregiving were both personal and cultural.

Appendix G: MASTER LIST: Summary list of superordinate and subordinate themes

THEMES	QUOTES FROM TRANSCRIPT	IDENTIFIER/TIMESTAMP
The Experience of Managing the Impact of ADRD		
Coping: "I'm alright, I'll manage"		
YC1		978
YC2	"unique" "planning ahead" "self-care	33, 42, 369, 382, 447
YC3	"finding the balance" "boundary setting", voluntary, "caring from acar and close	178, 179, 103,130, 224, 228, 312, 320
YC4	flow, non-resistance, storytelling, googling	527, 371, 376, 536, 432
YC5	blogs, ill-prepared, could not process	117, 261, 269
YC6	finding the balance, go with the flow, roller coaster, music, being involved/findin purpose, being a young carer, reflection, faith, not -interrupting, collage, no therapy but recommends	9:54:00, 11:17, 11:28, 20:54, 22:40, 44:00, 46:20, 41:45, 46:56, 48:11, 49:18, 56:34, 59:09, 11:40
YC7	storytelling, creating stories, blogs, PTG, make somethign positive	4:56:00, 39:31, 22:44, 58:53, 59:29
YC8	tantrum	359,
YC9	self-care, communcation	19, 59
YC10	adaptive techniques , positive attitdue , temporary, non resistance, social media	185, 245, 648, 653, 156, 832, 244, 380, 717, 759
YC11	buddhism, spirituality, outlet, social media, mindfulness, knowing center, self-ca	382, 24, 37, 66, 69, 24, 194, 184, 191, 310
YC12	faith, islam, managing own life, put self in PWD shoes, respond vs. react , god -	57, 518, 623, 54, 541
Caregiving and Systems Collide: "They don't understand"		
YC1	medical system	120
yc2	institutionaliation	355
yc3	workplace, "policies , HCS, coordinating care	96, 249, 339, 408, 126, 414
yc4	systems and routines, policies, inequitable systems	98, 264, 259
YC5		
YC6	the public, institutionalization, politics/Flordia state policies , medical system	1900-01-01 8:09:00 , 6:36, 7:52, 20:03, 1:02
YC7	familial- gender roles	17:58
YC8	medical	361,
YC9	medical , red tape, translate, accesiblity	73, 77, 246, 501
YC10	the public , end of life- hospice, childlike	396 , 492, 315, 469,480, 492
YC11	the public,	217, 296
YC12	institutionaliation, retirement home, laws/social policy, capatalism, LTC, the w	73, 277, 557, 275, 578, 577, 647, 575, 572
"The missed"		
YC1		105, 994
YC2	"missed opportunities"	371
YC3	it sucks to watch her	303
YC4		
YC5	missing out , missed future	51, 290
YC6	lack of awareness, early warning signs	2:15:00, 12:34, 17:43
YC7	hindsight, naivety, self-involved, denial	12:50:00, 36:43, 13:58, 35:21
YC8	going out	
YC9	mismanaged expectations	146,
YC10	missed cues, hindsight , disappointment , not realizing lasts , hindsight	310, 312, 220, 224, 234, 308
YC11		
YC12		
They are Still Somebody		
YC1	independence	91, 92, 93, 99
YC2	independence	482
YC3	maintain personhood through speech/communication	282
YC4	loss of , preserve dignity , "front-end vs. back end caregiving"	63, 61, 64
YC5		
YC6	the're still there, they didn't choose	9:31:00, 13:56, 14:37
YC7	honour mother	59:56:00
YC8	interact with PWD	1900-01-01 1:53:00, 25:53
YC9	navigate through, mother's preferences	153, 242
YC10	having difficult conversations, trust, inclusion	55, 66, 786
YC11	emotional support, my mom and hten the disease	104, 140, 146, 153
YC12	being gentle, dying her hair, robots , dignity, humanity , breakfast	248, 251, 600, 256, 628, 39, 114

Caregiving- me , myself and us		
Who Am I?		
YC1	WHO AM I	19, 65, 191, 503, 705, 858
yc2	"natural caregiver"	47, 450
yc3	labels, identity , young carer	14, 332, 368
yc4	reframing, victim, ownership & pride, "I am a full time"	234, 360, 374, 362, 363, 111
yc5	proud, title, put myself first	179, 184, 296
yc6	what are you going to do now that youre no longer	54:36:00
yc7	advocate, entitlement	3:21, 1:03
YC8	defines me, old soul, secondary, path , empathy, emotional self	269, 524, 292, 351, 408, 529, 14, 401
YC9	stuck, role, duty, acceptance, identity , better version of self	5, 227, 181, 123, 336, 451
YC10	adult child, what am I doing here , who I am, victim- why me? , learn about self , put in the role, a women, oldest sibling , my life , fran	513, 529, 831, 508, 512, 538, 535, 545, 624, 827
YC11	identiy, FT caregivers	199, 205
YC12	identity, essential skills, islam, growth , neing a young carer makes no differenc	302, 271, 268, 48, 660, 671
"I Need Support Too"		
YC1		696, 707, 731, 734
yc2		538
yc3	"support network" "YPAC" "therapy", "online groups", "social media", professional organizations	148, 152, 186, 188, 201, 313, 201, 213, 311, 461
yc4	desire for connection, representation, social media, inclusion, resources, lack of family support, friends	166, 153, 156, 438, 184, 187
yc5	community supports, counsellor, connection, social media	95-100, 108, 112, 311
YC6	cultural and language barriers, unaware , support group, social media, trial and error	5:52:00 , 7;26, 13:24, 13:50, 14:49,
YC7	outside help, social media, AA	6:17:00, 47:19
YC8	outside help, social media, AA	10:04
YC9	barriers, support groups, age gap, social media	354, 340, 434
YC10	support group, family, community, adult child group , outside help, vent session	604, 613, 766, 148, 64, 457, 619
YC11	parnter	43, 45, 181
YC12	emotional needs, hilarity for Charity, PSW, extended family support, the rest of	361, 377, 135, 210, 216, 641, 633, 638, 141, 156, 178
How Do I Make Sense of This? Learning as I go		
YC1	"reading medical books"	172
YC2	"health and aging classes"	31, 36, 40, 535
YC3	speech pathology, "I know everything" , formal presentations	32, 43, 371, 149, 472, 333, 467
YC4	being seen/validated,	203
YC5	blog	242
YC6	advocacy	5:24:00 , 11:05, 11:18, 13:02
YC7	advocate, inapprpriate approaches, dementia coach	59:46, 2:39:00, 26:39, 19:11, 18:43
YC8	medical knowledge, reverse cycle	414, 125, 344,
YC9	learning through caregiving	100, 101, 103
YC10	theorizing, speech therapist, career, head start, UN class, old persons disease	405, 518, 25, 844, 837, 591, 370, 588, 597,599, 600
YC11	buddhism, ram das	382, 143
YC12	animation, neuroscience	17, 624
I Am My Mother/Father's Keeper		
YC1	reciprocity, role-reversal	135, 138, 814, 823
YC2	role-reversal, independence, "us"	130, 167, 51
YC3	role-reversal, "tumultuous r'ship- better r'ship	91, 270-290
YC4	parent to parent, safety net	531, 341, 453
YC5	no one to take care of dad,	65
YC6	advice from father, wither away, having difficult conversations, vulnerable	1900-01-01 2:01:00 , 58:41, 59:34, 16:14
YC7	dyad	18:20:00
YC8	dyad	11568:00:00
YC9	equal planes, role-reversal, duty, protector	129, 133, 181, 428
YC10	it sticks, connection and trust , the drive back , the race, intimacy	632, 63, 280, 85, 166
YC11	full circle	10728:00:00
YC12	islam, companionship , special place in my heart	96, 160, 506

TURNING POINTS: DEALING WITH ADVERSITY		
Life Interrupted		
YC1	childhood	989
YC2	childhood	277, 283
YC3	relationships , employment, a year away from my life	156, 161, 298
YC4	fianncial harships , professional trajectory, relationships, hyper-independence	198, 200, 205, 162, 531, 295
YC5	social life, financial	61
YC6	school, life on pause, goals interrupted, finances	3:11, 6:01, 52:32, 5:44, 45:03, 53:46
YC7	forfeit	19:46
YC8	financial, accelerated childhood	366, 54, 295, 306
YC9	work, school, social, potential employment	252, 266, 274
YC10	looking forward to freedom, life interuppted/self-neglect, relationships, financially conscious, social, emotionally, physically , what do I do now	674, 444, 455, 484, 557, 669, 673, 720
YC11	put self last- to self	95
YC12	fight, demon, hobbies and activities	101, 532
Feeling Broken		
YC1	"the block"	96, 197, 229, 867, 404, 432
YC2	ambiguity	125, 491, 336
YC3	fear, sadness, grief, challenges, being robbed, worried about the future, anger	75, 346, 148 , 91, 93, 52, 383, 385
YC4	resentment, anger, insomnia, feeling stuck, withdrawl, regret	145, 452, 478, 218, 220, 164, 215, 547, 549
YC5	emotional challenge, milestones, escapism, stress/not ready, detests the disease, frustration, hopelessness	52, 55, 153, 190 , 191, 197, 226, 280
YC6	fear, conflicted feelings, heaviness, uncertainty x 5, tough, put feelings aside, spiral, anger, a range of emotions	1900-01-01 4:35:00 , 2:49, 15:43-16:28, 40:19, 41:27, 36:09
YC7	acceptance, roller coaster, anxiety, reluctance, escapism, depressed	5:58:00, 20:39, 21:31, 29:24, 33:00, 1:23, 1:02
YC8	breaks you , selfish, fear, helplessness, suppressed	96, 352, 545, 199, 436, 422, 173, 398
YC9	fog of grief, loss, anxiety	178, 185, 468
YC10	breakdown, mentally exhausting, guilt, loss and death, tense, physical emotional, fear, grief, dealing with death, ruminating , difficulty, uncertainty , processing decisions, awful- set up for failure, anger, confusion, helplessness, don't want to be in this space anymore	422, 563 , 690, 189, 360, 564, 332, 682, 252, 275, 279, 293, 381, 392, 417, 560, 680, 696
YC11	reluctance, confusion , fear	203, 309, 313
YC12	inner demon, mental health challenges, entitlement, reluntance - wasn't enjoyi	169, 179, 181, 458, 176
Feeling Alone: Caregiving in Silence		
YC 1	few social connections	226
YC2	disconnect; lack of understanding from peers	628
YC3	"misunderstood"	63
YC4	deep lonliness, by myself/individualistic nature, had to figure it all out on my own	169, 179, 181, 458
YC5	didn't tell anyone	115
YC6	isolating	15:26
YC7	feeling left out	29:24, 34:01
YC8	alone, reverse cycle	384, 445, 334,
YC9	isolating	250,
YC10	didn't see anyone	447,
YC11	feel alone	293,
YC12		
Subordinate Theme: **Polarity in Caregiving: A Devastating Gift**		
YC1	blessing vs. burden; regret vs. relief; acceptance vs. reluctance	1004, 413, 572
YC2	acceptance vs. reluctance; blessing vs burden; relief vs. grief/regret	304, 459, 305
YC3	relief vs grief	383
YC4	shame vs. empowerment; victim vs victor; opportunity vs. burden; undesired feelings vs. joy	64:379, 360:362; 365, 403, 534, 60
YC5	acceptance vs. reluctance	179:181
YC6	stronger vs. anger Blessing vs. tough, opporutnities vs. disruption , had it not been for caregiving	1:07:00, 24:13, 1:07, 1:08
YC7	gratitude vs. sacrifice	
YC8	growth vs. lost childhood, opportunities	351, 54, 526
YC9	opportunity to care , blessing, exhausting vs. roll with it	85, 93, 115, 457
YC10	relief vs. missing father, regret vs. regret, wouldn't wish disease vs. depth of time , awful vs. depth, juxtopsiiton , relaxed vs. emotions attached	234, 337, 554, 575, 584, 705
YC11	devastating gift, blessing grief, reluctance, opporunity, pride shame,ying yang, shadow light, logic emotion, fear fun, happening fading, victim savios, cannot wait scared as hell	
YC12	difficult vs. positive, joy vs. reluctance	63,

SA millenial caregivers		
cultural care practices & guiding principles		
YC8	rits and rituals	120,136
YC12	islam, mohammed, cheerios, culture, breakfast, an arab thing, god is watching,	100, 701, 245, 247, 114, 116, 232, 234, 239
barriers		
YC1		
YC2		
YC3		
YC4		
YC5	interperosnal barriers	298, 227, 229
YC8		
gender role expectations		
YC2		
YC5	pushed on us	72, 75, 77
YC8	constraints on women, empowerment	134, 152
yc12	just mother in law, role of men	700
duty/obligation		
YC1		
YC2		353
YC12	honour grandparents, my responsibility to family	268
YC5	kinda fell on me, duty as a daughter	74, 182
YC8	proud	162