

EXPLORING EXPERIENCES OF CHALLENGE AND RESILIENCE IN SOUTH ASIAN
IMMIGRANT OLDER ADULTS LIVING WITH MILD DEMENTIA IN THE GREATER
TORONTO AREA

by

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ABSTRACT

EXPLORING EXPERIENCES OF CHALLENGE AND RESILIENCE IN SOUTH ASIAN IMMIGRANT OLDER ADULTS LIVING WITH MILD DEMENTIA IN THE GREATER TORONTO AREA

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The prevalence of dementia is apparent in various ethnicities and is growing within the Canadian South Asian population. However, the notion of resilience in dementia is dismissed as the dominant biomedical view of dementia prevails. There is a need to reframe that discourse to that of a strength-based, resilience approach to uphold the identity and strengths of a person living with dementia. In this narrative analysis of identity development, two participants living with mild stage dementia and one caregiver shared their experiences of challenge and resilience. Participants' narratives have been re-storied to demonstrate their identity development and reveal their social world, while applying the Resilience Framework and using the intersectionality lens. Findings revealed that resilience for the two participants living with mild dementia meant 1) having purpose and meaningful worth, 2) having a strong sense of faith, 3) having supports that improve quality of life (family and day program), and 4) coming to their own terms with limited "control". These findings and further emergent meaning derived from the participants' narratives bear implications for education, practice, policy and future research.

DEDICATION

I dedicate this thesis to my beloved Dadi, Amena Begum. You are always in my heart.

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Thank you to my parents for their guidance and demonstrating through their own life, that there is indeed light at the end of the tunnel. Last but never least, a thank you to my partner for always providing a shoulder to lean on and your unconditional faith in me.

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PROLOGUE

The cure for pain is in the pain.

— Rumi, 13th century (Coleman, 2004)

It is interesting to see how life tests us in so many ways. Hardship, failures, roadblocks, insecurities - they all have the potential to eat away at a person's dignity. Such experiences and feelings are common as each person has their own unique struggles that require relevant resilience strategies. I, myself have fallen, felt defeated and completely hopeless several times throughout my life. But in hindsight, those experiences have shaped my identity.

One of the most defining moments in my life was the experience of immigrating to Canada with my parents. I was born in Dhaka, Bangladesh and there, I lived a fulfilling childhood complete with my family's love and warmth. I was grateful for the unconditional affection from my loved ones, the lazy days, the sticky feel and smell of humidity, the sound of rain falling on our tin roof, the fresh ripe mangoes that grew in our backyard. However, my parents saw little opportunity in Bangladesh and sought a life with a better, brighter future for themselves, and for me, their daughter. They wished for a life with improved job opportunities, a better education for me and overall, a safer and healthier environment within which to raise me.

When I was five, my parents and I immigrated to Toronto, Ontario. Upon arrival, my parents were faced with several new challenges and their vision of a flourishing new life was not realized immediately. These challenges included learning how to speak fluent English, being hired into minimum wage jobs despite their education and credentials from back home and having to live without close relatives nearby for support. We were strangers in a world by ourselves. My parents each worked two jobs just to get by. I also struggled as a young girl

learning a new language and adjusting to a new culture. I experienced culture clashes as I became caught between Western customs and mannerisms and those of my parents and community. In contrast to my former neighbor's and family's heartfelt, loud laughs and straightforward comments back home, everyone in Canada seemed *too* formal. It almost felt eerie, hostile. The cold, crisp air of Canada seemed to compliment peoples' reserved attitudes. I felt that I did not belong. I constantly missed my old life, crying and praying with hopes to go back one day. I missed living in my maternal grandmother's quaint tin house, being able to dance in monsoon rain, having year-round fresh fruits, vegetables and fish to eat and most of all, I missed my extended family. It was difficult not to think about what I had left behind.

Throughout the years, seeing my parents struggle to start and establish a new life in Canada brought me a new found respect for them. Their perseverance allowed me to not only appreciate everything I have but to also have the need to harness their energy forward in everything I do and how I see life. It is an inner force that I try to carry with me in life. I continue to tell myself that such struggles are a part of life. This is what growth and transformation entails - to fall down once in a while.

Years after we immigrated, my parents sponsored my paternal grandmother, a widow, to come live with us in Canada. I had little contact with her when growing up in Bangladesh, so I had a very difficult time warming up to her at first. To me, she was almost a stranger. I could see that she was alone and miserable here in Canada, but my father thought having her with us was the best choice. I have come to understand now, that throughout my childhood and adolescence, I had a distant relationship with my grandmother because I failed to understand her pains. I was not able to understand her loneliness or her longing for familiarity and acceptance, which I myself once felt. As I matured, I began to see that she wanted something everyone else wanted; a

feeling of belonging. Slowly, I put an active effort into building my relationship with my grandmother. The more time I spent with her and greater attention I gave her, I felt greater empathy for her life struggles and was in awe of her resilience at each point in her life. I grew a new found respect for her and her presence in my life remains since her death.

A significant reason as to why I chose to pursue a career in nursing is because I have always had an intrigue with understanding people's vulnerabilities, pains, and a drive to see them healed. It makes me happy knowing that I can make a difference in people's lives. It makes me happy to know that I am able to work with the most vulnerable of people. It makes me happy to know that I am a part of someone else's journey. It makes me happy knowing I have the privilege of taking care of other people. All of the above gives me a sense of purpose. It is a part of who I am, and being a helper is essentially my identity.

One of my very first exposures to nursing was in high school when I was volunteering at a nursing home. It was through that experience I gained an immense amount of respect for older adults, especially those with cognitive impairments. There was one particular resident living with dementia that I will always remember. She had been a very talented painter, with many of her works hanging in her room. As an aspiring painter myself, I was amazed by her skill and techniques and my respect only grew for her. At that point, it made me question the course of the disease and to what extent dementia could take over one's passions, aspirations and essentially one's entire life. I thought to myself that there must be aspects of the human spirit that allowed one to remain strong and resilient, despite the disease process. If it is something that I have been harnessing in myself until this day, what happens to it as someone ages? What happens to that strength in a person with dementia?

While in nursing school, I spent one summer working for a senior's day program. The day program was unique as it hosted older adults of South Asian origin, in which some of them had early stages of dementia. Knowing that many of them were first generation immigrants, it made me question how their current experience of dementia may have been shaped by their cultural context and experience of immigration. Immigration and settlement on its own is a great challenge, as my family and I have faced it ourselves. It was a major life-changing event which propelled us to be resilient. I could not help but fear and imagine my parents one day being in the same position as the seniors I looked after, knowing how much they had struggled to start a new life in North America. Speaking to the residents in my care individually, I began to see behind their illness and see their strength surface, and realized that they were indeed 'resilient' individuals. One particular woman who had dementia comes to mind. She was a very social and lighthearted person who would often speak of her former married life; she spoke of how she always remained faithful and strong despite the way her husband had treated her. Almost every time we spoke, she made reference to her faith in God and that only God could judge her. I knew from her tone, words and expressions that she had faced hardships but had a strong quality about her that marked her as a survivor. Furthermore, the repetitive narration of the same story seemed to highlight the significant meaning for her.

We live in a society that dreads aging and equates it with decline. The anti-aging culture views dementia as a condition that engulfs and ultimately destroys an entire person and as a result, there is little acknowledgement for the positive, resilient qualities that may still remain in a person. It is through my interactions with persons with dementia that I have witnessed the beauty of their history, their wisdom and present-day resilience. I have also come to see their many struggles. But, I truly believe that it is this understanding of others' pains and struggles that

connect us all. It is to know that yes, we are all vulnerable but also have the power to get up. To me, this understanding is the core of nursing.

CHAPTER ONE

*Oh soul,
you worry too much.
You have seen your own strength.
You have seen your own beauty.
You have seen your golden wings.
Of anything less,
why do you worry?
You are in truth
the soul, of the soul, of the soul.*

— Rumi, 13th century (Coleman, 2004)

Introduction

Living a dignified, quality life with hope and fulfillment are universal human desires. Rumi's poem above highlights the beauty of the resilient soul that sustains in the midst of struggle. The essence of being alive stems from a person's sense of self-worth and knowing that he or she is capable of withstanding hardship. The notion that one is still able to be resilient in the context of dementia is often ignored as the negative image of memory loss predominates in the public eye. However, one's self-identity and personal strengths remain intact amidst the challenges of living with dementia. If the sense of identity in a person with dementia remains (Basting, 2003), why can it not be the same for their capacity for resilience? However, so often researchers are preoccupied with cataloguing the negative impacts of such a condition. The context of a person's life and their individuality largely influences one's resilience. With an interest in gaining a deeper insight into the richly positive life experiences of older adults with

mild dementia, I undertook this thesis journey to contribute to the growing understanding of these individuals' capacity for resilience, with a particular focus on how culture may play a role.

It was striking to me to learn that dementia is a worldwide public health priority as the total number of people with dementia around the world is 35.6 million and is projected to double every 20 years (World Health Organization, 2012). Dementia is defined as a slow progression in deterioration of multiple cognitive domains that interfere with daily functioning and most often affects people over the age of 65 (Alzheimer Society of Canada, 2010). Despite the current and future trend, there remains a dominant medical discourse of the diagnosis of dementia in Western society (Mitchell, Dupuis & Kontos, 2013). This discourse of dementia along with the medicalization of aging equates dementia with a loss of embodied personhood and relationships that sustains one's sense of self-with-other (Mitchell et al., 2013). The focus on the physical aspect of degeneration of brain cells and the physical and cognitive manifestations of the condition draws away from the self, personhood, and identity that remain in a person. I believe that as a nurse and fellow human being, identity and selfhood are pertinent to acknowledge and help sustain in a person with dementia so that they may live a quality life.

Background for Research Question

South Asian Older Adults

After searching to understand the general context of dementia, I was interested in learning more about this experience for South Asian older adults. Dementia affects anyone regardless of ethnicity and country of origin. South Asia in particular has one of the highest occurrences, with 4.5 million people who have dementia (World Health Organization, 2012). These statistics may apply to the Canadian context as well, as South Asians in particular are the

largest visible minority in the greater Toronto area (GTA) (City of Toronto, 2013). It is projected that 64, 956 people will have dementia in Toronto by the year 2031 (Alzheimer Society of Canada, 2010). As the GTA is home to many South Asians, they may account for a significant number of older people living with dementia in the future. It was interesting to discover that South Asians in Toronto accounted for over one-half (52.4 percent) of all South Asians in Canada in 2006 (Statistics Canada, 2010). Of this group, almost three-quarters (72.3 percent) of the South Asian community in Toronto were immigrants in 2006 (Statistics Canada, 2010). Furthermore, 20 percent of people of South Asian origin were aged 45 to 64 in 2001, which accounts for the current and future aging population (Statistics Canada, 2007). One of these individuals could be a member of my family, most certainly of my community.

Discourses of Dementia

Dementia has long been portrayed as a frightening disease, conjuring up images of doom and death. I myself do not hold that “fear” but stay conscious of the *person* that lies beneath this image. It saddens me to see the negative discourse highlighted by popular literature titles such as *That Cranky Old Cat May Have Alzheimer’s* (Fujita, 2012) and *Death in Slow Motion: A Memoir of a Daughter, Her Mother, and the Beast Called Alzheimer’s* (Cooney, 2004). The marginalizing negative views of dementia are further evident from the perspective of people in power, including so-called legal and medical “*scholars*”. For instance, the medical philosopher Brock (1988) offered his unsettling consideration of justice and dementia:

I believe that the severely demented, while of course remaining members of the human species, approach more closely the conditions of animals than normal adult humans in their psychological capacities. In some respects the severely demented are even worse off than animals such as dogs and horses who have a capacity for integrated and goal

directed behaviour that the severely demented substantially lack. The dementia that destroys memory...destroys a sense of personal identity across time and hence they lack personhood. (p. 87)

Although Brock (1988) stated this about 26 years ago, views as such still remain present in public discourse. Twenty years after this remark, in 2008, Baroness Warnock, an ethicist and advisor to the British government suggested that a person with dementia may have a moral duty to die, especially if they are wasting human and fiscal resources (as cited in Malpas, 2009):

If you're demented, you're wasting people's lives—your family's lives—and you're wasting the resources of the National Health Service. I'm absolutely, fully in agreement with the argument that if pain is insufferable, then someone should be given help to die, but I feel there's a wider argument that if somebody absolutely, desperately wants to die because they're a burden to their family, or the state, then I think they too should be allowed to die.

Actually I've just written an article called "A duty to die?" for a Norwegian periodical. I wrote it really suggesting that there's nothing wrong with feeling you ought to do so for the sake of others as well as yourself. If you've an advanced directive, appointing someone else to act on your behalf, if you become incapacitated, then I think there is a hope that your advocate may say that you would not wish to live in this condition so please try to help her die. I think that's the way the future will go, putting it rather brutally, you'd be licensing people to put others down. Actually I think why not, because the real person has gone already and all that's left is just the body of the person, and nobody wants to be remembered in this condition. (p. 54)

I was disgusted and appalled to read what Baroness Warnock wrote. It is tragic to see that there is this belief that assumes a person experiencing memory loss is any less “real” than any other human being. Furthermore, the negative language that surrounds dementia and its medicalization propels dehumanized healthcare for persons with dementia which is evident in practices such as infantilization, intimidation, stigmatization and objectification (Herskovits, 1995; Kitwood, 1997; Sabat, Johnson, Swarbrick & Keady, 2011).

There has been a recent movement toward reframing the negative dementia discourse to reflect strengths and capabilities (Keating, Long & Wright, 2013), but unfortunately, the primary social discourse of dementia remains that of “loss” and “meaningless existence” (Harris & Keady, 2008; Innes & Manthorpe, 2012). There are several implications in viewing older adults with dementia in only a negative light which emphasizes weaknesses. A problem-oriented, deficit-focused lens ignores the capabilities and human value that the person still holds. This negative lens deflects attention from person-centered dementia care which focuses on personhood, and perpetuates policy and clinical practice grounded in a medical care model. The deficit-focused lens emphasizes the need to treat symptoms of dementia, while ignoring the fact that dementia is experienced within particular social, environmental and structural contexts (Innes & Manthorpe, 2012). The concept of resilience on the other hand acknowledges and emphasizes the internal and external qualities that allow a person living with dementia to positively respond to challenges despite society’s perception that the individual is incapable of doing so. It is necessary to promote a discourse of dementia that is based on hope and possibility. As humans we have a moral obligation to reject inhumane notions such as the belief that persons with dementia have a moral duty to die, that they are not “real” persons or that they should be

seen as less than animals. Through a resilience lens, dementia care helps refocus on the individual and triggers compassion for an otherwise undervalued population of older adults.

What is Resilience?

My interest in challenging the predominant negative discourse was to advance my understanding of resilience and what it means in the dementia context. My growing understanding included works such as by Wagnild and Collins (2009) and Windle (2011), who described resilience as the ability to “bounce back” following an adversity that threatens development and adaptation, while ultimately leading to good outcomes in spite of the adverse situation. This resonated with me because I was interested in understanding if people with dementia have this capacity to be resilient.

There is a vast amount of empirical literature describing resilience in general. Resilience research has predominately focused on personal factors rather than examining the impact of wider social-structural factors on individual resilience. There is a general lack of attention paid to cultural variability in experiences and measures of resilience (Wild, Wiles & Allen, 2013). Among minority groups in particular, variables such as strength of ethnic identity and comfort in relating to members of different groups can be important when dealing with challenges that arise from experiences of oppression and discrimination (Smith & Hayslip, 2012). Furthermore, there are considerable differences in relative importance placed on individualism (the value of independence), collectivism (understanding of humans as interdependent) and familialism (ideals of what a family should look like) which may influence resilience in different ways for various groups at different ages across the lifespan, including seniors (Wright & Masten, 2006; Hayslip & Han, 2009). Ungar (2010) recognizes that even psychological resources like self-esteem, empowerment, and self-efficacy are culturally and contextually dependent. As such, it is

important to understand the role culture plays in resilience specifically in the context of South Asian older adults living with dementia.

What is Culture?

Dreher and MacNaughton (2002) describe culture to be a social construction of learned patterns of behaviour and a range of beliefs attributed to and values held by a specific group. Culture contextualizes such phenomena as ethnicity, gender, class, and organizational systems. As a socially constructed phenomena, culture entails cultural norms, behaviours and values that are learned through socialization within the family and community (Allendor, Rector & Warner, 2009). Culture has the ability to shape us at an unconscious level, such that it influences assumptions and expectations that ground our behaviors and decisions (Allendor et al., 2009). Cultural identity is a complex amalgamation of such social constructions and psychodynamic processes (Clarke, 2008). It is also how one places oneself in relation to others, to create a sense of “us” in relation to “them” (Clarke, 2008). Furthermore, cultural identities are shaped in relation to societal norms (Goffman, 1968 as cited in Clarke, 2008). Identity is constructed by others and our position in society becomes based on feelings of being an insider or an outsider, inferior or superior in relation to these identities, while a deviance from a societal norm can lead to a stigmatized identity (Goffman, 1968, as cited in Clarke, 2008).

The seeing of “us” versus “them” is the heart of racism and exclusion (Clarke, 2008). These are experiences I am familiar with from my first days living in Toronto and having to hear racist remarks made by a white male to my father, referring to him as a “paki”. I was offended, and angry: How did he come to think that he had any right to say such a hateful thing? Moreover, why did he think he could get away with it? I can imagine that such hostility only made it harder

for my parents to consider Canada their new home. Experiences like this highlight prevailing attitudes that exist in society where people exclude those who they believe have inherent worth that is “less valuable” than they attribute to themselves. Someone living with dementia may be vulnerable to such attitudes based on their “ableness”, age, or race. Such a person could even face discrimination within the culture they situate themselves. The values, beliefs, norms and practices of a culture may include dominant ideologies that could be demeaning. Inequities predominate in certain cultures where ideals that are still patriarchal, classist, sexist, and homophobic exist. Such inequities that instigate the notion of “us” versus “them” is evident in the dementia literature. This will be explored in the context of South Asian cultures and their respective views on dementia in the subsequent literature review chapter.

Identity and Personhood in Dementia

Acknowledging, examining and embracing the identity of a person living with dementia further contribute to person-centered care. Identity is to be aware who one is, in both a knowing and feeling sense, and is a key component to personhood (Kitwood, 1997). Identity is one of the main psychosocial needs of people living with dementia (Kitwood, 1997). Personhood is the basis for person-centered care, where it is acknowledged that a person living with dementia has an ethical status which offers them absolute value and thus, the contention is that they be treated as deserving of deep respect (Kitwood, 1997). The notion of personhood arises when we see those with dementia first and foremost as *people*. In order to do that, we need to acknowledge that in fact, all human beings are flawed to an extent and ask ourselves why we think it is okay to label those who lose cognition as “less human”. Then the integral question arises: Who are we without memory, or more importantly without memory of “self”? Identity and personhood are beyond memory and moreover, memory loss does not equate with loss of identity (Basting,

2003). Identity remains and even evolves long after impairment in cognitive and motor functions (Basting, 2003). In fact, identity may be revealed through narrative accounts by persons living with dementia, which is where the role of qualitative research is critical (Basting, 2003). As a result, I utilized a qualitative research approach for this study which will be expanded upon in Chapter Three.

Many researchers within identity studies note that the construction of one's identity is a lifelong process (Charmaz, 1991; Kaufman, 1986; Orona, 1990; Strauss, 1959). Therefore, identity is formed, maintained and altered through interaction with others in the person's world. Selfhood is essentially "the human being relation to others" (Kitwood & Bredin, 1992, p. 275). Kitwood (1997) argues that to some extent, identity is conferred by others onto a person. Thus, the primary cause of identity loss is the negative societal discourse that no longer values the self because it is seen as "damaged" (Saba & Harre, 1992). There is a sense of division of "us" and "them" that results from the rhetoric of loss and normative expectations of interactions with the person living with dementia (Kitwood & Bredin, 1992). Goffman (1968 as cited in Clarke, 2008) highlights this "othering" notion in his work that focuses on social stigma. He argues that identity is compromised as a result of social stigma, whereby an individual with an attribute that is discredited by their society is not accepted because of this attribute (Goffman, 1968 as cited in Clarke, 2008). The "losses" associated with having dementia can be viewed as a deviance from a societal "norm" which can lead to a certain stigmatized identity. Such views of loss and social stigma currently surrounding dementia further emphasizes the need to highlight the strengths, resiliencies, and identities in persons living with dementia.

The Challenges of Living with Dementia

Although the intent of using a resilience lens and striving for person-centered care is to transform discourse to shine a positive light on persons living with dementia, in no way should the challenges of living with dementia be dismissed, ignored or deemed irrelevant to the experience. Dementia is defined as a slow and progressive deterioration of multiple cognitive functions that interfere with daily functioning and most often affects people over the age of 65 (Alzheimer Society of Canada, 2010). In a literature review of 33 qualitative studies by Steeman, de Casterle, Godderis and Grypdonck (2006), the lived experiences of early-stage dementia were explored. The notion of “loss” was highly apparent in the literature, most significantly the loss of cognition and its consequences, which included loss of control affecting many aspects of life such as relationships and activities of daily living, leading to feelings of incompetency (Steeman et al., 2006). Feelings of stress, confusion, uncertainty and insecurity due to the unpredictability of the disease and its related changes were apparent along with feelings of lowered self-esteem were evident through shame, guilt, uselessness, worthlessness, or stupidity (Steeman et al., 2006). However, there was a sense of moving on and coping with the changes that accompanied the disease including using self-protective strategies such as maintaining hope, using external memory aids (calendars, lists, notes, etc.), relying on a partner, or seeking support (Steeman et al., 2006). It was my goal as the researcher to first and foremost, understand the overall lived experience of dementia including all of its challenges, optimisms, and ways of coping in order to understand resiliency within the context of dementia. The intent of my research was not to downplay the challenges of living with dementia, but rather to explore both the challenges and facets of resilience of persons living with dementia.

The Staging of Dementia – An Outcome of Medicalizing a Lived Experience

The negative social discourse of dementia is in large part influenced by the biomedical perspective of health which focuses on disease progression. This facet cannot be completely ignored and as a registered nurse, I understand that it is important to systematize an approach so that I can assess the impact of a disease on functional capacity, so that I can anticipate prognosis, and can explain to the family what to expect next. However, the preoccupation with “staging” the losses of people with dementia seems objectifying and thus is alarming. The medical literature reports that as a person enters later stages of dementia, he or she experiences an increase in difficulties with communication, overall activities of daily living and physical functioning. This has important implications in recruiting persons living with dementia for research (Reisberg, 1988). From an ethical perspective, the most important concern is the voluntary participation of a person living with dementia who is cognitively intact enough to be able to provide full consent (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). It is noted that a person living with mild stage dementia may have insight about their changing abilities and can therefore inform others of their experiences of living with the disease as well as make contributions to influence the care they receive (Alzheimer Society of Canada, 2013). Thus, I felt it was appropriate and ethically sound for me to recruit persons who are in the mild stages of dementia for this study. A deconstruction of the stages of dementia according to Reisberg (1988) will be presented in the methodology chapter (Chapter Three) and Appendix A. However, I acknowledge that solely focusing on the progression of dementia without regard for personhood negatively impacts on the possibility of an alternative, more fulfilling experience of living with dementia.

Emergence of Purpose of Study and Research Question

As the dominant social discourse of dementia remains that of “loss” and “meaningless existence” (Harris & Keady, 2008; Innes & Manthorpe, 2012), I believe there is a need to reframe that discourse to reflect strength-based approaches and some research supports that the need for culture change in dementia care is upon us (Dupuis et al., 2012; Dupuis, McAiney, Fortune, Ploeg & deWitt, 2014). Culture change may be achieved by utilizing a resilience lens in understanding persons living with dementia and their identity and personhood. However, it is important to not negate the reality of the challenges of living with dementia. Furthermore, there is a lack of importance paid to the socio-structural factor of culture that influences resilience. South Asians are the largest visible ethnic minority group in the GTA, with an aging population. In considering these multifaceted aspects, there is a need to understand the subjective experiences of the challenge and resilience of South Asian immigrant older adults living with dementia. However, only persons living with dementia in the mild stages of the condition were recruited to participate in this research study for ethical reasons of being able to provide full consent. Keeping these aspects in mind, I present the Purpose of Study, Research Question and Sub-Questions below.

Purpose of Study

The purpose of this study was to explore the experiences of challenge and resilience in South Asian immigrant older adults living with mild dementia in the GTA.

Research Question

What are the experiences of challenge and resilience that emerge in the narratives of South Asian immigrant older adults living with mild dementia in the GTA?

Sub-Questions

1. What aspects of culture emerge in the narratives of challenge and resilience in South Asian immigrant older adults living with mild dementia in the GTA?
2. What aspects of identity emerge in the narratives of challenge and resilience in South Asian immigrant older adults living with mild dementia in the GTA?
3. What are the factors that facilitate and hinder resilience in South Asian immigrant older adults living with mild dementia in the GTA?

CHAPTER TWO

I said: What about my eyes?

God said: Keep them on the road.

I said: What about my passion?

God said: Keep it burning

I said: What about my heart?

God said: Tell me what you hold inside it.

I said: Pain and sorrow

God said: ...stay with it. The wound is the place where the Light enters you

- Rumi, 13th century (Coleman, 2004)

Literature Review

Resilience research dates back to the 1970s, originating in studies that sought to understand the resilient qualities of children living in high risk environments or those exposed to adversity (Rutter, 1979; Werner, 1982; Wild et al., 2013). While early resilience research focused primarily on the experience of children and youth, exploring resilience in later adult life is a growing interest and has been identified as a key area for future research (Wild et al., 2013). Resilience research has for the most part sought to understand personal factors rather than on structural factors that constitute the person-environment interaction (Wild et al., 2013). As such, understanding greater structural factors that influence resilience, such as one's culture has also been identified as an area for further exploration (Wild et al., 2013).

To understand resilience in South Asian immigrant older adults, in particular those living with mild dementia, I conducted a literature search using the search engines CINAHL, ProQuest Nursing Journals, Ryerson University Library and Archives, OVID and PsycINFO. The terms “resilience”, “resiliency”, “dementia”, “Alzheimer’s”, “culture”, “ethnicity”, “South Asian”, “immigration”, “aging” and “older adults” were used in various combinations using the Boolean operator “and”. Searches were further refined to be peer-reviewed and in English, with no specified time frame. A total of 333 research articles and six book chapters were found from all the databases. Each title and/or abstract was scanned for relevancy for the intended study. Twenty three titles, four book chapters and one PhD dissertation published between 1990 and 2013 met criteria for inclusion in the literature review for this thesis. The inclusion criteria mandated that the scholarly works be from either/or reputable journals, be written by author(s) with relevant credentials, and be peer-reviewed. The reference list of each of the selected articles were reviewed in an attempt to find additional relevant articles. Seven additional articles were identified as a result of this process. A total of 35 scholarly pieces were included in this review as they were either theoretical articles or empirical studies and their abstract contained information that could contribute to information about dementia, resiliency and/or culture and immigration. An algorithm outlining selection of the sources is presented in Appendix B.

Resilience Research through the Years

Resilience research first emerged in the psychology literature focusing on children (Wright, Masten, & Narayan, 2013). During the 1960s and 1970s, studies researching children of parents with schizophrenia identified resilience to be a key trait for adaptation. In separate studies by James Anthony (1974), Norman Garnezy (1974) and Michael Rutter (1979), it was noted that although children of parents living with schizophrenia were considered to be at-risk,

there was a subset of them that had effective adaptive patterns and displayed resilient traits. Some children resisted becoming consumed by their parent's condition but maintained compassion for their parent (Anthony, 1974) and some resilient children were characterized by traits such as high creativity, effectiveness and competence (Rutter, 1979).

A seminal study cited in most resiliency literature was a longitudinal study in the field of child psychology conducted by Werner and Smith (1982). The study explored the impact of psychosocial and biological risk factors, stressful life events and protective factors on 698 children born in 1955 in Kauai, Hawaii. The study began in 1954 with a cohort of all known pregnancies on the island with follow-up assessments up until adulthood from birth to ages 1, 2, 10, 18, 32, and 40 (Werner & Smith, 1982). The researchers sought to understand cumulative effects of poverty, perinatal stress, and a disorganized caretaking environment on the development of the children from birth to age 10. The early reports indicated that children showed significant deficits when family poverty accompanied perinatal stress, but major factors that protected children against adversity included affectionate ties with family, informal support outside the home, and dispositional attributes such as sociability (Werner & Smith, 1982). Follow-up reports indicated that almost one third of individuals from the 'high-risk' (with four or more risk factors including being born and raised in poverty, had experienced pre- or perinatal complications, living in families troubled by chronic discord, divorce or parental psychopathology; and were reared by mothers with less than 8 grades of education) category grew into competent, confident and caring adults that were employed, did not run into trouble with the law and did not have to rely on social services (Werner, 1996). Furthermore, their educational and professional accomplishments were equal or exceeded children who grew up in more economically secure or stable homes (Werner, 1996). Realizing that resilience research has

primarily focused on children and youth further peaked my interest in understanding resilience instead in an often ignored sub-population in society: older adults.

Several more scholarly works on the concept of resilience surfaced in the 1980s, with Rutter's (1987) paper being one of them. As a seminal theoretical piece in the disciplinary lens of psychiatry, Rutter (1987) characterized resilience as the positive end of the distribution of developmental outcomes among individuals in general at high risk for adversity. Furthermore, the article provided examples of protective processes and also provided one of the first discussions on the importance of identifying processes in resilience and ways in which risk effects may be reduced (Rutter, 1987).

In subsequent decades, scholars such as Windle (2011) refined the definition of resilience in a concept analysis, but also acknowledged that there is no single definition of the phenomenon. However, resilience has been described as “the process of negotiating, managing and adapting to significant sources of stress or trauma” (Windle, 2011, p. 159). Resilience has also been defined through the disciplinary lens of psychology as *good outcomes* in the face of serious threats to adaptation or development (Masten, 2001). Resilience may also be understood in terms of an innate mechanism that drives humans to seek self-actualization, altruism, wisdom and spiritual source of strength (Richards, 2002). As these definitions and aspects of resilience are mostly conceptualized based on western ideals, there remains a gap in the literature to understand resilience in other cultures as well, including South Asian immigrants.

Factors associated with Resilience

There is a common consensus in the literature that the key factors in understanding resilience include the elements of *protective factors*, *risk/adversity* and *outcomes* (Harris, 2008,

Smith & Hayslip, 2012; Wild et al., 2013). *Protective factors* are factors in which individual or environmental characteristics help predict good outcomes (Harris, 2008; Smith & Hayslip, 2012). There are three major categories of protective factors for children and adults including individual attributes, quality of interpersonal relationships and environmental supports (Goldstein & Brooks, 2006; Ong, Bergeman, & Boker, 2009; Vanderbilt-Adriance & Shaw, 2008). Examples of protective factors in older adults may be traits such as determination, coping styles such as turning to religion, healthy life style habits such as maintaining exercise, and also one's problem-solving ability (Smith & Hayslip, 2012). Such traits I have seen first-hand during my interaction with older adults. Protective factors may also be intertwined amongst themselves, rather than exerting their effects independently of one another (Smith & Hayslip, 2012). For instance, determination and having faith in religion together may enhance one's sense of resilience.

Generally, *risk* refers to the increased chance of an undesirable outcome in individuals who have a trait in common while *risk factors* are measurable characteristics of individuals or their environment that predict negative outcome (Wright & Masten, 2006). Common risk factors for older adults may include loss of social status and prestige and health challenges including dementia, depression and physical frailty (Harris, 2008; Staudinger, Marsiske & Baltes, 1993). For instance, physical frailty increases an individual's vulnerability for developing dependency and/or mortality when exposed to a stressor (Morley et al., 2013). However, there is a lack of consistency in how the common traits are used in the literature (Wild et al., 2013). For example, *risk* can be subjective and relative (Wild et al., 2013). What may be considered to be a *risk* for some people in certain situations could be harmless for some while being an asset for others (Luthar, Cicchetti & Becker, 2000; Masten, 2001; Wild et al., 2013). For instance, living alone

may be a risk for someone who requires greater support, while living alone may be an asset for another because it may garner their sense of independence.

An *outcome* of resilience may simply mean there is an absence or resolution of a negative outcome. For instance, when someone recovers from an illness and that illness no longer exists, resilience has contributed to a healed state. A resilience outcome may also be the presence of a positive outcome, for instance achieving social competence. Further, a resilient outcome may be a combination of both; when there is an absence of negative outcome and the presence of a positive outcome (Vanderbilt-Adrance & Shaw, 2008). This suggests that there is a varying degree to which one can be resilient. For instance, resilience can range from being able to achieve a state of contentment from a traumatic experience, to being able to carry on with mundane tasks of everyday life during a period of stress.

Resilience Traits

There are three perspectives of resilience inquiry present in the literature (Richardson, 2002). Resilience may be understood as either an inherent trait, a set of personal characteristics, or as a process of development (Richardson, 2002). The first perspective of resilience research in the time period after Werner and Smith (1982) from the early 1980s to the early 1990s focused primarily on the particular qualities necessary for resilience (Richardson, 2002). These particular traits included dynamism, humor in the face of adversity, patience, optimism, faith, and altruism, among other traits (Lavretsky & Irwin, 2007). In the early 21st century, the second perspective of resilience research expanded to explore the processes through which people attain these characteristics, which takes into consideration the role of environmental factors in the development of coping resources (Bennet, 2010; Richardson, 2002; Sapountzaki, 2007). In other words, the aim is to answer how resilient qualities are acquired by humans and to understand the

role of external, environmental factors in that process. Finally, the third perspective of resilience acknowledges that there is a force within everyone that motivates them to seek self-actualization, altruism, wisdom, and harmony with a spiritual source of strength, which poses the question of where the need to be resilient comes from (Richardson, 2002). These three perspectives on resilience research may be used to facilitate our understanding of how South Asian immigrant older adults are resilient in the context of mild dementia.

Resilience and Older Adults

Gerontology scholarship has historically focused on adversities, deficits and pathologies (Wild et al., 2013). However, resilience theory in gerontology acknowledges a strengths perspective which is a philosophical standpoint that recognizes the inherent power and resilience of individuals and communities (Browne, Mokuau & Braun, 2009). Likewise, resilience theory in the dementia context also possesses a strengths perspective (Harris, 2008). It is important to note that resilience literature is primarily focused on exploring the *experience* of vulnerability, rather than the *avoidance* of vulnerability. This helps acknowledge that vulnerability is a precursor to adversity and therefore a necessary antecedent for resilience (Felton & Hall, 2001). The concept of resilience also acknowledges that older adults may thrive in spite of and even at times *because* of their experience of difficulties in the past (Wild et al., 2013). However, whether or not these difficulties that were faced in the past contribute to resilience in the context of dementia remains a gap in knowledge. Literature that focuses on difficulties and resilience *associated with* living with dementia is limited (Harris, 2008; Harris & Durkin, 2002). To address some of the research gaps, this study will explore participants' past experiences of difficulty and vulnerability as one way of understanding the participants' present experiences of challenge and resilience.

There is considerable literature regarding “successful aging”. However, Gattuso (2003) argues that “successful aging”, which is emphasized by functional, physical, and mental well-being is not attainable by all. The term “successful aging” imposes a certain standard that older adults must conform to in order to be recognized as able beings in society. I contend that resilience is actually possible for everyone throughout the lifespan including seniors regardless of their physical, mental and cognitive state. Each person’s resilience, no matter how big or small the adversity and/or the outcome, is a sign of success. By dismissing the notion of “successful aging”, developing resilience can be the focus of all older adults, including those who live with dementia.

Resilience and Dementia

The inclusivity of resilience in older adults with cognitive impairments is demonstrated in a qualitative case study conducted by Harris (2008), who stressed that there is little research about resilience in the dementia context because people with dementia are considered “ineligible”, as participants on studies examining successful aging. The assumption that needs to be challenged here is that the diagnosis of cognitive impairment will lead to poor quality aging experiences. This view is problematic as it further contributes to the negative discourse of loss and decline in individuals with dementia and can hinder any sort of capacity that they still retain. Harris (2008) demonstrated that resilience is evident in mild dementia by conducting interviews with two older adults, an African-American male aged 71 and a Caucasian female aged 61 with early stage Alzheimer’s disease. Harris (2008) applied the interview findings to a resilience framework that outlines aspects of resilience that are commonly found in the literature: *assets*, *protective factors*, and *risks and vulnerabilities*. *Assets* that contributed to resilience from the interviews included coping strategies, having a positive attitude and productivity (Harris, 2008).

In this study, *protective factors* included aspects such as having a healthy father-daughter relationship, or being in a long-term supportive marriage (Harris, 2008). *Risks* and *vulnerabilities* included the older adult having other health problems and having children and siblings who provided limited support (Harris, 2008). Both participants had accepted their diagnosis, shown a positive attitude and good problem-solving and coping skills, and strived to maintain positive self-concepts through remaining productive members of their communities while using community resources to help them understand their condition (Harris, 2008). Inspired by Harris' (2008) work, in my study I explored the aforementioned key elements of resilience as a framework in the stories of challenges and resilience of South Asian immigrant older adults living with mild dementia. This framework and its application to the context of my study is elaborated upon in the methodology and discussion chapter (Chapter Three and Chapter Four respectively).

Overall, there is very limited research and information in regards to resilience in mild dementia. Harris and Durkin (2002) used a descriptive qualitative approach to understand how resilience is built through coping and adapting in early stage dementia. A total of 22 persons with early stage Alzheimer's disease and 19 family members were interviewed. Seven themes emerged from the interviews which contributed to resilience and coping including 1) talking about one's memory deficits, 2) being useful in society, 3) relinquishing unable-to-perform roles and replacing them with new or adapted roles, 4) using innovative techniques and technology, 5) taking a proactive stance, 6) engaging in holistic practices, 7) anticipating and preparing for future needs and spiritual activities (Harris & Durkin, 2002).

Receiving a diagnosis of dementia can be a devastating experience for the person as well as for their family. However, once cognitive difficulties have developed in a person living with

dementia, there is still some cognitive capacity for new learning and behaviour change (Clare, Kinsella, Logsdon, Whitlatch & Zarit, 2011). Clare et al. (2011) examined innovative approaches to help build resilience in persons living with early-stage dementia which included support groups, cognitive rehabilitation (person living with dementia with family and health professionals work together to develop ways of living with, managing, by-passing and reducing or coming to terms with difficulties with memory impairment), and a dyadic intervention program (which included persons living with dementia and their caregiver to sit down with a counselor to communicate care needs). The past experience gained through life may contribute to the development of psychological resilience in terms of resources for coping with challenges and difficulties (Clare et al., 2011). This may be relevant to the context of my study as one's past experience of immigration and the challenges faced may help build resilience for later life.

Dementia, Stigma and South Asians

As explored earlier, dementia and stigma are interrelated experiences. I wondered whether this interrelationship was typical regardless of ethnic background. In the context of my research question, I was interested to understand views and experiences of living with dementia in South Asian cultures. I was not surprised to see that the dominant negative social discourse of dementia is also noted in literature focusing on South Asians (De Lange, Vernooij-Dassen & Tilburg, 2003; Mackenzie, 2006). The majority of research on the views of dementia by South Asians originates from the United Kingdom (UK) and demonstrates overarching themes of stigma and relating the diagnosis of dementia to religion and spirituality (Adamson, 2001; Ahmad, 2000; De Lange et al., 2003; La Fontaine, Ahuja, Bradbury, Phillips & Oyebode, 2007; Mackenzie, 2006).

De Lange et al. (2003) reported on outreach work to access and recruit South Asian caregivers of family members with dementia in Bradford, UK. In an effort to recruit, the authors noted that they did not acquire the number of participants as anticipated. This was attributed to public perception of dementia as a form of mental illness (De Lange et al., 2003), which contributed to the sense of stigma associated with the condition. The authors hypothesized that there was a general reluctance for people to identify themselves as caregivers (De Lange et al., 2003). As one can see, the consequences of the othering process are present in the lives of the caregivers. However, whether or not this stigmatization is present in the lives of South Asian older adults with dementia has yet to be explored by researchers.

Furthermore, the way in which persons living with dementia and their families seek support or use services is largely influenced by understandings of dementia in different cultural contexts, which are operationalized through stigma (Mackenzie, 2006). This is reflective of Mackenzie's (2006) findings from a three-year project to develop and deliver culturally appropriate support group materials for South Asian and Eastern European family caregivers living in the UK. As was my experience, being classed as a minority ethnic person on its own brings about stigma. Families felt an associated stigma within the dominant white British cultural framework (Mackenzie, 2006). Family caregivers' minority status and being related to the person living with dementia intersected to compound the effects of stigmatization. It is also interesting to note that the similar words for dementia in South Asian and Eastern European languages were likely to be understood as disrespectful, thus the project had to be advertised for "Family carers of older people with memory problems" (Mackenzie, 2006, p. 236). Mackenzie (2006) also found that family caregivers believed that the diagnosis of dementia was likely to bring condemnation from others within their own culture.

In another study, La Fontaine et al. (2007) conducted a focus group of British Punjabi South Asians aged 17-61 years. Among those who attended, aging was seen as a time of withdrawal and isolation and problems were described as being physical or emotional, while cognitive impairment was seldom mentioned (La Fontaine et al., 2007). Further, findings implied that there is a belief that symptoms of dementia reflect lack of effort by the person or lack of family care (La Fontaine et al., 2007). However, to what extent the beliefs shared in these studies are attributed to each person's culture remains unknown.

The literature also suggests that in some instances, a person's religion and/or belief in supernatural powers influences their views about the etiology of dementia. One Muslim caregiver believed that his mother had dementia as punishment from Allah (God) for rejecting his sister when she ran away from an abusive marriage (Adamson, 2001). In this case, the caregiver interpreted text in the Koran to mean dementia was directly related to an action taken by his mother which displeased Allah. Some caregivers explained that it is not uncommon for beliefs about spirit possession and the evil eye being blamed for person's change in behavior that are clinical manifestations of cognitive-functional losses (Mackenzie, 2006). The belief in reincarnation influenced thoughts that the person's illness was a punishment from bad deeds of their previous lives (Ahmad, 2000). In these instances, spiritual beliefs in a higher power are the culture that participants associate with. Unlike the aforementioned literature that focused on dementia and stigma, it is evident from these studies however that culture plays a role in discourses of dementia for South Asian individuals.

Resilience and Culture

Some studies examined the role of culture in resilience within the context of aging. However, in searching the literature, I did not identify any studies exploring culture, within the

context of mild dementia and older adults. Instead, there was some literature within the context of resilience and culture that is in relation to younger populations. In a correlational quantitative study, Clauss-Ehlers, Yang, and Chen (2006) examined the influence of cultural resilience, ethnic identity, and gender identity on resilience processes across diverse racial and ethnic groups of 200 young women between the ages of 17 and 32 who attended a large state university in the United States. The study results revealed a significant positive relationship between enculturation and resilience, as connection to one's cultural roots not only buffered against stress, but also allowed for a support network that may have promoted resilience (Clauss-Ehlers et al., 2006). Such findings made me ponder if enculturation could also influence resilience in the cohort of South Asian older adults living with mild dementia.

More specific to the South Asian population, resilience was examined in a South Asian (Sinhala, Tamil, Muslim Sri Lankans) community impacted by human disasters (such as civil war) and environmental disasters (such as the tsunami) (Fernando, 2012). The study employed a grounded theory approach where the participants' ages ranged from 21-62 years old (Fernando, 2012). Results indicated that components of resilience were similar to those recognized within Western studies such as being mentally strong, adapting to circumstances and fulfilling one's duties (Fernando, 2012). In addition, the study revealed that there were two culturally specific components unique to the South Asian context including participants' strong will relating to either religious faith, or to karma and psychological gratitude (the acknowledged gratefulness to others in the community for providing help which may signify the importance of maintaining human connectedness for Sri Lankans) (Fernando, 2012).

I was fortunate to find one article that appropriately applied to adults over 65 years old by Lou and Ng (2012). In the descriptive qualitative study by Lou and Ng (2012), 13 Chinese older

adults living alone in communities within Hong Kong were interviewed in regards to their resilience factors that allowed them to cope with loneliness. The older adults displayed resilience in their acceptance of living alone and acknowledging the benefits it had for their families that they left (Lou & Ng, 2012). Resilience was also facilitated by the older adults' social relations with family members, peers that they exercised with and social workers at the elderly center (Lou & Ng, 2012). Finally, resilience was also influenced by unique cultural qualities, which were demonstrated through a family-oriented, relationship-focused resilience coping style that is in line with Chinese culture (Lou & Ng, 2012). The findings related to cultural focus on family suggest that unique values of a certain culture may influence resilience, which can inform the intended study of understanding resilience in South Asian older adults with living with mild dementia.

Resilience and Immigration

Resilience was found to be associated with immigration throughout the literature. In a mixed-methods study by Cheung (2008), 16 participants (eight couples) ranging from age 56 to 78 years old were recruited from an English as Second Language (ESL) class at a service agency in Manitoba, Canada. Couples expressed experiences of difficulties during immigration and integration including being homesick, being unable to adjust to the new environment due to their limitations in speaking English, and the desire to understand local culture remaining unfulfilled (Cheung, 2008). Cheung's (2008) study findings indicate that a satisfying, long-term marriage is a major protective factor for the resilience and adjustment of immigrant couples. There were three significant processes that led to the couples' resilience in immigration and integration. This included how there was a switch in traditional gender roles upon immigration, for instance, the women took jobs outside the home and men took a more active role in domestic responsibilities

(Cheung, 2008). Furthermore, increased intimacy and mutual reliance in the couples' marital relationships and management of conflict and compromise of differences also contributed to resilience (Cheung, 2008). External factors that enhanced immigrant couples' resilience included having formal and informal support networks available and attaining biculturalism (Cheung, 2008). Biculturalism refers to the person's ability to function both in their heritage culture and that of the host society (Cheung, 2008). Thus, the immigration experience in itself can be seen as an *adversity* or resilience, or both. In the context of my study, it will be useful to explore how South Asian older adults view their immigration experience and how their relationship with a significant other may have impacted their resilience.

The notion of biculturalism was also noted in a constructivist grounded theory study by Goldman (2012), whose research sought to understand subjective accounts of resilience in 18 first-generation immigrants living in Toronto (cultural backgrounds included Polish, Chinese, Colombian, Indian, among others). The key focus was to explore how cultural experiences influenced participants in their adaptation to mainstream Canadian culture (Goldman, 2012). The overarching theme that surfaced from data analysis of the semi-structured interviews was that of belongingness. Belonging indicated a process by which immigrants gained a sense of identification with and inclusion in Canadian society which was facilitated by themes of feeling acceptance and forming attachments (Goldman, 2012).

Feeling accepted was identified both in terms of immigrants fitting into their own cultural community as well as into the mainstream Canadian sociocultural environment, which together contributed to gaining a stronger perception of belonging in Canada overall (Goldman, 2012). Individuals found difficulty coping with losing attachments with family and community, while struggling to form new interpersonal attachments (Goldman, 2012). Participants felt loss in

several other facets of their lives including loss of career identity, socioeconomic status, loss of family and support networks which propelled feelings of loneliness and alienation (Goldman, 2012). However, cultural attachments (such as religious forms of affiliation) increased participants' perception of connection to Canada. Development of attachment to the mainstream Canadian sociocultural setting was facilitated by bonding outside of one's traditional ethnic background, which provided a sense of belongingness. Having a sense of cultural attachment is reflective of a *protective factor* in aiding the participants' feelings of belongingness as they shift from outsider to insider status in the Canadian society.

Literature Review Conclusions

First and foremost, very few studies have explored the experience of resilience in adults with mild dementia. Although, it is evident from the literature that culture may play a role in resilience, there is no research that specifically addresses culture and its role in resilience within the context of dementia. Furthermore, there is a limitation of studies that inquire about the lived experiences of South Asian immigrant older adults in particular. In fact, Lawrence, Samsi, Banerjee, Morgan and Murray (2010) highlight how in reviewing international literature and meta-synthesis of qualitative studies that examined the perspective of the person with dementia, none reported the experiences within minority ethnic populations. As a result, Lawrence et al. (2010) identified this as a limitation in the literature and sought to understand the subjective reality of living with dementia within the three largest ethnic groups in the UK (Black Caribbean, South Asian and White British), using a grounded theory approach. Research findings demonstrated that South Asian older adults were rarely aware of the progressive nature of the condition when asked and often thought that the degree of memory loss manifested in dementia represented normal aging (Lawrence et al., 2010). In terms of support needs, they took

confidence and pride in the presence of family support (Lawrence et al., 2010). Overall, South Asian older adults valued their position within the family and greater community (Lawrence et al., 2010). Lawrence et al.'s (2010) study took place in the UK, similar to all the other dementia literature related to South Asians (Adamson, 2001; Ahmad, 2000; De Lange et al., 2003; La Fontaine et al., 2007; Mackenzie, 2006), which highlights the need to conduct research with South Asian older adults living with dementia within Canadian society.

Although the theory of “person-environment” interaction is highlighted by resilience researchers, there continues to be an under-theorization of the role of wider contextual and the “structural” factors that play on resilience (Wild et al., 2013). Structural factors include those that are beyond personal factors and rather focus on external and socio-cultural factors including the socially constructed notion of culture. As it has been identified that exploring culture is a limitation in the field of resilience research, it is important that future research is conducted to fulfill the knowledge gap so that there is greater understanding of how aspects of one's identity influences their reaction to adversity. This gap can be partially fulfilled by conducting a narrative study in this thesis, which aims to understand experiences of challenge and resilience in South Asian immigrant older adults living with mild dementia in the GTA.

CHAPTER THREE

You are a volume in the divine book

A mirror to the power that created the universe

Whatever you want, ask it of yourself

Whatever you're looking for can only be found

Inside of you

- Rumi, 13th century (Coleman, 2004)

Methodology

The thesis journey has tested *my own* resiliency in several ways through set-backs, confusions and a circular motion of inquiry. One of the challenges has been the constant need to refer back to previously selected methodologies and theoretical frameworks and ask myself, “How will this approach best illuminate the stories of the participants?” Creating a research question and sub-questions, choosing theoretical frameworks and deciding on a methodology was a back and forth quest. However, this is wherein the beauty of qualitative inquiry lies; there is a necessary *fluidity* to the inquiry process. This chapter will outline and describe the theoretical frameworks that I used to guide this study, how I came to identify a research methodology and finally, the actual steps of data collection and analysis that I utilized.

Theoretical Perspectives

The two theoretical perspectives that were used to guide this study are the intersectionality lens (Crenshaw, 1991 as cited in Viruell-Fuentes, Miranda & Abdulrahim, 2012) and Resilience Framework used by Harris (2008). Intersectionality provides a lens to recognize inequities that prevail in society and how these inequities shape people's identities

(Crenshaw, 1991 as cited in Viruell-Fuentes et al., 2012). Application of an intersectionality lens was undertaken in this study to allow a deeper understanding of the *person* who experiences challenges and resilience and reveals power relations in society, while the framework Harris (2008) provided knowledge regarding the *process* of resilience. The Resilience Framework used by Harris (2008) outlines key components in the process of resilience. Each perspective helped highlight different components of resilience, which are equally important – *person* and the *process* are inextricably linked.

Intersectionality

Intersectionality acknowledges that there are multiple constructed identities that shape a person; for example, sexuality, ethnicity, culture, socioeconomic status and “ableness” (Cramer & Plummer, 2009). Through an intersectionality lens, social relations of domination and oppression are examined and how they operate along different axes (Anderson, 2004). Furthermore, these social positions of gender, race, or class are experienced simultaneously (Viruell-Fuentes et al., 2012) and work together to produce unequal power relations, creating social injustices that may result in health disparities (Van Herk, Smith & Andrew, 2011).

Intersectionality can be incorporated into research as a way of thinking, understanding and acting as well as method of analysis (Hancock, 2007). As participants in this study are subject to oppression associated with their age, race, minority status and “ableness”, an intersectionality lens will allow a critical analysis of the various dimensions of the immigrant older adult living with mild dementia. Furthermore, it has been noted in the literature that the reliance on a cultural explanation for immigrant health obscures the impact of health disparities (Viruell-Fuentes et al., 2012). This is because culture has been treated as static in the literature and fails to account for the changing dynamics in such populations and that ultimately, each

group of immigrant older adult is heterogenous (Koehn, Nevsmith, Kobayashi & Khamisa, 2013). In guiding this research study, I used the intersectionality lens to identify that there are an entanglement of identity categories that make up each participant, but ultimately I have recognized each participant as holistic integrated beings rather than different strands of identity (Hulko, 2009).

Resilience Framework

The Resilience Framework that was used by Harris (2008) in her seminal work exploring resilience in mild stage dementia will also be used to guide this study. As mentioned previously, resilience is the ability to overcome adversity (Yates & Masten, 2004). The presence of resilience requires two components: that there is or has been an adversity to overcome and that the person is doing alright (Masten & Coatsworth, 1998). The key concepts necessary for understanding the process of resilience include: *competence*, *adversity*, *assets* and *risk* and *protective factors* and *vulnerabilities* (Yates & Masten, 2004). Harris analyzed her findings through identification of these components in her participants' stories. *Competence* is one's adaptive use of resources within and outside a person to negotiate challenges and achieve positive outcomes (Harris, 2008). *Adversity* refers to experiences that threaten or disrupt adaptation or development (Wright et al., 2013). *Assets* are resources within a community, resources within a person and a person's social networks that increase the likelihood of a positive outcome (Harris, 2008). *Risks*, on the other hand refers to events or conditions that increase the likelihood of an undesired outcome (Harris, 2008). *Protective factors* help predict better outcomes in particularly in situations of risk or adversity (Wright et al., 2013). *Vulnerability* refers to the individual's susceptibility for undesired outcomes (Wright et al., 2013). The storied lives of the participants in this study were analyzed to identify these components of resilience.

Qualitative Approach: Narrative Research

Qualitative research informs knowledge building through the lens of the interpretive paradigm. The interpretive paradigm acknowledges that reality is built from the subjective meanings people attribute to their experiences. Thus, the nature of reality is socially constructed. These social realities exist due to varying human encounters that produce people's knowledge, views and interpretations (Henning, van Rensburg & Smit, 2004). Further, interpretivism investigates social phenomena that will enhance understanding of the social world that people live in (Henning et al., 2004).

The essence and goal of qualitative research lies in its ability to highlight meaning, depth and detail of people's lives. Narrative research in particular is a form of qualitative research that captures the lived and told stories of individuals (Riessman, 1993). Stories are powerful tools that demonstrate how people make sense of their experiences (Duffy, 2012). The story is essentially one's identity, as a story is created, told, revised, and retold throughout life (Lieblich, Tuval-Maschiach & Zilber, 1998). As humans, we know or discover ourselves and reveal ourselves to others by the stories we tell (Lieblich et al., 1998). In line with interpretivism, such stories reveal subjective social realities.

John Dewey (1983), a pragmatic philosopher upon whose work narrative research is built, acknowledges that people cannot only be understood as individuals but are always in a social context, and thus must be appreciated in relation to interactions with others. Narrative research acknowledges that reality is subjective and multiple (Chase, 2011; Creswell, 2007). Further, the researcher collaborates with the participants in the meaning making process and also reflects on her or his own stories (Chase, 2011; Creswell, 2007). In fact, the researcher enters the study, acknowledging that their own biases and values will affect the research process and

thereby affect the meaning making process of data (Creswell, 2007). The researcher lessens the distance between themselves and the participant, and in this way becomes a participant (Creswell, 2007). This can happen through a reflective journaling process whereby the researcher can identify how his or her own stories may be relevant and therefore influence how one interprets participants' stories. For instance, different words, phrases, terms may have specific significance for different people based on their experience. Thus, one will pick up on them to a greater degree than other words and phrases. This process of acknowledging and embracing one's position in the research process is known as researcher reflexivity. I will elaborate my reflexivity in this research process later in this chapter.

Narrative research allows a systematic analysis of stories for its content, flow, the way in which it is told and its ascribed meaning (Riessman, 1993). Narrative researchers view narrative as a distinct form of discourse, through which one can learn about any phenomenon by maintaining a focus on narrated lives to construct meaningful selves, identities and realities (Chase, 2011). Once collected, the stories and experiences are deconstructed and analyzed, and then reconstructed in a re-storied form that allow readers and stakeholders to understand the revealed meaning (Riessman, 1993). Narrative research further aims to examine how a participant's use of language reflects their social world and in doing so, constitutes their very identity (Duffy, 2012). Stories reveal meanings, conventions, dominant beliefs and values of the time and place in which a person lives and develops an identity (Duffy, 2012).

Narrative analysis is rooted in different disciplines including theology, philosophy, psychology, as well as practice disciplines such as nursing, medicine, social work and occupational therapy (Daiute & Lightfoot, 2004; Kim, 2006). Gathering data in a narrative study does not follow a strict approach, rather an informal collection of topics (Creswell, 2007).

“Narrative” method is actually an umbrella term that encompasses a variety of analytic practices. Narrative writers have provided different approaches in analyzing and understanding stories. Some commonly used narrative approaches throughout the literature include those first developed by Reissman (1993), followed by Lieblich, Tuval-Maschiach and Zilber (1998), then, Clandinin and Connelly (2000). Although each narrative method has a slightly distinct approach, they all serve the common purpose in collecting stories that reveal both conscious and unconscious meanings that are attributed by participants as they navigate their social worlds and develop identities.

In “narrative inquiry” as described by Clandinin and Connelly (2000), the researcher needs to understand participants’ stories as having a three dimensional space with the components of *interaction*, *continuity* and *situation*. According to Riessman (1993) however, the purpose of “narrative analysis” is to explore first-person accounts and see how respondents in interviews impose order on the flow of experiences to make sense of events and actions in their lives. Riessman (1993) highlights the need to not only examine the content of a story but also asks the imperative question of ‘Why was the story told *that* way?’ Finally, Lieblich et al.’s (1998) approach involves selecting from four possible types of data analysis: categorical form, categorical content, holistic form and holistic content.

Each scholar identifies a unique way to analyze stories. According to Clandinin and Connelly (2000), people experience life events in relation of the dimensions of interaction, continuity and situation. *Interaction* is the relationship between the personal and social. The personal includes an individual’s internal conditions such as feelings, thoughts and hopes. The social context refers to one’s external environment. *Continuity* is to the time frame of past, present and future. Lastly, *situation* refers to the specific place or sequence of places stories take

place. The narrative researcher's aim is to gain a deeper understanding of the events in one's life through speculation of such dimension through a reflective process.

Riessman (1993) however is more concerned with the aesthetic of language and tone used by the story teller. Riessman (1993) uses transcript data to display structural analysis through poetic features of language, organizing significant narrative text into stanzas, based on theme. It involves reducing a long response, deconstructing it according to a set of rules into lines, stanzas, and parts, examining its organizing metaphors and creating a schematic to display the structure (Riessman, 1993). The approach is based on Gee's (1991) theory that each stanza is a particular take on character, action, event, claim or piece of information. Each stanza is seen to represent a particular perspective, of what is seen, representing an image. This type of analysis through poetic structure is meant to articulate theme, emotion and fragments of one's experiences and environment. It is a unique approach to analysis but ultimately aims to deconstruct and highlight aspects of one's identity and social world. Reissmann (1993) acknowledges that studying narrative reveals much about social life, that is, culture *speaks for itself* through an individual's story. Issues such as gender inequalities, racial oppression, and other practices of power that are otherwise taken for granted by the speaker can actually surface through their story telling (Riessman, 1993). Narrators may speak in terms that at first glance may seem mundane, but such terms can reveal how culturally and historically contingent these terms are (Rosenwald & Ochberg, 1992).

Another analysis technique is through deconstructing categorical form, categorical content, holistic form and holistic content (Lieblich et al., 1998). Categorical form and content involve focusing on separate sections of one's story whereas holistic form and content involves understanding the story as a whole (Lieblich et al., 1998). Form analysis involves understanding

the structure of the plot, the sequence of events, its relation to the time axis, its complexity and coherence, the feelings evoked, narrative style, and choice of metaphors or words (Lieblich et al., 1998). In terms of content analysis, some data transcripts are read for its explicit content, such as what happened, why it happened or who participated in the event (Lieblich et al., 1998). Otherwise, it can be analyzed for its implicit content, by gaining insight about the deeper meaning of a story (Lieblich et al., 1998). In both cases of categorical and holistic analysis, data can either be further analyzed for its content or its form.

In summary, each narrative analysis contains distinct elements. However, the ultimate goal in narrative research remains to gather, analyze, deconstruct, and reconstruct the storied lives of individuals in order to reveal the self and the social world within which one lives. In exploring the various narrative approaches utilized in the literature, I could not identify one, single narrative research methodology I could utilize, based on the story-telling of my participants. Indeed, the analytic approach of any particular narrative methodology did not stand out for me. As a result, I sought an alternative that would allow me to stay true to narrative methodology's intent as well as the unique meaning that were emergent from the data of my own research project. Below, I describe the steps to the narrative process I undertook and how the particular choosing of Duffy's (2012) narrative analysis of identity development was an emergent approach. In this section, I will also elaborate on the elements of the Duffy's (2012) approach and describe how I applied it to each step of narrative research as appropriate.

Steps to Narrative Research

Identifying a Research Question

Deciding on a research question is the basis for a narrative approach. Commonly, narrative research questions focus on the life story or life history of an individual or group, as told by individuals (Duffy, 2012). However, the researcher must limit the scope of the research question, as no single story will capture a life or even part of a life (Duffy, 2012). With my interest in using a resilience lens within the context of Duffy's (2012) approach, the research question "What are the experiences of challenge and resilience that emerge in the narratives of South Asian immigrant older adults living with mild dementia in the GTA?" continued to resonate in me.

Participant Selection

Purposeful sampling was carried out in this study as the research question required participants with very specific characteristics. In a narrative study, the researcher needs to find one or more individuals who are accessible and are able to provide insight into a specific phenomenon (Creswell, 2007). The inclusion criteria for the study were set for individuals who were: over 55, a first generation immigrant from a South Asian country, in the stage of mild dementia, could speak English, and were living in their own homes in the GTA. As a progressive condition of cognitive impairment, there are several stages of dementia. It was important from an ethical perspective to recruit individuals who were in the early stages of dementia so that they were able to give full consent (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). In order for me to recruit participants from an

early stage of the trajectory, it was essential for me to gain a deeper understanding of the stages of dementia. Dementia is in fact an umbrella term for several brain disorders that constitute memory impairment as a result of different physical changes to the brain and includes Alzheimer's disease, vascular dementia, Lewy body dementia, frontal temporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease, Huntington's disease, Wernicke-Korsakoff syndrome and Down syndrome (Alzheimer Society of Canada, 2013; Kuhn, 2003). However, Alzheimer's disease is the most common type of dementia, affecting 64 percent of those with dementia in Canada (Alzheimer Society of Canada, 2013).

The progression of Alzheimer's disease can be categorized and measured based on a scale called the Functional Assessment Staging Test (FAST) which was developed by Dr. Barry Reisberg and colleagues in 1984 (Tappen, 1997). The FAST scale has seven stages with further sub-stages that predict the order in which functional decline occurs, from a period of insignificant, unrecognized symptoms to very severe decline, a slow and insidious progression particular to dementia of the Alzheimer type (Auer & Reisberg, 1997). Appendix A outlines a brief summary of the seven stages of FAST. The seven stages from one to seven are as follows: I) No cognitive decline, II) Very mild decline, III) Mild decline, IV) Moderate decline, V) Moderate severe decline, VI) Severe decline and VII) Very severe decline.

Stage II to stage IV of the FAST scale represents mild dementia (Reisberg, 1988). Adults who attend day programs would typically be characterized by traits in Stages II to IV. In stage II, the person complains of forgetting where an object has been placed or forgets words, names, and facts they were once familiar with (Reisberg, 1988). Stage III is the period in which the person experiences functional decline to the point there is interference with complex occupational and social tasks (such as traveling to new locations) (Reisberg, 1988). At this stage, the person may

begin to forget important appointments for the first time in their lives. Stage IV is the last stage of *mild* dementia in which there is deficient performance in the complex tasks of daily life such as paying bills, cooking, and cleaning (Reisberg, 1988). However, persons at this stage can still function independently in the community since they may still be able to dress, bathe, choose their own clothing and travel to familiar locations (Reisberg, 1988).

It was not my intent to use the tool to pre-screen for participants but rather to inform my understanding of the appropriateness of day programs as a site of recruitment for potential participants. As the study sought participants who were able to still carry out activities of daily living on their own with limited assistance and lived in their own homes rather than facility-based care, it was identified that adult day programs would be the ideal sector within which to recruit potential participants. Adult day programs do provide care for seniors in the early stages of the cognitive impairment process who will have already experienced symptomatology that have impacted on their ability to navigate their day, however, are still functionally able to live at home (Gaugler, Jarrott, Zarit, Stephens, Townsend & Greene, 2003). Therefore, several adult day programs throughout the GTA were contacted.

I inquired via telephone or e-mail if each day program had seniors who met the inclusion criteria. The director of one South Asian older adult day program that I once worked at and a program staff of another South Asian older adult day program responded. The gatekeepers of the two separate day programs were provided with the purpose of the research, some background information, the inclusion criteria, and the full consent form via e-mail. The gatekeepers agreed to assist in recruitment and approached potential participants with the information. They felt that it was also necessary to gain consent from the potential participant's caregiver to maintain transparency of the day program's activities. Two men and their caregivers from two different

culturally-specific day programs in the greater Toronto area agreed to sign the consent form and provided permission for interviewing. Potential participants were volunteers; one gatekeeper informed me that three out of the four participants she approached declined the invitation to speak with me about the possibility of participating in the study. The other gatekeeper informed me that the initial potential participant he approached also declined to speak with me about potential participation. The fact that potential participants felt the right to decline participation suggests that a neutral power relationship existed between day program staff who actively recruited attendees.

The first person I approached to talk about potential participation in my study was a man from the first day program. He was a man in his 70s from Pakistan. The pseudonym he picked for himself was Khan. The second man I talked with was also in his 70s, who was originally from Iran, but from Indian ancestry. He chose the pseudonym Aga for himself. Mr. Aga always attended the day program with his wife. As his communication and some clarity of speech was affected by dementia, his wife emerged as a facilitator of the storytelling. She chose the name Khushu as her pseudonym. Since English was Mr. Aga's second language, Mrs. Khushu was helpful in assisting to translate certain words and phrases for him in his mother tongue, Gujrati. Despite the set inclusion criteria, there were several additional overlapping traits between both of the individuals living with dementia who participated in my study. Both individuals were men, in their 70s, practicing Muslims, and living with close family. Mr. Khan and Mr. Aga along with his wife Mrs. Khushu agreed to participate in the study, and all three signed separate consent forms. Mr. Khan's son also provided consent, although he chose not to observe or participate during his father's interviews.

Ethical Considerations and Recruitment

As I was engaging in research with humans, it was imperative that ethical considerations were made, moreover because the participants I spoke with were from what is considered a “vulnerable population”. Once ethical approval was obtained from Ryerson Ethics Boards, I proceeded to gain consent from and access to adult day programs throughout the GTA in regards to recruiting attendees from their day program. Several day programs responded and in speaking to the gatekeepers over phone or e-mail, it was apparent that in most day programs, participants did not fit the inclusion criteria.

Ultimately, four individuals were identified as potential participants in this study. I met with each of them privately to determine whether they met the inclusion criteria. For the first two potential participants, one day program responded and described that they may have attendees that fit the study’s inclusion criteria, thus they welcomed me to visit their location. In visiting their location, the gatekeeper whom I corresponded with introduced me to two individuals that they thought would fit the inclusion criteria. I asked each individual if I could speak to them, to which they agreed. I showed them the recruitment poster (Appendix C) and spoke to them in regards to the study based on the brief presentation script (Appendix D) that I had prepared. The recruitment poster and the presentation script requested caregiver participation as well. However, this facet of recruitment was removed from the protocol as a Research Ethics Board approved amendment. It became apparent that caregivers would not be accessible for interviewing as their loved one’s participation at the day program was meant for the caregivers’ respite. Both individuals showed interest in participating however, one participant was in fact at a later stage of dementia, as confirmed by the gatekeeper and the other did not meet the inclusion criteria as he was not of South Asian descent, but rather an immigrant from the Caribbean.

In the case of the final two potential participants who eventually were included in the study, there were two gatekeepers in two different day programs who felt that their program may have potential participants that fit the inclusion criteria. The gatekeepers engaged in recruitment by approaching potential participants with verbal information about the study shared by me via e-mail. Gatekeepers approached potential participants that fit the inclusion criteria as well as their caregivers as they wanted to ensure the safety of those wishing to participate. Those who were interested in participating and their caregivers were provided with consent forms so they could read more about the study and what participation entailed. After first meeting with the two men, both agreed to participate in my study once I verbally explained all aspects of the study. Consent forms were signed by Mr. Khan during the first interview and his son had signed a separate copy prior to the interview. Consent forms were signed by both Mr. Aga and his wife, Mrs. Khushu as she was directly involved in her husband's interview. Sample consent forms can be found in Appendix E and F, one for the participants living with dementia and the other for the caregiver, respectively.

Ethical Considerations, Dementia, and Consent

A diagnosis of dementia is not synonymous with incompetency, as research has been conducted with mild dementia in the past (Harris, 2008; Weresak & Steward, 2009). Those in the earliest stages of dementia are still capable of making many decisions competently, including the decision to participate in research (American Geriatrics Society Ethics Committee, 1998; Weresak & Steward, 2009; Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010). I understand that it was not necessary from a research point of view to gain permission from their caregivers as the two men were independent adults capable of providing

both verbal and written consent. However, I chose to respect the wishes of the day programs to establish a trusting relationship as an outsider. I strongly believe that one of the most powerful ways to give voice and visibility to those with dementia is to listen to their personal experiences and insights. Involving persons with dementia as active participants in research is one of the many ways to ensure their dignity and inclusion in society is maintained (Hellstrom, Nolan, Nordenfelt & Lundh, 2007). However, safety, security, and dignity, also involve recognizing the need of family members to advocate and protect their loved ones. Thus, I made the decision to provide both Mr. Khan and Mr. Aga's caregivers with the opportunity to give signed consent.

On the day arranged for the first interview with Mr. Khan, I arrived to speak with him and discovered that the day program required a staff member be present at the beginning of the first interview to ensure that Mr. Khan was engaging in a safe process and his participation was totally voluntary in the context of his early dementia and ESL status. Since the presence of the staff member was not pre-arranged but was established as a safety measure for Mr. Khan, I did not have a specific consent form or agreement for the staff to sign. Instead, once Mr. Khan, the staff member and I were seated in a room with privacy, I explained to the staff the purpose of the interview and the need for confidentiality, and provided opportunities for her to ask questions about the process. The staff provided verbal consent and verbal agreement to confidentiality before we proceeded with the interview. Once the staff established that Mr. Khan was in a safe setting during the first fifteen minutes of the interview, and that I was sensitive to his level of communication ability, she left to attend to other day program duties and came back during the last five minutes of the interview to check on Mr. Khan. During her stay, I paid special attention to the sort of questions I asked Mr. Khan, ensuring that he was placed in a position of self-mastery and communication strength. During the staff's presence, I was fully aware of the

importance of keeping confidentiality and privacy. In the case of Mr. Aga, I understood that his wife, Mrs. Khushu would be present with him for two sets of interviews thus she was given a separate consent form to sign.

From a research perspective, I was cognizant that the participants were from a vulnerable population as they were older adults living with cognitive impairments, were of ethnic minority, and English was not their primary language. As such, special attention was paid to provide full written and verbal consent, while re-iterating to participants that they had the right to refuse questions, to stop the interview at any time and withdraw from the study for any reason. The day programs suggested carrying out the interview at their location and provided a separate room that maintained privacy. This option was shared with participants, to which they agreed. Once consent was obtained, I re-iterated with the participants that I anticipated conducting two in-depth interviews, beginning with the first one during the initial meet. All participants were given the option to choose their own pseudonym to maintain confidentiality of identity. During each interview I observed both participants closely for signs they were becoming disinterested or disengaged. In fact, during the first interview, my conversation with Mr. Aga ended at his request when his focus began to shift back to his feeling to return to the day program and participate there.

Data Collection

After recruitment, the next step in the narrative research process is to collect data, which is primarily done through interviewing (Duffy, 2012). Data collection occurred over two separate interviews with the participants. I confirmed with the gatekeepers that the men had been given a formal diagnosis of dementia as they had access to their individual files. Furthermore, prompts were used during interviewing mentioning diagnosis and living with dementia, in which the

participants acknowledged their condition. Mild dementia was determined based on the participant's ability to comprehend questions, reply appropriately and provide responses that included a series of relevant words linked in a meaningful way. An interview guide (please refer to Appendix G) was used to ask open-ended questions. Interviews were conducted in English, with translations made as required to bridge communication by either the staff member supporting Mr. Khan or Mr. Aga's wife. The interviews were audio-recorded with permission. All interviews were transcribed and de-identified by me as the Principal Investigator. The only other person that read complete transcripts was my thesis supervisor.

Although I carried out two in-depth interviews with each participant, "data" also included text based activities, and my observation of participants' body language and expressions. Story-telling was a two-way dialogue between myself and the participants, where I considered or shared my own individual experience and stories alongside the participant's personal experiences to co-create stories (Creswell, 2007). Furthermore, as stories were co-constructed, I was conscious of my own emotional reactions throughout which allowed me to actively position myself in the narration (Duffy, 2012). The second interview with participants was necessary to gather further detail about stories, and check for meanings and my interpretations (Duffy, 2012). I have provided a general overview of interview one and two in the following section.

Interview one. The first interview took place in a private room in each man's respective day program that they attended. As I sat down with the participants and the person accompanying them (Mr. Khan's first interview was accompanied by a staff member for only a short portion of the first interview and Mr. Aga's wife, Mrs. Khushu participated in both interviews), I spoke a little bit about myself and discussed why I was interested in doing this

study. I clarified any questions or concerns from the participants. I acknowledged it was important to remain genuine, keep an open and inviting atmosphere, establish trust and rapport, and ensure the participant's feelings of safety. The interview guide was used to keep track of questions rather than be a strict list of questions. Overall, I tried to maintain conversational dialogue, allowing for my questions to emerge as participants spoke about their experiences. Throughout the interview, I took notes on any particular observational detail or thoughts I had. The first interview was planned to be 40-50 minutes, however the interview was concluded when the participants expressed their desire to finish up and rejoin the day program activities. At the end of the first interview, each man was given a five dollar Tim Horton's card as a token of appreciation for their time.

Upon completion of the first interview with each participant, the audio recordings were transcribed and read through several times. Further questions and experiences I wanted to inquire about in the subsequent interviews arose as I reflected on the transcribed data. In discussing findings with my supervisor, it became apparent that an arts-based activity would help to gather more insight into both participants' experiences.

Interview two. The second interview allowed the opportunity to summarize my interpretation of the participant's stories from the first interview with them and check for accuracy. I asked participants to elaborate on some stories from the first interview, asked new questions and allowed questions to emerge as conversation took place. The activities were tailored for each participant's interest, capacity, and storied life. The first participant, Mr. Khan took part in a word association and puzzle activity. This allowed significant words that he related to his experiences, and the patterning in which he chose to lay out his words also represented meaning. With the second participant, Mr. Aga, the making of a creative piece (which ended up

being in the form of a reflective text) was facilitated, in answering the question “What is the most challenging thing that you have had to face?” and “How have you dealt with that challenge and how do you currently feel about it?” I gave his wife, Mrs. Khushu a canvas as well and asked her to answer the question: “What was the pivotal point in your relationship when you saw him lose his independence? How it made you feel and how are you coping with that right now?” I also participated in the activity as it aided in the co-construction of stories. At the end, each one of us reflected and shared our pieces and subsequent stories. Prior to giving a final thanks and bidding farewell to the participants, I presented each man with another five dollar Tim Horton’s card as a token of my appreciation.

Considerations during data collection. During the interview, it is important that the researcher develops a trusting relationship with the participant and creates a safe place where knowledge and stories can be co-constructed (Creswell, 2007). Prior to speaking to my participants, I was cognizant of the obvious power relations that existed between us. I acknowledged my seemingly “authoritarian researcher” role and actively sought to create an equal-power balanced relationship. I tried to achieve this by giving the participants the freedom to ask questions, repeating that they had the right to withdraw anytime from the study, relating to the participants if I had an experience in common, and by being respectful of their time when they wished to end the interview. Furthermore, I avoided scientific language and used conversational language. The years of training and work as a Registered Nurse utilizing therapeutic language with patients assisted in this goal. In one instance, one participant asked if their answer was “what I was looking for”. I replied, “there is no right or wrong answer, you can tell me what comes from your heart”. Reflecting on my theoretical lens of intersectionality, I was

especially aware of the unequal power relations that existed as these men not only had dementia but were also elderly and of minority status.

The researcher must also identify who the narrator of the story is, either the person who experienced the set of events or the witness to the experiences (Duffy, 2012). The narrators in this study include both first person and witness accounts. Mr. Khan and Mr. Aga helped to directly answer the research question while Mrs. Khushu indirectly helped to answer the research question. Although there is a narrator of the story, Duffy (2012) suggests that there may be another underlying voice, known as the *authorial voice*. The authorial voice seeps through a narrator's story-telling as the dominant discourse of a culture and is key in examining scripts of identity (Duffy, 2012). It is the voice of the dominant values, beliefs and attitudes of the culture that are internalized by the person telling a story (Duffy, 2012). Understanding this notion of authorial voice was integral in the data analysis of identity development.

Qualitative Research is Fluid: Deciding on a Narrative Approach

As stated previously, I did not feel comfortable selecting a single approach to address the research question. This was for several reasons specific to the study participants' remaining communication strengths and abilities. The excerpts from the two men in this study were clearly responses reflective of mild dementia. Their responses to questions during data collection were short, focused, and in many instances presented as yes or no answers. Sometimes, participants struggled with word-finding, evident with their need to take long and unusual pauses which is typical with early stage dementia (Rau, 1993). Further, responses also included many digressions and repetitions, also typical of communication challenges associated with early to mid-dementia (Rau, 1993). Prompting was required in order for the participants to stay on topic, explicate their answers, or provide additional details. Talking in abstract terms was often difficult and thus

concrete experiences were easier to explore (Rau, 1993). Each participant identified that they were not able to remember certain accounts from their life due to impairments in both long term and short term memory. Keeping these focused and repetitious responses in mind, it became apparent it would not be appropriate to stay true to one particular narrative approach. For instance, in order to align with Clandinin and Connelly's (2000) narrative inquiry and intent, responses would have to be reflective of temporality, a challenge in this study given participants were not able to recall chronology or logical time progressions due to impaired memory. This approach would be too limiting as it became apparent there was a different sort of depth and richness to the narrative aside from the temporality and chronology. The digression and repetitiveness of the participants' responses would make it difficult to follow Riessman's (1993) approach, which would require longer responses with enough variance in language in order to create poetic structure. Following Lieblich et al.'s (1998) proposed methodological approach in its entirety would also represent significant challenges because narrative themes could not be subjected to analysis for plot and sequence of events. It became apparent that an alternate approach was required.

As a result, the qualitative methodology literature was revisited to understand how to better approach analysis of the data for this study. Denzin and Lincoln (1994) stated that there are no tight categories in qualitative research as there are significant overlapping and commonality between the strategies of inquiry. In all the strategies of inquiry, there is a movement away from locating research within the meanings that people give to their worlds and to rather allow this meaning to emerge (Holliday, 2002). Qualitative methodology is characterized as inductive, emerging and shaped by the researcher's experience in collecting and analyzing the data (Creswell, 2007). Furthermore, it is acceptable for a research question to

change in the middle of a study to reflect better types of questions needed to understand the research question and to reflect the type of data being acquired (Creswell, 2007). After conducting a preliminary analysis of the transcribed interviews (which I will elaborate upon in this chapter), the notion of identity emerged as a strong narrative thread. As such, Duffy's (2012) narrative analysis of identity development was used to further analyze the transcribed data.

Narrative Analysis of Identity Development Description

The notion of identity emerged as a strong narrative thread in the present data from the two men with mild dementia interviewed for this study. As participants spoke to me about their past and present experiences, aspects of their identity (such as having memory loss, being a male, being a minority, and being an older adult) and the social world that they live in revealed themselves through their stories. Stories further revealed an authorial voice, which is the cultural discourse or worldview that influences the shaping of personhood and creation of personal identity (Duffy, 2012). Reflecting on the current negative discourse of dementia, involving older adults in research and analyzing their identity will contribute to the growing cultural movement towards person-centered care. Furthermore, an intersectionality lens allowed me to understand multifaceted aspects of identity such as race, gender and age and how they compound to influence each person's experiences and identity.

Duffy (2012) presented identity development as a form of narrative analysis. Narrative analysis of identity development focuses on how the outside stories of the cultural and social world contribute to the creation of an inside story of the self (Duffy, 2012). In combination with social constructionist viewpoint and an intersectionality lens, the self is understood as relational, dynamic, evolving, and is being constructed, deconstructed and reconstructed in interaction

through multiple roles and relationships with others within the context of one's "social world" (Duffy, 2012). In the following section, I describe how I applied Duffy's (2012) to data analysis.

Narrative Analysis of Identity Development Applied to My Research Study

The proceeding step in the narrative process after data collection included analyzing the gathered data, deconstructing the story for themes and re-telling the narrative from the perspective of the selected method of analysis, which in this case was identity development (Duffy, 2012). After the first interview with participants, I transcribed the audio-recording into scripts. The scripts were read several times to gather a preliminary understanding of each participant's personality and story, as well as to identify areas for further conversation. I also engaged in a conversation about the first interview with my supervisor, discussing areas for further exploration. After the second interview, which also included an activity, audio-recorded data was once again transcribed and I tried to make meaning of the participants' text-based activity outputs. Data analysis entailed several readings of the transcribed interviews and reflection upon the chosen activities.

The narrations on scripts were read for emerging themes loosely based on a thematic content analysis guideline proposed by Braun and Clarke (2006). Thematic analysis was used to identify, analyze and report patterns within data (Braun & Clarke, 2006). I analyzed and made notes of themes (with examples from direct quotes) that were similar and distinct between the participants to organize the findings. Themes were mapped based on the research question, sub-questions and based on participants' stories that resonated for me. The scripts were also read to identify key concepts of resilience based on the resilience framework utilized by Harris (2008). Since stories reveal authorial voice and the social world that one resides in, stories were also read and analyzed to understand if and how these factors have influenced the participant's identities.

In line with the intersectionality lens, stories were further read to understand how each participants' age, gender, race and social class emerged and impacted their narrative.

The notion of identity at first glance appeared to be a distinct theme on its own. However, with closer inspection and in dialogue with my supervisor, identity seemed to emerge as a strong narrative thread *throughout* and played a role in each participant's resilience. After themes were mapped and analyzed, I made drafts of visual diagrams to represent my interpretation of each participant's resilience story, incorporating factors to challenges and resiliencies, and the relationship between resilience and identity. The visual diagram allowed me to summarize and provide a holistic picture of the participants' resilience stories. The visual diagrams and mapped themes are presented in Chapter Four.

The last step in the narrative analysis process was to retell the story, from the perspective of identity development analysis. Analyzing identity development in particular required me to pay attention to how participants have come to believe and perform their identity, to identify interwoven stories and sub-stories that make up their identity, and to understand their connection to the larger social discourse (Duffy, 2012). This understanding was used as a guide to organize and re-tell stories. In re-telling each participants' story, I was also conscious of answering the original research question by illuminating the experience of resilience and challenges.

Researcher Reflexivity

As knowledge and meaning are co-constructed in the narrative process, my presence in the research was an integrated component. My presence was apparent in all aspects of the inquiry, including my initial interest in the research question, my interaction with the participants, the reading and interpretation of the raw data, the data analysis and finally, in how

the results were written up. This presence and moreover, this *awareness* of my position and influence on the research process is known as reflexivity (Etherington, 2004). Qualitative research not only acknowledges that there is a relationship between the researcher, the participants and the actual data that emerges, but that the researcher is also *influenced* by the process of engaging in research (Lamb & Huttlinger, 1989). In a reflexive approach, this reciprocal relationship is recognized and is made explicit for the reader (Lamb & Huttlinger, 1989). This understanding goes back to the notion that in narrative research, meaning is subjective and no one singular reality exists. Instead, meanings are constructed by the researcher based on several factors of one's social position, which includes gender, class, race, ethnicity, and age (Hsiung, 2010).

In order for me to be actively reflexive, it was important for me to critically examine my assumptions, values, biases and prejudices from such positions (Northway, 2000). These considerations affected my interactions with the participants in the study. Growing up, I was socialized to have respect for elders in the community and to believe that by older age alone, one is entitled to be associated with traits such as “wise” and “experienced”. As a result, I found myself instantly addressing the two men as “gentlemen”, in both my writing and my verbal reference to them during meetings with my supervisor and committee members. From my perspective, these comments may represent my awareness of the age gap between us; I felt this natural urge to think highly of them and look up to them. However, I am not immune to societal stereotypes of what it means to “age” as it is usually associated with becoming frail, being alone, and death looming over. It is such stereotypes that urged me to frame a research question that highlighted older adults' diverse voices and stories through a resilience lens.

I am a practicing Muslim who holds similar religious beliefs as Mr. Khan, Mr. Aga and Mrs. Khushu. As a result, I was able to relate to their reliance on faith in their process of meaning-making of their experiences. Further, my own growing interest in religion, spirituality and growth propelled me to understand its role in resilience. I found myself facilitating conversation around the topic of God and Islam not only because it was a strong theme in the participant's narratives, but also because I had a curiosity to understand how others applied faith to their lives and if it actually worked to provide solace. In hearing their stories of challenges and resiliencies, I felt a trigger of strength in me. Reflexivity is also viewed as promoting personal growth and self-actualization (Lamb & Huttlinger, 1989). I agree with Fontana and Frey (1994) that in learning about others we learn about the self. As we treat participants as human beings, we can no longer be "objective", but instead as fellow human beings we disclose ourselves and ultimately learn about ourselves as we try to learn about the other (Fontana & Frey, 1994).

Introspection is key in reflexivity and I found myself engaging in it throughout the research process. Relative to my struggles, I felt that the participants had endured much more hardship in their lives. In hindsight, issues that I felt worried about in my life almost felt *miniscule* in relation and I found myself thinking that "if the participants can live through resettlement, persecution, having a sense of their being lost, and seeing a spouse's health decline, then why can I not resurface from the challenges I myself face? Surely, I could find light in my life experiences." Moreover, it was refreshing to see the crescendo of confidence in each participant's voice when they spoke about faith and God. As each individual spoke, their strength made me question my reliance on faith – "did I believe enough? To what extent do I trust the path that has been chosen for me? Will I ever be at a stage like the participants where I can surrender and make sense of what is happening in my life?"

I pondered on such questions during and after my interaction with the participants, and to this day, sometimes their stories, responses and reactions to adversity echo in me. During the interviews, I was conscious of my surroundings or any aspect of the interview that resonated for me and wrote in a journal before, during and after each interview with the participant of my thoughts and feelings. Reading back on my journal entries, I noted that many of them were reflections of my ability as a researcher. I questioned the way I transitioned from question to question, or how I reacted to participants' answers verbally and non-verbally, and kept track of my emotions throughout. I remember feeling nervous during the first interviews, struggling to find the fine line between my role as a nurse and researcher and not to confuse the two. I constantly asked myself "Am I doing what a 'researcher' is supposed to be doing? What does this title of 'researcher' even entail?" I was concerned about how I carried out the interviews and engaged in reflection on how I could improve for the next meetings with my participants.

Critically examining the research process itself is an example of reflexivity (Maynard, 1994). This process is used to improve research practice through learning, examining the methodological design, and making explicit to the reader how decision making occurred (Northway, 2000). Overall, being reflexive in my abilities was one way to ensure quality of the research process. In fact, engaging in reflexivity is a way to promote rigor in research (Sandelowski, 1986). The transparency of the data is enhanced through "exposing" what is going on the research process and by sharing my values, beliefs and critically analyzing and revealing my social positions (Finlay, 2002).

Being involved in the creative aspect of the research process also helped me to be a reflexive researcher. For instance, I engaged in a word association activity with the first participant, Mr. Khan. For that activity, I wrote out words onto cards from our first interview for

him to either expand upon or for him to choose one word that he found the most appropriate in describing my pre-determined word. Later, he was to arrange the words on the table as he pleased. Upon reflection, I recognized that the words I chose demonstrated my bias and preference in highlighting words that resonated with me. I mitigated this bias as I also chose words that related to the research question and sub-questions, and those that made a reoccurrence in the transcript.

With Mr. Aga and Mrs. Khushu, I also did an art piece with them reflecting on my recent experience of adversity and resilience. I shared with them the experience of losing my paternal grandmother to cancer and how devastating and painful that was for me. I also shared that now I try to reassure myself in that God had done it for her best, it was a part of God's plan and the only way I can show her my love is to continue to pray for her. It felt as though sharing my story helped cultivate a greater connection with participants, especially Mrs. Khushu, who sighed in sympathy and recited a prayer once I told them the story. Mr. Aga listened and nodded. It also allowed the participants to get an insight into my life, so that I did not come off as just the "the researcher" and bridged a relationship in which we could relate to one another's experience of hardship and resilience.

Finally, I practiced creative reflexivity when I chose to create a piece of artwork at the end of each participant's story, demonstrating my researcher interpretation of the data (which are presented in Chapter Five). The images also act as a medium whereby I am able to embody the participant's stories of challenge and resilience, but in a visual form this time. It required me to reflect on several things. In creating the images, I had to put myself in the participant's shoes, while also exploring my own emotions, thoughts, and imagination. Through this reflective process, I was able to be more aware of my position in the research process and create a unique

and personal, creative relationship with the data. Finally, I provide an artistic image of the collective stories I share with the participants, positioned in the Epilogue of this thesis.

Rigor

Duffy (2012) highlights credibility, trustworthiness and transparency as key elements in maintaining rigor in narrative research. This study addressed both credibility and trustworthiness. Credibility and trustworthiness refers to the extent to which participants have been able to reflect upon the study findings (Duffy, 2012) and whether the results are credible from their perspective. Credibility was ensured through member-checking, wherein I recapped some information from the first interview and asked participants if my summary was accurate during the second interview. Mr. Khan in response to the summary replied “yes” (Interview Two) several times while Mr. Aga nodded (Interview Two) in response to my brief summary. Duffy (2012) also describes that the narrative researcher has an obligation to demonstrate transparency; that the researcher needs to explicate all procedures followed in the research process. I have attempted to do this by identifying research questions, disclosing where the research data came from, identifying, and describing the steps in the analysis of the data.

CHAPTER FOUR: RESULTS

In this chapter, I have elaborated on the narratives of the three participants in this study: Mr. Khan, Mr. Aga (aided by Mrs. Khushu) and Mrs. Khushu. Their stories have been reconstructed to best answer the study research question and sub-questions, to reflect the participants' identity development, and highlight aspects of their life that resonated for me while all in all, applying the resilience framework (Harris, 2008) and using an intersectionality lens (Crenshaw, 1991 as cited in Viruell-Fuentes et al., 2012). Following their respective stories, I have presented my reflection and interpretation of the findings. Lastly, I have mapped out the themes of resilience extracted from the participants' narratives.

Narrative One: Mr. Khan's Narrative

Your grief for what you've lost lifts a mirror

Up to where you're bravely working.

Expecting the worst, you look, and instead,

Here's the joyful face you've been wanting to see.

Your hand opens and closes and opens and closes.

If it were always a fist or always stretched open,

you would be paralyzed.

Your deepest presence is in every small contracting and expanding,

*The two as beautifully balanced and coordinated
as birdwings.*

- Rumi, 13th century (Coleman, 2004)

I had the pleasure of meeting Mr. Khan on a cool, but sunny May morning. Mr. Khan was an attendee at the same day program where I once worked several summers ago as a program assistant. As he had been approached by the day program director, I did not have any background information about Mr. Khan. I was curious to see what he would be like and how our interaction would be. Reflecting back on my position as a program assistant, I thoroughly enjoyed getting to know the unique personalities of each senior that summer. I was looking forward to meeting with Mr. Khan that day and wondered if he had been attending the day program (as it was not a dementia-only day program) the summer that I worked as well. I had two meetings with Mr. Khan, with our first meeting being about half an hour with a staff member present for half the conversation and during the last few minutes. Although the staff member was present during the first fifteen minutes of Mr. Khan's first interview, she played no role in the co-construction of knowledge. Rather she translated English to Urdu or Urdu to English for us, as necessary. Moreover, her presence was mainly to ensure Mr. Khan's safety. Once she realized that Mr. Khan was more than capable in conversing in English with me and that he was safe from harm, she left the room and our interview continued. The second meeting with Mr. Khan was almost an hour long with only him and I present. During our second meet, Mr. Khan and I took part in a word association activity.

Meeting Mr. Khan

Upon arriving to the day program, I was introduced to Mr. Khan as he was just about to start light physical activity. He was wearing a grey cardigan, black pants and black sneakers, sitting quietly with other day program attendees in a circle. I approached him and introduced myself. He greeted me with a gentle smile and we shook hands and proceeded to a separate private activity room, led by the staff member who joined us for the first part of our conversation. I was instantly intrigued and drawn to Mr. Khan's calm, gentle manner and further noted the poise and elegance in his voice. He almost reminded me of my own grandfather. We sat across one another at a table, with the staff member sitting next to him. Mr. Khan had his hands clasped in front of him and head slightly lowered, but made eye-contact with me once in a while. Overall, he had the demeanor of a polite and composed man. I set up the audio tape record and we started our conversation.

The Need for a New Beginning

Our conversation started on a light note. Mr. Khan and I conversed about how his day was coming along and how he was feeling at that moment. He stated that he was feeling well. He appeared content and calm sitting there with me, and despite my initial jitters of conducting my first ever research interview, I felt at ease speaking to him, mostly because he seemed at ease as well. He answered questions effortlessly and eagerly. He was not afraid to keep conversation continuing as he asked me if I had further questions for him by stating "*Anything else?*" [Interview One and Two] at the end of a couple of his responses. It was clear to me that he was quite a conversationalist and a people person, especially with his poise and grace in choice of words during the interviews. His word choices were varied and articulate and included words such as "*classification*" [Interview One], "*minority*" [Interview One], "*contradictory*" [Interview

Two], “*collectively*” [Interview Two] and “*phases*” [Interview Two], among other words of complexity.

We began speaking about Mr. Khan’s arrival to Canada and his experience with immigration from Pakistan during which conversation flowed in the direction of his length of stay at the day program. As we spoke about events in the past, he stated he was not exactly able to remember everything. His response exemplifies his polite mannerism and ability to converse in an eloquent manner:

Nafsin: *How long have you been coming to this program?*

Mr. Khan: *This I don’t...my memory you see is...*

Nafsin: *That’s okay, that’s okay...*

Mr. Khan: *My memory is not so sharp so kindly excuse me. (laughs, coughs)*

Nafsin: *That’s okay. It’s nothing you have to apologize for. When you moved to Canada...umm, did you come by yourself or with your family?*

Mr. Khan: *(pause, thinking hard) My memory you see is very, quite tampered now I don’t know. [Interview One]*

In fact, Mr. Khan apologized and explained he could not remember certain details was consistent throughout our conversations. However, as we delved into more conversation during the two interviews, Mr. Khan’s pre and post-migration stories began to unfold. Mr. Khan had arrived about 40 years ago from Pakistan with his wife and children. Despite practicing as a lawyer back home and having a stable income and social standing based on his educational achievement, he stated that his life had not been an easy one in Pakistan. He described his

struggles to me, in a coarse quiet voice different from the content, cool voice we had begun our interview with.

Nafsin: *Can you describe to me how you have adapted to Canadian life? Because your background is Pakistani, correct?*

Mr. Khan: *Actually, there you see (pause), Pakistan was a place where (pause) questions were there. Family questions. Religious questions. Actually, it was the religious problems over there. You see I enjoyed good time in Bhutto's time but after that, then there was classification so we were given a minority. So there was no life. So we not enjoy that life over there. [Interview One]*

As a self-identified religious man of a particular sect of Islam, Mr. Khan and his family faced racial and religious oppression in Pakistan. He described to me that as a religious minority, they were subject to violence and persecution. I noted a soft yet coarse worried tone in his voice as he spoke about his life in Pakistan. He described that people of his particular sect were often treated badly, not being able to feel comfortable in their own homeland due to “*some troubles, some questions, some so small things*” [Interview One]. In our follow-up interview, I further explored Mr. Khan's experience as a minority in Pakistan as I felt that narrative in his life contributed greatly to who and where he is today.

Nafsin: *You had said that there were attacks, or bad things that were happening to the minority.*

Mr. Khan: *Yes, naturally (nods head).*

Nafsin: *What did you witness? What kind of attacks?*

Mr. Khan: *Naturally, it was a different religions, so sometimes religions, political more things because I was in, I should say Bhuto's party, so they were against him also.*

Nafsin: *Whose party?*

Mr. Khan: *Bhuto.*

Nafsin: *Bhuto.*

Mr. Khan: *The leader, he was a very famous leader. So we were enjoying his party also.*

Nafsin: *Mhmm*

Mr. Khan: *So naturally there was a difference of politics, so naturally different ideas, different people.*

Nafsin: *Did you witness any violence?*

Mr. Khan: *Yes, I have witnessed violence also.*

Nafsin: *What kind of violence?*

Mr. Khan: *Religious violence you see...*

Nafsin: *Like was it physical attacks? Fires, bombings...*

Mr. Khan: *Yes, physical attacks.*

Nafsin: *Physical attacks...*

Mr. Khan: *Yes.*

Nafsin: *So, was this on...*

Mr. Khan: *Sometime from groups, small groups they will come to your, I should say locality and they create nuisance.*

Nafsin: *Mhmm and were you, did you -*

Mr. Khan: *And ladies were attacked...*

Nafsin: *Ahh...*

Mr. Khan: *They were feeling much, children were very much (pause, searching for words)*

Nafsin: *Attacked?*

Mr. Khan: *Yes.*

Nafsin: *Were you, were you ever attacked? Or your family?*

Mr. Khan: *No, actually I was a different type of person, I was just enjoying political party. I was, because of this difference we left our country. Otherwise, it was a very simple life.*

Nafsin: *(nods) Right.*

Mr. Khan: *And we were enjoying good life.*

Nafsin: *So you were a part of Bhuto's political party, you were a supporter or you were a part of the party?*

Mr. Khan: *You see different parties I belong to, People's Party.*

Nafsin: *Mhmm.*

Mr. Khan: *Bhuto's party, so naturally there were people against us.*

Nafsin: *Right, so you felt threatened and you had to leave.*

Mr. Khan: *Naturally.* [Interview Two]

Through Mr. Khan's storytelling, images of the oppressive and hostile social world of Pakistan during that time emerged for me. Mr. Khan's identity as a practicing Muslim and his identity associated with his political beliefs intersected to create an even more challenging position for him and his family. The authorial voice was strong in his storytelling to reveal a culture and society that dismissed freedom of choice, but rather instigated fear for those with less power.

During our second interview, I also carried out a word association activity with Mr. Khan, during which I asked him to name three words that described him. In other words, I wanted to know from Mr. Khan's perspective how he identified himself. Mr. Khan acknowledged being persecuted as a significant life event which has come to define who he is. One of the three statements that he described himself by was "*I belonged to [particular sect of Islam] community and faced many difficulties in my country*" [Interview Two]. It was apparent that the hardships he had faced shaped him as the person he is today. As I slowly got to know Mr. Khan bit by bit, I began to realize that his struggles contributed to his resilience and overall contentment with his current life, despite living with dementia.

Mr. Khan identified himself with two other words: "*lawyer*" and "*homeopathic doctor*" [Interview Two]. As he identified himself with his vocational pursuits, it was apparent that Mr. Khan took pride in the work that he did and held those accomplishments close to his heart. When I asked Mr. Khan about his past profession during our first interview, he replied:

Mr. Khan: *Profession. Well, don't ask about the profession. I have gotten everything. I was a practicing lawyer.*

Nafsin: *Okay.*

Mr. Khan: *So I have been doing several cases, criminal cases.*

Nafsin: *There or in Canada?*

Mr. Khan: *High court, Supreme Court...*

Nafsin: *In Canada?*

Mr. Khan: *A little practice.*

Staff: *In what?*

Mr. Khan: *Practice.*

Staff: *As a lawyer?*

Mr. Khan: *As a lawyer. I had another study in homeopathy also.*

Mr. Khan stated that he was involved in cases in the high court and Supreme Court. As he spoke these words his voice became slightly heightened in tone and intensity, reflecting his sense of pride and accomplishment. In his social world in Pakistan, although he was persecuted for his political and religious beliefs, his tone of voice suggested that his status as a lawyer meant that he was able to retain at least some respect from others. Interestingly, despite facing hardship himself in Pakistan, he felt fulfillment in giving back to his community as a lawyer. Although he

held a position of privilege associated with his education and social standing, he tried to use his position in his society to help others who were less fortunate. He explained that:

If they have any difficulties, so I solve that. If somebody's indebted, I will ask them to put such and such bank and get the money, pay lesser interest and pay all dues. Enjoy good life. You have to give the relief to the person, that is the only thing which requires satisfaction. If you are, if relief is suiting you, you enjoy naturally. If you oppose it, you can't do that. That's all. So naturally, the things which are is good. [Interview Two]

The perseverance of also pursuing a career in homeopathy after immigrating to Canada is significant in Mr. Khan's story of resilience. Like many other immigrants moving to a new country where their professional credentials are not recognized, making the shift to a completely different career is quite common. Mr. Khan explained to me how he had to fulfill further education in homeopathy and opened his own naturopathic shop. Pursuing a completely new, unrelated career to law required him to start from the beginning and work hard all over again. That too was accomplished within the conditions of being an ethnic minority, although in addition, this took place in an unfamiliar environment with English as his second language. It was beautiful to see that despite the challenges of starting from the beginning, Mr. Khan had found contentment in his second career, and strongly, and proudly identified with it.

Decision to Migrate as Resilience

The hostile climate in Pakistan was a significant *adversity* that Mr. Khan and his family had to endure. Keeping my research question in mind in regards to resilience, I proceeded to speak to him about how he had faced the particular challenge of oppression.

Nafsin: *Can you describe how they would treat the [sect of Islam] badly?*

Mr. Khan: *Naturally when there are different type of religious people over there, and that is why you don't feel comfortable. Or else some troubles, some questions, some so small things...*

Nafsin: *And how did that make you feel knowing that you were viewed that way?*

Mr. Khan: *We had to face them. So many challenges, so we continue with the time pass over there.*

Nafsin: *So it sounds to me you are saying that whatever the challenge is, just...*

Mr. Khan: *Naturally you have to face the circumstances whatever they are. You can't help it you see, everything is not in your control.*

Nafsin: *Whose control is it in?*

Mr. Khan: *Majority people they carry all these things. But anyhow, whatever time we had in our country it was respectable life. We had a lot of respect over there. [Interview One]*

During our dialogue, there were many instances that revealed Mr. Khan to be a resilient person. It was apparent in his decision to leave his country and seek a completely new life of peace in Canada. Further, Mr. Khan understood the reality of not having full control of his life situations. He acknowledged the need to face challenges as they appeared and to accept them in his life. In wanting to know more about Mr. Khan's challenges, I proceeded to ask him what his most difficult experience has been in life, and, his story of life in Pakistan returned:

Mr. Khan: *Hardest experience you can say...not in Canada but in Pakistan I had some, different community, different subjects, different call. Different, different type of opinions. Different religions. Naturally it is dissatisfaction.*

Nafsin: *How did you solve that problem for yourself?*

Mr. Khan: *I adjusted myself, according to the circumstances. This is how the life was there.* [Interview Two]

There was a pattern in Mr. Khan's resilience; the notion of acceptance and adjustment was prominent in his story. The two traits have allowed Mr. Khan to seek solutions in his life, and has also acted as a catalyst for empowerment. He acknowledged hardship, however has not let it control his life. He flows with the river, not against it. I also noted Mr. Khan's habitual nature in using the word "*naturally*" several times during our conversations; 27 times during our first interview, and 41 times during our second interview. "*Naturally*" [Interview One and Two] flowed effortlessly in dialogue; a term that Mr. Khan did not seem to have to ponder before using it. The significance of the meaning of "*naturally*" coupled with its repetition could possibly demonstrate Mr. Khan's expectation and thereby, acceptance of life taking its "natural" course.

Being Me as Resilience

Mr. Khan's move to Canada while he was in his 30s was a positive life altering event from which he gathered a sense of satisfaction. Unlike many immigrants who lose their social status upon arrival to a new, more developed country, Mr. Khan described that his social status was not affected by the move. When asked, he was not able to recall particular memories of immigrating to Canada and his beginning life post migration. However, he described it to be an overall easy transition upon his move. He explained that he did not require any help from anyone in settling down, and that mentally and physically he was strong. He was able to manage himself.

In contrast to his description of life in Pakistan, Mr. Khan's tone transitioned to that of contentment and feelings of safety as he described his life in Canada. He stated:

It's a peaceful place. (pause) Good people. You are meeting different religious people. And uhh, social people...coming from different places. Naturally we have good time over here. That is why we come over here to pass good time. So that the time should be utilized in a nice place. [Interview One]

Overall, Mr. Khan found a sense of belonging in Canadian society, where he was able to ensure his family's safety without comprising his identity nor his family's collective identity as Pakistani immigrants practicing as Muslims. In large part, his sense of identity came strongly from his feelings of belonging in the present context. As a Canadian citizen, he is able to practice his religion freely. In the beginning, he described that he was able to meet different people and “*enjoy different societies*” [Interview One]. Living in an open, accepting country is a *protective factor* in his experience of discrimination and ultimately aids in his resilience. From his perspective, his social world currently reflects a society that appreciates him for his authentic self.

The day program in itself played an important role in his feeling of belonging and well-being. As he was attending a day program specifically for South Asian older adults, he felt accepted into the environment, yet valued the fact that there are people of different cultures and religions. When asked what he engaged in at the day program, he stated:

Nafsin: *...But at this day program, what kind of activities do you do?*

Mr. Khan: *I come say for four or five days over here. And the rest I stay in the house.*

Nafsin: *(pause, listening to see if Mr. Khan has more to say) So I noticed when I walked in, you were playing carram board.*

Mr. Khan: *Yes.*

Nafsin: *Yea? You enjoy that game?*

Mr. Khan: *Yes, carram board is nice. That's my old game you see.*

Nafsin: *From back home?*

Mr. Khan: *Oh yes.*

Nafsin: *Yea...*

Mr. Khan: *Throughout my life I have been playing this game.*

Nafsin: *And when you play, does it remind you of something?*

Mr. Khan: *What do you mean by reminding?*

Nafsin: *Because you've played throughout your life, does it remind you of your past?*

Mr. Khan: *Oh yea, naturally.*

Nafsin: *Yea...*

Mr. Khan: *The days which I have passed my life, I have, I still remember that. Sometimes I dream that also. (chuckles)*

Nafsin: *(chuckles along). Dream your past life, yea? So, what other activities do you do here? What kind of exercises?*

Mr. Khan: *Uhh many. When I come over here, I do many exercise. I play some games also. I have good talks with my colleagues over here and we have nice time.*

Nafsin: *What do you talk about with your colleagues here?*

Mr. Khan: *Sometime we talk about the politics, sometime we talk about the religion. Sometime we talk about the general things you see, what is happening over here, the games.*

Nafsin: *So your colleagues here, they are all different religions?*

Mr. Khan: *Oh yes, naturally...*

Nafsin: *Yes? So...*

Mr. Khan: *Some are Hindus, some are Sikhs. All communities, and Christian too.*

Nafsin: *When you talk about religion with your colleagues who are of different religions, what...what do you talk about when each person is a different religion? Do you share...*

Mr. Khan: *We share about our beliefs, they tell their beliefs. I tell them my beliefs. And uhh, sometimes incidents of what goes on back home. So that is how we enjoy the good time here. [Interview Two]*

Mr. Khan further explained: *"I think no religion is bad. Every religion gives a way how to live, how to enjoy good life and the social things. The religious, sometimes we also enjoy religious over here. And people come over here"* [Interview Two].

The excerpts from our conversation revealed to me that the day program played a very important role in Mr. Khan's resilience and identity. During our first interview, he even described the day program to be almost like home for him. Mr. Khan valued companionship and the opportunity to share ideas and talk to people; being able to *connect* with others is what makes him happy. His constant phrasing of *"enjoy good time"* in regards to attending the day program illuminated how his participation there plays a positive role in his life. The diverse range of

people that Mr. Khan is able to meet and become friends with is a *protective factor* leading to a positive outcome in living a satisfied life. It is distinctly different from his interactions in Pakistan where he was not able to practice or talk about his religion openly. As an accessible resource in the community, the day program for Mr. Khan is an *asset* to his resilience. Taking part in the day program activities, having the opportunity to speak and become friends with the older adults there have overall become a support system. He further explained:

Actually, here it is very open life. You see, no body too much religious or have contradictory things. They enjoy good, every religion. Here, everybody enjoys each other so you have nothing against anybody. So, that is how we enjoy, collectively. We have our religious practice also and there is nothing wrong. [Interview Two]

You see here it is very open. I can discuss my religion, we can talk about the social life, practical life. There, you see we can't do that. Because, because they are against each other. Naturally, life is not so good there. [Interview Two]

A social world where people “*are against each other*” was not favorable to Mr. Khan. In other words, he did not like anything contradictory and considered such things to be *challenges*. He elaborated by saying:

Mr. Khan: *Contradictory means something opposing my feelings or my habits, everything is fine.*

Nafsin: *So no contradictions in your life right now?*

Mr. Khan: *No I don't. If I feel contradictory, I explain it...and I face it. That's all.*

Nafsin: *Who have you felt contradiction with...in Canada?*

Mr. Khan: *I don't like difference of opinion, sometime. I am making tea, you are taking cold. Naturally there's a difference between the two. So naturally I will go according to my own desire. They give so many things over here, I take only those things which suit me.* [Interview Two]

From the excerpt, it is evident that Mr. Khan had an enriched ability to communicate this notion of contradicting ideas through his explanation and use of an example through an analogy. The excerpt also demonstrates Mr. Khan presenting himself as a confident man who chose to face challenges by knowing his own values and choices and accepting the circumstances based on whatever contradictory thing that may come his way. For him, there is no war, there is no tension. He faces it, and “*that's all*”.

A Journey Led by Faith

Mr. Khan self-identified himself as a religious man whose faith plays a big role in his day to day life. From our conversations, it was apparent that he held religion and God close to his heart, as it provides him a sense of strength and peace. Because his religious beliefs were compromised in Pakistan, his strong sense of faith may have strengthened his decision to leave Pakistan. All in all, Islam helps him face challenges, cope and provides mental satisfaction. In conversing about his experience with losing his wife, he revealed to me how his faith, along with his memory has helped him be resilient:

Nafsin: *If you don't mind me asking, how did your wife pass away?*

Mr. Khan: *(long pause) My wife pass away? She was having some trouble you see. Stomach trouble. So after that she just died that.*

Nafsin: *How did you cope with your loss?*

Khan: *Hmm?*

Nafsin: *How did you cope with your loss?*

Mr. Khan: *See this religious memory things and reciting your (pause) good you see.*

Reciting good events you see. To satisfy yourself. To pacify yourself. [Interview One]

I wanted to understand to what extent religion played in Mr. Khan's current life as he described this coping mechanism from an event in the past. As such, I asked more probing questions in regard to his faith.

Nafsin: *Now you described that you have a strong faith. How does your strong faith help you face challenges?*

Mr. Khan: *(quiet, raspy voice) It gives me help in mental satisfaction. You see naturally when you do all these things, you decide some things, you remember something, you prepare yourself better mentally. Naturally when we go for five time prayers, naturally we pray in my prayers and God gives me help. And I feel a little confidence and pass me good time.*

Nafsin: *What do you mean by God gives you help? In what way?*

Mr. Khan: *(pause) Because the faith is always remembered, helping mentally. You see you are satisfied. If you go for five time prayer in your day, at least five time, you remember the God, all the time which has passed you see. [Interview One]*

Despite having dementia, memory is a binding factor in both Mr. Khan's coping strategies as well as in his faith. Reciting prayers while reminiscing about the past helped him

grieve his wife's loss. Also, I found it very fascinating that while acknowledging and apologizing for his "*tampered*" memory throughout the interviews, Mr. Khan clearly stated that faith and God is *always* remembered, no matter what. His confidence in his ability to remember faith exuded as we spoke. Mr. Khan also felt that his culture was synonymous with his faith and religion:

Nafsin: *Okay. In what way do you think your culture has helped or not helped with you dealing with memory loss?*

Mr. Khan: *You see actually, we people, five time daily we have namaz. Prayer you see. So naturally there is no need of anything else. [Interview One]*

In another instance during our first interview, Mr. Khan told me about his culture, where again religion was highlighted:

Nafsin: *What values has your culture taught you? What are some major values that your culture taught you?*

Mr. Khan: *My culture has taught me the religious you see, mostly. I mean good life, good manners.*

Nafsin: *What does it mean to have a good life in your culture?*

Mr. Khan: *Good life in culture means that I go on Friday prayers, meet with the people. Other places are here, I meet with different type of people over here so naturally I enjoy good life. What else? [Interview One]*

Faith in Islam and God are a major *protective factor* for Mr. Khan. At the end of the day, even if he loses everything else, his religion is there for him. It will always remain the constant in his life, unchanging. Not only does his faith aid in his resilience but it also manifests as a crucial aspect of his identity as we spoke, as he automatically associated his culture with prayer. Further, the fact that faith is *always* remembered suggests its future prominence as Mr. Khan expects to progress in his dementia.

I am not Dementia. Dementia is not me.

Reflecting back on my research question and using the intersectionality lens, I thought it was crucial for me to understand the role that dementia played in Mr. Khan's life. We continued with our conversation in regards to if and how his culture has helped him deal with memory loss:

Nafsin: *How do you think your community reacted to you having dementia?*

Mr. Khan: *We just joined the community, we go there for prayer, join the prayer and just exchange views over there, that's all.*

Nafsin: *Do you feel that people looked at you differently? Or were they accepting?*

Mr. Khan: *Naturally most things accepted you see.*

Nafsin: *Yea?*

Mr. Khan: *Because these things are common with everybody. So naturally you have exchange of ideas.*

Nafsin: *How did your family react to your diagnosis?*

Mr. Khan: *My family is helping me you see. Sometime I visit my youngest son, sometime I live with eldest son. So naturally, my family is enjoying good time with me.* [Interview One]

In contrast to the literature, Mr. Khan did not feel there was any stigma associated with his condition or with him as a person. Instead, he felt like his condition is something that happens amongst most adults as they age. Feelings of inclusion could be due to being active in a seniors' day program where he may encounter other attendees with dementia as well. I believe that as a result of his supportive family and community, Mr. Khan has been able to have a positive self-concept. Throughout our interview, his composure, poise and choice of words reflected that of a man who is comfortable in his own skin. Although Mr. Khan was apologetic in not being able to remember certain details as we spoke, it was apparent that he did not dwell on his diagnosis of dementia, as he only made reference to it when I asked:

Nafsin: *So how did you feel when you got your diagnosis of memory loss?*

Mr. Khan: *(pause) See...that was you see. I was ailing, you see.*

Nafsin: *You were?*

Mr. Khan: *I was sick. That is why my memory was tampered...yes.*

Nafsin: *So how did you, how did that make you feel when you found out about it?*

Mr. Khan: *You see, when it is a question of memory that is which I very little things I remember now. Hardly I can remember my symptoms of the body which I described to the doctor and get the medicines. And that's all.*

Nafsin: *So do you find that this diagnosis has affected your life?*

Mr. Khan: *What?*

Nafsin: *This memory loss. Do you find that it has affected your day to day life?*

Mr. Khan: *Naturally sometimes I ask my sons, my three sons and my one daughter, I ask them if I got something. I ask them in which year this happened. What was at that time? Where we were? Or when you are there, some marriages, some parties. So they just refer all, they help me when I describe these things.* [Interview One]

Despite Mr. Khan's diagnosis of dementia, he did not let it define him. It was not a part of *his* own identity. Instead, he considered himself to be a healthy person, stating that he "*enjoy a good life*" [Interview One]. He maintained his health by attending the day program and also maintained his health at home. He stated that "*both places are good*" for him. When I asked him to further elaborate on how he maintained his health at home, he stated: "*At home, you see, rest, enjoy, eating, drinking, sleeping and also performing my religious activities. That's all*" [Interview Two].

Reflecting on the importance of Mr. Khan's personhood and his resilience, I wanted to explore more of his self-concept.

Nafsin: *Would you describe yourself as a strong person?*

Mr. Khan: *Yes, I can control myself. Strength is there mentally you see. You don't forget absolutely everything. Remember some things, sometimes you forget something but the memory is good and health is good. Yea, so.*

Nafsin: *Now you describe that when you would remember your past life as you are sleeping, you said you would join this and join that. What do you mean by that? What did you join?*

Mr. Khan: *The ideas coming you see, if you are not sleeping, you remember where I was, what happened at that time. My wife was alive we had good time, then all my sons got separated and now the life went on. So you, sometimes memorize all these things you see by in what happened. In which there for some time, two years there, three years there, four years there, all we visited different places. Travelled over there. [Interview One]*

In Mr. Khan's perspective, his memory and overall health are facets in his life that he felt contentment with. In fact, Mr. Khan described utilizing his memory to help him cope (for instance reminiscing about the moments shared with his wife) as well with his biggest stressor in life - the inability to fall asleep:

Nafsin: *Can you tell me what causes the most stress in your life?*

Mr. Khan: *Hmm?*

Nafsin: *What causes the most stress in your life?*

Mr. Khan: *Stress...when I don't sleep. Naturally, mind goes remembering the things. Hardly I can get three hours, four hours sleep.*

Nafsin: *When you say your mind goes remembering things, what do you start to remember?*

Mr. Khan: *When you are not sleeping, you see naturally, you are waking all the time and recording starts and what happened at that time over there in that country and then we pass over here and we join this and join this, we met so many people, religious people, particular people, ruling people over here. And then after all this place, remembering these people that's there, also having company over here. Passing good time, that's all.*

[Interview One]

Rather than being a negative aspect in his life, memory was viewed as an *asset*. Memory helped him to reminisce old times until he could fall asleep. While acknowledging that his memory is an asset to his identity, and that the loss of memory is commonly associated with aging in the popular discourse, I wanted to explore what aging meant to Mr. Khan.

Nafsin: *How do you feel about aging?*

Mr. Khan: *(quizzical look)*

Nafsin: *Aging...what does that mean to you? Getting older...*

Mr. Khan: *I don't feel so much....some, some loss of memory sometime.* [Interview Two]

We delved into more conversation regarding living with memory loss. As I reflected back on working with many patients who are not happy with their quality of life due to ill health, I was curious to know if Mr. Khan had felt any self-pity or loss as a result of his diagnosis. I asked him if he experienced any loss or grief about memory loss, whether it made him sad. He responded:

Mr. Khan: *No...there some death of people I feel sad sometimes. See you can't forget your parents, you can't forget your wife and uhh otherwise, children are here. So, I don't feel any loss.*

Nafsin: *Do you feel any loss about losing your memory, having dementia?*

Mr. Khan: *(shakes head) No...no...*

Nafsin: *Is that something you have accepted?*

Mr. Khan: *I am satisfied.* [Interview Two]

Living a Life of Satisfaction

The word “*satisfaction*” played a prominent role in our conversation. In our interview conversation, Mr. Khan said the words, “*satisfaction*”, “*satisfy*”, and “*satisfied*” a total of 29 times. The reoccurrence of this word may have special significance to his identity. To Mr. Khan, being satisfied meant to be content and there were many aspects of Mr. Khan’s life from which he got a sense of satisfaction. As Mr. Khan and I engaged in our word association activity during our second meeting, “*satisfy*” is his response four times overall, making a noticeable appearance among other words (see Figure 1). The layout of his words can also be found typed out in Appendix H for greater visual clarity.

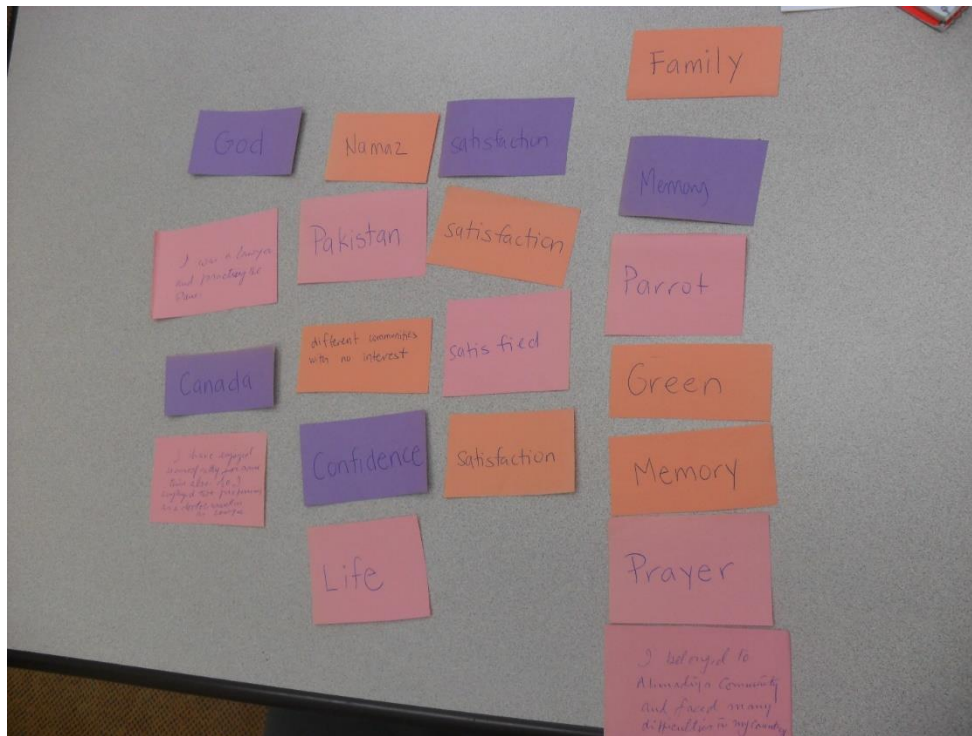


Figure 1. Mr. Khan's Word Activity Layout

Upon reflecting on our first conversation and transcript, there were certain words and themes that stood out to me. They were words that I felt played an important role in Mr. Khan's life and triggered an interest in me to understand more. Thus, in preparation for our second meeting, I put together word cards and incorporated them into our conversation. His response of "satisfaction" all related to God, Canada, Family and Life. Interestingly, when I asked about "memory", he simply stated: "Memory is...memory" [Interview Two]. It did not play a significant role in his life, as he did not have a positive nor negative association with it. The words I had written and his responses were laid out on the table and he organized them into a 'poetic structure', as the picture displays in Figure 1.

As noted in the picture above, the importance of "family" stood out to me during our first conversation. According to Mr. Khan, he has a loving supportive relationship with his family.

Before our second interview, as I sat in the parking lot of the day program, I noticed Mr. Khan being dropped off by someone driving a van. He was entering the building and I think he noticed me. As I walked toward the building, the man inside the van smiled at me and asked if I worked there. I had a strong feeling that was Mr. Khan's son. I told him I was the Master's research student interviewing his father. He gave me a friendly smile and laughed. He told me that I could call him anytime if I had any questions for him about his father. He handed me his business card, telling me he is also a financial broker and to contact him if I need any help with buying a house. I gave him a thank you for signing the consent form as well. He spoke to me about how he drops his father off at the day program so he does not feel alone and that it keeps him busy. He explained that he and his family have been trying their best in encouraging him to stay active.

It was apparent that Mr. Khan's family played a major supportive role in his life not only from my encounter with Mr. Khan's son, but from my conversation with Mr. Khan himself. Mr. Khan described he has a good relationship with his family where he stated that he is respected and that they "*enjoy good time together*" [Interview One]. His positive relationship with his family and supportive children act as both *protective factors* and an *asset* in Mr. Khan's health. We spoke about his relationship with his children which he stated: "*It's good. We have good relations. And in all the family, they respect me. We enjoy good time, sit together and exchange good ideas. I play with their children, they also very good. And having good time.*" [Interview Two].

Despite Mr. Khan's early struggles of living under oppression, he currently lives a life of "*satisfaction*". When asked if there are current stressors in his life, he referred to his inability to fall asleep sometimes. When this happens, he stated that he tried to remember memories from the past and slowly he is able to fall asleep. He also felt he did not get enough sleep as he woke up at

dawn to pray. Otherwise, he stated that there was no other challenge or *adversity* in his current life.

Overall, Mr. Khan is a resilient man. He was able to accept that he does not have control over situations and faces them for whatever they are. He has adjusted himself to the situation if it is “*contradictory*” to his beliefs and found a balance between his needs and the constraints he faces. Ironically, the facets of his culture and social world have both been a challenge to him while providing a sense of hope. Living under persecution in Pakistan compromised his identity as a practicing Muslim, yet it is the religion in itself that gives him “*confidence*”. As for living with mild dementia, he did not perceive it to be a negative aspect of his life as he found support and solace all around him. There are several protective factors that aid Mr. Khan in living a life of “*satisfaction*”, including his belief in God, his family, the day program and living in an accepting and open society. His resilient *outcome* is “*satisfaction*”, which from our conversations it was apparent that he lives at peace knowing that he has “*satisfaction*” in many aspects of life.

My Reflection and Interpretation of Mr. Khan's Narrative



Figure 2. My Reflection and Interpretation of Mr. Khan's Narrative

In reflecting on Mr. Khan's story, I drew my interpretation of his voice in the above picture. From my perspective, the image is a metaphor for Mr. Khan's narrative, representing, in my opinion, the two major phases of his life. The bird represents Mr. Khan. It leaves its cage hanging on a tree, wherein the cage symbolizes a place where the bird's freedom and identity (the ability to fly) is compromised. The cage hangs on a tree which represents Mr. Khan's social world in Pakistan. It is a place he wants to escape as it is confining and *contradictory*. The bird flies freely to a new tree where, where sits a nest, his new home. In this new home, he can be truer to his identity and practice his religion without restriction. The notion of dementia is neither explicit nor implicit in this image as I felt as though the condition was not prominent in Mr.

Khan's narrative nor a major part of his identity. Instead, the authorial voice was his life transition in moving from his homeland to his new home in Canada.

Narrative Two: Mr. Aga's Narrative with the aid of Mrs. Khushu

Study me as much as you like

you will not know me

for I differ in a hundred ways from what you see me to be

Put yourself behind my eyes and see me as I see myself

for I have chosen to dwell in a place

you cannot see

— Rumi, 13th century (Coleman, 2004)

After my interviews with Mr. Khan, I had the delight of speaking with Mr. Aga and his wife, Mrs. Khushu. Their interviews were arranged by a day program coordinator at a different senior's day program from Mr. Khan's, in the greater Toronto area. The day program coordinator advised me that it would be best to include Mr. Aga's wife in the conversations to assist in comprehension and in translations. The coordinator may have also felt it was necessary to have Mr. Aga's wife in the interview to ensure that as an outsider, I did not pose any harm to Mr. Aga. Acknowledging the duality of Mrs. Khushu's role in the interview, I agreed to speak to both participants despite my prior set inclusion criteria. I had originally intended to interview dyads consisting of a person living with dementia and their caregiver but day program staff indicated that family caregivers have obligations and work responsibilities that might make them difficult to recruit. Mrs. Khushu's interest in supporting and facilitating her husband's participation in the

study included being present and offering opinions and ideas that were relevant. She was highly committed to having Mr. Aga be the primary participant so that his voice was heard. The couples' mother tongue was Gujarati and Mrs. Khushu assisted in translation and clarification as necessary as well as contributed her own experience and insight in regards to Mr. Aga, their shared life and her experience as caregiver. I had two meetings with Mr. Aga and Mrs. Khushu. Our first meeting was about forty minutes long and the second meeting was about fifty minutes long. In this section, I present Mr. Aga's story first, in which his accounts have been organized to demonstrate his identity development. Following that, I provide a focus on Mrs. Khushu's story as her narratives not only filled in gaps in some of Mr. Aga's stories, they also enriched my understanding of the integrated and interwoven life of Mr. Aga and Mrs. Khushu.

Meeting Mr. Aga and Mrs. Khushu

It was a cloudy spring morning the day of our first scheduled meeting. Overall, I was feeling down due to a personal matter and my mood mimicked the dreary weather. On my way to the given address of the day program, I was stuck in traffic so I frantically drove in hopes to make it in time for our meeting. Following the driving instructions on my GPS, I drove into what looked like a complex of townhomes. There was no sight of a day program, just houses. It did not help that by this point it started to rain heavily. The unit number I was given ended up being a house, so I was terribly confused. I figured that it would not hurt to knock on the door and inquire about a possible day program in the area. The man who opened the door had a warm and inviting demeanor to him and provided me driving directions to the community center, which sat in the middle of the housing complex.

I drove to the community center, parked and walked into what looked more like a management building. I walked down the hall and to my right was a room. Inside was what

looked like an activity room with a couple of staff. I introduced myself to the staff, including the man who I had corresponded with over e-mail. After I was welcomed to settle down, he went upstairs to bring Mr. Aga and Mrs. Khushu. When they came downstairs, Mr. Aga's wife led the way. She was wearing coffee-colored pants, an orange full-sleeved shirt and a brown hijab (scarf covering her head). She had an inviting, warm aura about her, with soft wrinkles and a glowing smile on her face. She approached me to shake my hand. Her husband followed behind her, taking small, quiet steps. Mr. Aga had a self-contained demeanor to him. He was wearing black pants and a blue, striped collared shirt. His head was lowered, but he looked up at me to give me a gentle smile and I shook his hand.

I invited them to sit across from me at a table in the activity room. They both wore name tags. I took notice to Mr. Aga's name and complimented him on his name which sounded very unique to me. Mrs. Khushu explained that his name meant, "sabr", which translates to *patience*. That word, "sabr", strongly resonated within me. I instantly thought of the negative experience I was facing at that time. I had been undergoing a healing process myself, educating myself on the practice of Islam and how and if being spiritual would help me cope. I had even set my computer desktop to a quote that I had conditioned myself to memorize. It stated: "Sabr is more than patience...It's also accepting your situation as God's will. Sabr is the strength of your soul. It teaches you to not break when you've been bent..." In Islam, the notion of patience is key, with the fundamental understanding that Allah (God) has a greater plan and that He does everything for a reason. He does everything for *your* benefit, either for this life or the Hereafter. As a practicing Muslim who is striving to become more spiritual, I had been trying to practice sabr myself. All of a sudden, I felt a connection with this man who was otherwise a stranger to me.

As I began to speak to Mr. Aga, it became apparent that he was at a later stage of mild dementia in comparison to that of Mr. Khan. His speech was slower, a little slurred, he had a hard time putting some words to his thoughts and for the most part, could not elaborate on ideas to a great degree. I tried my best to engage Mr. Aga and ask him questions that would help us co-construct stories. As a participant, Mrs. Khushu helped to bridge any communication gaps between Mr. Aga and I. She actively facilitated and encouraged her husband to speak and be more open, while she also spoke about her experiences of being by her husband's side. She described him as a quiet man and that it would take him some time to get comfortable with me. When she stated this, I told Mr. Aga that I am very much the same and that I hoped he would become comfortable enough to speak with me.

Life in Canada: Getting up on two feet

To segue into our interview, we reviewed and signed the consent form first and foremost. In starting the interview, I attempted to delve into questions about Mr. Aga's experience with immigration. At times, he appeared somewhat indifferent during the interview, and would stare at the table that sat between us. He conversed with me to a lesser degree as compared to Mr. Khan. He was more inclined to speak when he received encouragement from his wife. He did not decline to offer comment, rather, he did not seem able to speak spontaneously. Rather, verbal exchange was dependent on the initial facilitation of the person with whom he was most comfortable and familiar (his wife). Although Mr. Aga was not very verbal during the interview, I did not feel the need to end the interview. There were instances when Mr. Aga was quite engaged in our talk, speaking to his wife in Gujrati or asking her questions for clarification. Mr. Aga did not display any protest behavior such as an unhappy face, rigid posture, or shaking of the head that indicated that he no longer wished to participate. Further, I also looked for any

signs of him being coerced by his wife, such as her persistence or force in him answering questions. Taking all these into consideration and utilizing my ethical judgment, I continued with the interviews.

In conversation with both of them, I learned that Mr. Aga and his wife have been residing in Canada for over 40 years. They emigrated from Iran along with their young son. Although they were settled in Iran for about seven years prior to their move, Mr. Aga was born in Dar es Salaam, Tanzania and his parents were born in India. Recognizing that he may have several cultural backgrounds, I asked him what cultural background he would associate with himself the most, to which he responded: *"Background...I don't know. I would say Africa."* [Interview One].

His wife continued to clarify the question for him and he self-identified that his cultural background also included the fact that he was a Muslim and Indian. Reflecting on Mr. Khan's significance of having to leave Pakistan, I wanted to explore the same for Mr. Aga during our first meet.

Nafsin: *Okay, okay. So, what did, what made you move to Canada?*

(long pause, no response, he sits staring at the table)

Nafsin: *Why did you move to Canada?*

Mr. Aga: *Because I like Canada, you know.*

Nafsin: *How did you learn about it?*

Mr. Aga: *I...uhh...used to hear from friend of mine.*

Nafsin: *Mhmm.*

Mr. Aga: *Canada is good.*

Nafsin: *Mhmm (nods). Were there any reasons as to why you left back home? Umm...did you move to Canada simply because you wanted a better life or was there something back home that was, you were not happy with perhaps.*

Mr. Aga: *I was okay (looks back down at the table)*

Nafsin: *Yea?*

Mrs. Khushu: *Ah, we were doing very well in Iran.*

Nafsin: *Mhmm*

Mrs. Khushu: *But uhh, my husband when he was studying in England. (turns to husband) You were studying in England? (speaks in Gujarati)*

Mr. Aga: *(responds in Gujarati)*

Mrs. Khushu: *She wants to know everything about it. You were studying in England and you went to visit America and Canada. (speaks in Gujarati)*

Mr. Aga: *She knows.*

Mrs. Khushu: *She doesn't know, she doesn't know. She wants to know a little bit about you.*

Nafsin: *I want to know about your life, your stories –*

Mrs. Khushu: *She wants to hear, she wants to know something about your story. [Interview One]*

In terms of moving to Canada, Mr. Aga expressed that he had no regrets with his move and his wife added that they were happy living here. I asked Mr. Aga if it was an easy transition

upon migration when he and his family first moved to Toronto. He described that it was “*not really easy but it was okay. I was used to it by then*” [Interview One]. He explained it was a “*troublesome*” experience, that “*It’s not very easy, like Africa. And I was used to it*” [Interview One].

It was apparent to me that Mr. Aga was finding it difficult to elaborate on his words, thus I tried my best in asking for clarification. His wife assisted in elaborating and I came to understand that their biggest struggle was financial. He had some support from friends in which he was able to secure a job and help provide for his family. His wife explained that Mr. Aga’s brother had come to Canada before them and were a source of support before they could get on their own two feet. Mr. Aga explains, “*In Canada, I was very happy with the job and all this. But I knew people...that says okay come on don’t worry...*” [Interview One].

Mr. Aga’s social circle had provided him a sense of reassurance and gave him the confidence that he would be okay. They were a *protective factor* for him in the past. Thus, I thought it might be important to explore his current supports, as such resources play a huge role in one’s resilience according to the literature. In fact, external supports were integral to Mr. Aga’s life. They included the day program as a resource, his family and most importantly, his wife. They all contributed to his health, well-being and overall resilience. Throughout our two meetings, we were able to delve deeper into these *protective factors*.

Almost losing Hope

During the interview, a *risk factor* that Mr. Aga expressed facing was his declining health and the subsequent affects it has had on his mental and emotional well-being. His memory loss

was evident during our conversations, as he had a difficult time recalling when he received a diagnosis of dementia:

Nafsin: *So, how long ago did you umm, get your diagnosis of memory loss?*

Mr. Aga: *That we got it in Dar-e-salam.*

Mrs. Khushu: *(explains to him in Gujarati)*

Mr. Aga: *(mumbles something in Gujarati to his wife) 10-15 years?*

Mrs. Khushu: *(further explains in Gujarati to him)*

Mr. Aga: *Ten years ago.*

Mrs. Khushu: *Three years ago. One of my uhh, his nephew came from Vancouver, and he could not recognize him. He could not recognize him. So he told his (Mr. Aga's) son that I think your dad is uhh getting some kind of problems. So my son said why don't you take him to our family doctor. And we took him to our family doctor and the family doctor requested we see a neurologist...or is it, I'm not sure. Neph -Neurologist I think. And got him to (pause) question him a few things. And on the spot, he stopped him from driving.*

Nafsin: *Mhmm.*

Mrs. Khushu: *And that really took everything off, took all his spirits, even put him into big time depression.*

Nafsin: *Mhmm*

Mrs. Khushu: *And after that, things started hitting hard (talks to him Gujarati).*

Mr. Aga: *Yap. [Interview One]*

I looked at Mr. Aga as his wife explained the story of his diagnosis. The moment she mentioned that the doctor revoked his driver's license, I noted the frown on Mr. Aga's face, his brows furrowed and arms crossed on his chest. The fact that Mr. Aga was hit hard by the experience was apparent, as his expression spoke for itself. I proceeded to explore his feelings from that significant experience.

Nafsin: *Mr. Aga, can you tell me what it felt like when the doctor told you, "You couldn't drive anymore"?*

Mr. Aga: *(arms crossed, his face looking at the table and head shaking side to side gently, speaking more to himself than to me) But I don't know why, I don't, I do not understand...*

Nafsin: *Why he told you that, you don't understand?*

Mr. Aga: *(mumbles words under his breath)*

Nafsin: *He didn't say what?*

Mr. Aga: *To get information to run the test, but he didn't say that.*

Mrs. Khushu: *He didn't give him a second opinion.*

Nafsin: *Mm, okay. And how did that make you feel?*

Mr. Aga: *I still can't drive.*

Nafsin: *But how does that make you feel when the doctor told you that?*

Mr. Aga: *I didn't like it but what can I do.*

Nafsin: *Right...*

Mr. Aga: *Thank God she is driving now, to help me.* [Interview One]

Although the event occurred years ago, it was clear that Mr. Aga was not over the fact that a second opinion was not taken, and that he himself was not given a second chance before losing his license. Although Mr. Aga acknowledged and was thankful for his wife driving him now, there still remained a sense of pain in his voice. As we continued to speak about other topics, the thought of losing his license still bothered Mr. Aga. We were having a conversation regarding Mr. Aga's independence, during which he reverted back to the experience of losing his license in the middle of the conversation. He stated: *"I can't agree when I go there...for the license plate"* [Interview One]. His wife proceeded to explain:

You see, it's bothering you. It hit him hard. So, he's not saying it right now. But he was very, very upset at the way the doctor treated him. The doctor, tell him, he didn't have his glasses, he made him write things, I didn't know we had to take hearing aids. He's not wearing it right now. We didn't take his hearing aids and on the spot he just failed. He didn't give him another chance. He just stopped. Right now you are not going to drive and that's it. That was unfortunate. He won't talk. Most of the time he would cry. And he just wanted to stay in bed. [Interview One]

The experience of losing his driver's license played a pivotal role in both Mr. Aga and Mrs. Khushu's story of resilience. From Mr. Aga's reaction, it was apparent that the act of driving was given immense importance in his social world. In many ways, driving in today's society is associated with a sense of strength, independence and moreover, masculinity. For Mr. Aga, driving may be related to his identity and role as a man and therefore, as a husband who has the ability to provide for his family. Without driving, he was unable to be free, to take care of himself. All in all, it compromised his identity as a self-sufficient person. Furthermore, the

sudden way in which he lost his license denounced his abilities as a capable person and devalued his personhood. Losing the ability to drive was a *risk factor* in determining a positive outcome in his life and had a further domino effect on the rest of his life. It may have made him feel powerless. For Mrs. Khushu, the event was a defining moment in their relationship which tested their resilience as a couple. She experienced a role transition to becoming his driver, both literally and figuratively.

Upon reflecting on the first interview, I felt that Mr. Aga's story of losing his license required me to delve deeper. Thus, for our second interview, I decided to help facilitate an art-based activity that would help me understand his resilience in regards to that life-altering event. Seeing as though verbal communication became difficult for him at times, in conversation with my thesis supervisor, we thought it would be appropriate for me to facilitate an activity.

During our second interview about two weeks later at the same location, there were still some instances when Mr. Aga seemed disinterested in conversing. Again, his wife played a key role in facilitating the discussion between us. When I introduced the activity near the end of the second interview, Mr. Aga expressed he was not very interested in doing any artwork himself. I had intended on carrying out a creative activity on paper that entailed the use of different colors, textures, and materials. I laid out an array of arts and craft supplies on the table; however, Mr. Aga did not reach for any item. To be honest, I was a little disappointed that he did not partake in the planned activity as I thought it would allow more creative depth and meaning. However, I was in no position to coerce him to take part. In introducing the activity, I asked him to divide the paper in two, with one side elaborating how he felt losing his license three years ago and on the other side, elaborating how he currently felt about it. Mrs. Khushu instead wrote down points

as he spoke about his resilience. His work is displayed below, comparing how he felt losing his license three years ago to how he feels now in Figure 3.

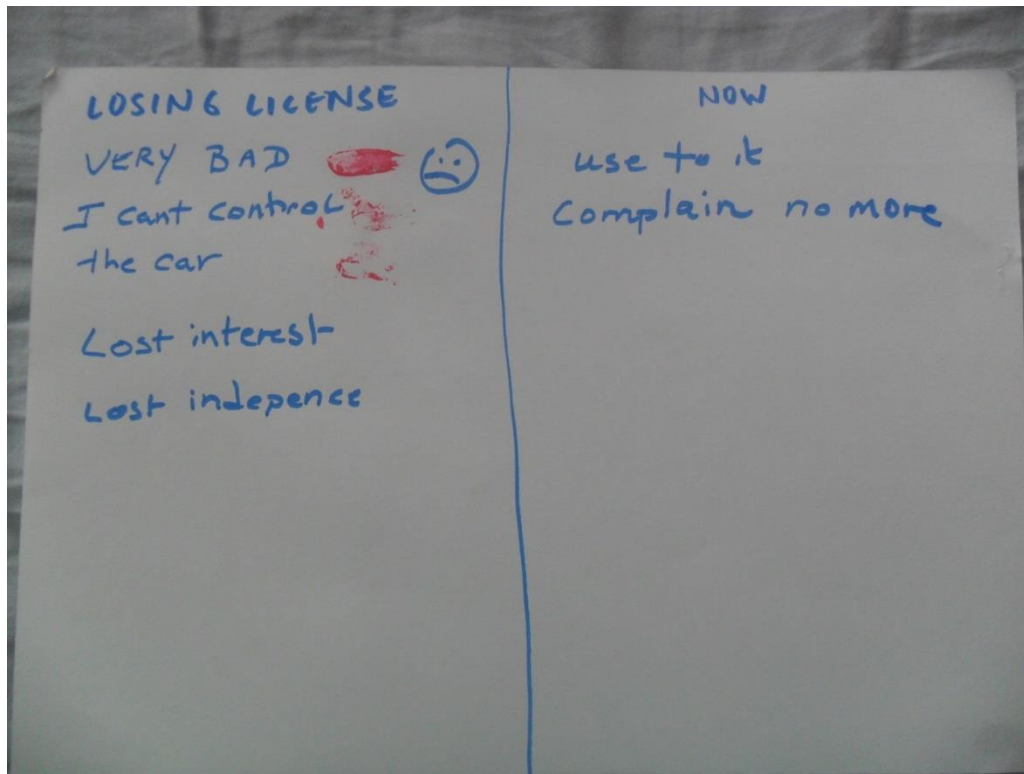


Figure 3. Mr. Aga's Reflective Text (as aided by Mrs. Khushu)

In comparing his past and present feelings of losing his license, Mr. Khan has been able to be resilient in his own way. In explaining his artwork facilitated by his wife, he stated that three years ago: *"I feel very bad...that I can't control my car. Control my car because I can't drive my car"* [Interview Two]. This notion of control is important, as control over his car may signify the ability to have control over the rest of his life.

We conversed about how he currently felt about the losing his license compared with his feelings three years ago.

Nafsin: *Okay. Okay, how about right now, how you currently feel right now?*

Mrs. Khushu: *(speaks Gujarati) How do you feel now?*

Mr. Aga: *I'm used to it now...*

Nafsin: *So how, what do you mean you're used to it? How have you come to terms with it?*

Mr. Aga: *I don't complain to the license people.*

Nafsin: *You don't complain to the license people...okay...Have you accepted this situation in your life?*

Mr. Aga: *I uhh don't want to accept it...but there's no way I can accept it.*

Nafsin: *Do...Does a part of you think it happened for the best?*

Mr. Aga: *Hmm?*

Nafsin: *Does a part of you think it happened for the best?*

Mr. Aga: *(shakes head) Not really.*

Nafsin: *No? Not at all?*

Mr. Aga: *(shakes head, is quiet)*

Mrs. Khushu: *No, I think it happened for the better. Now I accept it. Pehla (which means 'before'), I thought 'no' but now I agree. Because –*

Mr. Aga: *(interjects, uses a teasing voice, but with a hint of sarcasm) Because she drive my car, that's why.*

Nafsin: *(chuckles) [Interview Two]*

Although losing his license was something he has gotten “*used to*”, he has not accepted it. Mr. Aga may not have ‘bounced back’ according to the traditional definition of resilience, but there were elements to him that suggested he has at least tried to become accustomed to what happened, by stating that he is at least “*used to it*” now. In the aforementioned dialogue, there is also a glimpse of Mr. Aga’s ability to use humour, suggesting he is more in the direction of ‘bouncing back’ rather than towards the end of bleakness.

The diagnosis of dementia in itself did not severely impact Mr. Aga from his perspective. During our conversation, he never made reference to memory loss himself. Through our conversation, memory loss for him was almost insignificant. He did not *identify* with it. Instead, the experience of losing his driver’s license became the defining moment of diagnosis, rather than the diagnosis itself. For Mr. Aga, dementia may have been a *risk factor* in his resilience but it was not seen as the *adversity*. It was a *risk factor* for it impacted the perceived negative outcome of losing his driver’s license. The *adversity* instead was the experience of losing his license. He did not dwell on the diagnosis, rather the implication it has had on his life.

Finding Comfort in Marriage

As a result of losing his driver’s license, Mrs. Khushu became Mr. Aga’s driver, both literally and metaphorically. She has been a major support for him and his resilience. This is apparent in many ways including the content of her story-telling, her presence during the two meetings and the love that exuded from her as she spoke to him and last but not least, her expressed gratitude in being able to participate in the study, in that she hoped it would benefit her husband and others like him. That Mr. Aga has come to terms with this, somewhat is evident in the teasing tone he used when Mrs. Khushu stated that she thinks the decision was for the best.

He himself may not have embraced this notion, but he acknowledged that he understood that the change in his licensure did have benefits for her.

Mrs. Khushu acknowledged the decline in health that her husband faced and thus, explained how she tried her best in keeping him healthy. She stated that most of the time Mr. Aga wanted to sleep at home, which she was not happy about. As a result, she has gotten him to join the day program to help keep him active. She was concerned that Mr. Aga may otherwise be going into bouts of depression due to his inactivity. She stated:

I take him downstairs to have fresh air because with the weather right now, good but he won't stay. I have a feeling, partially, he is partial, I haven't told the doctor anything about it, but I think he's got a little bit of depression. Touch of depression. I think. But I'm getting it out of him because I am taking him everywhere. There's [name of day program] and uhh dialysis. So he's not – and if we are home, let's say the day we have nothing, I take him to the mall. So he, that he gets a chance to go out- [Interview Two]

Mrs. Khushu was understanding and took full responsibility of her new caregiver role. She knew that she played a pivotal role in Mr. Aga's life and has tried her best to be supportive. She was a clear *protective factor* as well as an *asset* in his resilience. As his mental well-being started to decline, she almost helped mold his life so he could gain and maintain a healthy identity by being engaged outside the home. She encouraged him, gave him a sense of strength and stood beside him no matter what. For instance, she also came to the day program three times a week with him as a participant. Having worked at a day program for a little while, I had never witnessed a caregiver accompany a person living with dementia for the full day. Normally, day programs are meant to be respite for caregivers and this was my first time seeing a caregiver

participate as well. Mrs. Khushu described finding purpose and meaning in being with Mr. Aga at the day program and her stay there was an extension of her identity as a caregiver. She stated:

Because if I'm not here, then he doesn't have anybody else and if I go then he might go a little out of the way and I don't want that. And I have to make sure that he is under control, I mean he's not aggressive or anything but let's say we have to monitor his drink because with dialysis their drinking is very limited and uhh what he will do is uhh get up and start helping people and he won't sit steady...this is one thing, he has a weak point. He just wants to be all the time up. But at home, when he's at home, he doesn't want to sit and watch t.v too long...So he'll watch then he'll, I think it's also his energy level is low. But I don't know whether I am doing that, but I think people with dialysis they have a lot of less energy. [Interview Two]

Although Mrs. Khushu exuded a nurturing demeanor, she rightfully acknowledged that she needed respite as well. She expressed that all five of her weekdays were busy accompanying Mr. Khan to dialysis and the day program. She confessed she would appreciate having a little break as well. She had been negotiating her caregiver role with her need for social well-being as well. She explained that she also enjoyed coming to the day program, liked to take part in activities and enjoyed meeting others. She stated: *"Forget everything else, whatever is bothering you, you forget. Here you just concentrating on make the best of every moment you have. You enjoy it."* [Interview Two].

Attending the day program acted as a *protective factor* for both Mr. Aga and Mrs. Khushu. For Mr. Aga, it is a place he enjoys coming to meet and talk to others. Nearing the end of both interviews, Mr. Aga was eager to go back upstairs and continue with the activities, getting nervous that our meeting would interfere. For Mrs. Khushu, the day program allowed her

to feel fulfilled in her caregiver role while maintaining a sense of belonging and connection in the community.

A touching observation I made was that not only did Mrs. Khushu devote herself to her husband, but their love for one another was most definitely reciprocal. Mr. Aga knew that his wife played a very important role in his life and was thankful to her in many ways. It was moving to see him recall on how they first met while blushing and with a big smile on his face: *“My father told me, this is the girl, she’s very nice. I said okay, I went...I went to where she was, and I got married right away.”* [Interview Two].

Upon hearing this, I noted Mrs. Khushu was smiling and blushing as well. He described his relationship with his wife as *“very nice”* and stated with a smile *“If I am not married with her, then I will repent. She...she’s very good”* [Interview Two]. Although he was not happy about losing his ability to drive, he appreciated that his wife has become his driver in many respects.

Keeping Faith at Heart

A significant factor for both Mr. Aga and Mrs. Khushu’s resilience was their strong faith. Remembering how much of an impact faith had on Mr. Khan’s resilience, I was curious to know whether and how faith played a role in their lives. To segue from our conversation on culture, I asked Mr. Aga if religion was a big part of his culture, he responded: *“Yup, by my religion is uhh...I go to mosque, I do everything there and I pray there and I go home. That was good.”* [Interview One]. I inquired if he continued to take part in his religious activities, to which his wife responded:

He does my dear. He loves it. My son keeps telling me continue it, but it's getting harder now. He loves that place. He likes serving. Even up here, he won't sit, he will help everybody if their ball falls, if they want drinks, they want their tables or something.

[Interview One]

By the “*place*”, she referred to him to him loving the mosque, where it not only serves him as a place of worship but also a place to serve others, which he also loves dearly. She explained to me that he also has an inner desire to pray. One of the five mandatory prayers is to be done right after sunrise, which requires one to wake up during a night's sleep. Mr. Aga has held on to this desire. Mrs. Khushu explained:

Oh yes, at four o'clock in the morning, I mean, coming at night from the mosque at 10:30, and to wake up at 4 o'clock, people would say forget it, but he says no he will get up right away to say his prayers. [Interview Two]

Being connected to faith was a *protective factor* to Mr. Aga, providing him with a sense of hope and strength. In dealing with challenges and to acquire mental strength, his dependence on God was apparent:

Nafsin: *Yea? So what gives you the sense of umm mental strength that you will be okay? What supports you in thinking that?*

Mr. Aga: *Well they tell me, don't say anything you are okay. If you have a problem, let me know and we will get it done.*

Mrs. Khushu: *(speaks in Gujrati)*

Mr. Aga: *Yea...God help me.*

Nafsin: *God help you? How does God help you?*

Mr. Aga: *Because I pray to God, and God say okay, we get it done, don't worry about it. We get it done.*

Nafsin: *Mhmm. So you put your faith and trust in him and that everything will be okay, right? Is that, is that what you mean?*

Mr. Aga: *(Nods)*

Nafsin: *Okay, how else does religion play into your life?*

(long pause, no response)

Nafsin: *Can you expand on how else religion plays into your life?*

Mrs. Khushu: *(explains to him in Gujarati)*

Mr. Aga: *Musulman is the truth.*

Mrs. Khushu: *True religion...*

Mr. Aga: *Truth, truth. If you have a problem, they help you.* [Interview Two]

Mr. Khan expressed knowing he could rely on a greater existence to help him through the trying times and that eventually things will be okay. He acknowledged that he may be vulnerable at times but at end of the day he will be alright because God is there for him, no matter what. Mr. Aga's dependency is more prominent now compared to the past. If he had a problem in the past, he "*used to finish it, and that's all*" [Interview Two]. Now, he acknowledges that he can "*handle by somebody helping, somebody will help me*" [Interview Two]. It is important to highlight that he is not a *completely* dependent person. There remains a sense of determination in him. When

he faces a problem, he only requires some help but does not require one to do everything for him. Mr. Aga acknowledged that he will need some help but ultimately a challenging situation will be overcome. Even when it comes to his kidney disease, he explained that the illness does not bring him mentally down. He remains resilient and refers to the illness and says: “*they try, but they can't*” [Interview Two].

The Struggle between Inclusion and Exclusion

Similarly, there are aspects of Mr. Aga's life that do not hold him mentally down that would otherwise bother others. Reflecting on the literature and the negative social discourse of dementia, I wanted to explore how others in Mr. Aga and Mrs. Khushu's community have reacted to Mr. Aga's memory loss.

Nafsin: *In what way do you think your culture, either your religion or the country you have come from, has helped or not helped with dealing with your diagnosis? Is there...what I mean by that, is there any sort of stigma related to umm memory loss in your culture do you find? How have people reacted to...*

Mrs. Khushu: *They ignore him...*

Nafsin: *They ignore him..*

Mrs. Khushu: *Big time. Big time.*

Nafsin: *Mmmm*

Mrs. Khushu: *(quiet voice) It's very sad (starts to tear up)*

(long pause)

Nafsin: *Do you want some Kleenex?*

Mrs. Khushu: *(speaks Gujrati to her husband, I am able to pick up a few words like 'friends' at the 'masjid' as my mother tongue, Bangla has some similarities to Gujrati)*

Mr. Aga: *They won't some of them they won't.*

Nafsin: *So they have changed, after knowing that, after knowing that -*

Mrs. Khushu: *When you cry, you cry alone. When you laugh, everybody is around you. Same with if you are poor, nobody is with you, if you're rich...it's like bees all around you. (quiet voice) That's how it is...*

Nafsin: *Has everyone reacted this way?*

Mrs. Khushu: *Everyone, I don't understand what you mean?*

Nafsin: *Everyone in your community. Has there been some supportive people?*

Mrs. Khushu: *A few...*

Nafsin: *Few...*

Mrs. Khushu: *This one guy who used to come here, he's right now, he's gone on holidays...wonderful.*

Nafsin: *But these are people at the masjid who are thinking this way.*

Mrs. Khushu: *(nods)*

Nafsin: *That's unfortunate because -*

Mrs. Khushu: *And yet at dialysis, there are people that are sooo cooperative...*

Nafsin: *Hmmmm. Do you think there's a lack of understanding of, of the condition in your, in the community –*

Mrs. Khushu: *I think so –*

Nafsin: *Or they don't really know?*

Mrs. Khushu: *I think so. Because they haven't come across something like that or they don't know who's gonna be hit hard again because this is becoming a very, very uhh fast spreading...*

Nafsin: *Mhmmm*

Mrs. Khushu: *...illness.*

Nafsin: *And how does it make you feel Mr. Aga when these people that were once your friends and colleagues, umm how does it make you feel when they choose to ignore you?*

Mr. Aga: *Ummm, I used to it, so I don't say nothing to them.*

Mrs. Khushu: *It doesn't bother him.*

Nafsin: *It doesn't bother you....but it bothers seeing him?*

Mrs. Khushu: *Yea. It bothers me.*

Nafsin: *It bothers you seeing him....how about your extended family. How have they reacted?*

Mrs. Khushu: *I don't have extended, I just have one son and two grandchildren. And they have accepted it but they are really...worried as day goes by, as time goes by. And my son is doing into all this research and all that. And he's saying it's something that we*

really have to really put up with it, keep active, push him to do things and that's how we are going on, and day by day we leave it in the hands of God because He's the one that gives each one a test and trials. [Interview One]

Those around them that were once supportive have distanced themselves as Mr. Aga's health began to change. His memory loss has affected the collective perceived identity of Mr. Aga and Mrs. Khushu as a couple. Seeing her husband being marginalized created a lot of pain for Mrs. Khushu. Mr. Aga however stated that he was not bothered by this. In fact, he did not even feel left out by his community. His diagnosis and perceived identity by others had affected Mrs. Khushu more than it had affected him. Thus, being marginalized is neither a *protective factor* nor *risk factor* from the perspective of Mr. Aga. For him, it appeared insignificant.

Lending a Hand

Despite how others may view Mr. Khan, his focus has been on being able to help others in his community, both at the day program and at the mosque. When I asked him to describe himself during our second interview, he stated that people like him and he enjoys helping others. His sense of self and identity came from him feeling purposeful and his ability to help others. He believed there are people who are worse off and they may need his help. He stated, "*Well some people they don't have food, some people they don't have something to eat, I like to help them*" [Interview Two]. Seeing that there are those who are less fortunate than him on a gradient signified a positive self-perception. Being able to help others became almost a job for him and was a motivation to attend the day program as well as the mosque (even if that may be a place where others may "*ignore*" him). Mrs. Khushu explained that Mr. Aga loves going to the mosque, not only to pray but to help others:

But uhhh my son gave me that little bit of a push saying that since Papa likes to go to mosque, don't refrain him. don't refrain him because he is enjoying, like he said he likes to help that are more handicapped, even if he can't take a glass of water, I've got some feedback that he will take a glass, even if his hands are shaking but he will make sure take water, he'll take the you know to take the things – prayer mat and all that to them. So I don't want to take everything away from him because I've taken a lot away from him. So by doing this, this is the thing that I would feel very much disappointed because he loves to do that... [Interview Two]

Mrs. Khushu added that “...the mosque says he himself needs help, and yet he likes to help, he feels good about” [Interview Two].

Mr. Khan found meaning and purpose in helping those around him. Although aspects of his social world may reject him, he did not fear it but rather went about doing what he thinks is right. In this sense, he is resilient against the *risk factor* of marginalization.

The Plea for More Support

Mrs. Khushu recognized the important role that the mosque played in Mr. Aga's life. She expressed wanting to be able to take him every day but even when she does, there seems to be a barrier even if she were accompany him every day. She stated:

He wants to go to the mosque every day. I can't be there because partition – ladies are separate, men are separate. So I had to call the uhh chairperson from the guys' side. I said, 'Is it possible, is it possible for you to keep an eye on him'? He said to me 'how can I keep on an eye on him when I have so many responsibilities? But I will try and see if I can get one of the volunteers to try and see if they can keep an eye' keep an eye on him

and see, you know don't go over drink or you know he's limited now – when we got home and I asked him, 'are you okay'? he said I was comfortable, he never got a chance to say anything more. So, right now I don't know how, where I can start out that people like this, maybe he's not the only one, might be more – more feeble people, more people in his condition which could get some help...outside, let's say in the mosque. Because if you want to go there, he loves the mosque. If there were a few, there are so many volunteers, keep just a few...specifically for feeble people that are you know, in need. Little bit of, just a support, you know kind of uhh push or something that they can, that they are comfortable, they're happy, they wanna come more often. I want that. [Interview Two]

In large part, going to the mosque was a *protective factor* for Mr. Khan's resilience and his overall well-being. Not only is it a place of worship that symbolizes his desire to maintain a connection with God, but it also allowed him the opportunity to serve others. Mrs. Khushu recognizes this a *protective factor* for Mr. Aga and wanted to ensure that it remained a place he can continue to find meaning in.

Mr. Aga's resilience has been tested in many ways. Most notably, losing his license has been a major *adversity* that he has faced. Although it has been in result of getting his dementia diagnosis three years ago, Mr. Aga did not lament about memory loss in particular during the interview. Rather, his frustrations revolved around losing his license and subsequently, his independence which impaired his identity. Furthermore, Mr. Aga and Mrs. Khushu's collective identity has been compromised based on how some people in their community stigmatize Mr. Aga. Mr. Aga, however has not taken this to heart and negates this aspect by continuing to find meaning in other parts of his life such as serving others and keeping his inner faith in Islam. Mrs. Khushu on the other hand was saddened about the lack of empathy from some people in her

community, but she has continued to play an integral role in Mr. Khan's resilience. She helps him navigate through health resources and provides unconditional support in a loving marriage that is reciprocal. However, Mr. Aga's health status has a subsequent negative result on Mrs. Khushu's own well-being and self-care. In relation to challenges, Mr. Aga's perception of his own resilience is to "*get used to*" circumstances and that God will ultimately take care of him. Mr. Aga's resilience story is multifaceted and with both internal and external factors that aid him to reach his resilient *outcome* of getting "*used to*" circumstances.

Narrative Three: Mrs. Khushu's Narrative

The intent of the research was to gain an understanding of the challenges and resiliencies of South Asian older adults living with mild dementia. However, the fluidity of qualitative research interpretive paradigm acknowledges and embraces emerging data. Mrs. Khushu's presence in the study was exactly that – she was an emerging, unexpected presence in the research study and she provided an important dimension to the research. Although initially expected to simply accompany Mr. Aga, her voice in the interviews provided rich narratives. Not only did she represent a *protective factor* for Mr. Aga and contributed to his sense of identity, her story-telling revealed many aspects of "their" interconnected social world and *her* identity began to unfold as well.

Mrs. Khushu's personality exuded warmth and compassion from the moment she entered the room. Throughout the interviews, she shared a deep, loving concern for her husband and his well-being. It was apparent that her world more or less revolved around Mr. Aga. There was no denying that the context of the interview and the interview questions in itself may have highlighted this aspect of her identity as his caregiver, but in hearing about her concerns, her day to day routines and seeing her overwhelming sadness in response to some people's ignorance of

his condition, it was apparent that Mrs. Khushu identity has been molded by her husband's life. From several of her excerpts, it was evident that Mr. Aga's needs and well-being took precedence over her needs and her well-being.

The self-sacrificing behaviors that Mrs. Khushu exhibits is not uncommon for female caregivers who are older adults. It is almost an *expected* trait for female caregivers to give up their identity for the sake of their partner's, reflecting the unequal distribution of responsibilities based on gender roles that prevails in society. Moreover, I come from a culture wherein patriarchy is prevalent and could see aspects of Mrs. Khushu's self-sacrificing behaviors as reflections of my own mother, grandmother, and aunt. As such, Mrs. Khushu's new-found role as the "driver" in the relationship may have two different implications. Being the driver can signify her independence and new found liberation. She is able to be the "leader", the one who now Mr. Aga must depend on in the husband-wife relationship. At the same time though however, she is at risk for losing her self-hood as most of her time is consumed by looking after Mr. Aga and driving responsibilities most likely involve tasks related to Mr. Aga's care. Thus, having the "privilege" of being the "driver" as a matriarch has two contradictory meanings that propels the never ending cycle of Mrs. Khushu's role as a "devoted" caregiver. In hearing her stories, I noted that there was a strong association of her identity as Mr. Aga's caregiver. Her social world comprised of environments where she had been preoccupied looking after her husband. This included caring for him at home, accompanying and monitoring him at the day program, taking him to the dialysis clinic and taking him to the mosque. As a result, her own selfhood may be at stake, and her narratives highlight a critical question of who, then, takes care of the caregiver?

Although Mrs. Khushu's life in recent years had been preoccupied in taking care of Mr. Aga, it is highly possible that she found meaning and purpose in being able to look after her husband. During the interview, she did not express any out right frustration or annoyance with taking care of Mr. Aga. Instead, she showed a genuine interest in the research study and was always encouraging her husband to speak for himself rather than depend on her. However, while she was the medium through which Mr. Aga expressed himself, her own distinct voice had also emerged. It seemed as though she wanted his voice to be heard and for him to no longer be someone who is 'ignored'. She had even suggested that the second interview take place between he and I only. Furthermore, Mrs. Khushu expressed her gratitude in that I was there, interested in Mr. Aga's experiences and was there to listen to their concerns:

So this is what I – now when I came to know through [staff member] that you are going to, that you are going to, you are one of the ones that are in this project, I was very happy about it. I said at least, if it's not at the mosque, it's somebody that is going to, that is looking into things! And I really, something and I said to [staff member], 'this is something really wonderful!' It is somebody. God sent, I feel as it is God sent that there is somebody that is going to do something about it and Insha'Allah things will be better. You know life is very, busy but um... [Interview Two]

Listening to Mrs. Kushus's genuine interest and sense of hope was refreshing. Her concern demonstrated a sincere desire to improve Mr. Aga's life, not for her sake or her burden, but more so for *his* sake. Hearing her words also instilled a new found purpose in me. I felt as a researcher, what I had aimed to understand was not only important because the 'literature' deemed it to be, but because the need for being valued and recognition were coming from real participants themselves. I also noticed Mrs. Khushu's response which was full of relief and

appreciation in how *God* had sent someone. Her excerpt demonstrated that she, just like Mr. Aga and Mr. Khan previously, has put her reliance on faith.

The comfort that God provided Mrs. Khushu was also apparent in the art activity that she took part in and helped to facilitate in with Mr. Aga and I. I asked her to reflect on an event that was a defining moment in her and Mr. Aga's relationship, which tested their resilience as a couple. Figure 4 is what she had written.

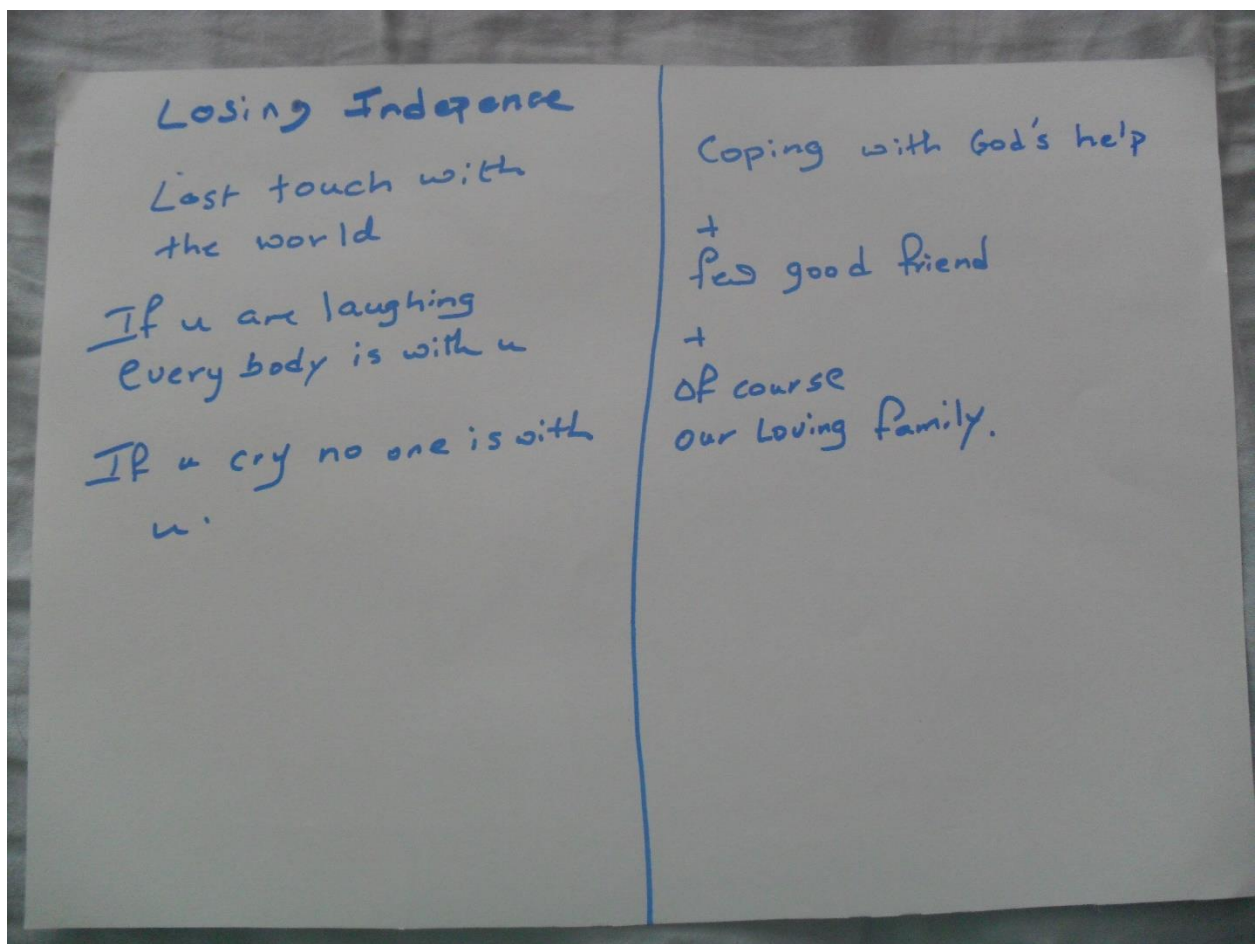


Figure 4. Mrs. Khushu's Reflective Text

She explained:

Mrs. Khushu: *I'm not so good at pictures*

Nafsin: *That's okay, it doesn't have to be a picture or it could be colours or –*

Mrs. Khushu: *(while writing she states) Losing independence and also...umm...lost touch with the world. You might ask me how, lost touch with the world...it's if you are laughing, if you are laughing, everybody is with you. Everybody is with you. If you cry, no one is with you.*

Nafsin: *(nods) I remember you used that quote last time*

Mrs. Khushu: *no one is with you...okay. *speaks gujrati*. Okay, on the other side you said, how do you cope with it. Okay...coping with God's help. With God's help. And few good friends and of course...*

**Mr. Aga interjects and speaks in Gujarati* [Interview Two]*

Mrs. Khushu had made the comment “*If you are laughing, everyone is with you. When you cry, no one is with you*” not once, but twice during our interviews. The repetition, the content and emotive powers of her words signified the extent to which her life has changed since Mr. Aga's ailing conditions. Seeing him lose independence was an *adversity* for Mrs. Khushu, but she herself was able to be resilient by seeking God's help, with family and good friends. However, this does not change the fact that Mrs. Khushu lives in a social world where she and her husband are still misunderstood, ignored and left out. Mrs. Khushu experienced associated stigma with Mr. Aga's condition and she internalized others' misinformed responses to him. Despite her gratitude, willingness to take on the 'driver' role in their marriage and the loving concern for her husband, there was no denying that pain resided in her life. Her voice in the interviews cried for more support and respite as a caregiver, while also advocating for more

recognition and value for people like her husband in the community, and empathy for their caregivers.

My Reflection and Interpretation of Mr. Aga and Mrs. Khushu's Narratives



Figure 5. My Reflection and Interpretation of Mr. Aga and Mrs. Khushu's Narratives

The image above is my interpretation of Mr. Aga and Mrs. Khushu's story. From my perspective, the image is a collective metaphor for both Mr. Aga and Mrs. Khushu's life. As losing the privilege of driving was a defining moment in Mr. Aga's life and subsequently in Mrs. Khushu's life, I wanted to highlight its importance through depicting their story with two vehicles. My intention was not to objectify the participants, but rather to demonstrate a visual comparison. The truck hauling the blue truck represents Mrs. Khushu, who is the guiding force

for the left truck, representing Mr. Aga. The right truck is the left truck's GPS and support. Although the blue truck cannot "drive" on its own and requires help, its integral identity of hauling other trucks remains intact, which is a metaphor for Mr. Aga's altruistic nature. The tire on the road represents how a piece of Mr. Aga's identity is lost, however the wrench and nail next to it portrays the car's potential to be repaired. I believe that although Mr. Aga's identity has been compromised as a result of losing his license, he has not completely lost himself. There is potential for sustenance in other parts of his life and can help him remain resilient, such as fostering his need to continue being a helper and facilitating access for his full participation at mosque.

Mapping the Themes of Resilience

The narratives in this study reflect unique identities and stories of resilience of two older adults who have accumulated different life experiences. As each man navigated their social world, they faced varying situations, struggles, as well as facets of life that brought meaning and joy. Albeit the two men have unique stories to tell, they shared similar aspects of living with mild stage dementia in their storied narratives of challenge and resilience. Four major themes were identified among their narratives. According to these men, resilience meant 1) having a strong sense of faith, 2) having supports that improve quality of life, 3) having purpose and meaningful worth, and 4) coming to their own terms with limited "control". Although these themes were evident in both participants' lives, each theme shaped resilience in varying degrees for the individuals, while some factors were more prominent for one man than the other.

As I listened to each participant's narratives, their identities began to unfold. Their past life events, the environment that surrounds them now and their current life with mild dementia mold who they are. My findings suggest that their resilience and identities work together in

tandem to create an *outcome* of resilience that is unique to each man. Identity and resilience work synonymously, like two gears complimenting one another. Resilience to challenges signifies facets of each man's identity while it is in essence, their sense of identities that allow them to face challenges. The narratives reveal that identities were also *fluid* for each man, never constant but changing as they found themselves in different situations or environments. Further, identities may have been a reflection of what the social world imposed on them. However, to what degree the two men took ownership of such traits varied. In either case, their identities either helped or hindered their resilience. The four major themes of 1) having a strong sense of faith, 2) having supports that improve quality of life, 3) having purpose and self-worth, and 4) coming to their own terms with limited "control" contributed to resilience and identity to create an outcome that equates to a unique degree of resilience for each participant.

Below are two visuals displaying the relationships between identity, resilience, its contributing factors, and outcome for each man. Each contributing factor's size correlates with how much of an impact it has on each man's resilience. Figure 6 is a depiction of Mr. Khan's resilience story while Figure 7 is a depiction of Mr. Aga's resilience story.



Figure 6. Mr. Khan's Resilience Story

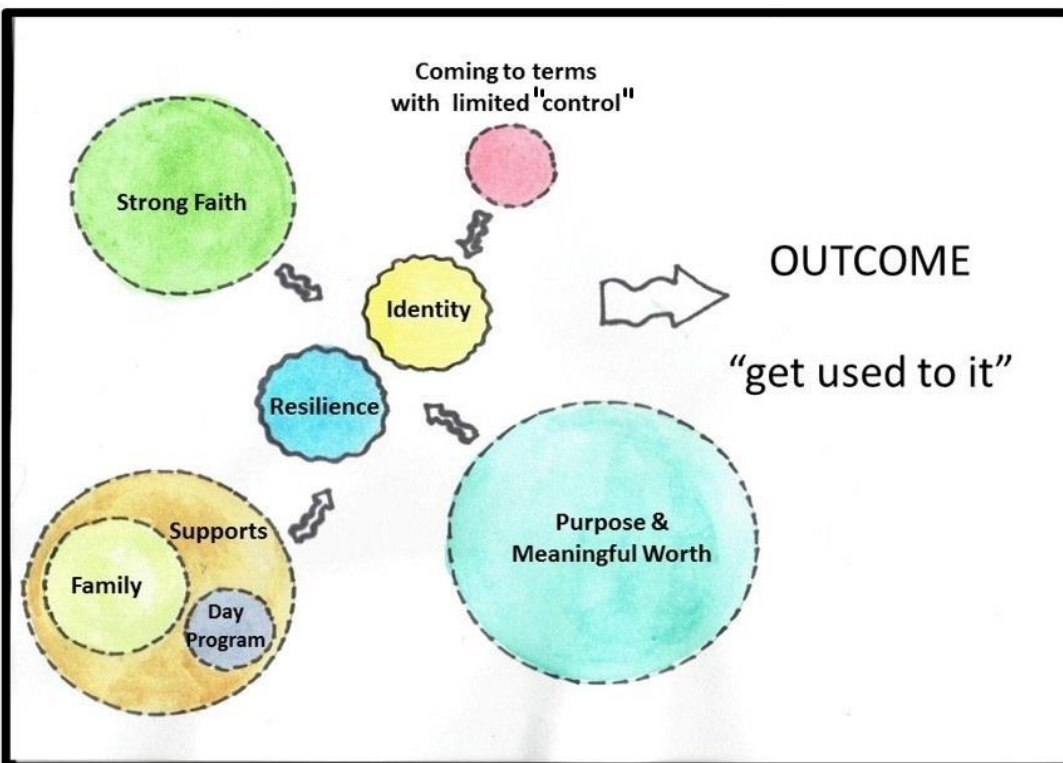


Figure 7. Mr. Aga's Resilience Story (with facilitation from Mrs. Khushu)

For Mr. Khan, “*satisfaction*” was significant in his story of resilience. Not only had he mentioned the word 29 times in our interview, but it made a prominent appearance during the word activity. In related facets of his life, being fulfilled and content equated to being “satisfied”. It is the complete opposite of what he considers a challenge, which is something that is contradictory to him. For Mr. Aga on the other hand, the notion of *getting used to* a circumstance was a reoccurring theme in his story. As evident from the diagrams, diagnosis of dementia was not relevant in the participant’s resilience story. Having a dementia diagnosis did not affect the participant’s self-perception of being able to be resilient, nor was dementia on its own viewed as an *adversity* to overcome for participants. Rather, the contributing factors in relation to resilience and identity in the diagrams relate to resilience in general. I will be explicating as to how these factors have contributed to their unique resilient outcomes.

Purpose and Meaningful Worth

Finding meaningful worth played a strong role in resilience. For Mr. Aga in particular, being able to serve those less fortunate provided him a sense of purpose. It also allowed him to put life into perspective. On a continuum, he did not consider having conditions of dementia and kidney disease as detrimental as there are people less fortunate than him and may need *his* help. Having meaningful worth was also a core part of his identity, as he chose to describe himself by his service to others. For Mr. Khan on the other hand, altruism did not play as prominent a role in his resilience story, but there were some elements of it in his past. As a lawyer back home, Mr. Khan provided his services to those less fortunate who would require legal assistance. He explained that when you give relief to that person, then this is what leads to “*satisfaction*”. Although this is a past event, Mr. Khan in the present context acknowledged that giving to others

is a meaningful experience that gives “*satisfaction*”. Otherwise, although not directly helping in an action oriented sense, Mr. Khan found meaningful worth in providing advice and guidance to his children and grandchildren. It has allowed him to have a stronger relationship with them as well as garner their respect. In serving others, each man was able maintain human connection whether it is with their near and dear ones or if is for someone whom they can expect nothing in return.

Having a Strong Sense of Faith

Faith was central to each participant’s story of resilience and also largely contributed to their identity. Having a belief in a greater existence acted as a *protective factor* which allowed these men to seek help from God in order to either surface in times of adversity or at least help them cope with situations. They believed that God listened and subsequently gave confidence and strength. For instance, Mr. Khan explained that God gave him mental satisfaction and that above all, faith is always remembered. Regardless of memory being impaired, faith is *always* remembered. Mr. Aga felt similarly in that he admitted that God helped him because he prayed to Him, after which God reassured him that He will take care of Mr. Aga and the situation.

It is not only the belief in God but actively practicing Islam that gave meaning to each man. Prayer in particular was an integral part of both participant’s lives. It is an emotion-focused coping style utilized by both men to help reduce negative emotional responses such as losing hope. For Mr. Khan, prayer was a daily routine as he did not miss any of his five daily timed prayers. This included the prayer at early morning even though it disrupted his already troubled sleep. Mrs. Khushu expressed that Mr. Aga is always keen to wake up early in the morning, even if it’s four a.m to get up and pray. Further, Mr. Aga expressed that he loves going to the mosque and his wife Mrs. Khushu acknowledged it to be important to his well-being. In Islam, a

fundamental belief is that the purpose of life is to worship Allah. Another core belief is that life is predestined and every hardship in life is a test of faith. Such beliefs may help foster feelings of purpose, hope and a sense of safety (knowing that everything is in God's control) for Mr. Khan and Mr. Aga.

Supports that Improve Quality of Life

There were two major supports that aided as *assets* in the participants' resilience. First and foremost, family provided a sense of love, assistance and encouragement for persons living with dementia. For Mr. Khan, his relationship with his children and grandchildren resulted in "*satisfaction*". They maintained respect for Mr. Khan and have supported him as his dementia progressed. He appreciated that he has been active outside the home because of his family's support in taking him where he desires. For Mr. Aga, his relationship with Mrs. Khushu was essential to his resilience. She encouraged him to be active and it is her support that allowed him to enjoy other aspects of life such as the mosque and attending the day program. She brought joy to his life from the day he met her and they continue to have a good relationship according to Mr. Aga. Further, he has a loving relationship with his grandchildren and expressed that they love him very much, with a smile on his face. Having the knowledge that one is loved and will be taken care of positively contributed to the men's resilience.

The second support in the participants' lives are the day programs. As the day programs were sites of recruitment, the examination of its impact on resilience and living with dementia was inevitable. For both participants, the day programs have had a positive impact on their lives. It provided a sense of belonging, a solution for social isolation, and a place to keep the mind and body active. Both day programs were South Asian culture specific (such that they provided cultural foods, celebrated cultural holidays, had designated time for prayers), which may have

also added to the sense of belonging. For Mr. Khan, the day program had become almost like home to him, where he enjoys coming and meeting different people and sharing ideas. He was grateful because he could simply be himself. For Mr. Aga on the other hand, although he was a little bit more quiet, he expressed that he enjoyed attending and taking part in activities. More so, the day program allowed him to do what he loves to do, which is to serve others that he feels may be unfortunate.

Coming to Terms with Limited “Control”

One’s perception in regards to having control played a significant role in resilience. Accepting that one did not have control over their situation acted as a *protective factor* for resilience, while not being able to accept this notion acted a *risk factor*. Each man in this study had a distinct perception of control. Mr. Khan had come to terms with not being able to control everything in his life and in response he could face circumstances. For Mr. Khan, control also equated to having strength. When asked if he considers himself a strong person, he replied by stating: “*Yes, I can control myself*” [Interview One]. For Mr. Aga, his biggest sense of control came from his ability to drive. As a result of losing his license, he lost a big chunk of his well-being and identity. Moreover, his independence was compromised and the ability to have control in other aspects of his life was taken away as a result of not being able to “*control*” [Interview Two] his car. Although this event occurred three years ago, he had not accepted it in his life. Throughout the interview, he interjected several times asking if he could still go to the license center to ask for permission in getting his license back. As a result of not being able to accept that he did not have control over the event of losing his license, he became emotionally and physically torn. He did not accept the situation, and continued to dwell on it until he “gets used to it”. In comparing the two men’s perception of control, Mr. Khan’s ability to easily accept not

having control is represented as a larger circle while Mr. Aga's is represented as a smaller circle as he found it more difficult to accept the adversity that has occurred in his life.

CHAPTER FIVE

This being human is a guest house

Every morning is a new arrival

A joy, a depression, a meanness, some momentary awareness

comes as an unexpected visitor...

Welcome and entertain them all

Treat each guest honorably

The dark thought, the shame, the malice, meet them at the door laughing, and invite them in

Be grateful for whoever comes,

because each has been sent as a guide from beyond.

- Rumi, 13th century (Coleman, 2004)

Discussion

The notion of identity and the four themes of resilience that were emergent in the participant's narratives will be further explored in the context of the current theoretical literature. As demonstrated in Mr. Khan and Mr. Aga's Resilience Story diagrams, the four themes of resilience: 1) having purpose and meaningful worth, 2) having a strong sense of faith, 3) having supports that improve quality of life, and 4) coming to terms with limited "control" also highlight each participant's identity. The purpose of this discussion is to demonstrate how these findings contribute to the existing literature, and how the new and unique findings from this study can also inform our interaction with South Asian immigrant older adults living with mild dementia. The discussion is guided by the resilience framework (Harris, 2008) and through an intersectionality lens (Crenshaw, 1991 as cited in Viruell-Fuentes et al., 2012). The discussion also revisits the negative discourse of dementia and demonstrates how this study and its findings stray away from that discourse. Finally, at the end of this chapter, the strengths and limitations of this study will be presented.

Identity and Resilience in Persons Living with Dementia

Identity as an emergent narrative thread helped guide the narrative analysis in both men's stories (Duffy, 2012) and its emergence resonated with the purpose of narrative analysis, which was to reveal identity and social realities through story-telling (Lieblich et al., 1998). The unique findings of this study are that both participants demonstrated a capacity for a sustained "self" which was intertwined with features of their resilience. This identity emerged through their story-telling of challenges and resilience and their overall presence (both verbal and non-verbal) interaction during the interviews. Aspects of the men's narratives are reflective of existing literature that has aimed to understand identity and selfhood in the context of dementia. Likewise, most studies aiming to understand identity and selfhood in the literature explore subjective accounts from persons living with dementia and demonstrate that selfhood is maintained in varying stages of dementia (Basting, 2003; Beard, 2004; Gillies & Johnston, 2004; Sabat, 2002). These existing studies in addition to this study demonstrate that the self is more than memory.

Mr. Khan and Mr. Aga's identities emerged regardless of their inability to remember the details of their past. Similarly, in an analysis of three autobiographies written by persons with dementia by Basting (2003), the autobiography authors did not rely heavily on memory to define who they were and currently are. They shared their unique experiences which ranged from receiving the diagnosis, living with the condition with a fighting spirit, as well as describing how God has played a helping role in their journey. Overall, they exemplified that self is more than memory as their writings do not rely heavily on memory to define who they were and who they are (Basting, 2003). Similarly, both Mr. Khan and Mr. Aga did not define themselves by their dementia. For them, the experience of memory loss was subjectively neutral. It did not define

who they are nor was it seen as a negative turning point in their lives that they chose to dwell on. Indeed, the self is more than memory in a person with mild stage dementia.

An enlightening finding from this study was that despite the fact that the two men live with dementia and require appropriate and adequate caregiving, the participants did not express any sense of self-pity or see themselves as burdens to others. Having a negative self-concept as a result of their condition was not a part of their identity. This is in distinction to the current literature. Gillies and Johnston (2004) looked at two existing studies that explored living with the loss of characteristics in those living with dementia and the experience of loss of self through bodily mutilation from cancer. In both conditions of dementia and cancer, participants shared common experiences of identity loss and identity maintenance as expressed by the affected individual and family caregivers (Gillies & Johnston, 2004). Participants expressed a sense of role erosion which was pertinent to their identity (Gillies & Johnston, 2004). Roles such as patriarch, breadwinner, husband or father had to be surrendered as they became more dependent on family caregivers. In both studies, participants spoke about their self-perceptions of being “burdens”, no longer being any use to anyone and with no social value (Gillies & Johnston, 2004). In contrast, the men in this study did not perceive themselves as “burdens” who should be pitied by others. Rather, they engaged in valuable relationships within their families and community and took part in activities that provide them with joy and meaning.

However, the participants’ pasts were not completely ignored in defining who they are. For Mr. Khan’s, a significant aspect of his identity was his vocational work as a lawyer and homeopathic practitioner, both roles which he took pride in. Similarly, Gillies and Johnston’s (2004) work further described that both persons with cancer and dementia reclaimed their identity through referencing earlier life accomplishments such as achievements at work, of travel

and parenting. Dementia and cancer participants also acknowledged that there were those who are worse off than them to allow for a sense of reassurance, retain a sense of dignity and find purpose in trying to help those less fortunate than themselves (Gillies & Johnston, 2004). This finding was again similar to Mr. Aga and Mr. Khan in their past and present ability to provide help to others. Mr. Aga in particular recognized that even though he had comorbidities, there were those whose situation were ‘worse’ than his and thus propelled him to help others, as he felt more “privileged”. Being altruistic was both a part of his identity as well as a *protective factor* in his resilience. Overall, identity as an emergent narrative thread was highly intertwined with the four themes of resilience: 1) having purpose and meaningful worth, 2) having a strong sense of faith, 3) having supports that improve quality of life, and 4) coming to terms with limited “control” and will be further discussed in relation to the existing literature in the following sections.

Finding Meaningful Purpose and Worth

Finding a meaningful purpose and worth was a *protective factor* in the men’s resilience as presented in their respective resilience story diagrams while also being a significant contributor to their respective identities. Similarly, in Basting’s (2003) accounts of the autobiographies by person living with dementia, it was also noted that self is deeply connected to one’s usefulness to society. This included the authors living with dementia being able to write about the experience of dementia, writing for others on how to be a minister while having dementia, and taking part in research (Basting, 2003). For Mr. Aga especially, being able to help others at the mosque and day program strengthened his identity as a contributing member of society. For Mr. Khan, recognizing that helping others brings “satisfaction” and being able to provide guidance to his children and grandkids gave him a sense of purpose and contributed to

his feelings of self-worth, and thereby built his capacity for resilience. Through helping others, self and value is maintained despite a diagnosis of dementia.

Having a Strong Sense of Faith

Having faith was both a strong aspect of Mr. Khan and Mr. Aga's identity while playing a critical role in their resilience. Coincidentally, both men practiced Islam and described their devotion to Allah and how praying gave them a sense of confidence and reassurance that life will be okay. There is a small body of literature that has explored the spiritual experience and needs of people with dementia. In this literature, it has been identified that there is a common need for persons living with dementia to stay spiritually connected (Stuckey, Post, Ollerton, Fallcreek & Whitehouse, 2002). People with dementia often turn to religion in the face of cognitive loss, such that their strong faith in God sustained their everyday lives (Katsuno, 2003; Snyder, 2003). Although the men in this study did not turn to religion *because* of their dementia, faith is held on to during both times of challenge and everyday life.

In a literature review of spirituality and coping with early-stage Alzheimer's disease by Beuscher and Beck (2009), it was revealed that spirituality played a major role in coping. Coping included surrendering to God, hope in an afterlife, hope in each moment and making connections with nature, relationships and God, and of course prayer, church attendance and meditation. Similarly, Mr. Khan and Mr. Aga utilize a positive, emotional coping strategy involving spirituality that aided in their resilience. They described taking part in daily prayers, attending the mosque and acknowledged that God would help them. Reliance in God also played a significant role in Mrs. Khushu's role as a caregiver, as she expressed that she continued to cope with first and foremost, God's help.

Supports that Improve Quality of Life

Day programs and family were *protective factors* as they facilitated feelings of belonging. Each participant found meaningful worth in their relationship with others in respect to both type of supports. This finding reinforces that identity is shaped by the role one plays in relation to others in his or her social world (Sabat, 2002). In revisiting the existing literature, I was not able to identify any research that aimed to understand persons living with dementia and their subjective experience of participating in day programs. Thus, the experience of attending a day program improving quality of life was a unique finding in this study. Furthermore, both Mr. Aga and Mr. Khan live in accepting and supportive home environments with family and supports that do not compromise their identities, which is a critical factor to their resilience. Considering their intersecting identities as minority, elders, living with chronic illness that is otherwise dismissed by public discourse, the two men were comfortable in their own skin. They felt loved, accepted and valued and did not express any feelings of being “less than” others.

However, although, in the case of Mr. Aga, his wife Mrs. Khushu cried as she explained how they as a couple have been neglected by some people in their community ever since Mr. Aga’s diagnosis. Mrs. Khushu’s sadness may be a reflection of the felt stigma that she struggles with. However, for Mr. Aga, the stigma that others imposed on him was acknowledged, but not given importance to. He did not identify with certain people’s negative reactions and thus, he did not express any sense of losing a part of himself based on how others viewed him. However, to what degree this is because he is innocent of others negative view versus his strength to not care what they think, is questionable. It is also possible that the acceptance of his condition by family and those at the day program overshadow the need for acceptance by his peers at the mosque, in which sense his peers at the day program and his relationship with this family act as *protective*

factors. In reflecting on our conversation, another possibility is that his dismissal may also be because he has the resilience for acceptance of the stigma.

Coming to Terms with Limited “Control”

Both men have had different experiences of *adversity* in their lives. These adversities were integral in the resilience process as there needs to be an adversity present in order for resilience to occur. The most prominent *adversity* in the context of dementia was faced by Mr. Aga. Not being able to “*control*” or drive his car resulted in his compromised well-being. This is not surprising as the literature supports that the loss of driving privileges for many with dementia is a major occurrence in the course of their condition (Dobbs, Harper, & Wood, 2009). In fact, individuals with dementia are reluctant to discuss the subject of memory loss due to fear of having their driving license revoked (Flanagan, 2011). The act of driving has symbolic importance, most notably in the social world. It signifies autonomy and for many, it is synonymous with self-respect and indicates competency, allowing the individual to hold onto a non-age-related, non-stigmatized identity (Eisenhandler, 1990; Odenheimer, 1993; Rothe, 1990). In reflecting with on the literature, it is apparent that Mr. Aga’s negative experience with losing his license was a typical experience and outcome that other male senior drivers with dementia may experience. Furthermore, losing driving privileges not only has an effect on the person living with dementia but contributes as a stressor to their caregiver as well (Dobbs et al., 2009). Mrs. Khushu also spoke about her grief in seeing Mr. Aga’s well-being decline since losing his license and shared her concerns of him possibly having depression since the incident. His experience has had a domino effect on Mrs. Khushu, who worried for her husband, which ultimately compromised her well-being as well.

Revisiting the Negative Discourse

The narratives of the two men in this study reveal that the negative discourse of dementia does in fact exist, as it prominently appears in Mr. Aga's story. Although he did not admit being affected by his diagnosis, it cannot be ignored that it still caused pain for his wife. There is a high chance that such views could affect others living with dementia who may perceive the marginalization more personally and thus suffer from self-stigmatization. His wife's narrative suggests he may be experiencing exclusion in his religious community and it is possible that he is not aware of this. This exclusion may be due to the community's misunderstanding of dementia that is only propelled by the negative, biomedical discourse preoccupied with the notion of progressive staging and degradation, and disability, rather than remaining strengths.

Contributing to the misunderstanding of dementia and disregard for personhood are appalling claims suggesting that persons with dementia "may have a moral duty to die", especially if they are wasting human fiscal resources (Malpas, 2009, p. 54). Comments as such are concerning and lack even a morsel of humanity. It seems as though reciprocity is necessary in order for someone to be deemed valued and therefore are worth being alive. However, both men in this study have helped serve their communities in the past and in fact still offer their service to others in their own unique ways, demonstrating their remaining social abilities. The most prominent resource that they are utilizing currently are day programs, but to deem that as a "waste" of fiscal and human resources is unjust and unethical. Why must one be "cogent" in their final years to justify use of human resources? Baroness Warnock also wrote in regards to person with dementia, that "the real person has gone already and all that's left is just the body of the person" (Malpas, 2009, p.54). However, the study findings demonstrate the opposite. The stories and voices of Mr. Khan and Mr. Aga reveal that not only are they "real" people, but they

are also people who are commendable for their life history and unique resiliencies. They have the capability to provide insight about their own lives, be altruistic, offer opinions, and form valuable relationships, among other traits.

The suggestion that persons with dementia “may have a moral duty to die” (Malpas, 2009, p.54) could also be a reflection of today’s society and its preference for utilitarianism over equity and respect for all members of society. The obsession with efficiency, to be “useful” and outcome dismisses valuable human life. The moral and ethical implications of such beliefs degrades the social position of those experiencing dementia, rather than evoke much needed empathy and compassion. Such beliefs pose critical questions. What is it about the brain that makes the use of human resources in the dementia context seem wasteful or unnecessary? Or perhaps, what is it about the cohort of individuals that have dementia which provoke others to believe that they are less than human? To what degree do ageist societal norms contribute to the disregard and devalue of persons living with dementia? These moral questions are difficult to answer, but bear asking nonetheless.

Such negative and stigmatizing views also exemplify the othering effect as described by Goffman (1968 as cited in Clarke, 2008). In analyzing the men’s narratives, both Mr. Aga and Mr. Khan were subject to this phenomenon of othering. Throughout their lives, they have either felt like an insider or outsider based on social context. For Mr. Khan, he was an outsider in Pakistan and now an insider in Canada and again in the day program. For Mr. Aga, who sees himself as an insider at the day program and at the dialysis clinic, is viewed as an outsider at the mosque. In both instances, the men are insiders where there are people whom they can relate to, which facilitates feelings of belonging. They are outsiders where there are people who are unable to relate to them, and otherwise see them as “less than”. Mr. Aga did not give credence to the

social stigma of his illness that prevails at the mosque. Instead, his experience of social stigma is related to his self-identity of feeling less than because he is not able to drive.

Leaving Behind the Negative Discourse

One approach in distancing away from the negative public discourse of dementia is to involve persons living with dementia in qualitative research. This strategy provides an avenue for their lived experiences to be shared and ultimately, promotes personhood as their voices are given value to. Albeit to different extents, Mr. Khan and Mr. Aga were able to take part in the interviews and provide narrations and insights onto their lived experiences. However, my unique experience of pursuing narrative research with individuals living with mild dementia who have some limitations in communication had implications for how I carried out the interviews. I was conscious in trying not to fulfill the need to gather “in-depth” data through being intrusive with questions, but rather tried to let conversation flow from participants as they desired. I also paced myself and acknowledged the precious presence of silences and pauses. Further, I integrated creative activities to allow a more “hands-on” method for the participants to communicate. In essence, I was carrying out person-centered research that took into consideration the uniqueness of each individual. However, the interviewing considerations in no way meant that meaning was not derived from participant’s narratives. Although it was not possible to compile a “story” as commonly done in traditional narrative methodology (with a beginning, middle and end) based on the collected data, the participants’ excerpts still allowed for insight of their challenges, resiliencies and identities. It was my role as the researcher to string together their narratives while staying conscious that their voices were not overpowered by my own researcher voice.

In contrast to the negative public discourse, the two men in this study were actually quite capable in participating in dialogue. Their ability to answer questions, use humor, sympathize

with other human beings, to string together narratives from the past and present, and moreover, their *presence* during the interviews highlighted their selfhood. There was a sense of reciprocity in that the men also acknowledged my presence and interacted with me. The relationship established is an example to that described by philosopher and theologian, Martin Buber (1937, as cited in Kitwood, 1997). Martin Buber's work describes that there are two ways of being in a relationship, either through an "I-Thou" or "I-It" interaction (1937, as cited in Kitwood, 1997). The "I-It" relationship implies detachment, instrumentality and a way to maintain distance with the other (Kitwood, 1997). In the "I-Thou" relationship, however, there is a strong recognition of the other, and it is characterized by spontaneity, subjectivity and acceptance of the unique other (Kitwood, 1997). According to Buber (1937, as cited in Kitwood, 1997), in order to acknowledge someone as a person, one must engage in the "I-Thou" relationship with them. As study findings demonstrate that Mr. Khan and Mr. Aga are indeed 'real' people, health care providers, service providers and the community in general can engage in an "I-Thou" relationship with them which will further propel person-centered care. Similarly, Mr. Aga and Mr. Khan are also capable of the "I-Thou" exchange as through their stories, it was evident that *they* are the ones who give value, form attachments, and interact with others.

Strengths and Limitations of this Research Study

This research study included two narratives which could be seen as a limitation given the small number of participants. However, the purpose of narrative methodology is to present a more in-depth, complex and contextualized co-constructed knowledge (Chase, 2011). Although the findings in this study may not be generalizable to all South Asian immigrant older adults experiencing mild dementia, it provides some insight into their lived experiences of immigration, challenges and resiliencies. However, there was a coincidence in participation of the older adults

both being males and practicing Islam limits understanding of resilience in other predominant South Asian religions as well as the experience of resilience and challenges in female older adults, which suggests areas for future research focusing on such gaps in knowledge.

Although I confirmed my interpretation of some of the data from the first interview with follow-up discussion with both participants, this could have been strengthened. After the second interview, I did not go back and confirm my overall findings and interpretation with participants. This could have been improved by arranging another meet-up or a telephone conversation with the participants. Keeping in mind that narrative analysis included knowledge co-construction that is laden with research bias and values, I tried to find a balance in reporting the data by including as many direct quotes as possible.

There were some findings in the research conclusion that could have been richer and therefore, strengthened. During data collection, the experience of grief for Mr. Aga as a consequence of losing his driver's license was an emergent story of adversity and resilience. It would have been interesting to uncover if that same experience has yet occurred in Mr. Khan's life and what the effects were on him. Further, as identity was an emerging theme that did not come to my attention until after the second interview, I believe the data would have been richer if I asked more questions directly related to identity, for instance: "How do you feel your surroundings currently have shaped your identity?" This data could have been integral to our understanding of subjective identity of South Asian older adults experiencing mild stage dementia. As a result, I believe the research findings would have benefited from a third interview that allowed further conversation of gaps in knowledge and further confirmation of the accuracy of my interpretation of the participants' stories.

CHAPTER SIX

You were born with potential.

You were born with goodness and trust.

You were born with ideals and dreams.

You were born with greatness.

You were born with wings.

You are not meant for crawling, so don't.

You have wings.

Learn to use them and fly.

- Rumi, 13th century (Coleman, 2004)

Research Conclusions and Implications

I embarked on this thesis journey as a result of being rattled with the lack of respect that exists in the public discourse related to older person living with dementia. I aimed to explore the experiences of challenge and resilience in South Asian immigrant older adults living with mild dementia, while trying to understand how culture and identity emerged in their narratives and what facilitated and hindered their resilience. I was able to answer and share these findings through presenting participants' stories and sharing my interpretations. Overall, their stories have provided deep meaning and bear greater implications for application to theory, education, practice, policy and future research which will be further discussed in this chapter.

In this thesis journey, I had the privilege to embody Mr. Khan, Mr. Aga and Mrs. Khushu's narratives. A major finding in this study was that contrary to the negative public

discourse, the diagnosis of dementia did not engulf Mr. Khan or Mr. Aga's entire well-being, nor did it take over their identities. Their identity remained intact while complimenting their resilient traits. Participants remained resilient and achieved their unique resilient *outcomes* while living with mild dementia through four themes: 1) having purpose and meaningful worth, 2) having a strong sense of faith, 3) having supports that improve quality of life (family and day program), and 4) coming to their own terms with limited "control". For these men, culture was synonymous with religion, which was a *protective factor* in their resilience, providing confidence and reassurance that God would provide help. One participant was subject to being left out by his community members, but this had no subjective effect on his well-being. In contrast to some of the existing literature, participants did not see themselves as "burdens" nor did they associate with the negative discourse of dementia. They expressed feelings of acceptance from family and community and where there was some stigmatization in the case of Mr. Aga, he expressed it did not affect him.

Rather than Mr. Khan and Mr. Aga be considered people who "have a moral duty to die", they are people who should in fact be *honored* and *respected* in our communities. What sets them apart is that not only did they acquire life history with their individual struggles, but they continued to live with spirit, resilience and compassion for others around them. Their interest in participating in research coupled by their presence and ability in voicing their stories during our interviews demonstrated their competencies. Their participation in research and their narratives have highlighted that instead of reinforcing the negative discourse of dementia, we need to help nurture the strengths that they hold as their condition of dementia progresses while continuing to create avenues in which their voices are heard.

Overall, this study contributed to the limited body of literature aiming to understand experiences of challenge and resilience in older adults living with mild stage dementia in the following ways:

- Resilience is indeed possible in South Asian immigrant older adults experiencing mild stage dementia
- Culture (which was integral to faith) has contributed positively to resilience
- There are areas for support to promote resilience in South Asian immigrant older adult experiencing mild stage dementia

Such findings have implications for theory, education, practice, policy, and future research which will be explored in the following sections.

Implications to Theory – What this Study Uncovers about the Resilience Framework

My interest in resilience research in the dementia context stemmed from reading Harris' (2008) seminal case study in which the Resilience Framework was applied. The findings from my study confirm Harris' (2008) findings that older adults in mild stage dementia are able to be resilient. Both the men in this study have overcome *adversity* at different points in their lives and are currently doing alright. *Adversity* was the experience of oppression living in Pakistan for Mr. Khan while more recently, Mr. Aga's adversity was the experience of losing his driver's license. In the case of Mr. Khan, he has "bounced-back" and is doing alright as he is living a life of "satisfaction". For Mr. Aga, he has not completely "bounced-back", but rather has resurfaced bit by bit since losing his license.

Similar to Harris' (2008) findings of *assets* and *protective factors* from the Resilience Framework, Mr. Khan and Mr. Aga's *protective factors* and *assets* also included having support

and a positive relationship with family, remaining productive members of the community (which relates more to finding meaningful worth in my study), not remaining bitter about the diagnosis of dementia and keeping one's religious beliefs strong. Also similar to Harris' (2008) findings, *competence* (adaptive use of resources within and outside a person to negotiate challenges and achieve positive outcomes) was evident in both Mr. Aga and Mr. Khan's participation at the day programs. While it could be stated that *competence* in general varied in both participants based on their personalities and the different stages of their dementia progression, this bears rethinking. Mr. Khan showed signs of increased personal and internal competence in comparison to Mr. Aga. It can be interpreted that Mr. Aga's competencies, although facilitated directly by Mrs. Khushu in many instances, were nonetheless as significant contributors to his resilience overall. It can be stated, therefore, that just like personhood is bestowed on a person by another (Kitwood, 1997), so is resilience bestowed on a person by another's acts of support.

What is unique about the presented study in contrast to Harris' (2008) work, is that I had aimed to understand challenges and resilience in a specific cohort of older adults with mild dementia – South Asian immigrants. In trying to understand the role of culture in the participants' resilience, it was apparent that participants equated culture with their religion and thus was a *protective factor*. Informed by own my family's difficult experience with immigration and coming to a new environment, I presumed that the participants may have also had similar experiences. However, there was a lack of stories from participants about the actual immigration process and stories related to the efforts put into settling in a brand new country. This could have been due to several reasons – that there were no significant experiences in relation to immigration; immigrating to Canada had solved a prior problem, thus there was no “adversity” in the immigration experience to share; based on the progression of dementia, remote memories

of immigration may have less prominence in their storied lives; or participants demonstrated resilience by choosing to live past and not ruminate on negative stories of the immigration experience. As such, while the Resilience Framework was useful to uncover and examine experiences of challenge and resilience in the present life moments of the participants, it was not possible to examine their immigration experience through this same lens. My study findings suggest that use of Harris' framework can be informative for interpreting the life experiences of older adults with mild dementia, however, the memories must be significant enough for the person to be able to explicate their meaning.

Implications for Education

Through using a resilience lens, this study uncovered that persons living with dementia have the capability to find meaning, joy and are able to resurface in times of hardship. Similarly, a resilience lens can be used to foster education, steer practice, mandate policy and guide future research. The concept of resilience in relation to older adults living with mild dementia has potential to be integrated in undergraduate studies. The philosophy of a resilience-focused, strengths-based approach to dementia can be integrated in nursing undergraduate studies to exemplify person-centered care. For instance, case studies involving persons living with dementia can be discussed along with how to make a relevant care plan promoting resilience. Findings from my study provide evidence that nurses do require cultural sensitivity education because culture, in particular enactment of faith, has significant meaning for resilience of older people living with dementia.

Implications for Practice

Nurses, service providers and other disciplines who work with persons living with dementia can utilize the resilience lens to understand strengths of persons living with dementia and encourage and provide opportunities for enactment of their remaining capabilities. However, this does not suggest that we should forget or dismiss the realities of dementia either. In order to develop resilience, adversity must exist (Masten & Coatsworth, 1998). Thus, those who work with persons living with dementia must first and foremost empathize with the condition, assess for the adverse conditions, while at the same time, identify and empower the strengths of the person.

This research study identified several factors that aid in resilience, which can be sustained in older adults with mild stage dementia and potentially aid in the person's resilience in later stages of the condition. Having a meaningful sense of worth has been found to be a *protective factor* in resilience. As day programs have been identified as setting a positive atmosphere for persons living with dementia, they can help continue to foster feelings of meaningful worth through activities. Activities that promote sense of worth may include ways to serve others and contribute to the greater community. For instance, day programs may appoint older adults with tasks in helping set up, serve or clean up during activities and meal time. Also, finding meaningful worth in the greater community can be achieved through organizing park clean-up days or facilitating gardening initiatives in the community.

Another *protective factor* of resilience that should be continued to be sustained in persons living with dementia is support that sustain spiritual practice. Mrs. Khushu made a direct plea for the need to have volunteers at the mosque who can be a companion to her husband, as the

mosque segregated prayer areas by gender. Going to the mosque not only fulfilled Mr. Aga's spirituality, but contributed to his social well-being as it a place where he could continue to serve others. Other individuals like Mr. Aga may have similar experience with dementia (or another chronic illness) that may impede on their ability to participate in religious gatherings. Thus, findings from this study suggest the need for additional support in mosques for persons living with dementia. Mrs. Khushu's sadness with the stigma that is apparent in her community highlights the opportunity for service providers to reach out to the community and provide education about dementia and the importance for religious facilities to be inclusive for older adults living with cognitive impairments. With greater awareness about the condition in the community, facilitators for access and compassion in general may be cultivated.

The fact that driving cessation was an *adversity* has implications for required support. The findings of my study reveal that the negative impact of driving cessation on a person living with dementia and caregiver has deep meaning. This study highlights the need to have specific support to navigate this life transition. Nurses can use this knowledge to implement driving cessation support into their practice. In working with persons living with dementia, nurses can assess for driving cessation and what impact it has had on the person living with dementia, and plan nursing interventions accordingly (such as therapeutic counselling). This finding highlights the opportunity for day programs or other community services to provide driving cessation support groups for persons living with dementia.

Implications for Policy

The resilience lens for dementia care can be implemented in the policies of organizations and service providers. For instance, mandating training for healthcare and other professionals that focus on ways to assess and support resilience in a person living with dementia is one

measure to promote personhood. Furthermore, I intend to share the findings about the significance of spiritual practice in older adults living with mild dementia with a representative from the Canadian Council of Imams. I will inquire if they would be able to help me facilitate an educational conference for faith leaders, or help me share my findings through a newsletter to other Imams. This could inform religious leaders throughout Ontario about how to facilitate elders to have meaningful faith experiences, while sustaining their faith practices throughout the mild stage of dementia.

Implications for Future Research

Several findings and gaps in this research study have implications for future research. As this research study aimed to understand subjective experiences of resilience and challenges in early stage of dementia of South Asian immigrant older adults, further research can be done to understand the same phenomena but in later stages of dementia. A unique aspect of this research study was that participants were recruited from culturally specific day programs. Both narratives revealed that day programs are an *asset* to resilience which made me question if the same would be said if participants attended a general day program. Thus, a future research question may be: “How and to what extent does an ethnically inclusive day program promote resilience for older adults with mild stage dementia?”

A limitation in this study was that the sample was not inclusive to non-Muslims nor to females. Thus, a future research question may be to explore females with mild stage dementia and how and if their experiences of resilience and challenges differ from males. As the significance of driving cessation was analyzed from a gender perspective, future research focusing on its impact on women would also be important to warrant support that is appropriate to their needs. The dismissive fashion in which Mr. Aga’s driving license was revoked can also

be examined in order to make practice alterations for screening that are more compassionate and person-centered. Mrs. Khushu's preoccupation with her caregiver role and being Mr. Aga's 'driver' also highlights the need to hear more voices from family caregivers and examine the extent and effectiveness of the support they receive. Finally, continuing to engage older adults living with mild dementia in qualitative research will allow their voices to be heard, will reinforce their status as valuable members of society, and accurately inform the care and support that we provide them.

Conclusions

Exploring the experiences of challenge and resilience in persons living with dementia is integral to our understanding and practice of person-centered care. As this study has demonstrated, the loss of memory does not equate with the loss of self or identity, nor does dementia define a person. Instead, the capabilities to live a life of hope and meaning remain. However, it is not enough that capabilities simply remain but rather, it is crucial that such capabilities are *nurtured*. Service providers, health care providers and community members at large have a social responsibility to uphold the value of persons living with dementia. It is through a resilience lens and through the understanding of the self that we can continue to foster meaningful relationships, hope and strength in persons living with dementia.

The narratives of the participants in this study have taught me a beautiful lesson and I hope that their voices also resonate with readers; there remain rays of light even in the midst of what we may perceive as "darkness". Mr. Khan, Mr. Aga, and Mrs. Khushu's stories have an element of inspiration to them and show us that resilience is indeed possible in the context of mild dementia, and that the negative discourse of dementia has no relevance and serves no purpose for them. My study reveals that challenging this discourse is warranted. As I have felt

empowered to disseminate the co-created stories of Mr. Khan, Mr. Aga and Mrs. Khushu throughout this thesis journey, I invite the reader one last time to interpret my artistic rendering of the participants' co-constructed stories in the next section; my epilogue.

EPILOGUE



Figure 8. Epilogue

APPENDIX A

Functional Assessment Staging (FAST)

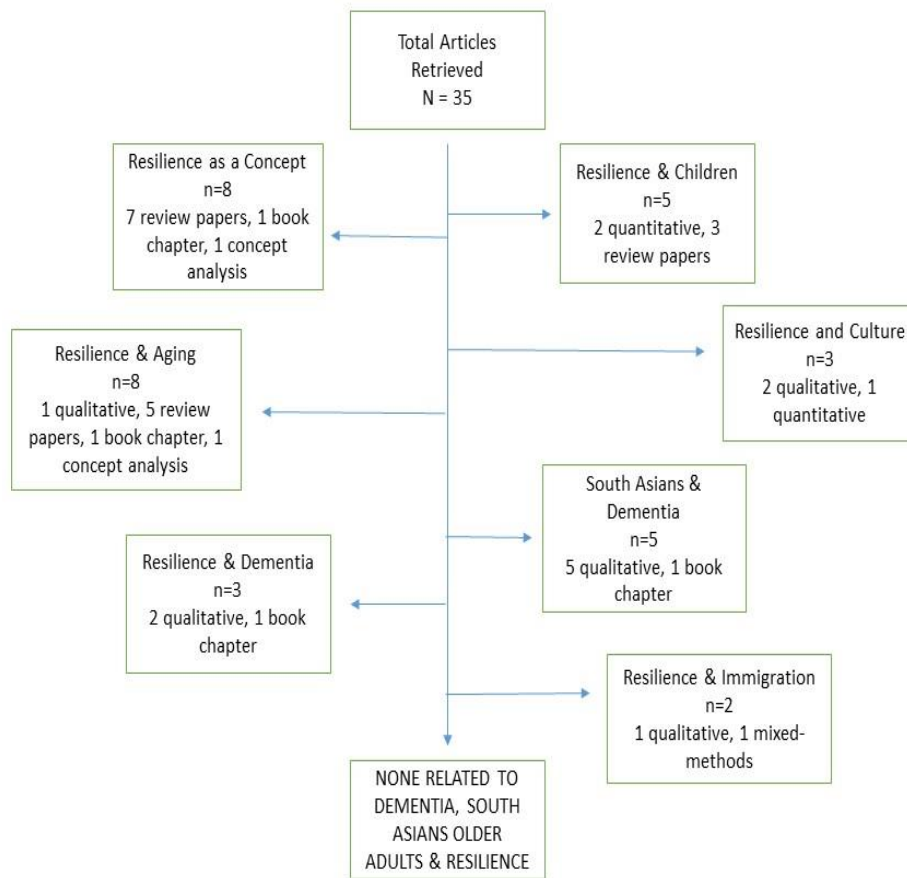
as adapted from Registered Nurses' Association of Ontario (2010) and Reisberg (1988)

FUNCTIONAL ASSESSMENT STAGING (FAST)

Stage	Description
1 No cognitive decline	No difficulties, either subjectively or objectively
2 Very mild decline	Complains of forgetting location of objects; subjective work difficulties
3 Mild decline	Decreased job functioning evident to coworkers; difficulty in travelling to new locations
4 Moderate decline	Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling finances; marketing)
5 Moderate severe decline	Requires assistance in choosing proper clothing
6a Severe decline	Difficulty putting clothing on properly
6b	Unable to bath properly; may develop fear of bathing
6c	Inability to handle mechanics of toileting (ie. forgets to flush, doesn't wipe properly)
6d	Urinary incontinence
6e	Fecal incontinence
7a Very severe decline	Ability to speak limited (1-5 words a day)
7b	All intelligible vocabulary lost
7c	Non-ambulatory
7d	Unable to sit up independently
7e	Unable to smile
7f	Unable to hold head up

APPENDIX B

Literature Review Algorithm



APPENDIX C



Are you a South Asian first generation immigrant over the age of 65 who has mild dementia?

A Student Researcher from the Daphne Cockwell School of Nursing,
Ryerson University completing her Masters thesis is seeking

PARTICIPANTS AND THEIR MAIN FAMILY/FRIEND CAREGIVER FOR RESEARCH ABOUT RESILIENCE WHEN LIVING WITH MILD DEMENTIA

You would be asked to:

1. Complete a 10 minute telephone screening interview to determine if you and your caregiver would fit with the goals of the study
2. If you agree to participate, you would be interviewed for approx. 2 hours
3. Upon completion, a 30 min follow-up interview session another day to confirm data interpretation

In appreciation for your time, you will receive an honorarium of \$20 value (\$10 per group at the end of the first interview and \$10 per group at end of follow-up interview)

Participation is entirely voluntary and confidential

For more information about this study, or to volunteer for this study, please contact:

Nafsin Nizum

[*insert temporary telephone number]

nafsin.nizum@ryerson.ca

APPENDIX D

Brief Presentation Script for Recruitment

Good morning/Afternoon everyone,

My name is Nafsin Nizum and I am a Registered Nurse and Masters in Nursing Student at Ryerson University. I am very grateful for the opportunity to come here and speak to you briefly about a research project I am working on. I am interested in learning more about how someone is resilient in early stage dementia. In other words, I would like to speak with you to understand how you have faced challenges in the past and face challenges currently with your diagnosis of dementia. If you choose to participate, I would also need to sit down with your caregiver who is a family member or spouse to have a better understanding of your experiences from their perspective.

In order to participate, you must have immigrated to Canada, be over the age of 65, and be able to understand and speak English. Your caregiver must be a family member or spouse who is over the age of 18 and can also understand and speak English.

If you and your caregiver are interested, you may contact me and I will ask you both some brief questions over the interview which will take about 10 minutes. Once that is complete and both of you fit the goals of the study, then I will ask to sit down with you and your caregiver at your home or another private location of your choice that is comfortable and convenient for you and conduct an interview that will take approximately one and a half hours. I will ask questions and speak to you about things such as your culture, your experience as a new immigrant and your current life as it relates to your diagnosis of mild dementia. I am going to talk about things like how you live day to day life, what sort of supports or help you have, and how memory loss has impacted your life. This will be followed by a second 30 minute follow-up interview that will take place 2-3 weeks after your first interview.

With your permission these interviews will be audio-recorded, and written out following the interview. However, your information will be confidential and code names will be used to hide your identity and information will be locked away. You have the right to not participate or withdraw at any point of the study.

Also, as a token of appreciation, I would like to offer to each of you a \$5 gift card to Tim Hortons. This will take place at both the end of the first interview and the follow-up interview, therefore you and your caregiver will receive \$20.00 in gift cards in acknowledgement of your participation.

If you would like to get in touch with me, the recruitment poster has my contact information. If you have any questions or concerns now or at a later time, I will be happy to answer them as well. Thank you for your time!

APPENDIX E



Daphne Cockwell
SCHOOL OF NURSING

Information/Consent Form

Exploring Resilience and Culture in South Asian older adults with mild dementia in the community

You have been invited to participate in a research study about resilience, dementia and culture.

This study is being conducted as part of the requirements for the completion of my Master's degree in nursing at Ryerson University, Daphne Cockwell School of Nursing. It is important you read this form as it provides information you will need to know in order to decide whether you wish to participate in this study. Before you give your consent to be a participant, it is important that you read the following information provided. Please ask any questions necessary to help you understand what you will be asked to do.

Investigators:

Principal Investigator: Nafsin Nizum, RN, MN student, Ryerson University, Daphne Cockwell School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario

Thesis Supervisor:

Dr. Lori Schindel Martin, RN, PhD, Daphne Cockwell School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario.

What am I trying to discover?

I am doing this research for my Master's in Nursing thesis in an effort to understand how you are resilient. In other words I would like to hear about your everyday experiences with dementia, including any challenges and strengths you may have.

What will happen during the study?

I will be conducting an interview asking questions and speak to you about things such as your culture, your experience as a new immigrant and your current life as it relates to your diagnosis of mild dementia. We will talk about things like how you live day to day life, what sort of supports or help you have, and what strategies you use to deal with how memory loss has impacted your life.

With your permission these interviews will be audio-recorded, and will be transcribed by the principal investigator following the interview.

If you consent to participate in this study, you will:

1. Take part in two face-to-face interviews of approximately 40-60 minutes each on two different days. The last interview will be an additional 15-20 minutes in which I will summarize and verify the experiences you have shared with me.
2. Consent to being audio-taped during the two interviews. With your permission these interviews will be audio-recorded.

The first and second interview:

Upon your consent, the first interview will take place at a comfortable and private location inside the day program. The location will be quiet and private and secure from any interruptions. With your permission, I will audio-tape the interview. I will also take notes during this interview to ensure I have documented all the experiences you have shared with me. The length of this interview depends on how you are feeling at the time. It will be approximately 40-60 minutes in total; you can choose to end it at any time.

The second interview:

The second interview will take place approximately 1 week after the first interview at a comfortable and private location inside the day program. The location will be quiet and private and secure from any interruptions. With your permission, I will audio-tape the interview. I will also take notes during this interview to ensure I have documented all the experiences you have shared with me. The length of this interview depends on how you are feeling at the time. It will be approximately 40-60 minutes in total; you can choose to end it at any time. The second interview will be an additional 15-20 minutes in which I will ask you clarification questions or to elaborate what we discussed during our first interview..

What is experimental in this study?

There is absolutely no aspect of this study that is experimental.

Are there any risks or discomforts to doing this study?

There is no experimental treatment in this study from which you could experience discomfort or distress. However, you may remember or speak of some unpleasant memories about your experiences with past and present challenges. At any point if you feel uncomfortable, you can discontinue your participation in the study either temporarily or permanently. If at any time during your participation in this study you feel distressed or sad and want to speak with someone you will be provided with an information brochure explaining counselling programs from your local Alzheimer's chapter.

Are there any benefits in doing this study?

There will be no direct benefits to you from participation in this study. It may be interesting to you to discuss your experiences with me, and this may represent some benefit to you. I hope to

learn more about the strengths that persons with mild dementia have. I hope that what is learned as a result of this study will help us better understand that persons with dementia are in fact people who are capable of facing challenges and developing personal coping strategies that could be shared with others.

Who will know what I said or did in the study?

Any identifying information obtained in connection with this study will remain confidential. No identifying information about you will be any report of the research. In interview data and research reports you will be referred to using a Pseudonym of your choice. Interview data you provide will be kept in a locked filing cabinet in the principal investigators home office. The researcher will keep what you share in the interviews strictly confidential.

During the interviews, what you share will be documented through note taking as well as audio recorded. This will ensure that I do not miss any of your valuable experiences shared. When I turn the interview audio recordings into writing, I will remove all the information that identifies you. The transcripts and the demographic forms will be put in a locked cabinet in the principal investigator's home office. The consent forms will be kept in a locked filing cabinet located in the principal investigator's home office that is separate from all other information for this study. All electronic transcript data will be kept in a personal password protected computer located in the principal investigator's home office. Electronic data will also be stored on an encrypted password protected USB stick which is an electronic storage device and this will be placed away in a locked cabinet in the principal investigators home office. The information collected as part of this study will be kept as described above for a period of 2 years after the study has been completed, at which point in time, all electronic and paper information will be erased or destroyed and disposed of in a confidential manner. Reports will not show your name or any information that identifies you.

All information you provide will not be used for any purpose other than this study. Full transcripts will only be seen by my immediate supervisor, Dr. Lori Schindel Martin. No other thesis committee members will see anything other than aggregate data (the data in a report form) that will not have your name or any identifying information attached. Some of your comments from the interviews may be used word-for-word to present results of the study, but no one will know that you were the person who said those words.

Incentives to Participate:

As a token of appreciation for your participation you will receive a \$5 Tim Horton's gift certificate after the first interview. Another \$5 Tim Horton's gift certificate will be provided for you after the second interview.

Cost and/or Compensation for Participation:

It is not anticipated that you will incur any personal cost for participating in this research study

What if I change my mind about being in the study?

It is your choice to be a part the study or not. If you decide to be a part of the study, you can withdraw from the study interview for whatever reason, even after signing the consent form. If you decide to withdraw, there will be no consequences to you. If you decide to withdraw, any information you have provided will be destroyed unless you say otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study. You can request that audio-taping be stopped at any time. Your decision not to participate will not influence the nature of your relationship with the organization you heard about this study from or Ryerson University now, or in the future.

Would you like a summary of the study results?

Yes

No

Please send them to this email address _____

Or this mailing address

Questions about the Study:

If you have any questions or concerns about the study now or at any point during or after the interviews, you may contact:

Nafsin Nizum (Researcher, MN student)

nafsin.nizum@ryerson.ca

416-979-5000 ext.2564

Or

Dr. Lori Schindel Martin (Thesis Supervisor)

416-979-5000, ext. 4257

lori.schindelmartin@ryerson.ca

This study has been reviewed by the Research Ethics Board at the Ryerson University Research Ethics Board (REB). If you have questions regarding your rights as a human subject and participant in this study, you may contact Ryerson University research ethics boards for information.

Ryerson University Research Ethics Board

Research Ethics Board

c/o Office of the Vice President, Research and Innovation

Ryerson University

350 Victoria Street

Toronto ON M5B 2K3

T: 416-979-5042

Toni Fletcher, Research Ethics Coordinator

416-979-5000 ext 7112

toni.fletcher@ryerson.ca

Consent:

My signature below indicates that I have read the information in this agreement and have had a chance to ask any questions I have about the study. I agree to be in the study and have been told that I can change my mind and withdraw my consent to participate in this study at any time. I have been given a copy of this agreement. I have been told that by signing this consent agreement I am not giving up any of my legal rights.

Participant's Name (please print) _____, Toronto, Ontario

Participant's Signature _____ Date _____

Investigator's Name

Investigator's Signature

Date

I understand and give my permission for the interviews to be audio-taped. I understand that I may ask audio-taping be stopped at any point during the interviews. I can still participate in the study even if I choose not to be audiotaped.

Participant's Signature _____ Date _____

APPENDIX F



Daphne Cockwell
SCHOOL OF NURSING

Information/Consent Form

Exploring Resilience and Culture in South Asian older adults with mild dementia in the community

Your loved one has been invited to participate in a research study about resilience, dementia and culture. This study is being conducted as part of the requirements for the completion of my Master's degree in nursing at Ryerson University, Daphne Cockwell School of Nursing. It is important you read this form as it provides information you will need to know in order to decide whether you wish your loved one to participate in this study. Please feel free to ask any questions necessary to myself, the principal investigator at the number 416-979-5000 ext.2564

Investigators:

Principal Investigator: Nafsin Nizum, RN, MN student, Ryerson University, Daphne Cockwell School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario

Thesis Supervisor:

Dr. Lori Schindel Martin, RN, PhD, Daphne Cockwell School of Nursing, Faculty of Community Services, Ryerson University, Toronto, Ontario.

What am I trying to discover?

I am doing this research for my Master's in Nursing thesis in an effort to understand how your loved one is resilient. In other words I would like to hear about their everyday experiences with dementia, including any challenges and strengths they may have.

What will happen during the study?

I will be conducting two interviews asking questions and speaking to him or her about things such as their culture, their experience as a new immigrant and their current life as it relates to their diagnosis of mild dementia. We will talk about things like how he/she lives their day to day life, what sorts of supports or help they have, and what strategies they use to deal with how memory loss has impacted their life.

With their permission these interviews will be audio-recorded, and will be transcribed by the principal investigator following the interview.

If they consent to participate in this study, they will:

1. Take part in two face-to-face interviews of approximately 40-60 minutes each on two different days. The length of the interviews depends on how he or she is feeling at the time. During the last interview I will summarize and verify the experiences he or she has shared with me.
2. Consent to being audio-taped during the two interviews. With their permission these interviews will be audio-recorded.

The first interview:

Upon their consent, the first interview will take place at a comfortable and private location inside the day program. The location will be quiet and private and secure from any interruptions. With their permission, I will audio-tape the interview. I will also take notes during this interview to ensure I have documented all the experiences they have shared with me. The length of this interview depends on how they are feeling at the time. It will be approximately 40-60 minutes in total; he or she can choose to end it at any time.

The second interview:

The second interview will take place approximately 1 to 2 weeks after the first interview at a comfortable and private location inside the day program. The location will be quiet and private and secure from any interruptions. With their permission, I will audio-tape the interview. I will also take notes during this interview to ensure I have documented all the experiences they have shared with me. The length of this interview depends on how they are feeling at the time. It will be approximately 20-30 minutes in total; he or she can choose to end it at any time. During this second interview I will summarize our first conversation, and ask them clarification questions or to elaborate what we discussed during our first interview.

What is experimental in this study?

There is absolutely no aspect of this study that is experimental.

Are there any risks or discomforts to doing this study?

There is no experimental treatment in this study from which your loved one could experience discomfort or distress. However, he or she may remember or speak of some unpleasant memories about their experiences with past and present challenges. At any point if he or she feels uncomfortable, they can discontinue their participation in the study either temporarily or permanently. If at any time during their participation in this study he or she feel distressed or sad and want to speak with someone, he or she will be provided with an information brochure explaining counselling programs from the local Alzheimer's chapter.

Are there any benefits in doing this study?

There will be no direct benefits to your loved one from participation in this study. It may be interesting for the participant to discuss their experiences with me, and this may represent some benefit to him or her. I hope to learn more about the strengths that persons with mild dementia have. I hope that what is learned as a result of this study will help us better understand that

persons with dementia are in fact people who are capable of facing challenges and developing personal coping strategies that could be shared with others.

Who will know what I said or did in the study?

Any identifying information obtained in connection with this study will remain confidential. No identifying information about the person will be any report of the research. In interview data and research reports, he or she will be referred to using a Pseudonym of their choice. Interview data he or she provides will be kept in a locked filing cabinet in the principal investigator's home office. Anything he or she talks about in the interviews will be kept confidential by all research study staff except in the following situations:

- a) If they give any information about experiencing abuse. As a registered nurse, I am professionally obliged to report any information I receive about elder abuse, which may be occurring now, had occurred in the past or is likely to occur. It is my obligation to bring this to the attention of a staff person who may then contact the police. If he or she shares any information about being harmed by others, a staff person of the day program will be brought in for their support.

During the interviews, what they share will be documented through note taking as well as audio recorded. This will ensure that I do not miss any of your valuable experiences shared. When I turn the interview audio recordings into writing, I will remove all the information that identifies the person. The transcripts and the demographic forms will be put in a locked cabinet in the principal investigator's home office. The consent forms will be kept in a locked filing cabinet located in the principal investigator's home office that is separate from all other information for this study. All electronic transcript data will be kept in a personal password protected computer located in the principal investigator's home office. Electronic data will also be stored on an encrypted password protected USB stick which is an electronic storage device and this will be placed away in a locked cabinet in the principal investigators home office. The information collected as part of this study will be kept as described above for a period of 2 years after the study has been completed, at which point in time, all electronic and paper information will be erased or destroyed and disposed of in a confidential manner. Reports will not show the person's name or any information that identifies him or her.

All information that is provided will not be used for any purpose other than this study. Full transcripts will only be seen by my immediate supervisor, Dr. Lori Schindel Martin. No other thesis committee members will see anything other than aggregate data (the data in a report form) that will not have the person's name or any identifying information attached. Some of your comments from the interviews may be used word-for-word to present results of the study, but no one will know that he or she was the person who said those words.

Incentives to Participate:

As a token of appreciation for your participation, your loved one will receive a \$5 Tim Horton's gift certificate after the first interview. Another \$5 Tim Horton's gift certificate will be provided for them after the second interview.

Cost and/or Compensation for Participation:

It is not anticipated that your loved one will incur any personal cost for participating in this research study.

What if the person changes their mind about being in the study?

It is their choice to be a part the study or not. If he or she decide to be a part of the study, they can withdraw from the study interview for whatever reason, even after signing the consent form. If he or she decides to withdraw, there will be no consequences to them. If they decide to withdraw, any information they have provided will be destroyed unless they say otherwise. If they do not want to answer some of the questions they do not have to, but they can still be in the study. He or she can request that audio-taping be stopped at any time. Their decision not to participate will not influence the nature of their relationship with the organization you heard about this study from or Ryerson University now, or in the future.

Questions about the Study:

If you have any questions or concerns about the study now or at any point during or after the interviews, you may contact:

Nafsin Nizum (Researcher, MN student)

nafsin.nizum@ryerson.ca

416-979-5000 ext.2564

Or

Dr. Lori Schindel Martin (Thesis Supervisor)

416-979-5000, ext. 4257

lori.schindelmartin@ryerson.ca

This study has been reviewed by the Research Ethics Board at the Ryerson University Research Ethics Board (REB). If you have questions regarding your loved one's rights as a human subject and participant in this study, you may contact Ryerson University research ethics boards for information.

Ryerson University Research Ethics Board

Research Ethics Board

c/o Office of the Vice President, Research and Innovation

Ryerson University

350 Victoria Street

Toronto ON M5B 2K3

T: 416-979-5042

Toni Fletcher, Research Ethics Coordinator

416-979-5000 ext 7112

toni.fletcher@ryerson.ca

Consent:

My signature below indicates that I have read the information in this agreement and have had a chance to ask any questions I have about the study. I acknowledge that my loved one can participate in this study if he or she wishes to do so.

Caregiver's Name (please print) _____ Date _____

Caregiver's Signature _____ Date _____

APPENDIX G

RESEARCH INTERVIEW GUIDE

** The interviews are intended to be guided conversations, with the questions likely to be fluid rather than rigid (Rubin & Rubin, 1995). As such, these are some guided questions for interview, however, the interview will be more conversation-like.*

Interview One

1. When did you move to Canada? How did you feel about leaving your country and moving to Canada?
2. Can you describe the experience of moving to Canada and settling down? Can you tell me about your life when you first came to Canada?
3. Did you face any challenges upon immigration? What sort of challenges? How did you handle these challenges?
4. What did you find helpful in settling down and making a new life?
5. Did you turn to any services in the community for help after immigration?
6. Can you tell me about how your life has evolved since immigration to Canada?

Interview Two

1. Can you describe how you felt when you received your diagnosis of dementia?
2. How did you deal with your diagnosis of dementia? What has helped you cope with your diagnosis?
3. Can you tell me how dementia has impacted your life?
4. What do you feel causes the most stress in your life?
5. How do you face such challenges?
6. What personal characteristics do you feel help you face challenges?
7. Have you sought any help and from outside sources?
8. How much importance does your culture hold in your life?
9. Are there any religious practices or rituals that help you in your day to day life?
10. In what way do you think your culture has helped (or not helped) you with dealing with your diagnosis?

APPENDIX H

Mr. Khan's Word Activity Layout

God	Namaz	satisfaction	Family
<i>I was a lawyer and practiced the law.</i>	Pakistan	satisfaction	Memory
Canada	Different communities with no interest	satisfaction	Parrot
<i>I have enjoyed Homeopathy for some time also. So I enjoyed two professions as a doctor as well as Lawyer.</i>	Confidence	satisfaction	Green
	Life		Memory
			Prayer
			<i>I belonged to Ahmadiya community and faced many difficulties in my country.</i>

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