Understanding the meanings of the personal lived experiences of spousal care partners participating a in Chronic Disease Self-Management Program

Describing the meaning and essence of the phenomenon

By

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Abstract

As predicted by the Rising Tide Study, the prevalence of dementia is increasing, and it is a chronic disease that is costly in its social, economic and health dimensions (WHO, 2012; Alzheimer's Society of Canada (ASC), 2010). As a chronic disease, dementia changes lives, and places significant physical, emotional, social, and economic burden on families (Lee & Cameron, 2004).

While there are many personal and social benefits to caring for elderly people at home, caring for loved ones with dementia is associated with well-documented increases in care partner burden, distress, and decreases in mental health and well-being (Sorensen et al, 2006). The burdens of caregiving occur so frequently that family care partners are often the "invisible second patients", and studies have shown that caring for someone with dementia can be more stressful than other caregiving and is associated with added physical and mental health difficulties (Brodaty & Donkin, 2009; Gilliland, & Bush, 2001; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Brodaty, Green, & Koschera, 2003; Sörensen, Pinquart, & Duberstein, 2002; Sarna &Thompson, 2008; Connor et al, 2008). It is recommended that health care providers support care partners to consider their own needs (Nuffield Council on Bioethics, 2009).

Chronic disease self-management programs designed to specifically meet the needs of people with chronic diseases have been evaluated and has been shown to be feasible, and beneficial beyond usual care in terms of improved health behaviors and health status, and reduced hospitalization and health care costs (Lorig et al, 2001). While self-management programs have typically focused on physical chronic conditions such as arthritis, heart disease, and diabetes, self-management programs for care partners experiencing burden of care, focusing on their own physical and mental health needs are not well established or studied in the literature. Self-management is often provided as an educational program, one of the most common being the Chronic Disease Self-Management program (CDSMP) (Bodenheimer, Lorig, Holman, & Crumbach, 2002). The CDSMP is a broadly implemented group program that educates individuals and has been shown to be effective in providing generalizable skills to help manage their chronic conditions and live well regardless of their chronic illness (Health Council of Canada, 2012a).

The purpose of this qualitative phenomenological study was to understand the experiences of care partners participating in the Chronic Disease Self-Management Program (CDSMP) while they are caring for a spouse living with dementia. The focus was on their experiences, the meaningfulness they attribute to participating in the CDSMP, whether it is helpful and suitable for them, and its overall contribution to the caring experience. A detailed exploration of the care partners' personal experiences and their personal perceptions of the CDSMP was undertaken. Their experiences were analyzed and interpreted to find essential themes that together allowed meaning of the experience to emerge. I recruited four (4) participants who had agreed to participate in the study which enabled in-depth inquiry into the essence of their experiences.

Three essential structures emerged from the data as the Vancouver School of Phenomenology process of analysis was completed: *transforming with others*, *transforming to a new normal,* and *transforming of focus*. Two themes that comprise the essential structure of *transforming with others* include sharing experiences and having a safe environment to release emotions. Two themes that comprise the essential structure of *transforming to a new normal* include a shift in roles toward new normal, and the contextual readiness for transformation. Three themes comprise the essential structure of *transforming of focus* and they include refocusing on self-care, continued self-management support, and celebrating accomplishments. Each essential structure and the thematic statements are presented in this paper with a description from the participants as evidence.

Insights from this study, based on the participants differing experiences, suggest that that in order for self-management programs to be most effective in meeting care partner needs, an assessment of program fit and any structural barriers, and consideration of the contextual readiness for transformation is imperative to the success of the intervention. A modification of the program to ensure sufficient time for dialogue between members is also reported as essential for maximum learning and transformation. The findings of this study suggest that spousal care partners of those living with dementia, who were contextually ready, participating in the CDSMP attributed their personal experiences as positive and helpful with improving their overall wellbeing.

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Dedication

I would like to dedicate this thesis to my grandparents, Mr. and Mrs. Eric and Vera Roberts. I thank you for my wonderful Christian heritage, your amazing love, and your model of what a marriage and family should be. It is because of your love, work ethic and example to me that I am able to be successful in my personal and professional life. Thank you for your encouragement over the years as I visited you every day, and for playing a major role in making me the person that I am growing to be. Thank you. I look forward to the day when we will meet again and dementia will be no more.

Table of Contents

Chapter One: Introduction

The world's population is aging, and the prevalence of chronic diseases in our society is at epidemic magnitude. Chronic disease puts stain on individuals, health systems, and communities with the prevention, management, and treatment responsibilities (Dorland & McColl, 2006; World Health organization (WHO), 2012; Stone & Packer, 2010; Barr et al, 2003).

Given that age is a primary and unchangeable risk factor for dementia, the growth of dementia is inevitable; a better understanding of dementia and how to support care partners is of increasing global importance (Gardner, Valcour, & Yaffe, 2013). As predicted by the Rising Tide Study, the prevalence of dementia is increasing, and it is a chronic disease that is costly in its social, economic and health dimensions (WHO, 2012; Alzheimer's Society of Canada (ASC), 2010). As a chronic disease, dementia changes lives, and places significant physical, emotional, social, and economic burden on people living with dementia and their families (Lee & Cameron, 2004).

Although informal or family care partners report some positive aspects of caregiving, care partners provide care to their family members at considerable cost and risk to their own psychological and physical well-being (Sörensen, Duberstein, Gill, & Pinquart, 2006; Ward-Griffin, 2012). The personal, social and health impacts of dementia caregiving have been well documented as care partners experience many challenges balancing caring with the other demands of life (Brodaty & Donkin, 2009; Schulz & Beach, 1999).

Providing support to informal care partners is essential in order to promote their well-being and prevent serious care partner burden (Zwaanswijk et al, 2013). Enhancing dementia supportive care, in order to improve the social well-being and quality of life of those living with dementia and their care partners, is integral to addressing the impact of dementia and improving public health (WHO, 2012; Hogan et al, 2008).

Acute care responses to chronic illness are no longer adequate and are inefficient and ineffective with uninvolved patients, causing unnecessary hospital admissions and readmissions to emergency rooms (Dorland & McColl, 2006; Lorig &Holman, 2003). An integrated and coordinated approach to provide support to people living with dementia and their care partners needs to focus on earlier diagnosis, provision of supports in the community, and a responsive health and social care system (WHO, 2012; ASC, 2010). Chronic diseases are gradually gaining attention in the public health arena resulting in increased acknowledgement that a more responsive approach to chronic disease is needed. Care should be proactive, and integrated within a system where clients can navigate, and are active partners in managing their condition rather than passive recipients of care (Health Council of Canada, 2012a).

Along with the health system changes required to care for those with long-term chronic conditions, self-management has also been suggested as a means of responding to the increased prevalence of chronic disease for prevention, management, and treatment (Stone & Packer, 2010). Self-management, empowering and equipping individuals with the tools that can help them to be effective partners in their own health, is one component of the Expanded Chronic Care Model. It recognizes broad prevention efforts, social determinants of health, and enhanced community participation (Barr et al, 2003; Health Council of Canada, 2010). The expanded chronic care model depicts self-management support as a key element of a system-wide approach to improving individual and population health outcomes related to chronic conditions (Health Council of Canada, 2012a). A self-management approach for persons with dementia and their care partners can enhance quality care and help meet the needs of this rapidly growing population (ASC, 2010).

The Stanford Chronic Disease Self-Management Program (CDSMP) developed by Kate Lorig and colleagues, a well-known evidence-based and widely studied program, has been evaluated as successful in improving participants' ability to self-manage their health for chronic diseases such as diabetes and arthritis (Johnston, Irving, Mill, Rowan, & Liddy, 2012; Woodcock et al, 2013). While the CDSMP has been scientifically evaluated for over 25 years across multiple populations and contexts, it has not been specifically evaluated for care partners who have reported significant burden of care (Lawn & Schoo, 2009).

Given that supporting care partners must take priority in the response to the epidemic of dementia and its impact, a study of the CDSMP for care partners of those living with dementia would be a beneficial endeavor. I evaluated this self-management program for its applicability for care partners and its contribution to the caring experience. An understanding of care partners' personal experiences as they participated in the program helped to provide a greater contextual understanding of the importance of self-management in the caregiving journey.

Chapter Two: Literature Review

2.1 Dementia

Dementia is a chronic progressive and irreversible class of disorders, due to diseases of the brain, in which there is a widespread impairment of multiple higher cortical functions, including memory, judgment, reasoning, orientation, comprehension, as well as changes in mood, behavior, communication and functional ability (Innes, Morgan, & Kostineuk, 2011). Most affected individuals demonstrate difficulties with executive functions and later develop difficulties with activities of daily living (WHO, 2012; National Institute for Health and Clinical Excellence (NICE), 2006). Dementia is associated with challenging changes in the affected persons' emotions and behaviors. Dementia not only affects the individuals living with the disease, but also greatly impacts and changes the lives of families, care partners, and communities. The complex care needs challenge the skills and capacity of care partners as complex problems arise, such as behavioral problems, wandering, mobility difficulties, communication difficulties, incontinence, eating difficulties, and delusions and hallucinations (NICE, 2006; Benedetti, Cohen, & Taylor, 2013).

A chronic disease is a long-lasting progressive condition that can be controlled but not cured (WHO, 2012). Living with dementia, a chronic condition for which there is no cure, can have a devastating effect on a person and his or her circles of support, and the impact can extend to social, economic, psychological, physical, cognitive, and cultural aspects of a person's life (Long-Term Conditions Alliance Scotland, 2008). Chronic diseases, including dementia, pose a significant expense to the health care system (Fireman, Bartlett, & Selby, 2004). Health expenditures are increasing significantly without evidence of proportionate improvement in health outcomes (Fries et al, 1993). Governments, policy-makers, and Health Authority administrators are keenly interested in whether investment in self-management support is the answer to the sustainability of healthcare by improving the quality of care, preventing complications, and hence decreasing utilization of healthcare services and reducing acute healthcare costs, and thereby allow more of the health care budget to be directed toward health promotion and prevention of disease (Wheeler, 2003).

Dementia, including Alzheimer's disease, is a global public health challenge facing our generation (Alzheimer's Disease International (ADI), 2013; WHO, 2012). Population aging is expected to lead to an increase in the prevalence in dementia (Zwaanswijk, Peeters, van Beek, Meerveld, & Francke, 2013). The prevalence for worldwide dementia among those aged 85+ is estimated at ranges from 18% to 38% (Gardner et al, 2013). Current estimates indicate that 35.6 million people worldwide are living with dementia, and the number is projected to double every 20 years with estimates of 65.7 million in year 2030, and more than triple to estimates of 115.5 million by 2050 (ADI, 2013; WHO, 2012). Worldwide, it is estimated 7. 7 million new cases of dementia are diagnosed each year, indicating one new case every four seconds (WHO, 2012).

In 2008 in Canada, approximately 500,000 individuals had dementia and the estimated prevalence by year 2038, is 1,125,200 or 2.8% of the Canadian population (Alzheimer Society of Canada (ASC), 2010). This represents one new case every five minutes in 2008, and one new case every two minutes in 2038 (ASC, 2010). The cumulative economic burden will be $872 billion by 2038 (ASC, 2010). With a shift from care facilities to home care (no formal care or community care), the increase in Canadians (65+) living at home with dementia is expected to increase from 55% to 62 % representing an additional 510,000 people by 2038 (ASC, 2010). Persons diagnosed with dementia live, on average, 7 to 10 years after diagnosis, and most of those years will be spent at home (McCurry, 2006). Population aging and the impact of the emergence of the global dementia epidemic demands attention to address the public health impact.

While the numbers are overwhelming, the significant impact of dementia on the lives of families, particularly the main care partner who provides daily care, is tremendous (WHO, 2012). A dementia care partner is typically a middle-aged or older female child or spouse of the person with dementia (Brodaty & Donkin, 2009). Most support and care is not delivered through formal care agencies, but by care partners; these care partners are often unpaid family, friends or neighbors (Innes, Morgan, & Kostineuk, 2011). Informal caregiving is a vital way in which elderly individuals are able to remain in their homes (Griffiths et al, 2010). There are more than two million informal care partners in Canada (Canadian Institute for Health information (CIHI), 2010). The unpaid care provided by families to elderly individuals results in approximately $25 billion in annual cost savings for the health care system (Hollander, Liu, & Chappell, 2009).

Given that gender is a recognized determinant of health within a population health approach, Botting, in her report on health care restructuring in Newfoundland and Labrador, noted that there is not enough attention paid to the potential for differential effects on women, men, and children as unpaid care givers with the shift from institutional to home-based care with more informal care provided at home (Botting, 2001). There is strong evidence that women are more involved in caregiving than men, including the proportion of women caregiving, the proportion that are primary caregivers, and the number of hours women spend on caregiving tasks. There are higher social expectations and lower social support for women than men since women are socialized and culturally conditioned to feel a sense of obligation to care for others (Goodhead & McDonald, 2007; Dupuis, Epp, Smale, 2004). Evidence also suggests that women and men approach caregiving differently; women tend to be more intensely involved in overall assistance to their family members than men. Women are more likely to spend more hours providing direct care in the areas of domestic and personal care, such as assisting with eating, bathing, dressing, and toileting (Dupuis, Epp, Smale, 2004). Women, particularly wives, may not view tasks such as meal preparation and housekeeping as caregiving because these activities may have always been part of their domestic roles.

The overwhelming number of people with dementia, its impact on lives, and the economic burden on families and nations makes dementia a public health priority (WHO, 2012). It is clear that dementia and its impacts cannot be neglected, and must be considered part of the public health agenda (WHO, 2012). In the report, “Dementia, A Public Health priority”, the World Health Organization (WHO) and Alzheimer’s Disease International (ADI) call for the promotion of a dementia friendly global society, emphasizing dementia as an international public health and social care priority (WHO, 2012). Their key message is also that the time to act is now by investing in health and social systems to improve care and services for people with dementia and their care partners, and to increase the priority given to dementia in the public health research agenda (WHO, 2012). Government policies and strategies that support family care partners are integral to caring for people with dementia (Health Council of Canada, 2012b). Policy development to promote formal assessment of care partners, improved support for care partners, and movement to integrated home care, will benefit both the person and care partner living with dementia, and the overall health care system as we address the "rising tide" of dementia in the future (Ward-Griffin, 2012).

2.2 Effects of caring on care partners

Care partners, also referred to as informal caregivers, carers, or primary caregivers, are defined as family members and friends who care for someone with whom they have a relationship, typically without pay, and outside the bounds of what is usual in family relationships evolving out of a relationship as a result of shifting levels of dependency (Nuffield Council on Bioethics, 2009). It is important to note that although health providers and researchers use these terms, the spouse, child or other family and friends, who provide care, may or may not identify themselves as "caregivers". Referring to a spouse or child of the person with dementia as "caregiver" can place the focus more on their role rather than on their relationship (Molyneaux, Butchard, Simpson, & Murray, 2011; Ward-Griffin, 2012). Some dislike being classified as "caregivers", as they see themselves as caring partners, relatives or friends, rather than taking on a new role with a new name (Nuffield Council on Bioethics, 2009). Therefore, within this paper, the term "care partner" will be used as a way to define those who have a relationship with the person living with dementia and partner in their care.

Care partners of people with dementia provide 75% more care than other care partners and experience nearly 20% higher levels of stress; the demands on the care partner tend to increase as the disease progresses (Alzheimer's Society of Ontario (ASO), 2005). While there are many personal and social benefits to caring for elderly people at home, caring for loved ones with dementia is associated with well-documented increases in care partner burden, distress, and decreases in mental health and well-being (Sorensen et al, 2006). The provision of care to a person living with dementia can also result in immense physical, psychological, emotional, social, and financial burden. The responsibility for unpaid caring work is more likely to fall on women's shoulders than on those of men (Botting, 2010).

Care partner strain and distress can be related to chronic health conditions (CIHI, 2010). Several studies concluded that care partners who experience chronic stress are more likely to experience negative health and psychosocial outcomes (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

As reported in the review by Sorensen et al (2006), the reported care partner impacts as a result of dementia care are differentiated according to psychosocial, physiological, health behavior and general health consequences. The psychosocial outcomes include care burden, increased depression and anxiety symptoms, decreased (confidence and belief in one's capacity to succeed at tasks), and reduced subjective well-being, quality of life, and positive experiences of caregiving. The physiological outcomes reported include increased stress hormones, poorer immune function, cardiovascular reactivity, and impaired metabolic function (Robison et al, 2009). The health behavior outcomes include poor diet, reduced exercise, and lack of sleep. The general health outcomes include poor self-reported health, increased medication use, and mortality (Sorensen et al, 2006; Braun et al, 2009). Most care partners provide a level of care that compromises their own health and well-being, as they help and support the person with dementia (Nuffield Council on Bioethics, 2009). Family care partners are often described as the backbone of the health care system, yet they are often invisible and vulnerable themselves (Health Council of Canada, 2012b).

2.3 Experience of Caring

The study of caregiving began two decades ago, and its negative impact on the well-being of care partners is well established (Russell, 2008). As the population ages and the incidence of dementia increases, the perspectives and experiences of care partners are increasingly important in designing supportive programs that decrease isolation, increase empowerment, and improve self-care (Ward-Smith & Forred, 2005). Care partners' stories indicate that when dementia comes into their lives, it often becomes the center of existence with sudden and complete changes for both the care partner and the person with dementia (Russell, 2008). Their stories tell of the satisfying and fulfilling aspects which are balanced with the stress and burden of providing care. Their personal experiences are worthy indications of the demands of providing care.

The experiences of dementia care partners have been studied using several qualitative methods; phenomenological studies indicate that care partners experience profound changes in their relationships as they described "losing" their loved one as if their "minds had been stolen" (Vellone, Sansoni, & Cohen, 2002). They report that there was a sense of loss and therefore periods of grief, and that their loved one had become childlike because of the mental impairment, and that they needed continuous supervision (Walker & Pomeroy, 1996). The primary care partners, mostly spouses, tend to avoid involving other relatives and family members because they had their own children and families (Walker & Pomeroy, 1996). The stories also describe changes in their lifestyles as they devoted their time to supervising and caring for their partner. Care partners regularly provided ongoing physical and emotional support to their partner, limiting their ability to participate in regular social activities and they may end up with a decrease in their own well-being (Bastawrous, 2013). The care partners stated that they neglect their own self-care and they have no time to eat healthy, exercise regularly, and let their "brains rest" (Bastawrous, 2013). The care partners experienced a lack of support and knowledge in caring for their loved one with dementia, and how to cope. They express the difficulties in caring, and the high stress levels. Care partners often reported that caring for their relative with dementia was physically demanding, there was a loss of hope of their loved one improving, and there was fear of the future (Zwaanswijk et al, 2013).

Dementia care partners described caregiving as being on a journey characterized by unpredictability, fear and a lack of control where the illness is progressive and irreversible (Golden, Whaley, Stone, 2012; Sarna, Thompson, 2008). They explained that in the context of dementia, there was no repair for the person with dementia, and that the "system is beginning to shut down" (Golden et al, 2012). Family members often described the experience as "enduring stress and frustration" (Butchner, Holkup, Buckwalter, 2001). One care partner reported, "I didn't realize that I was grieving… I didn't know that grieving could start with the diagnosis of an illness" (Nuffield Council on Bioethics, 2009). In the reports of care partners' experiences, there were feelings of grief, anger, guilt, distress, and resistance to utilizing respite care as it gave appearances of them not coping (Nuffield Council on Bioethics, 2009).

It is interesting to note that Greenwood et al's systematic review of qualitative studies on caregivers revealed that care partners rarely used the term "burden" to describe their caregiving experience despite the frequency of the term in the literature (Greenwood, Mackenzie, Cloud, & Wilson, 2009; Bastawrous, 2013). Despite the significant challenges associated with caregiving for those with dementia, many care partners report a genuine sense of accomplishment, satisfaction, and pride in their role (Sarna, Thompson, 2008).

Reviews of the dementia caregiving literature demonstrate an increase in attention to the experiences of family care partners, with a focus on the well-documented strain and physical, social and financial burden experienced (Brodaty & Donkin, 2009). The experiences of people with dementia and family care partners have much to offer in the understanding of the most important causes and the most important interventions in times of crisis (Toot, Hoe, Ledgerd, Burnell, Devine, & Orrell, 2013). Understanding the experiences of care partners is pivotal in the design of effective support services, and understanding the complex family care partner phenomena serves as a guide for developing interventions (Chan, Mok, Wong, Pang, & Chiu, 2010).

2.4 Factors that impact the caregiving experience:

The literature portrays a broad range of caregiving experiences, from extremely taxing to more positive and enriching (Shim, Barroso, & Davis, 2012). The effects on care partners are diverse and complex, and many factors may intensify how care partners react and feel as a result of their role (Brodaty & Donkin, 2009). The care partner health and wellness is thought to be moderated by a variety of factors including economic and social supports available, gender, care partner personality attributes/personal characteristics (such as optimism, self-esteem and self-mastery), culture, coping strategies used, functional abilities of the person living with dementia, secondary role strains, the quality of the relationship between care partner and person diagnosed with dementia, and marital communication (Etters, Goodall, & Harrison, 2008; Braun, Mura, Peter-Wight, Hornung, & Scholz, 2010; Brodaty &Donkin, 2009).

In a review of studies of caregiving, strong relationships before a diagnosis of dementia were found to help maintain well-being when caregiving (Quinn, Clare, &Woods, 2010). Care partners who express a positive caregiving experience describe both their past and present relationship in loving terms and expressed satisfaction with caregiving and not being highly burdened by caregiving (Shim et al, 2012). Care partners experienced less depression and stress when there was positive spousal communication (Braun et al, 2010). The limited evidence currently available indicates that care partners' well-being could be influenced by the nature of their motivations to care and the meaning the care partner finds in caregiving. Family care partners may be motivated to provide care for many reasons, including a sense of love, spiritual fulfillment, a sense of duty, or social pressures (Brodaty & Donkin, 2009; Quinn et al, 2010). Care partners who are motivated by guilt, sense of duty, or social and cultural norms are more likely to resent their role experience, and suffer greater psychological distress than care partners with more positive motivations (Brodaty & Donkin 2009). Finding meaning, and altruistic motivations can positively impact the care partners' well-being (Quinn et al, 2010). Schoenmakers et al (2010) in their systematic literature review concluded that care partner characteristics are more likely to be responsible for depression in care partners than the objective care needs of the person with dementia.

When looking at dementia care in rural and remote settings, Innes et al (2011) noted that the provision of care support and services is often less available. Rural care partners have access to fewer formal supports and have special needs regarding the management of behavioral problems in care recipients and in the promotion of healthy behaviors for themselves (Bédard, Koivuranta, & Stuckey, 2004). Gender, age, educational level, and ethnicity can influence the way care partners view their role (Broadaty & Donkin, 2009). Women care partners tend to experience more family conflicts, psychological stress, and depression (Ducharme et al, 2011a). Spousal care partners, as compared to offspring care partners, appear less able to respond to their loved ones' disruptive behaviors, make less use of problem-solving strategies, and report fewer family conflicts (Ducharme et al, 2011a).

Increased care partner burden is related independently to increased levels of behavioral disturbance in the person with dementia and to decreased levels of informal social support (Coen, Swanwick, O'Boyle, & Coakley, 1997). Behavioral problems are quite common in dementia and are perhaps the most difficult stressor faced by care partners (Zarit & Femia, 2008 a).

Zarit and Femia propose that discovering what interventions would be best for care partners depends largely on the coping methods prior to providing the intervention, and the success of interventions will be related to how they are individually tailored (Zarit &Femia, 2008 a; Innes et al, 2011). Passive coping strategies were associated with increased burden and decreased health related quality of life (Riedijk, Toot, Hoe, Ledgerd, Burnell, Devine, & Orrell, 2006). Studies support psychological interventions for care partners that aim to modify coping style (Li, Cooper, Bradley, Shulman, & Livingston, 2012). More preparedness is associated with less strain for family caregivers with less conflict (Wang, Shyu, Tsai, Yang, & Yao, 2012). Personal mastery appears to reduce the effects of caregiving stress on depression and health outcomes over time (Mausbach, et al, 2007). Fatigue is related to decreased personal mastery, and this relationship must inform interventions with the aim of alleviating fatigue in care partners (Roepke, et al, 2009).

Although it is well established that care partners experience negative health impacts, the protective factors that enable some care partners to maintain low levels of distress are not well established (Sorensen et al, 2006). More studies of the predisposing factors or predictors of improved health are needed to support care partners. Valuable lessons may be learned from care partners who report positive caregiving experiences related to the dynamic between the care partner and the person with dementia (Shim et al, 2012).

2.5 Impact on care partners

Many dementia care partners experience a considerable care burden, including feelings of depression, stress and decreased physical health (Schoenmakers, Buntinx, Delepeleire, 2010). Studies have consistently shown that care partners have elevated depression rates (Walker & Pomeroy, 1996). Feeling burdened or distressed, with symptoms of depression and anxiety are the most frequently reported outcome associated with caregiving, particularly among spousal caregivers (Schulz & Beach, 1999). Those who care for people with dementia report higher levels of stress, depression, and anxiety disorders, and lower levels of subjective health and psychosocial well-being and self-efficacy compared with non-care partners (Brodaty & Donkin, 2009).

Behavioural and psychological symptoms have a high prevalence among people living with dementia which can be a significant source of distress, and is associated with lower quality of life in the individual living with dementia and their care partners (Hurt et al, 2008). Stress can significantly influence the health and quality of life of an individual by its effects on psychological and physical health such as depression, immune system changes, and hypertension (ASO, 2010). The negative effects of caregiving on physical health are most likely to be found in psychologically distressed care partners facing dementia-related stressors (Pinquart &Sorensen, 2006).

In 1999, Schulz and Beach concluded that being a care partner experiencing mental or emotional strain is an independent risk factor for mortality among spousal care partners (Schulz &Beach, 1999). With the duties of caregiving, care partners often report a reduction in physical activity and quantity and quality of sleep (Bedard, Koivuranta, & Stuckey, 2004). Care partners' responsibilities often continue day and night and this may have significant practical consequences of additional stress and exhaustion due to broken nights, thus affecting the health of the care partner. Often, care partners demonstrate lower rates of engaging in preventative health behaviors, disruptions to paid employment, and personal, financial, family and social problems (Robison et al, 2009). Insomnia, fatigue, burnout and pain were also prominent symptoms reported by care partners (Horner, Jiwa, Cuesta, Fyfe, & Osborne, 2012). Depression is the most stated factor affecting care partners' sleep; sleep disturbance is associated with poor mental health and physical health, reduced quality of life, and elevated inflammation levels (Peng, & Chang, 2013). The burdens of caregiving occur so frequently that family care partners are often the "invisible second patients", and studies have shown that caring for someone with dementia can be more stressful than other caregiving and is associated with added physical and mental health difficulties (Brodaty & Donkin, 2009; Gilliland, & Bush, 2001; Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999; Brodaty, Green, & Koschera, 2003; Sörensen, Pinquart, & Duberstein, 2002; Sarna &Thompson, 2008; Connor et al, 2008).

In summary, the effects of being a family care partner, though sometimes positive, are generally negative, with high rates of burden and psychological morbidity as well as social isolation, physical ill health, and financial hardship (Brodaty &Donkin, 2009). This is commonly assessed by self-report rather than by clinical rating scales or structured interviews (Schultz & Beach, 1999).

Significant care gaps exist for people with dementia and their family care partners related to limited early detection, primary care support, and access to community resources (McAiney et al, 2012). Many care partners wait until they face a crisis or become overburdened before they seek help (McAiney et al, 2012). The challenges associated with caregiving include lack of informal support, lack of knowledge of disease progression, lack of preparedness to provide care, lack of access to home adaptation and assistive technology, and difficulties planning for future care needs (Ducharme, Levesque, Lachance, Kergoat, & Coulombe, 2011a).

2.6 The needs of care partners and the need for intervention

An understanding and assessment of care partners' challenges and needs is essential to develop interventions and supports that are tailored to their needs to positively impact their well-being (Zwaanswijk et al, 2013). Assessing the needs of both people with dementia and the care partners are integral to meeting their needs and they should be engaged in the delivery of tailor-made interventions (Beeber & Zimmerman, 2012). While it is important to consider the perspective of both the person with dementia and the care partner, the distinct needs of family care partners must be considered (Sarna, & Thompson, 2008; Braun, Scholz, Bailey, Perren, Hornng, & Martin, 2009). Care partner supports must be comprehensive, accessible, long term, and encompass educational, emotional, and instrumental support (Gan, Gargaro, Brandys, Gerber, & Boschen, 2010). As the needs of care partners are multiple and diverse, they can be assisted in varied ways.

2.6.1 Information and knowledge needs

There is strong consensus that all care partners would benefit from enhanced knowledge about dementia, the caregiving role, and the resources available (Biegel, & Schultz, 1999; Koch, & Lliffe, 2010). A high proportion of care partners report that getting information about the course of the disease of dementia, available supports, and having someone to talk to, were very important (Alwin, Oberg, & Krevers, 2010). The needs that care partners' express are mainly related to an early detection, an accurate diagnosis and a better knowledge of the disease and its progression (Koch, & Lliffe, 2010; Rosa et al, 2010).

The top informational needs identified by dementia care partners deal mostly with understanding the disease trajectory, dealing with behavioral changes in the person to whom care was provided and information on managing their own stress (Koenig, Steiner, & Pierce, 2011). Care partners require knowledge, technical skills, and judgment to carry out the tasks of care for their loved ones and research has shown that care partners who feel prepared to deliver care feel less burdened (Reinhard et al, 2008). An interpretative phenomenological analysis of the experience of providing care in the context of dementia emphasized the importance of helping family members gain an enhanced understanding of the condition as it found that a limited understanding of dementia appeared to add considerably to the difficulties faced by care partners (Quinn, Clare, Pearce, & van Dijkhuizen, 2008). The provision of support and information should be tailored to individual needs (Robinson et al, 2011). There is an identified need for follow up for both the person with dementia and their care partner from the time of diagnosis.

Strengthening care partners' competence and confidence improves their mastery, and interventions designed to improve specific tasks and problem-solving skills are helpful and decrease negative behavior in those they care for (Reinhard et al, 2008). Care partners who are well informed are better equipped to address the problems that dementia presents (Rabins, Lyketsos, & Steele, 2006). In addition to information on day-to-day care, and coping with symptoms, the literature also indicates important information needs related to legal, financial, and treatment (Koenig et al, 2011).

A recent review concluded that there is a need for communication skills training in dementia to improve the positive interactions (Eggenberger, Heimerl, & Bennett, 2013). Communication with care partners needs to be clear, and provided in terms that they can understand. Communication is an important part of action planning, and improving care partners communication with the person can significantly improve confidence to make changes (Vella, 2008). Communication skill training significantly improves the quality of life and well-being of those with dementia (Eggenberger, et al, 2013).

In addition, after the knowledge needs are met, the caregiver requires training in problem solving skills, and specific skills in managing behaviors. It is recommended that care partners be given practical advice on coping with the symptoms of dementia, and how to deal with the behavior of the person with dementia (Zwaanswijk et al, 2013). Care partners report that they need information and supportive guidance as to how to cope with behavioral problems, how the disease progresses, and how to effectively coordinate dementia care (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). Information regarding the role of contextual factors in behavioral management should be made available to care partners (Hurt et al, 2008). As care partners struggle with complex behaviors that often manifest as part of dementia, practitioners can teach them how the social and physical environments influence behavior, and model strategies that help facilitate improved functioning in the person with dementia (Piersol, Earland, & Herge, 2012).

2.6.2 Need for professional support for emotional coping with symptoms of dementia

Most informal care partners indicate a need for additional care partnerships and professional support (self-management support) in caring for the person with dementia (Zwaanswijk et al, 2013). Care partners identify needing professional support to provide practical advice, emotional support, and information about the progression of dementia, and how to link with community resources and supports available (Nuffield Council on Bioethics, 2009). Family members need to interact with the health care system to obtain information, services and equipment, as well as to negotiate with family and friends to mobilize support (Reinhard et al, 2008). Comprehensive management of the person with dementia includes building partnerships between health professionals and family care partners (Brodaty & Donkin, 2009). Professional support should have a wide focus that includes support for the care partners rather than being limited to exclusive focus on the person with dementia; this requires a shift from a medical model of service delivery to a broader social determinant of health and primary health care model (Nuffield Council on Bioethics, 2009).

There is an identified need for financial and social support for care partners in order to ease the stress and financial hardship incurred when caring for a person with a chronic illness, such as dementia (Nuffield Council on Bioethics, 2009). There are financial costs associated with caring such as lost earnings, respite care, and adaptive and assistive technologies (WHO, 2012). In many provinces, including Newfoundland and Labrador, there are family care partner allowances provided. In rural Newfoundland and Labrador, specifically Springdale, there is difficulty in recruiting home care workers for respite care, as they are non-unionized and low paid. Additionally, home care workers often have little formal education and training in most cases. The financial and social needs can be met by informing care partners of the community and financial supports to which they are entitled and can access in their community (Nuffield Council on Bioethics, 2009). A need for patient navigators, advisors or community network facilitators to ensure care partners of those with dementia are better informed and supported as they navigate the health care system has been identified (Greene, Aranda, Tieman, Fazekas, & Currow, 2011; Nuffield Council on Bioethics, 2009).

Determining appropriate support services is heavily reliant upon care partner assessment (Feinberg, 2008). Given care partners essential role in caring for family members with dementia, and the negative impacts documented, their needs and capacities to provide care should be carefully assessed by community supports professionals (Reinhard et al, 2008). This individual assessment of the care partner has been recently added to the new Inter- RAI assessment of the patient with dementia living at home in Newfoundland and Labrador (Suzanne Brake, Director of Aging and Seniors, Government of NL, personal communication, June 21, 2013). Recognizing the need for individualized care partner assessment, many studies recommend that care partners need structured, individual, and regular assessments to reinforce the importance of maintaining and managing their health (Aggar, 1993). Home assessments for specific needs of care partners and persons with dementia are associated with care partners' sense of mastery (Connor et al, 2008). Assessing the needs of both the person with dementia and the care partner is a prerequisite for linking care partners to resources and adherence to a comprehensive plan of care (Reinhard et al, 2008).

Assessing care partner needs, and providing support is a proactive approach that helps with avoidance of crises in caregiving, and thus prevention of crisis institutionalization and inappropriate bed utilization in emergency rooms and acute care units for those living with dementia. Also, care partners' utilization of ER and acute care is associated with their depression, the patients' behavioral and psychological symptoms, and the patients' functional status (Schubert, Boustani, Callahan, Perkins, Hui, & Hendrie, 2008).

A review of the literature shows that there are significant unmet respite needs, and a majority of care partners identified a need for provision of high quality respite care that is flexible to meet the varied needs of care partners (Jeon, Brodaty &Chesterson, 2005). As dementia progresses, the needs of both the person with dementia and the care partner change, and eventually it may be appropriate for formal services such as respite care, day center care, formal support within the home, and possibly institutional care (Nuffield Council on Bioethics, 2009).

2.6.3 Need for technology to meet needs

There appears to be great interest among care partners of persons with dementia in support services via telephone support, and online computer support, to meet their needs (Colantonio, Cohen, & Pon, 2001). The Internet holds much promise as a method of delivering various forms of support. Many web-based programs already exist, but there are some concerns about a digital divide between patients and care partners who are able to use technology effectively and those who cannot due to access, literacy or health (Health Council of Canada, 2012b). Interventions employing technology have a positive effect on the care partner and are especially important for those who live in rural areas (Thinnes & Padilla, 2011). There is exploration of the use of internet technology for psychoeducation and support with dementia caregivers, and participants express satisfaction (Hayden, Glynn, Hahn, Randall, &Randolph, 2012). Technology, especially the Internet as a medium removes the barrier of care partners' accessing support when there is no respite care. Smartphones, and the growth of online interaction through websites and social networking provide new opportunities for care partners of people with dementia to learn and share information. In addition, new technological advances in assistive devices and electronic monitoring programs such as the Philips Lifeline ^{TM,} care partner mobile applications, Medic Alert Safely Home ^{TM}, and care programs such as personal emergency response system provide opportunities to help with the challenges of supervision and improved safety (Atlantic Institute on Aging, 2011).

2.6.4 Need for intervention

In the early 1985, Haung posed the rhetorical question of "home care for the elderly- who benefits?" Once the toll of caregiving was ascertained, she reports that if caregivers relieve the health institutions of providing care, there must be ways found to lighten the burden and compensate families for their efforts (Haung, 1985). While we acknowledge the shared responsibility of partnering in care, and the added value that people living with dementia express by being able to age at home, it is still ever evident that care partners may be a vulnerable population who often neglect their own health needs and thus have poor health outcomes, and need support in order to manage their own health, and to provide quality care to their loved one (Dellasega, 1990).

Without care partners, people with dementia would have poorer quality of life and would need institutional care more quickly, but the support they provide comes at a cost of care partner distress and poorer quality of life (Brodaty & Donkin, 2009). When family care partners are supported in the community, with informational, emotional, and instrumental resources, the difficulties of caring are lessened, and it can lead to the provision of higher quality of care and better well-being for care partners (Brodaty & Donkin, 2009). Conversely, when care partners lack support and resources, they experience greater financial, physical, and psychosocial costs compromising the quality of care and care partner health outcomes (Bastawrous, 2013). Families and care partners make a significant contribution to helping keep those living with dementia at home. The family is still the main support and without this support, there would be a high demand for home care services on the health care system. Health services to support families are inadequate and there is need for inclusion of family care partners as clients of the health care system to prevent care partner health problems (Ducharme et al, 2011a).

Interventions to support care partners' health and well-being are important not only for decreasing reliance upon the formal health care system for those living with dementia, but also to decrease the burden of caring thereby improving the quality of life and health outcomes of care partners, promoting population and public health. In additional to the ethical reasons for supporting care partners, a pragmatic financial point can also be made that the only affordable way to provide care for people with dementia is for support to be delivered through care partners (Nuffield Council on Bioethics, 2009). The care partner should be able to have some self-care time and not feel solely responsible for the care needs of the person with dementia (Nuffield Council on Bioethics, 2009). Reliance upon care partners without being cognizant of the care partner's abilities to provide the care, and an assessment of their needs can create a stressful environment for the care partner and person with dementia (Navaie-Walsier, Feldman, Gould, Levine, Kuerbis, & Donelan, 2002). Care partners need support in information and skills to develop healthy responses and make informed decisions about their life.

A care partner who cannot cope requires support in order to care for the person with dementia at home; otherwise, the care partner will become a patient of the system and the person with dementia may end up moving into a long term care facility or acute care bed at a hospital. The failure to support care partners may result in negative consequences that may outweigh the benefits of treating and supporting people with chronic diseases themselves (Ranmuthugala, Nepal, & Brown, 2009). The efforts to support those living with dementia and their care partners to help them stay in their homes for as long as possible are an example of creating supportive environments. Interventions to reduce care partner burden have the potential to reduce care partner stress, improve care partner health, improve quality of care to person with dementia, and reduce premature admission to residential care, thereby improving population health outcomes (CIHI, 2010).

Supporting and ensuring the well-being of care partners translate into better outcomes overall as care recipients receive higher quality of care, and care partners remain healthy. The support can be either instrumental support for assistance with daily living needs, emotional support, or informational support (Brodaty & Donkin, 2009). The benefits gained from the shifting of long term care to the community via informal care partners can potentially be enhanced if care partners are supported effectively and the health needs of care partners met (Ranmuthugala, Nepal, & Brown, 2009). Supported care partners result in more knowledgeable and confident care partners who have less stress, and place fewer demands on the healthcare system (Connor et al, 2008). Interventions supporting care partners have been shown to be effective at increasing knowledge, reducing stress and depression levels, and delaying nursing home placement (Brodaty & Donkin, 2009).

2.6.5 Current interventions for care partners (what is presently working)

Interventions for care partners that have been studied can be classified into three broad categories- educational, support, and multi-component (Sorensen et al, 2006). Some interventions are designed to support care partners in their role by skills training, general dementia education, communication training, psychoeducation, support groups, and leisure programs. Other formal interventions include care planning, respite services, psychotherapy, and case management. The literature also indicates an array of methods for delivering interventions to care partners including on-line support workshops, telephone support and group sessions. Telephone support groups showed increases in knowledge and skills (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006). A pilot study of an Internet-based workshop, "Building Better Caregivers" showed significant reductions in care partner burden, depression, pain, and stress, and improvements in self-efficacy, and overall health. The on-line 6-week program reaches rural care partners, and participation was high (Lorig et al, 2010).

Case management, or consultation intervention includes practical advice and information, family consultation, and referrals to community resources. Case management has been reported to have mixed results on outcomes (Parker, et al, 2008). A systematic review by Peacock, and Forbes concluded that case management increased the likelihood of utilizing available formal support services (Peacock, & Forbes, 2003). The First Link TM program, an initiative of Alzheimer's Societies, which aims to link individuals with dementia and their care partners with support services has been shown to connect individuals to the services earlier in the disease process, increase capacity for dementia care, and improve awareness of available community services and resources (McAiney, Hillier, Stolee, Harvey & Michael, 2012; McAiney, Harvey, & Schulz, 2008).

Psychotherapy includes individual or group based behavioral and cognitive-behavioral therapy (CBT). CBT techniques are most common and help the care partner focus on identification and modification of beliefs, and development of a new behavior repertoire to deal with caregiving demands and promote subjective well-being (Pinquart &Sorensen, 2006). CBT studies report a reduction in depression and anxiety and positive impacts on coping and the persons with dementia's behavior (Parker, Mills, & Abbey, 2008). Stress management interventions can also effectively reduce the effects of chronic disease among care partners (Long, et al, 2004). A randomized trial studying the effects of a psychological intervention in a primary health care center for care partners of dependent relatives showed improvement in mental health condition (Rodriguez et al, 2012). Psychosocial interventions that focus on helping care partners cope better with their emotional state, reduce social isolation, and ways to deal with difficult circumstances have been shown to have positive effects on burden and satisfaction, especially early in the progression of dementia (Andren & Elmstahl, 2008).

Psychoeducation is the structured presentation of information about dementia, stress management, and techniques to manage behavior (Pinquart & Sorensen, 2006). "Empowering family caregivers: the powerful tools for family caregiving program" is an education program for family caregivers of older adults. This program is based on a self-efficacy model, and empowers family care partners to reduce the negative effects of caregiving and to practice self-care. An evaluation of this program showed high satisfaction ratings and reported improvements in self-efficacy, emotional well-being, and self-care behaviors, although there was significant drop out in the program (Boise, Congleton, & Shannon, 2005). A systematic review by Parker and colleagues, (2008) concluded that there is no significant impact of psycho-educational interventions found for the outcomes of well-being, self-efficacy or health, but significant results were found for depression and burden, although no follow up analysis was for longer than 6 months. Educational components integrated into comprehensive and individualized interventions including problem solving, and behavioral management strategies will improve dementia care partner support (Ducharme et al, 2011a).

Support groups provide opportunities for care partners to share personal feelings, encourage mutuality, and overcome social isolation. As with psychoeducational interventions, studies have concluded that support-only interventions demonstrate a significant improvement on care partner burden (Parker et al, 2008). A meta-analysis of care partner support groups in patients with dementia showed a significant positive effect on caregivers' psychological well-being and social outcomes (Chien, et al, 2011). A study by Chu et al (2011) showed decreased depression levels but no significant difference in care partners' burden after the support group intervention.

Respite care is a valuable intervention that allows other interventions to be implemented, as it is reported by care partners that they are often unable to travel to sessions and support groups because they have no one remaining at home to care for the person with dementia (Zarit & Femia, 2008a). Respite is substitute care to provide planned, temporary relief to the care partner through day care programs, in home respite, or institutional respite. In a study by Sussman and Regehr (2009), exploring the influence of community-based services on the burden of spouses caring for their partners with dementia, it was concluded that the most effective service is the provision of adult day programs which provide not only respite for the care partner, but also opportunities for social interaction for the individual with dementia. Offering respite care to informal care partners reduces caring duties, and enables them to spend time maintaining their social contacts with friends and relatives (Zwaanswijk et al, 2013). Care partners report an improvement in sense of well-being, reduction in fatigue, and increased opportunity for socialization with respite care programs (Hayes, 1999).

Other technological monitoring systems to manage the activity of persons with dementia have shown decreased anxiety in care partners and they report a "peace of mind", and improved quality of sleep (Lauriks, et al, 2007). In-home messaging units to educate and support family care partners have been studied and show promise in being valuable to care partners (Griffiths et al, 2010). Telephone-based multicomponent care coordination programs have been studied and conclusions indicate that it is a feasible model to support care partners through ongoing care coordination (Judge, Yarry, Looman, & Bass, 2012).

Multicomponent interventions involve combining components from different interventions, such as education, support, and respite, to address multiple stressors and risk factors (Zarit & Femia, 2008a; Parker et al, 2008). Studies report multi-component interventions as having significant outcomes across a broad range of outcome measures including self-efficacy, depression, well-being, and burden (Parker et al, 2008). As part of the REACH (Resources for Enhancing Alzheimer's Caregiver Health) project, several multicomponent extended period (6 months) interventions have been evaluated and support their use for outcomes of depression and care partner burden reduction (Burgio, Collins, Schmid, Wharton, McCallum, & DeCoster, 2009). Given the complexity of the caregiving experience, the variability in care partner resources, and the variety of outcomes, there is likely no single, easily implemented effective silver bullet solution for eliminating the stresses of caregiving (Biegel &Schultz, 1999).

In summary, a literature review of recent studies suggest that current interventions are overall effective and meaningful on reducing burden and depression, increasing knowledge and subjective well-being, but that sometimes the effects are somewhat small and domain specific (Sorensen et al, 2006; Brodaty et al, 2005; Gonyea, O'Connor, & Boyle, 2006). The most effective treatments for care partners have four overlapping characteristics: a psychological rather than purely educational approach, multidimensionality, flexibility, and sufficiency in the amount (Zarit & Femia, 2008b). Maintenance of the effects after the end of the intervention has not been well studied. Factors associated with more successful interventions are the extent to which they are tailored to the needs of the individual and address issues related to subjective burden, involvement of the care partner and person with dementia, and longer term involvement (Pinquart &Sorensen, 2006). Interventions that are individualized to fit the specific needs, values, and beliefs of care partners are most successful and supportive. Evidence suggests that individually developed multicomponent interventions including a diversity of services will decrease burden or distress, improve quality of life, and enable care partners to provide care at home for longer periods of time (Etters et al, 2008; Lorig &Holman, 2003). Interventions that simultaneously consider the person with dementia and the care partner are likely to achieve the largest effects (Schultz, & Martire, 2004).

<u>Methodological issues proposed as reason for small effects</u>:

Zarit and Femia (2008) identified some of the methodological issues that affected previous studies of current interventions, and offered strategies for addressing the limited effectiveness. Zarit and Femia argue that their examination of the literature suggest that the research strategies used for testing the effectiveness of interventions have not been optimal and the limitations in the approaches may have contributed to the positive but small effects in the above mentioned meta- analyses (Zarit & Femia, 2008b).

One methodological issue in past studies that may have affected the limited findings include a basic problem of viewing caregiving as a disorder, like depression, assuming that all care partners are depressed or experience subjective burden, and thus participants are screened on their caregiving involvement and not on their depressive symptoms (Zarit & Femia, 2008b). The goal of the interventions may have been to produce an outcome of reduced depression, but some participants may have not been depressed. Another methodological issue identified in past studies is the assumption that all care partners have the same risk factors, for example behavioral problems. Treating care partners for symptoms that they do not have is impractical, and likewise it is also not useful to target care partners for treatment of a risk factor unless the risk factor is present (Zarit & Femia, 2008b). Assessing the care partners' needs, and asking why they are seeking support is important when considering the types of interventions to offer.

Future studies evaluating interventions need to focus on a particular outcome measure (i.e depressive symptoms) and select care partners who have a minimum threshold of symptoms, allowing for a sample that would make it possible to detect treatment effects (Zarit & Femia, 2008b). The care partners' treatment group being studied also needs to actually receive the planned treatment with consideration for how much treatment is necessary to produce a change in the desired outcome. Further, intervention trials should engage care partners in discussion and target treatments for the problems that care partners identify and measure outcomes based on care partners' goals. Acknowledging that family care partners are a heterogeneous group, varying from one another on socio-demographic characteristics, their exposure to care related stressors, their subjective responses to the stressors, and their resources, will lead to interventions and evaluations that do not assume a tailored one size fits all treatment (Zarit & Femia, 2008b). Conceptually and theoretically sound interventions with reliable and valid outcome measures that adequately measure the constructs of the intervention are needed for future intervention trials (Parker et al, 2008).

2.7 Chronic disease self-management

The prevalence of long-term chronic disease, and the associated burden continues to escalate as the population ages. As this incidence increases, there is an impending crisis and effective strategies to prevent and manage chronic diseases are essential (Barr et al, 2003). The alarming increases in chronic conditions, including dementia, and the burden on individuals and families has led many developed countries to redirect part of their care from a medically-focused diagnosis and treatment model to a patient-focused prevention and self-management approach (Gurria, 2010; McWilliam, 2009). The present health care system designed to respond to acute illness cannot deliver adequate results in managing chronic diseases. Acute illnesses are responded to, while chronic diseases need to be managed, and this distinction has led to the development of new models of care, including self-management programs (Dorland, & McColl, 2006).

Self-management is the process each person develops to manage his/her conditions (Long-Term Conditions Alliance Scotland, 2008). One of the significant components of chronic disease management includes patient self-management programs in which individuals play an active role in managing their diseases. Self-management is a person-centered approach, is dynamic and reflects an ethos of empowerment (Long-Term Conditions Alliance Scotland, 2008). Lorig defined self-management as "learning and practicing skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" (Lorig, 1993, p. 11). Adams, Greiner, and Corrigan (2004) have defined self-management as "tasks that an individual must undertake to live well with one or more chronic conditions; these tasks include gaining confidence to deal with medical management, role management, and emotional management" (Adams, Greiner, & Corrigan, 2004, p. 57). Self-management programs can be effective in assisting people living with chronic conditions to learn new skills, organize their lives, and create a sense of order as they deal with the transitions and responses to illness (Kralik, Koch, Price, &Howard, 2004; Newbould, J., Taylor, D., & Bury, M. (2006).

Self-management is a common term in health education and health promotion programs (Lorig & Holman, 2003). Self-management is not a replacement for services, and is meant to empower the person with the information, skills, and confidence necessary to cope with the chronic illness, recognizing that it does not mean managing alone or that the burden of care rests solely with the person. It is about self-determination in partnership with supporters (Long-Term Conditions Alliance Scotland, 2008).

Chronic disease self-management programs designed to specifically meet the needs of people with chronic diseases have been evaluated and has been shown to be feasible, and beneficial beyond usual care in terms of improved health behaviors and health status, and reduced hospitalization and health care costs (Lorig et al, 2001). Evidence suggests that self-management programs can reduce the impact of chronic conditions, but it is not a cost free option. It requires resources be redirected into self- management with a focus on developing social capital through supporting informal care partners. Self-management helps people come to terms with the diagnosis, supports people to navigate an often difficult journey, supports changing needs, maintains focus on a person's needs ensuring services are organized around these, and supports the person to meet a range of challenges and to maintain control (Long-Term Conditions Alliance Scotland, 2008).

There are a number of self-management programs with common approaches used to enhance self-management (Stanford program, the Flinders program, the 5 A's, health coaching, etc.), and having health services work together to provide support is important in all approaches (Lawn & Schoo, 2009). There is an understanding that being actively engaged in one's own care is very beneficial for those living with chronic conditions; "People feel better and use health services differently when they have information, skills, and confidence to manage the physical and emotional impacts of their disease/burden" (Health Council of Canada, 2012a, p. 1).

Self-management is often provided as an educational program, the most common being the Chronic Disease Self-Management program (CDSMP) (Bodenheimer, Lorig, Holman, & Crumbach, 2002). Self-management education is problem-based, and focused on patient concerns and perceived problems (Lorig & Holman, 2003). Problem solving, decision-making, resource utilization, partnering with health care providers, taking action (skills mastery), and enhancing self-efficacy are core components of self-management programs (Lorig & Holman, 2003). The outcome of self-management with individuals having the knowledge, skills and confidence to manage their health and engage in healthy behaviors is brought about through the process of self-management education (McGowan, 2005). Traditional patient education provides information, whereas in self-management education teaches problem-solving skills and empowers the person to manage their condition. Programs teaching self-management skills are more effective than information-only patient education in improving clinical outcomes (Bodenheimer, Lorig, Holman, & Crumbach, 2002).

Traditional health promotion and education programs operated on the premise from epidemiological studies that people should change their behaviors to improve health status (Bodenheimer, Lorig, Holman, & Crumbach, 2002). While an improvement in healthy behaviors improves health status, it is not clear if this assumption holds true for those already living with chronic conditions. It is proposed that the improvements in health status are due to enhanced feelings of control of their illness and thus the attentions to self-efficacy theory (Lorig & Holman, 2003). Studies have shown that changes in self-efficacy were associated with changes in health status, and therefore self-efficacy must be considered a key component of self-management programs structured to include performance mastery, modeling, interpretation of symptoms, and social persuasion (Lorig & Holman, 2003).

While self-management programs have typically focused on individuals living with physical chronic conditions such as arthritis, heart disease, and diabetes, very little attention has been paid to the potential role of self-management in supporting care partners. It is essential that care partners be supported in considering their own interests, as well as those for whom they care (Nuffield Council on Bioethics, 2009). It is recommended that health care providers support care partners to consider their own needs (Nuffield Council on Bioethics, 2009).

2.7.1 Self-Management Support

The 2008 Canadian survey of experiences with primary care providers suggest gaps in self-management support including providers asking their patients about their goals in caring for their chronic conditions, and referring them to community resources that might help them reach those goals (Health Council of Canada, 2010). Self-management support is not just educating patients about their condition; it includes involving patients in goal setting, checking in with them on their progress, and connecting them with resources and supports (Health Council of Canada, 2010). Self-management support involves health providers collaboratively helping patients and their families to acquire new skills and confidence to enable them to manage their own chronic illness (Bodenheimer et al, 2002).

The systematic provision of assistance by health care providers and others is known as self-management support (Health Council of Canada, 2012a). Self-management support empowers the person with the skills necessary to cope with the chronic illness, recognizing that it does not mean that the burden of care rests entirely with the person. It is important that health professionals involved in dementia care provide support to informal care partners with education and coaching during the entire journey of caring for a person with dementia (Zwaanswijk et al, 2013).

2.7.2 Stanford Chronic Disease Self-Management Program

The Stanford Chronic Disease Self-management Program (CDSMP) developed in the mid-1980's and licensed by Stanford University in California is a program of highly participative classes, where mutual support and success build the participants' confidence in their ability to manage their health and maintain active, fulfilling lives. The Stanford program is peer-led and thus likely to be relevant to the lived experiences of the care partners. It focuses on problem solving, and goal setting from the person's perspective, and therefore patient motivation will likely be high. The group work involved in the Stanford program reduces isolation and facilitates self-efficacy (Lorig, Gonzalez & Laurent, 2012).

The program is a six-session program that occurs once a week for six weeks, and each session is two and a half hours. The in-person workshops are offered to group sizes of 10–16 participants. The CDSMP is a widely used and adapted self-management group program that is intended to help people living with chronic diseases to develop generalized skills and obtain the knowledge to become active partners in their own care, and to manage their chronic conditions and live well regardless of their particular illness (Health Council of Canada, 2012a).

The workshops are facilitated by two trained leaders with chronic diseases themselves.

Stanford requires leaders of the program to be certified. There are two levels of certification—Master Trainer and Lay Leader. Master trainers provide some oversight of CDSMP workshops, train workshop leaders, work in pairs, and serve as workshop leaders themselves. In addition, master trainers attend 4.5-day master training, facilitate one 4-day leader training within a year of completing master training, and lead a full 4-day leader training at least once a year to remain certified. Leader certification ensures that individuals are properly trained to facilitate the Stanford program. Lay Leaders are individuals who facilitate the CDSMP workshops. They work in pairs, attend four 6-hour days of training over 2 weeks, complete two practice teaching sessions during training, facilitate at least one 6-week workshop in the year in which they were trained, and must come from the same communities which the CDSMP intends to serve (Lawn & Schoo 2009). Lay-led self-management programs are becoming widespread in the attempt to promote self-care for people with chronic conditions (Foster, Taylor, Eldridge, Ramsay & Griffiths, 2009).

Each participant receives a workbook titled *Living a Healthy Life with a Chronic Condition*, which is the official workbook of the CDSMP (Lorig, Gonzalez & Laurent, 2006). The sessions consist of information on action planning, difference between acute and chronic conditions, dealing with difficult emotions, physical activity, muscle relaxation, pain and fatigue management, and healthy eating. It also deals with communication skills, informed decision-making, guided imagery, working with health professionals, and evaluating action plans (Lawn & Schoo 2009). Processes that facilitate interactions with clients without obstructing the diversity of perspectives create an environment conducive to learning and engage individuals in identifying self-management strategies that have meaning in their lives (Kralik et al, 2004).

The Stanford program is standardized and leaders are taught about the importance of upholding the quality of the program and maintaining the fidelity of the program to ensure that the program is evidence-based, and replicable each time it is offered. The peer facilitator two-day training teaches facilitators that if one adds, deletes, or makes any changes to the program it means that the program is not offered as it was designed and intended. Peer leaders are told that to have the proper impact, the program must be unaltered and as such a requirement is to conduct all activities exactly as they are written in the manual, watching the time carefully. Specifically, the training manual reports that adding time is not allowed because having more time to talk may uncover things that neither they nor the leaders can handle. It reports that time is limited for a reason, and adhering to the time and agenda is one of the top ten expected skills for leaders of the CDSMP (Lorig, Gonzalez, & Laurent, 2012). Thus, adjustments and modifications are not supported by the Stanford program and seen as not keeping with the fidelity of the program.

2.7.3 Evaluation of the Stanford Chronic Disease Self-management Program (CDSMP)

The Stanford CDSMP is a well-established and evaluated program that allows people to manage their condition and its consequences on their lives, in partnership with their health providers (Stone & Packer, 2010; Johnston et al, 2012).

The CDSMP is a broadly implemented group program that educates individuals and has been shown to be effective in providing generalizable skills to help manage their chronic conditions and live well regardless of their chronic illness (Health Council of Canada, 2012a).

The Stanford CDSMP focuses on the individual, encourages collaborative goal setting, and builds self-efficacy (Johnston et al, 2012). Also, through their lived experience, peers are ideally placed to engage and assist people with their chronic conditions (Lawn & Schoo, 2009).

The studies of CDSMP conducted by Stanford University established the evidence base for the program by demonstrating the effectiveness of CDSMP in improving the ability of participants to self-manage their health and health care (Woodcock et al, 2013). The Stanford Patient Education Research Center has developed and evaluated self-management programs for chronic specific conditions such as arthritis, HIV/AIDS, back pain, and also general programs where people with different conditions are included in the same program. It has been found in randomized controlled trials that these programs have significantly improved behaviors such as exercise, cognitive symptom management techniques (relaxation), and improved communication with physicians (Lorig & Holman, 2003). In addition, participants reported decreased pain, less fatigue, less distress/worry, and improved role function (Lorig & Holman, 2003). Findings from Stanford's evaluation of CDSMP are available on the Stanford web site: http://patienteducation.stanford.edu/research/.

In the Champlain health region of eastern Ontario, results of a mixed methods exploratory study investigating the impact of the Stanford CDSMP on participants' lives and barriers to self-management of their chronic conditions, showed that a change in physical activity was the most prominent behavioral change. There was also an improved sense of social connection, better coping skills, but the barriers noted by participants involved problems with the health care system and patient-physician interaction (Johnson et al, 2012). Other identified barriers to participating in the CDSMP program included lack of interest, lack of time, and illness. Attraction and retention of participants was also identified as an issue with the CDSMP. For some participants, it was reported that the benefits they had hoped to achieve did not transpire; they wanted more direct and immediate assistance and relief of the pain rather than learning to cope with the chronic condition (Johnson et al, 2012). Also, some participants had wanted more opportunities to practice the self-management activities during the sessions. Some participants noted the physician's lack of knowledge or links with community resources as a barrier to self-management. They reported a lack of time with physicians to discuss their personal health agendas. Many participants also reported other barriers such as financial issues, accessing community resources and programs, lack of transportation, timing and location of program, poor integration with routine clinical care and fatigue/pain as limiting factors in self-management (Johnson et al, 2012). Thorne & Patterson also report issues of attraction and retention of participants, inequities in access, and concerns that health care professionals who play a very important role in supporting self-management are not well integrated into the chronic disease self-management process (Thorne & Paterson, 2001). In addition, Thorne, Paterson, & Russell (2003) identified the complexity of chronic conditions, and suggested that effectiveness of self-care had to be considered within a number of other factors, including the context of the disease progression, effects of treatment, and aging and stress.

An evaluation of the CDSMP in rural Australia demonstrated statistically better scores at post-test on the domains of self-monitoring, insight, and health service navigation. Evaluation of the CDSMP in a Chinese population showed that the CDSMP primarily increased self-efficacy, exercise, and application of cognitive coping strategies of the participants (Siu, Chan, Poon, Chui, & Chan, 2007). A qualitative evaluation of the CDSMP in Shanghai exploring the impact on participants' perceptions of their behaviours, health status, and quality of life concluded that the program was perceived to be effective for participants mainly through behavioural change and self-efficacy development, with a need for a few modifications related to language barriers, and cultural adaptation of the program. Participants perceived that the CDSMP improved their knowledge, self-management skills, positive health behaviour, increased self-confidence, health status, and quality of life (Fu, Ding, McGowan, & Fu, 2006). A recent meta-analysis by the U.S Centres for Disease Control and Prevention of study participants in the CDSMP showed sustained mild to moderate effects on a number of outcomes from the standardized evaluation toolkit, including improved and sustained confidence or self-efficacy, and decreased social and role limitations (Brady et al, 2013). A recent qualitative study of the CDSMP found that participants value the group experience and social connection that the group environment fosters (Etters et al, 2008).

Lawn and Schoo (2009) proposed that although self-management approaches have many advantages, there are some disadvantages including the structured content making it difficult to address individual learning needs and styles, reduced capacity to address individual problems, group involvement is time limited, concerns about privacy and confidentiality especially in rural areas, on-going support needs are not considered, access and transportation concerns for certain participants, and recruitment efforts usually end with mostly females involved.

A peer reviewed meta analysis of health status, health behaviours, and health care utilization outcomes of the CDSMP in 2013 showed small to moderate improvements in psychological health and selected health behaviours, suggesting that the CDSMP produced health benefits for participants and is thus recommended as a valuable part of a chronic disease management strategy (Brady, Murphy, O'Colmain, Beauchesne, Daniels, Greenberg, House & Chervin, 2013). Many studies contributing to a growing evidence base about CDSMP have evaluated CDSMP program outcomes showing positive impacts in health behaviors, health status, self-efficacy in managing chronic health conditions, utilization of medical care, cost and cost effectiveness. CDSMP provides people who have chronic diseases with opportunities to develop skills and confidence to self manage their chronic disease problems and improve their quality of life (Brady, Murphy, O'Colmain, Beauchesne, Daniels, Greenberg, House & Chervin, 2013).

Past research studies evaluating chronic disease self-management programs are concluding that there is future need of qualitative studies and findings to adopt a comprehensive approach to further inform the success and hence implementation of CDSMP in broader contexts (Stone &Packer, 2010; Johnston et al, 2012; Newman, Steed, & Mulligan, 2004).

2.8 Justification of the proposed study

As discussed earlier, the research literature is replete with accounts of the burden and challenges experienced by those who care for loved ones with dementia (Sussman & Regehr, 2009). Family care partners care for family members at a considerable personal cost often compromising their own psychological and physical well-being, thus making informal care partnering a clinical and socially relevant issue (Sorensen et al, 2006). The burden on care partners is well documented and the care partners themselves are referred to as the silent patients, and thus require interventions to help them maintain their own health and wellness. Care burden is the effect on physical, psychological, social, spiritual and financial well-being (Sorensen et al, 2006).

Although care partner burden is one of the most commonly investigated caregiving outcomes, it is not always well conceptualized as it is mostly studied using quantitative measures which do not always capture the experiences or context that provide detail into the basis of the burden (Bastawrous, 2013). Many reviews have been selective in their outcomes of interest, focusing mostly on biomedical measures, excluding outcomes such as quality of life, self-efficacy, and activity participation (Stone & Packer, 2010).

Current care partner interventions documented in the literature focus on early diagnosis, case management, formal home care and day care, respite, educational support, technological support, information awareness, psycho-educational support, cognitive behavioral therapy, support groups, and coping and stress management. The evidence clearly suggests that self-management interventions by lay leaders for people with chronic conditions positively affect health outcomes, and significantly decrease complications associated with the disease. Yet, chronic disease self-management programs for care partners experiencing burden of care, focusing on their own physical and mental health needs are not well established or studied in the literature.

While the CDSMP has been evaluated for different groups such as people with arthritis and diabetes, a thorough appraisal of the program for care partners of people living with dementia was not evident in the literature. Given the evidence that caregiving can cause increased burden and negatively impact health status, a reasonable question is to ask how or if these programs can be integrated and further disseminated to support care partners of those living with dementia. In particular, as the CDSMP is a program offered throughout many different countries and throughout Canada, understanding how care partners might think about the program is an important consideration.

With the concerns mounting about dementia and its increasing prevalence, and the impact on informal care partners, a self-management process of helping care partners in meeting their needs (education, provider support, emotional support, etc.) to improve health is an approach that needs exploration. There is a gap in our understanding, as the phenomenon of the experiences of care partners completing the CDSMP is not understood since no qualitative or quantitative studies exploring care partners participating in CDSMP exist. There are no examples in the current literature of such a study. I cannot find any previous studies that have explored the experiences and impact of a disease self-management program, CDSMP or otherwise, for care partners of those with dementia.

Given that the most predominant self-management program, the CDSMP, has not been evaluated for the dementia care partner context, I proposed to study the experiences of dementia care partners participating in the program as an understanding of this phenomenon would serve as a guide for evaluating the CDSMP for care partners, and provide insight in the development or modification of self-management programs for care partners of those living with dementia. My goal of exploring the CDSMP with care partners of those with dementia is to understand their experiences as they learn about self-management. Would this support program help care partners become good self-managers?

Evaluation of the CDSMP has been very much outcome based, but this qualitative study will take a different phenomenological approach to understand the essence of the experiences of participants as they participate in the program. An enhanced understanding of the lived experiences of participants in a self-management program will inform policy development for interventions to support care partners of those living with dementia.

2.9 Review of adult learning principles and Dialogue Education^{TM}

Andragogy, the art and science of helping adults learn, suggests approaches to learning that are problem-based and collaborative, rather than didactic (Knowles, Holton & Swanson, 2005). It also emphasizes more equality between the teacher and the learner. Knowles identified six principles of adult learning: the learner's need to know, the self-concept of the learner, prior experience of the learner, readiness to learn, orientations to learning, and motivation to learn. Adults are internally motivated and bring life experiences and knowledge to learning experiences (Knowles, Holton & Swanson, 2005).

Professor Jane Vella developed the Dialogue Education^{TM} approach, and it is a carefully structured way to enhance learning. It builds upon the theories of adult education indicating that people should be actively engaged in their learning. The aim of the approach is not "teacher centered", but rather "learning centered", getting to the core of what is happening at the time of the interaction among learners, the teacher, and the subject matter content (Vella, 2002). Dialogue Education^{TM} focuses on the needs of the learners and promotes dialogue among participants, allowing learners to connect new information to their lives in meaningful ways (Driscoll, 2009). Dialogue Education^{TM} is about structuring learning experiences for audiences and follows the principles of effective adult learning.

Dialogue Education^{TM} is a learning-centered system deeply rooted in valuing the individuality of each learner. It promotes ways of thinking and learning together. The theme of the approach is to change the "top-down" mainly monologue structure of teacher-learner interactions and develop an educational design that promotes dialogue between the teacher and the learner, and also between learners themselves (Driscoll, 2009). This approach supports a movement from "teaching tasks" which does not invite dialogue to "learning task" which structures dialogue (Vella, 2002). The principles emphasized in Dialogue Education^{TM} include: needs assessment for relevancy, safety in the environment and process, sound relationships between teacher and learner and among learners, sequence of content and reinforcement, praxis-action with reflection or learning by doing, respect for learners as decision makers, immediacy of learning, clear role and role development, engagement of the learners (inclusion) in what they are learning, and accountability- how do they know they know (Vella, 2002).

Dialogue Education endorses three categories of learning: knowledge, skills and attitudes (KSA). After learning, the learner will acquire new knowledge, skills, and attitudes. The knowledge domain involves knowing the new information; the skills domain involves the development of new skills where s/he knows "how to" by applying and practicing the new information. The attitudes domain includes the feelings associated with knowing the value of the information, and involves the feelings associated with the learning (Vella, 2008).

The Alzheimer's Society of Ontario utilizes Dialogue Education™ in the development of their educational materials and programs and thus, it has been established in the context of dementia. The Alzheimer's Society's learning series, U-First training program, and First Link™ program link educational content to each group's experiences and encourage open dialogue and communication to enhance adult learning (Alzheimer's Society of Canada, 2013).

Care partners were surveyed to identify learning needs, and data showed that they enjoy interactive problem solving related to preparing for the future, shaping troubling behavior, and caring for themselves (Samia, Hepburn, & Nichols, 2012). In another study that explored care partners' educational needs and preferred methods of information delivery it was concluded that information must be provided by innovative methods that are congruent with different caregiving circumstances and by assessed learning preferences (Mastel-Smith, & Stanley-Hermanns, 2012). Psycheducational interventions that require active participation have shown the broadest effects on burden, depression, well-being, and knowledge (Pinquart & Sorensen, 2006). A systematic review of evidence of the effectiveness of educational and supportive strategies for enabling care partners of people with dementia to maintain participation in that role suggests that interventions that engage people with dementia and their care partners in education and training in the home setting are more successful. As such, interventions should provide care partners with problem solving, technical skills, support, simple home modification strategies, and referral to community resources (Thinnes &Padilla, 2011).

Approaches to adult education, specifically Dialogue Education™, provide a sensitizing framework to better understand how adults learn, and will help inform the research questions, data collection, and analysis. I will focus on the six core principles of Dialogue Education™: inclusion, safety, respect, immediacy, relevance, and engagement, allowing them to guide me as I attempt to best explore, elicit responses and understand participants' experiences of the CDSMP and their perceptions related to their needs in a self-management program for wellness.

Chapter Three: Methodology

3.1 Research purpose and questions

The purpose of this phenomenological study was to understand the lived experiences of care partners participating in the Chronic Disease Self-Management Program (CDSMP) while they are caring for a spouse living with dementia. The focus is on their lived experiences during participation in the CDSMP, and what that reveals about elements of self-management programs that are helpful for care partners. Exploring their experiences in this specific intervention program will provide a greater understanding of the CDSMP's usefulness for care partners and provide information about what is beneficial in order to create desirable futures in supporting care partners to decrease care burden, and improve outcomes for both the person with dementia and care partners. This qualitative inquiry can influence future initiatives toward improving care partner burden and be part of social change that increases commitment to supporting care partners.

Given the rising prevalence of dementia and its position as a public health priority, a better understanding of dementia and how to best support care partners to self-manage is of increasing importance as a response to meeting needs.

The specific research questions are as follows:

1. What are participants' needs as they care for their spouses with dementia?
2. How do participants feel about participating in the program?
3. What are participants' experiences when participating in the program?
4. What do participants think about the content of the program?
5. What do participants think about the structure of the program?
6. What do participants think about the delivery of the program?
7. How useful do participants find the program for self-management and wellness /or for the caregiving experience?

In this study, I explored the participants' experiences within the program and inquired as to how the program might change their experiences, rather than focusing on and evaluating the program itself. I did not look specifically at outcomes and whether the program achieved the behavioral and attitudinal changes intended. My research exploring the lived experiences of care partners of people living with dementia and participating in CDSMP could potentially inform program development for care partners in the future, and contribute to knowledge about self-management approaches in the dementia care partner context with the goal of reducing the burden of care.

In addition, as I am an executive Director of Health Services for the Central Health Authority in NL completing this research, there is a keen interest, among my peers and my senior leadership team, in the role of self-management in dementia care and supporting family care partners. Central Health has adopted the CDSMP as the official program offered in response to the increasing prevalence of chronic disease in the central region of NL. Central Health's target audience for the CDSMP delivery has currently been people living with diabetes and chronic obstructive pulmonary disease (COPD). Our Vice President of rural health, long-term care, and community supports, and our Chief Executive Officer, are both very interested in the findings of this study as new strategic directions and community program are explored for those living with dementia and their care partners. The experiences of participants in this study will help Central Health's leadership team in determining if the CDSMP is appropriate for care partners of those living with dementia, and if not, what types of modifications or other programs might be meaningful to support care partners.

3.2 Methodology

A qualitative methodology was chosen to explore the lived subjective experiences of care partners participating in the CDSMP while they are caring for spouses with dementia. A phenomenological approach was used in this study because it is a suitable method for understanding the phenomenon and lived experience of care partners of people living with dementia participating in the CDSMP. As the population ages and the incidence of dementia increases, the perspectives and experiences of care partners is increasingly important in designing supportive programs that decrease isolation, increase empowerment, and improve self-care (Ward-Smith & Forred, 2005). The experiences of people with dementia and family care partners have much to offer in the understanding of the most important causes and the most important interventions in times of crisis (Toot, Hoe, Ledgerd, Burnell, Devine, & Orrell, 2013). Understanding the experiences of care partners is pivotal in the design of effective support services, and understanding the complex family care partner phenomena serves as a guide for developing interventions (Chan, Mok, Wong, Pang, & Chiu, 2010).

A detailed exploration of the care partners' lived experiences and their personal perceptions of the CDSMP was undertaken. A phenomenological approach uses a small number of participants as a means to understand and get at the essence of the experience. Their experiences were analyzed and interpreted to find essential themes that together allowed meaning of the experience to emerge. The research describes the experiences as they naturally occur, and no attempt was made to manipulate the situation under study.

The use of this scientific approach to qualitative inquiry enhances the rigor and sophistication of the research design as the procedures outlined in the approach are followed (Creswell, 2013, p 53). It will ensure valuable information is received on participants' perceptions of the content of the program, their experiences of participating in the program and the program delivery, and the meaningfulness of the program on their health and well-being.

3.2.1 Method of Inquiry: Review of Phenomenology framework

Phenomenology, with its disciplinary roots in philosophy, literally means the study of phenomena. It is a theoretical framework that describes something that exists as part of the world in which we live. Phenomena may be events, situations, experiences, or concepts. "Phenomenology is the study of the essence of a phenomenon as it presents itself in lived experience in the world" (Tan, Wilson, & Olver, 2009). The goal of qualitative phenomenological research is to describe a "lived experience" of a phenomenon (van Manen, 1990; Waters, 2013). This methodology and theoretical perspective seeks to investigate the meaning of lived experiences, and is suitable when exploring how individuals are perceiving the particular situations they are facing, and how they make sense of their personal and social world (van Manen, 1990). The central question asked in phenomenology is "what is the meaning, structure, and essence of the lived experience of this phenomenon for this person or group of people?" (Patton, 2002 p. 104). The central thesis of phenomenology is that there is always a core, a nature of things, a shared understanding amongst a group of people, an essence that holds a phenomenon or experiences together (Patton, 2002, p. 104). The challenge for the researcher is to help participants express their world, and then to expound these dimensions such that the lived world is revealed (Finlay, 2008).

Pure phenomenological research seeks essentially to describe rather than explain, and to start from a perspective free from preconceptions (Husserl, 1970), but I will be using hermeneutical phenomenology which is oriented toward lived experience and interpreting the texts of life (Creswell, 2013, p 79). Knowledge is known through subjective experiences of people, and thus the study is conducted in the context of where participants live and work. Phenomenology becomes hermeneutic when its method is taken to be interpretative rather than descriptive (Creswell, 2013, p 79). Descriptive phenomenology assumes that phenomena have an essential essence and by "bracketing", it allows the phenomena to be studied objectively. Hermeneutic phenomenology seeks to go beyond description in order to discover meanings and rather than bracketing our assumptions, it maintains that our preconceptions are an integral part of the process of understanding (Merleau-Ponty, 1996).

A phenomenological research study is a dynamic process with an active role for the researcher in the process as the researcher tries to get close to the participants' personal world to get an "insider" perspective (Smith & Osborn, 2003). Access to the participants' personal world depends on, and is complicated by, the researcher's own conceptions (Smith & Osborn, 2003). While participants are trying to make sense of their world, the researcher is also trying to make sense of the participants trying to make sense of their world (Creswell, 2013). The researcher tries to understand what it is like, from the point of view of the participants, to take their side, and asking critical questions of the texts/manuscripts of participants. Phenomenological reflection is not introspective, but rather retrospective; it is reflection on experience that is already lived through (Van Manen, 1990, p.9-10).

Phenomenological studies are conducted on small samples, with an information-rich detailed case-by-case analysis of the individual transcripts, with the aim of describing the perceptions and understandings of the group. Researchers analyze in detail how participants perceive and make sense of things that are happening to them and thus require flexible data collection instruments, such as a semi-structured interview where the investigator will have a set of questions but the interview will be guided by the schedule rather than dictated by it (Smith & Osborn, 2003). An inquiry into the experiences of four spousal participants, although fewer numbers than recommended for the CDSMP, was a means to delve into the essence of their experiences. In essence, I was focusing on the depth of their experiences, rather than breadth. To have more participants in the program would have been too difficult to extract the meanings of their experiences. In addition, the challenges of recruiting larger numbers of participants, as will be described later, are significant in rural areas, and as such, recruiting four participants was both feasible as well as appropriate for this phenomenology study.

The purpose of this hermeneutic phenomenological study was to discover the essence of how participating in the CDSMP is experienced by care partners of those living with dementia rather than an evaluation of the CDSMP. The knowledge learned from this study can inform self-management opportunities to serve this population. Listening to the lived experiences of care partners of those living with dementia participating in the CDSMP may reveal insights to increase the quality of life during this journey. Understanding the experiences of care partners is pivotal in the design of effective support services, and understanding the complex family care partner phenomena serves as a guide for developing interventions (Chan, Mok, Wong, Pang, & Chiu, 2010). An understanding and assessment of care partners' challenges and needs is essential to develop interventions and supports that are tailored to their needs to positively impact their well-being (Zwaanswijk et al, 2013). The provision of support and information should be tailored to individual needs (Robinson et al, 2011).

3.2.2 Stanford Chronic Disease Self-Management program

The CDSMP is a six-session program that will occur once a week for six weeks. Two experienced trained leaders with chronic diseases themselves facilitated the workshops. For this study, two trained lay leaders facilitated the workshops. The workshop leaders were participants in this study as well, as they were interviewed at the end of each of the six sessions.

Each participant received a workbook titled *Living a Healthy Life with a Chronic Condition*, which is the official workbook of the CDSMP. The workshop leaders followed a set structured plan from a program manual; they did not provide medical advice, but rather emphasized practical techniques; the peer support among participants was a key component (Health Council of Canada, 2012a). The leaders were encouraged to not change the program material, and to follow all the protocols of the program as the authors of the program intended (Lorig, Gonzalez, & Laurent, 2006).

The 2.5 hour sessions consist of the following information:

- Session 1: Workshop overview, differences between acute and chronic conditions, and action plans

- Session 2: Problem solving, dealing with difficult emotions, physical activity and exercise, new action plan

- Session 3: Review action plans, better breathing, muscle relaxation, pain and fatigue management, endurance activities, new action plan

- Session 4: Feedback on action plans, future plans for health care, healthy eating, communication skills, problem solving, new actions plans

- Session 5: Review action plans, medication usage, making informed treatment decisions, depression management, positive thinking, guided imagery, action plan

- Session 6: Review action plans, working with health care professional and health care system, looking back & planning for the future, closing

Recently in 2012, the CDSMP has been updated from the 2006 program to include new topics such as: getting a good night's sleep, preventing falls, decision making, and weight management. The activity on advanced health care directives has been removed. There is also an updated section on healthy eating which includes portion control, label reading, and activity on making healthier food choices. Given the feedback from participants in this study, I feel that these additions provided additional benefit to care partners.

3.3 The setting

Geographic Area and citizen profile – Green Bay, Newfoundland and Labrador:

Statistics Canada (2006) estimates the population of Green Bay to be 8,140. Green Bay is located in the Central Northeastern portion of Newfoundland within Economic Zone 11 also known as The Emerald Zone. According to 2006 Census data of Statistics Canada, Green Bay has a total population of 8,140 people, who are dispersed throughout 23 communities spread over a large geographic area. Only 5 of these communities have more than 500 people living in them.

Green Bay is divided into Green Bay North and Green Bay South. Green Bay South includes the communities of Robert's Arm, Port Anson, Miles Cove, Pilley's Island, Long Island, Triton and Brighton. Green Bay South makes up 37% of the population of Green Bay. All other communities, with the exception of Sheppardville, are located in Green Bay North. Sheppardville is located 35km west of Springdale on the Trans-Canada Highway.
All communities in Green Bay, with the exception of Little Bay Islands and Long Island are connected by road. To access health services, residents of Long Island have a five-minute ferry ride to Pilley's Island, followed by a 10-km automobile ride to Robert's Arm or 51km to Springdale. Residents of Little Bay Islands have a 45-minute ferry ride to Shoal Arm (Little Bay) followed by a 19-kilometer automobile ride to Springdale. Both islands are serviced separately except when there are ferry maintenance problems. Scheduling poses a problem when one ferry services both islands. Central Health is responsible for the provision of health care services to the people of Green Bay. The Green Bay Health Center in Springdale is the last cottage hospital left in Newfoundland and Labrador.

Overall, Green Bay has an older population than the province. The median age for Green Bay is 40 years compared to 38 years for the province. There is a 3% higher proportion of citizens 50-64 years of age, 4% higher for 65 and older, and a 3% lower proportion of citizens 20-29 years living in Green Bay as compared to the province (Community Accounts, 2012).

All interviews were conducted in rural Springdale, Newfoundland and Labrador (NL). Two of the pre-program interviews were conducted in the participant individual homes; one pre-program interview was conducted in a family room at the long-term care facility where the participant spouse lives. Participants were given the option to choose the location of the pre-interview. One pre-program interview occurred in the kitchen of the home where the spouse does not live with participant any longer. Another pre-program interview occurred in the living room of the participant's assisted living home with the spouse living with dementia present for the interview. The pre-program interview conducted at the long-term care facility family room did not have the spouse present as s/he was in a room downstairs.

The CDSMP program was delivered at the retirement center meeting room in Springdale, Newfoundland and Labrador, the hub of Green Bay. I gathered up close information by talking directly to participants and seeing them behave within their context as they participated in the CDSMP program over the six weeks. The sessions were each facilitated in a cottage style room at a retirement center in Springdale, where one participant resided with his spouse. This location was chosen as it was helpful for the participant living there with his/her spouse to more easily attend the sessions. Also, one of the facilitators worked as a staff member at this assisted living center and was able to facilitate the session during her work time and thus this location helped with her ability to participate. The retirement center director also provided snacks for the mid-session break, and the room free of charge.

The room provided a very comfortable, relaxed setting. The room that the program was carried out in was accessible only by walking through the front doors of the center, where all had to remove outdoor footwear before proceeding to the room; all participants wore slippers. The room had three sofas, a coffee table in the center, and a kitchenette on the side. Participants, facilitators and researcher sat together on the sofas in an informal setting that was not like a typical classroom style. This informal style was reported by participants and facilitators to be very comfortable and contributed to a warm conversational style of learning.

3.4 Recruitment

Participants (four) were recruited in Green Bay, NL through health and community services, local community groups, Green Bay medical clinic (local physicians and nurse practitioner), local community advisory committee, community group-Life Unlimited for Older Adults, and Green Bay Health Center home care program. Purposive sampling entails deliberate selection of participants who fit with the study phenomenon and is frequently used in phenomenological studies (Patton, 2002). Participants were provided with an information letter and asked to give written informed consent before participating. I conveyed to participants that they were participating in a study, and explained the purpose of the study. I ensured confidentiality by assigning pseudonyms to individuals, masking their names in the data to protect their anonymity. The informed consent and confidentiality safeguard the rights of the participants. In addition, the two lay leaders were also participants, as they were interviewed after each of the six workshop sessions. The structured interview guide is attached in appendix C.

Recruitment was more difficult than expected. Potential participants reported that they did not feel that they could leave their spouses for the time required to attend the program. They voiced that their spouse wanted them near all of the time, and they would feel guilty to leave, as there were no family or other respite support. One care partner met with me and signed the informed consent, but five days later called to say that the stress of worrying about leaving his spouse for the program was too much and he withdrew from the study. As the people in Green Bay, NL knew about my study, family and friends submitted many names to me. From this list, I contacted eighteen (18) care partners; only four (4) were willing to participate as the others noted that they could not leave their spouse for three (3) hours per week for six (6) weeks in a row. Reasons for non-participation were barriers with family supports to care for their spouse, a hesitancy to leave their spouses because they were so reliant upon them, lack of time, and concerns with attending a formal session and what it would entail. Recruitment difficulties were also related to the remote, rural setting of Springdale, Green Bay, NL where there are fewer spousal care partners of those living with dementia than if the study was conducted in an urban setting. As such, the overall pool of potential participants was small, significantly smaller than in urban areas.

Analysis of the data collected began after the pre-program interviews and continued weekly as data was collected.

3.5 Data Collection

Data was collected from participants through multiple methods as described below, and a composite description of the essence of the experiences for all of the participants was developed. This description consisted of what they experienced, how they experienced it, and their perceptions regarding self-management and wellness.

As the researcher is a key instrument, and as I am the researcher for this study, I collected the data myself through multiple methods as outlined below:

- Pre-program individual interviews were held with each participant to understand more about the participants, who they are, what their caregiving roles were, and to provide more depth about their context. (See Appendix A for structured interview guide)
- Focus groups were held after each of the six sessions to obtain feedback from the participants on the session regarding the content, facilitation, and process of the program that week. (See Appendix B for focus group guide)
- Interviews with the two lay leaders were conducted after each of the six workshop sessions to gather information and understand their experiences of facilitating the program to care partners, and how they felt participants responded. They were also asked

about their thoughts on the content of the program for each session. These also served to help validate my own feelings and interpretations of how the participants responded to the material for each session, and confirm or not my thoughts regarding the program content for the care partners.

- Post-program (approximately 1 month) individual interview with each participant to understand the care partnering experience after the completion of the workshops. This helped understand whether any earlier identified benefits to the caregiving experience are sustained. (See Appendix D for structured interview guide). This will also provide the opportunity for member checks (checking back with study participants to confirm the findings).

- Participant observation during six sessions of program. Field notes were recorded during the sessions. Field notes focused on interactions of participants, responses to the curriculum, comments of participants, and other information as appropriate. (See Appendix E for sensitizing framework)

- Memoing & reflective diaries of the researcher's own introspective accounts: the researcher's field notes and reflections during sessions, focus groups, and interviews were recorded and dated identifying what the researcher hears, sees, experiences, and thinks in the course of collecting and reflecting on the process. The field notes were dated so that the researcher could later correlate them with the data collected for each time period.

- During the six workshops, there are brainstorming sessions where the participants' comments are recorded on flip charts. These flip chart notes from each session of the program were kept, dated and utilized as data.

3.5.1 Table: Timeline of data collection

	Jan 13-16, 2014	Jan 22, 2014	Jan 29, 2014	Feb 5, 2014	Feb 12, 2014	Feb 26, 2014	March 5, 2014	April 7-8, 2014 2014	May 15-16, 2014
	1 month pre CDSMP	**Week 1 CDSMP**	**Week 2**	**Week 3**	**Week 4**	**Week 5**	**Week 6**	**1 month post CDSMP**	**Member checks and peer review**

Preprogram interview with each of 4 participants	X								
Focus group		X	X	X	X	X	X		
Reflective diary/journal	X	X	X	X	X	X	X	X	
Interviews with facilitators		X	X	X	X	X	X		
Post program interview with each of 4 participants								X	
Participant observation/field notes	X	X	X	X	X	X	X	X	
Session flip chart notes		X	X	X	X	X	X		
Member and Peer checks									X

3.5.2 Interviews:

As the researcher, I gathered data though face-to-face interviews with participants. The pre-program interviews were conducted in participants' homes for 1- 1.5 hours. Each interview was recorded and transcribed later for analysis. The pre-program interview was guided by a semi-structured set of questions with the aim of obtaining information about the context and social background of the participant. These questions are attached in Appendix A. The interview was a fine balance between asking appropriate open-ended questions and allowing silences to assist the participant to proceed with their story.

The participant focus groups after each of the six sessions of the CDSMP took place in the same room as the program and lasted for about 20 minutes. The three participants and I sat on couches in a relaxed setting. The focus group interviews were conducted utilizing a semi-structured list of questions to facilitate the interview. The goal of these weekly interviews was to get a sense of the following: participants' thoughts about the program; what they experienced in that session; their thoughts on the content, structure, and delivery of the program; what, if anything, should be modified in the program to meet their needs; and how useful they found the session(s) with self-management, wellness, and the caring experience. The questions are attached in Appendix B.

The peer facilitator interviews after each of the six sessions of the CDSMP also took place at the same room that the program was carried out in and lasted for approximately 10-15 minutes after participants left the room. Each interview was recorded and transcribed later for analysis. A semi-structured list of questions was used to guide the interview and is attached in Appendix C. The aim of these interviews was to get their overall thoughts about the program delivered to this group of care partners. These interviews collected information on facilitators' thoughts about the content, structure, and delivery of the program for care partners of those living with dementia. Also, facilitators shared their thoughts about what, if anything, should be modified with the program to meet this particular group needs, and their feelings about how participants' responded to the session.

Approximately one (1) month after the six-week program was completed, another post-program interview was carried out with each participant. These interviews were conducted in the participants' home, lasted for approximately one hour, and were guided by a semi-structured list of questions. The list of questions is attached in Appendix D. This interview attempted to establish their experiences in the CDSMP, whether the participant found the program useful and whether new skills were being utilized to help with daily living, as a care partner. The interviews explored whether new skills were attributable to the program intervention. The one-month follow-up post program interview with participants afforded an opportunity to see if their experiences of participating were still perceived as before, and also provided an overview of whether learning occurred during the program. It allowed for some further identification of whether the program was suitable for meeting their needs and whether the results at one month after completing the CDSMP resulted in improving self-perceived wellness. This interview allowed for a review of whether the newly-learned material was being used in their context, and whether there was an impact as a function of the learning. The end goal of providing an intervention such as the CDSMP is not just epistemological, learning for sake of learning, but rather learning for the sake of transformation. The transfer of learning is measured by behaviors that take place after the program and whether concepts are being put into action with practicing of new skills (Vella, 2008).

At approximately six weeks after the follow-up interview, I met with each participant to complete member checks. This allowed me to review my findings with those who actually described their experiences. I reviewed the essential structures and themes, and participants confirmed and validated the meanings explicated.

I audio-recorded, with permission of participants, all interviews, and had them transcribed verbatim. I used a digital recorder encrypted with a password to protect the MP3 files. I listened to the recordings, and had them fully transcribed and stored on a computer. A back up copy of computer files (transcriptions) was made.

3.6 Context (pre-interviews)

Understanding the context and biographical experiences of the participants, as reviewed above, helps the researcher to understand the context of participants lived experiences as they partner in the care of their spouse who lives with dementia. The similarities and differences in their experiences helped inform interpretation of the meaning as they experienced the phenomenon of participating in the CDSMP together. It allowed for comparisons between participants with differing experiences. The pre-interviews clearly established the level of burden that is congruent with the literature reviewed.

A common topic in the pre-program interview with participants was the significance of connecting with others during the journey. There was a constant expression of the importance of social connections with their spouse, family and friends, and the staff that they interacted with daily at the facilities where their spouses lived, either with them or in separate location. There was a close connection with the staff at the long-term care center and independent living retirement center. One participant wrote letters to the staff, and described them as being like family. It was clear in the pre-program interviews that care partners identified their need for family connections and support in their journey. However, as is common in NL, many family members live away in other provinces as a result of out-migration. Participants also spoke of the use of technology to connect with others through Facebook, and sharing pictures via email. Participants voiced the importance of telling their story; one participant noted that she is currently writing a book/journal for her family.

Another common topic in all of the pre-program interviews was the reported great sense of loss- the loss of their spouse and loss of their own identity. With respect to the loss of their spouse, participants talked about their spouses not knowing them, not being able to call their name, and not being able to do the routine things that they always did. They experienced guilt associated with not being able to continue to care for their spouse at their home and being separated was identified as a fear. Participants voiced how their lives changed from how it once was such that no normal day or special occasion, such as Christmas, Valentine's Day, family gatherings, was ever going to be the same. Strong marriage relationships, with a strong commitment to care, was common among all participants. Participants all expressed how significantly their lives changed after the diagnosis and how life altered from their ordinary routines and normal relationships to one where they were consumed with caring, leading to isolated lives.

The great burden of care- stress, depression, lack of sleep, worry, isolation, hypertension, irregular heart rate, diarrhea, vomiting, fear, decline in physical health, weight loss/gain, lack of physical activity, emotional eating, worsening of existing health concerns were reiterated by all participants; life revolved around caring for their spouse. There were no reports of physician or health provider assessment of any participant as a care partner.

For the two participants who had their spouses living at a long-term care facility, they reported that they were aware that the time had come for taking care of themselves. There was an identified readiness for participating in self-management. Their families were also identifying the impact of caring and requesting their parent to refocus and take care of self. The one participant who had the spouse living at home identified significant challenges with attending the program because of not being able to leave his/her spouse. This was a challenge with recruitment as well. This participant had significant life circumstantial barriers preventing him from being able to attend and focus on self-management or self-care.

3.7 Program changes

The intent of this study was to facilitate the CDSMP as intended and outlined by the facilitator's guide as taught in the facilitator training. However, in this study, despite the experienced facilitators, the structure of the program changed organically as a response to the participants needs from one week to the next. Although the structure of the CDSMP is set to provide standardization of the program regardless of where it is completed, it was identified with these care partner participants that they needed more time to share their stories and engage in dialogue with one another.

According to the principles of adult learning, specifically Dialogue Education, adults are goal orientated, relevancy orientated, practical, and need to be respected as knowers. Adults like to be given the opportunity to use their existing knowledge and experience gained from life experience, and apply it to their new learning experience (Knowles, Holton & Swanson, 2005). Adult learners want to know the relevancy of what they are learning to what they want to achieve, learn by doing and most effectively when they have a strong inner motivation to develop a new skill or acquire a particular type of knowledge. Adults learn best in an informal situation, and personalized learning is preferred. The dialogue education approach is based on the principle that adults have enough life experience to be in dialogue with any teacher about any subject and will learn new knowledge, attitudes, or skills best in relation to that life experience (Vella, 2002).

During participation in the program, care partners reported weekly the importance of sharing experiences with one another, telling their story, and connecting with one another. The key message from all participants at each of the six sessions of the program was the importance of sharing and connecting with one another. Un-structuring the program, although not done intentionally, allowed for more time to share personal examples and experiences for this group. The participants also reported that the mid-session nutritional break was important and fit well within the structure as it fostered more social connection among members who didn't feel as comfortable sharing in the group setting.

Given that the numbers in the program were small, three instead of the recommended 10-16 participants, and that the amount of time for sharing was increased significantly, it is important to reflect and critically appraise whether the program was inadvertently modified such that it was no longer the reproducible Stanford CDSMP program, but rather an adaptation or derivative of the CDSMP, more likened to a support group. Did the program offered to the study participants function as the CDSMP or a social support group? If the program had the recommended number of participants, there would have been very limited time for dialogue and sharing of their stories and experiences. Given that sharing experiences and having a safe place to be emotional was expressed by care partners to be very important and was a predominant structure of their experience, it could be perceived that the lack of this opportunity would be a limitation of the CDSMP if it was followed exactly as recommended by the Stanford University.

The viability of the program offered in this study is also drawn into question with the modifications that organically unfolded as it was being offered to a study group of care partners of those living with dementia. There was difficulty with recruitment of participants who were care partners as they identified that they were not ready, or did not have the respite support to attend a six-week program. The small numbers in the program allowed the content to be covered as outlined in the CDSMP, but simultaneously permitted a significant increase in the amount of dialogue and sharing among participants. The incorporation of a pre-program interview with each participant before the program began, a focus group at the end of each of the six sessions, and a follow up interview after the program ended, changed the structure of the originally intended CDSMP. The addition of the focus groups, with a researcher after each of the six sessions, probably enhanced the attitude domain of learning and the feelings associated with the learning as it highlighted the value of the information. The connections with participants not only to each other but to the facilitators were also important to note. Interviews with participants prior to the program, as well as after the program ended, could have also contributed to a sense of safety and connections within the group.

Additionally, the intent of the CDSMP program is to have the facilitators be peers living with a chronic disease, but in this study the facilitators were not care partners of those living with dementia. With these adaptations, it is important to critically review the findings and any conclusions drawn. Would their experiences have been the same if the program was conducted specifically as outlined in the training manual?

3.8 Data Analysis/ Explication of the data

Data analysis followed the Phenomenological methodology. Phenomenological analysis attempts to comprehend and clarify the meaning, structure, and essence of the lived experience of a phenomenon for a group of people (Patton, 2002 pg. 482). In this study, the analysis sought to grasp the meaning of the subjective experiences of care partners of those with dementia participating in the CDSMP. To get at the essential meaning of the experience, a common approach is to abstract out the themes. In abstracting the themes, a process of reflection was used in the theme analysis.

To clarify the meaning, structure, and essence of the lived experience of spousal care partners, of those living with dementia and participating in the CDSMP, the Vancouver school of phenomenology was utilized for analysis. The Vancouver school of phenomenology is a unique blend of description, interpretation, explanation and construction and has proved to be a methodology that can lead to systematic illumination of human experiences (Halldórsdóttir, 2000; Hansdóttir & Halldórsdóttir, 2008). Its aim is to promote the common good and offers excellent opportunity for health professionals who want to understand the lived experience of the recipients of health services. The analysis goes from reading the individual transcripts as a whole, and moving to step-by-step identification of key statements, main themes, and essential structure within each dialogue and across dialogues. It then compares those with the data to determine over riding themes, and ends with verifying the structure/themes with the participants.

In my research, I followed the exact steps of the Vancouver school in the process of analyzing the data (Hansdóttir & Halldórsdóttir, 2008). The steps are summarized below:

1. *Reading and rereading the transcript*s to become familiar with the data as a whole.

2. *Underlining key statements* of the participants that related to their experiences in the program.
3. *Identifying and naming the themes in the underlined statements*, and noting those in the margins of the transcript of each interview.
4. *Identifying the essential structure of the phenomenon in the transcribed dialogue.* Taking the themes from the margins and exploring the essential structure of the phenomenon in each focus group and interview.
5. *Identifying the essential structure of the phenomenon from all of the cases.* Comparing the different interviews to find the common threads, as well as differences, to further construct the essential structures of the phenomenon.
6. *Comparing the essential structure with the data.* Having identified the essential structure of the phenomenon, comparing this back again with the transcripts to see whether it fit the actual data. What themes are not included and should they be?
7. *Identifying the over-riding theme that describes the phenomenon.* Identifying the key structures that tell the meaning of the phenomenon from the point of view of those who have lived it.
8. *Verifying the essential structure of the phenomenon with the participants.* The analytic framework is brought back to the participants to get their perspectives based on their own experiences (Halldórsdóttir, 2000; Halldórsdóttir & Hamrin, 1997).

The recording and transcription was not a complete objective record as it is missing the non-verbal behavior, and it requires a process of interpretation by the listener.

In this study, there was overlapping of observational work and analytical work meaning that analysis was happening in the process of data collection. The final stage of analysis occurred after all of the six workshop sessions ended, the follow up interviews completed, and member checks finished.

In this process, I utilized a computer program called NVivo, a tool for the organization and management of data, to help with analyzing the data. With NVivo, the researcher can analyze the data using powerful search, query and visualization tools to uncover subtle connections, and add insights and ideas. NVivo allows the researcher to track ideas and steps, use annotations to jot down thoughts, and create memos to capture detailed observations (http://www.qsrinternational.com/).

The complete data set was collected over a three month time period, and thus an intentional plan was implemented to address the temporal issues with the data collection and interpretation. The pre-program and post-program individual participant interviews were collected and documented separately as study findings and were first analyzed individually and then collectively to identify essential structures and overall themes. Each pre-interview was analyzed individually and then across the four collectively. The focus groups that were held after each of the six program sessions had the data collected separately as findings for each of the six weeks. The analysis of the focus groups was completed individually after each week, and then reviewed collectively after all of the six sessions are concluded. These focus group findings were analyzed separately and then collectively to identify and interpret the emerging themes. In the final steps of analysis and write up, the quotes of all participants, participant observations, field notes, reflective diaries, and brainstorming flip chart notes are quoted in this paper according to the week of the program that it was collected. Through this detailed approach, the temporal aspect inherent in data collection from people participating in a six-week educational program is accounted for and will enhance the rigor of the study and analysis. Each of the three main essential structures is described by changes that occurred throughout participants' involvement in the program.

3.8 Standard for Evaluation: Trustworthiness

While the evaluation of qualitative data differs from quantitative data, the standards include rigorous analysis and interpretation. Evaluation in qualitative research is based on trustworthiness, as outlined by Guba & Lincoln, 1989. The criteria for establishing trustworthiness are credibility, transferability, dependability, and confirmability (Guba & Lincoln, 1989). Prolonged engagement, persistent observations, peer debriefing, negative case analysis, progressive subjectivity and member checks are part of ascertaining credibility. As everyone's story is different, as researchers we cannot generalize the findings, but we can look at transferability as we can expect similar experiences and meanings to emerge for others with a similar context and similar characteristics of the study participants as a result of the phenomenon. Dependability speaks to the stability of the data over time, and thus being cognizant of changes over time helps establish dependability. Confirmability is achieved by the quotes of all participant voices ensuring the data and interpretation are rooted in participants' experiences (Guba & Lincoln, 1989).

Following a particular framework, such as the Vancouver School of Phenomenology, ensured an analysis process where other researchers can follow the analysis and interpretation, and would likely interpret the data in a similar manner. When credibility, transferability, dependability, and confirmability are achieved trustworthiness is established (Wiersma, 2014, lecture notes).

Meaning is not simply found by the researcher, but is created together with participants.

3.8.1 Positionality

A hermeneutic approach requires the researcher to engage in a process of self-reflection, as the position and assumptions of the researcher are not bracketed or set-aside, but rather are embedded and essential to the interpretive process (Creswell, 2013). Positionality allows one to clearly state the lens through which s/he interprets a social world. Researchers in qualitative research have traditionally been thought of as positioned inside or outside the social group being studied. However, there is recognition of the blurring of the apparent separation between these two positions.   Qualitative researchers need to consider carefully the potential risks to participants when conducting insider research (Moore, 2012).

The notion of researcher positionality has become a defining feature of qualitative inquiry- questioning of knowledge, and knowledge production, with researchers engaging in introspection of their "insider" or "outsider" status in the study community; power in researcher-researched transactions and their representation of data and/or the study community (Lincoln & Guba, 2000). Qualitative inquiry is committed to the examination of the self in relation to knowledge production and calls for considerations of the salience of the researcher's positionality in the research process (Kibera, 2011).

In section 5.4 of this paper, I have outlined my own personal reflections and how my research analysis is shaped by my positionality.

3.9 Participants

Purposive sampling was used for this study. The selection criteria were that participants were spousal care partners of people living with dementia in the Green Bay Area of Newfoundland and Labrador. Information about this study was presented at various Central Health meetings and community gatherings. I had hoped to recruit a group of four care partners who were currently in the spousal role of care partner with a person living with dementia. The care partner did not need to be currently residing with the person. I recruited five (5) participants who had agreed to participate in the study after reading the information letter. They each signed the informed consent. The information letter and informed consent forms are attached in Appendices F and G. One participant who signed the consent form called me a few days after and withdrew from the study due to concerns with leaving his spouse for the program sessions. The other four (4) participants were interviewed before the CDSMP, but one (1) participant dropped out of the study due to the death of her spouse three (3) days before the beginning of the first session of the CDSMP. I made contact a few times with this participant to see if she wanted to continue, but she declined as she was moving out of town with family for a time of support.

A qualitative inquiry with a group of three provided a purposeful sample that concentrated on the depth of experiences as care partners caring for their spouses who are living with dementia. It provided valuable insight regarding their experiences as they participated in the CDSMP. This focused study illuminated the research questions and helped clarify the phenomenon as shared themes and the essence emerged. This sample provided information rich cases and permitted in-depth analysis to yield understandings of care partner's experiences as they participated in the CDSMP while caring for spouses living with dementia. This number of participants allowed for in-depth review of the essence of their experiences rather than an evaluation of the program. While the group was homogeneous in that they were care partners, and not a mixture of spousal, family, and friends, they were diverse in many aspects such as age, gender, level of professional and informal support, living arrangements, and educational levels.

3.9.1 Characteristics of participants

Evelyn is a care partner who was referred to the researcher by a neighbor who works at Green Bay Health Center, Central Health. She is 79 years old, and lives alone. Her spouse was diagnosed with dementia three years ago and has since moved to a long-term care facility for specialized care. She is a retired teacher, has post-secondary education, is a mother to two sons, and was very involved in volunteering with community groups prior to her husband's diagnosis.

Ryan is a care partner who was referred to the researcher by one of his friends who heard about the study though a community meeting in Springdale. He lives with his wife at an assisted living home in Springdale. He is 91 years old, and provides full care to his wife who was diagnosed with dementia seven years ago. Ryan is a retired fisherman and carpenter and has no formal education. He is a husband to his wife for 67 years, and a father to his thirteen children.

Ann is a care partner who self-referred to the study after a discussion with the researcher about the study while attending a community program for caregivers. Ann lives alone in Springdale. Her spouse, diagnosed with dementia 13 years ago, lives in the nearby long-term care facility one kilometer from their home. Ann is 72 years old, is a committed wife, a mother to two daughters, a grandmother to three children, and a friend to many in her community. Ann is a retired food service worker at the long-term care facility where her husband resides presently. Her husband lived at home with her for nine years after the diagnosis, and he moved to the facility four years ago. Ann has a high school education, and a lifetime of self-directed learning about health, and dementia.

3.9.2 Participant Stories

A conversational interview, with the participants prior to attendance at the program, revealed the following stories of care partners on their journey of partnering in the care of their spouse living with dementia. This pre-program interview was a partnership between the researcher and the participant. The themes that emerged from the analysis of the transcriptions of the interviews can be best understood though each participant's story. Pseudonyms have been used to protect confidentiality.

<u>Evelyn:</u>

Evelyn is a 79-year-old female who lives alone in Springdale NL. Her husband was admitted to a protective care unit at a long-term care facility, one and half hours away, two years previously. Before that time, her spouse lived with her for 57 years, of which one year he had been diagnosed with dementia. Upon her husband's diagnosis of dementia, her world changed significantly and revolved around learning about dementia and partnering in his care. Evelyn cared for her husband at home for only one year after the diagnosis of dementia as the disease progressed very fast, and he required special care on a protective care unit soon after his diagnosis. Evelyn reported that her husband and her shared a wonderful strong marriage and raised a family of two boys. Both of their sons are now living in different provinces with their own families. Evelyn is a retired elementary school teacher, and her husband is a retired miner. She reports that they were a couple who did everything together after retirement, and were great friends. Evelyn reported that her husband was a gentle, loving man who adored family, and was very proud of her and praised her constantly. Evelyn was very involved with community groups including the local weight loss support group for many years, traveling to conferences, and organizing local meetings. Evelyn reported that her sons and her extended family are very supportive and check in with her daily to offer encouragement and support. Her husband's brothers take care of all of the chores such as snow clearing, lawn mowing, and gardening. Also, Evelyn described that she has additional support from her neighbors, friends, and church family.

At diagnosis and the one-year prior to admission to the care facility, Evelyn described her life as "*totally changed*". Her husband went from being a man who took care of her and her needs to him totally relying on her for everything. He became very paranoid, fearful, and was not sleeping at nights. She became isolated, deferred her own interests and focused only on caring, to the detriment of her own health.

While she reported many positive aspects in caring for her spouse, she reported feeling so much stress and exhaustion that she experienced vomiting, diarrhea, irregular heart rate, and very high blood pressure. Evelyn also stopped taking care of herself and due to unhealthy lifestyle choices she gained a significant amount of weight in one year. She described her life as a perfect love story with an ending that she didn't expect. She reported that she is in the process of journaling and writing a short book about their life together so that she can share it with her family and friends. Evelyn reported a resilient commitment to caring for her husband. She is still very involved in his care, but she reported that there has been great loss since the diagnosis to the point now where he does not appear to know her or have the ability to call her by name. She reported that the biggest burden is that she has a "broken heart", and has to live away from her husband.

Evelyn reported that she has coped and has accomplished things that she never thought she could have achieved independently. Evelyn visits her husband every day or every second day for the full day at the long-term care center where she assists with care, feeding, and daily tasks. She has developed strong relationships with the staff at the facility, and reports that they are like family. Evelyn reported a very strong commitment to partnering in the care of her husband, and presently drives 1.5 hours to and from the facility to visit 4 -5 days per week.

Evelyn reported that she was very grateful to be part of this study, and felt that the timing of this was right for her. Her sons and friends had been requesting that she refocus and start taking care of herself, and she also was at a place where she was ready to start the self-management program. She stated that the process of the pre-program interview with me as researcher was extremely valuable, and gave her an opportunity to tell her story, share her experiences, and journey of being a care partner of a spouse living with dementia. She reported looking forward to being part of the program and further to contributing to a study that may help others experiencing a similar journey.

Ryan:

Ryan is 91 years old, and lives with his wife in their apartment in an assisted living facility in Springdale, NL. He is the primary care partner for his wife who was diagnosed with dementia seven years ago. He described their marital relationship as "*couldn't be any better*". He described his wife as a gentle, loving woman; they have been married for 60 years at the time of the interview. They had 13 children, and only one son currently lives in the Green Bay area close to their home; all other children live away in other provinces with their families. Ryan and his wife lived together in a nearby community up until two years ago when they moved to Springdale to reside at the assisted living apartment so that they could avail themselves of the support provided such as meals, laundry, room maintenance, and security services. Ryan is a retired fisherman and carpenter and his wife was a stay at home mother.

Presently, Ryan described his life as a total reversal in their traditional roles. He reported, *"she used to take care of me, tended on me, did all of the home chores, cooking, and raising the children; now I have to do all of her personal care, and be with her constantly."* Ryan cried as he told of his wife's gentleness, and her commitment to him and their family. He reported that the lack of family support meant that they had to move to an apartment away from their long-time home, as he needed support to help take care of his wife. He tearfully described how his wife often forgets him, especially in the middle of the night, and how she is afraid of him and tries to push him out of the bed and room at times.

Ryan emphasized repeatedly how difficult it is to be responsible for the total care of his wife, including all of her personal care. He did report how thankful he is for the staff, whom he calls "girls" who support him at the assisted living complex, and described a caring, supportive environment. He reported that he can't leave the room for any time as his wife wants him present at all times, and she will become fearful and upset if he left. He reported that he does not ask for help with her personal care because he is embarrassed for her. Ryan was focused on the disease, what medications are necessary, how to care for his wife respectfully, how to deal with her complex behavior at times. He emphasized how he wanted to always be with her- not to ever have to place her in a long-term care facility separated from him. He described life as stressful, where he is isolated, and tired.

Ryan was committed to being a participant of the study because his son and daughter in law really wanted him to attend and he felt that he could learn something. He did report anxiety about participating in the program because he has difficulty hearing and challenges with reading and writing. He also voiced concerns about how he will have to leave his wife alone in the apartment in order to attend, and anticipated challenges with this.

Ann

Ann lives alone in Springdale as her spouse who was diagnosed with dementia 13 years ago lives in the nearby long-term care facility one kilometer from their home. Ann is 72 years old, is a committed wife, a mother to two daughters, a grandmother to three children, and a friend to many in her community. They have been married for 50 years, and she described their marriage as good. Ann is a retired food service worker at the long-term care facility where her husband resides presently. Her husband is a retired government highway maintenance worker. Her husband lived at home with her for nine years after the diagnosis, and he moved to the facility four years ago after his needs were more than she could meet.

Ann described her life prior to her husband's diagnosis of dementia, as a good life where they both had traditional roles in the family. They were both retired for the last 15 to 20 years and were focused on their family. They both spent a lot of time outdoors in nature, and going for walks.

Prior to the diagnosis of dementia in 2001, Ann explained that she saw some differences in her husband, and she knew something was not right. She reported being very satisfied with the health care system and how they received a diagnosis of dementia after seeing a specialist that they were referred to. Once the diagnosis was confirmed, Ann described her life as *"spiraling down*" and that the "*news hit hard*". She reported her reaction as wanting life to end, but after a few days she realized that she had to make the best of things. She described how her husband wanted to be out in the car constantly, and how her life was consumed with caring for him and driving him around for many hours each day. She stated that at times she would almost lose her patience and reported, " *I was ready to climb the wall*" because he was constantly interrupting her to be close to him or asking to be going outside. At the end of her husband's time living at home, he had periods of aggression with her and the children. Ann was often afraid, and she would not be able to sleep. She arranged the bedroom so that they had separate beds so that she could cope better and get some sleep. She commented that she had to "*change him out" four to five times a night due to his incontinence, and was exhausted and sleep deprived*". Ann told about how she could not leave the house or have anyone else stay with him because she could not trust that he would not act aggressively.

Ann told how she had come to the end of her ability to cope in a period of crisis, and had to call an ambulance to take him to the hospital in Springdale. She reported that he never came home after that day in year 2010. She said, "*it's a wonder that I didn't need to get admitted to the hospital along with him as I was so stressed, tired, and worn down*".

After her husband moved to the long-term care facility, Ann described that "*the burden was lifted"*, and she recalled, " *I could finally go to visit her daughter if she wanted to, and tonight I am free for the first time in ten years"*. Ann visits her husband every day at the facility and helps with feeding, grooming, and talking with him. She reported, " *Now it's almost like he died, only he is still in the bed"*. Ann continues to visit her husband daily for four to five hours per day, and continues to have challenges with finding the time to exercise or focus on self-care, but reported improvements in her mental health. The guilt of not being able to care for her spouse at home was juxtaposed against the feeling of having the physical and mental burden lessened. Ann has the support of her son and her daughter, who both live in Springdale, with daily activities such as gardening, bringing wood, clearing snow, and other laborious chores that she cannot do herself.

Ann described the information sessions that she attended in years 2009 and 2010 as being very valuable. A community group, Life Unlimited for Older Adults, partnered with the Alzheimer's society and offered "Dementia Days" where the disease was explained, videos shown, and a panel of care partners told their stories. Ann expressed that by having the opportunity to learn about dementia, share her story and by listening to the others' stories, she was able to learn and take comfort in knowing how others coped. She reported that this was very useful and helped her a lot, but she wished she had this session earlier in the journey in 2001.

She communicated that she is at a place now where she is ready to be part of the study and to attend the self-management program. She states, "*I don't want dementia to get me like it got my husband".*

Andrea

Andrea is a trained lay leader of the CDSMP and as such is also a participant in this study. She participated by co-facilitating the program and participating in a focus group after each of the six sessions. Andrea lives with a chronic disease, and works in a retirement home where she interacts daily with people living with dementia. Andrea is a trained leader and co-facilitates the CDSMP two times per year in the Green Bay area of NL.

Naomi

Naomi is also a trained lay leader of the CDSMP and is also a participant in this study and she participated by co-facilitating the program and participating in a focus group after each of the six sessions. Naomi works as a public health nurse and has some knowledge and experience working with people living with dementia and care partners. As a trained leader of the CDSMP, Naomi co-facilitates the CDSMP twice per year in Green Bay, NL.

Table: Characteristics of participants

	1- Evelyn	2- Ryan	3- Ann	4- dropped out before 1st session due to death of spouse	5- Andrea	6- Naomi
Spousal care partner	Yes	Yes	Yes	Yes	NO- lay leader	NO- lay leader
Age	79	91	72	80	50	40
Gender	Female	Male	Female	Female	Female	Female
Family support	2 sons live away; good friends support	11 children- only 1 living in same community	3 children- 2 living in same community	8 children- 3 living in same community		
Formal education level	Post-Secondary	Elementary	High School	High school	Post-secondary	Post-secondary
Living arrangement	Lives alone; spouse living in protected care unit at a long-term care home	Lives with spouse at an assisted living apartment	Lives alone; spouse lives in a facility in local community	Lives alone; spouse lives in a facility in local community		

This diversity among the spousal care partners most likely influenced how they engaged in the self-management program, and their response to the program.
Ryan, the only male participant, with no formal education, who is the eldest, was currently living with his spouse with primary responsibility for all of her care. There were significant barriers for Ryan to attend the sessions, and engage in the activities when he was present. Ryan missed two of the six sessions, and when he was attending, he was often preoccupied with how his wife was doing left alone in her room.

The other two female participants, Evelyn and Ann, had their spouses living in long term care institutions which enabled them to attend the program more easily as they were confident that their spouse was being cared for while they were away. In addition to the formal support, these two participants also had more family and friends support who assisted with daily chores and caring. Evelyn who had post-secondary education, and Ann who has high school education were very engaged in the academic aspects of the program with reading the book and homework. Ryan, on the other hand, who had no formal education and low literacy, did not accept the book, or engage in any of the brainstorming activities, action planning, or homework.

Chapter Four: Presentation of Findings

As the Vancouver School of Phenomenology process of analysis was completed, three essential structures emerged from the data. The analysis was completed using QSR N Vivo for MAC software designed for qualitative research. Manual processes such as hurricane diagramming were used where each of the research questions were at the center of the page and sticky notes with participant reports were placed around the paper in order to see themes emerging. The similarities and differences were interpreted to formulate essential structures that described the participants' experience.

In the analysis, there was a movement from what the participants were saying to what the meaning was. The essential structures are the key elements that define the experience; the themes describe the essential structures. Participants' responses are the evidence of the emerging themes and the essential structures are acquired via interpretation by the researcher using the Vancouver School of Phenomenology process.

The three essential structures that emerged are *transforming with others*, *transforming to a new normal,* and *transforming of focus*. Each essential structure and the thematic statements is presented with a description from the participants as evidence.

Transforming with others

- Sharing experiences
- A safe environment to be emotional

Transforming to a new normal

- Shift in roles to a new normal
- Contextual readiness for transformation

Transforming of focus

- Refocusing on self-care
- Continued self-management support
- Celebrating accomplishments

4.1 Transforming with others

The ability to connect with others and share stories was the most predominant, ubiquitous response from all participants, including the peer facilitators, in all interviews. The researcher also observed this during the six-week program. From the beginning in session one, the participants began to warmly greet one another, and cried together as they shared their stories.

> “ *It gives us the opportunity to talk” ... it’s important to have time to talk ” (Ann). “It is hard to put into words...talking with one another, sharing, and just being here together is helping me a lot.” (Evelyn)*

One facilitator, Naomi, commented:
“*There are two that have become friends in the first two hours.*”

There are two themes that comprise the essential structure of *transforming with others*. They include 1. Sharing experiences and 2. A safe environment to be emotional.

4.1.1 Sharing experiences

The ability to connect with others who have a common life journey provided participants with the opportunity to express both the joys of their life before and after the diagnosis and the challenges and impact of being a care partner of a spouse living with dementia. Storytelling provides a way to find meaning in their interconnected experiences.

Evelyn described in the focus group of week one how important it was to have the time to connect and share with others.

> *“I hope I don’t talk too much… I’m so happy to be here… I think the more we talk about our problems the better it is for us...this gives us the opportunity to talk, and talking together do help you know... It’s even a good distraction.”*

As a facilitator, Naomi commented in week one during the focus group that she felt that the group size would need to be small in order to allow more dialogue among the participants.

> *“It seems like they really enjoyed it… we gave them more time to talk with each other because the group was smaller than usual and we had the time”. I sensed that it was really important for them to have the time to talk together and share ... it looks like that is what they are seeking... someone to listen to them, and the ability to share… perhaps for them, this is more important than the activities in the program.”*

Beginning in week one and continuing until the end, participants all voiced that they learned better by being connected, engaged and by sharing their stories as they contributed to the activities of the program. Sharing experiences anchors learners in their own context in relation to new content (Vella, 2008). The learning is enhanced with the small group where there is freedom and safety to share their stories.

In this study, although the group size was much smaller and more time was given for sharing, the content was still covered. Care partners participated in the CDSMP which is structured with respect to content, and the program activities fostered engagement as the content was being learned. The program book and overview summary provided at session one provided the content covered throughout the program.

Ann expressed in week two:

> *We learn by describing our own situations and sharing them together… It helps to learn the new things about dealing with emotions, and the difference between acute and chronic conditions by understanding it through our own examples. The small group of us allows us to share our stories... that's how we learn... we learn from each other.*

The facilitator, Andrea, commented in week two:

> *The sessions are really interactive… they participate more… I don't think the program would be successful if we didn't allow them the time to talk and share their stories…. We are essentially un-structuring the program as we go because we have the time to do so with a small group.*
>
> (It is important to note that this non-adherence to the outlined time allotment in the master trainer schedule would be considered as not upholding the fidelity of the CDSMP, suggesting a lack of flexibility to change the program to meet the needs of care partners.)

Evelyn suggested in week five:

> *"If you do this program again, we need the time to talk. It should be part of the program. Telling your story is good medicine."*

The social connection was seen in the ways that the participants greet one another when they first see one another at each session, from their reports that they call one another several times during the week as a check in, and by their embracing and talking during the coffee break during each session.

Ryan, in session two, was crying and asked:

> "*Is it ok if I hug the them (other participants)? I have been thinking about them all week and it is so nice to see them again.*"

Ann reported in week five:

> *"I call Evelyn on the days that I know she is travelling to see how her day went and to make sure she got home safely."*

Andrea, co-leader, noted in week five*:*

> *"They are really talkative… the room is very relaxed and comfortable."*

In the one-month follow up interview, Ann commented*:*

> *"We were just like family… we talked about everything with one another".*

This essential structure of transforming with others by sharing experiences was verified by all participants, regardless of whether they identified a need for self-management program and regardless of their contextual differences such as educational level, age, gender, knowledge of dementia, access to resources, or level of family support.

All of the participants reported positive aspects of caring but also the burden and stress associated with being the primary care partner. It was reported that sharing their experiences and talking about their experiences, both positive and negative, was important and valuable in connecting with one another as they refocused on self-care and continued the relationship building with one another. With respect to content, at the end of each session of the six-week program, two participants reported that the content was relevant to them at this point in their lives. During the weeks, they emphasized that the topics of healthy eating, physical activity, relaxation, guided imagery, future planning, action planning were the most valuable to their own self-management in the context of being a care partner of a spouse living with dementia. The content was thought to be meaningful and relevant to two learners.

This concept of learning better by being engaged, and sharing is acknowledged in Dialogue Education^{TM}, where learners are active participants in the learning process. It explains that the dialogue in dialogue education is not between the teacher and the learner, but rather among the learners, of whom the teacher is one. The stated intended purpose of the CDSMP is to equip with the skills to coordinate all things needed to manage their health, as well as to help them keep active in their lives (Lorig &Holman, 2003). The purpose of the program is not merely epistemological, learning for the sake of learning, but learning for the sake of transformation (Vella, 2008).

4.1.2 A safe environment to be emotional

Enhanced connection with others was evident as participants experience the phenomenon of going through the program together and *having a safe environment to be emotional*. The cycle of loss reviewed in the program came alive for participants as they began in week one with an activity about dealing with difficult emotions, mid program activities such as the symptom cycle (depression), up to the end in week six with activities associated with problem solving and ways to cope. All care partners voiced, in several of the sessions, the sense of loss of their spouses and the enormous burden of care. All participants similarly described their isolation, worry, lack of control, and lack of self-care. The expression of their sense of loss appeared to decrease over time as the program progressed. The level of emotional response and crying decreased from one week to the next. The activity of dealing with difficult emotions in week two was described as being good for allowing the release of emotions that had been built up for a long time.

In session one, Ann began in the introductions with a story of how her husband was first diagnosed, and the loss now that he has to live in a long-term care facility because she could no longer take care of him.

She cried as she expressed:

> "*My name is Ann, and my life has changed so much since he was diagnosed with dementia… I wanted it to be not true… I wanted to never go home again… I wanted my house to burn so that I would not have to go back there to live again… I wanted it to be a dream.*"

She reported the sense of loss as:

> "*It's almost like he died, only he is still in the bed.*"

As the others recounted their stories*,* they all became very emotional, and the facilitators utilized their training in the program by responding appropriately by going to the participants offering them tissues and providing the time for participants to re-compose.

Andrea, co-leader, noted after session one*:*

> *The difference with this group, as compared to others with different chronic diseases, is the level of emotion in the room.. It seems like they had a lot of emotions build up… I think the relaxed setting, small group and them all having the same experience allowed them to express their emotions more freely."*

Evelyn commented in week one:

> *Sharing is good… we have the same stories, and we have the same burden… being able to release that to someone who is going through the same thing is very helpful."*

Naomi reported in week two*:*

> *There are a lot more emotions with this group… as facilitators we need to be prepared for that, and comfortable with it…. this group seems to be dealing with a lot.* She also noted, *"If we had a larger group, we would never be able to allow the time for this sharing and emotions. We slightly un-structured the program to allow this, but we also keep it moving along so that the content can be covered… otherwise they would stay here for five hours sharing and crying with one another… it's sad.*

Ryan cried during all of the sessions that he attended as he often described the same sentiments:

> *" I wish that I didn't have to watch her go through this… it's the hardest when she don't know me, I have to care for her like a baby… I have to be patient with her, be calm, not angry… it's hard for me to watch other spouses treat their spouses hard… I'm afraid that they will take her from me and put her in a long-term unit… I can't be sure if they will treat her good like I do… I will never let them take her… crying.* "

In week three*,* Naomi reported*:*

> *"They really seemed to like the relaxation CD… they are much less emotional, and they were more focused on how to care for themselves."*

In week four, one of the co-leaders commented:

> *I think that there were fewer emotions today... they seemed less emotional and more focused on the relaxation techniques, health eating, and caring for themselves… I would have thought that they may have been more emotional today (week 4) given the topics of future plans, but they were less emotional and more talkative about the healthy eating, and communication skills.*

In week five, the co-facilitator Andrea commented*:*

> *"They are very talkative, but it don't seem like they are as emotional as in first sessions… it is very relaxed, and open, and they seemed to really like the positive thinking, and guided imagery."*

My participant observations showed that in week five:

> *"The mood among the participants was very pleasant, cheerful, and there was a lot of laughing. They were still expressing their feelings, and sharing stories, but the emotion was more positive instead of tearful."*

The shift to positive emotions was evidenced by Evelyn as she commented in week five*:*

> *"…we have to be positive, and focus on what matters with us and our spouse, not the small things like whether they are wearing nice footwear... it should be about his happiness… my happiness."*

There is a movement toward more positive thinking, and more optimism.

In week six, Evelyn shared:

> " *I can't express how happy I feel today and how happy I am with this all… I do feel much better about myself now than I did the first day when I walked in… I have learned so much… every week it seemed like it got better, and today is the icing on the cake."*

It appeared that the level of crying decreased from session one to session three, where there was then a shift in session four onward to a happier, more pleasant mood, as participants were being more connected, learning skills to be better able to cope. Having a safe environment to be emotional as they connected by sharing their experiences and stories allowed them the opportunity to express their sense of loss. It appeared that the connection with each other by sharing their stories allowed progress and an understanding of their sense of loss as the program advanced.

While all participants regardless of their diversity similarly experienced this structure of transforming with others, the small group size, the increased amount of time given for dialogue, and the emotional response could potentially have set up an environment similar to that of a support group rather than a self-management program.

4.2 Transforming to a New Normal

All care partners stated that they neglected their own self-care and that they had no time to do the things they once did: being together with their spouses, socializing with family and friends, eating healthy, or exercising regularly. After the diagnosis, time was mostly spent supervising and providing care to their spouses. In the pre-program interviews, two participants expressed that they were ready for routine and normalcy again, and they were looking forward to getting out and attending the program for six weeks. Over time, there was a change in that the program became part of their new routine.

There are two themes that comprise the essential structure of *transforming to a new normal*. They include: 1. Shift in roles to a new normal, and 2. Contextual readiness for transformation.

4.2.1 Shift in roles to a new normal

For Ann, taking care of her husband required that she be constantly with him, doing all of his personal care, taking him for long car drives every day, and staying up with him many hours during the night because he was afraid, and couldn't sleep.

Ann reported in the pre-interview:

> *…things went from a life where my husband did all of the chores, and took care of me to me having to do everything…. Then one day, I was at the end of my line, and I was unable to handle it and the responsibility… I called the ambulance and got him taken to the hospital… he never came back home from there… he was admitted to a long-term care unit. The guilt was bad… but I knew that I couldn't do it anymore… I was tired and worn out, and it was beginning to affect my mind. After admission to long-term care, (...pause…) I remember the first night as I walked out of the home to my car… I remember saying to myself, I can go anywhere I want now, I can go home to sleep, or I can go to visit my sister…. It was like the burden was lifted. I knew that I would still be going there every day, but I didn't have to do it all by myself, all day every day.*

Ryan described his experience as:

> *Our lives completely changed... she used to do everything for me, and now I take total care of her… I never leave her… I'm with her all the time, and I takes care of her like a youngster. All of the things we used to do, we don't do anymore. She was a good wife, we had it good. We couldn't have had it any better you know… "* When asked if he does anything to socialize now or to take care of himself, he simply stated, *"I don't do anything anymore, just takes care of her.*

Evelyn told that her life turned completely upside down when her husband was diagnosed with dementia. She stated*, "we were not expecting it, and thought that it could never happen to us; we thought our love could overcome it.*" She described her past life as a love story where they did everything together- gardening, visiting family, travelling with transition to a life where she had to do things that she never thought possible after the diagnosis.

At the beginning of the program, all participants all voiced and confirmed again the significant change in their lives after their partners were diagnosed with dementia. There was a lot of emotional crying as they discussed this with one another. In week one focus group, all of the participants reported how happy they were to be attending the program, and how they were looking forward to the following week; there was an observed sense of excitement to be participating in the program and the study.

Andrea, co-leader, emphasized in week one, *"They really enjoyed it. They seemed to really enjoy it."*

Evelyn reported in week one:

> *"I'm so happy to be here… this is the best thing I have done in a long time.. I haven't done much this winter. I'm so happy that you chose me to be part of this.. I was so looking forward to today, and now, I'm looking forward to next week, getting out and*

> *doing this again… like I used to do with going out to my Taking Off Pounds (TOPs) group."*

In week two, Ann reported:

> *"I really enjoyed coming out to the session…it's actually helping… I pledge to do all of this walking and things that I never would do if I didn't come out to this. It's like things that I used to do."*

The action plans at the end of each setting was reported to be valuable, and helped them get back on track to start doing things that they used to do again. At each session, two participants were very eager to share their feedback on how they did with respect to achieving their action plans. The participant without any support in caring, who was at a different stage in the journey, did not get involved in action planning, and did not commit to any self-care during the weeks.

In week three, the participants and the facilitators commented on how *"enjoyable the relaxation CD was…It is the best content so far."* Participants were drawn to the muscle relaxation, and really enjoyed the CD with the Jacobson Progressive Muscle Relaxation session, noting that they wished that they could have the CD for their own home use. Also in week three, my researcher observations noted that the participants appeared very well dressed and had their hair styled like they were going out to an important event. When one participant commented to another, *"your new hair style looks very pretty",* she responded*, "I tried the new style for the meeting today. I'm glad you like it."*

In week four, the content was concerning future planning, health care directives, and problem solving. The participants embraced this, and discussed in detail with one another the types of things that they did to plan, and what worked for them. The weekly program was taking a new place in their lives as a new routine. Participants reported that action planning and problem solving activities of the program were excellent in that it increased their accountability to practice the new skills and provide feedback to the group as the program advanced. The weekly action plans allowed participants to apply their learning and to focus on self-management skills during the week and integrate it into their current lives. They took away the skills and insight to refocus on self, acknowledging that only the individual can change their own behavior.

Evelyn suggested:

> "*This routine of coming to the sessions, getting dressed up and attending the program weekly helps me get out of the house"*.

In week five, Ann reporte*d:*

> *"This program is getting me out of the house… it gives me something to look forward to… I'm really enjoying getting together with you all"*.

Evelyn also reported:

> *"…when you talked to me about the study and the program, I was at rock bottom, maybe at the bottom of the barrel, and suddenly I felt very happy thinking about what was coming each week. I would read my book, and be prepared for the next session."*

Also, in week six, two of the participants showed up well dressed with their cameras in hand ready to attend our closing celebration.

In week six, two participants who became good friends over the course of the program talked about attending a community event with the caregivers network in Green Bay. The two participants had participated in the community group together during the past week.

Evelyn noted:

> *" I think that I may consider being part of that group, and possibly even being a leader… it might be like it was when I was a leader at TOPS".*

As time progressed, two participants reported that they enjoyed the new routine in their lives and they were seeking the availability of other opportunities for this new place in their lives where they could connect with others and find a new sense of routine. The phone calls in between weekly sessions also changed over time as they called one another more often throughout the week showing the new sense of normal as they connected and built relationships with one another. In the post one-month follow up, it was apparent that the change in social isolation was decreased as they were spending more time with family and friends. For the one participant who had structural barriers to attending and participating, the program did not fit well with his life, and it did not become part of a new normal for him.

4.2.2 Contextual Readiness for Transformation

Through the contextual differences, it was apparent early in the study that one participant was at a different stage than the others in the journey of living with and partnering in the care for their spouse living with dementia. Two of the three participants had their spouses living at a long-term care center, while one participant was currently living with his spouse with full responsibility for her care and safety. The two participants with support of institutional care voiced in the pre-program interview and at each session that they were ready for a self-management program, and had some idea about the need for getting back to taking care of themselves, learning to adapt to a new life with a new sense of normal routine, but without the spouse as a contributing partner. The participant who did not have professional support with caring, did not engage in the program activities, and missed two of the six sessions due to issues with not being able to leave his spouse. This participant did not have the opportunities where he could focus on himself. He was still very focused on learning about dementia, what to expect, what medications were best, how to care respectfully, how to cultivate patience in providing care, and how to garner family support around him to assist with caring. In the one-month post intervention interview, he indicated that while he enjoyed the social and sharing with the other members, this program was not what he was looking for at this time in his journey; his focus was still on the constant care, how to get support, what to expect, how to plan to stay together with his spouse, and how to deal with the challenging behaviors. In addition, his age and gender may have impacted his ability to connect closely with others and benefit fully from this program. The challenges and barriers for this participant with lack of support, and the early timing in his dementia journey precluded his participation. The context, and his present situation did not allow for contextual readiness for transformation.

This participant did not identify a focus on self, as a priority in the pre-program interview or during the program, and did not report an improvement in perceived well-being as a result of participating in the CDSMP. He did, however, still voice the value in connecting with others who were experiencing the same journey. As the literature suggested, in this study there was further acknowledgement of the importance of assessing whether the CDSMP is needed and the level of contextual readiness before it is offered as an intervention. Indeed, if the structural barriers to wellness are not addressed (such as respite care and more home care), it is impractical to suggest that someone focus on caring for him or herself and it may lead to greater frustration.

In these kinds of circumstances, it is important to identify the structural barriers to focusing on self-care as well as the diversity in how individuals respond to the role of a care partner before a self-management program is offered. It is important to consider whether participation in such a program without addressing the structural barriers might be more damaging than useful if the readiness is not present.

Offering a self-management program before other identified needs, such as information about dementia, knowledge of how to deal with challenging behaviors, and future expectations, are met, may actually increase distress and frustration in the care partner. In rural and remote Newfoundland and Labrador, there are additional barriers to home support services for respite care with a lack of family support and difficulties with hiring home care workers due to outmigration of people for employment.

In the one-month follow up interview, Evelyn reported:

> *I feel that this program was at the right time for me... I needed it… I felt that all of a sudden I had five new friends and there was a lot of bonding… looking back at it now, I feel that I was able to sit up there in that room, and up until then I felt like I was not allowed to be happy…but it made me less stressed, and gave me permission to start thinking about me again, and how to be normal again.* She also commented, *it was a bit of an escape… dressing up and taking my book, and going off made it feel like I was back in reality. It felt like I had a purpose. It was a real let down when it was finished. I like the routine of getting back on track, going out to something, meeting people, and learning again with my book.*

Two participants indicated that at the beginning of their journey, soon after the diagnosis, educational support with knowledge about dementia, disease progression, and what to expect is what is needed. This is provided through the First Link^{TM} program with Alzheimer's Societies, and also through local dementia days provided by a local community group called Life Unlimited for Older Adults. The care partners reported that the informational needs related to dementia are at the beginning of the dementia diagnosis and journey. There is a shift in needs as those educational and information needs are met, to different information needs related to self-management and self-care.

Evelyn commented:

> *…at some point, a few months after the diagnosis, there is a need for social support to get out of the house, and now once I had more support to attend this type of program, a self-management program is needed to help me focus back on me, and to learn about how to cope with this reality again.*

In week one, when asked about content, Evelyn also noted:

> *I'm past the stage now about learning about dementia and the stages for my husband, now it is about me as well… The Alzheimer's Society programs on the phone are good for someone just diagnosed… the timing of this one was perfect for me. This was a different course- it was just different.*

Care partners reported that early in journey, they needed information regarding the diagnosis, what to expect, and education on how to care, and ability to cope with the loss and grief. It was indicated that at mid-journey, they needed access to self-management support, emotional and social support, and they needed help with letting go and accepting the decision that their spouse may need to move to institutionalized care or full care options. Care partners voiced that in the later stage of the journey, they needed self-care support and ongoing self-management support once the program is over. From a researcher perspective, I question whether having these needs met concurrently and early in the journey with a focus on self-care would be beneficial to prevent crisis and the significant strain on care partners.

Ryan, the participant who is living with his wife, listened and cried during the sessions. He did not allude in the pre-interview or in either focus group interview about the need to take care of himself. His focus was primarily about the challenges of caring, his love for his wife, and reminiscing about their past life together. Ryan did not participate in any program activities, or action planning. He did not contribute to the formal program activities but was engaged in the informal sharing of stories.

Two of the three participants noted that their information and knowledge needs were already met as they were at a stage in their journey where their needs were no longer related to disease specifics, the disease trajectory, or practical tasks for personal caring, but rather on how to refocus to taking care of themselves. One participant who was at a different stage of still living with his spouse living with dementia without a strong support system did not identify a need for a self-management program. His knowledge needs associated with the disease of dementia, the disease progression, technical caring skills, and approaches to acquire supportive and respite care were unmet.

Ryan did not engage because of being at different stage of the dementia journey and he was just unable to focus on transforming to a new life normal, and was unable to shift his thinking to himself. He was still focused on the constant caring for his spouse.

Also, it is important to note that recruitment was difficult because participants reported that they did not feel that they could leave their spouses for the program time and also there was no one to stay with them even if they felt that they could leave. As such, ensuring the appropriate supports are in place can contribute to contextual readiness for transformation.

The similarities in the perspectives of two of the participants with respect to their perceived and self-assessed need for the program, as compared with the one participant who was not indicating a need to focus on self, highlighted an important theme about completing an individual care partner assessment, and addressing the structural barriers before this program is offered. This would help to determine the most appropriate timing of the program intervention for best care partner support. Also, there is identified need of respite care to attend the program and for most success.

In this study program, the content was systematically covered as outlined in the manual and participant book, and the program incorporated activities for participants to be actively engaged with brainstorming, problem solving, and action planning to practice their skills with the new information. However, the CDSMP is still highly academic, and requires a certain literacy level and group learning style. For the participant who had no formal education, and who later indicated a preference for one-on-one learning in a private setting, the structured CDSMP did not offer him the right combination of the three domains of learning: knowledge, skills, and attitudes.

4.3 Transforming of focus

The purpose of the intervention, completing the six-week CDSMP, is to support care partners, empower and equip them with the skills and tools to improve coping, and to become effective partners in their own health and managing their lives. Self-management is a person-centered approach, is dynamic and reflects an ethos of empowerment (Long-Term Conditions Alliance Scotland, 2008).

There are three themes that comprise the essential structure of *transforming of focus*. They include: 1. Refocusing on self-care, 2. Continued self-management support, and 3. Celebrating accomplishments.

4.3.1 Refocusing on self-care

Self-management helps people come to terms with the diagnosis, supports people to navigate an often difficult journey, supports changing needs, maintains focus on a person's needs ensuring services are organized around these, and supports the person to meet a range of challenges and to maintain control (Long-Term Conditions Alliance Scotland, 2008).

Evelyn reported in the pre-program interview:

> *My son said to me… you are wearing yourself out mom, you are red in the face all the time…stop trying to be the perfect wife by going there to the long-term care unit with dad everyday… he will be fine...it is time for you to take care of yourself again.*

Ann reported in the pre-program interview:

> *I watched another lady in the long-term care unit where my husband lives almost kill herself by taking care of her spouse… he passed away last year, and in less than one year she ended up at the same long-term care center. She didn't take care of herself. I realize that if I don't take care of myself, dementia will get me in a different way than it got my husband.*

In week one of the program, Evelyn commented, *"My boys are so proud of me for attending this program."*

Evelyn reported in week six:

> *I need to take care of myself... dementia took my husband... it almost took me… it was taking me in a different way… I have to start living because dementia took my husband and it took me. Dementia can get me as well as the one they got.*

They both commented similarly "*We are different people today than we were on the first week."*

In week six, Evelyn said, *I needed this... dementia took my husband, I can't let it take me… in a different way you know…*"

Ann followed her comment with, *"Dementia can get you instead of the one they got if we don't take care of ourselves"*.

She ended by saying, "*I can't tell you enough what this has done for me*".

In the one-month post interview, Evelyn ended by saying,

> *"It was a wonderful experience, probably the most important one in my life. I feel like it took me… it took my feet off the ground... It helped me to stand back on my feet"*.

It is important to note that Ryan, who was not engaged, and at a different stage in the journey did not acknowledge any shifting of focus to self-care. He was still focused on how to do the caring, and what the journey will look like. For those who stated the importance of self-management, there was an increased acknowledgment over time as the program advanced from week one to six. As the program advanced, there was a clear increase in the number of comments from two participants related to the importance of focusing on self-care.

During the one-month post interview, the two participants reported that they were more empowered care partners with new skills to live well as they cared for their spouse living with dementia. They reported increased focus on self-care, improved coping, increased social connection, and increased physical activity. Also, one participant reported an enhancement with her family physician encounters where there was a new focus on her own health and wellbeing. As seen by the evidence (quotes) above, there was also an indication of increased overall subjective wellbeing, a sense of optimism, and improved ability to balance the demands of care and focusing on self-care. For two of the participants who were actively engaged in the program and reported it as being useful, the one-month follow up interview showed an improvement in reported ability to cope, with more focus on being physically active, eating healthier, and being prepared for visits to physicians. While focusing on these outcomes is beyond the scope of this study, these identified improvements show a transformation of focus toward self-management which can be linked to an improved quality of life and less reliance upon healthcare system as they build confidence to manage health and maintain active and fulfilling lives.

4.3.2 Continued self-management support

Self-management is not a replacement for services, and is meant to empower the person with the information, skills, and confidence necessary to cope with the chronic illness, recognizing that it does not mean managing alone or that the burden of care rests solely with the person. It is about self-determination in partnership with supporters (Long-Term Conditions Alliance Scotland, 2008).

It was identified by care partners that a process is needed to make sure they stay on track with follow-up or check in. This was an acknowledgement by the participants of the need for continued support after the six weeks. They voiced that they wanted the program to be longer than six weeks. The participants noted that continued support after session six would be beneficial for keeping on track. The relationships developed during the program were still ongoing one month after the program ended; there were still ongoing phone calls and going out to dinner together among two of the three participants currently.

In week five, Evelyn reported:

> "*Ann calls me all the time… she checks in to see how I'm doing, and to see if I got back ok... I call her as well… I have a new friend... it's nice… we just chat.*"

Andrea also described, "*I think they have bonded really well... they talk a lot during the session."*

In week six, Ann reported, "*…it's sad that this is over now... I really enjoyed it… I hate to think of this being over."*

During the one month post-interview, Evelyn remarked:

> *It would be nice to have something like that program ongoing… even if it was once a month that we got together... For me, I felt really good, and I just loved getting ready to go, and get there, and laugh, have tea, and share, and learn".*

She also reported:

> *That evening when it was over, I felt like I might never see these people again… But, now I have been looking for their email addresses and phone numbers, and I have been adding them as friends on Facebook… I feel like they are my friends and I will keep in contact.*

In the one-month follow-up interview, Ann reported, *"I phoned Evelyn this week… she is gone a lot with all of that travel. I calls her to have a chat, and to check in".*

There was a continuing of the new normal with sustained relationship building after the program has ended which has been identified as valuable for being accountable to keep focused on self.

In the member check meeting, one participant reported:

> "*Being part of this program was the best three or four months of my life since my husband was diagnosed…I miss it so much*."

Over time, the identified need for continued self-management support and the comments related to wanting the program to be longer than six weeks increased as it became closer to the end of the program.

Ryan reported in the one-month follow-up interview:

> " *I think that someone should come in and talk to me in a private room like this. I had a lot of trouble because I can't read and I'm kind of deaf".*

The one participant who was not able to be engaged did not acknowledge a need for continued self-management support, but he did voice in the one month follow up interview his previously stated needs of knowledge about dementia, and how to care for his wife. He also noted that he preferred one-on-one learning opportunities in his room like the follow up interview. For Ryan the one-on-one interaction was where he talked openly and expressed his needs, and identified that the program did not meet his needs.

4.3.3 Celebrating accomplishments

In week one, two participants agreed that the content was relevant and they found that it was applicable to them. The one male participant did not have much to say and did not offer any comments in response to my focus group questions.

Ann reported, *"I find it all very useful.*"

Naomi commented:

> *I think the content of this program could work for this group with some minor adjustments and revisions to the examples used to make it more applicable to care partners- for example, with the symptom cycle, it needs to be explained that their symptoms are related to the burden of care. (Week one)*

In the interview after session one, Ann reported, "*I just learned so much.*"

In week two, Evelyn commented, "This *session is helping a lot… I pledge to do all of this walking that I would not normally do….I find it really good."*

In week three, Andrea reported*:*

> *I think that the content these last three weeks is all totally applicable… it's still very important to un-structure the program a bit though so that they can share and talk because it seems like that is how they are learning… by sharing… comparing it with their own experiences.*

In week three, Naomi reported*:*

> *"…they do tend to tell stories with each brainstorming activity… they give examples that apply to what they are learning."*

In week four, Ann commented about the content:

> *"The healthy eating and future planning activities were my favorite".* Evelyn said*, "If I had known about this before it would have been good... I would have been more prepared... because I wasn't prepared for anything."*

In week five, Evelyn commented, "*…now I do all of that walking… without coming here to this, I would still be parking right close to every door."*

She also commented after being asked about the content, *"knowledge is the most powerful thing.*"

In week six, Evelyn shared:

> "*I can't express how happy I feel today and how happy I am with this all… I do feel much better about myself now than I did the first day when I walked in. I have learned so much; every week it seemed like it got better, and today is the icing on the cake."*

In week six, the two participants who attended arrived well dressed and ready to receive their certificates. They acknowledged when they arrived that they were getting their certificates today and were excited to be going out for a celebration dinner. The mood in the room was one of high energy, and anticipation.

Evelyn reported:

> *"I'm keeping my certificate in my car for a little while so that I can show it to my family, friends and the staff at the long-term care center… my boys are so proud of me for doing this… I'm so sad it's over today, but we will still get together. I have made new friends now."*

Ann asked me*, "...do you see two different women today? I feel better… this made a lot of difference for me."*

Evelyn also reported*:*

> *I went for a coffee the other day with five of my friends, and when we were going to our cars, I said to them, "Come over here, I have something to show you. I showed them the certificate and showed them what I had done for the last six weeks. I have a lot of certificates from other things, but this one is different… it took me back to reality, and it is making me feel really good.*

These comments are evidence of a feeling of pride and a sense of accomplishment by completing the program. There was a new meaning for two of the participants relating to a change in focus, and a life changed. These two participants indicated that they really appreciated and deeply valued the certificate provided at the end. When the certificates were presented and a group picture was taken, they reported that it felt good, and there was a sense of accomplishment that they had achieved something and for two it was a signal of a refocusing on self-care, and engaging in life again. Two participants expressed that their family members and friends were very proud and satisfied that they participated and have been refocusing on themselves with improved coping. The other participant, who was not contextually ready, did not show up at the last session of the program.

In week six, the activity related to brainstorming about the difficulties of living with a chronic disease, care partnering for a spouse living with dementia, was powerful. The list from week one was large, outlining things such as: denial, altered plans for the future, disappointment, loss of control, avoidance, burden, fear for safety of loved one, worry, daily schedules had to revolve around loved ones behavior/actions, stress, long drive to visit loved one/need to leave home for long periods, worry about whether they are being cared for, spouse not being able to call my own name, stigma (no support because people don't know how to deal with it), and isolation (people stayed away). But in week six, there were only a few items listed, and it was much less emotional. The things listed in the brainstorming session of week six for the difficulties of living with a chronic disease were: confinement, having to be with spouse always 24/7, denial, travel to visit (I became a very good driver). The difference in the lists and the level of emotion signified that their perspective was transforming.

In the one-month follow-up interview, Evelyn reflected:

> "*My life had stopped. I just stopped, and I had to wind it up again and get it going... The things I learned have stayed with me.*"

In the one-month follow up interview, Ann commented:

> *"I learned a lot; it was really good for me. Today I was looking at the neck exercises in the book. I did some of them, and it was really helpful. I was also reading the story… the guided image story from the book… it is very relaxing."* Further she said, *"...sometimes I get home at the end of the day, and I feel so tired... I remember the sessions, and I say to myself, I need to take a day off and not go to the long-term care center tomorrow. I need a day for myself. I take the day to go shopping or spend time with my sister."*

In the post one-month follow-up interview, Evelyn was referencing the stages of the symptom cycle, and reflecting on her life through that lens. The program appeared to have provided a new framework for her thinking about her life. This is an example of how learning occurred, and provided a tool for organizing her thoughts, navigating her journey, and improving coping. This is evidence that the learning occurred, is being applied, and behavior is changed as a result. It appeared from the discussion with Evelyn that the skills learned were being applied and used in her context. Her behavior had changed with increased exercise, improved healthy eating, increased insight into taking care of herself, and an overall improvement in self perceived well-being.

In week four of the program, one participant, Evelyn, talked about how happy she was to be part of the study where she may be able to help with programming for others who have spouses with dementia.

She commented:

> *"I am being really honest with you in answering the questions because I want the study to be a good one for you, and also so that others in my same situation can benefit from it."*

Contributing to this study seemed to give her an added purpose, and a new perspective in that her journey and now participation in the program could not only help her own capacity to cope, but also help others. Being cognizant of this study's purpose and participating is another transformation where participants had a sense of purpose again.

Two participants described that by attending the program, they felt better physically and emotionally, and that it did indeed improve their wellness. In week two, the physical activity and exercise activities were reported as a highlight of the week. In week four, the activities on healthy eating and future plans for health care were noted as being the most interesting and relevant. The guided imagery activity, a walk in the country, in week five, was highlighted as the best content of that week. In the closing week six, participants described the working with your health care professional and the health care system activities as being very relevant and useful for self-management and it thus evoked a lot of group discussion. They reported that they would recommend this program to others who are care partners of those living with dementia who are at the right stage. Two participants stated that their physical activity increased, their insight into need for shifting their focus from totally caring for spouse to some care of self, and their social connectivity increased as a result of attending this program.

4.4 Summary of Findings:

In summary, three essential structures with underlying themes emerged from the analysis of the experiences of participants, as they were involved in the CDSMP. The first essential structure of transforming with others was the most easily identifiable and was best explained with the themes of sharing experiences, and a safe environment to be emotional. All participants shared their experiences throughout the program and continually voiced the importance of having the opportunity to connect and share with one another. The connection with one another was enhanced during the program, as there was a safe environment to be emotional and share openly one another. As they continually shared their stories during their encounters, they engaged and connected with one another, and were able to learn the new program content by being anchored in their own context. The small group in this study was conducive to sharing and connecting with one another as learners experienced the phenomenon in a safe environment for emotional release.

The second essential structure of transforming to a new normal was described by two themes: a shift in roles to a new normal and contextual readiness for transformation. Two participants expressed that the new routine of attending the program and connecting with others was valuable and they embraced the opportunity for a new routine in their lives. There is diversity in how individuals respond to the role of care partner and thus the importance of assessing and identifying the contextual readiness and any barriers to focusing on self-care was evident. As participants who were contextually ready experienced the six-week program, there was a sense of engagement in life as it once was with a transformation to a new normal with routine and normalcy. There was a transforming from the role of caring to a sense of normal and purpose. The stage of the journey of the individual care partner is integral to the optimization of the timing for the intervention of the six-week program so as to best meet the needs of the care partners with respect to transforming the focus to self.

The third essential structure of transforming focus was portrayed through three themes: refocusing on self-care, continued self-management support, and celebrating accomplishments. Throughout the six weeks of the program, for two participants, there was an increased refocus on self-care and the importance of taking care of themselves. It was clear as well that continued self-management support is necessary for continued focus on self and sustainability of this refocus. Additionally, celebrating their accomplishments related to their self-care was considered very important by two participants as they expressed their sense of pride and accomplishment as they advanced through the CDSMP and received their certificates at the end of the program. There was a transformation of focus to the need for self-management and self-care that evolved over the duration of the study program for those participants who were contextually ready. By the sixth week of the program there was a deepened perception of the need for self-care with evidence of actions suggesting a transformation in their focus toward self. With the transformation toward the need for self-management, it was identified that self-management support would be beneficial for sustaining the focus on self-management and improving their wellness during the caring experience. The safe environment, the development of sound relationships, and participants actively engaging in sharing their experiences grounded the new learning in what participants already knew. The learning was evidenced by a transformation in mindset and lifestyle, and was not just learning for the sake of learning. Participants utilized their social and experiential context as the basis of their learning and skill development.

The essential themes summarized offer a glimpse into the experiences of three spousal care partners of those living with dementia participating in the six-week self-management program. The individual themes must be interpreted acknowledging that there is a temporal flow in the presentation of each theme. The themes must also be critically appraised in light of the fact that the program was changed from the originally intended CDSMP with smaller group size, increased time for dialogue, and the addition of the study components of interviews and focus groups.

Chapter five: Discussion of Findings

5.1 Synopsis of the research findings/ Overview

In this section, I will provide a discussion of the findings as it relates to the emergent structures and themes and each research question posed in the study. The review will provide a summation of the findings.

5.1.1 Transforming with others

One of the essential structures of the experience of participating in a self-management program was transforming with others, where participants described the importance of connecting with others who were on the same journey. Consistent with the literature, research on caregiving has demonstrated that having someone to talk to is very important (Alwin, Oberg, & Krevers, 2010). Studies have concluded that support group interventions demonstrate a significant improvement on care partner burden (Parker et al, 2008). A meta-analysis of care partner support groups in patients with dementia shows a significant positive effect on caregivers' psychological well-being and social outcomes (Chien, et al, 2011). A study by Chu et al (2011) showed decreased depression levels but no significant difference in care partners' burden after the support group intervention.

In my study, the pre-interviews with each participant provided the context of each care partner as they journeyed in the caring experience and provided opportunity for participants to identify their needs. In addition to attesting to the significant burden and strain of caring, it was also identified that they needed social support in their lives and to connect with others. Care partners acknowledged that they were socially isolated and needed people to talk with to share their stories, and opportunities for connecting with others. The participants voiced how they enjoyed telling their story to me as a researcher, and how it helped them to reflect and define their story.

The findings related to sharing experiences and transforming with others is similar to the experiences of other care partners of those living with dementia reported in the literature. The current literature, however, around social support and connecting with others is mostly related to peer support groups where the focus is on having a place and opportunity to express feelings. This was found in other studies to be valuable and provided improvements in care partners' psychological well-being (Brodaty & Donkin, 2009; Parker et al, 2008). The difference found in this study was that the focus was not on expressing feelings, but on self-management.

Participants expressed the importance of having sufficient time for dialogue between members for maximum learning. It was through active engagement, anchoring new knowledge in their prior experiences, as they shared with each other, that transformational learning occurred. As adults they needed to learn in a safe environment with a hands-on practical approach in order that the learning be transformational in their lives.

The literature demonstrated that adults are goal-orientated, relevancy-orientated, practical, and like to be respected. Adults like to be given opportunities to use their existing knowledge and experiences gained from their lives, and apply it to their new learning (Knowles, Holton & Swanson, 2005). Adult learners want to know the relevancy of what they are learning to what they want to achieve. They learn by doing and learn most effectively when they have a strong inner motivation to develop a new skill or acquire a particular type of knowledge. Adults learn best in an informal situation, and personalized learning is preferred. Dialogue Education^{TM} focuses on the needs of the learners and promotes dialogue among participants, allowing learners to connect new information to their lives in meaningful ways (Driscoll, 2009). Dialogue Education^{TM} is about structuring learning experiences for audiences and follows the principles of effective adult learning. Dialogue Education^{TM} is a learning-centered system deeply rooted in valuing the individuality of each learner. It promotes ways of thinking and learning together.

The responses from participants at each of the focus groups were congruent with the principles of adult learning, specifically Dialogue Education^{TM}, as they expressed the importance of the self-management program being flexible with group size, and time allotment for activities in order to foster personal connection and dialogue. The small group size created a safe environment for learners to share experiences that enhanced learning and support. With more learners, the time needed to cover new material becomes longer. Learning was supported by the small group. Participants voiced that the setting was comfortable, informal, and conducive to sharing and learning. Participants reported that the peer-led program was valuable as the facilitators had knowledge and experience with living with a chronic disease. They also reported that the informal arrangement in the room with couches and tables allowed for good interaction in an informal setting that allowed participants the freedom to share and engage when they wanted to but were not pressured to do so. The delivery of the program in a manner that allowed for self-directed learning was believed to be important and applied within this program. Respect for learners as decision makers and the ability to be in control of their learning were considered to be an integral part of the delivery of the program, as one participant chose to not do action plans or be as actively engaged. Given the added value that participants expressed about dialogue and connection in the learning environment, it may be helpful to consider how a self-management program for care partners can be congruent with the principles of Dialogue Education^{TM} allowing for maximum connection, engagement and transformation.

5.1.2 Transforming to a new normal

Care partners' stories in the literature reported that when the chronic illness of dementia presents, it becomes the center of existence with sudden and complete changes for both the care partner and the person with dementia (Russell, 2008). Care partners often reported that caring for their relative with dementia is physically demanding, there is a loss of hope of their loved one improving, and there is fear of the future (Zwaanswijk et al, 2013). Similar to the experiences documented in the literature reviewed, the participants in this study reported also that once dementia transpired, caring for and being with their care partner became the center of their existence and there was a complete change in the way life once was. Participants in this study confirmed this complete change in their lives when their spouse was diagnosed with dementia.

Other phenomenological studies indicate that dementia care partners experienced profound changes in their relationships as they described "losing" their loved one as if their "minds had been stolen" (Vellone, Sansoni, & Cohen, 2002). They reported that there was a sense of loss and therefore periods of grief, and that their loved one had become childlike because of the cognitive impairment, and that they need continuous supervision (Walker & Pomeroy, 1996).

The sense of loss was expressed in the statements of this study's participants as they described how their own lives completely focused on caring for their partner and supervising them at all times. Participants voiced how they felt that they actually had lost their spouse in one sense because s/he could no longer call their name or do things that they always did. There was much emotional sharing and crying as they discussed this with one another in the program. It appeared that by sharing and telling their experiences, they were working through the stages of loss, and accepting a different reality and re-engaging in a new life with a transformation to a new normal. Participants experienced an emotional response that transitioned from highly expressive crying, in weeks one and two, to more expressions of laughter and happiness in weeks three to six. Participants reported that they felt that attending the program provided a sense of normality and routine in their lives.

Care partners are a vulnerable population who often neglect their own health needs and thus have poor health outcomes, and need support in order to manage their own health, and to provide quality care to their loved one (Dellasega, 1990). Supporting and ensuring the well-being of care partners translate into better outcomes overall as care recipients receive the best quality of care, and care partners remain healthy (Brodaty & Donkin, 2009). Supported care partners result in more knowledgeable and confident care partners who have less stress, and place fewer demands on the healthcare system (Connor et al, 2008). Interventions supporting care partners have been shown to be effective at increasing knowledge, reducing stress and depression levels, and delaying nursing home placement (Brodaty & Donkin, 2009).

Although there is a significant impact on the lives of care partners as they partner in the care of their spouse living with dementia, participation in the CDSMP helped create an openness for a new normal with a re-focus on self, along with a continued strong commitment to partnering in care of their spouse. It was identified that there are positive aspects of partnering in the care of their spouse as it provides a sense of meaning, purpose, and emotional closeness. The program assisted with building capacity by increasing mindfulness of the need for self-care, and equipping with the tools and skills necessary to cope and live a rewarding life with a new normal.

The importance of an appraisal of the program fit became evident throughout the program, evidenced by the difference in one participant who was less engaged due to being at a dissimilar stage in the journey, with different levels of family and professional support. The program needs to be availed of at right time for the care partner so that the content is meaningful, relevant and useful considering the context of the learner so that best learning and application can occur.

The similarities in the perspectives of two of the participants with respect to their perceived and self-assessed need for the program, as compared with the one participant who had not indicated a need to focus on self, highlighted an important theme about completing an individual assessment of program fit to determine appropriate timing of program intervention for best outcomes related to engaging and practicing skills for self-care. Care partners in this study reported that there is need for an assessment to determine the needs and the most appropriate timing for a self-management program. This would allow possible connection with appropriate supports for the assessed stage of the spouse's journey. Zarit and Femia propose that the success of interventions will be related to how they are individually tailored (Zarit &Femia, 2008 a; Innes et al, 2011).

The literature reviewed showed that treating care partners for symptoms that they do not have is impractical, and likewise it is also not useful to target care partners for treatment of a risk factor unless the risk factor is present (Zarit & Femia, 2008b). Assessing the care partners' and asking why they are seeking support is important when considering the types of interventions to offer.

In the literature reviewed, the top informational needs identified by dementia care partners deal mostly with understanding the disease trajectory, dealing with behavioral changes in the person for whom care was provided and information on managing their own stress (Koenig, Steiner, & Pierce, 2011). Care partners require knowledge, technical skills, and judgment to carry out the tasks of care for their loved ones and research has shown that care partners who feel prepared to deliver care have less burden (Reinhard et al, 2008). It is recommended that care partners be given practical advice on coping with the symptoms of dementia, and how to deal with the behavior of the person with dementia (Zwaanswijk et al, 2013). Care partners report that they need information and supportive guidance as to how to cope with behavioral problems, how the disease progresses, and how to effectively coordinate dementia care (Peeters, Van Beek, Meerveld, Spreeuwenberg, & Francke, 2010). If these informational needs are not first met, the care partner, like Ryan, will likely experience challenges with focusing on self-care and self-management.

In this study, there were many differences among the care partners in terms of age, gender, level of professional and informal support, living arrangements, educational levels, and the disease trajectory of the dementia for spouses living with dementia. This diversity influenced how individual participants engaged and responded to the self-management program. An assessment of individual needs, program fit, and styles of learning would have been valuable to understanding their experiences. With respect to Ryan's experience as a negative case analysis, an assessment of his contextual readiness, barriers to participations, and learning needs would have enhanced this study. Upon reflection, it is questionable as to whether the self-management program was the best fit for him, and what impact the program had on him as his identified needs were unmet. The needs assessment and addressing the structural barriers are essential to the program being beneficial to care partners.

5.1.3 Transforming focus

The findings of this study in the participant pre-program interviews are congruent with the literature reviewed in that it is confirmed that dementia changes lives, and places significant physical, emotional, and social burden on families. Caring for loved ones with dementia is associated with well-documented increases in care partner burden, distress, and decreases in mental health and well-being (Sorensen et al, 2006). The provision of care to a person living with dementia results in immense physical, psychological, emotional, social, and financial burdens (Lee & Cameron, 2004).

Despite this impact of caring, participants in this study reported that the program facilitated a transformation in their awareness of the need for self-management so that "*dementia does not take me like it has taken my spouse*". As the program progressed, the self- identified need to take care of one's self, and the necessity of acquiring skills for self-management heightened. There was a transformation of their focus toward self-management.

Similar to the literature on self-management programs and others' experiences, participants in this study who were contextually ready, reported that they felt that attending the program transformed their focus back to taking care of themselves. Two participants also described that the new knowledge learned, both from one another and the program content, increased their insight into the need for self-management and self-care. While participating in the program over the six weeks, participants described their experience as one of social connection and enhanced support, while learning new knowledge and skills that transformed their focus back to self-care.

In contrast to the literature reviewed related to the CDSMP, the findings of this study identified the need for respite care in order to attend the CDSMP, and the lack of respite had a profound impact on the success of the program. The participants who had their spouses living at a long term care facility had the ability to attend the six-week program more easily than the care partner who had his spouse living at home with him. The care partner who did not have respite care had poorer attendance at the sessions, and affected the ability to stay at a two hour weekly session. This one participant noted that respite care, formal or informal, was a need in order to be able to attend a six-week program and also to minimize the impact of caring on his/her own health. The lack of respite, either support at home or the ability to bring a spouse to the program area, influenced the agreement of care partners to participate in the study thus causing a significant challenge with this study's recruitment. Offering respite care to care partners would be integral to the success of the program and would meet an important identified need.

Similar to the literature, the findings in this study confirmed the importance of self-management support. There was self-identified need of continued, *ongoing support and peer connection* after the CDSMP is over. This identified need for continued self-management support once the program was completed was an unmet need in the CDSMP, and this study. The one-month follow up interview confirmed the self-identified need for continued support, and the contact with me as researcher in this interview was reported to be valuable. Integration of a means to meet this need would provide enhanced success in the future delivery of the CDSMP to care partners of those living with dementia.

Participation in the program with the connection to one another, and the new learning evoked a feeling of accomplishment when finishing the program. Participants reported that they felt a sense of accomplishment by attending the program and receiving the certificate. They reported that their family and friends were also pleased with their accomplishment. Active participation in the program with dialogue and sharing experiences connects the new learning to what learners already know and leads to adult learning, action, and transformation. Participants reported in week six and again in the one-month follow up interview the importance of celebrating this research project. Two of the participants were excited to be going out to a celebration coffee break where they received their certificates with pictures taken. It was recommended by participants that this be incorporated into the delivery of the program in the future. In addition, participants voiced how pleased and thankful they were to be part of a study that could help create supportive opportunities for others in their community. By being actively engaged in this study, participants were very concerned about the research outcomes, and practice implications.

5.2 Key elements of the program that facilitated transformation

The findings of this study highlight that there are key elements of the program delivered to the participants that was essential in the transformation process.

The transformation happened spontaneously to two of the three participants as they connected with one another by telling their stories and sharing their experiences, learning how to refocus on self-care and self-management. These findings suggest that the support from others throughout the program can be as transformative as the content of the program itself. As such, future thought should be given to the importance of more time for dialogue and connection in learning environments for care partners. Participants experiencing a connection and transformation with others while participating in the CDSMP is a concept not found in the literature and provides a lens to contribute to new ideas around designing programs and opportunities for supporting care partners which we know the literature strongly recommends (Nuffield Council on Bioethics, 2009; Zwaanswijk et al, 2013; Health Council of Canada, 2012b).

The findings of this study highlighted the importance of connecting with others both for social support and for maximum learning. The safe learning environment with a small group size, and the increased time for dialogue, sharing of experiences, and telling their stories created the right feelings and emotions conducive to optimal adult learning and transformation.

Increased room for dialogue, as experienced with the small group size, where participants can relate the new knowledge to their experiences is essential to the transformation experienced by participants. The opportunity for deep personal connections, beyond peer support, was identified as essential to the success of the transformation as well.

The final important element of success of the program for care partners is the identification initially of program compatibility or fit. An assessment of the program fit, assessing where care partners are and their level of ability or capacity to attend the program, thus determining the timing of this program intervention is best for optimal outcomes related to wellness.

5.3 Practice implication/ significance of the study findings

The findings of this study suggest that spousal care partners of those living with dementia, who were contextually ready and participated in the Stanford CDSMP found that their personal experiences were positive and suitable in meeting their needs, and improving their overall subjective wellbeing. They reported that the program was supportive and empowering, decreased isolation, and improved self-management. They reported that they would recommend the program in this study to other care partners to help with self-management. The pre-interviews conducted as part of this study confirmed the substantial physiological and physical impact and burden of caring leading to a compromised overall health status and diminished well-being. Throughout the CDSMP, participants continually shared their stories, engaged and connected with one another, and were able to learn the new program content by being anchored in their own context. As the two participants who were contextually ready experienced the six-week program, they experienced a transforming with others, and a transforming to a new normal. There was a shift from the role of caring to a sense of routine and new normal. Their insight into the need for self-management and self-care evolved over the duration of the program, and the learning was evidenced by a transformation in mindset and lifestyle, and was not just learning for the sake of learning.

Given the positive experiences and the findings of this study, a modified self-management program can be a vehicle to supporting care partners and improving health. Based on the findings of this study, the adoption of a self-management program, with modifications, can be part of a responsive health system to the public health challenge of dementia thereby improving individual and population health. Insights from this study, based on the participants' similar and differing experiences, suggest practice implications in order for a self-management program to be most effective in meeting care partner needs.

The first lesson learned from the findings of this study is the idea that care partners have informational needs related to dementia diagnosis, the prognosis, what to expect, how to deal with challenging behaviors, and practical ways to take care of their spouse. These need to be met early in the journey soon after diagnosis. A self-management program should be offered only after those needs are met, and at a time when care partners are ready to focus on taking care of themselves. Further, by meeting the information needs and then offering the self-management program early in the dementia journey, care partners could more easily attend a six-week program as their spouse might be more likely be able to be left alone. Otherwise, respite care for the spouse living with dementia needs to be offered while care partners are attending the program in order for best attendance and focus. Early interventions may help caregivers in anticipating and accepting the future care role and transitions. As levels of stress and burden are low in the pre-dementia stage it provides better opportunities to empower the resources of care partners (deVugt &Verhey, 2013). An individual assessment of contextual readiness should be completed to identify the information and skills needed, the individual learning style, and any structural barriers to participation prior to the program being offered and availed of by the care partner. Also, an assessment of the stage within the caring journey is imperative to optimal program involvement and thus for the empowerment and equipping with the skills and confidence necessary for self-management.

The second lesson learned from this study is the importance of having flexibility in a self-management program to ensure sufficient time for dialogue between members for maximum learning and transformation. It was through active engagement with the anchoring of the new knowledge in their prior experiences, as they shared with each other, that transformational learning occurred. The recommended group size of 10 -14 would not be conducive to the required dialogue identified, and thus a smaller group to allow for maximum sharing of experiences is recommended. It is also recommended that the program be congruent with the principles of Dialogue Education allowing for maximum connection, engagement and transformation.

Any kind of program for care partners should be designed with a philosophy appropriate for adult learners, such as Dialogue Education^{TM}, and include learning needs and resource assessment, a focus on safety, sound relationships, sequence and reinforcement, praxis(action/reflection/action), immediacy, teamwork, engagement, and accountability (Vella, 2008). It is evident also that adult learners engage with content that they feel is applicable to them. It is important to start the education with where participants are. This concept is clearly demonstrated in Ryan's situation and points again to the need for an individual assessment of each potential participant with respect to their learning preferences and styles.

The third lesson from this study is the need for continued support, and a place for care partners to connect with one another and maintain their focus on self-care and self-management as they partner in the care of their spouse living with dementia. Participants identified peer connection, and continued support as being very valuable and a need for increased accountability to keep focused on self. Integration of a means to meet this need would provide enhanced success in the future delivery of the CDSMP to care partners of those living with dementia.

The fourth lesson is the need for a process to address the structural barriers to participation in a self-management. It is important to identify the structural barriers to focusing on self-care before a self-management program is offered. It is important to consider whether participation in such a program without addressing the structural barriers is more damaging than beneficial.

The fifth lesson learned from this study in offering a self-management program to care partners of those living with dementia is the need to incorporate a session or activity where the perceived accomplishments within the program are celebrated. Participants expressed that receiving the certificate at the end was very important and having a celebration session should be added to a self-management program.

The sixth lesson from the findings of this study is related to broadening the care partner participation from spousal care partners to also include children and other family members. Participants reported that they would have liked to have other family members attend along with them. They also referenced how their children were advocating that they participate in a self-management program as they acknowledged the strain and thus the need for their parents to refocus back to taking care of themselves. The spouse is most often the primary care partner and plays the principal role in taking care for the spouse with dementia at home. Given the established burden on the spouse it would be beneficial to include the other family members in the CDSMP so that additional capacity could be built to mobilize support for the primary care partner with a focus on self-care.

This study explicates a deeper understanding of the lived experience of participating in the Stanford CDSMP for spousal care partners of those living with dementia. It suggests that a modified CDSMP program with the outlined recommendations can be suitable as an intervention that can support care partners to improve their own well-being. .

5.4 Personal reflections/ Reflexivity/Positionality

My research, data analyses and conclusions are shaped by my positionality. Progressive subjectivity, understanding my own views and values, and acknowledging that they are changing is part of being aware of my situatedness and its influence on my research. Journaling of what I was thinking during the research enhanced my research findings and the meanings learned.

I am a 40-year-old married woman who is a health care leader in Green Bay, NL. I deeply value my family and friends, my health, and my responsibility as a healthcare professional. I started my professional career as a dietitian and diabetes educator, and subsequently advanced to an executive director of healthcare in a Regional Health Authority in NL. In my current healthcare leadership position with Central Health, the challenges associated with the crisis admissions of those with dementia to our ER, acute care, and long term care facility is a reality every week in Green Bay. Families who are unable to cope any longer have the unfortunate and stressful situation of admitting their loved one to a bed in the hospital. In Green Bay, our community profile and citizens' stories tell of the increasing prevalence of dementia, the challenges with linking with supports, and we thus see the impact on health systems with crisis admissions, and the home care program. As a dietitian and health care leader, I am very committed to my responsibility for health promotion, primary health care service delivery, and health system sustainability in rural NL. This commitment involves the pursuit of delivering health services that are responsive to citizens' needs and focus on prevention of disease and promotion of population health.

Self-management approaches, specifically the CDSMP, have been an ongoing part of my professional work, and therefore my experience influenced my research project. Additionally, I live with a chronic disease of Rheumatoid Arthritis (RA) and have participated in and am a peer facilitator for the CDSMP. These experiences also affected my data collection and analysis. During my starting position in healthcare as a dietitian and diabetes educator, and living with a chronic disease of RA myself, CDSMP was an ingrained approach that I studied and used to help empower and support those living with chronic diseases. My experiences of being a dietitian, health care leader, and living with RA myself definitely impacted my perspectives and this research project as I myself have found transformations in my own life as I participated in the CDSMP. My positive experiences, both personally and professionally, positioned me to have an affinity to believe in the benefits of this CDSMP for care partners of those living with dementia. Yet, while I had experienced the benefits of self-management, as a leader involved in the leader training of the program, I was also cognizant of the rigid structure and inflexibility of the CDSMP to adapt to the possible needs of care partners.

Personally, while in my current position as Executive Director of Health Services, I experienced having my grandfather, who lived next door to me all of my life as I grew up, being diagnosed with dementia. At first, when my own grandfather was diagnosed with dementia, he was supported at home for some time, but then due to challenges and limitations in support, he had to be placed in a long-term care facility one hour away from our family home. Upon admission, there were complex challenging behaviors associated with his dementia, and after a risk assessment, my pop had to have a wanderguard ^{TM} device attached to him to prevent him from exiting the facility. This was one of the saddest experiences of my life. These were grandparents that lived next door to me all of my life who were like second parents to me and my perception was that my grandfather went from being a successful businessman to another institutional resident who looked like he was lost, and I was the health care leader of that facility. This journey with him and my family undoubtedly influenced my perspective on my research as I was situated in a place where I saw firsthand the benefits, burden, and complexities of the journey of having a loved one diagnosed with dementia.

Due to my health care leader position in the small rural communities of Green Bay, as a researcher, in an attempt to be aware of situatedness, I was reflective of my own personal history, views, values, feelings and attitudes toward health, system utilization, role of self-management, and people's perceptions of me as researcher and health provider and leader. Given the rurality of Springdale, NL, participants saw me on a regular basis in our community during the phase of study, and maintained contact with me after the research had ended. Participants grew close to me during the study and I developed a relationship with them that has been sustained after the research. To ensure that the participants' experiences were expressed honestly, I explicitly stated on multiple occasions that my role as researcher was to help participants express their experiences, and that I did not want my role as health leader to influence their ability to express themselves honestly and openly. I did not want socially appropriate answers as I am aware that my positionality can shape participants' responses. I was able to listen with an openness respecting different experiences and not impose my preconceived ideas. I was honest with the participants and ensured confidentiality.

The regular contact with participants now is managed by continuing to be friendly and caring when we meet, but not to pursue further relationship building where I am perceived to be their formal support. I have discussed this positionality with participants and they are aware of the researcher, health professional, and personal dynamics in a rural community. I feel that participants know the boundaries, and are able to move forward seeing me on a regular basis where we are now acquaintances who can talk and interact like fellow community members in rural NL.

5.5 Research limitations

The most significant limitation in this study is the modifications that transpired to the original program as part of the study. The group size was considerably smaller than the recommended and as a result there was much more time allotment for participants to talk with one another, share their experiences, and extend support to one another. The facilitators naturally flexed the CDSMP to allow for more dialogue between participants and thus the participants' experiences may have been different if there was strict adherence to the guidelines for program facilitation.

This modification of group size and increased flexibility with respect to time for sharing created a deviation from the program that may have become more like a social support group. Therefore, it is difficult to project whether participants would have had the same meaningful experiences if the program was structured exactly as intended by the program specifications. However, although the structure was somewhat changed, the content remained the same. Since I was seeking to understand participants' experiences in a self-management program, I was able to explore the essence of their lived experiences, even though the structure of the program may have organically changed.

Recruitment was difficult in this study; I contacted eighteen care partners and only four were willing to participate as the others noted that they could not leave their spouse for 3 hours per week for 6 weeks in a row. There was the identification of barriers such as lack of family supports to care for their spouse, a hesitancy to leave their spouse because s/he was so reliant upon them, and concerns with attending a formal group session. This reiterates the need for a process to address any structural barriers before a self-management program can be offered. The inclusion of a respite program so that participants could have brought their spouse with them or had someone at home to care for them would have been valuable and enhanced the inquiry of whether a self-management program was useful for spousal care partners of those living with dementia. Additionally, there is need for continued follow up in order to explore long-term sustainability of improvements in well-being.

Another limitation of this research is the fact that it was a study program where participants were aware that their experiences were being studied to learn about self-management programs for care partners of those living with dementia. As part of the study, participants experienced being part of a pre-interview before the program started, a focus group interview after each of the six sessions, and a one month follow-up interview. These interviews would not be part of the normal CDSMP, and it is likely that this component changed participants' perceptions and experiences. For example, having the focus group after each of the six sessions created a further opportunity for engagement, sharing, and reflection upon their lives and how the information and knowledge could be incorporated in to their daily lives. This deviation from the standardized program may have improved their experience as they were feeling an enhanced sense of control in the program by being part of the study process. It also probably enhanced the attitude domain of learning associated with knowing the value of the information and the feelings associated with the learning. The conclusions from the participants and the structures and themes explicated were influenced by the study components of the program in addition to the modifications to the CDSMP.

Additionally, the diversity of the care partner participants added complexity to the study, and requires further discussion. There was diversity in terms of age, gender, level of professional and informal support, living arrangements, educational levels, and the timing of the dementia journey for spouses living with dementia. Two of the participants were female, and one male. The male participant was the eldest and had no formal education. Two of the three participants had spouses living in institutions and not with them at home and thus having a participant who was earlier in their dementia journey would have been beneficial. More spouses who were living together would have added value to the study. If the study group were more homogeneous where the participant characteristics were more similar, it would be easier to transfer the findings and themes to another similar group of care partners.

In this study, there was no assessment of the participants' needs, no identification of any structural barriers to focusing on self-care or any means to address any self-identified barriers. It is important to consider whether participation in such a program without addressing the structural barriers is more damaging than useful if the readiness is not present. Offering a self-management program before other identified needs, such as information about dementia, knowledge of how to deal with challenging behaviors, and future expectations, are met, may actually increase distress and frustration in the care partner. Upon reflection, it is questionable as to whether the self-management program should be offered to someone whose needs were not assessed, and whose structural barriers to participation were not addressed.

Finally, a limitation was the lack of ongoing self-management support and appraisal of the sustainability of any perceived improvements in well-being. While this study did not appraise the outcomes of the program, the participants did report an improvement in their perceived well-being as they participated in the study program, and reported that they needed continued support rather than the program being suddenly over after the six weeks. This is a limitation in this study as there was no means of addressing this need in the study purview.

5.6 Knowledge translation/exchange

An inquiry into the experiences of care partners of those living with dementia and participating in the CDSMP provided important valuable information on participants' perceptions of the program, their experiences of participating in the program and the program delivery, and the meaningfulness of the program for their health and well-being. The focus was on their experiences, the meaning they attributed to participating in the CDSMP, whether it was helpful and suitable for them, and its overall contribution to the caring experience. I was able to determine that the program, with modifications noted above, may be beneficial to meet the needs of care partners for self-management and wellness if they are contextually ready, and structural barriers are addressed. Exploring their experiences in this specific intervention program provided a greater understanding of the CDSMP's usefulness for care partners and provided information about what is required to be incorporated in a self-management program in order to support care partners to decrease care burden, and improve their well-being. This qualitative inquiry can influence future directions in improving care partner burden.

The CDSMP is a well-established and evaluated program that is implemented broadly, and I felt that it was important to know how care partners felt about participating in the program, what worked for them, and whether it was beneficial and practical in improving their caregiving experience. Gaining an understanding of their experiences in this specific intervention program has contributed to the new knowledge of how a self-management program could be adapted to be appropriate for care partners. It allowed me the opportunity to offer recommendations to influence future directions in supporting care partners.

This research will be disseminated through presentations and regular meetings to local community groups, the Green Bay Community Advisory Committee, community strategic planning days, Central Health Regional Health Authority's senior leadership team, the community supports committee of Central Health, the Green Bay Health Center primary health care lead team, the chronic disease prevention and management advisory committee, physician medical advisory committees, board of trustees meeting, and minister of health/deputy minister of health meetings. I will also share this research and possibly develop community of practice with peers at Central Health if there is wide interest. In my position as Director of Health Services in Green Bay, I will work with Central Health's primary health care facilitators to encourage a support group or network of care partners of those living with dementia. This research may lead to Central Health adopting the approach of supporting care partners through our self-management programs in their strategic plan related to chronic disease management. Providing quality care to those with dementia and their families is an issue that every healthcare authority is contending with, and thus recommendations to primary care providers and health leaders will be highly valued (Cook &Rockwood, 2013). Knowledge translation where study findings are effectively transformed into usable recommendations for providers and health authority leaders is a priority for this research into care partners' experiences with a self-management program, with the ultimate goal of supporting care partners and decreasing their burden of care.

5.7 Future research

An examination of the impacts of participating in the CDSMP with care partners would be needed as future research to supplement this study. If there were positive improvements in outcomes, a further study of the sustainability of these would be beneficial as well. Given the acknowledgement by all participants that there was a need for continued self-management support in order to sustain the positive experiences in their lives with a focus on self-management, a study of the sustainability of the program's suitability would be a worthwhile future project.

An assessment of contextual readiness, the inclusion of respite care and an appraisal of additional self-management support after the program would be a worthwhile future research project. Also, I feel that setting up a study to offer this program to participants earlier in their dementia journey for an inquiry into its usefulness would be an option that would add further insight into supporting care partners with a spouse who lives with dementia.

Additionally, I feel that a study inquiring into the gender differences between how male and female care partners respond to the role of caregiving, and their unique experiences of participating in a self-management program would be a great future study. Given that there are more women providing informal care, this would contribute to knowledge on the varied ways to support care partners to reduce their burden and proactively maintain their own health. With the adoption of a population health approach across Canada, including Newfoundland and Labrador, there is a focus on the determinants of health; gender is a known health determinant and therefore a gender-based analysis could shape self-management programs to support care partners.

Further, I would suggest that broadening the scope of care partners to include both spouses and children of the person with dementia would add additional understanding of the role that the CDSMP plays in supporting care partners in self-management as part of a supportive family structure, rather than solely by the primary care partner.

5.8 Conclusion

This research project helps affirm the World Health Organization (WHO) and Alzheimer's Disease International's (ADI) call for the promotion for a dementia-friendly global society. It also supports their appeal for investing in health and social systems to improve care and services for people with dementia and their care partners, and to increase the priority given to dementia in the public health research agenda (WHO, 2012).

This phenomenological study gained an understanding of the meanings of the lived experiences of spousal care partners participating in the CDSMP and supports the philosophy that providing support to informal care partners is essential in order to promote their well-being. The findings of this study confirm that the positive aspects of spousal care partners, such as a sense of meaning and purpose, and emotional closeness, are experienced along with the strains of providing direct care and the distress caused by the decline of their spouse.

This study described the meaning and essence of spousal care partners participating in the CDSMP. This inquiry provided an understanding of their experiences and three main structures were interpreted: transforming with others, transforming to a new normal, and transforming of focus. Two themes that comprise the essential structure of *transforming with others* include sharing experiences and having a safe environment to release emotions. Two themes that comprise the essential structure of *transforming to a new normal* include a shift in roles toward a new normal, and the contextual readiness for transformation. Three themes comprise the essential structure of *transforming of focus* and they include: refocusing on self-care, continued self-management support, and celebrating accomplishments.

The findings of this study suggest that spousal care partners of those living with dementia who participated in the modified CDSMP viewed their personal experiences as positive and suitable in improving their overall wellbeing. They report that the program was supportive and empowering, decreased isolation, and improved self-management. As the program was modified organically in many regards, this study can only be transferable to a program with a small group size where there is increased time for dialogue. This study explicates a deeper understanding of the lived experience of participating in the modified CDSMP for spousal care partners of those living with dementia. It offers that a self-management program, with the recommended modifications as discussed above, can be an intervention that can support care partners to improve their own well-being if they are contextually ready, and the structural barriers to participation are addressed.

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Appendix A- Pre group program structured interview guide

Time of interview:
Date:
Place:
Interviewer:
Interviewee:

(Some of these to determine context)

1. Tell me about your experience with dementia.
2. Does your loved one officially have a diagnosis of dementia/Alzheimer's disease?
3. What is your relation to the family member?
4. Do you live with this family member?
5. Do you work outside of the home?
6. Do you socialize with other family and friends?
7. Do you have a good knowledge of dementia and its progression?
8. Tell me about your experience of being a care partner of someone with dementia?
9. What has been the impact on your life of being a care partner of someone with dementia?
10. How do you perceive your well-being? How would you describe your own health? What things do you do to maintain your health?
11. How is your sleep?
12. What do you do to take care of yourself to maintain your health and wellness?
13. What supports do you have to help with caring?
14. Have you participated in any programs/support groups/ other interventions for helping you as a care partner?
15. What is your motivation for caring?
16. Do you know what supports are available in your community? If so, do you utilize the supports in your community? (I.e. respite care, home care, lifeline, peer advocates, meals on wheels, etc.,)
17. What is your biggest challenge of caring for someone with dementia?
18. What is your greatest need? (skills, $, physical help, emotional support, etc)
19. What other competing demands do you have?
20. What is your relationship like with ______?
21. How would you describe your relationship with your doctor, and other health care providers?
22. How do you communicate with your loved one?
23. Have your doctor or other primary care provider assessed your needs as a care partner?
24. What do you think about a self-management program for people who partner in care of those living with dementia?
25. Are there barriers to you attending such a program?
26. How do you best like to learn?
27. Do you have anything else that you would like to add?

Appendix B- Focus group guide - after each of the 6 sessions

Time of interview:
Date:
Place:
Interviewer:
Focus group members:

1) What are your thoughts about the program this evening?
2) What are your thoughts about the curriculum and content that we covered this evening?
3) What did you like about the content? What did you not like about the content? Is it useful or meaningful to you as a care partner?
4) What did you think about the structure of the program? Does it meet your needs?
5) What did you think about the delivery of the program? Is there any tension between the rigid structure and your needs?
6) What do you think should be modified or adapted from the session this evening to meet your needs as a care partner of someone living with dementia?
7) How useful do you find this session of the program with your self-management, your wellness, and your caregiving experience? What do you think you will use from the material today?
8) Do you have any other comments or questions?

Appendix C- Structured interview guide - peer leaders of program (after each session):

Time of interview:
Date:
Place:
Interviewer:
Peer leaders:

1) What are your overall thoughts about the program this evening?
2) What was your experience facilitating this session to care partners of those living with dementia?
3) What are your thoughts about the curriculum content that we covered this evening as it relates to care partners?
4) What are your thoughts about the structure of the program this evening as it relates to care partners? How did you find the participants responded to the structured delivery of the session this evening?
5) What are your thoughts about the delivery of the session this evening as it relates to care partners?
6) What do you think should be modified or adapted from this evening session to meet the needs of care partners of those living with dementia?
7) How did you find the participants responded to the session content this evening?
8) Do you have any other comments or questions?

Appendix D- One Month Post Program interview guide**:**

Time of interview:
Date:
Place:
Interviewer:
Interviewee:

1. Tell me a little bit about the program that you participated in 1 month ago. What was your experience like?

2. What did you think about the program content?

3. What did you think about the facilitation/delivery of the program? The leader?

4. Overall, what did you like about this program?

5. Overall, what did you not like about this program?

6. What was the most helpful thing for you?

7. What was the most unhelpful thing for you?

8. Has the information that was provided to you in the program been helpful to you with your self-management, your wellness, and your caregiving experience? (Has it helped you cope? Learn new strategies to deal with some of the changes occurring? Find new information and resources?) What have you taken and used in your life?

9. If there were anything that you would change about the program, what would you change?

10. What should stay the same?

11. Would you recommend this program for care partners of people living with dementia?

12. What should we keep in mind as we modify this program or develop a new self-management program for care partners of people living with dementia?

13. Do you have any other comments? Is there anything else that you would like to add?

14. Do you have any questions for us?

Appendix E- Sensitizing Framework for Participant Observations

DATE:

- Environmental location (i.e., time, location, other individuals in the vicinity)(describe the setting observed):
- When:
- What activities took place?
- Who participated?
- Social interactions (i.e., verbal exchanges with other participants, peer leaders)
- Behaviors (i.e., anxiety, crying, laughing, apathy,)
- Affect (i.e., emotional expressions, facial expressions)
- Body language and gestures
- Physical appearances
- Involvement in sessions and activities (i.e. Introductions, group activities, action planning, reporting back on action plans, problem solving, brainstorming sessions, etc.)
- Physical and social characteristics of facility

Appendix F- Cover Letter/ Information letter

Lakehead
UNIVERSITY

Master of Public Health Program

(807) 766-7250

(807) 766-7225

January, 2014

Dear Potential Participant:

My name is Melinda Noel and I am a student in the department of Health Sciences- Masters of Public Health program at Lakehead University. The purpose of this letter is to invite you to consider participating in a research project entitled: Understanding the personal experiences and meanings of spousal care partners participating in the Stanford Chronic Disease Self-Management Program and the contribution to the caring experience.

I would like to invite you, as a spousal care partner of someone living with dementia, to participate in the Stanford Chronic Disease Self-Management Program, which is a program that has been broadly implemented and well-studied. I would like to explore and understand the personal experiences of care partners participating in the Stanford Chronic Disease Self-Management Program and their perceived impact on self-management and wellness. The purpose is also to focus on experiences of the participants and whether the program is useful for them. I would appreciate your assistance in this study.

The Stanford program was developed at Stanford University and is designed to teach self-management tools. The sessions will run once a week for six weeks. The sessions will last approximately two and half hours. We will be hosting the sessions from 4:00 – 6:30 p.m. with meals and snacks provided on Thursday evenings beginning January 9, 2014 and ending February 13, 2014 at the Green Bay Health Center recreation room, Springdale, NL. A more detailed schedule will be provided to you upon your agreement to participate.

Your participation would involve two individual interviews and attending the Chronic Disease Self-Management Program approximately once a week for six weeks with a focus group session after each of the six sessions. Karen Lily, and Debbie Wheeler, are the lay leaders who will be facilitating the sessions. I, Melinda Noel, will be doing the individual interviews and facilitating the focus groups.

Prior to the beginning of the program, I will contact you to set a time for an individual interview to review your experiences of being a care partner. After each of the six program sessions, I will hold a focus group to ask for your feedback and talk about your views about the content and delivery and its applicability for care partners of those living with dementia. In addition, notes will also be taken throughout the session by the researchers, focusing on interactions, comments, responses to the curriculum, and other information as appropriate. At approximately one month after the sessions are completed, I will contact you for a final individual interview.

I would like to record the interviews and focus groups so that I can better understand your experiences and have an accurate record of our conversation.

All information gathered throughout this study, including the recordings of the interviews will be kept strictly confidential and will only be accessed by the researcher. Any identifying information will be removed in the final report and any possible publications. All information pertaining to the study will be kept in a locked filing cabinet at Green Bay Health Center for a minimum of five years, after which time audio recordings will be destroyed. Electronic transcripts, with all identifying information removed, may be kept indefinitely. If you choose to participate in this research, given the group format of the focus group sessions, we will ask you to keep in confidence information that could potentially identify a participant and/or their comments.

The findings of the research will be prepared for a final thesis report and possibly for publication at professional conferences and journals. To get a copy of the report, please contact me at (709) 673 5313 or email mnoel@lakeheadu.ca.

If you decide to give your consent to participate in this study, I will ask you to sign a consent form formally stating your consent to participate in the program.

Participation in this study is completely voluntary and you may choose not to participate. You may also choose to withdraw from this study at any time. Any decision not to participate or to withdraw from the study will have no impact on your experiences or access to services within your community. All information pertaining to you will be removed from the research and destroyed.

If you live in the Green Bay area, but reside outside of Springdale, I would like to offer to pay your travel costs to and from Springdale upon receipt of the appropriate documentation of mileage costs.

The Research Ethics Board at Lakehead University and the Ethics committee at Central Health have approved this study. If you have any questions related to the ethics of the research and would like to speak to someone outside of the research team, please contact Sue Wright at the Research Ethics Board at 807-343-8283 or research@lakeheadu.ca or Mr. Doug Prince, ethics chair, at Central Health at 709-257-5226 or doug.prince@centralhealth.nl.ca

Should you have any questions about this study, please feel free to contact Me, Melinda Noel at (709) 673-5313 or mnoel@lakeheadu.ca.

Thank you for considering this request to volunteer for this study.

Sincerely,

Melinda Noel November 9, 2013

Appendix G- Informed Consent

I have read the information letter provided by Melinda Noel, masters student at Lakehead University, describing the purpose of the study. I understand that I will be asked to participate in two individual interviews (one preprogram and one after program finished). I also understand that I will be asked to participate in the Chronic Disease Self-Management Program once a week for six weeks and participate in focus groups after each session regarding my perceptions and experiences of the Chronic Disease Self-Management program. The interviews will last approximately 60 minutes each. The focus groups will last between 30 to 60 minutes and will be audio recorded with my permission. In addition, notes will also be taken throughout the session by the researcher, focusing on interactions and responses to the program.

By signing below, I consent and agree to participate in this study. My consent is based on the conditions outlined:

1. I have reviewed and understand the information in the study cover letter.

2. My participation is completely voluntary and all data collected will be used for research purposes.

3. All information will be kept strictly confidential. My name will never be used.

4. I may withdraw from the study at any time by simply notifying the researcher. My withdrawal from the research will have no impact on my experiences and access to services in my community.

5. It is not anticipated that I will experience physical or psychological harm.

6. The findings of the research will be prepared for a final thesis report and possibly publication at local and professional conferences and journals.

7. No individual participants will be identified in published results. Any identifying information will be removed from the final report and any publications that might arise from this research.

8. All data will be securely stored in a locked filing cabinet at Green Bay Health Center for a minimum of five years. Audio recordings will be kept for five years. Transcripts with all identifying information removed may be kept indefinitely in electronic format on a password-protected computer for future review.

9. I may request an executive summary of the findings upon completion of the study. These will be available through Lakehead University in spring 2014 by contacting Melinda Noel at (709) 673 5313 or mnoel@lakeheadu.ca

This study has been approved by the Research Ethics Board at Lakehead University and the Ethics Committee at Central Health.

Name of Participant ______________________________

Signature of Participant____________________________

Date: ____

**I consent to having the interviews and focus groups audio recorded.

Signature of Participant: _______________________________

Date: ____

Signature of Researcher _________________________________

Appendix H - Table: temporal analysis of data

	What was Similar	What was Different	What changed over time
Pre-interviews	• Positive aspects of caring • Stress associated with partnering in care • Poor physical health (hypertension, bowel disruption, irregular heart rate, weight gain) • Burden of care (lack of sleep, exhaustion, stress, depression) • Responsibility of caring day and night • Expressed complete change in life after diagnosis of dementia - caring for spouse became center of existence • Isolation • Difficulty with coping • Decreased quality of life (isolation, total focus on caring) • Lack of self-care & preventative health behavior (healthy eating, physical activity, socialization, relaxation) – barriers to self-care • Good marriage relationship • Loss/Grief- losing their spouse • Fear of future/perceived hopelessness- spouse not going to get better • Worry and feelings of uncertainty • Lack of control • Guilt emotion • Lack of physician/health provider care partner assessment • Good attitude	• Stage of dementia and severity • Support network • Level of direct care tasks • Gender of participants (1 male; 2 females) • Education level of participants • Knowledge of dementia • Coping skills • Perceived need for self-management program • Access to resources/respite care	(see post interview)

	• Financial stability- all participants retired (no loss of work)		
Focus groups Week 1-6	• Sharing stories and personal experiences in program activities • Learning the new skills and material by being actively engaged (activity based learning) (2 out of 3 participants) • Participants looked forward to seeing one another from one week to the next (anticipation) • Strong sense of connection with the peers in the group and with facilitators. • Voiced that telling their stories and sharing their experiences was good/therapeutic • Indicated that the content was applicable and that they enjoyed the learning both at the sessions and also by preparing in the mid-week with their book • Reported that there was safety in the small group of those with similar experiences to tell their story and to be able to cry and emotionally respond • Two participants reported that they were ready for and needed such a program and it was the right time for them	• One participant not engaged in program activities- just listened and socialized/connected with others • Need of one participant for self-management program different form others • Ability of one participant to attend due to lack of respite care and support • One participant was less comfortable sharing in the group setting as compared to the one-to-one interviews (? related to hearing impairment, literacy level, or gender)	• Coping skills • Managing grief/loss • Building relationships with one another • Sharing stories and personal experiences • Level of emotional response (crying) (decreased) • Knowledge related to self-management (relaxation, communication, problem solving, distraction) • Program became part of routine • Sense of accomplishment • Identified need for support after program completed (? telephone support/check in) • Wanted program to go longer than 6 weeks • The phone calls between participants in the week was increased from the one recommended by the program to 2 or 3 calls per week to check in, and see how others were doing. The calls between participants are continuing 1 month after the 6-week program has ended. • Positive attitudes, and positive demeanor • Lack of respite care • Realization of need for assessment of whether this program is needed by care partner
Post-interviews			• Relationships continued between participants • Social isolation decreased- connecting with others- family, friends, and participants

			• Transformed focus on self • Transformed insight into need for self-management and self-care • Ability to manage and cope • More focus on healthy eating • More focus on physical activity and importance- setting goals • Discussing self-management program and goals at physician visit; preparing for visits with list of questions, symptoms, and medications • Focus on seeing health care provider/professional to assess self-health (physician apt for themselves)- seeking help • Identification that self-management program is beneficial at the appropriate stage of the journey • Recognize need to cope with challenges associated with dementia • Increased acceptance of the feelings of loss/ managing grief-spouse and life as it once was