

IDENTITY AND CAREGIVER BURDEN IN DEMENTIA: AN EVALUATION OF  
TELEHEALTH REMINISCENCE FOR INFORMAL CAREGIVERS

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By

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## ABSTRACT

In the literature, informal caregivers' perception of identity change/loss in their care-partner with dementia is anecdotally linked to loss of intimacy, while decreased intimacy and quality of the caregiver/partner relationship is associated with greater *caregiver burden*. A connection between perceived identity and burden is further implied by the potential benefit of reminiscence therapy for caregivers, and literature on reminiscence. Despite demonstrated benefit for persons with dementia, support for reminiscence with caregivers has been equivocal, though it is unclear as to why. The dissertation's main objectives were therefore to 1) quantitatively examine support for a theoretical model of perceived identity change, intimacy/quality of relationship, and caregiver burden; and 2) using this model as a theoretical guide, evaluate efficacy of a basic reminiscence activity. Rural dwelling caregivers are at particular risk for negative outcomes due to limited service access, and interventions unrestricted by geographic location are needed. Thus, the reminiscence activity was delivered via both in-person and Telehealth videoconferencing formats, and a third project objective was to examine Telehealth feasibility for both service delivery and research purposes.

Study 1 revealed caregivers' perceived identity change in their care-partner with dementia significantly predicted caregiver burden. A mediational model was supported in which caregivers' perception of identity change of the person with dementia reduced perceived quality of their relationship, which in turn increases caregiver burden. Study 2 involved random assignment of caregivers to respective in-person or Telehealth, control, or Reminiscence groups. Contrary to predictions based on Study 1's model, no effect of the Reminiscence activity on identity change, intimacy, quality of relationship, or burden was observed despite most caregivers reporting a positive experience. Study 3 demonstrated good feasibility for Telehealth delivery, including considerable travel savings and satisfaction with the medium. No differences in acceptability in-person delivery were found.

Identifying and understanding factors affecting caregiver burden is crucial towards development of effective intervention. Perceived identity change appears to be one possible factor in multifactorial prediction of caregiver burden, but reminiscence demonstrated no effect on burden. Telehealth proved to be a practical and acceptable format for rural service delivery and data collection. Limitations and implications of the project results are discussed.

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## **CHAPTER 1:**

### **1.1 General Introduction**

In addition to the devastating consequences for individuals diagnosed with dementia and their families, dementia has a tremendous economic and social impact. Dementia associated costs in Canada are estimated to reach 872 billion dollars for the period from 2008 to 2030, while Canadians spent over 231 million unpaid hours caring for persons with dementia, a figure expected to more than triple by the year 2038 (Alzheimer Society of Canada, 2010). The Alzheimer Society of Canada Rising Tide report (2010) cogently argues that empirically supported interventions for informal caregivers of persons with dementia are vital to countering care costs for the 1.1 million Canadians projected to be diagnosed with dementia by 2038. Informal caregivers are at increased risk for psychological and physical health problems as a result of caregiving duties, which can lead to earlier institutionalization of loved ones with dementia (Alzheimer Society of Canada, 2010). Studies have repeatedly shown that caregiver burden, as perceived by informal caregivers, is associated with negative outcomes such as depression, anxiety, and a decreased sense of well-being (e.g., Alspaugh et al., 1999; Clyburn, 2000; Gaugler et al., 2000; Gonyea et al., 2005; McConaghy & Caltabiano, 2005; Wright et al., 2010). Among this group, spouses account for the majority of caregivers and are at particular risk for negative outcomes (Smale & Dupuis, 2004), presenting a clear need for targeted intervention.

Reducing the negative factors associated with informal caregiving through use of evidence-based interventions and other needed supports is expected to result in a total economic benefit of 12 billion by the year 2038 (Alzheimer Society of Canada, 2010); this is in addition to the amelioration of the untold human costs. In order for the impact of interventions to be maximized they must be made accessible to caregivers regardless of geographic location. This includes caregivers in rural and remote areas of Canada who have limited access to specialized health services, despite the growing proportion of older adults in these areas (Stats Canada, 2010) at an inherently greater risk of developing dementia. Reminiscence Therapy, already known as an empirically supported quality of life intervention for persons with dementia, also

holds promise for informal caregivers (Charlesworth et al., 2011; Woods et al., 2005; Woods et al., 2009).

Investigations of Reminiscence Therapy for caregivers to date have largely assessed the same intensive program (Schweitzer, 2008), demonstrating equivocal results (Charlesworth et al., 2011; Woods et al., 2005; Woods et al., 2012). The underlying mechanism of benefit of Reminiscence Therapy for caregivers has not been identified in the literature. It is possible that the often reported loss of identity experienced by the person with dementia and perceived by others, may affect the emotional connection (i.e., intimacy) in the person with dementia's interpersonal relationships, including with their caregiver, and this detriment to their relationship may influence caregiver outcomes, including perception of burden. In support of this hypothesis, research has demonstrated that intimacy, and relationship quality in general, tend to decrease following the onset of dementia, and this decrease has been associated with negative caregiver outcome (Blieszner & Shifflett, 1990; Morris et al., 1988b). Reminiscence Therapy (single session), on the other hand, has empirically been shown to improve feelings of intimacy in healthy couples (Alea & Bluck, 2007). Identity integration and intimacy maintenance have been hypothesized as two of the functions of human reminiscing (Alea & Bluck, 2007; Webster, 2005; Westhof et al., 2010). Thus, it would appear that the therapeutic potential of Reminiscence Therapy for caregivers of persons with dementia may lie, at least in part, in its ability to enhance both identity, and either directly or indirectly, intimacy. In order to maximize the effectiveness of any intervention, however, it must be accessible to those in most need, including in older adults populations in rural and remote areas.

The use of telehealth, and specifically videoconferencing, for remote delivery of mental health services, including psychosocial interventions, is increasing and a growing body of literature provides support for both its clinical and practical effectiveness (see reviews by Perle et al., 2011; Richardson et al., 2009). Telehealth delivery of physical and mental health services and interventions has the potential to increase access to traditionally underserved populations, especially those in rural and remote areas.

The following research project consists of three studies. The first study examines the relationship between identity change and burden towards development of an empirically supported theoretical model. This is relevant to inform understanding of potential Reminiscence Therapy and related psychosocial intervention efficacy in the context of caregivers of persons

with dementia. The second study, using the proposed model from Study 1 as a theoretical guide, tested the basic premise that Reminiscence Therapy-like activities are efficacious for caregivers. The final study evaluated the use of Telehealth (eHealth SK) videoconferencing for delivery of a basic Reminiscence Therapy activity and comments on the suitability of the medium for psychosocial interventions and research alike.

## **1.2 Dementia**

Dementia is a condition resulting in physical, psychological, financial and interpersonal consequences, with impacts at both the individual and societal levels (Alzheimer Society of Canada, 2010). It is generally diagnosed in older adults and seldom develops before the age of 60 (Brookmeyer, Gray, & Kawas, 1998) and has an incidence rate that doubles every 5 years after age 60 (Jorm & Jolly, 1998). Dementia increasingly affects a large number of people globally (35.6 million as of 2010), at a rate that doubles approximately every 20 years (Prince et al., 2009). Prevalence varies across regions; however, in Canada, about 8% of adults over age 65 estimated to have dementia (McDowell, 2001).

Dementia is commonly defined as the loss of global cognitive abilities above what is expected in natural aging (Alzheimer Society of Canada, 2010). It is typically the result of a progressive neurodegenerative condition, the most common being Alzheimer's disease (AD). Dementia also occurs in the form of several subtypes including: vascular dementia, variants of frontotemporal dementia, diffuse Lewy body disease, Parkinson's Disease, and Huntington's Disease. Overall, dementia due to AD and combined AD/Vascular dementia account for up to 70% of dementia cases (Mandell & Green, 2011). According to the National Institute on Aging-Alzheimer's Association (NIA/AA) diagnostic guidelines (subsequently endorsed at the 4<sup>th</sup> Canadian Consensus conference on the Diagnosis and Treatment of Dementia (CCCDTD4), criteria for a diagnosis of dementia consist of cognitive and/or behavioral symptoms in at least two domains that have an effect on the individual's functionality, and represent a decline from previous levels of function (Gauthier et al., 2012; McKahn et al., 2011). Specifically, persons with dementia can experience a variety of symptoms including progressive memory difficulties, difficulties with language and communication, disorientation to place and time, problematic behaviors such as disinhibition, neglect of self-care and incontinence, as well as a high rate of comorbid mental illness (Gelder et al., 2005). In addition to the above, and of specific interest to the proposed project, individuals with dementia also tend to commonly experience a loss or

change of characteristic patterns of thought, feelings, social interaction, and behavior, or in other words, their identity (Gelder et al., 2005; Cadell & Clare, 2010).

### **1.3 Identity and Dementia**

According to the literature on identity and dementia, a sense of slowly losing one's identity is commonly experienced by those living with dementia, as they gradually lose intellectual function and the ability to participate meaningfully in social interactions (e.g., Hayes et al., 2009; Cohen & Eisdorfer, 1986; McGowin, 1993; Herskovits, 1995). Identity is generally considered to be a multidimensional construct, and several theories of identity have been posited related to the different components of identity (Cohen-Mansfield et al., 2006). The research on identity in dementia is reflective of this diversity as the definition of identity used by studies investigating identity loss in individuals with dementia varies considerably (Cadell & Clare, 2010). More broadly, theories of identity have been posited by multiple fields of research, with several supported theories originating from the social sciences, notably, social psychology.

#### **1.3.1 Defining Identity**

Identity is a commonly researched construct that has been assigned a variety of differing definitions in the literature, a fact that is perhaps reflective of the complexity of the basic idea of human identity. The concept of identity, in its most fundamental form, can be considered as an individual's response to the question "Who are you?" or "Who am I?" (Korte, 2007; Vignoles, Schwartz, & Luyckx, 2011). Based on their extensive review of identity theory and research, Vignoles, Schwartz and Luyckx (2011) posited the following comprehensive definition of identity:

...identity consists of the confluence of the person's self-chosen or ascribed commitments, personal characteristics, and beliefs about herself; roles and positions in relation to significant others; and her membership in social groups and categories (including both her status within the group and the group's status within the larger context); as well as her identification with treasured material possessions and her sense of where she belongs in geographical space. (p.4)

This definition of identity by Vignoles and colleagues (2011), was derived from the body of literature on identity and attempts to account for all four of the major "levels" at which identity is commonly defined by researchers and theorists; these being the individual, relational, collective, and material levels. According to the authors' synthesis of the literature, the individual or

“personal” level is made up of a person’s self-definition, which may include goals, values, beliefs, behaviors, decisions, self-esteem, self-evaluation, desires, fears, expectations, and life-story. The authors describe the relational level of identity as largely comprised of one’s definition and interpretation of their social roles (e.g., child, spouse, parent, co-worker, etc.). As the name would suggest, the relational level of identity depends on the interpersonal context of the individual, and thus is not established solely by the individual but in conjunction with his or her interpersonal environment, including the family or workplace (e.g., Chen, Boucher, & Tapias, 2006; Markova, 1987). The collective level of identity can be summarized as the individual’s identification with certain groups or social categories and the resultant feelings, beliefs, and attitudes experienced and held by the individual (Tajfel & Turner, 1986; van Zomeren, Postmes, & Spears, 2008). Finally, the material level refers to the material objects and places that people identify with and consider as part of themselves (Belk, 1988; Proshansky, Fabian, & Kaminoff, 1983).

From the above descriptions of the four levels of identity, a division is apparent between the internal (individual/personal level) and the external (relational, collective, material) based facets of identity. This division has also been described as the essentialist versus non-essentialist concept of identity (Woodward, 1997).

The essentialist concept refers to the fixed internal characteristics that define the individual, while the non-essentialist concept refers to the fluid external processes comprising identity (Woodward, 1997). A similar differentiation between internal and external identities is observed in psychology, specifically when examining views of identity in the personality and social psychology literature. Many personality trait-theorists suggest that identity, or the “self,” is made up of relatively constant personality traits, while in social psychology the self is thought to be constructed socially via one’s group memberships and social roles (Korte, 2007). These differing concepts of identity have been respectively referred to as the “personal” and “social” identities or selves (Korte, 2007). Two theories of identity posited by social psychology researchers are: Identity Theory and Social Identity Theory.



### **1.3.2 Identity Theory**

Identity Theory is a social psychological theory that posits that one's identity, or sense of self, consists of the relatively consistent ways in which one interacts with society (Stets & Burke, 2000). According to this theory, people's patterns of interaction tend to change with context and an individual's identity may consist of multiple context-dependent patterns of interaction. These patterns of interaction can be described as 'roles.' Common roles include occupational, communal, familial, marital, and gender. Each role contributes to a person's overall sense of self, and the more salient the role the more integral it is to a person's identity. Identity theory further suggests a reciprocal influence of interpersonal relationships on identity, in that the nature of interpersonal interactions shapes and maintains one's roles and therefore also shapes their identity (Hasselkus & Murray, 2007).

### **1.3.3 Social Identity Theory**

Social Identity Theory is a social psychological theory similar to Identity theory, the difference being its focus on group memberships rather than identity "roles" (Tajfel & Turner, 1979; Hogg, Terry, & White, 1995; Stets & Burke, 2000). It states that the groups an individual belongs to, including one's ethnicity, nationality, race, sex, sexual orientation, trade, teams, clubs, family, etc. are important sources of self-esteem and provide us with a sense of belonging and social identity. The theory also suggests that people enhance the status of groups and their members, for which they themselves are member of, in order to increase self-esteem. To achieve this, they classify others as either "us" (members of the same group or in-group) or "them" (members of a different group or out-group) through a process referred to as Social Categorization (Tajfel et al., 1970, Hogg, Terry, & White, 1995). Social Categorization leads to the introduction of in-group/out-group bias where people tend to have more positive attitudes toward in-group members and more negative attitudes toward out-group members, contributing to the development of favoritism, discrimination, racism, and stereotypical beliefs (Tajfel et al., 1970, Hogg, Terry, & White, 1995).

### **1.3.4 Theories of Identity in Dementia**

In line with the essentialist/personal versus non-essentialist/social perspectives of identity, most studies addressing the issue of identity in dementia appear to adopt either a social constructionist/interactionist (i.e., non-essentialist) (e.g., Cohen-Mansfield et al., 2006) or an

autobiographical or personal narrative (i.e., essentialist) perspective of identity (review by Cadell & Clare, 2010).

The social constructionist and interactionist perspective is based largely on the prior discussed, and theoretically compatible, Identity and Social Identity theories. Similar to these theories, social constructionist/interactionist perspective suggests a relational, social, and interactional bases for identity (Stryker, 1968; Tajfel & Turner, 1979; Hogg, Terry, & White, 1995; Stets & Burke, 2000). More specifically, this perspective posits that one's identity or sense of self, as well as one's perception of the identity of an "other," are largely socially constructed and shaped and maintained by one's beliefs, attitudes, and social interactions/experiences, which are in turn influenced by one's social group memberships and social roles (Hayes et al., 2009). On the other hand, the autobiographical and personal narrative perspectives believe that the presence of self-identity is based on the ability to recall autobiographical memories and produce and share self-narratives (Cadell & Clare, 2010). These perspectives are not mutually exclusive, but simply address different components or levels of a person's identity, in line with Vignoles and colleagues' (2011) description of the four levels of identity presented earlier: the individual, relational, collective, and material levels. As such, it follows then that the ability to interact with others and function socially (social constructionist/interactionist perspective) and recall and communicate personal events and experiences (personal narrative/autobiographical perspective) are both required in the maintenance of one's identity. The social and memory deficits often experienced by those with dementia would suggest that, in addition to functional impairments, dementia also negatively impacts the individual's very sense of being and of self.

### **1.3.5 Identity Loss/Change in Dementia**

In general, perceived change in or loss of identity is related to negative clinical outcomes, including well-being and mental health (Jetten, O'Brian, & Trindall, 2002; Haslam, Jetten, Postmes, & Haslam, 2009). In persons with dementia specifically, perceived changes in identity have been associated with decreased well-being and life-satisfaction (Jetten et al., 2010). Given this possibility bi-directional association with negative outcomes, the impact of dementia on identity is an important area of investigation. Though dementia has long been associated with the "loss" of and/or change in identity (Hayes et al., 2009; Cohen & Eisdorfer, 1986; McGowin, 1993; Cohen-Mansfield et al., 2006; Herskovits, 1995), recent literature has examined

empirically the threat to identity posed by dementia and whether it indeed results in actual identity loss, or if the self persists throughout the course of the disease.

The potential impact of dementia on the self was explored in a study by Clare (2003) who suggested that changes in the self were the result of “self-adjusting” or efforts to “self-maintain.” According to Clare, in response to the changes (e.g., memory loss) that occur as a result of dementia, and the individual’s awareness of these changes, the individual attempts to cope by either incorporating these changes into their self-concept (self-adjusting) or holding on to the prior sense of self in order to maintain continuity (self-maintaining). Based on this earlier work and their more recent review of the literature on identity and dementia, Cadell and Clare (2010) posited that as opposed to identity loss, the individual with dementia’s self is “altered” as a result of the disease and the varying ways in which the individual attempts to cope. Engaging in meaningful activities has been associated with persons with dementia’s sense of self-identity and maintaining autonomy (Phinney, Chaudhury, & O’Conner, 2007). The results of Cadell and Clare’s (2010) comprehensive review of the literature on dementia and identity would appear to support this contention. In their review of 34 studies, which included studies using qualitative and quantitative methods, Cadell and Clare (2010) found that despite the use of differing perspectives of identity and methodology, in general the research has shown that components of self-identity persist, at least in some degree, well into the late stages of dementia. However, they concluded that at least partial degradation of, and changes to identity occur, as a result of the degenerative disease process. Included in their review were studies utilizing Sabat and Collins’ (1999) social constructionist model of the self. This model suggests the existence of three types of self; Self-1 is referred to as the “personal identity” and is evidenced by the use of pronouns; Self-2 is one’s beliefs and attributes/traits; Self-3 is made up of the different social “personae” employed during social interactions, which appear analogous to social roles. According to Sabat and Collins, all three selves are observable through an individual’s speech. Using qualitative methods of analyses several studies have attempted to evaluate the existence of Sabat and Collins’ three selves in the speech of individuals with dementia (e.g., Fazio & Mitchell, 2009; Sabat & Collins, 1999; Sabat & Hare, 1992). In their review of this literature, Cadell and Clare (2010) concluded that, despite small sample sizes, participants with moderate to severe dementia’s use of personal pronouns and verbal defense of individual rights during conflicts, both demonstrate the persistence of the personal identity (Self-1) in dementia. The authors also

concluded that additional findings from the same studies demonstrating how participants with mild to moderate dementia retained the ability to discuss past personal attributes and reflect on new and changed attributes since the onset of dementia, represents evidence of the existence of Self-2 in at least the early to middle stages of dementia. Finally, only case study evidence was found and reviewed concerning the existence of Self-3 (multiple social personae or roles) in dementia. The authors reported that all three studies reviewed found at least trace evidence of past occupation related and familial role personae as well as the personae of the “dementia patient”. Overall, their review suggests that, although the methodology of the studies limits the generalizability of the findings, there is evidence that Sabat and Collins’ (1999) three selves can persist into the later stages of dementia. However, it is also apparent from the studies reviewed that change/decline of the self can occur. For example, the literature regarding Self-1 found that several participants demonstrated little use of personal pronouns. Studies looking for evidence of Self-2 found that participants were aware of “new” self-attributes that had developed since the onset of dementia, such as memory and speech difficulty. Additionally, the studies looking at multiple personae (Self-3) found evidence of a “dementia patient” personae.

Cadell and Clare (2010) also reviewed two studies by Cohen-Mansfield and colleagues (2000, 2006) using a “social roles” perspective to assess identity in a large sample of nursing home residents with dementia. The studies used self-report measures of social roles including occupational roles, familial roles, leisure activities, and attributes. The measure was administered to the person with dementia and also to their closest family member and the staff-caregiver in order to assess the perception of change in role identities by external informants. Similar to the findings of the qualitative literature regarding the three selves model, Cohen-Mansfield and colleagues’ studies found that all four types of social roles assessed appeared deteriorated or less important and that decline in role identity was correlated with cognitive decline, suggesting that although preservation of identity is evident at least some deterioration occurs with disease progression. Notably, familial roles showed the most preservation while occupational roles the least and family members perceived more change than the participants themselves.

Based on the above findings of studies of both the social constructionist and social role perspective of identity in persons with dementia it would appear that while personal identity in terms of the use of pronouns and awareness of changes to the self appears to persist in some form even into the late stages of dementia, social identities (i.e., personae or social roles) requiring

interaction and feedback from others appear diminished or lost to a greater extent. This conclusion was also observed by Sabat and Harre (1992) based on the findings of their study, and it has been suggested that the decline in social functioning experienced by the person with dementia results in less social interaction in which the self-identity is expressed and recognized, and therefore interactions are less conducive to identity-maintenance (Cohen-Mansfield et al., 2006). These changes in social interactions would presumably lead to changes in the person with dementia's social relationships in general.

#### **1.4 Social Relationships and Dementia**

Social relations/interactions appear to be a required activity for identity maintenance, and persons with dementia commonly experience both change/loss of identity and impaired social functioning. Consequently, the presentation of identity and quality of life in dementia is related to both the inherent biomedical factors of dementia and the immediate social environment. Indeed, there is increasing literature suggesting that some of the negative consequences linked to dementia may be due to a lack of social interaction that is supportive and respectful of the individual with dementia's "personhood" (O'Conner et al., 2007).

##### **1.4.1 Biomedical versus Psychosocial Model of Dementia**

Due to the overt neurophysiological symptoms of Alzheimer's Disease (AD) and the fact that AD is the most common cause of dementia, the field of dementia treatment and research has been traditionally guided by the biomedical model of dementia, which considers it to be an organic disease of the individual that is to be treated medically (Spector & Orrell, 2010). However, it is well established that there is not a one to one relationship between the individual diagnosed with dementia's degree of neuropathology and their level of functional impairment, which can exceed or fall short of what might be expected based on the neuropathological evidence (Snowdon, 2003; Spector & Orrell, 2010; Brody, Kleban, Lawton & Silverman, 1971). This incongruence, coupled with the demonstrated importance of psychosocial factors (e.g., coping, life events, social environment, mental health) on the experience of dementia (Spector & Orrell, 2010), has highlighted the weaknesses of a strictly biomedical model of dementia and in turn led to the proposition of "biopsychosocial" conceptual models that account for both the neurophysiological and psychosocial aspects of dementia, and the interaction between them (e.g., Kitwood & Bredin, 1992; Spector & Orrel, 2010; Sabat, 2001; Clare, 2008). A common theme among these models of dementia is the added importance of the person with dementia and their

“personhood,” which has resulted in an increased focus on person-centered care and expanded the scope of dementia treatment to include the psychosocial context of the individual with dementia, including their relationship and interactions with their primary caregiver and family (Sabat, 2001; Clare, 2008).

#### **1.4.2 Personhood and the Social Context of Dementia**

“Personhood” is described by Kitwood (1997a) as ‘the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being.’ The concept of personhood appears analogous to, or at least compatible with, the idea of the social role/identity of Identity Theory, and Sabat and Collin’s (1999) concept of “Self-3,” in that they are all concerned with the salience of the individual’s unique social identity as perceived by those around them. That there is often a lack of support and respect for the person with dementia’s personhood conveyed during social interactions with others (Kitwood, 1997a), appears in line with the research discussed previously showing degradation of the individual with dementia’s Self-3 or social identity/role. Consequently, the same research on identity in dementia has been utilized to promote the movement toward person-centered care in dementia that aims to emphasize the personhood of the individual with dementia in their social environment (O’Conner et al., 2007).

While the causal direction of the link between identity change/loss in persons with dementia and the lack of respect and support for their personhood in interactions with others is unclear, given the reciprocal nature of social interactions and relationships in general, a bi-directional relationship appears most likely. This likelihood is suggested by the social functioning deficits common to dementia as a result of progressive cognitive deterioration, and also the stigmatization and stereotyping of individuals with dementia. Specifically, as disease processes rob the individual of the ability to competently interact and function in a social context, the perception of this individual by others is changed or negatively impacted and the person with dementia’s former social identity is altered or lost. At the same time, the general stigma and stereotypes associated with the dementia label, influence how people interact and perceive the person with dementia, also leading to changes or loss of the person’s social identity/Self-3/personhood.

Persons with dementia often experience difficulty with verbal communication due to the cognitive impairment characteristic of dementia and this tends to progress with the course of the

disease (Ferris & Farlow, 2013; Schwam & Xu, 2010; O'Connor, 2007). This difficulty with communication has been shown to negatively impact their social interactions with others (Hendryx-Bedalov, 2000; Small, Geldart, & Gutman, 2000), and the inability to effectively communicate and interact socially likely contributes to the stigmatization and stereotyping of those with the disease. A study on stigma and dementia, specifically Alzheimer's Disease (AD), has shown that persons with AD tend to experience greater disease related stigma relative to other diseases such as Parkinson's Disease or cancer (Burgener & Berger, 2008). Other literature has demonstrated a common belief regarding dementia patients as being different and therefore considered as "others" or "them", part of an outgroup, which is thought to contribute to the stigma related to the disease (Naue & Kroll, 2008). This belief is likely the product of the stereotyping of individuals with dementia that occurs in society. According to the *Voices of Alzheimer's* summary report (Reed & Bluethmann, 2008), the word dementia is associated with negative preconceived attitudes and ideas regarding a dementia diagnosis and the individual with the disease. These attitudes are influenced by society's negative view of symptoms associated with dementia such as memory loss and disinhibition and result in the labeling of individuals with dementia, even in the early stages of the disease, as lacking cognitive skills and the ability to function independently and incorrectly deeming them incapable of making any meaningful societal contribution (Clare, 2002). This stereotyping and stigmatization has the potential to negatively impact the interactions of the person with dementia with others and may contribute to the less than optimal social environment described by Kitwood (1997a) who posited persons with dementia are often devalued and misunderstood within their social context.

From the literature it is clear there is increasing recognition of the importance of the immediate social interactional environment in the determination of outcomes for persons with dementia. Indeed, for persons with dementia the relationship with their primary caregiver is generally the greatest source of social interaction, thus playing an important role in the maintenance of identity and support of personhood and influencing quality of life.

### **1.5 Informal Caregivers of Persons with Dementia**

A caregiver is a person who assists another individual with physical care and or the coping and living with disease (Hileman, Lackey, & Hassanein, 1992). Caregivers are typically classified as being either *formal* or *informal*. The term formal caregiver refers to those, usually compensated professionals or volunteer support workers, involved in the standardized practice of

caring for dependent persons (Ferris et al., 2002). In contrast, an informal caregiver is typically an unpaid spouse, adult child, or close friend or relative of the care recipient, who engages in activities and experiences associated with the assistance to an individual unable to provide or manage on their own (Pearlin et al., 1990). The role of informal caregiver is usually assumed by a single person (FCA, 2001) and typically not planned on or prepared for by the individual charged with the responsibility for the care of a dependent loved one (Biegel & Schulz, 1999). Activities of informal caring vary with type and severity of the illness, but can include assistance with activities of daily living such as personal hygiene and feeding, household management duties and chores, medication and treatment management (Biegel & Schulz, 1999; Carretero, Garces, Rodenas & Sanjose, 2009). Workload and intensity of duties are also dependent on the characteristics of the care recipient and their condition, but most often involve the continual and daily performance of caregiving activities for more than 40 hours per week and lasting for a period of several years (five years on average; Carretero, et al., 2009; FCA, 2001). Given the objective of the project, the terms “caregiver” and “caregiving” as they appear herein, refer to the aforementioned definition of “informal caregiver” and the associated activities.

### **1.5.1 The Impact of Caregiving on Caregivers**

Though caregiving can be a potentially rewarding experience (Raschick & Ingersoll-Dayton, 2004), and the potential positive aspects are explored by several researchers (see review by Hunt, 2003), the vast majority of the literature on caregiving has focused on its negative consequences (Morano, 2001). Caregiving in general has been associated with greater psychiatric symptomatology and increased vulnerability to physical illness (e.g., Schulz, Visintainer & Williamson, 1990). Caregiving for persons with dementia may be particularly challenging and stressful as, in comparison to non-dementia caregivers, caregivers of persons with dementia tend to invest significantly more time performing caregiving activities and tend to experience a greater negative impact associated with this caregiving (Ory et al., 1999). Indeed, research involving caregivers has identified several negative physical and mental health outcomes of caregiving. Studies have shown that caregivers are at higher risk of mental health difficulties, finding a greater incidence of depression, anxiety, decreased well-being, and higher levels of stress among caregivers, as well as increased usage of psychotropic medication relative to non-caregivers (Yee & Schulz, 2000; Noonan & Tennstedt, 1997). In terms of physical health factors, caregivers generally give more negative self-evaluations of their health and have



psychosomatic and immunological problems, poorer cardiovascular health, and greater difficulty performing activities of daily life (Carretero et al., 2009). Additionally, caregivers are less likely to utilize medical services or engage in preventative health behaviors, in addition to a general tendency to neglect their own health (Lee et al., 2003; Grunfeld et al., 2004). Related to these increased health difficulties and lowered use of medical assistance is the increased risk of premature death among caregivers (Grunfeld et al., 2004).

These negative factors associated with caregiving have been conceptualized in varying ways in the literature, with most describing caregiving outcomes as associated with the interaction of external and internal factors. More specifically, the caregiving environment, including care recipient related factors, interacts with caregiver related factors such as coping ability, determining the level of stress experienced (Beigel & Schulz, 2003). The stress of caring and the associated negative outcomes for caregivers is commonly referred to as “caregiver burden.”

## **1.6 Caregiver Burden**

The usage of the term “burden” in the context of caregiving can be traced back to 1963 in Grad and Sainsbury’s publication regarding the care of mentally ill persons by family members in the family home. The authors’ definition of the term, and subsequently that of many others, referred to burden as the physical, emotional, and economic outcomes associated with caregiving (Gaugler et al., 2000). Various definitions of caregiver burden have since been posited in the literature. Commonly, caregiver burden is referred to as the “consequences of the activities involved with providing necessary direct care to a relative or friend that result in observable and perceived costs to the caregiver” (Clyburn et al., 2000). Zarit and colleagues (1980) reported that caregiver burden is the resultant state of the necessary tasks and or restrictions that cause distress or discomfort to the caregiver. More broadly it has been defined as the “negative subjective experience of the caregiver” (Chwalisz, 1996) or the “external demand or potential threat that has been appraised as a stressor” (Lawton et al., 1989). Finally, caregiver burden has been conceptualized as the level of conflict between the basic needs of the caregiver and the demands of caregiving (Braithwaite, 1996).

### **1.6.1 Subjective vs Objective Burden**

Due to the varying definitions of caregiver burden, contemporary conceptualizations tend to differentiate between the observed versus perceived costs of caregiving (Carretero et al.,

2009). The observed costs of caregiving are commonly associated with what is referred to as “objective” caregiver burden or the negative consequences of caregiving that are observable, concrete, and tangible (Maurin & Boyd, 1990). Perceived costs are in-turn related to the concept of “subjective” caregiver burden, which is described as the negative feelings or appraisals of the caregiving experience/situation (Nijober et al., 1999; Maurin & Boyd, 1990). Relative to objective caregiver burden, subjective burden is believed to be an important factor in predicting caregiver outcomes, as a higher level of subjective burden in caregivers has been linked to greater risk of physical and mental health problems (Nijober et al., 1999). Though subjective burden is thought of as being the subjective perception of objective burden, a direct linear relationship does not always exist between the two types of burden since one’s perceptions of burden are influenced by individual differences (Chwalisz, 1996).

The influence of individual differences on caregiver perceptions of stress is highlighted in Chwalisz’s (1996) Perceived Stress Model of Burden which states that individual differences in social variables, coping ability, and level of social support all impact on the caregiver’s perception of stress related to caregiving, which in turn influences the caregiver’s mental and physical health outcomes (Chwalisz, 1996). Other models of caregiving similarly employ a multi-dimensional conceptualization of burden, perhaps most notably the Pearlin Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990).

### **1.6.2 Pearlin Stress Process Model**

It has been suggested that the Pearlin Stress Process Model has had the most influence on the current understanding of caregiver burden (Carretero, et al., 2009). The model posits that the caregiving experience and its associated stress is an evolving process, involving various stressors that differ in nature (Pearlin et al., 1990). It describes two main types of stressors, those that relate directly to the type of disability and the individual being cared for and those that stem from the requirements of the caregiving role, respectively referred to as *primary* and *secondary* stressors. Pearlin and colleagues (1990) depict stressors as difficult events and situations resulting from caregiving that overwhelm the individual’s ability to cope and adapt. Similar to the Perceived Stress Model (Chwalisz, 1996), they further state that individual differences in social supports and coping moderate the impact of similar stressors across individuals on caregiver outcomes. These outcomes include well-being, physical and mental health, and the model also addresses importance of the caregiver’s social identity/roles (Pearlin, Lieberman,

Menaghan, & Mullan, 1981; Caserta, Lund, & Wright, 1996). The model suggests that the persistent strains of caregiving lead to negative changes in the individual's self-conceptualization, which in turn results in greater levels of stress and negative outcomes (Pearlin et al., 1981). According to Pearlin and colleagues (1981), it is during this process of stress manifestation that social support and individual coping ability may intervene as mediators.

The advantage of the Pearlin model of burden is that it accounts for the role of both individual factors and the social environment in determining stress (burden) and the resultant impact on caregiver outcomes such as mental and physical health. Of importance to the present project, the model also accounts for the impact of caregiving on the self, in terms of the caregiver's social identity. What it fails to address, however, is how the mediating factors act to lessen the impact on the self, and reduce the experience of burden.

### **1.6.3 Correlates of Burden**

Given that caregiver burden is essentially conceptualized as the hardships or negative consequences of caregiving on the caregiver, predictably burden has been associated with negative caregiver outcomes in the literature. Studies have repeatedly shown that caregiver burden, as perceived by informal caregivers, is associated with negative outcomes such as increased depression, anxiety, and a decreased sense of well-being (e.g., Alspaugh et al., 1999; Clyburn, 2000; Gaugler et al., 2000; Gonyea et al., 2005; McConaghy & Caltabiano, 2005; Wright et al., 2010).

Not only is burden linked to negative outcomes for the caregiver, higher levels of caregiver burden are also associated with negative consequences for the care recipient. In a study on the institutionalization of dependents formerly under the care of an informal caregiver, higher levels of caregiver burden were related to earlier institutionalization of the dependent (Logdson et al., 1999). Additionally, increased burden has also been linked to greater risk of abuse of the care recipient, including increased aggression and violent behavior (e.g., Havens, 1999; Lee & Kolomer, 2005).

### **1.6.4 Factors Predicting Burden**

Given the importance of the subjective experience of providing care for a loved one in determining the impact of caregiving on the individual, the identifying factors that contribute to an increased perception of burden has been a major goal of the literature regarding caregiver

burden. In the literature, several such factors have been identified as affecting how one perceives the stresses of caregiving, and thus the degree to which one experiences burden.

**1.6.4.1 Gender.** Several caregiver demographic factors have been associated with higher burden, including: younger age of the caregiver, being female, low income caregivers, and maintaining a job outside the home (Kramer & Kipnis, 1995; Navaie-Waliser et al, 2002). The experience of greater subjective burden in female caregivers has been given a fair amount of attention in the literature, possibly due to the proportionately higher number of women who assume the caregiving role and gender differences in burden have often been found in studies of informal caregivers (e.g., Lutzky & Knight, 1994; Stewart et al., 2014). In general, relative to males, female caregivers tend to be older, married, unemployed, have a higher level of education, and assume roles as the primary caregiver (e.g., Navaie-Waliser et al, 2002). In addition to experiencing greater perceived burden, female caregivers also tend to provide more intensive and complex care, take on greater responsibility for care provision, report greater work-related strain, have greater difficulty balancing care with other family and work obligations, be more likely to forgo respite activities, and experience greater negative consequences to mental and physical health secondary to caregiving (Kramer & Kipnis, 1995; Navaie-Waliser et al, 2002; Pinquart & Sorensen, 2006a).

Despite these identified differences in burden and outcomes for female caregivers, meta-analytic studies show that the differences relative to men, especially in caregiving activities and amount of care required may be somewhat overestimated, and that it is the subjective aspect of care that shows the most difference (Miller & Cafasso, 1992; Pinquart & Sorensen, 2006a). Two models attempting to explain why female caregivers perceive more difficulty and suffer more negative outcomes of caring were investigated by Lutzky and Knight (1994). Based on the literature addressing gender differences in attention to, and expression of, emotions, the first model posited that male caregivers are less likely to attend to their emotional processes and are thus more likely to fail to report caregiver distress, thus biasing self-report data (Lutzky & Knight, 1994). The second model states that men and women learn to respond to and cope with stress differently. According to the authors' review of the literature, men generally learn to use problem-focused strategies for coping that are more direct, while women are typically taught to use strategies that are more emotion-focused, such as avoidance, acceptance of blame, and dependence on others for support. The authors suggest that given that avoidant coping styles

have been linked to increased distress, female caregivers, being more likely to utilize avoidant strategies, thus perceive greater caregiving distress or burden. Evidence from the literature would appear to support both or a combined model as, once the level of stressors is controlled for, the greater level of subjective distress and burden reported by female caregivers is potentially explained by male caregivers' tendency to under-report their distress and female caregivers' general coping style and less available social support (Lutzky & Knight, 1994; Pinquart & Sorensen, 2006).

**1.6.4.2 Person with Dementia Factors.** Persons with dementia experience several difficulties which present a challenge to caregivers, such as impaired cognition and functioning, and behavioral problems (Aneshensel et al., 1995). Potentially surprising, however, is that while comorbidity with psychopathology, greater dependence for activities of daily living, and higher cognitive and physical deficiencies all appear associated with increased burden (Logsdon et al., 1998; Gaugler et al., 2000), the amount of behavioral problems demonstrated by the individual with dementia appears to be the strongest predictor of perceived caregiver burden (Dunkin & Anderson-Hanley, 1998; Aneshensel et al., 1995; Gaugler et al., 2000). It has been posited that the unpredictability of behavioral problems is behind their strong link to burden. The occurrence of behavioral problems tends to be irregular and thus more difficult to prepare for, while other dementia related characteristics and areas of dependency are more predictable and more easily planned for (Gaugler et al., 2000). In addition to disease associated factors, it also has been suggested that male care recipients, and a younger age of onset can contribute to greater burden experienced by the caregiver (Gaugler et al., 2000).

**1.6.4.3 Social Factors.** Aspects of the caregiver's social context have also been associated with greater levels of burden. For instance, caregivers who co-inhabit the same dwelling as the care recipient tend to experience greater caregiver burden (Brodaty & Hadzi-Pavlovic, 1990). Studies have demonstrated that caregivers who live with the care recipient tend to engage in care more persistently on a day to day basis, be more socially isolated, and have poorer physical and mental health (Brodaty & Hadzi-Pavlovic, 1990; International Psychogeriatric Association (IPA; IPA, 2002). How the caregiver is related to the care recipient has also been associated with burden, with spouses experiencing greater burden than children of the care recipient (e.g., IPA, 2002). This is thought to be due to the greater bond between spouses, and thus the greater impact the disease has (Gaugler et al., 2000). Expectedly, given the

literature linking female gender with greater burden, wives and daughters performing caregiving duties tend to experience greater burden than their male counterparts (e.g., Hawranik & Strain, 2000).

This relationship between caregivers' immediate social environment and their experience of burden is further testament to the importance of the psychosocial context of caregiving and dementia. Of special importance within this social environment is the interpersonal relationship between caregiver and care recipient.

### **1.7 The Caregiver/Care recipient Relationship**

As previously discussed, there appears to be an evidence-propelled trend toward an integrated biopsychosocial model of dementia. This trend is characterized by an increasing focus placed on the social context of the person with dementia. In line with this trend, several studies have demonstrated the importance of the caregiver/care recipient relationship. Due to the large time commitment involved in caregiving for persons with dementia, the majority of interpersonal interaction for both caregiver and person with dementia likely occurs within the context of this relationship. The quality of these interactions and the relationship as a whole is associated with the respective outcomes of both caregiver and care recipient (see reviews by Ablit, Jones, & Muers, 2009; and Quinn, Clare, & Woods, 2009). This is not a one-way interaction, however, as both the caregiver's experience of caring and the care recipient's experience with dementia and related difficulties, both in turn impact on the relationship between the two individuals (Ablit, Jones, & Muers, 2009; Steadman, Tremont, & Davis, 2007).

Research on the experience of dementia originally focused on the accounts provided by informal caregivers and their difficulties (e.g., Morris et al., 1988a). Later, the increasing focus on the "personhood" of the individual with dementia led researchers to focus on the experience of dementia by the individual and the impact of individual differences and history, and importantly, their social context, on their experience with the disease (Kitwood, 1997b; de Boer et al., 2007; Woods, 2001). More recently, a focus on the combined experiences of both the caregiver and person with dementia has led to increased examination of the interpersonal relationship between the caregiver and care recipient (Ablit et al., 2009). For informal caregivers and their loved one with dementia, this is typically a long-standing relationship which existed prior to the onset of difficulties and diagnosis, and which provides the social context for the experience of caring and receiving care (Ablit et al., 2009). The experiences of dementia and

caregiving in the present is influenced by characteristics of the pre-morbid relationship between the two individuals in addition to disease related changes and losses (Blieszner & Shiflett, 1990).

In a review of the literature regarding the impact of the caregiver/care recipient relationship on the experience of dementia and vice versa, Ablit and colleagues (2009) divided issues related to the topic into three key areas of study. The first area was concerned with the impact of dementia and related difficulties upon the relationship. Their review of the relevant literature concluded that caregivers of dementia tend to report less overall quality of relationship and in the case of caregiving spouses, lower marital satisfaction. The authors also found that a decline in reciprocity, communication, shared activities, and happiness is common in the relationship following the onset of dementia. In one study, intimacy was shown to decrease shortly after dementia diagnoses, but remained stable thereafter (Blieszner & Shiflett, 1990). Love, emotional warmth and closeness (often listed as components of a broader concept of intimacy) and affection were shown to remain relatively intact.

The second area suggested by Ablit and colleagues (2009) was based on a summary of findings from 16 studies examining the impact of the relationship on the experience of living with dementia. The authors further divided these studies into those assessing the relationship between pre-onset of dementia relationship and the experience of dementia, and those examining the current relationship and the experience of dementia. Their findings indicated that, in general, lower pre-morbid quality of relationship was related to increased burden, depression, and emotional reactivity in caregivers. Lower quality of the current relationship tended to be associated with increased depression in both caregiver and person with dementia, as well as decreased functional ability in the person with dementia and both increased burden and decreased sense of self-efficacy in caregivers.

The third and final area suggested by Ablit and colleagues (2009) included studies that examined different forms the caregiver/care recipient relationship can take in the context of dementia. The authors reviewed categories of relationship style, each representing differences in perception by the caregiver of the changes occurring in the person with dementia, the quality of the premorbid relationship, and the caregiver's motivation for assuming the caregiver role. Prior relationship quality was posited as a main determinant of which form the relationship will take (Neufeld & Harrison, 1998). According to Ablit and colleagues' (2009) review of the literature,

caregiver and person with dementia relationships tend to take on forms predominantly characterized by *continuity*, *reciprocation*, *detachment*, or *duty*. According to the authors, the continuity style of relationship describes caregivers who “work to maintain the past identity of the person with dementia” (Ablit et al., 2009, p. 504). Caregivers in this category tend to seek out positive responses from the care recipient, generally regard the caregiver role positively, and both caregiver and person with dementia continue to experience a sense of companionship and high level of mutuality (a component of intimacy) with one another for an extended period of time, and in some cases for quite a long period. The authors warn though that a sense of continuity can lead to delayed acceptance of the severity of the person with dementia’s difficulties and an eventual shift in the perceived form of the relationship by the caregiver, to one similar to detachment or duty.

The reciprocation form of relationship is described as the caregiver accurately perceiving the person with dementia as changed, and being motivated to care for the person out of a need to reciprocate for times in the past when the person with dementia has helped or cared for the caregiver (Ablit et al., 2009). Caregivers in this group also feel positive about their role, and companionship or a sense of mutuality (a component of intimacy) is preserved in the relationship. The authors noted however, that these caregivers tend to be aware and accepting of changes in the person with dementia and are able to successfully adapt to these changes without a shift in relationship style.

Perception of the person with dementia as “radically different” is associated with a relationship form characterized by detachment (Ablit et al., 2009). Caregivers feel obligated to care for the person with dementia, but expect no reciprocation or benefit from the relationship. They may take an approach to caring that lacks warmth, and there is a lack of emotional connection or interaction between the caregiver and the care recipient. The detachment style is believed to defend against emotional discomfort. It has been suggested that for detached caregivers a decrease in their perception of the person with dementia as different, or an increased saliency of the person with dementia’s identity, may increase emotional closeness and provide support. However, for some of these caregivers, increased closeness may appear as an overwhelming proposition (Chesla et al., 1994).

The final form of relationship reviewed by the authors is that characterized by a perceived sense of duty by the caregiver (Ablit et al., 2009). In this form of relationship, the



caregiver is motivated to care out of a sense of obligation or driven by a highly valued moral code. There tends to be a lack of mutuality in the relationship, and these caregivers may be at risk of experiencing greater levels of stress in the caregiver role.

Based on their review of the literature, Ablit and colleagues (2009) proposed a theoretical framework in which to conceptualize the caregiver and person with dementia's relationship and the changes that occur as a result of the onset of the disease. The authors' model posits that the form of the relationship within the dementia context is determined by pre-morbid relationship quality, and this form in turn determines whether relationship quality is maintained or degrades. The model suggests that the maintaining of relationship quality mitigates the negative aspects and challenges of caregiving and the experience of dementia, while lower relationship quality results in greater risk of negative outcomes for both caregiver and person with dementia. According to this model a cyclical relationship exists between decreased relationship quality and increased negative impact of caregiving on the caregiver. This link between the quality of the caregiver/person with dementia relationship and caregiver outcomes appears to be well supported in the literature. Low quality of relationship as perceived by the caregiver is associated with higher levels of depression in the caregiver (Knop et al., 1998; Rankin, Haut, & Keefover, 2001; Townsend & Franks, 1995, Williamson & Shaffer, 2001), and increased caregiver strain (Morris et al., 1988b; Uchino et al., 1994). Relationship quality has also been associated with increased caregiver burden (Campbell et al., 2008; Fitzpatrick & Vacha-Haase, 2010; Iecovich, 2011; Snyder, 2000).

According to Ablit and colleagues' (2009) review and subsequently proposed framework, intimacy and mutuality (a component of intimacy), between the caregiver and person with dementia are involved in the determination of whether relationship quality, and ultimately caregiver well-being, are maintained in the context of dementia. The following section further examines the role of intimacy and its impact on relationship quality in the context of caregiving for persons with dementia.

## **1.8 Intimacy**

### **1.8.1 Defining Intimacy**

Intimacy is a deceptively complex concept of which the most basic definition denotes the idea of closeness between two people. In the literature it has been defined and operationalized in varying ways. Moss and Schwebel (1993) proposed a multi-dimensional definition of intimacy,

attempting to integrate common themes appearing in definitions of intimacy contained in the intimacy research literature. The authors identified five core components of intimacy by which any form of relationship (romantic, friend, acquaintance, stranger, etc.) can be described. These components include *commitment*, *affective (emotional) closeness*, *cognitive closeness*, *physical closeness*, and *mutuality*. Commitment is described as the feeling of having a shared commitment and sense of cohesion with one another. The emotional, cognitive, and physical closeness components refer to two individuals' respective reception and expression of affect, cognitive material, and physical actions toward and from one another. Physical closeness can range from simple proximity to sexuality (Blieszner & de Vries, 2001). The mutuality component is described by Moss and Schwebel (1993) as the mutual interaction or an exchange, highlighting that intimacy is a process between two people and requires input from both. The authors note that although mutuality infers reciprocity between two individuals, it does not indicate equal investment into the relationship by both individuals.

According to Moss and Schwebel (1993), the basic idea of intimacy as closeness, though salient in most definitions of intimacy found in the literature, is deemed too broad a concept and sufficiently captured within the affective, cognitive, and physical closeness components (Blieszner & de Vries, 2001). Communication is also a common theme in many definitions of intimacy. While Moss and Schwebel (1993) acknowledged that communication is essential to the facilitation of intimacy, it is not, they argue, a core component as communication in and of itself is not necessarily related to intimacy. The authors also point out, as have others, that although intimacy is typically most essential to romantic relationships, various levels and components of intimacy can be found in, and describe, any form of interpersonal relationship (Blieszner & de Vries, 2001; Moss & Schwebel, 1993). They state that the type of relationship generally dictates to what degree the various components of intimacy will appear. For example, the commitment and physical closeness are more apparent and important in romantic versus non-romantic intimate relationships.

Other components mentioned in the literature may also be present in intimacy and may or may not be sufficiently subsumed within Moss and Schwebel's (1993) five-dimensional framework. These include acceptance, authenticity, assistance, and transcendence (Blieszner & de Vries, 2001). All of the components of intimacy however are thought to be interrelated and interact with each other (Moss & Schwebel, 1993), and all of the components can be mediated,

challenged, and/or fostered by a variety of variables including age, gender, sexual orientation, illness, death, geography, education, and technology. Given the focus of the present project, the following examines association between dementia and intimacy in the caregiver/person with dementia relationship.

### **1.8.2 Intimacy and the Caregiver/Person with Dementia Relationship**

Intimacy, and several concepts which appear related to intimacy, have been examined in the literature regarding changes in the relationship between the caregiver and person with dementia (see review by Fauth et al., 2012). These concepts, termed *affectional ties*, *marital closeness*, *relationship quality*, *closeness*, and *intimacy* proper, all tend to have overlapping meaning in that each is defined, at least in part, as the emotional closeness in the relationship between the caregiver and person with dementia. Thus, the respective literature involving each of these constructs is highly interrelated and relevant to the others (Fauth et al., 2012). In particular, relationship quality, covered in previous sections, appears closely linked to intimacy as one of the main components of relationship quality is conceptualized as the emotional closeness in the relationship (Lawrence, Tensntedt, & Assmann, 1998).

The potential benefits of maintained emotional closeness or intimacy in the context of the relationship between caregiver and person with dementia are well documented. Though for the most part based on correlational data which limits the ability to infer causation, in terms of the care recipient the potential benefits include greater overall well-being, slower decline of functioning, and fewer problem behaviors (Burgener & Twigg, 2002; Norton et al., 2009; Perren et al., 2007). Likewise, caregivers tend to show decreased burden and greater role satisfaction, as well as less emotional reactivity toward the care recipient (Spaid & Barush, 1994; Walker, Shin, & Bird, 1990; Fearon, Donaldson, Burns & Terrier, 1998). A higher premorbid level of intimacy has also been associated with more positive caregiver outcomes including: decreased levels of depression, lower caregiver burden, less reactivity to care recipient difficulties, improved communication with care recipient, greater quality of life, and satisfaction with the caregiving role (Kramer, 1993; Steadman et al., 2007; Williamson & Scultz, 1990).

Several studies have found that intimacy tends to decrease after onset of dementia (e.g., de Vugt et al., 2003; Morris et al., 1988a; Blieszner & Schifflett, 1990). Further a loss in intimacy or closeness is related to several negative outcomes for both caregivers and persons with dementia, including increased caregiver burden and mental and physical health difficulties

(Morris et al., 1988a; Blieszner & Schifflett, 1990; Lyons et al., 2007). Some conflicting evidence does exist however in regards to the relationship between intimacy and caregiver outcomes.

In contrast to the above findings, a study by Fauth and colleagues (2012) found that although caregivers with greater perceived emotional closeness to the person with dementia demonstrated greater physical health, they also showed increased negative psychological symptoms and affective imbalance. Fauth and colleagues (2012) posited that these ambiguous findings oppose the idea of decreased intimacy or closeness as purely a stressor, given the apparent protective factor against psychological symptoms. However, it is possible that while a lower level of emotional connection may provide the caregiver with a psychological buffer of sorts against the difficult experience of watching someone they care for deteriorate and decline, it may also contribute to an increased perception of burden related to caregiving duties. This postulation is in line with Ablit and colleagues' (2009) previously discussed theory of the form of relationship between caregiver and person with dementia, with relationships with a higher level of intimacy falling in the continuity form of relationship, and those with a lower level of intimacy falling in the detached category of relationship. As mentioned before, caregivers in the continuity category tend to maintain a sense of mutuality and acceptance of the caregiving role for a relatively long period of time, assumedly experiencing less care associated stress and thus fewer physical health difficulties. However, according to this model, caregivers eventually are overwhelmed by the reality that the care recipient has changed and it is possible that at this point the realization of their loss results in increased emotional and psychological strain, as perhaps demonstrated by the findings of Fauth and colleagues (2012) presented previously. Interestingly though, in this study increased intimacy did not result in greater reported depressive symptomatology (Fauth et al., 2012), making it difficult to assess the relative severity of the emotional difficulty found and whether this constitutes normal grieving related to a sense of loss of their loved one common in dementia. Increased psychological strain in the context of the perception or realization of the loss of a loved one, as they were previously, may simply represent normal grieving processes that caregivers with less of an emotional connection may not experience. Further, there is much debate over the differentiation between normal grieving processes and what constitutes diagnosable and/or treatment-worthy difficulties in the grief and bereavement literature (e.g., Fleming, 2013; Jacobsen, 2010).

While there is evidence that maintenance of intimacy has the potential for adverse psychological outcomes for caregivers, the potential benefits such as improved physical health, decreased burden, delayed institutionalization, in addition to the suspected benefits for the care recipient, would appear to outweigh the costs.

Though some debate remains, it is clear that changes in relational intimacy between the caregiver and care recipient due to dementia onset can have a significant impact on both individuals. Less clear, is the mechanism through which dementia impacts intimacy.

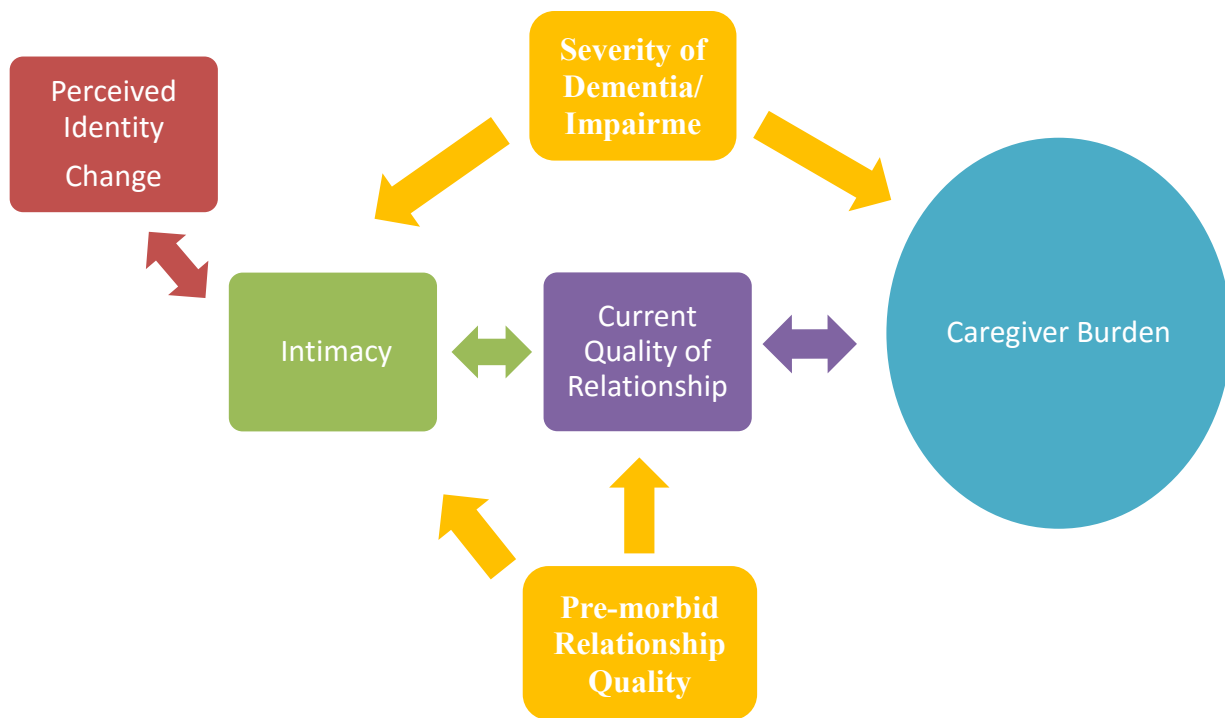
### **1.8.3 Intimacy Loss and Identity in the Context of Dementia**

Changes in identity as a result of the onset of dementia may impact the relationship, and more specifically, the emotional connection, between the caregiver and the person with dementia. As previously mentioned, changes in identity are commonly experienced by persons with dementia, as is a decrease in the emotional connectedness of the caregiver and person with dementia. Thematic analysis of the reports from couples where one partner has been diagnosed with dementia demonstrate that changes in each partner's roles and identity may represent the most difficult challenges resulting from onset of the disease (Robinson, Clare, & Evans, 2005). Further, the change in the caregiver/care recipient relationship due to dementia has been described as an increasing asynchrony, a loss of mutuality, and personal detachment from each other (Jones & Martinson, 1992; Lynch-Sauer, 1990; Hasselkus & Murray, 2007); during what has been labeled "the process of becoming strangers" (Wuest, Ericson, & Stern, 1994). Social psychological theories of identity suggest relational, social, and interactional bases for identity (Stryker, 1968; Tajfel & Turner, 1979; Hogg, Terry, & White, 1995; Stets & Burke, 2000). Given these bases, a change in identity due to dementia could also impact the caregiver's sense of identity, as well as the relationship between caregiver and care recipient.

Though limited, there exists literature pointing to the relationship between identity and intimacy in the context of dementia and caregiving. Changes in the identity of persons with dementia as perceived by their family caregivers were associated with changes in caregivers' reported sense of self, and importantly, a loss of intimacy in the caregiver/care recipient relationship which proved to be a significant source of distress (Hayes et al., 2007; Orono, 1990). Though no formal model for the relationship between identity and intimacy loss specifically could be located in the literature, this idea has been elucidated by several authors.

In Kitwood's (1997a) widely supported theory on personhood in dementia, it is argued that sustaining a sense of self is largely dependent on the relational context of the individual, specifically the relationship between the primary caregiver and person with dementia. Though it did not name intimacy as a key factor in identity maintenance, the idea that identity maintenance is dependent on emotions, feelings, relational capacity, and interdependence has been posited by several authors (see Hellstrom, Nolan, & Lundh, 2005).

While also not explicit, a model of identity and intimacy can be inferred from Ablit and colleagues' (2009) theory of relationship form, specifically the *continuity* category of relationship form. Already described previously, the continuity category is characterized as efforts to maintain the identity of the person with dementia by the caregiver, and a preserved sense of mutuality exists in the relationship, resulting in a lower level of perceived stress from caregiving. This description implies a relationship between the maintenance of identity, intimacy, and better coping. Such a model would appear to be supported by Hellstrom and colleagues' (2005) qualitative findings that maintaining a sense of self and important aspects of the pre-morbid relationship, combined with mutual understanding and acknowledgement of the changes occurring due to dementia, results in better overall coping by both caregiver and person with dementia. Clearly defining and establishing support for an interactional model of identity, intimacy, quality of relationship, and caregiver burden (Figure 1.1) is a primary goal of the first study of this project. Establishment of such a model would have implications for the focus and design of future psychosocial interventions for caregivers of persons with dementia.



*Figure 1.1.* Potential simple model of identity change, intimacy and current quality of relationship, and caregiver burden, moderated by dementia severity and pre-morbid relationship quality.

## 1.9 Psychosocial Interventions for Caregivers

The biopsychosocial model of dementia presented previously highlights the importance of the social context on the experience of dementia. The relationship between the caregiver and person with dementia is an integral part of this context. Given the aforementioned risks for adverse outcomes for those assuming the caregiver role, due to both the stress of caring and the negative changes that occur due to neurodegeneration, it is not surprising that the quality of this relationship tends to suffer. Over the last two decades an increasing amount of research has appeared in the literature regarding interventions aimed at ameliorating the negative outcomes of caregiving (see review by Mittelman, 2013). This literature has provided empirical support for a stress and coping model of psychosocial interventions for caregivers (Mittelman, 2013). Such interventions alone or in combination with pharmacological interventions have proven effective in alleviating negative outcomes. When administered alone, psychosocial interventions have the benefit of being free of potential side-effects common to psychiatric medications, and also may be more suitable for those with sub-clinical levels of symptomatology (Mittelman, 2013).

The stress and coping model applied to caregivers of individuals with dementia (e.g., Pearlin et al., 1990) posits that by improving the caregiver's ability to successfully cope with the stresses and burden of caregiving, coupled with the enhancement of perceived support, negative outcomes of caregiving can be ameliorated or possibly prevented. Psychosocial interventions for caregivers have in general shown small but significant benefits in reducing perceived burden and depressive symptoms (Pinquart & Sorensen, 2006b; Sorensen, Pinquart, & Duberstein, 2002). Those interventions incorporating both supportive and cognitive components, and focused on emotions, feelings of isolation, dealing with problem behaviours, and reducing the physical workload associated with care, were most successful (Cooke, McNally, Mulligan, Harrison, & Newman, 2001; Mittelman, 2013). Additionally, an aim of altering how the caregiver perceived the person with dementia and his or her behaviours was associated with reduced negative caregiving outcomes (Hepburn, Tornatore, Center, & Ostwald, 2001).

In general, interventions administered to individual caregivers have shown more efficacious than group interventions (Mittelman, 2013). According to Mittelman (2013), the greater flexibility and ability to customize interventions to suit the individual caregiver's needs, as well as the convenience of being able to conduct sessions in a place and at a time that fits the caregiver's schedule, are the main advantages of the individual approach. The author highlights



the importance of convenience for the caregiver, as they may need to find alternative care arrangements, which may increase stress. While interventions have traditionally focused on caregivers and the individual with dementia separately, more recently, dyadic approaches have shown promise.

### **1.9.1 Dyadic Approach to Intervention**

In line with a social contextual model for dementia and calls for a more dyadic perspective in understanding caregivers and persons with dementia (e.g., Braun et al., 2009), interventions that involve both caregiver and person with dementia aim to engage both individuals in coping with and management of the impacts of dementia (Judge, Yarry, Looman & Bass, 2013; Moon & Adams, 2012). Such an approach has an inherent focus on the relationship between caregiver and care recipient and is thought to offer several advantages over individual-focused interventions. Judge and colleagues (2013) highlighted several of these advantages, including the ability to process relational issues jointly and in a perhaps more meaningful way. Additionally, convenience is emphasized, as there is no need for alternative care arrangements and sessions may be conducted in the home. In a dyadic intervention, skills can be applied in session allowing for guided practice and problem solving. Finally, given the joint nature of the intervention there is the potential for great cost-benefit compared to individual approaches (Judge et al., 2013). Though to date the literature on dyadic approaches is limited, in general, there is growing empirical support for their efficacy (see review by Moon & Adams, 2012).

While dyadic interventions found in the literature assume various modalities, similar to individual focused interventions, the majority tend to include both cognitive, educational, problem solving, and supportive aspects (Moon & Adams, 2012). Others have focused on the caregiver and person with dementia's experience with dementia, and the transitions and changes that have resulted both in the self of each individual, and in their relationship. Auclair, Epstein, and Mittelman (2009) developed a spousal dyad targeted intervention based on counseling principles. The goal of the authors' intervention was to help maintain each individual's sense of self and repair or ameliorate damage to their relationship due to the onset of dementia. This goal is in line with the already mentioned findings by Hellstrom and colleagues (2005) based on an examination of qualitative data collected from spousal couples dealing with dementia. Hellstrom and colleagues found that efforts to maintain sense of self and important aspects of the pre-

morbid relationship, combined with mutual understanding and acknowledgement of the changes that have occurred due to the disease, results in better overall coping with the hardships related to dementia. This focus on maintaining the identity and the past relationship while also adapting to changes appears consistent with that of the continuity and reciprocation forms of identity from Ablit and colleagues' (2009) theory of caregiver relationship form (discussed previously).

Finally, the idea that maintaining a sense of self and elements of the prior relationship, perhaps most importantly the emotional connection between caregiver and person with dementia, would appear to be the goal of reminiscence therapies for caregivers and persons with dementia.

### **1.10 Reminiscence Therapy**

That reminiscence is the recall of memories about one's self and one's life is generally recognized as a universal definition. Reminiscence researchers would argue that human reminiscence is a complex phenomenon requiring a more inclusive definition (e.g., Westerhoff et al., 2010). A more comprehensive definition was posited by Bluck and Levine (1998) in an attempt to incorporate contemporary knowledge of reminiscence derived from empirical findings. The authors' definition is as follows:

Reminiscence is the volitional or non-volitional act or process of recollecting memories of one's self in the past. It may involve the recall of particular or generic episodes that may or may not have been previously forgotten, and that are accompanied by the sense that the remembered episodes are veridical accounts of the original experiences. This recollection from autobiographical memory may be private or shared with others (Bluck & Levine, 1998).

Westerhoff and colleagues (2010) point out three important elements of the above definition. First, it highlights that reminiscence is a naturally occurring phenomenon that all people experience and can share with others. Second, it specifies the fact that memories can be intentionally recalled and also that memories thought to have been forgotten can be remembered. Third, it recognizes that though people believe they accurately recall experiences from the past, memories are reconstructed in line with current self-schema, and in tune with the present social situation when shared (Bluck & Levine, 1998; Marsh, 2007). Using this definition, Westerhoff and colleagues (2010) cite the fact that reminiscence is both a volitional and reconstructed act as the bases for the belief in the therapeutic potential of reminiscing.

Reminiscence Therapy involves the discussion of an individual's past experiences with or without the use of aids (photos, memorabilia, props, etc.), with the aim of providing some benefit to the individual (Woods et al., 2009). Though in early works the act of reminiscing was viewed as a symptom of "senility in the elderly" (Buhler, 1935), more recently it has been accepted as a potentially therapeutic experience (Bluck & Levine, 1998). The idea that facilitated reminiscing may have therapeutic benefit was derived from the works of Butler (1963) regarding his idea of the "Life Review." Over the years it has grown in popularity and has been utilized as the basis for a variety of interventions.

Butler's (1963) Life Review approach was influenced by his psychodynamic background and based on the theoretical principle that often the individual's goals for reminiscing are to find meaning and to improve integration of the self. He believed that reminiscence was either a spontaneous or a guided/prompted process that brings unconscious material into consciousness, allowing it to be integrated into the current self. Butler's main contribution to the field of reminiscence was to promote reminiscence as a positive and beneficial activity.

Empirical investigation of reminiscence has since provided support for this conceptualization (Bluck & Levine, 1998). In terms of defining the act of reminiscence itself, three core attributes of reminiscing have been identified by Dempsey and colleagues (2012) after a review of the reminiscence literature. The three attributes were stated by the authors as the following: reminiscence is a process of recall; reminiscence is an interaction involving the communication of past experience; and reminiscence is an interaction between individuals. The contention that reminiscence is a *process* of recall stems from literature providing insight into both the mechanical and functional processes of reminiscing.

### **1.10.1 Reminiscence Process**

According to Merriman (1989), the act of reminiscing involves four components that represent a systematic mental process. It begins with the selection of the memory to be recalled (usually after a triggering stimulus is presented), followed by the individual becoming immersed in the recalled memory and the elicitation of positive and or negative feelings associated with the memory. Withdrawal from immersion occurs next due to either fatigue, a wish to avoid the evoked emotion, or an external signal (e.g., noise, prompting). The last stage is closure, which may involve the telling of the memory to another.

Bohlmeijer and colleagues (2007) also proposed a four stage process theory of reminiscence, however, theirs was concerned with the functional process of reminiscence as opposed to the structural process. The authors posited that reminiscing plays a role in identity formation and continuity. They explained that in stage one, through reminiscence the individual is made aware of how they have changed over time, enhancing the individual's present identity. The next functional stage involves finding meaning in one's life via the recall of positive past experiences as well as future plans. The individual's sense of mastery and control over their life influences their ability to move past negative past experiences, facilitates problem solving efforts for issues made salient during recall, and contributes to general healthy aging. Finally, after reminiscing, individuals who maintain a positive sense of self are able to reconcile past experiences that are inconsistent with their self-view and, as a result of reminiscing, experience an increased sense of well-being.

### **1.10.2 Reminiscence Function: Reminiscence vs Autobiographical Memory**

The literature on the function of the recall of personal episodic memories has traditionally occurred in parallel within the fields of reminiscence and autobiographical memory research. Though conceptually analogous, the focus of these two fields differs; reminiscence research is largely concerned with the clinical and phenomenological aspects, and autobiographical memory tends to be more concerned with the empirical investigation of theoretical/conceptual aspects (Webster & Cappeliez, 1993; Bluck & Alea, 2003; Webster, 2003). From these two bodies of literature, two respective, yet compatible, theories of the functionality of reminiscence have emerged.

In the autobiographical memory literature, three broad categories of reminiscence function have been identified and generally supported; these include the self, social, and directive functions (e.g., Bluck, Alea, Habermas & Rubin 2005; Bluck, 2003). All three were described in Pillemer's (1992) framework of autobiographical memory and later elaborated on by several authors (as described in the review by Bluck and colleagues (2005) and also in Bluck (2003)). According to the autobiographical memory literature, reminiscing is generally thought of as being universal amongst humans, but the extent to which an individual partakes in each functional type of reminiscence appears to vary by age and developmental need (Bluck, 2003). Further, these functions do not necessarily occur independently of one another, as one instance of reminiscence could potentially involve all three functions to a degree (Bluck, 2003).

In the reminiscence literature several specific functions of reminiscence have been identified that relate to, and expand on, the functional categories identified by Webster (1999) who attempted to provide empirical support for the most commonly theorized functions of reminiscence. Webster combined items taken from different published measures used in research investigating reminiscing functions to create the Reminiscence Functions Scale. Through factor analysis of data collected using the scale, he identified eight factors of reminiscence function: boredom reduction, death preparation, identity formation/integration/maintenance, problem solving, conversation, intimacy maintenance, bitterness revival, and teach/inform.

### **1.10.3 A Unified Model of Reminiscence**

In an effort to elucidate the apparent convergence of these two theories, Bluck and Alea (2002) pointed out that autobiographical memory's 'self' category is represented in the reminiscence literature by identity and death preparation functions; similarly, the social category by the teach/inform, intimacy maintenance, and communication functions; and the directive category by the problem solving function. Agreeing with Bluck and Alea's (2002) assertion regarding the overlap of the two theories, Webster (2003) attempted to unify the two approaches empirically by devising a circumplex model of reminiscence function based on factor analyses of existing data collected using the Reminiscence Function Scale. He found that reminiscence function could be described via the dimensional axes of self - social and reactive/loss – proactive/growth, on which the eight identified factors could be mapped by polarity and similarity to form the reminiscence circumplex. These findings have contributed to the current view of the respective theories and bodies of literature from these two fields as complimentary and interrelated, and a movement toward integration appears to be well underway (Webster & Cappeliez, 1993; Bluck & Alea, 2003; Webster, 2003).

### **1.10.4 The Identity Function of Reminiscence**

A major function of reminiscence is its role in the establishing and maintaining of one's sense of self over time. This assertion has been consistently supported in the autobiographical memory and reminiscence literature, both theoretically and empirically (e.g., Webster, 2003; Hyman & Faries, 1992). Autobiographical memory theory's *self* category of function and the aptly referred to *identity* function posited by reminiscence theorists, both point to the importance of reminiscence in the preservation of self.

In autobiographical memory theory, the self function of reminiscing is posited as being critical to maintaining continuity in regard to one's sense of self (see reviews by Bluck et al., 2005; Bluck, 2003; Bluck & Levine, 1998). Accessible self-knowledge or facts, events, and experiences stored in memory that are related to the self provide the basis for one's self-concept, or borrowing from cognitive theory, one's self-schema (Brewer, 1996). The formation of the self-schema is not a passive process as people have a tendency to both store new memories and recall past ones in a way that fits their current self-concept (Conway, 1996). This biased encoding and recall of self-knowledge serves to maintain stability and continuity of the self-schema (Bluck & Levine, 1998; Conway, 1996). Conversely, it also allows for instability of the self-schema and change in the self over time. As a person's goals and contextual circumstances change, the biases that influence encoding and recall of self-related knowledge are altered to reflect these changes (Bluck & Levine, 1998). The formation and maintenance of a coherent and continuous sense of self is posited to occur throughout development during childhood and adolescence (Fivush, 1998; Habermas & Bluck, 2000), and a stable sense of self is seen as an important part of healthy self-regulation in adulthood (Cohen, 1998). Additionally, the ability to recall self-knowledge toward identity maintenance may be especially important during adverse life conditions resulting in significant change, such as a personal loss or the onset of a serious disease (e.g., dementia) (Robinson, 1986).

Similar to the autobiographical memory literature, in the field of reminiscence research the identity development and maintenance function of reminiscing is well recognized. In general, the identity or integrative function of reminiscing, as it has also been termed in the reminiscence literature, refers to people's use of reminiscence as a means of understanding, exploring, and reinforcing their sense of self, in the present, by recalling who they were in the past (Watt & Wong, 1991; Webster & McCall, 1999).

### **1.10.5 The Intimacy Function of Reminiscence**

Reminiscence has also been implicated in the developing, maintaining, and strengthening of emotional connections, or intimacy, between people. In the autobiographical memory literature, the intimacy function falls under the broader *social* category of reminiscence function (e.g., Cohen, 1998; Alea & Bluck, 2007; Bluck et al., 2005). Specifically, it has been posited and demonstrated that the recall and sharing of past events in the presence of others promotes the formation and/or strengthening of an emotional connection between the teller and the listener

(Alea & Bluck, 2007, 2005). This may be attributable to the theory of personal disclosure processes, in which the disclosing of personal information between two people tends to form or strengthen a mutual bond (Laurenceau, Barrett, & Pietromonaco, 1998). The ability to promote and enhance the emotional connections between individuals is believed to be one of the most fundamental functions of reminiscence, as it potentially contributes to species survival (Pillemer, 1998).

In addition to the sharing of memories, private or internal reminiscing can also foster intimacy between two individuals. Findings in the autobiographical memory literature have demonstrated that the recall of memories involving those close to us can serve to maintain the emotional connection between the individual reminiscing and the person being remembered, despite the physical absence of the latter party (Alea & Bluck, 2007). This is similar to the theory of reminiscence function posited in the reminiscence literature by Webster (1997). Webster (1997) believed and demonstrated that one of the main functions of reminiscence is the maintenance of the emotional bond with a deceased loved one. While increased intimacy with a living person, under normal conditions, is considered desirable and beneficial, the maintaining of an emotional connection with one who is no longer living has been associated with increased psychological distress and decreased subjective well-being (see review by Westerhof, Bohlmeijer, & Webster, 2010). Given that reminiscence can serve several functions simultaneously, it remains somewhat unclear as to whether the association between intimacy maintenance with a deceased loved one and more negative outcomes is contributed to by other uses of reminiscing demonstrated to have negative outcomes, such as for the reduction of boredom.

Despite the potential negative uses of reminiscing, it is clear the recall of personal memories can serve several useful and beneficial functions to the individual. This potential for benefit has long been recognized and reminiscence has been used therapeutically in several therapeutic contexts.

#### **1.10.6 Reminiscence Based Psychosocial Interventions**

Since Erikson's (1959) assertion that review of one's life is a focal developmental goal in the later stages of life, and Butler's (1963) subsequent development of his psychodynamic anchored Life Review, reminiscence based interventions have gradually grown in popularity and use (Pinquart & Forstmeir, 2012). To date, reminiscence interventions have been taken on a

variety of forms, targeting a range of difficulties and goals. After examining the heterogeneity of reminiscence based therapeutic modalities, Westerhof, Bohlmeijer, and Webster (2010) differentiated between three categories of reminiscence intervention: simple reminiscence, Life-review, and Life-review therapy.

*Simple Reminiscence* interventions, according to Westerhof and colleagues (2010), are mainly comprised of the unstructured recall and the telling of autobiographical experiences. These interventions generally aim to facilitate the communication of positive past experiences, thus activating the social function of reminiscence, and foster positive feelings. The authors state that this form of reminiscence therapy is most suited to older adults living in nursing homes, who are in relatively good mental health, and value the sharing of memories with others. Only basic skills in facilitating spontaneous reminiscence and social interaction are deemed criteria for those conducting the intervention (Westerhof et al., 2010).

Comparatively, *Life Review* interventions tend to take the form of individual or group interview style sessions in which the person's entire lifespan is systematically reviewed, and the individual is guided through the evaluation of both positive and negative memories with an aim at integration with the self (Westerhof et al., 2010; Webster & Young, 1988). Via the life review process, the identity and problem solving functions are utilized to gain insight into one's development and evolution into their current self, leading to increased self-acceptance, sense of mastery, and sense of meaning in life (Westerhof et al., 2010; Bluck & Levine, 1998). Life review interventions are typically useful for those having difficulty finding meaning in their lives and/or who are struggling to cope with periods of transition or adversity (Westerhof et al., 2010). They are generally conducted by trained counselors with advanced skills in session structuring, interviewing, and helping clients conceptualize or re-conceptualize their past experiences and what they mean to their current self-understanding (Westerhof et al., 2010).

Lastly, *Life Review Therapy* is a more intensive and dynamic intervention aimed at refocusing a person's overly negative use of reminiscence toward utilization of the more positive functions of reminiscing (Westerhof et al., 2010). It is typically suited for those with more mental health difficulties (e.g., depression, anxiety) who tend recall past experiences that evoke negative feelings about the self and others. Through a variety of therapeutic frameworks, knowledgeable therapists work with clients to derive constructive meaning from their life-stories



toward development of a more positive self-identity (Bohlmeijer et al., 2008; Westerhof et al., 2010).

### **1.10.7 Efficacy**

In terms of general effectiveness, meta-analyses examining the efficacy of all three types of reminiscence intervention have found small to moderate effect sizes for a variety of psychosocial outcome variables (Bohlmeijer et al., 2007; Piquart & Forstmeier, 2012).

Piquart and Forstmeier (2012) conducted a large meta-analysis of 128 outcome studies examining the impact of simple, life review, and life review therapy modalities of reminiscence therapy on nine outcome variables. The authors found moderate effect sizes for ego-integrity and depressive symptoms, and small effect sizes for sense of purpose in life, death preparation, mastery and control, mental health symptoms, sense of positive well-being, social integration, and cognitive performance. In general, life review therapy produced the largest effect sizes for improving depressive symptoms and positive well-being. Patients with more severe depressive symptoms or chronic disease tended to show the greatest improvement.

**1.10.7.1 Reminiscence and Dementia.** Reminiscence based interventions are commonly employed in dementia care (Woods et al., 2005; Gibson, 2004). Though the effectiveness of reminiscence therapies in healthcare settings in general has been questioned (e.g., Moos & Bjorn, 2006), reviews of the literature have concluded that reminiscence specifically targeted for those with dementia show positive results in reduction of depressive symptoms and improved cognition (Woods et al., 2005), and also enhanced sense of self-worth, identity, and individuality (Dempsy et al., 2012). More specifically, another review found that, in line with the person-centered approach to dementia care, personalized structured life review interventions that include construction of a life review book had positive benefit on psychosocial outcomes, while a group reminiscence program seemed to have greater impact on cognition and a social reminiscence activity group had the greatest impact on well-being and perceived quality of life (Subramaniam & Woods, 2012).

Reminiscence has also shown promising, but limited, evidence of benefit for caregivers participating in reminiscence based group interventions in the form of reduced caregiver strain (Woods et al., 2005). More recently, however, large scale studies of regimented structured dyadic reminiscence therapy demonstrated no overt benefit for informal caregivers, and increased anxiety as a result of the intervention (Woods et al., 2013). In this study, it is possible

that the logistics involved in arranging transportation for both caregiver and person with dementia, travel time, and weekly commitment for an extended period (three months), was an additional source of stress and pressure on the caregivers. Given the energy and time demands placed on caregivers, interventions aimed at alleviating caregiver burden should aim to maximize convenience and flexibility for caregivers. Additionally, given a large proportion of older adults living in rural and remote areas, accessibility of interventions is also a major concern.

### **1.11 Rural Populations and Telehealth Videoconferencing Delivery**

The vast geographical expanse of Canada and widespread dispersal of its population combined with relatively limited resources and trained personnel, results in logistical challenges in the delivery of health services. That the proportion of older adults tends to be higher in rural and remote regions than in urban centres, makes services related to dementia care an important area of need. Through the use of emerging videoconferencing technology and expansion of communications networks, increased access to a wide range of services is now possible in a growing number of rural and remote areas with the potential, for both economic and human benefit. Mental-health services delivered via videoconferencing is one promising application of this evolving technology and capability. However, there remains the question of whether the therapeutic benefit of psychosocial interventions translates from the traditional in-person modality to delivery over videoconferencing. Limited but growing evidence exists for the efficacy of interventions over videoconferencing.

*Telehealth* is a catch-all term encompassing any health service delivery medium which involves the transmission of images, voice, and data via a telecommunication link between two sites (Perle, Langsam & Nierenberg, 2011). Videoconferencing is one delivery modality falling under the telehealth umbrella that is garnering increased interest and usage in health settings (Perle et al., 2011). More specifically, it is the synchronous (real-time) visual/audio communication between two parties separated by distance. Videoconferencing is thought to retain many of the advantages of face-to-face contact over non-visual and/or asynchronous mediums (i.e., telephone, chat, message boards, email), such as the ability to observe nonverbal behaviors and cues, and the ability to elicit spontaneous disclosures from clients (Jermone & Zaylor, 2000; Perle et al., 2011).

Although there exist inherent and unique challenges associated with Telehealth delivery in regards to jurisdiction and licensure, reimbursement, confidentiality, and general comfort with

and training in the use of equipment related to the technology (i.e., computers, displays, and software) (see review by Perle et al., 2011), research has demonstrated that psychologists and psychiatrists utilizing videoconferencing in controlled institution-type settings (e.g., prisons, military hospitals) report being satisfied with the technology (Magaletta et al., 1998). The results of studies assessing the attitudes of mental health professionals in general toward e-therapy and other internet based services (regardless of experience with such mediums), have shown to be more equivocal (Wangberg, Gammon, & Spitznogle, 2007; Mora et al., 2008). Regardless of these mixed attitudes on the part of mental health professionals, and perhaps more importantly, there is a large body of evidence suggesting universally high rates of acceptance and satisfaction with Telehealth mediums across a diverse range of populations and services (Richardson, Frueh, Grubaugh, Egede, & Elhai, 2009). Further, as access to computers and internet continues to proliferate, many predict wide spread adoption of Telehealth mediums for service delivery (Vandenbos & Williams, 2000), and interest and utilization continues to see exponential growth (Perle et al., 2011).

### **1.11.1 Rural and Remote Populations**

The benefit of Telehealth delivery mediums for increasing access to health and mental health services in rural and remote areas is obvious and implementation has been encouraged (Morgan et al., 2009). Inhabitants of rural and remote areas tend to be at risk of physical and mental health difficulties and are traditionally underserved or must travel significant distances to gain access to services (Morgan et al., 2009; Emmelkamp, 2009). Increasing access health services via computers, internet, and dedicated telehealth networks provides multiple advantages in terms of benefits to health and practicality (Perle et al., 2011; Jennet et al., 2003; Morgan et al., 2009). For example, a large review of telehealth services in Canada found several socio-economic benefit resulting from their use, including: increased access to health services, cost-effectiveness, enhanced educational opportunities, improved health outcomes, better quality of care, better quality of life and enhanced social support (Jennet et al., 2003). Additionally, one specific example of telehealth use to service rural and remote areas demonstrated a savings of considerable travel time (462 km on average per roundtrip) and reported high rates of client satisfaction with the telehealth system (Morgan et al., 2011).

### **1.11.2 Effectiveness for Telehealth Delivery of Psychosocial Interventions**

While the practical benefits of Telehealth are relatively clear, in terms of psychosocial interventions, the obvious question is whether the mechanism of therapeutic benefit of a given intervention is retained when delivered via a Telehealth format such as videoconferencing. Though a relatively large body of literature exists examining mental health interventions over Telehealth mediums, the majority of these have looked at clinical outcomes in terms of client satisfaction with their experience and their evaluation of the therapeutic alliance, as opposed to therapeutic effectiveness. Many of these studies also employ qualitative methods to gauge client outcomes (see review by Richardson et al., 2009). In line with previously mentioned research results, clients tend to report high levels of satisfaction with mental health interventions through videoconferencing, and reported similar levels of quality of the therapeutic alliance to that of face-to-face therapy (Perle et al., 2011; Richardson et al., 2009).

Despite the limited number of studies directly assessing the therapeutic efficacy of telehealth delivered interventions, the findings that are available indicate that psychosocial interventions delivered via videoconferencing are at least as effective as those delivered in a traditional face-to-face setting (Richardson et al., 2009; Perle et al., 2011). However, due to less than ideal methodology and sampling, and the fact that the majority of studies were examining cognitive behavioral therapy based interventions (e.g., Bouchard et al., 2004; Nelson et al., 2003), caution in generalizing these results to non-CBT based therapies is warranted.

### **1.12 Project Objectives**

The present research project addresses the following stated objectives. The objective of the Study 1 was to investigate the relationship between the caregiver's perceptions of identity change in the person with dementia, intimacy and quality of relationship between caregiver and person with dementia, and caregiver burden. It also aimed to investigate support for a proposed theoretical model of caregiver's perceived change about the person with dementia's identity and caregiver burden, that may potentially underlie Reminiscence Therapy efficacy for informal caregivers of persons with dementia described previously and represented in Figure 2.1 (p. 49).

Using the model of identity and burden proposed in Study 1 as a guiding theoretical basis, the objective of the second study was to evaluate, via experimental design, the efficacy of a Reminiscence Therapy-like activity for decreasing the perception of caregiver burden in informal caregivers of persons with dementia. An additional objective of Study 2 was to compare

modes of intervention delivery: traditional in-person delivery versus delivery over Telehealth videoconferencing.

The objective of Study 3 was to inform feasibility of future research and/or psychosocial interventions with informal caregivers of persons with dementia, such as reminiscence, over Telehealth videoconferencing. The third study involved examination of data collected during Study 2 related to caregivers' experience participating in the intervention, including their satisfaction and attitudes toward the intervention process and the use of Telehealth videoconferencing as a mode of delivery. The process of delivering the reminiscence activity was also documented and described, in order to inform future design and development of research projects and interventions intended for Telehealth videoconferencing delivery.

## **CHAPTER TWO: Study 1**

### **Identity, Intimacy Loss, and the Perception of Burden by Caregivers of Persons with Dementia**

#### **2.1 Introduction**

Dementia is a growing problem which impacts both individuals and society (Alzheimer's Society Canada, 2010). Beyond the individual person diagnosed with dementia, informal caregivers (typically a family member or friend) of persons with dementia who tend to be at risk of negative outcomes. Negative outcomes are commonly associated with a caregivers' level of perceived burden related to their caring duty (e.g., Alspaugh et al., 1999; Clyburn, 2000; Gaugler et al., 2000; Gonyea et al., 2005; McConaghy & Caltabiano, 2005; Wright et al., 2010). One factor related to caregivers' perception of burden is the quality of their relationship with the person with dementia, which tends to suffer after dementia onset (Blieszner & Shiflett, 1990; Morris et al., 1988b). Intimacy, or the emotional bond or perceived closeness between two people, is an important component of relationship quality or satisfaction (Lawrence, Tensntedt, & Assmann, 1998), and also tends to decrease post dementia diagnosis (Blieszner & Shiflett, 1990; Morris et al., 1988b). Less studied is the cause for decline in the emotional connection between caregiver and care recipient. Some authors have theorized, and qualitative studies suggest, that the loss of, or change in, identity of the person with dementia progressively occurring after onset is related to the reduced intimacy and connectedness in the caregiver/care recipient relationship (Hayes et al., 2009). The aim of the current study was to empirically examine the relationship between informal caregivers' perception of identity change in their care-partner with dementia, their relationship, and the perception of burden in providing care.

##### **2.1.1 Caregiver and Person with Dementia Relationship**

Contemporary views of dementia recognize the importance of psychosocial factors, in addition to the underlying neurophysiological characteristics, in determining the impact of the disease on the person who has been diagnosed, and subsequently, their caregiver (e.g., Sabat, 2001; Clare, 2008). Indeed, a biopsychosocial model has largely replaced the traditional

conceptualizations of dementia in the literature (e.g., Kitwood & Bredin, 1992; Spector & Orrel, 2010; Sabat, 2001; Clare, 2008). The relationship with their primary caregiver typically accounts for a large portion of the person living with dementia's social interactions and caregiving typically involves a major investment of time and energy by the caregiver; thus the quality of this relationship can influence the well-being of both parties. Several studies have demonstrated the importance of the quality of the caregiver and person living with dementia relationship in determining informal caregiver outcomes (see reviews by Ablit, Jones, & Muers, 2009; and Quinn, Clare, & Woods, 2009). A perceived low quality of relationship has been found to be associated with higher levels of depression in the caregiver (Knop et al., 1998; Rankin, Haut, & Keefover, 2001; Townsend & Franks, 1995; Williamson & Shaffer, 2001), increased caregiver strain (Morris et al., 1988b; Uchino et al., 1994), and perceived burden (Campbell et al., 2008; Fitzpatrick & Vacha-Haase, 2010; Iecovich, 2011; Snyder, 2000). In particular, intimacy in the relationship, a component of relationship quality (Lawrence, Tennstedt & Assmann, 1998), appears to be impacted by the onset of dementia.

### **2.1.2 Intimacy**

Though definitions vary, a common trait found in most conceptualizations of intimacy is the feeling of an emotional connection and closeness shared between two individuals (Blieszner & de Vries, 2001; Moss & Schwebel, 1993). Moss and Schwebel (1993) point out that an important aspect of intimacy is the sense of mutuality or the feeling of mutual interaction or exchange, highlighting that intimacy is a process between two people and requires input from both. The authors note that although mutuality implies reciprocity between two individuals, it does not indicate equal investment into the relationship by both individuals. The preservation or loss of a sense of mutuality, and intimacy in general, is an important determinant of outcomes for both caregiver and person living with dementia.

The maintenance of intimacy in the caregiver and person living with dementia relationship has been associated with several benefits. For the care recipient, a higher level of perceived intimacy has been linked to a greater feeling of general well-being, slower decline of functioning, and fewer problematic behaviors (Burgener & Twigg, 2002; Norton et al., 2009; Perren et al., 2007). Caregivers tend to show a decreased level of perceived burden and greater role satisfaction, as well as less emotional reactivity toward the care recipient (Spaid & Barush, 1994; Walker, Shin, & Bird, 1990; Fearon, Donaldson, Burns & Terrier, 1998). A higher

premorbid level of intimacy has also been associated with more positive caregiver outcomes including: decreased levels of depression, lower caregiver burden, less reactivity to care recipient difficulties, improved communication with care recipient, greater quality of life, and satisfaction with the caregiving role (Kramer, 1993; Steadman et al., 2007; Williamson & Scultz, 1990).

Also of importance is the impact of dementia on levels of relationship intimacy. Several studies have noted that intimacy in relationships tends to decrease after onset of dementia in one of the individuals within the relationship (e.g., de Vugt et al., 2003; Morris et al., 1988a; Blieszner & Schifflett, 1990). Further, decreased intimacy or closeness is related to several negative outcomes for both caregivers and person with dementia, including increased caregiver burden and mental and physical health difficulties (Morris et al., 1988a; Blieszner & Schifflett, 1990; Lyons et al., 2007). Interestingly, despite the majority of literature demonstrating the potential benefit of retained intimacy between caregiver and person with dementia, in one study by Fauth and colleagues (2012), it was found that a high level of intimacy was, in addition to positive outcomes, also associated with increased psychological distress in a sample of caregivers. However, in Fauth and colleagues' (2012) study, increased intimacy did not result in decreased reported depressive symptomatology, thus it is difficult to assess the relative severity of the psychological distress caregivers were reported to have experienced. Increased psychological strain in the context of the perceived loss of a loved one may simply represent normal grieving processes and there is much debate over the differentiation between what does and does not constitute diagnosable and/or treatment-worthy difficulties (e.g., depression) in the grief and bereavement literature (e.g., Fleming, 2013; Jacobsen, 2010).

While it is possible that a lack of intimacy provides an emotional buffer against the distress caused by deterioration and decline or loss of someone they care for, the negative outcomes associated with less intimacy in the literature suggests this potential buffering may be limited and is possibly explained by Ablit and colleagues' (2009) descriptions of the different forms relationships between caregivers and persons living with dementia take or the variation in caregivers approach to caring/coping. Caregivers who maintain a high level of intimacy in the relationship tend to maintain a sense of mutuality and acceptance of the caregiving role for a relatively long period of time, experience less care associated stress, and have fewer physical health difficulties. However, the authors suggest that eventually these caregivers are overwhelmed by the reality that the care recipient has in fact changed and it is possible that at



this point the realization of their loss results in increased emotional and psychological strain. This is possibly due to a loss of the emotional connection that may occur with the realization that their loved one living with dementia has changed (i.e., a perceived change in identity) and at the very least suggests that maintained intimacy provides a prolonged period of relatively positive functioning in the caregiver.

Further, according to Ablitt and colleagues (2009), low intimacy was characteristic of a detached form of relationship in which the relationship lacks warmth and the caregiver views the person with dementia as “radically different” than their premorbid selves, potentially resulting in increased perceived stress from caregiving, and greater physical difficulties.

In order to attain better theoretical understanding of the relationship between dementia onset and intimacy in the caregiver and the person with dementia’s relationship, it is important to understand what factors contribute to intimacy loss. Unfortunately, there appears to be little quantitative research conducted to date addressing factors contributing to the loss of intimacy in the context of dementia. Qualitative literature, however, suggests that identity may play an important role (Hayes et al., 2007; Hasselkus & Murray, 2007).

### **2.1.3 Identity Loss/Change and Dementia**

A sense of slowly losing one’s identity is commonly experienced by those living with dementia as they gradually lose intellectual function and the ability to participate meaningfully in social interactions (Hayes et al., 2009; Cohen & Eisdorfer, 1986; McGowin, 1993; Cohen-Mansfield et al., 2006; Herskovits, 1995). Identity is usually defined in terms of stable internal or “personal” characteristics, and external or “social” characteristics. Although research has demonstrated that components of the personal identity can persist well into the late stages of dementia, overall, the literature suggests distinct identity changes as a result of the degenerative process, especially to one’s social identity (see review by Cadell & Clare, 2010). Social identity refers to one’s pattern of interactions with others and the various social roles that one consistently takes on (i.e., familial, occupational, societal, etc.). That this social component of a person’s identity appears most impacted by dementia makes intuitive sense, given the communication and social deficits commonly observed in persons diagnosed with dementia (see review by Bourgeois, 2002), while personal identity characteristics such as the ability to communicate a self-narrative appear to persist longer in the course of the condition (see review by Cadell & Clare, 2010) as they rely on cognitive processes generally more resistant to decline

in dementia (i.e., remote memory and overlearned information). The social conceptualization of identity is based on social constructionist theories of identity, such as those found in the social psychology literature, which suggest a relational, social, and interactional bases for identity (Stryker, 1968; Tajfel & Turner, 1979; Hogg, Terry, & White, 1995; Stets & Burke, 2000). Given these bases, a change in identity due to the degenerative nature of dementia could also impact the caregiver's sense of identity, as well as the relationship between caregiver and care recipient, and more specifically the level of intimacy in the relationship.

#### **2.1.4 Identity, Intimacy, and Outcomes**

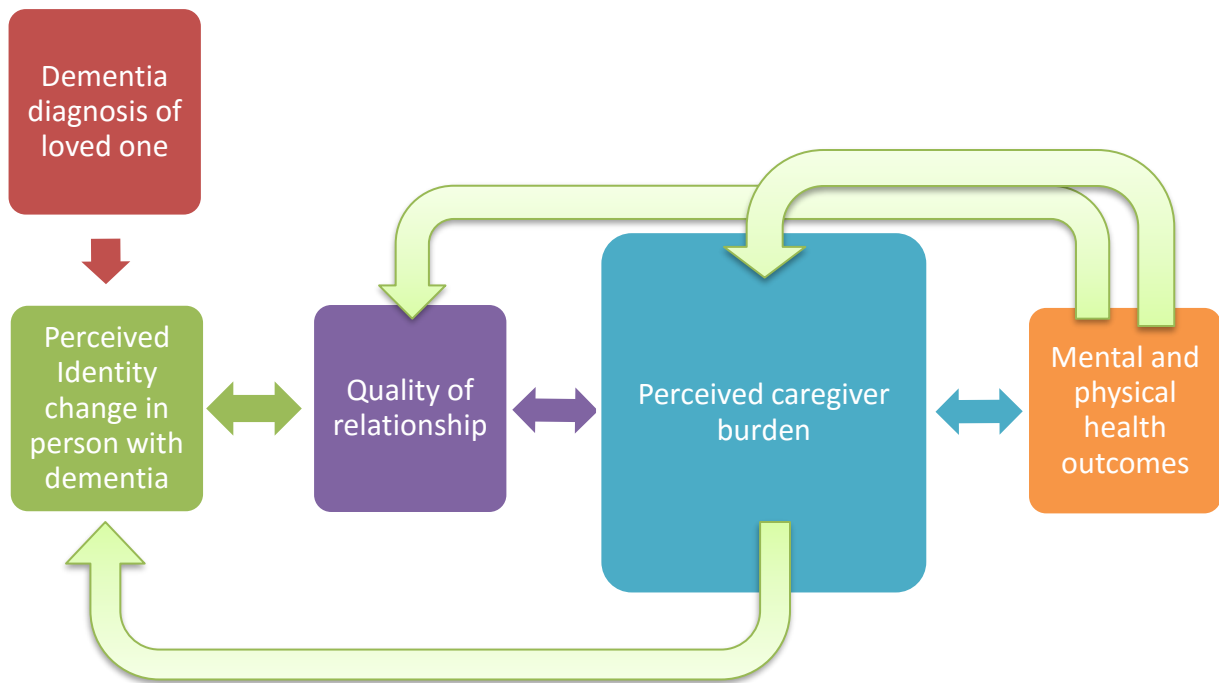
In general, the literature has demonstrated that perceived changes in or loss of identity are related to negative clinical outcomes, including well-being and mental health (Jetten, O'Brian, & Trindall, 2002; Haslam, Jetten, Postmes, & Haslam, 2009). In persons living with dementia perceived changes in or loss of identity has been associated with decreased well-being and life-satisfaction (Jetten et al., 2010). Nevertheless, the relation between caregivers' perceived identity loss/change in the person with dementia on the caregiver and their dyadic relationship has not been well studied.

The relation between identity loss/change due to dementia and dyadic relationships has been described as an increasing asynchrony, a loss of mutuality, and personal detachment from each other (Jones & Martinson, 1992; Lynch-Sauer, 1990; Hasselkus & Murray, 2007); during what has been labeled "the process of becoming strangers" (Wuest, Ericson, & Stern, 1994). A loss of mutuality, and feelings of detachment from one another would seem to describe a deterioration of relationship intimacy. As mentioned previously, a sense of mutuality in the relationship has been identified as a key component of intimacy (e.g., Moss & Schwebel, 1993), and the detached form of caregiving is defined by the absence of intimacy (Ablitt et al., 2009). Indeed, a loss of intimacy in the caregiver/care recipient relationship may be a direct result of changes in identity (Hayes et al., 2009). Qualitative studies have found that change in the identity of persons with dementia as perceived by their family caregivers was associated with caregivers' reported sense of own identity and their perception of intimacy in the caregiver/care recipient relationship, and was it reported to be a significant source of distress (Hayes et al., 2007; Orono, 1990).

Potentially further indicative of the existence of the relationship between identity, intimacy, and caregiver outcomes are the suspected benefits of reminiscence therapy based

interventions. Reminiscence Therapy in the context of persons with dementia and caregivers, facilitates shared recall of memories in which identities of both the caregiver and care recipient prior to dementia onset are salient. It is possible that this facilitated recall may act to prime the perceived saliency of these identities in present day. Increased saliency of former identities perceived by the caregiver and care recipient might then facilitate recovery of intimacy lost due to identity change, improving their relationship and reducing perceived caregiver burden.

Despite the importance of intimacy and caregiver relationship quality in determining outcomes for both person with dementia and caregiver alike, and the intuitive link between intimacy and reported identity change as a result of dementia, the relationship between identity, intimacy, and outcomes such as perceived caregiver burden have not been empirically examined. Based on the literature regarding identity change/loss in dementia and the potential implications for intimacy and quality of the relationship between the caregiver and care recipient, and ultimately the perception of caregiver burden, a theoretical model of the role of identity in predicting variance in burden was generated. This is presented in Figure 2.1. The objective of Study 1, therefore, was to address the apparent gap in the literature by empirically exploring the role of identity in burden and testing support for the proposed model. We hypothesized that the theoretical model (see Figure 2.1) would be supported. Specifically, we hypothesized that caregivers' perceived change in identity of their loved one with dementia would be negatively associated with their perception in the quality of their dyadic relationship. Further, we hypothesized that caregivers' perceived level of change in identity of the person with dementia and overall quality of caregiver/care recipient relationship would predict variance in caregiver burden. Finally, we hypothesized that relationship quality would mediate the relation between perceived identity change and perceived burden.



*Figure 2.1.* A proposed model of the directional relationship and mechanism of the relationship between perceived identity change in the person with demetnia and the perception of burden by the caregiver, with potential feedback.

## 2.2 Methodology

### 2.2.1 Data Collection and Participants

A cross-sectional correlational design was used. Consecutive primary informal caregiver of patients attending the University of Saskatchewan Rural and Remote Memory Clinic (RRMC) over a period of two years were administered the questionnaires (detailed below). The RRMC was designed as a one-stop clinic where rural families (living approximately 100 or more kilometers from either Regina or Saskatoon, SK, Canada) are assessed and reassessed by an interdisciplinary team of specialists from neurology, neuropsychology, nursing, physical therapy, and nutrition. In line with best practice guidelines for dementia diagnosis (Morgan et al., 2009), interprofessional assessment data are integrated with recent blood work and a CT head scan for diagnosis. Although data were collected from 99 caregivers of RRMC patients, only 58 persons received a diagnosis of dementia, and which was the sample for Study 1. Table 2.1 provides diagnostic and demographic characteristics of the sample of informal caregivers and persons diagnosed with dementia.

### 2.2.2 Measures

**2.2.2.1 Caregiver Burden.** As part of routine assessment at the RRMC, the Zarit Burden Interview (ZBI) was administered. The questionnaire measures informal caregivers' perception and feelings toward the caring of the care recipient. This scale is widely used and has strong psychometric properties, demonstrating adequate internal consistency (Cronbach's  $\alpha = 0.88 - 0.90$ ), and also predictive validity (Bédard et al., 2001; O'Rourke & Tuokko, 2003).

**2.2.2.2 Identity.** Only one quantitative measure of identity or identity change was found in the literature, likely due to the complex nature of the construct and the various theories as to what identity is comprised of (Cohen-Mansfield et al., 2005). The Self-Identity in Dementia Questionnaire (SIDQ) measured perceived changes in social roles as an indication of identity. Social roles, however, are only one theorized aspect of identity. Out of concern that the SIDQ may have been too focused a measure for the purposes of the current study, and also that administration of the questionnaire would likely have required monitoring and assistance and add to the workload of regular staff, a more general measure of identity was utilized.

Table 2.1

*Sample demographics and characteristics*

Patient Diagnosis	<i>N</i>	%
Alzheimer's disease	37	63.8
Vascular/Mixed dementia	4	6.9
FTD variants	12	20.7
Other dementia/due to medical condition	5	8.6
Total	58	100.0
Patient Gender	<i>N</i>	%
Male	29	50.0
Female	29	50.0
Caregiver Gender	<i>N</i>	%
Male	15	25.9
Female	43	74.1
Caregiver Relationship to Patient	<i>N</i>	%
Wife	22	37.9
Husband	13	22.4
Son	3	5.2
Daughter	17	29.3
Mother	1	1.7
Other Relative	1	1.7
Friend	1	1.7

Table 2.1

*- continued*

	<i>Mean</i>	<i>Min.</i>	<i>Max.</i>	<i>SD</i>
Patient age (yrs.)	73.3	53	87	8.5
Caregiver age (yrs.)	63.1	39	89	12.0
Dementia severity (CDR-SOB)	5.6	1.5	12	2.6
Years since diagnosis	0.3	0	4	0.7
Degree of contact with patient	11.2	2	12	1.9

*Note.* Dementia severity based on CDR-SOB scores (see description in measures) which range from 0 -18 (higher scores indicate greater severity of impairment). Degree of contact based on self-report measure completed by caregivers regarding how often they engage in face-to-face contact and contact via-telephone (scores range from 0 – 12, higher scores indicate more frequent contact). FTD = Frontotemporal Dementia.

For the purpose of this study, measurement of perceived change in identity was initially planned to be achieved through novel use of an Inclusion of Other in the Self scale (IOS; Aron, Aron, & Smollan, 1992). The IOS asks participants to choose from seven pictorial representations of gradating pairs of overlapping circles. These pairs range from completely separate circles (complete difference) to mostly overlapping circles (no difference). In this application, caregiver participants are asked to choose the pair of circles most representative of their perception of the relationship between the care recipient's current self and prior self (i.e., before their difficulties began/pre-dementia onset), in other words the degree in which they perceive the care recipient to be a different person (i.e., changed identity) than who they were pre-morbidly. In addition to the IOS, a rating scale (0 to 6, 0 indicating no difference, 3 medium change, 6 extreme change) was used as an analogous redundancy measure for the IOS. A yes/no close-ended question asked whether or not caregivers perceived their care recipient to be a different person than who they were in the past, prior to the onset of their difficulties.

Unfortunately, the IOS-based perceived change in identity scale proved too complicated for many caregivers to complete without assistance and several caregivers were either unable to comprehend the instructions and did not complete the scale or it was clear they did not understand what was being asked. As such, the rating-scale version for identity change and yes/no question were used in the analyses. Validity of the scale was explored post-hoc. Regarding convergent validity, the rating scale for perceived change in identity showed perfect agreement with the yes/no identity change (i.e., 100 percent of caregivers who endorsed "yes" also endorsed a level of perceived identity change on the rating scale of  $> 0$  ( $n = 54$ ), while those that endorsed "no" endorsed a zero on the scale). Both the identity change rating scale and the SIDQ were administered to the participant caregiver sample of Study 2 ( $n = 40$ ) for cross validation purposes. The correlation between the two measures approached significance (moderate effect size,  $r = .306$ ,  $p = .055$ ) suggesting that they may measure similar but not identical constructs. This makes intuitive sense given that the SIDQ measures change in social roles, one specific aspect/theory of identity, thus making the measure more susceptible to individual variation and an assumedly less sensitive measure of identity change. In contrast, the change in identity rating scale broadly asks caregivers to rate the degree of overall change in identity, as a whole, and thus it is hoped it would be more sensitive to change across the various aspects of identity.



**2.2.2.3 Relationship Quality.** Present quality of the relationship between caregiver and care recipient was measured using the *Burns Relationship Satisfaction Scale* (BRSS, Burns & Sayers, 1988; Burns et al., 1994; Heyman et al., 1993), a self-report measure with good psychometric properties (Burns & Sayers, 1988; Burns et al., 1994; Heyman et al., 1993). The BRSS asks caregiver to rate their level of satisfaction with various facets of their relationship with the person with dementia, including: communication, conflict resolution, affection and caring, intimacy and closeness, respective roles in the relationship, and overall satisfaction. Its appropriateness for use regarding any type of close interpersonal relationship including romantic, familial, and friend relationships is explicitly stated in the documentation and such usage is commonly found in the literature. Pre-morbid quality of relationship between caregiver and care recipient was also assessed using the BRSS, but instructions were modified by asking caregivers to rate relationship satisfaction *prior* to the onset of dementia in care recipient. This modification is consistent with that described by Steadman and colleagues (2007). Given the strong theoretical and demonstrated relationship between intimacy and relationship quality, and in order to minimize task load of caregivers during their visit to the RRMCC, a stand-alone measure of intimacy was not included; instead the intimacy and closeness item from the *Burns Relationship Satisfaction Scale* was used to inform assessment of perceived intimacy and the BRSS total score was used a proximal analogue for intimacy in interpreting the results of the analysis.

**2.2.2.4 Dementia Severity:** The CDR-SOB is an adaptation of the Clinical Dementia Rating (CDR) global scale and is most often used in clinical and research settings for the staging of dementia severity (O'Bryant et al., 2008). Both the global scale score and individual scales have demonstrated adequate reliability and validity (Morris, 1997; Berg, 1988). The CDR consists of clinician assessment of a patients' functioning in six domains, or 'boxes:' memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care (Morris, 1997). Each box is assigned a value between 0 and 3, 0 being least and 3 most impaired, and scores are summed (O'Bryant et al., 2008). Scores range from 0 to 18 with higher scores indicating greater impairment. The CDR-SOB (CDR-Sum of Boxes) has shown to be more sensitive than the traditional CDR to detection of early stage dementia and to changes in severity over time (O'Bryant et al., 2008).

## 2.3 Statistical Procedures

**2.3.1 Objective 1.** The first objective of the study was to determine the degree to which the caregiver currently perceives the person with dementia's identity as changed relative to their premorbid self. Further, it was hypothesized that correlational analysis would reveal this measure of identity would be negatively related to caregiver's perceived level of quality of the caregiver/care recipient relationship, and positively related to caregiver burden.

**2.3.2 Objective 2.** The second primary objective of the study was to establish support for the proposed model of identity and caregiver burden. It was hypothesized that caregivers' perceived level of change in identity of the person with dementia and overall quality of caregiver/care recipient relationship would predict caregiver burden. To address this hypothesis, measured level of identity change (rating scale) and present quality of relationship (total score BRSS) were regressed on perceived caregiver burden (ZBI). Severity of dementia (CDR-SOB), a known predictor of burden, was also included in the analysis. It was hypothesized that all predictors would be statistically significant after being entered in a hierarchical regression analysis, with identity change (entered in Step 2) accounting for a significant proportion of the variance in burden, while controlling for premorbid and current relationship quality and dementia severity (entered in Step 1).

Mediational analysis was used to test the hypothesis that relationship quality would mediate the relation between perceived identity change and burden. A multi-mediational analysis was used to test the hypothesis that intimacy serves as a mediating factor between identity change and relationship quality.

## 2.4 Results

As can be seen in Table 2.1, the mean CDR-SOB scores demonstrate that the sample represented caregivers of persons with relatively early stage dementia. Mean levels of caregiver burden, perceived change in identity of person with dementia, and both premorbid and current quality of relationship are presented in Table 2.2. Overall, the sample of caregivers of persons with dementia's ( $n = 56$  with ZBI data, 2 removed due to incomplete data) mean level of perceived burden fell in the mild to moderate range of burden ( $M = 30.2$ ) according to published interpretation guidelines (Zarit, 1983). Caregivers reported, on average, a medium level of

Table 2.2

*Mean levels of caregiver burden, perceived change in identity of person with dementia, and both premorbid and current quality of relationship*

Measure	<i>n</i>	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
Caregiver Burden (ZBI, scale 0 - 88)	56	30.23	15.94	6.00	71.00
Perceived Identity Change (Rating Scale, 0 - 6)	56	3.71	1.39	.00	6.00
Current Quality of Relationship (BRSS current, scale 0 - 42)	53	25.83	10.52	.00	42.00
Premorbid Quality of Relationship (BRSS premorbid, scale 0 - 42)	54	34.70	7.62	10.00	42.00

*Note.* Higher numbers equal greater levels perceived burden, identity change, and relationship quality, respectively.

perceived change in the person with dementia's identity ( $M = 3.7$ , scale of 0 to 6). Current quality of relationship was on average reported to be in the neutral (neither satisfied nor dissatisfied) to slightly satisfied range ( $M = 25.8$ , scale of 0 to 42), while premorbid (i.e., prior to the diagnosis of dementia) quality of relationship was retroactively rated in the moderately satisfied range, on average ( $M = 34.7$ , scale of 0 to 42). A  $t$ -test revealed this to be a statistically significant difference in the mean level of quality of relationship, current versus premorbid, as perceived by the caregiver ( $t(52) = -6.142, p < .001; d = 0.97$ , "large" effect size (Cohen, 1988).

#### **2.4.1 Exploration of Variable Relationships (Correlational Analysis)**

Table 2.3 presents the full results of the correlational analysis. Perceived level of change in patient identity as perceived by the caregiver was negatively correlated with caregiver age  $r = -.33, p < .05$  and current satisfaction with relationship  $r = -.36, p < .01$ , and was positively correlated with dementia severity  $r = .41, p < .01$  and burden  $r = .55, p < .001$ . Current satisfaction with relationship negatively correlated with dementia severity  $r = -.30, p < .05$  and burden  $r = -.58, p < .001$ , and positively correlated with premorbid relationship  $r = .47, p < .001$ . Notably, time since receipt of the diagnosis ( $r = -.036$ ), amount of contact time ( $r = .15$ ), and both age of the caregiver ( $r = -.196$ ) and the person with dementia ( $r = -.117$ ) were not significantly associated with perceived burden (all  $p$ 's  $> .05$ ).

Interestingly, 96.4% of caregivers of dementia patients ( $n = 56$ ) versus 65% of caregivers of persons without dementia or mild-cognitive impairment ( $n = 20$ ) endorsed a change in their care-partner's identity since the onset of current difficulties. A chi-square analysis determined this to be a statistically significant difference,  $X^2(2, N = 76) = 116.332, p < .001$ . Similarly, caregivers of persons with dementia had a higher mean level of perceived change in identity than caregivers of persons without a dementia diagnosis,  $F(1, 94) = 37.42, p < .001, \omega = .281$ .

#### **2.4.2 Investigation of Model Support**

**2.4.2.1 Hierarchical Regression Analysis.** Results of the hierarchical regression analysis are presented in Table 2.4. Of note, assumptions of a hierarchical regression appeared to be adequately satisfied. The sample size and design ( $n = 58$  with dementia, 49 with complete data), 3 predictors = 16.3 cases/predictor) allowed sufficient power to detect a large effect size (Fields, 2009). Assumption of independent errors was met (Durbin-Watson = 2.070 ( $>1$  and  $<3$ )). No multicollinearity was detected as the highest correlation between predictors was current and

Table 2.3

*Correlational analysis of demographic variables and measured variables of change in perceived identity, premorbid relationship quality, current relationship quality, and perceived caregiver burden.*

	Patient age	Caregiver age	Years since diagnosis	Contact time	Severity (CDR-SOB)	Perceived change in identity	Premorbid relationship quality	Current relationship quality	Perceived caregiver burden
Patient age	1	.10 <i>ns</i>	-.12 <i>ns</i>	-.30 <i>ns</i>	.04 <i>ns</i>	-.06 <i>ns</i>	-.23 <i>ns</i>	.07 <i>ns</i>	-.12 <i>ns</i>
Caregiver age	<i>n</i> = 57	1	.21 <i>ns</i>	.19 <i>ns</i>	-.21 <i>ns</i>	<b>-.33*</b>	-.10 <i>ns</i>	.12 <i>ns</i>	-.20 <i>ns</i>
Years since diagnosis	<i>n</i> = 58	<i>n</i> = 57	1	.15 <i>ns</i>	-.17 <i>ns</i>	-.10 <i>ns</i>	-.08 <i>ns</i>	.07 <i>ns</i>	-.04 <i>ns</i>
Contact time	<i>n</i> = 58	<i>n</i> = 57	<i>n</i> = 56	1	.00 <i>ns</i>	.11 <i>ns</i>	.01 <i>ns</i>	.02 <i>ns</i>	.15 <i>ns</i>
Dementia severity (CDR-SOB)	<i>n</i> = 57	<i>n</i> = 57	<i>n</i> = 58	<i>n</i> = 58	1	<b>.41 **</b>	-.08 <i>ns</i>	<b>-.30*</b>	<b>.39**</b>
Perceived change in identity	<i>n</i> = 56	<i>n</i> = 55	<i>n</i> = 56	<i>n</i> = 56	<i>n</i> = 56	1	.09 <i>ns</i>	<b>-.36**</b>	<b>.55***</b>
Premorbid relationship quality (Burns)	<i>n</i> = 54	<i>n</i> = 53	<i>n</i> = 54	<i>n</i> = 54	<i>n</i> = 54	<i>n</i> = 52	1	<b>.47***</b>	-.23 <i>ns</i>
Current relationship quality (Burns)	<i>n</i> = 53	<i>n</i> = 52	<i>n</i> = 53	<i>n</i> = 53	<i>n</i> = 53	<i>n</i> = 51	<i>n</i> = 53	1	<b>-.58***</b>
Perceived caregiver burden (Zarit)	<i>n</i> = 56	<i>n</i> = 55	<i>n</i> = 56	<i>n</i> = 56	<i>n</i> = 56	<i>n</i> = 54	<i>n</i> = 52	<i>n</i> = 51	1

*Note.* *ns* = not statistically significant ( $p > .05$ ), \* $p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Table 2.4

*Hierarchical Regression Analysis to determine predictive value of dementia severity, current and premorbid measures of perceived quality of relationship, and perceived change in identity of the person with dementia, of perceived caregiver burden.*

	<i>B</i>	SE	Std. Beta
<i>Step 1</i>			
Constant	40.785	9.525	
Dementia severity (CDRSOB)	1.454	.724	.244
Current quality of Relationship	-.765	.205	<b>-.512**</b>
Premorbid quality of Relationship	.027	.260	.014
<i>Step 2</i>			
Constant	31.730	9.357	
Dementia severity (CDRSOB)	.725	.716	.122
Current quality of Relationship	-.530	.207	<b>-.355*</b>
Premorbid quality of Relationship	-.202	.253	-.104
Perceived change in identity	4.132	1.422	<b>2.906**</b>

*Note.* *R-sqr* = .37 for Step 1. *Change in R-sqr* = .101 for Step 2 ( $p < .01$ ).

\*  $p < .05$ , \*\* $p < .01$

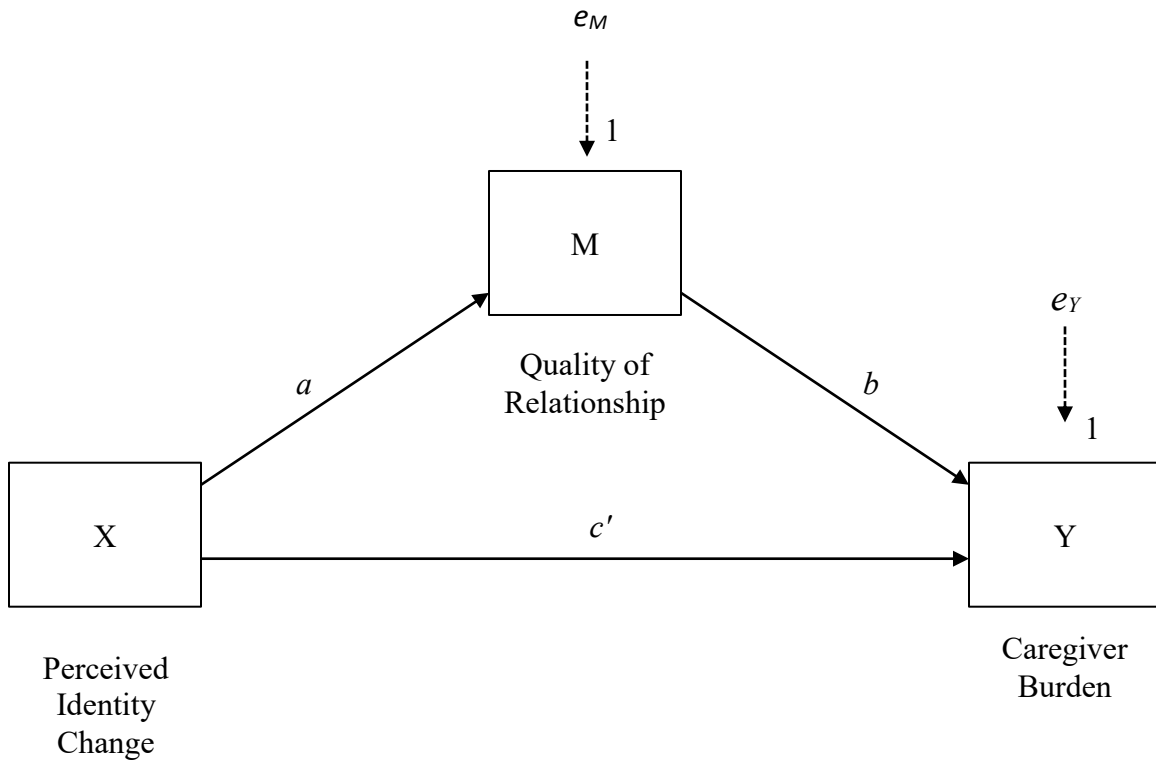
premorbid relationship quality ( $r = .473, p < .001$ ). Thus there is confidence the variables are measuring different constructs. VIF values were all close to 1. Tolerance values were all  $>.20$  and the majority of predictor variance loaded on different dimensions. Outliers were not deemed a problem as  $<.05\%$  of cases had a standard residual greater than two standard deviations from the mean.

Dementia Severity (CDR-SOB) and both Premorbid and Current Relationship Satisfaction (BRSS scales) were entered in Step 1 based on pre-existing literature indicating their respective predictive value of level of caregiver burden. Perceived change in the identity of the person with dementia (identity change scale) was entered in Step 2 as per the hypothesized model. Entering the variables from the first step resulted in a good model fit [ $F(3, 48) = 8.815, p < .001$ ] and accounted for 37% of the variance in Burden. Entering perceived change in patient identity into Step 2 also resulted in a good fit [ $F(4,48) = 9.8, p < .001$ ], and a 10% increase (47.2% total) in the amount of variance of Burden accounted for, representing a statistically significant change over Step 1 at  $p < .01$ . In Step 2, only current relationship satisfaction and identity change remained as significant predictors of burden ( $p < .05$  and  $p < .01$ , respectively). Overall the results of the hierarchical regression analysis appeared to support the proposed model, specifically the role of perceived identity change in the person with dementia in determining caregiver's level of perceived burden.

**2.4.2.2 Mediation Analysis.** Additional analyses were performed to further characterize, statistically, the relationship between the variables (i.e., perceived identity change, perceived level of intimacy, perceived quality of relationship, and perceived level of caregiver burden) as per the proposed model (Figure 2.2). A mediation analysis using the PROCESS program for SPSS (Hayes, 2013) was run and bias-corrected bootstrap confidence intervals were estimated using 10000 bootstrap samples, consistent with recommendations (Hayes, 2013). The bootstrapping and confidence interval method originally proposed by Preacher & Hayes (2006) has several advantages over previous mediational methods (namely Baron & Kenny, 1986), including increased statistical power, decreased probability of a Type 2 error, and no reliance on assumptions of multivariate normality. According to Hayes (2013), determination of power for mediational analysis using bootstrapping methods is still in its infancy, published guidelines for power in mediational analysis (Fritz & MacKinnon, 2007) suggest that the current sample size ( $n = 40$ ) would allow adequate statistical power to detect large effect sizes.

Model coefficients are presented in Table 2.5 and the results indicated that caregivers perceiving more change in the person with dementia's identity, subsequently perceived less quality of their relationship with the person with dementia ( $a = -2.478$ ), and caregivers perceiving less quality of relationship then perceived greater burden ( $b = -0.637$ ). In mediational analysis, the "indirect effect" is of most concern as it represents the predictive path of identity change (X) to relationship quality (M) to burden (Y) illustrated in Figure 2.2. Here, the "indirect effect" ( $ab = 1.578$ ) was statistically significant at a 95% confidence interval (0.4768 to 3.764) and so we can conclude that zero did not fall within the confidence interval and the mediational model is valid. The "direct effect" (identity change (X) to burden (Y);  $c = 4.283$ ) was also significant at a 95% confidence interval (1.732 to 6.834) indicating that perceived change in identity alone, also significantly predicted burden to a degree.





*Figure 2.2.* Simple mediation model of perceived identity change in the person with dementia, perceived current quality of relationship, and caregiver burden.

Table 2.5

*Model coefficients for quality of relationship as a mediator of the relationship between perceived identity change and perceived caregiver burden*

Antecedent		Consequent						
		<i>M</i> (Quality of Relationship)			<i>Y</i> (Burden)			
		Coeff.	<i>SE</i>	<i>p</i>	Coeff.	<i>SE</i>	<i>p</i>	
X (Identity change)	<i>a</i>	-2.478	1.000	< .05	<i>c'</i>	4.283	1.267	<.01
<i>M</i> (Current quality of relationship)					<i>b</i>	-0.637	0.734	< .001
Constant	<i>i</i> <sub>1</sub>	34.593	3.892	< .001	<i>i</i> <sub>2</sub>	31.031	7.594	< .001
		$R^2 = 0.115$ $F(1, 49) = 6.138, p < .05$			$R^2 = 0.450$ $F(2, 49) = 18.813, p < .001$			

**2.4.2.3 Multi-Mediational Analysis.** Building off of the results of the first simple mediational analyses, a second set of data collected from a sample of 40 caregivers (sample demographics and characteristics are presented in Table 2.1 of Study 2, p. 51 ) recruited from the RRMC for Study 2 was used in a multi-mediational analysis. The goal of this part of the study was to further delineate the mechanism (i.e., possible mediating variables) behind the association of perceived change in the person with dementia's identity with perceived caregiver burden. In addition to the same measures used in the previous analysis (i.e., perceived change in identity rating scale, Burns Relationship Satisfaction Scale, and Zarit Burden Interview), this analysis also included a measure of intimacy as a serial mediator variable along with relationship quality, in line with the proposed *theoretical* model of burden (Figure 2.3). Two measurements of intimacy were administered to this second sample; the PAIR (see Appendix F and test description on p. 88) which assesses the closeness aspect of intimacy and also a semantic differential measure (SMD) of the warmth aspect of intimacy (as described in Alea and Bluck (2007; see Appendix G and description on p. 88). Both these measures were highly correlated ( $r = .76, p < .001$ ). Though both closeness and warmth aspects of intimacy were significantly associated with burden ( $r = -.53, p < .001$  and  $r = -.56, p < .001$ , respectively) only the warmth aspect of intimacy (SMD) was significantly correlated with perceived change in identity ( $r = -.35, p < .05$ ). The warmth aspect was thus used in the multi-mediational analysis.

Model coefficients for the multi-mediational analysis are presented in Table 2.6. Overall, the results indicated an insignificant 'indirect effect' of the model ( $abd = .396$ ) at a 95% confidence interval (-.6844 to 2.2154) which included zero and so the multi-mediational model did not appear to have statistically significant support. The 'direct effect' was also statistically

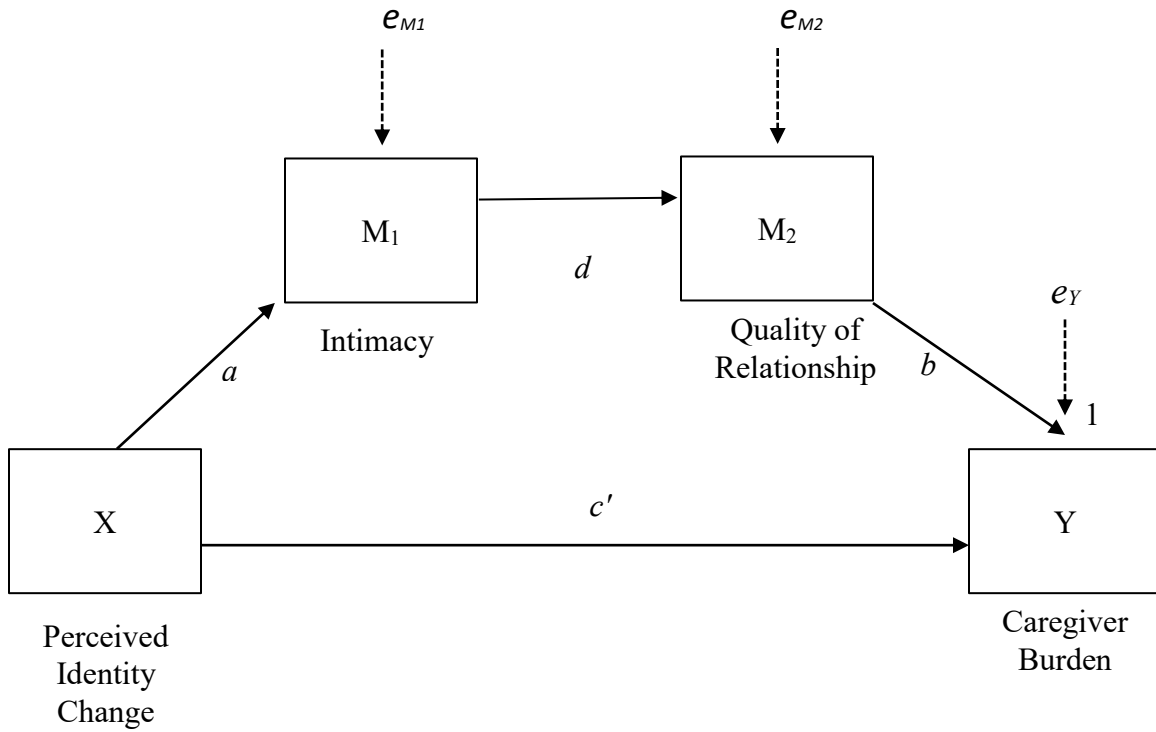


Figure 2.3. Multiple serial-mediation model of identity change, intimacy, quality of relationship, and caregiver burden.

Table 2.6

*Model coefficients for multi-mediational analysis using intimacy and quality of relationship as mediator variables for the relationship between perceived identity change and perceived caregiver burden*

Antecedent	<i>M</i> <sub>1</sub> (Intimacy)			Consequent			<i>Y</i> (Burden)					
	Coeff.	<i>SE</i>	<i>P</i>	<i>M</i> <sub>2</sub> (Quality of Relationship)	<i>SE</i>	<i>P</i>	Coeff.	<i>SE</i>	<i>p</i>			
X(Perceived Ident. change)	<i>a</i> <sub>1</sub>	-4.533	1.964	< .05	<i>a</i> <sub>2</sub>	-0.349	.746	.642	<i>c'</i>	1.838	1.535	.239
<i>M</i> <sub>1</sub> (Intimacy)				<i>D</i>	.410	.058	< .000		<i>b</i> <sub>1</sub>	-.316	.182	.091
<i>M</i> <sub>2</sub> (Quality of relationship)									<i>b</i> <sub>2</sub>	-.213	0.338	.532
Constant	<i>i</i> <sub>m1</sub>	79.023	7.696	< .000	<i>I</i> <sub>m2</sub>	-.1227	5.315	.819	<i>I</i> <sub>y</sub>	54.974	10.920	< .000
		<i>R</i> <sup>2</sup> = 0.123 <i>F</i> (1, 39) = 5.326, <i>p</i> < .05				<i>R</i> <sup>2</sup> = 0.621 <i>F</i> (1, 38) = 39.328, <i>p</i> < .000				<i>R</i> <sup>2</sup> = 0.343 <i>F</i> (3, 37) = 6.272, <i>p</i> < .001		

insignificant (-1.6844 to 4.9518). However, when run individually, intimacy demonstrated a significant ‘indirect effect’ (zero not present within confidence interval).

## **2.5 Discussion**

### **2.5.1 Perceived Identity Change in Dementia**

The first objective of Study 1 was to quantitatively investigate the perception of identity change among informal caregivers of persons diagnosed with dementia. As discussed previously, the perceived change in identity rating scale demonstrated good face validity. It also demonstrated good concurrent validity as it was able to discriminate between caregivers of dementia and non-dementia persons; good convergent validity with the yes/no question and adequate convergent validity with the SDIQ; and also good predictive validity for the a priori hypothesized variables (i.e., dementia severity, quality of relationship, and caregiver burden). Though further validation and reliability of the scale is recommended, based on the available data, it would appear to be a sufficiently valid indicator of perceived general change in identity. Responding to the rating scale, caregiver participants on average perceived a medium level of change in the person with dementia’s identity, consistent with the common theme of loss or change in identity following the diagnosis of dementia found in the literature (e.g., Robinson, Clare, & Evans, 2005; Large & Slinger, 2015). In particular it supports anecdotal observations made by caregivers (e.g., Hayes et al., 2007; Orono, 1990) and the results of the limited quantitative studies of perceived identity change among family caregivers of persons with dementia (Cohen-Mansfield et al., 2006b).

When asked a closed ended question as to whether or not they believed the care recipient to be a different person (i.e., changed identity) in the present compared to before the care recipient’s difficulties began, 96.4% of caregivers of persons who received a dementia diagnosis responded yes, while only 65% of caregivers of persons who were diagnosed with no cognitive impairment endorsed a change in the care recipient’s identity. Similarly, caregivers of persons with dementia reported significantly higher levels of change on the perceived identity change rating scale. That virtually all caregivers of persons receiving a dementia diagnosis endorsed a change in identity may suggest that something specific to the process of dementia has a similar impact on identity across individuals and dementia subtypes. Given that a (statistically) significantly smaller proportion (65%) of caregivers of persons with no cognitive impairment (though they may have presented with considerable mental or physical health problems)

perceived a change in their care partner's identity, the onset and progression of cognitive impairment in dementia may be implicated as a key characteristic of dementia which impacts identity. Nevertheless, this is still a relatively large number and points to the changes that can occur in patterns of behavior and social interaction as a result of other factors outside of dementia and cognitive impairment. The key to this disparity may lie in the fact that cognitive impairment in dementia results from neurodegeneration and can impact upon the individual's behavior and personality which is then perceived by the caregiver. Support for cognitive impairment as being linked to changes to the self and identity in the person with dementia has been fairly well established in the literature (see review by Caddell & Clare, 2010). Less quantitative research attention has been focused on perceptions of these changes by the caregivers, although Cohen-Mansfield and colleagues (2006b) found that higher levels of perceived change by caregivers was associated with greater cognitive impairment in the care recipient and the present.

### **2.5.2 Identity, Intimacy/Relationship Quality, and Burden**

The second objective was to explore the role of informal caregivers' perception of identity change in the person with dementia in influencing perceived burden of caring. The results of the present study found statistically significant negative correlational relationships between perceived identity change and current, but not premorbid, quality of relationship, and caregiver age. Unfortunately, a stand-alone measure of intimacy was not included in this part of the study due to logistic concerns, though a significant negative correlation was found between identity change and the intimacy and closeness item of the Burns Relationship Satisfaction Scale. Additionally, perceived identity change demonstrated a significant positive relationship with dementia severity and burden. The direction and significance of these findings were as expected based on the literature and fit intuitively with the proposed model. Notably, caregiver age showed a significant negative correlation to the perception of identity change; that is, advanced age of the caregiver was associated with less perceived identity change in the person with dementia. It is not immediately clear why this may be the case, but it is potentially an interesting finding worthy of future consideration in the context of identity and normal aging. It is possible that with normal aging a certain degree of identity change is perceived by our loved ones, thus gradually lowering the baseline from which additional changes in identity due to dementia occur and diminishing the extent of the changes perceived. This line of thought would appear to match

theoretical literature about shifting social and familial roles, perceptions of one's own self-efficacy and abilities, etcetera, thought to occur with healthy aging (e.g., Atchley, 1989). Alternatively, or possibly in addition to the above, younger caregivers may be more influenced by social processes such as stigmatization and stereotyping of older adults, and particularly persons with dementia, perceiving greater which may result in emphasizing or exaggerating perceived changes. Possibly related, though not found here, previous studies have demonstrated a negative relationship between caregiver age and perceptions of burden (e.g., Clyburn et al., 2000).

Regarding caregiver burden, the level of perceived burden of caring was positively and significantly linked to dementia severity, but not age, amount of contact with the care recipient, or time since diagnosis. In contrast, a significant negative correlation was found between burden and current relationship quality. These findings are also consistent with the literature (review in van der Lee, 2014) and add support to the well-established findings that perception of burden is largely subjective, and not merely reflective of the more quantifiable measures of the caregiver role (e.g., the amount of time spent caring). Subjectivity may suggest malleability of the perception/experience of burden. Therefore, studies such as the present one, seeking to identify factors that may influence this subjective perception and establish theoretical models of interaction are important in order to increase understanding of caregiver burden and guide thought, research, and development of interventions.

Additionally, there was a notable difference in the perceived premorbid versus current mean levels of relationship quality, with premorbid levels generally perceived as higher than current. This difference in means was shown to be statistically significant and is consistent with previous literature (Blieszner & Shifflett, 1990; Morris et al., 1988b) demonstrating a similar association between dementia and perceived relationship quality, further highlighting this degenerative process' potential impact on multiple spheres of function including interpersonal.

### **2.5.3 Identity as a Predictor of Burden**

The results of the hierarchical regression analysis demonstrated that perceived change in identity accounted for a significant and unique amount of the variance (10%) of caregiver burden even after controlling for severity of dementia, premorbid relationship quality, and current relationship quality. Interestingly, only current relationship quality and perceived identity change, and neither dementia severity or premorbid relationship quality, were found to be



significant predictors when all variables were included in the analysis, further pointing to the relative importance of identity as a predictive factor of caregiver burden in comparison to factors previously established in the literature to be associated with burden. The relative importance of perceived identity change and its impact on the social context of both caregivers and individuals with dementia, is further testament to the validity of a biopsychosocial model.

These results are important as they are in line with the study hypotheses and support the proposed model of burden (2.1). Though quality of relationship has been previously linked to burden in the literature, the results of the present study demonstrate first evidence supportive of the *theorized* relationship between perceived identity change and caregiver burden in dementia, highlighting a need for further consideration of identity as one possible factor influencing the perception of burden and informing future research and psychosocial intervention development. One area potentially worthy of attention and would appear to be informed by the results of the current study, is differences in approaches to caregiving/coping described by Ablit and colleagues (2009) which identified patterns of how caregivers interpret the changes in their loved one with dementia, their subsequent efforts to either maintain or detach from their emotional connection between them, and ultimately caregivers' ability to cope with the caring role. This would appear quite compatible with the model presented here and working toward integration of these works may lead to a method of reliably identifying caregiving style and predicting caregiver outcomes, both in general and in response to interventions such as reminiscence therapy.

#### **2.5.4 Support for a Mediational Model of Identity, Intimacy/Quality of Relationship, and Burden**

The results of mediational analyses further provided support for the proposed model: current quality of the relationship between caregiver and person with dementia (as perceived by the caregiver) mediated the relation between perceived identity change and variance in caregiver burden. Specifically, the mediational model elucidated significant predictive linkages between identity change and relationship quality, and subsequently between relationship quality and caregiver burden. To illustrate, the results support a model in which an incremental increase in the degree of change in the identity of the person with dementia reported by the caregiver, predicts a significant decrease in perceived quality of the relationship. In turn, an incremental

decrease in relationship quality predicts a significant increase in the level of caregiver burden reported.

Notably, the results of a multi-mediational analysis of data from a second sample of caregivers which included a measurement of intimacy as a serial mediator between identity change and quality of relationship, and ultimately caregiver burden, was not supported. This finding, though possibly due to study limitations (discussed below) is counterintuitive to the study hypothesis that perceived identity saliency increases or decreases affect intimacy, also suggested by theoretical and experimental research purporting that intimacy is linked to and alterable via reminiscence (Alea & Bluck, 2007). Reminiscence is believed to have both an identity and, seemingly subsequent, intimacy restoration and/or maintenance function.

Despite the lack of statistical support for the multi-mediational model, several limitations were apparent that increased the probability of a Type II error. First, though according to Hayes (2013) determination of power for mediational analysis using bootstrapping methods is still in its infancy, published guidelines for power in mediational analysis (Fritz & MacKinnon, 2007) suggest that the current sample size ( $n = 40$ ) would allow statistical power sufficient to detect only a very large effect size. Additionally, an expected high correlational relationship between the measures of intimacy and quality of relationship ( $r = .79$ ) was detected. This was possibly due to the presence of items in the quality of relationship measure relating specifically to intimacy and emotional closeness, but given that emotional closeness is such a fundamental part of relationships it is likely that any measure of relationship quality would have delivered similar results. Multicollinearity between mediator variables can cause erratic variations during analysis, thus impeding the ability to determine the role of intimacy as an independent mediator. This further suggests the possibility of a Type II error and that the limitations of the analyses, rather than a lack of validity of the model, may have caused the insignificant results. As such, despite these results, intimacy should still be viewed, at least from a theoretical standpoint, as a potentially important factor in the relationship between perceived identity change in the person with dementia and caregiver burden. Practically speaking, and for the sake of simplicity, given the intuitively close link between intimacy and quality of relationship it may be useful to equate the two factors, using the more encompassing factor of quality of relationship for future formulations involving identity. Nevertheless, it may be beneficial to include both factors in future research involving significantly larger sample sizes in an attempt to overcome the

statistical limitations of the present study. further suggests the possibility of a Type II error and that the limitations of the analyses, rather than a lack of validity of the model, may have caused the insignificant results. As such, despite these results, intimacy should still be viewed, at least from a theoretical standpoint, as a potentially important factor in the mechanism of identity change in dementia's impact on caregiver burden. Practically speaking and for the sake of simplicity, given the intuitively close link between intimacy and quality of relationship it may be useful to equate the two factors, using the more encompassing factor of quality of relationship for future formulations involving identity. Nevertheless, it may be beneficial to include both factors in future research involving significantly larger sample sizes in an attempt to overcome the statistical limitations of the present study.

There was a strong possibility that multicollinearity between mediator variables may have interfered with the analysis. As intimacy is an important component of quality of relationship, it makes sense that they would be highly correlated.

### **2.5.5 Reminiscence Therapy**

As the present study provides first evidence of the proposed model of identity change and caregiver burden, it similarly provides a theoretical basis and support for the potential benefits of Reminiscence Therapy for informal caregivers of persons with dementia. As such, the proposed model may serve to elucidate the mechanism of the anticipated therapeutic change, and allow an informed interpretation of the results, of future studies of Reminiscence Therapy efficacy.

In the past, Reminiscence Therapy has been demonstrated to be an effective quality of life intervention for persons with dementia (see review by Woods et al., 2005), and there is limited and equivocal evidence of benefits for caregivers (Charlesworth et al., 2011; Woods et al., 2005; Woods et al., 2012). There is, however, a paucity of data on Reminiscence Therapy for caregivers and most studies examine the same intensive and structured group dyadic reminiscence program, and generally do not provide theoretical discussion as to its efficacy or lack thereof. Given the support for the role of perceived identity change in predicting caregiver outcomes presented here which supports the theoretical understanding of reminiscence as natural method of identity and intimacy maintenance and restoration, Reminiscence Therapy would appear to have strong potential as a caregiver intervention. As such, that major randomized control trials of Reminiscence Therapy (i.e., Woods et al., 2012) have failed to demonstrate positive effect for caregivers may have more to do with characteristics of the specific format of

Reminiscence Therapy used, such as time commitment, duration of program, group format, dyadic format, etcetera that may have negated the therapeutic benefit. The importance of format may further be evidenced by Alea and Bluck's (2007) demonstration of the effectiveness of a relatively basic single-session reminiscence activity in improving intimacy in healthy older adult couples.

### **2.5.6 Limitations**

The results of Study 1, while representing both interesting and important evidence for the *potential* role of identity change in the influencing of caregiver outcomes, are not without limitations. First, the sample sizes were relatively small and represented caregivers of persons with generally early stage/mild to moderate dementia severity. As such, the results may not be generalizable to caregivers of persons in more progressed stages of dementia with more severe impairments. However, it may be a telling sign that even during the less severe stages of dementia, changes in identity are perceived and predict quality of the relationship and the subjective perception of burden. Given the theorized and demonstrated relationship between cognitive impairment/dementia severity and identity change, caregivers of persons in the later stages of dementia would be expected to perceive even greater change in identity and ultimately greater levels of burden as a result. That said, given the limitations of the design (i.e., no random selection or temporal separation) any inference of causation must be cautious as the potential for a bi-directional relationship between these variables exists.

Additionally, although other known predictors of burden were included in the study, several potential predictors and/or moderating variables (e.g., caregiver gender, coping style, diagnosis type, etc.) were not included in the current study's analyses and so the proposed model, though supported by the results, should not be deemed a comprehensive model, nor should identity change be seen as the most important predictor. Rather, identity change and the proposed model, should be viewed as one *possible* factor for and mechanism of the complex and multifactorial causation of perceived caregiver burden. Future studies should aspire to examine more comprehensive models of identity and burden through use of larger representative samples of informal caregivers. That 12 of the 58 caregivers from the sample were caring for persons with a diagnosis of FTD may have impacted the results given that more severe behavioural and personality changes tend to be prevalent among persons with FTD and caregivers tend to report greater burden. However, that 96.5 percent of caregivers reported a perception of change in

identity may suggest that perceived identity change is a consistent feature irrespective of diagnosis. Regardless, future studies should aim to control for a greater number of variables, including diagnosis subtype.

A final and important limitation of the study has to do with the measurement of identity change. Given the lack of a previously validated general measure of identity change as related to dementia, it cannot be stated with absolute confidence that the measure employed in this study has actually captured the intended construct. As mentioned, however, there were some promising indications that the question and corresponding rating scale utilized here was a sufficiently valid measure of perceived identity change. First, it appeared to have good face validity and there was little report of confusion in what the question was referring to by participants. Second, there appeared to be at least adequate concurrent validity. It was positively correlated with a more narrow and specific measure of social role identity change in persons with dementia (SIDQ; Cohen-Mansfield et al., 2006b), utilized in another sample of caregivers ( $n = 40$ ), at a possible moderate effect size approaching significance ( $r = .306, p = .055$ ) and 100% of those stating “yes” in response to a question regarding change in identity also indicated a level of change on the rating scale. Additionally, it appeared to demonstrate good discriminative validity between caregivers of those with dementia and those without. Finally, that the results of the current study demonstrated statistically significant evidence of a role for perceived identity change in the determination of caregiver burden, in line with the a priori theorized model and subsequently generated hypotheses, suggests that the perception of identity change may have been, at least sufficiently, captured by the tool used. Nevertheless, further validation and development of measurement tools are necessary to lend support for the results of future studies examining perceived identity change in persons with dementia.

## **2.6 Conclusion**

Consistent with the study hypotheses, the results of Study 1 presented strong evidence of caregiver’s perception of identity change in the care-partner with dementia as a predictor of caregiver burden and a potential target for interventions aimed reducing burden. A mediational model of perceived identity change, intimacy/quality of relationship, and burden was also supported. The demonstrated model provides an empirically supported theoretical framework for guiding potential research and development of future interventions.

### **Chapter Linkage One**

The results of Study 1 identified informal caregiver's perceived change in identity of the person with dementia as an important predictor of caregiver burden and thus revealing it to be a possible target for psychosocial intervention. Building from these findings, Study 2 was guided by the theoretical mediational model of identity, intimacy/quality of relationship, and burden presented and supported in Study 1, in an evaluation of the efficacy of a reminiscence activity in providing benefit to caregivers.

In line with the Study 1 model, Study 2 provides data on the efficacy of reminiscence to increase the perceived saliency of the person with dementia's premorbid identity and the expected resultant increases in perceived level of intimacy and quality of relationship, and decrease in the perception of burden. It also examines caregivers' responses and comments regarding their experience of both natural reminiscence in daily life and also the facilitated reminiscence activity of Study 2.

To accomplish the above, Study 2 utilized random assignment of a sample of rural and remote dwelling informal caregivers into control and reminiscence activity groups. Given the geographical restrictions of this population, both in-person and Telehealth videoconferencing delivery modalities were used, also determined via random assignment. Target variable data was collected at pre and post activity and then analyzed statistically for significant change. The results of the study are presented and their significance and implications are discussed in the context of the broader literature on identity, reminiscence, and caring for persons with dementia.

## **CHAPTER 3: Study 2**

### **Evaluation of a Reminiscence Activity for Geographically Restricted Caregivers of Persons with Dementia**

#### **3.1 Introduction**

The biopsychosocial model of dementia highlights the importance of the social context on an individual's experience of the disease (e.g., Kitwood & Bredin, 1992; Spector & Orrel, 2010; Sabat, 2001; Clare, 2008). The relationship between the person with dementia and their informal caregiver (typically a family member or close friend) is an integral part of this context. Despite there being potentially positive aspects to caring (see review by Hunt, 2003), caregivers tend to experience diminished physical and mental health, or what has been labelled *caregiver burden*, associated with the role (e.g., Alspaugh et al., 1999; Clyburn, 2000; Gaugler et al., 2000; Gonyea et al., 2005; McConaghy & Caltabiano, 2005; Wright et al., 2010). This tendency for caregivers of persons with dementia to experience negative outcomes is a significant contributor to the tremendous financial and social impact of the disease (ASC, 2010), resulting in calls for interventions aimed at improving outcomes for caregivers. Evidence-based interventions aimed at caregivers, together with additional supports, are projected to result in a cumulative economic benefit of 12 billion by the year 2038 (Alzheimer Society of Canada, 2010), in addition to the amelioration of untold human costs. In order to maximize their impact, interventions aimed at persons with dementia and their caregivers must be made accessible to those in need regardless of geographic location. This includes those in rural and remote areas of Canada who have limited access to specialized health services, despite the growing proportion of older adults living in these areas (Stats Canada, 2010) who are at greater risk of developing dementia (advancing age is the largest risk factor for dementia; Alzheimer Society of Canada, 2010).

Given the stresses of caring and the changes and decline in functionality that occur in the individual with dementia, it is not surprising that the quality of the relationship, including the emotional connection (intimacy) between the two individuals, tends to suffer after onset of the disease (e.g., de Vugt et al., 2003; Morris et al., 1988a; Blieszner & Schifflett, 1990). Both the perceived quality of the relationship and intimacy have been linked to negative caregiver outcomes, including perceived caregiver burden (Morris et al., 1988a; Blieszner & Schifflett, 1990; Lyons et al., 2007). Reminiscence Therapy, an empirically supported and commonly used quality of life intervention for persons with dementia (Baillon et al., 2004; Chiang et al., 2010; Chung, 2009; Woods et al., 2005), has been suggested as having potential therapeutic benefits for caregivers as well (Charlesworth et al., 2011; Woods et al., 2005; Woods et al., 2009).

### **3.1.1 Reminiscence Therapy**

Reminiscence Therapy (Reminiscence) is a therapeutic method involving facilitated recall of personal memories (Woods et al., 2009). It is widely used for persons with dementia, especially in Europe, (Gibson, 2004; Charlesworth et al. 2011; Woods et al., 2005; Woods et al., 2009) and has shown to provide several benefits such as improved mood, lowered heart rate, less depressive symptoms, and improved quality of life (Baillon et al., 2004; Chiang et al., 2010; Chung, 2009; Woods et al., 2005). Recently, Reminiscence Therapy programs involving both the informal caregiver and care recipient have grown in popularity due to anecdotal reports that they may improve the caregiver/care recipient relationship, resulting in mutual benefits for both individuals (Woods et al., 2009). Such a dyadic approach is in line with calls for recognition of the importance of the immediate social interactional environment of the person with dementia (O'Connor et al., 2007), as well as findings associating the quality of the caregiver/care recipient relationship with caregiver burden (Campbell et al., 2008; Fitzpatrick & Vacha-Haase, 2010; Iecovich, 2011; Snyder, 2000) and desire to institutionalize (Winter et al., 2011). Nevertheless, the theoretical basis for how Reminiscence Therapy might influence relationship quality in the context of dementia has not been studied.

One reason for Reminiscence Therapy's potential to improve relationships may be its association with identity and intimacy. Reminiscence and autobiographical memory theorists posit both identity development and maintenance, as well as intimacy maintenance, as primary functions of the act of reminiscing (Alea & Bluck, 2007; Webster, 2005; Westhof et al., 2010). In the empirical literature, the recall of positive memories of events shared by two healthy people



has been shown to improve the perceived intimacy in the relationship (Alea & Bluck, 2007). The identity and intimacy functions of reminiscing are perhaps key to the potential benefits of Reminiscence Therapy for caregivers. The impact of dementia on intimacy and the quality of the caregiver and person with dementia relationship have already been mentioned. Further, changes in identity of both caregivers and persons with dementia after dementia onset have been shown to be important predictors of negative outcomes for both caregivers and care recipients (Hayes et al., 2007; Orono, 1990), predictors of declines for the caregiver/care recipient relationship (Hayes et al., 2009; Cohen & Eisdorfer, 1986; McGowin, 1993; Cohen-Mansfield et al., 2006; Herskovits, 1995).

**3.1.1.1 Reminiscence Therapy for Caregivers.** Despite the apparent potential for Reminiscence Therapy's use with caregivers, no intervention protocols have been developed specifically for use with caregivers. The efficacy for caregivers of dyadic Reminiscence Therapy protocols initially intended to benefit the person with dementia, has received limited but growing attention in the literature. Small trials of a structured and relatively intensive dyadic Reminiscence Therapy program with established efficacy for the person with dementia, demonstrated benefits for the caregiver such as a reduction in stress and increased quality of life (Thorgrimsen, Schweitzer & Orrell, 2002), and also reduced depressive symptoms (Woods et al., 2005). Despite these encouraging results, the only large scale randomly controlled trial of the same program which included outcome measures for caregivers, found no quantitative indicators of benefit for caregivers relative to controls; in fact, caregivers who received the intervention reported a greater level of anxiety (Woods et al., 2013). The cause for the increased anxiety is not clear, as self-report feedback indicated the program was perceived positively by the caregivers. The Reminiscence Therapy program used in these studies involved both caregiver and person with dementia to travel to a designated meeting centre once a week, for 12 consecutive weeks, to participate in structured two-hour group dyadic Reminiscence Therapy sessions (Woods et al., 2012). Qualitative data from the same large trial, however, identified themes in caregiver responses indicating that the time commitment and lack of respite may indeed have affected their experience of the program (Melunsky et al., 2015) as well as some ambiguity regarding the benefit of the group and dyadic format and also the highlighting of change or loss in their loved one by the reminiscence itself. Reportedly, the group format may have caused feelings of insecurity and inapplicability for some caregivers, and the presence of

the care-partner may have induced feelings of guilt. Thus it is possible that the time commitment, disruption to established routines, travel requirements and other factors related to attending the regular sessions were a source of increased stress and anxiety for caregivers and attenuated any positive benefit from the intervention program. Additionally, given the group setting, level of participation may have varied across caregivers which possibly resulted in a diluted experience. Finally, potential modifying variables, such as premorbid relationship quality, and caregiving relationship style, may have influenced the efficacy of the program, but data on these variables were not collected. Poorer quality of the premorbid relationship is associated with lower levels of intimacy and poorer caregiver outcomes (Morris et al., 1988a; Williamson & Schulz, 1990; Kramer, 1993; Morris et al., 1988b), while it is theorized that some caregivers, especially those with a detached relationship style of caregiving, may find any increase in intimacy due to Reminiscence Therapy distressing (Chesla et al., 1994).

Given the limited amount, and equivocal results, of literature regarding Reminiscence Therapy for caregivers with persons of dementia, as well as an absence of guiding theory in these previous studies as to the mechanism of any potential therapeutic benefit, the present study aims to evaluate the efficacy of a basic Reminiscence based activity for caregivers of persons with dementia. In line with reminiscence literature, the present study is guided by theory positing an identity and intimacy maintenance function of reminiscence in humans (Alea & Bluck, 2007; Webster, 2005; Westhof et al., 2010). Specifically, we propose a novel hypothesis that priming the saliency of the person with dementia's pre-dementia identity as perceived by the caregiver, can be achieved via a reminiscence activity involving the facilitated recall of positive memories of a past event from a time when this identity was still intact. This increased saliency of the person with dementia's prior self, or increased identification in the present as the person which the caregiver previously knew (i.e., father, husband, sibling, etc.), may help restore/enhance the emotional connection (intimacy) within the caregiver/care recipient relationship, and consequently decrease perceived caregiver burden. The results of Study 1 identified perceived identity change as a significant predictor of caregiver burden. Mediation analyses further supported the theorized predictive model of identity change on quality of relationship (and possibly intimacy) mediating perception of burden. Using this supported theoretical model from Study 1, it follows that an intervention such as reminiscence aimed at decreasing the caregiver's level of perceived identity change in the person with dementia, would then restore or increase the

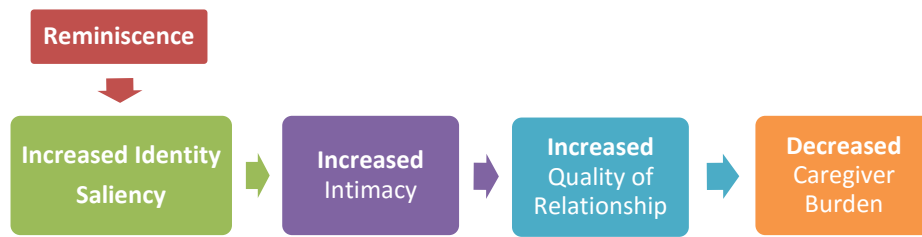
sense of emotional connection (intimacy), which would in turn improve perceived quality of the relationship, and then decrease the level of burden perceived and improve caregiver outcomes (see Figure 3.1).

Using the empirically supported model from Study 1 as a guiding theoretical framework for evaluating the Reminiscence activity's efficacy, or lack thereof, will provide valuable insight into the underpinnings of the Reminiscence activity's therapeutic mechanism. Further, use of a basic Reminiscence activity in a single individual session format with only the caregiver, as opposed to structured, lengthy, and intensive dyadic group Reminiscence Therapy programs utilized in previous studies (e.g., Woods et al., 2012). This should control for potential confounding factors that may mitigate Reminiscence activity's efficacy and establish whether Reminiscence, in its base form, has benefit for caregivers of persons with dementia. As such, the results of the present study will be a valuable contribution to the literature on Reminiscence Therapy and inform future development of theory driven interventions for caregivers.

### **3.1.2 Telehealth Videoconferencing**

Access to health services can be improved via effective use of technology, especially for those living in rural and remote communities (e.g., Morgan et al., 2010). Rural memory clinic patients using Telehealth video-conferencing for screening and follow-up interviews reported that the service was significantly more convenient than similar in-person service, and also reported an average reduction in travel of 462 km per round trip (Morgan et al., 2010). Videoconferencing has also been shown to be useful for group support interventions (O'Connell et al., 2014). Other emerging data suggest that mental health services provided through telecommunications, including videoconferencing, can be as effective as in-person delivery (Greene et al., 2010; O'Reilly et al., 2007). These findings give limited, yet encouraging support for the use of videoconferencing for health service delivery in general.

In general, the literature on videoconferencing as a medium for psychosocial intervention delivery, though limited, suggests that the therapeutic benefit is largely retained (Jermone & Zaylor, 2000; Perle et al., 2011; Richardson et al., 2009; Perle et al., 2011) and that users are highly satisfied with the services received (Morgan et al., 2011; O'Connell et al., 2013; Richardson, Frueh, Grubaugh, Egede, & Elhai, 2009). Only a small number of studies have specifically looked at Reminiscence Therapy via videoconferencing. These tended to be pilot studies aimed at assessing the efficacy of individual Reminiscence Therapy over



*Figure 3.1.* Model of the expected mechanism of efficacy of reminiscence in decreasing perceived caregiver burden.

videoconferencing for persons with dementia (see reviews by Subramaniam & Woods, 2010; Kuwahara et al., 2006) and offer evidence that the therapeutic properties of Reminiscence Therapy translate to delivery over technological mediums. No studies were located examining Reminiscence via videoconferencing for caregivers of persons with dementia. Thus, an additional aim of the present study, is to evaluate whether the potential therapeutic benefit of a Reminiscence activity for rural dwelling caregivers of persons with dementia is translatable to remote delivery via videoconferencing; thus contributing to this important and emerging area of research.

### **3.2 Methodology**

#### **3.2.1 Participants**

Forty informal caregivers of persons diagnosed with dementia were recruited from the University of Saskatchewan Rural and Remote Memory Clinic (RRMC) active (defined as contact with diagnosed patients and their caregivers within the previous two years) patient database to participate in a single session reminiscence activity and agreed to participate in the study. The RRMC was designed as a one-stop clinic where rural families (living approximately 100 or more km from either Regina or Saskatoon, SK, Canada) are assessed and reassessed by an interdisciplinary team of specialists from neurology, neuropsychology, nursing, physical therapy (Morgan et al., 2009), and, more recently, nutrition. In line with best practice guidelines for dementia diagnosis (Gauthier et al., 2012), assessment data is integrated with recent blood work and a CT head scan and a diagnosis is determined (Morgan et al., 2009). Caregivers of RRMC patients who had received a diagnosis of dementia, regardless of relationship, were invited to participate. Based on the design and results of Alea and Bluck's (2007) study showing a relatively large effect size of the reminiscence activity on intimacy, combined with the method of analyses selected for the present study (described below), it was estimated that 40 participants (10 per condition) would provide sufficient statistical power to detect a significant effect size. Table 3.1 provides diagnostic and demographic characteristics of the caregiver and person with dementia sample ( $n = 40$ ).

Table 3.1

*Sample demographics and characteristics for Study 2*

Patient Diagnosis	<i>n</i>	%
Alzheimer's disease	28	70.0
Vascular/Mixed dementia	2	5.0
Frontal-Temporal dementia	7	17.5
Other dementia/due to medical condition	3	7.5
Total	40	100.0
Caregiver Gender	<i>N</i>	%
Male	10	25.0
Female	30	75.0
Patient Gender	<i>N</i>	%
Male	21	52.5
Female	19	47.5
Caregiver Relationship to Patient	<i>N</i>	%
Wife	19	47.5
Husband	6	15.0
Son	4	10.0
Daughter	10	25.0
Mother	1	2.5

Table 3.1

*-continued*

	<i>Mean (n)</i>	<i>Min.</i>	<i>Max.</i>	<i>SD</i>
Patient age (yrs.)	75.6 (40)	55	89	9.6
Caregiver age (yrs.)	64.7 (27)	45	90	12.8
Dementia severity (CDRSOB)	5.2 (35)	2.5	15	2.8
Years since diagnosis	2.0 (37)	0	7	2.3
Degree of contact with patient	11.3 (34)	3	12	1.9

*Note.* Dementia severity based on CDR-SOB scores (see description in Study 1 measures, p. 54) which range from 0 -18 (higher scores indicate greater severity of impairment). Degree of contact based on self-report measure completed by caregivers regarding how often they engage in face-to-face contact and contact via-telephone (scores range from 0 – 12, higher scores indicate more frequent contact).

### 3.2.2 Procedure

The experiment procedure was adapted from that of Alea and Bluck (2007)'s study. Participant caregivers were randomly assigned across four groups once they agreed to participate: the in-person reminiscence activity group ( $n = 10$ ), and control vignette group ( $n = 10$ ), and the Telehealth reminiscence activity group ( $n = 10$ ) and control vignette group ( $n = 10$ ), via a predetermined randomized sequence. This procedure for random assignment was assumed to control for confounds such as selection bias, sub-type and severity of dementia of the care recipient, and characteristics of the caregiver/care recipient relationship. Collection of data from both in-person and Telehealth videoconferencing group participants took place concurrently over the course of approximately one year.

**3.2.2.1 In-person Delivery.** The reminiscence activity administered to the experimental groups consisted of the reminiscence/autobiographical memory activity used by Alea and Bluck (2007), and the protocol for the control condition was also borrowed from their study. Alea and Bluck attempted to create as close to a real-life experience of sharing memories as possible, where memories were shared in a relaxed environment with a listener that appeared engaged. Thus, for the in-person groups an interviewer travelled to the caregiver's home (min. roundtrip distance travelled was 200 km, the max. was 698 km) to meet with each caregiver. Regardless of assigned experimental condition, each caregiver first completed the pre-intervention measures, they were then asked to recall two events from their past. Caregivers in the experimental conditions were asked to recall two positive memories involving the care recipient prior to their onset of difficulties with dementia, while control caregivers were presented with orally presented with two vignettes depicting positive memories between two people. For each memory they were given a contextual suggestion (e.g., a vacation/day-trip or a romantic experience/enjoyable time spent with the other person). Each participant received 2 minutes to think about the memory and then 10 minutes to relay the details of the memory to the interviewer. Throughout the discussion of the memory by the participant, the interviewer provided non-verbal feedback demonstrating interest and engagement (facial expressions). Standard verbal prompts (i.e., what, when, where, who, how-type questions) were used to promote a detailed telling of the memory. This same procedure was used again for the second memory. After both memories were discussed, the post measures were administered. Instructions for the post measures stressed that the participants answer according to how they felt at that precise moment following the recall of the memories,



regardless of how they answered during the pre-measurement. Sessions generally took approximately 60 minutes to complete. Interestingly, it was soon realized that when visiting rural caregivers from the in-person groups in their homes, the interviewer was often offered food and beverage. In order to control for potential confounds between the Telehealth and in-person conditions, any offer of food or beverage was politely declined. Additionally, in-person group caregivers often initiated a fair amount of small talk and at times asked questions or told anecdotal narratives related to their experiences as a caregiver. In order to counter this potential confound, a maximum of 15 minutes of non-study related discussion was allowed for both in-person and Telehealth groups.

After the initial session, each participant caregiver was to be contacted approximately two weeks after the session via telephone and follow-up measures were to be administered orally. Despite hope that attrition during the follow-up segment of the study would be minimal, complete follow-up data from only 26/40 participants was able to be collected during the targeted time-frame. Follow-up data were, therefore, not used in the Study 2 analyses.

The control groups followed the same procedure as the experimental groups described above. However, instead of being asked to discuss two personal memories, caregivers listened to two standard vignettes read by the interviewer, both describing a fictional couple/pair's positive memories of a vacation and a romantic/enjoyable time. This specific control group is active in that it equates the time with the interviewer with the reminiscence activity group. Moreover, it also involves recollection of positive memories. It critically differs though in the personal saliency of these memories, and recall of these autobiographic memories (though not their own) has potential implications for the hypothesized influences of intimacy and identity.

**3.2.2.2 Telehealth Videoconferencing Delivery.** Participants assigned to the Telehealth intervention and control groups were asked to attend their local health service centre equipped with a dedicated Telehealth Saskatchewan videoconferencing room and connection. There are more than 200 such locations across Saskatchewan. Telehealth Saskatchewan uses a closed secure network that is highly protected against unauthorized attempts to access patient information and thus able to maintain a high standard of patient confidentiality. Videoconferencing sessions were conducted in the Telehealth suite at the Royal University Hospital in Saskatoon, SK, Canada the result of in-kind support from Telehealth Saskatchewan which has partnered with the RRMC and is interested in increasing Telehealth-based intervention work.

The facilitator/interviewer and the participant caregiver were linked on screen via real-time video and audio. Both interviewer and participant were alone in private rooms at their respective sites without distraction, though the layout of the rooms varied across sites. The videoconferencing experimental and control conditions followed the same reminiscence activity and control (vignette) procedure described for the corresponding in-person groups. Participants in the videoconferencing condition were asked to read their answers to measure items aloud and these were transcribed by the interviewer.

### **3.2.3 Measurement**

Perceived identity, intimacy, perceived quality of the both the current and premorbid caregiver/care recipient relationship, and caregiver burden, were assessed and measures were administered at pre-intervention, post-intervention and at two week follow-up. Identical measures and schedule were used for the control condition. To control for potential influence of severity of dementia on intervention outcomes, the care recipient's dementia severity was determined according to their Clinical Dementia Rating Scale - sums of box scores (CDR-SOB), recorded during their most recent assessment at the RRMC.

**3.2.3.1 Caregiver Burden.** Participant caregivers' perceived level of burden associated with caregiving was assessed using the Zarit Burden Interview (ZBI). The 22-item questionnaire measures informal caregivers' perception and feelings toward the caring of the care recipient. The ZBI and its short form have demonstrated strong psychometric properties, including adequate internal consistency (Cronbach's  $\alpha = 0.88 - 0.94$ ), and predictive validity (Bédard et al., 2001; O'Rourke & Wenaus, 1998; O'Rourke & Tuokko, 2003).

**3.2.3.2 Identity.** Measurement of perceived change in identity of the person with dementia by the caregiver was achieved using the same rating scale and corresponding question used and described in Study 1 (p. 49). As described in Study 1, the scale proved to have good convergent, concurrent, and predictive validity.

For cross-validation purposes (previously reported in Study 1), the only measure of perceived identity change found in the literature was also administered and included in the analyses. The Self-Identity in Dementia Questionnaire (SIDQ) was used by Cohen-Mansfield and colleagues (2006b). Based on a social-role theory (i.e., social constructionist/non-essentialist) of identity and self, it aims to assess change across four social role domains including familial, occupational, and recreational roles, as well as character attributes.

Participants are asked to identify one role or attribute for each of the four domains and then rate on a rating scale (1/"not at all" to 5/"very important") how important a particular role was to them in the past and then to rate how important it is to them in the present. For the purposes of this study differences between past and present ratings were summed for a total score indicative of general perception of identity change.

**3.2.3.3 Intimacy.** The caregivers' perceived level of intimacy with the persons with dementia was measured using the same measures as Alea and Bluck (2007). The Semantic Differential scale of relationship warmth (SMD) was designed by Alea and Bluck (2007) and derived from the semantic differential scale described in Osgood, Suci, and Tennenbaum (1957). Alea and Bluck's (2007) SMD showed good reliability (Cronbach's alpha = 0.95 at pre-intervention and 0.97 post-intervention) and demonstrated sensitivity to subtle change, recording a large effect size in their study of the same reminiscence activity proposed for use in the present study. The SMD measures relationship warmth through the use of fifteen adjective-pairs listed as oppositions (e.g., lonely–satisfied) and placed at the opposing ends of a 7-point rating scale. The participants are then asked to rate how they currently feel about their relationship with the person with dementia.

A second measure of intimacy, the *Personal Assessment of Intimacy in Relationships* (PAIR; Schaefer & Olson, 1981) was also administered as it focuses on the emotional and other aspects of intimacy. This 30 item scale measures four aspects of intimacy including emotional, social, recreational, and intellectual intimacy. The PAIR reports individual sub-scale scores as well as a summed overall intimacy score (Alea & Bluck, 2007; Schaefer & Olson, 1981; Trief et al., 2002). The PAIR also has strong evidence for reliability and validity (Trief et al., 2002) and includes a social desirability subscale.

**3.2.3.4 Relationship Quality.** Present quality of the relationship between caregiver and care recipient was measured using the *Burns Relationship Satisfaction Scale* (BRSS, Burns & Sayers, 1988; Burns et al., 1994; Heyman et al., 1993), a self-report measure with good psychometric properties (Burns & Sayers, 1988; Burns et al., 1994; Heyman et al., 1993). The BRSS asks caregivers to rate their level of satisfaction with various facets of their relationship with the person with dementia, including: communication, conflict resolution, affection and caring, intimacy and closeness, respective roles in the relationship, and overall satisfaction. Pre-morbid quality of relationship between caregiver and care recipient was also assessed using the

BRSS, but instructions were modified by asking caregivers to rate relationship satisfaction *prior* to the onset of dementia in care recipient. This modification is consistent with that described by Steadman and colleagues (2007).

**3.2.3.5 Reminiscence Questions.** All participants were asked to respond on five-point rating scales to closed ended questions related to the frequency of and their emotional response (happy vs sad) to natural reminiscence in their daily lives involving past positive memories of their care-partner. All participants were also asked to provide written comments, thoughts, or feelings regarding the same. Participants receiving the reminiscence activity were additionally asked to respond on five-point rating scales to closed ended questions related to their level of enjoyment of and interest in future participation in the reminiscence activity. They were also asked to provide any written comments, thoughts, or feelings regarding the reminiscence activity.

### **3.2.4 Study Design**

The goal of Study 2 was to compare outcomes for participant caregivers randomly assigned to the reminiscence activity or to the control activity with the aim of exploring the efficacy of a basic reminiscence activity in improving intimacy, overall quality of the dyadic relationship with the care recipient as perceived by the caregiver, and decreasing the perception of caregiver burden. This experimental design involved the random assignment of caregivers to Telehealth videoconferencing, or in-person, control versus experimental groups (2 x 2 design). There were six dependent variables (DVs) measured for the four groups, (both Telehealth and in-person control and reminiscence activity groups), these being: perceived identity change measures (SIDQ and identity change rating scales), scores on intimacy measures of closeness and warmth (PAIR and SMD scales), a current relationship quality measure (BRSS scores), and caregiver burden (ZBI). All DV measures were administered pre-intervention and post-intervention for a total of two repeated measures (two time-points).

## **3.3 Objectives, Hypotheses, and Statistical Procedures**

### **3.3.1 Objective 1**

The first objective of Study 2 was to establish whether equivalency in delivery mode across groups, specifically in-person versus Telehealth delivery via videoconferencing, existed for both the single session reminiscence activity and control conditions, respectively. Group means were compared using individual MANOVAs at both time points (pre and post). It was

*hypothesized* that there would be no significant difference in DV means between the two delivery formats at either time point, and thus any therapeutic value of the in-person reminiscence activity would be retained over the videoconferencing medium. In the event that hypothesis one was correct, the in-person and Telehealth groups were to be collapsed into only two groups, the reminiscence activity group and the control group, for the objective 2 analysis, in order to increase statistical power.

### **3.3.2 Objective 2**

The second objective was to evaluate efficacy of the reminiscence activity versus the control. It was *hypothesized* that participant caregivers receiving the in-person reminiscence activity would demonstrate statistically significant improvements in scores over time (pre and post intervention) (i.e., significant decreases in identity change and burden, and increases in intimacy and quality of relationship). The two-way interaction (parallel groups over time) was also *hypothesized* to be statistically significant, demonstrating greater improvement over time of all DVs for the reminiscence group in comparison to the control group. To address whether differential improvement over time occurred on any or all of the DVs for the groups receiving the reminiscence activity versus the control groups, a Doubly Multivariate Approach to Profile Analyses was utilized as it allows for non-commensurate DVs and avoids the assumption of sphericity (not applicable for only two time-points) and it allowed sufficient power for the relatively small group sizes (20 per group). This analysis compares multiple DVs from discrete groups, measured prospectively over two points in time. Dementia severity served as a covariate. Importantly, it also enabled observation of whether the two groups demonstrated parallel change over time on specific DVs, but not on others (in this case the doubly parallel time by DVs interaction was expected to be significant for all DVs).

### **3.3.3 Objective 3**

A third and final objective of Study 2 was to gain insight into participant caregivers' natural reminiscing behaviors and experience, and also their experience of participating in the facilitated reminiscence activity. Toward this, participant responses to rating scale questions regarding natural reminiscence and the reminiscence activity were included in exploratory descriptive and correlational analyses. Group means for the rating scale responses regarding the reminiscence activity were also compared using ANOVAs to rule out delivery format (in-person versus Telehealth videoconferencing) as a possible determinant of participants' experience. It

was *hypothesized* that participants' experience during the facilitated reminiscence activity would not be significantly impacted by the delivery medium.

Responses to open ended questions requesting participants' comments, thoughts, or feelings regarding natural reminiscence and their experience during the reminiscence activity were thematically analyzed in order to identify common themes or patterns across participants.

### **3.4 Results**

The mean pre-measurement (baseline) levels for the study variables are presented in Table 3.2. As in Study 1, scores on the CDR-SOB indicated the care recipients were generally in the relatively early/mild stages of dementia ( $M = 5.2$ ). Casual examination of the mean scores on the baseline measures revealed very similar mean levels of perceived burden, identity change, warmth aspect of intimacy, and current and premorbid relationship quality as in Study 1. Overall, the sample of caregivers of persons with dementia's ( $n = 40$ ) mean level of perceived burden fell in the mild to moderate range of burden ( $M = 37.2$ ) according to published interpretation guidelines (Zarit, 1983). Caregivers reported, on average, a medium level of perceived change in the person with dementia's identity ( $M = 3.7$ , rating scale of 0 to 6) and a mean of  $M = 4.9$  on the SIDQ. Current quality of relationship was on average reported to be in the neutral (neither satisfied nor dissatisfied) to slightly satisfied range ( $M = 23.0$ , scale of 0 to 42), while premorbid quality of relationship rated in the moderately satisfied range, on average ( $M = 35.3$ , scale of 0 to 42).

#### **3.4.1 Pre vs Post Measurement Comparison**

Demographics and characteristics for the four randomly assigned groups are presented in Table 3.3 and group means for the study variables are presented in Table 3.4. A MANOVA was run to assess whether study variable means significantly differed across the four groups and to verify the success of the random assignment. The effect of experimental group on the pre (baseline) measurement of the study variables was non-significant, (Pillai's trace)  $V = .440$ ,  $F(21, 96) = .786$ ,  $p = .730$ ,  $\eta^2 = .147$ . As such, individual MANOVAs were run to determine whether differences existed between delivery method (Telehealth videoconferencing vs in-person) for reminiscence activity groups and control groups, respectively, at the post time point. There was no significant effect of delivery mode for the reminiscence activity groups (Pillai's trace)  $V = .237$ ,  $F(6, 13) = .673$ ,  $p = .674$ ,  $\eta^2 = .237$  at pre-measurement. A significant effect of

Table 3.2

*Mean levels of measures of caregiver burden, identity change, quality of relationship, and intimacy for 40 caregivers.*

Measure	<i>Mean</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>
Caregiver Burden (ZBI, scale 0 - 88)	37.20	13.85	12.00	72.00
Self-Identity in Dementia Questionnaire (Total difference score)	4.92	3.15	.00	12.00
Perceived Identity Change in Person with Dementia (Rating scale, 0 - 6)	3.70	1.30	.00	6.00
Current Quality of Relationship (BRSS current, scale 0 - 42)	23.03	9.00	6.00	42.00
Premorbid Quality of Relationship (BRSS premorbid, scale 0 – 42)	35.33	7.82	9.00	42.00
Semantic Differential Scale (Intimacy – Warmth)	62.30	16.87	21.00	101.00
PAIR (Intimacy – Closeness)	93.13	17.48	51.00	133.00

*Note.* Higher numbers equal greater levels of perceived of burden, identity change, intimacy, and relationship quality, and intimacy, respectively.

delivery modality was found for the pre-measurement control groups (Pillai's trace)  $V = .780$ ,  $F(6, 13) = 7.692$ ,  $p < .01$ ,  $\eta^2 = .78$ . On further inspection it was found that pre-measurement current quality of relationship (BRS scale scores) was the only variable that differed significantly between the Telehealth control and in-person control,  $F(1, 20) = 4.751$ ,  $p = .043$ ,  $\eta^2 = .209$ . There was no significant effect of delivery mode for either the reminiscence activity groups (Pillai's trace)  $V = .235$ ,  $F(6, 13) = .666$ ,  $p = .679$ ,  $\eta^2 = .235$  or control groups (Pillai's trace)  $V = .210$ ,  $F(6, 13) = .575$ ,  $p = .744$ ,  $\eta^2 = .210$  at post-measurement. Given that only one variable (pre-measurement quality of relationship) differed significantly, and the small effect size, it was believed that this difference was due to natural variation in group means resulting from random assignment and not indicative of a true effect of the delivery mode. Therefore, the threat to the pre-post comparative analysis was deemed minimal and the Telehealth and in-person groups were collapsed for the subsequent pre-post comparison in order to maximize statistical power.

A Doubly Multivariate Approach to Profile Analyses was utilized to investigate the efficacy of the reminiscence activity as it allows for non-commensurate DVs and avoids the assumption of sphericity (not applicable for only two time-points). Equal group sizes were used, thus the assumption of homogeneity of variance/covariance matrices was not applicable. There were more cases than DVs in all groups, thus the assumption of multivariate normality was assumed to not be violated. Multivariate and univariate outliers were not found and the linearity of relationships among DVs appeared intact. A time (pre, post) x condition (reminiscence, control) between and within design was utilized. Contrary to the study hypotheses, condition by time interaction (deviation of profile parallelism between conditions over time-points) was statistically insignificant  $F(7, 32) = .701$ ,  $p = .671$ . No statistically significant main effects were found for either condition or time (pre-post). Thus there appeared to be *no* change in identity, intimacy, quality of relationship, or burden measures relative to control as a result of the reminiscence activity.



Table 3.3

*Individual group sample demographics and characteristics (n).*

Demographic	Rem (In-person) <i>n</i>	Control (in-person) <i>n</i>	Rem (Tele-health) <i>n</i>	Control (Tele-health) <i>n</i>
Patient Diagnosis				
Alzheimer's disease	8	8	6	6
Vascular/Mixed dementia	1	1	0	0
Frontal-Temporal dementia	1	1	3	2
Other dementia/due to medical condition	0	0	1	2
Patient Gender				
Male	6	6	5	4
Female	4	4	5	6
Caregiver Gender				
Male	1	2	3	4
Female	9	8	7	6
Relationship to Patient				
Wife	6	4	5	4
Husband	0	1	1	4
Son	1	1	2	0
Daughter	3	3	2	2
Mother	0	1	0	0

Table 3.3

*- continued*

	Rem (In-person) <i>n</i>	Control (in- person) <i>n</i>	Rem (Tele- health) <i>n</i>	Control (Tele-health) <i>n</i>
Patient age (yrs.)	78.0	78.3	74.2	71.9
Caregiver age (yrs.)	65.3	66.0	63.5	64.0
Dementia severity (CDRSOB)	5.2	4.7	6.1	4.7
Years since diagnosis	2.9	0.9	2.1	2.1
Degree of contact with patient	11.6	11.2	11.0	11.4

*Note.* Dementia severity based on CDR-SOB scores (see description in Study 1 measures, p. 54) which range from 0 -18 (higher scores indicate greater severity of impairment). Degree of contact based on self-report measure completed by caregivers regarding how often they engage in face-to-face contact and contact via-telephone (scores range from 0 – 12, higher scores indicate more frequent contact).

Table 3.4

*Mean levels of measures of caregiver burden, identity change, quality of relationship, and intimacy across condition groups and pre and post time points.*

Measure	Time	Condition			
		Rem (In-person)	Control (in-person)	Rem (Tele-health)	Control (Tele-health)
Caregiver Burden (ZBI, scale 0 - 88)	Pre	42.1 (17.3)	31.9 (11.8)	34.6 (15.7)	40.2 (8.4)
	Post	42.4 (15.1)	31.6 (13.8)	32.7 (14.8)	36.9 (7.7)
Self-Identity in Dementia Questionnaire (Total difference score)	Pre	4.7 (2.5)	4.7 (3.2)	5.1 (3.0)	5.2 (4.1)
	Post	5.2 (3.0)	5.5 (3.5)	4.4 (3.3)	5.5 (4.4)
Perceived Identity Change in Person with Dementia (Rating scale, 0 - 6)	Pre	3.7 (1.7)	3.9 (0.6)	3.7 (1.3)	3.5 (1.4)
	Post	3.1 (1.5)	2.0(1.6)	2.8 (1.1)	2.1 (1.6)
Current Quality of Relationship (BRSS current, scale 0 - 42)	Pre	20.8 (11.3)	26.5(6.1)	25.4(8.8)	19.4(8.3)
	Post	20.3 (13.2)	24.9(12.1)	26.0(8.4)	22.1(9.8)
Premorbid Quality of Relationship (BRSS premorbid, scale 0 – 42)	Pre	34.6 (7.5)	37.9 (3.6)	35.4 (9.8)	33.4 (9.3)
Semantic Differential Scale (Intimacy – Warmth)	Pre	57.0 (21.6)	62.4(18.6)	67.5 (11.9)	62.1 (14.7)
	Post	53.6 (23.2)	64.4(18.2)	71.8 (14.8)	63.7 (18.0)
PAIR (Intimacy – Closeness)	Pre	87.1 (23.1)	93.4 (17.4)	99.2 (14.1)	92.8 (14.5)
	Post	89.7 (26.6)	98.2 (17.1)	101.7 (17.2)	94.3 (16.1)

*Note.* Higher numbers equal greater levels of perceived burden, identity change, relationship quality, and intimacy, respectively. Standard deviations listed in brackets.

### 3.4.2 Questions Regarding Natural Reminiscence Behaviour and the Reminiscence Activity

Descriptive analysis of responses to questions related to participants' everyday reminiscence behaviours revealed the following ( $n = 40$ ; all results presented in Table 3.3): In response to the item, "In general, reminiscing makes you feel" (1-5 scale, very sad to very happy): 20% endorsed feeling "Somewhat sad," while the majority of participants (80%) indicated being either "Somewhat happy" (32.5%) or "Very Happy" (47.5%) ( $M = 4.1$ ,  $SD = 1.14$ ). This suggests that most participants find natural reminiscing in their daily lives to be positive, while a smaller number may experience reminiscing as more negative. Performing an ANOVA revealed no significant difference between Telehealth versus in-person delivery group means,  $F(1, 39) = .169$ ,  $p = .683$ ,  $partial \eta^2 = -.02$  (small effect size). In response to the item, "In general, how often do you reminisce about past positive memories involving your care-partner" (1-5 scale, never to very often): The mean response was  $M = 3.5$ ,  $SD = 1.01$  with 5% (2) of participants endorsing "Never," 7.5% (3) rarely, 32.5% (13) "Sometimes," 40% (16) "Often," and 15% (6) endorsed "Very often," suggesting that over half of participants (55%) frequently engage in natural reminiscence and the vast majority (87.5%) reminisce at least sometimes in daily life. Once again, there was no significant difference between group means for the two delivery formats,  $F(1, 39) = 1.201$ ,  $p = .280$ ,  $partial \eta^2 = .005$  (trivial effect size).

Descriptive analysis of participant responses to closed-ended questions related to their experience of the facilitated reminiscence activity ( $n = 20$ ; results presented in Table 3.3) revealed the following: In response to the item asking, "How enjoyable..." the experience was (1-5 scale, not very -> very), participants endorsed a mean of  $M = 4.3$ ,  $SD = .97$ , with 10% (2) of participants endorsing Not very, 5% (1) Neutral, 30% Somewhat, and 55% (11) Very enjoyable, suggesting the vast majority of participants (85%) found the reminiscence activity to be at least somewhat enjoyable. No significant difference was found between in-person group and telehealth group means via ANOVA,  $F(1, 19) = .828$ ,  $p = .375$ ,  $partial \eta^2 = -.009$  (trivial effect size). In response to the item asking if they would be interested taking part in a similar activity again (note: it was clarified to participants that their response did not represent any commitment to participate in future activities) (1-5 scale, not at all interested -> very interested), participants endorsed a mean of  $M = 3.7$ ,  $SD = 1.14$  with 5% (1) of participants endorsing not at all, 15% (3) not very, 10% (2) neutral, 50% (10) Somewhat, 20% (4) Very interested. These responses

Table 3.5

*Descriptive statistics for participant responses to questions regarding natural reminiscence and their participation in the reminiscence therapy activity.*

Item	<i>N</i>	<i>M</i>	<i>SD</i>
“In general, reminiscing makes you feel”	40	4.10	1.14
Response		%	
1.Very Sad	0	0.0	
2.Somewhat Sad	8	20.0	
3.Neutral	0	0.0	
4.Somewhat Happy	13	32.5	
5.Very Happy	19	47.5	
“In general, how often do you reminisce about past positive memories involving your care-partner?”	40	3.5	1.01
Response		%	
1.Never	2	5.0	
2.Rarely	3	7.5	
3.Sometimes	13	32.5	
4.Often	16	40.0	
5.Very Often	6	15.0	
“How enjoyable did you find discussing memories of past positive experiences with the interviewer today?”	20	4.3	0.97
Response		%	
1.Not at All	0	0.0	
2.Not very	2	10.0	
3.Neutral	1	5.0	
4.Somewhat	6	30.0	
5.Very	11	55.0	
“In general, would you be interested in discussing positive past memories involving your care-partner with someone in a similar fashion as today?”	20	3.7	1.14
Response		%	
1.Not at All	1	5.0	
2.Not very	3	15.0	
3.Neutral	2	10.0	
4.Somewhat	10	50.0	
5.Very	4	20.0	

suggest that most participants (70%) were at least somewhat interested in participating in future reminiscence activities. Again there was no significant difference between delivery format group means,  $F(1, 19) = .336, p = .569, \text{partial } \eta^2 = -.034$  (small effect size).

Further analyses were performed for exploratory purposes to identify any significant correlational relationships between participant responses to the questions regarding natural reminiscing and the facilitated reminiscence activity. Frequency of natural reminiscing ( $r = -.333, p < .05$ ), enjoyment of the facilitated reminiscence activity ( $r = -.543, p < .05$ ), and interest in future participation in similar facilitated reminiscence activities ( $r = -.524, p < .05$ ), all revealed significant small to moderate magnitude negative correlations with decreased perception of social role identity (SIDQ scores). The frequency in which participant caregivers reported engaging in natural reminiscence in their daily lives was significantly and positively correlated with both the closeness (PAIR scores) and warmth (semantic differential scores) measures of intimacy ( $r = .442, p < .01$  and  $r = .370, p < .05$ , respectively) as well as interest in participation in future facilitated reminiscence activities ( $r = .527, p < .05$ ). The relationship between enjoyment of natural reminiscence and the warmth aspect of intimacy approached significance ( $r = .303, p = .058$ ). Interest in future participation in facilitated reminiscence activities was also positively correlated with the warmth aspect of intimacy ( $r = .452, p < .05$ ) and enjoyment of the activity ( $r = .762, p < .001$ ). Participant enjoyment of the facilitated reminiscence activity additionally showed significant positive relationships with enjoyment of natural reminiscing in their daily lives ( $r = .605, p < .01$ ). Notably, perceived caregiver burden (ZBI scores) approached significant negative correlations with enjoyment in the facilitated reminiscence activity ( $r = -.436, p = .055$ ), interest in future participation enjoyment of the activity ( $r = -.424, p = .062$ ), and frequency of natural reminiscence ( $r = -.300, p = .060$ ).

### **3.4.3 Thematic Analysis**

All participant caregivers ( $n = 40$ ) provided written narratives in response to open ended questions asking them to comment generally on their thoughts or feelings about natural reminiscence and, for those in the experimental groups ( $n = 20$ ), their experience with the reminiscence activity. These responses were analyzed thematically using an inductive (i.e., data as opposed to theoretically driven) approach similar to that described by Braun and colleagues (2006). That is, participant's responses to these questions were analyzed at a semantic level with the aim of identifying common patterns or themes across caregivers, related to their expressed

thoughts, feelings, and experiences (Braun & Clarke, 2006). Two independent coders were used to determine reliability of the findings of the thematic analysis and limit the potential for researcher bias (Table 3.4). Nevertheless, the value of inter-rater coding and reliability has been questioned by some in the thematic analysis literature, as it has been suggested that thematic analysis is similar to initial coding from grounded theory in that it is an active and reflexive process that is inherently shaped by the perspective of the coder and that reliability between raters may merely reflect similarities in training (Charmaz, 2006). As such, a lack of agreement does not necessarily indicate decreased validity of the identified theme, but rather may simply be attributed to individual differences in perspective between coders and thus themes identified by only one coder may still be valid and are presented. Analogous themes identified by both coders were combined under single encompassing headings for ease of presentation and comparison. Identified themes and the corresponding number of participants whose comments espoused them are presented in Table 3.4. Proportion of the sample in which a theme was found as well as rate of agreement between coders for a given theme are also provided.

**3.4.3.1 Themes Related to Natural Reminiscence in Daily Life.** The most common theme arising from caregivers' responses was an expression of *positive feeling/sentiment toward reminiscing* or more specifically their memories of past shared positive experiences with their care-partners. For example, one participant wrote, "I think it is a good idea to [reminisce] more often. We get caught up in negatives too easily. I feel good about remembering good times, even good times at present." This theme was shared by the majority of caregivers (up to 72.5 percent of participants) and there was an 89.7% rate of agreement between coders. In contrast, the second most common theme was *ambiguous/bittersweet feeling or sentiment toward reminiscing* (12.5 – 20% of participants, 62.5% coder agreement), such as one caregiver's statement that, "I find it happy for the most part, but it does make me a bit sad because I know that the dad I knew as a child, and most of my adult life, is not the same person now." Additionally, 10 to 12.5 percent of participants (80% agreement) indicated a *negative feeling or sentiment toward reminiscence*, for example one caregiver wrote that reminiscing makes them feel, "Sad. Because we won't be doing the good things again." In the responses of three participants (7.5% of the sample, 100% agreement) a theme indicating that reminiscing results in *increased saliency of changes* in the person with dementia. Additional themes of *neutrality or*

Table 3.6

*Themes identified among responses to questions regarding reminiscing daily life and the facilitated Reminiscence activity.*

Reminiscing in General ( <i>n</i> = 40)				
Theme	Coder 1 (No. of Participants)	Coder 2 (No. of Participants)	% of participants	Rate of agreement
Positive toward rem/positive memories	29	26	65 – 72.5	89.7%
Negative	4	5	10 – 12.5	80%
Ambiguous/bittersweet	5	8	12.5 – 20	62.5%
Can't remember	0	1	0 – 2.5	0%
Neutral	3	0	0 – 7.5	0%
Forgot the past or identity/wistful	1	0	0 – 2.5	0%
Change is more salient	3	3	7.5	100%
Reminiscence Activity ( <i>n</i> = 20)				
Theme	No. of Participants	No. of Participants	% of participants	Rate of agreement
Positive toward Rem/positive memories	12	12	60	100%
Negative	2	0	0 – 10	0%
Ambiguous/bittersweet	3	3	15	100%
Can't remember	0	2	0 – 10	0%
Neutral	0	1	0 – 5	0%
Forgot the past/wistful	1	0	0 – 5	0%
Change is more salient	3	0	0 – 15	0%
Present hardship/distress	2	0	0 – 10	0%

*Note.* Participant number cells corresponding to themes not identified by a respective coder are greyed out.



*no feeling* (7.5%) expressed toward reminiscence and *difficulty remembering the past and a wistful feeling* (2.5%) were identified by only one coder.

**3.4.3.2 Themes Related to the Facilitated Reminiscence Activity.** For the open ended question referring to participants' thoughts or feelings toward the facilitated reminiscence activity, the theme *positive feeling/sentiment toward the reminiscence activity* was most common amongst caregivers. For example, one participant wrote, "Nice to remember things you don't think of on a daily basis...When things were normal. [The reminiscence activity] was relaxing, nice." This theme was shared by 60 percent of participants and there was a 100% rate of agreement between coders. *Ambiguous/bittersweet feeling or sentiment toward reminiscing* was another theme identified by caregivers (15% of participants, 100% coder agreement), characterized by one caregiver who wrote, "I enjoy talking about him and his qualities. But also bitterness and anger about his loss." Other themes identified by only one respective coder (0% agreement) included *negative feeling or sentiment toward reminiscence* (10%), *difficulty remembering or forgot the past and a wistful feeling* (15%), *increased saliency of changes* (15%), *neutrality or no feeling* (5%), and *present hardship/distress* (10%).

### 3.5 Discussion

#### 3.5.1 Telehealth Videoconferencing vs In-person Delivery

One of the objectives of Study 2 was to establish whether the mode of delivery, in-person versus Telehealth videoconferencing delivery, had any effect on measurement of the dependent variables or the potential effect of the reminiscence activity. Consistent with the study hypothesis, significant differences in dependent variable means between delivery groups, at both pre and post time-points, were not found for all but one (a small effect of delivery format on pre-measurement of quality of the relationship between caregiver and the person with dementia). Thus, it was deemed likely that, rather than an effect of the format during pre-measurement, the difference in means for this single variable was likely due to pre-existing variation between respective samples of caregivers. Though random assignment of participants was utilized for this study to control for group differences, it does not completely eliminate the possibility that groups may significantly differ due to chance. The relatively small sample size used also increases the likelihood of this occurring.

That significant group differences were not found between the in-person and Telehealth videoconferencing formats suggests that the formats were generally equivalent, though the lack

of effect of the intervention limits the generalizability of this finding. This is important, as it adds to the limited research on comparisons between traditional and novel delivery methods for psychosocial interventions and data collection (e.g., Bouchard et al., 2004; Nelson et al., 2003). Growing evidence for telehealth videoconferencing equivalency should encourage increased usage of the medium for service delivery to populations with limited access due to mobility/transportation difficulties (e.g., older adults, physically disabled) and/or geography (e.g., rural and remote areas). Similarly, access to these populations and the ease and convenience of research and data collection may be improved through use of Telehealth delivery, which may encourage increased research of important issues for these traditionally at-risk populations.

### **3.5.2 Reminiscence Activity Efficacy**

The primary objective of Study 2 was to evaluate the efficacy of the single session reminiscence activity adopted from Alea and Bluck (2007) to increase the level of intimacy perceived by informal caregivers of persons with dementia and subsequently decrease perceived burden of caring. Based on the evidence demonstrated in Study 1 supporting the theorized predictive model of perceived identity change and intimacy in the perception of caregiver burden, the literature supporting an identity and intimacy maintenance role for natural reminiscence and reminiscence based activities, and some support for reminiscence as having benefit for informal caregivers, it was hypothesized that caregivers would show benefit from receiving the facilitated reminiscence activity relative to controls. Specifically, it was believed that in line with the guiding theoretical model, caregivers in the reminiscence activity group would show significant improvement in post versus pre measurements of identity change, intimacy, relationship quality, and caregiver burden, relative to controls. Contrary to these expectations, no significant benefit of the reminiscence activity was observed in the present study. This is generally consistent with the findings of the large randomly controlled trial of a structured multi-session dyadic group reminiscence program (Woods et al., 2012) which also found no positive benefit for informal caregivers participating with their care-partners with dementia (though different outcome measures were used). It was thought that several potentially confounding variables found in the Woods et al. RCT, such as the time, scheduling, and logistic demands of the program, as well as use of a predetermined and scripted program of facilitated reminiscence, in a group format, may have mitigated any benefit of reminiscence for caregivers.

Despite attempting to control for these factors by using a relatively brief single session of a facilitated caregiver-only reminiscence activity, delivered in the caregivers' homes or via Telehealth (to reduce travel burden), the present study failed to demonstrate any change in included outcome variables. Nevertheless, in contrast with the largely atheoretical approach to the evaluation of reminiscence in previous studies including Woods and colleagues, the use of a guiding theoretical framework in the design of the present study allows for more informed interpretation of the results, toward guiding future work. Though there is no clear explanation for the failure to observe the expected outcome, based on the model of reminiscence efficacy prescribed to here, several things are immediately apparent that may help explain the lack of benefit to caregivers.

The results of Study 1 demonstrated evidence for a model of perceived burden in which dementia's impact on the identity of the person with dementia serves as a catalyst for negative change in the emotional connection and relationship between caregiver and person with dementia which in turn results in increased perception of burden in providing care. That no effect of the reminiscence activity relative to control was found in Study 2 for all variables including perceived change in identity, suggests that the single session reminiscence activity failed to alter the caregiver's perception of change in their care-partner due to dementia. Rather than being contraindicative of the validity of the proposed model of reminiscence efficacy (Figure 3.1) suggested by Study 1's supported model of identity and burden, no change in perceived burden is precisely what the model would predict to occur in the event any attempted intervention failed to alter caregivers' perceptions of identity change. Using the same reminiscence activity as the present study, Alea and Bluck (2007)'s study on the effect of the single session reminiscence activity on intimacy in healthy adults and older adults provided direct evidence for the intimacy maintenance function of reminiscence and indirect evidence for its identity maintenance function. That the present study failed to replicate this effect presents the possibility that an important change relative to healthy individuals in the function of reminiscence may occur following the onset of dementia in one member of the dyad.

One possible explanation for this difference in outcome of reminiscing may be that when reminiscing about someone without dementia, the prospect of future interaction and experiences with that person, as they were and as the person reminiscing has always perceived them to be, still exists. In contrast, the caregiver's perception of change or loss of identity in the person with

dementia removes that prospect and it is perhaps for this reason that the identity and intimacy maintenance or restoration functions of reminiscing (Webster, 1997; Westerhof et al., 2010), fail. Possibly related to this line of reasoning, autobiographical memory/reminiscence function literature (e.g., Webster, 1997) posits that while increased intimacy with a living person, under normal conditions, is considered desirable and beneficial, the maintaining of an emotional connection with one who is no longer living has been associated with increased psychological distress and decreased subjective well-being (see review by Westerhof, Bohlmeijer, & Webster, 2010). While this does not necessarily fit with the present study's findings of no change in either perceived identity change in the person with dementia nor intimacy, future studies should examine the potential similarity between onset of dementia and loss of a loved one in terms of changes in the function and consequences of reminiscence and general adjustment of the caregiver. Though beyond the scope of the present study, existing literature exploring the possible connection between onset of dementia in a loved one and potential grieving and bereavement processes in informal caregivers (e.g., Sanders & Corley, 2003; Sanders et al., 2008) may provide valuable insight and should be consulted for future studies.

An additional factor that may have contributed to the lack of impact of the reminiscence activity on the outcome variables during the present study is individual differences in coping and approach to caring, or caregiving style, between caregivers. Coping and caregiving approaches in dementia have been examined in the literature. For example, Ablit and colleagues (2009) described distinct relationship “styles” based on caregivers’ perceptions of changes in the person with dementia and which appear largely synonymous with differences in coping. According to Ablit and colleagues, caregivers’ adopted style dictated how they perceived changes in their loved one with dementia and the impact of those changes on their sense of mutuality or intimacy in their relationship with the person with dementia. Based on this literature it is possible that caregiving or coping style could interact with whether reminiscence was a positive or negative activity. For example, according to Ablit and colleagues, a caregiver adopting a “detachment” style or approach views the person with dementia as “radically different” and as a result experiences and or perceives little emotional connection or intimacy in their relationship with the person with dementia and may experience increased distress or feelings of being overwhelmed. In contrast, a caregiver demonstrating a “continuity” style seeks to avoid recognition of change in the person with dementia’s identity and as a result maintains a strong emotional connection

with their care-partner. When considering reminiscence then, one might expect those with a detached caregiver style not benefit from reminiscence, while the caregivers with the continuity style may be more able to benefit from reminiscence. Although caregiver style was not taken into account in the present study, it may be an important factor to control for in future research on reminiscence based interventions for caregivers and psychosocial interventions for caregivers in general. Moving away from one size fits all type interventions to targeted interventions for subgroups of caregivers based on individual differences such as coping style or approach to caring, may ultimately prove most effective in improving caregiver outcomes.

### **3.5.3 Caregivers' Natural Reminiscence and Experience of the Facilitated Reminiscence Activity**

Participant caregivers' responses to questions regarding the frequency of, and their feelings about, natural reminiscence in their daily lives showed that a majority of caregivers (87.5%) engage in reminiscing about positive past memories involving their care partner and doing so elicits positive feelings in the majority of caregivers (80%). However, a fair number (20%) also reported feeling somewhat sad as a result of reminiscing about their care partners and 12.5 percent reported rarely or never engaging in reminiscence, indication of heterogeneity in caregivers' experience of reminiscence, and perhaps linked to the individual differences in approaches to caring or coping style discussed above.

The vast majority of caregivers also tended to enjoy the facilitated reminiscence activity (85%) and most (70%) indicated at least being somewhat interested in participating in similar reminiscence activities in the future, consistent with Woods et al.'s (2012) findings that, despite no empirically demonstrated benefit to caregivers from the reminiscence program, most caregivers' reported positive perceptions of reminiscence and their experience in the program. Interestingly, 20 percent of caregivers from the present study reported being "Not very" or "Not at all" interested in future participation, while 10 percent reported not finding the reminiscence activity enjoyable, showing that a consistent minority tended not to find the experience of reminiscence positive and to be avoided, either in their daily lives or in a facilitated setting.

Correlational relationships among responses were largely intuitive, based on the proposed model and literature. Caregivers who find more enjoyment in natural reminiscence tended to enjoy the facilitated reminiscence activity more, engaged in reminiscence more often, and were more interested in participating future facilitated Reminiscence activities. Greater perceived

intimacy (both warmth and closeness aspects) was significantly related to greater frequency of natural reminiscence. Enjoyment and frequency of natural reminiscence and interest in future reminiscence activities were negatively related to levels of perceived change in social identity, but not the perception of general identity change, suggesting that specific aspects of identity may be more important than others when trying to measure the impact of reminiscence. This is not surprising given the complex nature of the concept of human identity. Future studies should, thus, include multiple measures of identity change.

#### **3.5.4 Salient Themes**

Thematic analysis of caregivers' responses to open ended questions regarding both natural reminiscence and the facilitated reminiscence activity, respectively, revealed several themes or patterns. In general, these themes reflected responses to closed ended questions described above. Themes of positive feeling about or sentiment toward natural reminiscing, and also toward the facilitated reminiscence activity, were most prevalent and showed a high rate of agreement between coders. Interestingly, a theme of ambiguity/bittersweetness was relatively prevalent among a considerable proportion of caregivers' responses as well, while a theme of negativity toward reminiscing was expressed by a smaller number of caregivers. Increased saliency of change as a result of reminiscing was a theme that also emerged in the eyes of one coder. A similar finding of change in the person with dementia being more apparent as a result of reminiscence was also found in thematic analysis of informal caregiver of person with dementia responses to group dyadic reminiscence (Melunsky et al., 2015). That themes of ambiguity/bittersweetness, and to a lesser extent, increased saliency of the change in the care-partner, emerged, highlights the complexity of the caregivers' perception of and emotional response to reminiscing. Once again this points to heterogeneity among caregivers and a need for considering individual differences such as style of coping or approach to caring.

#### **3.5.5 Limitations**

Several limitations were apparent in the design of Study 3. First, participant caregivers all hailed from rural and remote regions and though not deemed a major risk to the validity of the results, given the unique challenges and circumstances that can come with living in such areas, the present study's findings may not generalize to caregivers living in urban settings. Similarly, though participants were randomly assigned to condition groups they were not randomly selected. While random assignment is believed to have controlled for between group sample

differences, the lack of random selection introduces the possibility that the study sample is not representative of the broader participant population. Nevertheless, approximately 70% of those recruited for participation agreed to participate in the study, possibly mitigating any major threat to the generalizability of the results.

Another potential limitation of the study design was the use of a mixed sample of relationship types between caregiver and person with dementia (e.g., spouse, parent, child, etc.). Despite the use of only dyads of adults and older adults in romantic relationships in Alea and Bluck's (2007) study, which the present study aimed to replicate, relationship type was not controlled for. However, due to the small sample size and given that perception of identity change in persons with dementia is not exclusive to caregivers in romantic relationships with their care partner, emotional connections are present among all forms of meaningful relationships, and the identity and intimacy maintenance functions of reminiscence are not theorized to be specific to romantic relationships, it was not believed feasible nor necessary for relationship type to be controlled for in the present study. Similarly, sex of the caregiver was not controlled for. There is some literature suggesting differences in experience of burden and coping styles between male versus female caregivers of persons with dementia (e.g., Lutzky & Knight, 1994; Stewart et al., 2014; Pinquart & Sorensen, 2006) and Alea and Bluck (2007) found gender differences in the effect of the reminiscence activity on intimacy. Future studies of reminiscence utilizing larger sample sizes, and possibly examining coping styles, should consider controlling for gender and relationship type of the caregiver.

An additional apparent limitation of the present study was the use of a single session of the reminiscence activity. Though Alea and Bluck (2007) found a significant effect of the same single-session reminiscence activity on intimacy in healthy adults and older adults, and the lack of positive benefit to caregivers found in the present study was consistent with the findings of the intensive and longer term (12 weekly sessions) reminiscence intervention RCT used by Woods and colleagues (2012). It is possible that the benefit of reminiscence is dose-dependent and one session was not sufficient to elicit an effect on perceptions of identity, intimacy/quality of relationship, and burden. Similarly, though the effects of the reminiscence activity on intimacy found by Alea and Bluck (2007) were apparent immediately following its administration, it is possible that the impact of the reminiscence activity on the outcome variables used in the present study was not immediately apparent until an undetermined amount of time afterward. A follow-

up measurement time-point of 1 to 2 weeks post reminiscence activity was initially planned. However, due to difficulty collecting data within the targeted follow-up timeframe, related to participant availability/inability to contact participants, this time-point was not available and thus not included in the present study's analysis. Future studies utilizing the reminiscence activity may wish to consider a follow-up measurement point in order to capture any delayed impact of the activity.

Finally, it is possible that the measures used to capture the outcome variables of perceived identity change, intimacy, quality of relationship, and caregiver burden lacked sufficient responsiveness to measure change occurring as a result of the reminiscence activity. While there is no data purporting the responsiveness of the majority of these measures, Alea and Bluck (2007) found the measures of intimacy, especially the SMD measure of warmth, to be sensitive and capable of measuring a significant change between pre and post measurement of the same reminiscence activity adopted for use in Study 2.

### **3.6 Conclusion**

Despite a supported theoretical model (see Study 1) predicting otherwise, the results of Study 2 indicate that the basic reminiscence activity had no impact on perceived identity change, intimacy, quality of relationship, or caregiver burden. This result, combined with previous findings of no positive benefit to caregivers in the literature, are contraindicative to blanket use of reminiscence based interventions for informal caregivers of persons with dementia. Although a majority of caregivers found the current study's reminiscence activity and natural reminiscence to be a positive experience, negative and ambiguous feelings toward reminiscence also emerged from caregivers' responses and narratives. This points to heterogeneity among caregiver experiences and highlights the importance of considering individual differences, such as approach to caregiving and/or coping styles, in future efficacy studies and applications of psychosocial interventions.



## **Chapter Linkage Two**

Study 2 utilized both in-person and Telehealth videoconferencing delivery formats to conduct a research study on efficacy of a facilitated reminiscence activity for rural and remote dwelling informal caregivers of persons with dementia. Given the travel and service access challenges of this geographically restricted population, and the subsequent logistical challenges of collecting research data, use of communication technology such as videoconferencing holds potential to mitigate some of these challenges. Using data collected during Study 2, Study 3 aimed to investigate the feasibility and acceptability of the Telehealth videoconferencing medium for delivery of psychosocial interventions, and carrying out of research, with rural and remote dwelling caregivers.

In determining feasibility and acceptability, Study 3 focuses on the practicality and acceptability of the use of the Telehealth videoconferencing format. Travel distance, cost, and time savings over in-person delivery are examined as is caregivers' level of satisfaction with the Telehealth format. Study 3 also presents data on the equivalency of Telehealth in relation to in-person delivery for both the administration of the reminiscence activity and also for research data collection.

Data for the above were collected during pre and post measurement of the Study 2 protocol as well as during a follow-up telephone session. Quantitative and qualitative data were collected and analyzed in order to more richly capture caregivers' experiences. Study 3 presents the results of these analyses and provides discussion as to their contribution to the literature on Telehealth and its support for continued and expanded use with this population.

## **CHAPTER 4: Study 3**

### **Feasibility and Acceptability of Data Collection and Delivery of a Reminiscence Activity for Rural and Remote Caregivers of Persons with Dementia via Telehealth Videoconferencing**

#### **4.1 Introduction**

Informal caregiving for persons with dementia can have negative impacts on the spouse, child, relative, or friend tasked with the role of caregiver (Alzheimer Society of Canada, 2010). Empirically supported interventions and support addressing the potential negative outcomes associated with informal caregiving, together are believed able to contribute to an expected cumulative economic benefit of 12 billion by the year 2038 (Alzheimer Society of Canada, 2010); not taking into account mitigation of caring's non-financial toll on the individual assuming the role of caregiver. Interventions must be made accessible to caregivers regardless of geographic location in order to achieve greatest reach and impact. This entails ensuring access to caregivers in Canada's extensive rural and remote areas, with chronically limited access to specialized health services. Providing service to these areas is particularly crucial given the growing proportion of older adults in these areas (Statistics Canada, 2010), who are at an inherently greater risk of developing dementia due to its increased prevalence with advancing age. Given that caregiving for persons with dementia is often a 24-hour job, any additional hardships or significant expenditures of energy required as part of participation in an intervention program, may diminish the potential benefit of said program. Local accessibility and an emphasis on convenience for the caregiver, should thus be an important factor in any intervention targeting caregivers. As opposed to traditional in-person delivery, the use of videoconferencing technology is one method which may both increase access and convenience for caregivers, especially those living in rural and remote areas.

Additionally, Telehealth may allow improved ease in accessing rural and remote participants for, and facilitate their participation in, research. The objective of Study 3 therefore was to examine the feasibility and acceptability of a reminiscence activity delivered over

Telehealth videoconferencing to rural caregivers of persons with dementia.

#### **4.1.1 Telehealth Videoconferencing**

Effective and novel use of communications technology can improve access to health services for caregivers living in rural and remote areas (e.g., Morgan et al., 2010). Good feasibility (i.e., the practicality and implementation of the service or intervention) and acceptability (i.e., the reaction of the targeted users to the service or intervention), an important sub-component of feasibility, have been reported in studies on the use of Telehealth videoconferencing for delivery of psychosocial interventions (e.g., O’Connell et al., 2014; Dal Bello-Haas et al., 2014). For example, Telehealth videoconferencing has been used in several health assessment settings for screening and follow-up interviews, and rural patients who utilized the service reported that it was significantly more convenient than similar in-person services, and on average saved 462 km in travel per roundtrip, per patient (Morgan et al., 2010). Similar travel savings as a result of Telehealth usage with rural and remote populations have also been reported elsewhere (e.g., O’Connell et al., 2014). Further, videoconferencing has been reported to be useful for providing effective group support interventions for informal rural and remote caregivers of atypical subtypes of dementia (O’Connell et al., 2014). Additionally, there is growing but still limited data suggesting that mental health services and interventions delivered via various Telehealth mediums, including videoconferencing, are just as effective as traditional in-person delivery (Greene et al., 2010, O’Reilly et al., 2007) and that users report high levels of satisfaction with the medium and services (e.g., Morgan et al., 2014; Richardson et al., 2009) and various interventions for caregivers of persons with dementia have been deemed feasible over the medium (O’Connell et al., 2014; Dal Bello-Haas et al., 2014).

Despite these encouraging findings, several questions have also been raised about the medium. For example, O’Connell and colleagues (2014) noted that during their caregiver support group a question arose as to whether non-verbal expressions of emotion were as salient through videoconferencing compared to in-person, and whether this may have mediated group communication and overall effectiveness. It was observed that as a result of this difference, group communication may have been made more explicit than it would perhaps have been if delivered in an in-person format. The authors also noted that some caregivers in their support group equated the “virtual nature” of their interactions with the group to a sense of “distance” in

their relationship with other caregivers in the group that they thought may not have existed during in-person delivery.

## **4.2 Objectives**

In general, research on the experience and benefits of Telehealth videoconferencing as a mode of delivery for psychosocial interventions, such as reminiscence therapy, for rural and remote living caregivers remains limited. Given that the convenience and experience of specific interventions delivered via Telehealth, as well as satisfaction with and attitudes toward such services, may influence the efficacy of and willingness to participate in a given intervention (Dal Bello-Haas et al., 2014), it is important that the feasibility and acceptability of specific Telehealth programming be examined and thus this was a major objective of Study 3. A second objective was to evaluate feasibility from the service provider or researcher side. Examining participants' convenience, experience, satisfaction, and attitudes toward a given intervention and delivery modality, in this case reminiscence and Telehealth videoconferencing, provides important insight into the feasibility of future provision and informs design and development of future interventions and research projects intended for the Telehealth medium.

## **4.3 Methodology**

The methodology of Study 3 was adapted from that of Dal Bello-Haas, O'Connell, Morgan, and Crossley (2014), which details the process of evaluating the feasibility and acceptability of a novel Telehealth delivered reminiscence activity. Informal caregivers of persons with dementia (from rural Saskatchewan, Canada) who participated in the reminiscence activity (see description on p. 85) activity of Study 2 ( $n = 20$ ) were administered a questionnaire package in addition to various outcome measures. This package included open ended and rating scaled questions regarding their experience and satisfaction with the intervention process and its mode of delivery. Items related to willingness to participate in future interventions were also included and fifteen caregivers who participated in the research project over Telehealth videoconferencing completed the Telehealth Satisfaction Scale (Morgan et al., 2014) during a follow-up telephone interview.

### **4.3.1 Feasibility**

**4.3.1.1 Practicality.** Toward determining feasibility, the practicality of the format will be considered. As such, logistical data such as distance travelled to access Telehealth and distance saved for travel to Telehealth versus travel to Saskatoon, SK, Canada were analyzed and fuel

cost was estimated. Although there are well over 200 Telehealth suites across the province (typically located in hospitals or medical clinics), given their rural location, many caregivers will still need to travel significant distances to a Telehealth suite. Data on the current geographic location of each participant, including postal codes, was taken from the patient records of the RRMC. Savings in travel distance by attending the nearest Telehealth suite, versus travel to Saskatoon, was calculated using Google Maps - an online mapping program that calculates travel distance based on the fastest available route. Saskatoon was chosen as the comparison geographic location because it is the largest city in the province and access to specialty interventions would typically only be available in major urban centres, necessitating travel. Travel costs to the researcher in order to conduct the in-person reminiscence activity delivery and data collection for Study 2 were also calculated.

Finally, descriptive statistics and anecdotal notes regarding the novel process of administering the reminiscence activity via Telehealth videoconferencing are included. Specifically, statistics regarding attendance as well as notable observations, challenges and their solutions, and required modifications are reported. Moreover, the process of in-person reminiscence versus Telehealth reminiscence was compared allowing for an assessment of treatment fidelity (i.e., does the Telehealth reminiscence activity protocol sufficiently resemble the in-person protocol).

**4.3.1.2 Acceptability.** Acceptability of the Telehealth videoconferencing delivery medium was examined using attendance rate, questionnaire data on satisfaction with the Telehealth medium and session, thematic analysis of participant's comments on experience with Telehealth, and comparison of attitudes toward the reminiscence activity and willingness to participate in the future between participant caregivers in the Telehealth versus in-person delivery conditions.

**4.3.1.3 Telehealth Satisfaction Scale.** The *Telehealth Satisfaction Scale* (TeSS) collects information regarding attitudes toward and measures satisfaction related to specific aspects of services administered via Telehealth videoconferencing (Morgan et al., 2014). Participants rate items on a 4-point rating scale (1 = poor, 2 = fair, 3 = good, 4 = excellent). Scores can range from between 12 to 44; higher scores indicate higher satisfaction. The TeSS was demonstrated to have high internal consistency and reliability (Cronbach's alpha = 0.90; Morgan et al., 2014).

**4.3.1.4 Thematic Analyses.** Responses to an open-ended request for comment on caregivers' experience with Telehealth videoconferencing were analyzed using thematic analysis. Thematic analysis is a method of data analysis that attempts to objectively identify and report themes present in participant responses (Braun & Clarke, 2006). Using an identical method as Study 2, responses were analyzed using an inductive approach (i.e., data as opposed to theoretically driven) similar to that described by Braun and Clarke (2006), and focused on the semantic or surface level of participants' responses. That is, analysis did not attempt to go beyond the surface level of what was explicitly written or stated by participants with the aim of identifying common patterns or themes across caregivers, related to their expressed thoughts, feelings, and experiences (Braun & Clarke, 2006). Once again, two independent coders were used to describe reliability of identified themes and limit researcher bias and highly similar themes identified by both coders were combined under single encompassing headings for ease of presentation and comparison.

**4.3.1.5 Telehealth vs In-person Delivery.** Descriptive analysis of closed-ended questions regarding enjoyment of and willingness to participate in future facilitated reminiscence activities interventions, was previously presented in Study 2 and is considered again here through comparison of caregivers in the Telehealth versus in-person delivery groups. Differences in group (Telehealth versus in-person) ratings for questions were also examined statistically.

## **4.4 Results**

Demographics and characteristics of the overall caregiver sample ( $n = 40$ ) were previously presented in Table 2.1 of Study 2 (p. 51).

### **4.4.1 Feasibility**

**4.4.1.1 Implementation, Protocol Modification, and Logistical Practicality.** In general, the Telehealth videoconferencing equipment in the interviewer suite, as well as the various remote suites worked flawlessly. There were no technical difficulties with the equipment except for one occasion where it was indicated that the speakers on the remote end were not loud enough. Staff at the remote end performed troubleshooting and were able to solve the issue in a matter of minutes. Questionnaire materials and consent forms were emailed to the remote Telehealth suite coordinators at the time of booking. These materials were printed out by the coordinators and provided to the participants upon their arrival, without complication.

The Telehealth sessions followed the procedure previously detailed in Study 2 (p. 84). As described in Study 2, the only major modification to the Telehealth session protocol over the in-person protocol was that participant caregivers were instructed to not write their answers on the questionnaire forms, but to verbally speak their answers to the interviewer. The interview than recorded the answers verbatim onto forms. This eliminated the need for faxing or transportation of confidential participant data and limited those handling this data to the interviewer alone.

**4.4.1.2 Travel and Cost Savings.** All participants indicated they travelled by private vehicle to the telehealth site. Participants travelled a mean distance of 21.9 km (min 1 km, max 106 km,  $SD = 32.8$ ) to attend their nearest Telehealth site with an average roundtrip being 43.8 km of driving. On average, participants lived a driving distance of 298.5 km (min 82 km, max 544 km,  $SD = 100.5$ ) from Saskatoon (597 km roundtrip). An average travel savings of 553.2 km per roundtrip was calculated, resulting in an estimated average monetary fuel savings of approximately \$55.21 CAD in per caregiver (based on an average provincial gasoline price in Saskatchewan of .998 CAD per litre according to GasBuddy.com as of May 26, 2016 and using a conservatively estimated gas mileage of 10 km per litre).

Regarding travel distance and cost required to conduct in-person research with rural and remote caregivers, in order to administer the Study 2 protocol to the in-person caregiver groups ( $n = 20$ ), the interviewer would have been required to make 20 trips by car at an approximate average of 385.7 km driving distance (min 200 km, max 698 km), per roundtrip, for a total driving distance of approximately 7, 714 km. Using the same average gasoline price and estimated gas mileage as above, the estimated average and total fuel costs would be \$38.49 CAD and \$769.85 CAD respectively.

#### **4.4.2 Acceptability**

**4.4.2.1 Attendance.** Attendance to Telehealth sessions was perfect for all 20 participants in the two Telehealth groups. Sessions were booked via telephone by the interviewer who served as a go-between for the participant and remote telehealth suite booking staff. A reminder from the staff via email or telephone was planned, though some participants reported that this did not occur. Regardless, participants were called by the interviewer the day before the scheduled session to confirm.

Table 4.1

*Mean ratings for items on the TeSS*

Item	<i>n</i>	<i>Mean</i>	<i>SD</i>	<i>Min.</i>	<i>Max.</i>
Voice quality	15	3.5	.83	1.0	4.0
Video quality	15	3.7	.46	3.0	4.0
Personal comfort in using Telehealth equipment	15	3.6	.51	3.0	4.0
Ease of getting to the Telehealth department	15	3.4	.83	2.0	4.0
Length of interview	15	3.3	.62	2.0	4.0
Explanation of process by interviewer	15	3.5	.64	2.0	4.0
Thoroughness, Carefulness, Skillfulness of interviewer	15	3.4	.51	3.0	4.0
Courtesy, respect, sensitivity, and friendliness of the interviewer	15	3.8	.41	3.0	4.0
How well privacy was respected	15	3.7	.46	3.0	4.0
How well staff answered questions about the equipment	15	3.5	.74	2.0	4.0
Overall Telehealth experience	15	3.5	.52	3.0	4.0
Total	15	38.9	4.3	33.0	44.0

*Note.* Items rated on a 4-point Rating scale (1. Poor, 2. Fair, 3 Good, 4 Excellent). Total score range of 12 to 48.



**4.4.2.2 Telehealth Satisfaction Survey.** Caregivers' mean ratings in response to items on the TeSS (4-point Rating scale – 1. Poor, 2. Fair, 3 Good, 4 Excellent. Total scores range from 12 to 48) are presented in table 4.1. In general, caregivers indicated a high overall satisfaction with the medium (Total Score mean  $M = 39.1$ ,  $SD = 4.2$ ). The lowest item mean rating was “length of time of interview” with a mean rating of 3.33. The highest mean rating for an individual item was 3.8 (courtesy, respect, friendliness of interviewer). In response to two additional yes/no questions on the TeSS, 100% of participants indicated they would use Telehealth again and would recommend it to another person.

**4.4.2.3 Thematic Analysis.** As part of the TeSS, participant caregivers were asked to provide a feedback comment on their experience with Telehealth videoconferencing. Identified themes and the number of participants who endorsed them are presented in Table 4.2. Proportion of the sample in which a theme was found as well as rate of agreement between coders for a given theme are also provided. Two themes generally emerged from caregivers' responses. Ten of 15 caregivers (100% inter-coder agreement) espoused a theme of *time and travel savings* resulting from use of Telehealth videoconferencing over having to drive to a major urban centre for services. For example, caregivers stated, “Being 2 hours away from Saskatoon, [Telehealth] saves us time and effort of travel,” “Being this far north, it's not just the drive [to Saskatoon] either, it's all the preparation also,” and “[Telehealth] is wonderful. Saves time, parking, travel, and decreases the anxiety of [care partner].” A second theme of *facilitating research participation* was present in the responses of three caregivers (100% inter-coder agreement) with one caregiver remarking, “[I am] more likely to participate in research [through Telehealth]” and another stating that Telehealth is “a good way to communicate for [research] purposes.”

#### **4.4.3 Telehealth vs In-person Delivery**

Caregivers' scale ratings regarding enjoyment of the facilitated reminiscence activity delivered in Study 2 and interest in participating in similar reminiscence activities in the future were presented in Table 3.3. To further determine acceptability of the Telehealth medium, mean levels of enjoyment and interest in future participation endorsed by caregivers who received the reminiscence activity via Telehealth videoconferencing versus those who received it at home and in-person, were compared via independent ANOVAs. Neither the enjoyment nor the future interest in participation question demonstrated a statistically significant difference between

Table 4.2

*Themes identified among responses to questions regarding reminiscing daily life and the facilitated reminiscence activity.*

TeSS Comments ( <i>n</i> = 15)				
Theme	Coder 1 (No. of Participants)	Coder 2 (No. of Participants)	% of participants	Rate of agreement
Travel and time savings	10	10	66.7	100%
Facilitates research participation	3	3	20.0	100%

groups,  $F(1, 19) = .828, p = .375, \eta^2 = .004$ , (trivial effect size) and  $F(1, 19) = .336, p = .569, \eta^2 = -.003$ , (trivial effect) respectively.

## **4.5 Discussion**

The goal of the present study was to examine the feasibility and acceptability of Telehealth videoconferencing as a medium of delivery for a facilitated reminiscence based activity, and data collection/research, for informal caregivers of persons with dementia dwelling in rural and remote areas. This goal was accomplished using data collected from the randomly assigned Telehealth and in-person groups of caregivers of Study 2.

### **4.5.1 Practicality**

Overall, the facilitated Telehealth reminiscence activity from Study 2 appeared highly feasible in relation to in-person delivery, both in terms of practical benefit and ease of implementation. This is consistent with previous studies reporting good feasibility of Telehealth videoconferencing based interventions and health services for caregivers (e.g., O'Connell et al., 2014; Dal Bello-Haas et al., 2014). Specifically, the ease of implementation and reliability of the Telehealth Saskatchewan equipment was excellent in the current study and little in the way of modification was required in order to both deliver the reminiscence activity and carry out research (i.e., collect questionnaire data on the targeted outcome variables).

One of, if not the, main advantage to Telehealth delivery of services for rural and remote dwelling persons is the intended savings and alleviation of time and financial cost related to travelling long distances to a major urban centre, as would traditionally be required in order to receive specialized services. As found in other studies of Telehealth videoconferencing (e.g., Morgan et al., 2014), considerable savings were achieved by participant rural and remote dwelling caregivers in travelling to their nearest Telehealth suite to participate in the reminiscence activity and data collection versus hypothetically travelling to Saskatoon. An average savings in travel distance of 553.1 km per roundtrip was demonstrated in the current study. This is comparable to the 455.8 km average roundtrip travel savings reported by Morgan and colleagues (2014) and equates to an estimated \$55 CAD in financial savings related to fuel costs alone and approximately 5.5 hours of travel time (at 100 km/h highway driving speed). Regarding financial costs, the real world savings are likely significantly greater as this estimate considered only the fuel costs associated with travel. Other costs potentially incurred by informal caregivers of persons with dementia in rural and remote settings related to meals, potential

lodging, time off work taken to travel, and costs related to arranging homecare or supervision of the person with dementia during the caregiver's absence, would likely drive the total financial burden of travel much higher. Similarly, the current study did not take into account the human costs of travel, including potentially elevated stress in the caregiver and/or person with dementia, as well as the time allotment related preparation for travel. Future Telehealth feasibility studies may wish to examine such indicators of financial and human costs of travel in order to better approximate this aspect of Telehealth delivery.

From a researcher/service provider perspective, utilization of Telehealth provides benefit over travel to rural and remote dwelling participants' homes for in-person delivery. The total travel distance and fuel cost of the Study 2 in-person delivery ( $n = 20$ ) were estimated at 7,714 km total (385.7 km average round trip per participant) and \$769.85 CAD total in fuel costs (\$38.49 CAD per roundtrip), respectively. This equates to a total travel time of 77 hours for the researcher/service provider to collect data/administer the reminiscence activity. Once again, these are conservative estimates that do not include price of any necessary lodging, meals, missed work, child-care, car insurance/maintenance, etc. Nor does it appreciate the inherent risk of driving, especially in rural areas on roads of varying integrity and inclement weather particularly during the winter months. Additional literature has previously reported similar cost benefit to data service provision and research conducted via Telehealth (e.g., Shore et al., 2007; Smith et al., 2002).

Adding credibility to the above estimations regarding the benefit to participants and researcher/service provider alike, were the findings of the thematic analysis which identified themes (i.e., time and travel savings, facilitation of research participation) reinforcing the above results and further pointing to the feasibility of future utilization of Telehealth for similar activities and/or research purposes.

#### **4.5.2 Acceptability**

The results of Study 3 also demonstrated several positive indicators of acceptance of the Telehealth videoconferencing format by the participant caregivers. Though caregivers were only requested to attend a single session, perfect attendance of the Telehealth participants in Study 2 appears to represent good acceptance of the format and willingness to participate in research and activities delivered via videoconferencing. Similarly, high rates of attendance were also reported among rural and remote dwelling individuals in previous, multiple session interventions, over

Telehealth videoconferencing (O’Connell et al., 2014; Dal Bello-Haas et al., 2014). This apparent willingness may also be a function of the convenience of limited travel and/or the perceived necessity or desire for the activity/service being provided.

In addition to high attendance, participant caregivers in the Telehealth groups of Study 2, on average, endorsed relatively high levels (item means ranged from 3.3 to 3.8 on a scale of 1 (Poor) to 4 (Excellent) of satisfaction related to all aspects of the delivery format (as measured by the TeSS). Other studies reporting Telehealth satisfaction utilizing the TeSS with rural and remote populations have found similarly high levels of satisfaction (e.g., 3.4 to 3.7 item range reported by Morgan et al., 2014; Dal Bello-Haas et al., 2014). That 100 percent of Telehealth participants endorsed a willingness to use the format again, as well as a willingness to recommend Telehealth videoconferencing to others, is an additional indicator of a high level of acceptance by participant caregivers. This embracing of a technology based interface is perhaps surprising given the average age of the participant caregivers of Study 2 (64.7 yr.) and the stereotype of older adults as being “technophobes” (e.g., Neves et al., 2012; Roberts, 2009). That caregivers responded so well to the technology may be the result of a combination of factors such as overgeneralization and exaggeration of technology anxiety in older adults (Roberts, 2009), as well as the relative ease of use and intuitiveness of the Telehealth Saskatchewan videoconferencing equipment and interface. Regardless of the reason, the high level of satisfaction is further testament to the acceptance of the format even among a population often thought to be technology-averse.

An additional indicator of acceptability of the Telehealth videoconferencing format was the high level of enjoyment and interest in future participation endorsed by caregivers and the lack of a significant difference between means on these items between the in-person and Telehealth caregiver groups. This finding is in line with previous literature suggesting equivalency in between in-person and videoconferencing or other technology based modalities for psychosocial interventions. In general, clients tend to report high levels of satisfaction with mental health interventions through videoconferencing, similar levels of quality of the therapeutic alliance to that of face-to-face therapy, and are at least as effective as those delivered in a traditional face-to-face setting (Richardson et al., 2009; Perle et al., 2011).

Unlike participant caregivers’ self-reports in O’Connell and colleagues (2014) study, of a feeling of difference between the virtual interactions of a videoconferencing support group

compared to in-person that impacts the sense of closeness with other members of the group, there was no report or comment made identifying any perceived difference between the two formats, though it should be noted that specific comment was not requested. Similarly, the observation made by the authors that non-verbal behaviours were less salient over the medium resulting in the perception that emotions were made more explicit, possibly as a compensatory strategy to overcome the limitations of the equipment, was not observed during Study 2. It should be noted that Study 2 utilized a one-on-one format, allowing for the entire monitor to be used for one person's image, whereas O'Connell and colleagues described a monitor with several smaller images of the group participants. Nevertheless, given that a large proportion of human communication is non-verbal, the idea that non-verbal communication such as micro-gestures/expressions may be lost through the medium has potentially important implications for its use as a mode of delivery of psychosocial interventions. Literature on non-verbal communication demonstrated its role in the conveyance of emotion (Mandal & Awasthi, 2015) and the importance of non-verbal micro- and macro-expressions in the development of the therapeutic alliance between client and therapist (Ramseyer & Tschacher, 2014).

Finally, mean levels of the Study 2 target outcome variables did not differ significantly across in-person and Telehealth groups for all but one measure, which was thought likely due to a spurious anomaly in the sample characteristics that random assignment of the relatively small sample size, failed to control for. In general, these results combined with those described above provide a strong indication of the acceptability of the Telehealth format in comparison to in-person delivery, for research and service delivery.

#### **4.5.3 Limitations**

Limitations of the current study include its small sample size and use of a specific participant population (i.e., rural and remote dwelling informal caregivers of persons with dementia), potentially limiting the generalizability of the results. Additionally, while questions regarding enjoyment and interest in future participation in the Reminiscence activity were administered at the end of the session with the participant, the TeSS was orally administered over the telephone approximately one to three weeks after the Telehealth session and thus caregivers' recollection of their experience over Telehealth may not have been as accurate. Finally, all participants were recruited from the RRMC and given the RRMC's use of the same Telehealth videoconferencing system for clinical interviews, it is likely that at least some of the participants

of the present study had previous personal experience with the format that may have influenced their perception of their current experience.

#### **4.6 Conclusion**

Based on the reported savings in travel, fuel costs, time, and suspected additional human costs, in addition to the indications of acceptability of the medium in the form of high levels of satisfaction on the TeSS and enjoyment and interest in future participation in Telehealth delivered reminiscence activities, it is clear that findings of the current study demonstrate the feasibility and acceptability of Telehealth delivery of the reminiscence activity. Similarly, it also highlighted the relative equivalency of the format versus in-person delivery, facilitation of research participation, and reduced cost over collecting data in-person, pointing to its usefulness as a data collection and research platform. Continued and expanded utilization of Telehealth videoconferencing should serve to increase service access to rural and remote dwelling caregivers, as well as facilitate data collection and investigation of important research questions involving this high-risk population.

## **CHAPTER 5: General Discussion**

### **5.1 Project Overview**

The research project described in the preceding chapters involved three studies with several broad objectives focused on addressing the issue of identity change in dementia and its role in the determination of negative outcomes of caring for persons living with dementia. Specifically, Study 1's objective was to investigate the relationship between identity, intimacy and quality of relationship, and the perception of caregiver burden and it also aimed to investigate support for a proposed theoretical model of perceived change in identity and caregiver burden (see Study 1, Figure 2.1, p. 49).

Based on this model and the literature on reminiscence theory, it was believed that Reminiscence Therapy may have been an effective method of reducing the subjective perception of caregiver burden; however, the findings of studies examining its effectiveness were equivocal (Charlesworth et al., 2011; Woods et al., 2005; Woods et al., 2012). As such, the objective of the Study 2 was to evaluate, via experimental design, the efficacy of a basic reminiscence activity for caregivers.

Participants for the project were informal caregivers of persons with dementia living in rural and remote areas. Given the challenges of service access and provision, the mode of delivery is an important consideration in the planning of psychosocial interventions for this population, as inconvenience and stress related to travel and accessing services can negate any potential benefit. Telehealth videoconferencing is an emerging format of service provision that may aid in overcoming the challenges facing rural and remote caregivers. Evaluating the feasibility and novel use of Telehealth videoconferencing for delivery of a reminiscence activity as well as its appropriateness for data collection was the third major objective of the present project (Study 3).

The aim of the three project studies was to make novel contributions to the dementia literature on identity, caregiver burden, and the use of videoconferencing technology for service delivery and research. The following provides a brief review of the studies' respective findings, discussion of their broader implications, and direction for potential future areas of study.



## **5.2 Identity Change and Support for a Model of Caregiver Burden**

### **(Study 1)**

Although there are reports that aspects of an individual diagnosed with dementia's identity can persist even in the late stages of the condition (e.g., Cadell & Clare, 2010), qualitative studies have demonstrated that significant loss or change in identity is often perceived by their family members or loved ones (Robinson, Clare, & Evans, 2005; Large & Slinger, 2015). Quantitative data on specifically on caregivers' perception of change in the person with dementia's identity could not be located, though there is some data suggesting family members perceive a change in the saliency of the person's social identity (Cohen-Mansfield et al., 2006b). Study 1 therefore aimed to provide first quantitative data on informal caregivers' perceptions of identity change as well as illuminate the relationship between perceived identity change and other important variables including perceptions of burden.

The novel rating scale for caregivers' perceived level of identity change in the person with dementia appeared to demonstrate sufficient validity and potential as a simple measure of perceived change in self or identity. Using this scale, caregivers in Study 1 (and also Study 2) reported a "medium" level of change in identity of the person with dementia and a significantly higher level than caregivers of persons with difficulties other than dementia. That nearly all caregivers, 96.5 percent, endorsed a perception of a change in identity compared to 65 percent of non-dementia caregivers. These results are in line with qualitative data found in the literature (e.g., Hayes et al., 2007; Orono, 1990) demonstrating caregivers' awareness of the impact of dementia on their care-partner's self-identity. Dementia has long been observed to impact the self-concept or identity of the diagnosed person. These changes in self appear directly related to the cognitive and behavioural changes that occur and increase with progression. Although there is some evidence in the literature suggesting family members' perception of changes in social roles (one aspect of identity), the current project provides first quantitative evidence of perception of persons with dementia's identity change in general.

Though implied by caregiver narratives (e.g., Hayes et al., 2007; Orono, 1990), informed by reminiscence theory (e.g., Webster, 2005), and inferred from evidence of reminiscence increasing intimacy in healthy older adult couples (Alea & Bluck, 2007), Study 1 of the research project also provided first evidence of the project's hypothesized relationship between perceived identity change and quality of the relationship and caregiver burden. Though far from a

comprehensive model of burden, support was found for the theorized model of perceived identity change and burden which posits that greater perception of changes in the identity of the person with dementia by the caregiver results in a reduction in the emotional connection or intimacy and quality of relationship between the two, as perceived by the caregiver. According to the model the caregiver would be predicted to then perceive an increased level of burden in caring for their care-partner whom they no longer recognize as being completely the same person as they were prior to dementia. Support for this model was provided by hierarchical regression analysis demonstrating change in identity as a significant predictor of burden when controlling for other known predictors such as quality of relationship and dementia severity. Mediation analysis further offered potential support for the *theorized* directional pathway of the predictive model (Figure 2.1) as the relation between perceived change in identity and subjective burden was found to be mediated by quality of relationship (and presumably intimacy).

The support for perceived identity change as one *possible* factor in the clearly multifactorial determination of subjective caregiver burden provides quantitative evidence, and elucidates the functional impact of, what has often been observed anecdotally in the literature (i.e., the perception by loved ones of identity loss or change in the person with dementia). That perceived change in identity was shown to affect the intimacy and the quality of the relationship between the caregiver and person with dementia, which then serve as mediators for identity change's impact on burden, helps explain the mechanism of the long-observed detriment of dementia on these important quality of life outcomes (e.g., Alspaugh et al., 1999). To illustrate, these results may, in-line with the biopsychosocial model of dementia, suggest that the impact of the neurodegenerative process, and subsequent decline in cognitive functions characteristic to dementia manifests, in changes to the diagnosed individual's typical pattern of behavior and alterations to their normal pattern of social interaction with those around them, including the caregiver. These changes are then likely perceived by the informal caregiver (i.e., their spouse, child, etc.) as fundamental changes to the person with dementia's essence of being, or self-identity and interpreted as a loss of the person the caregiver once knew. The perception of their loved one as now a different or changed person may then degrade the emotional connection or sense of intimacy they share with that person as they no longer believe them to be the same person with whom the emotional connection was formed. The fractured emotional bond, at least from the caregiver's end, may then colour the caregiver's interactions with the person with

dementia. They in turn experience a reduction in the sense of warmth and closeness, reciprocity and mutuality, and support and understanding they derive from these interactions. Given the fundamental importance of reciprocation in formation and maintenance of relationships (see review by Buunk & Schaufeli, 1999), the perceived lack of such results in a degradation of the caregivers' overall satisfaction with, and appraisal of the quality of, their relationship with the person with dementia and negatively impacts their interactions. As the caregiver now expects and perceives less return benefit or hope for reciprocation in response to their efforts (i.e., expressions of warmth and affection, provision of care), now lacking positive reinforcement, and they may then perceive activities related to caregiving as more burdensome.

Converse to the above illustration, that not all caregivers report significant levels of burden, and that significant positive aspects of caring are gleaned by caregivers as well (e.g., see review by Lloyd et al., 2014), highlights the subjective nature of burden. This does not contradict the model of identity and burden supported in Study 1; on the contrary, just as the model posits a negative cascade by which the degree of perception of change in the person with dementia's identity subsequently proportionately erodes intimacy and the quality of relationship, ultimately enhancing the perception of burden, the model also implies the inverse. Specifically, the model implies that caregivers who maintain a perception of the person with dementia's identity as largely intact following diagnosis will also maintain their emotional connection, relative quality of relationship, and experience less burden. Maintaining intimacy and the emotional bond with the person with dementia and avoiding an overly negative perspective on caring is likely key to allowing caregivers to be more open to and embracing of the potential positive aspects of caring. Allowing these positives to be emphasized in turn may then serve as positive reinforcement for continuing care, perhaps leading to delayed institutionalization of their care-partner as has been seen in the literature (Roff et al., 2004), as opposed to greater burden's association with earlier institutionalization (e.g., Bedard et al., 2000).

The implications of caregivers' perceived change versus maintenance of the person with dementia's identity for caregivers' experience of subjective burden, as predicted by the model supported in Study 1, and illustrated above, are relatively clear. Further, the model identifies perceived identity as a viable target for intervention's aimed at reducing burden. The idea of maintaining the salience of the person with dementia's identity and sense of self despite the changes inherent to the condition, would appear at least compatible with, if not central to,

Kitwood's (1997a) concept of 'personhood' and the movement toward person-centered care in dementia. This approach to care aims to emphasize the personhood or the 'the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being' of the individual with dementia in their social environment (O'Conner et al., 2007). In line with this broad approach, reminiscence based interventions aimed at bringing the past to the forefront for a person with dementia have been employed, and have demonstrated positive impact for persons with dementia. Using the framework of the Study 1's model, it would appear that reminiscence's theorized (e.g., Webster, 2005), and demonstrated (Alea & Bluck, 2007), function of identity and intimacy maintenance fits intuitively with the model's predicted mechanism of burden reduction.

### **5.3 Evaluation of a Reminiscence Activity for Informal Caregivers (Study 2)**

Using the supported model of identity and burden presented in Study 1 as a guiding theoretical basis, the objective of the second study was to evaluate, via experimental design, the efficacy of a facilitated and basic reminiscence activity for decreasing subjective caregiver burden in informal caregivers of persons with dementia. Reminiscence-based interventions have been used with informal caregivers of persons with dementia, though typically as part of a dyadic approach and primarily aimed at benefitting the person with dementia. Equivocal results exist in terms of potential benefit to the caregiver (e.g., Woods et al., 2012). Nevertheless, there has been little theoretical investigation into why reminiscence may or may not be an effective intervention for caregivers and the rationale for its use with this population appears to have been largely based on anecdotal observation and self-report from caregivers (e.g., Hayes et al., 2007). Study 2 aimed to address this gap in the literature.

According to the literature on reminiscence/autobiographical memory, human natural reminiscence is theorized to serve an identity and intimacy maintenance and restoration function (Alea & Bluck, 2007; Webster, 2005; Westhof et al., 2010) and facilitated reminiscence about past positive experiences with a loved one was shown to increase perceived intimacy with that loved one, in healthy older adults (Alea & Bluck, 2007). Based on these findings and the model of identity and burden presented in Study 1, it followed that caregiver's reminiscence about positive experiences involving their care partner as they were, prior to the onset of the dementia, would serve to restore the saliency of the person with dementia's previous identity and thus

strengthening the emotional connection (intimacy). This in turn was thought to improve the perception of the quality of the relationship in the eyes of the caregiver and, as predicted by the Study 1 model, decrease subjective caregiver burden (see Figure 3.1, p. 81).

Despite this intuitive theoretical mechanism of efficacy, the largest RCT for reminiscence therapy found no benefit to caregivers and, in fact, caregivers demonstrated increased caregiver stress and anxiety (Woods et al., 2012). Several potential confounding factors were present in that study, however, that may have negated the benefit to caregivers (i.e., length of sessions and duration of program, time commitment, group dyadic format, structured sessions, necessity of travel, etc.). As such, Study 2 attempted to control for these potential confounds by using a single session of a relatively brief and basic reminiscence activity. The necessity for travel was also removed as, given the participant sample consisted of rural and remote dwelling caregivers, sessions were conducted either via in-person or Telehealth videoconferencing.

Unfortunately, no significant effect of the reminiscence activity was detected, either pre-post or in comparison to the control group. There was a lack of demonstrated benefit to caregivers despite attempts to control for potential confounding factors possibly present in previous studies of reminiscence therapy efficacy. Taken with previous literature on reminiscence efficacy, the results of Study 2 suggest that at the very least single session reminiscence based interventions may not be an effective approach when broadly administered to caregivers. Although the cause of the lack of a significant effect of the reminiscence activity is unknown, several possible explanations are immediately apparent. For example, while the same single-session reminiscence activity employed in Study 2 was found to improve intimacy in healthy older adults (Alea & Bluck, 2007), it may be that partners of non-dementia individuals are able to envision a reuniting with their partner as they were in their reminiscence. For caregivers of persons with dementia on the other hand, reminiscence of past positive memories involving their care-partner who now has dementia perhaps brings the recognition that, given the irreversible nature of dementia, reuniting with their care-partner as they were prior to dementia onset is not possible. This would be consistent with experience of a sense of loss common in loved ones of persons diagnosed with dementia (Robinson, Clare, & Evans, 2005; Large & Slinger, 2015) and it is perhaps that reminiscence in this context becomes similar to that of reminiscence about a deceased loved one.

Reminiscence involving a deceased loved, or attempts to strengthen the emotional connection with one that is no longer there, is believed to result in psychological distress (Westerhof et al., 2010; Webster, 1997). Alternatively, it may be due to individual differences between caregivers, such as approaches to the caregiver relationship and coping style, which according to Ablitt and colleagues (2009) characterize how a given caregiver reacts to the changes in their care-partner due to dementia and whether or not they act to maintain or withdraws from the emotional connection between the two of them.

Though outcome measures showed no statistical significance in regard to efficacy of the reminiscence activity, the majority of caregivers reported enjoying the facilitated reminiscence activity and being interested in participating in future activities (though possibly influenced by social desirability). Similarly, the thematic analysis of participant responses revealed themes of positivity toward both natural and the facilitated reminiscence activity. However, a smaller proportion of participants endorsed at least somewhat negative attitudes toward reminiscing in general. Additionally, themes of ambiguity or “bittersweetness,” and also negativity toward reminiscence were identified during thematic analysis. These findings were somewhat similar to thematic analysis of caregiver responses to an intensive group dyadic reminiscence program, where at least some caregivers indicated ambiguity in their feeling regarding reminiscence (Melunsky et al., 2015). Similar to the previous discussion above regarding the potential similarity of reminiscing about past positive experiences with the care-partner from a time prior to their onset of dementia and that of reminiscing about a deceased loved one, priming the saliency of the person’s pre-dementia identity or self while also recognizing the permanence of the changes to the person, may result in conflicted emotions or ambiguity when appraising the experience. Viewing this from the perspective of Ablitt and colleagues’ view of the different approaches or forms of caregiving, the dissonance created by reminiscence may lead to anxiety and the activation of coping strategies or approaches. Contrasting their proposed continuity versus detachment approaches would suggest that caregivers may strive to maintain (continuity approach) the perception of the partner as they were before dementia, thus also maintaining their emotional connection and improving outcomes (at least in the short-term), or they may focus on the change and solidify their perspective of their care-partner as completely different (detachment approach), pulling away from their emotional connection with them and increasing negative outcomes. A higher proportion of caregivers adopting a predominantly detached

approach to caregiving would potentially explain the consistent findings in the literature, and also demonstrated in Study 1, of caring for a person with dementia being associated with decreased intimacy and quality of relationship, among other negative outcomes. In the context of Study 2's non-significant findings, and recalling Study 1's theorized mechanism by which reminiscence potentially influences subjective burden, caregivers adopting a detached style or approach to caring/coping may experience the following. When confronted with the theorized dissonance created by the expected increased salience of their partner's pre-dementia identity (as a result of reminiscing) detached caregivers may then recognize the relative permanence of the change, emphasizing it, and subsequently their endorsement of change remains relatively unchanged compared to baseline. This postulation highlights the potential importance of caregiver approach or coping in determining the likelihood of benefit to reminiscence and possibly other interventions. The importance of coping style has been previously identified in the literature as being a consistent predictor of burden (van der Lee et al., 2014).

The above discussion provides interesting prospective avenues of continued study from which to build from the findings of Study 2, highlighting the informative value and contribution of its findings to the literature on reminiscence for caregivers of persons with dementia. It should be noted, however, that without the theoretical basis and guidance of the model established in Study 1, the ability to make informed insights and explore theoretical interpretations of results would have been limited.

#### **5.4 Feasibility of Telehealth Videoconferencing for Service Delivery and Research (Study 3)**

The third and final study's objective was to assess the feasibility of the reminiscence activity delivered via Telehealth videoconferencing from Study 2, in order to inform future research and/or psychosocial interventions targeting informal caregivers of persons with dementia and the potential future use of the delivery medium. Study 3 involved examination of data collected during Study 2 related to rural and remote dwelling caregivers' experience participating in the intervention, including their satisfaction and attitudes toward the intervention process and the use of Telehealth videoconferencing as a mode of delivery. The process of delivering the reminiscence activity was also documented and described, in order to inform future design and development of research projects and interventions intended for Telehealth videoconferencing delivery. In general, the results of Study 3 indicated a high level of feasibility,

in terms of both practicality and acceptability of the Telehealth videoconferencing delivery format for the facilitated reminiscence activity and related research data collection, including equivalency of the format for these purposes with in-person delivery.

In order to determine feasibility, the practicality and acceptability of the format was examined. Regarding practicality, caregivers were found to gain considerable time, travel, and fuel cost savings as a result of using the Telehealth videoconferencing format versus being required to travel to the nearest major urban centre for specialized services. Similar savings were reported in previous literature on Telehealth use with rural and remote dwelling caregivers (e.g., Morgan et al., 2014). From a service provision and research standpoint, there were similar savings in travel, time, and financial costs in the conduction of data collection with the in-person group of caregivers.

In terms of acceptability, similar to previous findings on the use of the format with informal caregivers of persons with dementia (Morgan et al., 2014; Dal Bello-Haas et al., 2014) caregivers reported a high level of satisfaction with the quality of the experience provided by the equipment, staff, and interviewer/facilitator. All caregivers endorsed that they would use Telehealth videoconferencing again and recommend its use to others. Qualitative data also indicated themes of caregivers' appreciation of the time, travel, and stress reduction that results from the use of Telehealth, and the delivery formats facilitation of research participation. Additionally, quantitative analysis determined relative equivalency between the Telehealth videoconferencing format and in-person delivery in regard to protocol, caregivers' experience and attitude toward the reminiscence activity, and the measurement of outcome variables. In the literature, Telehealth mediums including videoconferencing have generally been found to be acceptable and equivalent in terms of the quality of interpersonal communication and the efficacy of psychosocial interventions (Richardson et al., 2009; Perle et al., 2011).

Overall, Study 3 demonstrated the good feasibility of the use of Telehealth videoconferencing for both service provision and research purposes with rural and remote dwelling informal caregivers of persons with dementia. Determining feasibility of psychosocial interventions and programs of research targeting this at-risk population is important due to the challenges to access faced by this geographically restricted population. While the relative equivalency of format for psychosocial intervention has support in the literature, fewer studies have examined its feasibility for use as a research platform. The results of Study 3 lend important



support to the continued and expanded use of the Telehealth videoconferencing medium in order to overcome the challenges faced by rural and remote caregivers.

### **5.5 Limitations**

General limitations of the findings of the current research project were as follows (for more detailed discussion of Study-specific limitations see previous individual study limitation sections). First and foremost, the population and sample factors which limited the statistical power to detect potentially significant results in both Study 1 and 2. In Study 1, there was likely insufficient power to simultaneously detect, via multi-mediational analysis, the expected sequential mediational roles of intimacy and quality of relationship in the model of perceived change in person with dementia identity and burden. Although this limited the ability to demonstrate the complete Study 1 model of identity and burden, both variables were identified as significant mediators through separate single mediational analyses. This increases the likelihood of a Type II error during the multi-mediational model analyses and, along with the high degree of correlation between the measures of intimacy and quality of relationship, is possibly indicative of the validity of the complete multi-mediational model.

A small sample size, in addition to limiting the power to detect significant results in Study 2 as well, also limited the inclusion of additional outcome variables in the evaluation of the efficacy of the reminiscence activity. Measures of quality of life related variables such as general life satisfaction, depression, anxiety, and general stress would have been informative and may have demonstrated change due to the reminiscence activity. Including the same measures as previous evaluations of Reminiscence Therapy for caregivers would have allowed for better comparison and interpretation of results in the context of the findings of other studies such as Woods and colleagues RCT trial (2012). Similarly, measuring and controlling for other variables known to be associated with the subjective burden such as caregiver gender, type of relationship, coping style or caregiver approach, dementia subtype, and degree of problem behaviors exhibited by the person with dementia may have revealed significant change in the target outcome variables such as burden. That said, there is literature suggesting that caregiver burden may be intractable to specific intervention due to its complexity and the broad and global aspects of caring it captures (Acton & King, 2001). Thus, alternative outcome measures may be more amenable and/or sensitive to intervention.

A potential compromise to the lack of quantitative measures would have been to include more extensive qualitative data collection regarding both potential outcome variables such as stress and anxiety, and control variables such as coping style and problem behaviours. In the current project, while adopting a greater qualitative approach may have allowed for better insight in the outcome of the reminiscence activity and the interpretation of the quantitative data collected, the added time commitment on the part of the participants and thus risk of added stress and burden, as well as the limited availability of the Telehealth platform, would have discouraged doing so. Future studies should aim to use considerably larger samples in order to include analyze more complex models of burden and include a more comprehensive list of outcome and control variables. They should also attempt to make more extensive use of mixed method designs. That said, it is important to limit participant time commitment and load, especially in the case of caregivers of persons with dementia. This is due to the considerable challenges to scheduling and respite presented by their caring responsibilities. The potential for added stress merely as a result of participation should be carefully considered and avoided as it can taint results and cause undue harm and distress to participants.

In addition to small sample size and limited inclusion of important variables, the measure of perceived identity change utilized may have limited the ability to capture the impact of the reminiscence activity. Despite the positive signs indicating relatively good face, concurrent, convergent, and predictive validity of the rating scale measure, identity is a complex construct with no definitive definition. Given the relative lack of published scales of identity change in general, and specifically scales designed to measure identity change of an individual as *perceived* by others, the scale used in the current project may provide a good starting point for further development and validation of a tool for measuring perceived identity change.

Combining the data from both the in-person and Telehealth delivery groups also created a potential threat to the analysis of Study 2. Though research protocol, variable means, and data on participant experience of the reminiscence activity appeared largely equivalent across delivery formats, it is possible that this difference in standardization influenced the effect of the activity and thus pose a threat to the validity of the analysis. Nevertheless, in light of the evidence pointing toward general equivalence from Study 2 as well as encouraging evidence reported in the literature (e.g., Richardson et al., 2009; Perle et al., 2011), it was believed that the benefit of

combining the samples to increase statistical power outweighed the potential effect of error due to differences in delivery format.

As with any questionnaire data, social desirability bias may have influenced caregiver responses to questions regarding their enjoyment of the reminiscence activity, interest in participating in the future, and satisfaction with the Telehealth format. Additionally, generalizability of the results of the studies to non-rural or remote dwelling caregivers may also be affected, given the unique risks and challenges inherent to this population.

Despite these general limitations, it is believed the results of the current project are sufficiently robust and provide valuable insights into the role of identity change as a predictor of subjective caregiver burden in dementia, the efficacy of reminiscence based efforts to address caregiver burden, and the feasibility of the Telehealth videoconferencing format.

## **5.6 Conclusion**

The current research project makes several novel and important contributions to the literature on identity change in dementia and its role in the prediction of subjective caregiver burden among informal caregivers. It further offers additional data on the efficacy of reminiscence based activities and the feasibility of Telehealth videoconferencing delivery for provision of such service, as well as its appropriateness as a research tool.

Study 1 provided quantitative evidence of caregivers' perceived identity change in their care partners with dementia and demonstrated support for the *theorized* model of caregiver burden and a theoretical basis for the potential efficacy of reminiscence interventions. Using the model established in Study 1 as a guiding framework, Study 2's evaluation of a proven basic reminiscence activity failed to demonstrate the expected impact on caregivers' perception of identity change in the person with dementia or caregiver outcomes such as intimacy, quality of relationship, or caregiver burden. Thus, the potential for a Type II error notwithstanding due to sample size, the outlook for the continued use of reminiscence based interventions for informal caregivers of persons with dementia appears somewhat dubious, at least in terms of a blanket application across informal caregivers. Finally, Study 3 described Telehealth videoconferencing's feasibility as a practical and acceptable delivery format for reminiscence activities and research with rural and remote dwelling caregivers.

In addition to these contributions to the literature, a strength of the project was its development and use of a theoretical model to guide the selection design and implementation of

the reminiscence activity of Study 2, as well as creating theory-driven selection of outcome variables and creation of study hypotheses. The strong theoretical basis also served as a framework from which to interpret study findings and integrate the broader literature.

Delivery format consideration was also a major part of the project given the rural and remote dwelling caregiver sample used. Ensuring accessibility of the reminiscence activity was a key factor in evaluating its efficacy by controlling for the potential added stressors of travel and time commitment that may have affected caregiver participation outcomes. The use of technology to facilitate ease of access for caregivers was also a vital component in ensuring the generalizability of the findings to, and feasibility of, any potential real-world application.

Future research on identity and burden in the context of informal caring for persons living with dementia should aim to replicate these results while addressing the identified limitations of the current project, and utilize and build upon the supported Study 1 model. Although sample size was a major limitation, the lack of inclusion of potentially important variables was also a shortcoming. In particular, the results of the project also pointed to the potential importance of the heterogeneity in caregiver approaches to caring and/or coping with changes in the person with dementia. Future intervention evaluations should thus attempt to control for coping style or approach to caring when analyzing caregiver outcomes, such as burden. Nevertheless, it may be that caregiver burden is too complex or global to be alterable by individual targeted interventions and intervention research should perhaps focus on altering and improving caregiver coping strategies instead. Regardless of the intervention target, however, it is important that, as in the current project, a theoretical framework be used to guide the research and that accessibility and use of technology platforms for delivery and data collection be considered.

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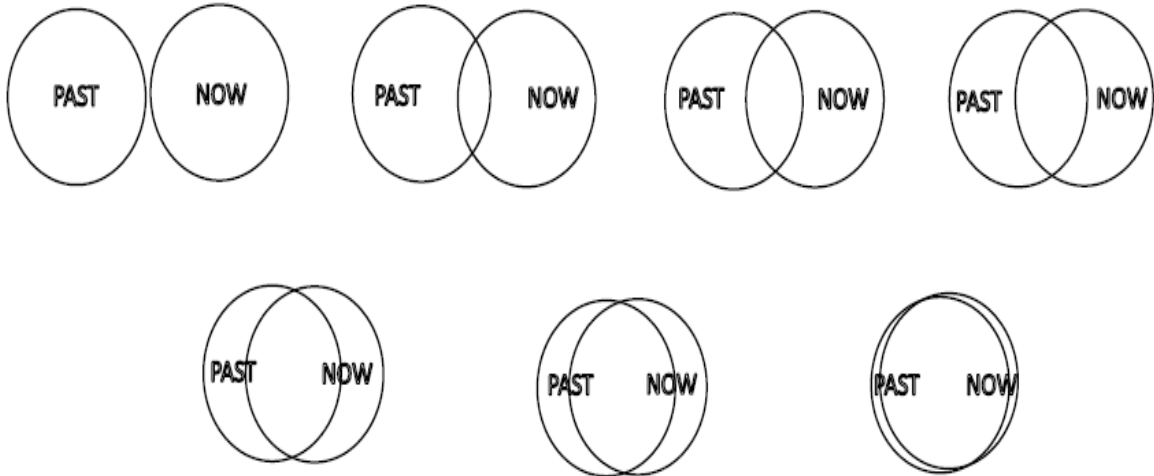
APPENDIX A

*Inclusion of the Self in the Other Scale and rating scale of Perceived Identity Change*

Name: \_\_\_\_\_

Date: \_\_\_\_\_

Please circle the picture below that best represents the degree to which you currently view your (*spouse, partner, loved one, relative, friend, etc.*), as they are now, to be the same person as they were in the past, before their difficulties began.



Do you feel your (*spouse, partner, loved one, relative, friend, etc.*) is different from who they were in the past, before their difficulties began?

(Circle) Yes / No

If yes, to what degree would you say they have changed?

0 -- 1 -- 2 -- 3 -- 4 -- 5 -- 6

No Change      Medium Change      Extreme Change

## APPENDIX B

### Self-Identity in Dementia Questionnaire

#### 1. In your opinion which family relationship is most important to your care-partner?

---

**In your opinion, how important was this relationship to your care-partner in the past, before they started having difficulties related to dementia? (circle one)**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

**In your opinion, how important is this relationship to your care-partner now, in the present?**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

#### 2. What was your care-partner's occupational role (including homemaker) in the past? (If multiple, choose the most important)

---

**In your opinion, how important was this occupational role to your care-partner in the past, before they started having difficulties related to dementia? (circle one)**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

**In your opinion, how important is this occupational role to your care-partner now, in the present?**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

#### 3. What was your care-partner's important leisure activity/hobby in the past? (If multiple, choose the most important)

---

**In your opinion, how important was this leisure activity/hobby to your care-partner in the past, before they started having difficulties related to dementia? (circle one)**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

**In your opinion, how important is this leisure activity/hobby to your care-partner now, in the present?**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

#### 4. What was an important attribute/trait/accomplishment of your care-partner? (If multiple, choose the most important)

---

**In your opinion, how important was this attribute/trait/accomplishment to your care-partner in the past, before they started having difficulties related to dementia? (circle one)**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

**In your opinion, how important is this attribute/trait/accomplishment to your care-partner now, in the present?**

1. Not important at all    2. Not very important    3. Somewhat important    4. Fairly important    5. Very important

## APPENDIX C

### Burns Relationship Satisfaction Scale

Place a check (x) in the box to the right of each category that best describes the amount of satisfaction you feel in your relationship with your loved one currently.

	0 Very Dissatisfi ed	1 Moderately Dissatisfi ed	2 Slightly Dissatisfi ed	3 Neutra l	4 Slightl y Satisfi ed	5 Moderate ly Satisfie d	6 Very Satisfi ed
1. Communicati on and openness							
2. Resolving conflicts and arguments							
3. Degree of affection and caring							
4. Intimacy and closeness							
5. Satisfactio n with your role in the relationshi p							
6. Satisfactio n with the other person's role							
7. Overall satisfactio n with your relationshi p							
Total score on items 1- 7 ^							

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APPENDIX D

Prior Relationship Satisfaction Scale

Place a check (x) in the box to the right of each category that best describes the amount of satisfaction you feel in your relationship with your loved one prior to the onset of dementia/symptomatology

	Very Dissatisfied 0	Moderately Dissatisfied 1	Somewhat Dissatisfied 2	Neutral 3	Somewhat Satisfied 4	Moderately Satisfied 5	Very Satisfied 6	Sub Totals
1. Communication and openness								
2. Resolving conflicts and arguments								
3. Degree of affection and caring								
4. Intimacy and closeness								
5. Satisfaction with your role in the relationship								
6. Satisfaction with the other person's role in the relationship								
7. Overall satisfaction with the relationship								
Sub Totals								
Total Score								

APPENDIX E

**THE ZARIT BURDEN INTERVIEW**

Please circle the response the best describes how you feel.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always	Score
1. Do you feel that your relative asks for more help than he/she needs?	0	1	2	3	4	
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4	
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4	
4. Do you feel embarrassed over your relative's behaviour?	0	1	2	3	4	
5. Do you feel angry when you are around your relative?	0	1	2	3	4	
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0	1	2	3	4	
7. Are you afraid what the future holds for your relative?	0	1	2	3	4	
8. Do you feel your relative is dependent on you?	0	1	2	3	4	
9. Do you feel strained when you are around your relative?	0	1	2	3	4	
10. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4	
11. Do you feel that you don't have as much privacy as you would like because of your relative?	0	1	2	3	4	
12. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4	

13. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4	
14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4	
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses?	0	1	2	3	4	
16. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4	
17. Do you feel you have lost control of your life since your relative's illness?	0	1	2	3	4	
18. Do you wish you could leave the care of your relative to someone else?	0	1	2	3	4	
19. Do you feel uncertain about what to do about your relative?	0	1	2	3	4	
20. Do you feel you should be doing more for your relative?	0	1	2	3	4	
21. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4	
22. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4	
<b>Total Score (out of 88)</b>						

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APPENDIX F

**Intimacy Questionnaire I (PAIR)**

Please indicate how well the following statements describe your relationship as it is **RIGHT NOW, that is AT THE PRESENT MOMENT**. Circle your response.

	<b>Very Strong Disagreement</b>			<b>Very Strong Agreement</b>	
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
1. I have some needs that are not being met by my relationship.	1	2	3	4	5
2. I think that we share some of the same interests.	1	2	3	4	5
3. We have an endless number of things to talk about.	1	2	3	4	5
4. My partner disapproves of some of my friends.	1	2	3	4	5
5. I sometimes feel lonely when we're together.	1	2	3	4	5
6. I don't think anyone could possibly be happier than my partner and I when we are with one another.	1	2	3	4	5
7. We seldom find time to do fun things together.	1	2	3	4	5
8. My partner frequently tries to change my ideas.	1	2	3	4	5
9. Many of my partner's closest friends are also my closest friends.	1	2	3	4	5
10. I feel neglected at times by my partner.	1	2	3	4	5
11. My partner and I understand each other completely.	1	2	3	4	5
12. We enjoy the out-of-doors together.	1	2	3	4	5
13. I feel it is useless to discuss some things with my partner.	1	2	3	4	5
14. Having time together with friends is an important part of our shared activities.	1	2	3	4	5

	<b>Very Strong Disagreement</b>			<b>Very Strong Agreement</b>	
	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
15. My partner can really understand my hurts and joys.	1	2	3	4	5
16. Every new thing that I have learned about my partner has pleased me.	1	2	3	4	5
17. We like playing together.	1	2	3	4	5
18. I feel “put-down” in a serious conversation with my partner.	1	2	3	4	5
19. We have very few friends in common.	1	2	3	4	5
20. I often feel distant from my partner.	1	2	3	4	5
21. There are times when I do not feel a great deal of love and affection for my partner.	1	2	3	4	5
22. I can state my feelings without him/her getting defensive.	1	2	3	4	5
23. My partner has all the qualities I’ve ever wanted in a mate.	1	2	3	4	5
24. We enjoy the same recreational activities.	1	2	3	4	5
25. I share in very few of my partner’s interests.	1	2	3	4	5
26. When it comes to having a serious discussion it seems that we have little in common.	1	2	3	4	5
27. We usually ‘keep to ourselves.’”	1	2	3	4	5
28. My partner helps me clarify my thoughts.	1	2	3	4	5
29. We enjoy spending time with other couples.	1	2	3	4	5
30. My partner listens to me when I need someone to talk to.	1	2	3	4	5



APPENDIX G

Intimacy Measure II (SMD)

For each of the following items, fill in the circle (0) that best describes how **you feel about your relationship RIGHT NOW, that is, at THE PRESENT MOMENT**. Base your responses on your **first impressions** and **immediate feelings** about the item.

INTERESTING	0	0	0	0	0	0	0	BORING
BAD	0	0	0	0	0	0	0	GOOD
UNPLEASANT	0	0	0	0	0	0	0	PLEASANT
FULL	0	0	0	0	0	0	0	EMPTY
WEAK	0	0	0	0	0	0	0	STRONG
SATISFIED	0	0	0	0	0	0	0	DISSATISFIED
LONELY	0	0	0	0	0	0	0	FRIENDLY
STURDY	0	0	0	0	0	0	0	FRAGILE
REWARDING	0	0	0	0	0	0	0	DISSAPPOINTING
DISCOURAGING	0	0	0	0	0	0	0	HOPEFUL
ENJOYABLE	0	0	0	0	0	0	0	MISERABLE
TENSE	0	0	0	0	0	0	0	RELAXED
STABLE	0	0	0	0	0	0	0	UNSTABLE
HAPPY	0	0	0	0	0	0	0	SAD
STRESSFUL	0	0	0	0	0	0	0	PEACEFUL

APPENDIX H

Reminiscence Questions

What are your thoughts, feelings or comments regarding reminiscing about past positive experiences involving your care-partner today with the interviewer?

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How enjoyable did you find discussing memories of past positive experiences with the interviewer today?

1	2	3	4	5
Not at all	Not Very	Neutral	Somewhat	Very

In general, would you be interested in discussing positive past memories involving your care-partner with someone in a similar fashion as today?

1	2	3	4	5
Not at all	Not Very	Neutral	Somewhat	Very

In general, how do you feel about reminiscing about past positive experiences involving your care-partner?

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In general, reminiscing about past memories of positive experiences involving your care-partner makes you feel:

1	2	3	4	5
Very Sad	Somewhat Sad	No Feeling	Somewhat Happy	Very Happy

In general, how often do you reminisce about past memories of positive experiences involving your care-partner?

1	2	3	4	5
Never	Rarely	Sometime	Often	Very Often

APPENDIX I

TELEHEALTH SATISFACTION SCALE (Telehealth participants only)

How satisfied were you with:	Poor	Fair	Good	Excellent
1 The voice quality of the equipment?	○	○	○	○
2 The visual quality of the equipment?	○	○	○	○
3 Your personal comfort in using the Telehealth system?	○	○	○	○
4 The ease of getting to the telehealth department	○	○	○	○
6 The length of time of the interview.	○	○	○	○
7 The explanation of the process treatment by the Interviewer?	○	○	○	○
8 The thoroughness, carefulness and skillfulness of the researcher?	○	○	○	○
9 The courtesy, respect, sensitivity, and friendliness of the researcher?	○	○	○	○
10 How well your privacy was respected?	○	○	○	○
11 How well the staff answered your questions about the equipment?	○	○	○	○
13 Your overall experience at using Telehealth? i113	○	○	○	○
<p>Would you use Telehealth again?      <input type="checkbox"/> No  <input type="checkbox"/> Yes</p> <p>Would you recommend telehealth to another person?      <input type="checkbox"/> No  <input type="checkbox"/> Yes</p>	<p>Comments:</p> <hr/> <hr/> <hr/>			

## ***Participant Consent Form***

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**Project Title:** Reminiscence for Caregivers of Persons with Dementia: A Model of Burden and Delivery Consideration

**Researcher(s):** Joe Enright, Student Investigator, Graduate Student, Psychology, University of Saskatchewan, 306-966-1321, joe.enright@usask.ca

Megan O'Connell, Ph.D. RD Psych., Principal Investigator, Assistant Professor, Psychology, University of Saskatchewan, 306-966-2496, megan.oconnell@usask.ca

**Supervisor:** Megan, O'Connell, Ph.D. RD Psych

**Purpose(s) and Objective(s) of the Research:**

This research is interested in collecting information that will inform development of future interventions aimed benefitting caregivers of persons diagnosed with dementia. More specifically, it will look at the connection between the hardships experienced as a part of caring and certain characteristics of the relationship between the caregiver and their loved one with dementia. It will also involves the use of memories about positive past experiences.

Another component of the study looks at different methods of delivering services such as in-person and Telehealth videoconferencing delivery.

**Procedures:**

Participation will involve an interview with the student researcher (Joe Enright), which will take place either in your home or over the Telehealth Saskatchewan videoconferencing network at your local Telehealth site. During the interview you will first be asked to consent or decline to participate after reviewing this form. If you provide consent, you will then be asked to fill out several questionnaires regarding your perception of identity change, emotional connection, relationship satisfaction, and feelings associated with caregiving. Following this, you will be asked to discuss two past positive memories with the student researcher. Any personal details of this discussion regarding these past memories will not be recorded. You will then be asked to fill out the same set of questionnaires as before and one additional questionnaire regarding your satisfaction with the method of service delivery. In total, it is estimated that the interview will take approximately 1 to 1.5 hours of your time. After the initial interview you will be contacted by telephone for follow-up approximately one week later and you will be asked to provide answers to the same set of questionnaires one last time over the phone. It is expected that this follow-up interview will take 15 to 30 minutes of your time. Please feel free to ask any questions regarding the procedures and goals of the study or your role.

**Funded by:**

The funding for this project is in forms of scholarships and fellowships to Joe Enright.

**Potential Risks:**

As no personal identifying information will be on the study materials and no specific details of your discussion of memories will be recorded, and access to your data will be restricted to the researchers, there is minimal risk of a breach of privacy or confidentiality. Your information will be linked with other data collected through the RRMC clinical service only by use of a number code.

Sometimes people experience sadness or other emotional reactions when recalling past events. As you will be asked to recall positive experiences, we do not anticipate any significant experience of emotional or any other form of distress as a result of participation in this study. However, if you do experience any form of distress or discomfort during any part of the study, you are encouraged to bring this up with the student researcher immediately, or contact either of the researchers listed at the top of this page at any time. Dr. O'Connell is a registered psychologist and Joe Enright has received training and practical experience in clinical psychology and is supervised by Dr. O'Connell. Should you feel the need, you are also encouraged to contact Saskatchewan HealthLine by dialing 8-1-1 and ask to speak to a mental health professional. Following completion of your participation you will be provided with a debriefing form which will go into further detail as to what the study is investigating and how you can be kept informed of the eventual results of the study.

**Potential Benefits:**

The remembering of positive memories may not lead to any significant direct benefit to you, but the results of this study may be used to inform development of future beneficial services for caregivers of persons with dementia and their care recipients.

**Compensation:**

If you attend a Telehealth site for your initial interview, an honorarium of \$6 toward travel and parking expenses will be provided. Receipt of the honorarium will still occur in the event you choose to withdraw from the study at a later date.

**Confidentiality:**

Participation in this study is strictly voluntary and you have the right to withdraw at any time without any effect to future service and treatment by the Rural and Remote Memory Clinic. Should you choose to withdraw from the study all data collected from you up to that point will be destroyed if you so desire. To maintain privacy and confidentiality, interviews will be conducted privately, either in your home or over the secure Telehealth Saskatchewan network. Follow-up interviews will occur telephone. No video or audio recording of any kind will occur during the interviews. Your name and other identifiable information will not appear on any study materials (i.e., questionnaires) used for data collection. In lieu of your name, a number will be assigned to you and used to identify your data. A master list of participant names and their identifying numbers will be created and stored separately from the data. Only the researchers, Dr. O'Connell and Joe Enright, shall have access to the master list and collected data. Although the data from this research project will be published and presented at conferences, the data will be reported in aggregate form, so that it will not be possible to identify individuals. Moreover, the Consent Forms will be stored separately from the questionnaire forms, so that it will not be possible to associate a name with any given set of responses. Please do not put your name or other identifying information on the questionnaires.

**Storage of Data:**

All questionnaire data will be stored in a locked cabinet in a locked room on the campus of the University of Saskatchewan. The master participant list and consent forms will be stored in a separate location, in a locked cabinet of a different locked room on the University of Saskatchewan campus. The data collected during the study will be kept for a period of 5 years under the custodianship of Dr. O'Connell. After data are no longer in use, they will be destroyed beyond all recovery.

**Right to Withdraw:**

Your participation is voluntary and you can answer only those questions that you are comfortable with. You may withdraw from the research project for any reason, at any time without explanation or penalty of

any sort. Whether you choose to participate or not will have no effect on your access to services (for example at the Rural and Remote Memory Clinic) or how you will be treated. Should you wish to withdraw, please notify the researcher by telling them directly or contacting them using the information at the top of page 1. In the event you do withdraw, any data collected from you up to that point and all record of your participation will be destroyed. You may withdraw your participation at any point from now until August 30, 2015. After this date, you may still request that your data be withdrawn, however, your data may already have been used in the presentation of results of the study.

Having attended the Rural and Remote Memory Clinic in the past, you may have been provided with services directly or under the supervision of the lead researcher, Dr. Megan O'Connell. In order to ensure that your decision to participate in/not participate in/ or withdraw from the study will in no way affect your relationship with Dr. O'Connell or future services received from the Rural and Remote Memory Clinic, Dr. O'Connell will not be informed of the identity of those who decline to participate or withdraw from the study. Should you agree to participate, J. Enright will avoid informing Dr. O'Connell of your choice of participation unless absolutely necessary. Additionally, if you received service at the Rural and Remote Memory Clinic between September of 2013 and June of 2014, it is possible you may have come into contact with the student researcher, Joe Enright, who was a practicum student under the supervision of Dr. O'Connell during this period. Though the student researcher may have worked with you, his practice placement at the Rural and Remote Memory Clinic has concluded and he will not be involved in the provision of services at the Rural and Remote Memory Clinic in the foreseeable future.

**Follow up:**

To obtain results from the study, please inform the researchers of your desire to be provided with a summary of the results. A summary sheet will be offered to you and you also have the option of being informed of public events where the results of the study will be presented, and information regarding any future publication related to the study and its findings.

**Questions or Concerns:**

If you have any questions or concerns please contact the researcher(s) using the information at the top of page 1. This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office [ethics.office@usask.ca](mailto:ethics.office@usask.ca) (306) 966-2975. Out of town participants may call toll free (888) 966-2975.

**Continued/On-going Consent:**

In order to ensure that you fully consent to each stage of participation, you will be asked to reaffirm your consent at the end of this interview. This form will also be reviewed with you prior to the follow-up telephone interview described above, and you will be given the opportunity to consent or withdraw again at that time.

Your signature below indicates that you have read and understand the description provided; I have had an opportunity to ask questions and my/our questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

***A copy of this consent will be left with you, and a copy will be taken by the researcher.***

APPENDIX K  
Psychometric Properties Table

<i>Measure Name</i>	<i>Author</i>	<i>Description</i>	<i>Psychometric Properties</i>
Zarit Burden Interview (ZBI)	Zarit et al. (1980)	Measures caregivers' perceived level of burden associated with caregiving. Consists of 22 5-point rating scale questions pertaining to caregiver's perception and feelings related to various aspects of caregiving. Scores range from 0-88, with higher scores indicating a higher level of perceived burden.	Internal consistency (Cronbach's $\alpha = 0.88 - 0.94$ ; Bédard et al., 2001; O'Rourke & Wenaus, 1998; O'Rourke & Tuokko, 2003).), predictive validity for care recipient behavioral problems and caregiver depression ( $R^2 = .57$ , $p < .001$ ; Hebert et al., 2000)
Inclusion of Other in Self: Perceived Change in Identity Scale (IOS)	Original IOS: Aron, Aron, & Smollan (1992)	Asks participants to choose from seven pictorial representations of gradating pairs of overlapping circles. These pairs range from completely separate circles (complete difference) to mostly overlapping circles (no difference). In this application of the IOS for the present study, caregiver participants will be asked to choose the pair of circles most representative of their perception of the relationship between the care recipient's current (post-dementia onset) self and prior (pre-dementia onset) self. Scored from 0-6, with higher score indicating greater change.	N/A
The Burns Relationship Satisfaction Scale (BRSS)	Burns & Sayers (1988)	The BRSS is a 7 item questionnaire which asks participants to rate, on a 7-point rating scale, their level of satisfaction with various facets of their relationship with another person, including: communication, conflict resolution, affection and caring, intimacy and closeness, respective roles in	Internal consistency: coefficient alpha = .94 (Burns & Sayers, 1988). Convergent validity $r = .80$ (Locke-Wallace MAT), $r = -.89$ (Dyadic Adjustment Scale) $r = .91$ (Norton Quality of Marriage Index) (Heyman et al., 1993)



		<p>the relationship, and overall satisfaction. Higher scores indicate greater satisfaction. Pre-morbid quality of relationship between caregiver and care recipient will also be assessed using the BRSS, but instructions will be modified by asking caregivers to rate relationship satisfaction <i>prior</i> to the onset of dementia in care recipient. This modification is consistent with that described by Steadman et al. (2007).</p>	
Semantic Differential Scale of Relationship Warmth (SMD)	Alea & Bluck (2007)	<p>The SMD measures relationship warmth through the use of fifteen adjective-pairs listed as oppositions (e.g. lonely–satisfied) and placed at the opposing ends of a 7-point rating scale. The participants are then asked to rate how they currently feel about their relationship with the person with dementia.</p>	<p>Reliability at pre-condition measurement: Cronbach’s alpha = .95, at post measurement: Cronbach’s alpha = .97</p>
Personal Assessment of Intimacy in Relationships (PAIR)	Schaefer & Olson (1981)	<p>A 24 item scale measuring five aspects of intimacy including emotional, sexual, social, recreational, and intellectual intimacy, but items assessing sexual intimacy will not be administered to non-partner caregivers. Participants indicate their level of agreement to items on a 5-point rating scale. The PAIR reports individual sub-scale scores as well as a summed overall intimacy score with higher scores indicating a greater degree of intimacy. It also contains a social</p>	<p>Internal consistency: Cronbach’s alpha = .90 (at both pre and post measurement; Alea &amp; Bluck, 2007).</p>

		desirability scale with a suggested cutoff of 30.	
Self-Identity in Dementia Questionnaire	Cohen-Mansfield et al. (2000)	Assesses perceived changes in social identity. Caregivers are asked to identify the most important role of the care recipient from each of four role domains of self-identity including professional, family/social, hobbies/leisure time activities, and personal attributes/achievements/traits. They are subsequently asked to rate on a 5-point rating scale (“not at all important” to “very important”) how important the role is to the care recipient, in the past prior to the onset of difficulties, and now in the present day.	Internal consistency for professional, family, hobbies/leisure time activities, and attributes/trait/achievements role identity scales had Cronbach alphas of 0.82, 0.83, 0.82 and 0.84, respectively (Cohen-Mansfield et al., 2000). Test-retest reliability was examined in a subset of participants averaging an agreement of 86.7% ( $n = 10$ ; Cohen-Mansfield et al., 2006).
Telehealth Satisfaction Scale (TeSS)	Morgan et al. (2014)	A 10-item scale measuring satisfaction related to specific aspects of services administered via Telehealth videoconferencing. Participants rate items on a 4-point rating scale (1 = poor, 2 = fair, 3 = good, 4 = excellent). Scores range from between 10 to 40; higher scores indicate higher satisfaction.	Internal consistency (Cronbach’s alpha = 0.90; Morgan et al., 2014)