A PLACE LIKE THIS: A STUDY OF ELDERS' PERCEPTIONS OF LIVING IN A CARE HOME THAT HAS ADOPTED THE EDEN ALTERNATIVE PHILOSOPHY OF CARE

by

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ABSTRACT

Care facilities for elders have been guided by a medical model of care, with a focus on physical conditions. The Eden Alternative (EA) philosophy is being introduced in many facilities in attempt to move beyond the medical model and address psychosocial needs. However, little research exists to demonstrate its impact on the day-to-day lives of the residents living in these facilities. The purpose of this qualitative study was to understand how the EA has influenced the lives of elders in facilities. Data was generated through personal interviews with 9 participants from two facilities that are committed to adopting the philosophy of care. Three dominant ideas emerged from the data in response to the research question. First, the philosophy did influence participants’ lives in three meaningful ways: (1) through opportunities for personal choice (2) through opportunities to maintain personal identity and (3) through opportunities for caring. However, the second idea that emerged related to the extent to which the philosophy had infiltrated the day-to-day experience of living in a care facility. Specifically, according to participants’ stories, the philosophy’s goal of creating a sense of home or community was not yet realized. Finally, the third major idea that emerged was that the presence of two competing societal discourses that both supported and/or competed with the implementation of the Eden Alternative philosophy: *life is what you make it* and *I am old and useless*. Recommendations for practice highlight the importance of learning elders’ life stories but also recognize that health professionals need to raise questions about our current societal discourses of aging and long-term care and can use the Eden Alternative philosophy to begin to reconstruct discourses that recognize elders as valuable, contributors to our society.
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CHAPTER 1 SETTING THE STAGE

We are an aging population. There are approximately nine million elderly people being added to the world’s population each year (Sadik, 2000). It is expected that by the year 2020, the world will have one billion people over the age of 60 (Sadik, 2000). Canada alone is considered to have an old population. “By rule of thumb, a population in which at least 10 percent of the population is aged 65 years and over is deemed old” (Chappell, Gee, Macdonald, Stones, 2003:2). Already 13% of Canada’s population accounts for people over the age of 65. This number will increase to 15% by 2011 and 22% by 2031 (Health Canada, 1999; Statistics Canada, 2001). It is expected that the number of people 80 years old and older will increase from 41.2% to 43 % by 2011 with an estimated 1.3 million people in this age group (Statistics Canada, 2001). This age group is the fastest growing in Canada (Chappell et al, 2003). Victoria, BC is Canada’s “oldest” city with 18.2% of its population being 65 years of age and over (Chappell et al, 2003).

With an aging population it is not surprising to discover that more than one third of the population aged 85 years and over lives in residential care settings (Chappell et al, 2003). In 1995-96 alone, approximately one quarter of a million Canadians were living in long term care facilities, with 81% being over the age of 65 and 73% being women (Statistics Canada, 2001). In BC, 29% of women and 17% of men aged 85 years or over live in a residential care setting (British Columbia, Ministry of Health Services, 2004). Individuals who move into care facilities tend to be those who require higher, complex levels of care (National Advisory Council on Aging, 1999). This typically includes chronic health problems such as Alzheimer’s and other dementias, strokes and incontinence. The need for beds in care
facilities will likely continue to increase with the increase in the number of people who are very old (National Advisory Council on Aging (Canada), 1999) despite policies to support people living at home.

**Historical Development of Long Term Care**

Long term care facilities, also called residential care facilities, nursing homes or care homes can be defined as settings for older individuals who can no longer live independently because of a chronic illness or disability that limits their ability to function, and thus require a range of services and twenty-four hour assistance with daily activities such as personal care (Noelker & Harel, 2001; Kane, 2001). Historically, long-term care began during the last century as almshouses or poorhouses. These institutions housed the sick and poor who had no family or informal caregivers. Societal values and beliefs at this time placed social disgrace and blame on individuals who lived in these institutions. Poverty and frailty, even in old age, were equated with personal failure (Noelker & Harel, 2001; Siebert, 2000). Also during this time, religious and charitable organizations built homes for the elderly. These homes however, “were only for the deserving older persons of good character and members of their own associations and organizations” (Noelker & Harel, 2001:4).

Institutions built in the early 1900s offered little nursing care and were generally not inspected by the government (Siebert, 2000). No insured institutional health services existed outside of acute care until the mid 1900s (Cowles, 2000; Siebert, 2000). The introduction of social security programs in the United States and Canada did not offer economic support for individuals residing in public institutions. The goal was to financially support the elderly to remain in their homes so that these public institutions would eventually become obsolete.
The intent took into account the issue of poverty for the aged but not their physical and medical needs (Cowles, 2000; Noelker & Harel, 2001; Siebert, 2000).

The development of long term care facilities nevertheless continued with the increase in life expectancy, declining family size, women working outside the family home, improved medical technology and medical insurance (Cowles, 2000; Noelker & Harel, 2001; Siebert, 2000). Nursing homes became institutions that offered medical and physical care to the chronically ill elderly persons who could no longer manage on their own or with family support (Noelker & Harel, 2001).

Over the last forty years, the focus of long-term care facilities has been on quality of care. Standards and regulations, quality assurance and residents’ rights were implemented (Kane, 2001; Noelker & Harel, 2001; Siebert, 2000). Early efforts that examined quality of care focused on assessing and regulating structural features of institutions such as room size, training and education of staff and staff to resident ratios. Services, procedures and the care process were then standardized. In other words, guidelines in the delivery of care, appropriateness of care and timeliness of care were established. Care and quality indicators such as The Minimum Data Set (as cited in Kane, 2003) were developed in order to track or monitor care being provided. These regulations and care and quality indicators have had positive outcomes such as the availability of geriatric medicine, least restraint policies and intolerance of abuse and neglect (Kane, 2003; Noelker & Harel, 2001).

Long Term Care Today

Today, residents of long -term care settings are promised individualized care and an interdisciplinary care plan that is based on a comprehensive assessment of their needs. Residents are given assistance with activities of daily living such as bathing, dressing,
toileting and eating. The goal is to support elders by providing them with the necessary tools and equipment so that they can function to the best of their ability despite their chronic illness and/or disability. The hope is to promote, restore and facilitate independent functioning as much as possible (Beaulieu, 2002; Cowles, 2000; Kane, 2001; Siebert, 2000).

Recent literature suggests that the model of care in long-term care facilities is shifting from a biomedical model where physical and medical care are the foci, to a bio-psycho-social model where the focus is on the ‘whole’ person. In other words, in addition to physical and medical care, social and emotional needs of the resident and family are also addressed (Cowles, 2000; Loxley, 1997). Besides providing medical and nursing attention, facilities now employ an interdisciplinary team comprised of dieticians, physical and occupational therapists, recreational and music therapists, social workers and pastoral care workers in order to promote physical function, social interaction and emotional and spiritual well-being (Beaulieu, 2002; Cowles, 2000; Kane, 1995; Kane, 2001; Siebert, 2000). Ideally, residents are asked about their likes and dislikes, they are given choices in regards to their daily routine, and they are offered opportunities for social interaction.

Research on long-term care facilities.

Although significant changes have occurred in care facilities over the years, research to date continues to show similarities to sociologist Erving Goffman’s (1961) total institutions (Khan, 1999; Paterniti, 2003). According to Goffman,

> Every institution captures something of the time and interest of its members and provides something of a world for them.... First, all aspects of life [in total institutions] are conducted in the same place and under the same single authority. Second, each phase of the member’s daily activity is carried on in the immediate
company of a large batch of others, all of whom are treated alike and required to do the same thing together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next... (Goffman. 1961: 4-6)

Goffman considered care facilities for the elderly to be a type of total institution. Living in a total institution or in a care facility involves a loss of privacy, loss of choice, fixed schedules, and standardized treatment (Khan, 1999). Moreover, individualized care and interdisciplinary assessments in care facilities continue to be ruled by physical and cognitive decline (Kane, 2001). Care plans typically focus on problems or concerns with activities of daily living such as bathing, dressing, toileting and eating (Kane, 2001; Guse & Masesar, 1999).

At the time this research was started, the literature and studies available on long term care showed that care facilities place value on the accomplishment of tasks (Duncan-Myers & Huebner, 2000; Guse & Masesar, 1999; Liukkonen, 1995). These points were illustrated in a study conducted by Arja Liukkonen (1995). She completed a two-part study in two nursing homes in Finland. In the first part of the study, she attended daily staff meetings over a 28-day period to explore the nature of care and the care models used by staff to care for residents. The findings revealed that the discussions focused on physical issues, medical treatment, medications, and bodily excretions.

These emphases clearly reflect a task-oriented approach to caring, in which interaction is formal, the emphasis is on the technical performance of the job, and the elderly individual is left with little scope for real autonomy. Much less attention is paid to the everyday lives of the institutionalized elderly (Liukkonen, 1995:360).
In other words, older people entering care facilities soon discover that everyday events and activities become fixed and scheduled (Duncan-Myers & Huebner, 2000; Guse & Masesar, 1999); their lives built around inflexible routines that are designed for staff and ultimately promote operational efficiency (Guse & Masesar, 1999; Kane et al, 1997).

In addition, elders living in care facilities have minimal choice regarding when and in which activities they participate. “Opportunities for choice and independent decision-making are diminished to the extent that the individual resident needs must conform or fit with the larger group needs within the facility” (Guse & Masesar, 1999, 528). Resident activities are scheduled and offer little flexibility. Studies have shown that these activities help pass the time but offer little in terms of meaningful interactions (Aller and Ess Coeling, 1995; Kane, 2001; Khan, 1999; Lukkonen, 1995). For example, Aller and Ess Coeling’s study which examined what quality of life meant to residents who lived in a 150-bed care facility in Ohio, found that “residents noted the importance of recreational activities and hobbies but described them as being more ‘to pass the time’ than a meaningful part of their lives” (Aller and Ess Coeling, 1995: 23).

Other research has found that much of residents’ time is spent waiting for assistance with everyday tasks such as bathing, dressing, toileting (Fiveash, 1997; Khan, 1999; Liukkonen, 1995). Liukkonen (1995) for example, interviewed 31 residents about their experiences of living in a care facility and described their experience of “waiting.”

*All residents had to wait their turn before they could get down to their daily routines (washing, dressing etc.)... They waited for their meal to be served. They waited for visits by friends and relatives. Waiting for visitors was commonly thought to be*
meaningful but waiting for daily routines was clearly a major bother and burden (Liukkonen, 1995: 362).

In addition to “waiting” Liukkonen’s study also found that participants feared that any criticism could result in repercussions with care or ability to continue to live in the care facility and that obedience was extremely important. She quoted one of her participants: “You have to wait, even though you know you could and that you have enough energy to do it yourself. You have to obey every word. If you fall over, then it’s your fault” (Liukkonen, 1995: 365). Other studies illustrate similar findings. For example, David Khan’s ethnographic study (1999) with 21 participants conducted in 145 bed care facility in the Western United States found that elders have a strong need to comply with rules and are reluctant to complain. Residents wanted to separate themselves from “complainers”. “I don’t want to be a complainer, so I try not to find fault with things” (Khan, 1999:123). Barb Fiveash’s ethnographic study (1998) in a care facility in Australia also found that participants felt a lack of power and control and as a result, perceived a strong need to get along with nursing staff.

Most key informants felt that they had little power or control and that it was necessary to get on the good side of the nurse. To be a good resident, key informants believed it was necessary to be subservient and compliant (Fiveash, 1998:170).

Literature has found that when individuals cannot control where and with whom they live, with whom they interact and what their daily activities will be, there increasingly becomes a loss of identity, a sense of depersonalization, learned helplessness and dependency (Duncan-Myers & Huebner, 2000; Guse & Masesar, 1999; Kane, 2001; Noelker & Harel, 2001). Furthermore, research on learned helplessness indicates that such structure and rigid
routines or regimes have detrimental effects on “...the human spirit, creating listlessness, depression, and abandonment of efforts to exert control” (Kane, 2001, 295). The literature also reveals that the development of resident dependency is not necessarily due to physical decline but rather the result of the regime of institutionalized care (Nolan, Grant, & Nolan, 1995).

Other studies point to the lack of communication between staff and residents. In such task oriented environments where getting as much done as quickly as possible is the culture, little time is left for conversations. The conversations that do occur appear to be initiated by staff, focused on treatment and are short in duration. Research has revealed that even though residents would like to spend time talking and interacting with staff, they did not initiate conversations because staff was seen as being too busy. In other words, social and emotional needs of elders are ignored (Liukkonen, 1995; Nolan, Grant, Nolan, 1995; Paterniti, 2003). It is not surprising then that elders living in care facilities soon learn to equate medical treatment with attention (Duncan-Myers & Huebner, 2000; Guse & Masesar, 1999). The lack of communication between nursing staff and residents was found in a thirteen month long ethnography study completed in a 90-bed care facility in the USA. J. Neil Henderson collected data via participant observation, structured interviews with 30 high functioning residents, and anonymous staff and family questionnaires. The main purpose of the study was to understand the nature of long-term care “at the interface of the Certified Nursing Assistant (CNA) and the patient” (Henderson, 1995:40). Henderson discovered that staff felt there wasn’t enough staff to do much more than “basic care” – the bed and body care. He also found that psychosocial care was delivered primarily through scheduled social activities arranged by the Activities Coordinator as well as housekeepers who spent more time talking
with residents while cleaning their rooms than the CNAs who were expected to move more quickly from room to room in order to complete personal care tasks (Henderson, 1995).

The problem therefore with the current model of long term care (whether biomedical or biopsychosocial) is that it continues to inadequately address psychosocial needs and quality of life issues for its residents. Elders who live in care facilities are considered to be medically stable and not requiring acute medical attention, intervention or treatment. The lives of the elderly should then be more than just addressing their physical conditions and/or needs. Yet, many current models of long term care neglect to address psychosocial needs and do not recognize that care facilities are also homes, residences where individuals are to live their lives. For the purpose of this study I will refer to residential settings for the elderly as “care homes” from this point onward, in attempt to move beyond their institutional nature.

What is the Eden Alternative?

In an attempt to address psychosocial needs of elders living in care homes, Dr. William Thomas who was a medical director of a nursing home in the United States founded the Eden Alternative philosophy of care in the 1990s. He created the philosophy in response to several problems he recognized as inherent in the medical model of long term care. Primarily, he found that elders were suffering from loneliness, helplessness and boredom (which he calls the three plagues of long term care) and that no medical intervention could cure their suffering (Thomas, 1996). He believes that elders living in care homes are “existing” rather than living. He too refers to Goffman’s work. He notes that although care homes often have serene sounding names such as Golden Acres, they are still total institutions. “... Nursing homes are what are known as “total institutions”. They have more
in common with prisons, reform schools, military boot camps and cloistered convents than they do with idyllic-sounding retreats” (Thomas, 1996:11).

Central to the philosophy is that residents in care homes receive far too much treatment and not enough care. According to Thomas, physicians are taught that the provision of treatment equates with caring but he believes they are very different.

*Today, the resident’s life is analyzed in great detail, dissected and recombined into a treatment plan that defines every hour of every day of his or her life ... The typical resident [in other words] is bloated with therapy and starving for care” (Thomas, 1996:19-20).*

Caring on the other hand is helping people to grow.

*Genuine care requires us to recognize within each person the need to grow, the yearning for action, the desire to do as well as to be...the only reason to offer treatment is when the treatment either helps residents to grow or enlarges their capacity for growth. (Thomas, 1996:21).*

Thomas states that there are three key principles to care. First, it is essential to recognize and promote each individual’s ability for growth. Second, work with the elderly must focus on their needs and abilities and not our own. Third, caring is ongoing and lifelong. It never ends. Thomas also points out that there are barriers to growth. These are the three plagues of long-term care: loneliness, helplessness and boredom. It was these three plagues that drove Thomas to develop the Eden Alternative philosophy of care (Thomas, 1996).

Dr. Thomas developed the Eden Alternative philosophy in hopes of improving the quality of life for elders in residential care. The *mission* of the Eden Alternative is to improve the well-being of Elders and those who care for them by transforming the long-term care
institution into human habitats or communities (Thomas, 1996). Thomas’s vision was to eliminate loneliness, helplessness and boredom (Thomas, 1996). He created ten principles to guide the process of achieving this vision (see Appendix E).

The aim of the Eden Alternative is to transform the institution of long term care by creating human habitats or communities where children, animals and plants are part of the everyday lives of residents, families and staff (Thomas, 1996). Decision-making is placed back in the hands of elders and staff is encouraged to be flexible and abandon structured routines. The ultimate goal of the Eden Alternative is to create a “life worth living” for everyone in the community by providing opportunities to give as well as receive care, through loving companionship, and by imbuing variety into daily activities. These are the antidotes to alleviating loneliness, helplessness and boredom (Thomas, 1996).

Today there are almost 250 ‘institutions’ around the world that have adopted the Eden Alternative Philosophy. In 2004, Canada had eleven registered care homes (Beatty & George, 2004). In British Columbia, there are now four organizations that are currently registered Eden Alternative care homes (Thomas, 2002). The process to becoming a registered Eden facility involves several steps. Thomas has developed these steps and process for becoming an Eden organization in order to insure that organizations that state they are “Eden” are truly committed to adopting the philosophy of care. In other words, Thomas has trademarked the name to insure the integrity of the philosophy (Beatty & George, 2004).

The first step involves understanding the basics concepts of the Eden Alternative. This includes understanding (1) the Eden mission statement and the three plagues: loneliness, helplessness and boredom; (2) understanding the ten principles and how they form the basis
of the Eden Alternative; (3) understanding the structure and roles of the Eden Associate, the Mentor and the Regional Coordinator. The Eden Associate is an individual who has participated in extensive education and training and thus is prepared to support the education and process of adopting the philosophy in the facility. Mentors are Associates who have been recognized for their commitment to creating better living environments for our Elders (Thomas, 2002). Regional Coordinators conduct Associate trainings and oversee the Eden Alternative growth in their region. In other words, the role of the Coordinator is to cultivate people and organizations in their region that have committed themselves to the Eden Alternative philosophy (4) The final part of step one is to understand the Eden Tree. The Eden Tree is an opportunity to display the progress an organization makes as it adopts the philosophy. As each principle is embraced, symbols are placed on the tree and are used to celebrate those who give great care. Step two involves reading Thomas’ book entitled, Life Worth Living. This book explains the Eden Alternative and provides the how to steps of adopting the philosophy of care. Step three is education. Individual staff members are sent to Eden Associate training so that they can become well equipped to support the education and the process of adopting the philosophy in the organization. Step four involves completing surveys to determine how willing and open staff is to committing to the philosophy and creating changes to establish human habitats. Step five involves organizations developing new mission and vision statements that incorporate the values of the Eden Alternative. Step six – the final step is applying to become a registered Eden organization (Thomas, 2002). The registry acknowledges organizations that are committed to adopting the philosophy of care. The application to become a registered Eden organization is a formal process. Three criteria must be met: (1) The Administrator must be an Eden Associate, (2) The organization
is dedicated to implementing the ten principles which is reflected in the organization’s mission and vision, (3) The organization is in compliance with regulatory guidelines and standards (Beatty & George, 2004).


Recent studies on the philosophy have illustrated some significant findings. The Eden Alternative first began as a research project in 1991 at Chase Memorial Nursing Home, a rural 80-bed care home in New Berlin, New York. Thomas was the medical coordinator at the site. From January 1992 – December 1993, Thomas compared this Edenizing home to a control home of similar size and location. At the end of the study period he examined the cost of medication per resident, the number of prescriptions per resident and the cost per prescription per month for the period. Even though the care homes started with a similar level of medication use, the study indicated a decrease in medication use. Chase Memorial spent $1.44 per resident per day while the control care home spent $2.32 per resident per day. This is a 38% difference (Thomas, 1996).

Thomas also looked at mortality rates. He reviewed records from January 1990 to December 1993. The data was divided into two groups: pre Eden and post Eden. At the start, both care homes showed a rise in mortality rates. During the eighteen-months following the adoption of the philosophy, there were 15% fewer deaths at Chase Memorial. By the end of the study there was a 25% difference in the mortality rates. During this study, Thomas also found a decrease in the staff turn over rate. At Chase Memorial there was a 26% decrease in the care aide turn over rate compared to the control care home (Thomas, 1996).

The Texas Eden Alternative Research project wanted to replicate Thomas’ study in another area, with a larger sample and more variables. This outcome study occurred in six
care homes that were implementing the Eden Alternative philosophy and a group of control care homes with similar demographics. The data collection consisted of two categories:

(1) Clinical resident information. Indicators for this category included: medications, mobility, pressure sores and skin problems, infections, incidents and deaths. The inventory for Eden included various numbers of animals and number of children (2) Staff attendance and retention information. Pre and post surveys were conducted regarding (a) quality of resident life and (b) quality of work life. Data relevant to staff included monthly tracking of the number of teams, number of documented staff complaints, number of staff injuries, absenteeism, and number of full time equivalent (FTE). The analyses were conducted at both the individual and cumulative care homes levels over a two-year period in mid 1990s. The preliminary analysis at the midpoint of the study revealed a 33% reduction in the use of as needed anxiolytics and antidepressants; a 44% decrease in staff absenteeism and a 60% reduction of pressure sores. At the end of the two-year study, the analysis illustrated that the decrease in pressure sores was maintained. There was an overall reduction in staff absenteeism of 48% (Ransom, 2000).

Another study was conducted in southeast Texas by Judith Drew and Virginia Brooke at a care home that began implementing the Eden Alternative in 1997. It was a two-year project that evaluated the care home’s ability to adopt the philosophy and to measure changes associated with implementing the Eden Alternative philosophy. The initial findings suggested residents experienced fewer infections and falls and used fewer psychotropic medications. These findings also suggested changes in residents’ ratings of their perceptions of control over their life and general satisfaction with the nursing home. Staff reported more
resident participation in activities and families noted improved functioning and mood in residents (Drew & Brooke, 1999).

A subsequent study in Texas conducted by Martha Hinman and Deborah Heyl in the late 1990s assessed the effects of the Eden Alternative on residents’ physical, emotional and social function. The care home was 167-bed assisted living and long term care home in southeastern Texas. It was a descriptive case study, which used a grounded theory approach to assess the impact Eden Alternative had on functional behaviors. The data was collected in three phases: (1) observations of residents’ interactions with plants, animals, children (2) ratings from selected functional indicators in the Minimum Data Set (MDS) and (3) open ended interviews among ten staff members. At the end of their study, Hinman and Heyl found that the added stimuli of plants, animals and children in an Edenizing care home helped promote physical and social functions among residents (Hinman & Heyl, 2002). A total of 95 interactions were observed over 15 visits. Interactions with animals comprised 67.4%, followed by interactions with multiple stimuli (12.4%). 67% of these interactions represented physical functions, 54% were social functions, 19% involve mental activity and 17% illustrated an emotional response. No differences were found between the selected MDS ratings during the pre and post Eden time periods. All staff interviewed reported positive effects of Eden stimuli on resident physical function and more resident spontaneous movement (Hinman & Heyl, 2002).

Although these studies revealed some significant findings there were also limitations. First, these studies were conducted by people and in facilities that have adopted the Eden Alternative. They therefore have a bias - they want it to work. Second, the philosophy’s aim is to address psychosocial needs of elders yet the research thus far has mostly addressed
medical issues such as decrease in medications, infections and falls. Third, the studies have primarily been quantitative in nature and those that were qualitative asked for staff and family perceptions, not residents. Fourth, the studies on the Eden Alternative are not peer reviewed journal publications. Finally and most importantly, research to date on the Eden Alternative is limited by the lack of understanding of the personal experience.

How can we know if the Eden Alternative truly addresses psychosocial needs of elders unless we ask elders about their experiences and learn how it has influenced their lives? Elders alone are the experts of their personal experience and are thus the ideal informants to share the effectiveness of this new philosophy of care.

**Purpose of Study**

The purpose of this study is to begin to hear elders' perceptions of living in a care home that is committed to the Eden Alternative philosophy of care. The study seeks to gain an understanding of elders' experiences with the Eden Alternative and to learn how the philosophy has impacted their lives in care homes. Relevant to the focus of this study is the assumption that residents living in care homes are the experts of this experience and are in the best position to comment on the impact of the Eden Alternative.

My goal was to utilize a qualitative research design to develop an understanding of how these participants made sense of their experiences of living in a care home that is committed to the Eden Alternative and to explore how the philosophy addressed their psychosocial needs. This goal was congruent with the strength of qualitative research: developing knowledge of a specific phenomenon and increasing insight into an issue (Sandelowski, 1995). The research question that guided this study was “How has the Eden Alternative philosophy of care influenced the lives of elders living in a care home?”
questions are: (1) what are elders’ experiences with loneliness, boredom and helplessness? 
(2) What are elders’ experiences with companionship, spontaneity and variety and giving 
care to others?
CHAPTER 2 METHODOLOGY

This chapter will discuss the methodology I employed in the study. I will first discuss the design of the study and the rationale for choosing this design. Next, I will present the theoretical principles that guided the study’s research process. Third, I will discuss the research process in detail. This will include: the recruitment of participants, the interview process, data management and data analysis.

Design and Rationale

Choosing a Qualitative Study

The study was based on a qualitative design as it was felt to be the ideal method for “… capturing the experiences and the lived meanings of the subjects’ everyday world” (Kvale, 1996:70). A qualitative design is conducted in natural settings, its’ focus is descriptive and interpretative and it assumes that people use what they hear, feel and see to make sense of social phenomena (Rossman & Rallis, 2003). Reflecting on this, I felt a qualitative approach was the best way for me to hear participants’ stories and gain an understanding of how they perceived their experiences of living in a care home were influenced by the Eden Alternative philosophy of care.

I employed the phenomenological tradition of inquiry as it supports the investigation of lived experiences. Its purpose is to obtain descriptive and interpretive data. It involves extensive and prolonged engagement with participants through a series of in depth personal interviews (Creswell, 1998; Kvale, 1996; Rossman & Rallis, 2003). Key to this tradition of inquiry is a recognition that reality is what people perceive it to be (Kvale, 1996).
Phenomenology was thus best suited to explore participants’ experiences with the Eden Alternative, as it studies “subjects’ consciousness, to grasp the qualitative diversity of their experiences and to explicate their essential meanings” (Kvale, 1996:53). Ultimately, phenomenology allowed me to move beyond the superficial meanings of their experience and develop a deeper understanding of their lived experiences.

Conceptual Framework

The design of this qualitative, phenomenological study was drawn from two theoretical approaches: hermeneutics and narrative inquiry. In this section I will discuss how these approaches guided my research process.

Hermeneutics.

Hermeneutics is a branch of phenomenology. It takes the process of understanding the lived experience one step further by digging deep within the text to reveal hidden truth and meaning (Kvale, 1996). Moreover, the text is interpreted to find the intended meaning in order to establish a co-understanding of the experience. The process is interactive and recognizes that the outcome of the research is co created between the participant and researcher. These principles direct the researcher to pay attention to his/her role in the process and to take notes of his/her own thoughts, feelings and perceptions of the experiences. I used the principles of the hermeneutical circle in order to achieve a deeper understanding of each transcript. In other words, I worked in a circular motion between parts of the text and the whole. I first examined the text as a whole and attempted to make sense of the experience. I then returned to parts of the text that seemed significant to the experience and worked at gaining a deeper understanding of that part of the text. Once this was
accomplished, I returned to the whole and examined it again in light of the deeper understanding of the parts, in order to obtain a richer understanding of the whole. This process of moving back and forth continued until a deep understanding of meaning was achieved.

I also reflected on my own thoughts, feelings and values, always questioning how they influenced my interpretation of the text. I found this liberating, as I was able to acknowledge (and not attempt to ignore), that my life history and who I am plays a role in the research process. I then shared my interpretations with the participants and solicited their feedback. I also turned to my faculty advisor, committee and colleagues who were familiar with the research topic and asked for their input and reactions to my interpretations. This interactive process facilitates a deeper understanding of the experiences (Kvale, 1996).

**Narrative Inquiry.**

An understanding of narrative inquiry helped me make sense of participants’ experiences through their stories. “People are storytellers by nature. Stories ...have a central role in our communication with others” (Lieblich, Tuval-Mashiach, Zilber, 1998: 7). I viewed participants’ storying as an important means for them to represent, explain and organize their experiences. This involved a focus on the structure and content of stories that participants told in order to make sense of their experiences (Kvale, 1996; Lieblich et al, 1998). Participants’ stories helped me to make sense of their identities, values, beliefs and ultimately how participants constructed and perceived their reality.

While narrative research is conducted with a smaller number of participants then in comparison to sample sizes in quantitative research, the data generated from life stories is quite large. Also, in narrative research there are no two interviews that are alike. Each
interview is thus unique and filled with rich data. Moreover, the data generated is influenced by the ongoing interaction of the interviewee and interviewer. Therefore as I interviewed participants, I encouraged them to tell stories. I asked open-ended questions and assisted them to develop and clarify their stories by asking probing questions (Kvale, 1996; Lieblich et al, 1998).

For the data analysis, narrative principles helped guide the process in the following manner. First, I noted not only what participants said, but also what wasn’t said. Keeping in mind that language is used to construct reality, I made note of words used to tell the story and paid attention to their meaning within the story. I also examined words used repeatedly and determined their significance in the story. Next, keeping in mind that knowledge is socially constructed I paid attention to how and when stories unfolded. Lastly, as I listened to participants’ stories, I questioned what discourses participants used to make sense of their social world and how these discourses influenced the story being told (Lieblich et al, 1998). By discourses I mean … “the inter-related systems of statements which cohere around common meanings and reflect sets of assumptions, values and beliefs that are socially shared” (O’Connor, 2003: 2); they are the storylines that people use to make sense of their world and personal experiences (O’Connor, 2003).

Research Process

A note on the process.

The research for this study was conducted in two phases and at two sites. The first phase was from January 2004 – April 2004. The second phase occurred from January 2005 – July 2005. The participants were recruited at two care homes in the Vancouver Lower Mainland area that are both Registered Eden Alternative facilities. For the first exploratory
phase of the study, I recruited four participants from one of the care homes. I interviewed the participants and analyzed the transcripts. This phase of the research was a requirement of a research course, for the Master’s Program at the School of Social Work and Family Studies at UBC. I used the information and ideas generated from this phase to further refine the questions for the next phase. For the second phase, I recruited and interviewed five more participants at the other care home. Once I analyzed their transcripts, I then used all the transcripts from both sites and approached the analysis as a whole. Although, the research was conducted in two phases the process was similar. Any differences in the process will be highlighted in the following sections.

**Recruitment of participants.**

In January 2004, I received permission to access potential participants for the study at one the first care home mentioned above. Approval was then obtained by the University of British Columbia’s Behavioural Research Ethics Board to proceed with the study. This care home has been a Registered Eden Alternative facility for more than four years. It is a small care home that contains less than 100 private rooms. It has nine cats, most of which are owned by residents and the others belong to the care home in general. There are two dogs that visit daily which belong to employees and numerous birds on all three floors of the building. I will refer to this site as care home A.

The second phase of the study occurred one year later. I approached the other care home in December 2004 and requested permission to access potential participants for the study. Once I received permission from the care home to access potential participants, approval for continuation of the study (for the purpose of my thesis completion) was obtained by the University of British Columbia’s Behavioural Research Ethics Board. This care home
has been a Registered Eden Alternative facility for more than five years. It is a larger care home, consisting of more than 200 private rooms on three floors. This care home has approximately five cats, a rabbit, many birds and two fish tanks. I will refer to this site as care home B. Both care homes provide all levels of care.\textsuperscript{1,2} Although, neither care home admits individuals requiring extended care, they both maintain the philosophy of \textit{aging in place}. In other words both care homes continue to provide care for residents who progress from the intermediate level to the extended care level. See care home profiles in Table 1.

Table 1: Care Home Features

<table>
<thead>
<tr>
<th>FEATURES</th>
<th>CARE HOME “A”</th>
<th>CARE HOME “B”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Residents</td>
<td>&lt;100</td>
<td>&gt;200</td>
</tr>
<tr>
<td>Number of Floors</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Levels of care</td>
<td>Intermediate (IC), special care (IC3), extended care (EC)</td>
<td>Intermediate (IC), special care (IC3), extended care (EC)</td>
</tr>
<tr>
<td>Animals</td>
<td>9 cats, numerous birds, daily visits from 2 dogs</td>
<td>5 cats, 1 rabbit, numerous birds, 2 fish tanks</td>
</tr>
<tr>
<td>Plants</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Children</td>
<td>Weekly visits</td>
<td>Irregular visits</td>
</tr>
</tbody>
</table>

Criteria for participation in the study included:

- Individuals who have been living at least six months at the care home
- Individuals who communicate in English;
- Individuals who were able and willing to participate in the study;

\textsuperscript{1} Intermediate care level: individuals who need assistance with functional activities of daily living due to physical and or cognitive impairment but can transfer and ambulate (with or without aides) independently. Extended care level: individuals who need ongoing assistance with activities of daily living including transfers and ambulation.

\textsuperscript{2} In attempt to maintain the confidentiality the of the care homes, the exact numbers of residents and years of being a registered Eden Alternative care home have not been disclosed.
• Individuals who were able to give voluntary, informed consent.

The rationale for requiring elders to have been living in the care home for at least six months was because research has found that adjustment to living in care homes typically takes several months (Beaulieu, 2002; Patchner & Patchner, 2005). I stipulated that the participants must be able to communicate in English because it is the only language I speak fluently. I limited the criteria for participation to exclude individuals, who are not able to give voluntary, informed consent because I felt I had neither the time nor the resources within the limitations of this study to adequately address the issues that are associated with elders who have more severe capacity issues. In order to insure that voluntary, informed consent was obtained, I first reviewed the study’s purpose as well as the consent form with participants. Second, I asked participants to share with me their understanding of the study’s purpose and their understanding of what was stated in the consent form prior to obtaining written consent.

Two recruitment strategies were implemented: At care home A, copies of an information handout about the study were given to staff (see Appendix A). I asked them to identify elders who met the criteria and who might be interested in the study. These professionals only obtained permission from potential participants to release their names to me in order to learn more about the study and were not informed which elders chose to participate in the study. At care home B, I attended a residents’ council meeting to discuss the purpose of the study and left copies of the information handout for the council members. Council members were invited to keep a handout for themselves and were asked to distribute other copies to residents they thought would be interested in the study. Council members were not informed which residents chose to partake in the study.
Participant profiles.

Nine participants were recruited in total. The recommended sample size for phenomenological studies is anywhere from three to ten participants (Creswell, 1998). Although this sample size cannot be generalized to the experience of all individuals living in care homes, I was satisfied that it was not only conducive to gaining a better understanding of elders’ lived experiences but also in attaining insight in any themes that emerged. The participants were chosen on the basis of purposeful sampling criteria (Maxwell, 1996). In other words, individuals were chosen who met the criteria for the study and whom I felt would be able to provide me with the necessary information to answer my research question and the purpose of this study. This type of sampling strategy is congruent with conducting qualitative studies that examine particular phenomena (Maxwell, 1996).

The sample consisted of Caucasian; middle class individuals who had some family support and who mainly had physical issues. In care home A there were three females and one male. The three women were widowed and the one man was married; his spouse was living in the same care home but on a different floor. The participants’ ages ranged from 76 to 97. In care home B there were four female participants, of whom two were widowed and two were divorced. There was one male participant who was married and his spouse lived nearby. The participants’ ages ranged from 71 to 93 years. Length of residency (LOR) in the care homes ranged from nine months to thirteen years. Four of the participants had previously lived in other care homes and one participant moved to another care home prior to the completion of the study. All participants were given pseudonyms to insure confidentiality. See participant profiles in Table 2.
### Table 2: Participant Profiles

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age</th>
<th>Marital Status</th>
<th>LOR</th>
<th>Career</th>
<th>Care level</th>
<th>Pet in room</th>
<th>Care home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diane</td>
<td>81</td>
<td>Widowed 2x</td>
<td>13 years</td>
<td>Homemaker, entertainer</td>
<td>EC</td>
<td>B</td>
<td></td>
</tr>
<tr>
<td>David</td>
<td>76</td>
<td>Married</td>
<td>8 months</td>
<td>Unknown</td>
<td>IC2</td>
<td>A</td>
<td></td>
</tr>
<tr>
<td>Elizabeth</td>
<td>97</td>
<td>Widowed</td>
<td>6 years</td>
<td>Homemaker, foster parent</td>
<td>IC3</td>
<td>Bird</td>
<td>A</td>
</tr>
<tr>
<td>Lucy</td>
<td>77</td>
<td>Divorced</td>
<td>7 years</td>
<td>Lab technician</td>
<td>IC3</td>
<td>B</td>
<td></td>
</tr>
<tr>
<td>Nancy</td>
<td>83</td>
<td>Widowed</td>
<td>3 years</td>
<td>Homemaker</td>
<td>EC</td>
<td>Two cats</td>
<td>A</td>
</tr>
<tr>
<td>Paul</td>
<td>71</td>
<td>Married</td>
<td>3 years</td>
<td>Professor</td>
<td>IC2</td>
<td>B</td>
<td></td>
</tr>
<tr>
<td>Mary</td>
<td>87</td>
<td>Widowed</td>
<td>5 years</td>
<td>Homemaker, secretary</td>
<td>EC</td>
<td>A</td>
<td></td>
</tr>
<tr>
<td>Susan</td>
<td>75</td>
<td>Divorced</td>
<td>11 years</td>
<td>Preacher</td>
<td>EC</td>
<td>Cat</td>
<td>B</td>
</tr>
<tr>
<td>Sonia</td>
<td>93</td>
<td>Widowed</td>
<td>10 years</td>
<td>Homemaker, artist</td>
<td>EC</td>
<td>B</td>
<td></td>
</tr>
</tbody>
</table>

**Interview process.**

The data was generated through one to three in-depth, personal interviews lasting thirty minutes to two hours each. Four participants were interviewed three times. The average amount of time spent with these participants was 2.5 hours each. Two participants were interviewed twice. The average amount of time spent with these participants was 1.5 hours each. Three participants were interviewed once. One interviewed lasted over two hours, the other two interviews were approximately 45 minutes to an hour long each. Besides formal interviews, there were several telephone conversations and informal discussions that occurred with each participant. The reasons for not being able to conduct second and third interviews with participants were as follows: (1) too ill; (2) had moved to another care home; (3) did not respond to follow up telephone calls or requests to meet.
Although personal interviews are typically more time consuming, it was felt that this was the best method to ensure that participants were able to share their unique experiences with the Eden Alternative philosophy of care and be in control of the process. The aim of the personal interviews was to evoke an informal, conversational dialogue (Maxwell, 1996).

The interviews took place at a time and location that was convenient for the participants. Most of the interviews took place in participants’ private rooms. Three of the interviews occurred in a lounge in the care home at the participants’ request. Like the interviews held in private rooms, the doors of the lounge were closed to avoid any disruptions. Yet, on various occasions, interviews held in private rooms as well as the lounge, were interrupted by either staff or other residents. On one occasion, a staff member interrupted to bring a participant an evening snack. On another occasion staff invited a participant to attend an activity. On three occasions the interviews were interrupted by visiting residents. These interruptions disrupted the flow of the conversations and two interviews were terminated as a result of the interruption. Both locations however, afforded me the ability to strategically position the tape recorder (on a bed or table) to optimize the quality of the recording.

Informed consent (see Appendix B) was obtained at the start of the first interview. Although the interview questions for care home A and care home B varied somewhat (see Appendix C), the focus of the interview was on hearing the participants’ experiences with the Eden Alternative and understanding how the Eden Alternative has influenced their lives. The interviews were semi-structured in nature with questions that were open ended and used to guide the conversation. Probing and follow up questions were used to clarify information and meaning of participants’ responses as well as my understanding. This often involved asking
for examples or stating, "Tell me more about that". The semi-structured interview is consistent with qualitative research as it has “a sequence of themes to be covered, as well as suggested questions. Yet, at the same time there is an openness to changes of sequences and forms of questions …” (Kvale, 1996:124). I kept this consciously in my mind, as I wanted participants to be in control of the conversation. This meant that although I had an interview guide prepared, I allowed the participants to guide the conversation. Because of this not all the questions on the guide were asked at every interview nor were they asked in the sequence that they were written on the guide. Once the participants told me they had said everything they wanted to say, I summarized my understanding of the main ideas. This permitted immediate verification of my interpretation or correction of any misinterpretation. These member checks supported the validity of the data collected (Maxwell, 1996).

Six participants had second interviews. The focus of the second interview was to clarify information from the first interview and explore possible themes that were emerging. For the four participants who were interviewed three times, the focus of the interview was to review my understanding of their experience and to elicit further clarification and feedback. These interviews were reflective dialogues of the meaning of the participants’ stories and experiences (Rossman & Rallis, 2003). This reflexivity was an important step in establishing credibility (Maxwell, 1996). The rationale for choosing this strategy and methodology was because the multiple interviews and the length of the interviews allowed for prolonged engagement. This allowed for the development of rapport, which set the stage for the participants to share rich, descriptive data. It facilitated a thorough understanding of the meaning of elders’ experiences living in a care home that has adopted the Eden Alternative philosophy of care.
Data management.

The participants agreed to have the interviews audio taped and transcribed. All the interviews were transcribed verbatim by one of three transcribers. All three transcribers were required to sign a confidentiality form (see Appendix D). In addition to the interviews, observations and field notes were utilized to enrich the data collected from the interviews and thus facilitate a thorough understanding of the phenomenon. I also kept a journal with me at all times to jot down any thoughts, feelings about the interviews, the process and data analysis. The data was kept in a locked filing cabinet. All identifying information was removed. Each set of transcripts was placed in separate folders and individual folders were created for each theme.

Data analysis.

The analysis of data was ongoing, beginning with the first interview. As I listened to each participant’s story and experiences, I made note of pertinent ideas to be raised and immediately following each interview and telephone call, I wrote field notes in relation to my observations and reflections. This aided the context development of each participant’s story. Once the interviews were transcribed, I listened to the tapes and read the transcripts simultaneously. As I did this, I made any necessary corrections and made note of statements, which contained raised voices or sarcastic tones. These were seen as indications that what was being discussed at the time had some importance to the participant. I also made note of other cues that suggested what was being said had some significance. For example, one participant tapped her finger on the table when making an important point. These statements were highlighted and reviewed for significance.
I read and re-read each transcript in its entirety as well as my field notes. I used both contextualizing and categorizing strategies for the analysis. The combination of these strategies was essential to answering the research question and was ideal for a phenomenological tradition of inquiry (Maxwell, 1996). I first employed a contextualizing strategy to gain a holistic understanding of each participant's unique story (Sandelowski, 1995). This involved reading each transcript several times in order to understand the stories told and to identify the discourses that guided their values and beliefs (Kvale, 1996; Sandelowski, 1995). I read each transcript line by line and paid close attention to how the stories unfolded. Not only did I make note of what was said but also how it was said and at what point in the story it was told. I paid close attention to the choice of words, repetition of words and/or phrases. I also made note of what was not said. This helped me move beyond the content, challenge common sense understandings and begin to pull out emerging themes from the transcripts (Kvale, 1996; Maxwell, 1996). I then wrote a summary of my understanding of each participant's experience.

Once I completed a written summary of a participant's experience, I followed up with the second interview. During the second interview I first used the transcripts to ask for clarification on statements made in the first interview. I then reviewed with participants the written summary of my understanding of their experience and again asked for clarification and solicited their feedback. Lastly, I gave the participants a copy of the summary and asked participants to read the summary for the third interview and provide any further feedback. All the participants agreed with my understanding of their experiences. They did, however, add comments, offered clarification and also suggested alternative words or phrases that
described their experiences. The third interview allowed for the final clarification of information and agreement on the understanding of the experience.

After I had gathered participants’ feedback, I used a categorizing strategy as a means to compare and contrast the data (Rubin & Rubin, 1995). I photocopied each participant’s transcripts on different colored paper. Keeping in mind my research question, I cut out lines, phrases or words that related to the Eden Alternative. For example, I searched for indicators of loneliness, boredom and helplessness as well as opportunities for companionship, spontaneity and to give care to others. I also examined the use of specific words that reflected participants’ experiences. For instance, participants repeatedly referred to the care home as a place. So I began to attend carefully to how participants referenced the care homes. In addition, I cut lines, phrases, words that reflected how participants positioned themselves within their stories. As I moved through the analysis, themes began to emerge. I then sorted everything that I had cut and put them into piles. The piles were then given a name that reflected the theme it represented. Each pile was then examined individually and the lines were pasted together in order to develop each theme. This strategy forced me to move back and forth between reading, memoing and interpreting the data. The process was circular in nature (rather than linear) and allowed me to broaden my understanding of the experiences and the emerging themes (Coffey & Atkinson, 1996).

This circular process highlighted that the Eden Alternative had influenced elders’ experiences. Three comprehensive ideas emerged. Participants perceived themselves as having (1) opportunities for personal choice, (2) opportunities to maintain personal identities and (3) opportunities for involvement with pets and animals. Yet, when I went back to the categorized data and questioned if there were any limitations to Eden’s influence, I
discovered that the care home was not yet perceived to be a home or community. Three dimensions of this theme emerged: (1) the way in which participants described where and how they lived, (2) how participants distinguished themselves from other residents, (3) and how they separated themselves from staff.

I then returned to the data and posed the question: What is the significance of the care home not being perceived a home or community? There are several aspects to this answer. First, there was a recognition of losses in abilities and independence and needing assistance with their personal care. Second, there were two competing societal discourses were at play. One, participants lived by the storyline *life is what you make it* and assumed personal responsibility for how they were going to live their lives in the care home. In other words, participants were determined to make the most of their situation and assumed ownership and credit for making the care home “work” for them. They sought out companionship, opportunities for spontaneity and to give care to others. They made the choice to become actively involved and participated in the activities offered. Yet the other storyline *I am old and useless*, which reflected the societal discourse of aging and long-term care, challenged participants’ sense of personal agency and influenced not only their experiences but also their self-identity.

I revised my findings numerous times before being satisfied that the theme and storyline accurately represented participants’ experiences. I also sought feedback from my faculty advisor and research committee, colleagues and others who are familiar with the topic. This process was an important step in peer feedback (Creswell, 1998; Rubin & Rubin, 1995). The data analysis process eventually became an exercise in examining the deep meaning of the experiences (Kvale, 1996).
Credibility and validity.

Steps to insure the credibility and validity of the study were discussed throughout this chapter. Prolonged engagement was essential in establishing credibility. Six of the nine participants were interviewed twice and four of the nine participants were interviewed three times. Moreover, I engaged in informal conversations with all the participants during the research process. Often I met participants in hallways at the care homes when I had scheduled interviews. These informal encounters supported the establishment of rapport, prolonged engagement and ultimately the credibility of the study (Creswell, 1998).

Both descriptive and interpretative threats to credibility were addressed. Through the use of member checks, I was able to first review the transcripts with participants during the second interviews for accuracy. This insured descriptive validity. Second, by giving the participants a summary of my understanding of their experiences and preliminary analysis to review and edit, interpretative validity was addressed (Maxwell, 1996; Creswell, 1998).

Various aspects of the research process affected the study. First, because of the lapse of time between the two phases of the study, I felt more closely connected to the participants residing in care home B. A year had past since I had met and interviewed participants from care home A. Also I had learned more about being a researcher over the year and ultimately my interview skills had improved with the second group of participants. I was also more organized and had more time during the second phase of the study for the data collection. As a result, the interviews in the second phase tended to be longer and more in depth. Also only participants from the second phase of the study were interviewed three times.

In addition, although my intention was to gain an understanding of participants’ experiences, it was an effort to not evaluate the care homes’ effectiveness of adopting the
Eden Alternative. Moreover, while the care homes are both committed to the Eden Alternative philosophy, I realized that I struggled to bring the two phases of the research together because I perceived the care homes to have distinct differences. In care home A, for example, the presence of animals was prominent. Cats and dogs roamed the halls; birds were on every floor. These animals were the focus of participants' interviews. Although care home B did have animals, their presence was not as prominent, perhaps because it was a much larger care home. Nevertheless this care home felt busy. Interviews occurred in the daytime, evenings and weekends. During these times, there were always activities taking place or music playing. Participants talked about these many activities and having the choice to participant or get involved.
CHAPTER 3 FINDINGS

Three dominant ideas emerged from the data in response to the research question. First, the implementation of the philosophy did influence participants’ lives in three meaningful ways: through opportunities for personal choice; through opportunities to maintain personal identities; and through opportunities for caring. Yet, the second idea that emerged regarded the extent in which the philosophy had been implemented at this point in time. More specifically, according to participants’ stories, the philosophy’s goal of creating a home or community was not yet realized. Finally, the third major idea that emerged was that two competing societal discourses were at play, which limited the influence of the Eden Alternative philosophy: life is what you make it and I am old and useless.

To illustrate these findings, I will first discuss how the Eden Alternative influenced participants’ lives. This will be done by presenting two participants’ stories as examples of how the Eden Alternative created opportunities for personal choice and opportunities to maintain personal identities. These stories will then be followed by a discussion of how opportunities for caring were created through involvement with pets and animals created occasions for companionship, spontaneity and variety and to give care to others. Second, I will discuss how the participants perceived the care home. Third, the tension between the discourses of life is what you make it and I am old and useless will be discussed with particular attention being drawn to how it links to the implementation of the Eden Alternative philosophy in a care home.
The Opportunities

The Eden Alternative provided opportunities for personal choice. Seven of the nine participants, for example, discussed a sense of personal choice in their daily lives. Paul’s story is presented as an extraordinary example of how the Eden Alternative created an opportunity for personal choice. Six of the nine participants also referred to an ability to maintain their personal identity. Diane’s story is presented as an illustration of how the Eden Alternative facilitated opportunities to maintain personal identities. Her story is a good example of Eden’s ten principles at work. Following Paul’s and Diane’s story, I will discuss briefly how the participants made sense of the philosophy and then discuss how opportunities for caring were generated through the daily involvement with pets and animals which ultimately created opportunities for companionship, spontaneity and variety, and to give care to others, thus contribution to the alleviation of the three plagues.

Paul: The right and freedom to makes choices.

Setting the Stage

Paul is a 71- year- old Caucasian, married man with two sons. Paul’s sons live in the southern United States and his spouse, who lives in the area, visits him once a week. He is an academic and worked as a university professor in Canada as well as abroad.

I saw Paul several times during my visits to the care home as well as during our formal interviews. He walks independently with a shuffling gait but otherwise appears physically well. He typically wears slacks, a shirt and a sweater vest. He has his own private room, which is decorated sparsely.
I met formally with Paul three times. Our initial interview took place in a sitting room with his friend, Lucy, present at his request. The doors of the sitting room were closed to avoid any disruptions. Paul chose to meet in the sitting room because it is the room in which he and Lucy typically spend their day playing Scrabble. The interview lasted approximately one hour. Lucy sat at the back of the room, reading a book, while Paul and I talked. For the second interview we met privately in his room to discuss my understanding of his experience. During this interview, I sought clarification of his experience and gave Paul a written summary of my understanding of his experience. I asked him to review my summary for accuracy and provide feedback for the final interview. The final interview was also held in his room privately and lasted thirty minutes. Being true to his profession, Paul had reviewed the written summary, provided oral and written comments and made grammatical corrections.

*Experience of Living in a Care Home*

Paul has been living in a care home for three years. He moved to the care home just one year after retiring. He believes that he lives in a care home because his spouse believes he is an alcoholic and that she had him placed in the care home. He began to explain his understanding of why he is living in a care home, when he shared with me how he describes where he lives. To people whom he considers “open”, he describes the care home as a “zoo” which I have used the informal definition found in Webster’s Dictionary (1986) to understand. The definition is: *a place, situation or group marked by crowding, confusion or unrestrained behavior*. Paul describes it as a zoo because of the various types of people (which he refers to as *inmates*) that live in the care home. He refers to residents as *inmates*
because in a sense he feels that those who live in a care home have no choice but to live there due to their physical decline, age and/or cognitive issues.

*This is a zoo, where we are confined to cages. ... But, and this is important,*

*we are not locked into cages, and ... that is one thing that makes me very happy about the place. Let me indicate to you three categories of people that are here. Number one: the very old. There’s a person that Lucy and I have a very high respect. It’s an old lady in her mid nineties. And she’s just simply old. And then the second category of person here are those who are physically broken down. Lucy is a good example of that. And she is physically broken down ... My interpretation on the basis of what she says is that she’s had some nasty falls due to strokes. Ok, then why am I here? I’m neither very, very old nor have I ever had a nasty fall. And I’ve never had a stroke. So the third category of inmate is the ones who in the unkind language would be called nutty. And I’m defined as, as being in that category.*

Paul uses unusual terms to describe where and with whom he lives. The terms ‘zoo’, ‘cages’, ‘inmates’ are rather harsh words to describe care homes and the people who live in them. At least part of his selection of words is related to his attempt to be funny as he notes that, “I partly use that terminology in humor”. He places himself in the nutty category because “I am nutty in that my behavior with the wine is uncontrolled. That’s according to her [spouse]. ...She had me put here”. He clarifies that people in the nutty category, are those residents, he included, who have a “mental health problem.” Seeming to contradict himself however, he also notes that this is his spouse’s label of him and not how he self
identifies. He perceives himself as being in the category of the *nutty* because he does not fit the description of the other two categories.

*The nutty means candidates for a mental hospital. ... I am defined by my wife and the system in general. I have to be in the third category, because there is no other category. Very old? No. Physically broken down? No. Therefore I am the nutty.*

In contrast to his wife, and perhaps the ‘system’, Paul does not feel he has a problem with drinking too much. He suggests that the amount of alcohol he consumes daily is under control and indicates he remains in the care home because he is happier living there than with his spouse. Contradicting his earlier statements regarding the lack of choice residents have for moving into a care home, he notes:

*Now, I know I myself could go home ... the family doctor told me several weeks ago that I have my life under control and if I wanted to, I could go home. And I told him, I responded to him by saying, I prefer to be here, than at home. ... I have more independence here. ... My life since moving here has been more peaceful .... I have more freedom of action. And part of the freedom is interacting with her [pointing to Lucy].*

His use of words such as “freedom, independence and peaceful” imply a freedom from personal judgment for his actions. “I have more freedom here than I would have living with [spouse]. The daily activities would, to some extent, be dictated by her [spouse]”. In this quote Paul indicates a perception that his spouse attempted to control his actions. He, living at the care home, is at peace with who he is and how he chooses to live his life. This sense of peace and perception of choice is reflected in the following quote.
... I can go in the afternoon, every second day ... often in the company of Lucy, but I can go to the bottle store and buy a bottle of what she and I call ‘Holy Water’. It’s what you would call red wine. Yeah, so we always have ... some on hand. And we like to sit together, ... and we play scrabble and consume a bit of Holy Water.

Interestingly, drinking alcohol daily is not typically tolerated in care homes. In fact, there are various policies around alcohol consumption in care homes. Some will have scheduled “happy hours” with a limit of how much residents can drink and residents with known alcohol issues are often given de-alcoholized beverages. Other care homes keep residents’ alcohol in nursing stations and staff monitors the amount of alcohol consumed by residents. Some care homes even require a physician’s order. Few care homes permit unmonitored alcohol consumption (Klein & Jess, 2002). Living in a care home that is committed to the Eden Alternative philosophy, Paul feels he has been able to monitor his own alcohol consumption. How often he purchased wine and how often he chooses to drink is ultimately his decision and not that of the care home. This reflects the Eden Alternative’s eighth principle where decision- making is placed back in the hands of elders.

In addition to his ability to consume alcohol, Paul was also able to establish close friendships and engage in meaningful activities. His close friendship with Lucy in part developed because of their similar educational backgrounds; both are university graduates. It is not surprising then that Paul enjoyed activities where he used his mind, like playing scrabble.

In describing the friendships he has formed at the care home, Paul describes a special friendship he has established with Lucy. Paul and Lucy share similar educational
backgrounds, which Paul clearly valued. Again contradicting being “nutty” and obviously still valuing his intelligence and cognitive capabilities, Paul notes: “You have to appreciate that Lucy and I … share a similar level of education”. He explains that they enjoy playing scrabble with a glass of wine daily and throughout their game they have ongoing conversation. “There are two things that I get the most pleasure out of. The one is exercise and the other is being with, her [Lucy].”

Paul’s relationship with Lucy is one in which he can identify himself as a well-educated man who continues to be mentally stimulated and who continues to challenge others mentally as he once did as a professor. His relationship with Lucy allows him to self identify as “normal” rather than nutty. He also implies that residents have a personal choice to be active or not in their daily lives and that his choice is to be active, both physically and mentally.

... The aspect which is very important to me, and I think to her [Lucy], is that we, when we play scrabble, we don’t just sit there like zombies and make a move and the other person makes a move. We have an ongoing conversation. It never stops and yet there’s a conversation everyday. ... We are challenged to improve our minds, to make spare time enjoyable. ... That’s something that she and I do to make living here enjoyable. ... There was the one man who sat at the card table who was engaged in conversation and games. There’s another man who came into the room, he sat on an armchair and leaned back and shut his eyes. So (laughs), he was mentally challenged in the negative sense of the term.
In essence then, Paul has opportunities to choose activities, which he finds meaningful and which ultimately contribute to his physical, mental and emotional wellbeing. His ability to partake in activities he finds meaningful is indicative of principle six whereby the opportunity to do things that we find meaningful is necessary personal growth (Thomas, 1996).

**Eden’s Influence**

Paul was not familiar with the Eden Alternative philosophy of care. When I explained it as a philosophy that aims at improving the lives of those who live and work in care home, he responded that the Eden Alternative then depends on each individual. He connected the philosophy with the need for those who live in care homes to continue to be active physically and mentally in order to maintain a good quality of life. Paul did not express feeling lonely, bored or helpless. This is in part because of the friendships he developed as well as the ability to choose how he spends his days. Being able to make daily choices is an aspect of living at the care home that he values and enjoys. When talking about choices, Paul noted,

*Yes we have the right and the freedom to make choices. For, example, later this afternoon, … we have choices and I know that Lucy and I are going to get out the Scrabble and sit at this table here.*

Paul discussed socializing with various friends, exercising, playing scrabble, reading and having a glass of wine.

*There were people who didn’t want to spend their evenings lying in bed watching television. [We] sat around the card tables. There were three of them [friends] all three of whom died of old age. That was horrible, but there was also Lucy and*
another female [who] would sit at the card table and play. These three they really
made the evenings pleasure full.

Later, in the interview, Paul denied feeling lonely and stated, “That’s one of the important
aspects of associating with this old, broken down lady here. I don’t feel lonely because of her [Lucy]. ...

Paul perceives he is living in the care home because his spouse believes he is
alcoholic and that “she wants to have more control over me,” in particular, control over his
alcohol consumption. Yet, at the care home Paul feels a sense of freedom and ability “to live
independently”. Living at this particular care home that has adopted the Eden Alternative
philosophy of care, Paul is able to purchase his own wine and keep it his room. He enjoys
having wine while socializing with his companions in the evening. Ultimately, his perception
is that he has choices and that since living at the care home he is in control of his life.

Summary

Paul’s story is an example of how the Eden Alternative created opportunities for
personal choice. Living in this care home, Paul’s quality of life improved. He describes
living in a care home in a non-conventional manner in order to make sense of why he is in a
care home. His explanation for living in a care home is that he is perceived to have a mental
health problem because he consumes excessive amounts of alcohol. Yet, his experience and
his story is one of choice and feeling accepted. His sense of independence, freedom and
peace since living in the care home is intertwined with not feeling judged for his
consumption of alcohol. He stated, “...I am accepted here”. The Eden Alternative
philosophy of care has influenced Paul’s life in the sense that he is able to make choices in
his daily life. This is exemplified particularly around his use of alcohol. He is able to
purchase wine, keep it in his room and drink as he wishes. He has been able to establish friendships and thus have companionship daily. His close friendships (particularly with Lucy) seem to have alleviated any sense of boredom or helplessness that he might have otherwise experienced and has given him a sense of fulfillment in his life.

Diane: Me, I’m just so busy (involved).

Setting the Stage

Diane is an 81 year old Caucasian, widowed woman who has been living in the same care home for thirteen years. She has a rare illness that has resulted in a gradual physical decline, which has left her needing assistance with all her activities of daily living.

Diane was married twice and had seven children with her first husband. He died the year before Diane moved into a care home (1991) from congestive heart failure. One of her children passed away two years ago; her other children live in the area and visit her weekly. Diane’s family visits usually occur in one of the common areas where there is a big toy box filled with various toys for her grandchildren to play with. Her second marriage was to a fellow resident in the care home, whom she married shortly after moving into the care home. He passed away approximately three years ago.

Diane described herself as an “entertainer” noting that she had sung at restaurants and clubs for years. “I sang and led a sing-along. I got them all singing. I get great pleasure out of getting people singing”. Her favorite pastime is writing music and poetry. In fact, some of her poetry has been published while some of her jingles have been used for television/radio commercials. Diane is currently working on writing a song that she hopes to be considered for the 2010 Olympic theme song.
Diane is the President of the Residents’ Council, and as such she was my first resident contact at one of the settings for this research. She expressed interest in participating in the study because she wanted to tell me about the difference the Eden Alternative has made to the lives of elders living in care homes. Despite her interest, I had to call Diane several times to schedule appointments for the interviews; she was never in her room. I was grateful that she (unlike the other participants) had an answering machine. When Diane and I finally connected and were able to discuss a time to meet, it became clear she was busy. She needed to check her calendar to insure she was not going to double book. This meant she made sure that our appointments were at a time that she wasn’t involved in an organized activity, at a meeting or on Sunday when she had visitors.

On the occasions that I met with Diane, both for interviews and informally when I was at the care home visiting other participants, she was always well dressed in a skirt and blouse or dress. She has short grey hair, wears earrings, necklaces, rings and a bit of lipstick. Although Diane is unable to walk, she is quite independent in getting around the care home in her scooter.

I met formally with Diane three times. Our interviews were always held in her private room, which was decorated with two of her own antique style dressers with mirrors, her bookshelf with books and family photos. Other framed family photos and framed paintings she had painted over the years filled the walls of her room. During our interviews, I sat on Diane’s bed and she sat in her scooter in front of me.

*Experience of Living in a Care Home*

Our first interview lasted approximately one hour. During it, Diane described her life as being very busy; this was a constant theme throughout the interviews. In fact, she raised
being busy at least ten different times. Being *busy* seemed to be tied to (1) escaping boredom; (2) escaping pain and grief and (3) being of service to others.

The interview began with Diane identifying the similarities of her current life to her life prior to living in the care home.

...Well I was married when I was eighteen and I had my first one [child] when I was nineteen, and, I mean, I've really been busy ever since ... I got involved in choir work with children and we entertained a lot, you know, sometimes I'd play the piano till two or three in the morning (chuckle). But I mean I wasn't bored... And so we were always busy. It was never boring. ...Actually I've been busy, ever since ... I can't remember a time when I wasn't busy. And since I've been in here, actually I'm certainly not bored. No I don't have time (chuckle) ... to be bored. ... I'm just so busy, you know.

“Being busy” was a theme that dominated Diane’s description of her life at the care home. She discussed the many activities she attends. The activities are clearly a means to escaping boredom.

*I take part in the musical things in here. We have a chime choir and I'm in that ... I like to draw and paint. I'm in the art thing. I mean, every day I have my calendar and I can just look up and see what's up on the day. ...There's so much going. I mean ... I can't understand people saying there's nothing to do.*

Secondly, being busy also meant Diane did not have to dwell on things that have caused her emotional pain. For instance, she talked about losing her second husband, her sister and then her youngest son, all within three years.
...So that’s why I say there’s been lots happening. And I think that’s why I like to keep busy, you know. But I think if you carry on and keep busy you can handle most things, you know. ...That’s why I say if I were bored, and I had time to think about all these things, then maybe they would bother me, but I don’t have time to commiserate on my pains (chuckles).

The third way Diane kept herself busy was by positioning herself as being of service to other residents. She distinguishes herself from residents and calls herself a volunteer. “And I’ve worked with them [residents’ council] for about ten years. I worked as a volunteer for ten years here. I play the piano to entertain some of them and sing to entertain some of them. The residents, it’s all for the residents.” Similar to Paul’s story, Diane’s experiences were indicative of principles six and eight, whereby Diane was able to make decisions about how she was going to live her life as well as participate in activities that were meaningful. Moreover, her perception of helping other residents was reflective of principle four – having opportunities to give care to others.

Eden’s Influence

Diane was quite familiar with the Eden Alternative philosophy of care and was eager to talk about the difference it has made living in the care home. As she discussed the importance of the Eden Alternative it became evident that it was Diane who positioned herself as “separate” from other residents. She referred to residents as “they” or “them” and seemed to exclude herself from the group of residents. She positioned herself as the person who promoted the benefits of the Eden Alternative.

Yes, well I was saying that the Eden Alternative, the important thing about it is the care and that’s the thing in a care home that’s most important and
personal care and personal touch that you give to these older people. It [Eden Alternative] has improved a lot of things ... people [now] stop in the halls and speak to each other and talk, maybe take someone who’s lonely, take their hand. ... The medical touch is important too, of course, but it has to go hand in hand with the personal touch, in my opinion. ... [The Eden Alternative] ... is being in a place where there’s closeness, empathy between people. And I think its better. I’ve seen people get up and join in things and people who can’t even hardly stand up get up and actually dance to music and everything, because they’ve just been, somebody has put their arm around them and said, come on and go up and dance. To me that is, that does a lot more than even pills do.

Her role as a volunteer, as someone who is of service became clear as she discussed how much she likes working with people. “I like to be involved with what other people need, or how they feel. I mean I care for them. I’ve got very fond of some of these old people in here”. She referred to her first husband who used to say to her, “you could really give a lot of people pleasure in an old folks’ home”. So that keeps coming back to me. I think, well I can. And I give myself pleasure too, because I enjoy doing it”.

It became evident that it is the Eden Alternative that allowed her to maintain this role and foster her sense of self. This became clear as she discussed that being “involved” rather than “busy” is a better choice of words.

I think “involved” is the best word right there. Because when you get put into an old folks’ home and you’re not involved in anything, you feel left out and down. That’s what Eden does. It involves people in their home; like they were in their own place.
In other words, the care home’s implementation of the Eden Alternative philosophy has facilitated Diane’s ability to be involved, to be of service to others and maintain her sense of self in the care home.

Summary

Diane’s story highlights how a resident in a care home can still be an active member of their community. I was intrigued with Diane’s ability to distinguish herself from others and maintain her sense of self. Diane’s sense of purposefulness illustrates how the Eden Alternative promotes the continued growth of residents in care homes.

Conclusion.

The stories of Paul and Diane demonstrate how the Eden Alternative permeated their experience of living in the care homes. Their stories also reflect two ways in which the philosophy influenced participants’ lives. Specifically, Paul’s story pointed to a sense of increased personal choices while Diane’s story pointed to an ability to maintain personal identity. The third meaningful way that the Eden Alternative influenced participants’ lives will be discussed next.

Living with pets and animals.

According to Dr. Thomas opportunities for caring promotes human growth. An important aspect of creating opportunities for caring is embedding plants, animals and children in the everyday lives of elders. They are, in other words, the necessary tools in creating opportunities for caring. In both care homes, pets and animals lived alongside the elders. As a result, participants’ stories often focused on the pets and animals that live in the...
care homes. Having pets and animals live in the care homes served three primary functions: they offered companionship; fostered variety and spontaneity in the setting; and created opportunities to give care to others. The daily presence of the animals clearly influenced participants’ lives in meaningful ways and added to their quality of life.

Making Sense of the Eden Alternative

The importance of pets and animals first emerged with the discussion of the meaning of the Eden Alternative philosophy. Only one of the nine participants (Diane) was familiar with the philosophy. This surprised me. I had assumed that the participants would have at least heard of the philosophy given that both care homes had been incorporating this philosophy of care for several years and both care homes had literature on the Eden Alternative on the walls throughout the homes. Four participants were completely unfamiliar with the philosophy and the other four participants had heard of the terminology but were not clear as to what it meant. For example when asked, “Have you heard of the Eden Alternative philosophy of care?” Elizabeth responded, “No, what is it?” “I don’t know what that is?” Other participants had heard of the philosophy, but were not sure what it is about. Their responses suggested that although they had heard of philosophy and were aware that it was taking place, they did not see themselves as having been included in its development. Mary, for instance, said, “I don’t really understand that, you know? I know it has been explained to me but I can’t for the life of me figure it out. I don’t know if it’s plain decency, you know?” Nancy responded, “That Eden thing … [What do I know?] Not very much. Well, I read about it but I never heard anything about it… they have meetings and something like that.” Even those who felt they should be were not necessarily clear of the philosophy’s focus. For
example, although as a member of the Resident’s council Sonia felt she ‘should’ know, she indicated:

*You know I’m not just sure what they do, what they’re driving at there. I’m not sure that I see any difference in it. And yet they speak as if, that is, the ones who suggested this, they speak as though it’s a great success. But to tell you the truth, I don’t know what it is and I’m a member of the council.*

For those participants who appeared unfamiliar with the philosophy, it was briefly described to them. The description included the philosophy’s attempt to improve the life of those who live and work in care homes and focused on the three plagues: loneliness, helplessness and boredom and their antidotes: plants, animals and children.

Even though the participants were unfamiliar with the philosophy, it was interesting to learn how they were able to make sense of the philosophy. Specifically, the participants readily grasped the notion of home life and the importance of pets. They however did not discuss any connection between children and plants, the philosophy and their lives in the care home. For example, five participants made sense of the philosophy by connecting it to their life prior to moving into the care home and past experiences with animals. Their responses suggested that they placed value on the presence of the animals and felt that the animals or pets were an important part of life, wherever they were living. Mary for example stated, “There’s a couple of dogs here too. I don’t know what it is about animals that makes you feel the hominess of them”. David also connected the pets to home life and explained that the residents would be lost or hopeless without pets in a care home.

*Well it sounds reasonable. Yeah, it’s like what you would find if you were living in your own home... If you take all the animals away from a place like*
Like David, Diane saw the presence of animals as an important aspect of creating a home.

*You see, all these people, a lot of them had pets before they came in here.*

*And they love to feel a cat, hold a cat or a dog. Some of them, you know ... I mean this brings back the years that they had in their homes and things that they had. So that's what they're trying to do here is bring things for people, not so much like a care home, [but] as home. That's the way we want them to think about this place, as home.*

For Nancy, living in this particular care home meant that she could once again live with her cats. Her cats had been on their own at her previous home for seven months with her neighbor looking after them. She was thrilled that she was able to have her cats move to the care home.

*Well, I was here before they [cats] came and then I was worried about them at home, who was looking after them ... then they said here, ‘oh bring your cats here, we're going to have cats’... I couldn't believe it!*  

*Creating Opportunities*

Living in a care home that is committed to the Eden Alternative philosophy, meant participants had opportunities for caring through the involvement with pets and animals. Having animals live at the care home with elders created opportunities for companionship, spontaneity and to give care to others which ultimately alleviated loneliness,
boredom and helplessness. Although the participants did not spontaneously talk about their pets or animals in the care home, as providing companionship, when directly asked they were able to tell stories, which indicated that, the animals did offer companionship and as a result, alleviated loneliness. For example, one cat clearly provided companionship for David:

*They’ve got a blue-eyed Persian here; she’s a lovely little kitten. Yeah, for a long time, she’d come in here in the evening and hop up on the bed and sleep down on the foot of the bed all night. She’d sleep on top of my bed here all night . . . She just curled up on the foot of my bed and slept all night and it was great!*

Nancy indicated feeling a sense of importance and feeling cared for by her cats when she stated, “That one [cat] sleeps on my leg every night . . . in between my two knees. . . . And this one is so jealous . . . anybody come try to talk to me, she gets right in there”. Mary noted how welcomed the animals made her feel when she arrived at the care home claiming, “There’s a little, well, not little, cat here . . . and when I first came here he – he did make me feel at home . . . Every time I came up to the elevator, he used to come and walk me to my room”. And Susan described mutuality and reciprocity between her and her cat when she stated,

*I love animals and as long as they love me, we get along fine. Well, she’s [cat] just a darling. . . . She loves me and I love her. . . . She is a good companion and it’s amazing, she never talks back. I love that [chuckles].*

The second way pets and animals influenced participants’ lives, was through the natural creation of spontaneous moments, which ultimately alleviated boredom. David, for example, chuckled after he reported, “It’s a friendly cat . . . When I go down the hall I always stop and play with her, stroke its ears and she puts her head up.” Similarly, Nancy told stories
of how her cats never leave the room, always scaring off the other cats and Elizabeth shared how her bird sings along with a stuffed animal that plays Christmas music. The animals offered spontaneous moments where dogs chase cats and cats chase dogs. In reference to a cat living at the care home, Mary said, “She is, she is a little monkey . . . she hides under the bed as far away as possible . . . she’s getting a little bigger now but she used to jump for fun all the time.”

Third, besides providing opportunities for companionship, variety and spontaneity, the pets and animals also created opportunities to give care to others. Susan, for example, talked about changing the kitty litter and feeding her cat. She said, “I figure if I want to have a pet, I’ve got to look after her”. After being in hospital for several weeks, Nancy was anxious to return to the care home. “Well the cats are here. The girls [staff] said they meowed and meowed in the corridor. I’m surprised they [cats] stayed here so long by themselves.”

The participants were not familiar with the Eden Alternative, yet they were able to make sense of its possibilities. Primarily, the participants connected the notion of home life and the importance of pets. Interestingly, when making sense of the philosophy, they did not make any connections to children or plants. Perhaps this is indicative of participants’ lack of daily involvement with children and plants. In other words, the pets and animals that lived alongside the participants in the care homes clearly created various opportunities for caring which ultimately alleviated loneliness, helplessness and boredom.
Summary.

Paul and Diane’s stories are examples of how the Eden Alternative created opportunities for personal choice and maintaining personal identity while opportunities for caring through involvement with pets and animals promoted companionship, variety and spontaneity and to give care to others. These three opportunities enhanced participants’ quality of life.

This is not a Home

Even though the Eden Alternative philosophy influenced participants’ lives in the three meaningful ways discussed above, the philosophy’s goal of creating a home or community was not yet achieved. According to the participants’ stories the care home was not perceived as a home or a community. This perception was revealed in three specific ways. First, the participants referred to the care home consistently as a place rather than a home or community. Second, they did not identify with the other residents but rather pointed out differences between themselves and others. Third, they distinguished themselves from the staff and described the relationship as inequitable. Each of these three perceptions will now be discussed separately.

This place.

Throughout the interviews all the participants referred to the care home as a place. Calling the care home a place was used so often in the interviews that without noticing, I too began to refer to it as a place. The word place refers to “an establishment; physical environment; a building or locality used for a special purpose” (Merriam-Webster’s Ninth New Collegiate Dictionary, 1986:896). Home on the other hand is defined as a “social unit
formed by a family living together; a familiar or usual setting; a place of origin” (Merriam-Webster’s Ninth New Collegiate Dictionary, 1986: 577). A *place* reflected elders living where they received personal care they no longer could do for themselves. It symbolized their age, physical losses and subsequent inability to live independently. Mary for instance noted, “So, of course I being a hemiplegic, I couldn’t stay in the house myself... because I couldn’t make the stairs to lock the house”. Ultimately it represented the essence of institutional care. Words such as *care home, care facility, elderly people’s home, retirement home* were used to describe where they live. Attached to these words or phrases were descriptions of these *places*. “A *place* which offers a room and food to those who are not completely physically able... This *place* is called care home.” (Paul) One participant, Susan, takes the description of a care home one step further as she describes it as providing a sense of security and necessity yet, still suggesting institutional care.

*A care home means that we are protected and looked after. Our needs are met. We don’t have to worry about having meals prepared, because they are prepared for us. If you get a headache, you can go down to the nursing station and they will give you a pill. If you happen to fall, you have a little buzzer you can press and they’ll come and pick you up off the floor.*

The care home or *place* was also characterized by schedules and routines that existed on a daily basis – again pointing to institutional care. Lucy pointed this out when she stated:

*How’s my life changed? Well, let’s say it’s more, what’s the word, I wouldn’t say organized but boom, boom, boom, scheduled, where, you know, I mean you have your breakfast at eight ... something else at nine, something else at ten, everything is run on a plan.* (Lucy)
Almost all of the participants alluded to the perceived reality that those providing the care dictated the personal care tasks and the need for routines and schedules.

_I woke up this morning at ten minutes after six. And I wished that I could get up, because I hurt in the mornings when I wake up. If I can get up and move around a little bit, I forget about my aches and pains. When I wanted to get up early, they [staff] wouldn’t let me. They were too busy._ (Sonia)

Waiting was clearly a part of the routines, schedules and personal care tasks.

_Well you have to get up at a certain time, be down for breakfast. When I first came, everybody was going down in their housecoats. My mother would have been shocked. So, I wouldn’t. Well, I guess it was respected, but some of the girls [staff] – it was more important that you be down at a certain time and then you sit there for half an hour and wait – so what’s the point._ (Mary)

All nine participants nevertheless felt that it was a “good” place to be. Participants stated that they needed care and believed that they were receiving the best care possible. For example, Sonia commented, “I don’t think there’s a place that you can get better care.” Susan said, “They’re very dedicated people that work here… you have to be, to work in a place like this. Both Lucy and Diane compared where they were living to other care homes. Ironically, Lucy who in a previous quote stated that her life is run on a plan and is full of schedules and routines later indicated that it is for these very reasons that the care home is a good place. “I went to see these other places. I heard about them and this is the cleanest, best run place there is.” Likewise, Diane noted, “Actually I think that it’s probably one of the best. … And, from what I gathered, when I questioned some of the girls who’ve worked in other places, this is one of the best.”
What also made the care home a good place was having private rooms. Seven of the nine participants referred to having their own rooms and the importance of having privacy. Elizabeth, for example, compares where she is living now to the care home she lived in previously. “Here we have our own room and our own bathroom. At [names other care home] we were four to a room with the curtains drawn over you. Here we can shut ourselves in and have real privacy.” Moreover, having private rooms was a way that participants maintained a sense of self. All the participants personalized their rooms with family photos, their own furniture, favorite books and their own art-work. Private rooms also offered a sense of control. Susan for instance noted, “I have a private room... with a lock on my door. Oh I love that! ... If I don’t want company, I just lock my door, which is nice. And you don’t have to feel like well they can just come barging in on you.”

Two of the nine participants did refer to the care home as a home. Interestingly these were the two participants who had lived in the care homes the longest: Diane and Susan. Their reference to the care home being a home highlighted their need for care and a sense of security, suggesting that coming to view this place as a home was a process. “It is home. I always feel better when I go out and I come back here. I’m glad to come back.... I always feel safer and better once I get in the doors here. So gradually through the years, it’s become home” (Diane). Another participant, Lucy, indicated that she struggled with the “process”. “Well a room isn’t quite a home is it?” but later on in the interview, she stated:

Well, I should say home, I suppose, and that’s what it is, what it’s supposed to be rather. It’s just that I can’t yet accept that this is my home. Yes my room is, I do say that now, is my home but I just can’t off the top of my head say my home.
Mary, on the other hand, clearly reported that the care home was not a home. "I wouldn't call it a home, no. You don't have rules like that at home, do you?" This quote suggests Mary perceived the care home as an organization or system that is governed by a set of regulations or rules she did not implement.

Lastly, although "community" was not directly addressed in the interviews, none of the nine participants indicated a perception of community. More specifically, participants did not describe their experiences of living in the care home in terms of "we" situations but rather "me and them" situations. These experiences are explicitly linked to the following two sections whereby the participants discuss their perceptions of other residents and their relationship with staff.

**Othering: I am not like them.**

That the care home has not been perceived as a home was illustrated not only by participants' descriptions of where they lived but also in the manner they positioned themselves as different from other residents. This was done in a variety of ways. The first way participants separated themselves from others was by seeing themselves as 'helping" or being of service. Three participants positioned themselves in this manner. Diane clearly demonstrates this separation. In her position as President of the Residents’ Council she perceived her role insuring residents’ concerns were addressed.

*See with the Council meetings, I have the CEO come. And maybe the head of Dietary or another time the head of Laundry. So that people can express their feelings about what they think is not right. And they do. This way you have constant touch with management....It just makes so there’s more interplay between the residents and management. Right? And see, that wasn’t there before. But that is now. Since I hit the*
place, I’ve been doing that....I seriously thought about dropping out of it this year.

And I thought ‘No!’ I like it. I like working with people.

It is clear that Diane does not identify with other residents. In fact, it would be difficult to make out she is a resident from this quote. There is no sense of “we” with her and other residents. Similarly, David positioned himself as being a care giver to his spouse rather than a resident. He implied that he does not live at the care home because he needs care but rather to be of service to his spouse.

[I came here] because my wife’s here. She’s up on the third floor. She has forgetfulness and stuff, dementia. ... They didn’t want me in here until I said I had a bad knee and bad eyes... My daughter thinks that my wife has improved quite a bit in her attitude and that’s since I moved in.

Lucy also self identified as being of service to others. She positioned herself in this role by establishing a library in the care home.

I like to be able to mold myself into different jobs. Now those books, I mean I never had a library in my life. But I saw a need for it here. And in order to keep myself going active, I find I have to push myself into something and have it as a main job ...Those books mean a lot to me. However, other people do like books. And I would like them to use the books... just be able to come in and get a book and go, and if they don’t like it, bring it back and get another.

Lucy also referred to another resident who was a Minister and stated, “She contributes a great deal to this place. To those who respond to her kindness, it’s great”.

The second way participants separated themselves from others was according to cognitive status. Those who were cognitively impaired were positioned as ‘other’. Eight of
the nine participants made this distinction. Mary for instance reported, "There are people that are here that are ill and they just wander in your room and try to say it's theirs and I don't know how to handle them . . . but there's a lot of Alzheimer's here." Paul noted, "I can't speak for the others because a lot of the others are vegetables." Lucy explained that not all residents are the same and are kept separately.

There is a wing of this place that is under lock and key and they cannot join in and participate with the so-called normal people. So they are looked after differently. Same food ... same facilities but it is just that they have to stay in that specific area and its nice, they fix it up nice. When I first came here seven years ago it, it was a unlocked area but they found the people did wander and ... they couldn't keep track of these, the wanderers, and they felt that they needed to put restriction on it and they have and everybody seems quite happy.

Diane took the need to recognize the difference a step further and suggested that not all residents are the same and thus should be separated.

[A care home] to me means a retirement home. But it's not, it's changing from that. ... Well it's getting to be, they closed places like Riverview and everything else and a lot of the people who have mental problems ... they're all being placed in the care homes so a lot of them in here are not getting the psychiatric care that they need, in my opinion. ... it's very hard on both parties. Riverview was wonderful. I don't know why they closed all that down. It's too bad they still don't have it. I'm not putting down the mentally ill, because they need specialized care. But roaming around the halls here is not the answer. They need specialized care or specialized floors, where they are being looked after.
Sonia did note that those who do have cognitive impairments are eventually separated, when the impairment is advanced.

*In there they have their own garden, and they have their own care. They can’t get out, you know, not without accompaniment. And that’s for the people with Alzheimer’s.*

*We have two sections of that. But an awful lot of them are being put in rooms in here.*

*When they get really progressive, then they’re locked into that section.*

This quote points to the fact that residents are not alone in making the “separation”. It is also supported by the institutional practices. Also noted in this quote, as well as some of the above quotes, is that besides there being a creation of “other” or “they” there is no reference to a “we.”

Interestingly, Susan commented that people thought she was living in a mental institution. “Well, if I tell them [friends] it’s [name’s care home], they look at me as if I had gone to Essondale – the insane asylum”. This quote suggests that Susan possibly feared her friends who did not live in the care home saw her as separate from them. All participants however did not share this perception. Paul explicitly noted that the place is not a mental institution. “This place is called care home. So, that’s a good term actually ... it escapes from using a term, which implies mental hospital. I do not regard the place as a mental hospital.”

The third way participants distinguished themselves from others was to separate themselves from those they considered to be complainers. The ‘complainers’ were the others. David for example stated, “No complaint ...not from me anyway. But then you’ll always find people that complain . . . you can’t please everybody and no matter what you do, somebody’s going to complain about it.” Susan reported, “I mean some people are just plain miserable.
They complain about every blessed thing there is to complain about. About the food, about
the way they’re treated, about how they’re being neglected...” Elizabeth likewise said,

Well there’s a lot of complaints going on, you know, they complain behind
everybody’s back but they don’t mean it. The food and not being allowed to go
walking wherever they want to go, shopping and they take volunteers with them to go
shopping, they don’t like that ... but half of them don’t even know where they’re going
or how they’re going to get there or how they’re going to get back. They need
somebody to look after them.

Lastly, four participants seemed to link the care home with medical care or hospital
care. This was implied with two participants referring to others as patients. This indicates
once again institutional care rather than home. Nancy, for instance, asked me about residents
who lived on the third floor, “What about the people upstairs, they’re mostly Alzheimer’s
patients.” When talking about the animals, David stated, “I think they’re good therapy for
the patients here too.” Interestingly, another two participants referred to themselves as
patients when discussing personal care – again possibly emphasizing institutional care rather
than home. For example, when I asked Sonia why she referred to the residents as ‘patients’,
she responded, “Because I feel we are patients.” She explained that she linked being a
patient with needing help with personal care. Similarly, Diane also referred to residents as
‘patients’ when discussing needing assistance with physical care. “They [staff] shouldn’t be
looking after patients if they can’t give them the personal care they need.” Diane referring to
residents as patients implies that residents are ill, once again suggesting institutionalized care
rather than a home. Her quote is also indicative of the third dimension of the theme. It
reflects the power imbalance between residents and staff.
You and them: The power imbalance.

The participants not only distinguished themselves from other residents but also from the staff. The participants routinely referred to staff as ‘they’ or “them” in the generic sense rather than speaking of individual staff and using proper names. Participants not only referred to staff as “they” or “them” but also tended to use ‘you’ rather than ‘I’ pronouns when describing experiences. The participants depersonalized their experiences almost as though they were looking in on what was occurring so that it did not affect them directly. Sonia for example when referring to the staff, stated, “Some of them are very nice but some of them, they don’t do it with a good heart.” This quote illustrates not only how she refers to staff but also the word it symbolizes the depersonalization of the care experience. This depersonalization was not only evident with the care experience but also with social activities. For example, when discussing activities, Nancy stated, “Oh they have exercises here; there is always somebody that comes in and entertains you and everything”. David similarly commented, “And in the summertime they have a garden outside and you can go out and tend them, look after the plants if you want to.” Elizabeth refers to having choices, yet does not personalize the experience. She referred to the staff as they and the care home as this place.

Yeah, a happy atmosphere you get here. It’s not a, oh gosh do I have to do this, and do I have to do that. They don’t boss you to do . . . things. They ask you if you’d like to do them, if you don’t all you have to say is you don’t feel up to it, and they let you alone. And that’s what I like about this place.

Although Susan referred to feeling respected, she as well did not personalize the experience.
Well they don’t impose themselves on you for one thing. Like they will knock on the door before they come in which is, I think, very nice because they could just burst in and say, ‘Hey I have arrived!’ But they’re not like that. They do knock and they will come only if they have to, or if you call them, that’s a bit different.

Even when participants did personalize their care experience they still continued to distinguish themselves from the staff. In other words, at times, participants would use the “I” pronoun rather than “you” but continued to refer to staff as “they”. Lucy when discussing availability of staff stated, “They’re pretty good. There are some that are not ideal. But they’re pretty well, I can go up to the nurses’ station and ask for something and if it’s plausible they’ll help me.” Although sounding positive, Lucy’s quote begins to suggest the power imbalance in the resident /staff relationship. “They” clearly have the power. Elizabeth like Lucy implied staff’s position of power when she said, “But they’re very good to you here, very caring. And I don’t even need to ask for anything, they seem to know. They come in and tell me what’s good for me and we both agree on it”. This quote highlights not knowing individual staff and reaffirms the sense of depersonalization that participants’ stories suggest.

Sonia not only described the power imbalance when she discussed the personal care she needed, but also indicated the lack of staffing which ultimately reinforces this institutional mindset of “us and them”.

When I wanted to get up early, they wouldn’t let me [emphasis original]. They say we can’t get you up now. You’ll just have to wait. They were too busy. And I’d have to wait until somebody was ready to come in and help me dress. I have waited as much as two and three hours.
Interestingly, she also acknowledged the power imbalance that exists within the staff as well. While discussing how a care aide wouldn’t help her get up at a particular time, Sonia stated she told the care aide, “Well I says, you know you’re a care aide here. You’re not a nurse. A nurse has more authority than you do.” Lucy takes the position of power one step further and refers to the power of the management team.

*I just think it’s pretty good if you’re having a problem they’ll help you, the staff, they’re pretty good that way. I would say they help me with my room. I’ve got so much stuff that I will not get rid of it, you know? They don’t complain to higher ups … they just accept me now.*

Diane also conveys the distinction between residents, staff and management when discussing feeling concerned about residents wandering in the halls.

*I don’t blame, of course, the people upstairs [management], they don’t see all this happen; only when you’re a resident you see these things happen. They’re not down here going through the hall, you know.*

Moreover, the words *higher ups* and *people upstairs* in Lucy’s and Diane’s quotes also indicate a “top-down” bureaucratic approach to how the care home is operated. They suggest that decision making in the care home occurs beyond the control of residents and that the management team holds the ultimate power.

In addition, while some of the power imbalance could be explained by the reality that participants needed staff’s assistance, participants’ stories also made it clear that it could also be linked to their position in society as being old and unwell. The following quote from Mary illustrates this point.
If you get a new pair of slacks or something and you send them to get your name put on – you don’t usually get them back. ... And then they [staff] tell me that I just think I did [lose clothes], which I don’t just think I did and but who is going to believe me?

When they look at me and they look at a healthy person who is working, you know [emphasis original].

Diane added another layer to being elderly and unwell as she expresses concern for other residents. She indicates that the power imbalance is perhaps the greatest among residents who are unable to advocate for themselves.

It makes me mad when they’re so busy and yet, they have to time to sit down and have a talk in the hall. That’s not good enough. And I’m not just thinking of myself, I’m thinking of other people too. In fact, especially other people, some of them, they can’t fight back; I can fight back [emphasis original]. I can report it and I can say what I think but some of them can’t. And if they get the wrong pills, they don’t know.

This quote also illustrates that while on one level the participants accepted this power imbalance, on another level there were points of resistance to their powerlessness.

Other than Paul, the rest of the participants were clear that they were living in a care home because they could no longer live independently. Living in the care home was their personal acknowledgement that they needed assistance with their activities of daily living. Ultimately their declining health, advancing age and their need for assistance became the reason and significance of why the care home was not perceived as a home. This place was a reminder that they were no longer independent. They were living with others with whom they did not identify nor chose to live with. They were living with rules and schedules that
were imposed by others who held the power. This created the perception of living in an institution and not a home.

Summary.

The participants did not perceive the care home as a home or community. The first indication that the care home was not seen as a home or community was in the way the participants described where they lived. They referred to the care home as a “place” rather than a home or community. This “place” symbolized participants needing care, and routines, schedules and rules that accompanied living in an “institution” or “hospital”. The separation between the individual participants and the other residents marked the second indication that the care home was not perceived as a home or community. This separation was noted in four ways. First, participants did not perceive themselves like the other residents. Second, participants did not identify with residents who had cognitive issues. Third, participants did not identify with residents who were considered “complainers”. Fourth, participants referred to other residents and to themselves as patients. The third indication that the care home was not viewed as a home or community was participants’ perception of their relationship with staff. The participants’ stories revealed a power imbalance in their relationship to staff. Although the power imbalance may be partly explained by inadequate staffing levels, the depersonalization of participants’ experiences clearly reflected a perception of an imbalance in power.

The Societal Discourses at Play

The participants’ experiences of living in a care home were also influenced by competing societal discourses. These discourses help to contextualize the experiences of a care home that is committed to the Eden Alternative and highlights the unspoken values,
assumptions and beliefs that form the backdrop for implementing the philosophy. Two of these discourses were particularly apparent in participants’ stories. First, the participants lived by the storyline life is what you make it. It reflected a sense of personal agency or self-determination to make the most of their situation. The concept of personal agency or self-determination is the ability to be in control of and shape one’s own life (Auger & Tedford-Little, 2002). Yet, the discourses of aging and long-term care countered participants’ sense of personal agency and reinforced the storyline of being old and useless. The data already presented thus far has alluded to this tension. For example, Paul’s story is about personal choice and self-determination. He had the ability to be in control of his own life and he lived by the storyline life is what you make it. Yet, the participants also referred to living in a place that was governed by rules, regulations and schedules, which is linked to the storyline of I am old and useless. This tension clearly affected participants’ experiences and perceptions of living in a place rather than a home or community.

In this section I will first present the storyline life is what you make it. Participants’ sense of personal agency and self-determination will be illustrated through a discussion of (1) loneliness and companionship and (2) boredom and variety and spontaneity (3) giving care to others. Second, through a discussion of physical helplessness, I will present the tension that exists between the storylines life is what you make it and I am old and useless and illustrate how this tension influenced participants’ experiences. Third, I will discuss the implications of the storylines on the implementation of the Eden Alternative.

Life is What You Make it

Participants recognized that they needed care and that they could no longer live in their own homes. They accepted that living in a care home meant living with others whom
they did not choose to live with. They also accepted the rules, routines and schedules as a way of life when living with a large group of people. Throughout the interviews, this acceptance clearly developed as the storyline – *life is what you make it*. In fact two participants used the active phrase. “I’m a person who thinks life is what you make it” *(Sonia)*. Others used such phrases as *it’s up to you, the choice is yours, and make the best of it* to describe their beliefs and how they wanted to continue to live their lives. Susan described the recognition of needing care and making the best of it.

> There are people that sit and pout. “I don’t want to be here. I don’t like the people who are around me.” They can have any number of reasons why, except the honest to goodness truth. They can’t live on their own. They need the care that we get here. And so make the best of it. I mean life is good here.

**A sense of personal agency.**

* A discussion of loneliness and companionship.

All nine participants were able to describe friendships they had established at the care home, in the community or previous friendships they had maintained. Having companionship meant that they did not experience loneliness. Seven of the nine participants denied feeling lonely. Not experiencing loneliness was perceived as an outcome of their own efforts and not a function of the Eden Alternative philosophy. Susan, for instance, felt that being lonely or not lonely is a “*state of mind*”. Elizabeth indicated her sense of personal agency and self-determination in alleviating loneliness when she said, “*No, I never feel lonely, I’ve got my bird ... I never let myself get lonely*”. Mary suggested that finding companionship was a means of personal survival for living in the care home.
They [staff] put me with these two other ladies and I don’t know what was wrong but they wouldn’t talk to me. [They] would whisper back and forth and one of the care aides saw this so she put me at another table. As [laughter] it happened there was a lady and a man they had been married for 72 years and guess what? They were the mother-in-law of my sister’s husband’s brother’s wife [laughter]. It was wonderful! I’ve lasted ever since [emphasis original]. At first I didn’t know I would be able to stay, you know? ... Because I couldn’t stay with nobody talking to me.

Lucy clearly had made the decision to seek companionship and to be involved in order to avoid loneliness.

Well, maybe at the first I did but I’m determined [emphasis original] and have been since I have had to come into facilities like this that I’m going to get out and do things. I’m going to visit with people here. I’m going to take part in activities.

Paul also indicated the importance of his friendship with Lucy but also referred to his perceived personal responsibility to seek out friendships with others residents. “I don’t feel lonely because of her ... if I didn’t have [her] friendship, I would probably search diligently [emphasis original] to find somebody that was enjoyable to interact with.” The words “determined” and “diligently” indicate that finding companionship and avoiding loneliness does not come easily but requires hard work. This self-determination and hard work to obtain companionship meant that one was cared for and needed. It also meant that one was responsible for addressing this need.

I have a little neighbor next door. She practically lives in my room ... She likes my company. She tells me right out point blank that she doesn’t know what she would do without me. And she worries about me if I’m not feeling well (Elizabeth).
The participants' sense of personal agency and their belief in *life is what you make it* not only endorsed their endeavors to seek companionship in order to avoid loneliness but was also linked to having choices. Participants perceived themselves to have the personal choice to determine how they were going to live their life in the care home. More specifically, they perceived themselves to have a choice of how actively they were involved in the everyday life of the care home. The care home was perceived to support participants' endeavors by providing various activities but the responsibility still remained with the individual to be involved.

The choice is yours.

*A discussion of boredom and variety and spontaneity.*

Out of the nine participants, only Lucy admitted that she did experience boredom. Yet, even though participants denied feeling bored and discussed activities they participated in, they indicated that there was little variety in their daily activities. Phrases such as: "*Most of the days are pretty much the same*", "*a typical day is just about the same*" were used to describe life in the care home. David for instance talked about reading and spending time with his spouse who lived in the care home in the special care unit. He however also revealed a sense of routine and lack of variety in his daily life when attempting to schedule our next interview. "*Saturday or Sunday, it doesn’t make a difference to me, I’m not doing anything*". Elizabeth also indicated a sense of boredom when our interview concluded and I offered to put back her table that I moved to accommodate the recorder. She said, "*No dear, I can do it. It will give me something to do*". And even though Mary said there are a "*lot of things to do*" in the care home she also implied that the activities are not consistent and are to pass time and not of particular value.
They did start an exercise program but it's not consistent. It's whenever somebody feels like doing it, otherwise they don't. I like doing crossword puzzles. My favorite thing is do the jumbo in the Province. I watch TV a little bit. [But] I don't really have anything very important to do you know.

It clearly was more important to be actively involved with the same activities on a day-to-day basis rather than not being involved at all. Being actively involved in activities rather than “sit and vegetate” (Lucy) coincided with the notion life is what you make it. In other words, participants indicated a sense of personal responsibility and determination to avoid feeling bored. Susan for instance referred to not being bored and indicated a sense of personal agency:

*No, I'm not bored because I love to knit, I love to embroider, and I love to read. I can spend hours reading. And there are always good books. They have some very good books in here. So, I don’t think you need to be bored, and I don't think you need to be lonely. It all depends on you.*

Avoiding boredom meant being busy. Being busy meant participating in activities at the care home. The participants indicated that the care home and the Eden Alternative supported their endeavors for personal agency through the provision of various activities. Certainly in care home B, the atmosphere felt busy and participants discussed being involved in many activities. In fact, two participants at care home B asked me to reschedule appointments so that they would not miss activities they wanted to attend. Paul for instance stated, “*Can we make it another time, it just that it interferes with the Strawberry Tea.*” Diane discussed the different activities, “*There’s exercises, the art program, music program, dancing, tea or this show.*” Participating in activities at the care home was seen as a personal choice. Mary, for
example said, “There’s lots of things to do, you get involved if you want to”. Similarly, Susan noted the personal choice but also indicated that not all residents choose to participate.

*There are so many programs that you have your choice, you can do as you please or you can sit and pout if you want to. But you don’t have to. It’s not rigid... There’s nothing you have to be at. It’s your choice. You make of it what you want to make of it. Like you do with all your life, eh? There are a lot of people who never leave their stupid rooms. And they miss out on programs. To me, that is not living. That’s being a corpse that’s still breathing.*

Paul pointed out that other residents do not choose to participate in activities.

*We choose whether to go to exercises. And a lot of the people don’t go. They lie on their beds and watch television, all morning, all, afternoon and all evening. And let their bodies decay.*

Both Susan and Paul’s choice of words “sit and pout” “let their bodies decay” suggest an aversion to those other residents who are perceived to be inactive. Here again they separate themselves from other residents. Nancy takes it one step further as she questions how other residents survive living in the care home.

*We play cards two days and [I] read the paper. ... No, I don’t get bored. I watch TV. I watch all the sports on TV, football, baseball, hockey, golf”. ... I don’t know how the other people [residents] that are here put their time in. I don’t how they survive.*

The words “corpse”, “decay”, “survive” suggest a lack of life while it is the notion of activity that gives meaning to life.

In addition to being involved in activities in the care home, five of the nine participants attended groups or other social activities outside of the care home. This offered
participants some variety in their daily lives. Three participants attended church in the community; one attended two stroke clubs, while the fifth participant attended women’s groups at a community centre.

Lucy, who was the only participant who acknowledged experiencing boredom, attempted to keep herself busy. She participated in activities, played scrabble with Paul, and created a library for the other residents. Yet, a feeling of boredom persisted.

[How often I feel bored] Well, I think I would rate it, oh, maybe once a week or it builds up. In other words I have to get out of here. ... Once a week I have to get out of here.... and go shopping, even if I don’t buy anything other than my lunch at the White Spot (laughs).

Clearly, what helped Lucy was to create her own opportunities for spontaneity.

Participants perceived that they had the personal choice to determine how actively involved they wanted to be in the everyday life of the care home. Although they indicated that there wasn’t a lot of variety in the daily activities, what seemed more important was to partake in activities and to be involved. In addition, participants created variety in their daily activity by seeking out community interest groups or simply going on outings. Not being active was frowned upon and pointed to the notion that it is activity that gives meaning to life.

Being actively involved in the everyday life of the care home did not only mean participating in activities but also meant finding ways to be useful and to give care to others. Being able to find opportunities to care for others ultimately reaffirmed participants’ sense of personal agency; they were able, in control of their life and ultimately not old and useless.
The other side of “othering.”

A discussion of giving care to others.

The participants were readily able to share various stories of how they give care to others. It was evident that giving care to others was an important factor of living in the care home and in the storyline life is what you make it. Elizabeth, for example, shares a story about giving care to other residents who are less well than she.

It’s interesting too, you know I have a lot of really sick people that don’t know who they are, where they’re going, where they came from and [they] come in to see me, they all know I’ve got candy to give them. A lot of them are diabetic so you got to be careful with that too. But I’m happy with that kind of a life. I wished I’d taken up nursing when I was young and then I could help these people that come in and see you and put their arms around you and give you a kiss on the forehead and then they go away happy. They figure that somebody loves them in here. It’s funny to experience all that . . . and it’s good too.

This quote suggests that Elizabeth feels good about being able to do for others. Lucy took it one step further when she indicated that giving care to others was a means of finding personal happiness.

...When I first came here I was just ... trying to see what’s going on and trying to make myself happy, if possible. I was going to give of myself to others. I mean the bookcase is one. Sharing my things. ... They didn’t have any books in the library on this floor and I had a hundred and fifty or more books and I sure didn’t have any room in my room that they gave me, to keep
those books so I got them to hear my story and they brought me the big bookcase there, [pointing to bookshelf in sitting room].

David added another layer to giving care to others. Giving care to him meant feeling needed and having a sense of purpose. He talked specifically about giving care to his spouse who lives in the care home but on a separate floor.

She's up there and she knows me about a third of the time, the other times she thinks I'm a very good friend . . . I spend a lot of time going up and down visiting my wife. Actually, according to my daughter, she thinks that my wife has improved quite a bit in her attitude and that's since I moved here.

Sonia added another dimension of giving care when she shared a story about helping staff – those who give care to her.

Well, yes, there are lots of times when I’m useful. For instance, in the Christmas decorating, last year I went down to the girl and she was climbing up and down the ladder putting up the decorations. And I went to her and I says what can I do? I can’t lift and carry but you can stack a bunch of things on my knee and I can bring you these too, and all you have to do is come down the ladder and I can hand you your piece and you can take it up to the top. And by the time you get the other piece, I’ll have another piece for you there, you know. And I enjoyed that. And another time I set all the tables. Another time I prepared all the flowers in little vases like that.

Giving care to others was an important aspect of being involved in the everyday life of the care home. Without hesitation participants shared stories of their ability to give care to others in the care home. These opportunities reinforced their self-determination and the storyline life is what you make it.
Although the Eden Alternative created opportunities for personal choice, opportunities to maintain personal identities and opportunities for caring, the participants’ conviction in the storyline *life is what you make it* supported their sense of personal agency and self-determination. Through this conviction the participants were able to create opportunities for companionship, variety and spontaneity and to give care to others. This was positive, in that it assumed that participants felt they had some control over their lives. However, it could also be limiting because it meant that the care home and the Eden Alternative received little recognition for its role in elders’ successes. Moreover, an unintended consequence could be that if it was an individual responsibility to make the living experience a success, systemic responsibility could effectively be discounted or hidden.

**I Am Old and Useless**

Participants’ stories revealed that they were very much influenced by the dominant societal discourse of aging and long-term care. In other words, societal values and beliefs about aging which equate growing old with becoming ill, becoming ill with becoming dependent and becoming dependent with becoming useless, influenced participants’ perceptions.

*I’m old: It’s not the fault of this place.*

*A discussion of helplessness.*

Five of the nine participants described feeling helpless. Their sense of helplessness was directly related to their physical losses, subsequent needs and dependence on others to assist them. Here, the storyline *I am old and useless* begins to reveal itself. Mary, for example, described her physical losses, fear of losing further abilities and increasing her
sense of helplessness. 

"[I can't] make my own bed or anything that involves standing I can't do. I guess I could try, but I don't want to break a hip ... I have no control over my balance."

Elizabeth took the issue of physical decline and helplessness one step further when she discussed her subsequent needs and the assistance she requires with her activities of daily living.

Well, I've always been able to look after myself. I've always been able to dress myself, wash myself. Do everything myself, make my bed, everything when I came here. Then I broke my hip. And that changed the whole story. Even after I broke my hip, I was still able to do things. Not as good as I did before. So now I'm going blind. I need more help. I need help with somebody picking out my clothes for me. What to wear. And I need someone to help me put them on sometimes because I just can't see.

... It's funny you think you're superwoman when you come in here. Superman. You can do anything. You try to show off to other people. It doesn't always work.

This quote portrays Elizabeth's sense of self-determination but it also hints at the conflict that exists between the two storylines. The tension of the two storylines becomes evident when Elizabeth continued her story and equated her physical decline with inadequacy. "...So you haven't picked a very good person" [emphasis original].

Participants' sense of helplessness with their physical decline was compounded by their subsequent needs and dependency on staff to assist them. This sense of physical helplessness countered participants' sense of self-determination and the storyline life is what you make it:

Nevertheless now, when I go to bed, I'm helpless. I can't reach the phone. I can't reach anything. I can't get myself up to the toilet. I, I'm absolutely helpless. I lie in
absolute frustration, because I’ve had that on [call bell] and they’ve come in three or four times, and turned it off on me. They’re mad because I’ve been ringing it so long.

... So I developed a one two three SOS. When that didn’t do any good, I put SOS, Please! You know or please SOS, or help me. I try to ring it just to lengthen my words. And that makes them mad. And what am I to do, I’m laying there, I can’t turn over in bed by myself (Sonia).

Both Sonia and Diane however commented that feelings of physical helplessness are connected to larger systemic issues rather than the immediate staff. Both these participants recognized that at least some of their helplessness was related to inadequate staffing levels and recommended an increase in staffing. Diane stated, “I would get more help in. There’s not enough now. They’re always in a rush. They don’t have time to do the little things. And we brought this up at our last council meeting on Tuesday and the CEO agreed that we do need it.” Raising their concerns to the CEO also points to residents’ perseverance with the storyline life is what you make it.

In an attempt to maintain their sense of personal agency, participants were reluctant to be burdens to their families. When discussing the loss of her eyesight, for example, Elizabeth stated, “I do feel sort of alone with it ... I don’t want to put it on anybody’s else’s shoulders. I don’t even want to talk to my own children about it.” David, on the other hand, discussed moving to the care home so he would not be a burden to his daughter.

It also leaves my daughter and her husband to live their lives too ... if you are living with somebody like that and you’re old... I would imagine they would [say] I don’t want to leave the old man by himself at home, so maybe we won’t go here or maybe we won’t go there or maybe we won’t do this.
Ultimately, he did not want to be an obstacle in his daughter’s storyline of life is what you make it.

Although not directly related to physical losses, Diane too talked about not burdening her family with her grief. Clearly, Diane attempts to preserve her personal agency and conceal her grief and vulnerability to her family.

I don’t break down and cry, because I’m always thinking of how it affects other people, you know. Not when I’m with them, you know. I don’t let my family see or anything, like my feelings. And then I get it out when I’m by myself... Well you know what I mean I don’t want to put my pain on someone else’s shoulders. I act as though I’m fine, because they have things to cope with too. I don’t want to be a burden and I don’t want to burden anybody else with my problems.

The storyline I am old and useless was evident in a previous quote from Mary who implied that her sense of powerlessness in the care home could be linked to her position in society as being old and unwell. “…Who is going to believe me [emphasis original]? When they look at me and they look at a healthy person who is working... [emphasis original]” In this next quote Mary’s reveals how her experiences are influenced by the power of this dominant discourse.

I don’t really have anything important to do ... something worthwhile ... I’m not important for any reason ... it isn’t so much this place, it’s the fact that I’m disabled and I can’t do what I want ... I’ve been busy all my life. I feel useless here ... but that’s not the fault of this place. It’s because I’m old. You know, I don’t think anyone can make you feel useful unless you can be useful. And yet, if you’re not old, you’re not here ... you’d be dead. I’d rather be old than dead.
Although the participants created opportunities for companionship, variety and spontaneity and to give care to others by engaging in the everyday life of the care home, they could not escape experiencing a sense of physical helplessness. This sense of physical helplessness was closely linked to the storyline of being old and useless. While the Eden Alternative lessened the effect of this dominant discourse of aging and long-term care by supporting the storyline life is what you make it, it could not put an end to the discourses’ longstanding influence on elders’ lives.

Summary.

Participants’ lives were impacted by two competing discourses at play. First, the storyline life is what you make it supported participants’ sense of personal agency and self-determination. Being involved in the everyday life of the care home created opportunities for companionship, variety and spontaneity and to give care to others, which ultimately promoted their sense of personal agency and self-determination. Even though these opportunities were meaningful activities, they did not alleviate participants’ sense of helplessness. This sense of helplessness was reinforced by the discourse of I am old and useless. Participants’ sense of helplessness was related to their age, physical losses and the subsequent care they required. Although subtle, the participants’ stories alluded to how the powerful discourses of aging and long-term care impacted their experiences as elders. Ultimately, because of their age and position in society, participants perceived themselves to be insignificant, inadequate and a burden.

Conclusion

The study highlighted elders’ experiences of living in care homes that are committed to the Eden Alternative philosophy of care. More specifically, the Eden Alternative
influenced participants’ lives in three meaningful ways: (1) Through opportunities for personal choice (2) through opportunities to maintain personal identities and (3) through opportunities for caring. Yet, the participants did not perceive the care home as a home or community. This became clear in three separate ways. First, the participants described the care home as a place where they needed to live because they required personal care they could no longer manage on their own. Second, they expressed a lack of personal affiliation to other residents. Third, participants experienced a sense of power imbalance within their relationship with staff.

Participants’ experiences of living in a care home were also compounded by two competing discourses at play: life is what you make it and I am old and useless. In other words, although the storyline life is what you make it supported their sense of personal agency and self-determination in making the most of their situation, participants struggled with their age and declining physical health. The storyline I am old and useless reinforced participants’ sense of physical helplessness and reinforced their perception of living in a place and their position in society as being old and unwell.

The presence of the two competing discourses ultimately both supported and competed with Eden’s influence in participants’ lives. First, the philosophy played a role in reducing the influence of the discourses of aging and long-term care by supporting participants’ endeavors to live by the storyline life is what you make it. Second, the participants lived by storyline life is what you make it and assumed personal responsibility for their successes. This, in the end, resulted in a lack of recognition of the philosophy’s influence in their lives.
CHAPTER 4 DISCUSSION

The results of this study were consistent with the findings of previous research. Like previous studies mentioned in preceding chapters, the participants discussed various aspects of institutional life. This included routines and schedules, a distinction from other residents and the power imbalance experienced within their relationship with staff. Yet, in response to the research question: “How has the Eden Alternative philosophy of care influenced the lives of elders living in a care home?” three dominant ideas emerged. First, the philosophy did influence participants’ lives in three meaningful ways: (1) through opportunities for personal choice (2) through opportunities to maintain personal identities and (3) through opportunities for caring. However, the second idea that emerged related to the extent to which the philosophy was implemented at the time of the study. More specifically, according to participants’ stories, the philosophy’s goal of creating a sense of home or community was not yet realized. Finally, the third major idea that emerged was that the presence of two competing societal discourses both supported and/or competed with the implementation of the Eden Alternative philosophy: life is what you make it and I am old and useless. This chapter discusses how these findings can increase our understanding of the psychosocial needs of elders living in care homes. Practical ways to support elders’ psychosocial needs in care homes are suggested.

Taking Advantage of the Opportunities

The findings revealed that participants’ had opportunities for personal choice, opportunities to maintain personal identities and opportunities for caring. In this section, I
will first discuss the implications of the first two opportunities and then discuss the implications for the third opportunity.

Paul’s story tells us that he had the choice to live his life on his own terms. Diane’s story illustrates how the Eden Alternative can work. The stories of Paul and Diane suggest the importance of knowing the “whole person” in order to address psychosocial needs and improve quality of life. Yet, research on institutional life for the elderly has shown that nursing staff focus on personal care tasks – the bed and body work, which is typically provided at the expense of learning about the resident as a person, a prerequisite in helping residents preserve their sense of identity and address their psychosocial needs (Kane, 2001; Paterniti, 2003). Although providing personal care and establishing relationships are not mutually exclusive, staff is often too busy assisting residents with activities of daily living that little time is left to get to know residents’ life stories. The concern then becomes that if we don’t know residents’ life stories, their personal identities and have a sense of their personhood, how can we begin to address their psychosocial needs?

Through participant observations and working as a care aide, Debora Paterniti (2003) conducted a qualitative study in a nursing home in the USA, which examined how residents brought personal identity claims to nursing home life despite staff’s characterizations of them in terms of their activities of daily living requirements. One participant for example was labeled a “feeder”. This participant however used mealtimes to recount her favorite life stories. She was an avid storyteller. Paterniti points out:

...Residents don’t leave their pasts behind... but use past identities, skills, and preferences to bring significance to their present lives. ...They construct identity and
personhood within, and often against, the descriptive imperatives and tendencies of the institution (Paterniti, 2003: 59).

Although the focus of the Eden Alternative is on addressing the psychosocial needs of elders, the importance of knowing residents' life stories, personal identities and maintaining a sense of personhood is not made explicit in Thomas' ten principles. The principles reinforce the importance of acknowledging the three plagues and their antidotes; the importance of meaningful activities; bringing decision-making back in the hands of elders and that human growth is never ending. Yet, Thomas does not explicitly link psychosocial needs back to personal identities and personhood, although the link may be implicit.

The concept of personhood was developed by Tom Kitwood in response to the needs of persons with dementia; but the basic ideas of personhood can apply to any individual. Kitwood defines personhood as a "...standing or status that is bestowed upon one human being, by others, in the context of relationship and social being" (Kitwood, 1997a: 8). The concept refers to sense of self; an "I" reference, a personal identity (Kitwood, 1997b). Individuals need to belong, have companionship, feel valued and be engaged in stimulating activities (Goldsmith, 1996). Kitwood found that persons with dementia have five great needs, which come together through the one central need of love: comfort, attachment, inclusion, occupation (to be occupied), and identity. I would argue that all individuals have the same needs. According to Sabat and Harre, restoring personhood would mean that social isolation would be decreased and personal, meaningful relationships would exist (Sabat & Harre, 1992). In this study, Paul's sense of personhood emerged when he returned my summary of
his experiences, complete with grammatical corrections – this being true to his professional identity as a professor. In his relationship with Lucy, Paul formed a close and meaningful attachment and was able to maintain his personal and professional identities. Diane’s sense of personhood, on the other hand was maintained by being of service to others.

The concept of personhood is not contrary to Thomas’ philosophy of care. Rather the concept of personhood compliments the philosophy and perhaps should be included or intertwined within the ten principles in order to make explicit the importance of knowing the “whole person” when addressing loneliness, helplessness and boredom.

Another reason why personhood, personal identities and life stories should be part of Eden’s principles is simply because not everyone is fond of animals, plants and children. For example, a fellow social work student who comes from a Chinese family background advised me that Chinese elders are not fond of animals and would not have them as pets in their homes. Yet, what we do know is that everyone can identify with loneliness, helplessness and boredom as well as their antidotes: companionship, variety and spontaneity and to give care to others.

These findings provide important information for helping social workers conceptualize their practice. First, the findings highlight the importance of the life story. It has long been within social work practice to complete a life story of each new resident that moves to a care home. Over the years, this role may have been undermined due to fiscal and time constraints. Yet the participants in this study clearly indicated its importance.
The life story “is used to provide staff with the background and special characteristics of a resident and it allows staff to see the resident as a unique person with a particular history and not just as another patient” (Patchner & Patchner, 2004: 364). In other words, the life story moves beyond the physical and medical needs and presents a well-rounded picture of a resident (Beaulieu, 2002; Patchner & Patchner, 2004). The life story discusses the resident’s family background, children and grandchildren; significant others and significant life events; education and work history; hobbies and interests; likes and dislikes and what is important to the resident. Ultimately, it creates a representation of the whole person, which reveals a resident’s personal identity and recognizes their personhood (Beaulieu, 2002; Patchner & Patchner, 2004). It is crucial that the social worker not only composes an accurate life story of each resident, but also insures that it is shared amongst the staff. In a care home that has adopted the Eden Alternative philosophy, with residents’ permission, neighborhood meetings may provide an opportunity to share life stories.

Second, the findings emphasize the importance of a psychosocial assessment. The term psychosocial is often used by social workers to describe the group of social and emotional needs and the care given to meet them in order to assist elders with attaining or maintaining a high quality of life (Vourlekis, Gelfand, & Greene, 1992). The assessment typically encompasses the domains of physical health and physical losses, psychological and emotional needs and wellbeing, sexuality, social functioning and spirituality (Beaulieu, 2002; McInnis-Dittrich, 2005; Patchner & Patchner, 2004). In care homes that have committed to the Eden Alternative, the psychosocial assessments would be critical in identifying the possible presence of loneliness, helplessness and boredom and as well as providing a means to explore opportunities to alleviate these plagues.
Although social workers in care homes have the specific role of completing psychosocial assessments and life stories, it is important to note that all staff working for elders in care homes need to endeavor to learn about elders’ life stories, be able to identify and address the three plagues: loneliness, helplessness and boredom and ultimately work at getting to know the “whole” person. Moreover, when staff know the “whole” person and what is important to each individual, it becomes easier to support opportunities for caring.

In this study, opportunities for caring were created through the everyday involvement with pets and animals in the care homes. These pets lived in the care homes either as pets of specific residents or as pets of the care homes in general. They undoubtedly offered opportunities for companionship, opportunities for variety and spontaneity, and opportunities to give care to others. The participants spontaneously talked about the pets and animals. They thoroughly enjoyed telling stories about their personalities, spontaneous moments that created excitement in the care home and the companionship the pets and animals provided. Yet, only pets and animals were embedded in residents’ lives. Plants and children were not part of residents’ daily lives and so, while pets and animals made a significant impact on participants’ lives, plants and children did not.

Even though plants were located indoors (in hallways and common areas) and outdoor gardens existed in both care homes, the participants’ discussions of plants or gardens were minimal. Moreover, their discussions of plants and gardens focused on availability of gardening programs rather plants and gardens having an important role in their daily lives. Although both care homes did have activities that involved visiting children neither care home had children involved with residents on a daily basis.
The Eden Alternative philosophy of care involves a paradigm shift of how we care for elders in care homes. It entails transforming the institution of long term care into human habitats. “A cornerstone of the Eden Alternative concept is that residents should have close and continuing contact with as much of the human habitat as they choose to embrace” (Thomas, 1996: 38). This is accomplished by imbuing biological and social diversity in care homes. In other words, the transformation of the long-term care institution to a human habitat involves embedding plants, animals and children in the everyday lives of elders (Beatty & George, 2004; Thomas, 1996). According to Thomas, it is not enough to have scheduled gardening programs and visiting pets and children programs. The benefits of visiting programs are limited. They are similar to scheduled gardening programs. They occur at a certain time, with a certain group of residents chosen by staff. These programs do not allow for any variety or spontaneity nor do they promote opportunities for caring. Embedding plants, animals and children in elders’ daily lives, on the other hand, encourages opportunities for caring which ultimately alleviates loneliness, helplessness and boredom (Thomas, 1996).

The benefits that pets provide the elderly, particularly those living in care homes, have been well documented (Hinman & Heyl, 2002). Research has shown that “animal companionship reduces loneliness and contributes to a general sense of well-being throughout life” (Sable, 1995:335). Pets have been linked to a reduction of stress, anxiety, depression and improved socialization, mood, and physical activity (Hinman & Heyl, 2002; McLnnis-Dittrich, 2005; Sable, 1995; Weinstein, 1998). Moreover, the human-animal bond has a dimension that does not always exist in human relationships – that is, pets give and receive love unconditionally (McInnis-Dittrich, 2005; Sable, 1995). In addition, pets are
typically considered members of a family. In a study by J. Millighan (1986) a resident dog changed the lives of nursing home residents.

*People who wouldn’t communicate, nor show any interest in anything, even those who had given up on life and just didn’t want to live anymore, became aware and interested when he[dog] came to us. ... We became so attached to him... His presence makes the Centre more of a home and less of an institution (Milligan, 1986:308-9).*

Research has also shown benefits of the elder–child relationship. In an observational report, Sandra Stuart Siddall (1993) discussed her observations of elders, (both cognitively intact as well as those with dementias) interacting with infants and toddlers. Although not formal research, Siddall, a Director of Nursing of an 82 bed nursing home noticed significant benefits throughout a two year period. She observed cognitively intact residents reminisce about their own children as well as spending lengthy periods of time watching the children. She quoted one resident as saying, “I’d rather watch that little girl play with that ball than watch T.V. or eat” (Siddall, 1993: 41). She also described the positive effects children have had with residents with dementias, who didn’t recognize family or friends, whose language was limited and who weren’t involved in activities. The interactions with children resulted in these residents’ faces to light up, smile and even talk to the children.

In Hinman & Heyl’s study (2002) the care home had numerous pets – six cats, fours dogs, two aviaries, four aquariums, two guinea pigs, two rabbits and several doves and parakeets. The care home also had multiple indoor and outdoor gardens and a children’s library and playground. Yet, the children were not part of residents’ daily lives; they were limited to visitation programs. Interestingly, the findings of this study revealed that most of the interactions occurred with animals (67.4%), while interactions with children were only
11.6% and plants were 8.4%. In other words, embedding pets/animals in the daily lives of residents had the most significant impact.

I, therefore, must question whether the results of Hinman & Heyl’s study and the results of this study are indicative of the lack of embedding children and plants in the care homes. In other words, having plants and children involved in the daily life of elders would create further opportunities for caring. Animals, plants and children are the tools needed to create opportunities for caring and ultimately promote human growth.

**Making the Connection and Addressing the Power Imbalance**

Although the Eden Alternative influenced participants’ lives in the three meaningful ways discussed above, it was less successful in creating a home or community. The participants did not perceive the care home to be a home or community but rather a place where they received the personal care they could no longer do for themselves. This perception was closely linked to their lack of connection to other residents and even more so to their relationships with staff. In other words, participants did not identify themselves with other residents and described a power imbalance within their relationship to staff. This lack of connection and the perceived power imbalance resulted in a lack of ownership for the care home. In order to promote a sense of ownership for the care home and thus create a sense of home or community, a sense of connection needs to be established and the power imbalance must be addressed. In this section, I will first discuss the implications of residents feeling connected to one another and then I will address the power imbalance within the relationship between residents and staff.

Participants did not identify themselves with other residents. Participants perceived themselves to be of service to others and perceived other residents as somehow ‘different’ –
for example as having cognitive impairments, mental illness or being complainers. This lack of affiliation to other residents contributed to the perception that the care home is not a home or community.

Care homes adopting the Eden Alternative must first be aware of the longstanding stigmas and discourses attached to individuals with cognitive impairment and mental illness. Dementia for example has been historically depicted as a downward spiral, a death sentence, with no hope, no cure. The person with dementia is often thought as having disappeared; as being non existent; or described as a ‘complete loss of self’ (Kitwood, 1997b; Downs, 1997). Mental illness has been portrayed in a similar manner whereby the person with mental illness is often thought of as “crazy”, “out to lunch”. These stigmas and discourses in all probability would impact the development of a sense of connection between residents. Although community living does not guarantee a connection between all its members, it is still important for care homes implementing the Eden Alternative philosophy to be cognizant of the stigmas and discourses attached to individuals with cognitive impairment and mental illness. Plants, animals and children are the tools for creating opportunities for caring and perhaps can provide an avenue to create a connection between residents.

The power imbalance between residents and staff adds further to the constraints and complexities of implementing the Eden Alternative. While the participants perceived to have opportunities for personal choice, opportunities to maintain personal identities and opportunities for caring, they did not perceive to have an equitable relationship with staff nor did they see themselves as having real power in decision-making. This ultimately influenced their perceptions of the care home not being a home or community. The participants’ sense of
power imbalance was tied to their needing staff's assistance as well as their overall involvement in the operations of the care home.

One implication of this is that inadequate staffing levels may foster power imbalances because residents are at the mercy of overworked staff and have little control in decision-making. The participants recognized that there were insufficient levels available to adequately meet their needs in the care homes. Research has shown that insufficient staffing levels are not a new phenomenon and nursing assistants or registered care aides have more work to do than they can manage (Noelker & Harel, 2001). Furthermore, adequate staffing means more than just meeting the staff to resident ratio. It also encompasses sufficient staffing. In other words, there are nursing staff shortages, in particular with registered nurses (RNs) (Noelker & Harel, 2001). Between 1997 and 2001, for instance, long-term care experienced a decline in the number of RNs in almost all regions of Canada. “...By 2006, 19% of the RN workforce in long term care is estimated to have died or retired. This represents the highest proportionate loss among all the employment sectors that recruit registered nurses” (Samuelson, 2003:30). These shortages result in staff working double shifts and regular overtime. The outcome: exhausted staff who are unable to complete their work to the best of their ability and who are more likely to hurt themselves and/or residents (Noelker & Harel, 2001).

Moreover, studies have also shown that having more direct-care staff is linked with better care. “Specifically, higher numbers of registered-nurse hours per resident-day have been associated with fewer violations of care standards and improved functional ability of residents” (McGregor, Cohen, McGrail, Broemeling, Adler, Schulzer, Ronald, Cvitkovich, Beck, 2005:646). Studies have also found that higher ratios of recreational workers to
residents had advantageous effects on residents' cognitive function and social and language skills (as cited in McGregor et al, 2005). It therefore becomes clear that staffing levels must increase in order to insure that elders receive the care they need.

In order to promote a sense of ownership for the care home, those committed to the Eden Alternative need to not only address staffing levels but also address the lack of decision making power given to residents within the care home. Participants had opportunities for how they chose to live their daily lives but the amount of decision making power they had in relation to the operation of the care home was limited. While some participants referred to bringing feedback, suggestions or concerns to the attention of the Residents' Council the extent to which participants' comments influenced the day to day operation of the care home was questionable. I say this because while principle eight of the Eden Alternative targets de-emphasizing top-down bureaucratic authority and bringing decision making back to elders, participants' stories did not suggest they had an active voice in the operations of the care home. For example, other than Diane, participants were unfamiliar with the Eden Alternative. They also did not indicate being involved in the creation of the rules, schedules and regulations that governed the day-to-day operations of the care home. Most did not even see themselves as having any power in controlling personal routines that did not respond to their unique circumstances.

Various issues need to be addressed then, in order alter the perception that the care home is not a home or community and promote a sense of ownership for the care home. First, while making gains on creating connections between residents may be difficult due to the complexity of stigmas and discourses associated with cognitive impairment and mental illness, the tools of the philosophy may create opportunities for caring and bring residents
together who share a common interest in plants, animals and children. Second, the power imbalance perceived within the residents and staff relationship needs to be addressed. This would include insuring there is sufficient staff to meet the needs of residents and involving residents in making decisions about how the care home is operated.

Recognizing the Contextual Limitations

The findings revealed that a tension existed between two dominant discourses. First, the participants lived by the storyline life is what you make it. They assumed personal responsibility for how they were going to live their lives. The Eden Alternative philosophy supported participants’ endeavors through the three opportunities. Moreover, the Eden Alternative played a role in maintaining the storyline life is what you make it. This was accomplished by not only supporting participants’ ability to create opportunities for companionship, variety and spontaneity and to give care to others, but also by supporting participants to make their own decisions about how they wished to live to their lives. For example, Paul monitored his own alcohol consumption, Diane was an entertainer and resident advocate, while Lucy established a library and David took care of his wife. These participants were thus able to assume responsibility for their successes.

However, the contextual limitations of supporting this storyline must be recognized. First, by supporting the storyline life is what you make it the onus is then placed on residents for the success of the philosophy’s implementation. Moreover, if elders assume total responsibility for their successes, they are in danger of assuming responsibility for their failures as well. Elders, in other words, would be left to their own devices to combat the storyline I am old and useless, thus blaming themselves rather than recognizing the powerful discourses of aging and long-term care.
The complexities of these contextual limitations become even more apparent when considering the societal discourses of aging and long-term care. To begin with, the participants of this study experienced a sense of helplessness. Their sense of helplessness was directly related to their physical losses and subsequent needs for personal care. Although participants felt that staff provided the necessary care, they felt that staff were often rushed and weren’t always thorough. Participants recognized that their sense of physical helplessness was in part a result of larger systemic issues - insufficient staffing levels available to adequately meet their needs.

This lack of sufficient staffing and participants’ sense of physical helplessness is not surprising given that Western society does not value its elders. When we consider that Western culture values being young and healthy, it becomes evident that aging is associated with physical and cognitive decline and is ultimately seen as the visible sign of mortality (Chappell et al, 2003). Today’s society tends to view and treat the elderly as less than equal (Dhooper, 1997) whereby the elderly “are neither ‘seen’ nor ‘heard’ in the sense of being fully valued, or perceived as playing any worthwhile role” (Woodward, 2004: 53).

This societal discourse of aging, which devalues elders, also reinforces ageist attitudes.

*Ageism refers to the ways in which age discrimination marginalizes, devalues, and hinders older people from feeling good about themselves and their contributions to the societies in which they live (Auger & Tedford- Litle, 2002:103).*

These discourses and ageist attitudes in turn position older people apart from young people. Retirement policies are one example of how the societal discourse of aging and ageist
attitudes separates the “old” from the young. “In a culture that values productivity defined on the basis of financial earnings, the contributions of older individuals go unnoticed and unappreciated” (Auger & Tedford-Little, 2002:103). These discourses and ageist attitudes not only affect how elderly people are perceived but also how they view themselves.

Moreover, these discourses influence how long-term care and in particular, care homes are commonly perceived. First, care homes are typically viewed as the “end of the road” where the old, frail, sick and dependent go to die. This societal discourse is widely held by elders themselves “who would rather die than move permanently to a nursing home” (as cited in Kane, 2001:295). The care home not only represents their frailty, physical and cognitive deterioration but also the final stage of their life and approaching death. Second, Being older and even more so, living in a care home aren’t valued in our society and thus the work is not valued either. Work in care homes is not viewed as “glamorous. Third, what makes life in a care home even more difficult is that those caring for elders are also influenced but the discourses of aging and long-term care.

Although, the Eden Alternative was developed to counter the discourses of aging and long-term care and challenge the storyline I am old and useless, it faces the challenges and complexities of the discourses described above. But, it is important to recognize that the Eden Alternative is not alone in challenging the discourses of aging and long-term care. There are other approaches that also work at countering the discourses of aging and long-term care such as the resident centered approach, the concept of personhood and the gentle-care approach.

In recognizing the contextual limitations, there is a need to find a balance that allows elders to maintain the storyline life is what you make it but also make visible the powerful
discourses of aging and long-term care so that elders do not assume responsibility for failures that are an outcome of the current discourses of aging and long-term care. Furthermore, much more work needs to be done in terms of shifting the discourses. Education at all levels must reflect storylines that recognize elders as valuable contributors of our society. Also, policies need to be recreated to reflect elders’ voices. Moreover, the baby boomers who have been successful in shaping policies throughout their lives will soon constitute our aging population. In all probability their demands will increase, affect policy changes and improve services. In the end these policy changes will facilitate the Eden Alternative ability to replace the nursing home institution with human habitats. In other words, there will be a “growing view that a nursing home is no longer a place to die but a place to live” (Patchner & Patchner, 2004:370).

Conclusion

The medical model of care, which has dominated care homes for the elderly for many years, has focused on addressing medical and physical needs. Elders’ needs in long-term care have thus been equated with treatment and cure rather than caring. As a result, inadequate attention has been paid to elders’ psychosocial needs. Dr. Thomas developed the Eden Alternative philosophy of care in attempts to address psychosocial needs and offer a wholistic approach to caring for the elderly. The purpose of this study was to understand from elders’ perspectives how the Eden Alternative has impacted their lives and addressed their psychosocial needs.

This study was based on a qualitative design with a phenomenological tradition of inquiry, which was informed by hermeneutics and narrative inquiry approaches. The data analysis, which utilized both contextualizing and categorizing strategies, illustrated that
living in care homes that are committed to the Eden Alternative philosophy of care gave participants opportunities for personal choice, opportunities to maintain personal identities and opportunities for caring through involvement with pets and animals.

Even though the Eden Alternative created these opportunities, the participants, continued to perceive care homes as institutions rather than as homes or communities. This perception was revealed in three ways: (1) the way in which participants described where they lived, (2) by distinguishing themselves from other residents and (3) through their relationship with staff. Nevertheless, participants assumed personal responsibility for how they were going to live their lives in the care homes and lived by the storyline *life is what you make it*. Yet, a tension existed. The storyline *life is what you make it* conflicted with the storyline of being *old and useless*. In other words, although the participants were able to maintain a sense of personal agency and self-determination and create opportunities for companionship, variety and spontaneity and to give care to others, the care home was still regarded as a *place* where they lived because they could not live independently and they were *old and useless*. Even though the Eden Alternative helped restore participants' sense of personal agency, the discourses of aging and long-term care continued to not only influence participants’ experiences but also impact their personal identities.

There are several factors that care homes adopting the Eden Alternative should consider. First, while opportunities for personal choice and maintaining personal identities point to a need to know the “whole” person, opportunities for caring through daily involvement with pets and animals alerts us to the potential to create further opportunities by embedding children and plants in the everyday lives of elders. Second, even though the Eden Alternative created these three opportunities, it was less successful in creating a home or
community. In order to promote a sense of ownership for the care home and create a sense of home or community, a connection between residents needs to be established and the power imbalance within the resident/staff relationship needs to be addressed. Third, care homes that adopt the Eden Alternative philosophy of care must not only be cognizant of the existing tension between the discourses life is what you make and I am old and useless but also recognize the constraints that may be contextualizing how they choose proceed with the implementation.

Limitations and Next Steps

The participants of this study were Caucasian middle class individuals. In order to gain further insight and understanding of elders' experiences of living in care homes that are committed to the Eden Alternative, individuals from (1) other backgrounds such as immigrant and non-English speaking, (2) individuals with cognitive impairments or mental illness and (3) individuals with no family should be interviewed. This would help to address the heterogeneity of resident’s experiences. Second, in this study residents' failure to recognize the facility as a home and to perceive themselves as being part of a community emerged as a surprising finding. This is an area that requires further exploration. For example, what are residents' perceptions about community and home? Moreover, how culturally bound is the understanding of care facilities. For example, this study suggests that Western ideals of personal choice and autonomy appear to be strongly supported by the Eden philosophy, but the extent that this philosophy can or does promote alternative values associated with other cultures, such as Eastern understandings of relational being and community, is a particular area that would benefit from further understanding. Another line of inquiry linked to this picks up on the emergence of new research that is focusing on the
meaning of place. More specifically, research is now examining the concept of place as home. The theoretical understandings of place as home should continue to be explored within care facilities that have integrated Eden philosophy. Finally, this study suggests the need for longitudinal studies in order to examine and document changes as the implementation of the philosophy progresses.

It is also recommended that social workers highlight the importance of learning elders’ life stories and make certain that elders’ personhood is recognized. Moreover, psychosocial assessments should be utilized as a means to explore the three plagues and their antidotes in order to address quality of life issues. Second, future research should continue to explore the impact of embedding the elements of plants, animals and children in the lives of elders who live in care homes. Third, social workers and other health professionals need to not only raise questions about our current societal discourses of aging and long-term care but also follow in the footsteps of the Eden Alternative philosophy and examine ways to reconstruct discourses to recognize elders as valuable contributors of our society. In turn health care policies and standards can then be developed to reflect elders’ needs and voices.

I’m going to live to the fullest that I can live.
I want to be part of everything that is possible to be part of.
(Susan)
REFERENCES


APPENDIX C: INTERVIEW GUIDES

INTERVIEW GUIDE, CARE HOME A

Can you tell me how you came to live here?

Tell me what your life has been like since you moved here?

Describe for me what a typical day looks like here?

What does the Eden Alternative philosophy mean to you?

What do you enjoy most about living here?

If you could change anything about this care facility what would it be?
APPENDIX C: INTERVIEW GUIDES

INTERVIEW GUIDE, CARE HOME B

How is your life the same as before you moved here? How is it different? And why?

When you describe where you live to someone, how do you describe it?

Can you give me an example of a typical day.

Have you heard of the EA philosophy of care?

IF YES: I am interested in hearing from your perspective, what it is like to live at this care home which has adopted the EA philosophy of care.

IF NO: It’s a philosophy that is trying to improve the life of people who live and work in care homes and I’m trying to learn what it’s like for you living here.

You have been living here for _____ years. Have there been changes in the way things are done here?

Plagues: Have you formed friendships since you moved here? Can you describe for me your friendships?

Other people that I have spoken to that live in a care home have told me that they feel lonely. What has been your experience?

Tell me about activities or leisure interests that mean the most to you.

Other people that I have spoken to that live in a care home have told me that they feel bored. Do you find yourself feeling bored here? Can you give me an example.

Do you have opportunities to be useful or give care to others? Can you give me an example

Do you ever feel helpless? Can you give me an example.

What do you enjoy most about living here?

What do you enjoy least about living here?

If you had a magic wand and could change things about [name of care home], what would you change?
APPENDIX E: THE EDEN ALTERNATIVE PRINCIPLES

The Eden Alternative Principles

1. The three plagues of loneliness, helplessness and boredom account for the bulk of suffering among our Elders.

2. An Elder-centered community commits to creating a Human Habitat where life revolves around close and continuing contact with plants, animals and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.

3. Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.

4. An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.

5. An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.

6. Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.

7. Medical treatment should be the servant of genuine human caring, never its master.

8. An Elder-centered community honors its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them.


10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.