SUPPORTING PERSONHOOD WITHIN DEMENTIA CARE: THE THERAPEUTIC POTENTIAL OF PERSONAL PHOTOGRAPHS

by

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ABSTRACT

This qualitative study explored the potential of a photo-based biographical tool designed to familiarize long-term care (LTC) staff with residents' life stories to support personhood and contribute to person-centred dementia care. Literature on personal photography, life story work, reminiscence, and social constructionist theory in relation to discourses of personhood and self informed this investigation. Data generation entailed creation of two *Visual Life Stories (VLS)*, produced through guided conversations with residents with dementia and their families, and subsequent focus groups conducted with staff from two care facilities that assessed feasibility and therapeutic value of this tool within the LTC context. Analysis revealed that: a) visual prompts supported residents' ability to recall and share their life stories, b) family members participation was integral to *VLS* production, and c) despite positive staff feedback on the value of *VLS*, micro-level demands and macro-level policies were perceived as barriers to implementation.

DEDICATION

To Glen—for his continuous support and inspiration.

And to the many generous individuals who have shared their life stories with me over the last decade. In the process, they have taught me so much about how to live well and age gracefully.

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CHAPTER ONE: INTRODUCTION

Context

Estimates from the Canadian Study on Health and Aging (CSHA Working Group, 1994) suggest that by 2021, the healthcare system and affected families can be expected to care for over 500,000 Canadians with dementia, a group of diseases characterized by a progressive decline of mental functions and involving symptoms including memory loss, disorientation, and functional impairment. A recent Canadian study (Canadian Study on Health and Aging Working Group, [CSHA], 1994) suggests that the incidence of dementia within resident populations is increasing significantly. Long-term care (LTC) facilities are defined in the National Population Health Survey as "public or private residential care facilities or hospitals with at least four beds, that provide care for periods of at least six months. Hospitals, nursing home and residential facilities for people with disabilities are examples" (Trottier et al., 2000, p. 51). In response to the phenomenon highlighted by the CSHA statistics (1994), gerontologists have produced a growing body of literature that calls into question current dementia care delivery—perhaps, most notably that which relies on what Kitwood (1997) terms the *standard paradigm* or tendency to focus on the treatment of symptoms to the relative exclusion of important psychosocial aspects of the disease. To address this problem, many healthcare practitioners and researchers advocate for the therapeutic necessity of addressing the subjective experience and perceptions of the person living with dementia (Bond, 1999; Cotrell & Schulz, 1993; Gibson, 1994; Kitwood, 1997; Noelker & Harel, 2001, Taft et al., 1993; Woods & McKiernan, 1995).

Practitioners and researchers in the field have further suggested that the biomedical model's inability to meet the needs of individuals living with dementia is rooted in its failure to prioritize the *person* that exists within the disease process. A fundamental aspect of foregrounding the person behind the disease, as described by Kitwood (1997), involves the need for a new model of dementia care that hinges on an understanding of *personhood* as "a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (p. 8). Kitwood (1997) argues that the failure to recognize personhood, manifest in the attitudes and behaviours of others is, in part, responsible for "the catastrophic series of changes in the brain that lead to the death of brain cells" (p. 40). Kitwood (1992) maintains that there is a need for dementia care that "looks far more to human than to medical solutions" (p. 2). Moreover, it is argued that a limited (biomedical) focus on the neurological aspects of dementia fails to capitalize on the therapeutic opportunities that exist within institutional settings.

Much of the paradigmatic shift away from a biomedical emphasis advocated by Kitwood rests on a move toward *person-centred care*. First linked with dementia care by Kitwood (Brooker, 2004), the concept of person-centred care has become pervasive in the field. Brooker (2004) claims that Kitwood used the term person-centred to "bring together ideas and ways of working that emphasized communication and relationships" (p. 215). In both research and practice, a key facet of person-centred care, care that affirms personhood (Downs, 2005, personal communication), is the importance of social contexts in which persons with dementia live. As Woods (1999) argues, there is growing appreciation for the importance of the social environment in which care is provided and received.

Purpose

Within the field of gerontology, a growing body of research highlights the fact that a biomedical view is both the dominant lens through which we currently view dementia (Kitwood, 1997) and the platform upon which long-term dementia care is based. One of the problems with the biomedical model of care is that it tends to downplay the therapeutic importance of the whole person (Woods, 1999), thereby impeding caregivers' ability to consider various psychosocial factors affecting the person with dementia. To counter this trend, this study begins from the research premise that residents' personal photographs might be used to help develop a new frame of reference for formal caregivers to, for example, better understand or interpret so-called dementia behaviours, in part, through facilitating communication. In short, this study proposes that the use of personal photographs will facilitate caregivers' recognition of residents as unique individuals with unique life histories. In this way, it is argued, formal caregivers might be better able to *re-position* (Sabat et al., 2004) residents and help construct a reality that supports personhood within dementia care. Although the use of photographs in the field of gerontology is in its infancy (Shenk & Schmid, 2002), this investigation seeks to draw on recent literature to add to our understanding of how personal photographs might contribute to improved dementia care. Recognizing the importance of social milieu (Sabat, 1998) in the overall health and wellness of residents of long-term care settings, this study proposes to develop and explore the therapeutic potential of a biographical tool incorporating residents' personal photographs that is designed to increase long-term care staff members' access to residents' biographical information or life stories.

Research Questions

Working from the premise that personhood is a vital component of dementia care, this study seeks to develop an understanding of the therapeutic potential of residents' personal photographs within long-term care by exploring the following three interrelated research questions:

1. How might formal caregivers' increased familiarity with residents' biographical information, through their personal photographs, support personhood and encourage person-centred care?

2. How might the incorporation of *Visual Life Stories* (*VLS*) in institutional care respond to the expressed needs of formal caregivers? Is there a demand among formal caregivers for increased access to residents' biographical information?

3. What organizational opportunities for or barriers to implementation of the *VLS* are identified by formal caregivers?

CHAPTER TWO: LITERATURE REVIEW

A search of the literature pertaining to the exploration of therapeutic potential of

personal photographs within dementia care was conducted using the following keywords:

dementia, dementia care, life story, person-centred care, personhood , photography and

visual methods, reminiscence, and self. Although increasing in number, relatively few

studies were found on the use of residents' biographical information to support

personhood or contribute to more person-centred dementia care. Even more rare is

research that incorporates the voice or perspective of the person with dementia. Similarly,

studies exploring the use of personal photographs within dementia care are scarce and

largely confined to reminiscence-based research. This review will begin with the

literature on personhood theory, an emerging field within dementia studies.

Personhood Theory and Dementia Care

According to Kitwood and Bredin (1992), the presence of dementia in

contemporary society "raises very deep questions about what it means to be a person" (p.

274). These researchers suggest further that the fundamental question of what makes 'a

person' is questioned more frequently with the progress of dementia, particularly in the

context of institutional care. Memory loss, confusion, increased dependency, and the

range of symptoms that characterize dementia generally interfere with society's ability to

see the person—often producing stereotypical conceptions of, for example, a person with

dementia, as someone experiencing a 'living death.' Personhood theory challenges us to

question both current understandings of dementia and the care delivery that prioritizes the

neurological deficits of dementia. Jonas-Simpson (2001) warns that the tendency to treat a care recipient as if he or she were a "non-person leads to care that is paternalistic, task and disease-oriented, and functional rather than humanistic, person-centred, and quality enhancing" (p. 306). The consequences of this, Kitwood (1997) suggests, are manifested in the downward spiral of the individual's psychosocial acuity. This situation is exacerbated by institutionalization. Thus, increased attention to the social and psychological aspects of care delivery (such as those dealt with in this study) is necessary to come to terms with and mitigate the consequences of neurological impairment (Kitwood, 1997).

Personhood

This study uses Kitwood's (1997) relational definition of personhood that emphasizes interdependence (Allen & Coleman, 2006) of staff and residents and highlights the critical role care providers might play in the preservation of personhood of individuals in their care. Although AD and related dementias generally have a progressively negative impact on an individual's ability to communicate and may lead to the tendency of caregivers to dehumanize or depersonalize care recipients, this definition highlights the vital role played by social relationships between formal caregivers and residents in the well-being of persons with dementia.

Much of the research in the area of personhood theory highlights the importance of communication in the maintenance of personhood. That is, despite the progressive deterioration of their cognitive abilities, persons living with dementia "continue to be social beings in need of communicating" (Romano, 2004, p.81); it is crucial, therefore, to

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recognize the need to facilitate communication within dementia care, particularly

between persons with dementia and the formal caregiving staff. Brooker (2004) stresses

how the development of relationships within dementia care occurs through "day to day

interactions," (p. 218) rather than expressly through activity programs or psychotherapy

sessions. Thus, researchers' ability to discover innovative approaches to enable

caregivers to determine the needs and preferences of persons living with dementia

represents an extremely challenging and vital part of dementia care work.

Person-centred Dementia Care

Allen and Coleman (2006) state that the theory of person-centred care, as

constructed by Martin Buber (1958), and developed by Tom Kitwood (1997), is the basis

of the "new culture of dementia care" (p. 209). Brooker (2004) states that "person-

centred care is about seeing all people as valued" (p. 216). Brooker and Surr (2005) offer

that the maintenance of personhood is in fact the "primary outcome of person-centred

care for people with dementia" (p. 21). Although the term has been applied to other

populations and used differently within the literature, in this study, person-centred

approaches to dementia care represent an attempt to confront what Kitwood (1997) refers

to as the "malignant social psychology" (p. 4) that surrounds dementia, and dementia

care. Other researchers, such as Brooker and Surr (2005), Crisp (1999), Kitwood and

Bredin (1992), Sabat (1998), and Woods (1999), suggest that dementia does not

necessarily entail an inevitable trajectory toward "global deterioration" (Kitwood &

Bredin, 1992, p. 280), but rather, that persons with dementia can achieve relative levels

of well-being, despite living with a dementing illness (Kitwood, 1993, 1997).

Furthermore, gerontological studies of personhood demonstrate the reciprocal benefits that residents and formal caregivers accrue when an institution foregrounds person-centred policies and practices (Coker, 1998; Crisp, 1999).

Promoting a shift away from custodial care toward person-centred care, Ronch (2004) speculates that the impact of the institution is negative for both staff and residents and maintains that a *re-framing* of the staff-resident relationship leads to better care: he discusses the "humanization of the culture of care" (p. 75). In a similar vein, Crisp (1999) maintains that conventional care practices reinforce society's negative perceptions toward aging and dementia such that caregiver's primary interactions with residents are profoundly (negatively) impacted. The failure of conventional care practices to address residents' psychosocial needs is also highlighted by Wellin and Jaffe (2004). They point out that, because personal care duties, such as bathing and toileting, must be documented for long-term care licensing inspectors, violations in this realm of care delivery and not those of "socioemotional dimensions of care...expose facilities to stiff penalties" (p. 284).

In an attempt to move beyond the above problematic, this study builds on the work of Crisp (1999), Kitwood (1993; 1997), McIntyre (2004), Ronch (2004), and others noted above, to discuss personhood in relation to the role of institutional support. In particular, this study offers a tool to potentially strengthen humanizing communications and interactions between staff and residents, and in so doing, it presents a balanced approach to care that clearly deviates from the prioritization of "bed and body work" (Gubrium, 1975, cited in Vittoria, 1998, p.92).

Dementia Care and "Problem Behaviours"

Within institutions, the demands placed on formal caregivers to address cognitive impairment are considerable. The fact that institutionalization presents difficulties for residents, who, as a result of dementia, are facing the devastating challenges that accompany the disease, such as social isolation, loneliness, and estrangement (Gibson, 1994), further complicates the situation. Examples of dementia-related behaviours include agitation, wandering, and aggression (Gibson, 1994; Ice, 2002; Kitwood, 1997; Noelker & Harel, 2001; Taft et al., 1993; Woods & McKiernan, 1995; Woods, 1999).

These types of challenging behaviours might be seen to be "the result of unmet needs" (Cohen-Mansfield cited in Bourgeois, 2002, p. 137). Kolanowski and Rule (2001) present a conceptual model developed by a group of nurse researchers, the "Need-Driven Dementia-Compromised Behavior Model" (p. 14) within which dementia-related behaviours are said to "arise in pursuit of a goal, or as an expression of an unmet need" (p. 15). These conceptual studies assert that neglecting psychosocial needs can exacerbate the challenges of living with and caring for persons with dementia. Volicer and colleagues suggest that, while there are a number of complex psychosocial factors at play, "agitation attributed to boredom may reflect an inability to access words to explain the need for purposeful activity" (cited in Bourgeois, 2002, p. 137).

While the biomedical approach to dementia care has resulted in the prioritization of "the management of undesirable behaviors" (Cotrell & Schulz, 1993, p.205), increasingly, non-pharmacological interventions are sought to prevent and manage dementia. In general, person-centred research strives to be proactive, attempting to locate, and ideally to offset, the source of dementia-related behaviours. Ice (2002) similarly

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underscores the need to move beyond a focus on problem behaviours, suggesting that researchers need to develop therapeutic resources or tools whose impact is broader in scope than currently provided by the parameters of activity programming.

Chaudhury (2002b) offers just such a resource to assist formal caregivers to better understand and address challenging resident behaviours: the *place-biosketch*. Residents' biographical information (gleaned from discussions with family members) and memories of particular places (e.g. childhood homes, schools, neighbourhoods) are compiled into a four-page account that included text and photographs. Research into this approach suggests that staff recognize the value of residents' biographical, place-based knowledge and see it as a potential resource for better understanding resident behaviour and, thereby, guiding care planning and practice. The *place-biosketch* is a biographical approach, distinguishable from activity-based interventions; as such, it has the potential to foster more humane staff-resident relations. In the words of a nurse manager cited in the study, "The biosketches made me look at them as people I know, and this helps me interact with them with feeling—not just doing a job" (Chaudhury, 2002b, p. 45).

With the quest to effect change in the culture of care (Kitwood, 1997, p. 42) through "a more fluid approach to engaging residents than simply providing planned activities programs" (Ice, 2002, p. 355), this study offers an innovative approach to identifying how caregivers can better support residents' personhood. This study suggests that a significant barrier to improved dementia care stems from the tendency to perceive 'problem behaviours' as the "property of the person with dementia, rather than as arising in interaction with the care environment" (Woods, 2001, p. S12). Thus, a facet of this

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study attempts to address the links between dementia-related behaviours and the care environment vis-à-vis personhood of care recipients.

Dementia Care and the Self

The self has been studied extensively across a variety of disciplines, such as philosophy, psychology, and anthropology, and as de Medeiros (2005) states, definitions of the term vary widely across academic disciplines. In gerontology, the notion of the loss of self is prevalent in discussions of aging, particularly in relation to dementia. Basting's (2003) findings that the "the cultural value of the self is deeply connected to one's usefulness to society" (p. 96) is critical to understanding how persons with dementia are stigmatized by popular notions of the loss of self. Basting contends that a symbiotic relationship currently exists in Western society between "memory and identity" (p. 97). If "we cling to the mistaken notion that personal memory alone constitutes selfhood" (Basting, 2003, p. 97); as much of the research devoted to managing dementia-related behaviours purports; then there is a tendency to link screaming, wandering, and agitation to individual deficiencies, the 'loss of self' characterizing dementia, rather than considering the many social factors aggravating the situation.

To redress this multifaceted tendency, the study draws on seminal work by William James (1918) and G.H. Mead (1934) that defines *self* within social contexts. The self, as defined by Mead (1956), is "a character which is different from that of the physiological organism proper" (p. 212); it "comes into being through social processes" (p. 212). This study is based on the notion of the self, not as a function of biology but as a social construct dependent on social experiences and relationships. From this perspective,

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a person's conception of self is rooted in his or her social setting, the context in which he or she lives. Moreover, Mead's (1956) suggestion that, "the word, 'self,' ... is reflexive, and indicates that which can be both subject and object" (p. 213). Aquilina and Hughes (2006) present a distinction between "inner" and "outer" selves, with the former denoting "the private and subjective experience of being self-aware," and the latter, signifying "public observable aspects of self, which depend on psycho-social structures including social relations" (p. 150). The *self* thus defined is a fundamental concept in discussions of aging, and within this study, represents a concept that not only bridges the psychosocial realities of living in care, but also provides an important impetus for rethinking conventional modes of dementia care.

Herskovits (1995), in her exploration of the current conception of AD that emerged in the 1970s, states that "the overwhelmingly dominant pernicious effect of the current Alzheimer construct is the dehumanization or debasement of 'self'" (p. 152) that has contributed to a "*monsterizing* of senility," (p. 153) whereby individuals suffer the loss of characteristics associated with being human. This debate suggests that behavioural challenges associated with AD may, in fact, stem from how this disease is commonly depicted as a form of social death (Robertson, 1991, as cited in Herskovits, 1995). The loss of self that is thought to accompany dementia is popularly equated with the death of the person (Aquilina & Hughes, 2006). This study however, works with research that focuses on the possibility of 'continuity in selfhood' (Chaudhury, 1999; Cohen-Mansfield et al., 2000; Sabat, 1999) and the belief that "the self is a product of ongoing construction" (Crisp, 1999, p. 101); its conceptual framework acknowledges the

important role that caregivers play in supporting the self (Beach & Kramer, 1999; Small et al., 1998).

Sabat and Harré's (1992) influential work on selfhood within dementia suggests that throughout our lives we engage in constructing our self-identity. Similarly, Crisp (1999) refutes the popular idea of 'loss of self' in dementia. Both studies suggest that, as Crisp states, positive conviction "makes it possible for us to recognize that people who have dementia are still engaged in the process of defending, negotiating and reconstructing an identity for themselves" (p. 102). By implication, caregivers' responsiveness to residents' selves must extend beyond the physiological manifestations of aging (and disease) to consider appropriate care for older adults with dementia. To this end, Sabat (2002) offers a "social constructionist tripartite approach to personhood" (p. 109) that focuses on personal identity (Self 1), mental and physical attributes (Self 2); and the socially presented selves or personae (Self 3).

Of the three types, Self 3 is of particular importance to this study, because, as Sabat (2002) suggests, Self 3 "requires the cooperation of at least one other person" (p. 93) and is therefore dependent on the social situation. Sabat (2002) contends that social interactions often place persons with dementia in a position of vulnerability, in which they are seen as *confused* or *demented*. In institutional settings, the cooperation required for residents to construct "valued Self 3 personae"(p. 109) necessitates that caregivers resist the tendency to view and respond to residents according to their clinical diagnoses. This objective might be facilitated through providing caregivers access to residents' biographical/life history information, which, in turn, might allow both to work together to

enable residents to develop a stronger sense of self, or so this study will attempt to support.

Cohen-Mansfield and colleagues' (2000) recent qualitative investigation into self-identity and dementia reveals how self-identity might change in the course of the disease and how awareness of this process might be used to improve residents' quality of life. Findings from Cohen-Mansfield and colleagues' (2000) study reveal that staff members are eager to learn more about residents' past experiences and personhood; paradoxically, however, information regarding residents' identities was not readily available in either of the two nursing homes studied. In fact, the informants suggested that there might be a number of ways to better support residents' selves: using photographs; facilitating conversations; listening to stories; or recalling memories. The authors, therefore, contend that a process that enables caregivers to understand a resident's past self-identities might enhance his/her sense of self or personhood in the present.

In a similar investigation, Vittoria (1998) explores how the self of residents of an Alzheimer special care unit (SCU) might be preserved. Vittoria (1998) presents a model of *communicative care*, in which "selves are evoked and preserved and identities are constructed and respected" (p. 92), as a social-psychological alternative to the medical model of care. Vittoria (1998) suggests that current staff-resident relations suffer from the hierarchical structure inherent in institutions and, as a result, are often adversarial in nature. Vittoria's (1998) findings indicate the existence of two main components of the staff's *identity work* pertinent to the present study. The first component, termed *getting into the resident's world*, is conceived of as a means of assisting staff in redirecting behaviour and empathizing with or providing comfort to residents. The second

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component, *the series of selves*, including the *storied self* of the resident's past, the *new self* of the present, and the *imagined self* of the future, involves staff members envisioning aspects of residents' lives (p. 119). Vittoria's study (1998) illustrates the positive outcomes that become possible with the move toward a person-centred approach to dementia care that enables staff to work with and support residents' sense of self.

Thus, this study sets out from the notion that residents' life history/biographical information has the potential to contribute to understanding of residents' *series of selves*, and might be seen as an attempt to follow up Vittoria's (1998) work toward a "communicative care" model.

Personal Photographs and Dementia Care

Part of the growing body of research on the importance of social-psychological aspects of dementia (Kitwood, 1997) to care includes an emerging field of gerontological studies related to photography. In order to address the stated research questions, this study examines the literature pertaining to personal photographs within the field of aging studies, especially that specific to the means by which residents' personal photographs might provide a vital visual component to the delivery of person-centred dementia care.

Historical Significance

From the outset, it is important to address the historical development of personal photography, or 'snapshots,' in relation to the current cohort of older adults. Older persons brought up during the first half of the 20th century might be said to have matured over the same period in history in which photography developed. Furthermore, cultural historian Langford (2001) draws attention to Eastman Kodak's early claims to the power

of photography: "'the snapshot as memory; the camera as storyteller; photography's ability to capture time and extend the experience of the moment'" (p. 4). By 1919, Langford contends the popular Kodak slogan, "'Pictures always tell a story better and quicker than words'" (2001, p.4) helped to establish a strong connection between the photograph and memory for a growing public, indeed, photographs became an important aspect of many people's social and psychological identities. Berman (1993) highlights this fact, quoting the reaction of a woman to a house fire: "After the family were [*sic*] safe, I'd grab my photographs, I can replace possessions, but not a lifetime of memories" (p. 2).

Personal Photographs and Identity

The relationship between photography and identity is particularly germane to the current cohort of older adults whose life course, for the most part, precedes the digital age. Most commonly, their collected and preserved photographs represent important social events such as weddings, baptisms, graduations, and holiday shots. With respect to the personal value we attribute to photos, Weiser (1999) suggests that people's photos are collected because they matter: "they constitute almost a mirror-reflection of their owner, in that we usually won't keep photos around that we don't like or that don't matter. The ones that are most special to us express many things about us and our life" (p. 5). Additionally, Holland (2001) contends that photographs record and reflect daily activities, and furthermore, that "personal photographs are embedded in the lives of those who own them" (p. 121). It is reasonable to assume, therefore, that residents' photographs offer a potentially important resource to dementia care that seeks to maintain

residents' individual identities and to develop meaningful connections between residents and formal caregivers (by highlighting the importance of particular social relationships, Brooker & Surr, 2005). Holland (2001) reminds us that the photographs that we keep are often valued less for their 'quality' than for the 'context' they reflect. Similarly, Harrison (2002) suggests that family albums provide the viewer with "data about personal lives, forms of subjective understanding and identity construction" (p. 859).

Photographs might be linked to one of the categories Kitwood (1997) sees as being fundamental to the psychological needs of a person with dementia: the category of identity. According to Kitwood (1997), "To have an identity is to know who one is, in cognition and in feeling. It means having a sense of continuity with the past; and hence a 'narrative', a story to present to others" (p. 83). Furthermore, Kitwood (1995) describes identity, especially for those with dementia, as a collaborative effort: "To some extent identity is conferred by others, as they convey to a person subtle messages" (p. 84). Thus, within dementia care, the use of residents' personal photographs might be seen to be a critical part of sustaining identity. For example, a caregiver's ability to refer to a resident's experience living in the bush, which might be obtained through viewing or sharing a photograph of her in a logging camp, could be extremely beneficial to both the resident and the caregiver. In the face of the resident's declining memory and increased difficulties with communication, access to this type of photographic information might pique interest in a resident and enable caregivers to more effectively engage that resident in meaningful social interactions. If, as Small and colleagues (1998) found in their research around a special care unit (SCU), there is a lack of 'unique biographical identity' available to caregivers beyond that depicting the person with dementia 'as a resident in an

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SCU,' then it is reasonable to believe that personal photographs might present significant means of filling this void.

Photographs and Social Life

Harper (2002) maintains that, "photographs portray the intimate dimensions of the social—family or other intimate social group" (p. 13). For formal caregivers, the opportunity to view photographs of residents in social groups at other stages in their lives (i.e., in non-institutional contexts when and where they can be seen to be more independent and capable) might have a profound effect on the relationship between caregiver and care-recipient. That is, photographs of significant life events and places present windows into the older adult's life history, permitting the viewer to share important events and memories of the subject's life and to attain a sense of the person behind the disease. Coker's (1998) research to identify barriers to the collection and documentation of residents' personhood-related data by nurses in a LTC setting revealed that staff want to "know the residents in the context of their families, in a social context, and in a community context" (p. 437). Personal photographs are an ideal way of responding to this desire because they not only reveal aspects of the individual's life, but they also possess the capacity to depict larger social networks or situations. As Weiser (1990) suggests, photographs often reveal that we matter to others and that others matter to us—a crucial part of the recognition and maintenance of personhood.

Photographs and Reminiscence Work

The potential of personal photographs to support personhood and contribute to more individualized dementia care is perhaps most apparent in the literature on reminiscence.

Haight and colleagues (2003) offer a broad definition of reminiscence as a "phenomenological process of recalling the past that provides people with both pleasure and pain. It has healing qualities and provides a vehicle for socializing with others" (p. 165). In their exploration of the adaptive value of reminiscence on physical and psychological health, Cappeliez and O'Rourke (2006) found that particular types of reminiscence relate to well-being in later life. Specifically, these researchers found a correlation between "the use of memories to identify a pattern of coherence in one's life," (p. P237), to connect with one's identity, and well-being.

Within the larger body of gerontological investigations into reminiscence as a therapeutic intervention, there is research that investigates the use of photographs as autobiographical material capable of facilitating or stimulating memory recall and thereby helping older adults to articulate important life experiences (Chaudhury, 2002a; Gibson, 1994; Hagens et al., 2003; Haight et al., 2003; Koretsky, 2001; Rubinstein, 2002; Sherman, 1995). The unique ability of photographs to support reminiscence is highlighted by Weiser (1999) who states that 'sight-based' information is a fundamental part of our experiences and thus there is "a strong visual component to our experiences, and to our memories of them" (p. 1).

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Within the field of reminiscence-based research there is a growing body of work exploring the therapeutic potential of personal photographs for those living with dementia within institutional settings. Gibson's (1994) research represents a seminal attempt to apply what is known about the efficacy of reminiscence for the general older adult population to reminiscence work with persons with dementia. This study highlights the reciprocal benefits associated with reminiscence programs, such as helping "staff acknowledge their abysmal ignorance of the people in their care" (p. 58), a corollary of which was an increased curiosity amongst staff regarding residents' life histories. In Gibson's study, reminiscence work that uses residents' photographs enhanced participants' sense of personal identity and positively impacted the perceptions of staff who, in turn, were better able to see the person behind the disease in the context of the care-recipient's life course. In a similar vein, Chaudhury (2002a) used residents' photographs of childhood homes as visual prompts or *reminiscentia* (Sherman, 1995): objects that have a particular facility to trigger recollection or reminiscence, in this case among residents with dementia. Cohene and colleagues (2005) also successfully engaged participants with Alzheimer disease in photo-based reminiscence sessions in order to create their multimedia interactive life story. As reminiscentia, photographs might be understood to function in relation to both residents and formal caregivers.

To some degree, reminiscence-based work capitalizes on the propensity of personal photographs to depict and share with the viewer positive aspects of residents' life histories. Clarke and colleagues' (2003) exploration of a biographical approach (through story-telling) to supporting person-centred care found that "photographs, in particular, seemed to bring the person's biography alive for all concerned and provoked

strong memories, which may otherwise have been difficult to appreciate" (p. 702).

Similarly, support workers cited in this study echoed this sentiment: "photographs in particular provided a talking point between themselves, the patient and their relatives" (Clarke et al., 2003, p. 702). In terms of a warning, literature on reminiscence work frequently cautions against drawing on themes or topics that may be difficult for the individual; however, as studies of personal photography suggest, photographs of an individual's life are predisposed to drawing on positive memories. Holland (2001) asserts that personal photographs (at least in this culture) can be said to most often depict "happy memories" (p. 147). Personal photography tends to show people "as they would wish to be seen", or, "how they have chosen to show themselves to one another" (p. 121). Likewise, Blaikie (1994) contends, "photographs are supposed to represent how we see ourselves and others see us," noting that, family albums do not contain "signs of hardship, labour, grief, sibling rivalry, painful adolescence or death" (p. 241).

Photographic Uses in Institutional Settings

Long-term care facilities do have experience using residents' personal photographs with the intent of foregrounding the person behind the outward manifestations of age and disease. Rigdon (1991) found that a 'Patient of the Month' program that used photographs to tell the resident's story helped staff to discover critical aspects of the featured resident's personhood (cited in Coker, 1998). Photographs are also used within long-term care institutions as an orientation tool to help persons with dementia navigate the institutional environment (Day et al., 2000). In some facilities, families and residents are encouraged to place photographs or other memorabilia within

'Memory Boxes' or showcases. These architectural features are located at entrances to residents' rooms and are designed to serve two functions: 1) to help those with dementia who might be disoriented to 'landmark' or locate their room (Cohen & Weisman, 1991, p. 71); and 2) to serve as reminders to caregivers and other visitors of the person residing within. Photographs are also commonly used to help individualize or create a home-like environment in residents' rooms.

Life Story Work within Institutional Settings

The use of residents' life stories within institutional settings increasingly appears in the dementia care literature in the form of the production and application of a "concrete memory resource" (Hagens et al., 2003, p. 97). Most commonly, these resources have taken the form of memory or life stories, books or boxes: compilations of residents' own words, letters, documents and personal photographs. Examples of recent studies include: Burgio and colleagues (2001) exploration of the potential of memory books and Hagens and colleagues (2003) study of *remembering boxes* as communication tools designed to improve care staff communication skills; as well, Haight and colleagues (2003) studied the potential of life story books to reduce caregiver stress. Chaudhury (2002b) gathered residents' "personal place-related experiences," (p. 42) such as childhood homes, schools and neighbourhoods, to compile memories and photographs in a biographical document called a *Place Bio-Sketch*. These memory-based resources are products of what Gibson (2004) defines as 'life story work,' as they illustrate "various ways of engaging and interacting with people...to encourage and assist them to recall and to record in tangible form their personal histories" (p. 176). Individuals with dementia are

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engaged by caregivers and researchers in various forms of reminiscence in order to compile an "aide memoire to remind themselves and others of the past" (Gibson, 2004, p. 176). The intent of these collections in the relevant literature is twofold: to facilitate reminiscence for the resident and also to educate staff about the life stories of persons in their care. As such, studies exploring how life story work might help support personhood vis-à-vis tangible resources offer vital insights to this investigation.

However, while a growing body of literature is focused on life story work, scant research exists on the impact of staff exposure specifically to residents' photographs. Neto and colleagues (2006) investigation is a recent example of a study with results relevant to the long-term care environment. These researchers explored the effects on nursing staff in a hospital's intensive care unit of displaying personal photographs at patients' bedsides. They found that patients' photographs helped nurses to personalize care of the patient by "creating a reminder of patient's preillness state" (p. 198). Following from this, it might be that exposure to images of older adults when they were younger and more vital individuals, now obscured by age and disease, might provide care staff with a new lens from which to view residents.

The use of photographs described in this study represents a new direction in biographical approaches using life story work as a means to use readily accessible residents' photographs in the quest to affirm personhood, thereby adding to research in this area.

Conceptual Framework

The conceptual framework for this study is derived from the gerontological discourse surrounding personhood and person-centred care (Brooker, 2004; Brooker & Surr, 2005; Crisp, 1999; Downs, 2000; Kitwood, 1993, 1997; Kitwood & Bredin, 1992; Li & Orleans, 2002; Sabat, 1998; Sabat & Harré, 1992; Touhy, 2003; Werezak & Morgan, 2003; Woods 1999, 2001). It explores the related body of research on *self*, 'continuity' and 'maintenance' of the self (Beard, 2005; Chaudhury, 1999; Cohen-Mansfield et al., 2000; Sabat & Harré, 1992; Vittoria, 1998, 1999). For people living with dementia, Brooker and Surr (2005) contend that, "understanding a person's past history is crucial to providing person-centred care" (p. 17). Consequently, biographical approaches that draw on residents' life histories, (Chaudhury, 2002a; Clarke et al., 2003; Coker, 1998; Gibson, 2004; Hagens et al., 2003, and Heliker, 1999) also inform this study. This study also explored literature focused on reminiscence work (Gibson, 1994; Sherman, 1995; Woods & McKiernan, 1995), personal photography (Harrison, 2002; Holland, 2001; Langford, 2001; Weiser, 1993) and the use of photographs as visual prompts to facilitate recall (Chaudhury, 2002a, 2002b; Rubinstein, 2002; Sherman, 1995).

This investigation is grounded in the assumption that the "deterioration of the person in dementia is not a simple consequence of neuropathology" (Kitwood, 1998, p. 23). Working from social constructionist notions of intersubjectivity (Kitwood & Bredin, 1992), this study builds on the research of Downs (2000), Li and Orleans (2002), Sabat and Harré (1992), among others, which underscores the notion that "personhood emerges in a social context" (Kitwood & Bredin, 1992, p. 275). As Woods (2001) argues, personhood is "created (or diminished) in the social relationships around the person with

dementia; it is a product of the caregiving relationship" (p. S13). This perspective suggests a self-fulfilling prophecy results with a diagnosis that begins by "positioning people with dementia as helpless and confused" (Adams, 1999, p.49). The negative impact of this initial 'positioning' (Sabat et al., 2004) on the person with dementia is that subsequent social interactions between staff and residents are based on a diagnosis that assigns priority to patient needs as medically defined. To counteract the potentially harmful affects of the biomedicalization of dementia on the person, researchers might focus on developing the quality of social relationships between formal caregivers and residents and thereby identifying ways to re-position the person with dementia in the process of care.

Building on this body of gerontological research, this study works with the notion that dementia care that focuses only on the medical needs of residents does not attend to personhood, and as Kitwood (1997) suggests, is therefore detrimental to both persons with dementia and their formal caregivers. Predicated on the notion that *good care* is possible when persons with dementia are supported in maintaining a vital role in the social world (Kitwood, 1993; Sabat & Harré, 1992), this study capitalizes on the power of personal photographs to facilitate the compilation of residents' life stories through reminiscence. In particular, it looks at the therapeutic potential of sharing residents' life histories with caregivers. It discusses how the addition of a staff resource, a photo-based biographical tool, *Visual Life Stories (VLS),* to care practice might represent a means to a "more fluid approach" (Ice, 2002, p. 355) to affirming personhood and achieving person-centred care.

CHAPTER THREE: METHOD

Overview of the Research Design

This study was designed as a systematic inquiry using the methods of guided conversations, focus groups and participant observation. Purposive sampling was used, and data generation was presented through an *audit trail* (Lincoln & Guba, 1985) consisting of transcripts, field notes, and the use of computer assisted qualitative data analysis software.

This study consists of two parts. First, two *Visual Life Stories (VLS)* presentations were created (one per dyad) through a total of seven guided conversations (one set of three and one set of four) with two residents with dementia and their families. The production of residents' *Visual Life Stories* took place over approximately a six-month period (November, 2005 - June, 2006). Guided conversations ranged from 30 to 90 minutes in length. Prior to beginning each guided conversation, the researcher explained to participants the purpose of the *VLS* presentation and asked both the resident and the family member to contribute their comments. In both instances, the interviews were first undertaken with a family member, and the second, third, and (in one case) fourth were undertaken with the resident and a family member. Resident-family participants were selected with the assistance of a nurse clinician. Biographical information was obtained from participants through guided conversations led by the researcher focusing on the participant's collection of family photographs. These interviews were recorded and transcribed verbatim. Field notes were taken following each interview. These qualitative

inquiry techniques helped to establish the "transferability" of the study findings, following Lincoln and Guba's (1985) second criterion for trustworthiness. These techniques helped to create a database that is *transparent* and that may assist with future investigations into this area of study.

During the guided conversations the researcher collected the residents' personal photographs and recorded the stories they shared. The photographs were then scanned into digital form (JPEG) to be used as the visual portion of the presentation and the transcripts of the conversations were used to develop a script (see Appendices 7 and 8) that became the audio portion. Combining these audio and visual components, I created the resident's *VLS:* an audio-video presentation in Apple Keynote 3 and Apple GarageBand 3 burnt to DVD format in Apple iDVD 6. The *VLS* was then viewed by the residents and their families and approved for use in part two of the project.

Guidelines for life story content suggested by Ryan and colleagues (2005), among others, were considered in relation to photographic content selection. Kolanowski and Rule (2001) recommend that, in general, life stories should cover the following areas: descriptions of events and people from major life periods; life events such as work, travel and marriages; important relationships with people or pets; ethnic or religious practices; and special skills or awards. Therefore, throughout the selection process, photographs supporting the most biographical information from across the life course and that were the most personally relevant to residents and their family members were selected. It is important to remember that the *VLS,* following de Medeiros' (2005) definition of life story, presents residents' biographical information as they would like to be represented to others. That is, "the stories that people tell about themselves...as they wish to have others

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see it" (de Medeiros, 2005, p. 6). To this end, resident involvement was essential to the creation of their *VLS*. Residents were involved in the selection of the photographs to include in their presentations; in addition, I continually assessed their comfort level in sharing their stories and photographs.

The second part of the study entailed focus groups that were conducted to ascertain formal caregivers' perceptions of *VLS* use. These focus groups represent a key facet of this investigation, providing a means to bridge the gap between the conceptual framework of the proposed study and the practical implications of implementation raised in this discussion. Once the two *VLS* prototypes were completed and approval granted by the families and residents to share their presentations with staff, four focus groups were arranged at the two care facilities. Focus group participants were recruited from a range of care team positions. A total of 26 staff members participated in the focus groups: 17 staff from the direct care team, including 7 registered care attendants, 1 registered care attendant/ housekeeping, 4 registered nurses, 2 licensed practice nurses, and 3 recreation therapists; and 7 staff from the leadership or management team including: 1 director of care, 1 associate director of care, 1 nurse clinician, 1 social worker, 1 financial assistant, 1 dietitian, and the 1 leisure services manager. Two clerical staff, 1 secretary and 1 care clerk, also participated. In order to promote procedural consistency within the focus groups, the researcher moderated all focus group sessions. Focus group size ranged from six to eight participants, plus the moderator.

Focus groups were held on site and were organized with the assistance of the Director of Care for both care facilities. Interview questions presented within the focus groups queried participants' experiences of caregiving, solicited participants' perceptions

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of the possible contributions that knowledge of residents' life histories/biographical

information via personal photographs might contribute to their ability to provide care,

and furthermore, the *VLS* tool's ability to support residents' self-identity and personhood

(Kitwood, 1997). Focus group sessions were recorded and transcribed verbatim. Field

notes were taken during and immediately following the group interviews. Participants

also completed a demographic questionnaire. Questions addressed in the groups provided

a framework from which emerging themes were organized through content analysis

methods that facilitate the systematic distillation of textual data into themes or core

constructs (Miles & Huberman, 1994).

Ethical approval for the study was obtained from the Office of Research Ethics,

Simon Fraser University (SFU). Consent forms (see Appendices 4 and 5) were signed

prior to commencement of data generation, and participants were assured of

confidentiality throughout the research process. Participants were also given the

opportunity to withdraw from the study at any point. Although consent to participate was

given by proxy for the two resident participants with dementia, the researcher established

on-going verbal consent from the residents throughout the data generation process.

Data Generation

Study Site

This study was conducted with the participation of residents, family members,

and staff from two long-term care facilities located in Vancouver, British Columbia.

These facilities operate as part of a not-for-profit caregiving organization that has adopted

a holistic philosophy of care. Grouse Mountain Acres (GMA) and Spruce Hill Residence (SHR) are medium-sized multi-level care facilities; both contain special care units.

Study Sample

One resident-family dyad participated from GMA, and one resident-family dyad participated from SHR. Of the 26 staff members that participated in the focus groups, there were 13 participants from each facility. A total of 6 men and 20 women participated in the focus groups sessions. Length of employment at the two facilities among group members ranged from 1 month to 19 years, with an average length of employment of 8.3 years.

Resident and Family Member Participants

One resident and his or her family member from both of the two facilities were contacted to ascertain their interest in participating in this research project. Participation required that participants' cognitive status needed to be sufficient to enable meaningful communication with the researcher; additionally, the prospective participant needed to have a family member or significant other willing to help collect the photographs and take part in the guided conversations. Participant appropriateness was determined in an informal way through a meeting with prospective resident-family participants prior to proceeding with the creation of the *VLS*. At this time, I provided the potential participants with an overview of the study, described the consent process, ascertained their willingness to participate, and determined appropriateness. The first two family members

and residents that were contacted agreed to participate and were deemed suitable, thus no one declined to participate in this study.

Focus Group Participants

The researcher met with the Director of Care (DOC) at both facilities, three weeks prior to the first focus group session. At this time, the DOC was given a study outline, a description of the study selection criteria, a focus group poster, and consent forms to provide to prospective participants. To maximize attendance at the focus group sessions it was decided to conduct the group discussions on work premises during working hours. Each focus group included a range of care staff drawing from those who were working the day that the groups were scheduled. To draw on and work with existing care team dynamics, selection criteria required that a range of positions within the staff hierarchy were represented in the composition of each focus group.

Instruments and Procedure

Data generation was directed by the goal of obtaining rich, quality data to both construct residents' *Visual Life Stories* and to obtain the insights of staff on care practice and the feasibility of *VLS* implementation within care facility settings. To this end, a family guided conversation and resident-family guided conversations were used in the creation of the *VLS* (see Appendix 1). The instruments used with staff participants within focus groups included a semi-structured interview guide (see Appendix 2) and a participant questionnaire (see Appendix 3). The *VLS* was constructed using an iMac with Apple's Keynote 3 and GarageBand 3 software. Focus group participants viewed the *VLS*

presentation on an Apple Macintosh 20-inch Intel iMac (OSX 10.4) that the researcher transported to the study sites.

A brief description of the researcher as instrument is also included in this section.

Family-Resident Guided Conversations

This study followed Chaudhury's (2002a) research methodology, employing guided conversations using personal photographs as visual prompts. No structured interview questions were asked of residents and their family members; rather, discussions more closely followed the rules of ordinary conversations (Rubin & Rubin, 1995). Family members took part in the first guided conversations that were designed to obtain factual biographical information as well as the family member's perspective on the stories associated with selected photographs. The purpose of the second joint guided conversation was to gain the resident's critical perspectives on experiences surrounding the selected photographs, thus supplementing the content of the *VLS* provided by the family. After the joint guided conversations took place, the photographs and information obtained were assembled to form the content of the *VLS* (See Appendix 6 for details of *VLS* production). The third (and fourth for the resident from SHR) family/resident guided conversation involved previewing the *VLS* to permit editing of the presentation, to ensure accuracy, and to obtain approval and consent to use the *VLS* with focus groups composed of care facility staff.

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The Visual Life Stories (VLS)

Two thirteen-minute *VLS* presentations were created for this project, one for a resident from GMA and the second for a resident from SHR. The *VLS* is designed to provide a visual account, using a chronological life span framework (Gibson & Burnside, 2005), of individual resident's life stories through personal photographs. The viewing of the *VLS* by staff participants exposed them to the personal photographs preserved by residents or their families over their lifetime. The concept of a 'visual life story' is based on the definition of life story as a personal narrative that thematically link[s] events' (de Medeiros, 2005) that occur in a resident's lifetime. Within the relevant literature, life stories are generally presented as text-based personal narratives; however, this study allowed residents' personal photographs to tell their story to formal caregivers. The sharing of visual and narrative biographical information was made possible through the *VLS* DVD format.

If, as Clarke and colleagues (2003), Coker (1998), Heliker (1999), and Mills (1997) contend, biographical approaches enable formal caregivers to provide individualized person-centred care, this study offers the *VLS* as a vehicle for the transmission of residents' biographical information to caregivers. Thus, the *VLS* is intended to provide formal caregivers with the resident's biographical/life history information and to provide a point of departure for discussion focused on how the resident's care plans might better incorporate this information. The *VLS* will also be available for subsequent viewing by staff or volunteers absent from scheduled care plan meetings.

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Capitalizing on photography's ability to convey pictorial accounts of significant life events and experiences from across the resident's life course, this study developed aspects of Magilvy and colleagues' (1992) ethnography of rural home care. Following the fieldwork portion of Magilvy and colleagues' (1992) study, in order to illustrate specific aspects of their findings, researchers shared their photographs from the field with caregivers through a slide presentation at staff meetings. According to this team, the slide presentation created a forum for the exchange of information that, in this instance, facilitated the provision of home care. They noted that the slide show fostered conversation regarding the provision of rural home care in ways that were previously unheard of by the research team: "the slides shown in the group setting stimulated [these] narrations and yielded a richer description and understanding of rural life and the delivery of home care" (Magilvy et al., 1992, p. 256).

In a similar vein, the *VLS* is designed to present staff members with an opportunity to obtain key biographical resident information to facilitate staff discussion based on this information. Each focus group viewed and discussed one *VLS* developed from the personal photographs of a resident from their respective facilities.

The Researcher

This qualitative study adapted the premise that the researcher is the "main measurement device" (Miles & Huberman, 1994, p. 7). The concept of researcher as an *instrument*, advanced by many qualitative researchers, for example Belle Brown (2000), Finlay (2002), and Maxwell (2005), supports the contention of the "inseparability of researcher and research" (Sandelowski & Barroso, 2002 p. 215). According to Finlay

(2002), "thoughtful, conscious self-awareness" (p. 531) and the understanding that

researchers are central to data generation, selection, and interpretation, is known as the

practice of reflexivity—a practice that increases "the integrity and trustworthiness" (p.

531), and the rigor of qualitative investigations. Qualitative researchers (e.g., Finlay,

2002; Lincoln & Guba, 1985; Maxwell, 2005; Morse & Field, 1995) suggest that

adopting a reflexive stance contributes to the researcher's ability to maintain neutrality

and consistency throughout the research process, contributing to *confirmability* and

dependability as established by Lincoln and Guba (1985). To this end, I considered the

impact of my personal motivations, beliefs and capabilities throughout this investigation,

as such; in the social constructionist paradigm, this research represents a "co-constituted

account" (Finlay, 2003, p. 535) of the research focus.

Focus Groups - Interview Guide

Focus groups were the primary means of data generation for this study, broadly

defined as "a research technique that collects data through group interaction on a topic

determined by the researcher" (Morgan, 1997, p. 6). Madriz (2003) states that unlike

widely used one-to-one interviews, focus groups represent a "collectivist rather than

individualistic research method that focuses on the multivocality of participants'

attitudes, experiences, and beliefs" (p. 364). The rationale for the use of this method

stems from the nature of the research focus. As a review of the literature indicates, this

project explores a new area of inquiry within dementia care; therefore, the focus group

technique provides a vital "means of initial inquiry" (Belle Brown, 2000, p.110) that will

help to establish a baseline perspective on the therapeutic potential of personal

photographs within dementia care. These focus group discussions offered insight into

formal caregivers' different experiences, within the context of the practical aspects of

care delivery.

A semi-structured interview guide was used to direct focus group sessions.

Potential questions were piloted with the nurse clinician to help establish appropriateness

for participants. Each group session began by welcoming participants and offering a brief

description of the study and an outline of the parameters of the discussion such as length,

audio recording, and transcription. In order to offset the existing power hierarchies within

groups, all participants were actively encouraged to contribute to the discussion.

Following the introduction, participants were asked to respond to three practice-

related questions: how they currently acquire residents' life history information; how this

information is used in care delivery; and to describe some of the challenges caring for

residents with dementia. Participants then viewed the *VLS* of the resident from the facility

in which the participants work (time constraints prevented staff from seeing both 13

minute *VLS* presentations produced in this study). Subsequently, participants were

queried on their perception of how this tool might assist with person-centred care

delivery, the feasibility of *VLS* implementation within their organization, and on staff

understanding of family interest and potential participation. Before the session ended,

participants were asked to share opinions not previously raised in the discussion (Belle

Brown, 2000).

Qualitative Data Analysis

Family-Resident Guided Conversations

Permission was obtained to record the two family member guided conversations and the two resident-family guided conversations. These interviews lasted between 45 and 90 minutes and were transcribed verbatim by the researcher. Field notes were recorded immediately following the interviews detailing participant observations. Biographical information gathered during these sessions helped to develop a script and guide the layout of the visual component of residents' *Visual Life Stories*. Personal photographs supplied by participants were scanned and imported to a Keynote 3 presentation. The third interview (and fourth, with SHR dyad) with residents and family members was undertaken to assess the perceived accuracy of *VLS* content. Based on family/resident feedback, minor changes were made to residents' presentations, and approval was given for use within focus group sessions.

Focus Group Interviews

Following standard qualitative research methods (Miles & Huberman, 1994; Priest et al., 2002), content analysis of focus group data was undertaken. As Berg (2001) states, content analysis is "a passport to listening to the words of the text, and understanding better the perspective[s] of the producer of these words" (p. 242). Krippendorff (2004) maintains that there are good reasons content analysis methodology is frequently applied to focus group data. He states that unlike structured interviews with pre-set questions, focus groups permit relatively open discussions, and content analysis of

focus group transcripts permits researchers "to explore the conceptions that are manifest in such conversations" (Krippendorff, 2004, p. 27).

Reflecting the emergent nature of this type of naturalistic inquiry (Patton, 2002), the task of analysis began in the field in a very preliminary way through field note taking. To facilitate accurate transcription and immersion in the focus group data, the researcher completed transcripts soon after the end of sessions. This process helped to develop a sense of the whole or the orienting gestalt of the interview data (Sandelowski, 1995). In so doing, the first criterion of Lincoln and Guba's *trustworthiness*, (a qualitative parallel to validity and reliability) *truth value* was supported. That is, these techniques heightened the likelihood of capturing the meaning-making process (Gubrium & Holstein, 2002) created within the group interviews.

Formal analysis of the raw data (Sandelowski, 1995) began once the field notes were completed and the focus group sessions were transcribed verbatim. Descriptive summaries of focus group responses were made soon after, permitting comparing and contrasting across groups. Following Krueger and Casey (2000), participant responses were considered according to the criteria of frequency, specificity, emotion and extensiveness. After obtaining a sense of the whole, CAQDA software, NVivo, was used to systematically manage the textual data through coding, marginal remarks and memoing (Miles & Huberman, 1994).

The first step in the data analysis process was first-level coding, which entails the development of a coding scheme (Patton, 2002, p. 463), highlighting what is of interest in the data: it involves labelling or "assigning units of meaning to the descriptive or

inferential information compiled during a study" (Miles & Huberman, 1994 p. 56). Thus, the unit of analysis was key words, phrases or sentences elicited from participants. Using the unit of analysis, codes were developed and assigned to textual data. Social history document helps, workload demands prevent getting to know resident and communication challenges with dementia, are examples of the codes used. This procedure helped the researcher to look across questions to identify themes (Miles & Huberman, 1994). In this stage of analysis, questions contained in the interview guide, based on the conceptual framework, but refined with the research, were referenced to provide a framework with which to identify core content (Sandolowski, 1995) and organize emerging themes.

Once codes were assigned, the next level of analysis involved reduction of the codes into categories, and categories into themes. This analytic approach to data reduction as revealed in responses to the focus group questions, enabled further grouping of data to help advance analyses of previously coded data (Miles & Huberman, 1994). Likewise, immersion in the data—reading and re-reading of the transcripts—helped to clarify the categories used and, to generate useful sub-categories, thus ensuring that the framework for analysis was data driven (Sandelowski, 1995).

As transcript coding proceeded, marginal remarks were applied to foster the analytic process by moving from raw data to more abstract levels and to help to keep track of new interpretations. Field notes reflecting participant observations added to this analysis.

Throughout this process, the content of the text was constantly compared in order to identify meaningful patterns (Berg, 2001) and common themes across group interviews

(Miles & Huberman, 1994). Coding and recoding of the data were considered complete when saturation was reached or when no new information from participants had been heard (Krueger & Case, 2000). That is, when collapsed codes identify the range of themes across groups.

In summary, content analysis for this exploratory study permitted the distillation of data into themes; while some degree of conceptualization resulted, the intent was not to arrive at an overarching conceptual scheme or theory (Berg, 2001; Miles & Huberman, 1994; Strauss & Corbin, 1990). Through content analysis of focus group data however, themes were identified that represent baseline perspectives or caregivers' perceptions of the therapeutic potential of residents' personal photographs.

CHAPTER FOUR: FINDINGS

This chapter is divided into two parts. The first part of the chapter describes the findings from the *VLS* production phase of the study. These findings are based on the experience of working with the resident-family dyads in *VLS* production, within which the critical role of family involvement came to light. Resident and family member participants' responses to viewing their *VLS* are presented. As research using life story work and other biographical approaches within dementia care illustrates, the potential to affect the well-being of residents by seeing the person behind the patient (Clarke et al., 2003) was revealed. The second part of this section describes the findings from the focus group interviews. Staff participants in each focus group were asked to respond to a semi-structured interview guide. Findings from the focus groups provide insights into various aspects of person-centred dementia care, the ability of the *VLS* to help maintain residents' personhood, and the feasibility of *VLS* implementation in the context of long-term care.

Part One: *Visual Life Stories* Production

Resident and Family Member Participant Findings

The creation of two *Visual Life Stories* was central to this study. The construction of residents' *VLS* presentations involved the engagement of two residents with dementia and their family members in guided conversations using their personal photographs as visual prompts.

Grouse Mountain Acres (GMA) Participants

The participant at GMA was an 83-year old woman (Claire) diagnosed with vascular dementia, and her eldest daughter. At the time of the interviews, Claire had been assessed as being in a moderate to advanced stage of dementia. Her ability to communicate verbally was compromised. During data generation, this resident was moved into the facility's Special Care Unit. She had lived in that facility for just over one year. Both the first and second interviews were held in a 'quiet room' within the facility. The challenge with this family was in managing the great number of photographs selected from across the resident's life span. In addition to photographs, the daughter also provided a copy of her mother's favourite poem, "Stopping by Woods on a Snowy Evening" by Robert Frost.

During the second guided conversation with the resident and her family, the researcher went through the selected photographs individually with the resident. Claire's daughter added additional cues to help her mother recall particular stories or facts when appropriate. This session was a critical part of the *VLS* construction, helping to include the voice of the person with dementia in the presentation of her life stories. With the assistance of the photographs, Claire was frequently able to not only support her daughter's stories, but more importantly, to add her own account of the stories surrounding her photographs.

Resident and Family Member Responses to the VLS

The third guided conversation involved viewing of the *VLS*. This meeting was held in Claire's room in the SCU. Claire and her daughter sat in chairs in front of the

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computer while the researcher sat to the side. Throughout, Claire was enthralled by the presentation. In response to her *VLS*, the resident exhibited a range of emotions; she was saddened by photographs of her deceased husband, laughed over funny anecdotes, and chimed in at the portion of the presentation when part of her favourite poem was read. The part of the *VLS* that was a real highlight for Claire focused on the photographs and the associated memories of the remote place where she had lived with her husband when she was newly married. This was a place where several of her children were born. According to her daughter, this place has a special meaning to her mother, and the emotional content of Claire's comments while viewing these photographs supported this assertion. Some of the remarks voiced by Claire when viewing her presentation include the following: *"Happy memories, happy memories," "Oh I forgot about this,"* and *"It brings me back."* Claire smiled as she shared these feelings. Claire even commented on the importance of collecting and saving family photographs, she stated, *"Isn't it nice to do something like that, then you know how important it was to keep that picture."*

Through the guided conversations with Claire, her 'recollection of past places' (Chaudhury, 2004) effectively transported her back to Mt. White when she was a young mother. Claire's daughter mentioned the importance of her mother's conviction: when Claire looks out her window at GMA, at the North Shore Mountains, she perceives the mountains to be Mt. White and this belief comforts her. This example illustrates how opportunities for maintenance of self, meaningful social interactions, and "getting into the world of the resident" (Vittoria, 1998, p. 107) might be missed when staff members are unaware of her life stories. Worse yet, if staff chose to correct her, it might then be an example of what Sabat and colleagues (2004) refer to as "malignant positioning,"

interfering with a valued identity, that of someone with varied interests who loves adventure, and possibly causing her embarrassment.

Claire's reaction to her *VLS* also revealed how the chance to re-live memories associated with her photographs provided her the opportunity to revisit aspects of her younger and more independent self. In her words, *"Oh! You've taken me, taken me in my thoughts, deeply. "* When asked to describe how she felt at viewing her collection of photographs, Claire stated, *"Like I'd never feel again. "* Although this resident enjoyed a life filled with predominantly happy memories, many of which were photographed, some photographs evoked feelings of sadness. For example, at seeing a picture of her deceased husband as a young man, Claire lamented, *"Why did God take him so soon. "* Yet, these feelings of sadness did not overwhelm her; in fact, she was able to come to terms with her losses through this experience: *"I was lost when he went, but for the time we were married, we were very happy. "* This process of resolution was supported by the presence of her daughter, who seemed to share her mother's feelings of loss and joy. This family member was extremely supportive of the goal of the *VLS*; in addition, her daughter expressed how viewing the presentation presented a unique opportunity for her to be close to her mother: *"even in her sadness...it wasn't bad, it was her true feelings, which I haven't heard her express with such emotion for years. "*

Spruce Hill Residence (SHR) Participants

The participant from SHR was a 78-year old man named Jack, also diagnosed with vascular dementia. At the time of the interviews, Jack was determined by previously administered cognitive assessments to be in a mild to moderate stage of the disease.

Following a stroke, this man came to live at the facility in 2004. Participating with him was his wife of over 20 years. The first guided conversation with Jack's family member took place in the facility's meeting room. Along with the family photographs, the resident's spouse brought to the meeting a chronological list of important dates and events in her husband's life; the two had worked on creating this list together. This list helped to speed the process of formulating a chronological account of the resident's life.

The process of guided conversations with Jack and his wife differed from the first participants in that this family had fewer photographs to prompt reminiscence and discussion. Their collection did not contain any photographs from Jack's childhood or young adult years but did have several of his parents as younger adults. However, in order to provide a visual connection to more of the stories shared by these participants during the guided conversations, the researcher accessed the Internet. The visual component of this resident's *VLS* was supplemented by images downloaded from the Internet. For example, a photograph of the city hall from the town he lived in as a boy was downloaded and incorporated into his *VLS*.

Resident and Family Member Responses to the VLS

The viewing of the *VLS* presentations evoked similar emotional responses in the two dyads. Jack and his wife openly shared their enthusiasm over the presentation and the opportunity it provided to appreciate the range of Jack's experiences from across his life course. On viewing the draft *VLS,* the couple requested minor additions of content to more fully represent Jack's life history which then necessitated a fourth meeting to permit Jack and his wife to view a revised version of the *VLS* prior to conducting the focus

groups. At seeing the completed presentation, Jack was brought to tears and nodded in agreement when his wife commented, "you forget what a good life you've had."

This resident provided less verbal information about his feelings throughout the interview process, perhaps due to his personality or the degree of communication challenges associated with his condition. However, Jack displayed the depth of his feelings during the viewing of his *VLS* at which time he actively listened and became emotional when the presentation ended. When his wife declared that he has had a "full life," he tearfully nodded, "yes."

The family member from SHR identified the potential of the *VLS* to make residents known to staff at the time of admission. Apparently Jack had a difficult time when he transitioned into care; according to his wife, Jack was "lost in his new environment." In the opinion of this family member, staff exposure to Jack's *VLS* upon admission might not only have ameliorated her husband's feelings of alienation at this difficult time, but it also might have helped meet his current need for increased engagement in meaningful activity. Apparently, Jack is not as active as either he or his wife would like to him to be.

Family Member Participation - A Critical Component of VLS Production

The process of *VLS* production revealed the critical role that family members played in the creation of residents' presentations and represents an important consideration to inform the construction of future *Visual Life Stories*. Beginning with the collection of personal photographs, followed by participation in the guided conversations,

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family participation was found to be a vital part of *VLS* construction, the absence of which would present a challenge to the creation of this biographical tool.

Family involvement in the guided conversations was found to support the person with dementia to reminisce and to share their life stories. That is, family members' familiarity with the photographs and the associated experiences depicted in the pictures helped residents to recall details such as names and places and the feelings associated with them thus making possible a more detailed and fact-based *VLS*. Family member participants reported enjoying the chance to take part in the *VLS* creation and witness their relative engaged in the positive experience of sharing their life stories with others. Indeed, it was the family members who first identified the possibility of using the *VLS* as a reminiscence tool for residents.

Both family members highlighted the possible use of the *VLS* for reminiscence purposes and requested copies of their relatives *VLS* so that their relative could view it in their room at their leisure. Although the *VLS* was not designed for use as a reminiscence tool, the overwhelmingly positive reactions from the residents and their families for the visual presentation of their life stories suggests this is an area for possible use and further research.

The positive reaction to the completed *VLS* displayed by family participants might also be considered as fulfilling a need to continue to contribute to the care of their relative. Their involvement in creating a concrete resource designed to provide care staff with residents' biographical information draws on their expertise as a family member in a fruitful and rewarding way. As Nolan and Dellasega (1999) and Woods and colleagues

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(1999) found, family members often feel excluded from involvement in their relatives

care. The eagerness of the family members to participate in this study might be seen as

evidence of informal caregivers' desire to support personhood and contribute to the more

individualized care of their relative through their continued involvement in the

psychosocial aspects of care delivery. Thus, family participation in *VLS* production

represents a potential vehicle to support meaningful familial involvement in caring for

persons with dementia who live in institutional settings.

Part Two: Focus Group Findings

This section begins with summaries of responses by care facility staff members to

the questions posed within the focus group sessions. Content analysis of the textual data

obtained through focus groups discussions led to the identification of the five themes is

then described below. The first three themes illustrate staff perceptions of the potential of

the *VLS* as a staff resource; they include: "Knowing the resident;" "Pictures tell a lot,

that's true;" and "They want everybody to know everything on the very first day." The

final two themes that emerged from the data reveal staff members' perceptions of micro-

level and macro-level challenges to *VLS* implementation within the LTC context.

Question Summaries

Question One

Responses to the question of how care facility staff members find out about peoples' lives

prior to admission overwhelmingly pointed to the social history document drafted by the

several members of the management team, as supplying them with a "good sense" of

residents' life histories. This document compiles residents' social and medical

information through interviews conducted with families and residents. This social history

is then placed in the file and circulated on the units. However, while nurses mentioned

receiving and reading this document, just one registered care attendant mentioned

accessing it. In contrast, the RCAs reportedly find out about residents' life histories

directly from residents, as they provide care.

In addition to this social history, the participating facilities also conduct a

financial interview and a leisure assessment; both of which staff report give them further

insight into the resident's life history.

Although the recipients of the social history document evaluated it positively,

those who are responsible for its' creation and distribution offered an opposing view.

Management staff stated that the introduction of the Residential Access Policy in 2002,

with its system of "first available bed" placement, has resulted in their inability to collect

biographical information prior to admission. Without wait-lists, these staff members have

a very limited period of time to collect social histories, moreover, it was noted that it is

not appropriate to interview family in this frequently stressful period, pre-admission.

Additionally, this policy change has meant that individuals who are placed in these

facilities are of a higher care level and less able to contribute biographical information

themselves. Consequently, the potential of the *VLS* to fill the gap created by current

policy was highlighted in the discussion generated by this question across groups.

DEMENTIA CARE, PERSONHOOD, PERSONAL PHOTOGRAPHS

Question Two

This question did not generate much discussion in any of the four focus groups. It might be that the way it was asked was confusing to participants, or, perhaps that using biographical information while providing care is an integral part of that care and therefore difficult to separate out or to clearly articulate. However, comments illustrated overall agreement amongst participants that using residents' biographical information while caring was useful to completing the task at hand, while respecting the resident.

Question Three

The question of what challenges staff members face in providing care for residents with dementia evoked a lively discussion in each of the four focus groups. Providing care in the current residential care climate is characterized by time constraints, a growing workload notable for its high ratio of residents to care staff, and a resident population of increasingly higher care levels. Furthermore, staff noted that language barriers and family expectations represent additional challenges. It appears that the use of volunteers to help offset some of these demands within the two facilities is not perceived of as a viable support system. Whether volunteers are under-used or difficult to attract was not addressed in the group discussions and was not clear.

Given the demands of participants' jobs outlined about, the fact that staff were permitted to participate in the focus groups during work hours might be seen to indicate the desire or openness of the facility directors to explore new ways to meet the psychosocial needs of the resident population. Is should be noted that from the time the facilitator met with the DOC to arrange the focus groups, through to running the groups,

that staff time was presented as extremely limited and that time constraints were a barrier to longer group discussions.

Interestingly, none of the participants referred to the specific philosophy of care that they work under as a source of information on how to meet the challenges related to providing care to residents with dementia.

Question Four

In general, participants in all of the focus groups were highly receptive to the *VLS* presentation. Each focus group discussion generated a different perspective on how a *VLS* might be helpful to them, in their respective position, as they care for residents with dementia. RCAs noted how the *VLS* showed them things that they have in common with the resident, thereby contributing to a more personal connection with residents and improved staff/resident relations. The transmission of new biographical information to care attendants was also identified as a means to support more meaningful staff/resident interactions. While the RCAs comments related to informal care interactions, participants who work in recreation therapy identified the value of the *VLS* to the development of more individualized and meaningful activities. Comments made by RTs during the focus groups revealed how the *VLS* contributes to maintenance of self for the resident featured: *"It shows who they are and is a reminder of truly they still are."* With biographical information more readily available, staff can gain new insights and tailor programs to residents.

With respect to family involvement, the nursing participants felt that most families would welcome the addition of the *VLS* to the delivery of care. One nurse noted

how families at times overwhelm staff with information about a resident. It was also noted that families' participation in supplying facilities with a resident's biographical information becomes more critical as the person living in care becomes less able to communicate for him or herself.

Question Five

The staff participants across groups identified several barriers to *VLS* implementation within their facility. Theses barriers include; privacy concerns of family and residents, potential for exploitation, the time needed to develop a *VLS* and the staff time to view the presentation, technological support, and finances. Although the need for family participation was raised as a potential barrier to implementation, more often, family involvement was mentioned as supportive. That is, in the opinions of most staff, many families would welcome the *VLS* as a supplement to care practice.

Although not explicitly stated as relevant to *VLS* implementation, participants did explain the ways in which facilities currently gather, store and disseminate residents' biographical information. That is, although formatted differently and with less depth, the gathering of residents' social histories is currently practiced in participating facilities. It might be that the facilities' directors would be open to the inclusion of the *VLS* as a means to address the challenges of current placement policies and to further contribute to more person-centred care.

Question Six

When asked for additional comments, participants across groups raised questions about the logistics of *VLS* implementation. For example, who would produce the *VLS*, the

ideal length of the presentation, and what content should be included in the *VLS*. The facilitator used this time to ask participants what they thought of a resident narrating their own *VLS*. In order to further involve the resident in the creation of their *VLS*, the possibility of having the resident narrate their own *VLS* was put to participants. As the likelihood of residents being able to perform this task was considered low the suggestion of a family member acting as narrator was raised and considered as a more realistic option. Finally, a manager asked about the steps taken to produce the presentation, raising the topic of a template that staff could use to produce *VLS* presentations of their own in future. Most participants thought that a 10-minute *VLS* would be an ideal length for future presentations. This length was considered as the maximum amount of time staff could realistically devote to viewing a resident's *VLS*.

Themes from Focus Groups

In both study sites and across care team positions, staff members' expressed how the demands originating from within the organization, and in response to current policy, create barriers to the support of residents' personhood and the delivery of person-centred care. In combination, these themes shed light on the feasibility of *VLS* implementation in the long-term care context.

1) "Knowing the resident": Staff Perceptions of the Importance of Familiarity with Residents' Biographical Information in the Provision of Person-Centred Care

Comments shared by both management and direct care staff within focus groups reveal the importance of "knowing" the resident. Currently, staff of Grouse Mountain

Acres and Spruce Hill Residence report obtaining residents' biographical information in two ways: 1) from a social history document; and 2) from contact with resident themselves. Most staff members, those who read the social history document, maintain that it supplies them with a "good sense" of residents' lives prior to admission. In turn, this knowledge helps staff to provide more person-centred care. For example, recreation therapists are better able to design engaging and therapeutic programs for residents they "know."

The importance of familiarity with residents' biographical information was also highlighted by participants who work as registered care attendants (RCAs). Although just one staff member reported reading this document, most RCAs shared anecdotes of how they use their knowledge of residents to facilitate person-centred care. Comments by these front line workers reveal a process of getting to know residents over time, through hands-on care. RCAs also noted that this process of getting to know a resident can be hampered by a lack of family involvement, language barriers, and communication challenges related to dementia.

Although focus group participants expressed an awareness of the value of biographical information to good care, it became clear that this type of information was difficult to access. Viewing Jack's *VLS*, staff members were surprised to learn about his passion for restoring old boats; despite the fact that he had been a resident for almost two years, staff were unaware of a hobby rooted in his former occupation. As the *VLS* might be considered as a "presentation of self" (de Medeiros, 2005, p. 6), the fact that he chose to include his hobby in his presentation indicates that he would like to share this interest with others. Also, because his *VLS* is devoted to this hobby, his interest in boats might be

considered as a key part of his identity. From this example we might speculate that a lack of knowledge of a resident's life history and personal interests might lead to missed formal and informal care opportunities tapping into a resident's identity and failing to support his or her personhood.

Although the majority of staff opinions revealed the importance of "knowing" and personally connecting with residents' life histories in order to provide person-centred care, not all considered this knowledge a priority. Several nursing staff participants revealed a predisposition toward residents' medical rather than biographical information. For example, one RN shared how on admission day, residents are bathed, in this way nurses are able to "see the body itself…we do a head to toe assessment." Another nurse reported obtaining all the resident's vital information from their Activities of Daily Living Chart, posted in residents' rooms.

2) "Pictures tell a lot, that's true": Staff Perceptions of Residents' Personal Photographs

Following viewing of the *VLS*, staff comments revealed their enthusiasm for the potential of the *VLS* to support them in their specific roles within the care team. The possibility of creating a more positive social environment was revealed. Participants' descriptions of care situations illustrated how both informal (e.g., a meeting in the hall, helping a resident dress) and formal resident/staff interactions (e.g., bathing a resident or engaging them in a planned activity) might be positively affected through exposure to the *VLS* by helping staff employ a more personalized approach to the care situation.

Moreover, staff members' comments indicate an appreciation for the qualitative difference between visual presentations of residents' life stories versus text-based documents, such as the social histories currently used within the two facilities. In the words of one RCA, "It [the VLS] tells you a lot about them." In the same vein, a recreation therapist shared that " it's nice to see them younger, standing up, with their family surrounding them so that we can kind of see them as human beings before they had, before they were a human-being with this disability, so you can relate more to them." That is, unlike a text-based life history, "a piece of paper," the photographic image allows the viewer to see the resident in the context of their familial and social relationships, at times when they were less dependent on others and more capable.

Staff responses to the *VLS* indicate how it helped several participants to uncover and remember things they have in common with the resident thereby opening up the possibility of more meaningful resident/staff communication and the valuing of persons with dementia, a key part of Kitwood's (1997) conception of personhood. This point was also touched on by a director who noted how the photographs used in the *VLS* facilitates an "...immediate connection which you don't always get when it's just written on black and white, it's not the visual."

3) "They want everybody to know everything on the very first day": Staff Perceptions of Family Support for the *VLS*

Focus group participants were probed for insights regarding the potential of family involvement, a key part of the production of a resident's *VLS*. Both the direct care and management team mentioned the topic of familial involvement frequently. Members

of the management team shared how family members often 'expect' staff to know a great deal about their relative's life history, beginning at the time of admission. A nurse perceived this expectation as a way for family members to continue to participate in the care of their relative now living in a care setting. Another staff member highlighted the importance of family input when a resident has dementia and is unable to provide biographical information about him or herself: "That's the only way we're going to find out."

While staff indicated that families would likely support the addition of the *VLS* tool to care delivery and that, in general, family involvement was considered a positive part of care provision, the differences between the two participating facilities was noted. That is, levels of family involvement in residents' care was a topic of discussion in two focus groups: a recreation therapist summed up this discussion, stating that "there are two different types of families—those that are involved and those that are not." Apparently, the two sites enjoy markedly different levels of family involvement, with more family participation in resident care experienced at GMA.

4) Macro-Level Policies in the Care Facility Context

Placement/Admission Policy: Within the focus group discussions, staff from across the care teams referenced macro-level policy decisions that have impacted their work as caregivers. For example, they mentioned a breakdown in the ability of facility staff to compile and disseminate accurate biographical information on their resident population. Staff responses described how the social histories currently used in the facilities are not as thorough and accurate as they would like them to be, and once were.

Management staff, the creators of this document, noted how changes in healthcare policy have negatively affected their ability to gather comprehensive, accurate, biographical information, pre-admission. Specifically, as part of the continuing care policy implemented in the province of British Columbia several years ago, residential care settings are no longer allowed to maintain wait-lists. Although wait-lists have been the source of much public frustration and criticism, some management staff reported that facility wait-lists allowed them the time necessary to collect and disseminate prospective residents' social histories within the facility prior to admission. According to one staff member, the wait-list permitted a "window of opportunity" to "start getting everything from information about their medical situation, psychiatric, family, finances and everything."

The change in admissions to residential care referred to by staff participants is the Residential Access Policy (R.A.P.), introduced in April 2002 (BC Ministry of Health Services, 2002/03). In an effort to address "inappropriate utilization and long chronological waitlists," this provincial policy, that is based on complex care criteria and a first available bed system of placement, has filtered down to the facility level, and according to staff, impedes staff access to residents' biographical information prior to admission. Implementation of R.A.P. means that staff members no longer have time to access and compile individuals' biographical information before a person moves to the facility: "Quite often we won't see the family because we'll see the person in the hospital, and the family's working, and it's such short notice so our information is very, very piecemeal and fragmented so anything I send is basically based on a 24-48 hour window

of opportunity where you're getting information over the telephone, third-hand, not necessarily 100% accurate, which is what staff get (Manager)."

According to a member of the management team, whereas at one time the family would fill out a "whole package of information," changes in placement policies have effectively limited staff in their quest to "know the resident" at the time of admission. Considering the point of view of the prospective resident and their family, one manager stated that it makes little sense to fill out information ahead of time for a facility that may not be the first bed available in the system.

Rising Resident Care Levels: Another example discussed within focus groups of a macro-level policy that filters down to impact care practice relates to the increasing care levels of the resident population. According to several management staff, recent changes to Continuing Care policy in the province has meant that residents' themselves are less able to contribute to the compilation of their social history within facilities. Whereas previous provincial assessment tools meant that individuals of higher functional abilities were placed in residential care, since 2002, in order to qualify for placement, an individual must be at a lower functional level and is more likely to have significant cognitive impairment. In 2002/03, 88 % of residents were admitted at the highest care levels: Intermediate Care 3 (IC3) and Extended Care (EC) (Ministry of Health Services, 2002/03). According to a leisure manager; "We used to be able to get quite reliable information from the resident themselves, now virtually, you can't really." This policy outcome, identified by several management staff, serves to highlight the potential role of the *VLS* to assist residents who are increasingly unable to present biographical information to formal caregivers without assistance.

A further finding from the focus group data related to higher care levels is the issue of resident to staff ratios. Staff members report that extreme time constraints and a heavy workload related to the high resident to staff ratio characterized in both facilities interferes with their ability to provide person-centred care. According to one RCA: "We're on the go all the time, we just don't have time to sit down with one specific resident." As noted, time constraints faced by staff are in part responsible for the allocation of staff resources to meet the acute medical needs of new residents.

In addition, the biggest care challenge noted by staff relates to the increasing care levels in the resident population with respect to mobility level. Although dementia was discussed in terms of necessitating increased patience and empathy from staff, more often, what seemed to represent a bigger challenge to care delivery was the number of residents who are classified as extended care.

This finding is interesting in light of the amount of research, addressed in the literature review, that has been devoted to the challenges that dementia-related behaviours present to staff (Kolanowski & Rule, 2001; Noelker & Harel, 2001; Woods & McKiernan, 1995). In this study, the fact that residents either were or were not at the extended care level was raised more often in discussions than residents' level of dementia as contributing to an inability to deliver more person-centred care. Problematic behaviours were discussed only briefly when probed by the facilitator. Issues of residents' mobility levels was raised by registered care attendants in all four focus groups. The job of RCA involves assisting residents with a variety of daily functions such as toileting, bathing, and dressing. If a resident is at the extended care level, assisting the resident with these functions is physically taxing for the RCA. Reed-Danahay (2001)

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reports that nursing homes predominantly employ female staff. All of the RCAs who participated in this study were women. The frustration of this reality is evident in the following quotes, the first from a director: "I've got one care aide for eighteen residents," to which an RN added, "And half of them are extended care," suggesting a focus on physical needs, 'bed and body work,' rather than psychosocial needs of the resident population. Noting frequent comments by staff (from all levels of the care team) regarding the challenge of rising resident care levels, we might speculate that the *VLS* has the power to respond to shortcomings created by current policy and therefore that it might be considered a tool to assist in the development of the social component of care.

5) Micro-Level Demands in the Care Facility Context

Staff Perceptions on Workload, Time Constraints, and High Care Levels: The myriad demands of working in a care facility with respect to increasing workloads, time constraints and higher resident care levels were voiced across all groups, and across positions within the care teams. Direct care staff in particular discussed the challenge that these issues present to the delivery of personalized resident care. RCA comments on the demands of their position, included; "We don't have time;" "We're always racing against the clock;" and "Half the time your mind is working fifty miles an hour and you're thinking...you wonder what is that resident thinkin' of you." The result of these demands on many of the RCAs is that they report not accessing the social histories that are currently prepared within the study sites. A staff from clerical support voiced feelings of guilt associated with the time pressures on the job:" "Everybody's looking for attention and you try to stop. 'How're ya doing'? "How're ya doing'? And I know that's not

enough." Similarly, recreation therapists reported on the challenge of programming for residents with diverse cognitive and physical abilities, as well as diverse interests.

Those participants who occupy management positions also spoke of how they are challenged to provide person-centred care. One manager expressed how the intake of residents with higher care levels has resulted in the prioritization of the medical needs of the resident population. That is, great efforts are made upon admission to connect residents with a variety of medical specialists such as the podiatrist and ophthalmologist in an effort to thwart acute medical problems in future. Another manager expressed the difficulty staff face getting to know the resident or provide person-centred care given, "the day-to-day reality if they're running around dealing with seven extended care people." Finally, a manager from GMA noted how the family members' expectation that staff are knowledgeable about the person in their care is challenging, given the high turnover experienced in this facility (reported as 30 % resident turnover every three years).

Given the perceptions of both the direct care staff and management staff of increasing time constraints and workloads, the question of *VLS* production was raised in several of the group discussions. Several staff members queried the researcher as to "who would be doing it?" This question represents an important consideration with respect to the feasibility of *VLS* implementation in care facility settings and warrants further discussion.

Organizational Policies and Direct Care Staff Access to Residents' Biographical Information: The identification of another challenge to the support of residents'

personhood and the delivery of person-centred care that arose in focus group discussions relates to direct care staff members' exposure to residents' biographical information. Organizational level policies currently in place within the study sites function to exclude staff on the front line from discussions at care plan meetings, meetings in which residents' social lives are discussed. As is the case in most long-term care facilities, within SHR and GMA, the registered care attendants, the staff who provide the vast majority of direct care to residents, do not attend care plan meetings (Ronch, 2004)— meetings in which residents' biographical information is shared with management level staff. Focus group data also revealed that RCAs do not generally seek out residents' biographical information contained in their files, rather, they predominantly learn about residents from the individuals themselves. Given that residents with dementia are compromised in their ability to communicate their preferences, interests, and experiences, this approach might be seen as inadequate and highly problematic. Until such time as RCAs attend care plan meetings, the idea was raised within groups that an organizational policy could be put in place mandating direct care staff (along with other staff and/or volunteers) viewing of residents' *VLS* presentation. In this way, the *VLS* has the potential to support a more fluid approach to dementia care whereby staff from across care positions benefit from this critical information.

CHAPTER FIVE: DISCUSSION

Review of Findings and Implications

The relationship of the research findings to the conceptual framework will be discussed throughout this chapter. Drawing on a wide range of gerontological literature, this investigation is grounded in social constructionist notions of personhood, as defined by Kitwood (1997), that stress the critical role that formal caregivers play in the well-being of residents with dementia by helping them to connect with their life history and by caring for them as individuals. This is one of the few studies that has examined personal photographs as a means to transmit residents' biographical information, and the only study found by this researcher that explores the potential of a visual presentation of residents' life stories to support personhood and promote more person-centred care.

In an effort to explore the therapeutic use of residents' personal photographs in the long-term care context, a biographical photo-based tool, the *VLS*, was created in collaboration with residents and family members. Analysis of textual data from guided conversations with residents with dementia and their family members reveal the effectiveness of visual prompts to "'act as inducers of reminiscence'" (Sherman, 1995, p. 193). That is, the personal photographs used to facilitate recall within the guided conversations supported residents to both corroborate and add to family members' accounts of the experiences depicted within the selected photographs. Through the process of sharing their autobiographical accounts residents were able to connect with Self 1, "the self of personal identity" (Sabat, 2002, p. 91). Both residents and their family

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members vocalized their enjoyment in the opportunity to reminisce and to re-live the memories associated with their family photographs.

Focus group discussions designed to ascertain formal caregivers perceptions of *VLS* use revealed that formal caregivers understood the potential value of greater access to residents' biographical information in the quest to individualize care. Although prior to exposure to the *VLS* most staff viewed the facility's current method of producing text-based social documents as adequate, following the presentation, staff comments indicate a desire for more detailed resident life histories. Many staff members also shared their perceptions that a visual presentation is an effective, enhanced way to transmit a resident's biographical information and share with the viewer key aspects of a resident's social life. One member of the management team expressed this opinion in the following quote, "It *shows* who they were and is a reminder of truly who they still are."

The visual presentation of a resident's life stories in a group setting was shown to provide a rare opportunity for formal caregivers, from both the direct care and management team, to participate in a discussion of a resident's life history. Following the *VLS* presentation, participants across focus groups engaged in lively discussions that, for example, provided insight into the featured resident's current behaviours, preferences, and attitudes vis-à-vis information from across their life course. For example, details of SHR resident Jack's childhood allowed staff to re-interpret his current financial concerns in a more favourable light. Similarly, GMA resident Claire's lifelong religious practices were more clearly understood by staff following presentation of her *VLS*. As Magilvy and colleagues (1992) concluded, a visual presentation in a group setting created a distinctive opportunity for the exchange of information. Consequently, the ability of the *VLS* to

generate dialogue about resident's psychosocial needs within care plan meetings

distinguishes it from current text-based documents and thus represents an exciting area of

potential *VLS* use.

Analysis of focus group data also revealed that the majority of staff recognized

how the *VLS* might help them to support residents' personhood and deliver more person-

centred care. *VLS* presentations within the focus groups evoked discussions about the

featured residents' social selves, Sabat's (2002) Self 3—"socially presented selves, or

personae" (p. 93). Exposure to Claire's *VLS* allowed staff members to identify common

interests and to more fully appreciate her experiences, as a mother, a wife, of living in a

remote mining community, and her great love of gardening and her family. Jack's *VLS*

presentation highlighted his lifelong interest in old cars, thus opening up a new area for

meaningful activity and social interaction between not only staff members, but also other

residents.

The ability of the *VLS* to place the resident, not only within their life course

experiences, but also in various social contexts, including their family context, was

discussed amongst staff participants. One nurse shared in a focus group that the *VLS*

provided a window into the values of the resident's entire family. This finding echoes

Coker's (1998) finding which revealed that nursing staff were anxious to know more

about residents' families as they considered families to be an "extension of the

individual," (p. 443), thereby representing a possible avenue for critical insights about

residents in their care.

Crisp (1999) maintains that, "a prerequisite of helping people with dementia to maintain their personhood is that we ourselves continue to see and treat them as fellow human beings" (p. 106). Staff responses to Claire's *VLS* illustrate how access to a greater depth of her biographical information allowed staff to see beyond the labels of 'resident' and 'dementia' and to effectively re-position her (Sabat et al., 2004): in the words of one staff member, "You just begin to see more of the person behind the disease." Likewise, another staff participant's words illustrate how exposure to her *VLS* had effectively re-positioned Claire in her eyes: "If you walked upstairs right now and you see Claire walking by you'll think of her more as the person she used to be instead of the person she is right in from of you and less of the dementia and more of her history." These comments reveal how the *VLS* might help staff to limit "malignant positioning" (Sabat et al., 2004, p. 178) and, in keeping with Kitwood's (1997) view of personhood, help staff to see "the person behind the patient" (Clarke et al., 2003, p. 697) by supporting the development of more meaningful relationships by positively affecting the lens through which caregivers view residents with dementia.

Overall, the support of staff members for the potential of the *VLS* to positively impact residents' psychosocial environment and improve their well-being was evident across focus groups. However, despite the receptiveness of staff to the *VLS*, and their recognition of its potential contribution to person-centred dementia care, focus group discussions also revealed several challenges that negatively affect their ability to provide individualized care and the possibility of *VLS* implementation.

Staff members shared how macro-level policy decisions have filtered down to impact care delivery at the organizational level. Changes to admission policies

implemented in British Columbia in 2002 that were designed to address lengthy wait-lists for residential care have negatively affected the ability of staff to collect accurate and thorough life histories for new residents. That is, the policy of first available bed placement means that staff are given little notice prior to receiving a new resident and do not have the time that wait-lists once allowed them to gather residents' biographical information. Whereas at one time residents were more able to share with staff their life history information themselves, admission requirements currently in place mean that increasingly residents are of higher care levels and are more likely to have communication challenges associated with dementia. The impact of this trend is that residents are less able to make themselves known to staff and increasingly are in need of support to present their biographical information to formal caregivers.

The impact of the admission of residents' of higher care levels was discussed within the focus groups as contributing to increased workloads and extreme time constraints. At the organizational level, high resident to staff ratios function to impede the ability of staff to get to know the resident in their care. Although the study sites state that operate under a holistic model of care, the current climate seems to present a significant challenge to formal caregivers ability to foster a positive psychosocial environment within the care facilities and to deliver this type of care. Moreover, staff members themselves require the organizational support to deliver *good care* (Kitwood, 1997). As Brooker (2004) states, "in person-centred care, the relationships between all people in the care environment should be nurtured" (p. 219).

Given the receptiveness of staff to the presentation of residents' biographical information in a *VLS* format, the therapeutic potential of this tool appears to be

promising. However, findings from this investigation serve to highlight the paradox that exists between theory and practice in dementia care. As more and more gerontological research highlights the importance of moving beyond a biomedical focus in dementia care, and during at time when in many parts of the world the term person-centred has become virtually "synonymous with good quality care" (Brooker, 2004, p. 215), significant barriers exist at the practice level—barriers that continue to make true person-centred care a goal, but not yet a reality.

Implications of the Research

The implications of this study relate to the advancement of dementia care practice in several important ways. To begin, the willingness of family to participate in this study has important implications of for future investigation. Family involvement might be seen as evidence of support for care practice that exceeds "routinized care" (Diamond, 1986 as cited in Kolanowski & Rule, 2001, p. 14), to care that supports residents' identity within the institution and more closely attends to residents' psychosocial needs and desires.

Furthermore, the process of *VLS* production was found to help establish opportunities for positive interactions between families and staff. As was discussed in the focus groups, many family members are interested in continuing to participate in the care of their relative following placement in a facility. Staff reported that they find it a challenge to provide families with constructive outlets for sharing their relative's biographical information. Involvement in the creation of a *VLS* not only draws on their expertise as a member of the family and intimate knowledge of their relative, but also

provides a vehicle for families to continue to be involved in some aspects of their relative's care.

Additional implications of this study are in informing long-term care policy by highlighting staff perceptions of the challenges to deliver person-centred care. This study allowed for preliminary insights into macro-level forces that impact the ability of organizations to deliver and respond to the demands of person-centred care. Although focus group participants voiced the desire to spend more time with residents and to know more about their life histories, findings suggest that, even within a facility that is based on a holistic philosophy of care, staffing issues and increasing workloads represent significant barriers to the delivery of individualized care. Given the issues raised by care staff relating to increasing care levels and rapid placement, the goal of collecting comprehensive social histories on residents, of making the resident known to staff and thereby easing their transition into care, has become more of a challenge. A biographical tool such as the *VLS*, which a staff member noted is a way to "speed up the process of getting to know someone," might therefore become critical in addressing problems specific to the current long-term care situation in BC.

In addition to implications for dementia care practice, findings from this study also have significance for gerontological inquiry in general. First, results of the first phase of data generation involving residents and their families revealed how persons with dementia can be involved in the creation of their own life stories. As Ryan and colleagues (2005) and Cohene and colleagues (2005) found, persons with dementia can be successfully involved with the saving and sharing of their life stories. In this study, the subjective experiences associated with participants' personal photographs, as shared with

the researcher, were added to the histories obtained from family members; in this way their perspective formed an integral part of this biographical tool. Moreover, the guided conversations conducted with residents, based on their photographs, helped to give voice to the person with dementia, supporting their identity, in part through sharing with staff those stories of which they are proud.

The use of photographs described in this study to create a photo-based biographical tool represents a new way to make use of readily accessible residents' photographs in the quest to promote person-centred care. In so doing, this study also adds to research in the emerging area of photography and gerontology.

Despite the apparent utility of the *VLS*, technological concerns must be addressed. In terms of the material construction of the *VLS*, the researcher gained insights into the benefits and limitations of current communication technologies. The computer provides an invaluable resource in the quest to provide person-centred care via providing a means to gather and share residents *Visual Life Stories*; however, given the nature of computer software and the constraints of working with time-based audio files, the construction of this type of tool requires significant computer literacy, access to communication technology and technical support. One expects however, that these constraints will become less significant as technology advances and as digitally-based communications become more ubiquitous, with more people using digital photography and audio to create and store personal data.

Suggestions for Future Research

This study has important implications for research involving residents with dementia. One implication that surfaced during this study relates to the use of the *VLS* as a reminiscence tool for persons with dementia. As Chaudhury (2002a) established, this study demonstrated how the use of personal photographs with persons with dementia could be an effective way to facilitate reminiscence in this population. However, whether it is possible to use the *VLS*, designed for staff use, as a reminiscence tool for residents with dementia remains a question that is open to future inquiry.

The creation of the *VLS* used in this study was the product of a collaborative effort involving the resident, the family member, and the researcher. However, as noted, not all family members are willing or able to participate in the production of a *VLS*. Whether or not this type of tool could be created through guided conversations using strictly generic photographs, obtained from the Internet, represents another unexplored area warranting further investigation. Although the end product might not have the same impact on the viewer, it might help to supply staff with some biographical information, supported by a visual component, in an accessible format that participants in this study found connected them with the resident featured in the presentation.

This study sought to produce a biographical tool incorporating residents' personal photographs and to obtain the perspective of formal caregivers regarding its potential to support personhood and assist with the delivery of more person-centred care. Findings from this study indicate that staff members perceive the *VLS* as a means to achieve this end. However, whether or not staff exposure to a resident's *VLS* actually translates into more person-centred care practices was not evaluated in this study. Future studies, using,

for example, Kitwood's Dementia Care Mapping, which represents a means to "take the standpoint of the person with dementia," (Brooker, 2004, p. 215) might be a way to evaluate the effectiveness of the *VLS* in contributing to individualized care. Dementia care mapping, involving participant observation techniques, prior to and following viewing of a resident's *VLS* would help to clarify the impact of the *VLS* on care delivery and shed light on quality of life issues for residents with dementia.

Limitations

This investigation had a number of methodological limitations. The first limitation was the focus group composition. Madriz (2003) warns that in some work situations individuals may feel uncomfortable opening up and offering opinions in front of those in a supervisory position. To offset the effects of these types of power relations on the group dynamics, each session began with assurances that the researcher is interested in the opinions of all those present. However, although participants were assured that there was no "right" or "wrong" answers to the questions, content analysis of the textual data revealed less input from direct care staff in groups where the majority of the participants were from the management team.

A second methodological limitation of this study relates to sample size and focus group length. Given the extreme time demands that are placed on caregiving staff throughout the day, the number of staff available to participate during staff hours was less than anticipated. When the researcher approached the Director of Care for help with staff recruitment and presented the idea of holding the sessions after hours, the researcher was advised that this was less likely to attract participants. Therefore, as the focus group

sessions were conducted during work hours, the researcher, acting as the facilitator, was mindful of the time, consequently, discussions were not as long as envisaged.

This study was also limited by its recruitment of resident-family dyads. Residents and family members were recruited through the assistance of the nurse clinician. Selection criterion for participation in this study indicated that the resident must be able to participate in meaningful communication, not only in terms of dementia level, but also in terms of language. The result of this criterion was a failure to create a more culturally or ethnically diverse sample. Although staff members noted language barriers as a challenge in caring for residents with dementia, the production of a *VLS* with non-English speaking residents and their families was not addressed in this study. However, given that this is a photo-based tool, the possibilities of creating a *VLS* for a resident who does not speak the dominant language, and who may arguably be in more need of support in sharing their life stories with staff, represents an exciting area for future study.

Participant Screening and Privacy

In addition to methodological limitations of this study, two points of concern should be recognized and inform future studies. The first consideration relates to participant screening. Because the development of a *VLS* employs reminiscence, participants must be carefully screened. Recognizing the diversity of life experiences within resident populations, researchers and formal caregivers need to carefully consider which individuals this tool might be appropriate for, as well those for whom it might not. For example, older adults suffering from the effects of psychological trauma might not be appropriate candidates.

Another consideration that is critical to *VLS* production relates to resident privacy rights. Resident participants in this study resided within private sector non-profit organizations; therefore, their privacy was protected by the British Columbia Personal Information Protection Act, 2004 (Office of the Information & Privacy Commissioner for British Columbia [OPIC], 2006). Section 30 of this Act specifies that all information unique to the individual be protected under law.

Conclusion

"There exists a point of convergence between the life course as remembered time and the sequencing of our memories through the medium of the photograph, and, to the extent that we collect photographs of ourselves and construct a plausible story around them, we are all essayists." (Blaikie, 1994, p. 490).

This study offers important insights into a potential means of foregrounding the person behind dementia. By involving residents and their families in reminiscence-based guided conversations, it highlights the ability of persons with dementia to actively contribute to the collection and presentation of their life stories. The data generated in this study illustrates how readily available autobiographical material, personal photographs, might be capitalized on in the effort to provide care that supports personhood, and thus, empowers formal caregivers in their ability to provide more person-centred care.

Focus group discussions revealed how exposure to a greater depth of information about residents, via the *VLS* biographical tool, generated a greater interest in individuals'

identities, beyond their care levels and physical needs. That is, staff members'

overwhelmingly positive responses to the presentations, in part due to the power of the

photograph to convey critical information about the individual, indicate a desire of staff

to know more about the people in their care. This finding echoes Cohen-Mansfield and

colleagues' (2000) results suggesting that formal caregivers' curiosity about residents is

piqued through exposure to detailed social histories.

However, the impact of recent changes to continuing care policy was found to

challenge staff in their ability to deliver individualized, holistic care. This issue illustrates

an advantage of the focus group method; it allows group members to "brainstorm

collectively" (Berg, 2001, p. 112) and for key issues to be raised that were not yet

considered by the researcher. Examples of the challenges experienced currently in long-

term care include increasing workloads, resident care levels, and time constraints.

If, as Dawn Brooker (2004) maintains, "Filing cabinets in care facilities around

the world are full of information about people's lives but still care staff will not know

even the rudimentary facts" (p. 220), then the need to look at alternative ways to collect

and share residents' biographical information, such as through the *VLS*, is long overdue.

APPENDIX 1

Family and Resident Guided Conversation Descriptions

Family Guided Conversations:

Two guided conversations, one per resident's family, will be conducted to obtain from family members their loved one's life history/biographical information. This information will then provide the narrative component of the resident's *"Visual Life Stories"* (*VLS*) presentation. Conversations will focus on family photographs reflecting the lifespan of the resident. The guided conversations will include discussion of both factual information and family members' subjective experiences as they relate to the selected photographs. Therefore, no structured interview questions will guide the family conversations. The conversations are expected to last between 1 and 1 1/2 hours and will be audiotaped and transcribed verbatim. Participants will be ensured of confidentiality throughout the research process.

Resident Guided Conversations:

Following the family guided conversation described above guided conversations will be conducted with the two participating residents. Family members will be invited to attend. As with the family guided conversations, no structured interview questions will guide the session. Rather, the resident guided conversation will be focused on the selected photographs obtained from the family members and reflect the experiences depicted in the selected photographs. The purpose of this session is to gain the resident's

perspective on the experiences surrounding the selected photographs, thus supplementing

the content of the *VLS* provided by the family.

Resident-Family Guided Conversations:

Following completion of a draft of the *VLS*, residents and their family members

will be involved in a follow-up guided conversation (s) to obtain their feedback on the

prototype and obtain consent for use within the focus groups sessions composed of care

facility staff.

APPENDIX 2

Focus Group Questions & Probes

1. Can you tell me how you currently find out about residents' biographical information beyond their condition of dementia?

2. What are some ways that you currently use residents' biographical information to provide care?

3. What are some of the biggest challenges you encounter caring for residents with dementia?

    Probe: What are some of the ways that you deal with these challenges?

    The focus group will now view the VLS; remaining questions probe participants' responses to the VLS tool.

4. Having seen the *VLS*, in what ways do you think it could be a useful tool in your role as a caregiver?

    Probe: Do you think family members would welcome this type of tool?

5. a) What are some of the barriers that exist within the facility to implementing the *VLS*?

    b) What are some practices that might assist with its' implementation?

6. Is there anything else that you would like to add to this discussion?

APPENDIX 3

Focus Group Participant Questionnaire

I work at Spruce Hill Residence ☐ I work at Grouse Mountain Acres ☐

1.   Male ☐   Female ☐

2.   Please describe which floor/units of the care facility that you work in (e.g. SCU,

2nd floor, all floors, etc.).

_____

_____

_____

3.   What is your current position at the care facility? Please briefly describe key

aspects of your work, particularly in relation to resident care.

_____

_____

_____

4.   How long have you worked for either SHR or GMA?

        _____ years/months (Please Circle)

Thank you for your participation.

APPENDIX 4

SIMON FRASER UNIVERSITY

Informed Consent by Participants (Staff Members at Care Facility) in a Research Project - Form 2

Project Title: *Supporting Personhood within Dementia Care: The Therapeutic Potential of Personal Photographs*

Supervisor:

Dr. H. Chaudhury, Department of Gerontology

Purpose:

The purpose of this project is to investigate staff experiences providing care for residents living with dementia in general, and specifically, to obtain feedback regarding a biographical approach to supporting residents' personhood (i.e. the person behind the challenges of dementia) via residents' personal photographs.

Procedures:

If you agree to participate, you will be asked to participate in one focus group interview that will be conducted at your work site in the interest of convenience. The student will moderate the focus group interview. The focus group questions will be about your experiences (that you are comfortable sharing with others) in providing care to older adults living with dementia within a long-term care setting. Specifically, I will seek your thoughts about the value and potential role of *Visual Life Stories (VLS)* of one resident in understanding the person beyond the manifestations of dementia related behaviours and how this understanding might inform the care planning and practices. The focus group interview will take approximately one hour and will be tape recorded. All or part of the interview will be typed out. The interview content will be used in the student's proposed academic research.

Risks and Benefits:

There are no risks to participating in this project. Although you will receive no direct benefits, your participation will provide an important learning opportunity for the student conducting the project, as well, you will contribute to academic research designed to address the challenges associated with dementia care.

Confidentiality:

Any information resulting from this interview will be kept strictly confidential. All documents will be identified only by a code number. Your name will not be identified in any reports. Materials will be maintained in a secure location. The audio tape will be erased following completion of the project.

Contact for information about the study:

If you have any questions or desire further information with respect to this project you can contact either (student) Elizabeth Kelson by phone at 604-897-9414, or by email at ekelson @shaw.ca, or (supervisor) Dr. Habib Chaudhury at 604-291-5232. You can obtain copies of the results of this study, upon its completion by contacting Dr. Habib Chaudhury at the contact numbers listed above.

Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact Barb Ralph, Ethics Officer, Office of Research Ethics, Simon Fraser University by phone at 604-291-3447 or by email at bralph@sfu.ca.

Consent:

Your participation in this project is entirely voluntary and you may refuse to participate or withdraw from the project at any time without consequence.

Your signature below indicates that you have received a copy of this consent form for you own records.

Your signature indicates that you have been informed that the research project is confidential and consent to participate in this thesis project.

_____   _____

Participant's signature   Date

_____

Printed name of the participant

_____   _____

Witness's signature   Date

APPENDIX 5

SIMON FRASER UNIVERSITY

Informed Consent by Family Members of Residents with Dementia at Care Facilities in a Research Project — Form 2

Project Title: Supporting Personhood within Dementia Care: The Therapeutic Potential of Personal Photographs

Supervisor:

Dr. H. Chaudhury, Department of Gerontology

Purpose:

The purpose of the family interview is to obtain the life history/biographical information of a resident of a care facility. Participating family members will gather family photographs of their family member (the resident), and share with the interviewer the stories surrounding these photographs. This information will then be compiled by the interviewer in a PowerPoint presentation referred to as a *Visual Life Stories* (*VLS*).

The *VLS* will therefore present both visual and narrative components, and will serve as a prototype of a tool designed to facilitate caregiving staff's awareness of residents' biographical information. The purpose of this project is to investigate staff experiences providing care for residents living with dementia in general, and specifically, to obtain feedback regarding a biographical approach to supporting residents' personhood (i.e. the person behind the cognitive and behavioural manifestations of memory loss) via residents' personal photographs.

Procedures:

If, as a family member, you agree to participate, you will be asked to gather family photographs reflecting the life history of your loved one now residing in a care facility. You will then be asked to participate in an interview, based on the collected photographs, detailing the experiences surrounding the selected photographs, as you understand them. The interview will be conducted in your home or other convenient location of your choice. The student will conduct the interview. The interview will take from one to one and a half hours and will be tape recorded. All or part of the interview will be typed out.

You are also asked to approve contact by the student with your family member, of whom you are a legal guardian. Following the family member interview, the student will engage the resident in one session of a guided conversation related to the selected photographs. In this way, the perspective of the resident will be included in the presentation of their *VLS*.

Risks and Benefits:

There are no risks to participating in this project. Although you will receive no direct benefits, your participation will provide an important learning opportunity for the student conducting the project, as well, you will contribute to research that affirms the personhood of those living in residential settings.

Confidentiality:

Any information resulting from this interview will be kept strictly confidential. All documents will be identified only by a code number. Your name, or that of your family member, will not be identified in any reports. Materials will be maintained in a secure location. The audio tape will be erased following completion of the project.

Contact for information about the study:

If you have any questions or desire further information with respect to this project you can contact either (student) Elizabeth Kelson by phone at 604-897-9414, or by email at ekelson @shaw.ca, or (supervisor) Dr. Habib Chaudhury at 604-291 - 5232.

You can obtain copies of the results of this study, upon its completion by contacting Dr. Habib Chaudhury at the contact numbers listed above.

Contact for concerns about the rights of research subjects:

If you have any concerns about your treatment or rights as a participant in research, or about the responsibilities of researchers, or if you have any questions, concerns or complaints about the manner in which you were treated in this study, please contact Barb Ralph, Ethics Officer, Office of Research Ethics, Simon Fraser University by phone at 604-291-3447 or by email at bralph@sfu.ca.

Consent:

Your participation in this project is entirely voluntary and you may refuse to participate or withdraw from the project at any time without consequence.

Your signature below indicates that you have received a copy of this consent form for you own records.

Your signature indicates that you have been informed that the research project is confidential and consent to participate in this thesis project.

_____   _____
Participant's signature   Date

_____
Printed name of the participant

_____   _____
Witness's signature   Date

APPENDIX 6

VLS Production

A. There are three main objectives relating to the production of this biographical tool:

1) The *VLS* will be designed to facilitate formal caregivers access to critical biographical/life history information of residents in their care through a visual presentation of personal photographs supported by narrative describing experiences associated with the selected photographs. The cooperation of family and/or friends is a critical component of the *VLS* production.

2) Viewing of the *VLS* will create a space within care plan meetings that allows for a dialogue around specific residents life stories, contributing to, for example, how best to communicate with that individual, thus facilitating the creation of a more individualized plan of care. Additionally, the *VLS* will be available for care giving staff (e.g. RCAs) not attending care plan meetings.

3) While the *VLS* is designed to support the personhood of all residents by contributing to person-centred care, it is perhaps of greatest importance to residents living with dementia who have compounded challenges associated with communication, and therefore, face greater challenges vis-à-vis the maintenance of self and personhood, and to those directly responsible for providing their care.

B. Making Your Own Visual Life Stories

The *Visual Life Stories* (*VLS*) is a tool designed for use by formal caregivers of residents living with dementia within an institutional setting. The *VLS* is a digitally-based application designed to present residents' individual life stories using personal photographs and narrative detailing relevant experiences from across the subject's life course.

Steps Taken in Creating a VLS:

1. Collecting resident's personal photographs and conducting reminiscence-based session or sessions with the resident and family member.

2. Transcribing select stories shared during the reminiscence session or sessions to create script - narrative component of *VLS*.

3. Scanning photographs and arranging them in chronological order. The number of photographs depends on availability and desired length of presentation. As a guide, approximately 45 slides can be covered in a 13-minute presentation.

4. Preparing text-based script (in a Microsoft Word for Mac 2004) from stories shared by resident and their family member.

5. Opening Keynote 3(or similar software program such as PowerPoint) and selecting master presentation.

6. Creating Keynote 3 slides and inserting photographs in chronological order to complete the visual component of the *VLS*.

7. Outputting Keynote presentation as either an Apple QuickTime 7 movie or individual JPEG files of each slide.

8. Using GarageBand 3 (or similar program capable of combining audio and visual components) to record audio component of presentation by reading from the prepared script and combining the audio and visual components (inserting either the QuickTime file or the JPEG images).

9. Exporting the completed *VLS* from GarageBand 3 as an MPEG or QuickTime 7 movie.

10. Previewing the content to ensure that the material is complete and the audio and video are synchronized.

11. Opening the MPEG or QuickTime 7 movie into iDVD 6, choosing a template and burning to DVD.

12. Reviewing completed DVD with resident and family member to check for accuracy and to gain feedback.

APPENDIX 7

VLS Script - SHR Participant

Slide 1 – Title slide

Jack Brown was born in…

Slide 2

Sundre, Alberta August the 19th, 1925.

Slide 3

On the day Jack was born, the weather was cloudy and calm; the temperature ranged from 44 to 58 degrees Fahrenheit, with scattered showers, the crop conditions were considered good.

Slide 4

Sundre is a farming community in northern Alberta that is located west of High River, at the junction of highway 14 and highway 24.

Jack had two sisters, Lily and Mary, he also had two older half-siblings. As a boy, Jack was called Jack Junior by his family.

Slide 5

Jack Brown Sr. was born in Rubislane, Slovakia on July 31st, 1895. In 1926 he married and moved to Canada. Jack Sr. was a farmer, a man Jack Jr. describes as a "man of few words." His father worked the farm in Sundre from 1926 - 1953.

Slide 6

Jack's parents were a part of a migration of Hutterites to Canada from different parts of Europe and Slovakia who were trying to escape persecution. As a group, they have been persecuted for their religious beliefs and sought out locations such as Canada where they felt safe from discrimination.

Slide 7

In 1969, after living in various farming communities throughout Canada, Jack Sr. retired from farming and moved to North Vancouver, BC where he lived with his son until the mid-1970's.

Slide 8

His mother, Lily Martin was also born in Slovakia and moved to Canada in 1927. In that year, Lily married Jack Brown Senior. Together, this couple ran a farm. They had three children together, Jack in 1929, Lily in 1931, and Mary in 1935. It was a hard life on the farm; Jack remembers his mother as a hard working farmwife: "if she wasn't working in the kitchen, she was knitting socks or somethin' like that." When Jack was young all this work was done by the light of a kerosene lamp.

Jack's recalls that his mother was in ill health when he was a young man. Jack developed a very close connection to his mother on their long drives into town when Jack would take her to her various medical appointments. Lily passed away in 1963.

Slide 9

When Jack was a boy he went to the local country school, later on, he studied for 2 years at private school in the prairies, a Hutterite school. Jack was a good student who excelled at math and reading. He remembers his father taking him out of school at harvest time, to help with the threshing.

Slide 10

Jack started to drive at the age of twelve, into town and on the farm. At that time, he was four years under the age limit. Jack recalls that, "you could go for half an hour before you would find somebody else on the road."

Slide 11

When Jack was a boy during the war years, although the farm enabled them to make their own butter and have their own meat and eggs, other foods like sugar and coffee were rationed. In order to get these items, you had to use a coupon from a ration book.

When Jack was a young man Jack Sr. gave him a half section of land to farm. Jack planted wheat on part of the farm. He recalls the incident that motivated him to follow a different line of work...

Just before harvest time, on the 19th of August, a foot of snow squashed both " a good stand of wheat" and Jack's desire to pursue farming.

The part of farm life he did enjoy most was learning about farm machinery, especially engines. This interest began for him when he was a boy and would fix his toy trucks.

Slide 12

Jack left the farm behind when he was in his late 20's. Although he was never particularly fond of farming, he was able to take the skills he learned there and develop them in his various occupations throughout his life.

Slide 13

From there, he moved 14 miles west, to High River, Alberta.

In High River, Jack was able to turn his natural aptitude for mechanics into a thriving business of his own, fixing farm equipment.

Slide 14

Jack ran his business for 10 years. He built up a loyal clientele during these years and continues to be friends with some of his previous customers.

Slide 15

Jack was first married in 1952. Helen and Jack had four children together: Paul in 1954; Allison in 1956; Barney in 1957 and his last son Harvey was born in 1961. The

growing family lived at various places throughout the Lower Mainland. In 1971 Jack's first wife passed away following a brief illness.

Slide 16

Jack took this photograph of his sons Paul and Harvey and his daughter at her graduation. Allison graduated from the University of Victoria with a degree in Commerce. Today, she works as an auctioneer in Surrey. Son Harvey went to the University of Iowa and currently lives in Edmonton and runs a movie theatre. Paul, Jack's oldest boy lives in far away Mexico City with his small family. Son Barney currently lives nearby in Vancouver and visits his father often.

Slide 17

Jack's sister Mary was about 12 years older than Jack and lived in Whistler...

Slide 18

...the two were quite close.

Slide 19

In this photograph, Jack's son Paul, and his grand children visit with Jack Senior. When Jack Sr. moved into care in Squamish, Jack Junior would visit him every other Sunday.

Slide 20

Jack's father lived there until he passed away at the age of 89.

Slide 21

Jack was a member of a senior's centre in the Lower Mainland for many years. In the early 1980's Jack would meet a woman through the centre who would change his life forever.

Slide 22

Jack met Patricia Catherine Gold, nicknamed Madge, at the Centre in the early 1980's. The two were bridge partners. At that time, Jack was not yet retired from his work with machinery. Every Friday night the two would play bridge together; through the Centre they went on several trips together.

Slide 23

One memorable trip they took with friends was to Fiji in 1980's. Madge recalls that the couple had great time swimming in the ocean and eating the fish they caught.

Slide 24

Jack and Madge courted for one year. On June 13th, 1987 the two wed in a beautiful ceremony at Crown's Nest Anglican Church.

Slide 25

Their reception was held at the Commodore Ballroom in downtown Vancouver.

Slide 26

Madge's son Tom walks his mother down the aisle.

Slide 27

Following a night at the Hotel Vancouver, the couple embarked on their

honeymoon – a trip to England to tour the big museums, art galleries, and to see some

shows.

Slide 28

Jack welcomed his stepchildren, Charles, Ivy, Sid and Tom into his growing

family. Tragically, the family lost their son Charles after an accident in 2006. Today, Ivy

and Sid live in Portland, Oregon and Tom is a great support to both Jack and his wife.

Slide 29

Madge and sister-in-law Mary at Webster's Garden in Victoria.

Slide 30

Jack also enjoyed traveling. A real highlight for Jack was when he visited Korea

with his son; the two traveled around for several weeks.

Slide 31

He also enjoyed trips to warm places, such as St. Kits and Florida.

Slide 32

Madge and Jack used to visit their friends the Jones's at Shuswap Lake for a

month every summer. Jack looked forward to these trips as, aside from boating and

fishing, he was kept busy helping his friend fix things around the cottage, there was always something that needed to be repaired, and Jack was just the man to do it.

Slide 33

They also traveled to other places throughout British Columbia. Jack loved to drive. Both he and Madge took one very long car trip down to New York to visit with Jack's youngest son.

Slide 34

Jack has been able to use his mechanical skills in his association, since 1986, with the Vancouver Antique Boat Club. This photograph of an old steamboat is one of the boats that Jack helped to restore.

Slide 35

In this photograph Jack is on the deck of his own boat, 'Chasing Wind.' Today, he keeps up to date on the Club's various projects through a friend who regularly attends the meetings and then reports back to Jack.

Slide 36

In the year 2000, Jack had a heart attack. Jack worked hard on his rehabilitation.

Slide 37

Jack with friends during his rehabilitation at George Derby Centre.

Slide 38

Jack soon mastered his scooter.

Slide 39

In December 2001, Jack spends Christmas at St. Jude's.

Slide 40

The family celebrates Jack's 70th birthday at his favourite Italian restaurant.

Slide 41

This photograph was taken at Madge and Jack's apartment, Christmas 2005. The whole family gathered to enjoy the season together.

Slide 42

Jack's son Paul and his niece enjoy a visit with Madge and Jack.

Slide 43

Jack and his friend on their scooters making their way to a Boat Club event at English Bay.

Slide 44

Jack's interest in old boats continues today…

Slide 45

Jack moved to Spruce Hill Residence on November 1st, 2004. Today, Jack enjoys playing cards on the computer, surfing the Internet, listening to music, and joining in the various programs offered.

Slide 46

In December of 2005, Jack passed a significant milestone: he became a great-grandfather. Jack welcomed his first great-grandchild into the family; baby Rebecca.

Slide 47

The End - collage of photographs.

APPENDIX 8

VLS Script - GMA Participant

Slide 1: Title Slide

Claire Simpson was born Evelyn Claire Woods was born in Moose Jaw on September 1, 1921.

Slide 2:

In the year 1926, when she was 5 years old, the Woods family moved to Vancouver. Claire was the third child in the family. She had an older brother Samuel, and sister Gail, and a younger brother, Sid. In those early years, Claire's father opened a gas station under the Cambie Street bridge. Early in her life, during the depression, Claire's family rented a house in the Cedar Cottage area; this home had no running water, electricity and an outhouse. In 1931 the Woods' moved to the West Side of Vancouver where they rented a home at First and Cornwall for $25.00 a month. At this home, Claire and her younger brother Sid would study their Catechism by lamplight.

Slide 3:

- No dialogue - duck photo.

Slide 4:

Pictured here is Claire at the age of 9, when the family celebrated her first communion.

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Slide 5:

When Claire was 9 years old she belonged to the Woodward's Junior Girls Choir.

Slide 6:

In 1932 Claire's performance at the BC Festival earned her the "Gold Shield."

Slide 7:

- No dialogue - singing contest photo.

Slide 8:

In 1936, when Claire was 13 years old, the family moved to a house on Main Street in Vancouver's West side, where her mother Kathryn Margaret Woods, a very resourceful woman, set up a bed and breakfast. Eventually her Mum saved the $1800.00 necessary to purchase the home. In order to pay the mortgage, Claire's Mum continued to rent out rooms to visitors.

Slide 9:

- No dialogue - siblings photo.

Slide 10:

Claire and her siblings grew up in this home. In the front room, was the piano on which her sister Gail would play while Claire sang along.

Slide 11:

Her father was affectionately known as "Buster."

Slide 12:

In the late 1930's, Daniel Woods left the family and moved on to Chilliwack where he ran a small farm. Claire's mother continued to run the bed and breakfast and raise their growing children.

Slide 13:

In Claire's words, "this is what I used to look like."

Slide 14:

Claire remembers their home as being close to the beach. They spent many days swimming in the ocean and playing on the beach.

Slide 15:

Claire recalls that they "practically lived in Stanley Park." This photo was taken by her brother Sid, in 1943.

Slide 16:

Pictured here is Claire's mother. Claire and her Mum enjoyed a very close relationship.

Slide 17:

Claire would meet her true love during the War; her brother Samuel served in the Army; on one occasion, while on leave, Samuel brought home his friend Johnny to stay at their home on Main Street.

Slide 18:

According to Claire, she was "waiting at the door" the first time she saw her future husband. "He just came in, and said 'hello."

Slide 19:

- No dialogue - photo of young couple.

Slide 20:

Claire and Johnny corresponded by mail throughout the remainder of the War, soon after they were engaged.

Slide 21:

- No dialogue – photo of the couple by cherry trees.

Slide 22:

Johnny and Claire, arm in arm walking down Granville St., just after Johnny returned from the War.

Slide 23:

- Blank – couple, portrait.

Slide 24:

The gang on the steps of the Main Street home.

Slide 25:

Claire and Johnny were married on August 3rd, 1946. Here, Claire is seated in the front room of the Main Street home. Her dress had a train that came all the way down to the floor.

Slide 26:

On her wedding day, Claire had a variety of carnations in her bouquet; they remain her favourite flowers.

Slide 27:

Claire was very fond of her in-laws. In this picture, Johnny is seated on the left, in the rear brother-in-laws, Thomas and Ernie, on the right is her sister-in-law Vera. Claire's Mother-in-law Ruby, and father-in-law William are seated in the middle of the photo.

Slide 28:

- Blank – Mother-in-law photograph.

Slide 29:

In 1947, the newlyweds moved out of Vancouver and up north to the town of Mt. White, about five miles up the mountain. Mt White was located north of Squamish. Here, Johnny worked in the coal mine, and Claire looked after their growing family. They would live in this company town from 1947 – 1960.

Slide 30:

This is the newlywed's first home in Mt. White; it was heated by a wood stove, and the tin roof ensured the snow would slid off it easily. In those days, Highway 99 was not connected to Vancouver so in order for Claire to visit with her family or go shopping for anything other than what the little shop in town supplied the family had to travel by train into the city. The Simpson's then had to take a boat the rest of the way to Vancouver.

Slide 31:

On a trip to Vancouver, Claire proudly shows off her baby daughter.

Slide 32:

Claire enjoyed her life with Johnny and the kids in Mt White. Due to it's remoteness, Claire would often communicate with her mother in Vancouver through letters.

Slide 33:

- Blank – photo of Mt. White kids.

Slide 34:

Claire remembers the snow as being "unbelievable."

Slide 35:

Claire would bundle up her kids in warm clothing during the long winter months.

Claire's memories of this period in her life are proof to her of the wonderful part of having been alive.

Slide 36:

- Blank - photograph of Claire shoveling snow.

Slide 37:

"It was such a happy, wonderful place to live."

Slide 38:

While living on the mountain, Claire developed several friendships that lasted over many years. Shown here are Claire with her friend Toni and her children. Toni also appears later on, in more recent photographs.

Slide 39:

Mrs. Park and her husband "Casper" were also good friends. Claire first met Mrs. Park when Johnny brought her up to Mt. White before they were married. At this time, Mrs. Park took charge of the sleeping arrangements, and Claire stayed with her instead of in the bunkhouse. Since that time, every time there was a new baby, Mrs. Park would look after the children. Claire and Mrs. Park were friends "always."

Slide 40:

In this picture, Claire and Johnny and Cathy, and her doll 'Mrs. Wrinkles,' made the trip down from Mt. White to spend Christmas at the Main St. house.

Slide 41:

On another trip down to the city, Claire poses with Cathy, and eldest son, Glen. In 1960, after about 13 years of living in Mt. White, the mine closed down.

Slide 42:

Although Claire was so happy in Mt. White that she would liked to have stayed: in her eyes, "it was heaven," the family was forced to relocate. Johnny had to find employment elsewhere. Johnny soon found work as a telephone dispatcher for *BC Electric,* and the Simpson's bought a new home in the city.

Slide 47:

The new home was located at 27th and Cedar. Johnny and Claire chose the

Kitsilano area as it was close to schools for their 6 kids. It was very important to Johnny and Claire that their children have a good education. Their home was also close to the church, and as Claire's siblings also lived in the area, it's location provided a vital connection to extended family. Claire was very attached to Vancouver's beaches; Kitsilano and Jericho were just a short distance away.

Slide 48:

Johnny enjoyed his work—the job suited him; he was very sociable, and he was well-liked by his co-workers. During these years, Claire worked hard to run the household.

Slide 49:

Elsa, Claire's last baby was born in the late 60's, just before Cathy graduated from high school. Claire was an "at-home" Mom. In addition to looking after the kids, Claire loved to cook and work in the garden, often alongside her husband. Throughout these years Claire was an active member of her church choir.

Slide 50:

Though they didn't have a lot of spare time, the couple always managed to take the kids on a trip during the summer holidays. Many times they traveled to Quebec City to visit with Johnny's family. They also went to swim and fish in Tofino and to the Okanagan to camp. The Simpson's loved to go to warm places, where they could swim, fish, and basically get away, relax and be together.

Slide 51:

This is a picture Claire took of their beloved Labrador retriever, 'Midnight.' This dog was a big part of the family; he used to sleep at the foot of Claire's bed and was a great watchdog.

Slide 52:

- Blank – vacation at Oliver.

Slide 53:

The family vacation home in the Okanagan.

Slide 54:

The family enjoying the summertime in Okanagan.

Slide 55:

On this day at Okanagan Lake, it was so hot that Claire and Johnny just had to get in the water.

Slide 56:

Pictured here is Johnny, holding the catch of the day!

Slide 57:

Everything in Claire's life revolves around her family. Claire has many nieces and nephews - they continue to be a big part of her life.

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Slide 58:

This photograph of Claire and Johnny was taken in the mid-1980's.

Slide 59:

The whole family at Christmas time. In the 80's these drapes were very fashionable! Christmas at the Simpson household was about food and family. Claire would begin to bake at least a month prior in preparation for the big day.

Slide 60:

Claire's second youngest son, Ed.

Slide 61:

Glen and Cathy, and their 4th child, David in 1986.

Slide 62:

Cindy, the couple's third child, with Glen and Elsa.

Slide 63:

In this photograph, Johnny is seen fishing on the Thompson River. Claire's beloved husband passed away in 1979.

Slide 64:

In honour of Claire's birthday, the family takes her out for Italian food.

Slide 65:

- Blank – Cindy and Claire photograph.

Slide 66:

Throughout her life, Claire was connected to the church community. Pictured here, she dines out with the church ladies and the parish priest.

Slide 59:

- Blank - Claire's 70th birthday celebration, brother Sid looking on.

Slide 60:

Eldest son Glen is seen here in his boat fishing, like his father he loves to fish.

Slide 61:

- Blank – Glen and dogs photograph.

Slide 62:

- Blank – Polaroid – Elsa and Claire.

Slide 63:

Claire and the men of the family enjoying a visit in her front yard.

Slide 64:

Another birthday cake, on Claire's 80th birthday.

Slide 65:

Claire and some of her lifelong friends.

Slide 66:

Claire was proud of her garden, she loved to work in the garden, and in particular, she loved her lilacs.

Slide 67:

The peonies in the backyard.

Slide 68:

Gathering of the kids, on the steps of the Simpson home.

Slide 69:

Claire has four grandchildren: Rebecca, Sam, Roxy and David. She also has two great-grandchildren: Bob and Jay.

Slide 70:

- Blank - photo of Claire and the family pets.

Slide 71:

- Blank - another photo of Claire surrounded by pets.

Slide 72:

Claire moved to Grouse Mountain Acres on August 15th, 2003. Baking and listening to music are some of the activities that Claire continues to enjoy.

Slide 73:

Highlights for Claire are when her family visits, often picking her up and taking her on outings.

Slide 74:

She also enjoys poetry. This poem, by Robert Frost, Stopping by Woods on a Snowy Evening, is one of her favourites; she knows it by heart...

> Whose woods these are I think I know.
> His house is in the village though;
> He will not see me stopping here
> To watch his woods fill up with snow.
> My little horse must think it queer
> To stop without a farmhouse near
> Between the woods and frozen lake
> The darkest evening of the year.
> He gives his harness bells a shake
> To ask if there is some mistake.
> The only other sound's the sweep
> Of easy wind and downy flake.
> The woods are lovely, dark and deep.
> But I have promises to keep,
> And miles to go before I sleep,
> And miles to go before I sleep.

Slide 75:

In this photograph, Claire sits in her room at Grouse Mountain Acres. She smiles into the camera, held by her daughter Cathy; reflected in her eyes is the happiness and contentment that Claire has attained, through a life filled with her family, and a great deal of love.

Slide 76

The End - collage of photographs.

REFERENCES

Adams, T. (1999). Developing partnership in dementia care: A discursive model of practice. In T. Adams & C. L. Clarke (Eds.), *Dementia care, developing partnerships in practice* (pp. 37-56). London: Bailliere Tindall.

Adams, T. & Gardiner, P. (2005). Communication and interaction within care triads. *Dementia, 4(2),* 185-205.

Allen, F. B. & Coleman, P. (2006). Spiritual perspectives on the person with dementia: Identity and personhood. In. J. C. Hughes, S. J. Louw & S. Sabat (Eds.), *Dementia: mind, meaning, and the person* (pp. 205-221). Oxford, UK: Oxford University Press.

Allen-Burge, R., Stevens, A. B., & Burgio, L. D. (1999). Effective behavioral interventions for decreasing dementia-related behavior in nursing homes. *International Journal of Geriatric Psychiatry, 14,* 213-232.

Aquilina, C. & Hughes, J. (2006). The return of the living dead: Agency lost and found? In J. C. Hughes, S. J. Louw & S. R. Sabat (Eds.), *Dementia, mind, meaning, and the person* (pp. 143-161), Oxford: Oxford University Press.

Basting, A. D. (2003). Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies, 17,* 87-99.

Beach, D. L. & Kramer, B. J. (1999). Communicating with the Alzheimer's resident: Perceptions of care providers in a residential facility. *Journal of Gerontological Social Work, 32(3),* 5-26.

Belle Brown, J. (2000). The use of focus groups in clinical research. In B.F. Crabtree & W.L. Miller (Eds.), *Doing qualitative research* (2nd ed., pp. 109-124). Thousand Oaks, CA: Sage.

Berg, B. (2001). *Qualitative research methods for the social sciences* (4th ed.). Boston, MA: Pearson Education, Inc.

Berg, B. L. (2004). *Qualitative research methods for the social sciences* (5th ed.). Boston, MA: Pearson Education, Inc.

Blaikie, A. (1994). Photographic memory, ageing and the life course. *Ageing and Society, 14,* 479-497.

Bond, J. & Corner, L. (2001). Researching dementia: Are there unique methodological challenges for health services research? *Ageing and Society, 21,* 95-116.

Bond, J. (1999). Quality of life for people with dementia: Approaches to the challenge of measurement. *Ageing and Society, 19,* 561-579.

Bourgeois, M. S. (2002). "Where is my wife and when an I going home?" The challenge of communicating with persons with dementia. *Alzheimer's Care Quarterly, 3(2),* 132-144.

British Columbia Ministry of Health Services. (2002/2003). *Report on health authority performance agreements*. Ministry of Health Planning, BC retrieved August 18, 2006 from http://www.healthservices.gov.bc.ca/socsec/pdf/haagreement0203.pdf

Brooker, D. (2004). What is person-centred care in dementia? *Reviews in Clinical Gerontology, 13*, 215-222.

Brooker, D. & Surr, C. (2005). *Dementia care mapping: Principles and practice*. Bradford, UK: Bradford Dementia Group.

Brown, J. B. (2000). The use of focus groups in clinical research. In B. F. Crabtree & W. L. Miller (Eds.), *Doing qualitative research* (2nd ed., pp.109-124). Thousand Oaks, CA: Sage.

Canadian Study of Health and Aging Working Group. Patterns of caring for people with dementia in Canada. *Canadian Journal on Aging, 13*, 470-487.

Cappeliez, P. & O'Rourke, N. (2006). Empirical validation of a model of reminiscence and health in later life. *Journal of Gerontology: Psychological Sciences, 61B(4)*, 237-244.

Cappeliez, P., O'Rourke, N., & Chaudhury, H. (2005). Functions of reminiscence and mental health in later life. *Aging & Mental Health, 9(4)*, 295-301.

Chaudhury, H. (1999). Self and reminiscence of place: A conceptual study. *Journal of Aging and Identity, 4*, 231-253.

Chaudhury, H. (2002a). Journey back home: Recollecting past places by people with dementia. *Journal of Housing for the Elderly, 16(1/2)*, 85-106.

Chaudhury, H. (2002b). Place-biosketch as a tool in caring for residents with dementia. *Alzheimer's Care Quarterly, 3(1)*, 42-45.

Clarke, C. L. (1999). Dementia care partnerships: Knowledge, ownership and exchange. In T. Adams & C. L. Clarke (Eds.), *Dementia care, developing partnerships in practice* (pp. 5-35). London: Ballière Tindall.

Clarke, A., Hanson, E. J., & Ross, H. (2003). Seeing the person behind the patient: Enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*, 697-706.

Cohen, U. & Weisman, J. (1991). Principles for design: Building organization. In, *Holding on to Home: Designs for people with dementia* (pp. 65-89). Baltimore, US: University of Johns Hopkins University Press.

Cohene, T., Baecker, R. & Marziali, E. (2005). Designing interactive life story multimedia for a family affected by Alzheimer's disease: a case study. *CHI* 2005, April 2 - 7, Portland Oregon, USA.

Cohen-Mansfield, J. (2000). Approaches to the management of disruptive behaviors. In M. P. Lawton & R. L. Rubinstein (Eds.), *Interventions in dementia care* (pp. 39-63). New York: Springer.

Cohen-Mansfield, J., Golander, H., & Arnheim, G. (2000). Self-identity in older persons suffering from dementia: preliminary results. *Social Science & Medicine, 51,* 381-395.

Coker, E. (1998). Does your care plan tell my story? Documenting aspects of personhood in long-term care. *Journal of Holistic Nursing, 16(4),* 435-452.

Cotrell, V. & Schulz, R. (1993). The perspective of the patient with Alzheimer'sdisease: A neglected dimension of dementia research. *The Gerontologist, 33(2),* 205-211.

Crisp, J. (1999). Towards a partnership in maintaining personhood. In T. Adams & C. L. Clarke (Eds.), *Dementia care, developing partnerships in practice* (pp. 95-119). London: Ballière Tindall.

Day, K., Carreon, D., & Stump, C. (2000). The therapeutic design of environments for people with dementia: A review of the empirical research. *The Gerontologist, 40(4),* 397-416.

de Medeiros, K. (2005). The complementary self: Multiple perspectives on the aging person. *Journal of Aging Studies, 19,* 1-13.

Downs, M. (2000). Dementia in a socio-cultural context: An idea whose time has come. *Ageing and Society, 20,* 369-375.

Drisko, J. (2004). Qualitative data analysis software: A user's appraisal. In D. Padgett (Ed.), *The qualitative research experience* (pp. 193-209). Belmont, CA: Wadsworth.

Easton, K. L., McComish, J. F., & Greenberg, R. (2000). Avoiding common pitfalls in qualitative data collection and transcription. *Qualitative Health Research, 10(5),* 703-707.

Edberg, A-K. & Hallberg, I. R. (2001). Actions seen as demanding in patients with severe dementia during one year of intervention. Comparison with controls. *International Journal of Nursing Studies, 38,* 271-285.

Fern, E. F. (2001). *Advanced focus group research.* Thousand Oaks, CA: Sage Publications, Inc.

Finlay, L. (2002). "Outing" the researcher: The provenance, process and practice of reflexivity. *Qualitative Health Research, 12,* 531-545.

Gaskell, G. (2000). Individual and group interviewing. In M. W. Bauer & G. Gaskell (Eds.), *Qualitative researching with text, image and sound, a practical handbook* (pp. 38-56). Thousand Oaks, CA: Sage.

Gibson, F. (1994). What can reminiscence contribute to people with dementia. In J. Bornat (Ed.), *Reminiscence reviewed: evaluations, achievements, perspectives* (pp. 46-60). Buckingham: Open University Press.

Gibson, F. (2005). Fit for life: the contribution of life story work. In M. Marshall (Ed.), *Perspectives on rehabilitation and dementia* (pp. 175-179). London: Jessica Kingsley.

Gibson, F. & Burnside, I. (2005). Reminiscence group work. In B. Haight & F. Gibson (Eds.), *Burnside's working with older adults, group processes and techniques* (4th ed., pp. 175-190). Mississauga, ON: Jones and Bartlett Publishers Canada.

Grësel, E., Wiltfang, J., & Kornhuber, J. (2003). Non-drug therapies for dementia: An overview of the current situation with regard to proof of effectiveness. *Dementia Geriatrics Cognitive Disorders, 15,* 115-125.

Gubrium, J. F. & Holstein, J. A. (2002). The active subject in qualitative gerontology. In G. D. Rowles & N.E. Schoenberg (Eds.), *Qualitative gerontology, a contemporary perspective* (2nd ed., pp. 154-171). New York, NY: Springer.

Habermas, T. & Paha, C. (2002). Souvenirs and other personal objects: Reminding of past events and significant others in the transition to university. In J. D Webster & B. K. Haight (Eds.), *Critical advances in reminiscence work: From theory to application* (pp. 123-139). New York, NY: Springer.

Hagens, C., Beaman, A., & Ryan, E. B. (2003). Reminiscing, poetry writing, and remembering boxes: Personhood-centred communication with cognitively impaired older adults. *Activities, Adaptation & Aging, 27(3/4),* 97-112.

Haight, B, Bachman, D. L., Hendrix, S., Wagner, M. T., Meeks, A., & Johnson, J. (2003). Life review: Treating the dyadic family unit with dementia. *Clinical Psychology and Psychotherapy, 10,* 165-174.

Harrison, B. (2002). Seeing health and illness worlds – using visual methodologies in a sociology of health and illness: a methodological review. *Sociology of Health & Illness, 24(6),* 856-872.

Heliker, D. (1999). Transformation of story to practice: An innovative approach to long-term care. *Issues in Mental Health Nursing, 20,* 513-525.

Herskovits, E. (1995). Struggling over subjectivity: Debates about the "self" and Alzheimer's disease. *Medical Anthropology Quarterly, 9(2),* 146-164.

Holland, P. (2001). 'Sweet it is to scan..." Personal photographs & popular photography.' In L. Wells (Ed.), *Photography: A Critical Introduction* (2nd ed., pp. 117-164). London: Routledge.

Hollander, J. A. (2004). The social contexts of focus groups. *Journal of Contemporary Ethnography, 33(5),* 602-637.

Ice, G. H. (2002). Daily life in a nursing home: Has it changed in 25 years? *Journal of Aging Studies, 16,* 345-359.

Iliffe, S. & Wilcox, J. (2005). The identification of barriers to the recognition of, and response to, dementia in primary care using a modified focus group approach. *Dementia, (Feb.) 4,* 73 - 86.

Hughes, J. C., Louw, S. J., & Sabat, S. R. (2006). Seeing whole. In J. C. Hughes, S. J. Louw & S.R. Sabat (Eds.) *Dementia: mind, meaning, and the person* (1-39). New York: Oxford University Press.

James, W. (1918). *The principles of psychology, volume one.* New York: Dover Publications, Inc.

Jonas-Simpson, C. (2001). From silence to voice: Knowledge, values, and beliefs guiding healthcare practices with persons living with dementia. *Nursing Science Quarterly, 14(4),* 304-310.

Kavanaugh, K., & Ayres, L. (1998). Focus on qualitative methods, "Not as bad as it could have been": Assessing and mitigating harm during research on sensitive topics. *Research in Nursing & Health, 21,* 91-97.

Kitwood, T. (1993). Towards a theory of dementia care: the interpersonal process. *Ageing and Society, 13,* 51-67.

Kitwood, T. (1997). *Dementia re-discovered: The person comes first.* Buckingham: Open University Press.

Kitwood, T. & Bredin, K. (1992). Towards a theory of dementia care: Personhood and well-being. *Ageing and Society, 12,* 269-287.

Kolanowski, A. M. & Rule, R. A. (2001). The way we were: Importance of psychosocial history in the care of older persons with dementia. *Activities, Adaptation, & Aging, 26(2),* 13-27.

Konetzka, R. T., Stearns, S. C., Konrad, T. R., Magaziner, J., & Zimmerman, S. (2005). Personal care aide turnover in residential care settings: An assessment of ownership, economic, and environmental factors. *The Journal of Applied Gerontology, 24(2),* 87-107.

Krippendorff, K. (2004). *Content analysis, an introduction to its methodology* (2nd ed.). Thousand Oaks, CA: Sage.

Krueger, R. A. & Case, M. A. (2000). *Focus Groups, a practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.

Langford, M. (2001). *Suspended conversations: The afterlife of memory in photographic albums.* Montreal: McGill-Queens University Press.

Li, R. & Orleans, M. (2002). Personhood in a work of forgetfulness: An ethnography of the self-process among Alzheimer's patients. *Journal of Aging and Identity, 7(4),* 227-244.

Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Madriz, E. (2003). Focus groups in feminist research. In N. K. Denzin & Y. S. Lincoln (Eds.), *Collecting and interpreting qualitative materials* (pp.363-388). Thousand Oaks, CA: Sage.

Magilvy, J. K., Congdon, J. G., Nelson, J. P. & Craig, C. (1992). Visions of rural aging: Use of photographic method in gerontological research. *The Gerontologist, 32(2),* 253-257.

Marsh, C., & Ross, G. B. (1999). *Designing qualitative research* (3rd ed.). Thousand Oaks, CA: Sage.

Martin, G. W. & Younger, D. (2001). Person-centred care for people with dementia: A quality audit approach. *Journal of Psychiatric and Mental Health Nursing, 8*, 443-448.

Maxwell, J. A. (2005). *Qualitative research design, an interactive approach* (2nd ed.). Thousand Oaks, CA: Sage.

McCallion, P., Toseland, R. W., Lacey, D., & Banks, S. (1999). Educating nursing assistants to communicate more effectively with nursing home residents with dementia. *The Gerontologist, 39(5),* 546-558.

McIntyre, M. (2003). Dignity in dementia: Person-centred care in community. *Journal of Aging Studies, 17,* 473-484.

Mead, G. H. (1956). Self, the self and the organism. In A. Strauss (Ed.), *The social psychology of Jack Herbert Mead* (pp. 212-260). Chicago: The University of Chicago Press.

Miles, M. B., & Huberman, A. M. (1994). An expanded sourcebook, qualitative analysis (2nd ed.). Thousand Oaks, CA: Sage.

Mills, M. A. (1997). Narrative identity and dementia: A study of emotion and narrative in older people with dementia. *Ageing and Society, 17,* 673-698.

Mills, M. A., & Coleman, P. G. (1994). Nostalgic memories in dementia—A case study. *International Journal of Aging and Human Development, 38(3),* 203-219.

Moore, T. & Hollett, J. (2003). Giving voice to persons living with dementia: the researcher's opportunities and challenges. *Nursing Science Quarterly, 16(2),* 163-167.

Morgan, D. L. (1997). *Focus groups as qualitative research* (2nd ed.). Thousand Oaks, CA: Sage.

Morgan, D. L. (1998). *The focus group guidebook, focus group kit 1.* Thousand Oaks, CA: Sage.

Morse, J. M., Barrett, M., Mayan, M., Olson, K., & Spiers, J. (2002). Verification strategies for establishing reliability and validity in qualitative research. *International Journal of Qualitative Methods 1(2),* Article 2. Retrieved August, 8, 2006 from http:www.ualberta.ca/~ijqm/

Morse, J. M. & Field, P.A. (1995). *Qualitative research methods for health professionals,* (2nd ed.). Thousand Oaks, CA: Sage.

Neto, C. Shalof, T., & Costello, J. (2006). Critical care nurses' responses to patient photographs displayed at the bedside. *Heart & Lung, May/June,* 198-204.

Nolan, M., & Dellasega, C. (1999). 'It's not the same as him being at home': Creating caring partnerships following nursing home placement. *Journal of Clinical Nursing, 8,* 723-730.

Office of the Information & Privacy Commissioner for British Columbia. The OPIC's Role and Mandate. Retrieved November 29, 2006 from http://www.opic.bc.ca/legislation/FIPPA/FIPPA-ACT(18MAY2006).pdf

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Post, S. (1995). Alzheimer's disease and the "then" self. *Kennedy Institute of Ethics Journal, 5(4)*, 307-321.

Priest, H., Roberts, P., & Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data. Part 1: Theoretical issues. *Nurse Researcher, 10(1)*, 30-42.

Reed, J. & Payton, V. R. (1997). Focus groups: Issues of analysis and interpretation. *Journal of Advanced Nursing 26*, 765-771.

Reed-Danahay, D. (2001). 'This is your home now!' Conceptualizing location and dislocation in a dementia unit. *Qualitative Research, 1(1)*, 47-63.

Romano, D. M. (2004). Making the paradigm shift: Enhancing communication for clients with Alzheimer's disease using a client-centred approach. *Journal of the American Psychiatric Nurses Association, 10(2)*, 81-85.

Ronch, J. L. (2004). Changing institutional culture: Can we re-value the nursing home? *Journal of Gerontological Social Work, 43(1)*, 61-82.

Rubin, H. J. & Rubin, I. S. (1995). Chapter 6: Interviews as guided conversations. *Qualitative interviewing: The art of hearing data* (pp. 122-167). Thousand Oaks, CA: Sage

Rubinstein, R. L. (2002). Reminiscence, personal meaning, themes, and the 'object relations' of older people. In J. D. Webster & B. K. Haight (Eds.), *Critical advances in reminiscence work: From theory to application* (pp. 153-164). New York: Springer Publishing Inc.

Ryan, E. B., Clark, S. & Spadafora, P. (2005). Writing my life story, with a little help from my friends. *Long Term Care, October*, 31- 34.

Sabat, S. R. (1998). Voices of Alzheimer's disease sufferers: A call for treatment based on personhood. *The Journal of Clinical Ethics, 9(1)*, 35-48.

Sabat, S. R. (2002). Selfhood and Alzheimer's disease. In P. B. Harris (Ed.), *The person with Alzheimer's disease* (pp. 88-111). Baltimore, MA: The Johns Hopkins University Press.

Sabat, S. (2002). Surviving manifestations of selfhood in Alzheimer disease, a case study. *Dementia, 1(1)*, 25-36.

Sabat, S. R. & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society, 12*, 443-461.

Sabat, S. R., Napolitano, L. & Fah, H. (2004). Barriers to the construction of a valued social identity: A case study of Alzheimer Disease. *American Journal of Alzheimer's Disease and Other Dementias, 19(3),* 177-185.

Sambrook, R., Hermann, N., Hebert, R., McCracken, P., Robillard, A., Luong, D., & Yu, A. (2004). Canadian outcomes study in dementia: Study methods and patient characteristics. *Canadian Journal of Psychiatry, 49(7),* 417-427.

Sandelowski, M. (1993). Rigor or rigor mortis: The problem of rigor in qualitative research revisted. *Advanced Nursing Science, 16(2),* 1-8.

Sandelowski, M. (1995). Focus on qualitative methods, qualitative analysis: What it is and how to begin. *Research in Nursing & Health 18(4),* 371-375.

Sandelowski, M. & Barroso, J. (2002). Finding the findings in qualitative studies. *Journal of Nursing Scholarship, Third Quarter,* 213 – 219.

Shenk, D. & Schmid, R. M. (2002). A picture is worth...: The use of photography in gerontological research. In G. D. Rowles & N. E. Schoenberg (Eds.), *Qualitative gerontology, a contemporary perspective, 2nd edition,* (pp. 241-262). New York: Springer.

Sherman, E. (1991). *Reminiscence and the self in old age.* New York: Springer.

Small, J. A., Geldert, K., Gutman, G. & Clarke Scott, M. A. (1998). The discourse of self in dementia. *Ageing & Society, 18,* 291-316.

Sterin, G. J. (2002). Essay on a work, a lived experience of Alzheimer's disease. *Dementia, 1(1),* 7-10.

Strauss, A. L. (1990). *Basics of qualitative research.* Newbury Park, CA: Sage.

Touhy, T.A. (2004). Dementia, personhood, and nursing: Learning from a nursing situation. *Nursing Science Quarterly, 17(1),* 43-49.

Trottier, H., Martel, L., Houle, C., Berthelot, J. M. & Légaré, J. (2000). Living at home or in an institution: What makes the difference for seniors? *Health Reports, Spring 2000, 11(4),* 49-61.

Vittoria, A. K. (1998). Preserving selves, identity work and dementia. *Research on Aging, 20(1),* 91-136.

Vladeck, B.C. (2002). Unloving care revisited: The persistence of culture. In A. S. Weiner & J. L. Ronch (Eds.), *Culture change in long-term care* (pp. 1 - 9). NY: The Haworth Social Work Practice Press.

Warren, C. A. B., Barnes-Brus, T., Burgess, H., Wiebold-Lippisch, L., Hackney, J., Harkness, G., Kennedy, V., Dingwall, R., Rosenblatt, P.C., Ryan, A., & Shuy, R. (2003). After the interview. *Qualitative Sociology,* 26(1), 93-110.

Weiser, J. (1993). *Phototherapy techniques: Exploring the secrets of personal snapshots and family albums.* San Francisco: Jossey-Bass Publishers.

Wellin, C. & Jaffe, D. J. (2004). In search of "personal care:" Challenges to identity support in residential care for elders with cognitive illness. *Journal of Aging Studies, 18*, 275-295.

Werezak, L. J., & Morgan, D. G. (2003). Creating a therapeutic psychosocial environment in dementia care: A preliminary framework. *Journal of Gerontological Nursing, 29(12)*, 18-25.

Whitworth, A., Perkins, L., & Lesser, R. (1999). Communication in dementia care: A partnership approach. In T. Adam & C. L. Clarke (Eds.), *Dementia care, developing partnerships in practice*, (pp. 121-143). Bailllieré Tindall: London.

Woods, B. & McKiernan, F. (19950. Evaluating the impact of reminiscence on older people with dementia. In J. D. Webster & B. K. Haight (Eds.), *The art and science of reminiscing: Theory, research, methods, and applications* (pp. 233-242). Washington, DC: Taylor & Francis.

Woods, R. T. (1999). The person in dementia care. *Generations, 23(3)*, 35-39.

Woods, R. T. (2001). Discovering the person with Alzheimer's disease: Cognitive, emotional and behavioural aspects. *Aging & Mental Health, 5 (Supp. 1)*, S7-S16.

Woods, L., Priest, H., & Roberts, P. (2002). Priest, H., Roberts, P., & Woods, L. (2002). An overview of three different approaches to the interpretation of qualitative data. Part 2: Practical Illustrations. *Nurse Researcher, 10(1)*, 43-52.