

Creating Life Albums with Personal Care Home Residents Who Have
Dementia: Assessing the Impact on Selected Family Visit Interaction

By

Johanna Anneke Gillis

A Thesis submitted to the Faculty of Graduate Studies of the University of Manitoba

In partial fulfillment of the requirements for the degree of

Master of Science

Department of Family Studies

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Abstract

The goal of this research was to develop life albums for personal care home residents with dementia and to evaluate their use by family visitors. Life albums were created for 6 residents and their families, guided by the concepts of reminiscence and life story work. The research was guided by a theoretical perspective of social exchange. Findings showed that the life albums provided a focal point of interaction between residents and family visitors and confirmed that persons with dementia have stories they can share which are valued by family members. In addition, the involvement and benefits to visitors varied, depending on their family relationship with the resident. In the future, research aimed at understanding the different experiences of spouses and offspring in creating and using life albums would be beneficial.

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For my sister, Kristel

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Chapter 1 Introduction

Background

Dementia is a degenerative brain syndrome that is characterized by progressive cognitive, behavioural and physical declines in ability to cope with every day interaction (Lindsay, 1999). Dementia is a broad term for many illnesses characterized by similar symptoms. In 2001, 364,000 Canadians had dementia, of which 16,340 lived in Manitoba (Alzheimer's Society of Canada, 2003). By the year 2020, it is estimated that the number of Manitobans with dementia will more than double to reach 34,000 (Alzheimer's Society of Canada, 1999) and more than 750 thousand Canadians are expected to have dementia (Alzheimer's Society of Canada, 2003). The estimated net cost of dementia, including health care, long-term care, supportive community services in Canada is about \$5.5 billion per year (2003).

Approximately eighty percent of residents in personal care homes (PCH) have a diagnosis of dementia (Lindsay, 1999). Beyond the financial burden on the Canadian Health Care System, 97 per cent of people with dementia had an informal caregiver, which implies a burden on the families of Canadians. Over 70 per cent of residents in institutional care with dementia had women as informal caregivers, the majority of whom were spouses. In addition, nearly 20 per cent of informal caregivers reported symptoms of depression (Alzheimer's Society of Canada, 2003).

Research during the past two decades has contributed to increasing awareness that caring for the needs of persons with Alzheimer's Disease and related dementia is different than caring for someone with a physical illness or disease. As a result there has been a paradigm shift during the past decades in the approach taken by

researchers, clinicians and health care administrators in regard to the care of persons with dementia. The understanding and perceptions of progressive dementia such as AD disease have changed from being a disease that attacks an individual's brain thus requiring medical treatment to a social disease that affects the family system requiring support and care (Dupuis, 2000; Killik, 2003; Thomas, 1996).

In the 1960s, dementia was seen as a frightening disease with the main goal of care being palliation (Butler, 1963; Huppert & Wilcock, 1997). Individuals with dementia were viewed as uncommunicative, behaviourally inappropriate and socially invisible. In the 1990s, research and innovative programs have altered the perception of dementia to portray individuals with dementia as communicative and capable of contributing to social interaction and experiencing a reasonable quality of life (Alzheimer's Society of Canada, 1999; Murphy, 1994; Usita, Hyman & Herman, 1998). Along with this alteration in perception of the disease, the model of care has and continues to change from a medical one of custodial care to a communicative and therapeutic one of care focused on maximizing abilities and supporting social needs of residents (Thomas, 1996; Vittoria, 1998). Although alternatives to institutions have become more available, PCHs continue to be the most common method of providing care to persons with dementia.

Families' roles caring for relatives with dementia in an institution still have to be defined and incorporated. Currently there is no consensus on the part that families should play, nor are suitable training or tools available to connect the staff, family and dementia patient living in a PCH. There is some agreement that training to integrate the roles among staff, family and other visitors would help share the load of work and

promote positive outcomes in the resident and caregiver (Baxter, 1999; McCallion, Toseland, & Freeman, 1999; Murphy, 1994). This is also exemplified through recent, although limited, changes in the composition of formal long-term health care teams, which have traditionally been composed of doctors, nurses and physiotherapists, to include other professionals in coordinating and programming for the social needs of residents and their informal caregivers (Baxter, 1999; Cameron, 2000). For example, professionals in the health care-team responsible for resident care at Deer Lodge Centre and Riverview Health Centre, two of Winnipeg's largest long-term care facilities, now include social workers, recreation, music and occupational therapists, professional home economists, and pastoral care workers (Cameron & Gillis, 2000). These long-term care teams have been involved in programs and projects related to life story work through reminiscence, various life story projects, and different activities including gardening, music, art, and dance (Cameron, 2000; Deer Lodge Centre, 2003; Guse, 1998).

Goals and Objectives

The overall goal of this research was to examine the relationship between the development of life albums for six personal care home residents with dementia and selected aspects of visitor interaction with the residents. The specific objectives of the research were: (1) to create and compile a life album for six personal care home residents with dementia, (2) to compare and contrast family members' perceptions of the quality of their visits with the residents with dementia before and after the development of life albums, and (3) to contribute to knowledge in the substantive

areas of “reminiscence” and “life review” by extending these concepts to include residents with dementia.

This study assesses perspectives of family visitors on the effects of creating a collaborative life story documented into a picture book called the life album. In-depth interviews were conducted to understand what the visiting experience was like with and without the life album. Visitor perspectives of how the album may have contributed to the abilities of residents with dementia to communicate with visitors and to improve the quality of visits were analyzed. There had been little previous research on combining different types of life story work with persons who have dementia. This study explored the life album’s use as a tool in restoring a balanced social exchange in day-to-day visits.

Chapter 2 Literature Review

The progression of dementia varies across individuals in terms of specific patterns and rates of cognitive decline (Huppert & Wilcox, 1997). Life review requires the ability to retrieve and analyze memories. However, reminiscence is a broad concept that incorporates many forms of remembering the past and life narratives may have different forms within the rubric of reminiscence. However, individuals with dementia of mild to moderate severity usually lack the ability to tell the complete story, that is, to reminisce, and the greater complexity of life review is unattainable. Usita et al. (1998) suggest changing the focus of a life narrative for individuals with dementia to include more input from others. Life albums are a reconstruction of life events on behalf of persons with dementia and as such the albums speak for a person, describing some of the details of who he or she was and is (Guse et al., 1999).

There are five main bodies of literature incorporated into this report and together, the synthesis of this literature has guided this qualitative study. First, the literature describes Alzheimer's Type dementia and its stages for a better understanding how dementia affects the mental, emotional and behavioural abilities of a person resulting in various communication and social issues. Second, research on caregiver burden is reviewed, illustrating caregivers' struggles with feelings of burden and to varying degrees the lack of social support and outlets for their social needs. Third, current trends in PCHs contribute to understanding how and where the life album can help to improved quality of life for residents and their family members. The last two bodies of literature present the theoretical concepts that

guided this study. Fourth, “reminiscence” is reviewed to understand how the life album fits within reminiscence to meet the social and personal communication needs of persons with dementia and their families. Finally, literature on social exchange is reviewed as the guiding theoretical framework for analysis of the effects life albums on the social exchange between residents and visitors.

Alzheimer's Disease and Related Dementia

In Canada, the most prevalent cause of dementia is Alzheimer's Disease (AD) which comprises approximately 60 percent of all cases (Rockwood & McDowell, 2002). The next most common illness included under the rubric of dementia is vascular dementia (also known as multi-infarct dementia and arteriosclerotic dementia) followed by less common illnesses such as Korsakoff's disease, Creutzfeldt-Jakob disease, and Parkinson's disease (Goldsmith et al., 1997). Persons with dementia are likely to have problems with concentration, short-term memory loss and decreased reasoning abilities and will have varying levels of disorientation to time, space and person. In addition there are problems with behaviour and being understood (Alzheimer's Society of Canada, 2003; Goldsmith et al., 1997, Usita et al., 1998). Most of the literature tends to incorporate AD with other forms of dementia. Participants in this research had different forms of dementia. In general, dementia results in special care needs that focus primarily on social interactions of everyday life, with safety being a primary concern, often requiring twenty-four hour care and supervision, especially during the middle and late stages of the disease process (Alzheimer's Society of Canada, 2003).

In terms of the progression of dementia there are three general stages that characterize the symptoms associated with it. The overall progression results in behavioral, mental and physical abilities declining over the early, middle and late stages (Alzheimer's Society of Canada, 2003).

Early Stage

Subjective memory complaints, forgetfulness and depression or anxiety characterize this stage. Short-term memory loss and diminishing ability to make complex decisions occur are the earliest symptoms. In terms of behaviours and physical abilities, withdrawal from usual activities, restlessness and mild coordination problems are most common. Cognitive changes are progressive, however an optimum environment and supported social interactions can maximize abilities and function. The ability to acquire new knowledge also deteriorates. The progression of dementia initially includes a loss of ability to carry out instrumental activities of daily living (IADL's) such as cleaning house, buying groceries and managing finances (McDowell & Clair, 1987).

Middle Stage

Cognitive and mental disabilities further decline in the middle stage. Obvious, non-compensatable memory deficits, disorientation, difficulty in recall, comprehension and judgement characterize this stage. This stage is also where many people begin to wander and display repetitive behaviours. Finding words and language association problems as well as general disorientation are also characterized as mental changes in middle stages of AD and dementia. Common behavioral changes for persons with dementia include constant movement such as pacing,

engaging in repetitive behaviours and rummaging. A change in sleep patterns can occur, which can include day and night reversal and disrupted night sleep with wandering which is further aggravated by time of day disorientation. Other behaviours involve fear of darkness, fear of being alone and decline in personal grooming habits. All of these behaviours are exacerbated by living in an unfamiliar environment such as a PCH (Thomas, 1996).

Late Stage

In the late stage of the disease, institutional care is usually a necessity. Assistance is needed for all activities. Disorientation to knowing person, place or time is severe. In this stage the person becomes very dependent and has problems with speech and language such as finding correct words and problems with sound association. Also characteristic of this stage is dramatic physical decline, becoming bed ridden and losing of other bodily functions (such as, swallowing, hand-eye coordination, and bladder and bowel continence).

Caregivers

Caregivers often have difficulty understanding the meaning of repetitive behaviours, increasing the lack of understanding between the persons with dementia and the caregiver, both formal and informal (Alzheimer Society of Canada 1999; Care Guide, 2003). Often individuals with dementia have short tempers and their behaviour can become aggressive, specifically towards their primary caregivers, resulting in universal concern for the well-being of caregivers caring for someone with dementia (Alzheimer's Society of Canada, 2003; CareGuide, 2003; Dupuis, 2000; Thomas, 1996). The impact of dementia extends far beyond its devastating

effects on an individual. Dementia has been cited as a social disease which is endured by a family system and by the community (Alzheimer's Society of Canada, 1999). Because dementia goes beyond cognitive decline to include the inability to interact through comprehension, recognizing or responding to otherwise familiar people, places and things, providing care becomes a challenge. As the prevalence of this illness increases there is now considerable effort spent researching and producing specialized care strategies for those with dementia (Goldsmith, et al., 1997; Thomas, 1996). However, feelings of burden and helplessness among family caregivers are not always addressed in the PCH (Baxter, 1999, Dupuis, 2000; Lyons & Zarit, 1999; Marwit & Meuser; 2002). Informal caregivers are an important resource to the PCH. A position statement developed by the National Advisory Council on Aging (NACA) claimed that 30 per cent of services to residents in long-term care are provided by informal caregivers (1999). McCallion et al. (1999) suggested that the burden on family members increase with the progress of the disease. Even when someone in the middle to late stages of dementia is placed in an institution, family members often experience increased burden, coupled with a decreased ability to help. Furthermore, communication impairment creates isolation between residents and family caregivers and little work has been done to address this issue.

Several studies have used picture boxes or life stories in chart information in PCHs and have shown that this information helps family members feel empowered in their new caregiving role (Baxter, 1999; McCallion et al., 1999; Murphy, 1997). When informal caregivers are asked to provide the information in life story charts or picture boxes, they became important members of the health care team (Baxter,

1999). Murphy's (1994) work addresses five key goals of having family members create a life story of the residents. They are "to offer a basis for caring interactions..., to help in the assessment of needs..., to improve the process of care planning..., to give spouses a sense of value as informants and to provide staff with ready made triggers" (p.3). Life stories and picture boxes are simultaneous, multi-dimensional tools that can add to aspects of residents and family caregivers health and well-being. In effect, these are relatively simple constructions that encourage social interaction and promote communication, which in turn appears to alleviate caregiver burden (Baxter, 1999; Murphy, 1994). More recent work illustrates that offering emotional support to caregivers and persons undertaking life story work with residents who have dementia is an important aspect of replacing feelings of burden and helplessness with a sense of validation and usefulness (Killik, 2003).

The Personal Care Home

The PCH remains the major alternative environment to living at home and has traditionally been based on a medical model of care. Though individual institutions do vary, until recently PCHs have generally provided ward-like environments with staff present to ensure medical care needs were met. In particular, there was no effort to group residents by cognitive abilities or provide individualized programming. Together this has added to the diminished capacity of residents with dementia to engage in conversation, and had made it difficult to maintain any form of quality of life through interactions in the PCH. The medical model of care, "in which disease has primacy over person [and] . . . personal identity tends to be stripped away, and where individual selves become secondary to treatment of pathology," (Vittoria,

1998, p. 92) does not optimize quality of life for the person who is physically able but cognitively impaired.

The Eden Alternative model developed by Thomas (1996), is an example of how trends in personal care home philosophies are changing and argues that the traditional medical model of care confused caring with treatment. The medical model focuses on the treatment of disease and illness, leaving social needs and caring for the person's abilities at the wayside. Thomas (1996) suggests that the needs of elderly residents in personal care homes should revolve around the elimination of boredom, loneliness and helplessness. One of the ways Thomas (1996) advocates that this social model be integrated is by having personal care homes focus on creating a diverse environment. This environment is created through meaningful interaction, social integration within the community and encouragement of family involvement as part of daily living in a PCH. Although Deer Lodge Centre, a PCH in Winnipeg, Manitoba, is not an "Edenizing" facility, its care philosophy incorporates many social and emotional needs into daily care of residents. The Collaborative Research Unit at Deer Lodge Centre has focused summer research programs on interdisciplinary projects aimed at maximizing abilities of residents. Findings from the 1998 Interdisciplinary Summer Research Program suggested that life albums were tools to facilitate communication with persons who have dementia and the informal and formal caregivers. The life albums explain who the resident was and is (Guse et al., 1999).

Theoretical Framework

Reminiscence

There are many concepts of reminiscence in the literature; however, a comprehensive reminiscence theory has yet to be developed. Several authors have attempted to develop a framework, but no standard or accepted framework has been established to date (Butler, 1963; Cohen, & Taylor, 1998; Haight, 2001). Over the past decade, there has been a heightened awareness of the benefits of reminiscence and recording of life histories for elderly persons who have some form of dementia. Whereas traditionally reminiscence was reserved for the cognitively intact, self-reflective individual who wished to engage in the therapeutic process of life review (Butler, 1963), it has now been extended to others less able to engage fully in this process (Usita et al., 1998). The benefits of reminiscence are now extended to persons who are at risk of losing their personal identity such as persons with cognitive impairment living in PCHs (Baxter, 1999; Haight, 2001; Killik, 2003; Usita et al., 1998; Vittoria, 1998). The study conducted by Usita and colleagues (1998) found that “participants with AD interacted with the interviewer and shared some information about their selves, suggesting that they could fulfill one of the main social functions of narratives” (1998, p.194). Their work also shows that residents with dementia are able to incorporate current events in their life stories.

The ability to incorporate current events into the stories and communications of persons with dementia has also been reported by Hirst (1998), whose work supported the inclusion of recent experiences in the self-schema of the person with dementia. Hirst (1998) postulated that when families and visitors that assist someone

with dementia in composing a life story, they provide a “positive and effective channel for engaging in social interaction and maintaining interpersonal communication. We must remember that adults with AD have reservoirs of memories that can be tapped” (p. 196).

Life story creations are becoming increasingly common place in PCH settings, as research and advocacy in long-term care for elderly with dementia had been moving away from the medical model of care toward a more social health model of care (Thomas, 1996; Vittoria, 1998). The following sections outline the history of reminiscence and four evolving concepts of reminiscence which show the variations between traditional life review, the communicative life story work undertaken in many personal care homes, the collaborative life story and life album creation. Figure 1 below illustrates these four concepts of reminiscence. Each column reviews the purpose, structure and type of media used. The principle of communication style used among the different types of reminiscence is shown as a continuous line along the bottom of the page.

History of Reminiscence with the Elderly. Before the 1960’s reminiscence was viewed negatively. Butler (1963) pointed out that “younger therapists especially, working with the elderly, find great difficulties in listening” (p.65), mostly because they perceived the elderly person’s reminiscence as dysfunctional, and therefore the value and significance of the reminiscence was lost. Currently, the positive value of reminiscence is at the forefront of literature, especially in creating life stories and albums for cognitively impaired persons living in institutions (Guse et al., 2000; Hepburn et al. 1997; Usita, et al. 1998). However, as Guse and colleagues (2000)

explain, there has been some confusion over the terms used for different forms of reminiscence.

Life Review	Communicative Life Story	Collaborative Life Story	Life Album
THERAPEUTIC Structured process of rediscovery	TOOL TO: communicate needs of loved one and promotes individualized care	INTERACTIVE PROCESS: provide interaction and build relationships in personal care home	TOOL TO: synthesize communicative and collaborative life stories
STRUCTURED	STRUCTURED	UNSTRUCTURED	SEMI-STRUCTURED
SELF -INITIATED	CAREGIVER INITIATED	COLLABORATIVLY INITIATED	COLLABORATIVLY INITIATED
PSYCHOLOGICAL-REDISCOVERY	MEDICAL MODEL	SOCIAL MODEL	SOCIAL MODEL
WRITTEN OR ORAL REFLECTION OF SELF	CHART OR PICTURE BOX INFORMATION (MEDIA SPECIFIC)	MEDIA FLEXIBLE	PHOTO ALBUM (MEDIA FLEXIBLE)
INDIVIDUAL CHOICE TO SHARE DIFFICULT SELF-REFLEXION	BIOGRAPHICAL	IMAGINATIVE Requires ability for caregiver to think abstractly without task orientation	INDIVIDUAL CHOICE TO SHARE All levels of ability can share in process of creating tangible /interactive tool
Not possible for cognitively impaired	Cognitively impaired omitted from process		
COMMUNICATION STYLE			
Normative	Empathetic		Alternative

Figure 1 Proposed Continuum of Reminiscence

Reminiscence is the act of telling past life happenings with the intent of infusing others with these memories. Life review is the act of reminiscence with the added components of evaluation and analysis and is a structured process of rediscovery (Butler, 1963; Guse et al., 2000). The communicative and collaborative

life stories are forms of reminiscence that are available to older persons who have difficulty retrieving memories, cannot write or are at risk of losing their individuality, as in the case of residents in institutions. The life album is a continuation of a life story although the amount of life material available through recollection and photographs is not directly related to the fullness of their album (Guse et al., 2000). In other words, from relatively little memory, one can make a rather full and complete picture story through using local archives, memorabilia, photographs, Internet resources and other material.

The Life Review. The Life Review is a traditional narrative initiated by the self. It is self-reflective and is written or audio taped. The recall must be rich in detail, chronological, salient and emotionally reflective. The life review narrative is a process of reflection and therefore it is the storyteller's story to share with whomever he or she chooses. This encourages normative communication style, where the storyteller is in control of what stories to share with others. He or she chooses the direction and depth as well as who reads or listens to the story. There is always some form of judgement exercised by the story creator with the intent to reinvent history to better suit how the person wishes to be remembered (Murphy, 1994). Butler's work (1963) on life narrative also focuses on reorganizing an individual perception of self in preparation for death. Hence, this story form is a type of therapy and requires a great amount of energy and the ability to be reflective.

The Communicative Life Story. The communicative life story is a narrative for elderly persons who have dementia. This form of narrative is a tool that helps staff and informal caregivers establish individualized care for the resident with

dementia (Hepburn et al., 1997). It is initiated and developed by the family caregiver and is widely available in chart information or picture boxes. The form of communication that guides this life story is empathy. The creator of the life story tries to put him or herself into the shoes of the person whose story is being told. The creator tries to answer the question, "What is it that he or she would want in their daily care?" In this case, the creator relays to staff and other visitors what is important for the resident with dementia. This type of communicative life story has been created as a tool to encourage and provide an outlet for informal caregivers to participate in the care of their family members once they have moved to a PCH. Specifically, caregivers are given a chance to use their expert knowledge of the resident to inform staff as to how to individualize the care for the resident (Hepburn et al., 1997). Therefore this story form becomes a tool to use by everyone involved in the care of the resident with dementia rather than a therapy for the resident.

The Collaborative Life Story. The collaborative life story form focuses on improving interaction and relationships through social contexts. This form of life story aids in finding a voice, cues and interaction for the resident with dementia. Frank (2000) coined the word "alterity" to recognize the radical alternative experiences that the story creator (the caregiver) will never know about the storyteller's (resident with dementia) experience. In other words, a collaborative story creation encourages focusing on the relationship that is developing within the resident's reality. Vittoria (1998) called this type of story a socially constructed story and focused on communicating in "the destinations of the mind" (p.108). An example provided by Vittoria was about an older man whose career was a banker and

was recently placed in a special care unit for Alzheimer's and would not eat at regular meals. Whenever the man approached the staff he attempted to conduct business and bank matters with them. Using "alterity," a staff person would arrange to "iron out the details over dinner," and they would sit at a table, ask to be served and continue to discuss "business" over dinner. This process reinforced the resident's reality of being *at work*, while providing basic needs by making sure the resident ate regularly. This type of interaction required that family members or staff become familiar with the history and language of the resident, which gave them the ability to interact within that history and language rather than focus on today's realities.

Recent research emphasized that listening to and capturing what a person with dementia provides in the form of words, gestures, and movements is important in preserving the person. It affirms that this form of capturing stories "offers opportunities for respecting the personhood of the individual" (Killik, 2003, p.1).

The Life Album. The life album is an alternative life story for persons who have dementia. These stories can act as a communication tool to help individualize conversations and care among staff, family members and the resident. Life albums are a continuation of the collaborative life story, with the added component of having a tangible product that can act as a communication tool for visitors and caregivers alike. The album can help to "jog" the resident or caregiver's memory to remember something that had previously been recorded in the album. From these memories, some form of interaction would occur, regardless of reality of current time and place. Life albums are a collection of memorabilia, photographs, mementos, quotes, archival and other material that tells the resident's story from his or her current perspective

and were developed from the cues that the resident was able to communicate (Guse et al., 2000).

The life album can help to enhance visits with family and friends and is one way to facilitate spending quality time with the resident. Because the social context is where stories naturally are told, and context is an important part of maintaining identity, worth and social interaction, it is the story telling interaction and not the narrative outcome that becomes important in the creation of stories with persons with dementia (Usita et al., 1998). At the same time, the person developing the life album is collecting the information, spending time with the resident, placing memorabilia, photographs, archival, and other materials into a photo album, which is then given to the resident as a gift for sharing his or her stories. Hence, there is a sense of reciprocity established between the resident and the visitor, who is often the caregiver. This reciprocity is very important in maintaining an interactive, socially rich environment (Killik; 2003; Usita et al., 1998). Use of life albums then enables others to begin talking with the individual and get to know him or her better. Caregivers also use the life album as a tool to balance memories of old times and the unique, new way residents with dementia see and remember things that are often expressed as funny, mumbled, and uncensored metaphors. In a previous study, one caregiver spoke about the positive experience of using a life album during a family reunion,

You can't really carry on a conversation. You go to visit and talk about things and fifteen minutes to half an hour and she's dozed off....Then [my] Aunt...who came in for [the residents].... Birthday party this year had the benefit of using the life album. The book provided a real opportunity for some

good laughs and conversation.... [the resident] could be cued to talk (Gillis, 1999, p. 18).

Limitations to Life Story Methods

There are a few studies that acknowledge limitations and drawbacks to creating life stories with people who have dementia. As with any individual who relies too much on one activity, there is a risk drifting into "routinized entertainment" (Murphy, 1994). There is also a concern that while some people are inclined to only celebrate the past, there are people whose memories bring pain or sorrow. If the resident or family members have these feelings then sharing life stories may have a negative impact on interactions.

Another issue that can cause some difficulty in this area is the inability for staff, family members or visitors to cope with different style of communication. Vittoria (1998) also points out the unique ability for special care unit staff to be able to "play along" or "visit the destinations of the [resident's] mind with good humor and a caring persona" and that this ability is not shared by all persons (p.132). Vittoria recognized there were staff who did not understand and found working within the resident's reality too difficult. Another limitation is that family and staff may view the creation of a life album or story in "the same light as filling in an assessment form or doing a report in the day book. It is threatening because 'book' implies 'writing' and many workers naturally feel intimidated at this prospect" (Murphy, 1994, p.21).

Although there has been a recent surge of interest in creating theoretical frameworks of reminiscence with people who have dementia, there has been no

consolidation of the several constructs. As well, there have been competing concepts of reminiscence with opposing views of what the resident is capable of doing and what the purpose of reminiscence is. Due to the lack of agreement in the construction of reminiscence theory with cognitively impaired residents it was best to qualitatively examine the relationship between creating and using life album with residents with family visiting experiences and the concepts of reminiscence. As a result, this research helped inform future theory development in the area of reminiscence work with people who have dementia. As such, there is significant impact that any research working with residents who have dementia has on future theory development.

Social Exchange Theory

The theoretical perspective of social exchange theory has informed this research. Social exchange theory emphasized the relationship between individuals as a series of interactions that were based on social costs and benefits (Sabatelli & Shehan, 1993). Central to exchange theory is the concept of reciprocity; that is, as one gives there is an expectation to receive. As part of reciprocity, there is a series of expected codes of conduct, norms and considerations that influence the nature of social exchange; therefore it is not a direct act-for-act reciprocity that matters, but the overall "rule of distributive justice and includes duties as well as privileges and is guided by the norm of reciprocity" (Bengtson & Dowd, 1980-81, p.63). Bengtson and Dowd (1980) suggest that decline in interaction between family members and older adults is based on a lessened ability of the older adult to reciprocate. In turn, this lesser ability to reciprocate on the resident's behalf leads to interaction that becomes stressed, negative and burdensome. In terms of residents with dementia, the

interaction between them and their visitors were diminished by the residents' progressive inability to retrieve memories of mutual life events.

Relationship satisfaction from a social exchange perspective is based on past experience and cultural norms and expectations between the parties involved in the relationship. The interaction that one has between an individual and oneself is compared to what the expected interaction might have been. One assesses interaction to see if it was balanced or understandable and if relationship satisfaction was achieved. External resources may be required to have balanced exchanges with their family visitors. In the present research the life album was intended as a focal point of interaction between resident and visitor that might restore the balance of social exchange.

Chapter 3 Methodology

The purpose of this study was to assess the relationship between the development and use of life albums for personal care home residents with dementia and selected aspects of visitor interaction with residents. Life albums were created and compiled for six residents with dementia living in Deer Lodge Centre, Winnipeg, Canada. The life albums were used by visitors as an interaction tool, and interviews explored the relationship of life albums to visitors' perceptions of quality of visits with residents.

The primary focus of this project was describing the process of creating a life album for persons with dementia and understanding the experience and perspectives of visitors when using the life album in visits. This was exploratory research, which used qualitative methods. The following sections outline the general approach, context in which this study took place, phases of data collection, ethical considerations and the analysis undertaken.

Approach of This Research

This research was based on a qualitative process, gathering data rich information on three main phases including creating the life albums and interviewing visitors before and after the creation of the life albums. This study utilized observations (documented in researcher field notes), in-depth interviews, and the life albums as data. This qualitative approach provided reflections on patterns and concepts and the relationship among these concepts of visiting and valuing life story creation, which in turn were related to the real world everyday experience of the participating families. Data triangulation was accomplished by conducting two sets

of interviews, by compiling detailed field notes after each life album session visit and by using the descriptive data from the life albums. This allowed examining the same phenomena from different perspectives.

To add to the reliability and validity of information collected, and to the richness of data potentially offered by visitors, a second interviewer (not the researcher) conducted the Time 2 interviews. This helped to ensure interview data captured in Time 2 would be rich with details and reflective of the process, something that may not have occurred with the researcher because of the intimate rapport and relationships that had been established over the course of the intervention program. Participating families may have felt a need to constrain any negative features of using the life albums. Time 1 and Time 2 interviews were designed to focus on effects of the intervention program, by comparing what visiting was like without the album (Time 1 interviews), with what visiting with the album was like (Time 2 interviews). Morse and Field (1995) indicate that using loosely structured methodology to guide the qualitative research process can be of benefit, "The structure and process of the qualitative study provides the reader with understanding and enables others to make sense of reality" (p.16). They also stress the importance of refraining from rigid details on protocol, especially if the purpose is to describe and learn about the nature of the phenomenon. In the case of this study, the aim was to describe and understand the nature of effects the life album had on visiting experiences.

The Place

Deer Lodge Centre (DLC), located in Winnipeg, Manitoba, Canada, is a long-term care and rehabilitation hospital for adults, primarily seniors, and has

approximately 479 beds divided among long-term and rehabilitation care. DLC has a unique and strong history in caring for wartime veterans and maintains a large portion of personal care beds for veterans. Among its services the Centre includes research and education facilities and a library. It has evolved over the years to become a facility that is recognized across North America as a leader in the field of geriatric research and care (Deer Lodge Centre, 2003). DLC's familiarity and participation in a variety of research projects made the setting ideal for this qualitative study. The philosophy of staff includes the concept that participation in research enhances and invests in the well-being of residents (Deer Lodge Centre, 1998).

This research was based on and is subsequent to previous research undertaken at DLC in a 1998 Interdisciplinary Summer Research Program. Directed by Lorna Guse, it brought together a group of seven research assistants, including the researcher of this study, to conduct an intervention-based research project with older adults. The study had two components, with one group of residents involved in a strength training program and the other group participating in the creation of their own personal life albums. The results of this research project led to an unexpected and overwhelmingly positive reaction and persistent requests by staff, family and visitors to continue with both interventions (1998). As a result, this researcher felt further exploration of the life album process and its benefits to residents with dementia would be a valuable contribution to the literature and to clinical practitioners in long-term care.

DLC staff provided access to the researcher for conducting this life album research, providing both office space for conducting interviews, a phone with

confidential voice mail for family visitors to leave messages and staff support in identifying participants, which included making initial contact with families. Based on inclusion criteria, residents were approached by unit managers, who provided information on the study. One staff person, a specialized nurse clinician, was designated the DLC research manager for the project and was responsible for recruitment. The research manager helped unit managers to screen potential participants before approaching families.

Participants

The participants for this study were recruited using a purposive, convenience sample. For the residents, inclusion criteria were that the resident had mild to moderate impairment with a diagnosis of dementia verified by unit managers, the ability to use English and willingness to participate. For family participants, inclusion criteria were that he or she visited a resident at least twice a month, were willing to participate in interviews, could speak English, and were available during data collection period.

Seven families provided consent and started participation in the life album project. One participating family withdrew consent from the project and therefore the life album intervention with the resident was stopped. Withdrawal from the project stemmed from two major reasons. First, the resident was being moved to a new unit during Week 3 of visits. This move was felt by the visitor to be causing some disturbing behavioral and cognitive impairment in the resident. Second, the participating family visitor felt the historical research being presented to the resident was inaccurate and the researcher was delving too deep into memories that were too

painful. During ethical review stages, this was identified as a potential hazard of the life album project. A decision was made that should anyone in a family feel undue emotional or psychological stress because of the evolving stories and materials being collected it would be recognized that the life album may not be appropriate for the family and an alternative activity should be found. In this case, the family asked for no alternative activity other than to be left alone during the resident's transition from one unit to another. Their wishes were respected and no other visits were held.

Six families received life albums and participated in both the Time 1 and Time 2 interviews. An overview of relevant key characteristics of the family visitors and of the residents is provided below. Of these six families, one resident died, and thus one family visitor was unable to complete the research; a follow-up interview with the family member was held. The participating family visitor did use the life album during the memorial service. The comments of the family visitor have been incorporated into the Time 2 analysis.

Family Visitors. Of the six participating families there were three spouses, two offspring and one extended family member who signed consent as visitors and participated in the intervention program. They had all been visiting at Deer Lodge Centre since the resident was first admitted from 10 months to 4 years before the start date of the life album project in January 2001. In addition, they had all assumed primary caregiver roles for the resident prior to admission. Three of the family visitors had been giving care to the resident because of long-term illness for over ten years, and the transition to the personal care home resulted in a significant shift in their roles and lives. All except one of the family visitors said their care giving had

become so burdensome that it was nearly impossible to maintain a satisfactory level of home care for the resident, leading to no other alternative than to have him or her paneled and placed in Deer Lodge Centre.

It was very hard. There were mood swings...and [the resident] behaviour was from time to time quite frenetic. So in the end I had [the resident] paneled and the doctor certainly agreed that I'd had about my maximum...because I was developing an ulcer from the stress.

...I had had home care for [the resident] for over a year...the last summer, in 1998 with [the resident] was very, very difficult...because getting him up in the night to go to the bathroom...was very difficult. And a few times he got up by himself and I didn't hear and he fell, and you know that was probably the last summer he went to the cottage and before I got some help.

...It's been totally my whole life devoted to caring...now visiting.

For the most part, family members visited well beyond the participation criteria of twice a month. Two of the participating visitors came every day for four to six hours each day. Two visited residents at least twice a week and two visited whenever possible but had a routine visit of once a week.

The spouses visited more often than offspring. Spouses were at DLC daily for hours at a time. Children of the resident and extended family often had other responsibilities that needed attention and had a more difficult time visiting to the degree that they felt the resident would like for them to visit.

Well...[the resident] didn't look after themselves, you know, and I guess that makes me angry...My freedom in a way has been taken away from me. But like I said, I still struggle with the fact, when I know somebody's not going to be there...that maybe I should go, you know? But I have to hold back because I gotta look after myself at the same time.

Residents. There were six residents who participated in the intervention program and had life albums created for them. Of these six residents, three were men

and three were women, who varied in age from 63 to 96. Based on unit managers' diagnoses (verbally provided to the researcher) and over the course of the intervention program the researcher was able to informally evaluate the residents' cognitive status. All residents appeared to have some mild to moderate cognitive impairment. Caution is necessary because some family members did not feel that these were accurate diagnosis and had other reasons for why the resident might appear cognitively impaired.

Two of the residents seemed to be progressive in declining abilities, much like the stages of AD outlined in the literature review, while the remaining residents varied in cognitive abilities from visit to visit, similar to diagnoses of multi-infarct dementia (Parkinson's or stroke related). Some days these residents seemed to be unable to orient themselves to person, time or space while other days they would recognize the researcher and ask about what topics of their lives would be the focus of the visit. This made each resident's involvement in the project take a unique and different process; thus, no two life album processes were the same. Residents, depending on their physical and social stamina, enjoyed the visits at different times of the day and for different lengths each time.

Data Collection

Data collection was conducted over a sixteen-week period. Data collection consisted of four phases. The interviews and data collection phases overlapped and were staggered. Varying the starting time of data collection from person to person served two purposes. One, it allowed the family members flexibility and control over when data collection began and when they wanted to be interviewed. Two, the

questions asked and the information gathered in interviews was enhanced by leaving time between interviews, which allowed experiences from previous interviews and data collected to inform the next set of interviews (Morse & Field, 1995). Morse and Field describe qualitative research as a “dynamic, unfolding process” (p.132). Therefore, thinking about each interview as it happened and getting a chance to analyze the data while interviews were still in process allowed for early feedback and reorganization of interview questions.

After the Time 1 interview the researcher and the resident met two to three times a week for approximately 10 to 13 weeks, to reflect and share life stories, which were compiled into a life album. Chapter 4, Table 1 illustrates the individual intervention programs that were established with each participating family. The researcher worked in conjunction with family visitors and residents in preparing the life albums. Visitors participated in varying degrees in the sessions. Then visitors and the residents used the albums for a period of two to four weeks at which point the family visitor completed a Time 2 audio taped interview. The following outlines in more detail each of the phases.

Phase I

Once all research information was provided to the participating visitor and written consent was obtained, an audio taped qualitative interview was conducted with each visitor. The visitors participating in the Time 1 interview were asked to reflect on the nature, quality and duration of visits with the resident. There was an interview schedule developed to help guide questioning and focus the overall interview (see Appendix A). However, there was plenty of opportunity for visitors to

reflect beyond the scope of questions and share what they felt to be most important in their visiting experiences. The semi-structured interview examined the family member's experience in the PCH, specifically asking about visiting and caring for the resident. The researcher also used Spradley's descriptive question matrix (1979) to ensure enough details were captured. Utilizing the descriptive question matrix and the concepts of "grand tour" and "mini-tour" questions ensured that all aspects of the visiting experience were captured. A question matrix was designed as an ethnographic observation tool and was used as an interview guide to ensure all dimensions of the social situation were explored, such as space, actors, objects, activity, events and time. For example, a grand tour question asked, "Can you describe what a regular visit to [the resident] is like?" was responded by the visitor with "sometimes [the resident] doesn't recognize me." This response then was followed with the mini-tour question, focusing on a specific visit. Where the visit occurred and how the visitor coped were highlighted and probed, with details of the space, place, feelings and activities that shaped their experience.

Because social exchange theory was used to guide this research, it was also of particular interest to focus the original grand-tour questions on certain dimensions that would describe the social exchange between the resident and family visitor. The interview schedule asked questions that revolved around the rewards or benefits of visiting, the stress or costs of visiting, previous and current roles among family members, and what interaction/conversation occurred between the resident and family member. For example, family members were asked, "Before [the resident] became ill with dementia, what was your relationship like? What were the rewards and costs of

the interaction? Is there anything that you prefer now? What do you most wish to change when you come to visit _____ in the PCH?" (Appendix A). The Time 1 interview resulted in a baseline measurement of quality of visits and was also an opportunity to get to know the resident through the family visitor's looking glass.

Phase II

Phase II was the life album intervention program, developed by the researcher for each resident. This program outlined scheduled sessions and visits, and planned for the collection of information to create the resident's life album. The intervention program was established in such a way that the final product, the life album, would be a socially constructed interpretation of the resident's life. Outside of the scheduled session with the resident the researcher went to local archives, libraries and Internet locations to research and find materials pertinent to the resident's life story. The sessions between the researcher and resident and visitors also were based on Spradley's descriptive question matrix (1979) and on life stories methodology (Wallace in Gubrium & Sanker, 1996). The use of these methodologies structured the visits so as not to overwhelm, confuse or agitate the resident and to provide maximum support by family visitors.

Life stories methodology recognizes that there are two major methodological tools. The first is to follow an investigation of the objective facts (life review, life story) and the second is to follow a collaboration of the subjective process (collaborative, social constructions). Wallace (1996) suggests facts are not as important as meaning, values, and definition of the situations. "From this perspective life stories are ideal for studying how life is seen and experienced by individual life

narrators" (p.138), in this case the resident's experiences as understood by the researcher.

For the residents, the question matrix was reformulated to facilitate the establishment of rapport and alleviate anxiety in remembering specific information. For the resident, grand tour questions were posed in the first two or three weeks of sessions. Based on responses and other information from visitors, memorabilia and artifacts were collected; mini-tour questions focused on more details and were asked only in later sessions and with the aid of photographs and information collected. Having props such as photographs, baby booties, needlework, newspaper clippings meant there was less pressure for the resident to remember salient details but for mini-tour details to come directly from the props used, which helped to maintain communication during the mini-tour questioning. The process was documented through the researcher's field notes. In addition, the life albums were used as data for content that made a successful life album.

Phase III

Once the life album was completed, albums were given to the resident and family to use during visits. The family members were asked to use the albums in at least two visits and to pay particular attention to their experiences using the life album. There was approximately two to three weeks made available between the time the resident received the life album to when the Time 2 interview was scheduled with the visitor. Before scheduling Time 2 interviews visitors were asked if they had a chance to use the albums in visits and were asked at the same time to take note of any special circumstances or experiences they had using the life album.

Phase IV

Once the family had a chance to visit at least twice using the life album, a Time 2 interview was scheduled. The Time 2 interview followed the same schedule as the Time 1 interview, however a new component asking about their experience using the life album was added (see Appendix B). The interviews helped to understand how the visitors perceived the effects of the life album in their relationship and social interactions with the resident.

An interviewer was enlisted to conduct the Time 2 interviews. The interviewer was well versed in qualitative research methodology with previous experience conducting qualitative interviews. The interviewer is a geriatrician, practicing in Winnipeg, and was aware of the potential range of emotions and perspectives that were shared by visitors. The researcher provided the interviewer with interview schedules, a list of visitors to be interviewed and descriptive data on each of the intervention programs. The descriptive data outlined the total number of intervention sessions held with the residents, the number of sessions attended by the visitor, the date residents received the completed life album, any illnesses or breaks within the intervention program and other information that would be helpful. For example, a special note was prepared for the one family visitor who never shared the album with the resident because of the resident's death three days before the album completion.

Ethical Considerations

Application for approval of the study was made to two organizations, the University of Manitoba Joint-Faculty Research Ethics Board (JFREB) for Ethical

Conduct for Research Involving Humans and the Deer Lodge Centre Research Foundation for access to residents and their families. Both organizations granted human ethics approval of the study in December 2000 (see Appendix C). Approval was based on planned ethical practice during the data collection, which protected the rights of participants. These included the right to be informed about the study, to refuse to answer or participate in any aspects of the study and to protect and maintain confidentiality of participants (Morse & Field, 1995).

All family participants signed written consent forms. Copies of the signed consent forms, along with a research information sheet (see Appendix D), were provided to the visitors. Two consent forms were signed by family visitors, one form for the resident's participation (see Appendix E) and one form for the visitor's participation (see Appendix F). In addition, each unit manager who provided care for a participating resident was provided with a copy of the research information sheet and a blank consent form for their information and records.

Due to the vulnerable nature of the residents with dementia, continual informed consent was maintained verbally between the researcher and the resident. The willingness of the resident to participate was determined by conscientious monitoring of the resident's mood and reactions to the researcher's questioning on a visit to visit basis. This verbal ongoing nature of consent is outlined among qualitative methodologies as key to protecting the ongoing rights of participants to be informed and to be able to refuse any part of participation in a study (Creswell, 1994; Morse & Field, 1995).

At the outset, a protocol for dealing with perceived non-consent of visitors was established. At each visit, if the resident appeared to not want to participate in a life album session, his or her wish was granted. Either an activity of another kind would take place or the researcher returned at another time. After three consecutive visits, if the resident consistently asked the researcher to leave, or he or she did not want to talk to the researcher about the life album, this would be considered the resident's privilege and consent for the project would be withdrawn. No participating resident throughout the intervention provided regular and consistent feedback that was interpreted as withdrawal of consent. There were a number of times where residents did not feel like visiting. For example, one resident said, "I'm a little tired of looking at photos," and as a result the researcher asked the resident what else he would like to do, if anything. At the resident's request the researcher and resident read highlights and horoscopes from the newspaper. One other resident occasionally would say, "go away...I don't want anyone here today." The researcher would go away and return later and the resident would be happy to see the researcher and willingly share memories. In addition the willingness of visitors to participate in the study was also respected. For example, one family visitor changed her mind about participating in the study and withdrawal from all aspects of the study was respected.

Measures have been taken to ensure confidentiality and sensitive materials remain protected. Taped interviews once transcribed were destroyed. The transcripts omitted all names, indicating only the first letter of any name in the transcripts for help with context in analysis. Only the researcher and two of her advisory committee

members had access to the transcripts. These are kept in a secure and locked location and will be destroyed after the research is complete.

Three participating families and the residents indicated they wanted to share the resident's life stories and to have the life albums shared with others. In these cases, letters of permission were obtained from the visitor to duplicate and use pieces of the life albums for research purposes only. Because ethics approval was based on the notion that confidentiality of participants would be maintained and no names would be used at any times, any names on the life album pages used for this study have been omitted.

Data Analysis

After data collection was completed, three different data sources were available for analysis, including descriptions of the life albums, transcriptions of Time 1 and Time 2 interviews, and the researcher's field notes. Because of the small number transcripts (6 participants with a total of 12 transcripts) coding of the interviews for content analysis was done using Word for Windows and the Spike function outlined by Burnard (1998). Burnard advocated using word processors to categorize qualitative data in social science research over coding by hand. This Spike process was helpful especially considering more expensive qualitative data-handling programs were either not feasible or practical (1998). Some members of the researcher's advisory committee were provided and reviewed samples of the transcript coding to ensure reliability and confirm data saturation.

Life Albums

The content of life albums was assessed for common components, layout and design. This descriptive information was compiled as part of the context on which the study was focused. The analysis of life albums was based on categorizing and clustering of common themes among each of the albums. These components were discussed with the intent of informing readers how the life albums were created and the type of stories and content that were chosen for inclusion in them. The researcher compared patterns of life experiences and media used in the life albums across participants. Emerging themes were documented; for example all residents had signature stories that were discussed, including themes of childhood memories, marriage or family, careers, wartime experiences, hobbies and vacations or special events. Photographs and examples of pages from the life album were used as exhibits to illustrate the common themes and patterns. These exhibits provide visual images of the context and give the reader an understanding of how these pages stimulated a participant's recall of an event (Morse & Field, 1995). At the same time, details were not analyzed for individual differences among life albums, as the purpose was not to jeopardize the confidentiality of participants' involvement.

In-depth Interview Analysis

Time 1 and Time 2 interviews were transcribed into Word for Windows with reference to names only by the first letter. Content analysis of transcriptions of all the in-depth interviews was performed, which involved development of categories and themes that were prevalent in the transcripts (Morse, & Field, 1996). Using the Spike function of Word allowed for "multiple cutting, storage and pasting of sections of

text” into separate files, each containing a theme and their sub-categories (Burnard, 1998, p.56). This approach helped to organize and rearrange the data into patterns and categories consistent with the relationship investigated. The focus of the analysis of the Time 1 and Time 2 interviews was on the themes and categories which helped interpret the family visitors’ perceptions of the social exchange between the resident and family. The best way to show how the data have been reduced into categories and themes to interpret the relationship is by following a spatial matrix (Creswell, 1994); therefore a coding matrix was developed and followed during analysis (see Appendix G). The coding matrix included categories of the benefits and costs to both visitor and resident. Further reduction of data resulted in categories related to psychosocial and physical benefits and costs for each the visitor and resident based on visitors’ perspectives.

Qualitative analysis is based on data reduction and interpretation. Following and displaying analysis through a matrix ensured a complete and focused analysis of the experience studied and helped in determining when data saturation was reached (Creswell, 1994; Morse & Field, 1995; Spradley, 1980). Data became saturated when the review of interview materials resulted in no more themes emerging for each of the categories. Once data saturation was reached it became possible to assess the meaning of the underlying themes and relationships (Morse & Field, 1995).

Time 1 and Time 2 Interview Comparisons

Comparative analysis among the categories and themes established in the Time 1 and Time 2 interview analysis resulted in an understanding of how the life album intervention affected the social exchange between the visitors and the residents

(Creswell, 1994). The themes established for comparative analysis were borrowed from theoretical concepts of social exchange and focused on the outcomes of the life album when comparing the Time 2 to Time 1 benefits and costs. Therefore the themes of the comparison of costs and benefits fit into the categories of balance or imbalance. Any factors, even if not the direct result of the life album, that changed the configuration between the costs and rewards between Time 1 and Time 2 shared by visitors were documented.

Field Notes

Field notes recorded throughout the duration of data collection by the researcher. They provided data, recording the creation of the life album and the kind of activities in which visitors and residents engaged regularly. These notes provided ongoing recording of phone calls, visits with visitors, and life album sessions with the residents. The field notes, together with the life album descriptions, provided a complete story on the life album creation process. As well, these notes included the subjective feelings, concerns and expectations of the researcher, allowing her to reflect and improve objectivity in analysis (Creswell, 1994). Field notes provided the details on characteristics of the participating families, their visiting schedules, dates and duration of life album sessions. Also, dates and times of non-visiting work undertaken by the researcher were recorded, including visiting archives and school libraries, researching the Internet, and placing phone calls to various places, such as Veterans Affairs. The field notes were used to validate and enhance categories and themes that emerged from the interviews. Any divergent themes or categories were compared with field notes to understand the potential value or prevalence of the

theme or category. Finally the field notes provided an audit trail so that all the steps taken throughout the data collection and analysis phase could be retraced by other researchers (Morse & Field, 1995).

Summary

This research used qualitative methodology to study the use of life albums by family visitors of residents. First, family visitors signed consent forms and participated in a Time 1 interview on the nature, quality and duration of visits with the residents. Second, working in conjunction with family visitors and residents, the researcher prepared the albums over a 10 to 13-week intervention period. Third, the visitors used the albums for a period of two weeks. Finally visitors participated in interviews at Time 2, indicating their experiences visiting the resident while using the life album. Throughout the process the researcher maintained detailed field notes. During the analysis phase, the qualitative interviews were transcribed and analyzed. Content analysis of each interview focused on themes of costs and benefits to the psychosocial and physical well being of visitors and of residents. Comparative analysis of the differences between Time 1 and Time 2 interviews was done. This comparative analysis focused on the outcomes of the life album, noting whether the effects of the life album created a balance or imbalance between costs and rewards of the visiting experience.

Chapter 4 Results

The first part of this chapter is descriptive and sets the context for the findings of the study. The second and third parts analyze the two sets of visitor interviews. Finally a comparative analysis of outcomes of the life album is presented. Time 1 and Time 2 interviews were analyzed separately, focusing on the categories and themes that relate to the social exchange framework guiding this research and outlined in Chapter 3.

Analysis of Time 1 interviews provides a baseline of what the visiting experience was like at Deer Lodge Centre for the participants. The analysis of Time 1 interviews includes different components of the family visitors' relationships with the residents, focusing on the changes in costs, stresses, rewards and benefits of their continued relationships and visiting experiences at DLC.

Time 2 interviews focused on analysis of the visiting experience using the life album. During Time 2 interviews, family visitors offered their perspectives on how the life album affected their visits with the resident. Analysis explored the benefits and costs of the life album as a tool and process from both the visitors' experiences and their perspectives of the residents' experiences.

Finally, qualitative comparative analysis was undertaken to assess the outcomes of the life album project when compared to the Time 1 baseline interviews. In this case, Time 2 interviews were assessed against those of Time 1 to see if any differences in visiting were experienced by participants that related to the life album project.

Figure 2 below illustrates the pathways of data collection and analysis. The researcher maintained field notes throughout the process and reviewed the completed life albums for common components involved in creating the life album. These data were combined with comparison analysis between responses from Time 1 and Time 2 interviews to assess the affect the life album had on the interaction between residents and visitors.

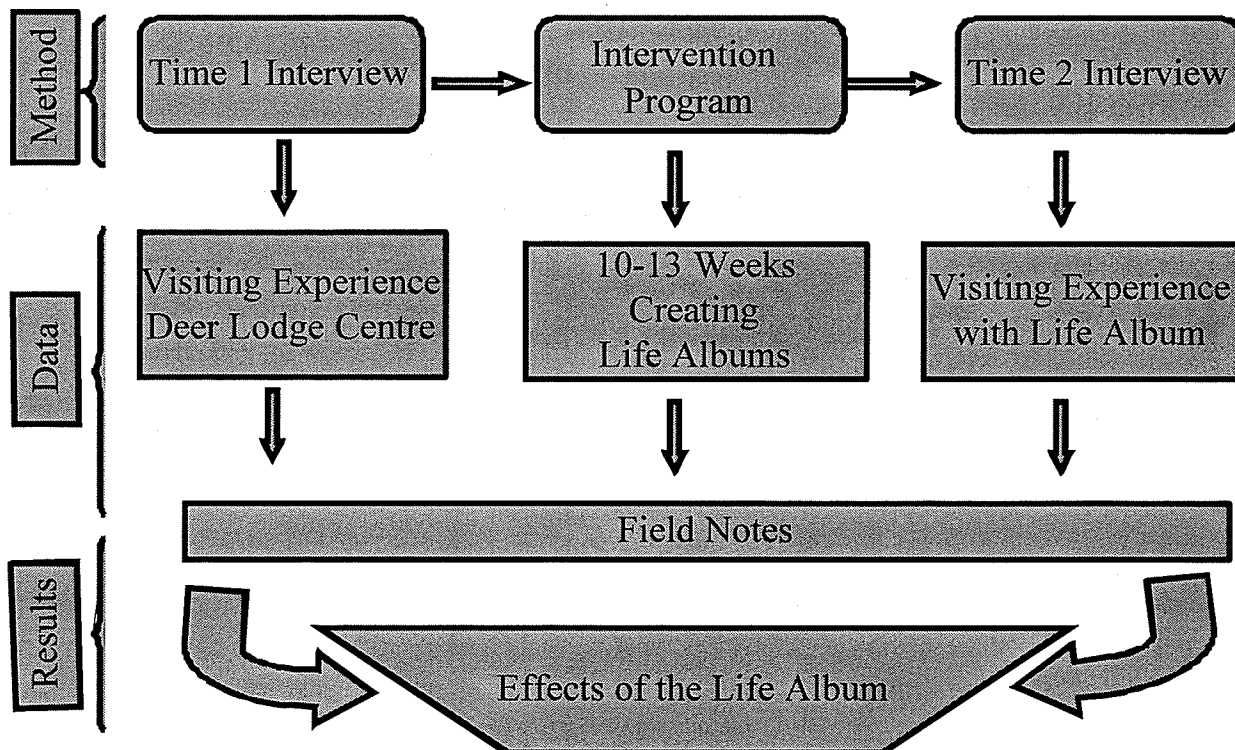


Figure 2 Pathways of Data Collection and Major Components of Analysis

Figure 3 below illustrates in more detail the basic elements of analysis. Once the data were collected, two overall types of analysis were undertaken. The first component of analysis involved identifying the common elements of the life album, resulting in a description of the life album and creation process. Second, analysis of

interviews was undertaken, which was guided by social exchange and therefore focused on costs and rewards of the visiting and relationship experience (collected in Time 1 and Time 2 interviews) and of visiting with the Life Album (collected in Time 2 interviews). Analysis of these overall themes were then divided into categories related to psycho-social and physical characteristics. Comparative analysis of the two sets of interviews assessed the outcomes of the life albums to see if they changed visitor perceptions of the social exchange during visits.

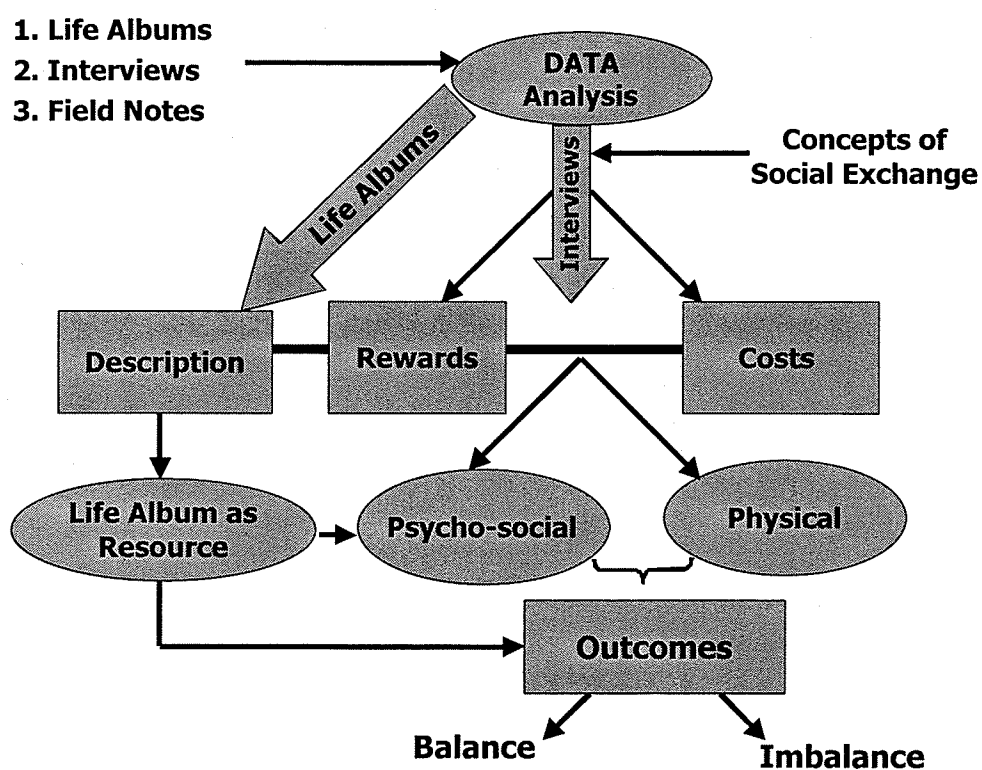


Figure 3 Data Analysis Themes and Categories

Life Album Intervention Program

Once the Time 1 interviews were completed with each family visitor, then the researcher began weekly visits with the resident. A visiting program was established,

the timing and duration of which varied, based on what seemed to be most appropriate and supportive of each resident. Some residents liked long visits and were also more likely to participate in many activities at DLC and were available less often. In these cases the residents were visited only once or twice a week for periods of about one hour. In other cases residents wanted or were able to concentrate on the visit for a short while. These residents were visited three times or more a week for duration of twenty to thirty minutes. In most cases residents were visited two to three times a week for ten to thirteen weeks between January 2001 and May 2001. Table 1 outlines details of the life album intervention project for each of the participating families. In some instances, visits were temporarily stopped because residents became ill and required hospital stays; these breaks in the intervention program are outlined in the table. Table 1 shows the variation in number and duration of visits between the researcher and resident and between family visitor and the researcher.

Table 1 Life Album (LA) Intervention Project 2001 characteristics

Family ID#	First LA visits	Finish date of LA	# of LA visits	# of weeks of intervention	length of visits/ mins	# LA visits with family visitor
1	Jan 30	May 8	33 visits	13 weeks	20 –30	4 visits
2	Feb 6	May 15	12 visits (no visits during weeks 5 - 10)	9 weeks	40 – 50	7 visits
4	Feb 8	May 4	20 visits (no visits during week 10-11)	11 weeks	45- 75	14 visits
5	Feb 13	April 30	20 visits	10 weeks	45 – 50	4 visits
6	Feb 13	May 5	23 visits	13 weeks	30 – 50	1 visit
7	Feb 13	May 5	17 visits	12 weeks	30 –40	2 visits

The residents' abilities to recognize and participate in the creation of life albums by sharing their life stories varied greatly. Even after describing the intent of each visit, some residents thought the researcher was just a friendly visitor and showed great surprise when they were given a life album at the end of the visitation program. It was not until the last four weeks of visits that the life album started to take shape. During the last month of visits, the researcher brought sample pages of the life album to get feedback and ideas from the resident and, when available, the family members. The title pages of the life albums were the first shown to the resident and were very well received (see Exhibit H1). For each topic addressed in the life album the researcher first developed an initial page and showed it to the resident, so that feedback and comments could be incorporated in the life album.

Family visitors were aware of the pending final product but had no real idea of what to expect, as none of them had seen examples of life albums. In every case, family visitors expressed pleasure with the outcomes. Many showed surprise that his or her "little bit of involvement," providing a handful of photographs and memorabilia, could be compiled into a life album that could be shared with others. Several said the content and visual layout were adaptable to almost any visit. No information in the albums appeared to cross the boundaries of what would otherwise normally be discussed in social exchanges with extended family, friends and guests.

Creating the Life Albums

A life album is a collection of memorabilia, photographs, poetry, archival and other materials that capture the lives of an individual in a photograph book format (Guse, 1999). The layout of the life album followed simple page design, keeping the

cognitive ability of the resident in mind. There was one topic with a few details per page, using a lot of colour, which focused on nature and themes over the course of the resident's life (Exhibit H2). Wherever possible quotes of the residents were included (see example Exhibit H3, which shows a resident's quote added to a page of pictures of these children as babies). Use of quotations was a successful tool, as it seemed that residents remembered their own words and would nod, laugh, agree and add to their words if repeated back to them. In addition, visitors placed a great value on seeing the residents' words on the page, knowing that they had recently contributed those words and stories. In addition, it was important for the researcher to make the level of information in the life album appropriate for a broad audience, a fact appreciated by the visitors in Time 2 interviews.

Each life album contained several forms of media in their creation, including pictures, maps, artifacts, researched information from archives and libraries, and Internet locations. Albums were constructed of commercial stylistic papers and stickers reflecting hobbies, and letters or cards that expressed appreciation to the resident. Other than these media consistencies, each album was unique and varied in length from twelve to thirty standard letter size pages. The following sections highlight each of the seven components included in the life album.

Pictures. Pictures were deliberately chosen to reflect the signature stories shared by the resident and his or her family (Frank, 2000). Signature stories were stories told often by the resident or visitor, reflecting important memories and personality attributes for which the resident would like to be remembered. Signature stories also represented closures to chapters of one part of life and new beginnings.

Exhibit H4 shows a picture selected by the family visitor to reflect the fun loving, good-natured teasing fun of the resident. The page included a small part of the conversation held between the researcher and resident, one filled with laughter and story telling.

Exhibit H5 shows a photo of one resident's signature story, taken upon the return of the resident's spouse from WWII. Although the couple was married during the War and were both serving duty overseas, they had not yet lived together. The resident, when looking at this picture, reflected that this was the moment in the life where she and her husband started their own family. The page also includes a map to help others viewing the album locate and discuss the geographic aspects of where the resident's married life began.

Maps. Maps proved to be a valuable tool for enlisting discussions of shared places and memories. The visitor stayed focused on the page, reading aloud names of places, which in turn would trigger memories and further discussion from the resident. Residents would sometimes look at the map and draw imaginary lines their paths had taken. Exhibit H6 and H7 both show maps of the location of two residents' service during WWII. Exhibit H6 illustrates a resident's journey as a member of the Manitoba Dragoons, a battalion that took part in the liberation of Holland. Exhibit H7 shows a more global and artistic map and enlisted discussion with the resident of his excursion in the navy during WWII across India, Europe and Asia.

Photocopied artifacts. The use of colour photocopying allowed for three-dimensional objects to be photocopied for inclusion in the life album. The colour photocopies show the details and aspects of the dimensions for the observer to take

note and appreciate the history of the artifact. Some examples of artifacts copied include covers from picture albums, showing the cracked and yellowed pages (Exhibit H8); WWII dog tags (Exhibit H9), showing the indents and texture from the residents registration number; hospital wrist bands from babies' births (Exhibit H10); and a resident's baby shoes (Exhibit H11), showing details of the original buckskin booties. All of these exhibits illustrate a unique aspect of the resident's history and show how things have changed. As a result many family visitors commented on other younger generations who would benefit from seeing these pages, and the researcher noted there was a history lesson involved when looking at the albums.

Researched Information. Residents shared stories of their younger days. Often pictures would not be available to accompany these stories so the researcher would use other sources such as the Manitoba Archives, Hudson Bay Archives, or historical archives kept at local schools and Veterans Affairs. Exhibit H12 illustrates how newspaper advertisements retrieved from microfiches of Winnipeg Free Press newspapers at the Hudson Bay Archive add to the courting story told by one resident and spouse. Exhibit H13 shows three album pages that were the result of the researcher's visit with a librarian of the school the resident attended. The school was still in operation and the librarian had boxes of old school photos in the attic. Together the researcher and librarian sifted through the pictures, coming across an old picture of the school, a class photo that included the resident, and some of the resident's teachers and an old school attendance record. These were all items the resident and visitor had previously not seen, which added interest to visits and became a significant part of the life album.

Exhibit H14 is a series of photos and written materials sent by Veterans Affairs to the researcher, describing excursions of the Navy during WWII. Exhibit H14 shows materials that do not reflect direct stories of the residents but were collected about topics that were of interest to the resident and were linked to the stories about which the resident talked.

Internet materials. At times residents spoke of their youth, but available materials for these memories were limited. As a result the Internet provided a valuable tool to find pictures of places or children from the same cohort that would reflect the activities discussed. For example, Exhibit H15 shows an artistic drawing taken from the Internet of a park, a place where the resident remembered playing with her sisters.

Hobbies Pages. Because each resident had hobbies, they became important parts of the life album. Stylistic papers, stickers, current magazine pictures and photographs of the crafts completed by the resident were used to compile these life album pages. Exhibit H16 shows two pages where humour and life works were combined to illustrate the woodworking hobby undertaken by one resident.

Letters and Cards. The last important component of every album was the inclusion of letters or cards previously given to the resident. These often provided other peoples' perspectives on positive characteristics of the resident, such as those illustrated in Exhibit H17. Sometimes letters were more formal such as Exhibit H18, recognizing the resident's participation in an event that was an important memory.

Because this research was a collaborative life story and not reminiscence for self-improvement, the albums were highlights of the resident's life. Primary approval

of the content came from the resident but family visitors also were involved. Cues from family visitors were incorporated, resulting in a form of consensus approval. Two family visitors who were not involved in the day-to-day visits and in the content of the life albums noted during Time 2 interviews where differences between reality and what was in the album, and they planned on fixing these items themselves. This emphasizes the importance of the collaborative nature of the life album and considering the realities of both the family visitors and the residents.

A key finding of this research was that life albums are a valuable tool in facilitating interaction among those who visit less often and for special occasions. Not only are the residents drawn into conversations in which they could take part, but also the regular family visitors used the life album to emphasize positive emotion and memories of the resident. Thus others felt comfortable joining in the conversations and focused less on the memory loss of the resident. Also, one family used the life album at the resident's memorial service.

One resident held a long career as a foreman for a local meat packing plant. During visits the spouse indicated the resident sometimes became disoriented and talked about having to go check on the livestock or the freezers. During a visit to the local Manitoba Archives the researcher found a study called the Meat Packing Industry Oral History Project (1985) which included a series of taped interviews with employees operating during and after WWII. The researcher included a summary of this information in the album. These pages helped trigger dialogue on what the industry was like in Manitoba during that time. Exhibit H18 shows an article found at the local archives about St. Boniface as the original home for meat packing in

Winnipeg. After reading it to the resident, he shared his reflections on the industry replying, "It might not be about [a local company] but it's an interesting piece."

At Time 2 interviews, visitors indicated the life albums were brought to many other visits by the family to share with others. Comments made by family visitors regarding the content of the life album indicated it was at an appropriate level of detail that made the visitor and residents comfortable sharing the stories with others.

I enjoyed the participation in [the project] and the nice product...I showed it to the padre, he thought it was pretty excellent. I will probably coach [my daughter] on the album and I think that will be productive.

I was surprised at the amount of work and energy that was put into it...and I think an honest attempt at really doing it up in grand style...professionally done you might say...with little comments here and there were tastefully done.

I got a lot of pleasure out of going through all these old pictures and trying to find things that would be appropriate for her to put in the album.

I was very pleased...with all the effort put into it, going to the school and getting pictures and all that sort of thing. She got literature on the packing houses where [the resident] worked. Just seeing it all come together...what a good job...I've used it for the family...The children have looked at it when they came to visit and a few of the staff have looked at it.

So I went and delved into the [life album]. I always wanted to but never got around to doing it...but I did it because we did the life album together. So I found lots of things out... now my daughter-in-law in Vancouver will get a copy first.

What it did was bring up the good things...good fortune, fun, sporty things we did and trips.

Although it was a study this [life album] is still something for us that will be left behind for us you know. My family...the [life album] is something to hold on to. It's being used more for special occasions and visits with other people.

For the resident who died, the significance and content of the life album was also felt to be appropriate to share with others and was shared at the resident's funeral.

Luckily it was mainly [the resident's] thoughts that got into the album. The whole project was interesting...and it is a fabulous...book. All the interesting information is in there. I think everyone at the funeral looked through it...it's a treasure.

In addition, during visits one family visitor mentioned that it was a wonderful feeling to have someone else as interested in the resident's personality and life as it was. Although this was not stated often, it was definitely a feeling documented by the researcher in her own field notes. Field notes reflected that the benefits of the creation of the life albums seem to be greater for the family visitor than for the resident. The process and album seemed to validate why they visited and spent so much time in what they expressed as a stressful situation. Stresses of the situation were discussed in the interviews.

These were supposed to be our golden years...well they're not!

I need to know I did my best and when this chapter is done I'll get back to me and do things for me when [the resident] is gone.

Time 1 Interviews: The Visiting Experience at Deer Lodge Centre

The Time 1 interviews were structured to assess the current social context of the residents' and family visitors' experiences when together at Deer Lodge Centre. Family members talked about what they did and what the circumstances and issues were that posed problems or negative feelings during the visits.

The visitors that participated in the study displayed a high level of involvement in the residents' lives. They often were at DLC several times a week.

Frequent visits were advantageous in supporting the creation of the life album, which helped the researcher gain perspective on the benefits and costs of visiting and maintaining relationships with the residents. In keeping with the theoretical framework of this research the key themes and categories used were based on social exchange concepts of reciprocity and examined what the visitors described as benefits and costs to their social exchanges with the residents. Each interview was different, and participants brought with it a different set of history, personal resources and feelings (attraction) of the relationship being discussed. How their situations were perceived resulted in statements that could be interpreted either as satisfactory or not.

Benefits

Visitors expressed benefits to their visiting at DLC when compared to their situations at home just prior to moving a family member into Deer Lodge Centre. There were a number of benefits expressed related to the psychosocial and physical benefits of having formal supports available to the resident.

Psychosocial Benefits. The biggest benefit expressed by visitors of residents living in DLC is visiting, in itself, with the family resident and with others who were in similar situations.

[The resident] has some friends on the unit and we banter back and forth and it's all very nice.

The good days are when we have good visits, I suppose the days when [the resident] is up and communicates with me a little bit more than on other days.

The good visits now are when [the resident] is telling his stories to my [spouse] and that's good.

When [the resident] is feeling up to it we can go down to Main street and sit with another family who is here at Deer Lodge...we got to know each other

just because our [spouses] were both here at Deer Lodge Centre and are veterans.

Another benefit, in terms of psychosocial benefits to visitors, was the social support and activities provided at DLC for residents and are most often extended to family visitors as well.

Tuesday at 2:30 the piano guy is there and he bangs out a few tunes and we join in and do some singsonging and we enjoy this very much.

Oh yes, they have programs like the zoo, uh, Oak Hammock Marsh, Fort Whyte Centre, the Air Museum, stuff like that. I usually volunteer to take [the resident] and one of the other patients and we usually go by bus. It's sort of a picnic style thing. It's very nice.

A lot of the good visits are when we go on outings with Deer Lodge Centre. Like the petting zoo for instance was just terrific.

The spouses found these social activities break the monotony of everyday visits and they enjoyed taking part in the activities. Other family visitors felt that when the resident participated in a number of these activities he or she was were at peace, knowing the resident was not suffering from boredom or loneliness. Outings gave the family visitor respite from regular visits by putting less pressure on the expectations of their own visits.

For the most part, from the family members' perspectives, the residents were relatively content with their living arrangements at Deer Lodge Centre. The visitors felt that the residents were happy to socialize with others who shared similar circumstances and abilities. Only one family visitor felt that this was not the case and that the resident had a difficult time making new friends in Deer Lodge Centre, and hoped that participating in the life album project would help bring the resident to take interest in other activities as well.

Physical Benefits. For the majority, the roles of caregiving just prior to the resident's move into DLC had become burdensome and reached a point of crisis, where something had to change because the health and well-being of the family visitor had been compromised. The move to DLC alleviated the physical burden of caregiving. Two of the non-spouse family visitors felt that the timing of the transitions were adequately spaced so as not to cause an unmanageable stress in their lives. In both cases, the residents' move to DLC changed the caregiving role to one that was more pleasant than what was experienced just prior to the transition. They all changed terminology from "caregiving" to "visiting." However, most still found caregiving roles to fill at Deer Lodge Centre like shampooing hair, fixing, buying and cleaning clothes and staying during meal times to make sure the resident ate and was adequately cleaned afterwards.

Today has been a good visit so far. I came just before lunch and sat with him through lunch...now I will stay and we will go down to the cafeteria for dinner...I can visit now, which before I was too busy caring for [the resident].

Costs

Visitors expressed a number of psychosocial and physical costs to visiting with residents at Deer Lodge Centre. Although almost every visitor also mentioned economic costs, they seemed to think that this was the least of their concerns and would or could not identify these as negative costs in the relationship. For this reason, the analysis focuses on psycho-social and physical costs which played significant roles in the ability for the visitor to find a manageable balance in the relationship with the residents living at DLC and the rest of their lives.

Psychosocial costs. The visitors expressed a number of costs associated with losing the social relationship that they once had with the resident. They discussed how illness or disease had changed this key social relationship in their lives. For spouses it seemed to have the greatest impact:

I suppose it's just being alone and not having the companionship of [spouse] anymore, you know. You bring up your family, you're retired, your life is going to be good, you know and then these things happen...He said these were supposed to be our golden years...well they're not.

you do have burdens but if I didn't come, I would miss [the resident]. There isn't the companionship any more that there used to be between [the resident] and I. But that's because [the resident's] not well anymore.

It's when it's time to go home that's when it gets rough... [the resident] realizes we no longer live together...I want to bring [the resident] home with me but I can't...it's just impossible...then of course [the resident] comes out with stuff like I don't love [the resident] anymore. It's very disconcerting to say the least.

If [the resident] is down that day or more confused than normal, then I don't have a good day and I go home feeling, I don't know if you would say frustrated but sort of down, unhappy. Worried.

The average or bad visit would be when there are more silences than conversation.

I'm doing this so that I can feel good later. You know, when you marry for better or for worse, sickness and health...there isn't much of that anymore but that's the school I'm from...it's tiring.

If I come in a bad mood, it's a bad visit.

There's days I can't understand what the [resident] is saying that's often an emotional day.

Yeah, when you have to say 'No, you can't come with me' and 'I'll be back tomorrow' and that's not good enough and you see the sad look on [the residents] eyes.

Not only was most of the visitors' free time spent visiting the resident at the Centre, but also spouses found that other family members and friends did not visit frequently and the family resident had lost touch with many people. In the interviews, spouses shared their perspectives on the lack of social supports and provided reasoning for why their offspring and other family members were withdrawing from the resident.

[My daughter] is coming a little less now because I've told her to. Because she has a job and she has a home of her own to maintain. We have another daughter, but she has a young boy and so she doesn't come as much. We have a son but he's busy too. They're all good.

Most of my time is spent with [the resident] but if someone else is around, certainly I talk to them.

Well, my daughter has a huge job. So she doesn't get much chance to visit but she gets in every chance she gets...she's been a great mainstay. Well the staff is very nice, very supportive. I belong to a support group here and they are, we are supportive of one another on a continuous basis.

There are times where I reach a point where I have to get away...That's a bit of a release for me...otherwise it'll be pretty well just the steady grind and I guess there's a certain monotony to it.

They have their own problems and life to keep up with, they don't need this as well.

In other instances, spouse visitors felt upset and hurt that his or her offspring or other family members and friends did not visit or provide more support.

I have five children and they don't visit...they tell me I'm here too much. I shouldn't be visiting this much...but my thing is, if I'm visiting too much then they should come and give me a day off. But they won't do that. They just feel [the resident] doesn't need visits because he's here and he's cared for.

I don't know why they never visit --- they say I do too much and I tell them well they could help out -- but they don't... I think they're scared but at the same time feel guilty.

Offspring and other family members expressed different changes in their social relationships with the residents. They said things that relayed a sense of guilt for not being able to fill the social gap in the residents' lives.

Of course, you'd always like to come more often and to stay longer but it's just not really possible.

If [the resident] is down or in a bad mood [they] don't want me to know about it. [The resident] doesn't want me to see that [they] are depressed so we don't have depressing visits because [the resident] puts on an act sort of...

I'm emotionally attached to [my parent – the resident]. So I can have an understanding a little bit that her brain is not functioning right...but at the same time, I guess I'm angry and I think, how could you, you know, not take care of yourself...I shouldn't be taking care of a parent yet.

Sometimes you're embarrassed because she hasn't got a lot of tact...and she doesn't do well in a group...all the confusion...and then you think, well oh gosh, maybe we shouldn't have done it [brought her to a family gathering].

Another key cost that was mentioned consistently among spouses and children was the time and energy spent with the resident. Visitors usually sat in silence, just sitting and being company for the resident. The visits were at the cost of being able to develop and foster other social relationships. Often when asked what else the family visitor did during their spare time, they mentioned social events that they missed. As one person said, "You just have to be here because [the resident] needs you."

The primary perspective shared by visitors of the residents' experience was related to moments when the resident realized that he or she was at Deer Lodge Centre to live and would not be returning home. It was these moments that the social exchange between the visitor and residents was very painful and stressful, and family

visitors expressed great sadness in not being able to grant the wishes of the resident to go home.

I would just dearly love [the resident] to accept the fact that [he or she] is in Deer Lodge, the best place for them, but [the resident] just won't accept it...but there is no possible way that I could bring [the resident] home.

Less frequently mentioned, but still significant, was the stress of living with many other residents who were cognitively impaired. Family visitors felt that the other residents were a reminder of why they were at Deer Lodge Centre and if the other residents were more disorientated and displayed problem behaviours, visitors felt this was a glimpse of what was still to come.

One family visitor expressed concern that the parent was having trouble meeting new people and socializing at Deer Lodge Centre. The family visitor felt that this was the root of some depression and had hopes that the life album would be a source of pleasure and meet some of the social needs of the resident that the family visitor could not provide. Although this was not mentioned by other family visitors, non-spouse visitors seemed to have some level of expectation that the life album program would help alleviate some of the loneliness and boredom they perceived filled some of their family residents' lives on a day-to-day basis. Three of the non-spouse visitors went on holidays during the life album intervention program, and they made special efforts to notify the researcher of their absence from visiting and asked that the life album intervention be continued during their absence.

Physical Costs. All visitors expressed the stress placed on their lives of their having a family member with dementia living at Deer Lodge Centre. All caregivers reported at least one symptom of sleep disturbance, physical ailment (back and leg or

hip pain), headache and/or depression. Family visitors talked about taking medication for ulcers, depression or chronic pain, which they felt related in part to cumulative, long-term effects of caring for and coping with the illnesses of the resident. Only one out of the six family visitors did not discuss being on medication for at least one of the above mentioned ailments.

In addition, many family members did not have much time to take care of themselves physically. Often the family visitors talked about being physically unhealthy and not expending time and energy on physical/personal health activities.

For example:

I don't do as much as I probably should because I spend more time with [the resident].

There's no point...when I'm not here I worry and I can't focus. So I might as well be here with [the resident].

Visitors felt that the residents were isolated, with limited physical space to be active. Some relayed that residents were either gaining weight or losing weight at a rate that was unsatisfactory to the visitor because in their minds it was a sign of physical decline. The two main contributors to this physical decline related to their visiting experience. Meal times were not enjoyable with poor tasting food and lack of an appealing social atmosphere. Only in the summer were the visitor and resident able to get outside for a walk or to do something active. The winters were long and most visits occurred in the resident's room or in the common cafeteria area known as Main Street.

Time 2 Interviews: Visiting with the Life Album

During the Time 2 interviews, in addition to answering the same questions asked during Time 1 interviews, visitors discussed their perspectives of the effects the life album had on the visiting experiences. During the interviews, visitors expressed the benefits and pleasure experienced from using the life album during visits or with the process of creating the life album. Visitors also shared some of the potential costs associated with the life album process.

Benefits

Psychosocial benefits. The benefits expressed by visitors during the Time 2 interviews were related to the psychosocial benefits of using the life album during visits. They said that the life album process was beneficial to the relationship between family visitor and resident because there was an additional person taking an interest in the life of the resident. Indirectly, the researcher acted as an additional social support because she was interacting with the resident and visitor, establishing a rapport and friendship with these families.

Someone else to talk to other than...because when you are a child and have family...and [the resident] really only had me and [my spouse and one other friend] we picked up once and a while to visit who would come once and a while. Just very few people who would be coming up to see [the resident]. So just someone else to talk to.

Because I really enjoyed visiting with [the researcher]. It was very nice visits...I think it's a wonderful thing to do for people....

[The resident] thinks her and [the researcher] are really good friends now...[the resident] doesn't remember the girl's name but will say, "I had a friend visit, a girl"...I'm the same though, I thought oh...nice...but...[the resident] has never really noticed that she's not there any more.

We came, became friends to [the researcher]. [The resident] teased her too...plus she got me getting into the life album.

I wouldn't have done it for anybody but she was careful with the pictures and there was this sense of now or never. But this was getting like exciting.

I enjoyed doing it, I enjoyed the visits...I was very pleased...when it had started being put together and she showed it to me a little bit, you know, a little bit to start with and then slowly it got finished. I was pleased...and my girls were anxious too. They wanted to see it and have it done too.

Family visitors talked about the life album as a tool to help with their own and others' visits with the resident.

They [resident's offspring] will be pleased to have the album...I'm sure they will sit with [the resident], when they're here by themselves with [the resident], they'll go through it and look at it and talk about it.

The life album is a tool that will and already has facilitated visits a little bit because visits tend to, sometimes are hard to handle...

Oh it's a great help. Absolutely. When I run into some difficulties, I will pause and pause on the album. And then say, how about looking at some pictures. And it's like starting over again sort of.

Oh, I look at it almost every time I come...with [the resident] and sometimes, sometimes if [the resident falls asleep] I sit and look at it by myself.

What it did was bring up the good things.

So it [life album] tends to remember all the positive...because when you're here [at Deer Lodge Centre] it's different; frustration and stress and this [life album] was fun.

Family visitors felt that the life albums would be a lasting and tangible evidence of the residents' lives, which was especially important because albums were created during a time when the residents were not easily able to express themselves. The album showed others who visited less frequently the value of the resident's story and what was most important to the resident during his or her life.

Like when people come from out of town for their condolence they have the album to go through. It has [the resident's] thoughts...it makes it extra special.

I think it will help [the resident] hold on to what [the resident] has. It's like a family tree but has a life story to it.

It's a treasure, and it's a beautiful idea.

I think for me personally, the satisfaction, it's because we have this beautiful memory book really. And, as I say, we would never have done anything with those boxes [of memorabilia] otherwise.

And I think the best part of it when [the resident] dies, we'll have that album and we can put it out for people to look at, you know. And I guess that's what I thought was just so wonderful like.

Costs

Psychosocial costs. Visitors offered some perspectives on their feelings of sadness emphasized by the life album process. Visitors did say at times the memories brought tears or feelings of nostalgia to the forefront. All visitors who expressed these feelings of sadness followed these comments by indicating they would not want to have foregone participation in the project because of these feelings and wanted to have the album as a tool and as a keepsake.

Yeah, I swelled a little...I guess I was a little bit teary but it was good. But I guess that's why we said we wanted it done and why we would participate.

For spouses, the album brought feelings and memories that they wanted to share with the resident again, even if it produced feelings that elicited strong emotions, which were difficult. In the long run the album facilitated a connection to their lives lived together.

It's produced lots of nostalgia. There's nothing wrong with that. Uh. Bringing back some of the good times that the pictures suggest, you know, the pictures, the old times and so on.

No...but you just talk about it and [the resident] either laughs or cries over some little thing out of it...it's just the emotion...because I've cried too. But it's not causing [the resident] to become overly upset.

For offspring the album offered new perspectives of the residents' lives that were previously unknown. For one particular visitor, who remembered a difficult childhood and early adulthood, the pages of their youth that were filled with happy memories and fond quotes was difficult.

Yeah. I don't remember the good times...and I think about that, you know. Just go to that picture and I figure that there's so much sadness in our lives...but here is this album that kind of takes a spin on that. It's good for [the resident]... I think now about how much [the resident] did for all of us kids and with almost nothing, I mean...wow, you know?

Physical. One other perceived cost, when probed, was the time it took to participate in the study. Although all said that it took extra time, in most cases it was a pleasant experience and something that the visitors wanted to do. It took their minds off the everyday or weekly routine to which they had become accustomed. At the same time, some did share that physically having to locate photographs or memorabilia was another thing on a long list that needed to be done. The costs relayed in this matter were feeling pressure to get the materials to the researcher.

Another cost was regret. Once the album was complete a few family visitors thought other pictures might have been better suited to the album. The following are some quotes to exemplify these stresses.

I'll tell you what it did. I nearly missed my bus a few times because I would get the pictures out, looking for what I thought she might want. Because it's hard to know...so I didn't know how much she was going to get out of the pictures...so I rushed to get them together.

Just finding the time to go through the boxes to find the photos.

Just the idea of having to get the pictures out...once we did it, it was easy.

...I got quite a lot of pleasure out of going through all these old pictures and trying to find things that would be appropriate for the album. But I think I could have thought of hundreds of pictures, you know. But just to get the time to go through all those old things.

Comparative analysis: Outcomes of the life album

Once analysis of each of the interviews was complete, some comparative analysis was possible by examining the experiences of visiting using the life album compared to the visitor's experiences of visiting without the life album. Comparative analysis was also undertaken for the questions asked at Time 1 that were repeated at Time 2. In keeping with the theoretical framework of social exchange theory, the comparative analysis examined the outcomes of the life album from the perspective of whether or not the process of creation or use of the life album provided a change in the visiting experience. The researcher also analyzed visitor interviews to see if outcomes of imbalance or balance in the social exchange relationships between the visitor and resident occurred.

Expressions of imbalance (stress/eustress). In both Time 1 and Time 2 interviews the visitors express the difficulty of dealing with a family member who had dementia and was living in a PCH. The residents' situations did not change because a life album was created, and the family stress of dealing with a person who has dementia was still there.

On the other hand, the life album was a distraction, something unique and positive on which to focus. It was a positive imbalance, because the participation in the intervention was discontinued. Getting the album was a process that resulted in a

tool. The life album gave the family something unique to hold and use, a welcomed surprise that broke the status quo of everyday visits.

We've looked at it because we were interested in looking at it. I don't think it will continue. After the fact, like I think initially [the resident] thought, wasn't this great but [the resident] doesn't remember, you know. But we will appreciate having it.

Well, it's just making all of a sudden she's got this book though...what a nice surprise.

I didn't feel that she was just a researcher or whatever. She made friends with us. At first, like you don't know what it is...well what's this all about. But as time went on, it was fun. I say we worked together. So that's positive...She left empty pages, so I'm going to fill those in. It's just that it made me very happy. I wouldn't have thought to do it myself, you know. I mean I've got it all up here, what we did together was actually put it in an album.

I don't know. I think it's a wonderful thing to do for people. If, you know, if the people, if people like me and my [spouse] are interested in this, I think it's wonderful...to make something like that possible for us.

Expressions of balance (management/coping). The visitors saw the life album as a communication tool, both for less frequent visitors and for their own visits during times when they were otherwise not able to engage in conversation with the resident. Some visitors had expressed having a very hard time coping with their situation. They felt that the life album was a distraction and an opportunity to share with others who came to visit. All six visitors stated they would use it in visits with less frequent visitors. The visitors hoped that it would make it easier for their offspring and others to visit by encouraging conversation with the residents and triggering memories through looking at the album.

I'm really positive the family will look at it when they come and visitors that come to the room.

I'm hoping that the kids will interact with [the resident] around the life album...one of my [offspring] that lives out in BC has heard about it and she said "Whatever it costs, I really would love a copy of it" and she has made a special trip to go see [the resident] before. So that was a good thing too because I was shocked.

My [offspring] living here have seen it and they thought it was great too. But I want them to be with [the resident] to look at it together. But because they don't visit like...So I got to make it work somehow [to get the kids out to use it with the resident].

Four of the five families able to visit using the life album indicated they would use the blank pages at the back to continue adding pages as things in the future. They felt that the life album as a tool and as a process would help them stay active in their visiting roles at Deer Lodge Centre.

I will fill in some of the empty pages and make a copy for [offspring's names] so that [they] can know [the resident's] mind focused on the children...always concerned about them.

And she's left some pages she told me so that if I wanted to add something to it. At the end I will I think that's nice.

I won't necessarily update the part that's already finished. But there's quite a few empty pages and so from time to time I will just introduce some new pictures into it.

Visitors in general felt that the value of the album would extend beyond the life of the resident and planned on either making copies of the album for younger family members (residents' children or grandchildren) or displaying the album at memorial or funeral services when the resident died.

It's [the residents] legacy...story, you know. It's like a family tree but it's got a life story to it. I will have it out at [the resident's] memorial service some day.

Well I thought it was really nice that we would end up with some history of this [resident], who isn't going to live forever. And while we had all of these

things in a box, you know, you never get at doing anything with them. This way it sort of collated all that stuff and we have a very nice book...keepsake.

The one family who received the album only after the resident had died did use the album at the memorial service and felt it was a great value.

I think everyone at the funeral looked through it, I don't think everybody read everything ... not enough time. A lot of people had a chance to know stuff about him...it's a treasure. I think it's just a treasure and a beautiful idea. Because like when people come from out of town for their condolence they have the album to go through. And because it has [the resident's] thoughts it makes it extra special. Things that [the resident] said [the researcher] wrote down.

Summary

All participating family visitors discussed the benefits and drawbacks to having a family member in a PCH. Each resident had received in-home care prior to admission into Deer Lodge Centre, and as a result family visitors struggled with their new roles of visiting. Each family visitor was very involved in the resident's life, visiting more than once a week for hours at a time. Family visitors expressed the new situation as something that brought physical and social relief, because staff and other visitors now could provide support. The residents were not easily able to communicate, often having trouble with speech and relating to time, person or space. Coupled with the family visitors strong sense of involvement and need to still be there for the resident resulted in lack of time or energy for visitors to spend on other social activities for their own benefit.

The life album did not change the visitors or residents' situations. Family visitors still visited frequently, for long duration, and were still faced with visiting someone cognitively impaired, which decreased the amount of social exchange. The

life album process seemed to be a social respite for visitors and residents, with a third person who took an interest in the resident's life and focused on finding memorabilia to remember life events. The life album was the outcome of the ten to thirteen weeks of visits and highlighted the positive events and times of the resident's life. Family visitors benefited from having the album, not only to facilitate visits with the resident by triggering memories and encouraging conversations around topics close to the resident, but also to use as a tool when others came who visited less frequently. The album provided a positive focus for the visitors and residents to discuss life with others, including siblings, offspring, staff and clergy.

Chapter 5 Discussion

The goal of this study was to create and evaluate use of life albums with PCH residents who had dementia. The life album creation was a ten- to thirteen-week process, which focused on the concepts of reminiscence and the use of a collaborative life story to help those with dementia to better participate in the visits. The themes and categories used in the analysis of interviews were based on the theoretical framework of social exchange. The residents who participated in this study had stories they wanted to tell, and the family visitors experienced satisfaction from their visits using the life album. In addition, the outcomes and effects of the life album study were different for spouses than for the offspring or the extended family member.

Researchers support the value of documenting and using stories in promoting the abilities and meeting the social needs of persons with dementia (Killick, 2003; Murphy, Killik & Allan, 2001). There is a need for continued investigation to find ways in which family members and caregivers can be supported and encouraged to provide opportunities for ongoing communication and creative expression with PCH residents. The findings of this study suggest that family visitors, especially the spouses, benefit from this type of support by validating their involvement in the resident's life.

The Creation of Life Albums and the Concept of Reminiscence

The life album intervention program was based on the development of a collaborative life story. Consistent with previous literature, the stories that were told by the residents during the intervention varied greatly in depth and meaning and

sometimes were difficult to follow (Goldsmith, et al. 1997; Usita et al., 1998). The residents often used metaphors, repetitive phrases or single words to tell an entire story; it was the researcher and the family visitor listening to the residents reminiscence that lead to these stories being created into pages of a life album. The researcher focused on the organization of the story components so they would be understandable to others in a social visit. In other words, the cues of what was remembered came from the resident and then the story creator/listener worked within the reality of these cues.

Originally the researcher planned to tell the residents' stories and capture the way the residents saw their world; however, the reality was the researcher was working within a family system. Visitors, especially spouses, were involved with the process, so flexibility was needed. Visitor involvement led to some shifts in the collaborative nature of the stories being created as there were three people creating pages in the life album. The result was a mix of components in the life album. As illustrated in the continuum of reminiscence shown in Figure 1 of Chapter 1, the life album process is a form of reminiscence that harmonizes the communicative and collaborative story. From the researcher's perspective, the albums brought a balance between providing information on who the resident was by including memories and memorabilia shared by visitors and residents, as well as components of the resident's current reality by including quotes and memories contributed by the resident during visits.

Both visitor interviews and researcher field notes showed that visitors were surprised by the level of detail and information that the resident was able to

contribute, consistent with recent research examining the abilities of persons with dementia. Killik (2003) suggests that people with dementia continue to amaze researchers and family members when they articulate their perceptions on some of life's philosophies, such as spirituality and nature, the meaning of life, and on concepts like family, time, silence and touch. Killik reiterates that persons with dementia have insights to offer on life that are valuable, and, if they have these insights then they must have a need to find outlets to express them. The creation of the life albums showed that life lessons can be expressed and are valuable to the resident, the family visitors, and to others less knowledgeable of the resident's life or history (such as staff, acquaintances or offspring who visit infrequently).

Unlike other forms of reminiscence research, the life album is a tangible tool that results from blending the communicative and the collaborative life story. The communicative life story focuses on the concept of empathy, meaning the story creator speaks on behalf of the resident to inform others of who the resident is by including materials on personality, life history and personal biography, physical health and current network of relationships (Goldsmith et al., 1997). The collaborative life story is based on the principle of alterity. This means appreciating the resident is experiencing a unique set of thoughts and finding a way to identify and facilitate opportunities for the resident to express themselves within their own realities (Frank, 2000; Vittoria, 1998). Vittoria articulated that few people have the ability to go along with "visiting the destinations of the mind" of the resident with dementia, and finding a way to support both the needs of the resident and the family

members to communicate with each other requires more creative thought. The life album may provide the balance needed to meet both realities.

Visits were established to encourage reminiscence. This meant considerable work outside of the visits to come prepared with materials to help facilitate the resident in relaying their stories. The use of memorabilia and information collected outside of visits was instrumental to further discussions and creating stories with the resident that built on more of the stories told in previous visits. This was the concept outlined as Spradley's descriptive question matrix (1980) adapted by using props and materials instead of probing questions to guide mini-tour questions. In addition, all five senses could be used to cue the resident, and where applicable the family member, into delving into the mini-tour questions. As a result, the resident and visitor acted as a team, with the resident identifying and discussing the grand-tour question and the visitor often participating in the detailed mini-tour questions.

The Visiting Experience at Deer Lodge Centre

Interviews at Time 1 provided a baseline of information on the visiting experience at Deer Lodge Centre. The analysis of these Time 1 interviews outlined the social context of residents and family visitors, including information on activities undertaken during and away from visits. The interviews showed there was a high level of involvement by all family visitors, with a commitment to maintaining a relationship with the resident and ensuring the resident felt that someone would be there for them when needed.

Social Exchange Theory

Applying the theoretical framework of social exchange showed how the relationship and outcomes of satisfaction change over time between the visitors and residents (Sabatelli & Shehan, 1993). The findings capture anecdotal evidence of the costs and benefits (rewards) of the visiting experiences of family members. How visitors assess the reciprocity of their relationship with the resident was different for spouses than for offspring or extended family visitors.

Benefits. Visitors commented on benefits to their visiting at Deer Lodge Centre when compared to their previous situations at home. As a result of this comparison, visitors felt that the primary benefits were psychosocial and physical in nature. First, the resident and visitor could once again visit, whereas at home there were too many physical needs that took priority over spending time with the resident in a social situation. From a social exchange perspective this improved motivation to visit because the cost (physical care and chores) would not outweigh the benefits or rewards of visiting (Klein & White 1996). Also, differences between spouses and offspring were noted.

All six visitors were very involved, and they wanted to make sure the residents knew the visitors cared for them. When affectional ties were recognized by the resident through a smile or gesture, then visitors felt the rewards were great and made their efforts worthwhile. This is consistent with social exchange theory that reciprocity is not evaluated on an act-by-act, give and receive basis, but on the overall distributive justice and the normative expectations of the relationship (Sabetelli & Shehan, 1993). For offspring and the extended family members their recollection of

all that the resident had previously provided made the current visits with little feedback a part of giving back what they received. On the other hand spouses focused on their marriage vows and the fact that their current caring routines were part of their agreement to share both healthy years and years in sickness. Both exemplify the concept of reciprocity and distributive justice. On whole the visitors felt positive about the resident having others who were in similar circumstances with whom to share time.

The physical benefits were relatively straight forward; there were staff and trained professionals who could now deal with the physical needs of the resident, alleviating the pressures and strains of having to provide extensive physical caregiving to the resident. Consistent with the literature (CareGuide, 2003; Dupuis, 2000; Marwit & Meuser, 2002; National Advisory Council on Aging, 1999), the culmination of physical demands of caring for the resident and the toll on the physical well-being of the caregiver was the impetuous for the resident's move to Deer Lodge Centre.

Costs. The costs most often expressed by the six visitors were psychosocial in nature, related to the costs of losing a relationship with the resident and finding it difficult to communicate. As already mentioned, current interactions with the resident is compared to what the expected interaction might have been. If they are comparable or understandable, relationship satisfaction is achieved; if there is low satisfaction in the relationship then external resources may be required to have a balanced exchange with their family visitor (Sabatelli & Shehan, 1993; Klein & White, 1996).

There was a difference in perceptions of spouses and offspring. One daughter felt the caregiving role had come too early in life and was frustrated by the burden it had placed on her while trying to establish a career. In contrast, two non-spouse visitors shared feelings of satisfaction with their own efforts in visiting and caring for the resident, when compared to others in similar situations. They felt that the roles they were playing had been anticipated. Also consistent with the research (Baxter, 1999; Killik, 2003; Thomas, 1996) is the experience of the visitors having few outlets or resources available to support their caregiving roles in Deer Lodge Centre. As a result, visitors felt their physical, emotional or social needs were placed on hold.

Spouses expressed greater concerns and costs associated with their relationship and environment within the personal care home than offspring. Spouses felt shortchanged in their retirement, expecting to have "golden years" with the freedom to enjoy each other's company. Instead, spouses were more involved in the activities at Deer Lodge Centre than they expected. Perspectives offered during interviews revealed that there was limited social or emotional support available to them within the institution. The support that was most appreciated during the life album intervention program was the rapport established with the researcher. This finding is consistent with research explaining the transition to caring for someone in an institution does not lessen the sense of burden or the desire to retain a role in the life of the resident (Dupuis, 2000).

On the other hand, offspring and the extended family member expressed different costs. They had greater outside responsibilities and spent more time managing and balancing their caregiver role with other activities. They were more

likely to have conflicting priorities such as working, and caring for children and grandchildren.

Visiting with the Life Album

Life albums were used for two weeks before the second interviews were conducted. Interviews at Time 2 showed the life album process was one way to facilitate spending quality time with the resident. This is especially important, as family visitors felt that they did not have much variation in their day-to-day routine. One of the primary complaints heard from family visitors was that their social supports declined because less frequent visitors had trouble dealing with the personal care home environment and the loss of the person they used to know. It was expressed by spouses talking about their children, "Oh they have their own families and lives to live," or "Maybe they would take an interest if there was something to actually do with [the resident] but they can't just sit and visit."

Social Exchange

The experience of the visitors using the life album can be applied to the factors of social exchange that mediate relationship satisfaction. Consistent with literature focusing on the use of reminiscence with persons who have dementia, the life album acted as a tool, or in exchange terminology an external resource, to promote story telling and helped preserved the residents words and feelings for the resident, their relatives, friends and staff (Goldsmith et al., 1997; Killik, 2003; Murphy, 1994). If the visitor evaluated the costs and rewards against what was anticipated for the relationship with the resident he or she may have felt dissatisfaction or strain on the relationship. In this case, external resources may be

used to gain a more balanced exchange to support better relationship satisfaction. The life album acted as an external resource that fed into the balance of costs and rewards (benefits) of the visiting experience. Because the life album resulted in a sense of satisfaction, peace of mind, and pleasure by doing something creative for the resident, then a sense of balance and relationship satisfaction was more likely to be experienced. A key finding of this research was that the life album as an external resource helped support and improve relationship satisfaction between the resident and visitor. The participating visitors were pleased that they were able to show the album to others. The album helped validate the rewards they felt by visiting regularly and helped articulate these positive feeling of the resident to others.

Outcomes of the Life Album. Using the life album as a tool in visits with the resident and with others who visited the family visitor and/or resident resulted in three primary benefits. First, visitors expressed the value of having the researcher establish a rapport with the resident and family visitor and that the experience of working with someone else was beneficial to further relating to the resident and seeing the resident in a new light. Second, the life album was a tool to use for others who come to visit. Third, the life album was seen as a keepsake and a way of memorializing the resident in such a way that the positive contributions of the residents were a valued gift. These outcomes support the literature that has emphasized the need to offer support to family visitors who take a more involved role in the residents' life. As Klein and White (1996) discuss, improving the resources of a situation increases the generalized balance of exchanges among friends and family.

Expressions of Imbalance. These can be seen as positive, something exciting and new in the visits, or as negative, such as the continued pressure and stress of the situation. The residents' situations did not change because life albums were created. On the other hand, the life album was a distraction and temporary activity to create a little change in daily routine. In most cases this was a welcomed imbalance. Also, visitors felt the life album is a tool that will continue to be used when surprise or infrequent visitors come to see the resident.

There were costs associated with the life album because there was sadness created through the life album process. In one instance, the memories caused the family visitor some unwanted stress. Family members felt uncomfortable with old memories and as a result they withdrew participation in the study. This is an example where this process created an unwanted imbalance.

Expressions of Balance. Visiting is a normative event, with certain etiquette associated with discussions and activities that constitute a good visit. In general, people enjoy visits when they share and find meaning in each other's stories (Usita et al., 1998). Most people enjoy looking at photo albums and scrapbooks because they all have relatively similar experiences with families, holidays and home and neighbourhood. The life album was a communication tool for visitors to use during times when a support or an external resource was needed to facilitate interaction with the resident.

Even though the process was not therapeutic for the resident, there seemed to be elements of therapeutic reminiscence for the visitors (Frank, 2000). At least one spouse felt the life album facilitated a connection to their lives lived together and

gained perspective on the parts of their lives that mattered most and made them the most happy. In this instance the visitor felt they were provided a new perspective that made visits somewhat easier. For offspring, the life album presented different memories and stories of the residents that had not been known before. For one visitor, the parent's life album was difficult to see, as the life album offered new perspectives on life events that the visitor had experienced very differently. The visitor commented on the emotions tied to seeing the resident talk positively about a very difficult time. As a result the visitor has started viewing these memories differently. Both of these show that some degree of traditional reminiscence, although not explicit or part of the study, resulted from the life album process for the visitors.

Differences Found in Family Visitors' Involvement

The literature indicates that spouses and offspring experience their roles differently at home from caring for someone in a personal care home setting (Baxter, 1999; Dupuis, 2000). This is consistent with findings from this study, which showed the development and effects of the life album were different for spouses than for offspring. This was especially true when considering the level of involvement from family visitors throughout the intervention.

Spouses took special interest in the weekly developments and continued to bring memorabilia, photographs and other materials weekly. Spouses also scheduled their visits to ensure that they would be present when the researcher made her visits with the residents. The spouses seemed to benefit more than the other family visitors did by the intervention program itself. The spouse visitors expressed appreciation for

the whole intervention program and the rapport and support provided by the researcher throughout the intervention program.

Although offspring and extended family member were pleased with the albums and found positive uses for the albums, they used the intervention program more like a respite for frequent visits. This is in keeping with literature (Lyons & Zarit, 1999; Zarit, 1997) finding differences between spouse-caregivers and other family caregivers. Zarit (1997) emphasized the need for spouse-caregivers to receive support and found support groups a successful way for reducing the emotional burden of caregiving and found in turn this reduced negative behaviours expressed by the residents.

Methodological Considerations

This section discusses the research process and how the approach to the study may have had an impact on the outcomes of assessing potential effects of the life album in visitor interactions. Triangulation for this study was important because of the potential that the intimate nature of visiting over time and sharing of information between visitors and the researcher would lead to some research bias. Maintaining field notes and having another person conduct Time 2 interviews reduced the chance for intersubjectivity (Morse & Field, 1995). In addition, data collection and analysis were driven by a theoretical framework, which provided the researcher a focus in analysis and sorting of data deductively.

Research Methodology

The Time 1 and Time 2 interviews with family visitors investigated what the visiting experience was like from their perspectives. The researcher's field notes

provided a checkpoint for validating and providing a different perspective on events. Together, data were triangulated and allowed a greater understanding of visiting at DLC and the effects that the life album had, as recommended by Morse and Field (1995). Since a theoretical framework drove the content analysis of interview transcripts, the themes evolving from analysis were bound by the concepts of social exchange. This thematic analysis was undertaken to focus the data on aspects of the relationship that would explain the effects of the life album as a tool (resource) to use in visits.

Field Notes. The use of field notes became an important source of data on tracking where flexibility was applied and changes on a visit-by-visit basis. Field notes ensured there was minimal loss of data because details following a life album session, interview or phone conversation with the visitors were recorded (Creswell, 1994). In the end, having salient details as well as the researchers experiences and thoughts recorded were valuable in understanding differences in visiting routines and family participation in the project. The field notes were used to supplement the data collected from interviews and life albums and helped to clarify any researcher biases by writing the researcher's own feelings, problems, hunches, impressions (Morse & Field, 1995).

Since there were no logs kept by visitors on the day-to-day changes in visiting and on their experiences with the life album creation, the researcher's field notes were the source to note changes during the process. Conversations with family visitors were documented, which provided a time-line of events so that visitors' perceptions could be viewed from the stage of the program where they were recorded.

Time 1 and Time 2 Interviews. Having approximately 16 weeks between Time 1 and Time 2 interviews was useful in ensuring the credibility of information provided by the visitors. This was because there was a longer time in the field for the researcher to establish rapport, interact and observe the participants. Therefore, it became more credible that the researcher was capturing the lived-experience of the participants rather than changes in behaviour in the setting because of the researcher's presence (Morse & Field, 1995).

The use of an interviewer unknown to the visitors in conducting Time 2 interviews was useful in ensuring reliability and perhaps provided richer data and increased validity of results. One important aspect of having Time 1 interviews conducted by the researcher and Time 2 interviews conducted by a different person was the assurance that questions would be asked differently at Time 2. Thus, researcher bias was decreased and internal validity was improved. The two-week time between the last visit with the researcher and the Time 2 interview also provided visitors opportunities for reflection. The potential for interviewer bias grew as the researcher became more involved in the lives of the participants and started to form her own thoughts on how the life albums were affecting the families. Morse and Field (1995) discuss one of the drawbacks to the qualitative interview is that leading questions, however unintentional this may be, can produce responses that the researcher is wanting to hear rather than truly getting at the meaning of the participants' experience. In order to minimize the opportunities for researcher biases, the researcher wrote hunches and thoughts in her field notes, which resulted in her increased awareness of these biases by recording them, and improved ability to

identify and place them aside during data collection and analysis. A second interviewer meant that a broader base of questioning and richer data would increase validity (Morse & Field, 1995). However, the drawback to this is also the chance for inconsistent interview style and the potential for gaps in interview questioning because the second researcher is not as aware of the details of the process.

Life Album Methodology

The life albums were the results of stories that were collaboratively developed over the ten to thirteen week period. The researcher had expected involvement by visitors would be limited to interviews, a couple of phone calls and meetings to borrow photographs and memorabilia. In fact, visitors, especially spouses, were involved on a regular basis. Information had planned to be recorded as the residents' recalled events, regardless of accuracy as advocated by researchers of the collaborative life story (Killik, 2003; Vittoria, 1998). Even though visitors were informed and agreed to this intent, in actuality the visitors wanted reflections to be recorded as they remembered them to have occurred. The regular involvement of family members meant flexibility in meeting the visitors' need to document stories of the residents to coincide with the memories shared by the visitor. In other words, inviting the family to participate in the creation of the life album added to the depth of information collected but required balance with ensuring the information presented was in such a way that all participants agreed on the recollection and the content of the life album.

Life album work outside the visits was done to collect different materials and information not provided by the resident or visitor and was brought into visits with

the resident. As Chapter 4 outlines, this information included archived newspaper articles, advertisements, old school attendance reports, photographs of elementary school teachers and other artifacts. In some instances, the researcher would use the new materials to ask questions of both resident and spouse and allowed for time for the resident to answer; the spouses were often taken aback by the memories of events shared by residents. It is therefore important to investigate any information provided during visits, which will inevitably lead to finding pictures, stories and ideas to fill the album that are new to those closest to the resident and will draw interest from everyone who will use the album. This improves the resourcefulness of the album as a tool to improve visits.

Klein and White (1996) describe how the use of external resources to provide motivation can help maintain a balance or positive social exchange in a relationship. Some family visitors made additions to the life albums after they were presented to the resident and visitor. Some also delved further into the meaning of what the residents were saying and emphasized the positive of the resident's life. Since the researcher provided support and shared an outsider view of what the resident was expressing, it seemed to have created a momentum for the visitor to continue developing empty pages of the life album.

It is important to remember if the life story is to be used by family visitors, then the resident's recollection of events needs to coincide with the visitor's recollection of events. From a reminiscence perspective it is valuable to explain and describe the residents' experiences and stories as they are shared with the researcher, but if someone in the family system disagrees, then this information should be

considered and respected as well. In this research, one family withdrew participation from the project because the recollections of the resident, although not negative for the resident, stirred negative memories for the family visitors. Because the family visitors were also participants in the project and because stories were not created in isolation from the family system but designed to support the family system, the project was not completed and withdrawal from the study was respected.

Tracking Quantitative Data

The family visitors were involved in the residents' life regularly, visiting more than once a week during the intervention program. Initially the visitors were asked to keep a log of their visits, but after two weeks this component of the study was found not to work and was stopped. It was evident that it was an unreasonable expectation on visitors to ask them to identify variations in routine visits; they did not identify with small changes and found it cumbersome and repetitive. Log sheets were designed to be completed by the visitor at each visit, having them record responses to four Likert-type scale questions on the quality of visit, the length and time of day of visit and any changes from previous visit (see Appendix G for Log Book Sheet). Visitors felt there were no changes in the resident's cognitive status, length of visits or quality of visits from day-to-day and their responses were repetitive and uninformative. Visitors were reluctant to document quantitative data and the researcher's field notes reflect a realization that small changes in visit-to-visit go unnoticed by visitors until time had lapsed for reflection back on those days.

Finally, the status of the residents' cognitive abilities were difficult to quantify. Only one of the participating residents had been diagnosed with AD and

other participating residents had other forms of cognitive impairment. Family visitors did not always accept the diagnosis provided to them, and as a result the researcher was sensitive to the family visitors interpretations of the residents' conditions and did not pursue the need to acquire a definitive diagnosis of mild to moderate cognitive impairment. Instead, the researcher relied on unit coordinators to identify potential participants for the study and to confirm over phone the resident's cognitive status. The researcher's field notes indicate behaviours and conversations with the residents were consistent of those expected with someone with mild to moderate (early to middle stages) impairment. (Family visitors often felt there was no cognitive impairment, just "trouble hearing" or "getting words out that make sense" or "trouble participating in conversations.") The use of a Mini-Mental Status Exam (MMSE) score to determine the cognitive status of the residents was not provided to the researcher and was not pursued because it was found to be unimportant to this study.

Limitations to the Study

The novelty of participating in a study created excitement and a positive motivation in visits, possibly resulting in a Hawthorne type effect and changing the degree of satisfaction in the visiting experience (Clark, 1999). Hawthorne effect includes the notion that psychological stimulus such as being singled out and made to feel important will increase productivity and improve social relationships (Clark, 1999). It is possible that having a person, other than the primary visitor, take interest in the day to day lives of the resident was valuable to the visitors regardless of the final product; perhaps any activity would have had similar benefits. Having said this,

even if the relationship with the researcher was an influence, specific information on the life album process indicates that there is inherent value in the life album as a tool.

Second, interviewers were not the same person at Time 1 and Time 2 interviews. The two could differ in their interviewing techniques, causing some concern with issues of accuracy. At the same time, this can be seen as advantageous, since different questions were asked, giving greater opportunities for gaps to be filled.

Third, participant selection was based on very broad criteria, resulting in a heterogeneous group of participants. The differences between spouses and offspring can not be concluded to be representative of experiences by other visitors at Deer Lodge Centre or to visitors of residents in other PCHs.

Because the researcher established a rapport with visitors and residents and the nature of the intervention program involved a series of visits over the course of three months, there was a certain intimacy and friendship that developed over time. Visitors and residents shared information beyond what was needed for the study, and then the researcher withdrew. The effect of her withdrawal on families is not known and could have been difficult for some.

Summary

The value of creating life albums extended beyond the collection of resident's stories and materials placed into an album as a communication tool. Visitors appreciated the positive focus of the life album project. Although the life albums do not in any way change the situation of the resident's illness or aspects of having to live in the PCH, creation and use of life albums did provide a temporary positive focus and validation of who the resident was. The intervention program provided a

social support and the outcome was a tool that could cue residents to discuss positive aspects of life. Having said that, differences between spouse and offspring visitors lead to some interesting findings and discussion. The social support throughout the intervention program was a benefit to spouses. This finding suggests the need for finding continued roles and resources to support spouses of residents on a regular basis. On the other hand, the support to offspring and other extended family was related to relief to have someone else take an interest in the resident. The process acted as a type of respite in regular visits with the resident. Second, the life album as a tool provided a positive focus for visits and made for a memorable keepsake of the resident.

Chapter 6 Implications and Conclusions

The concept of persons with dementia needing to and being able to express themselves about who they are and what they need and want to remember is important to continue to investigate. Research that increases the awareness that people can and will benefit from hearing the stories of their elders with dementia is an important part of maintaining the social care of families.

Implications

Research has emphasized finding roles and supports for family visitors of residents in the personal care home (Dupuis, 2000; Killick, 2003; Thomas, 1996). There are differences between caregiving and visiting of spouses and offspring or other family members. Anecdotal evidence shows that all levels of the personal care home community including staff, residents and family appreciate life album work. However, this appreciation will not extend into program implementation unless research documents the benefits and effectiveness of life albums. With increasing fiscal restraint and health care reform there is a tendency for evidence based programming to be the norm, therefore, further research is warranted on the value of the life album as a social support. Creation of life albums led to sharing life events, social interaction and validation of who the resident was both for the resident and for informal caregivers. As Killik (2003) asserted, "We must also create opportunities for communication and creative expression and we may need to offer emotional support to support those who undertake this work" (p 18).

Implications for Future Research

First, the complexity of characteristics and heterogeneity of the participant group meant only descriptive and anecdotal evidence was available. Research that can extend to a broader generalizability is important. To conduct similar research with a focus on family roles, such as spouses, daughters or sons may provide valuable information on how life albums benefit family members differently. This research may have practical implications, as the life album process may be a creative way for developing a support group for spouses. Support groups for spouses have been shown to decrease burden felt and improve physical well-being of spouse caregivers of PCH residents (Dupuis, 2000; Zarit, 1997).

Second, this study resulted in an understanding of the experience of visitors in creating and using the life albums. However, future research warrants investigation to answer other questions. It would be instructive to know how creation of life albums differs from other intervention programs. How effective the life albums are, compared to other intervention programs, should also be studied. Conducting such research would require a comprehensive triangulation of data and incorporation of some form of quantitative analysis, perhaps linked to the recent instruments being developed and tested on caregiver well-being and grief assessment (Marwit, & Meuser, 2002). Further study of the life album may find that there are characteristics unavailable through other supportive programs that make the life album a unique, inexpensive and creative way to support, and decrease emotional burden of, caregivers.

Third, the results confirm and further define how persons with dementia and their families can communicate and share stories. This contributes to the conceptual developments of reminiscence for those with dementia and to the theoretical of social exchange and restoring the balance of reciprocity as theorized by Sabetelli and Sheehan (1993). Future investigations may lead to the creation of a theoretical framework of reminiscence that would in turn contribute to the development of tools for assessing the outcomes of life story work with persons with dementia.

Practical Implications

Practically, the tool of life albums has been further refined and more information has now been collected on the process of creating a life album. The life album as a tool can be used by professional staff who have patients with dementia and can benefit from the understanding of the process and content outlined in this study. Creation and use of life albums may have a place in caregiver support groups and in youth leadership or volunteer initiatives. As interdisciplinary care teams grow in PCHs there is a role for professionals, such as Professional Home Economists, to support the caring of visitors and family members along with the residents.

Previous investigation of the practical application of life story work in PCHs warn against any one professional staff creating life albums exclusively, because of the potential for burn-out and uniformity (Goldsmith et al.; Killik, 2003; Murphy, 1994). However, professionals such as home economists, recreation therapists or social workers can facilitate programs and development of resources for volunteers and family members to undertake life album creation to support social aspects of care in PCHs.

Administrators of PCHs are changing the principles and approach to care to include more integrated and interdisciplinary teams. It is important to recognize that family members and informal supports of residents need some special attention. The Eden Alternative philosophy of care stresses that life in a PCH should not focus on the illness of the resident but on alleviating feelings of boredom, loneliness and helplessness (Thomas, 1996). Deer Lodge Centre, although not an "Edenizing" care home, did incorporate components of these principles into the care their residents receive. The life album project seems to be one way that would encourage visitors to listen and create something positive from residents' stories. In order for this to occur staff time and assistance is needed. Perhaps hiring a home economist as a staff person could provide resources to focus on integrating families into the daily life of personal care home care. The need for a professional role in PCHs that support and provide resources for the integration of family visitors into the care team is becoming more prevalent and is supported by this research.

Conclusions

This study resulted in the development of six life albums for residents who had dementia and assessed the effects of using the life albums during visits with family members. The creation and use of the life albums offered several practical, anecdotal benefits. Of particular relevance included the affirmation that persons with dementia living in PCHs have interesting and valuable stories to share with others and that for the six residents who had life albums created this was a valuable experience for family visitors. Another key finding was that spouse and offspring visitors benefited differently from the life album process.

The creation of the albums provided an opportunity for residents to express themselves and for families to understand the residents' current perspectives on their lives. The process and use of life albums allowed the visitors and residents to review life events within a social setting that did not focus on disability but rather on the abilities of residents to share their stories. The content and creation of the albums can be for anyone, with varying levels of details focusing on what works best to promote and give voice to the resident. Based on the findings of this study, there are three main conclusions to be emphasized.

First, life albums were enjoyable to make for the researcher, residents and visitors who participated in the process. There were aspects of historical, archival interviewing and Internet research in gathering of materials. These materials were then placed into a life album much in the same way as would be done in the hobby of making scrapbooks. There is potential for this type of project to be incorporated into a social support group for spouses or offspring or intergeneration and volunteer program with schools (Alzheimer's Society of Canada, 2003; Dupuis, 2000; Thomas, 1996).

Second, the life albums provided a focal point on which families, professionals and residents can work and socialize together. The life album as a communication tool and focal point encourages a balance of social exchange by providing a tool which encouraged visitors to adapt to the abilities of the person with dementia (Goldsmith et al., 1997). The life albums are a positive reflection on the resident's life. More importantly, the life albums were created together with the resident during a time when families have focused on the things the residents cannot

do. The album unlocks past memories and visually illustrates that the resident is capable of sharing valuable stories and that “there’s life beyond the illness” (Goldsmith et al., 1997). This study reaffirms Killik’s work which emphasizes the need and benefits of “memorializing [and] capturing what the person with dementia gives us in words, gestures, and movements so that it is not lost...It preserves the moment for the person, relatives, friends, and staff” (2003, p.18).

Third, there were differences in the process for spouse visitors than for offspring and other visitors, which has implications for the focus of future intervention programs and selection of participants. If life album programs are instituted into PCHs, it may be of value to have separate spouse visitor groups from offspring visitor groups, as spouses wanted to be very involved and enjoyed the process as much as the researcher and resident. Offspring on the other hand benefited from having the tool, but they felt some respite in their visiting schedules during the intervention program because another person (the researcher) was taking an interest in the resident and visiting regularly.

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APPENDIX A

Time 1 Interview Schedule

TIME 1 INTERVIEW SCHEDULE

1. How do you feel about _____'s condition?
3. What is your relationship with _____ like? Probes: length of time in caring role; nature of visiting experiences i.e. caregiving/visiting – domain of care
4. What are the stresses associated with visiting _____ at Deer Lodge?
5. What are the satisfactions associated with visiting _____ at Deer Lodge?
6. Would you walk me through a typical visit?

a particularly bad visit

a particularly good visit
7. What would you change about your visiting experiences if you could? (Possible probes: space, activities, availability of things to do, what kind of things?, more social interactions with different people?)
8. What kind of expectations do you have for your visits? (Probe if these expectations are fulfilled)
9. Who helps you with _____? (Possible probes: staff, other family members, resident, other residents).
10. What needs do you have at this time? (Probe for reason of each need)
11. What are some _____'s favorite things to do? Do you enjoy these things as well?
12. Have we missed anything?
13. Do you have any questions for me?

APPENDIX B

Time 2 Interview Schedule

TIME 2 INTERVIEW SCHEDULE

[The following questions are to be reviewed briefly with all participants. These questions will be somewhat repetitive as visitors were asked these questions in Time 1 Interviews]

1. How do you feel about _____'s condition?
3. What is your relationship with _____ like? Probes: length of time in caring role; nature of visiting experiences i.e. caregiving/visiting – domain of care
4. What are the stresses associated with visiting _____ at Deer Lodge?
5. What are the satisfactions associated with visiting _____ at Deer Lodge?
6. Would you walk me through a typical visit?

A particularly bad visit

a particularly good visit

7. What would you change about your visiting experiences if you could? (Possible probes: space, activities, availability of things to do, what kind of things?, more social interactions with different people?)
8. What kind of expectations do you have for your visits? (Probe if these expectations are fulfilled)
9. Who helps you with _____? (Possible probes: staff, other family members, resident, other residents).
10. What needs do you have at this time? (Probe for reason of each need)
11. What are some _____'s favorite things to do? Do you enjoy these things as well?
12. Have we missed anything?
13. Do you have any questions for me?

Life Album Questions

1. Have you seen the life album and had a chance to visit _____ (resident) and look at the life album together with him/her? Can you tell me about those visits?
2. How many times have you looked at the life album? With who did you share the life album?
3. Can you describe some of your experiences throughout these past three months with the creation of the life album? Probe: How did you feel you contributed to the life album process? What was _____ (the residents) participation in the process like?
4. Can you tell me some of your thoughts on the life album? (benefits or opportunities for improvement)
5. Tell me about any benefits or rewards that came out of creating and/or using the life album? Were there any things that the life album changed in your visiting experience? If so, what?
6. What, if any, were the stresses or costs associated with participating in this project? (i.e. time, physical exertion, emotional stress)
7. What, if any, were the stresses or costs associated with using the life album in visits?
8. How might you use the life album in the future?
9. Do you think there will be any drawbacks to in the future related to this study? Probe: The researcher will not be visiting regularly anymore, will this be a stress on the resident or yourself?
10. Is there anything else that you would like to share related to this project?

APPENDIX C

Ethics and Research Access Approval



THE UNIVERSITY OF MANITOBA

OFFICE OF THE PRESIDENT
Office of Research Services

244 Engineering Building
Winnipeg, Manitoba
Canada R3T 5V6

Tel: (204) 474-8418
Fax: (204) 261-0325

APPROVAL CERTIFICATE

14 December 2000

TO: Johanna A. Gillis (Advisor C. Harvey)
Principal Investigator

FROM: Karen Grant, Chair
Joint-Faculty Research Ethics Board (JFREB)

Re: Protocol #J2000:031
"Creating Life Albums with Personal Care Home Residents who have
Dementia: Assessing the Impact on Selected Family Visit
Interactions"

Please be advised that your above-referenced protocol has received human ethics approval by the **Joint-Faculty Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.



DEER LODGE CENTRE

REQUEST FOR RESEARCH ACCESS

I. Identification: Please print or type

Complete Box A

A. Title of Study: Creating Life Albums with Personal Care Home Residents Who Have Dementia: Assessing the Impact on Selected Family Visit Interactions

Principal Investigator:

Johanna Anneke Gillis

Address: 209 Human Ecology Bldg.

Postal Code:

R3T 2N2

Telephone: Home

Work (204) 474-9831

(204) 474-8311

Other Members of Team:

Name: Dr. Carol Harvey, Department of Family Studies - Thesis Advisor

Name: Dr. Lorna Guse, Faculty of Nursing - Thesis Committee Member

Name: Dr. Douglas Brownridge, Department of Family Studies - Committee

Complete Box B, C or D as appropriate

B. Student

Student: Johanna Anneke Gillis
Name

Signature, _____

Phone No. _____

Faculty Advisor: Carol D.H. Harvey
Name

Signature _____

Phone No. _____

Educational Institution: University of Manitoba

Faculty/Dept. & Address: Graduate Studies: Department of Family Studies

Course For Which Research Required: Thesis

Deer Lodge Centre
REQUEST FOR RESEARCH ACCESS

2

C. Deer Lodge Employee

Department: _____

Supervisor: _____

D. Other

Organization: _____

Position Held: _____

Supervisor: _____

Telephone: _____

II. Time Lines

Duration of Project: January 2001 – October 2001

Anticipated Start Date: January 8th 2001 End Date (data collection): May 2001**III. Significance of study and benefit to Deer Lodge and/or patients/residents.**

The Purpose: The purpose of this qualitative research is to examine the relationship between the development of life albums for six personal care home residents with dementia and selected aspects of visitor interaction with the residents. A life album is a collection of photographs, memorabilia, archival information, magazine and library material that are compiled into a loose-leaf book to reflect the resident's life story. The objectives of this research focus on the comparison of family members' perceptions of the quality of their visits with their personal care home resident with dementia before and after the development of life albums.

The benefits: Often visiting residents with dementia is burdensome and difficult. Receiving support, even for a limited time can help family members to gain perspective and alleviate some of the burden. All participants will have a life album as a permanent keepsake of the resident's life and participation in this project. Deer Lodge Centre will be thanked and named in all dissemination of findings.

IV. Resource Requirements

1. What contacts will be required with staff? (List staff members with title and amount of time required.)

Minimal contact with staff will be required. Initially Judy Inglis and Cathy Baxter will be asked to help select possible participants residing at Deer Lodge Centre. The Unit Coordinators with possible participants will be asked to make initial contact

Deer Lodge Centre**REQUEST FOR RESEARCH ACCESS**

3

with family. Once data collection begins no staff time will be required – however, a summary of the results will be provided to all interested staff.

2. List Centre supplies and equipment that may be required. Describe plans to cover expenses.

The Jack MacDonell Scholarship from the Centre on Aging is funding the materials for this research. All other costs for life album material will be the responsibility of the researcher. The use of a photocopy machine would be greatly appreciated.

3. List space requirements.

Office space with a locked filing cabinet to keep life albums, transcripts and tape recorded interviews confidential and safe at Deer Lodge Centre is requested. In addition, a telephone number where participants can leave a message requesting information regarding the project would be an asset.

Add additional page(s) as required.

See Attached University of Manitoba Ethics Review Submission

TO BE COMPLETED BY DEER LODGE CENTRE:

Dec 19th 2000
Date

Dec. 18, 2000
Date

Dec 18, 2000
Date

Jan 3 2001
Date

Approval

Designated DLC Manager

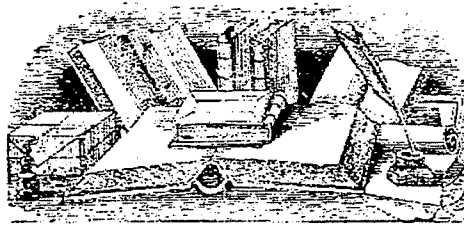
Faculty Advisory (Students only)

Signature of Administrator

Deer Lodge Centre Administration

APPENDIX D

Research Information Letter



Dear Family,

You and your family member living at Deer Lodge Centre are invited to participate in a research project. The focus of the research is life albums. Our goal is to understand your perception of using a life album when you come to visit your family member here at Deer Lodge Centre.

WHAT IS A LIFE ALBUM?

A life album is a collection of memorabilia, photographs, poetry, archival and other materials that capture the lives of an individual in a photograph book format. A life album is an information source and a positive look at one's life.

WHO WILL MAKE THE ALBUM?

The life album will be created by Anneke Gillis, student member of the research team. Anneke will ask you and your family member who lives at Deer Lodge to help create the life album. You will be asked to share memorabilia and any photographs related to your family member's life experience. You do not need to have memorabilia or photographs in order for a life album to be created. Anneke Gillis will work with whatever material she has to make your family member's album unique.

WHAT WILL YOU BE ASKED TO DO?

You will be asked to be interviewed by Anneke. Then she will visit your family member 10-15 times. The goal of these visits is to reminisce and to share stories with your family member. From the memories collected, Anneke will create an album that represents your family member's life. Once again, you will be asked to be interviewed after you have had a chance to use the life album in your visits with your family member.

You would participate in four parts of the project:

1. You would note some things in a logbook every time you visit. The date, length of visit and some questions about the visit will be included in the logbook entries. Each entry takes 1 – 2 minutes.
2. You will be interviewed by Anneke, who will ask about visits at Deer Lodge Centre. It will take about an hour, and it will be audiotaped.
3. You will be asked to visit twice using the life album with your family member. This will be about six weeks after your interview.
4. You will be interviewed again. Anneke will ask about what your visits were like when using the life album. It will take about an hour.

WHAT WILL YOUR FAMILY MEMBER BE ASKED TO DO?

Approximately twice a week for six weeks your family member will visit with Anneke. She will talk to your family member and encourage reminiscing. She will ensure that no undue stress will occur. If your family member does not feel like reminiscing then the visit will focus on other activities. During these visits Anneke will collect some information in order to create a life album that represents your family member's life.

WHAT IT'S IMPORTANT TO KNOW:

Your tape recorded interviews are confidential. Only the researchers will use the information gathered in the interviews and logbooks. The information will be stored in a locked filing cabinet.

Your participation in this project will not harm you or your family member. However, it is important to know that sometimes unhappy and difficult memories might arise when remembering the past. Support will be available should this occur.

Participation in this study is voluntary. You and your family member may withdraw at any time without affecting the services you and your family member receive from Deer Lodge Centre.

The life album will be given to your family member at the end of the research. Any information in the life album will be kept private unless both you and your family member want to share the stories with other people.

Your interview tapes can be returned to you after the research is complete. Approximately a year from now, the tapes and interview notes will be destroyed.

Your participation and that of your family member is very important. We hope you will join this interesting research project.

WHAT YOU WILL GET:

1. A life album to use and keep
2. A chance to join an interesting research project
3. A summary of the research when it is complete

If you have any questions you may call either of us.

STUDENT:

Anneke Gillis, PHEc

H: 4

W: 474-9831

e-mail: umberten@cc.umanitoba.ca

ADVISOR:

Carol D.H. Harvey, Ph.D., PHEc, CFL

Department of Family Studies

University of Manitoba

Ph: 474-9794

e-mail: charvey@ms.umanitoba.ca

APPENDIX E

Consent Letter - Visitor

**Creating Life Albums With Personal Care Home Residents Who Have Dementia:
Assessing the Impact On Selected Family Visit Interactions**

Family Member's Consent Form

I understand that I am being invited to participate in a project that will investigate my visiting experience with my family member who resides at Deer lodge Centre.

I have been informed that my participation is voluntary and that I can refuse to answer any questions I may be asked. As well, I may stop the interview at any time at my discretion without prejudice or consequence.

I understand that on completion of this study I will be provided with a written summary of the findings.

I am aware that if I have any questions about this study or its conduct I may contact the researchers, Anneke Gillis at _____ Dr. Carol Harvey at _____

I have also been informed that this research project has been examined and approved by the Joint Faculty Research Ethics Board at the University of Manitoba and by the Collaborative Research Unit at Deer Lodge Centre. Any comments or concerns I may have regarding the procedure may be reported to the Director of the Collaborative Research Unit at Deer Lodge Centre, Judy Inglis at 831-2107 or to the Human Ethics Secretariat at the University of Manitoba at 474-7122.

I understand that participation in this project will not harm me or my family member in any way.

I am aware that in some instances, painful or difficult memories may arise and it is my choice to acknowledge them or not to discuss them. Help will be provided should I choose to pursue these memories.

Having reviewed this statement, I agree to participate in this study.

Name: _____ Signature: _____

Date: _____ Witness: _____

APPENDIX F

Consent Letter – Resident

**Creating Life Albums With Personal Care Home Residents Who Have Dementia:
Assessing the Impact On Selected Family Visit Interactions**

Proxy Consent Form for Resident

I understand that I have been asked to sign this form on behalf of my family member who resides at Deer Lodge Centre, I agree my family member will participate in 10-15 visits and life album sessions. The goal of the visits is to reminisce and to create a life album based on my family member's life.

I have been informed that the participation of my family member living at Deer Lodge Centre is voluntary. My family member may refuse to visit with Anneke Gillis, student researcher, at any time without prejudice or consequence.

I understand that on completion of this study the life album will be my family member's to keep and use.

I am aware that if I have any questions about this study or its conduct I may contact the researchers, Anneke Gillis at _____ Dr. Carol Harvey in the Department of Family Studies, University of Manitoba, at 474-9794.

I have also been informed that this research project has been examined and approved by the Joint Faculty Research Ethics Board at the University of Manitoba and by the Collaborative Research Unit at Deer Lodge Centre. Any comments or concerns I may have regarding the procedure may be reported to the Director of the Collaborative Research Unit at Deer Lodge Centre, Judy Inglis at 831-2107 or to the Human Ethics Secretariat at the University of Manitoba at 474-7122.

I understand that participation in this project will not harm my family member in any way.

Reminiscence sessions will focus on positive life events. However, I am aware that in some instances painful or difficult memories may arise and it is mine or my family member's choice not to discuss them.

Having reviewed this statement, I agree to the participation in this study of my family member residing at Deer Lodge Centre.

Name of resident: _____

Name of proxy: _____ Signature: _____

Date: _____ Witness: _____

APPENDIX G

Coding Matrix

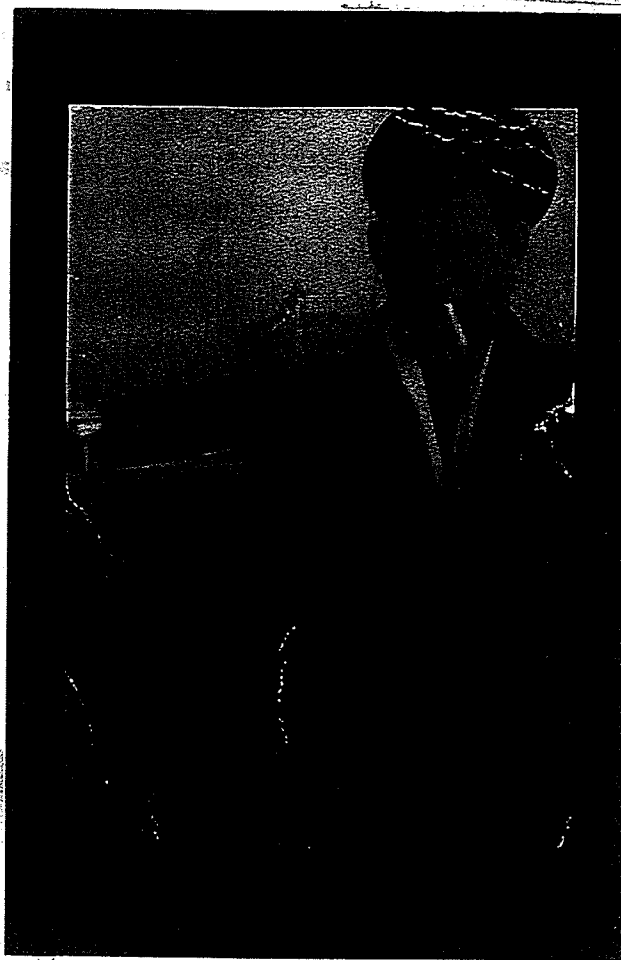
Coding Matrix for Time 1 and Time 2 Interviews

Category	Visitor		Resident	
	Time 1 (Baseline)	Time 2 (with Album)	Time 1 (Baseline)	Time 2 (with Album)
Benefits (Rewards)				
Psychosocial	<i>Reflection on benefits of visiting to self socially and psychologically (personal well being)</i>	<i>Perspectives of benefits from album for self – socially and psychologically (personal well being)</i>	<i>Benefits of visits to resident as perceived by visitors</i>	<i>Benefits of life album to resident as perceived by visitor</i>
Physical	<i>Perspectives on benefits of visiting to self in terms of physical health</i>	<i>Perspectives of benefits from album for self – in terms of physical health</i>	<i>Benefits of PCH experience and visiting to residents physical well-being</i>	<i>Benefits of life album intervention and tool to physical well-being.</i>
Costs				
Psychosocial	<i>Perspectives of loss and costs associated to personal and social well-being</i>	<i>Perspectives of loss and costs to being involved in life album project and of using life album</i>	<i>Visitors' perspectives of costs to resident of visits in PCH</i>	<i>Visitors' perspectives of costs to resident of life album sessions and using life albums</i>
Physical	<i>Perspectives of costs to physical health because of visiting routine in PCH</i>	<i>Perspectives of costs to physical health because of involvement in life album process</i>	<i>Visitors' perspectives on costs of PCH experience and visiting to residents physical well-being</i>	<i>Visitors perspectives on costs of life album sessions and using life albums on physical well-being of residents</i>

APPENDIX H

Exhibits

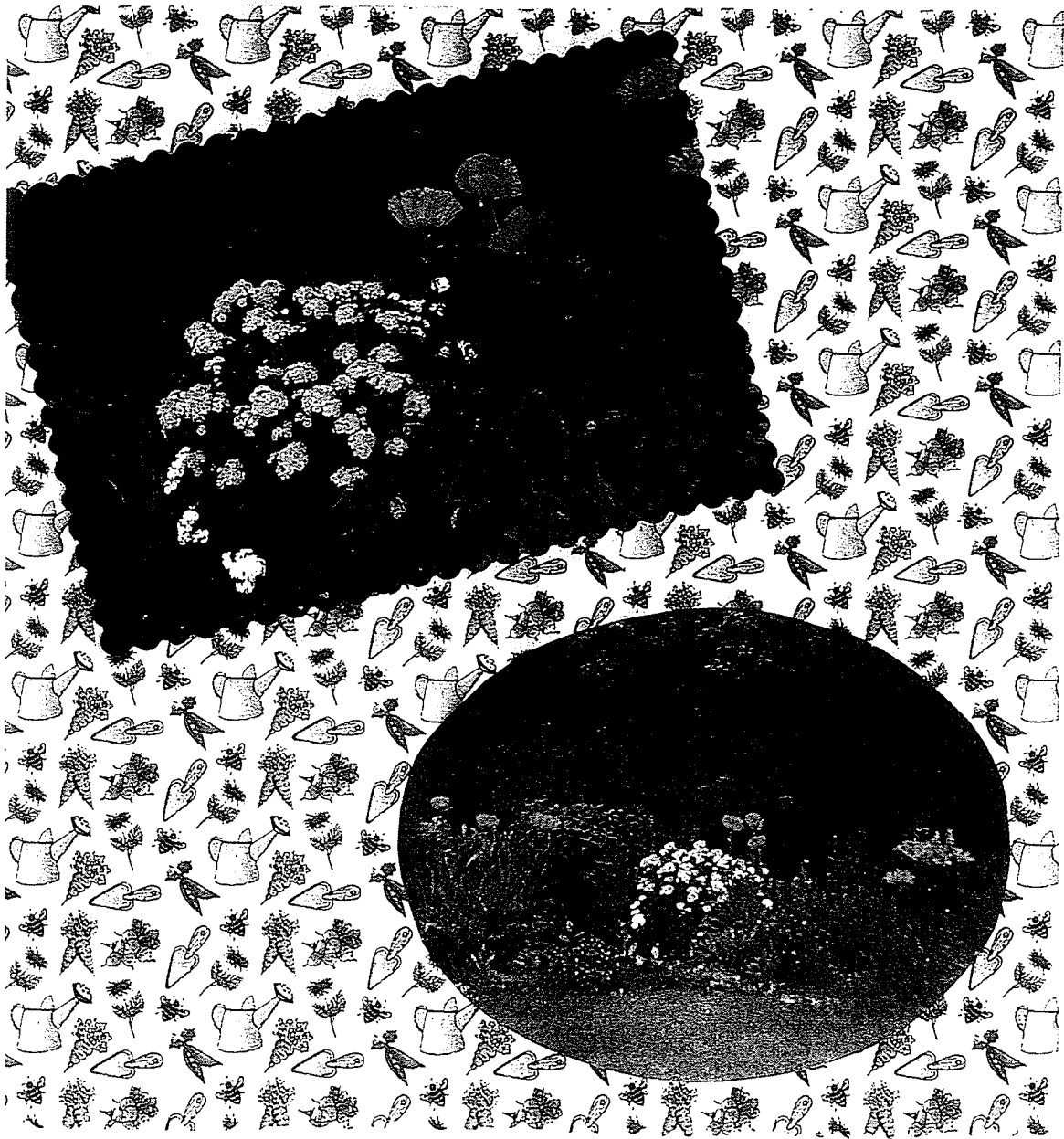
Please note that the exhibits compiled in this appendix are photocopied from the original life albums and have been modified. All names referenced on the page have been omitted in order to maintain confidentiality.



✧ A Life Album ✧

Exhibit H1

The Beautiful flower gardens at Hillside are tended to by
The grass cutting was → job...



GARDEN DAYS...

The proud father of six...

*"We have five girls and a boy we
picked up along the way...
couldn't ask for better!"*



Exhibit H3-1

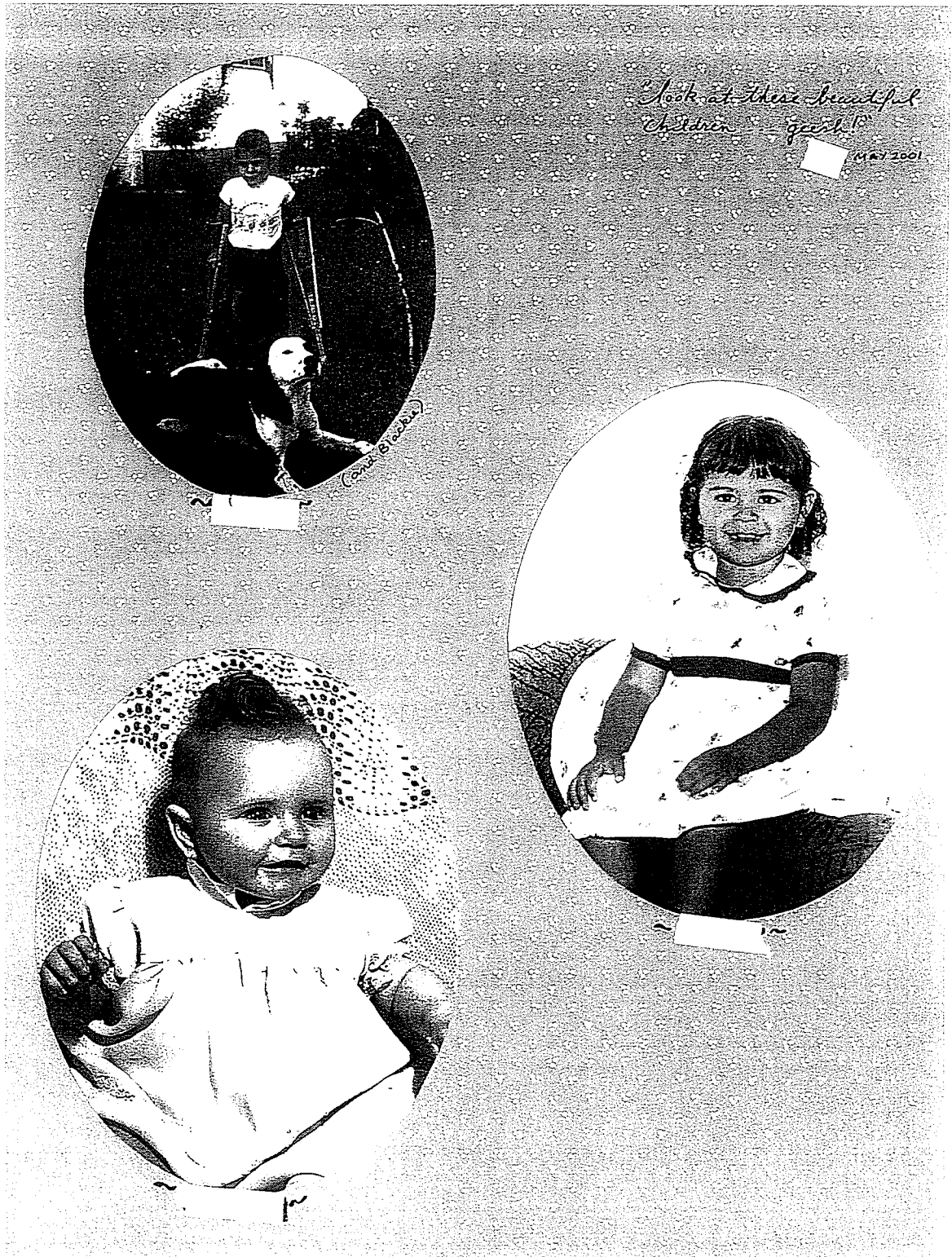


Exhibit H3-2

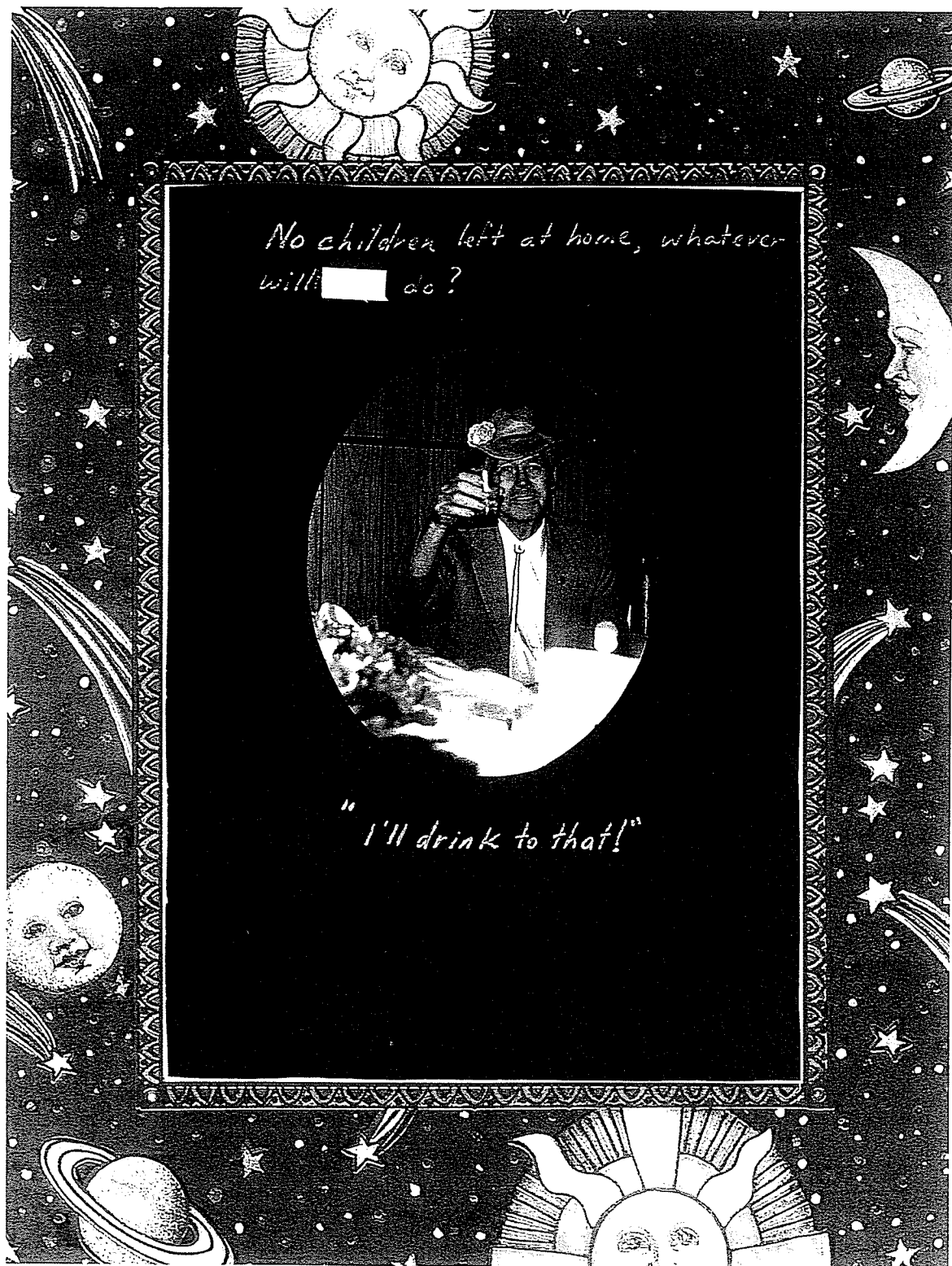


Exhibit H4

Welcome Home Picture
 1945
 taken in beautiful Netley, Manitoba

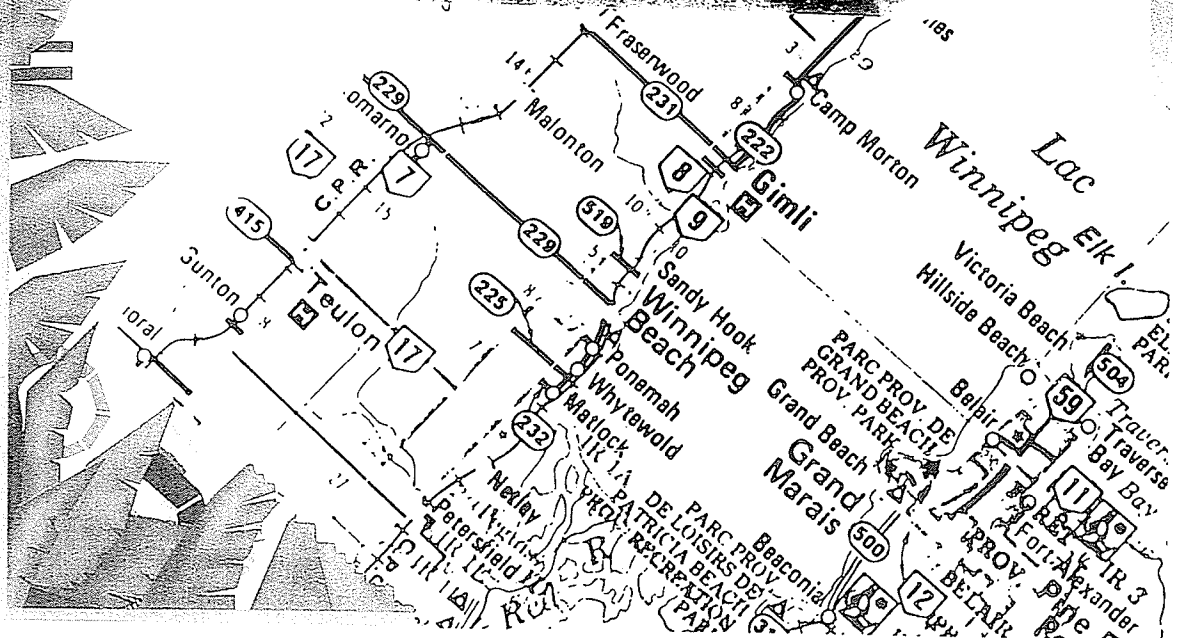


Exhibit H5

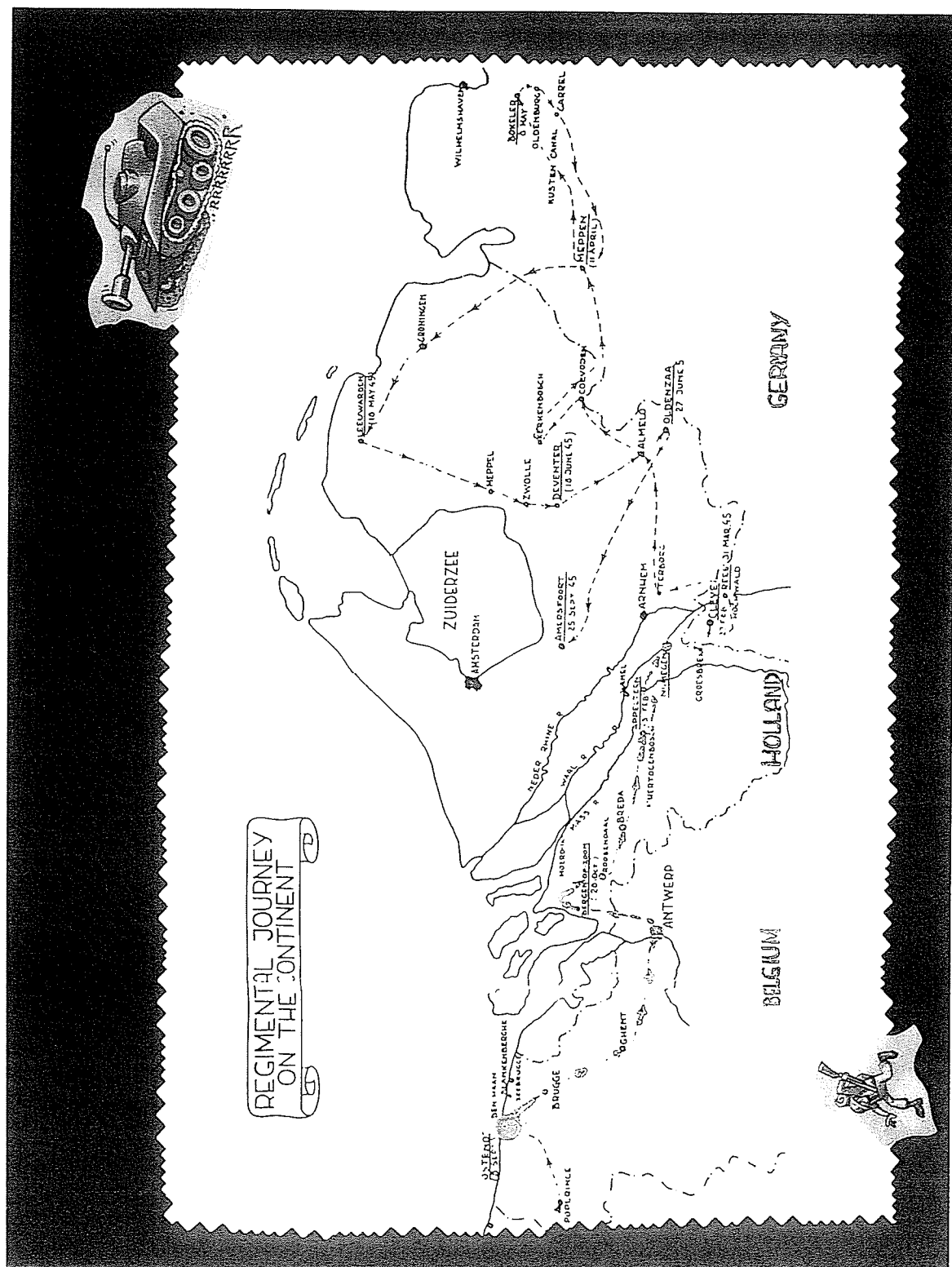


Exhibit H6

WWII

These were the days that the boys of Canada were eager to sign up for duty and was no exception. He had a recent wrist injury that had developed into a bone infection and resulted in surgery that would keep him from being accepted in the Airforce and in the Army. After his wrist had healed considerably, he once again tried to join the WWII cause and was successful in joining the Navy.

signed up for service with the H.M.C.S. CHIPPAWA Navy training program in 1943. He had a short training before he was sent to sea ~ This map shows many of the places that i convoys took him...

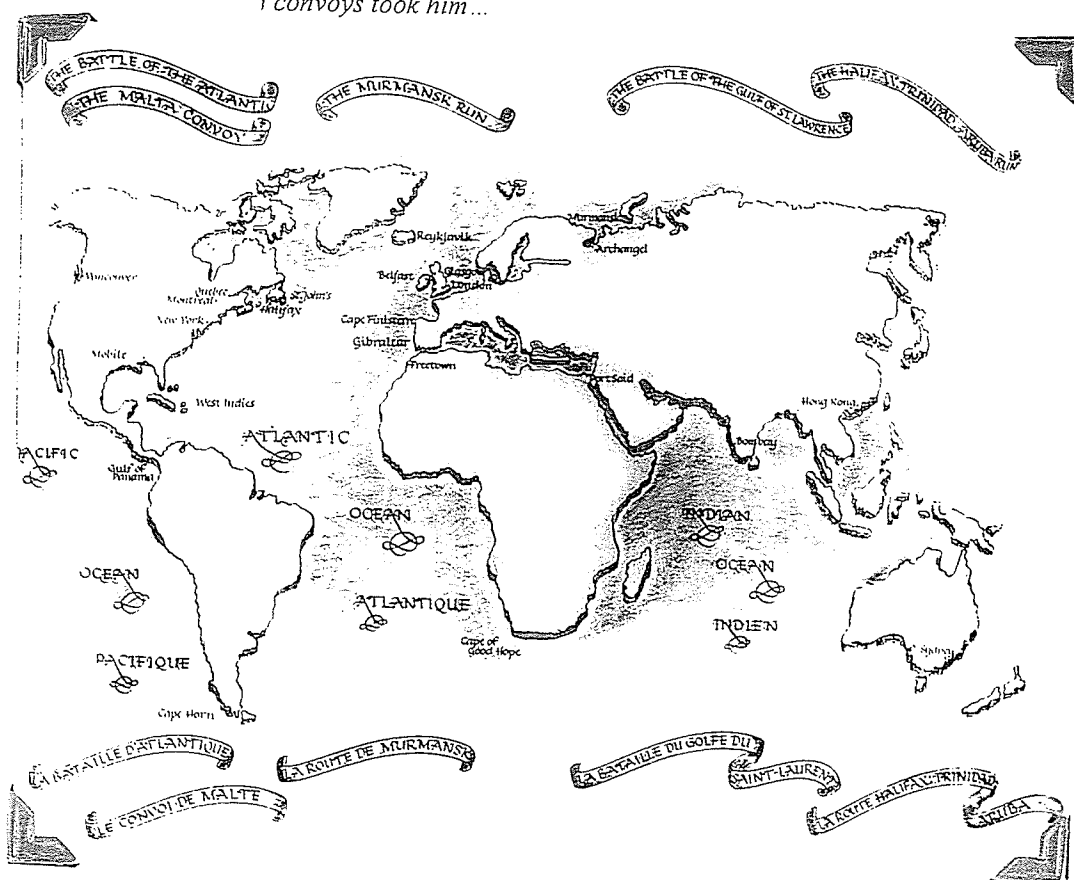
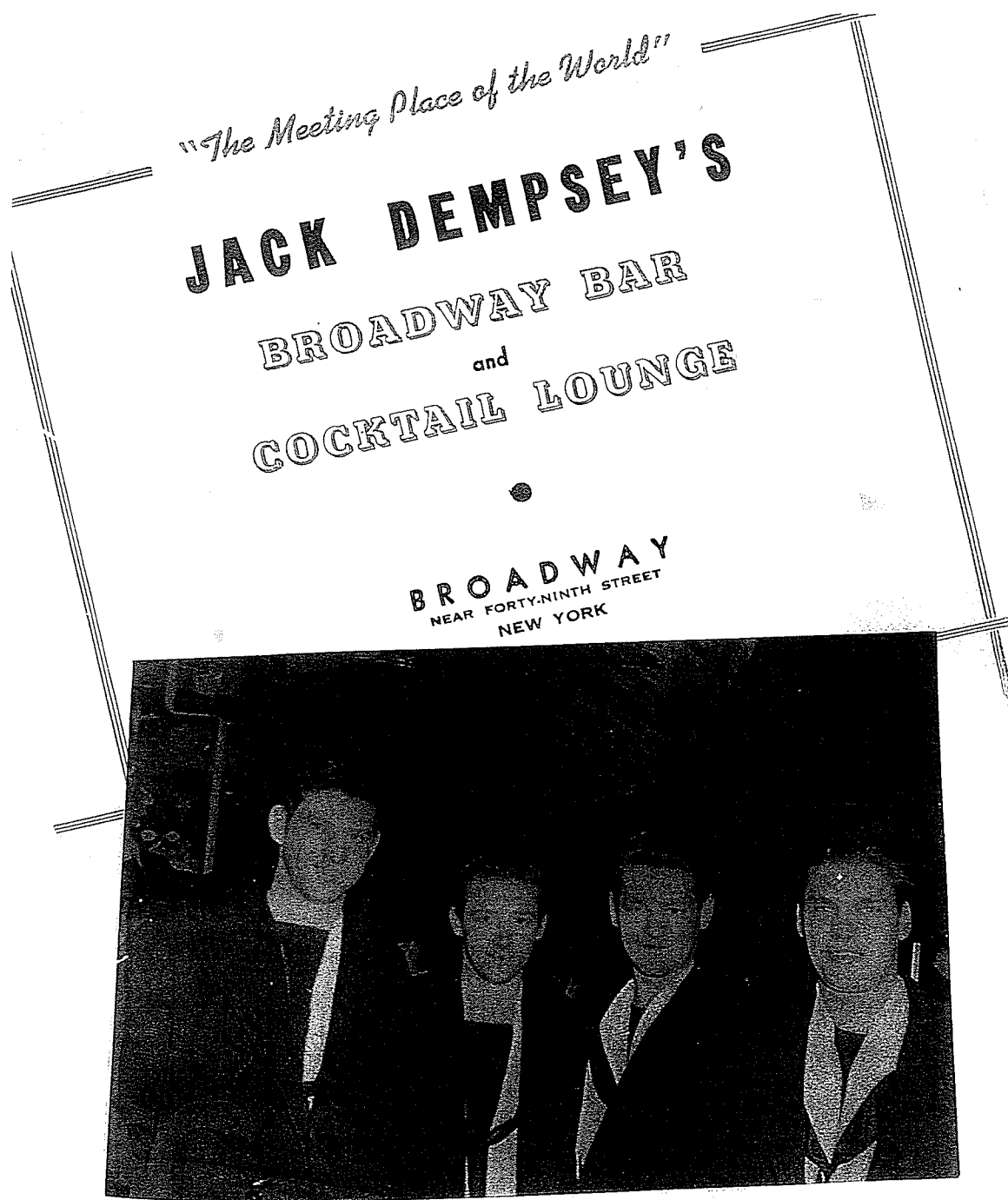


Exhibit H7



What do young navy men who are big sport fans do when they're on leave and away from home? They go out boozin' to Jack Dempsey's Broadway Bar and Cocktail Lounge. Jack Dempsey was the Heavy Weight Champion of the World and was a big fan...

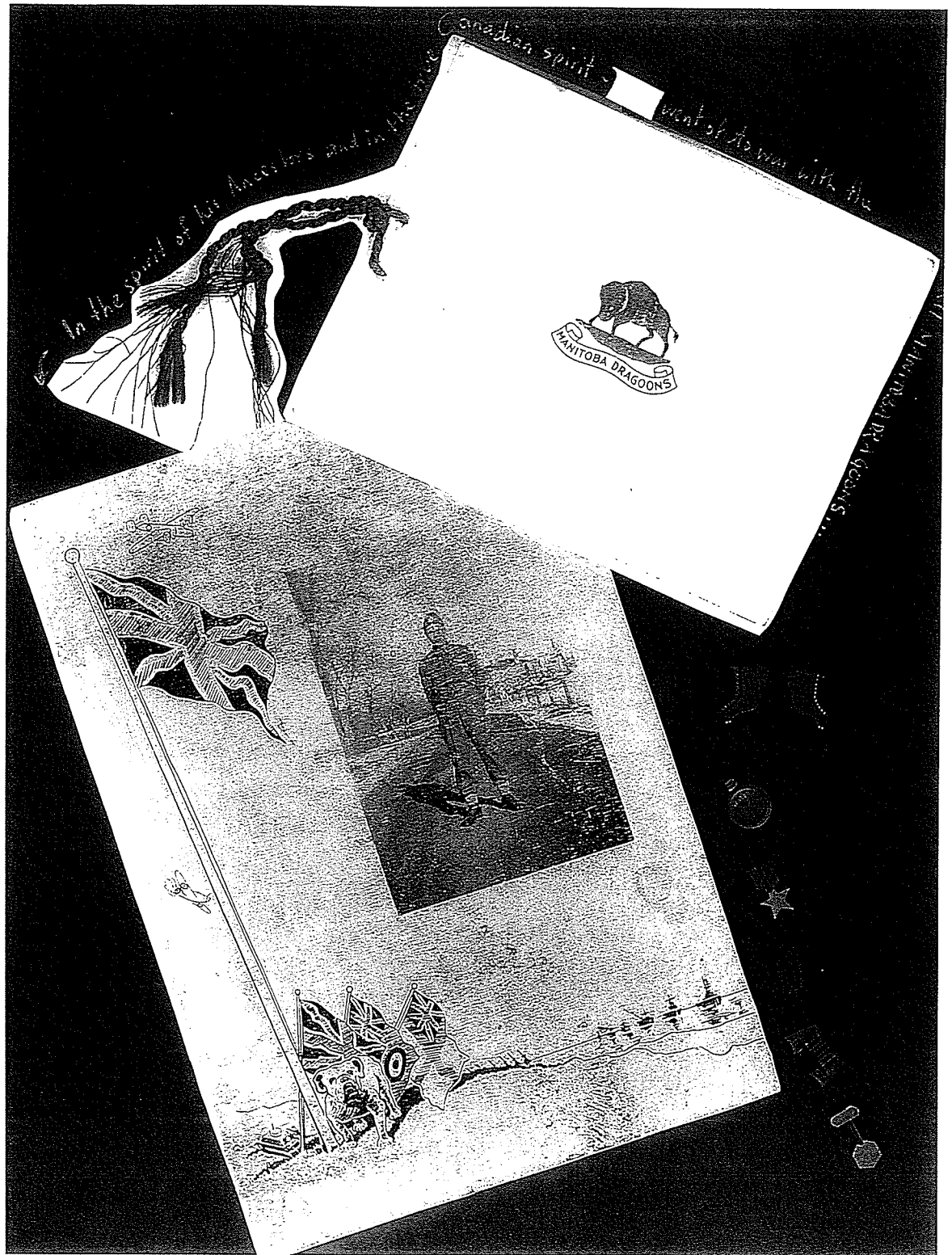
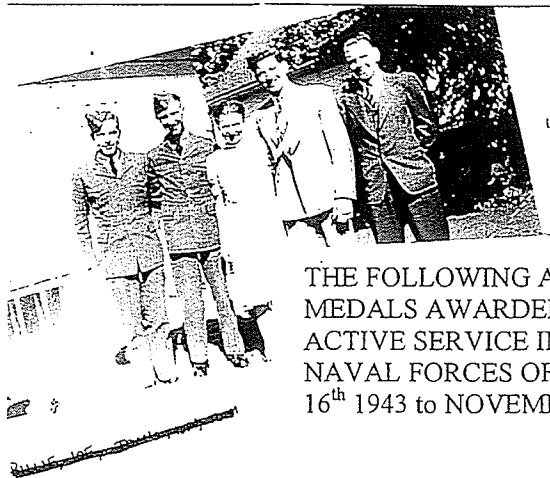


Exhibit H8-2



THE FOLLOWING ARE A SAMPLE OF
MEDALS AWARDED TO [REDACTED] FOR HIS
ACTIVE SERVICE IN THE CANADIAN
NAVAL FORCES OF CANADA FROM JUNE
16th 1943 to NOVEMBER 6th 1945...



The Atlantic Star



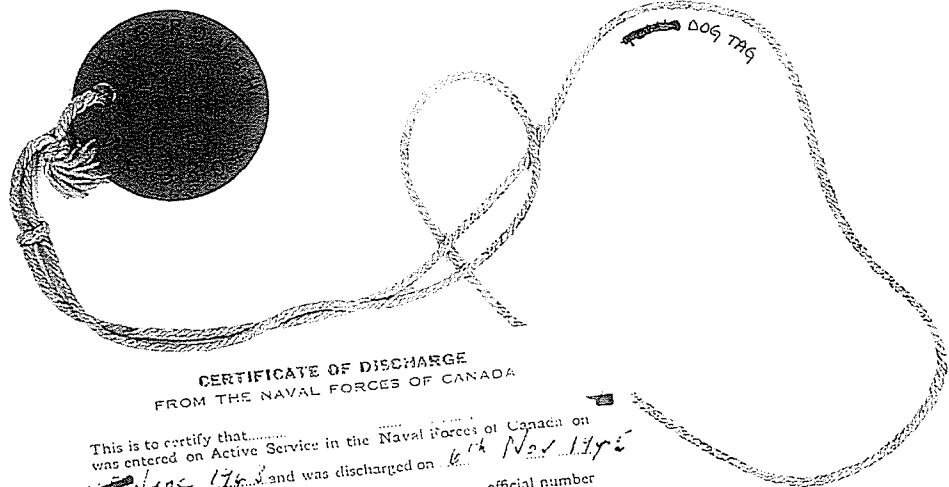
The 1939-1945 Star



The Burma Star ~



Clasp representing eligibility for the Pacific Star



**CERTIFICATE OF DISCHARGE
FROM THE NAVAL FORCES OF CANADA**

This is to certify that [REDACTED] was entered on Active Service in the Naval Forces of Canada on [REDACTED] and was discharged on 6th Nov 1945
with the rate of [REDACTED] official number [REDACTED]

for the following reason:

Signature of Dischargee:

M.C.S. [REDACTED]

[REDACTED]

[REDACTED]

Commanding Officer

C.N.S. 1711-10-M-245 (1/20) C.N.S. 1570-S, 2341

December 23, 1945

... came from a family of all sisters so she was
delighted to have a son ~

"HIP HIP HOORAY!
HIP HIP HOORAY!
IT's A BOY"



*The proud first time
parents...*



Exhibit H10

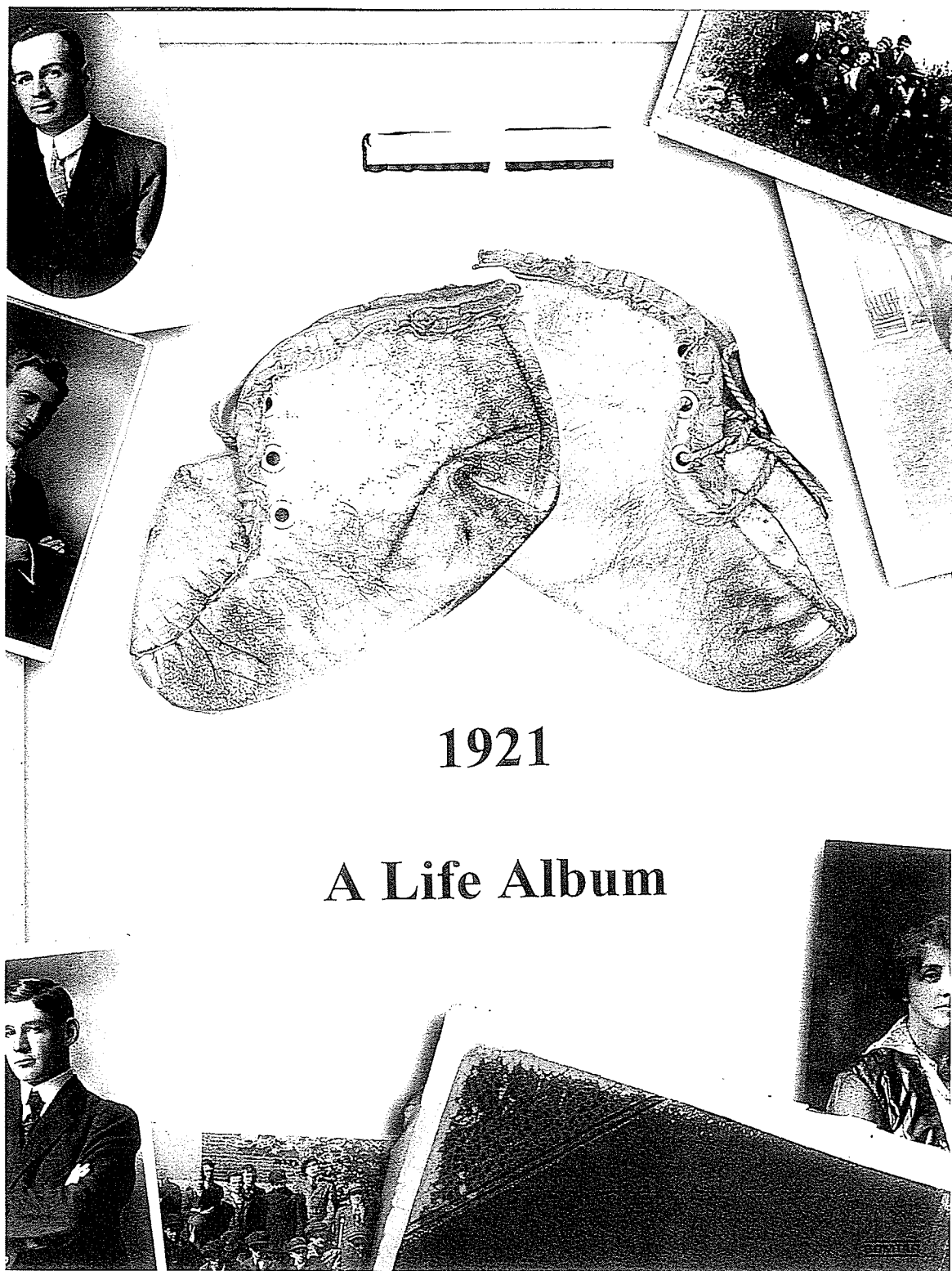
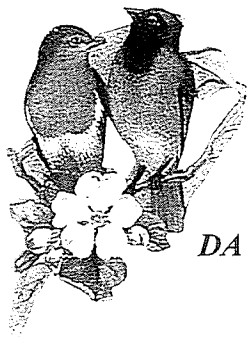


Exhibit H11



AUGUST~ SEPTEMBER ~ OCTOBER 1954

DAY 1:

is working at the Maternity Pavilion,
General Hospital

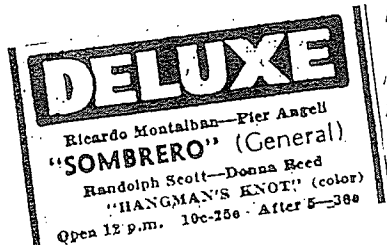
is a taxi cab driver who is dropping someone
of at the Hospital. He then goes about his regular
routine of asking one of the girls out for coffee...
today is turn ~ reluctantly agrees, not
quite sure about yet mostly because he
appears to be TOO nice!



DAY 6:

and are dating... as a matter of fact,
they're about to go see a movie at the DELUX,
West Kildonan Theatre. While in the parking lot,
pulls out a ring and asks, "Will you marry
me?"

has no idea what movie they see!



WINNIPEG FREE PRESS, SATURDAY, SEPTEMBER 25, 1954



WEEK 7: OCTOBER 1954...

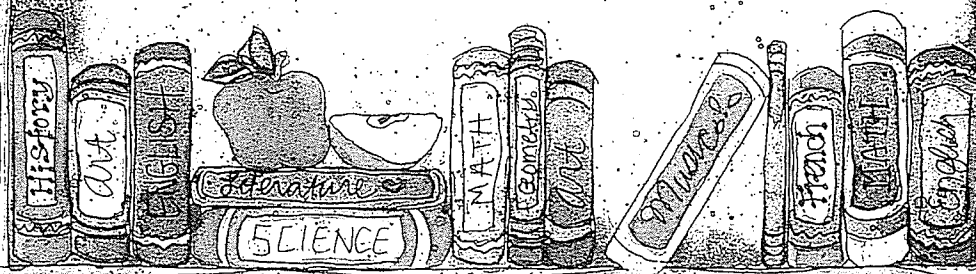
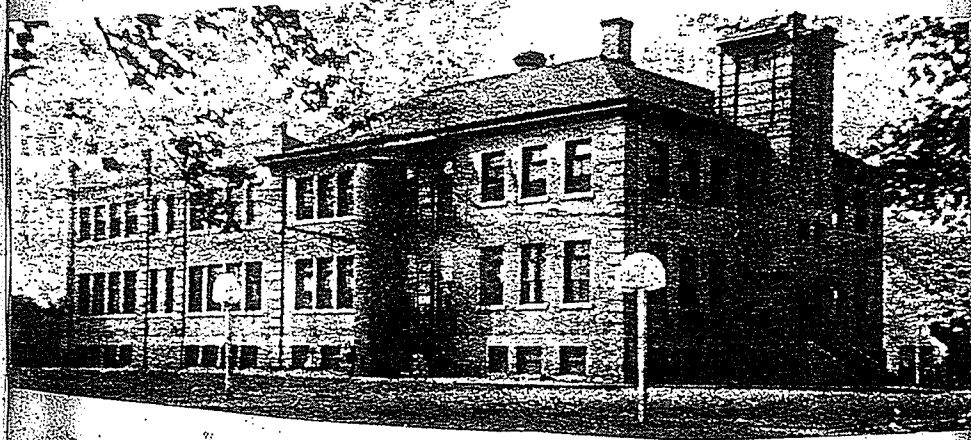
and are joined in Holy matrimony.

was a catch because he had his own house, he was a
hard worker, he was tall with blue eyes and he was so kind
and respectful... was a real catch because she was
young, beautiful, fun and energetic and she had gorgeous
legs.

SCHOOL DAYS

■ went to Glenwood elementary school in St. Vital. ■ also went to Glenlawn Collegiate for a year before he decided it would be better to go out into the workforce. Today Glenwood School and Glenlawn Collegiate are still in operation.

In his grade 11 year he decided to go work for Burn's Meat Packing plant... a decision that would later result in a lifelong career.



THE ATTENTION OF ALL TEACHERS IS CALLED TO THE FOLLOWING:
 Sub-section "k," Section 197, Manitoba Public Schools Act.
 It shall be the duty of every teacher to report to the Department of Education and to the local Inspector of Schools for the Department of Education as the case may be, when taking leave of absence from the school, giving post office address of the school and when resigning from the school, giving post office address of the school and when resigning from the school.

GRADED SCHOOLS
 THIS REGISTER MUST NOT BE TAKEN FROM THE SCHOOL

Every teacher must keep his certificate at the school for to examine on his first visit.

PROVINCE OF MANITOBA
 CANADA

**PUBLIC SCHOOL
 DAILY REGISTER**
 FOR RECORDING THE ATTENDANCE OF
PUPILS

In the S.D. of Glenbow No. 1499
 For the Year 1931-32

PRINTED FOR THE EDUCATION DEPARTMENT FOR MANITOBA
 BY PHILIP PURCELL, KING'S PRINTER FOR MANITOBA

SCHOOLS FREE BY THE DEPARTMENT OF EDUCATION



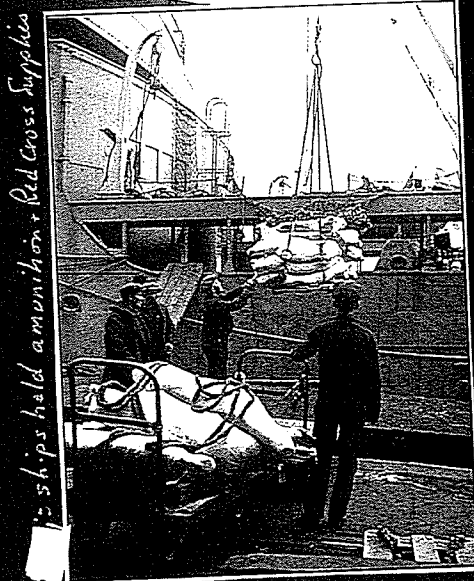
Exhibit H13-2



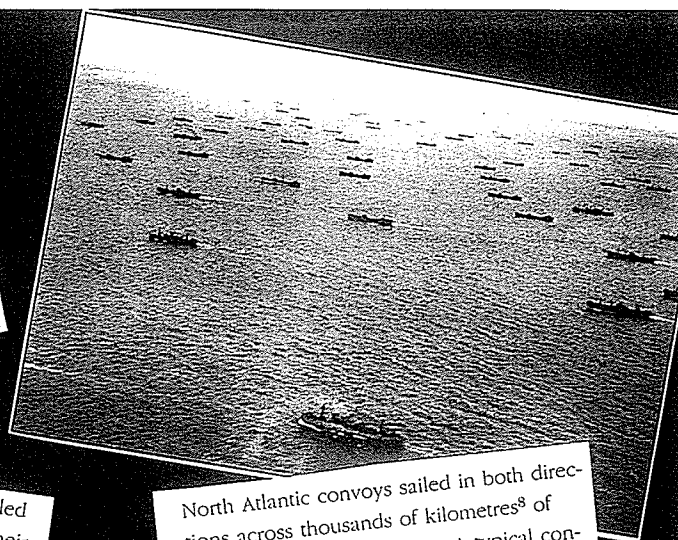
Exhibit H13-3

It has been estimated that a Canadian merchant ship of 10,000 tonnes dwt could carry enough food stuffs to feed 225,000 people for a week. Cargo could also include clothing, fuel, steel, aluminum, lumber, aircraft, tanks, jeeps, trucks, guns, munitions, and whatever else was required for the war effort. Not surprisingly, they became the prized targets for enemy surface raiders and U-boats.¹⁰

North Atlantic route—they sailed the oceans of the world. They carried their cargoes to and from the ports of Europe, Asia, Africa, South America, Australia/New Zealand and the Far East. They carried food stuffs and ammunition, clothing and steel, oil and aircraft—whatever was required for the war effort. After Hitler invaded Russia, they sailed the deadly Murmansk Run.



Ships held ammunition + Red Cross Supplies



North Atlantic convoys sailed in both directions across thousands of kilometres⁸ of open and dangerous ocean. A typical convoy of 40 ships might be ten columns wide with four ships in each column. It would be headed by a flagship, carrying the convoy commodore, and ideally escorted by warships patrolling its outer flanks. Ammunition ships and tankers with their highly volatile aviation fuel were on the inside.

The End of the Pacific War

As millions of people celebrated Victory-in-Europe (V-E) Day, the Allied leaders grimly prepared for the final struggle in the Pacific, where the full weight of the Allied forces would now be applied against Japan.

Canada, too, prepared for the assault. Nearly 80,000 Canadians volunteered to join the Pacific forces and began concentrating at nine stations across Canada in July 1945. Canadian naval participation was also to have been impressive: 60 ships, manned by 13,500 men. However, the war was over before this help was needed. President Truman of the United States had made the fateful decision to use the atomic bomb.

On August 6, 1945, the first atomic bomb was dropped on Hiroshima, Japan, a city of over 100,000 people. The results were terrifying. A third of the city was obliterated; the rest lay in ruins. Three days later, a second and larger bomb totally destroyed the port of Nagasaki. The Japanese government sued for peace on the following day and, on August 14, 1945, Japan accepted the Allied terms of unconditional surrender. The Second World War was over.

returned home in 1945

Some tid-bits provided by the Canadian Department of Veterans Affairs

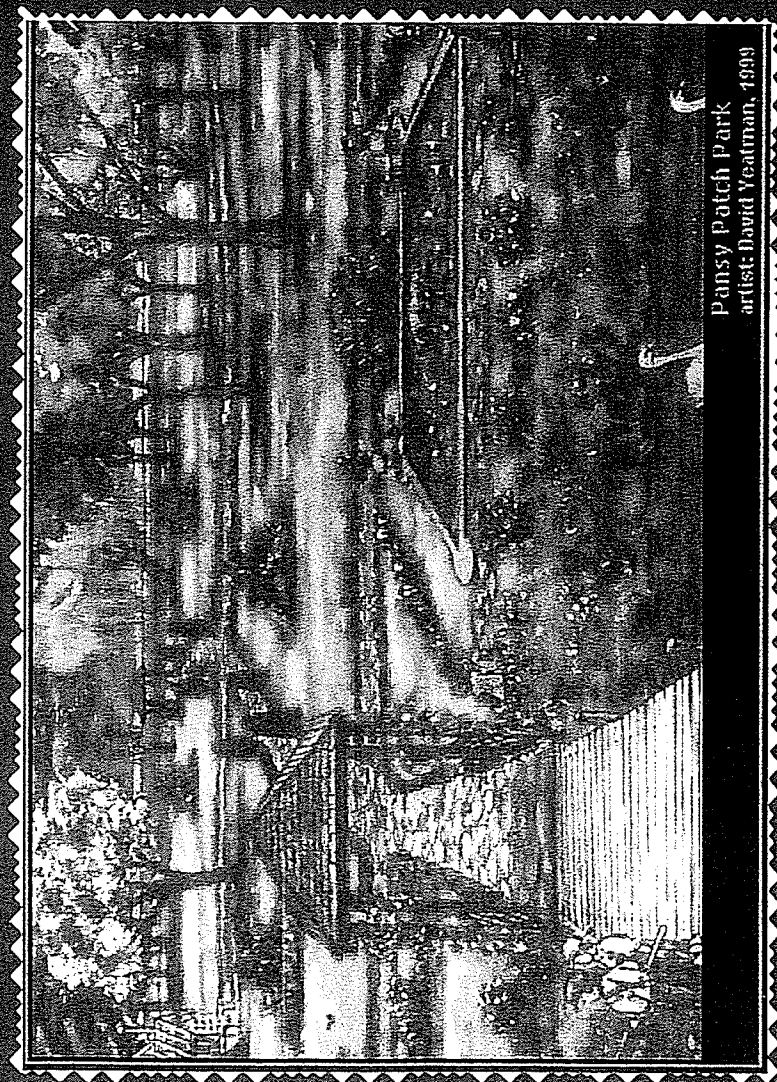


Exhibit H15

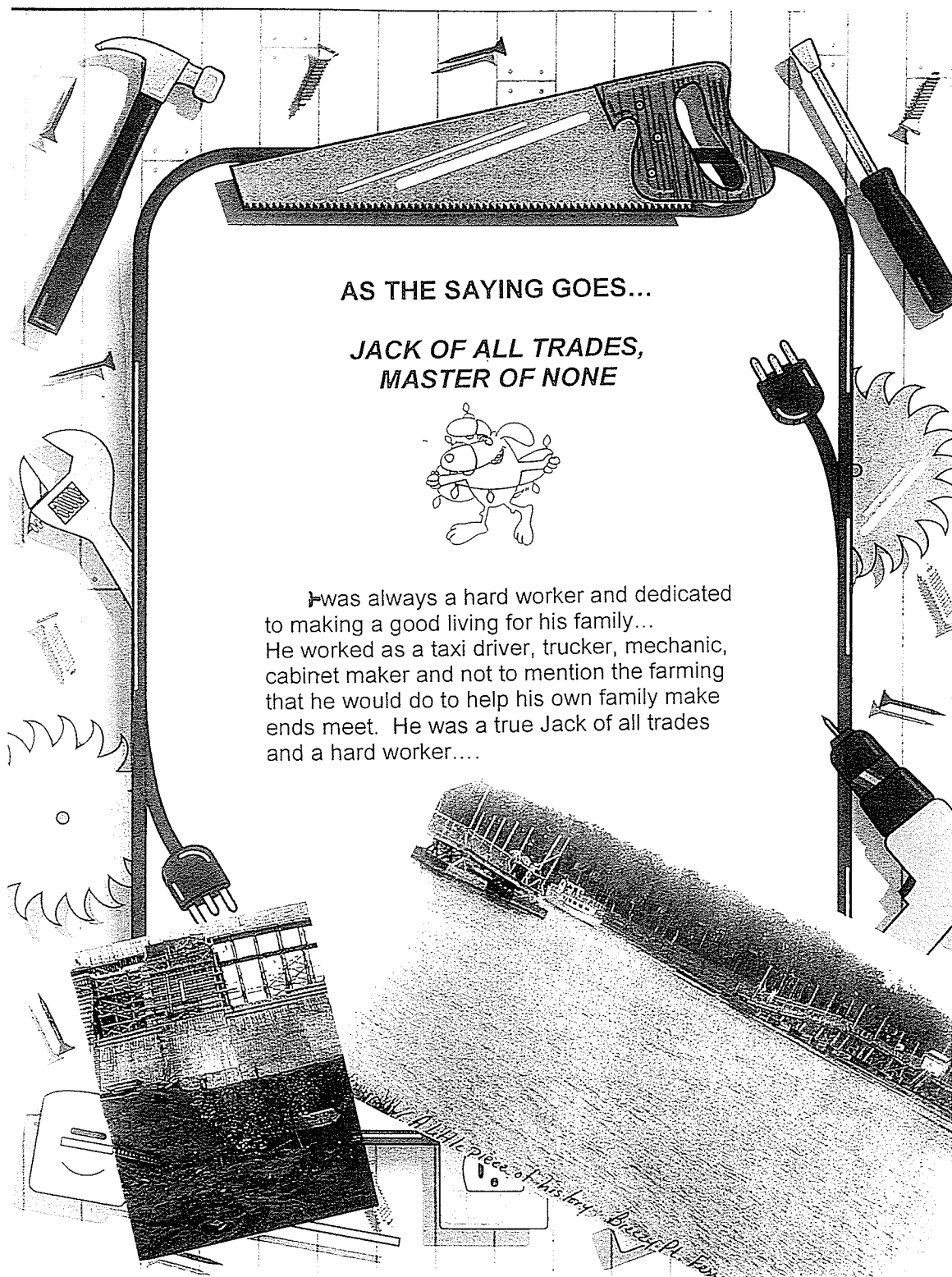


Exhibit H16-1

soon found out that once he retired, he would need to keep busy with other things...

retired from cabinet making but his love for working with his hands and creating beautiful things continued

Here is a sample of some work that he continued to do on his own free time.



What a beautiful cradle!



Dearest Mommy:
taken

This is but a very small token
of our love.
In the past few days we have
realized how vital your presence
contributes to our happiness and
well-being. We are so tremendously
proud of you and ~~are~~ resolved to
do our best to make this family
the happiest and most content family
in the world - always. I know we

To lend that certain touch,
And send the best of wishes
To the folks we like so much;
And so as Christmas comes again

You'll always be remembered
By the ones who wish you well!
This wish is sent to tell,
Can do it because it is a
make you happy & we
constant supply of joy & we
just to see you that way always
I'm with you always

~ a caregiver
at heart ~
The world's best
mother + wife...



It Happened Here

by EDITH PATERSON

Meat-Packing Plants A Novelty In 1893

St. Boniface has long been noted for its huge meatpacking plants, and on May 13, 1893, The Free Press described plans for what seems to have been the first such institution on that side of the Red River. For many years, slaughter-houses had been located at various points on the outskirts of Winnipeg, in keeping with an early bylaw forbidding them inside the city limits.

In 1875, wolves were reported plentiful near the slaughterhouse just west of the city, and Alex McMillen shot two with a revolver.

As Winnipeg grew, various other sites were obtained, but plans for the 1893 plant were more elaborate than anything previously attempted. As usual with new ventures, this newspaper presented a detailed report:

AN IMPORTANT INDUSTRY

An important industry which should result in considerable benefit to this city will shortly be started by Messrs. J. V. Griffith and Company. The firm has decided to erect on the east side of the Red River, a little distance from the Louise Bridge, a large slaughter-house, pork-packing plant and cold-storage building. The size of the structure will be 120 x 60 feet, three storeys and a basement. The basement will be built of solid stone with concrete floors, well drained, while the upper portion will be of brick; there will also be a solid brick smokehouse attached, 20 feet square and two storeys high. The departments into which the upper storeys are divided are as follows: First storey, boiler and engine room, shipping room, tank, lard and cold-storage rooms, with an entrance into the smoke room, and spacious stairways leading to the floors above and to the basement. The second storey contains the slaughtering portion of the establishment, with shackling, sticking, scalding and chill rooms; all modelled after the great Chicago plants.

(Just how the piggies proceeded to the second storey where they met their fate was not made clear, and it is hard to envision them trotting up the stairways, however spacious! But perhaps the plant was on sloping property, with a second storey entrance at ground-level.)

The second storey will also have the offal tanks and runways for carrying away the slaughtered animals to the chill rooms, also lard-tanks and cutting rooms, with refrigeration.

The upper storey contains the ice and store rooms; from the former, cold air vents run down to the other rooms. The whole place will be well ventilated.

At present the Canadian Pacific Railway is putting in a spur track to run along the broad side of the building. The ice house was built in the winter and is now full of ice. Work on the stone foundation of the larger building is well under way. The cost, not including any fittings or plant,

will be about \$12,000, and total cost about \$20,000.

The property of the firm contains about five acres and the building will have one of the most improved systems of cold storage on the continent. The capacity will be about 200 hogs per day and when running at full capacity, about 30 to 40 hands will be employed. Everything will be in readiness by July 1.

But people in rural points were "up and coming" too. On May 16, it was reported that S. L. Head of Rapid City had a good idea for shipping meat. Previously it had been transported "on the hoof" to markets in eastern Canada and overseas, but Mr. Head decided it would be more feasible to ship "dead" meat. Described as "one of Rapid City's most clear-headed businessmen, with a reputation for looking at all sides of a dollar," he had estimated it would be a great saving in hay and feed and other expenses if the cattle were slaughtered and shipped in refrigerated cars to cities down East.

Accordingly, for the past several months, Mr. Head had been perfecting arrangements to carry out his idea, with the result that a few hundred yards from the station and close to the railway track he had a good-sized building, nearly completed, affording facilities for slaughtering and for cold storage of meat until it could be shipped.

He was already purchasing cattle, hogs and some sheep from farmers in the district, a carload from Westbourne near Portage la Prairie, and more from Strathclair. Owing to the low prices obtained for the previous year's crop at the prevailing low prices in the district for livestock, farmers were taking advantage of the opportunity to ship the meat, without the deterioration in weight and quality that often occurred transporting live animals.

Mr. Head was contracting to have them killed in the slaughterhouse, which was fitted with hoists and overhead trolleys for conveniently transferring the carcasses to the cooling house.

This building was filled with huge slabs of ice — three by three by 10 feet piled to the roof, with passages between for hanging the meat. The ice was taken from a nearby river.

The first carload, of 30 beef carcasses with the balance in pork, was shipped to Toronto, starting off on the Manitoba and North Western rail line. Mr. Head was also prepared to supply the ice for the refrigerator cars.

"Ice is a crop that never fails in Manitoba," he told a Free Press reporter. "And it is always No. 1 hard."

It might not be about bones but it is an interesting story.

APPENDIX I
Sample Log Book Sheet

Family Visitor Log Book Entry

Date: _____ Length of visit: _____

Relationship to [residents name]: _____

Please place an **X** on the following lines describing how you feel about your visit today:

The best visit ever |-----| The worst visit ever

The time just flew |-----| The time dragged

Very Frustrating |-----| Not at all frustrating

Very satisfying |-----| Not at all satisfying

Please write any comments about today's visit:

Was this a good visit or a difficult visit? (If you can, please explain why?)

Please indicate any information, life story material or memorabilia that you are willing to share for the creation of the life album (if you have nothing new from last time please leave this blank.)
