

Just Managing: Lifeworlds While Waiting for Long Term Care

by

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Abstract

The purpose of this qualitative study is to understand the life world of older people who are waiting to be admitted to long term care. Four older women were interviewed, the interviews transcribed and analyzed for themes. Of the four women, one was frustrated and impatient with the need to wait; three were continuing to live to the best of their abilities coping with their various illnesses but not focusing on the length of the waiting time. Themes common to several participants were: coping with social isolation, not wanting to be a burden on friends and family and using life experience to deal with the present and the future. Individual themes included fear of living alone, making the best of things, gratitude for the past and worries about the future.

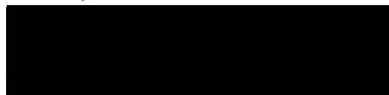
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Dedication

To The Unheard

I don't want to move

"I don't want to move," she said
sitting among her life

The cactus came from Home,
It's a piece of Mother's
We brought it here in 1911.
We got those plates in China
We were all born in that bed
That painting is like the fields where we walked in Devon
Oh Father gave me some money and I had that furniture made
Father and Mother bought that on their honeymoon in 1898
We gave that tea set to Mother
Mother and Aunt each bought 6 cups and saucers
Aunt gave her 6 to Mother
Father liked that one because of the cow

One of the children gave me that
Don't throw it out.

CHAPTER 1

INTRODUCTION

Preambles

Raison d'être: The Process

Once upon a time there was a woman of a certain age who said to herself, *I want to learn more, now is a good time to fulfill an ambition, do my MA.* Work in an intermediate care facility as a private companion and as an activity assistant provided questions for a thesis about relocating to the care home. At least that is what she thought it was about. A very positive aspect of working in the care home was learning how to rescue people when they were no longer able to be independent with some of their activities of daily living, helping them in a respectful way and responding to their reality, whatever it might be. This was a huge contrast from the Early French Immersion classroom, her former venue.

Much of the day in the care home was like play, helping people to be contented, having no agenda or responsibility to help them along the road to a successful life. Loving and enjoying people while marvelling at the mysteries of the human brain was how she saw her job. That might sound ideal, but eventually it would not be enough. She wanted to try to help new residents and their families who were finding entry to the care home difficult. Some new residents were settled in quickly, attended activities, made friends, did not appear to make their families feel guilty for having abandoned them; others withered away and died within a short time. She saw that once an Alzheimer's type illness was established, a meek and mild person could become quite the opposite. She was curious.

How is it that some people adjust so well to the care home and others don't? Have they had experiences in their lives that help them adjust? What is it like to be waiting, knowing you are coming in? Are there things people do that help them prepare for this move? Some have already downsized from houses to apartments to sheltered housing, how do they do that? Do collected possessions become burdens? How do they know what to keep?

During the time that she was pondering these questions her father had been in extended care and died, and her stepmother had moved from the family home, to

sheltered housing, to a care home and had died. She, herself, was now living in the family home with generations of collected possessions. Her aunt, another collector, had moved to a smaller apartment in sheltered housing. The woman in question had been intimately involved with that move and the sorting of possessions. The woman, herself, had moved four times in five years, each move because of changes in her nuclear family or job.

A project about relocating to long term care exploring the lived experience of waiting for placement incorporated what she wanted, a qualitative study interviewing people who were waiting to enter long term care and expecting to have their names come up within six months of the second interview. She received approval, found participants and interviewed them. Much to her chagrin and surprise, somewhere during the time it took to complete the interviews, transcription and analysis, the thesis took on a life of its own. It was no longer about only the participants but about herself, her beliefs, her perspectives on the world and how she interpreted her life and that of others. Stories and poems erupted.

Was this a thesis? Maybe the story-poems were only a step to understanding and would have to be rewritten in objective prose?

Such thoughts caused considerable trepidation, procrastination and fear.

Another shift occurred. The thesis was no longer about waiting for the future but about life in the present.

What was life like at this moment in time for these people? How were they coping with their various illnesses and losses? What was important to them? What life experiences were they expressing in the interview? Did the past and present connect? What were they thinking about? What were they feeling? What would they tell her?

She wanted to see through their eyes. First she had to be able to see through her own so she read and reflected. *What was important? What threads ran through her life?* She wrote of herself in the third person. In her journal, she wrote of her aunt in the first person and caught a glimpse of what it could be like to be her participants. But she had always known her aunt, the participants, were comparative strangers. Repeated listening to the audio tapes, reflection, reading 'how to' from experts, allowing insights to surface, selecting lines and stories, reflection, listening for nuance, reflection, listening for the

unspoken, reflection, fitting the voice to the participant, questioning if this approach was really a thesis, all that took months.

Ann Insight: The Greatest Gift is Time

When I am old and lonely
I want the young ones to listen to my stories
over and over
until they are word perfect

In my middle age, the old ones' stories
enrich me
I feel complete
content
richly full
satisfied from hours well spent
time with an old one
no eye on the clock
eager to leave

Inspired
Enriched
Fully content with now

Problem and Significance

Early in 1993 my father was admitted to an acute care hospital and then put directly into an extended care facility. The decision of the medical personnel and his wife, his primary caregiver, was that it was not possible to care for him at home. He lived until the summer of 1995, never having come to terms with the move (he called the residents, himself included, “inmates”). I felt very guilty that I could not bring him home to be looked after and that I could not do more to help him understand why he was in a facility. He had had no part in the decision to live in extended care and like others I have met would not have been able to admit they needed the care provided in a facility.

This personal experience piqued my curiosity and had sharpened my observations while at work in an intermediate care facility. Some new residents appeared to adjust easily, others did not. I began to ask questions. Was the transition to long term care a common problem? How did people adjust? Were there people who made the transition easily? How was that accomplished?

The research literature shows that relocation to long term care is difficult for many people. In 1992, Barnhouse, Brugler, and Harkulich (as cited in Johnson, 1996) used the diagnostic label “relocation stress syndrome” to encompass the symptoms exhibited by many of the older people. Such a label may legitimize to medical professionals some of the symptoms shown by many older people after they move but is such a label necessary? It is a medicalization of a socially constructed problem wherein the older person is labeled as “the problem.”

Purpose

The purpose of this study is to try to understand the lifeworld of older people who are waiting for relocation to a long term care facility. Van Manen (1997) uses Husserl’s definition of lifeworld as the “world of immediate experience” (Husserl, 1970, as cited in Van Manen, 1997, p. 182).

Interviewing people at this time is significant because the studies that I have read gathered data after the client had entered the facility (Johnson, Schwiebert, & Rosenmann, 1994; Reinardy, 1995; Young, 1998). Some researchers have interviewed

family members but not the residents (Dellasega & Mastrian, 1995; McAuley and Travis, 1997; Rodgers, 1997). I interviewed people who expected to enter care within approximately six months. It was important to find cognitively unimpaired participants who were willing and able to articulate their feelings and preparation processes, if present, while they were on the waiting list.

Interviewing those who are not significantly cognitively impaired is both a strength and a limiting factor of this study. The strength is that they can be interviewed and can articulate their feelings. A limiting factor is that many of the people entering care homes have some form of dementia. The ability to understand that they are waiting for a place in a long term care facility may not be possible for those people who cannot relate cause to effect or who have considerable short term memory loss. From my experience there are many new residents who do not understand why they are in a facility and are angry at being there, apparently abandoned by family. By gaining an understanding of how people with no obvious cognitive impairment feel as they approach long term care it may be possible to ease the adaptation process for the physically frail older person.

Johnson (1996) has studied the meaning of relocation for a group of elderly religious sisters who were living in a Motherhouse that was to be renovated. The moves were not by choice. She cites Colsher and Wallace (1990) by saying "Relocation has been found to be preceded by depression, anxiety, declining functional ability and self-perceived health, and decreased life satisfaction" (p. 173). She says that there has been limited research into the reasons why relocation produces such negative effects when it could result in greater benefits. Perhaps it is in the weighing of the benefits; for example, the loss one's own home and control of daily activities against more social contact, decreased work load, nursing care and physical security. Johnson interviewed her participants two weeks after relocation (p. 176). The renovations occurred during one year and the sisters were kept informed of the progress during that time. In spite of the help that they were given and the vows of obedience that were a part of their lives there was evidence of relocation stress syndrome (p. 183).

The people with whom I have worked have had little or no formal support for their move. The nursing assistant does an orientation with the new resident and the family

and a longtime resident welcomes the person with a visit and a small gift. The new resident does not have an uninvolved person available with whom to talk about their move. The ability of family members to be supportive varies considerably because they have to come to terms with their own feelings at this time. It could be very beneficial to have an intervention available for those who need it but what will help? Johnson (1996) says:

Careful assessment for relocation stress syndrome and the extent to which the elder is adapting to the idea of relocation and to the actual relocation, is critical for nurses. Further study of how relocation stress syndrome is differentially manifested in elders with varyingly elaborate support networks will help nurses plan interventions that are sensitive to the particular needs of these elders. (p. 184)

Not only the nurses are part of the interventions, but the elders themselves, their families, and community workers. Given the wealth of life experience of older people, listening to what they are experiencing is, to me, both logical and appropriate as a first step.

In order to understand to the best of my ability the lifeworlds of my participants, I wrote and reflected upon anecdotes from my life. Those which I believed would help the reader see through my lens, are included.

Relocating Ann

Part of my attachment to this topic is my personal experience with relocation. In 1994 the opportunity arose to move into my parents' retirement home. My father was in extended care and my stepmother had had a stroke which necessitated her relocation from the family home. This was, for me, a sudden life change. I took a leave of absence from my teaching position and moved 225 kilometers back to the community where I had been raised, but had not lived for 30 years; to a house which I had visited during those 30 years but which had not been my home. I made the life change decision for both emotional and practical reasons. I wanted to spend more time with my father before he died, try to help my stepmother and I was ready for a change from teaching full time in the early French

Immersion program. My siblings and I wanted a family member to occupy the house. My father had moved to this community in 1930. As a family we don't relocate very often or, in my case, easily.

Moving is traumatic for me. To become "at home" I settle in very gradually, assessing my situation then checking my comfort level. My mental image is of a Mother Goose figure settling carefully into her nest. In the next section I will elaborate on my relocation of 1989 before which I had taken time to reflect on the ramifications and repercussions of moving and had said good-bye to that portion of my life before moving on. I made the 1994 decision in less than a month. As I was packing my classroom I felt that I would never return to either living in that community or to teaching. A chapter of my life had ended. I was leaving my identity as an established member of the teaching community. Colleagues and others in the community had become close friends so I was leaving a supportive social network. To me, the way in which this relocation occurred could be similar to a move from home to long term care.

How would I adjust? What would I keep? Some family members and childhood friends would be close by, would that help? How would I find new friends? How would I occupy myself?

In 1994 I was physically moving home, to the community of my childhood where I had not lived for more than 30 years. I was moving to a house that held memories of a teenager who was ready to leave but whose parents seemed to be holding on. As the youngest and only female child I felt obligations to my parents that, in my mind, differed from those of my brothers. The house, itself, had more unhappy feelings associated to it than happy memories. *Could I adapt?* I asked myself this question many times in the two months preceding the move. *How could I be me?* In some ways there was a time warp. I felt as if 30 years of life experience were being erased, I was once again a confused eighteen year old, wondering whom to please, if I were competent at anything, where I was headed.

Today my adaptations to this place are like those of a plant which takes a few years to thrive after being transplanted. My roots are here in the family home; photos, mementos, furniture, all are familiar. I have added my belongings, representations of the

life I have led as an adult. Slowly, I am changing the place to fit the twists of my growth. As these changes make this place home, my spirit flowers and is content. The fruit that I envisage is the sense of family continuity to the next generations when my nieces and nephews bring their children to visit as they were brought by my siblings.

The 1989 move had been planned. I had taken two years to prepare emotionally and physically. It was from the community where I was successively newly married, a teacher, a member of the community, a new mother, divorced, a single mother. Twenty years of growth and experience physically far away from my family for most of the year had encouraged self-reliance. It was time though, to move closer to my parents and for my children to be adolescents in another environment. Also, I wanted to establish myself professionally in a gentler climate before retirement. The process took two years from the time that I made to decision until the move, similar to the length spent on the waiting lists of some long term care facilities. Since I began this study, the admitting policy for long term care has changed but still people have to wait. I remember my process, consciously saying goodbye to the house I had designed, the land, and my favorite places; preparing my children, sorting “stuff” physically and emotionally; rearranging priorities, loosening ties. In outwardly obvious ways the move was positive.

What brings pain in my heart and tears to my eyes as I write this is the loss of the space where I felt truly free and at one with my natural spirit. I picture myself roaming that land of clean sharp air, the scents of the forest and fields. I forget the frustrations of -40 C, the narrow-mindedness of some of the people, the sheer volume of work, the distance to travel, the bugs.

Is this how an older person facing institutional life feels, remembering what touches the heart, knowing one can't go back? Perhaps moving to long term care is more like the first move I described, unanticipated, unprepared for, needing a long adaptation time afterwards.

Moving to long term care is, I assume, different from the moves that I made by choice while physically and mentally capable. From my reading of qualitative research methods I assume that that the experience is varied but I am curious to know how others will articulate that experience.

Long Term Care is Different From One's Home.

One of the reasons for an older person to move is to be nearer to family (Choi, 1996, p. 326) so a care facility could be chosen for that reason. The facility may be located in a community far from the person's former home. Keeping old friends can be difficult when a person of any age relocates but physical infirmities of self and aging friends can add to the difficulties of maintaining social support when the move is to another community.

In most care homes residents have no control over meal times, tea times, or bath time. They have one room or may share a room. Privacy is very limited. The behaviors of some residents may be disturbing. When they are living in their own homes people generally have control over the activities of daily life; as a resident of long term care those aspects of their independence are compromised.

Focus

The focus of this study is to gain understanding of the participants' lifeworlds in their present living situations, and to find out what preparations they are making for entry into a long term care facility, if any.

Working as an activity assistant allows me to observe new residents adapting to facility life, or refusing to do so. Some people become angry, some withdrawn and sad and some are relieved to be there. Those who are unhappy may become reconciled to the change in time, even happy but some become sadder, refuse to eat and appear to wither away and die.

As a family member I have watched my parents' generation reach the point where they were no longer able to take care of themselves independently in their own homes. As a daughter I wrestled with my feelings when visiting my father in extended care. What could I do to ease his feelings of incarceration while knowing my limits as well? As a friend I have listened to others' who were struggling with the aging of their family members. Some situations have been similar to my experience, some very different. The phenomenon of aging and an increasing need for help with tasks of daily living touches

not only the person who is aging but family members, friends, agencies such as home care and government health policies.

On the surface, the decision to move to a place where one has no need to do housework, make meals, ensure that medications are taken appropriately and someone is always there to help may seem like the answer to all life's difficulties for a frail elderly person but what is it like to be at that point in life where tasks that were formerly easy have now become very difficult or impossible to accomplish without help? What is it like to be in that body? I want to try to understand what it is like to be facing entry to a care facility. Is the care facility stay seen as temporary, marking time until "called home to Jesus" (personal communication by a resident)?

What is it like to be moving, probably for the last time? This phenomenon involves an understanding of the beliefs and values of the person involved. It is much more than a reduction of physical belongings to what will fit into an eight by twelve foot space, although that is perhaps a good analogy. To me identity is involved when I try to put myself in their shoes, not that identity is defined by belongings but that identity is the space within me that does not live well confined. I make my own jail by the way I react to events. I am learning how to keep my spirit free in spite of some physical constraints but suspect that I have more resources than someone in constant pain from arthritis or fatigue from a heart condition for example. Some people seem to have personal qualities that keep them lively in spite of physical frailty, others seem to choose to give up rather than be restricted. What are those qualities?

Research Question

What is the lifeworld of an older person on a waiting list to enter a long term care facility?

I will ask the participants if they are preparing to enter long term care, how they are managing their illnesses, housekeeping, and other activities of daily living. The interview protocol (Appendix C) includes these questions.

Context

The terms nursing home and long term care facility have been used interchangeably to refer to institutions where there is 24-hour nursing care. To be admitted to a government funded institution, a person is assessed by a nurse assessor who comes to the person's home, asks questions, checks physical and mental status, assesses the abilities of the caregivers, then decides the appropriate level of care for the person. If the person is at a level that is appropriate for a nursing home her name is added to a wait list. The system is now on a "needs" basis where clients are placed according to the urgency (Fiona Sudbury, Manager, Facility Access, VIHA–South Island, personal communication, April, 2002). When I began interviewing the participants wait lists were organized according to the date of assessment. Some people expected to wait two years before entering the chosen facility. Wait times vary considerably in different provinces of Canada, and in different countries, an interesting topic for another study (*Australian Institute for Health and Welfare*, 2002; Meiland, Danse, Wendt, Klazinga, & Gunning-Schepers, 2001; Hoek, Penninx, Ligthart, & Ribbe, 2000; Thompson, 1997; DeCoster, Roos, & Shapiro, 1995).

There are several types of homes available to older people. People assessed as needing intermediate care are supposed to be more independent than those assessed as needing admission to extended care facilities. There are also private nursing homes which do not require assessment by the nurse assessor.

Retirement homes have no nursing care but do provide meals in a central dining room and housekeeping in the residents' living quarters. The retirement home that I visit regularly is like a good hotel with apartments; some have full kitchens the rest have a small refrigerator and space for approved small appliances such as microwaves, toasters and kettles. The apartment size varies from studio to two bedroom penthouses. The retirement homes with which I am familiar are run for profit although staff members may be very caring and helpful.

Because the people who live in a retirement complex are supposed to be independent I consider them to be living in their own homes. For some residents the retirement home is a step toward long term care. The residents may not admit that to be

the case, but in my experience they have moved in because they do not want to do their own housekeeping, or they cannot accomplish those tasks or their spouse is in long term care and they want spend time together. Although there is no nursing care, residents may have caregivers or helpers who come in or they may go to adult day care. Because waiting time for placement in long term care facilities is uncertain, there are some retirement home residents who are at a very similar level of disease progression as are those who are already in care homes. There are retirement homes in Victoria with an intermediate care wing, Berwick House for example. For a resident, the distinction between the two is very important (personal communication from older family members). The retirement home may be called sheltered housing or congregate housing, the term used by Young (1998).

Community dwelling older people sometimes attend adult day care after the long term care assessor has decided that attendance would be beneficial (Heather Shave, personal communication, 1999). Some reasons to attend are to reduce social isolation, to be bathed, to provide respite for the primary care giver. A hot lunch and activities are provided. Clients may be taken by bus to and from home, brought by car or may drive themselves.

Those who live in a care home are often called residents, not patients, as they would be in an acute care hospital. The participants in this study are community dwelling physically frail, cognitively competent older people who are expecting to move into a long term care facility.

CHAPTER 2

REVIEW OF RELATED LITERATURE

The various effects of relocating an older person people have been discussed and studied for more than 30 years. Research has been conducted on relocation to different communities, to different types of housing, from the community to a nursing home, within a nursing home and between institutions (Choi, 1996; Gallagher & Walker, 1990, Johnson, 1996; Lee, 1999; Lee, Woo & Mackenzie, 2002; Mikhail, 1992; Reinardy, 1995; Rutman & Freedman, 1988; Thomasma, 1990; Wilson, 1997; Young, 1990; Young, 1998).

Why Relocate?

The relocation literature cited relates to people over 70 or with health conditions that warrant moving. Choi (1996) says that there are two waves of relocation, one after retirement and another “later” (p. 326). The most frequently given reasons for the later move are: a change in the health of the person or the spouse, personal vulnerability, to be closer to family and financial hardship (Armer, 1996; Choi, 1996; Colsher and Wallace, 1990; Young, 1998).

Relocation Stress Syndrome

Moving an older person from a familiar to an unfamiliar environment has psychological effects that have been documented in older persons entering a long term care facility (Mikhail, 1992). This move, she says can exacerbate existing health problems taxing the person’s already compromised system as he or she adapts to the new environment. The label *relocation stress syndrome* has been given to this problem (Carpenito, as cited in Porock, Martin, Oldham, & Underwood, 1997; Manion & Rantz, 1995) the psychological symptoms of which, 80 percent to 100 percent of the time, include anxiety, apprehension, increased confusion, depression, and loneliness (Manion & Rantz, 1995). Even the intent to move can be associated to depressive symptoms (Colsher & Wallace, 1990). Since Mikhail (1992) there has been a considerable amount

of research into the effects entering a nursing home from the community had on an older person. She and others (Johnson, 1996; Thomasma, 1990; Wilson, 1997) say that the period of adjustment can last from weeks to months. The new environment and routines are different from those at home, mealtimes are regulated in time and choice of food, bathing is supervised and may be weekly, the number of familiar things that can be brought in is limited, privacy is limited. The care facility may be in a different community from the home so that the new resident may be some distance from the community in which she had been living (Choi, 1996). Even the cognitively intact resident may not be the one to make the final decision to enter long term care (Schneider and Sar, 1998). Johnson, Schwiebert, and Rosenmann (1994) say that it is often the physician who makes the final decision. The ability to make decisions, of the perception of having a choice is important (Gallagher and Walker, 1990). Having the decision imposed on the person may make a difference in the time needed for adjustment to this new environment (Reinardy, 1995; Young, 1998).

Types of Relocation Research

Reed and Payton's 1997 study is one of the few that interviewed people before relocation into a nursing home and three times thereafter. They also facilitated focus groups with the staff. Their main interest was to elucidate how the institution could be more like a home. One of their findings was that there was that the residents and staff had different perceptions of the residents' social life. In their article, they did not discuss specific findings from the pre-admittance interview, which is the timeframe of my research. Rutman and Freedman, in 1988, say "Relatively few studies have focused specifically on the pre-location (anticipatory) period" (p. 18) and they list studies from the 1970s and early 1980s. The focus of their work is on people who had applied to move into a rent-subsidized apartment from their own home. These people may have been moving from one part of Toronto to another as well as from their own homes. Data was gathered by questionnaire. Their focus was on the meaning of home to the participants. The connotations of home, although closely related to my study, are not the focus.

Pringle (1998) discusses patients waiting to be admitted to long term care from an acute care hospital bed. The acute care bed is not appropriate for a variety of reasons, she contends, but the people are not well enough to be discharged to go home. Where can they go? Of those discharged to go home, 50 percent experienced another medical crisis within two weeks. She says that little is known about of the life experience of these people and their families, although she does say that family tensions and lack of a place to call home are common problems.

Lifeworlds Before Relocation to Long Term Care

None of the literature that I have surveyed has focused specifically on the thoughts, feelings, and lived experience of prospective residents during the period of waiting to be admitted to the care facility. I want to know what is it like to be waiting? Why are they moving? How do they feel about the move? For those living independently, are they looking forward to not shopping, cooking, doing laundry, arranging for help to do some of the work or get to appointments? How do people feel about their belongings? What will they do with the belongings that will not fit in a care home room? How do they select what to take? What is really important? This study could add to the information available in the literature dealing with relocation helping us to understand what moving to long term care means from that older person's point of view.

CHAPTER 3

METHODOLOGY

Research Method

Forward

The research question “What is it like to be on the waiting list for a long term care facility?” helped to define the research method. At the beginning of this study hermeneutic phenomenology seemed the most appropriate way to answer my questions. Van Manen (1997) says:

hermeneutic phenomenological research may be seen as a dynamic interplay among six research activities:

- (1) turning to a phenomenon which seriously interests us and commits us to the world;
- (2) investigating experience as we live it rather than as we conceptualize it;
- (3) reflecting on the essential themes which characterize the phenomenon;
- (4) describing the phenomenon through the art of writing and rewriting;
- (5) maintaining a strong and oriented pedagogical relation to the phenomenon;
- (6) balancing the research context by considering the parts and the whole. (pp. 30-31)

As the study progressed I had more questions to be answered and a deeper understanding of how my ways of being impacted that which I saw, felt and interpreted. Ely, Vinz, Downing, and Anzul (1997) state that:

as researchers our stances, our angles of repose, do affect what we are interested in, the questions we ask, the foci of our study, and the methods of collection as

well as the substance of analysis. And the meanings we make from our research projects are filtered through our beliefs, attitudes and previous experiences as well as though both the formal and informal theoretical positions we understand or believe in. As researchers we bring multiple stances to our studies—in degrees of conscious and subconscious awareness—as we choreograph, depict, and resculpt stories and meanings from what we are examining. (p. 38)

Creswell (1998) asks, “How much of the ‘self’, the researcher, is present in the narrative? ... How does the writer give ‘voice’ to the researcher?” (p. 170). He continues:

Strategies to convey the position of the writer include disclosure by the author of his or her biases, values, and context that may have shaped the narrative. Also the writer can be “present” in the narrative report through devices such as ... interpretive commentaries. (p. 172)

In order to clarify to the reader my lens, I included personal anecdotes and commentaries which are intended to illustrate how and why I arrived at the participants’ themes.

Afterward

During the course of this study, my work evolved from the starting point of Van Manen’s (1997) guidelines as stated above to a more eclectic approach. Ely et al. (1997) recommend that the researcher have theoretical base but be ready to incorporate other ideas; “alternatives and possibilities rather than rigid corsets” (p. 33). The method which evolved relied heavily on writing, reflecting, reading and rewriting (Ely et al., 1997). The order varied. In a tribute to Gregory Bateson, Bochner (1981) wrote what he called

Bateson’s Rules of Thumb:

- 1) Study life in its natural setting being careful not to destroy the historical and interactional integrity in the whole setting.

- 2) Think aesthetically. Visualize, analogize, compare. Look for patterns, configurations, figures in the rug.
- 3) Live with your data. Be a detective. Mull, contemplate, inspect. Think about, through, and beyond.
- 4) Don't be controlled by dogmatic formalizations about how to theorize and research. Avoid the dualisms announced and pronounced as maximums by particularizing methodologists and theorists....
- 5) Be as precise as possible but don't close off possibilities. Look to the ever larger systems and configurations for your explanations.
Keep your explanations as close to your data and experience as possible.
- 6) Aim for catalytic conceptualizations; warm ideas are contagious. (p. 76)

Bochner explains his concept of "warm ideas" as:

ideas that compel us to move closer to our subject matter; ideas from which we can cast new rays of insight, open up new lines of thought, extend our territory into new avenues of inquiry, and amplify our understanding beyond what we knew before (p. 77).

The conceptualizations generated instigate more ideas. These statements apply to the research method which evolved during this project.

Access to Participants

Posters (Appendix A) were put up at the Seniors' Center, a Retirement Home, the Public Library, and the Seniors' Hotline Office, in accordance with the Ethics Committee's request. In the community where the research was conducted there is an organization which serves older people in several capacities. Volunteers are trained as Seniors' Peer Counselors and as Friendly Visitors. There is, as well, a group of Volunteer Drivers who take people to appointments. Most of these volunteers who are over 65 themselves visit people who are isolated in their homes. I presented my project at meetings of the Friendly Visitors, the Seniors' Peer Counselors, and to the Coordinators

of the Volunteer Drivers. I met the Family Caregiver Network Coordinator and wrote a short article for their newsletter to explain the project and ask for participants. In each case a third person asked the potential participant if she would be willing to be interviewed before I contacted her. There was no coercion of the potential participant by the third person and nothing to be gained by participating. Three of the participants said that their children had said it would be a good idea to talk to someone else. Two participants were approached by the manager of the seniors' residence, one by a friend and one by a son.

Participants

The criteria for participation were that the people were on the waiting list to enter a care facility, that they could understand the consent (Appendix B) and that they were able and willing to be interviewed. I assumed that if they met these criteria, any cognitive loss they might be undergoing would not affect the data collection. That they were willing to be interviewed implied to me that they were likely to be more positive than negative about entering a care home because I have found many older people to be unwilling to speak out when they are angry, especially older women. Participants who did not want to enter a care home would have added another dimension to this study.

The four participants were women born between 1908 and 1914. Two were born in England, one on Saskatchewan, and one in Manitoba. Three had been married and had children. All had worked during their adult lives; one was a nurse, one a teacher, one apprenticed as a milliner then did housework, and the fourth worked in a fruit and vegetable cannery for part of her married life. The three who had been widowed for several years each had one child living within 20 kilometers. Each had looked after her husband until his entry into a care home or until his death. The unmarried one had lived with a couple, both of whom had died several years ago. The nurse and the teacher were living in a retirement complex; the other two were living alone in apartments. I read and discussed the consent (Appendix B) with each participant before collecting any data.

Data Collection

Data collection was by two audio taped semi-structured interviews, conscious observation, and journal. The interview protocol appears in Appendix C. Conscious observation includes the way the apartment is furnished, and the way the participant reacted to me and my interview questions. My reactions are recorded in the journal. These include direct observations as well as reflection on my reactions to the participant and to the interview; insights to my reactions are also included. The interviews were fully transcribed. The first interview was to sign the Consent (Appendix B), to ask the questions (Appendix C) and listen to the stories; the second was to verify the themes I had identified. Olivia read the transcript and agreed with the themes I had identified. Lin was my first participant, and I used the first interview to establish rapport. It was not taped, the second one was. She moved to a long term care facility soon after so I used my journal entries from the first to confirm the themes that I had identified from the taped second visit. Win's first interview was very long and she was unable to read because of her sight so we discussed the themes. She told me more stories which confirmed the themes I had identified. Several months passed before the second interview with Mina so I followed the same procedure. I was satisfied that saturation had been reached with her as well because her stories at the second interview had the same themes as the first interview.

Framework for Interpretation

Assumption? Interpretation?

“How would you interpret that (statement)?” asked my supervisor.

My mind blanked. Interpret? What do you mean? Insight trickled in, ohhhh, every participant statement that I choose shows what I have heard, assumed meant something, categorized to a theme. That is an interpretation, usually unconscious. Bringing my assumptions to consciousness with words will be an interpretation. Who is this thesis about? How can I know what determines what my participants choose to say? What I hear is based

on ... what? My values, beliefs, life experience, powers of observation, listening with my heart.

Moving house has challenged my assumptions about who I am. The year we turned 9, 11, and 40 I moved my children and myself to Chicoutimi, Quebec, for a year. The explanation I gave for this upheaval was to learn French, which would enable me to relocate from Northern B.C. as a French Immersion teacher to a place closer to my family.

The drive across Canada was interesting but very long. I was nervous upon our arrival in Chicoutimi; we stopped for lunch just outside the city so I could gather my resources. Where would we live? Did I know enough French to be able to find a suitable place? When a flock of Hell's Angels roared past I silently questioned the wisdom of this venture. Our Northern B.C. community had no "motards" as far as I knew. If these were representative of the community in which we were to live for a year perhaps I had made an error in judgment.

Reflection; this situation could be analogous to that of a person entering a care home feeling very unsure of the decision to move, unfamiliar behaviors from people with dementia can be disturbing.

I was registered at the University of Quebec at Chicoutimi. I spoke some French, the children spoke none. In time, after we were comfortably settled in a basement suite, registered in grade 4 and 6, hockey and gymnastics, routines established, I was told how brave I was to have driven across the country to do this thing. Except for the moments at the rest stop it had not occurred to me that courage was needed. The process of acquiring a second language tested other assumptions.

Learning to be comfortably fluent in another language was like seeing life through another lens, or taking on another skin. Eventually I was "*bien dans ma peau*" in French to the point that some English words and spelling took thought. This process improved my ability to listen, observe, and empathize with participants for this study, increased my ability to hear their voices for, in becoming a French speaker, I had to set the old way aside to make room for the new way of communication. At one point when I was consciously remembering the formal grammar lessons before speaking, I decided that if I

could just shut off the English I would learn the French faster because I would be skipping the translation step. With perseverance this strategy worked. In listening to my participants I wanted to use the same technique, be entirely present, shutting off as much of my internal dialogue as possible, in order to hear, see, and feel with as little “translation” as possible. Mary Catherine Bateson (1994) says, “I believe that participant observation is more than a research methodology. It is a way of being” (p. 7). I am an incorrigible people watcher, curious about motives for actions. It is one of my ways of being.

Validity

Listening to the transcripts I found myself wondering about accuracy then remembered that I wanted to hear the points of view of my participants. Kaufman (1986) says “In studying identity in old age, external measures of validity are not critical if one is concerned with eliciting informants’ *current interpretations* of their lives” (p. 24). She distinguishes between life stories and life histories by using story to mean what the participants have told her, and histories to mean accounts supplemented by resources other than the participant’s version. What people choose to tell me is what is important to them. “The self draws meaning from the past, interpreting and recreating it as a resource for being in the present” (Kaufman, 1986, p. 14). The memories are colored by their life experiences, tinted by mine.

The backgrounds of the participants are important because they help me understand how they have learned to cope with the present situation. Students of symbolic interactionism argue that “people are not passive observers and reactors to their surroundings; rather they actively participate in their environment, creating their social reality and sense of self as they engage in community life and as they interpret and evaluate the meaning of their interactions with others” (Kaufman, 1986, p. 19). By hearing about their lives I can have a better perspective on their ways of being now as physically frail older women. Kaufman (1986) says “individuals not only symbolically preserve and integrate meaningful components of their pasts, but they also use these

symbols as frameworks for understanding and being in the present” (p. 18). The stories that I have been told are these frameworks.

Rigor

Rigor, as explained by LoBiondo-Wood and Haber (1998), includes the criteria of credibility, auditability, fittingness, and confirmability (p. 237). For this study, the results were confirmed by the participants during the second interview and by research literature. To ensure auditability or accountability, I have included quotes from theoreticians and researchers and excerpts from my personal journal to enable the reader to follow the paths of my thinking from “research question and raw data through various steps of analysis to the interpretation of findings” (p. 237). For fittingness, I have carefully chosen my participants’ own words to express their realities. The second interviews confirmed thematic consistency and ensured rigor.

Another way in which I evaluated the findings can be summarized by the following set of critical questions developed by Shannon Moore (from Denzin & Lincoln 1994, Whitemore, Chase & Mandle, 2001, as cited in S. Moore, unpublished doctoral dissertation, *Towards an Integral Model of Transcendence*, September, 2002).

- I. Are the findings *faithful and credible* in relation to the original data?
- II. Are the findings *trustworthy* and *authentic* demonstrating *fidelity* in relation to participants’ voice and phenomena under investigation?
- III. Were the findings *critically* appraised?
- IV. Does the process of analysis and synthesis of findings demonstrate *integrity*?
- V. Were the sources of data and selection of participants *ethical and sensible* in relation to the phenomena under investigation?
- VI. Does the data collected *improve our understanding* of the phenomena under investigation?

The answers to these questions have ensured rigor in this study.

Data Analysis

The steps used by Heliker (1997) to analyze her data are appropriate for this study. Each interview was transcribed and examined in its entirety to obtain an overall impression. Each interview was analyzed, coded and themes identified with accompanying quotes from the transcription. Heliker verified her analyses by conferring with her participants throughout the process; for my study a second interview with each participant ensured the appropriateness of my themes. Related and repeated themes among the interviews were then identified and documented. Excerpts from the interviews were included in the final report to validate the themes.

Themes Defined

Theme has been defined by various researchers. Ely et al.'s (1997) definition is "A theme can be defined as a statement of meaning that (1) runs through all or most of the pertinent data, or (2) one in the minority that carries heavy emotional or factual impact" (as cited in Ely et al. 1997, p. 206). Kaufman (1986) explains that "In the descriptions of their lives, people create themes—cognitive areas of meaning with symbolic force" and "Themes are organizational and explanatory markers that emerge as individuals relate their life stories" (p. 25). Van Manen (1997) says: "*Theme is the experience of focus, of meaning, of point*" "...*a simplification....*" "*Theme is the form of capturing the phenomenon one tries to understand.* Theme describes an aspect of the structure of lived experience" (p. 87).

Theme is the process of insightful invention, discovery, disclosure. As I arrive at thematic insights it may seem that insight is a product of all these: *invention* (my interpretive product); *discovery* (the interpretive product of my dialogue with the text of life); *disclosure of meaning* (the interpretive product "given" to me by the text of life itself). At best, theme is a descriptive tool which allows (some) understanding to an idea. (p. 88)

Another researcher could have identified other themes, as I might have at a different time in my life. Ely et al. (1997) explain that, “If themes ‘reside’ anywhere, they reside in our heads from our thinking about our data and creating links as we understand them” (p. 205). The purpose for including my reflections is to clarify for the reader how I have winnowed the themes from the participants’ narratives.

Individual Themes

“As each life is unique, so too are the themes”(Kaufman, 1986, p. 25). Although the participants of this study were of the same generation, born between 1908 and 1914, their lives had followed different paths. Two had been born in England and had emigrated: Olivia, the teacher, single and in her thirties, Win married and in her fifties. Lin and Mina had been born in Saskatchewan to farming families who had different family expectations. Themes unique to their lives emerged from the analysis of the interview transcripts. Some individual themes from the participants’ interviews have aspects that are related to the shared themes but because each participant had a unique aspect to the theme I chose to discuss them separately.

Van Manen (1997) explains his process of data analysis with examples of how he thematically interprets transcribed interviews. The purpose of drawing the themes from the transcriptions is to try to understand what is important to each participant in her present environment.

To isolate themes, I have used Van Manen’s (1997) “selective or highlighting approach” wherein “we listen to or read a text several times and ask, *What statement(s) or phrase(s) seem particularly essential or revealing about the phenomenon or experience being described?*” (p. 93). I also used Giorgi’s (1985) technique of imaginative variation by asking myself “*If this element is changed would it change the reality of the participant?*” When I was dissatisfied with results thus gleaned I used the “detailed or line-by-line approach” (Van Manen, 1997, p. 93), in which each sentence or sentence cluster is analyzed.

Once the themes emerged I wanted to portray each participant’s themes in ways that would bring the person to life. One reason was respect for the participant. “Curiosity

and respect. We fall short in these disciplines” (Bateson, 2000, p. 12). Another reason is that the writing became analysis.

Writing the Research

Writing the research was integral to the method and to the analysis. Ely et al. (1997) provided the method and incentive that if one can “trust the process of discovery” (p. 8) understanding will emerge. “Writing to *learn* what we know rather than to *state* what we know” (p. 10) had to be experienced before I understood what these researchers meant. Persuading myself to just write to see what would emerge “Stories and poems erupted” (preamble this thesis) built my faith in the process. Writing qualitative research is not linear, it is “messy and chaotic work ... generating and forming ideas into some coherent presentation” (p. 11) with participant data, observation logs, journals, life experience, and reflection providing the components.

Ely et al. (1997) continue, “the key to crafting research writing worth reading in the willingness to engage, puzzle, create and recreate the shapes of our writing so that they are increasingly congruent with our stance” (p. 159). The suggestion to “explore the meaning for ourselves first” (p. 19) was the incentive for my life experience anecdotes which would clarify my stance both to me and to the readers because “What we find and report about others is intimately meshed with our own ways of seeing-or-not-seeing our ‘selves’” (p. 137).

Ely et al. (1997) use the metaphor of “angles of repose” to explain that “Stance is the various perspectives through which we frame the collection and interpretation of data” (p. 33). They continue, “as researchers we need to be conscious of what causes us to be startled, provoked, angry or challenged by the material and meaning of our studies (p. 37).

They say “... there is more insistence that the writer make explicit to the reader his or her stance, pertinent history, and relevant strengths and limitations” (p. 354). As I wrote my life stories I was sometimes surprised at the emotion evoked. As I re-experienced times in my life I was more able to understand why some of the participants’

stories affected me. By including them in this study the reader is better able to understand how I made my choices in the analyses. Ely et al. explain:

The researcher belongs in the study not only as a consciousness that filters the experience but as an actor as well. The presence and behavior of researchers- as individuals with particular personalities and with cultural, socio-economic, age and gender identifications—have ripples on the participants ... there are the specifics of the setting... And the researcher will never know the half of them. ... participants have motives and agendas that factor in to shape an interview or shape observed behavior. This in turn affects the writer. (p. 363)

It may suffice to say that where we stand about research, how we see our place in that endeavor, translates to how we write, and to the forms that we select in our writing. (p. 159)

Literary Forms

As I listened to the taped interviews and read the transcriptions, I envisioned the words, anecdotes and whole impression of the person. Playing the mental images as one would a video allowed my impressions and feelings to surface. These helped choose how best to represent the participant. Ely et al. (1997) say:

Through imagination and craft, the researcher tries to penetrate the dimensions of experience below surface appearances and to represent these in compelling words that make the essence come alive. ... it is the ability to imagine how things are for others and how conditions might be improved, to identify the tension between the perception of reality and the vision, each needing to address and draw from the other. (p. 368)

Goldberg (1986) ideas were inspiring as well.

Then we can handle details not as individual material objects alone but as reflections of everything.... Understand that when we write about a cup or a mesa or the sky or a bobby pin, we must give them good attention and penetrate into their heart. (p. 76)

The purpose of the literary forms as described by Ely et al. (1997) is to deepen understanding, to enable the readers to become involved as they read; that readers will be able to engage with the participants as people not as informants, that the readers will have “aha” moments as they relate the narratives to their lives. Ely et al. (1997) give examples of drama, poetry, anecdotes, and vignettes which bring the research to life. Another technique is pastiche, interweaving texts in different fonts to characterize voices (p. 99). For these researchers “Narrative is a method of inquiry and a way of knowing—a discovery and an analysis—” (p. 64). That has been the way in which this study has evolved.

CHAPTER 4

RESEARCH FINDINGS

Seeing the Trees

The most surprising “findings” have been the insights which I have gained about my own lens on life. In order to write about my participants I needed to search within myself, the better to understand my perspectives as the interviews unfurled and as I immersed myself in them. The first section of this chapter illustrates some of those perspectives and insights to help the reader understand my interpretations of the participants.

What is it

What is it about the older people that attracts me? Seeing pictures of old faces, wrinkled, some weather beaten, I stop to examine. I feel love, and then delight in most of their quirks. The following example illustrates my frustration and delight. I accompanied a very old person to a new doctor where, seeing this woman through others’ eyes, my love for her indomitable spirit welled up.

“There’s nothing much wrong,” and “If I have a pain I just ignore it until it goes away,” she said as she walked somewhat unsteadily to the scales. The doctor asked if she had a cane or walker. “Yes,” she said “but I don’t use it.” Habitually, she is annoyingly vague about the specifics of her pain, to the point where diagnosis is difficult. They discussed her recent fall which happened because she had lifted a foot to examine it and had “tipped over.” Her doctor thought that her wrist was cracked but she didn’t want an x-ray or cast.

“It’s getting better,” she said.

As I reflect on the preceding anecdote I wonder why I react differently to the independence shown by the older person than I would to a peer or a younger person. I want to make things better, stop the pain for people yet, with effort, I can respect the older person’s decision. With peers and younger people I think they are foolish not to look after themselves when they have a life ahead. Do I view older people with rose tinted lens, a form of agism?

When I moved to my parents' home the wealth of memories evoked by an item surprised me. Even knowing this I was embarrassed by the condition of some of an older relation's clothing until I looked through her lens.

Well Worn

Elbow to wrist worn through
 Shrunken, shapeless
 The sweater has seen better days

"One of these days I'm going to mend it
 It's warm,
 I wore it at O'Hara."

Reflections on Flexibility

"Just bend like this, squat and stretch," instructed the Yoga teacher.

"We don't do that," said my knees.

"Going down is fine," said my spine, "It's the coming up that requires technique."

When had they stopped being able to that? I hadn't noticed insidious inflexibility. Is there a relationship between physical stiffness and my way of seeing and living, its mental counterpart? During a visualization, going to my center I see a length of pipe turning, revolving on a dark background like a screen saver in the dark warm well of my core. I want to see a soft and pulsing reddish pink blob, gently turning and revolving on a warm soft background, a disembodied cartoon heart; but I see a piece of one inch metal water pipe. Momentarily I wonder if it is because I have just bought orchard irrigation materials for a deeply absorbing project. Is that a wishful thought? Am I really so inflexible at heart? Becoming more so? Intolerant? How?

How can I write another person's story if I am really inflexible? How am I blinded by my stiffness? Is there a relationship between stiffness and stance or is it mixed? And is it "either/or" or shades in between?

"Have an intent for Yoga practice," instructed the teacher.

Increased flexibility is mine.

I don't like the pain that comes with stretching.

Then she told us to translate the intent to a quality. I translated flexibility to tolerance, then acceptance, of myself and others. I know I accept the foibles of others, be they colleagues, friends, or family with whom I have no past conflict. If people whose approval I want, even unconsciously, criticize my decisions I am quick to judge their agendas. This is especially true if I believe my competence to be in question although, in some circles, I have for many years been considered a competent adult.

Perhaps the crux is believing in myself, accepting myself as I am, accepting where I can and cannot bend, and knowing the difference.

Facets

As I approach a participant's door, I wonder what aspects of the person I will see today, and which facets of myself I will display consciously and unconsciously.

Here and now I can only be aware of how I react, sometimes as a younger family member, sometimes as a friend, occasionally as a scientific observer. I want to listen with my heart as well as with all my other faculties. I consciously try to set aside concerns from my life the better to concentrate on the here and now of the time with her. My preferred demeanor is open, caring, listening. Later reflection may show how my perceptions have been colored by my life experience, that is, when I want to be the scientific observer. In speaking of the narratives that she has chosen Bateson (1990) says they are "... shaped by each person's choice and selective memory and by the circumstances of our work together. No doubt they are shaped again by my own selection, resonating variously with my own experience" (p. 33). Ely et al. (1997) use the term "angles of repose" (p. 35) to describe point of view. The metaphor of the multifaceted crystal is used by Laurel Richardson (1997, p. 136). The lens through which

I view my participants and through which they view me can be described as facets of a crystal which we show to enhance a particular role. “‘Truth’ is always in flux” say Ely et al. (1997, p. 34).

When the school year started I was aware of figuratively putting on my teacher overcoat, it could have been called an aspect of my personality. During the month of July it would gradually come off as a snake sloughs its skin. Now I understand that coat to have been protection against the rigors of a profession which demanded aspects of my personality that took an effort to maintain and others that I felt I needed to hide. I agonized for and with a grade 3 child who memorized books to hide her inability to read (perhaps she thought that was reading) but still I exposed her problem by sending her out to the Resource Room during class time and helping her myself after school. I was firm with a parent who wanted her grade 2 Child Prodigy to work entirely independently at the back of the classroom because that child’s ability to cope with his less gifted peers would benefit from classroom interactions. His intellectual ability was never in question, his social skills were. In both examples I needed my teacher overcoat to cover my discomfort at singling out a student for special treatment. My overcoat was insulation against the possibility of not doing the best for all concerned or of having made errors in judgment. I was the professional. In my role as a qualitative researcher that overcoat is in the closet. I want my caring heart to hear, feel, and to the best of my ability express the reality of my participants. I want to be visible absorbing their life stories through clear lens.

The Participants

For each participant I have included biographical information from the interviews. I asked for some details but left others to the discretion of the participant believing that they would tell me what was important. Perhaps the information would have been different on another day. I have used the information directly because:

Composing a life involves a continual reimagining of the future and reinterpretation of the past to give meaning to the present, remembering best those

events that prefigured what followed, forgetting those that proved to have no meaning within the narrative. (Bateson, 1990, p. 29)

I wrote interpretive sections to represent each participant in a form which would animate the person and “make ongoing meaning for ourselves and to communicate that meaning with people in order to involve them in thinking about and living our research experiences” (Ely et al., 1997, p. 61) because “Form shapes meaning” (p. 59). As I reread the interviews my mind’s eye replayed them as films. The form for each participant evolved from asking what written form seemed closest to the person’s presentation of herself to me.

The interpretative section was closely related to the analysis for themes. Olivia’s storylines are interpretation and data analysis. Mina’s story was possible to write after I had coded and themes had emerged. Win’s stories were too well told to change, they are the best representation of her personality. Lin’s personality was more apparent in her nonverbal communication than in her words so relating her stories to mine brought her to life through my eyes.

Lin

Biography

Lin lives in a modern, well-appointed retirement home where meals and housekeeping are supplied. She has a one bedroom apartment filled with her gleaming furniture, pictures that she has painted or purchased, and many mementos of her life. Quality, taste, and beauty are the words that come to me as I enter her apartment. Pictures emerge in my mind as she talks, snapshots from my past, my visualization of her past, a pastiche layered and rich.

Lin’s parents homesteaded in Saskatchewan. Born in 1909, she told me about her childhood, the little girl walking to the prairie horizon for the big orange sliding down the sky; with friends at the slough pond, imagining they were ... who knows where, doing who knows what. Lin and her two sisters cornering Lazy Daisy, the horse they drove to school.

Later, the adventurous young woman training as a nurse at the Royal Jubilee in the late twenties, applying to hospitals in the Orient, repelling unwanted advances from an Indian gentleman on the ship carrying her to the Country Hospital Shanghai in the early thirties. Her first glimpses of sampans, junks, smells, sights, and sounds of life on the river as they steamed to port realizing the dream of the child listening to a former missionary tell stories of her time in China.

After two and a half years of her three-year nursing contract, Lin met her future husband at the home of a mutual acquaintance in Shanghai. They were married six months later and lived in Shanghai until war necessitated their escape. They came to Canada with their two daughters. Lin's husband found work, their third daughter was born, and in time they moved to the Okanagan where they had an orchard. Lin returned to nursing to help out with the family finances because, she said, her husband was going to have a breakdown trying to make ends meet in his new venture.

Lin did not talk about their retirement years or looking after her husband until his death a few years before the interviews.

“How are you preparing to enter a care home?” I ask.

“Oh, I'm writing my memoirs. I'm making photo albums for each of my children.” Her face lightens and beams. I read that no other answer is necessary from her body language and ask no other questions. Upon reflection I realize that I have assumed the ‘how,’ that the memoirs and photo albums for each daughter will keep her alive for her family. They will be able to continue to see her as a strong, adventurous young woman sailing off to China to seek her future even when she is frail and forgetful, or dead.

“It was the best thing I ever did,” she said of her time in China.

I reflect on the poignancy of remembering others so old and frail or dead, who led adventurous exciting lives, were parents, scholars, artists. Remember Robert Frost as he stumbled in his reading at John Kennedy's inauguration? At one time he was swinger of birches. When I taught school I imagined how some of my students would “turn out,” with older people I am curious about who they have been.

“Tell me about how your Mom met your Dad,” I imagine one of Lin’s great grandchildren asking. Perhaps they have been to visit her in the care home, perhaps the child has found the album and wants the security of knowing roots. Now the tears start as I hit a chord. The photo albums in my home record the lives of my grandparents, parents, and my generation, the importance of family stories, and the continuity implied. I am named after my maternal grandmother and one of my father’s more interesting aunts who died before I was born. I like to hear stories about Aunt Annie. My grandmother used to tell me stories of her youth during the late 1800s in the city of Quebec. My albums record events for which there are memories and stories. I feel very sad for those without family while knowing there are people to whom family is not important.

“That was my grounding,” said Lin, speaking of her childhood. She can be alone now in her old age because of her memories of childhood on the prairies, playing in the slough, catching gophers, cornering the horse for harnessing. I didn’t ask how because my heart was instantly there. *In the barn with calves, kittens, dogs, my friend and I playing circus or Saanichton Fair. Building forts in the bales, “driving” the Model T tractor, saddling sawhorses to ride the range... somewhere. Voyages to distant times by “Let’s say that...”*

Twenty years in the Peace River country gives me direct experience of the slough, and the prairie sunset. In 1969 the little school in our area still had outhouses and the students in grade 8 had ridden horses to school. In 1969 few of the students had running water in their homes, no phones in part of the area, some had no electricity. When Lin talked about her childhood, I was back near Fort St John on our farm. The land, forest, and wide blue sky touched my soul. When troubled I seek forest places and vistas of land and water, my grounding.

A sense of humor is a quality often mentioned by Lin about people in her life. This quality appears to me to be a necessary criterion for Lin. What she meant, I assume, is that people didn’t take themselves too seriously, a sense of the ridiculous, seeing the funny side of situations, not telling jokes but understanding the living jokes. Herself as a child snaring gophers, cutting off the tails for the bounty, then releasing them in hopes of another tail growing. Her mother had been a stenographer before moving to the farm to

be a pioneer wife. Lin said, “She had a good sense of humor” and “My husband had a good sense of humor. I think that pulled you through a lot of things.” The interview was punctuated with laughter at the escapades of her youth.

Telling me how easily she could adjust seemed to be the entry point to the importance of her present life task. Showing me the albums she had made for her children and telling about life in China was important. Yes she could adjust because she just had to.

“I’ve been lucky,” she said. “I’ve had good life.”

Interpretation: **Lin Says, “That’s the way it is.”**

I’ll put up with it anyway

I adjust very easily

When you get to be an age you just have to go with it

Go with the wind

you just have to adjust yourself

When you get to be a certain age you just have to move with the gang

I just can’t possibly look after myself

As you get older you just have to make up your mind to adjust to different things

When you’ve been married for 60 years and suddenly things fall apart you have to really readjust yourself

and you can’t rely on the family too much I mean it’s not fair

they’ve got to live their lives and that’s important

but I’ve had a good life

I can’t complain

I’ve had a good husband and a good family

Lin’s Themes

Lin concentrated on her personal history in the times that she spoke with me. Her prairie childhood, the move to a West Coast city to enter nursing, nursing in China, returning to Canada to live again in a West Coast city, then in the Okanagan, are all

examples of how she had lived in different cultures. She linked stories from her past to her present situation by saying, “With all I have seen and done, I can go with the wind.”

I adjust very easily.

“Well when you get to be an age you just have to go with it. You go with the wind.”

... you just have to adjust yourself to it and then you get to be a certain age you just have to move with the gang.

As you get older you just have to make up your mind to adjust to different things especially when you're, like for instance, losing my husband. That was terrible, it's still terrible. I miss him terribly but uh when you've been married for 60 years and suddenly things fall apart you have to really readjust yourself.

“When you go abroad, you have to adjust to the way of life, the way other people live.”

“I can adjust because of my life.”

Lin had made up her mind to adjust, and would make the best of the situation. By calling on her life experiences she could adjust.

A sense of humor pulled you through a lot.

At no time did Lin acknowledge her own sense of humor which was embedded in her stories. For her to say that somebody had a good sense of humor was a criterion of approval. This theme is different from the others because it is a lens through which she interpreted her world.

“He had a good sense of humor and was jovial with everybody.” Her husband.

“She had a good sense of humor.” Her mother.

“I could see there was a twinkle in his eye.” The minister.

She chuckled telling the story of herself as a child cutting off the tails of the gophers in hopes that a new one would grow. The sense of humor of which she spoke is, to me, related to being able to adjust. Both take a certain flexibility of mind. Seeing the funny side of things and adjusting to a different culture require, in my way of thinking, the ability to see life from more than one point of view, through a different lens.

I've been very lucky, I've had a good life.

I've had a good life. I can't complain, I've had a very good life. I had a good husband and a good family and when we left the Orient, we were lucky ... yeah, we got on the last boat. We were lucky.

"I've been lucky all my life all the things that happened."

Well, I think I was lucky to have been born and brought up on the prairies ... I mean, that's been the root of my life. ... is my grounding living in the open, out in the open, the fresh air, the sunshine, and the wide open prairies, flat and you have the whole thing to yourself.

"I think we were lucky to be nurses at that time."

Lin's appreciation of her life is the third example of her ability to see from more than one point of view. She compared her nursing training to that of nurses of today but said nothing directly about the lives of others. Comparison was implied by her statement of how lucky she had been.

Lin: Summary

Lin said that she was no longer able to look after herself, that she didn't want to move, but that she could adjust because she had to. Her life stories illustrated that ability. She was grateful for the way in which she had been raised and for the life she had lived. Her grounding in the natural world, sense of humor, and self-reliance developed from

childhood enabled her to adapt to the different cultures in which she lived. She could also adapt to the culture of the care home.

Thinking about Lin reminds me of the prairie crocus, the first flower after the long winter—a delicate mauve anemone which pops out of the barely thawed gumbo, her feathery leaves are blown wildly by the unrelenting wind. The wind buffeting Lin was her health but, like the little crocus, her solid roots enabled her to be pliant.

I struggled with the data from Lin, rereading and listening several times, writing and reflecting, finally coding line by line to find repetition. The themes that emerged were related to what I interpreted as her philosophy of life, the roots growing from her childhood on the prairies. Still the labels of the themes were not exact enough to satisfy me. Interpretation and grouping was not clear. I assumed that writing her memoirs was for her family, maybe not. Maybe the memoirs were her way of taking stock of her life the better to leave it. She was looking inward and to her past.

On later reflection, how these themes are related! The sense of humor Lin appreciates takes flexibility of mind, seeing the funny side of things, understanding from a different point of view. So does her ability to adapt to different situations, feeling lucky about the directions her life had taken. What is the metatheme? Viewing life from the facets of her lens?

Olivia

Biography

Olivia, who was born in 1913, the third of six children, emigrated from England in 1947 to the district in which she now lives. She taught school for five years on one of the Gulf Islands before transferring to Vancouver Island where she taught in two different elementary schools before her retirement. She and the couple with whom she had emigrated made their home together until their respective deaths 15 and 25 years ago. She called them her chosen family. She continued to live in their condo until a few years after their deaths when she moved into a one bedroom apartment in a retirement complex. Now she has only her church family here in Canada. Until her health deteriorated she traveled to England most summers and family members came to North America where she toured with them.

In the retirement complex, meals are served in a formal dining room and housekeeping is supplied with the rent. There are 105 apartments in the three floor building, ranging from studios to apartments with two bedrooms. There is an activity coordinator who organizes entertainment, a craft room, library with computers, and a TV room. There is always someone at the reception to provide some security by checking on people coming in the door. Olivia moved in to avoid social isolation and to have more help than was available in the condo. For several years she lived comfortably in this complex, traveling abroad, walking, and socializing with friends when she was at home. When the cancer developed she was able to have help from the home support system to stay in her present situation until the cancer overcame her. Her biggest complaint with her present life was being unable to take the long walks she enjoyed so much.

In spite of her deteriorating health she maintains a rigorous self-discipline. The home support worker arrives at seven a.m. to help her get dressed. After breakfast she reads the paper and does the three crosswords; the afternoon is for reading books, on the balcony weather permitting. After dinner she watches the news, then, with the help of a home support worker, prepares for bed. Occasionally she goes out with friends although at the time of the interview she could seldom do that. She is no longer able to go to church because she cannot sit through the service. In spite of increasing physical weakness I saw her rushing to open doors for other people. She seemed surprised that others were concerned about her. I saw her several times after the second interview when I was in the complex and she never failed to ask about the health of the person I was visiting.

During the interviews Olivia spoke mostly of the present and of her concerns for the future. She seemed surprised at the turns of her life, indeed surprised that she was still alive.

Olivia's words taken from the interviews and written in the form of a poem have helped me to understand some aspects of this woman whose fine courageous spirit has touched my heart.

Interpretation: Olivia's Storylines

Waiting.

We're waiting
 still 12 months to get in
 it's a long waiting time
 They said a 2 year waiting list
 my name's been down now for nearly 12 months
 a long waiting period

we don't have much feeling about it
 at times I get a bit impatient
 at times you get a bit impatient and wish ...hurry up
 when my arm is difficult I get more impatient
 I know I've got to wait
 the awful part is knowing you're waiting for someone to die
 that's the awful part when I hope it won't be too long

Surprise.

I didn't think then I would want it so quickly
 go into hospice ... no warning
 go the next day, I couldn't possibly
 I didn't think I was ready

I didn't expect to be here when spring came again
 I thought 3-4 years was all I could expect

I'm surprised I'm still here
 it is surprising I was quite expecting to go

I didn't think I could last long
I didn't expect it to move as quickly
six months later the time had come

Unnamed.

A growth still here
I had 3 or 4 years before **it** started
the last couple **it's** developed
and there's no use **it** ...

it started in 89
removed here
it wasn't on the breast **it** was higher
the next year **it** came back
I knew **it** was coming back

it came back five years later
they decided not to take **it** out
live with the cancer growing in
it's a lot smaller
it was quite massive

growth **itself** is somewhat smaller
thought **it** would move, spread down
it began developing more quickly
I'm surprised I'm still here
I seem to spend my time sleeping or dozing
I don't understand why I just don't go off.

Finally.

I'm sorry I can't help a great deal

I'm still waiting

I just wonder sometimes whether I...

comfortable here

I don't want to move

but the money won't hold out much longer

I'm still not sure if the phrases above are lists or a poem. Lists and self-discipline work well together for me because it is by lists that I organize myself. Lists are appropriate for a person who was as self-disciplined as Olivia but do not show her caring spirit. Poetic lists?

Olivia's Themes

Olivia was on the wait list for a facility because cancer had changed the direction of her life. She spoke of "it," seldom saying the word cancer, perhaps a way of separating herself from the disease. She told the cancer story separately from the other topics but "it" was still always there, waiting, influencing her decisions. Surprise at being alive and denial that she was very ill were both themes.

The transcript statements about the cancer are included in one quote.

It started in '89. I'm surprised I'm still here.

I had three or four years without any worries but the last couple it's developed and there's no use in it that's the problem. It came back, I knew it was coming back. When it came back five years later and they decided not to take it out I figured that ... I couldn't have many years left to live with the cancer growing in. It is surprising, I was quite expecting to go. I thought it would move spread down maybe either heart or lungs or something or other and that would be it. I can't understand why I just don't go off.

I have combined Olivia's concern about her present situation and the long wait period because without the cancer she would not have been waiting. She had refused

entry into hospice because she did not think she needed it yet, but now it was time. At the time of the first interview she had hoped to go into intermediate care, by the second interview that was no longer an option. During the interviews she repeated how the wait seemed long, adding that she was running out of money. Her concern was both financial and for the difficulties related to the cancer.

I'm very concerned about my present situation. I find it a long waiting period.

"You know you've got to wait, at times I get a bit impatient."

"Now I need more help."

Expense is of course another side. In those days it was more reasonable and I could well afford it. Things are different now with the rates here going up and interest going down I'm living on capital. I don't want to make the move but the money won't last out much longer.

Olivia showed little emotion by her choice of words or by her nonverbal language. Her voice tones changed when she talked about her concern about money, being alone at night, and her arm becoming "difficult."

I can cope, others have more need.

At the same time that Olivia was concerned about her situation she didn't think that she was at the point of needing to be in hospice. Her statements contradicted themselves, which leads me to wonder if she sometimes believed the cancer would be cured.

"I didn't think I was ready for hospice."

"I felt when we were talking in terms of hospice or extended care that there were people who needed it much more than I did."

"The awful part is somebody has to die."

"I'm sorry I can't help a great deal."

My reflection: I wonder what Olivia is thinking. She says she is surprised at the speed with which the cancer has moved and she says that she didn't expect to live so long. She said that she was now ready to go to hospice or extended care but had refused the bed when it was offered the first time. I don't know whether she regrets that refusal.

Near the beginning of the second interview her voice became shrill as she said:

I still find think it came on so very suddenly that when my name was put down I had not thought that I was going to be needing it for years. And then in a few months I'm suddenly.... I would've got in if I could have done right away I needed to have help. It seemed to come on very quickly.

Knowing one will eventually die and accepting that death is not far away are different.

The missing theme.

Olivia talked about her family, her interests, and her teaching career in answer to specific questions. When I try to put myself in her shoes I can understand better her contradictory statements as stated above. Perhaps I too would not be telling stories of my adventures which would remind me of when I was healthy and able, too much contrast with the present.

I am curious about her relationship with her family in England. She said that they exchanged visits annually when she was healthy, that nephews and nieces picked her up at Heathrow when she went to England. She said "It's difficult with no family close by," but her church family was very helpful. I have no stories from her past on which to hang the attributes I saw in the present, just details such as: with whom she lived, when she came to Canada, where she taught; no answers to my questions about why and how she is as she is.

Reflection: That statement says more about me than it does about her! Where is her family at a time like this? Can they not afford to make a last visit to her? I'm outraged before I

reflect that maybe she hasn't told them how close she is to death, maybe she hasn't been able to say that out loud. Maybe her family doesn't do things that way.

Later reflection: I'm missing something here, peripheral vision, in this case peripheral feeling says there is something important just out of 'sight.' The themes which have emerged are superficial compared to what's missing. What is the metaphor for Olivia, how do I encapsulate her warmth and caring, her self-discipline, and surprise that others care for her? If Lin is a prairie crocus, perhaps Olivia is an oak tree. That brings tears to my eyes, the metaphor fits! Why? The oak is strong as is Olivia. The oak in winter shows the spread of branches reaching outward. Perhaps the leaves are the people she has touched in her lifetime, the acorns her legacy of strength. Am I reaching too far with this metaphor?

Olivia had an enlarged photograph of a bluebell in her apartment. When I mentioned seeing bluebell woods, Olivia told me the sole anecdote about England:

Did you see the bluebell woods? In the beech among the beech trees the silvery bark on the beech trees and the blue carpet on the ground? Whenever I went home in the spring we had to go and find the bluebell woods.... If there were beech trees it was even more so.

I had noted that at no time did Olivia talk about missing her nephews and nieces, but said "I was lamenting the bluebell woods and (a family member) took that photo and sent it to me, it is bluebells but not the real bluebell woods." The trees in the photo were not beech. Family members picked her up at Heathrow and delivered her back there. She said they were very good to her.

Maybe the missing part is family. There are no family stories. She did talk about lack of family here in Canada. In dealing with the reality of cancer has she withdrawn emotionally? Maybe part of her self discipline is not to acknowledge her feelings, that has been my experience with others of her generation and British background. Maybe she has always been reserved emotionally.

Kenyon (1996) says, "We are private or economic stories, inner stories, public stories, physical stories, family stories, emotional stories and cultural stories" (p. 26). The

explanation which fits the best for me is that Olivia chose to tell me economic, physical, and some public stories. When I asked how she felt about moving into a care home, she said, “We don’t have any feeling really.” When I asked if she had been preparing mentally or spiritually, she answered “Oh, yes” and changed the subject.

Now this section feels more complete because I understand Olivia’s choices differently. I am still curious but if respect is part of my way of operating, a partial picture will suffice.

Mina

Reaction

What a strong reaction to Mina! I was rushing to arrive on time and anxious when knocking at the door. Last time she only talked for 10-15 minutes, would this interview be more relaxed? It had been several months since the first interview, would she remember me? Her son had reminded her about the study and who I was although he would not be present at the interview. Having a family member know what I was doing felt like a safeguard to me, less chance of “Oh somebody was here, I don’t know what they wanted.”

Mina opened the door and looked up at me. The next thing I knew we were holding hands and I felt ... *loved? A rush of love? My heart melting? This was unexpected.* Later when listening to the tape I wonder if the attraction is partly in the tones of her voice. I know that I react to tones and inflection as much as or more than I do to actual words. My best explanation is that the side of her that I saw was of the most gentle loving Mother. By the end of the interview I was “My Dear” and “My Love.”

To depict Mina I have chosen excerpts from the transcribed interviews, rearranged the order, changed names and added words and phrases. Ely et al. (1997) call this form vignettes “portraits created through condensing and compiling” (p. 74). As I reread this story I can hear her quiet, slightly accented voice, well punctuated with husky gentle chuckles, and softly spoken “yeah.”

Biography and Interpretation: Mina’s Story

This is my story yeah. I was born in a little place in Saskatchewan in 1908. My father he worked for a farmer and I had nine brothers and sisters, yeah. After a while, my dad, he got a farm. We worked hard, yeah, we had enough to eat but entertainment that was out. My grandchildren they don't understand heh, heh. I tell them how it was then, yeah. I married my husband in 1925 and we had a little boy. He died when he was two months. We moved to Winnipeg, my husband, he was a barber. We had my son Edward in Winnipeg. Times were tough, there was no work so my husband, he had people in Vancouver so we moved, but the climate didn't agree with him, he had asthma so we moved to the Okanagan yeah. I didn't like it there and I wanted to move but they said wait awhile and I lived there 15 years, yeah. I liked it. We lived in Osoyoos and I worked in the cannery canning vegetables. We had lots of visitors there and I cooked lots of meals. My neighbor said you should put out a shield saying Free Meals. People would come and stay. You couldn't just chase them away. Some of those old Germans they were funny. They expected a meal. So, we moved around.

My husband he died in 1981. He never lost the wheezing. He had Parkinson's and was so mixed up. He went out into the street one day, he said someone was chasing him. I looked after him until my son said he had to go into a home and we put him into a home. He lived there two years and four months. I didn't have it so easy.

I'm 93 and sometimes I'm so tired I just want to go and rest. They say it's nice there in the home and sometimes I just want to rest. Sometimes I buy those frozen dinners and when it's cool I make soup with lots of vegetables, but the second day you don't feel like eating it. I do my best and my family they're very good. They invite me over my son and his wife and my grandson and his wife. They're all very good. I'm so proud that I could see my granddaughter graduate. I have two grandsons and three great grandchildren. I always thought I'd be on my own but the last while I haven't been feeling so good. I can't get in the bath alone I have, you know, when you get dizzy. I have two homemakers and they're very good to me. I have arthritis in my back and legs and sometimes my blood is too high and

sometimes too low. The doctor he says walk as much as possible and I do but sometimes I get so tired. The doctor and his wife they're very nice. I try to get a little exercise, I dust sometimes. The homemaker, she vacuums and cleans. Everybody is very good. The minister's wife she visits and the lady down the hall. They're very good. Well, my dear, that's about all I can tell you, yeah.

Mina's Themes

The themes from Mina's interviews revolved around the hardships she had survived and her family of whom she was so proud.

I have a very good family, but they have their own lives to lead.

"They're all very good, every one of them," she said. "He's (her son) here every morning, if he's not here he phones," and "He's a wonderful son and his wife, too."

"My son he does a lot of running around," "I have a wonderful family."

"I feel so proud that I can live and see my great granddaughter graduation."

I wonder if being ready to rest in a care home is related to not wanting to be a burden to her family? It is implied when she says "They have their own lives to lead."

I do my best. I worked hard. I didn't have an easy life.

Mina's childhood was, by my middle class standards, underprivileged. Her tone of voice implied that she was reporting, perhaps comparing the lives of her grandchildren to hers. The words alone could be construed as self-righteous without hearing her voice. In talking about her grandchildren she said,

those kids don't know what hard time is. They want this and they want that I said well we didn't have. We were 10 of us. We had to get along with what they had. When it came to pleasure that was out. I worked hard in my young days.

After her marriage there were other hardships. “I had one little boy, well he only lived two months.” They left the prairies because “It was hard times, people had no work” They eventually settled in the South Okanogan where, “I worked in the cannery,” and cooked for the many visitors who came to stay, “Everybody came to see (us). I had to do a lot of cooking there. They came and well you couldn’t chase them away so you had to make lunch.” She does not tell what else she had to do. In my experience, there is more to having visitors than cooking.

When her husband became ill:

I looked after him for about a year and a half and I couldn’t handle him any more he went out into the street ... he said, ‘Somebody’s chasing me.’ he was so mixed up.... They put him in a home. He lived there for two years and four months.

He died more than 20 years ago yet she remembers exactly the number of months that he was in the home. She may have repeated that story many times to etch it in her memory, there may be emotions I did not detect. I interpreted no regret or guilt in her tone of voice, just a statement of how she had done her best through a difficult time.

Mina continued to do her best, “The doctor said keep on walking.” Several times during the interviews she repeated the doctor’s order and “I try to walk as much as possible. It isn’t easy sometimes but I do my best.” My favorite is this statement, “I sometimes go and dust. I get a little exercise.”

This image delights me as I picture myself shrivelled and bent, dusting for exercise. Given my penchant for avoiding housework I will have to be in the grip of a dementing illness. “You just never know,” says one of my favorite older people.

I want to rest.

From the stories that Mina told me, I assume that she meant that she had earned her rest. Her health was a factor as well, “Some days I get so tired I just feel like I would

like to do nothing,” and “I get very tired fast and my back bothers me.” The care home would be, she says,” a good chance for me to go and rest.”

Writing this section about Mina evokes my ready tears and chuckles again. Why did I choose that name for her? To me it is the short form of another name, an endearment. The love I felt at the second interview flows as I picture her and hear her voice in my mind.

Win

Biography with Anecdotes

Win was born in England in 1914. On leaving school she followed her two sisters to work in a hat factory as ‘odd girl’ then for a three year apprenticeship. She continued to work after her first marriage and the births of her three daughters. She remembers the time doing piecework in a room with 40 others as fun with jokes going back and forth, and the freedom to do a bit of shopping if she chose. When she was laid off and as a single parent had to support her children she was able to find work as a shop assistant in a shoe store. Her memories of this job are not pleasant. Eventually she met and married her second husband with whom she appears to have had a happier marriage. In 1965 they immigrated to Canada; he was 56. Hard times continued when he was laid off before she had arrived in Canada having left the two older daughters in England. She missed them dreadfully. Her husband found work that lasted until nine months before his 65th birthday which meant he did not qualify for a pension. Win did housework and home support to make ends meet. She cared for her husband at home until his death several years ago from congestive heart failure and a lung infection. She now lives alone in a comfortable but modest one bedroom apartment. She has good hearing, vision in one eye, arthritis, and congestive heart failure. She is very sociable and determined.

Win’s indomitable spirit is well illustrated by anecdotes taken from the interviews. Her pragmatic attitude toward her adventures and lively descriptions made clear pictures while the very dry delivery kept me laughing even though the subject was not funny.

After listening to the tapes several times I am hearing incongruity between the words and the tones with which they were delivered. As I read the transcripts I hear her

voice but do not see her body language, and wonder what was making me find her amusing, not laughing at her but with her when, for example, she said that she was frightened of having oxygen. Her husband needed it so she told him that if he left the tube off his nose again she would just throw a match in there because she was afraid of the oxygen just going around the room. At first I thought she was joking but her voice was serious, almost shaky.

The following anecdotes are taken verbatim from the transcribed interviews.

In the bathroom.

When I was down below back in the night I got up about four o'clock in the morning to go the bathroom and the toilet was behind the wall all connecting from the bath and the toilet and I went to get up and I thought I'll wash just rinse my hands went to walk and I tottered backwards I must have been half asleep but I fell back into the bath and I lay there and I couldn't move myself me legs were over the top and I couldn't get any leverage and pull out to get out but I shouted for John he'd got his hearing aids out so he was just deaf and he didn't hear me. Luckily he woke and he wanted to go to the bathroom and he came in and he said what are you doing in there (laugh). He said you look like a crab (laugh) I'd got me hands you know trying to grip me legs over the tub (laugh). Oh I did hurt my leg ... I must have caught that down on the wall as I went big egg come up still got a mark there.

In the street.

I fell over in the street in with me walker. Because the wheels as I went off the sidewalk they got caught in a rut you know they spin round those wheels and they got trapped somehow and I felt it tip over and hadn't got sense to leave the handles. I went with it. And I looked up and down the street I was going for a walk and I thought there's not a soul in sight and I sat on the edge of the sidewalk and couldn't get up and then a truck came along two young lads in it and they looked back and ... what's she doing ... they backed it was very good of them

they came back and they jumped out and they said what's the matter I said I've fallen and I can't get up (laugh). They got me up they said shall we take you home I said no I've come out for a walk I said next time I'll bring a book and sit and read till somebody comes Yeah it seems silly at the time but things happen so quickly.

Making a living.

We had a slack season this was when I was on my own with the girls and uh we'd got a slack season and I thought golly I've got to get a job somewhere so I went in to town and I saw in the Co-op window female assistant wanted and I thought well I could sell shoes. Nothing to it. So I went in and I said um I'd like to sell come in to be an assistant, by the way John's mother lived in Wales, not in England and she'd got a she called it an antique shop I called it a junk shop. She'd got everything and it was in Abergelly Road and when I asked for this job about this job the man said have you done it before I said I thought I've got to tell a fib I said oh yes so he said where did you work I said it wasn't here it was in Wales. These things come in my mind you know just like that. He said and can you tell me where it was I said it was in Abergelly Road. Whether he knew Wales or not and knew of that road and knew I was, knew it, I don't know. He said well I'll tell you, you come on a month's trial and at the end of the week he said you soon got back into it again didn't you? (laugh)

Never sold a shoe in my life I hated it... But I stood it I was there till. I said to my boss I'll have to get a job somewhere else cause I've got to earn my rent. He said, "I understand but you come back soon as we get some work pick up again." That was the trouble with it you had a slack season.

In the time between the interviews, Win had purchased an electric scooter.

Getting out.

Oh it's lovely I go round the waterfront park and I'm gettin' my neighbor out livin' below me she's got one and she's had hers oh it'll be years now but she was not afraid but didn't like to go out didn't enjoy it and I said to her last week let's go down the waterfront and go round the park and she said you lead and I'll follow. So that's what we did. Then we went back round the waterfront and had some lunch and she said thank you for taking me out.

... two of us you see and last Sunday her son called for her take her to lunch so couldn't go out with me but I went down the Sunday concert on my own but I sat on there and I enjoyed it but it's nice if you've got someone with you.

Win manages to live with no home support except her daughter who phones or visits each day. Win eats meals from Chef on the Run or prepared entrées from the grocery store as well as fruit and vegetables that she can safely prepare with her limited vision and her arthritis. She is very careful in the bath so that she doesn't fall and she has several Nitrospray containers so that one is always available if she has an angina attack. She tries to get out each day on her scooter or walking and maintains contact with friends by phone. She does exercises on her bed so that she can't fall.

Win is realistic about her future. "I know I'm not going to get better, I've got congestive heart failure." "Still, we've all got to come to it." Her realistic attitude toward her needs and wants has over ridden the emotional aspects of giving up her home. She said once, "It's just when you've got to give up your home." "It's no good thinking I don't want to part with anything cause they've got to go." "... you've got to tone down according to the room, don't you?" Her name came up once for the care home, "I changed me mind, I said I didn't want to go ... but I've got to make me mind up this time." She has started planning what she will take when she goes to the care home. During visits to a friend who lives there she looks around the room to decide what will fit and how she will arrange her furniture.

Win is afraid at times and lonely. She said that unless she makes the effort there are days when she might not see another living soul. "You got so many people in the apartment but you don't see anybody unless you're coming or going or in the elevator with somebody." "They don't know what you're doing in that room behind that locked

door.” “I just sit here on my own and you don’t enjoy it so much.” “It’s nice to keep doing something and when you’re on your own I just don’t want to do anything.” “I go out every day if I can because there’s people about.” Sometimes at night she wakes up with pain which could be indigestion or her heart. She is frightened because she has to depend on her own judgment to decide if it is necessary to call someone. When she gets into the care home there will always be someone there at night and during the day. It will be easier to find people to talk to and do things with.

Interviewing Win has been a delightful experience. Her ability to make the best of difficulties, laugh about them, and carry on with her brand of creative solutions is inspiring. The last thing she said was that she could play cribbage with others in the care home but “I’ve never learned ... if I got someone to show me I’d learn I think I’d be able to do it.”

Win’s Themes

Win’s practical attitude to life is illustrated in the anecdotes written with her biography. Her pragmatic attitude extends into the themes of independence, fear, and loneliness. Win expressed her fear by talking about how she worried.

I’m a worrier.

Considering her heart condition Win says, “I could get a heart attack any time” and “It’s in the night it’s worse because some nights I don’t feel so good and I think now is that coming on and I think the more you think of it the more you panic.” Although she is frightened by the possibility that the pain she is feeling is her heart she appears to be telling herself not to think about it. Later she says again, “With this congestive heart failure I get frightened. I get frightened at night.” In the apartment block where she lives, “People come in at shut the doors and that’s it but over there (at the care home) you are seeing someone all the time aren’t you and you feel safer when there’s someone about.”

Not only does Win feel safer with people around her, she enjoys being with people.

It gets lonely.

Is this theme loneliness or sociability? Loneliness because of the words Win used but she loves to talk to people and to help people.

Win's loneliness can be assuaged by helping others, an acceptable way to be with others and maintain her independence. When Win apprenticed as a milliner she liked doing piece work. "Cause ... you're altogether, you get about 40 of us in a room." "All the jokes that went back and forth it was real fun." "I used to love it." Now living in her apartment she says, "I sit here on my own and you don't enjoy it so much." "I went down to the Sunday concert on my own.... I enjoyed it but it's nice if you've got someone with you." She makes an effort to be around other people. "I go out every day I can because there's people about." She said, "Unless somebody phoned me some days I don't say a word if I haven't spoke to somebody, an' I can't sing." In the next sentence her practical side comes to the fore. "Well, I can hum."

Win's theme is different from the shared theme of isolation in that she was actively pursuing the company of others and said that she enjoyed the company of others.

I just manage.

Intertwined through Win's stories was her ability to "make the best of things," to do what had to be done. "You never know what's coming, do you? You've got to make the best of things every day. You can plan but it still doesn't work out sometimes."

There is an emphasis on **I**. "Cause you don't like to, well you can't be knocking on doors and they say if you need anything knock on my door but you don't. No I wouldn't do that." Her daughter purchased a cell phone so Win could contact her when she was at work but, "I'm not gonna call her, it's not fair." "I'm managing my angina really good now," she said when she explained how she had Nitrospray available wherever she was. "Carry on as usual, do what I can."

When she is admitted to the care home the energy she now uses for self-care could be directed elsewhere. "I could probably help somebody."

... there'd be lots of interesting things I could do. I can't sew now ... but there's lots of little things I could do ... I could sit and read to people if they couldn't see. I can see now with large print books.

Win: Summary

Win's stories illustrated her ability to find solutions to her difficulties, then make the best of situations, indeed, sometimes turn them around. She said could not sing, so she would hum. She would carry a book so she could read the next time she fell in the street. "It's just when you've got to give your home up and I think uh well I've got my own room." "It's no good thinking that I don't want to part with anything cause they've got to go." Her attitude was realistic about her health, creative and practical in how she managed her life.

Reflection: What a mixture of humor and pathos! There was nothing funny in facts of the stories Win told, but her delivery and her quick responses caused me to laugh. Falling on the sidewalk with a walker is not funny, the mental picture of her reading a book until someone can help her up tickles as I imagine the reaction of the helper. My vision of her throwing a match into her husband's bedroom to teach him to be more careful with his oxygen brings giggles as does the image of her not speeding with her electric scooter. Just how good is her eyesight? I admire her zest for life.

Shared Themes

The theme labels are shared, the ways in which the participants demonstrated the themes was unique.

They Have Their Own Lives, I Don't Want to be a Burden

A common theme for the four women was how being in a care home would obviate the necessity for depending on family and/or home support and coping with the exigencies of managing a home. All four women had family members (with Olivia it was the church family) who checked on them, may have done housework for them, shopped

with or for them, and taken them to appointments. Win, Mina, and Olivia had home support as well, which was a financial concern. None of the four wanted to depend on family “They have their own lives.” Lin said, “You can’t rely on the family too much, it’s not fair ... they’ve got to live their lives that’s important.” In the care home all their physical needs would be looked after, it would not be necessary to pay extra for home support, or to depend on family for getting food into the house, or housekeeping.

They knew that their families worried about them too. “I don’t want to be a burden” is a common thread. In the care home being looked after physically would be managed by someone else so there would be less worry, they could rest, or in the case of Win, have fun. Win’s daughter had purchased a cell phone so Win could contact her at any time. Win didn’t want to bother her daughter. The family members would know that a professional was giving medications, and was available in case of falls, heart attacks, or other crises.

Olivia said, “After the door shuts that’s it until seven a.m.” She did not say that she was sometimes frightened at night as Win did, but I assume that she was at the very least lonely sometimes in the evening or other times when she couldn’t sleep. From what I learned about her it is unlikely that she would phone friends in the evening just to talk because a phone call might be an inconvenience to them.

None of these women complained about home support workers, in fact they praised them, “The girls are very good,” but sometimes home support people do not arrive or a new one is sent. In a care home these women would not have that worry. From personal communication with older people depending on home support, a new worker or one not showing up puts unneeded stress on the person. If the person doesn’t want to be a burden to the family in such an instance hardship could occur. The care home was independence from being a burden on the family.

Reflection: Now there is a paradox. Going to a care home can also be seen as a loss of independence. For these women losing their homes gave them freedom from dependence on family and/or caregivers.

Isolation

Win didn't like the social isolation which occurred in her apartment. She was sometimes frightened at night and lonely in the daytime. There would always be someone around at the care home. Olivia, too, said that after her home support worker left in the evening, "That was it." For Win and Olivia their experiences of isolation were related to fear of something happening when they were alone.

Mina did not indicate a need for other people but her son visits or phones each day, and others in the apartment visited her. She had the home support workers in weekly. Lin said that she was happy alone with her memories but she lived in a retirement home where she went to a central dining room for her meals and could attend activities. She walked the hallways for exercise and met people with whom she could talk.

Insight from reflection: Isolation is in the eye of the beholder, as are many other things, independence for instance! People have told me that the care home is isolation and loss of independence.

Using Past Experience as a Key to the Present and Future

Lin and Win used skills from the past to adjust to the present, but differently. Lin attributed her ability to adjust to her life experiences saying, "With all I've seen and done I can go with the wind." Her life stories were important right now, when she had to move to the care home she would manage because, "I adjust very easily. It'll be fine." She would be occupied with memories of her lucky life.

Win told how she had apprenticed as a milliner and later had sold shoes to make a living for her family. In her present circumstances she continued to find ways to manage in spite of her heart disease, arthritis, and poor eyesight. When she visited her friend who already lived in the care home she planned what she would bring when her turn came. Win's solutions were pragmatic and for the future; Lin looked inward to the past to cope with the present and future.

Mina's life had been full of hardship. She was ready to rest because of her past. She said, "It'll be a chance to go and rest," which was a change from the past.

Olivia, the teacher, told me about the present. I assume that the self-discipline in her daily life at the time of the interviews was indicative of her way of being when she was younger but have no evidence from her stories.

Reflection: Is this theme more my way of being than that of the participants? I believe that the keys to the future lie in the lessons of the past. On the other hand, themes emerging here make no pretense at universality. I see patterns from the past as the key to the future whether they are repeated or changed because of lessons learned.

Summary

Figure 1. Lin's Themes

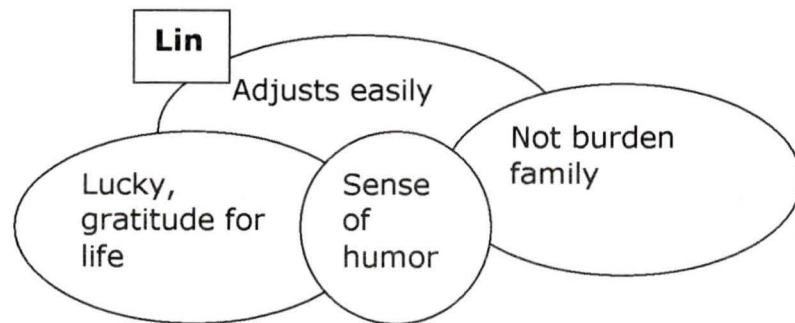


Figure 2. Olivia's Themes

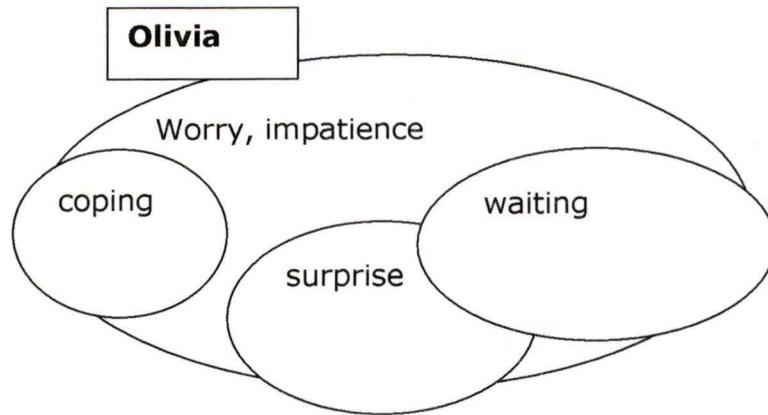


Figure 3. Mina's Themes

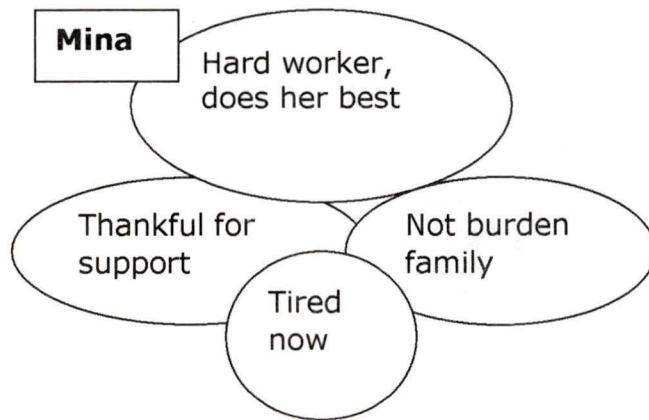
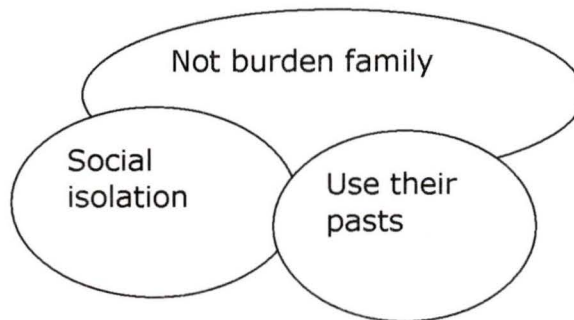


Figure 4. Win's Themes



Figure 5. Shared Themes



As I lived with the participants' stories and the words of Ely et al. (1997) and Richardson (1997), the following lines from the interviews emerged as a summary of the themes. It is appropriate that the participants have the last words in this section.

Facing the Future

When you get to a certain age you have to adjust

I just can't look after myself

I don't want to be a burden, they have their own lives

It's hard to give up your home

I don't know how long the money will last

I've had a hard life and I want to rest now

I can manage now but ...

It will be a relief to be in there.

No more worries about finding helpers

My children won't worry so much

My daughter got a cell phone so I could phone her any time

but I don't like to bother her.

CHAPTER 5

DISCUSSION AND IMPLICATIONS

Summary of Results

As their illnesses progressed the four women in this study became more isolated. Without the strength to initiate social contact they were more dependent on friends and family who would phone or call but they did not want to be burdensome. This is a simplified version of the chain of events but useful as part of the summary. Their life stories illustrating how they had managed when they were healthy were keys to the ways in which they were coping before entering long term care. I had assumed that being on the wait list meant that waiting would be a theme, that waiting would take precedence over other activities in their lives. This was the case only for Olivia; the others were carrying on with their lives as best they could. They were coping with their illnesses, fears, and worries, trying to keep active as they had done when they were healthy.

Relationship of the Themes to Research Literature

Isolation

Win and Olivia talked about the isolation of their apartments. Olivia lived in a residence where others spoke with her when she was in the common areas. She felt isolated in the evenings and nights. Win's apartment had only the laundry as a common area so she visited by phone and went out daily to be with other people. She was particularly nervous at night. Johnson et al. (1994), Lee (1999), and Molony (1997) have found that a reason to enter long term care was fear of living alone. Home is no longer safe. In their review of the literature on residential care placement, Lee, Woo, and Mackenzie (2002) summarize research results with the themes of feelings of loss but security in being in a care home, as well as the acceptance of having made the best possible choice. At a care home residents can socialize if they choose to do so (Armer, 1996; Bondevik & Skogstad, 1998, Krause & Borawski-Clark, 1994) and have the reassurance that there will be someone available to talk to during a sleepless night. Win told me how much her friend who was already in a care home appreciated a nurse

bringing a hot drink and talking to her during the night. Win was looking forward to being able to help others in the care home by reading or visiting with them. Olivia found the time between the evening and morning home support worker very long. Although she did not say she was afraid or lonely, she was very happy to talk to me as often and for as long as I wanted to visit her. Social isolation is, I believe, a detriment for older people staying in their homes. Fears can become magnified when there are no other people about. To see and to eat at a table with others and have the choice to chat is important in helping to maintain one's perspective.

Burden

A theme that was voiced by Win, Lin, and Mina was not to be a burden to the family. They were very appreciative of the help from friends and family but did not want their families to feel obliged to see to them. The fourth participant was surprised that her church family phoned, visited, and took her out. One of the findings of Johnson et al. (1994), Schoenburg and Coward (1997), and Wielink and Huijsman (1999) was that people made the decision to enter the nursing home in order not to be a burden on the family or acquaintances. None of these researchers elaborated to any great extent on this theme, it was a part of their findings. Lustbader's (1991) book *Counting on Kindness: The Dilemmas of Dependency* helps a caregiver to understand how an older person might feel as her level of dependency rises. The decision to go to a care home to avoid being a burden was also a way to be independent, to have a measure of control over the decisions for the future.

Control

Win had chosen to go to a care home in spite of the objections of her daughter. Olivia needed to go because her cancer had progressed. Although Lin's and Mina's decisions had been made with the help of others, they were in agreement. Making the decision to enter long term care can be very difficult for the person and for family members whose feelings of guilt may persist for a long time (Dellasaga & Mastrian, 1995). The participants of this study were able to make decisions regarding their futures

although they may have been helped by their families. Often it is the physician or a family member who makes the decision that the older person is to live in a nursing home (Johnson, Schwiebert, & Rosenmann, 1994; McAuley & Travis, 1997). When the person who is to enter care has had a part in making the decision, the adjustment process is facilitated (Johnson et al., 1994). Reinardy (1995), who compared the well-being of newly admitted nursing home residents with their participation in the decision to move, found perceived decisional control to be a factor influencing adjustment. Related factors were the person's coping style, personality, and seeing the move as advantageous. The participants of this study had weighed the advantages and disadvantages of going to a care facility and had decided that the move was the best option.

Study Limitations

The purpose of this study was to describe the lifeworlds of the participants before they entered long term care. "As each life is unique, so too are the themes" (Kaufman, 1986, p. 25). Lives are individual though culture and historical events may be shared. As Bateson (2000) says of her work, "No group this small can be used to prove any generalization, but attention to them can provide takeoff points for reflection," (p. 227) and "We are both representative and unique" (p. 228). The review of literature in Chapter 5 indicates that the themes of isolation, being a burden, and decisional control—from the lifeworlds of the participants of this study—are similar to those reported by people already admitted to care homes. This study is unique in that the concentration was on the lifeworlds while waiting for admission to long term care.

Choosing to hear the stories of the participants only is both a strength and a limitation because "all the stories of the past are filtered through the circumstances of the present looking to the future" (Bateson, 2000, p. 50). I wanted to understand the participants from their stories only as they were told today. Families may well have had a different picture.

Having a study of four participants is both a strength and a limiting factor. Four is a small number, a limiting factor, but using four participants enabled me to be deeply immersed in the data. It was interesting to note that with four participants from diverse

backgrounds three themes were shared. A project with a larger number of participants is a topic for further study.

Three of the four participants in this study wanted to be in a care home, one was resigned to the move because she realized that she could no longer look after herself. A study which included men and which included people who were neither resigned nor happy with the move would add more dimensions to the information gathered here. The participants for this study were able to understand the Consent (Appendix B); many of the older people who are waiting for admission to a care facility have illnesses which include forms of dementia and short term memory loss. Although a purpose of this study was to find out how older people who were mentally competent felt about the move, this is a limitation to the information gathered. I can only assume, at this point, that a person with a form of dementia might not want to be a burden if she were able to remember and link cause and effect.

Implications

With a description and greater understanding of a situation, in this case older people waiting to enter long term care, it may be possible to find ways of helping others. The first step was, for me, to try to see from their eyes what their lives were like, how they were coping and feeling. The people, themselves, should be the source of information. The personal characteristics that they possessed which helped them to be positive about a move to long term care could be keys to help others.

This study has changed how I react to residents at the care home where I work, and to other older people whom I meet. I am now more aware of the need to take more time to listen, and to validate their feelings and them as individuals. Some have said, "Thank you for listening," or "Thank you for stopping to talk to me," sometimes there will be a big smile. The extra few minutes taken are well worthwhile.

Ability to Adapt

Although the research on adaptation and intervention were often in the same article I have separated them where possible. In some cases the researchers began their

studies before the person was admitted and the interventions were later. The purposes of the studies I have noted have been different from mine, which was to find out how the person was feeling about the move to long term care.

The findings which I have judged to be relevant to my work follow. When the person evaluates the move as desirable adaptation will be achieved more quickly (Young, 1990, p. 77). Personal belongings may be a source of identity and as such having them in the new home is a way to facilitate adaptation. The social structure of the nursing home is an important factor in adaptation. Dillworth-Anderson found the physical design of the facility and the encouragement of participation in groups helps the new resident to adjust (as cited in Young, 1990, p. 79). Loneliness is a predictor of a person not adapting to the care home (Young, 1990, p. 78). The person who has maintained self-worth is more likely to adapt according to O'Conner and Vallerand (1998), who conclude, "Feeling good about oneself may lead to better self-care and to longevity- promoting activity levels in individuals who might otherwise give up and waste away" (p. 373). In her descriptive study of 34 rural older persons Armer (1996) discusses five factors which affected their adjustment to congregate housing: perceived choice, social interaction and support, predictability (familiarity with the place), prior life satisfaction, and recency of loss. Regarding loss she explains, "... the degree of confidence and competence gained through coping with prior and recent losses had significant effects of adjustment to relocation" (p. 37). Wilson's (1997) study also found that the adjustment phase included development of a positive attitude and a social network.

The literature suggests that those people who have control in their life choices and positive feelings of self-worth adapt more easily to the care home. Accordingly, interventions have been developed.

Interventions

The interventions described below are related to my research questions and confirm my findings. An assumption with which I began this study is that listening and hearing the older person is vitally important. The interventions below are client-centered

as is my assumption. How any interventions could be administered a topic for another study.

Johnson et al. (1994) recommend that nurses try to involve newly relocated residents as much as possible in the decisions regarding their care. Their rationale is that if the person feels she has some control she will adjust more quickly. Krause and Borawski-Clark (1994), also, relate feelings of self-worth and control to the ability to deal with stress. They contend that social support has a role to play in enhancing self-worth thereby improving the person's ability to cope with stressful events.

Young (1990) recommends using a transition framework as an intervention. The idea of an ending, a neutral time, and a new beginning will help the person adapt to relocation by the acknowledgment and emotional support for the person's losses and gains in each phase.

If the older person is well-informed and familiar with the chosen facility and supported both before and after the move, relocation could be less stressful (Dellasaga & Mastrian, 1995; Lander, 1997; Olesen & Shadick, 1993). Harkulich and Brugler (1991) have developed a 14 point list to help make relocation less stressful. Manion and Rantz's (1995) plan is more detailed but contains the ideas developed by Harkulich and Brugler (1991). The ideal situation would be to have the person, family members, and medical personnel discussing the options, all having had a part in making an educated decision, all having the same agenda: What is best for the older person? Ideally these discussions would have begun well before the older person needed to be in the care home. Mullen (1977) describes a model of care which includes similar steps. The first step is *Cognitive mastery* of the situation by the older person and the family. This includes tours of facilities and assessment of the total situation of the older person and the family. *Compliance* from the environment, the second step, is the family's ability to find the resources necessary to support the older person. The next step is *Control*. Often it is the family who takes control of the decision making. Ideally everybody would work together. Step four, *Coalitions*, involves family and health personnel working together. *Communication* among family members, health personnel and the older person who may have health related communication difficulties is helpful in dealing with this stressful

time. *Choice* is the final step in this model. Several alternatives may be available (p. 15). Using the interventions of other researchers and the information from my study a comprehensive intervention plan could be developed

Different Illnesses

Perhaps there is a difference in the preparation needed with people who have different illnesses. Olivia, with terminal cancer, was more concerned with the present than the others, perhaps that is her nature. Different participants might confirm this supposition. Win visited with friends already living in the care home to which she intended to go so was familiar with it. Sometimes people at the home where I work recognize others who have been at the local day care center. Increased exposure to the idea of going to a care home with the goal of decreasing fear of the unknown, would be beneficial according to Manion and Rantz, (1995), who recommend multiple visits ahead of admission.

Home

Van Manen's (1997) statement "Home is where we can *be* what *we are*" (p. 102) resonates in me but what if how *we are* has changed? When she was still able to cope with most aspects of her life Win said "It's just when you have to give up your home." Olivia had given away many of her belongings when we spoke the first time so I sense now that she had already given up her home and was waiting as patiently as she could to move into care. Lin said, "You just have to adjust." Mina was tired, "Sometimes I just want to rest." These women were more prepared to move because of changes in their abilities to cope in their homes. They were also able to weigh advantages and disadvantages of staying in their homes and moving to a place where they would not be a burden on their families and where they would feel safe. For people with less logical ability, the move can become difficult for the person and the family who take the responsibility of relocating the older person from her home.

When my father was in extended care I often took him for drives and occasionally brought him to the house where I was living, the house which had been his home for

almost 30 years before he was put in hospital and then extended care. One time he was at this house with me he looked around and said, "I don't have a home." I was too shocked and hurt to ask what he meant. Many of the furnishings were the same; the yard was the same. Why wasn't it home to him? Now I can only speculate, perhaps for him having a home meant having a wife.

When an older person speaks of "home" the meanings can vary. For some people home is where they lived as children, where their parents lived, perhaps another country. For others the places that they raised their families is home. They may have moved several times, so, for them, it is the people who make the home rather than the place. If they have adjusted, residents call the care facility home and are glad to return after a trip away. They may still refer to another time and place as home so the word "home" can mean different places at the same time.

The four women had relocated several times during their lives. Olivia talked about her trips to England as going home yet she had lived in Canada for more than 50 years. She had made a home with her chosen family, a married couple. Win was the only one who expressed regret at giving up her home but her fear of being alone or a burden took precedence over wanting to stay at home.

Is home an idealized memory filtered through the lens of time? Although the concept of home could be the focus of a project like this one, I chose to use it as part of peripheral vision, because in order to be considering long term care their needs had changed, therefore what was preferable for living arrangements had changed. My belief is that if a person can be at peace within, she can be at home in various physical settings.

Quality of Life

Quality of life is another concept central to this study. Like the concept of home, quality of life varies from person to person and during a lifetime. Lin and Olivia lived in sheltered housing which had improved the quality of their lives. For some people the same retirement complex would be the opposite. A purpose of finding out how to help older people adapt is to improve well-being (Ruffing-Rahal & Anderson, 1995) which can be closely related to quality of life. The factors involved are very difficult to define

given the uniqueness of humans. I refer to it in general terms. Olivia, for example, was unable to go for the walks she so loved, unable to dress and undress herself. She was paying home support workers to come in twice a day to attend to her and worrying about the expense. She appeared to me independent, reserved, and concerned for others. What quality was there in her life?

Mina, Lin, and Win did not want to be a burden to their children but all three needed help which the children and caregivers supplied. They did not want to affect the quality of life of their children but to maintain themselves in their apartments needed considerable help. They had decided that a care home would improve their lives.

What is home and a good quality of life at one time of life can change as that person changes, sometimes drastically and quickly, sometimes slowly. The participants of this study were able to articulate those changes and to some extent their needs. They were either willing or resigned to the move into care because of their abilities to reason. Being reasonable about emotional issues such as moving may not be possible. Gleaning some understanding about the emotions may help in developing interventions for those people moving into care who can no longer reason.

Other than Lustbader (1991), the phenomenon of 'being a burden' has received little direct attention in the research. What did the participants mean exactly? How is being a burden related to autonomy, self-worth, decision-making ability?

Directions for Further Research

The question, "What would help you to prepare for moving to a care home?" could garner yet another facet to the picture. This question allows a prospective resident room to speculate and to voice concerns. A similar question, "What would have helped you to prepare for moving to a care home?" asked after a person has been admitted and settled in would be interesting. There have been interviews with people who are already in care homes but have not asked what would have helped them prepare. Is it possible to hasten adjustment to long term care by interventions before moving? Some research (Johnson & Hlava, 1994; Lander, Brazill & Ladrigan, 1997; Manion & Rantz, 1995) says

yes but a cost effective method of doing so has not, in my opinion, been found. This is another area for further research.

A study with a wider range of participants is a direction for further research. Participants on a list for a care home in spite of their wishes might give far different answers to the ones which I received. My participants were either resigned or looking forward to living in a nursing home; they expressed no anger at the prospect. There were no men in this study; the inclusion of men would add an important dimension. There are young people, less than 70 years of age, living in nursing homes, but their physical and mental conditions require them to live in a care facility. Talking to people in this category would be very interesting. Three participants of this study were from England or English parents, the fourth was probably European. Including people from other cultures, different ages, and illnesses could add scope to the information already available. Questions that included quality of life and the meaning of home would add other dimensions.

Conclusion

The most surprising result of this study was the amount of introspection I deemed necessary to do justice to my participants and to make clear my biases. The benefits far outweigh the effort.

The participants of this study had lived long, full lives and I believe that they were waiting similarly to how they had lived. I am very grateful for the time spent with them because I have found valuable life lessons from each one. Olivia waiting for space in hospice feeling badly that some one has to die before she can go in and worrying about the feelings of others, grateful for the caring of others, surprised that she has lived with her cancer as long as she has. Lin's spirit of adventure and grounding in the natural world writing memoirs for her family. Mina's loving gentleness, doing her best. Win finding humor and creative solutions for her difficulties. The process of interviewing and reflecting on the stories from the transcripts has been considerably more personal and insightful than I ever imagined. There is so much to learn from people. Perhaps it is in increasing the practice of listening with my heart, reflecting, and then trying to be

objective that is so valuable to me. Learning to express in writing what touches my soul has been another unsought experience.

Bateson (2000) says “Personal anecdotes invite the listener to reflect on the familiar and turn it through different angles of refraction, perhaps many times” (p. 229) and

I find that I learn more from writing than from any other activity, because the process forces me to recycle experience, harvesting the learning in what I already know. Becoming a writer has meant for me learning to learn from experience, often by ruminating on past events and encounters and rethinking them, getting more and more juice out of them, as they open up a spiraling cornucopia of vision (p. 229).

Some of my questions have been answered. The description of what it is like to be waiting for long term care has been answered for the participants of this study. The manner in which they coped with their illnesses and activities of daily living has been described. The ways that they were preparing to enter a care facility varied. Writing one’s memoirs was an interesting preparation. Reducing the amount of personal belongings was the preparation I expected. This had happened with Olivia, Win was in the planning stages, Mina and Lin did not say anything about their possessions but talked about the past and their families, topics important to them.

The theme of isolation was not surprising because I imagine how it can be to be living alone, physically frail, coping with house management and keeping enough energy available to have social contacts. In a care home there is the possibility of social activities and caregivers present in case of illness or falls. With no home to manage more energy could be available for enjoying life as much as possible in the time remaining. That is the perspective of a person who has limited patience with housework whereas homemaking is identity to some people. For Win and Olivia living where they could see others and for Mina where she could rest was preferable to the isolation of their homes.

Using past experience to cope with the present was part of my original question about preparation for the care home but evolved further during data analysis as I realized how much it is a part of my way of being. Finding patterns from the past and applying

them to present and future has partially answered the questions about how these women were coping each day. A simplified summary is that Mina was doing her best, Lin was living in her memoirs, Olivia was disciplined, and Win found people to talk to. People are, however, very complex so a simple summary does not do them justice.

The theme of not being a burden was a surprise. At the beginning I had assumed that my participants would tell me that they were sorting their belongings and preparing mentally to enter care, the idea that entering care would relieve their children was not what I expected to hear perhaps because of my family culture. In our family we are expected to look after each other. Now that I am aware of this theme, I hear residents where I work say the same thing. Listening for the unexpected has been an important lesson to me as a researcher.

More research is needed on the meaning of “burden.” Are burden and independence related? What exactly does “being a burden” mean from the point of view of the person of that opinion? What is independence? Making one’s own decisions? Freedom from making decisions? Mina said that she did her best to do what the doctor told her. Allowing someone else to make the decisions is a decision, perhaps making and understanding the priorities is more important. It was more important to the participants of this study that they move than to need the help of their families. The meanings to an older person of independence and burden would be very interesting.

What is it like to be on the wait list for a care facility could be answered “It depends.” It depends on the person, her life experiences, family situation, and the reasons for needing care. There are no simple answers.

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Appendix A: Poster

CAN YOU

HELP A STUDENT

ANSWER THE QUESTION

What is it like to be waiting to be entering a nursing home?

Ann, a University of Victoria M. A. student wants to talk to people who are waiting to enter Long Term Care. The purpose of this project is to listen to the points of view of the prospective residents.

Please leave a message for Ann at **656-0815**.

Appendix B

Human Research Ethics Consent Form

You are being invited to participate in a study entitled Transition to Long Term Care: the Lived Experience of Waiting for Placement that is being conducted by Ann Aylard. Ann is a graduate student in the department of Educational Psychology and Leadership Studies at the University of Victoria. You may contact her if you have further questions at 656-0815. As a graduate student, this research is part of the requirements for a degree in Learning and Development and it is being conducted under the supervision of Dr. Geoff. Hett. You may contact the supervisor at 721-7783.

The purpose of this research project is to gather information about what it is like for a person to be on the wait list to enter a long term care facility. Research of this type is important because little has been written from the point of view of the prospective resident.

You are being asked to participate in this study because your name is on the list for a facility. Participation will have no bearing on services that you are currently receiving or in your standing on the wait list for long-term care. If you agree to voluntarily participate in this research, your participation will include two or three meetings, one to gather the information and one to discuss how I have used your information. The length of time for the first interview should be about one hour so if you would prefer to break this time into two sessions that can be done. The other meeting is to review with you what I have written. The meetings will be held at a place and time convenient to you.

There is a risk that our discussion might bring up emotional issues. If this is the case I can provide a list of professional counselors that could help you. The potential benefits of your participation in this research include telling how you are feeling as you wait to enter long term care and contributing to the body of knowledge that can help others.

Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation. If you do withdraw from the study your data will be destroyed.

In terms of protecting your anonymity a pseudonym will be used and identifying life details will be altered with your approval. Your confidentiality and the confidentiality of the data will be protected by the use of code names on the tapes and transcripts which will be stored in a locked cabinet to which only I will have access. Data from this study will be disposed of within one month of the completion of the final revisions. It is anticipated that the results of this study will be shared with others by the publication of the thesis.

In addition to being able to contact me at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Associate Vice President Research and the University of Victoria at 721-7968.

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researcher

Participant signature

Date

***A COPY OF THIS CONSENT WILL BE LEFT WITH YOU,
AND A COPY WILL BE TAKEN BY THE RESEARCHER***

Appendix C

Interview Guide

Explain the purpose of the interview, establish rapport.

Read, discuss and sign the consent form.

(The order of the interview questions and the demographic information may vary according to the situation.)

Demographic information

Full name

Date of birth

Place of birth

Occupations

Formal Education

Demeures

Family past

present

significant

Activities social

hobbies/pastimes

other

Significant experiences

Interview guide

What is it like for you to be on a wait list for a long term care facility?

(This is the main question and one that will, I hope, elicit the information. If the participant is reluctant to talk, I will use some of the questions below. My job is to ensure that we stay on the topic so the questions below are to lead the participant to express feelings about moving to a care facility.)

Tell me what you like to do during the day?

I understand that you have some health concerns, how are able to do all that you need to do?

What lifestyle changes do you see as possibilities in your future?

The second meeting time will be to verify how I have used the information they have given me. It will start with a reminder that participation is voluntary and an explanation of what I have done with the information. We will, then, discuss the material.

VITA

Surname: Aylard

Given Names: Elise Ann

Place of Birth: Victoria, British Columbia, Canada

Educational Institutions Attended:

University of Victoria	1996 to 2002
University of Alberta	1970 to 1971
University of British Columbia	1963 to 1968

Degrees Awarded:

B.Sc.	University of British Columbia	1968
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Honours and Awards

B.C. Scholarship	1963
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Title of Thesis:

Just Managing: Lifeworlds While Waiting for Long Term Care

Author

Elise Ann Aylard

2002