Development of Life Story Guidelines

For Family Members with Cognitively Impaired Relatives

Residing in a Personal Care Home:

A Practicum Project

By

Catherine E. Baxter

Submitted to the Faculty of Graduate Studies
In Partial Fulfilment of the Requirements
For the Degree of

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Development of Life Story Guidelines for Family Members with Cognitively Impaired Relatives Residing in a Personal Care Home: A Practicum Project

BY

Catherine E. Baxter

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of Manitoba in partial fulfillment of the requirements of the degree

of

Master of Nursing

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Abstract

The literature on family caregiving suggests that family members express a strong need to share their expertise in caring for their family members with nursing home staff. Moreover, they hope the important information they provide will be used in the planning and provision of care for their relatives. While family members report a strong desire to share their specialized knowledge and expertise with staff, they are often unsure how to communicate this information. The purpose of this practicum project was to develop guidelines that could be used by family members, to write a life story that would communicate the specialized knowledge they possess, about their relatives with Alzheimer's Disease, to nursing home staff.

In order to determine what information should be included in the life story guidelines, key informant interviews with family caregivers of cognitively impaired relatives and focus group interviews, with selected staff at a long-term care facility were carried out. Content analysis was conducted and seven categories were identified and incorporated into the guidelines. These included: Relationships, Life Experiences, Accomplishments, Personality, Philosophy, Interests, and Daily Living.

Life story workshops were then conducted to introduce the life story guidelines to family members. Following the workshops, family members used the guidelines to develop a life story for his/her relative with Alzheimer's Disease. The usefulness of the guidelines was evaluated and final revisions to the guidelines were made.

DEDICATION

To my husband Mark, for his love and constant support.

To my children, Meghan and Laura, who keep me focused on the really important things in life.

To my parents, who are always there for me.

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CHAPTER 1

STATEMENT OF THE PROBLEM

Major events and life transitions pose challenges to those experiencing them. The relocation of a cognitively impaired elderly relative with Alzheimer's Dementia (AD) into a nursing home is a major life transition experienced by a significant number of family members (Johnson, Morton & Knox, 1992). Over the next several decades the incidence of AD is expected to increase. As the incidence of AD rises, the number of elders requiring placement in a Personal Care Home (PCH) will increase, and so too will the number of family members undergoing this difficult transition.

Nursing home placement can relieve family caregivers from the heavy burdens of physical care, yet family members do not relinquish their caregiving responsibilities entirely once their relative enters a PCH. Research has clearly demonstrated that institutionalization does not mark the end of family caregiving but rather denotes a change in the nature of the care provided and marks a significant transition in the caregiver's role (Bowers, 1988; Rowles & High, 1996; Rubin & Shuttlesworth, 1983). Following the placement of a relative into a nursing home, caregivers are faced with a new set of challenges including: how often to visit, how much help to provide, how to initiate relationships with staff and how to redefine their own identity and role (Dellasega & Nolan, 1997).

Family caregivers need to create new ways of caring and establish ways to "share the care" of their relative with nursing home staff (Duncan & Morgan, 1994).

The literature on institutional caregiving suggests that family members express a strong need to share their expertise in caring for their family member with the nursing home staff. Moreover, they hope the important information they provide will be used in the planning and provision of care for their relative (Bowers, 1988; Duncan & Morgan, 1994, Kellet, 1996; Ross, Rosenthal & Dawson, 1997). While family members report a strong desire to share their specialized knowledge and expertise with staff, they are often unsure how to communicate this information. Therefore, **the goal of the practicum was to provide family caregivers with a method of communicating the specialized knowledge they possess, about their cognitively impaired relative, to the staff of a nursing home, in Winnipeg, Manitoba.**

Improving communication between family members and nursing home staff is important for several reasons. Firstly, when family members feel their expertise is received by nursing home staff with respect and regard, this exchange fosters a climate of mutual cooperation and respect. Secondly, family members feel more empowered in their new caregiving role when they are treated as important members of the health care team. Finally, family members often know the resident's needs better than anyone else. By sharing this information with staff

they can assist them in providing more individualized care (Hepburn, Caron, Luptak, Ostwald, Grant, & Keenan, 1997).

Objectives

Recent research has demonstrated that Life Histories, if compiled into a written form, are useful to staff who care for residents residing in a PCH (Pietrukowicz & Johnson, 1991). Because cognitively impaired residents, by the nature of their disorder, are unable to tell their own story, the family members' knowledge of the personal and social histories of their relatives is required to develop their life stories. Involving family members in writing the life stories of their cognitively impaired relative provides a mechanism for them to communicate the specialized knowledge they possess about the residents to nursing home staff (Hepburn et al. 1997). While the writing of a resident's life story has been documented as an effective means to involve family members in nursing home care, few guidelines exist to assist them with this process. In the following practicum the student will develop life story guidelines that can be used by family members as a framework for writing his/her cognitively impaired relative's life story. The following objectives for the practicum have been identified:

1. To develop guidelines for family caregivers that will assist them in completing a Resident Life Story (RLS) for their cognitively impaired family member who resides in Deer Lodge Centre.

2. To conduct a pilot project, to trial the RLS guidelines, on the PCH units at Deer Lodge Centre.

3. To evaluate the usefulness of the guidelines as a tool to assist family members in completing a resident life story

CHAPTER 2

REVIEW OF THE LITERATURE

As in other industrialized nations, the Canadian population is aging. If current demographic trends continue, it is projected that by the year 2031 there will be approximately seven million people aged 65 and over living in Canada. The greatest increase in the elderly population is expected to occur amongst those aged 80 and older (Health and Welfare Canada, 1990). The significance in the growth of the oldest cohort of seniors is underscored by research which demonstrates that the incidence of Alzheimer's disease, the most common form of dementia, increases with age. While AD affects 1% of Canadians over the age of 65, this number rises to a striking 26% of persons 85 and over. Furthermore, it is estimated that at least 49% of persons 85 and over, who reside in a Personal Care Home (PCH), have AD (Canadian Study of Health and Aging Working Group, 1994).

Alzheimer's Disease and Family Caregiving

Alzheimer's disease is a devastating disorder that progressively attacks the brain and impairs memory, thinking and behavior. Early deficits include loss of recent memory, as well as problems in orientation, language and abstract thinking. As the disorder progresses individuals with AD fail to recognize familiar faces, develop problems with attention, concentration and simple task completion.

Individuals often develop behavior problems such as wandering, agitation and aggression. In the late stage of AD the disease progresses to include multiple losses such as loss of ambulation, loss of bowel and bladder control, loss of meaningful communication and finally progression to a vegetative state (Soukup, 1996).

In most cases AD affects at least two members of a family. The most obvious victim is the person diagnosed with AD. The second less obvious person affected is the family member who assumes responsibility for the care of the person with AD. This person is commonly referred to in the literature as the family caregiver. The actual onset of family caregiving for a relative with AD is often ambigious. During the early stages of AD the person can function at home with only supportive assistance from family. Caregivers may provide supportive assistance for several years prior to the date that they identify as the point of onset of caregiving. However, as the disease progresses, the increasing level of mental dysfunction renders the person incapable of caring for his/her own physical or emotional needs and family members are called on to provide constant care and supervision (Soukup, 1996).

Over the past fifteen years an extensive body of literature on family caregiving has emerged. Early studies on family caregiving focused primarily on two major issues: namely, the tasks caregivers perform and the burden of

providing care (Abel, 1990). While the importance of these earlier studies cannot be underestimated, one major weakness was the predominant use of cross sectional designs. As a result, caregiving tasks and burdens were viewed as static and there was little recognition of variations in family care over time (Given & Given, 1991).

The works of Wilson (1989) and Lindgren (1993) provide a more comprehensive account of how family caregiving for a person with dementia changes over time. Wilson (1989), using grounded theory methodology, generated a theory explicating the process of family caregiving for a person with AD. Wilson identified 3 stages that families move through while caring for a relative with AD. The first stage titled "taking it on" occurs when family members assume caregiving responsibilities . The second stage , "going through it" encompasses the ongoing assistance family carers provide to a family member with AD. Caregivers enter the third stage of caregiving "turning it over" once the decision to place an elderly relative in a PCH has been reached.

Similarly Lindgren (1993) concludes that the nature of caring for a spouse with AD can be described as a career process with three identifiable stages. In the first stage, the encounter stage, the caregiver confronts the diagnosis of AD. During this stage the caregiver struggles to understand the diagnosis and adjusts to the impact of the diagnosis. This requires learning new skills and making life

style changes. In the second stage, the enduring stage, routines of care become established and spousal caregivers become enmeshed in their caregiving role. The final stage, is characterized by the decisions, activities, and adjustments, undertaken by the caregiver to relinquish the role. The caregiving career is relinquished either through death of the ill spouse or through institutionalization. Both these studies emphasize the dynamic and progressive nature of family caregiving and demonstrate how the needs of caregivers change over time.

In the theories articulated by Wilson (1989) and Lindgren (1993) the final stage of caregiving concludes once the impaired elder enters a long term care facility. According to Bowers (1988), this belief, that institutionalization marks the termination of the family's caregiving role has been a prevalent view in the caregiving literature. Once the frail elder enters a PCH the responsibility for the care shifts from the family caregiver to the institution. At this point many researchers have viewed the family's role to have ended. However, several research studies have documented that the majority of family members continue to maintain substantial contact with the impaired elder following placement in a PCH (Bonnel, 1996; Bowers, 1988; Rowles & High, 1996; Rubin & Shuttlesworth, 1983). Recent studies have demonstrated that family caregivers continue to provide their elderly relatives with emotional support and maintain frequent contact with them while they are residing in a PCH. Family members

remain fully involved in nursing home decisions and assume primary responsibility for individualizing and personalizing care for the impaired elder. Family caregivers continue to invest immense amounts of time and energy in an attempt to maximize the impaired elder's quality of life (Rowles and High, 1996). In addition, family members pay the elder's bills, run errands, and shop for the resident. Family caregivers continue to feel responsible for monitoring and evaluating the quality of care provided by the nursing home staff and for teaching the nursing home staff how to care for their elderly family member (Bower, 1988). Thus, rather than representing the end of family caregiving, more recent research has conceptualized this period of time as a period of transition. None of these studies however, has addressed the needs of family caregivers during this period of transition.

The Transition to a Personal Care Home

Chick and Meleis (1986) define transition as the "passage from one life phase, condition or status to another." (p.239). A transition brings a period of uncertainty, which is followed by a reordering of one's life (Brown & Powell-Cope, 1991). Each transition results in changes in roles, relationships, abilities and patterns of behavior (Schumacher & Meleis, 1994). As the following discussion demonstrates, the passage or movement from community based family caregiving to caring for a relative in an institution has been conceptualized in the

nursing literature as a period of transition (Brown and Powell-Cope, 1991; Johnson, Morton and Knox, 1992; Young, 1990).

Pearlin (1992) conceptualized the institutional placement of an impaired elder as the second in a series of three transitions. The decisions, activities, and adjustments undertaken by the caregiver to transfer the responsibility for the care of the elder to an institution characterize this period of transition. According to Pearlin the first transition occurs when the caregiver assumes responsibility for providing assistance to the impaired elder within the community setting. The final transition encompasses bereavement and occurs following the death of the care recipient.

Similarly Johnson, Martin and Knox (1992) noted that the relocation of a patient to a nursing home environment denotes a period of transition for family caregivers. These researchers believe that how well the family manages this transition may be manifested in the outcomes and experiences for the patient.

Bartlett (1993) conducted in-depth interviews with 24 wives of institutionalized husbands. The purpose of the research was to gain an understanding of the wives' experience of their husbands' nursing home placement. Bartlett concluded that the wives underwent two major transitions. The first transition occurred when the husband became ill and the caregiving role

was assumed. The second transition occurred when the husband was transferred to a nursing home.

In a recent article by Dellasega and Nolan (1997) the authors describe a six stage model of caregiving which builds on the earlier work described by Wilson (1989). The six stage model of caring is comprised of the following stages: 1) Building on the past; 2) Recognizing the need; 3) Taking it on; 4) Working through it; 5) Reaching the end; and 6) A new beginning. In this model placement of a relative in a PCH occurs at the end of stage five. The authors argue that stage six, does not signify the end of caregiving , but rather represents a new but still involved stage. They also suggest that many caregivers will require assistance to ensure a smooth transition and to develop a different type of relationship with their relatives. According to the researchers, while the transition to institutional caregiving is by no means a universally difficult experience, there is little doubt that attention to the carers' needs during this time could do much to ease the transition. The researchers recommend the development of specific nursing interventions that assist family members to move forward to a new beginning.

All of these studies recognize that the relocation of a relative to a PCH is a period of transition for family caregivers. However, ways to assist family members through the transition have not been addressed.

Conceptualizing family caregiving as a series of transitions is valuable to the extent that it embraces the continual and evolving process of family caregiving over a period of time. The literature on transition emphasizes that each stage of caregiving has characteristic properties and challenges that require different skills and coping strategies (Schumacher and Meleis, 1994). This highlights the need for interventions to be 'stage specific' and tailored to the carers' needs at particular points in the caring trajectory (Dellasega and Nolan, 1997).

Placement in a Personal Care Home

Placing a relative with AD in a nursing home is an extremely difficult decision for family caregivers (Wilson, 1989). Often relatives will only consider nursing home placement once all other resources have been exhausted (Ade-Ridder & Kaplan, 1993). Furthermore, widespread acceptance in our society of the benefits of community care further denigrates an already negative perception of institutional care (Dellasega and Nolan, 1997). Consequently, families often view placing a relative in a PCH as the "ultimate negative choice" (Wilson, 1989, p.98). This tension places family caregivers in a particularly difficult situation (Nolan, Walker, Nolan, Poland, Curran, Kent & Williams, 1996). On the one hand, family caregivers may feel relieved that the responsibility for providing 24 hour care has been alleviated, yet on the other hand they experience overwhelming feelings of guilt, sadness, loneliness and grief (Matthiesen, 1989;

Rosenthal and Dawson , 1991). Moreover, once the impaired family member is placed in a PCH the family caregiver must redefine their caregiver role and create new ways of caring that will maintain a sense of attachment and worth (Dellasega & Nolan, 1997).

Redefining the Caregiver Role: Sharing Expertise and Knowledge

As indicated in an earlier section of this literature review, the majority of family members wish to maintain involvement in the care of their family member. Determining how often to visit, how much help to provide and how to develop and maintain relationships with staff are just a few of the challenges caregivers face (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Moreover, as part of their new role, family members must establish ways to share the care of their relative with nursing home staff.

Several research studies have examined the relationship between family caregivers and health care professionals in long term care settings. Early research studies examined this relationship from a task based perspective. (Rubin & Shuttlesworth, 1983; Shuttlesworth, Rubin, & Duffy, 1982; York & Calysn, 1977). These studies used quantitative designs to gather information from staff and family regarding who should perform which task. The results of these research studies revealed that there was substantial role ambiguity surrounding particular tasks. For example, the research study by Rubin and Shuttlesworth

(1983) found considerable ambiguity in regards to who was responsible for certain tasks. These researchers surveyed 64 nursing home staff members and 137 family members who had relatives residing in a nursing home. The results of the statistical analysis revealed that family caregivers and staff members had differing views on who should assume responsibility for the nontechnical aspects of care. Moreover, where discrepancies did exist, each group tended to assign the responsibility to itself. These researchers concluded that meaningful family involvement in care depends upon agreement in task assignments. They recommended that increased communication with relatives and among staff was required to clarify ambiguous areas of responsibility.

Similarly, a later study by Schwartz and Vogel (1990) also used a quantitative design to examine the division of tasks between family and staff in a nursing home. These researchers found that even though family members were willing to share the responsibility for care, staff members frequently underestimated the family's desired involvement.

Although the focus on the subdivision of tasks has some merit, it presents us with an incomplete picture of the scope of the family caregivers' involvement in care. As the following research studies demonstrate, the tasks that family members perform only represent one component of care. In fact, family

caregivers often view the tasks they perform as the least important part of their caregiving role (Bowers, 1988; Duncan & Morgan, 1994).

Bowers (1988), using grounded theory methodology, examined family involvement with elderly relatives in long term care institutions. Bowers suggested that family members view quality care as a collaborative process between family and staff rather than a division of tasks between them. Family members expected staff to provide technically competent care but also emphasized the importance of providing sensitive and individualized care. Caregivers felt part of their role included sharing their personal knowledge of the care recipient with staff and teaching the staff how to deliver high quality care. The ultimate goal of care was to preserve the dignity, self-esteem and identity of the impaired elder. Bowers named this "Preservative Care". Mutual trust and collaboration between staff members and family caregivers was seen as essential; unfortunately family members reported that staff rarely sought their expertise.

Similarly, in a later study, Duncan and Morgan (1994), conducted 30 focus group interviews with 179 family caregivers who were involved in caring for a relative with advanced cognitive impairment. These researchers found that caregivers placed little emphasis on the tasks that staff performed. Duncan and Morgan (1994) wrote: "From the point of view of the nursing home as an organization, a routinized, task-based division of labor may be essential. Yet,

from the point of view of these family members, this emphasis on the technical rather than the social and emotional aspects of the residents' care could create an imbalance" (p.242). In this study the family caregivers did assign primary responsibility for the technical aspects of care to the nursing staff, however, they expected recognition that they too possessed expertise that could make a significant contribution to care. One of the conflicts the caregivers described in the study stemmed from the staff's failure to recognize this expertise. A second source of conflict amongst family members in the study arose from an overly rigid division of tasks. Family members rejected the idea that they held exclusive responsibility for the social and emotional tasks. Instead family members wanted staff to provide both technically excellent and emotionally involved care. Thus the relationship these family members sought with staff went beyond a task based division of labor to include a shared exchange of knowledge and emotional support.

Kellet (1996) identified similar themes to those identified by Bowers (1988) and Duncan and Morgan (1994). In this study, Kellet (1996) used a phenomenological approach to explore the experience of family members caring for older relatives within a nursing home setting. The author reported that following the admission of an impaired relative to a nursing home, family caregivers needed to create new ways of caring that allowed them to maintain a

sense of attachment and worth. Kellet argued that one of the key ways that family members maintain a sense of worth is by ensuring that their specialized knowledge of the older person is used as the basis of planning quality care.

Ross, Rosenthal and Dawson (1997) investigated the visiting experience of wives whose husbands had been admitted to a long-term care institution. In this study the wives visited their husbands frequently. One of the primary motivations the wives had for visiting was to provide assistance to their husbands. The type of assistance provided often included help with technical tasks, such as feeding, laundry and taking their partner for walks. Assistance also came in their role as advocates. The wives intervened with staff when they perceived that their husbands were misunderstood. One wife in the study described how she was able to assist the staff to understand her husband's behavior better. The staff attributed his behaviors to confusion whereas she was able to explain that his difficulties were more likely a result of his limited sight and hearing.

The value and importance family members attach to sharing their expertise with staff is further supported in a study on AIDS family caregiving (Powell-Cope, 1994). The family caregivers in this study also reported a strong need to give of their expertise in caring for their loved ones and to establish and maintain partnerships with the health care professionals. Furthermore, they

expected their expertise would be received by the health care professionals with respect and regard.

Similarly Hasselkuss (1988) reported that family members frequently modified the treatment plan developed by the health care professionals. Family members felt that they knew the care recipient's needs better than anyone else, and therefore possessed special knowledge which they could use to teach the health care professional how to care for their family member. Family caregivers generally felt empowered to care for their elderly family member when they were treated as important members of the health care team.

The review of the literature clearly demonstrated that family members can contribute significantly to the care of persons with dementia, especially through their knowledge of the elder in both impaired and wellness states (Rowles & High, 1996). Family members tended to have an in-depth understanding and awareness of their relative's life circumstances, personal histories, values and preferences. Yet, family members felt they had no way to share these important aspects of their relative's life with the nursing home staff. Including the knowledge and expertise they possess about their cognitively impaired relative in a life story, is one method to communicate this information that has been described in the literature.

Life Histories

Butler (1963) first brought attention to the importance of the "life review" process among the elderly. Butler defined life review as "the act or process of recalling the past" (p.66). These memories, once recalled, can then be organized into a coherent life story. According to Hirst (1997) life stories help to define a person's roles, needs, preferences thoughts and values. It reveals the person's experiences and actions and helps to validate the person's worth.

The value of life stories to nursing staff has been documented in the literature. In a recent qualitative study Hewitt (1998) examined how the presence of life stories affected the way carers viewed their client's identities. Hewitt found that knowledge of the person's life story enabled the staff to get to know the client, define the person and revealed his/her personality. Similarly another study by Pietrukowicz and Johnson (1991) examined the impact of life histories on nursing home staff attitudes. These researchers found that the presence of a life history caused the staff to perceive the resident in a more positive manner. Furthermore, the presence of a life history emphasized the more personal side of the elderly resident and helped protect their personal identity, against the depersonalized institutional routines. Finally, Buzzell and Gibbon (1991) argued that in a long term care setting information on the person's life history, strengths and beliefs should be incorporated into the plan of care. They suggested that

consideration of the person's past play an important part in planning individualized care.

Despite the importance of this information, the literature suggests that personal life history information is not always collected as part of the admission assessment to a long term care facility. In a recent study Coker (1998) conducted a close examination of the health records in a long-term care institution. Coker (1998) points out, that the information collected during the admission assessment focuses primarily on the physical and functional needs of the resident. Little information regarding the individual's values, strengths and memories was obtained. Similarly, Hewitt (1998) commented that the care plans in long term care settings generally reflect the person's physical needs in the here and now. She emphasized that while these map out each client's current needs they ignore their histories.

The presence of dementia makes it difficult to collect information on the person's past, as the person with AD is often unable to tell staff members about his/her past experiences. Thus for these persons, who can no longer communicate their past histories, family members must play an integral role in conveying this information to staff.

A life story book "is a document of a person's life that incorporates personal stories and experiences" (Hewitt, 1998, p.62). Hewitt (1998) suggested

that life story books are one way family members can record this information for staff members. The author suggested that the life story books can supplement the current documentation with more personal information regarding the person's life. Although family members possess the in depth information required to complete a life story book, the act of writing a life story is often perceived as difficult (Murphy, 1994). Hepburn et al. (1997) developed the Family Stories Workshop, in an attempt to address this issue. The Family Stories Workshop, was a process through which family members of persons with dementia, developed stories of the impaired elders' lives. The stories were shared with the staff members working in the PCH where the resident resided and were designed to convey the texture and detail of the life of the person who could no longer act as his or her own historian. The results of this project were extremely positive. The family members involved in the workshops felt they were more involved in the life of the institution and were able to develop narrative histories that could be shared with staff. While most of the participants simply developed written histories, several included photographs, and personal belongings for the staff. The authors did not systematically evaluate the effect of the histories on staff members however, the anecdotal feedback from staff was positive. Staff members reported that having a greater understanding of the resident as a person who has lived a life, raised a

family, enjoyed recreation and had a career may have resulted in more sensitive, empathetic and respectful interactions.

The Family Stories Workshop provides family members with a useful mechanism to communicate important information to staff regarding their impaired relatives. The following practicum will build on this concept. Guidelines to assist family members of cognitively impaired elders to write a resident's life story will be developed and a trial of the guidelines will be undertaken in a pilot project.

Conceptual Framework

Transition is one of the concepts central to the discipline of nursing (Meleis, 1975; 1985; 1986; 1991). Nurse client interactions generally occur during transitional periods of instability precipitated by developmental, situational or health illness changes (Schumacher & Meleis, 1994). Family caregiving has been conceptualized as a series of situational transitions. The placement of the impaired elder in an institution represents a difficult period of transition in family caregiving, which results in changes in roles, relationships and patterns of behavior (Johnson, Morton, & Knox, 1992; Young, 1990).

Chick and Meleis (1986), conducted a detailed concept analysis on the concept of transition. Building on this earlier theoretical work, Schumacher and

Meleis (1994) developed A Nursing Model of Transition. This model was used to guide the practicum.

A Nursing Model of Transitions

Universal Properties of Transitions

Despite the diversity of transitions, some commonalties across categories exist (Chick and Meleis, 1986). These commonalties are referred to as the universal properties of transitions (Schumacher & Meleis, 1994). The first universal property is that transitions are processes that occur over time. The second, is that with transition, changes occur in one's identity, roles, relationships, abilities and patterns of behavior.

Transition Conditions

Schumacher and Meleis (1994) identified six transition conditions. These included meanings, expectations, level of knowledge and skill, the environment, level of planning, and emotional and physical wellbeing.

Meanings

Meanings refer to the person's subjective appraisal of the transition and the evaluation of its likely effect on his/her life. The meanings attached to a transition may be negative, positive or neutral. The inclusion of meaning emphasizes the importance of understanding transition from the perspective of those experiencing it.

Expectations

Expectations are defined as "other subjective phenomena that collectively influence the transition experience " (Schumacher & Meleis, 1994, p.122). Persons undergoing a transition may or may not know what to expect and their expectations may be realistic or unrealistic.

Level of Knowledge/Skill

During a period of transition there is a need for new knowledge and skill. The concept of uncertainty is interwoven with the need for new knowledge and skill development. Uncertainty arises from a lack of knowledge about the actual transition and the changes in roles, relationships and patterns of behavior that are required.

The Environment

The environment refers to the external facilitative resources that are available during the transition. Resources are defined as "the cyclic process of perceiving, building and evaluating the helpfulness and supportiveness or support outside the person that may help during transition" (Schumacher and Meleis, 1994, p.123).

Level of Planning

The level of planning refers to the amount of planning that occurs before or during a period of transition. Effective planning requires the identification of

problems and needs that may arise during the transition. Extensive planning helps to ensure a smooth transition.

Emotional and Physical Well-Being

A wide range of emotions accompanies a period of transition. Stress, emotional distress, and role conflict often occur. An overwhelming emotional response to the transition is significant in that it may interfere with the assimilation of new information. Similarly, physical well-being is also important during a transition. If physical discomfort is present, the person's ability to learn new skills may be affected.

Indicators of Healthy Transitions

Schumacher and Meleis (1994) identify three indicators of healthy transitions. Firstly, when a successful transition is occurring feelings or distress are replaced by feelings of well-being. Secondly, a successful transition is accompanied by role mastery of the skills and behaviors required in the new situation. Finally, a sense of well-being regarding one's relationships indicates a successful transition has occurred. According to the authors, clinical interventions can be applied to facilitate a healthy outcome.

Nursing Therapeutics

Schumacher and Meleis (1994) identify three nursing measures that are widely applicable to therapeutic interventions during a period of transition. These

include, promotive, preventive and interventive. Promotive interventions occur prior to the transition occurring and involve the assessment of the client's readiness for the transition. Preventive interventions prepare the person for the transition and interventive measures involve the use of role supplementation.

Application of A Nursing Model of Transitions to the Practicum

Dellasega and Nolan (1997) identified that admitting a family member to a PCH is a significant period of transition for family caregivers. According to these authors there is a need to devise interventions that will assist family members to move through this period of transition. Schumacher and Meleis (1994), in a nursing model of transitions, provided a framework for the student to develop and carry out a nursing intervention, aimed at family caregivers who have had a relative with AD admitted to a PCH.

According to the model, a nursing measure can be applied that will affect one or more of the transition conditions. This in turn will influence the outcome of the transition. In this practicum, the student developed guidelines that could be used by family caregivers of cognitively impaired elders to prepare a life story. Providing family members with the guidelines and teaching them how to complete a life story was the intervention. This intervention was designed to provide family members with a method to communicate information about their family member to the nursing staff. The review of the literature on family

caregiving demonstrated that family members wish to participate in caregiving by sharing their specialized knowledge regarding the impaired elder with nursing home staff. The literature further revealed that family members are often uncertain as to how to communicate this information to staff. By conducting a life story workshop and providing guidelines for completing a life story, the student will increase the family members' knowledge and skill level in this regard. It is anticipated that this in turn, will enhance the family member's sense of role mastery as they develop a means to communicate their knowledge and expertise regarding their impaired relative to nursing home staff.

According to Schumacher and Meleis (1994), a nursing model of transitions, has implications for nursing practice by providing nurses with a framework to describe the needs of clients during a period of transition. In this practicum project parts of the model were used to guide the intervention that was implemented. **The nursing intervention** that was carried out was developed to address the transition condition, **level of knowledge and skill**. Increasing the family member's level of knowledge and skill would in turn, increase his/her sense of role **mastery**. Thus, the model provided a framework for the development and implementation of a nursing intervention that was used in nursing practice. Figure 1 highlights the parts of the model that were applied to this practicum.

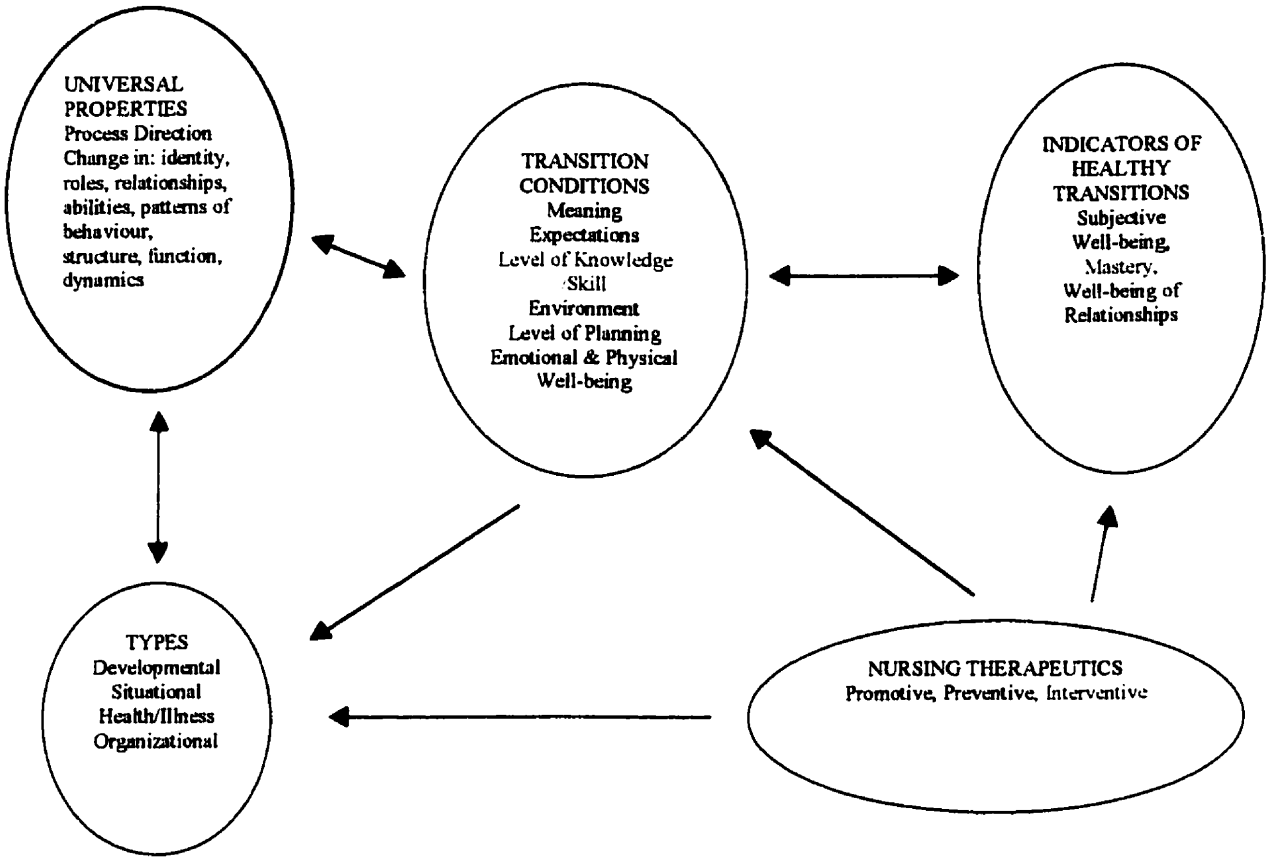

Figure 1: A Nursing Model of Transitions

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CHAPTER 3

PRACTICUM DESIGN

There were two phases in the practicum. During the first phase the Resident Life Story guidelines were developed. During the second phase a pilot project, to conduct a trial of the guidelines was carried out. The following section will outline the methods that were used during each stage of the practicum.

Phase 1: Development of the Resident Life Story Guidelines

In order to determine what information should be included in the resident life story guidelines, a comprehensive review of the literature on life stories and life albums was first carried out. Once the review of the literature had been completed, key informant interviews with family caregivers of residents with AD who reside in Deer Lodge Centre were conducted. Finally, focus group interviews were held with selected staff members at Deer Lodge Centre. Both the key informant interviews and the focus group discussions provided the student with an opportunity to validate the themes identified in the literature.

Key Informant Interviews: Family Caregivers

Key informant interviews were conducted with family members of cognitively impaired residents who had resided in Deer Lodge Centre for at least one year. The purpose of these interviews was to determine what information is

important to include in a resident life story, from the perspective of family caregivers.

A purposeful sampling technique was used to recruit the participants for the key informant interviews. When selecting the purposeful sample, participants were identified according to their knowledge of the research topic (Morse, 1989). Participants who had been involved in institutional caregiving for at least one year were chosen for the interviews. This group of caregivers was chosen for their expertise and knowledge of caregiving in an institution. These caregivers have had the opportunity to observe the care of their relative in an institution and were able to identify gaps in the information staff members have regarding their family member. Three key informant interviews were conducted. One interview was conducted with each of the following family caregivers: A spouse whose cognitively impaired husband had been admitted to Deer Lodge Centre Personal Care Home; a spouse whose cognitively impaired wife had been admitted to Deer Lodge Centre Personal Care Home; and an adult child whose cognitively impaired parent had been admitted to Deer Lodge Centre Personal Care Home.

Early research on family caregiving viewed caregivers as an homogenous population. However, as Cantor (1983) argues, the homogenization of such crucial variables as type of relationship and gender has obscured the differences between and among groups of caregivers. For this reason the student felt that

interviewing a husband, wife and adult child caregiver would yield richer data reflecting the differing views of the different groups of caregivers.

Potential informants were identified by the Unit Co-ordinators on the Personal Care Home Units at Deer Lodge Centre. The Unit Co-ordinators approached potential participants to obtain their permission to have their names submitted to the student. Once permission had been obtained the names of potential participants were provided to the student and the involvement of the Unit Co-ordinator ended. Three potential participants were then sent a letter from the student outlining the purpose of the project and indicating that the student would be contacting them by telephone to discuss participation in the project (Appendix A). All three family members agreed to participate in the project and face to face interviews were then scheduled at Deer Lodge Centre. At the start of the interview the project was explained and written, informed consent was obtained (Appendix B). The key informant interviews took approximately one hour to complete and each participant was interviewed once. In order to ensure completeness of the data obtained, the key informant interviews were tape recorded and the data later transcribed (Morse, 1989).

Inclusion Criteria

In order to be considered as a participant for the key informant interviews the following criteria had to be met:

- The family member must have a cognitively impaired relative residing in Deer Lodge Centre Personal Care Home for at least one year.
- The family member must visit the institutionalized elder at least twice a month.
- The family member must be able to speak and understand English.

Interview Guide

In choosing the type of interview that would be conducted it was necessary to first consider if a quantitative or qualitative design would be used. Quantitative research involves the systematic collection and analysis of numerical data, often under conditions of considerable control (Polit & Hungler, 1991). Quantitative research designs are most appropriately employed when the purpose of the research study is to predict causal relationships or to test and validate hypotheses (Parse, Coyne & Smith, 1988). Qualitative research, on the other hand, involves the systematic collection and analysis of non-numerical narrative data, under conditions of minimal researcher imposed control (Polit and Hungler, 1991). Qualitative research designs are most appropriate for research that are discovery

oriented, explanatory, descriptive and inductive in nature (Woods & Catanzaro, 1988).

A qualitative approach was deemed most appropriate for the key informant interviews as the type of information the student sought to obtain was descriptive in nature. In order to develop guidelines, that accurately reflect the specialized information family members wish to communicate to staff, it was necessary to ask them to describe what they would like to see included. A formal, unstructured interview format was used for the key informant interviews. An interview guide that contained a set of brief, general questions outlining the topic areas to be discussed was used. However, both the student and the participant were free to deviate from the prepared outline in order to explore other areas that pertained to the topic of interest and that were particularly relevant to the participant (Wilson, 1985). Unstructured, formal interviews allowed the student to move from one content area to another, to follow up on the respondent's responses, and to get information in the participant's own words. Thus this format elicited the type of data needed to generate the resident's life story guidelines. At the same time, the presence of an interview guide, outlining the content areas to be discussed provided structure and guidance to the student.

A copy of the complete interview guide that was used for the key informant interviews can be found in Appendix C.

Focus Group Interviews: Staff

Focus group interviews were conducted in order to determine what information was important to include in a resident life story, from the perspective of nursing home staff. A focus group interview format was chosen for the interviews with staff members for several reasons. Firstly, focus groups can provide insight into the beliefs and attitudes of participants regarding a particular behavior. Secondly, data regarding perceptions and opinions are enriched through group interaction because individual participation can be enhanced in a group setting and finally, a focus group format allowed the student to meet with larger numbers of staff members at one time (Carey, 1994).

According to Carey (1994) focus group members are generally homogenous in terms of prestige or status. This homogeneity is useful as people are more likely to share information with others who are seen as similar. If the group is too heterogenous, the lower status group will defer to higher status members and not contribute fully to the group discussion. For these reasons three focus group interviews were held. Each one with a different occupational group of DLC staff members. One focus group was conducted with a sample of five Registered Nurses (RN's) who work in the Personal Care Home at Deer Lodge Centre (DLC). A second focus group was held with a sample of 11 Health Care Aides (HCA's) who work in the personal care home at DLC and a third focus

group was held with a sample of four Social Workers who are involved in the personal care home program at DLC.

Each of the members in the three groups selected was chosen on the basis of his/her common experience related to the practicum topic. In long term care settings the RN's are responsible for admitting new residents to care, directing the work of the HCA's, developing the resident care plans and acting as the primary contact for family members. Therefore, the student felt that this group of staff members could provide valuable data regarding the type of information that would be relevant to consider when planning resident care. Health Care Aides were included as they are the group of employees that provide the majority of direct care for the residents in long term care settings. In addition, Health Care Aides are seen by family members to be key employees to teach how to care for their family member (Duncan & Morgan, 1994). Finally, social workers were interviewed as they are frequently the first contact the family member has with the PCH. Social Workers often play a key role in easing the transition from home based caregiving to institutional based caregiving, and thus possess valuable insight into the needs of family members during this difficult time.

Initially, short information sessions were conducted on each of the PCH units at DLC and in the department of social work. The presentation outlined the project and invited staff members to participate in the focus group discussions.

Following each session an information letter was left on the unit/department for each staff member. The information sheet described the project and invited them to attend a focus group at the designated time and place (Appendix D). Interested staff members were asked to write their name on the form provided and return it to the student. A sealed envelope with the student's name was provided and an envelope was placed on each unit to collect the completed forms. The student contacted, by telephone, those staff members who indicated an interest in participating in the focus group (Appendix D). At the start of the interview the purpose of the practicum was explained again briefly and written, informed consents were signed by each participant (Appendix E). Each focus group interview took approximately 1 hour to complete. The interviews were tape recorded and the data later transcribed in order to ensure the completeness of the data obtained (Morse, 1989).

Interview Guide

A copy of the complete interview guide that was used in the focus group interviews can be found in Appendix F.

Data Analysis

The purpose of data analysis, regardless of the type of data one has, is to impose some order on a large body of information so that some general conclusions can be reached (Polit & Hungler, 1991).

Methods of analysis range from a broad approach with the purpose of identifying general concepts to a very detailed analysis of transcripts (Carey, 1994). The purpose of this practicum guided the methods of analysis used to interpret the data. The goal of the focus group and key informant interviews was to obtain data that could be used to develop resident life story guidelines. The development of the guidelines was considered comparable to the development of a survey questionnaire where the identification of significant content themes and "natural vocabulary" would not require intense analysis (Carey, 1994). Thus, the data obtained from both the key informant and focus group interviews were analyzed for general themes and topics but no attempt was made to look for relationships between categories.

Content analysis was used to examine the interview data. When conducting content analysis, the entire interview was reviewed and several important topics were identified. These topics became the primary categories. The primary categories were broad so that a large amount of data was sorted into seven general groups. Once the categories had ample data, subcategories were then developed (Morse and Field, 1995). When each category was reasonably full and no new data were emerging, the student formulated the guidelines for the resident life story. In developing the guidelines, salient themes identified in both the interview groups and the literature were included.

Ethical Considerations

In this practicum the student had to be cognizant of the rights of the project participants (Oiler, 1990). Munhall (1988) identified three ethical guidelines for qualitative researchers, which were adhered to in this practicum: 1) The therapeutic imperative of nursing (advocacy) takes precedence over the research imperative (advancing knowledge) if conflict develops. 2) Consent to participate in research is interpreted to mean that participants are collaborators in the research process, and 3) on going negotiation between the researcher and the participant is required to protect the rights of the informant.

In order to ensure the above requirements were met, the following steps were taken. First, if during an interview, any situation should arise that required immediate intervention, the interview would be terminated and the intervention provided. If however, the situation did not require immediate attention, and the participant was willing to proceed with the interview, the interview would be completed and then the appropriate intervention provided. Secondly, written informed consent was obtained from each participant prior to the initiation of the interview. Once the consent form was signed the participant retained the right to revoke the consent and withdraw from the interview at any time. Finally, prior to beginning the practicum, ethical approval from the faculty of nursing, ethics committee was obtained. Once ethical approval had been secured access to Deer

Lodge Centre was requested. Once access had been approved, the practicum began.

Phase 2: The Pilot Project

During a pilot project unforeseen problems with the guidelines can be determined. The effects of such problems may be negligible but, in other cases, modifications to the guidelines may be required. By conducting a pilot the necessary revisions can be completed and refinements made prior to introducing the guidelines throughout Deer Lodge Centre (Brink & Wood, 1990). Furthermore, testing the guidelines, with a small group of family members and staff, will validate if the guidelines adequately reflect both the information family members wish to communicate with nursing staff, and the information staff wish to learn about the resident. Therefore, a pilot project, to try out the guidelines, was conducted.

Background

The pilot project was conducted over a four week period of time, and was conducted at Deer Lodge Centre. Deer Lodge Centre (DLC) is a large long term care facility in Winnipeg, Manitoba, Canada. In September 1998, DLC launched the F.I.N.E. approach to resident care. The four key elements of this approach include: Flexibility, Individuality, Normalcy, and Excellence. Central to the

F.I.N.E. approach is the recognition that each person is a unique individual with his/her own habits and preferences. The goal of the F.I.N.E initiative is to improve the quality of life for the residents at DLC by providing care that will allow each person to feel valued and respected. The proposed pilot project complements the F.I.N.E. initiative undertaken by DLC nursing administration.

Deer Lodge Centre was considered an ideal location to try out the RLS guidelines as the philosophy of the F.I.N.E. approach encourages and supports individualized care. Hepburn et al. (1997) stressed the importance of considering the prevailing culture of an organization when introducing family life stories. In those long-term care facilities, in which management embraced the concept as consistent with an existing vision and mission, participation was more enthusiastic and implementation worked best.

Pilot Project Description

There were two major components of the pilot project. Firstly, two life story workshops were held, for family members of cognitively impaired residents residing in Deer Lodge Centre. Those family members who attended the workshops and agreed to participate in the pilot project used the guidelines to complete a life story for his/her cognitively impaired relative. Once the life story had been completed the family members were asked to complete a survey, evaluating the usefulness of the RLS guidelines. Secondly, information sessions,

explaining the RLS guidelines, were conducted with selected staff members at DLC. Following the information sessions, staff members who wished to participate, were asked to review the RLS guidelines and to provide feedback on the guidelines.

Resident Life Story Workshop

Two workshops were conducted to teach family members about the purpose of a Resident Life Story and to introduce the guidelines for completing a RLS. A poster was placed on the resident/family bulletin boards, on all the PCH units, inviting family members, of residents with Alzheimer's Dementia, to participate in the pilot project (Appendix G). In addition, a letter was given to the primary caregiver of all residents with AD who resided in the PCH at DLC. The letter explained the pilot project and invited family members to attend the workshop (Appendix H). A registration form was included with the letter and family members were asked to register if they were interested in attending the workshop. Once the registration form had been received, the student contacted the family member to confirm participation (Appendix H)

In order to accommodate the different schedules of family members two workshops were conducted. One workshop was held in the afternoon and the second was conducted in the evening. A total of 10 family members were registered to attend the workshops. However, 14 people actually attended as four

participants brought a second family member with them. The additional family members were not asked to leave but rather were invited to participate in the workshop. At the start of the workshop, the pilot project was explained to the participants and a written, informed consent was obtained from each person (Appendix I). The workshops were approximately two and one half hours in duration. During the first hour, the Resident Life Story concept was introduced and discussed. In the one and one half hours remaining the family members participated in exercises that would assist them in completing a RLS . Towards the end of the workshop each family member was provided with a copy of the RLS guidelines and then invited to participate in the remainder of the pilot project by completing a Life Story for their family member. Participants were provided with the student's phone number and encouraged to call if they needed any assistance. Finally, Workshop evaluation forms were distributed to family members (Appendix J).

Informal workshops were deemed an appropriate format to use when teaching family members for several reasons. Firstly, the workshop format was interactive and fostered learning through participation. Secondly, the workshop format provided opportunities for the learned material to be put into practice and finally, the informal atmosphere of a workshop promoted a readiness to learn.

Evaluation of the RLS guidelines

Family members

The family members, who agreed to participate in the pilot project, were asked to complete the RLS in approximately 3-4 weeks. The family members were also asked to complete a survey evaluating the RLS guidelines (Appendix K). Family members were asked to comment on the strengths and weaknesses of the guidelines and were asked to include any suggested revisions. Once the data from the questionnaires had been received, any necessary revisions to the guidelines were made.

In the final analysis, the resident life story guidelines will only be useful if family members view them as a valuable means to communicate information regarding the cognitively impaired elder. Evaluation was needed to assess the usefulness of the guidelines as a tool to assist family members complete a RLS and to identify possible revisions, which needed to be made.

Staff Information Sessions

The staff members on the new, 36 bed, general PCH unit at DLC were asked to participate in the pilot project. The new unit opened in December 1998, and admitted 36 residents over a two month, period of time. Accordingly, the staff on the new unit were still getting to know a large number of new residents. The student felt this group of staff members would be in an ideal position to

review the guidelines as they could provide valuable insight regarding the type of information they would like to know about the new residents they care for. The Life Story Guidelines were placed on the unit during week one of the pilot project. The RLS guidelines remained on the unit for a period of four weeks.

Formal, information sessions were chosen for teaching staff members about the guidelines. Staff members had limited time available during their work day to attend education sessions, therefore, short presentations outlining the purpose of a resident life story and explaining the pilot project were conducted. Because a large number of nursing staff work different shifts, three educational sessions were conducted. One on day shift, one on evening shift and one night shift. In order to reach those staff members, who were unable to attend any of the information sessions, an information package was also developed and left on the unit for all staff members to read. Following the information sessions, a copy of the guidelines was left on the unit. In addition, a questionnaire was given to all staff members (Appendix L). The survey asked questions regarding the adequacy and relevance of the information provided in the RLS guidelines. Staff were also asked to comment on any major omissions in the guidelines as well as any suggested revisions. A copy of the student's phone number was provided and staff were encouraged to call the student with any questions regarding the RLS guidelines or questionnaires.

Establishing a System for Program Management

A system for program management is the development of an indicator that is designed to help determine if the program is proceeding as planned. According to Dignan and Carr (1987) time is perhaps the easiest indicator with which to deal. Time lines can be developed for the completion of various tasks and when the "milestones" are reached early or are not reached at the appointed time, trouble spots in program implementation can be identified. The time line for the pilot project is outlined in Table 1.

Table 1: Time line for pilot project

Week 1	Week 2	Week 3	Week 4
Conduct the Resident Life Story Workshops Distribute the evaluation of the RLS guidelines to family members Conduct information sessions with staff members. Distribute the RLS guidelines evaluation to staff	Assist family members complete Life Story as required.	Assist family members complete Life Story as required.	Collect evaluation surveys from family members once the life story has been completed Collect staff members surveys evaluating the RLS

CHAPTER 4

DEVELOPMENT OF THE LIFE STORY GUIDELINES

Content analysis was used to examine the data. When conducting the content analysis the data were reviewed and seven categories were identified. These categories were broad in scope and included; Relationships, Life Experiences, Accomplishments, Personality, Interests, Philosophy, and Daily Living. Subcategories were then developed for each of the primary categories. The Resident Life Story Guidelines were then formulated based on the themes and subcategories that emerged from the data (Appendix M).

Categories

Relationships

Family Tree

Information regarding the resident's family history was identified as important to include in a life story. Respondents suggested collecting information regarding the names of family members, and where they live. One participant remarked that this information would be useful when having a conversation with the resident as "Sometimes (the resident) keeps talking about this name and you don't always know who the person is." Thus, by knowing the names it would help staff "fit everyone into the picture." Another respondent commented that information outlining how many children they had, where they have lived, and

their grandchildren's names would be helpful "so you can make some of those connections with (the resident)". The importance of including information regarding the person's family history was also identified in the literature. In one article, by Coker (1988) nurses stated that it was important to know the resident in the context of their families. The participants in this project felt that knowing the resident's family history would help them put things into perspective.

Interestingly, several respondents commented that the life story should only include the names of family members that are important to the resident. There was concern that by including every relative "there could be too much (information)". As one participant remarked;

> You might want to state that patient X has five siblings. You might want to say where they live. But, I think if you say ... they're not very close to most of their siblings, but are very close to so and so, I think probably that is enough information. You know who the really relevant people are.

Life Story Guidelines

In order to capture the information on the resident's family history, a family tree was developed and included in the life story guidelines. The family tree included spaces for the names of the resident's parents, siblings, spouse, children and grandchildren. In the directions family members were encouraged to

include additional information, such as, where the person was living, date of birth, and date of death if applicable.

Family Relationships

In addition to information regarding the names of family members, participants in this project felt it would also be valuable to know about the dynamics of family relationships. As one staff member commented;

> I think it would be helpful to have a comment about the dynamics of the relationships. Because so and so is not in the picture right now and then suddenly they show up.

Two other participants made similar remarks; one stated "I would definitely want to know the quality of that relationship" and the other suggested that, he would like to know the names of family members but would also like to know "if they get along with them."

Although information regarding family relationships was considered important, respondents voiced concerns about discussing family dynamics. One participant remarked;

> Keep in mind the age of clientele we're dealing with. A lot of these people are pretty secretive about families. Illegitimate births, adoptions, people who have died and not allowed to be buried in a Catholic cemetery because of some taboo, so I think you need to be careful.

A similar concern was raised by a family member who commented;

> If we were to get into family relationships perhaps it might be too personal. I could tell you things that I wouldn't want... I would want to know how far they would go, and I would think they should only go so far..

The other two family members that were interviewed did not share this opinion however. When asked if there was any information that was too personal to include one participant remarked " I should be telling you everything if I want you to give good service to my spouse" and the other remarked " I don't think so. I mean for you to help me I got to let you know everything. If I try to hide some of it, what's the sense of it."

All respondents agreed that information regarding family relationships should be voluntary. As one person phrased it.

> We need to set limits as to how much they're going to say and have that be O.K. For if they don't want to tell you what their marriage was like or if they don't want to tell you what they're family situation is...

Friendships

In the key informant interviews, family members talked about the importance of also including information regarding friendships. One participant,

when asked what information she would include in her husband's life story, told the following anecdote:

> I met (my husband) at their wedding. This is neat. I was maid of honour and he was best man. And they're very very good friends. He just passed away a few years ago but they were just like brothers.

Similarly, the participants in the Social Work focus group identified an interest in knowing about the person's social supports.

The value of including information on family relationships and friendships is further supported by the literature. According to Happ, Williams, Strumpf, and Burger (1996) "the critical attribute of relationship is closely linked to 'knowing the person'" (p.9). The authors continue that "since one of the common experiences of old age is loss of friends and family members, relationship takes on an added meaning in the care of older persons" (p.9).

Life Story Guidelines

The subcategories, titled family relationships and friendships were therefore included in the life story guidelines. Families were asked to include information regarding; the person s/he is closest to; which family members visit regularly? Which family members provide the most support? And, the names of family members s/he no longer sees. As well, information on his/her closest friends was included. In the directions family members were instructed that any

information regarding family relationships was voluntary and they should only include information that they wish to share with staff members.

Accomplishments

Participants suggested that information about the resident's lifetime occupations and involvement in the community should be included in the life story. As well, information regarding the major achievements in his/her life was viewed as important. These three subcategories comprised the general theme, accomplishments, in the life story guidelines.

Lifetime occupations

Family members identified lifetime occupations as an essential component of the person's life story. Each of the key informants spoke of the type of work his/her relative did throughout his/her life. For example, one family member, speaking about his father, remarked "He was well known in the community as a tradesman, as a carpenter" and another commented that her husband "was a career officer, a radio navigator. His whole life was the air force... He retired early... after that he went to Manitoba Hydro. He worked there for six years and really enjoyed it".

Staff also commented on the need to gather information on what kind of work the resident did and his/her work history. Similarly, information regarding the individual's occupation was identified in the literature as an important

component of the life story (Alzheimer Society of Canada, 1993; Coker, E., Blazekovic, L., Graham, C., Keery, L., Mittl, M., & Sinclair, J. 1998; Murphy, C. 1994).

Community Activities

Each of the family members spoke of his/her relative's involvement in community activities. One participant, when asked what he could tell the writer about his wife that would help the nursing home staff get to know her better as a person, responded "She liked to get involved with the school doing school work projects with the kids" Another participant, recalling what information he would include in his father's life story stated, "When the kids were young he was very active in sports programs and community type things and was well known for that."

Staff members commented that including information about the person's past involvement in the community would help them to know more about the type of person the resident was. For example, one staff member commented,

> A lot of our clients are well known in the community. So we have people from all over the place visiting.. It's important to know why all these people are visiting them. And what they've contributed to their community before they ever came to this stage...

Major Achievements

In analyzing the data it became apparent that simply listing past occupations and community activities did not adequately reflect the person's life story. When describing the person's past life, family members not only described what they did, but also spoke passionately about what they had achieved. For example, one family member whose relative was a tradesman added that,

> He made the bulk of his money doing general carpentry work but was always called upon to do fine work by people who knew his abilities. So he was respected for that, as someone who could do a good job... He was proud of the fact that he was looked on as a craftsman.

Likewise, the staff respondents wanted to know about the resident's major accomplishments. One staff member commented that knowing what someone has accomplished "really puts a good spin on the type of person you're dealing with". Another staff member commented that he would like to know "whatever is most important to (the residents) in their past lives." He felt by knowing more about their accomplishments it would help the staff members relate better to the residents.

Life Story Guidelines

In an attempt to reflect both the events and the importance of those events, three subcategories were included in the life story guidelines. Family members

were asked to provide information on the person's lifetime occupations, community activities and to discuss the person's major achievements.

Life Experiences

Radwin (1995) described what information the nurse needed to gather in order to develop a fuller understanding of the patients s/he cares for. Radwin contends that in order to understand both the patient and the broader perspective s/he must gain an understanding of the patient's past experiences. Furthermore, the Alzheimer Society of Canada (1993), developed A Personal Care Book that could be completed by family caregivers for a relative with AD. Information on significant past experiences and major life events is amongst the suggested information to collect. Likewise, Murphy (1994), conducted a review of life story work in several long term care facilities and community agencies in Britain. Several of the life stories described in this article included information on past life experiences, holidays and war experiences.

The person's life experiences were also considered by the participants in this project to be an important dimension of the life story. Major life events, milestones, war experiences and traumatic events were the four subcategories derived from the data and included under the general theme, life experiences.

Major Life Events

When family members were asked what information they would include in their relatives' life story, they described the persons' childhood and young adult years and told stories about the places they had traveled throughout their lives. The experiences that were significant varied with each interview but all participants identified significant life events that they would want included in a life story. For example, one family member recounted, "We did a lot of fishing and a lot of trailering. We would take summer holidays and we toured Georgian Bay and a couple of times we took the kids out of school for a month".

Staff respondents also saw the value in including information on past life events. In the words of one participant it was important because "it gives us some inkling of where they might be coming from". A staff member in another interview reported that "it would also help you to break down the barrier for communicating for you would have something to talk to them about".

Milestones

Hepburn et al. (1997) conducted a series of workshops to assist family members complete a story of his/her relatives life. In the workshops the family member was encouraged to use a time-line to map the facts and events of the person's life against the decades in which they occurred. The authors suggested

that the main benefit of developing a time-line is that shaping and pivotal moments in the person's life are often identified.

Major milestones in the resident's life were identified by each of the family members interviewed. Childhood, marriage, raising children and retirement were all mentioned as significant events in the person's life. One family member, presented an overview of the important aspects in his wife's life. In the course of this discussion several milestones were mentioned. "She came from a coal mining family in England... We dated and ended up getting married in 1944...Then we moved back to Canada after the war...."

War Experiences

Information about the residents' war experiences was identified by respondents in all six interviews as important to include in the life story. One staff member identified that it was particularly important to include in the life story as Deer Lodge Centre is a veteran's facility. She stated, "Because we're a veteran's facility, (it's important) to know what their war experiences may have been because that often contributes to the things they might experience in terms of behaviours later". She added that it was also important to know which war the person served in. Another staff member, in a separate focus group discussion, commented that it was important to know "If they were a veteran whether or not they want to talk about it. You don't want to pry but if they want to talk about it

you want to make yourself available". Adding to the discussion another staff member indicated that "you certainly need to know if they were a POW."

Family members also identified war experiences as information they would include in their relatives' life stories. For each of the family members interviewed the war was considered a significant part in the person's life. For example, one family member stated, "Serving in the second world war was a big thing in his life and something he liked to tell us about".

Past Trauma

Family members not only described the positive events in their relatives' lives but also spoke of some of the traumatic and difficult times they had encountered. When one family member was asked to identify some of the major events in his father's life he responded by saying,

> I don't know much about his youth years except he grew up in the north end of a town that was divided ethnically and had what I'm told was a hard life in a broken home. His mother left his home when he was nearly 10 years old so he grew up with just he and his dad making his way.

The family participants who were interviewed spoke of both the difficult times and the good times and felt both were important to include when telling their relatives life stories.

The staff members who participated in the focus group discussions also indicated that past traumatic experiences should be included in the resident's life story. In order to illustrate the importance of this information one staff member relayed the following anecdote. "We had a resident and she had to be taken by an ambulance and she had a traumatic experience with the police (in the past). She thought the ambulance guys were the police and just lost it"

Knowledge of past traumas was seen as important information because it would help staff members understand why a person is reacting in a particular way. Staff reported that they would plan certain aspects of care differently if they were aware of past events. This point is clearly demonstrated in the following story one staff member told;

> There was someone who was burnt in hot water and we couldn't get her in the bathtub. We finally figured out later it turns out she was scalded when she was a child. Little things like that. It doesn't seem like much but when you go to put someone in a tub and you don't know they have a phobia about a tub. If you knew this ahead of time you could give them a sponge bath or maybe let them hold the shower and shower themselves. You wouldn't put them through the experience.

Life Story Guidelines

Each of the subcategories, Major Life Events, Milestones, War Experiences and Past Trauma, was included in the life story guidelines. Probes were provided for each section. In the section titled Major Life Events, family members were asked to include information regarding childhood experiences, cities or countries the resident has lived in, places they have traveled and courtship and marriage experiences. Under Milestones, family members were provided with a timeline and were asked to record the major events in the person's life against the decades in which they occurred. In the section titled War Experiences, family members were asked to include information on when the resident served and in what war. They were also asked to mention if the person was a prisoner of war and if s/he likes to talk about the war years. Finally, family members were asked to describe any traumas or difficult times the resident experienced in the past.

Personality

Personality Traits

The analysis of the data revealed that aspects of the resident's personality were important to include in a life story. Each of the family members spoke of his/her relative's personality prior to the onset of the illness and how it differed from his/her personality now. Furthermore, participants identified both the

strengths and weaknesses in his/her relative's character. One family member remarked;

> Before he became ill he was very, very easy going. I was the strict one. Whatever I wanted was fine. He never got mad. We never argued. Then he started to get mad and that was not in character at all.

Another family member, talking about his wife, commented that "She was very independent, stubborn in one way and she had the capabilities of practically doing anything." He continued, "She had to be very busy all the time and she still has a touch of it. She's always folding things over."

Similarly, one staff member commented, that it was important to remember, that the person you are seeing now is very different to how he/she once was. To illustrate this point she recounted a story of a resident she had once cared for. "I remember, I had one man who took out his picture of when he was in the army and kept showing it to me and to other people saying, and this is who I am, not here, but in the picture." Another staff member in the same focus group interview commented that it was important to "(Get) acquainted with the person that they were before they became ill, for sometimes you find out what they were like before and it's relevant to how you can deal with them now." Finally, participants in another focus group discussed the value of knowing about the kind of person the resident was, and any fears or phobias they had.

The importance of including information on the resident's personality was further supported by the literature. Kenny, (1997) writes that understanding the individual's prior personality characteristics would provide staff members with a better understanding of why the person with dementia reacts the way they do. Similarly Williams, (1994), states that recognition of the resident's varied abilities and talents developed over the individual's long life, is an important element of individualized care. Finally, Farran and Keane-Hagerty (1989) report that "understanding who the person was in the past allows the nurse to capitalize on the patient's abilities that still remain" (p.14).

Life Story Guidelines

Based on the results of the data analysis the subcategory, personality traits, was included in the life story guidelines. Family members were asked to include information on the person's character prior to the illness, his/her strengths and weakness, talents and fears.

Personal Boundaries

Respondents suggested that information should be gathered on the person's need for privacy. One participant remarked that it was important to know if he/she is "a person who likes being by themselves or (does he/she) enjoy being with other people". Another person wanted to learn "if they like to speak about their life, their past, what they like to talk about and what they don't".

Staff members were particularly interested in learning about the need for privacy during personal care. One staff member commented on the need to include information on, "How private they are with care" and another remarked that it was important to know if they have "always been a private person and do they have a specific preference for a male or female caregiver."

Respect for the individual's privacy was also identified in the article by Coker (1998). The participants in this project stated it was important to know what aspects of privacy were important to the residents. This study also highlighted the importance of knowing and respecting how the resident wished to be addressed. The nurses in this project commented that this was important as professional staff members often assume familiarity when permission has not been given.

Life Story Guidelines

The information regarding privacy was captured in the subcategory, personal boundaries, in the resident life story guidelines. In this section, family members were asked to comment on the individual's need for privacy, personal space, and preference for being in groups or alone. In addition, family members were asked to include information regarding the topics the resident liked to discuss and what topics were considered too personal to talk about. Family members were also asked to comment on the individual's preference for male or

female caregivers and finally, they were asked to state how the person would like to be addressed by staff members.

Philosophy

According to Hepburn, et al. (1997) there is a difference between writing a life story and reporting a chronology. They emphasize that the "participant's work will be to remember or put together small tales that reveal something not only about the events of the person's life but also about its meaning and about the character of the person" (p. 828). They went on to say that in this way, the product they were developing in the family story workshops differed from the traditional social histories gathered in nursing homes, as they illuminate as well as, report on the person's life. The participants who were interviewed in this project also identified the importance of including information that portrayed, what was important to the residents throughout their lives. In an attempt to capture this information, the category, titled philosophy, was developed. Two subcategories were identified from the data. These included, values and beliefs and meaning and purpose.

Values and Beliefs

In both the caregiver interviews and the focus group discussions, the participants, talked about the value of knowing the person's beliefs. The staff members identified two primary reasons for wanting this information. Firstly,

they felt it was important to know if the person attended church regularly in the community. Staff members reported that they are often in the position of taking residents to chapel and expressed concern that they did not want to take someone who would not have chosen to go. As one staff member stated, she would like to know, "Were people involved in church and would that be an important thing to involve them in. Some people, they're not active in the church and would not want to go." Similarly another staff member stated "we might have someone who is an atheist and sometimes we assume (he/she wants to go) like when we have church on our unit".

The second reason staff members cited for wanting to understand a person's religious beliefs was to know what rituals needed to be attended to when the person was dying. The following concern was expressed by one person, "what if someone's dying, if someone's Catholic that's quite important." Another staff member remarked "what if someone's say a Buddist, or some religion we don't know much about. There are certain rituals that a person goes through and it's really helpful to be aware, because you don't want to disrupt something that's really sacred to them."

Family members also described the involvement of their relative in particular faith groups. For example, one family member stated, "when we were in Ottawa we belonged to the church there and he was an elder". Likewise,

recording spiritual information was an important component of personhood, described by Coker, (1998). Recording the customs or religious practices that the person cherished, as well as his/her involvement in a specific faith or cultural community was considered by the nurses is this project as valuable information.

Meaning and Purpose

Staff members expressed an interest in learning about the meaning and purpose the residents would assign to their lives. One staff member remarked that he would like to know, "whatever is most important to them in their past life." Another staff member commented "it's like we identify ourselves by our careers. Well we identify our clients in probably similar ways. What did you do with your life? What was your main purpose?" It was also important for family members to portray what was important to their relatives in the life stories. For example, one family member, when asked what type of information he would include in his father's life story remarked, "One of the things I would put in (was) that he was absolutely a dedicated family man and father". For this family member it was important that the staff understood that in his father's life, family had always come first.

The article by Coker (1998) lends further support to the value of documenting this information. In this pilot project, Coker identified the personhood theme, hopes and dreams. The nurses interviewed in Coker's project

felt it was important to learn about the person's goals both fulfilled and unfulfilled. They explained that this information would "foster acknowledgement of the person's progress toward self-actualization"(p.443).

Life Story Guidelines

The two subcategories, values and beliefs, and meaning and purpose, were included in the life story guidelines. In the subcategory values and beliefs, family members were asked to discuss the resident's involvement in a specific faith group throughout his/her life, any religious or cultural practices and rituals he/she finds important. As well family members were asked to comment on the importance of religion in the person's life and to describe any principles that have guided his/her life. In the second subcategory, meaning and purpose, family members were asked to comment on the things that were most important to the resident and to write about the person's goals, both fulfilled and unfulfilled.

Interests

Participants in this project suggested that information should be gathered about the resident's interests. One participant remarked,

> I think it's really important to know what the person did, what their interests were throughout their life, what kinds of social activities did they belong to. Were they interested in sports?

Other staff members commented that they thought it was important to

learn what kinds of activities the resident enjoyed previously. Interests in hobbies, pets, and music were all mentioned as examples of information that would be valuable to include in the life story. One participant summed up the discussion on interests by stating that family members should include "Whatever it is that is most interesting to (the resident) that you could use to relate to them"

Similarly, when family members were asked what information they would include in their relative's life stories, they discussed past hobbies and interests. Knitting, sewing, carpentry, fishing and camping were all mentioned as examples of past interests.

The literature also supports the importance of including past interests in the person's life story. Coker (1998) asked project participants to identify what they considered to be important aspects of a resident's personhood. Interests and activities were identified as one important component . Both past and present interests were considered important. Likewise a personal care book developed by the Alzheimer Society of Canada (1993) suggests including information on those activities the person currently finds pleasurable.

Life Story Guidelines

In order to capture information on both past and current interests two subcategories were included in the life story guidelines . The first subcategory

asked for information on past interests and the second subcategory asked for information regarding current interests. Probes were included in each section. For example, family members were asked to identify conversation topics the resident might enjoy. As well as the hobbies, the sports, or the type of music the person prefers.

Daily Living

The final category derived from the data was Daily Living. While participants wanted the life story to reflect the person's life prior to the onset of AD they also felt the impact the illness had on the person was a significant component of his/her life story. Therefore, the subcategory titled, Impact of Illness was included in the life story guidelines. In addition, the staff members who participated in the project, expressed an interest in learning about the person's daily routines. Learning about past habits and routines was considered important as it would provide staff with the information needed to individualize care for each resident. In order to capture this information a second subcategory, Daily Routines was included under the Daily Living Category.

Impact of Illness

The early stages of AD and, the impact the illness had on the lives of both

the individual and the family caregiver, was discussed in detail in the family member interviews. The impact of those early caregiving years was still vividly recalled and was considered by respondents to be an important component of his/her relative's life story. As one family member, phrased it, "it's a part of who they are". One family member, recounting the important events in his wife's life included the following story about the time he noticed something was wrong.

> When she got sick that became an awkward situation because you didn't know if it was yourself doing it. You'd find things missing and you'd say now where did I put that, then one day you finally catch up that she was the one making mistakes. Took a while, took about three years because they work very hard to hide their problems and if you confront them.... the anxiety..... they'd get themselves all worked up.

He went on to explain how her personality had changed with the onset of the disease. He stated she became "very aggressive. At the very beginning when she found out you knew about it then she became aggressive".

> Similarly another family member talked about the first stages of the disease

and how it changed certain aspects of her husband's personality.

> You know one thing that's funny. You know you have company and leftovers and you say take them. Well he seemed to get upset when they

were taking them which was so completely out of character... Strange. And then my little grandson came to visit and he was jealous of him, so out of character, completely.

Family members also spoke of the challenges in caring for a relative with AD at home. As one family member recalled,

I couldn't trust her at night when we were sleeping she could get up at three in the morning and take off. So I had to remove all the dead bolts off the doors and sort of lock her in and then she wouldn't like that, and when she said she was going out she would use her body to, she wouldn't hit one, but she'd threaten and then she'd use her body to push"

The impact of the disease on the person's life was also considered by staff members to be important information to include in the resident's life story. One staff member stated,

I think it would be interesting to know what the history of the illness has been in terms of time frames. It would be interesting to know from the family member's perspective what that has been like. You know if they had someone who was wandering or aggressive or different things.

Likewise, another staff member, in a separate focus group interview indicated that she would like to know;

> What kind of experiences their caregiver had at home. What they were like at home. So when they come to us we know what to expect or we learn how to deal with a problem the caregiver has already learned how to deal with.

Finally, staff members wanted to learn, from the caregivers, what impact the disease had on the rest of the family:

> Also with the changes in health how the relationships between the spouse and the primary caregiver have changed. You have a couple who travel a lot for example, and then with the decreasing health of one person and how that impacts the other person for if you have a sick spouse you don't want to leave. You want to be there and you don't take the time to do the things you need to do so it impacts on them as well and not just the resident.

Daily Routines

Information regarding daily routines was considered important by staff as it would help them individualize the care for each resident. Staff members expressed an interest in learning the resident's likes and dislikes, what the person likes to eat, and preferences regarding personal care. As one staff member phrased it.

> Some of the little things like when they take their teeth out at night are they out. Do they want to soak them. So they want to wear dresses all the time and when you put them in sweats are you putting them down and you've offended them. Or if they wear socks, some people need to have socks on when they're in bed

Another staff member remarked how it was important to know the resident's routine as it would assist with developing an appropriate care plan. She remarked, "Well you'd know how to approach them. ADL in the morning or care as an evening routine". Likewise another staff member commented that it was important to consider the person's past routine "we have to consider when they just come into a facility their routine at home did they sleep in or when they like to read the paper at a certain time". One staff member summarized the discussion by saying;

> I think the small details are really important because that's how you sort of individualize their care by providing for them what they need. And they feel special because you're doing the things they've done for a very long time.

Life Story Guidelines

The Alzheimer Society of Canada, published A Personal Care Book in 1993. This booklet was designed to provide information to professional

caregivers, in order that they might provide care effectively in the absence of the family member. The second section of this booklet, focused on the daily routines and habits of the person with AD and the impact the disease has had on the person's behavior. While this booklet calls for more detail than was indicated in the life story guidelines, it did serve as a reference in developing the Daily Living section. The two subcategories, Impact of Illness and Daily Routines were included in the life story guidelines. In the Impact of Illness section, family members were asked to include information on when the illness began and the impact the illness had on the rest of the family. In addition, information regarding any changes they had noticed to the resident's personality since the onset of the illness, any difficult behaviors and possible triggers to behaviors was requested. Finally, family members were asked to include any useful tips they had developed for managing difficult behaviors. In the subcategory, Daily Routines, family members were asked to describe a typical day. Probes were provided and suggested including usual wake up time, usual bedtime, preferred times for bathing, and a typical breakfast, lunch and dinner. As well, family members were asked to include information regarding the person's likes and dislikes related to the activities of daily living.

Format

Murphy (1994) describes two main formats for life stories. The first format is a structured format. In this design the caregiver is asked to answer a series of detailed questions. For example, What is your relative's favorite possession? Or, when was s/he born? The questions are often contained in a booklet format and there are assigned spaces left after each question to write the responses. This style of life history is helpful to those family members who prefer to have questions spelled out. However, as Murphy (1994) points out, this format limits the type and amount of information collected and does not allow family members the freedom to include other information that they may wish to include. In addition, it does not allow family members to insert photographs or other pictures throughout the life story.

The second format described by Murphy (1994) is a semi- structured format. In this format the caregivers are given a blank page and provided with headings at the top. Probes on what information would be useful to the staff members are included in each section but family members are encouraged to include any information they think would be helpful. Each page contains a mixture of text and pictures. Family members can write as much or as little as they like and additional pages can be added as necessary. Murphy suggests that the advantage of a semi-structured format is that it offers the person the freedom

to include the things that they think are important. Furthermore, family members are able to add pictures and photographs throughout the story.

The design chosen for the life story guidelines in this project was a semi-structured format. This format was felt to be the most appropriate for several reasons. Firstly, the participants who were interviewed for this project felt that the life stories needed to be tailored to reflect the things that were important to each resident. For example, when one staff member was asked what information he felt should be included in the life story, he responded;

> I would say whatever the family wishes to divulge...Whatever's relevant and it will not be the same thing for every person. In some cases it will be one or two individuals that were important in their life, in another case it will be their hobbies. So I think the important thing is not to make them all fit into one size box.

Another staff member commented that the amount of information that family members would want to include would vary. She stated, "I think some families will write a few lines and others will write a volume." The semi-structured format would allow the family member to tailor the RLS to reflect his/her relative's life by choosing which sections they wished to complete. In addition, family members could decide how much or how little written information they would like to include.

Secondly, in the focus group discussions the staff members emphasized the importance of including pictures in the life story. As one person stated;

> I think having photographs included is really important...For when someone is admitted to a cognitively impaired unit, by that time some of their physical features are changing as the illness progresses. You get a different sense of the person with pictures from the past".

Likewise, another staff member, in a different focus group interview, commented; "I find pictures a really wonderful way of showing who they were before. Old war pictures and wedding pictures. It really helps you to remember they were once young and able to do everything." By using a semi-structured format, family members would be able to insert pictures and photographs throughout the life story.

Thirdly, participants felt the life story should be ongoing. In the words of one staff member, "it needs to be ongoing because people decease, get married and so on". Similarly, another suggested "it could be a flexible thing and then other family members could add to it". Still another staff member suggested that it would be helpful if staff members could also add information to the resident's life story as they came to know him/her better. She thought a separate section in the binder for staff to write what they had learned should be included. In the semi-structured format pages can be added to as required, thus allowing the life story to

be an evolving account of the resident's life. To facilitate the addition of extra pages the life story guidelines were placed in a binder that could easily be opened and closed. A separate page with the title, staff notes, was also included for staff members to add their comments.

Location

During the interviews, participants were asked where they thought the life story guidelines should be located. The nursing conference room and the resident's room were the two locations most frequently cited. While some participants had no concerns about keeping the life story in a prominent place, others expressed concerns regarding the confidentiality of the information. For example one participant remarked, "I would feel like I could tell any of the staff anything and feel it was truly confidential because people are professional". Yet, conversely another participant stated "this is their private story, you don't want everyone to read their private story." Because there was no consensus amongst the participants, the student felt this was an issue that needed to be discussed with each family member as the guidelines were provided.

Of equal concern, was the issue of who should have access to the life story once it was completed. All the participants felt strongly, that those staff members who provided care to the resident should be able to read the life story.

All participants agreed that in order for the life story to be useful, all levels of staff needed to have access to it.

Evaluation of the Life Story Guidelines

Family Members

A total of six family members completed the life stories and returned the evaluation surveys of the life story guidelines. At the end of the project two additional family members continued to work on the life stories, but were unable to complete them within the four week time frame of the pilot project. Overall the responses to the guidelines were positive. Five out of the six family members rated the guidelines as either helpful or very helpful in all four of the areas evaluated. These included: information contained in the guidelines; layout of the guidelines; instructions for using the guidelines; and an overall rating of the guidelines. Only one respondent rated the guidelines as somewhat helpful in the latter 3 areas. A complete summary of the results is presented in Table 2.

Table 2

	Very Helpful	Helpful	Somewhat Helpful	Not Helpful
Information contained in the guidelines	4	2		
Layout of the guidelines	4	1	1	
Instructions for using the guidelines	2	3	1	
Overall rating of the guidelines	3	2	1	

In the second portion of the survey, family members were asked to comment on three questions regarding the usefulness of the guidelines: Did the guidelines capture the type of information you felt was important to include in your family member's life story? Can you suggest any other information that you feel should be included in the guidelines? Can you suggest any information that you feel should be removed from the guidelines? In response to the first question the comments were extremely positive. For example, one family member wrote, "Yes, it breaks it down to categories and gets you thinking as to what to put into each group". And another participant remarked, "Yes, the guidelines are drawing information from all facets of my mom's life". The answers to the second question indicated that the majority of the respondents felt the guidelines were comprehensive and did not identify any information that should be added. For example, one family member commented, "There was ample space to add any personal individual category of information". Another remarked, "no, it seems to be all there". However, one family member suggested that "more step by step written instructions" would be helpful. And one family member noted that adding one question on the impact of the illness on the person with AD would be beneficial for staff. The participant wrote, "Possibly a section on how we feel she is impacted by her situation. Does she truly realize what's happening?" Finally,

in response to the third question, none of the participants indicated that any information should be removed from the guidelines.

Based on the responses to the evaluation surveys two revisions to the guidelines were made. Firstly, written instructions were added at the beginning of the guidelines. Secondly a question was added under the subsection, impact of illness, in the daily living section, to provide family members with the opportunity to comment on the impact of the illness on the impaired elder.

Staff Members

A series of three information sessions were conducted for staff members on a 36 bed, general PCH unit at DLC. The information sessions outlined the purpose of the guidelines and explained the pilot project. In addition, a copy of the guidelines were left on the unit for a four week period. Staff members were asked to review the guidelines and complete an evaluation survey. The evaluation survey consisted of four questions: do the guidelines capture the type of information you feel is important to know about the residents you care for? Can you suggest any other information that you feel should be included in the guidelines? Can you suggest any information that you feel should be removed from the guidelines? And finally, do you have any additional comments? A total of 27 surveys were distributed to all of the nursing staff working on the unit. Unfortunately, only 2 surveys were returned. The low response rate was likely a

result of the pilot project being carried out in the month of July. July is peak holiday time for staff members and a number of staff were away on vacation. Thus, many of the staff members may not have had an opportunity to receive the survey and return it. Due to time limitations, it was not possible to distribute surveys to any additional staff members. Although additional responses from staff would have been beneficial, over 20 staff members participated in the development of the guidelines through their participation in the focus group interviews. The substantial input from staff in the development stage was felt to compensate somewhat for the low participation rate on the evaluation surveys.

The comments from the two staff members were extremely positive. Both respondents felt the guidelines were quite complete. One remarked "Yes, this is a very useful tool for both regular and replacement staff". The other commented that the guidelines were "quite complete". In response to the second question the first staff member commented that the guidelines were "concise and complete". The second participant did not have any suggested additions to the guidelines, but did remark that it would be useful if the guidelines were reviewed and updated by family members every three to six months. No comments were made by either participant in response to the third question and only one of the two respondents commented on the final question. The staff member remarked that he/she would prefer if the information in the life story was "kept concise and easy to read".

Based on the responses from staff members, no additional revisions to the guidelines were necessary. One comment suggesting family members update the life story periodically was added to the written instructions preceding the guidelines.

CHAPTER 5

LIFE STORY WORKSHOP

Purpose

The purpose of the life story workshop was two fold. Firstly, to introduce the guidelines for completing a RLS to family members. Secondly, to assist family members utilize the guidelines to develop a life story that will convey a sense of the unique personality of the person with AD.

Content

Introduction

Two life story workshops were conducted and a total of 14 family members, representing 10 families, attended. Each workshop was approximately two and one half hours in duration. During the first 30 minutes the life story concept was introduced and the rationale for completing one was discussed (Table 3).

Table 3

Why Complete a Life Story?
• **Staff will get to know the person and better understand aspects of the person's behaviour.**
• **The life story can be used as a diversional activity when the person is feeling distressed or distracted.**
• **It can be used by family members when they visit to provide ideas for conversation and reminiscence.**
• **It can be used to tailor care more directly to the needs of the individual.**

As well a detailed discussion outlining what information should be included in a life story was held (Table 4).

Table 4

What goes in a life story?
• **A simple rule is to include what the individual with dementia would want you to include.** • **It is important to remember you are in control of the narrative material.** • **The information should reflect the life of the person with dementia.** • **It is not necessary to complete all sections included in the Life Story Guidelines but rather you should complete the sections you feel are most relevant.**

Workshop Activities

Following the introduction and discussion of the life story concept, the life story guidelines were distributed to family members. Over the next one and a half hours the family members participated in exercises that would assist them to complete a life story for their relatives (Table 5).

Table 5

Workshop Exercises
• **Story Summary** • **Family Tree** • **Time Line** • **Story Telling**

Story Summary

The first workshop activity was developed from a similar exercise described in the article by Murphy (1994). The purpose of this exercise was to emphasize the difficulty in summarizing someone else's life in a few words. Participants were asked to pair up. Each person was instructed to spend five minutes telling his/her partner about an important event that occurred in his/her life. The process was then reversed. Each participant was then asked to spend five minutes writing up a brief summary of the story s/he was told. The summary was to be no longer than two sentences. Each participant was then asked to read what the other person had written and answer the following questions:

- How does it feel to read about an important part of your life second hand?
- How accurate is the summary?
- Has it captured the feelings the event created?
- Has it captured the significance of the event?
- Has the person used your words or his/her own words in writing the summary? And which would you prefer?

Family Tree

In order to assist family members to complete the section titled, Relationships, in the life story guidelines, participants were asked to complete a family tree. A copy of a family tree was provided and each person was asked to fill in the names, date of birth, and date of death (if applicable) for each person in the family. In addition, family members were asked to think about which family members the resident was closest to and who the most important people were in his/her life.

Time Line

The third workshop activity was designed to assist family members to complete the sections titled, Accomplishments and Life Experiences, in the life story guidelines. In this exercise family members were asked to complete a time line. The purpose of the timeline was to map the events and experiences in the person's life against the decades in which they occurred. This activity helped family members recall the chronology of events, as well as the key moments and experiences in the person's life. This exercise was described in the article by Hepburn, et al. (1997) and adapted for use in this project.

Story Telling

The final workshop activity was a story telling exercise. Participants were asked to recall three stories about the resident. Each person was asked to write the

stories down and then begin to search for common themes linking them. This exercise was designed to help family members complete the Personality and Philosophy sections of the life story guidelines by examining what the stories revealed about the character of the person and the significance of certain events in his/her life. As with the third workshop activity this exercise was also described in the article by Hepburn, et al. (1997).

General Discussion

Finally, in order to assist family members to complete the final two sections of the Life Story Guidelines, Interests and daily living, a general discussion was held. Each of the two sections was reviewed and the type of information that could be included was outlined.

Evaluation of the Life Story Workshop

A total of eleven of the fourteen family members who participated in the workshop, completed an evaluation form. Overall, the results from the evaluation were extremely positive. The majority (n=10) of the respondents rated the presenter as above average or excellent in each of the four areas evaluated. These included: Were the stated objectives met? Was the presenter competent in the subject matter? Was the presenter able to answer questions? And finally, did the presenter stimulate and hold the participant's interest? Only one participant rated the presenter as average in the latter 2 of the 4 areas. All of the respondents rated

the content of the workshop as above average or excellent in all three areas assessed. These included: Was the content well organized? Was the content pertinent and relevant? And finally, were the audio visual aids clear? A complete summary of the results is presented in Table 6.

Table 6

Presenter		Excellent	Above Average	Average	Below Average	Un-acceptable	Don't Know
	Met stated objectives	6	5				
	Competent in subject matter	9	2				
	Able to answer questions	8	2	1			
	Stimulated and held interest	6	4	1			
Content							
	Well organized	8	3				
	Pertinent and relevant	7	4				
	Clarity of audio visual aids	7	4				

In the second portion of the evaluation survey, participants were asked three questions: What was the most important information provided in the life story workshop? Do you have any suggested improvements for future workshops? And finally, Do you have any additional comments? The answers to these questions varied, but all the comments were extremely positive. In response to the first question family members commented that one of the most important things learned in the workshop was to realize that the information they provided about their relatives could be useful for staff members. For example, one family

member wrote that she had learned, "that the information given was to be used by personnel to better know the people they are caring for." She continued, "This should result in a more intimate relationship for the resident's benefit." Another participant commented that the most useful information was receiving a copy of the life story guidelines to help "think out the history". Still another remarked that it was valuable to learn "it is very difficult to tell someone else's life story. Even if he is my father. Enlightening". Finally, the comment was written by one participant that "Most important was the sense that this can be a family project and everyone's impact will only enhance the final product".

In response to the second question regarding improvements to the workshop, eight participants did not provide any comments or did not have any suggestions for improvement . However, three participants did provide suggestions for improvement. One family member commented that " a little more one on one guidance with some of the details of filling out the guidelines (would be helpful)". Another wrote that having "actual caregivers in attendance" would be a benefit. And the third participant remarked that it would be nice to "meet as a group and discuss the results later".

Several family members provided additional comments. The remarks made in this portion of the evaluation pointed to the overall success of the workshop from the perspective of the participants. For example, one person

wrote, "I view this as an opportunity to share something with my mom and family members". A second participant remarked that "this session certainly brought back a lot of memories and they will be shared with the resident".

CHAPTER 6

SUMMARY

The placement of a relative with AD in a PCH has been conceptualized in the literature as a period of transition for family caregivers. Following the admission of a relative with AD to a long term care facility family members must establish new ways of caring. The review of the literature, conducted in this practicum, revealed that one way family members can continue to participate in their relative's care is by sharing their expertise in caring for the person with AD with the nursing home staff. While family members report a strong desire to share their specialized knowledge and expertise with staff, they are often uncertain as to how to communicate this information. This practicum evolved in an effort to provide family members with the knowledge and skill required to communicate the specialized knowledge they possess about their cognitively impaired relatives to the staff of a nursing home.

A nursing model of transitions (Schumacher and Meleis, 1994) was used to guide this practicum. In accordance with this model an intervention was applied. Family members were provided with guidelines and taught how to write a life story. This intervention was designed to increase the knowledge and skill level of family caregivers in communicating information regarding their relatives

to nursing home staff. It was hoped that this in turn, would enhance their sense of role mastery as they developed a means to participate in the care of their relative.

The intervention applied in this practicum project was successful in increasing the family members' knowledge and skill in completing a life story. Firstly, the life story guidelines that were developed provided family members with a useful tool that they could use to help them formulate their relative's life story. As one family member commented, the guidelines helped because "it breaks it down to categories and gets you thinking as to what to put into each group". Another family member commented, when he was reviewing the final life story with the student, that " I couldn't have done this without the guidelines, I wouldn't have known where to begin".

Secondly, the life story workshop was also a successful part of the intervention that assisted family members to develop the knowledge and skill required to complete a life story for their relative with dementia. As one family member wrote, "(The workshop) assisted me greatly in how to tell the story". Another commented that "Without the workshop your ideas might not be accurate. The workshop helped to throw ideas around and give more suggestions." Still another participant remarked "(the workshop) clarified the points to be looked for which could therefore assist the nursing care workers".

Thus, both the life story guidelines and the workshop, provided family members with the necessary information and tools to complete a life story for their relative.

It was beyond the scope of this practicum to measure the effect of this intervention on the family caregiver's sense of role mastery, however, there was anecdotal evidence to support the premise that writing a life story provided family members with an effective means to participate in the care of their relative. When asked what was the most important part of the project one family member remarked "that the information given was to be used by personnel to better know the people they are caring for. This should result in more intimate relationships for the resident's benefit". In response to the same question, another participant commented, "that the information supplied will be used and not just left on a table to collect dust". Still another remarked, "that the staff will be looking at this album when it is done". Clearly family members saw the life story as a way to communicate information about his/her relative to the nursing home staff. Finally, one family member commented to the student as she was leaving the workshop that "there is so little I can do for my Dad. This is something I can do for him".

The model proposed that a nursing intervention could be applied that would create conditions that are conducive to a healthful transition. The comments cited above lend support to this premise. Providing family members

with the life story guidelines and conducting a life story workshop was successful in enhancing their level of knowledge and skill in regards to writing their relative's life story. Involving family members in the writing of their relative's life story served as a vehicle for the continuation of caregiving once the impaired elder had been admitted to a long term care facility. These findings were consistent with those reported by Hepburn, et al. (1997). These authors found that the life story workshops "succeeded in involving its participants in a process that integrates them into the life of the institution" (p. 831).

Interestingly, there was also some anecdotal evidence that writing a life story provided family members with an additional benefit that was not anticipated at the beginning of the practicum. One family member wrote, "I found the process of doing the life album very fulfilling for me. It makes you stop and think just how special the people in your life are." Another commented that "The project allowed me to have a more 'at a distance' observation of my husband, his feelings of what was important, and to review his illness: Its onset and progression – an area that I had suppressed along with my emotions of last summer".

According to Schumacher and Meleis (1994) "when a successful transition is occurring feelings of distress give way to a sense of well-being. Subjective well-being during a transition includes effective coping" (p. 124). The comments

reported above lend further support to the model and suggest that in addition to enhancing the family member's sense of role mastery, writing a life story may also have improved the subjective well-being of some participants. The act of writing the life story may in fact have helped some family members cope better with the impact of the dementing illness. These findings were also consistent with those reported by Hepburn et al. (1997). These authors reported that involving family members in family story workshops helped them deal better with the impact of the illness.

A nursing model of transitions provided a useful framework for this practicum project. However, one limitation of the framework was identified. Schumacher and Meleis (1994) identify three types of nursing therapeutics that can be applied to assist clients through a period of transition. Although the authors define each of the types of interventions, the discussion on each type is limited. Future projects designed to apply each of the specific types of interventions will be useful to expand and clarify each of the types of interventions. Further elaboration of the nursing therapeutics will assist practitioners in choosing the type of intervention which should be applied.

Limitations of the Project

Although the project was successful in meeting the stated goal and objectives there are several limitations to the practicum. First, the feedback from

staff, regarding the guidelines was extremely limited. Because only two staff members returned the surveys, the staff feedback should be viewed with caution. There is the possibility that the comments provided by these two staff members do not reflect the opinions of the larger group. Future research, to gather information on the adequacy of the guidelines from a staff member's perspective would be valuable. In addition, a small number of family members participated in the project. Three family members were involved in the development of the guidelines and ten family members participated in the pilot project to trial the guidelines. Because of the small sample size the project results cannot be generalized to the total population of caregivers. However, the inclusion of information ascertained from the literature did ensure that the findings of other research studies were incorporated into the guidelines. Finally, it was beyond the scope of this practicum, to evaluate if the life stories were useful to staff in the planning and provision of resident care. In order to address this issue future research, examining the effect of the life stories on staff members is required.

Implications for Nursing

In the words of Schumacher and Meleis (1994), "because transitions have profound health-related effects on clients, there is a need for nursing therapeutics designed to prevent negative consequences and enhance health outcomes" (p.125). The life story guidelines that were developed in this practicum , as well as the life

story workshop, provide nurses with one intervention that they can apply to assist family members continue their involvement in caregiving following the admission of a relative with AD into a long-term care facility. By providing family members with a copy of the guidelines and teaching them how to write their relative's life story, nurses can assist family members to communicate the specialized knowledge they possess about their relatives with the nursing home staff.

In the future, nurses working in long-term care settings should consider offering the life story workshop to family members in order to assist them to write their cognitively impaired relative's life story. Education initiatives, designed to teach nursing staff about life stories, would help to prepare nurses to conduct the workshops. Finally, examining the value of the information contained in the completed life story for both the nursing home staff and the family caregiver is an important focus for future research.

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Appendix A

Letter Explaining Practicum to Potential Participants: Family Members

Name
Address
Postal Code

Dear (Name):

I am asking for your participation in a project to **develop life story guidelines for family members of cognitively impaired residents residing in a Personal Care Home.** The purpose of this project is to provide family caregivers with a method of communicating the special understanding they have about their cognitively impaired relative, to the staff of Deer Lodge Centre. The project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba. Dr. Cynthia Cameron, Associate Professor of Nursing, at the University of Manitoba, is the project supervisor.

Your name has been chosen from a list provided by Deer Lodge Centre but the staff do not know who will agree to be interviewed. Your participation involves taking part in an interview that will last approximately one hour. The interview will be tape recorded and then the information will be typed. You will be asked some questions about the type of information you would include if you were writing your cognitively impaired relative's life story. Your participation is voluntary and a decision not to participate, will not in any way affect the care of your family member, who currently resides in Deer Lodge Centre. You may withdraw your participation at any time. I will be phoning you in about one week to ask about your willingness to participate in this project. The interview could take place at Deer Lodge or a location convenient to you.

Your responses to the questions in the interview will be confidential and known only to the student and her supervisor. This project will not affect the usual communication between you and the nursing staff at Deer Lodge Centre.

If you have any questions please feel free to contact Cathy Baxter at Deer Lodge Centre at 831-2593 or Dr. Cynthia Cameron at 474-7452.
I hope you will consider being interviewed.

Cathy Baxter, RN,BN (Graduate Nursing Student)

Explanation of Practicum to Potential Participants: Family Members (Telephone Contact)

Hello. My Name is Cathy Baxter, I am a graduate student in the Faculty of Nursing at the University of Manitoba. About a week ago I sent you a letter explaining a project to develop resident life story guidelines. Did you receive the letter? If no, would you like to receive a copy of the letter? I will leave a copy at the nursing station on your family member's unit at Deer Lodge Centre. (If they indicate they are not interested in receiving a letter I will thank them and make no further contact).

(If they did receive the letter I will proceed.) In the letter that I sent I indicated that I would be contacting you to tell you more about the project to develop resident life story guidelines. May I tell you about the project? Is this a good time to talk? (If the person answers 'yes' to both questions, I will proceed) If not, when would it be best for me to phone? (Date) (Time)

I am interested in developing guidelines for family caregivers, that will assist them in completing a Resident Life Story for their cognitively impaired family member who resides at Deer Lodge Centre. The time required to complete the interview would be approximately one hour. You would be asked questions about the information you would like to include if you were writing your relative's life story.

Although participation in the project would not directly benefit you, it is anticipated that the life story guidelines will assist other family members to write a life story for their cognitively impaired resident. The life story can then be shared with the staff of the nursing home to assist in planning and providing care.

It is your decision whether or not you want to participate in the project. Whatever you decide is fine. Your decision will not influence the care your relative receives in any way. If you agree to participate but later change your mind, that is all right. Also, if you would prefer not to answer some of the questions, you do not have to.

Do you have any questions you would like answered? Are you willing to participate in the project? (If willing, arrangements for an appointment will be made. If not interested, the person will be politely thanked for his/her time and no further contact made).

Appendix B

Key Informant Consent Form

I, _____agree to participate in the practicum project, to develop resident life story guidelines.

I understand that this project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba. I have been informed that Cathy Baxter is being supervised by Dr. Cynthia Cameron, Associate Professor of Nursing at the University of Manitoba.

I understand that the purpose of this project is to provide family caregivers with a method of communicating the special knowledge they possess, about their cognitively impaired relative, to Deer Lodge Centre staff.

I will be interviewed once in an interview room at Deer Lodge Centre (or other place of my choosing). The interview will take approximately one hour to complete. I agree that the interview will be tape recorded and then the information typed. The typed information will be kept in a locked filing cabinet for a period of seven years. I understand that at the conclusion of the study the tapes will be destroyed.

I understand that all the information I reveal will be kept strictly confidential and when the information from the interviews is written up in the report, my identity and the identity of my family member residing at Deer Lodge Centre will be kept strictly confidential. No one other than the student and her supervisor will see my responses.

I understand that my participation in this project is completely voluntary, and that a decision not to participate, will not in any way affect the care of my family member, who currently resides in Deer Lodge Centre. I understand that I am free to withdraw from the project at any time; and that I am free to refuse to answer any question. The risk associated with participation in this project is minimal. If I find any of the questions difficult to answer, the interview can be stopped. If following the interview I would like to discuss any issues further, a referral to another health care provider can be made. Upon completion of the project, a copy of the Life Story Guidelines will be sent to me if I wish.

A copy of the consent form will be provided to me. If I have any questions following the interview I can contact Cathy Baxter at 831-2593 or Dr. Cynthia Cameron at 474-7452.

My signature below indicates my willingness to participate.

Signature_____Date_____

Witness_____

Please forward a copy of the Life Story Guidelines to me:

Name_____

Address_____

Appendix C

Key Informant Interview Guide

Pre-Interview data

Identification number: _____

Date of interview_____

Gender of respondent: M_____ F_____

Relationship to cognitively impaired elder residing in

DLC:_____

Length of time relative has resided in DLC_____

Additional comments regarding interview

_____

_____

_____

_____

_____

_____

Interview

A resident life story conveys information and detail regarding the life of a person who can no longer act as his/her own historian. The purpose of the following

interview is to identify what information you, as a family member, see as important to include in a life story. Interviews are also being conducted with staff members to find out what information they would like to see included in a resident life story. Finally a review of the literature has been conducted. The information from all of these sources will be used to develop guidelines, that will assist other family members, to prepare a life story for their cognitively impaired relatives.

Interview Questions for Family Members

1. What can you tell me about your relative that would help the nursing home staff get to know him/her better as a person? (Possible probes: employment history, community involvement, family involvement)
2. What would you identify as the major events in your family member's life? (Possible probes: happy events, previous trauma)
3. What information, about your family member's personality prior to his/her illness, would you identify as important to include in the life story (Possible probes: fears, coping strategies, need for privacy).
4. If you were going to write your family member's life story, what additional information would you include? (Possible probes: any photographs, favourite objects, books, foods, clothing preferences, hobbies, interests)

5. Can you now tell me if there is any information that you feel should not be included in your family member's life story? (Possible probes: Information your family member may feel is too personal)
6. Who do you think should have access to the information contained in the Resident Life Story?
7. Do you have anything else you would like to add?

Appendix D

Letter Explaining Practicum to Potential Participants: Staff

Name
Address
Postal Code

Dear (Name):

I am asking for your participation in a practicum project to **develop life story guidelines for family members of cognitively impaired residents residing in a Personal Care Home.** The purpose of this project is to provide family caregivers with a method of communicating the specialized knowledge they possess about their cognitively impaired relative, to the staff of Deer Lodge Centre. The project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba. Dr. Cynthia Cameron, Associate Professor of Nursing at the University of Manitoba is the project supervisor.

Your name has been chosen from a list provided by Deer Lodge Centre but your participation in the project will be kept confidential. Your participation involves taking part in a focus group interview that will last approximately one hour. You will be asked some questions about what information you, as a staff member, would like to see included in a resident life story. The interview will be tape recorded and then the information typed. Your responses to the questions in the focus group interview will be confidential and known only to the other focus group participants, the student and her practicum supervisor.

Your participation is voluntary and a decision not to participate, will not in any way effect your employment at Deer Lodge Centre. You may withdraw your participation at any time. The focus group interview will take place at Deer Lodge in room (--) and will be held on (date) at (time). If you are interested in participating in a focus group interview, please complete the attached response form and return it in the envelope provided. A box will be located at the nurses station/reception area to collect the completed forms. Once I receive your response form I will contact you by telephone to confirm your participation.

Please feel free to contact Cathy Baxter at Deer Lodge Centre at 831-2593 or Dr. C. Cameron at 474-7452.
I hope you will consider being interviewed.

Cathy Baxter, RN,BN (Graduate Nursing Student)

.....

Name_____

Phone Number_____

I would like to participate in a focus group interview _____

I will attend the focus group on (Date) _____ (Time) _____

Explanation of Practicum to Potential Participants: Staff (Telephone Contact)

Hello. My Name is Cathy Baxter, I am a graduate student in the Faculty of Nursing at the University of Manitoba. I indicated in a letter that I left on the nursing unit that I would be contacting you to tell you more about the project to develop resident life story guidelines.

May I tell you about the project? Is this a good time to talk? (If the person answers 'yes' to both questions, I will proceed) If not, when would be the best time for me to phone? (Date) (time).

I would like to thank you for volunteering to participate in a focus group interview. During the interview you will be asked questions about what information you, as a staff member, would like to see included in a resident life story. The time required to complete the focus group interview will be approximately one hour.

Although participation in the project would not directly benefit you, it is anticipated that the life story guidelines will assist family members to write a life story for their cognitively impaired relative. The life story can then be shared with the staff of Deer Lodge Centre to assist in the planning and provision of care.

It is your decision whether or not you want to participate in the project. Whatever you decide is fine. Your decision will not influence your employment at Deer Lodge Centre in any way. If you agree to participate but later change your mind, that is all right. Also, if you would prefer not to answer some of the questions, you do not have to. You can refuse to answer any questions you want to.

Do you have any questions you would like answered? Are you still willing to participate in the project? (If willing, the date, time and location of the focus groups will be discussed. If not interested, the person will be politely thanked for his/her time and no further contact made).

Appendix E

Focus Group Participant's Consent Form

I, _____ agree to participate in the practicum project to develop resident life story guidelines.

I understand that this project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba. I have been informed that Cathy Baxter is being supervised by Dr. Cynthia Cameron, Associate Professor of Nursing at the University of Manitoba.

I understand that the purpose of this project is to provide family caregivers with a method of communicating the special knowledge they possess about their cognitively impaired relative, to the staff of Deer Lodge Centre. The purpose of the following interview is to identify what information I, as a staff member, would like to know about the cognitively impaired residents I care for.

I will participate in one focus group interview which will be conducted in one of the classrooms at Deer Lodge Centre . The interview will be approximately one hour in length. I agree that the focus group interview will be tape recorded and the information transcribed. I understand that at the conclusion of the study the tape will be destroyed.

I understand that all the information I reveal will be kept strictly confidential and when the information from the focus group interviews are written up in the practicum report, my identity will be kept strictly confidential. No one other than the student and her practicum supervisor will see my responses. Upon completion of the project, a copy of the Life Story Guidelines will be sent to you if you wish.

I understand that my participation in this project is completely voluntary; and that a decision not to participate, will not in any way affect my employment at Deer Lodge Centre. I understand that I am free to withdraw from the project at any time; and that I am free to refuse to answer any question. A copy of the consent form will be provided to me.

My signature below indicates my willingness to participate.

Signature_____

Witness_____

Date_____

Please forward a copy of the Life Story Guidelines to me:

Name_____

Address_____

Appendix F

Focus Group Interview Guide

Pre-Interview data

Identification number: _____

Date of interview_____

Number of participants_____

Type of care worker (RN/RPN, HCA, Social Worker)

_____

Additional comments regarding

interview_____

_____

_____

_____

_____

_____

Interview

A resident life story conveys information and detail regarding the life of a person who can no longer act as his/her own historian. The purpose of the following interview is to identify what information you, as a staff member, would

like to see included in a resident life story. Interviews are also being conducted with family caregivers, of cognitively impaired residents residing at DLC and a review of the literature has been undertaken. The information from all of these sources will be used to develop guidelines, that will assist family members, to prepare a life story for their cognitively impaired relatives.

Interview Questions

1. Can you begin by telling me what information you would like to know from families about the cognitively impaired residents you care for?
2. I would ask you to be a bit more specific now and tell me what information you would like to see included in a resident life story? (Possible probes: life events, work history, community involvement, family history, hobbies, interests, values)
3. How do you see yourselves using the guidelines? (Possible probes: planning care, recreation activities)
4. Where do you think the guidelines should be located?
5. Does anyone have anything to add?

Appendix G

Attention Family Members

If you have a family member who has Alzheimer's Disease and resides in Deer Lodge Centre, you are invited to participate in a:

Life Story Workshop

The purpose of this pilot project is to evaluate the usefulness of guidelines that have been developed to assist family members to complete a life story for their relatives who reside in Deer Lodge Centre.

For more information please contact Cathy Baxter at 831-2593

Appendix H

Letter Explaining Pilot Project to Potential Participants: Family Members

Name
Address
Postal Code

Dear (Name):

I am writing to ask for your participation in a pilot project to **evaluate the usefulness of guidelines that have been developed to assist family members, to complete a life story for their cognitively impaired relatives who reside in Deer Lodge Centre.** The project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba.

Your participation involves taking part in a workshop that will take approximately three hours. There is no charge to participate in the workshop. During the first hour, the idea of Resident Life Stories, will be introduced and discussed. In the two hours remaining you will be given information that will assist you in completing a life story for your cognitively impaired family member. At the end of the workshop you will be asked to complete a life story using the guidelines provided. You will be asked to complete the life story in three to four weeks. Once you have completed the life story, you will be asked to fill out a short survey evaluating the usefulness of the guidelines.

It is anticipated that the life story guidelines will assist other family members to write a life story for their cognitively impaired relatives. The life story can then be shared with the staff of the nursing home to assist them in planning and providing care.

This project will not affect the usual communication between you and the nursing staff at Deer Lodge Centre. Your participation is voluntary and a decision not to participate, will not in any way affect the care of your family member, who currently resides in Deer Lodge Centre. You may withdraw your participation at any time. If you are interested in attending the workshop and participating in the pilot project, please complete the attached response form and return it in the envelope provided. A box will be located at the nurses station to collect the completed forms. Participation in the project will be liinited to five family members per workshop. Once I receive your response form I will contact you by telephone to confirm your participation.

I hope you will consider participating in this project. If you have any questions you can contact Cathy Baxter at 831-2593 or Dr. C. Cameron, project supervisor, at 474-7452.

Cathy Baxter, RN,BN (Graduate Nursing Student)

.....

Name_____

Phone number_____

I would like to participate in the pilot project _____

I would like to attend the following workshop (Date) (Time) _____
(Date) (Time) _____

Explanation of Pilot Project to Potential Participants: Family Members
(Telephone Contact)

Hello. My Name is Cathy Baxter, I am a graduate student in the Faculty of Nursing at the University of Manitoba. I received your registration form to participate in the Resident Life Story Workshop on (date).

Is this a good time to talk? (If the person answers 'yes' to this question, I will proceed with **a or b**)

a) I wanted to thank you for registering for the workshop and to confirm that there is space available on the date you requested. Do you have any questions about the project you would like answered? Thank you again for your interest in the project. I will see you on (date), (time) and (location).

Or

b) I wanted to thank you for registering for the workshop, unfortunately the workshops are full. If you would like I will place your name on a waiting list and contact you if any one cancels. (The person will be politely thanked for his/her interest in the project. Further contact will only be made if space in one of the workshops becomes available).

Appendix I

Pilot Project Consent Form: Family Member

I, _____agree to participate in the project, to develop resident life story guidelines.

I understand that this project is being conducted by Cathy Baxter, a graduate student in the Faculty of Nursing at the University of Manitoba. I have been informed that Cathy Baxter is being supervised by Dr. Cynthia Cameron, Associate Professor of Nursing at the University of Manitoba.

I understand that the purpose of this project is to provide family caregivers with a method of communicating the special knowledge they possess, about their cognitively impaired relative, to Deer Lodge Centre staff.

I understand that my participation involves taking part in a workshop that will be approximately three hours. There is no charge to participate in the workshop. At the end of the workshop I will be asked to complete a life story using the guidelines provided. I will be asked to complete a life story in three to four weeks. Once I have completed the life story, I will be asked to fill out a short survey evaluating the usefulness of the guidelines.

I understand that all the information I reveal will be kept strictly confidential and when the information from the surveys is written up in the Project report, my identity and the identity of my family member residing at Deer Lodge Centre will be kept strictly confidential. The responses from the surveys will be stored for seven years in a locked filing cabinet. No one other than the student and her prroject supervisor will see my responses.

I understand that my participation in this project is completely voluntary; and that a decision not to participate, will not in any way affect the care of my family member, who currently resides in Deer Lodge Centre. I understand that I am free to withdraw from the project at any time; and that I am free to refuse to answer any question. The risk associated with participation in this project is minimal. If I find any of the questions difficult to answer, I can withdraw from the workshop. If, following the workshop I would like to discuss any issues further, a referral to another health care provider can be made. Upon completion of the project, a copy of the Life Story Guidelines will be sent to me if I wish. A copy of the consent form will be provided to me.

If I have any questions following the workshop I can contact Cathy Baxter at 831-2593 or Dr. Cynthia Cameron at 474-7452.

My signature below indicates my willingness to participate.

Signature_____ Date_____

Witness_____

Please forward a copy of the Life Story Guidelines to me:
Name_____

Address_____
_____
_____

Appendix J

Life Story Workshop Evaluation Form

The purpose of the following evaluation is to assess if the Resident Life Story workshop provided you with the type of information you needed regarding life stories. The comments you provide will be used to make revisions to the workshop. Would you please take a few moments to evaluate the session you have just attended? Thank you.

Instructions: *Please circle the number that best represents your response to each question. Feel free to explain your responses in the space provided following this section.*

Presenter	Excellent	Above Average	Average	Below Average	Unacceptable	Don't know
1. Met stated objectives.	5	4	3	2	1	0
2. Competent in subject matter.	5	4	3	2	1	0
3. Able to answer questions.	5	4	3	2	1	0
4. Stimulated and held interest	5	4	3	2	1	0
Content						
1. Well organized	5	4	3	2	1	0
2. Pertinent and relevant	5	4	3	2	1	0
3. Clarity of Audio Visual Aids.	5	4	3	2	1	0

-

_____

_____

_____

_____

What was the most important information to you?

Do you have any suggested improvements for future Resident Life Story Workshops?

Additional Comments.

Appendix K

Family Members Evaluation of the Resident Life Story Guidelines

The purpose of the following evaluation is to assess if the Resident Life Story Guidelines were helpful in assisting you complete a life story for your relative. The comments you provide will be used to make revisions to the guidelines.

Please circle the number that best represents your response to each question. Feel free to explain your responses on the line next to each rating.

	Very Helpful	*Helpful*	*Somewhat Helpful*	*Not Helpful*
Layout of the guidelines.	**4**	**3**	**2**	**1**
Information contained in the guidelines	**4**	**3**	**2**	**1**
Instructions for using the guidelines	**4**	**3**	**2**	**1**
Overall rating for the guidelines	**4**	**3**	**2**	**1**

1. Did the guidelines capture the type of information you felt was important to include in your family member's life story? Please comment

_____

_____

2. Can you suggest any other information that you feel should be included in the guidelines?

_____

_____

_____

3. Can you suggest any information that you feel should be removed from the guidelines?

_____

_____

_____

4. Did you find the workshop helpful in assisting you to complete a life story for your relative? _____

_____

_____

5. Do you have any additional comments?

_____

_____

_____

Appendix L

Staff Members Evaluation of Resident Life Story Guidelines

The purpose of the following evaluation is to assess if the Resident Life Story Guidelines capture the type of information you would like to know about the cognitively impaired residents you care for. The comments you provide will be used to make revisions to the guidelines.

1. Do the guidelines capture the type of information you feel is important to know about the residents you care for? Please Comment.

_____

_____

_____

2. Can you suggest any other information that you feel should be included in the guidelines?

_____

_____

_____

3. Can you suggest any information that you feel should be removed from the guidelines?

_____

_____

_____

4. Do you have any additional comments?

_____

_____

_____

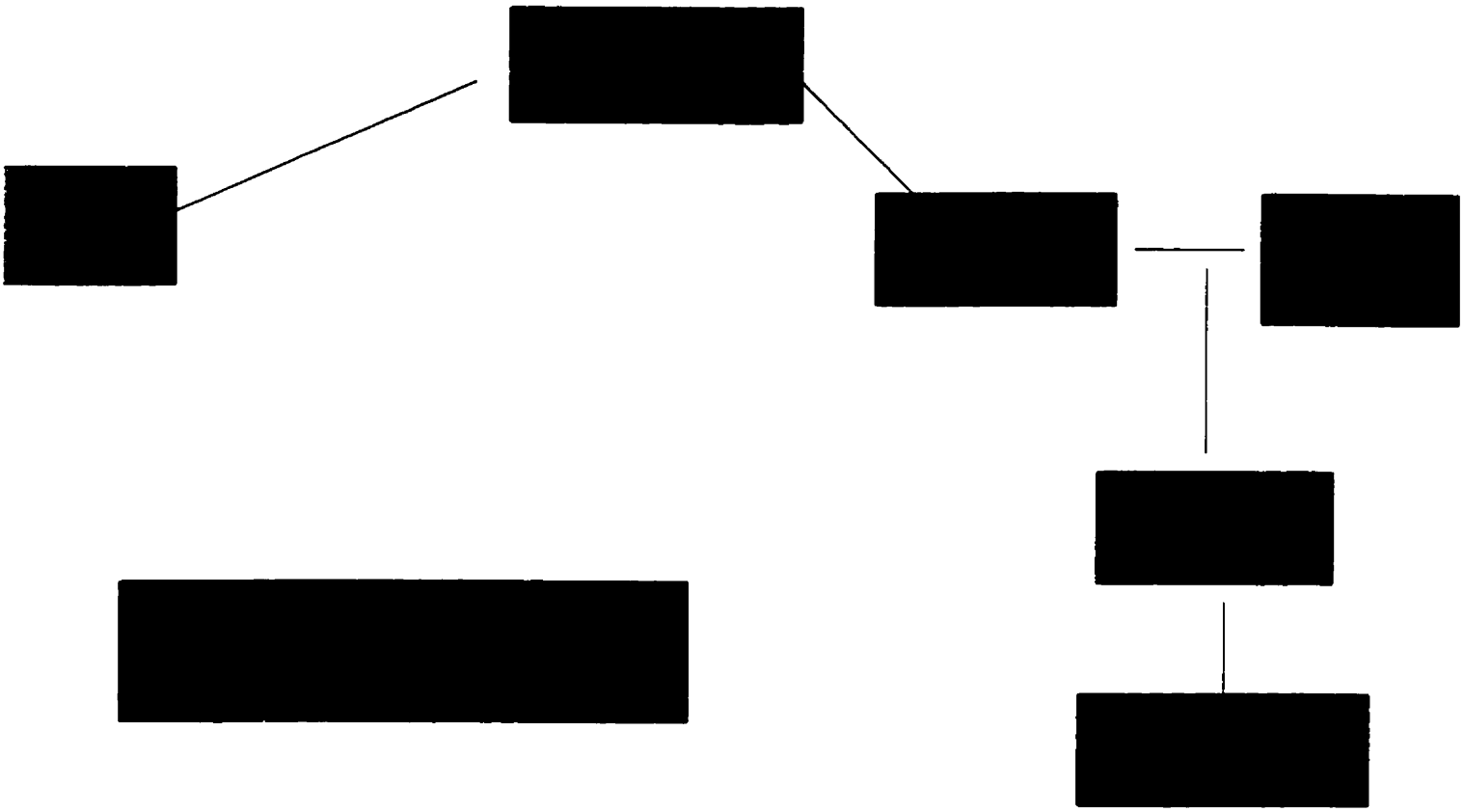
Appendix M

LIFE STORY GUIDELINES

Instructions

1. There is no right way or wrong way to write the life story. Don't worry about being complete. It is more important to reflect the life of the person with dementia as you want it reflected.
2. You are writing the life story of your family member. Include only that information that you want to include or that information you think your family member with dementia would want you to include. It is not necessary to complete every section of the guidelines. Complete the sections you think are relevant.
3. You can write as much or as little as you like. Photographs, pictures, postcards or mementos can be added to supplement the written information. If you don't want to include original photographs or pictures, color photographs can be used instead.
4. A three ring binder or photograph album can be used to store the life story information. This will allow you to add information as you wish. Remember the person's life is still ongoing and important events can be added as they occur. Updating the book regularly will also help keep the information current.
5. It is important to consider who you would like to read the life story when it is finished. When you bring the life story into the facility talk to the nursing staff about where you think it should be located. Some possible locations are; your family members room, or the nursing conference room.

Relationships



Family Relationships: (Who is s/he closest to? Which family members visit regularly? Which family members provide the most support? How important is family? Are there any family members s/he no longer sees?)

Friendships: (Who are his/her closest friends? Does s/he still have contact with them?)

Life Experiences

Major Life Events: (i.e. Childhood experiences; cities/countries lived in; places traveled; courtship and marriage experiences)

Milestones (Birth; graduation; marriage; birth of children; retirement; divorce)

War Experiences: (i.e. Dates of service; type of service; country s/he served in; if s/he was a POW; if s/he likes to talk about the war).

Traumatic Events/Difficult Times

Accomplishments

Major Achievements:

Lifetime Occupations:

Community Activities:

Personality

Personality Traits: (i.e. Character; strengths and abilities; talents; fears; what does the person prefer to be called)

Personal Boundaries: (Need for privacy; personal space; preference for being in groups or alone; what topics would the person share with others; what topics are too personal to discuss; comfort with male vs female caregiver)

Interests

Past Hobbies and Activities: (i.e. Crafts, woodwork, reading, sports, music)

What currently gives him/her the most pleasure? (i.e. conversation topics, type of music, activities, pets, walking)

Philosophy

Values and Beliefs (Importance of religion; involvement in a specific faith group; religious practices and rituals; principles that guide his/her life)

Meaning and Purpose: (What is most important to him/her? What goals have been fulfilled? Are there any unfulfilled goals?)

Daily Living

Impact of Illness

The illness began.....

Impact of the illness on the rest of the family:

Impact of the illness on the resident:

Personality changes since the onset of the illness:

Any difficult behaviors? (i.e. wandering, restlessness, agitation or aggression)

Possible triggers to behaviors: (i.e. bathing, dressing, toileting, noise, being rushed, gender of caregiver)

Useful tips for managing behaviors:

Daily Routines

A Typical Day (usual wake up time, usual bedtime, bedtime routines, a typical breakfast, lunch and dinner, preferred times for bathing,)

Morning

Afternoon

Evening

(i.e. specific likes and dislikes related to, dressing, bathing, eating and sleeping)

Staff Notes