

Ending the Silence: Older Lesbians, Concerns
and Considerations as Caregivers.

by

Linda Margaret Kearley

B.A. Hon., Mount Saint Vincent University, 2003

submitted in partial fulfilment of the
requirements for the degree of
Master of Arts in the Joint Women's Studies Programme

at

Saint Mary's University
Mount Saint Vincent University
Halifax, NS

May 7, 2007

Copyright by Linda Margaret Kearley, 2007



Library and
Archives Canada

Bibliothèque et
Archives Canada

Published Heritage
Branch

Direction du
Patrimoine de l'édition

395 Wellington Street
Ottawa ON K1A 0N4
Canada

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence

ISBN: 978-0-494-30281-1

Our file Notre référence

ISBN: 978-0-494-30281-1

NOTICE:

The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:

L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protègent cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.


Canada

MOUNT SAINT VINCENT UNIVERSITY
SAINT MARY'S UNIVERSITY

JOINT M.A. IN WOMEN'S STUDIES

The undersigned hereby certify that they have read and recommend for acceptance a thesis entitled *Ending the Silence: Older Lesbians' Concerns and Considerations as Caregivers* by Linda Margaret Kearley in partial fulfillment of the requirements for the degree of Master of Arts.

Dated April 16, 2007

Supervisor:

Dr. Valda K. Leighteizer

Committee Member:

Dr. Diane Carter Tingley

Examiner:

Dr. Jeanette A. Auger

MOUNT SAINT VINCENT UNIVERSITY
SAINT MARY'S UNIVERSITY

DATE: May 2007
(Month & Year of Submission)

AUTHOR: Linda Margaret Kearley

TITLE: Ending the Silence: Older Lesbians' Concerns and Considerations as Caregivers

DEPARTMENT OR SCHOOL: Women's Studies

DEGREE: Master of Arts

CONVOCATION: May

YEAR: 2007

Permission is hereby granted to Mount Saint Vincent University and Saint Mary's University to circulate and to have copied for non-commercial purposes, at their discretion, the above title upon the request of individuals or institutions.

Signature of Author

THE AUTHOR RESERVES OTHER PUBLICATION RIGHTS, AND NEITHER THE THESIS NOR EXTENSIVE EXTRACTS FROM IT MAY BE PRINTED OR OTHERWISE REPRODUCED WITHOUT THE AUTHOR'S WRITTEN PERMISSION.

THE AUTHOR ATTESTS THAT PERMISSION HAS BEEN OBTAINED FOR THE USE OF ANY COPYRIGHTED MATERIAL APPEARING IN THIS THESIS (OTHER THAN BRIEF EXCERPTS REQUIRING ONLY PROPER ACKNOWLEDGMENTS IN SCHOLARLY WRITING), AND THAT ALL SUCH USE IS CLEARLY ACKNOWLEDGED.

(iii)

Table of Contents

Abstract	(vi)
Dedication	(vii)
Acknowledgments	(viii)
Chapter One: Introduction	1
Summary of Chapters	12
Chapter Two: Methodology	13
Autobiography	15
Queer Theory, Qualitative Research, Feminist Oral History, and Content Analysis	18
Textual Analysis	19
Observation	20
Oral History & Story Telling (Narratives)	22
Storytelling (Narratives)	23
Historical Research	24
Observations and Demographics	25
Strengths and Limitations	26
Purposes of this Study	32
Importance of This Research	34
Theoretical Framework: Using autobiography	38

Chapter Three: Literature and Discussion	40
Services, Resources and Social Issues	55
Age Gaps and Research Issues	62
Sexual Identification and Coming Out	74
Economics	86
Social Networks and Community	87
Personal Narratives: Stories of Older Lesbian Women's Experience ..	91
Summary	100
Chapter Four: Autobiography	102
Chapter Five: Discussion of Issues and Findings	134
Observation Notes (Toronto, Canada, February, 2003)	134
Observation Notes (Golden Threads, Provincetown, United States, June 2004)	136
Discussion of Issues	140
Chapter Six: Implications and Conclusions	143
Implications	143
Reflections and Conclusions	146
Works Cited	151

Abstract

Ending the Silence: Older Lesbians, Concerns and Considerations as Caregivers.”

Linda Margaret Kearley

May 7, 2007

This thesis examines the social construction, development, and identity of the lesbian caregiver and her experiences, as well as the impact of sexual orientation on the role of being a caregiver within mainstream society and in the health care system. Using an autobiographical approach derived from Brookes, Leighteizer, Auger, Gallagher and others combined with support from secondary and primary literature sources and observations I analyze the/a lesbian caregiver's self identity and presentation in contrast to, and connected with, the caregiving identity. Discuss the construction of “the lesbian identity” in society and culture as done in order to maintain the perception of the “maternal, feminine” caregiving role. Outlining the importance of utilizing autobiography in researching lesbians experiences, and building on the notion that women's voices and experiences build upon the foundation of traditional models of research, I also utilize feminist perspectives to discuss the need more than ever for women's voices to be heard.

Dedication

This work is dedicated to my mother and my partner, who worked everyday to make it possible for this thesis to be completed. Through experience and connections rather than disconnections to each other we make it possible to hear the merit and value of our own voices and our own experiences:

Women's discovery of the problems that ensue from rendering oneself selfless in order to have "relationships" was momentous in releasing women's voices and making it possible to hear what women know. It was like seeing under the surface or picking up the undercurrents of the human conversations: what is known, and then not known, felt but not spoken. Women's choices not to speak or rather to dissociate themselves from what they themselves are saying can be deliberate or unwitting, consciously chosen or enacted through the body by narrowing the passages connecting the voice with breath and sound, by keeping the voice high in the head so that it does not carry the depths of human feelings or mix of feelings and thoughts, or by changing voice, shifting to a more guarded or impersonal register or key. Choices not to speak are often well-intentioned and psychologically protective, motivated by concerns for people's feelings and by an awareness of the realities of one's own and others' lives. And yet by restricting their voices, many women are wittingly or unwittingly perpetuating a male-voiced civilization and an order of living that is founded on disconnection from women (pp. x.xi).

Gilligan (1993)

Acknowledgments

There are numerous people to thank for making it possible to complete this thesis project. It is hard to know where to begin and to be sure not to forget anyone who helped to make the realization of this journey possible. First I would like to thank my partner Wendy for being there, for supporting me and believing I could make this a reality even when I did not think so myself. "Thank you" just does not seem enough. You are strong, courageous, funny, my anchor and my foundation in everything I do.

When I think of my advisors, I can only think of the support, encouragement, strength and guidance that they have given me along the way. To my supervisor Dr. Valda Leighteizer for all of those numerous hours, all the e-mails and the phone calls, and for listening and supporting me. Even though many times I lost faith in myself, you did not and always had enough faith and belief in me for the both of us. Without your support, knowledge, experience and guidance I know that the completion of this thesis would not be possible. How many ways can I say "Thank You" and how much you have meant to me on this journey and in this part of my life? I want to convey my gratitude and appreciation for your time, your guidance and your friendship.

To Linda Allan, I really want to thank you for all of your help and technical support with what I consider to be the 'devil' that is otherwise known as my computer; for all of those hours of fixing what looked like impossible; and for

getting all of the pages of printing to turn out right, and the help with all of my computer concerns. To Dr. Pat Baker for agreeing to work with me as a committee member and providing me with all of her experience, time and knowledge, for offering herself as a sounding board and sitting with me and bouncing around ideas, and theories for this project. Great blessings for you in the future, much health and happiness always. To Dr. Diane Tingley I cannot say how much I appreciate you coming in at such short notice and becoming part of this project. I owe you a debt of gratitude and thanks. Your help has offered me much insight into this project and your support provided me with a lift that really helped get me through some of the tough times. "Thanks so Much" for being there.

Thanks also go to Dr. Jeanette A. Auger for agreeing to be the external reader on this thesis. I appreciate having your wisdom, knowledge and input on this work. Your work has been an inspiration to me throughout this process and this project. Thank you for your time and support of my thesis. I would also like to Thank Louise Ardenne for all of her support, friendship, and inspiration to me over the last few years. You were always there for me and I am truly grateful to have had you in my life and to have all your encouragement and faith in me. I will always be grateful and blessed to be able to call you friend.

Some final words and thoughts are for my mother, without whom this entire thesis would not have been possible. Even though I no longer look upon your face, I feel you in my heart, I hear you in music I listen to and in my own

words, I see you in my own reflection. I want to thank you for giving me a gentle soul, a loving heart, an intelligent mind, and a survivor's will to go on. You were strong, courageous, gentle, kind, and always there for me. How do I honor you, praise you, except to say with pride and love that you were and are my Mother. Your energy and aura is still with me and I carry you with me now and always. I count myself truly blessed to carry your name. My only regret is that you will not stand beside me on my convocation day but I know that your spirit will soar to see some of my dreams, some of our dreams realized. I love you "Mum" and "Thank You". Finally a few more words for my partner, my wife Wendy: you remind me of all the reasons why this is important and your love is what got me through all the tough times. Your love and patience has provided me with a solid foundation to work from and got me through yet another degree and I know if there is another, you will always be there providing your love, patience, support and help all the way. You are my partner and my best friend.

Chapter One: Introduction

This research project is a major achievement in my life and explores the interconnections of the public and the private aspects of caregiving, primarily through one lesbian's experience. This project provides a much needed examination of a largely under-researched population: lesbian women who are caregivers. Although lesbian's lives and experiences have been explored in a wide variety of research over the past several decades (see, for example Auger, 2003; Kehoe, 1991; MacDonald & Rich, 1991), my work expands on aspects of caregiving research, focusing on the interaction between the personal and the social factors that make older lesbians' caregiving experiences unique. Using my lived experience as a lesbian caregiver (in my case, caring for my mother) as a primary site for understanding, interpretation, and analysis, this thesis provides a micro level view of the complex power relations that intersect my identity as a lesbian and my role as a caregiver.

Research studies and literature on caregiving have largely ignored the concerns and considerations that exist for older lesbian women. One of my research goals is to make the issues and experiences of older lesbian caregivers visible. Much of the research on aging or on caregiving tends to treat the caregiver as a generic or neutral category (see, for example Cox & Waller, 1991; Aronson, 1994). When biology, sex, and gender are taken into

account, the research tends to present the picture of the lives and caregiving experiences of all older women as essentially the same (see, for example Beagan, 2005; Henderson, 2005). There is a tendency to group the concerns and experiences of older lesbian women caregivers together with their heterosexual counterparts in various areas of research connected to aging and disability. Some studies indicate that older women experience a variety of concerns with some aspects of caregiving, such as: loneliness, depression, grief, loss of a loved one, lack of support, or access to resources (see, for example Auger, 2002; Auger, 2003). These are, of course, issues that can also be of concern to older lesbian women. However, dealing with the health care system or within families, the experiences of caregivers who are also lesbians can be radically different than those of our heterosexual sisters. Older lesbian caregivers face discrimination, homophobia, rejection, and isolation from resources that are often targeted towards, or primarily available to, their heterosexual counterparts. In some instances, families may expect more from lesbian women as caregivers because of the perception that, as 'socially unmarried' women, lesbians have fewer explicit nuclear family responsibilities, so that caregiving is less burdensome for them than their siblings. While I did not locate any literature to substantiate this claim, my own experience with my

brothers was definitely flavored by their expectations that, since I did not have a family, I could and would be more easily able to care for our mother.

In a similar vein, research focused on issues of aging and/or disability and sexual orientation tends to present the LGBTQ community as a relatively homogenous population. Thus, older lesbians remain invisible within much of the research on gays and aging as well as much of the research on LGBTQ populations and disability (see, for example Quon, 2003).

Aging, gender, sexual orientation, race, class, and ability have a significant impact on the social meanings and possibilities for women who take on the role of the caregiver. Auger (1990) suggests that the social world of older lesbians includes a "triple jeopardy" of aging, sexism, and homophobia. This triple jeopardy affects the type of experiences that older lesbian women can have as caregivers. I have modified Auger's notion of "triple jeopardy" of ageism, sexism, homophobia by using it within the construction of the meaning of community, and just who can fit into which of three forms of the conception of community: the gay and lesbian community; the lesbian community; and the heterosexual community. Inside each community there is still room for further division of the notion and concept of community, and how these divisions impact on older lesbian caregivers' experience, their lives, and their relationships.

By division I refer to the fact that within the communities mentioned above, certain forms of caregiving receive some support, services and programs, which assist the caregiver with the demands of caregiving. Issues and concerns relating to lesbian women's experience of caregiving are not easily visible and are often ignored; therefore our specific needs and considerations are not being met by what is provided in the communities in which we reside. The notion of "coming out of the closet" can take on new meaning when there are reconstructions of the concept of the "closet" from within these communities that do not include having to negotiate the role of caregiver. The lesbian caregiver must constantly negotiate her/my identity and sexuality carefully in order to receive care and support for those she/I cares for. Additionally, she/I must maintain the perception of what is expected for the mainstream concept of what a caregiver is and should be. There is little acknowledgment of the different forms of lesbian identity inside these communities when negotiating sexual orientation, gender, femaleness, and sexuality along with the role and status of being a caregiver: "Somehow, way back of our first closet we have built another one, and into it we have shoved our gay deaf and our gay blind, and our gay wheelchair cases" (Quon, 2003:22). I would add that this closet also includes older lesbians as caregivers, and poor lesbian women.

In the current societal structure my unpaid labor and work has little value. My full-time responsibilities as a caregiver mean that I have not had the privilege of being employed in the traditional sense, even though I have worked ever since I was a young child. As Quon points out, this places me, in many ways, way in the back of the first closet. For older lesbian women there are complex problems and concerns. Issues that surround the ideology of women who choose not to take advantage of patriarchal or heterosexual privilege can affect the kinds of supports and resources available to assist them in their role as caregivers. There are also problems associated with notions of sexuality and intimate relationships for lesbian women who are also dealing with being full-time caregivers after forty; the ageism, the stress and isolation that can be part of the caregiving process can affect our intimate relationships. The very act of having to disclose the nature of our sexuality and sexual orientation to others connected to the caregiving role, such as family members, health professionals, and people in the workplace during the caregiving process, shapes our caregiving experiences.

Facing invisibility and, for some, being in the closet, makes connections to the LGBTQ community difficult, if not impossible at times. For some older lesbian caregivers the perception of community becomes distorted and erased; the notion of home as a haven away from the pressures and scrutiny of trying to

be part of mainstream heterosexual society, and a culture that still considers heterosexuality the norm for sexual expression and lifestyle, makes the experiences of caregiving for older lesbian women even more invisible and distorted. Whether our lesbian identities are 'closeted' or not, disclosure has a material affect on the caregiving experiences and the nature of the relationships inside the parameters of the roles of caregiving for an older lesbian. Disclosure within the family affects the changing intimate nature of certain relationships, such as (for example) the relationship between two lesbian partners and the effects of the caregiving experience on that relationship.

Part of the aim of this project has been to provide a framework that will help to develop a guide for lesbian women who are growing older and are dealing with aspects of sexuality, coming out, intimacy issues and health issues that can be affected by their full-time caregiving responsibilities. Many aspects of growing older, aging, and caregiving are universal; however, aspects of aging and caregiving specific to lesbian women still remain among the least examined or studied issues concerning lesbian women's lives.

A central concern for this thesis is to ensure that consideration of the role of caregiving for older lesbians is explored as a multi-layered issue that includes those who are cared for, those who are providing the care, and those who are connected either directly or indirectly to the caregiving process. This project is

also a close examination of the internalization of this process for a lesbian caregiver in providing care. I explore the processes through which an older lesbian woman negotiates her perception of self and her lesbian identity as the demands of caregiving change and evolve. There is little argument that aging populations are growing. Within this population are older lesbian women who not only face the many challenges of their own aging process but who are also parenting, for lack of a better term, either their own parents or their aging and ill partners inside a society and culture that to a large extent still views their lives and "lifestyles" as abnormal.

This thesis investigates the area of the caregiving experience in lesbian life for lesbian women who are close to forty years of age or older. As I approached this age myself, I realized that the way in which I dealt with my primary caregiving role in my twenties and then in my thirties changed dramatically; these changes, coupled with a lack of information in this area, developed my focus on this particular age range. As Kristina Hash (2001) suggests, currently there are not many professionals or services which deal with or are equipped to deal with and understand the special caregiving needs of midlife and older lesbians and gay men. The notion that research and caregiving literature based on traditional populations can be applied to examine

the specific concerns and considerations of older lesbian caregivers fails to explore the extent to which sexual orientation affects the caregiving process.

Autobiographical analysis of my own experience of caregiving as a lesbian woman helps to set some of the foundational background to this thesis. Using such an internalized examination, I explore the impact of society, community, academy, health professions, and family on the caregiving experiences of older lesbian women and their caregiving experiences. I use a literature analysis along with an autobiographical analysis/narrative to expand on an understanding of the experience of older lesbian women who provide care for others, such as parents or same-sex partners. I believe that some of the above issues and concerns have to be examined more closely in order to build a more visible lesbian community. The issues for older lesbian women who are in the caregiving role need to be made visible by having our voices heard, by telling our stories and experiences inside LGBTQ communities as well as in mainstream western society and culture.

The work presented here illustrates that much remains to be done to identify and to eliminate the problems associated with stereotyping of, and discrimination and homophobia towards, lesbian women who are caregivers. Being both inside and outside various levels of the macro problem of the caregiving experience for older lesbian caregivers, situating myself as the

subject and the object of the research process, positions me to build a more complex understanding and to posit alternative visions through the voices/stories/experiences of older lesbians who are also caregivers.

There is some emphasis in this thesis on the problems that may exist within the lesbian and gay community for older lesbian women facing caregiving concerns and issues. I have looked at issues for those who come out after forty, who change their familial situations, who are exposed to violence, who may experience homophobia, and who consider retirement in their new roles as older or even elderly lesbian women who are in the caregiving role. These issues and other concerns that have been mentioned above are included within the scope of the literature that has been examined for this thesis, which includes the following questions: Why are so many lesbian women who are caregivers, many of whom are older, hidden from the lesbian and gay community as well as from academic research on growing older and aging? What should be done to eliminate the invisibility of older lesbian women who are in a caregiving role, and their families and issues related to sexuality and intimacy?

This thesis also explores issues related to the role of caregiving and aging, with an acknowledgment of the connections to disability, sexuality, and sexual intimacy in older lesbians' various relationships. Although the main focus remains on the caregiving experience of the older lesbian woman, this thesis

elucidates connections between lesbian caregivers and aging parents; the role of caregiving and the effects on primary intimate and romantic relationships with a partner, as well as other social relationships as they are connected to the caregiving experience and what effects these connections can have. Since I maintain the focus on caregiving, I include these components only as they are relevant to this thesis. It is impossible not to look at the effects on sexual, emotional, and psychological intimacy in lesbian relationships where one partner is a primary caregiver of an elderly parent who may or may not also be disabled, increasing the level of demands on the lesbian caregiver.

While societal attitudes toward lesbian sexuality, identity and orientation have in some ways changed, upon examination of the literature it remains clear that homophobia, sexism, ageism, and heterosexism are still areas of concern. In order to understand how the caregiver role may be affecting an older lesbian woman's life, I utilized secondary sources to explore some of the issues that are directly or indirectly related to how a lesbian woman becomes a caregiver. The time in which we are born and grow up provides the context of our environment, culture, and society, which also influence how we are who we are at different stages in our lives. Time and changing societal attitudes and expectations shapes and/or alters how we view ourselves and how others view us. Our development over different periods of time as women and as lesbians has an

effect on how we see ourselves in the role as caregivers, as women, and as lesbians. Thus, social contexts set the stage for how lesbian women now in their forties, fifties and sixties relate to their sexual orientation and their identity as lesbian women and as primary caregivers. This is not to suggest that lesbian women who are younger than forty are not also faced with similar types of concerns as lesbian caregivers, but I have considered the unique position of older lesbian women.

Herstory on the lives, experiences and issues older lesbians face provides the groundwork for me to delve more deeply into how issues of homophobia, discrimination, and ageism affect the lives of lesbian women caregivers, and the effect on their sexual and intimate relationships with their friends, families, lovers, partners, colleagues, and most importantly with themselves. These issues are described in this thesis within the literature review through the themes of research, academic institutions, social institutions, medical institutions, government, social services, and community programs. Through this work I have gained some understanding of the experiences that have shaped the lives of lesbian women who are now in their forties and beyond. The paths of these lesbian women's lives do not necessarily follow the same issues and concerns that face younger lesbian women today.

Without women's own voices and stories of their/our own lives and experience as lesbian caregivers, lives remain hidden and stories untold. It is clear that obtaining an accurate herstory has to include information from oral tradition and not rely solely on data from other sources. This is an important part of why I have chosen the methods I have in this thesis; both the autobiographical method and utilizing secondary sources from an extensive literature search construct a picture of the experience of the lesbian woman as a caregiver. Recognition of the usefulness of the oral tradition of story telling as a research tool may actually help to explain why older lesbian caregivers continue to remain invisible: such invisibility may in fact be a reflection of current traditional research methods, which value objectivity and empirical evidence over "stories".

Summary of Chapters

Chapter Two is an indepth exploration of the types of methodological and theoretical frameworks used. Chapter Three contains a literature review of some primary and secondary sources, discussing personal narratives, archival exploration, and content analysis of issues and concerns related to older lesbian women. Chapter Four utilizes autobiography and analysis to situate one lesbian woman's (mine) experiences within the context of this research. Chapter Five outlines some observations, issues, and findings from this research. Chapter Six discusses implications and conclusions.

Chapter Two: Methodology

The purpose of this section is to focus on the methods I used to conduct my research. I wanted to know what would happen to my life as I became an older lesbian and was finished as a caregiver. What would become of me, and, as I approached an age where I would hope to consider retiring, would I be able to retire? What would life as a lesbian caregiver be like when I got older? Would I still be a caregiver to someone else or would someone be my caregiver? To conduct this research, I chose a qualitative approach using a variety of sources. I drew upon a selection of literature and autobiography that would tell some stories of the experience of older lesbian women caregivers and how these experiences affect, either positively or negatively, the quality of the caregiving experience. Most of the work I have done is with the thought in mind that I regard the women in my literature review as human beings instead of objects. Keeping this in mind, I tried to place myself among those lives and experiences between the pages and the words so my analysis was among them rather than about them. I wanted to let their own personal herstories and narratives render an account that was as accurate as possible and in the words of the older lesbian woman. As I write this piece of work I realize that to be a researcher one does not have to know everything about a topic in order to gain an understanding of the topic one is researching.

Each approach used for this research project offers a productive way in which to organize and sort the data which has been collected. Each component of this process has allowed me to create an impression that starts with the focus that many different experiences contribute to the quality of the caregiving experience that an older lesbian may have. While I had certain expectations of how this work would evolve, each approach assisted me in understanding that ideal conditions for research do not always exist and we have to be able to make a departure from what is traditional and create a style that works for the project as well as the researcher. This work is intended to be an exploration of the experiences of lesbian women who are caregiving or have been caregivers and are now older or aging, and who are hoping to be able at some point to retire from the traditional workforce, as well as being able to retire from or leave the role as a caregiver, if that is at all possible. I also discuss those primary caregivers who have not fit into what is considered the mainstream workforce. The experiences of older lesbian women and lesbian caregivers are not traditionally part of mainstream society or culture, nor are their experiences part of the mainstream LGBTQ community, which tends to be youth orientated. I wanted to work to change the process in which lesbian women are viewed, particularly older lesbian women and lesbian caregivers who are not visible within communities both outside and inside the academic sphere.

Autobiography

It is important to start here with a definition of what autobiography is.

Maggie Humm (1995) states in "The Dictionary of Feminist Theory" that

Autobiography is a written or verbal personal interpretation of one's life. The term first appeared in 1809 making autobiography a quintessentially modern form. 'Autobiography' does not apply to all life writing. Other forms include Central American testimonios. Autobiography has been a major form of working-class women's writing and in Britain dates from the eighteenth century with writers such as Mary Collier. Harriet A. Jacobs' *Incidents in "The Life of A Slave Girl"* (1861) inaugurated a tradition of American Black women's autobiographies, grounded in the experience of slavery and confronting issues of readership and genre. Toni Morrison argues that autobiography is crucial in Black culture because autobiography represents both the individual and the group (Morrison, 1992). Similarly Third world autobiography takes the form of resistance writing and is often future orientated, rather than reflecting the past (pp.16-17).

This thesis utilizes the notion of grounding the writing in the experiences of one older lesbian caregiver. Like Toni Morrison, I believe that autobiography is crucial to culture. In this writing, I apply autobiography to lesbian culture, and expand the application to explore and confront issues of gender, age, and sexual orientation. I also see this writing as a form of resistance, and set my focus on the future while reflecting on the past. Writing in such a way has provided me with the opportunity to regain a sense of agency and self.

In the "Encyclopedia of Feminist Theories," Lorraine Code (2002) states that

The development of interest in women's autobiography has also extended beyond the literary and has provided the impetus for questioning disciplinary as well as generic boundaries. Within the social sciences, there has been a demand for 'self-reflexivity' and acknowledgment of a self which is situated within a particular lived history, as against the traditional assumption that the self of the theorist was objective, and, therefore, agendered. For feminist historians, women's autobiographies provide not just a source material about lives which have been traditionally overlooked but ways of thinking about subjectivity and its forms and representations within historical accounts (p.34).

In this thesis, I utilize autobiography in this self-reflective manner, to explore subjectively the ways in which my experiences were specifically gendered. Further, as Code notes below, I use my own life experiences as a source of knowledge, a way to know more about not only myself, but also about how my choices were informed by a gendered social construction of that self.

Code (2002) further explains:

Autobiography has also supported radical development within teaching, providing a means for women to employ their own autobiographical accounts as sources of knowledge and recognize *themselves as subjects within their own worlds*. The use of autobiography in the classroom can be a means of crossing not only subject disciplines but the divide between author and reader and theory and practice as well. Autobiography has played an important part, too, in feminist recognitions of the heterogeneity of women's lives and the differences among women which can get lost in theoretical generalizations; in its engagement with a *particular point of view*, autobiography can provide a more complex view of Woman than simply the Other of man, seeing her instead as the product of distinct histories, marked by complicated crossings of gender, ethnicity, race and class (p.34).

For this thesis I would add that my own herstory is a view of a distinct herstory, whose own crossings are complicated by class and gender, as well as

by age and sexual orientation. Such a source of information and knowledge provides an individualized account of the life experiences of the older lesbian caregiver. By utilizing my autobiography I have aimed to not be lost within theoretical generalizations; rather, I make theory supportive and part of the foundation of my lived experience as an older lesbian caregiver. Ann Louise Brookes (1992) points out that

Learning to critique through autobiographical reflection and analysis is one means by which researchers, teachers and students can begin to know and examine the biases and assumptions which organize different ways of working. Such an approach is beneficial because it does not depend on an artificial separation of the personal from the public (p.3).

I would add here not only different ways of working but also different ways of presenting the 'self's' own lived experience. By utilizing autobiography as part of this thesis there is little separation from what is personal, to me, in my lived experience as an older lesbian caregiver, from that which is perceived to be the public and the personal in my role as a lesbian caregiver. In fact, for me, such an approach helps to open up this experience and to fill in the gaps and show my reality, from my own perspective, using my own voice and words.

Leighteizer (1992) states that

... lesbians are not merely presenting self to the world, we are actually engaged in the process of creating self through social practices which, through lesbian culture, we distribute, utilize, and recognize (p.4).

For me this is a particularly poignant point: the creation of 'self' for me is interconnected to my construction as a woman, a lesbian, a caregiver, and a

lesbian-woman-caregiver. None of these components can be or are separated in my journey as a caregiver. Each part of my 'self' represents critical factors in the outcome and impact of being a lesbian and a caregiver. Unlike Leighteizer, I have engaged with the process of creating the 'self' without the support of lesbian culture most of the time, and have spent most of my experience immersed in the mainstream culture. Recognition of my own lesbian 'self' becomes distorted and it becomes difficult to distinguish between society's and culture's perception of my lesbian identity, and a sense of 'self' from within my own reality. Leighteizer (1992) goes on to say that this is why there is a need for biographies of women and autobiographies by women, in which we recall our own individual unique experiences (p.4).

Queer Theory, Qualitative Research, Feminist Oral History, and Content Analysis

Joshua Gamson (2000) points to the importance of utilizing a qualitative style of research. Gamson (2000) notes that

The study of sexualities in general, and homosexualities in particular, has long been closely intertwined with qualitative research by which, as a general starting point that I will quickly *complicate*, I mean a loose set of research practices (ethnography and participant observation, in-depth interviewing, textual analysis, historical research, and the like) distinct from quantitative methods and often suspicious of the epistemological assumptions of positivism, and a correspondingly loose but distinct set of research foci (cultural meaning creation and interpretive processes, collective and personal identities, social interaction, the practices of everyday life, and so on) (p.348).

Looking at what Gamson has said helped me to focus on the value of using textual analysis, observation, and historical research. Each of these factors are components I used in helping to construct a view of the experiences of older lesbian women caregivers which may affect the quality of the caregiving journey and process. Each method helps to tell unique parts of the story of some lives of older lesbian women as they go through the process of being a caregiver and what such a journey can be like, and how it is affected by different factors and considerations that are defined by the parameters of our own experience from different angles.

Textual Analysis

Bauer (2002) notes that

Methods are no substitute for good theory and a substantive research problem. The theory and the problem, which embody the prejudices of the researcher, will inform the selection and categorization of the text materials, either implicitly or explicitly... There are two kinds of texts: texts that are made in the process of research, such as interview transcripts and observation protocols; and texts that have already been produced for some other purpose, such as newspapers or corporate memos. The classic materials of CA (Content Analysis) are written texts that have already been used for some other purpose. However, all these texts can be manipulated to provide answers to the researchers questions (p.136).

From the work of Martin Bauer (2002) I have utilized key parts to accomplish some of my own research. I examined the individuality of those telling their stories in each piece of literature to gain some insight into what could affect the quality of an older lesbian woman caregiver's experience, and

related it back to my own experience of growing older as a lesbian and a caregiver. The most important part of Bauer's work for my work is the manipulation of the texts analyzed to gain answers to questions of what affects older lesbians who are also caregivers and how we grow older, and how I see some of the connections to the lesbian caregiving role and experience for the older lesbian woman. This approach can be used to answer questions about older lesbian women as well as the lesbian caregiver to construct a style of thinking about how to analyze the problems and data that have developed throughout this thesis.

Later in this thesis, I discuss some observations made during a trip to Toronto, Canada's largest LGBTQ community, as well as while in Provincetown in the United States attending a conference called Golden Threads. As Bauer notes may be done as a methodology (p.136), I applied principles related to sights and sound that are related my journey as a caregiver.

Observation

Angrosino and Mays De Perez (2000) discuss the importance of observation in research:

Observation has been characterized as "the fundamental base of all research methods" (Adler & Adler, 1994, p.389) in the social and behavioral sciences and as "the mainstay of the ethnographic enterprise" (Werner & Schoepfle, 1987, p. 257). Even studies based on direct interviews, employ observational techniques to note body language and other gestural cues that lend meaning to the words of the persons being interviewed. Social scientists are observers both of human activities and of the physical settings in

which such activities take place. Some such observation may take place in a lab or clinic, in which case the activity may be the result of a controlled experiment. On the other hand, it is also possible to conduct observations in settings that are the “natural” loci of those activities (p.673).

While CA (content analysis) provided me with a strong foundation to explore the issues that are connected to older lesbians’ quality of the caregiving experience, primarily through an autobiographical lens, observation allowed me to explore closely issues that affect the lives of older lesbians who are also in the caregiving role, by going into other communities and even another country, to get a different perspective on how such experiences as growing older and caregiving are connected to many similar issues and concerns. One of the main reasons I took the journey to “Golden Threads”, a gathering for older lesbians and their partners in Provincetown in the United States (2004) was to observe women in a LGBTQ setting different from Halifax, Nova Scotia. There, a large gathering of older lesbians, over two-hundred and fifty women, allowed me to note first hand the activities, experiences, reactions, body language, and communication that takes place in a location where it is possible for older lesbian women to feel more free to express themselves. I hoped that I would gain more insight into what it means to be not only a lesbian but also a lesbian caregiver. The same can be said for the journey to Toronto, Canada. Would I discover a clear representation of life for the lesbian caregiver who is over forty? In Toronto, what I observed of the lesbian experience there provided me an

opportunity to allow the stories and voices of how different the older lesbian woman caregiver's experiences could be, and could come alive without the aid of the actual interview process. Spending time in those communities allowed me an opportunity to listen to those around me, as well as participate in conversations with other older lesbians on issues related to growing older, being a LGBTQ caregiver, and what it means to be visible or not. This approach was included to add validity and to be complementary to the CA (content analysis) of the literature reviewed.

Oral History & Story Telling (Narratives)

Where exactly the lines between oral histories and story telling cross is sometimes hard to determine. Reinharz (1992) notes:

Oral histories are typically, though not exclusively, done with two frequently overlapping people: older and relatively powerless people. In many societies older individuals are seen as repositories of historical knowledge. They may have the time and inclination to share what they know, but may lack access to publication and may not choose to express themselves in written form. Many feminist writers and researchers have adopted the oral history method precisely for the purpose of enabling people to publish their views who otherwise would not have done so (p.141,142).

The methods employed in this thesis are used to allow for, as Reinharz says, a way of providing a forum to publish views or reveal parts of selves that have been kept hidden for years, and in some cases, decades. This is why I have chosen to include storytelling, as a means to assist in visualizing what is hidden in the oral histories used for this project, and as one of the pieces that

completes a more whole picture of the experiences of older lesbians and what may affect their older years beyond the role of being a caregiver.

Storytelling (Narratives)

Bauer & Jovchelovitch (2002) put into perspective one of the main focus areas of this thesis, which is to confront everyday experiences of older lesbian women's lives that have an impact on the caregiving phase or stages of their lives. Bauer & Jovchelovitch (2002) explains:

Indeed, narratives are infinite in their variety, and we find them everywhere. There seems to be in all forms of human life a need to tell; storytelling is an elementary form of human communication and, *independently of stratified language performance, it is a universal competence*. By telling people recall what has happened, put experience into sequence, find possible explanations for it, and play with the chain of events that shapes individual and social life. Storytelling involves intentional states that alleviate, or at least make familiar, events and feelings that confront everyday life. Communities, social groups and subcultures tell stories with words and meanings that are specific to their experience and way of life. The lexicon of a social group constitutes its perspective on the world, and it is assumed that narrations preserve particular perspectives in a more genuine form (p.58).

Storytelling is, for this thesis, a means to analyze lesbian experience, aging, and the caregiving experience as it is connected to their way of life. It is important to bear in mind that some of the literature/stories that have been utilized throughout this thesis have been published by other authors and may contain problems with accuracy or with my interpretation, but still they provide this project with data that is closer to the actual realities of the issues, concerns

and lives of older lesbian women who are caregivers that are being examined for this thesis.

Historical Research

The work of William Tierney (2000) puts into perspective the importance of collecting and analyzing historical data. Tierney (2000) explains:

A society such as exists at the end of the 20th century, which has been so deeply absorbed in transformation and renewal, generally has used life history as fleeting memory. Those who suggest that history is little more than collective memory overlook how ideology frames, constructs, and defines what is seen and/or obscured. Memory is assuredly not outside of history; rather, the two are conjoined in mutual constructions. In earlier work, I observed that discussions about the purpose of life history revolve around the twin concepts of portal and process (Tierney, 1998). A life history might be done as a portal, an entryway, through which the author and reader might understand a culture different from their own. The assumption is that a life history's purpose is to enable the reader to come to terms with different social phenomena, perhaps, or to learn vicariously about a world quite different from his or her own (p. 544).

I use this method to examine the issues that have had an effect on the lives of older lesbian women and their caregiving experience. Tierney's concept of the portal approach is relevant to my research, as much of what I am trying to gain insight into is deeply connected to the past, particularly lesbian culture of previous years and decades and how it can connect to my experience as a lesbian caregiver. As Tierney suggests, using historical data is a way for me to learn vicariously about other older lesbian women's lives who may also be in the role of caregiver and what has shaped the experiences and present day, which

has a direct bearing on the quality of the caregiving experience they expect or are living.

Observations and Demographics

For a project such as this there might normally be no mention of those who I interacted with, observed and read about for this research project, but part of the point of this thesis has been to give voice to those who otherwise would remain invisible. For this reason, I will take some time to include the selection process for the older lesbians' stories that were utilized for this thesis. The subjects in this thesis were drawn from various sections/sources of literature. Many of the narratives chosen were from Canadian and American sources; some of the sources chosen were from Australia.

The lesbians found within the pages of the literature chosen were from both rural and urban centres. Some were affluent and well educated by academic standards, while others were rich only in life experience. In an effort to gain a picture of what could affect the quality of the caregiving experience a lesbian woman may have, each piece used for this thesis was selected to include as diverse a background as possible of lesbian life and culture.

The pieces of literature chosen were specifically about older lesbian women or those who have lived their lives connected emotionally, psychologically, sexually, and physically to other women for part or most of their lives. It is important to consider that many of these women lived in a time when

lesbianism was viewed as deviant or abnormal and, as a result, never identified as lesbian. While I had no personal connection to any of the women in the stories/narratives I chose to use for the thesis, I could identify with many of their issues and concerns.

Some of the lesbian women in the selected stories/narratives have been married; some had children from heterosexual unions; some had children through alternative methods; as well, some had no children. Women ranged in age from forty to one-hundred and one years of age. Some of the women in the stories/narratives identified as differently abled. As well, they were from different cultural and racial backgrounds, showing the range of lesbian women who are growing older and are or have been in the role of caregiver. Some women had been very “out of the closet” and participated in the LGBTQ community. Others remained “in the closet”, some for the sake of those whom they presently care for or have cared for.

Strengths and Limitations

There are many limits with how far a researcher can go with the approaches I chose to use for this thesis. There are gaps in what is on the pages versus the actual reality of each individual lesbian woman’s experience. As well, it is impossible to include all relevant literature that is related to the issues that lesbians face when dealing with being a caregiver and growing older. There is also a concern that few of the stories/narratives chosen for this

thesis were specifically on the issue of the lesbian caregiving experience because there is so little of this experience written. I had to develop my thesis around issues and experiences that could affect an older lesbian woman's quality of life or the impact of the caregiving experience in relation to the quality of life experience.

Aside from the limits there are some obvious strengths by doing research this way; it allows an opportunity for my and other older lesbian's voices, experiences, and life stories to become visible. It is my hope that some of the forgotten names and faces will come alive and be available to those who have not known of their existence prior to this work. Some of the lesbian women who have struggled with growing older and with being caregivers, have fought and resisted pressure from mainstream culture and societal pressure, but often have had to bend and conform into a mold that was set by others. Some of their stories have unfolded before me through the retelling of oral herstories. Some older lesbian women and lesbian caregivers have had a chance to have some of these stories heard here.

I use the autobiographical method in addition to utilizing primary and secondary literature sources; each acts both as support for and as a foundation for a discussion and exploration that focuses on the older lesbian woman's experiences. Stories and narratives that are connected directly/indirectly to the caregiving process have not previously been interwoven in such a way that

narrows in on more specific issues and concerns that may impact on the older lesbian woman caregiver. By providing a description and analysis of how problems or situations are experienced by the lesbian women who live them, I seek to build an analysis that will expand on actual experiences as my strategies for analysis and action, instead of trying to fit lesbian women's experience into existing theoretical frameworks. This provides for a continually evolving and modified methodology that grounds my analysis and action strategies in the real life experiences of a lesbian woman. My final theoretical framework is based on those realities, combined with support from secondary literature sources. My perspective is one individual's experience as a lesbian woman who has been a full-time caregiver. It is time for me to take that experience as a lesbian feminist woman and work toward ensuring that the lives of lesbian women continue to be a topic that will be developed as an area of research, that, over time, will include different areas of concern of older lesbian women. This thesis is a contribution to a body of work that has not adequately explored issues and concerns on this topic.

This analysis allows for a less rigid way of thinking about the connections between the personal and the public. This approach enables the inclusion of the voices of older lesbian women without actually doing in-depth personal interviews. It is difficult to find and do research on older lesbian women who are caregivers. Many of these women remain invisible due to homophobia

experienced by them; some are simply consumed with the tasks of caregiving. It was not possible to set about finding a group of women to interview for this thesis. In addition, even if I had been able to locate women who are older, lesbian, and caregivers, I needed first to more deeply understand my own experience. Thus, by using literature to bring a qualitative approach to the hidden voices of lesbian women and their invisibility, I include differing perspectives connected to the lesbian's caregiving role.

To give the broadest range possible in exploring whether or not sexual orientation has impacted in either a negative or positive way on the lives of lesbian women as they age, and in their roles as caregivers, the literature is both academic and non-academic. Questions I explore include: has getting older had any effect on their lives as lesbian women who are also caregivers or has their experience as caregivers remained the same? Are there any specific differences between each decade in the lives of older lesbian women in relation to various issues of concern with regard to their experiences as caregivers?

The focus of this thesis is not to suggest that there are not other groups that struggle with issues that bear some similarities to lesbian women's concerns, such as age, sex, sexuality, race, intimacy issues, disabilities, education, resources, and economics. However, the concerns and issues of older lesbian women are complex and multi-layered and not always easy to examine closely when looking solely through the lens of those who are

caregivers. Availability of, and accessibility to, current data to compare it from the past remains a challenge. Even the most current research relies on secondary sources that were published over a decade ago, or on very limited samples that cannot, in many ways, reflect the realities of the lives of lesbian women who are informal, unpaid caregivers. The lack of material on this large group of women points to a need to do current research that focuses in on the specific needs, concerns and impacts on the lives of these women and fills in some invisible areas of lesbian women's lives.

I am also interested in examining how various issues may be used to influence policies that can have an effect on the lives, and the rights, of older lesbian women who are or have been, caregivers. Such policies include: Survivor's Pensions; Canada Health Act; Property Acts; Matrimonial Act; Medicare; Old Age Pension; Canada Pension; Long Term Care Policies; Policies in Aging Organizations. Any of the aboved mentioned policies can be connected to older lesbian women's experience as caregivers, their ability to live their lives openly with freedom and equality, as open lesbians and sexual beings, as well as to adapt well to the aging process while living in socially constructed roles as caregivers. My search for resources on lesbian aging experiences that have examined the issues that surround older lesbian women who are caregivers for partners, siblings and elderly parents, has provided some insight into what is needed. Due to the lack of actual academic sources on the specific experiences

of older lesbian women as caregivers, I also incorporate some issues on aging that are interlinked with what has already been mentioned, such as available financial resources, community networking resources and accessibility to community. Issues and concerns related to the caregiving experience are underrepresented and are understudied; what little there is does not explore in depth the wide range of concerns and issues of older lesbian caregivers or the complexities and the multi-layered experiences that affect the quality of their lives as lesbian caregivers. While exploring this topic and the issues of concern for older lesbians, the meaning of community for some lesbian women caregivers surfaces. I explore where lesbian women will fit within the community infrastructures that are available to them as they grow older. Where will they go when their role as an unpaid informal caregiver is over, either from the death of those they were caring for, or because their loved one has now moved into a long term care facility in the communities in which they live? How are they supposed to be able to afford such a luxury as retirement when, as in my case, there has been no opportunity for much paid work or resources to put into savings such as RRSPS, GICS, Canada Savings Bonds, etc. for almost the entire length of my potential productive years in the paid labor force. There is no pension plan for the unpaid caregiver; if there were I would have a twenty-one year pension as part of my income.

Purposes of this Study

The purposes of my research are as follows: to increase knowledge about what issues are of importance to at least some lesbian women caregivers and their families; to raise an awareness of the exclusion that exists within the LGBTQ community and the straight community with regard to the needs of the older lesbian woman; to point out some of the isolation that exists for older lesbian women caregivers, due to the sometimes forced invisibility of this large group; to point out the lack of representation of older lesbian women who are caregivers in the area of research and education; and to conduct research on some of the barriers, obstacles, stereotypes, discrimination, and oppression that some older lesbians face as they age and are caregivers.

Aging and sexism affect all women but it is not possible for me to examine here the differences between different groups of women. There is of course the possibility at a later date of a more in-depth study of the experiences of lesbian women caregivers as they age, before and beyond the retirement years that may or may not still include caregiving. Another important aspect of future research could include using no minimum level age, because the role of caregiving begins and ends at different stages of life development for women in many different groups, who may or may not be lesbian. Yet another important research project could include a wide range of experience related to the aging process as well as the caregiving process for both straight and lesbian women of

different countries, racial backgrounds, economic backgrounds, age ranges, gender transitions, religious backgrounds, etc. So little has been done thus far that the research possibilities are seemingly endless.

If the results of research are to accurately reflect the reality of the lives of the participants, or those who may not have been included as participants, presumptions and assumptions about how lesbian caregivers live their lives must change to more adequately and accurately reflect their lives. It is important to remove the notion of accepting lesbian women through providing what, at times, amounts to nothing more than superficial tolerance. Older lesbian women caregivers in research studies and mainstream society are often lumped together with all women due to commonalities such as gender, as a supposedly viable alternative to providing equality and equal opportunity to have their own voices heard. For this marginalized group, the merging of the older lesbian women's experience as caregivers with the rest of the female population who are traditionally seen as caregivers, helps to entrench their invisibility and quell their stories, experiences and voices. As a lesbian researcher who has been a full-time caregiver, I include perspectives on caregiving by and for older lesbian women who offer me a glimpse into lives that are rich with experience, courage, strength and knowledge that has not always been part of my own.

Importance of This Research

The style of research in this project allows for limited movement within the scope of the topic due to the fact that the research can only go as far as the literature and the autobiographical data examined allowed. This type of project may not allow for much closure; it may only provide the reader with more questions about which to inquire. While at times frustrating to see the negative aspects of this type of research, in such research it is possible to see where the problems lie in discussing the experiences of older lesbian women caregivers outside traditional research arenas.

I have examined how research is conducted by using the literature base as evidence of what is being done and what is being missed or ignored. Some of the problems seem to lie with researchers not looking more closely at issues related to class, sexuality, passion, intimacy, age, race, and educational, economic and ethnic differences facing older lesbian women who are caregivers. All of the personal accounts that I have read of the experiences of older lesbian women, and the autobiographical analysis of portions of my own life, have raised very different concerns and issues from those of their/our female heterosexual counterparts.

The differences in the issues raised help to point out the danger in generalizing about an entire gender or sexual identity or orientation. In this regard, it is also important to note that not all lesbian women identify as lesbian;

some identify as gay; some as queer; some as woman identified; others prefer no labels for their intimate love of other women. There are also those who are making the transition from being male to being female who identify as lesbian, and/or who have chosen other women as their sexual and life partners.

Each personal account of older lesbian women differs with respect to how education, social connections, employment, health, caregiving, and sexuality affect the process of being a caregiver, of growing older and aging, and the life satisfaction of lesbian women. Many of the pieces of literature examined for this thesis discussed issues related to sexism, agism, homophobia, and the lack of role models for older lesbian women who are caregivers, as shaping how they responded to the role of being a caregiver. It is also important to note that just because one is a lesbian or gay researcher does not automatically exclude the possibility of being exposed to or trained to do research in a traditional manner that can be full of bias and often tends to exclude people.

Change in any part of a lesbian woman's life can be positive or negative; it can be easy or difficult. The lesbian woman of color who is in a caregiving role has different forms of oppression and discrimination to deal with than white lesbian women caregivers. There are different obstacles and barriers that face lesbians with disabilities who are caregivers. In addition, there is the prejudice related to growing older and aging, true for all women, including older lesbian women caregivers. Assumptions and presumptions about their lives is one of

the worst problems facing lesbians who are caregivers. Nevertheless, some or many of the lesbian women I know accept and honor their sexuality and have taken on the risks of either coming out or staying in the closet before and during the process and journey of being a caregiver.

The question still remains, why not come out and be heard? For some older lesbian women there are risks of rejection and isolation from family, friends and peers, as well as fear of hostility, anger of others towards those who are being cared for, and/or a fear of discrimination, oppression and homophobia. While in the role of caregiver, much of a lesbian's identity as a lesbian can be repressed and hidden to appease others in the picture while functioning in a traditionally maternal role as the caregiver. It is important to see the value in this research, as it leads to exploration of others and of the self, and how a caregiver's sexuality and sexual orientation has an impact on how well she does in the role of the caregiver and her connections to others. I see folding in or including my experiences as a lesbian caregiver within this thesis as a way to add emotion, feeling, experience, and personal knowledge as valuable research tools to explore this topic in an academic way.

As has been pointed out, older lesbians come from eras in which there were few role models or supports in place in society to assist them on their journeys as caregivers, or in the aging process for that matter. Today it appears to be a little easier for the younger lesbian woman to express who she is as both

a woman and lesbian. In times past, the old woman, the crone and the witch have been valued in many cultures. Today, many previously positive images and representations of older women have been twisted and perverted to make valueless the process of aging and the role of women in society, including their roles as caregiver. It is time to develop a culture of respect and an admiration for the older lesbian woman who has had to make a life, in many instances in the shadows. We need to bring these lives into the light, to be presented as a positive and empowered way of living. My aim has been to try and end the silence, to bring the value of such roles forward and to move away from the assumption that there is a single mode of expressing lesbian identity, younger or older. It is the hope that this project will stimulate further research in the lives of more lesbian women caregivers and their families.

Academic writing and reading practices have to include new styles and methodologies to analyze the social construction of the lesbian woman's identity, her female identity, her female sexuality, and finally the lesbian woman caregivers' identity, that points to this being a multi-layered/multi-faceted topic that goes through stages. One does not just become a caregiver who happens to be a lesbian; we are constructed by the society, culture and community in which we are born.

Theoretical Framework: Using autobiography

The theoretical considerations for this thesis are connected directly to the methodology because much of the research for this thesis is textualized.

Brookes (1992) states that...

From my understanding of feminist perspectives, I view myself as both the subject of this text and the subject producing it. In naming myself as the subjective self producing this work, I theocratically shift from a truth perspective to one which I hope readers (and me) to see me as a producer and maker of knowledge. From this perspective, I am beginning to better understand the concept of knowledge socially constructed. I can also better appreciate the importance of autobiography as method. In other words, until I understood myself as a producer of knowledge, I could not consciously or politically analyze, from a perspective of power, the male-construction of this society (p.48).

I am building on Brookes' work to analyze and examine how lesbian women are constructed as caregivers and how we present ourselves everyday in a western culture that is so strongly influenced by a patriarchal structure. I also utilize Brookes' concept of the subjective self producing work. I analyze the/my self; in a male constructed society, women are people shaped by their social world and in turn, the social world shapes and produces the people in society. Every individual is influenced daily, minute by minute, by their interaction with others. Our presentation of self is accomplished through speech, action, appearance; others' responses are governed in fact by their knowledge of the social world and the interpretation of us is done through the image they have of us (Leighteizer, 1992). It is with this notion that I come to look at a lesbian caregiver and explore the shaping and construction of the lesbian, of the woman,

of aging, and of the caregiver. In the next chapter, I review some of the literature as connects to this work.

Chapter Three: Literature and Discussion

In this chapter I explore literature of various kinds, dealing first with aspects of the aging process for lesbians, to give a foundation and support for this type of research. I then discuss briefly work on the connected research topic on older lesbian women, which is in no way meant to imply that all lesbians who are caregivers are older. It is important to note that while I was able to find literature on older lesbians and make connections to the caregiving process from this group for this thesis, it was not possible to find literature on younger lesbian women who are also caregivers. In fact, after utilizing an autobiographical approach to this thesis, I now contend that lesbian women caregivers are constructed and evolve over time and the point at which they become caregivers and enter, leave and re-enter into that role varies over time and different age ranges. Due to my own age range and others that I have shared similar experiences with, the exploration and examination of older lesbian women's experiences of aging is relevant for this project. I explored the experiences and issues that can affect the quality of life that older lesbian women may have as they age and develop, and how those experiences are connected to the caregiving process.

I have chosen to focus on an area which is of personal interest to me: the relationship between growing older and the caregiving role for lesbian women. Much of how a lesbian woman caregiver relates to the role of the

caregiver is directly connected to her past: how she develops and grows and ages over time, and how those who have come before have dealt with the challenges of aging, health, money, love, and sexuality which, in some cases, have many issues that parallel the caregiving process. Due to a lack of research and literature in the past on this topic and the issues connected to it, I have chosen to search the related area of lesbian aging to examine some of the connections to the caregiving role and process. This literature analysis will not be focused on any particular aspect of older lesbian women's experience as we age, but rather will help to provide a foundation and a place in which to build some explanations of the ways in which a lesbian woman can come to the role of the informal and unpaid caregiver. It covers a broad area of different facets of the older as well as the younger lesbian woman's experience connected to major life events as she moves toward the stages in her life that may include children, coming out, work, school (university, college etc), retirement and other major changes that are affected by many of the other life experiences of the lesbian woman.

What experiences contribute to enjoyment, fulfillment, health and happiness in the lives of older lesbian women who are caregivers? The lesbian experience has been explored in different ways in a body of research that has spanned several decades. However, many of the articles, books, magazines, films, and gay and lesbian community resources indicate that the experience of

lesbian women as caregivers while younger and when we grow older is still excluded, underrepresented and distorted. Often it is also left out of consideration in research that is currently being done, or is simply included as an add on to the project and is not the main focus of the research in studies that explore the caregiving question. For example, in the much needed study “Caregiver Portraits: Narratives of 14 Women Caregivers in Nova Scotia”, (Beagan, 2005) a research project conducted in Halifax , Nova Scotia, an effort was made to include women that are often excluded from research studies in the area related to caregiving. The study was a small one which did include the portraits of two or three lesbian women caregivers; the importance here is that the study was done but the study’s main focus was not specifically about the lesbian caregiving experience. This is not in any way to take away from the importance and value of such a study but to point to a need for research on lesbian women’s experience as caregivers.

After I came out as a lesbian and finally left the small town I lived in and moved to Halifax, Nova Scotia, I had to deal with not being part of what is traditionally known as mainstream society. I found it difficult, as a lesbian woman, being silenced within the patriarchal structures placed within the context of the gay and straight communities in which I had lived before and after I moved away from the small town I grew up in. This is not to suggest that all LGBTQ and heterosexual communities are the same. In this chapter I look at work in

and out of the lesbian and gay community for how 'equality' is experienced by the lesbian who is older and also a caregiver.

For lesbian women in their forties and beyond there are challenges and considerations in family relationships, sexual relationships, friendships, and professional relationships that are not always faced by younger members of LGBTQ communities in the same way. These challenges are affected by the critical component of our sexual orientation, which affects all aspects of our lives and well being as we journey through different stages of life. As I approached my forties I found myself seeking out the lesbian community more and more, only to find that such a community does not appear to exist in a form that I could easily identify or access as a lesbian woman whose life is filled with her role as a full-time caregiver. I know from personal experience as an individual lesbian woman, it can be difficult to access information and a support network to become part of a lesbian community, which at times appears to have a certain amount of fluidity and norms which are not fixed or rigid, and is part of a much larger group of the rainbow community. Therefore, gathering evidence to develop a theoretical question is a somewhat daunting task which at times has been both frustrating and rewarding. The fact that a topic of this kind poses many challenges does not dissuade me from trying to research that which has often been ignored or dismissed in traditional academic research.

Time lines, previous time periods in the LGBTQ movement and within mainstream culture, are important, as is the question of how life was for lesbians in a different time and place in our culture and society. Coming from such different time periods could affect the outcome of the quality of life of an older lesbian woman who has been molded into the informal unpaid caregiver. It is important to consider material that was written many years ago in order to assess the life experiences of those lesbian women caregivers who are now older. It is important to consider the chronology of various decades of older lesbian women's lives due to the significant changes that appear to take place in these lives that may be altered with each passing decade. Connecting to chapter two, the importance of sequential experiences from different time periods of my life, reflect and expose the construction of me from the "self" to become the lesbian caregiver.

The experience of the older lesbian woman has also often been ignored, even when there has been a consideration of the lesbian woman as a whole and all of her experiences, including being a caregiver. Growing older is a major event in all women's lives; the experiences we have as lesbian caregivers may be a critical component in how well older lesbian women are able to make the transition to old age in a positive and empowering way that leaves them happy, healthy, and fulfilled. Aging affects all women, lesbian, bisexual and straight, but there are concerns that are specific to lesbian and bisexual women. Due to

experiences that relate to sexual orientation that may have been negative, many older lesbian women choose to remain in the closet to protect themselves and their loved ones from discrimination arising from their sexual orientation. This decision may have a huge impact on the caregiving role that we have taken on.

Older lesbian women's experiences appear to be invisible and continue to be excluded from study, which points in part to relevance for my study. While the experience of aging for lesbian women is different from the role and process that lesbian women may have as caregivers, it does not escape notice that there are similarities for comparison and discussion on lesbian caregiving. Is the invisibility of both of these groups related to the ignorance and indifference of the research community or does it have more to do with the fact that many lesbian caregivers are also older lesbian women who may not want to be visible, coupled with a lack of willingness to be out of the closet? Where the study of older lesbians is concerned, issues related to sexism, agism and homophobia still remain, which are also relevant to lesbian women who are caregivers, many of whom are older women now. Auger (1990) states that

In the feminist academic press there is little or no mention of lesbian elders, and the gerontological world seems oblivious to the sexuality of old people in general, let alone that of old lesbians. When articles on sexuality do appear in noted journals like *The Gerontologist*, they are about heterosexual practices or, and these are rare occurrences, homosexual men. Lesbians who are old are thus in triple jeopardy, as they represent at least three groups in North American culture. They are not young, they do not enjoy the privilege of patriarchal masculinity, and they do not receive the social rewards of heterosexuality. Those who are not white suffer

yet another stigma, as do those who are differently abled. The demographics of aging reveal that some 11 percent of Canadian people are sixty-five and older. Of this group, 58 percent are female. Using Masters and Johnson and Kinsey reports on sexuality, we can conservatively assume that one in ten of these women are lesbian. Theoretically, we are speaking of some 156,000 women aged over sixty-five (pp.25-26).

While the figures have probably changed since Auger's article was written, they will have only increased. Canada's demographics are shifting; in the past fifteen years, a larger percentage of our population has become older. Of this percentage a good many of those individuals are also in the role of caregiver. If one also includes older lesbian women mentioned in some of the other categories that Auger pointed out, older lesbian women in current and past academic research would be underrepresented in the extreme. An American study by Cahill, South, Spade (2000) titled *Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual, And Transgender Elders*, indicates that

One to three million Americans over 65 is gay, lesbian, bisexual, or transgender. The number and proportion of GLBT elders will increase significantly over the next few decades, along with the over all elder population. By 2030, one in five Americans will be 65 or older. Roughly four million of these will be gay, lesbian, bisexual or transgender (p.1).

In Canada it is possible to estimate that the percentages would be comparable in relation to geographical population bases. If we assume these figures to be close to being accurate then it is also safe to assume that a large percentage of the LGBTQ community will be caregivers of partners, friends, siblings or elderly parents. A portion of this group will be lesbian women who are

younger but a good percentage will be older. The aim of this research has been in part to try and build on previous work such as Auger's, to resist the pressures of mainstream society and culture as well as academia to keep the older lesbian women's voices quiet, closeted and invisible, and not to be lumped in with and swallowed up by a much larger group. My desire has been to put forth in this chapter more empowerment for LGBTQ liberation by encouraging unity in the lesbian and gay community, and by hoping to educate those in the straight community, as well as inform those in both communities that this kind of exclusion and segregation still exist. I want to educate and inform as well as promote my own desire for liberty and dignity in the mainstream straight communities as well as LGBTQ communities.

Older lesbian women's concerns and issues are complex and multi-layered, and it is not always easy to examine closely some of those concerns that are tied to similar issues and concerns for older lesbian women who are caregivers, and how these experiences shape the quality of that role. Kehoe (1989) states that

It is not surprising, given the general climate of homophobia of this earlier era, which so many older lesbians were and have remained deeply closeted. A 74-year-old who grew up in a small southern town reflected: I have no regrets about my life long designation as a lesbian, but did experience years of unhappiness when I had to live in the closet because of it and forced myself to pretend to heterosexuality in my social and sexual relationships when within me, emotionally and physically, none existed. That is one of the cruelties of the homosexual's lot in our society, and it represents to

me all those miserable years which now in my old age can no longer hurt me, now that it is too late to matter (pp.21-22).

Even though Kehoe's study was conducted in 1989, it remains a critical piece of research which examines the lives of older lesbian women. Many lesbian women who are caregivers like me reflect similar realities. One older lesbian woman's reflections are not enough to make assumptions about the state or experience of all older lesbian women's lives who became caregivers, but this reflection does bring to light some of the concerns associated with isolation and being in the closet and how such isolation can affect the quality of the caregiving experience. We also cannot assume that just because we have moved into the new millennium that the concerns raised in Kehoe's piece are not still relevant today. Issues related to sexual identification and the coming out process later in life, as well as economic concerns, social networks, services and resources, and community remain as important concerns in the year 2007. It is my hope that a more comprehensive study of current research will assist in painting a clearer picture of the experiences of older lesbian women today. Research like Kehoe's reminds us that there are many areas of concern to consider with regard to the older lesbian women's retirement years.

How does growing older affect the quality of life and life satisfaction for the older lesbian woman who is a caregiver? The issue of aging affects women in all societies and in every culture because all women face changes as they age, but what impact does caregiving have on this process? Are these changes

different, better or worse for the older lesbian woman? Where is the information for older lesbian women that may be of interest to their particular needs if they are caregiving as well? Where is the support within the lesbian and gay community that is specifically geared towards quality of life issues for the older lesbian woman caregiver? More questions than answers seem to appear when this topic is explored.

Another consideration of this research is to look before and beyond the older years to advanced aging, and explore what happens to older lesbian women after they leave the workforce and grow older, eventually become elderly and also have to contend with their role as caregivers. It is also important to take a closer look at issues for older lesbian women that surround issues related to caregiving for sick and aging partners, of elderly parents, or others; issues related to available financial or community networking resources and accessibility to community within both the lesbian community as well as the straight community.

While exploring this topic I had hoped that the meaning of community for some older lesbian women would surface, as well as showing where these women fit and want to fit within either the mainstream community or the LGBTQ community infrastructures that are available to older lesbians after they retire. The discussion has provided some reflection on the types of care and services needed and what is available right now for older lesbian women who are already

retired and for those who will retire in the near future. I want to place some emphasis on the problems that may exist within the lesbian community that may affect the quality of the life experience for older lesbian women. It is also important to place some focus outside of that community and delve into issues that exist within the mainstream communities for some older lesbian women who live outside the lesbian community.

Many older lesbian women remain in the closet and as a result live what appear to be lives similar to heterosexual women in mainstream society, a perception that can and does affect the role of a lesbian woman caregiver. Many of my earliest memories are of being a caregiver and being a lesbian, including living in the closet out of sight and invisible to my true "self". Living life not connected to the lesbian and gay community can have a negative impact on the quality of the lesbian caregiving experience as well as the quality of growing older and the aging process. I examined and analyzed some problems that older lesbian caregivers may face while living within lesbian and gay communities, problems such as: isolation, rejection, fear, violence, discrimination and homophobia based on gender and age as well as sexual orientation, in connection with my own experience as a lesbian caregiver. I say lesbian and gay community with the intention of pointing out the lack of visible representation of older lesbian women who are also caregivers, in what is considered by mainstream society to be a singular community with both lesbians and their gay

male counterparts living in one largely connected unified sub-culture. As further discussion and observations will reveal, this is not always the case and does tend to have in some cases a negative impact on the quality of life a lesbian can have. The success of one group within such a labeled sub-culture does not mean the success of other groups within such a sub-culture, as observations and the literature for this thesis indicate.

It is not yet clear at what point in Canada resources and social networks became available for older lesbian women. Some of the earliest known social and support networks were in the United States. Kehoe (1989) indicates that

It was not until 1955, with the founding of the Daughters of Bilitis (DOB) in San Francisco, that lesbians had an alternative social outlet to the gay bars, which by then had become more dangerous places to frequent for the sake of one's career. In the mid-1950s *The Ladder* began publication, providing for the first time a magazine exclusively for lesbians. It provided information and education that brought awareness and insight to many, especially those on the West and East coasts, where chapters of DOB were being established and moving the organization into an activist middle-class position (p.21).

Further, Sharon Deevey (1990) discusses a study that gathered information about older lesbian women's experience:

The Mail survey combined Almvig's questionnaire on lesbian life experiences and Muhenkamp's Personal Lifestyle Questionnaire (about health behaviors): 142 copies were distributed by "snowball sampling". Older lesbian women were located by letters to the researcher's personal network, an advertisement in Golden Threads (an over 50 lesbian correspondence club newsletter). Flyers distributed at a national Old Lesbian Conference, and a request for participation at the Over-Forty tent at the Michigan Women's Music Festival (p. 21).

Deevey's article points out those researchers in the United States had access to a certain number of resources with which to do research on lesbian women's experience of growing older. It is important to note that accessibility to resources of this kind was in the late 1980s and early 1990s. This could be placed in the literature review, but it is important to illustrate some of the difficulty that older lesbian women have had in even finding a place to belong, in either the lesbian or gay community or in mainstream community or culture. Do the same problems remain after so much time has passed?

In this thesis I briefly explored some of the risk factors for lesbian women after they reach retirement age, in their new role as older or even elderly women that may exist before, during or after their experience as caregivers. I have considered these new roles along with the other issues and concerns that have been mentioned within the scope of the literature examined for this paper, including the following: 1) Why are so many older lesbian women hidden from the lesbian community as well as from academic research on growing older? 2) What should be done to eliminate the invisibility of these older lesbian women who are also in the role of the caregiver? 3) What are some of the risk factors in experiencing a "quadruple jeopardy", that is being old, a woman, a lesbian and a caregiver? 4) How do intergenerational attitudes affect the forms of support available for the older lesbian woman caregiver as she ages? 5) Do older lesbian women deal with homophobic attitudes from mainstream culture and

society that affect growing older and the aging process for these women if they can retire not only from the paid workforce but also as caregivers? 6) Is it ever really possible to retire from the role and status of being a lesbian caregiver? While there are not always clear answers available for these questions, they inform both my reading and this writing.

As mentioned above, older lesbians face numerous problems and deal with many issues that surround their sexual orientation. Lesbians can face homophobia, discrimination and violence especially as they grow older; they may also have to deal with the "triple jeopardy" of ageism, homophobia and sexism. Add on the issues associated with the role of being a caregiver, and the issues become ever more complex. These issues can create invisibility for a large group of women who live in many communities all across Canada and the United States. There appears to be a kind of ignorance that seems to prevail in Western culture that continues to help perpetuate the myths and stereotypes that surround the aging, older lesbian woman. There is complexity with regard to dealing with the issues that surround women who choose not to take advantage of patriarchal or heterosexual privilege. Lesbians who are not willing to be part of what is still considered, in many ways, the only normal way of living as a woman, who are sexual beings with sexual identities that do not include male partners, pose many challenges for the society and culture in which they live. These problems are intensified when we add on the role of the caregiver

and the perceptions of what the caregiving role can mean to a lesbian woman in what is considered a traditional, motherly, feminine, maternal and nurturing role for “straight” women.

In attempting a critical analysis of some of the issues that surround older lesbian women caregivers as they grow older and work towards trying to retire, it is important to note that many older lesbian women's voices that should be heard will not be heard in this thesis. Many of those women remain shut off from the rest of the world by choice, by force, or by fear. It is up to each of us as individuals to decide what may be the reason for this and to focus on what is important and to consider it in this piece of work. This is why I felt it important to observe what it may appear to be like for other older lesbian women caregivers. I went to Toronto, one of Canada's largest LGBTQ communities, to experience on some level, what is accessible and what is not for older lesbian women who may also be in the caregiving role and why some of these older lesbian women may remain shut off from the rest of the world. I also wanted to examine how supportive, open and available resources could be for older lesbian women in a large urban LGBTQ community. Further in this thesis, I share my observations of a trip to Toronto, Canada, and to a conference in the United States, where I discovered that there are few representations of my life as an older lesbian who is also a caregiver.

Services, Resources and Social Issues

It is important in research, social programs, health care programs and education to consider older lesbian caregivers' lifestyle and the environment in which we choose to live. These issues further complicate the caregiving role, process, and journey. Kerner (1995) points to the issues related to the very real health concerns that older lesbians continue to face as they age and asks about "... the stone butch who can't deal with having her breasts touched and who can't deal with having a vaginal exam?" (p.314). It is important for any researcher to recognize that many older lesbian women who are also caregivers can have different issues to contend with; how they are approached with regard to their lives and their sexuality has to be openly discussed with respect for the variations in these lesbian women's lives.

Another article by Auger (1992), "Living in the Margins: Lesbian Aging" points out that, with regard to research and different institutions created and maintained by a largely homophobic society

Research, as well as everyday life suggests that some older lesbians, believing in rigid sex roles (the so-called "butch" and "femme"), identify more with heterosexual men than with feminist lesbians. *Some older lesbians feel themselves judged by their feminist sisters on this issue* (p.367).

Health care and research issues, programs, articles, papers, information and education have to reflect a more accurate picture of the lives of older lesbian women who are caregivers from their own point of view. These lesbian

women caregivers' realities can vary a great deal from the medical and health care systems' perceptions and presumptions of lives that are largely invisible to those connected to such systems.

Auger discussed issues related to discrimination within the lesbian community; but what about discrimination within other communities, such as the medical or health care community or system? Linda E. Noyes, RN, (1982) wrote an article "Gray and Gay" about the type of care health care professionals provide lesbian women. The type of health care lesbian women who are caregivers can and do receive, impacts on the process and journey in the role of being a lesbian caregiver. Noyes makes several points of interest. For example, she discusses the reality of such a system labeling older lesbians and gays with certain characteristics, which can lead to different forms of discrimination and homophobia. Her article also points out the problem that, until 1973, homosexuality was considered a mental illness; some of this perception remains today within the medical and health care system. This article points out the importance of research acknowledging the role of the researcher and research in general to dispel myths and stereotypes, in this case about older lesbian women who are also caregiving. Another important point that Noyes refers to is the notion that, based on some studies "... 'old age' in the gay community seems to begin at a much earlier chronologic age. Many previous studies regarding age and homosexuals have grouped subjects between the ages of forty to forty-

six as 'old' "(p.637). The perception of growing older and old age outside as well as within the LGBTQ community offers numerous barriers to the lesbian woman who is older or elderly and caregiving, when she might possibly lose the only acceptable status she may have had while in the 'paid' work world. The unpaid work world of caregiving is not considered. When lesbians move towards their older years, it is becoming apparent that they will be faced with discrimination on several fronts, along with all that comes with being a caregiver.

Charity V. Schoonmaker's article (1993) "Aging Lesbians: Bearing the Burden of Triple Shame", describes her experiences as an older lesbian woman in 1993.

...I am writing this article under a pseudonym. To do otherwise would mean that I would not feel safe enough to tell my personal story for fear of reprisal. I want to tell my story to illustrate what it is like to be an aging lesbian in this society today. What I feel today is the result of what my yesterdays were like (p.21).

Her description gives a clear message that even today in this so called modern society and culture, an older lesbian woman who is a caregiver often still hides in fear of discovery and what such discovery may mean to those she is caring for. This author is a professional woman with the apparent privilege that money and education seems to afford those able to obtain it. Yet her life as an older lesbian woman is one of multiple layers of oppression. As a lesbian caregiver I have none of those privileges; living in poverty often over-shadows knowledge as does working as an unpaid caregiver for over twenty years. The

levels of oppression and discrimination in these circumstances are often intensified. Schoonmaker writes:

After spending two-thirds of my life learning to deal with the internalized shame of being both a woman and lesbian, I am very tired of being invisible and unimportant. The negative stereotypes used against the old feel just like those against women and lesbians, hurtful, patronizing, demanding, objectifying, dehumanizing, and cruel. I wonder what my fate will be in the hands of a society which considers everything, even its people disposable (p.29).

If an older lesbian woman in this position feels this way, how do all the older lesbian women who are also living as caregivers who have no visible means of voicing their experiences feel? How does it reflect on their ability to express who they are in a world that does not include literary expression? It is apparent that much needs to be done to change this intolerance toward such a large group of the population.

Health considerations, age differences between partners, and roles for older lesbian women caregivers are also concerns that, as a researcher, I had not taken into consideration before. Jeanne Adleman (1995) points out many of these concerns in the article "We Never Promised You Role Models".

Adleman indicates that there are many concerns for older lesbian women who have partners younger than themselves. At a conference on significant age differences, Adleman discusses some of the concerns and issues:

For a long time, almost the only concern the mainly young and midlife participants voiced was fear of taking care of a partner in her late years. Then I pointed out that older partners have no

monopoly on sickness, surgery, convalescence, or even death. We who are older also risk becoming caretakers of younger partners, who may experience health problems we ourselves have long ago surmounted. Moreover, even age similar partners risk future caregiving in times of need (p.88).

It is true that younger lesbian women may have the gift of youth and so called vitality and boundless energy. Or do they? In my later years as a lesbian caregiver a great deal of time, energy, strength have been given to me from my much older partner in helping to care for my mother and now for me in my own failing health. It is not all that it seems, particularly for the older lesbian woman dealing not only with the aging process but also with the impact of her role in the caregiving process. For older lesbian women, the role of caregiver is a very real concern and reality. Some older lesbian women may also have the role of caregiver for an elderly parent as well as that of a younger or older partner. Caregiving can become a very big part of older lesbian women's lives and affect the quality of the older and elderly years that they may have.

Baba Cooper (1988) wrote "Over The Hill: Reflections on Agism Between Women" in which she discussed the experience of growing old in women and points out that the experience varies from woman to woman. She also discusses the silence of agism in the women's movement and among professionals who may serve these women as they get older. Cooper's writing also indicates that there is a large industry in society that makes huge amounts of money on women over sixty.

This information helps to point out some of the critical problems that some lesbian women may face as they get older. Many older lesbian women who are caregivers have to carefully dish out their hard earned money for services and programs in communities that may in fact refuse to acknowledge who they are as older lesbian women and as caregivers, requiring services, information and resources that take into consideration their identities as older lesbians who are caregivers. Cooper's work also delves into the issues that are related to intergenerational concerns for older lesbian women, by looking beyond retirement, acknowledging that a lesbian caregiver who is leaving the paid workforce could still be very much in the role of the caregiver as well. Cooper discusses problems that exist within both the lesbian and straight communities for older lesbian women. She points out that it may be necessary for older lesbian women to relinquish their need to get services from women other than themselves, as they did when they were younger as a minority group and banded together for support and comfort.

Cooper indicates that the notion of expecting older women who are often also in the caregiving role to provide some sort of understood service to the younger generation, can mean that the youth of both lesbian and straight communities have exploitative expectations of the older women (p.25). This notion may help to provide some insight into why it is so difficult for older lesbian women who are caregivers to bridge the gap between themselves and younger

lesbian women who are often not in the caregiving role. It may be related to assumptions and presumptions about the type of expectations that each generation has of the other. These assumptions may affect the type of quality and kinds of services and resources that are offered in and outside the LGBTQ community.

Do our attitudes towards youth affect our perceptions of aging when, as lesbian women, we go beyond our older years and become elderly? Cooper (1988) also makes interesting points about the treatment of older lesbian women, both inside and outside of what she terms the lesbian world:

How do old lesbians want to be treated within the lesbian world? This is difficult to say. There is a kind of care we take with women we wish to know. We give them our attention. We make allowances for their peculiarities. We monitor our own behavior for impositions or assumptions which we cannot justify to ourselves or to them. Caring treatment involves effort and emotional work well invested in the interests of friendships between women (p.33).

Cooper points to a few concepts that may help to illustrate some of the complexities of the needs of older lesbian women that go beyond the scope of my research here. Referring to Cooper's few concepts addresses issues related to how and what kinds of services older lesbian women need or want. Much has to be taken into consideration for those who are in the caregiving role, which can attempt to describe what older lesbian women caregivers want, need and should have with regard to services, programs, social networks, support networks and housing. When doing research on older lesbian women's lives

there are many layers in these women's lives that create barriers and obstacles to getting a true picture of their experiences. There also may be elitism in their own LGBTQ communities which can be related to intergenerational problems, class, race and economic status which can create many sub groups within a community that has already been separated from mainstream society. Therefore it is impossible to generalize about such a diverse group of older lesbian women who are caregivers. Researchers have to move away from stereotypical notions about the similarities of lesbian women when they grow older and age.

Age Gaps and Research Issues

"Lavender and Gray: A Brief Survey of Lesbian and Gay Aging Studies", by Margaret Cruikshank (1991), is an article which points out some of the problems with studying older lesbian and gay people. Cruikshank brings to our attention the problem with gerontologists' awareness of the issues for older lesbians. The article also indicates that some gerontologist researchers are at fault for not bringing issues of older lesbians out in research, if they continue to ignore a large part of the population. This article refers to numerous pieces on the topic of aging for both lesbians and gay men; in the section on women the author makes reference to a piece that refers to some older lesbians as "Lace Curtain Lesbians". In this article such a reference indicates the lack of understanding of different forms of lesbian life and, from Cruikshank's point of view, is a representation of older lesbians who deny they are gay. It also adds to

the foundation of the perception of the caregiver as female, motherly, maternal, nurturing and straight. The demeaning term "lace curtain lesbians" is a way in which to make the notion of the older and still sexual lesbian woman as more acceptable, as does seeing the lesbian caregiver in the same light within a traditional mainstream perception or reality. It is hoped that some women may be more inclined to discuss their relationships if researchers can move away from labels the participants may perceive as threatening or not representative of their lifestyles. It would be important to include extensions of the type of relationships that women have with one another, lesbian and straight (pp.77-79).

In an article by Buffy Dunker (1987) " Aging Lesbians: Observations and Speculations", from her own experience the author discusses the perception that she and other lesbians had of their sexuality when young. The author points out that many of her lesbian peers were young in the 1920s and did not have a clear understanding of what being lesbian meant. Sexuality and discussions of sex were considered taboo. The author also points out that it wasn't until the early seventies when the gay and women's movements grew that some older lesbians felt safe enough to come out (72-75).

Fear from that time period in which these women lived their youth has shaped the way in which they interact with the rest of society and culture. Coming from certain time periods also helps to shape how a lesbian woman reacts and adapts to the role of being a lesbian and a caregiver for part or most

of her life. In "Odd Girls and Twilight Lovers: A History of Lesbian Life in Twentieth-Century America", Lillian Faderman (1991) discusses many facets of lesbian life, including dealing with discrimination and homophobia. As she points out, lesbianism was the love that dare not speak its name; the government and media were on a witch hunt to seek out and expose lesbians and gays.

It was not true, of course, that lesbians during the 1950s invariably paid for their nonconformity through misery, as the pulp novelists said they did. But whatever joy they found had to be procured outside of the mainstream culture, institutions and society and they had to be clandestine about it, in a society that withheld from them blessings it gave freely to all heterosexuals (p.148).

As women, researchers, straight, bisexual, lesbians and human beings we have a responsibility to make visible the invisible. These lost voices of lesbian women need to have space and a place in which as lesbians they feel they have come home to the rest of humanity and are free to express themselves. Among those lost are the voices of lesbian women who face the role of the caregiver, often alone and isolated, and unheard, of which I am one.

Another study of merit that should be discussed is Karen A. Gallagher's (1995) thesis "Centering The Margins: What Can Be learned From Listening To The Voices Of Lesbians Over 55?", in which she discusses her work with a small group of lesbian participants who share in their own voices the experience of growing older and dealing with issues of importance for older lesbian women. As a researcher I noted the importance of letting the stories of older lesbian

women's lives be told in their own words. Through their own words it is possible to gain insight into how individual experiences vary with regard to growing older and being a caregiver. Each story relates a unique personal journey through the aging process as an older lesbian woman. Gallagher places an emphasis on the value of qualitative work versus quantitative research. This work places value on the rich information to be gained from individualized stories of lesbian life from an individual perspective (pp.2-17). From this piece of work I really began to see the merit in utilizing the autobiographical approach in my thesis to explore the topic of growing older for lesbian women and its connections to the lesbian caregiving process for me as an older lesbian. In this thesis it is also important to provide as much information from as many individualized sources as possible that are connected to the lesbian caregiving process. Personal narratives provided me as a researcher with a clearer picture of the reality of the older lesbian woman caregiver's life from the reflections on their own experience of moving towards a time when they are growing older and may also be in the caregiving role.

Adelman (1986) wrote/edited the book "Long Time Passing: Lives of Older Lesbians" that was developed out of a need to do research on growing older and aging for lesbian women. The author/editor of this groundbreaking research decided it was important to give voices and names to some of the

women who provided some information on lesbian women as they grew older and aged. Adelman wrote that

...what is unique about the aging process of lesbians is the stigma and the discrimination we face and the repertoire of creative solutions that we develop to cope with it. The histories of the women in this book tell the story of the building of our community upon a foundation of such creative coping. They describe what it was like to be lesbian in the pre-World War II era, when marriage was the only socially and practically viable option for women; when few jobs were open to women; when moving about as a single woman was in itself both unacceptable and difficult (p.12).

As has been previously discussed by other authors in this review, many older lesbians' lives are shrouded in silence and invisibility, as are lesbians who are caregivers. This book gave me insight into how a lesbian woman in part is constructed to become the caregiver that I eventually became. A lot depended on when and where you grew up. It is apparent to me that as a lesbian woman I had few options available to me growing up in a small town where marriage seemed to be the only option for me, as there were few jobs or opportunities. This book provided much needed background information into what life was like for lesbian women in past decades that are now approaching their older years or are elderly and also in the caregiving role. As a researcher and an older lesbian caregiver it gives me some understanding of why there is reluctance on the part of some older lesbian women to come out of the closet and be heard and tell their stories and experiences.

Another book, written by Barbara Macdonald and Cynthia Rich (1991)

"Look Me In The Eye: Old Women, Aging and Agism", is a good example of the value of information that is provided in the form of personal narratives of the experience of being an older lesbian woman. Written from two older lesbian women's perspectives, this book gives us an intimate view into the lives of two lesbian women as they head into older age caring for and looking after each other. Macdonald's introduction makes a point that speaks volumes with regard to the importance of the continued research on older lesbian women and lesbian women who are caregivers: "... the experience of having the reality of your own life, your joy or your grief, unconfirmed by the reality around you is to know that you are the "other" and that you must somehow chart your own course" (pp.4-5). This reality that she speaks of is the perception about the lives of lesbian women, whether or not they are also in the role of being a caregiver; agism is added to the reality. The notion of homosexuality as separate and apart from the rest of the population is reinforced. This book reminds us of the importance to really listen to the voices of those who are oppressed and discriminated against, by making the research environment a place where there is a sense of community. Macdonald and Rich are not just discussing agism within society in general; their main focus tends to be on the discrimination within the LGBTQ community as well. When discussing the role and status of the older lesbian

caregiver it is important to keep in mind how agism, sexism, racism, and homophobia all make an impact on the caregiving experience for lesbians.

Another article, written in 1986, "A Portrait of the Older Lesbian", by Monika Kehoe, points out that women outnumber men in the over 60s age group. Yet, there are still few studies done on women, or courses in universities that are devoted to the aging process of women; even fewer studies are done on lesbians who are caregivers. Kehoe also points out that some lesbian women make up what she terms a 'hidden subculture', the aging lesbian. This 'hidden subculture' remains separated from the lesbian community and is invisible to mainstream society. This 'hidden subculture' becomes even more hidden and divided when a lesbian woman is also in the role of caregiver, fitting in neither the LGBTQ not in the mainstream straight culture, where little or no value is placed on such a role. She suggests that some of these older lesbian women's invisibility may be related to the masculine structure of the English language, a structure that pervades the medical and health care system where a lesbian caregiver ends up spending a great deal of her time, energy and resources.

Until the last decade, language, and its structure, was often gendered and exclusive to a male perspective and style that would leave out the voices of women and their experiences. Older lesbian women's experience as caregivers would have been far down the list of important research topics, as would issues related directly to being female, including health concerns related to

menopause, lesbian sexuality, aging and coming out later in life, many of which are interconnected and interrelated. The reason why such experiences have little or no value may be connected to the male dominated research field which tends to see many women's issues as unworthy of study.

In "Lesbians: In Canada" Jeanette A. Auger (1990) wrote an article titled "Lesbians and Aging: Triple Trouble or Tremendous Thrill", in which she discusses the issues and concerns around becoming an older lesbian woman. Auger indicates that there are not many images of old lesbian women in Canadian popular culture or anywhere else. I would add there are few if any images of older lesbian caregivers and their experiences. The discussion also points out that lesbian women are thought not to exist within the communities and the society in which they live. This is even more pervasive in the communities that older lesbian caregivers are in, such as the medical or health care communities. Auger also alludes to more difficult concerns related to lack of representation of older lesbian women in feminist press or in the gerontological field of study. This lack of representation is even more apparent with regard to older lesbians who are also caregivers, even though we are seeing a few studies being done on the topic of lesbian caregiving. Most studies that are being done have the lesbian experience of caregiving as a minor portion of their research and the studies. Some of these studies have been mentioned in this thesis. Auger drives home the point that older lesbian women

are disadvantaged three fold: they are not young, do not enjoy heterosexual privilege and do not enjoy patriarchal masculinity, and I would also add they are in the invisible role of the caregiver. Auger is also one of the few authors examined for this thesis who points out that there are also problems associated with not being white or male (p.25).

In the same article Auger also discussed doing research on issues of concern related to older lesbians past retirement years: "Lesbians who are old are hidden or invisible partly because there is a lack of research on them. Also, it is often difficult to identify older 'lesbians' in the first place. For example, in working with and for seniors, I heard about 'possible' older lesbians mostly by accident. Other lesbian women that I have talked to speak of their own isolation within lesbian and heterosexual cultures" (p.26). Auger brings up some very important issues that should be considered when doing this type of research. It is difficult to determine who are older lesbian women and even harder to locate older lesbian caregivers and where a researcher should go to find participants who may be willing to be included in a study on this topic. There is also the related problem of too small a sample that may not include a wide representation of the population in the area in which the study or research is being done. So, how will a researcher be able to access the issues, needs, concerns and wants of older lesbian women after they leave the paid workforce and beyond their roles as caregivers if they have been able to be part of the paid workforce?

Auger also discusses the difficulty with placing labels on the type of lifestyles in which lesbian women live. For instance, she points out that research and everyday life can at times suggest that some older lesbian women believe in rigid sex roles, when in fact older lesbian women can change and evolve with their identity and lifestyles, and many do so with the added burden of being full-time caregivers. Sexuality and sexual identity are not necessarily fixed and can be fluid over a lifetime. The role and identity of the lesbian caregiver is also not fixed and changes constantly and evolves over time. Some of the older lesbian caregivers whose stories form a part of this thesis have indicated that they were previously married and living in traditional heterosexual relationships until they revealed and unveiled their lesbian identities. Understanding how some lesbian women have lived helps to provide some basis for having changes made in services, programs, organizations and institutions regarding the type of help and care that mainstream society provides older lesbian women who are caregivers. Currently, these services are lacking, based on a false perception of these women's realities. Another point that Auger makes indicates that because the older lesbian population is diverse, so are their needs, which includes lesbian women who are caregivers. Lesbian caregivers cannot and should not be lumped into one large generalized group when examining what kinds of needs and issues they have.

In 1982, Raymond Berger wrote several articles as well as an in-depth study on older gay men and lesbian women. His study focused primarily on the aging gay man, but his articles have made some relevant points about older lesbian women as well. In the article "The Unseen Minority: older gays and lesbians", Berger indicates that there is a large portion of the population that is either gay or lesbian. In the article he estimates the percentage of this group as approximately 8%, a figure that translates into over one and three-quarter million in the United States, or, as is pointed out, twice the number of elderly who live in institutions (p.236). I would also contend that such a figure would be much higher if one was to include the bisexual, transgendered, and queer identified members of the rainbow community as well. Berger discusses briefly some of the issues around gaining information on older lesbian women. "If there is a dearth of research on the older male homosexual, even less information exists about the older lesbian" (p.237). Berger's work helps to illustrate how difficult it is to find data on lesbian women as they grow older. I would contend that this helps support my position that the area of study on lesbian caregivers still remains limited to this day. Even with the completion of some studies on lesbian caregivers and a research study into the health of members of the LGBTQ community in Halifax, Nova Scotia, overall there are still large gaps into many issues of concern to lesbian women who are growing older and who are caregivers.

Researchers still have difficulty locating older lesbian caregivers; they tend to socialize in private circles and tend to avoid the public institutions of the gay community, the bars and clubs. Much of their time is consumed by their roles as caregivers. There is some merit in what Berger's article suggests, but there are other possible reasons why older lesbian women are difficult to research. It may be that the so called gay community is far too masculinized and male oriented for older lesbian women. The current mode of some social events and leisure activities may offer little of interest to women the LGBTQ community claims to serve. In some cases, groups, organizations, social events and services can be completely geared towards the gay male's needs. Lesbian women tend to be excluded or are added on as an afterthought in the planning of such resources. When the role of a full-time, informal, unpaid caregiver is included, I would also say that would increase the probability of even higher levels of invisibility because of multiple issues and concerns this group has as lesbian women.

As a caregiver, the level of daily responsibility increases as the needs of the person we are caring for changes. As my mother's health problems escalated so did my level of responsibilities. For example, managing the tasks, chores and work related to just caring for our pets looked like a well formulated battle plan: rise at 6:00am take dogs out, 6:15am bring dogs in, 6:20am put out all dogs' medication and supplements, 6:30am feed dogs, 7:00am begin mum's

daily schedule, which consumed and dominated the rest of my day until well after midnight, every day of the week. This work is not seen, but yet it must be done in order to keep the wheels of the household functioning in order for me to provide my daily contribution to the community and to society. This kind of work is very labor intensive and provides a vital boost to the economy, to culture and society. My life as a caregiver has always looked like this, very rigid and run, ironically, almost in a military like fashion. Every task has a function and a role and it is an intricate component of the whole machine. My life as the 'caregiver' functions like a machine. I am like a machine that requires constant adjustment in order to continue to provide a satisfactory output. When we are full-time caregivers, even our possibilities for informal socializing are cut back; there is no money to hire someone so we can go out; there is the need to be available for care needs; and, of course, there is our own exhaustion.

Sexual Identification and Coming Out

Quam and Whitford (1992) discuss perceptions of older lesbian and gays in "Adaption and age-related expectations of Older Gay and Lesbian Adults", in which the authors point out that

The history of research about older gay men and lesbian women is a short one. Studies of older persons have typically ignored the possibility that respondents may be sexual, or that they may be gay or lesbian. The majority of research about homosexual populations focuses on younger respondents. While both of these exclusions may result from sampling difficulties, societal attitudes towards aging and towards homosexuality play an important role (Minnigerode & Adleman, 1978) (p.367).

Some other factors that may have also been excluded in studies of older aging lesbians and gay men may be issues related to love, intimacy, passion and sexuality, as well as the different types of gender roles and sexual practices of lesbian women, along with the notion that sexuality becomes non-existent as the aging process continues. Older lesbian women who also are caregivers still have many concerns related to sex and sexuality that we had when we were considered younger and very sexually active. We may also have concerns of not being able to be sexual or very sexually active because of the impact of our caregiving responsibilities. Even though many health and sexual issues are faced by heterosexual women who are caregivers, there are other considerations in the case of lesbian women that continue even as we grow older and experience the changing nature of the role of caregiving. There are lesbian women who don't go to medical professionals for routine health prevention, such as pap tests and breast exams, because many feel a heterosexual model of health care is too invasive. They also may have found such a model to be more invasive with regard to our sexual orientation and our caregiving within this model of health care.

Meigs (1991) writes in her book "Inversions" the article "Falling Between the Cracks", a very profound statement that may help to reinforce what I believe may be one of the central themes of this thesis. She writes: "The entire future of a lesbian, or any gay person, lies in the few seconds of coming out, and the freedom one gains comes with new experience of unforeseen penalties" (p.106).

These experiences and unforeseen penalties may be or have been painful or joyful, but at the very least the process of coming out allows older lesbians to express part of their essence as human beings that we have kept suppressed. In the process and journey of being a lesbian caregiver, this experience has been different for me. There is a perpetual cycle of oppression and suppression and little in the form of expression and freedom that Meigs talks of, when constantly put into the position of having to come out over and over again in order to fulfill your duty and responsibility as a caregiver first before being a lesbian. The fact that anyone has to have their lives hinge on an expression of who they are is a sad reflection on what small steps we have taken in an evolution beyond hate, prejudice and discrimination.

The choice made by women who are older to expose their identities as older lesbian women to a researcher is a privilege that I do not take for granted. It has become possible for me to continue to study with the help of some of these amazing women, through their words and voices written in the pieces of work that I gathered for this research. As Meigs (1991) writes further in her article

To us lesbians, it is natural to enjoy the little power we have in an overwhelming heterosexual world. But the lesbian who comes out in a book finds along with the euphoria of sisterhood comes the *gradual knowledge that she has been sealed in*. She discovers that she has done straight people a favor by coming out; now, whether they are mildly or violently homophobic, they know what to expect. If they found it difficult to say the word lesbian, they are now unable not to say it (p.109).

Discussing openly who we are makes it far more difficult for mainstream society and culture to dismiss older lesbian women's existence. Once out in the open it is possible to start to build a community that is more inclusive of the diversity that has always been there. If writers such as Meigs write about the coming out process and make their work readily accessible, it may help to provide role models and support for older lesbian women who have not yet come out. It is time to make it easier for some older lesbian women who are caregivers to be able to retire and say "I am an older lesbian woman," and to be accepted, not just tolerated.

In the book "Lesbian Studies: Present and Future" edited by Margaret Cruikshank (1982), Matile Poor points out that the process of aging is difficult for older lesbian women in many ways. She touches on many subjects related to lesbian and gay activities as lesbians and gays move into their older years, and what older lesbian women need when they grow older. Poor says it is difficult to determine what models of aging older lesbians have, if any, because of their invisibility. Poor asks valuable questions related to the younger women in the lesbian community, in terms of what sort of assistance they may be able to offer to the older lesbians around them. One area where support and encouragement is needed is in the coming out process for women in middle age and beyond. These older lesbians face many of the same problems as their younger counterparts. Poor also recognizes the value of seeing one's own experience and images in the pages of journals, interviews, novels and photographs (p.167).

These depictions of older lesbian women's lives help to validate the experience of these women. Such depictions and issues are often intensified when a lesbian not only has to deal with getting older but also with the constantly changing and evolving role of being a caregiver. While many of these women's younger counterparts face similarities, their roles as caregivers is often different and may have very different implications than for lesbian women who are older.

Invisibility appears to be a common theme in much of the literature examined and analyzed for this thesis. There seems to be a silence and a fear of society's judgement on these women even after they progress towards growing older and aging. Silence, visibility, and openness to express older lesbian woman caregiver's identity may be connected to a fear of violence. In "Violence and Social Injustice Against Lesbian, Gay and Bisexual People", Steven J. Onken (1998) wrote of the conceptualization of violence against lesbians and gay people. He makes connections between issues related to power and oppression of groups not living within the boundaries that mainstream society dictates. Looking at such boundaries and issues around them may shed some light on how lesbian caregivers are viewed and view themselves based on how members of the mainstream (straight) society and culture react to them. There is a perception that heterosexuality is still really the only normal way in which to express one's sexuality, and such a notion is further complicated in how lesbian women caregivers can be viewed from such a lens. Onken (1998) points out that

The term homophobia is often used interchangeably with heterosexism. Homophobia is defined as a fear, usually irrational, of homosexual people based on their sexual orientation including "a prejudice often leading to acts of discrimination, sometimes abusive and violent." Heterosexist beliefs in the superiority and privilege of heterosexuality fuel homophobic behaviors. "Like racism, sexism, and other ideologies of oppression, heterosexism is manifested both in societal customs and institutions, such as religion and the legal system...and in individual attitudes and behaviors" (Herek, 1993, p.221) (p.10).

Perhaps it is these beliefs, which can permeate social and cultural institutions, that in part prevent older lesbian women caregivers from asking for and obtaining what it is that they need to prosper and grow in the process and journey of their caregiving role.

The issues for the older lesbian woman caregiver are many and can be related to health, economics, emotionality, sexuality, psychology, agism, sexism, misogyny and issues connected to equality. Some authors discuss the struggle that older lesbian women had to go through while younger and discuss some of the issues connected to homophobia. Many of these kinds of struggles can have a profound impact on the quality of the caregiving experience. In "The Gay and Lesbian Liberation Movement" by Margaret Cruikshank (1992), she discusses many issues related to the lesbian and gay liberation movement. Authors in this book point out issues related to the politics of hate and fear and what some of the older lesbian women caregivers may have had to face when younger and still deal with as they journey through the caregiving experience and beyond. An author from this book, Lisa Keen (1992) states

In the 1950s, the movement later called gay rights consisted of a few secretive organizations in several large cities. In the sixties it grew slowly. Inspired by Stonewall and mass comings out, gay rights became a movement. Neither the early German advocates of homosexual rights nor the courageous women and men who joined homophile groups in the years 1950-70 could have foreseen this development. A student looking for articles on homosexuality in Reader's Guide in 1949 would have been directed to the headings "sex perversion," "abnormal," and "queer people" (pp.88-89).

It is interesting to consider whether or not lesbian caregivers need to work towards some kind of movement today. Little had changed by 1966 when Time called homosexuality "a pernicious sickness" and a "pitiable flight from life" (21 January 1966:41). A mass movement was needed to change this way of thinking. Much still needs to be changed, particularly within the medical/ health care culture with regard to perceptions of members of the LGBTQ community and its caregivers of today. Laws ending discrimination against homosexual persons are only the first step. We are now in the year 2007 and much has changed but much still remains the same. Laws have been implemented but they are not always enforced, and many lesbian women caregivers still have to stay in the closet out of fear of reprisals because of the expression of their sexuality and identities as women which impacts on their full-time caregiving roles. The invisibility of many lesbian women remains due to society's unwillingness to affirm openly that being a lesbian is a positive and fulfilling way for a woman to live her life, particularly if she is a caregiver.

"Lesbians at Midlife: The Creative Transition", an article by C.

Charbonneau & P. S. Lander (1991), points out some issues that older lesbians may have as they come to terms with their lesbian identities at mid-life and beyond:

... the change in self-identity and the lifestyle was profound, and all of them felt a need to explain the shift in some broad context. Some presented the shift as a process of self-discovery, which included feeling "for the first time I am me" or "the fog has lifted." Others talked of their shift as a choice, where there were other options: to be celibate, to be bisexual, or to remain heterosexual (p.41).

This article shows that there are many changes in evolving as a lesbian or bisexual woman and all of these changes have an impact on our life and role as caregivers. These issues related to identity and changing lifestyle are complex and require much strength and courage on the part of the women going through the transition. This kind of life change is very intimate and personal and, for some lesbian women caregivers, may in fact be difficult to share with institutions set in a society and a culture that frowns on women deviating from the roles and status that have been assigned or constructed for them.

Berger (1984) also discusses, in "Realities of Gay and Lesbian Aging", the possible advantages that the aging gay person experiences, although it is important to note that this perspective is primarily that of an older gay man. Berger points out that some gays do not have to deal with the same losses that their heterosexual counterparts do. The loss of roles is one point of particular interest to me. Berger indicates that straight people are faced with the loss of

the role of parent and provider as they age. He suggests that gays are less likely to be faced with this kind of loss (p.238). This is not the case with many lesbian women caregivers, many of whom do have to assume the role of parent and provider, and in fact, may have to deal with the loss of a parent. Some of the literature I read indicates that many older lesbian women are faced with the loss of their children's love if they come out later in life, and may lose their support, which could be devastating both emotionally and financially. It is also important to consider the sense of loss a lesbian caregiver may feel at not being able to have children of her own because of her role as a full-time caregiver; thus she has no support from children as she gets older.

There is also a different trend in lesbian and gay families today, in which there is an increase in the number of children that lesbian women are raising either through previous heterosexual marriages or with a lesbian partner. This can bring added stress and strain to a lesbian woman who is also trying to raise children, having to deal with issues relating to her sexual orientation in her role as parent and as caregiver. According to Nelson (1999), in the book "Queer Families, Common Agendas: Gay people, Lesbians, and Family Values"

For lesbian women, achieving the status of "mother" is often a complicated and conflict-ridden process. There can be great disagreement among social bodies who are empowered to validate women as mothers (and domestic groups as families), including family members themselves, as to who is or is not a mother. These notions, often based on heterosexual, heterosexist and patriarchal conceptualizations of "the family" create family experiences and family dynamics that are unique to lesbian women. Furthermore, different types of lesbian families, for example blended families and

those created by donor insemination, share some experiences related to their social context, but also differ in terms of their family dynamics. Social and community services and programs directed toward families need to recognize the existence of lesbian families, the variety of forms of lesbian families, and the specialized needs of different types of lesbian families (p.27).

The roles that defined earlier generations and families have changed and continue to change and lesbian women's families are no exception. With a rapidly aging population this is even more so today, as more and more members of the LGBTQ community will or are having to face the challenges of being full-time caregivers. Many social and community service programs that are available for caregivers are often directed only towards traditional heterosexual models of family units. These types of models can make it difficult for lesbian women who are also caregivers to come out later in life and openly express their sexual orientation. Some lesbian women who were living in heterosexual relationships have children that may not be comfortable dealing with their mothers' new sexual identification. Social and community service programs have to adapt to the changing forms of family and learn to modify programs based on the diversity of the whole population, not just a select group that has been considered the only acceptable form of family. Dynamics are changing; so is the nature of how lesbian caregivers age. Lesbians who want to consider coming out do so in direct relation to their families' and partners' needs, which may be very specific depending on the life experiences of individual lesbian women who are caregivers as well. Social service and community programs not only will have to

adapt but will have to be able to accommodate the variety of older lesbians and their own individual lifestyles.

The LGBTQ community must learn to understand differences of the lives of lesbian caregivers within the structures of its own evolving culture and communities, to expand and go beyond the same old tired worn out methods of connections and interactions that hopefully will be able to cross the boundaries of sexism, racism and agism to be more inclusive to lesbian women who are full-time caregivers . So, as we can see, there are many issues for lesbian caregivers, who have to deal with various roles related to their own individual family situations both before and after they come out, and deal with their sexual identities and how it relates to the rest of their lives and their journey as a caregiver, and how it affects that process.

In 1982 Raymond Berger wrote his study "Gay and Gray" in which he gives some insight into the perception of the older gay man by society and culture...

stereotypes serve a social control function. They are a deterrent to selection of the homosexual lifestyle, particularly for young people who have no role models of successful homosexual elders. This could be an important insight for the lesbian caregivers to come who have no role models and those who could share insights and advice of what could be coming in the role of the caregiver who is also a lesbian. Sahir and Robins (1973), for instance, found that most homosexual men were apprehensive about aging and did not believe they would grow old "gracefully." So the elderly homosexual remains a tragic figure, both in professional literature and in the popular media (p.15).

This notion may also apply to older lesbian women as they age and start thinking about coming out as they deal with the daily management of their caregiving duties and responsibilities. Even though much of what we do day in and day out requires strength, energy, courage, love, commitment and dedication, for the most part, we appear disillusioned and lost. The myths about the older gay man may make aging a difficult process, but for the older lesbian woman who is a caregiver, there may be many more layers of problems to deal with, related to being female and lesbian.

Berger wrote another article in 1984, "Realities of Gay and Lesbian Aging" in which he discusses a study to determine the needs of the lesbian and gay population. This article points out that within the culture much misinformation exists in the absence of accurate literature and information on the lesbian and gay population. Today there is an obvious lack of accurate information on lesbian women who are in the caregiving role. Berger also claims that the reluctance of some lesbians and gays to participate in the gay rights movement has helped to perpetuate ignorance about the lesbian and gay population. I agree that this may have an impact of the kind of life a lesbian caregiver has, within all the boundaries set by all of the communities in which she resides. One point of keen interest to me is the recognition that Berger gives to a critical difference between lesbian and straight women, which is the coming out process of lesbians.

Homosexual women and men at some point have been faced with having to come out to friends, family and peers. Heterosexual women or men are not faced with this sometimes life altering process, which can change the support systems in place for the individual lesbian woman. This can be a very critical factor for the older lesbian, who may wait until later in life to come out (Berger, 1984, pp. 57-58). The changes and problems that may be associated with aging may also be complicated by the coming out process, as well as by a lack of involvement within the lesbian and gay movement. This movement may provide some of the only sources of services and information available for the older lesbian woman.

Economics

On the positive side, Kehoe (1986) does point out that older lesbian women are survivors and tend to plan to work towards their older years. I might add that being a caregiver for most of her life may in fact be an advantage, given the nature of having to plan and map out the schedule of other people's lives for years, which provides many skills to plan her own later years. Kehoe's article discusses the fact that many lesbian women who are beyond the age of sixty were faced with little or no family support, social security, food stamps or welfare cheques. These women had to be self-sufficient when they were working. The problem may be that many older lesbian women in both Canada and the United States may be forced to work well into their old age. Due to being out of the paid workforce for many years, as I was as a caregiver, they/I still will not be able to

retire if programs are not in place to make it possible for them/me to do so (pp. 157,159). This point helps to illustrate the notion that older lesbian women who are also caregivers are at a clear disadvantage when it comes to having a share of the resources, a situation that does not compare to that of either straight or gay male counterparts. Women traditionally are viewed as the caregivers and lesbian women are often viewed as an available source of free labor. This fact, along with the lack of opportunities to expand their resources, make it so that many of the lesbians who are in the caregiving role would have little chance to “grab a piece of the pie” so to speak. These kinds of problems with working and having an income that would allow consideration of retirement, while also continuing to be a caregiver, can have serious implications for the older lesbian woman caregiver’s ability to ever retire or enjoy comfortably their older years.

Social Networks and Community

Mary Reige Laner (1979) continues the discussion of issues for older lesbian women with regard to problems that continue to surround research on older lesbians. Laner points out that there is a tendency for researchers to study men more than women. If males were the primary caregivers in our culture, it would not be any problem to find a large body of research on the topic and the impact of the caregiving experience. The author also brings up an interesting point with regard to research on homosexuality: “much of the research that is available does not bother with the aspects of aging amongst lesbians and gays” (p.267).

Research not only lacks in consideration of older lesbian women but also lesbians as caregivers. The state of the rapidly aging population in both Canada and the United States and the need for care for older and elderly members of the population, is indeed very surprising today for many who are members from the LGBTQ community, which indicates the need to delve more seriously into issues related to caregiving for members of the LGBTQ communities. In the gay community there appears to be a clear lack of consideration of the needs of older lesbian women. Kimmel (1978), in his article "Adult Development and Aging: A Gay Perspective", pointed out that

There is a need for increased advocacy of the special concerns of vulnerable members of the gay community. In an important sense, a community may be defined by its function of caring for its vulnerable members. For the gay community, these would especially include adolescent and elderly or infirm gay persons; deaf, blind, disabled or handicapped gay persons; gay parents; minority gays; and gay persons living in poverty. Greater community support needs to be provided for these groups of gay persons, possibly through community centers or special programs designed to provide special gay services in conjunction with existing programs (p.127).

Kimmel makes some valid points, but this author does make the same mistake that much of the research on older lesbian and gay men continually makes, that is, the lumping of LGBTQ issues all together as one group. Kimmel generalizes with regard to lesbians and gays and the category of older lesbians and gays with reference to the elderly. He makes connections between the elderly and infirm which can also be extended, although he does not do so, to include situations and issues that affect lesbian women who are caregivers.

Categorizing elderly lesbians with those who are ill is making an assumption that all older lesbians are most likely to be sickly. If you are in a role as a caregiver where much of your time deals with disease, illness and even death, the result of the caregiving process will likely be illness for the caregiver regardless of the age of the caregiver. In previous literature, we found it may very well be the older lesbian woman is doing the care giving and is not the one being cared for.

In "Rv Life Begins At Seventy", Shevy Healey (1995) says that

What makes our seventies so grand is our good health and our ongoing desire to keep trottin, keep learning, keep going. Our own ageist expectations of what our old age would be like left us unprepared for the reality of our aging: a time when our lives are very much in progress, sometimes scary, irritating, and frustrating, yet always full, rich and poignant (p.87).

The life of the older lesbian woman caregiver can be very different from the preconceived stereotypical views of the lives of women, lesbians, and the old by a society and a culture that would have us believe that there is nothing worthy of exploration and examination in growing older and aging and caregiving for lesbians. In fact, I am discovering the rich tapestry of lives and personalities of this group of women that make up a very important part of humanity.

Meigs (1995) talks about being in love and being old in "About Being an Old Lesbian in Love" in which she points out that

I believe that we old lesbians have earned the right to consecrate our energies to the best uses of ourselves. If it happens that these best uses are so different for each of us that they are unnegotiable, that is less important to me than the old-age miracle of our love story (p. 99).

Falling in love and dealing with intimacy and passion as lesbian women get older has not had much of a place within the literature read for this thesis, yet it is very much a part of the lesbian woman's experience even though she is a caregiver. There is much to be learned from hearing of the life experiences of the lesbian women who lived in a time when being a lesbian was completely unacceptable by mainstream society and culture, but who held on and continued to live with dignity despite the intolerance they experienced. These authors have helped to illustrate some of the problems and the barriers with which older lesbian women who also may be caregivers have to contend.

In 1988, one of the largest US studies on lesbian aging was done by Monika Kehoe, with over 112 participants: "Lesbians Over 60 Speak for Themselves", in which she examined how older lesbian women live and survive in a hostile society. The study also examined how these women felt about being labeled as different or other (p.1).

The purpose of the study was to gather information on the hidden population of older lesbian women. Due to the fact that this study is so large, I will focus on only a few points of interest related to the topic of this thesis. Kehoe indicates that

Social life for lesbians born in the early 1940s or before varies as it does for all their female counterparts. Some, afflicted with illness or physical handicaps, will lead more restricted lives. Others with very limited incomes and few resources, will also suffer social limitations. The women surveyed and reported on here are not among those who have experienced severe hardships (p.41).

Kehoe points out that there are many considerations to contend with when doing this sort of study. It is important to note that Kehoe does indicate that many of the older women in this study are not facing the hardships faced by many women who are also caregivers and poor, disabled, or from different racial or ethnic backgrounds. It is noteworthy that the lack of consideration of lesbian women from any of the aboved mentioned group, exposes the reality that much of the caregiving and aging experience has not been examined. Kehoe's study covers too many areas of interest to be completely assessed for this thesis. However, her study could be a critical factor in a more extensive expansion on this topic. Her study does examine issues related to lesbian identity and sex. In her study one woman comments "I think I would not like to be identified by sexual preference either as a homosexual or a heterosexual. Gay refers more to a subculture. I don't separate love and sex, but homosexuality is more likely to be love deviation than a sexual one since most people can achieve orgasm in a variety of ways" (p.47). Her study also offers numerous comments on issues related to social networks, economics, services, resources, age gaps and research issues. It is not hard to see the connections between her work and the topic of this thesis.

Personal Narratives: Stories of Older Lesbian Women's Experience

Many resources used for this project discuss various experiences of older lesbian women's lives, but Marilyn Murphy (1991) offered an in-depth look into the journey of one older lesbian women's experience. In the book "Are you girls

traveling alone? *Adventures in Lesbianic Logic*", Murphy discusses a woman's experience and life as a lesbian. For the purposes of this thesis I chose some excerpts from her book that are connected to issues related to the older lesbian woman's caregiving experience. In one section of the book Murphy discusses the support, strength, courage and empowerment of older lesbian women at an early women's conference for older lesbians, as she listens to the words of older lesbian activist Barbara Macdonald. If such activists were readily accessible to lesbian caregivers we might be empowered in our roles and positions within the different communities that we share with those we care for.

Aging is a biological fact; but it is also an experience we fear because we carry the dread of the old woman within us. We imagine her, old ugly and boring and not like us. We do not have to dread our arrival at each age plateau, Barbara tells us. She jogs our memory of dreading thirty, forty, fifty, and realizing what we dreaded was not there, of thinking that it must still be ahead of us. The dread is of nothing, she reminds us, because we are ourselves at every age, and will continue to be so. She reminds us that we Lesbians say "No" to the adjustments expected of women at every stage of our lives; and old lesbians are no different. The grandmother stereotype is as oppressive to old lesbians as the wife/mother stereotype is to younger women (p.122).

Murphy's impression of Macdonald's speech indicates that for some older lesbian women, aging and approaching their older years does not have to be met with dread but can be embraced as positive; that it is possible to combine a lesbian identity and aging as a positive experience. I wonder if such notions can be extended to the role of being an older lesbian caregiver? For me there is a certain kind of 'dread' that is there because being in the caregiving role, with so

many faces and constructed roles within it, I have not always been myself. Nor is it possible for me to ignore the kind of adjustments that were needed to adapt to the constant changes and demands of being a caregiver. For me this did not allow time to embrace the positive aspects of aging, as both Murphy and Macdonald suggest is possible.

This next excerpt is taken from a section of Murphy's book that is dealing with aspects of death, wills and estate planning.

I am convinced that we lesbians and gay men would be much better off if we gave our families the opportunity to adjust to our lives while we are not living them. Those family members who cannot adjust with love, can adjust with politeness. If they can do neither, we can create families of choice from among the large and varied communities of Lesbians and gay men. Certainly heterosexuals expect their families to adjust to their choices. Heterosexuals do not "respect" their families' feelings about their love choices when those feelings are racist, anti-Semitic, or classist, for example, the way we "respect" our families homophobia. Heterosexuals marry persons of the "wrong" race, religion, nationality, class. They marry persons their families think are too old, too young, too stupid, too educated, too lazy, too ill for them. They would not attend a family gathering at which an "unacceptable" wife or husband was not welcome. They demand their families accept or, at the least, tolerate their choices. And most families do just that. Lesbians and gay men should demand no less from our families that our heterosexual siblings do. "But I love her/him," is all the reason heterosexuals think is necessary to justify their choices. Why should we need more? And just as the knowledge of their "wrong" love choices does not cause the premature death of their mothers and fathers, neither will the knowledge that our love choice is the "wrong" sex kill off our folks. Our families' homophobia is a social disease that can be cured by love, patience, education, and the everyday sight of Lesbian and Gay parents and grandparents, aunts and uncles, sisters and brothers, children and grandchild, nieces and nephews and their companions' lovers, living our lives and our deaths out of the closet (pp.103-104).

While Murphy uses sarcasm to illustrate what some may think of as obvious, issues of similarities exist and parallel lesbian, gay and straight lifestyles. What Murphy does well is to point out the lack of acceptance for alternative lifestyles different from the straight community. Often this is even more so within the role of a caregiver from the LGBTQ community who has to deal with or live inside or outside of the medical/health care sub-culture. These kind of presumptions and assumptions about the just 'given' for straights with regard to their roles as caregivers, versus their often biased views of the lesbian caregiver, makes the caregiving journey all the more difficult and stressful. In the same chapter Murphy goes on to explain further the importance of carefully drawn wills to prevent problems from arising among family members who are unwilling to accept a lesbian or gay lifestyle or the inheritance rights of a surviving partner. Issues that relate to end of life decisions become more important as age, health and finances affect the quality of growing older, particularly for older lesbians who are also caregivers.

In a book entitled " Dyke Life: A Celebration of the Lesbian Experience", author Jeanne Adleman (1995) discusses various aspects of being an older lesbian woman in which I find connections to my becoming older and to aspects of the caregiving experience for me. In chapter five she discusses issues of importance that were raised by older lesbians she interviewed. At this point in the chapter Adleman discusses the notion of role models:

I have frequently heard a longing expressed by midlife and younger lesbians for “role models”, as if each will not have to become old in her own way if she lives long enough, and as if being old were a role. There seems to be a temptation to “heroicize” the lives of old dykes, which to some old lesbians may feel like a long-awaited recognition of their struggles against oppression. But each time someone is seen as a role model, she is simultaneously being stereotyped. Once on the heroic pedestal, her imperfect traits become invisible. She is no longer a whole person whose life includes sadness, physical distress, impatience, anger, rage, loneliness, or possibly unbearable stress, intermingled with the wisdom, love, compassion, courage, reflectiveness, and other qualities that go with the status of role model.

Old lesbians have a stake in presenting our lives as satisfying. It helps us understand our lives as worthwhile and to keep thinking of new satisfactions that may lie just ahead (p.89-90).

Adleman expresses concern about the perceptions of an older lesbian woman's life and her experiences. While I believe that there is some merit and value to what Aldeman says, it is also important to point out that, for lesbian women who have become caregivers, there is value in having a sense of community, and support from other lesbian women who are older and who also are in the caregiving role. Roles do often stereotype lesbian women and their realities but in mainstream society it is often impossible to escape them. However, I would rather be visible with all my imperfections than to remain isolated from myself in mainstream society and culture and from the LGBTQ community. If the need of other lesbian women to have, as Adleman puts it, “role models”, is strong enough, it may have an affect on the type of caregiving experience an older lesbian woman such as myself can have. Rather than role models I prefer to think of social networks and support networks that could be

there to fill the void that some older lesbian women who are caregivers may have while going through the caregiving process. This notion of an idealized, heroicized old dyke can take away from the reality of the older lesbian woman's experience, but if the dyke is also a caregiver it may also add a sense of empowerment. Such a notion and perception can be inverted to become a positive for lesbian women who not only deal with growing older but also deal with issues surrounding the lesbian caregiver's role and journey.

Adleman goes on to discuss a very important issue with regard to older lesbian women's experience and what a writer or a researcher's reality may be and how they differ.

When I try to describe or explain myself, or a period in my life, I unconsciously or consciously select only some things. What I select depends on the context of the person I am speaking with or writing for, or who is asking questions. It is impossible to condense one's whole self into a single facet, or even a few facets. Interviews, whether formal or informal, are the product of the interviewee's state of mind, body, and emotions at the moment; of the interviewer's direction of questions; of the writer's purposeful selection of what has been provided by the subject; and of an editor's purpose in making changes. So if you meet an old lesbian and appreciate certain things about her, don't look at her with shining eyes and tell her what a role model she is for you. Surely you mean it as a compliment, but it is not her reason for being. Just tell her the specific things you appreciate about her (p. 90).

It is important to be aware of what we are gathering with regard to research data; as Adleman points out, much of what is being interpreted is only select portions and pieces of an individual older lesbian woman's life. This is why I have chosen certain points in my journey as a lesbian caregiver, in order

to illustrate the impact that such a role has had on my life, not just as a woman but also as a lesbian. It is only a snapshot of a whole that has evolved and has been constructed and created for the singular purpose of fulfilling the caregiver role. I chose specific points in this process because it was what could be appreciated about being a caregiver. This, once again, indicates the importance of continued research with older lesbian women and the differences in each of their/our realities, for those who are caregiving as well as growing older on their own terms.

In another section of the same chapter Adleman discusses a few financial considerations that are recalled from excerpts of interviews from two different sets of older lesbian women.

Rusty (1923) lives alone in a one-bedroom apartment in the Tenderloin district of San Francisco, an area she describes as being "colorful on good days" but most of the time "a sewer... I'm still dreaming of having a home some day," she says. Rusty worked as a machinist or mechanic most of her life, for thirty-one years in the navy. "They brought me back from Vietnam more dead than alive, when I was forty-seven. A year or two later, my medical discharge came through. I can live on my pension and social security by being very, very, careful. I save for things I want, and also work when I can. For the past few years, I worked in a laundromat near my apartment: fifteen hours a day, seven days a week, at minimum wage. I was able to go out and eat occasionally and buy certain things that make me happy, like a good TV and stereo, and a good leather jacket on sale." Rusty, like the other women still to be introduced in this chapter, is white.

Doreen and her partner, Bev (1919), also speak of managing carefully, but the resources they manage are very different from Rusty's. Bev and Doreen met through Golden Threads and have been together for four years. Doreen had a painful marriage for twenty-seven years and raised six children before falling in love with a woman and beginning an eleven-year

relationship. When it ended she remained single for several years. In contrast, Bev had lived many years with one partner, very quietly and very closeted, until the partner's death after a lengthy illness. Having come out to herself in 1941 and finally retired in 1989, Bev found herself free to be as out as she wished.

Doreen sold her house to move to Bev's in a prosperous section of Berkeley. Both have worked most of their adult lives, Bev as a university librarian and Doreen as an elementary-school and community-college teacher. "We watch our finances and we're careful," Doreen says as Bev nods, "but we do just about anything we want to do, including travel" (p. 84).

All three of the women in the above account give a brief view into the quality of their older years and how those years can be affected by the level of resources and wealth that has been accumulated over a lifetime of work. The resources or lack of resources for a lesbian woman who has been a caregiver for over twenty years, as I have been, can have a profound effect on quality of life when we get older. In my situation, I now have about twenty-three years of productive paid working years left in order to acquire financial resources to live on when I get older. The loss of my mother's income after her death has placed my living far below the poverty line. Since there is no compensation for caregivers for all of their work, I have been left to fend for myself. I also do not have the support that comes with heterosexual privilege, of having a male partner or being seen as straight, fitting into mainstream society and a cultured vision of what older should be like. Such points also provide opportunities to question where women who have been a huge part of the unpaid labour force, such as stay at home mothers, primary caregivers of the elderly, sick and differently abled, fit into the picture of future retirees? Will they even be able to

consider the possibility of retirement? Some may never be able to realize the life of a retiree. Due to lack of information available on such groups, as a researcher I have tried to make extensions from the pieces available from my own experiences to form some sort of answer to these questions. Some of the answers are found within the words of each piece chosen for this thesis. I would surmise that the affect on these other groups could in fact be at least as devastating, if lack of resources has been a constant in any of the above groups mentioned, as it has been for me as a lesbian caregiver.

The last narrative here is a piece titled "Reflections of an Aged Lesbian", which appeared in Rites magazine from Dec/Jan 1994 , by lesbian author Mary Meigs, in which she discusses the gaps between generations as old age begins to appear. Her reflections provide insight on many issues that affect the aging process and how that process can affect the process of caregiving for a lesbian woman who is growing older in the mainstream society and culture.

Sometimes I see the mothers of lesbian friends sitting shyly, for the most part silent, while the tide of conversation washes over and past them. If they are given a chance to talk, their faces brighten and they become noticeably younger. Unfortunately, the older you get the less it is assumed that you have anything to say. The strained brightness one sees on the faces of aged women who are silent in a group comes from a longing to be asked what they think. Recently I talked to a 50 year-old lesbian friend (I think of her as young) who told me about a workshop on aging she had taken part in. She said that many aging lesbians there had spoken of their "invisibility" and that she herself had begun to be "looked through" when she went to a bar. Younger lesbians, she said, have a tendency to belittle everything we older ones have learned in the course of aging. Now, at last, all negative aspects of aging are being aired and discussed, and declarations are being made: that

we don't want to be treated like old people (we are the same people!). And we wish to have equal time for talking and equal respect for our thoughts. Once upon a time in the era of wise women, old lesbians were looked upon as the bearers of wisdom and it can happen again if young lesbians will look beyond the physical signs of aging which seem repugnant to them or which make them want to laugh. Contempt for age and the worship of youth are the result of patriarchal brain washing but they also come from the emphasis on the body at the expense of everything else. I don't think that lesbians have the same fear of growing old as gay men and straight women, but we can't escape the message that society keeps beaming at all women: young is beautiful and old should be kept segregated and out of sight. Grow old at the peril of yourself! Perhaps younger lesbians who read this will think that I'm exaggerating, but it's like the story of Picasso's portrait of Gertrude Stein. Stein said "I don't look like that" and Picasso said "You will" (p. 5).

It is true that if we live, we will all grow older and have to face the caregiving experience. In many ways we face similarities with our straight sisters, straight brothers and gay brothers, but there are differences, as was reflected in differences on social networking, invisibility in a group that is already considered outside of mainstream society, and often inside the LGBTQ community as well.

Summary

The literature that has been examined for this chapter was selected based on what it had to offer with regard to the study on older lesbian women and connections to the lesbian caregiving experience. In addition, their life experiences before and beyond becoming older, assist in creating a background or backdrop to the autobiographical portion of this thesis on some issues, concerns and experiences that may affect the lesbian caregiver and her

experiences. On the basis of this literature it is clear to me that much needs to be done to eliminate the problems associated with the stereotyping, discrimination, homophobia and prejudice that goes on in and outside the LGBTQ community for the older lesbian in the caregiving role no matter in what community she may reside.

Some of the literature listed in the works cited pages was only briefly discussed in this literature review. Other pieces of literature in the works cited pages appear throughout the rest of this thesis; some items of interest that have not been discussed are listed in other parts of this thesis, for the use of others who may find a benefit from the pieces not discussed in detail in this section. Other pieces of work reflect discoveries related to lesbian women as they grow older. Some of the events and experiences that are connected or related to their ability to enjoy the older years are also connected to the role of caregiver that some have had to take on. In the next chapter, I recount some of my own stories, combined with an analysis of these stories. I do this as a way of providing a context for my lived experiences inside several socially constructed roles.

Chapter Four: Autobiography

In the previous two chapters I have discussed literature from various sources that speaks to the importance of research on older or aging lesbians, our invisibility within most research on caregiving, and have explored the importance of finding ways to let our voices be heard, our lives be seen. In this chapter, I share some of my own stories, that are mine and also my mother's, for our lives came to form a symbiotic relationship. My identity became inextricably bound to my mother's, and hers with mine, so that from an outsider's perspective, it may have been difficult at times to say with certainty where one of us started and the other ended. This is one of the effects of being a primary caregiver for so long for someone whose health deteriorated over the years. There was almost nothing that I did that was not first wrapped around concerns for how to care for my mother within this action; a seemingly simple trip to the grocery store involved careful co-ordination of two or three people's work schedules, or a physically arduous trip that included my mother.

In the chapter immediately preceding this, I discussed the importance, from a research perspective, of personal narrative (see Gallagher, 1995, and MacDonald and Rich, 1991) as a means of offering space for one's voice to be heard. In chapter two, I detailed the use of autobiography as a methodology, drawing there upon the works of Brooks (1992), Leighteizer (1993), and Martin (1993). I take the opportunity here to let my voice be heard, to share some of my stories, and to render visible a life that has been largely invisible, both in

academic research, and in the communities in which I live and work. I do this not through self-indulgence, and not to fill up pages in a thesis, but because this task is central to a contention made throughout this thesis: that as lesbians we are invisible too often; as aging or elderly women, we are again too often either discounted or rendered invisible; and as caregivers, our own self can disappear, subsumed into the role of “caregiver”, which can become all that is visible to others. Thus, a new kind of triple jeopardy is created, and here I attempt to diminish some of that jeopardy.

As a feminist there is a danger in minimizing the experiences and the lives of all (lesbian) women whose courage and strength as caregivers have provided support, love, compassion and advocacy for those they care for, and who cannot always speak for themselves. Smith (1987) argues that a sociology for women

...begins from the discovery of a point of rupture in my/our experience as woman/women within social forms of consciousness - the culture or ideology of our society, in relation to the world known or otherwise, the world directly felt, sensed, responded to, prior to its social expression. From this starting point, the next step locates that experience in the social relations organizing and determining precisely the disjuncture, that line of fault along which the consciousness of women must emerge (p.49).

While for many women the qualities of support, love, compassion, and advocacy may be indeed an expression of who they are as women and/or as lesbians, it may also be in fact the patriarchal construction of women's experience. Smith's statement draws attention to the need to look to the rupture

in our experiences. The/my 'truth' lies not in the discourses on caregiving but in my experience as the caregiver and the advocate, the one who provides the support, love, and compassion; by placing myself within a historical framework I endeavor to determine the outcome of my caregiving experience as a lesbian woman. Where the line of fault begins in this caregiving journey is important in the construction of my identities as a lesbian, a daughter, and a caregiver. The result is not always positive.

Meigs (1981) asks, "Does every life deserve an autobiography? Does mine?" (p.7). Biddy Martin (1993) indicates that there is a value in the telling of the lesbian life story. My journey as a lesbian caregiver is one of those stories. Connecting the parts of this journey, with the impact of my sexual orientation on my role and status as a caregiver, provides a more complete picture of the complex realities of the caregiving journey and processes. Lesbian autobiographical narratives are about remembering differently, outside the contours and narrative constraints of conventional models. Events or feelings that are rendered insignificant, mere "phases" or permanent aberrations when a life is organized in terms of the trajectory toward adult heterosexuality, marriage, and motherhood, become differently meaningful in lesbian stories. Martin (1993) indicates that "[r]endering lesbianism natural, self-evident, original, can have the effect of emptying traditional representations of their content, of contesting the only apparent self-evidence of "normal" (read heterosexual) life course" (p.279).

This chapter is a story of my construction as both a caregiver and a

lesbian woman. I do not see the development of either of these facets of myself as separate entities; in fact I see the construction of these parts of me as parallel and deeply intertwined in one another. There is a duality, and both parts of my identity mirror one another but are, for the most part, not complementary to each other. This is a story of how we construct our identities and, in fact, how often we are made to fit societal standards and norms set by the culture in which we live, through our daily practices. This process of becoming a caregiver has led me to a sense of losing power and that which defines who I am, and the struggle now is to reclaim myself, by looking at how I was shaped by these roles which I feel I did not choose but felt compelled to accept.

This is a story that is not just mine but also my mother's, who, I now realize, was linked to my sexuality whether or not she wanted to be. We were as linked in life as we were in the process of dying and finally death. Divulging my sexuality, what I felt was private and personal to me, was often done in order for Mum to get the care and services I knew she needed and deserved. Issues that related to my need for privacy coupled with a lack of consideration on the part of health care professionals with regard to my right and choice to decide how, when, or if I would discuss and declare my sexuality, made it hard to relate to them. It appeared to provide the health professionals with validation and justification in dealing with me and Mum differently than my heterosexual counterparts. This kind of experience over and over again made the pressure and burden of being in the caregiver role harder and much more intense. While

it seemed that I was required to be very open about who I was, when I did disclose my sexual orientation, it made those Mum and I dealt with very closed to both of us and what she needed. How well could I advocate on Mum's behalf when I did not know whether or not health care-providers even wanted or cared to give treatment to a 'dyke's' Mum? For example, I remember one occasion, sitting and waiting for the medical team to come and discuss Mum's situation with us. Three of us, my partner, our roommate, and I were in the waiting room area; also there were other women whose husbands were terminal and on the same floor of the hospital. We sat waiting in that uncomfortable kind of silence that always seems to exist in these situations, the kind of environment that often promoted what I dreaded the most: small talk. One woman next to me said, "Are those your sisters?" Without waiting for my response, she continued, "It is so nice for you to have your family here. A lot of siblings leave it to one but it is good that you have their support." I pondered whether or not I should disclose who I was and who they were, but then I faced reality. My brother, who had finally arrived, walked up and sat down next to me and the same woman said to me, "Having your husband here must be such a comfort to you. It is nice to have your sisters here but nothing takes the place of having your husband by your side." I felt cornered but unable to respond. I finally retreated back into my closet that seemed to be much tighter and increasingly harder to fit into.

As a lesbian caregiver many issues arose that I had to contend with in order to get care, treatment and assistance for my mother. How to divide my time

between that role and my life as a lesbian woman was a major issue. Either I could spend my time devoted to Mum, which was twenty-four hours a day, or I could try and spend time with my partner as lovers, friends and companions. There was little room to split myself between the two; there always had to be a choice. My choice was always for my role as a caregiver and for Mum's care. This constant stress and strain on my relationship with my partner took its toll on both of us. We were often viewed as two women considered to be asexual and happy in their role as caregivers, and not seen as a couple with the same issues that any couple would have in the caregiving role. In the role of the caregiver, I had to choose between the notion that my own needs did matter, or deny those needs to ensure top quality care for Mum.

The operations of homophobia are often covert and implicit rather than overt and explicit; most of what took place was subtle. For me there are certain practices, uses of language, and ways that both Mum and I were treated that made us feel immersed in a discriminatory environment and made me very uncomfortable. For example, when in a hospital program for Mum that lasted over a twelve week period, the health professionals spent a great deal of time focused on my sexuality and sexual orientation, asking me, How many women did I know? How many women did I live with? Were all of the women I lived with my sexual partners? When I asked why my sexuality was relevant to assisting my mother with her care, the answer was always vague and side stepped and backed up with the assertion that all of the questions were needed in order to

provide a clear picture of the type of care Mum needed. Mum said to me on one occasion: "You would think you were the one that was sick, they are always talking to you and do not even seem to know that I am even here."

My response in these situations was my 'choice' but the practice of always placing my sexuality in the forefront of what Mum needed often put me in a position in which the medical profession questioned my behavior and mental state with regard to my sexuality, and that affected the medical resources and treatments available to her. The more discussion there was about my sexuality and my sexual orientation, the longer it seemed to take to get appointments, the longer the waits, the less information I seemed to get to assist me in Mum's day-to-day care needs. Could I prove that these long waits, unanswered phone inquiries, lack of information, withheld information, slow treatment plans had anything to do with my sexual orientation? I could not, but I often ran into heterosexual caregivers (wives & husbands, mothers & fathers) in the halls of the hospital who would let me know that they were so pleased that the whole process was going well, that the hospital and medical professionals kept in close contact with them and always filled them in with all the latest information. Was this a coincidence? Maybe or maybe not. A lot of what I experienced was subtle and not overt. It seemed that as long as I fought to maintain some level of privacy with regard to my sexuality and sexual orientation, I was perceived as unapproachable and not willing to encourage dialogue that could shape the course of Mum's care and treatment. For instance, there was the occasion of

Mum's being enrolled in a twelve week treatment program. Every session that Mum was in began in the morning and ended in the early afternoon. Every session began the same, starting with seeing the first member in the medical care team, the doctor, who always started with questions about my sexual orientation, as if it had changed since the last time I had been there. "So, now let me see here, you live with your mum and you are not married right?" "I told you last time and the time before that." "Yes, well now, and you have "roommates" that help you with your mum's care?" "Yes, and they are all female "roommates" and no there are not any men around to help out." After several days of this routine, I became aware that the end goal was to get me to disclose once again that I am a lesbian and that one of these women is my lover. My mother required this treatment program and the first step daily was to hold this conversation with the doctor. We could not continue the day's treatment without the doctor's okay and so, daily, I felt there was no choice but to continue to play this game of cat and mouse to get the results from the previous day so we could continue. Ironically, and frustratingly, was the fact that a good portion of his time was taken up with this line of questioning, which left little time for Mum to discuss her issues and concerns regarding her care and treatment. I was caught in a double bind. If I refused to engage in this conversation or became too hostile in my objections, there was the possibility that the doctor would leave without approving Mum's regimen for the day, or that a note would be made on my mother's chart that her caregiver was unapproachable and/or uninterested in co-

operating with the medical team. Thus, our daily routine came to include my confirming once again that I was a lesbian.

One of the situations we found ourselves in, one which lasted for hours, began when we took Mum to the Emergency Room because I suspected she had a stroke. Mum and I spent over twelve hours in the ER while people who had much less serious ailments, had come and gone. I went to the desk of the intake paramedic where I was told, as he looked me up and down, that his hands were tied and he couldn't do anything to help me until a doctor had seen her. I said to him, "A doctor has to see her, to give her a blanket to make her more comfortable? What about all of these other people that have blankets and ice packs that have not seen doctors?" He said to me, in tones I had heard many times before in my life, "Why don't you ask 'your friend' that 'one' that came in with you, to help you?" I then asked him, "Why is it that so many of these people are getting in ahead of her when they only have sprains or cuts to deal with, and she has a suspected stroke? According to the hospital's triage policy Mum's condition would be considered a priority." "Now, look, I am sorry but I have work to do. You will have to sit down and wait your turn." By myself, I lifted my 165 pound mother out of her wheel chair and placed her gently in a more comfortable chair. After more than eight hours of waiting, Mum could no longer stand it and said to me crying, "Please, Linda, please I cannot stand anymore, can't you do something? Please take me home, I just want to go home. They do not want to help me." So, after being told that once we left the hospital they

were not responsible if anything happened, I lifted my mother out of the chair and put her into her wheelchair and took her out to the car. Once outside by the car, Mum said to me, "What are we going to do now, I am too heavy for you to lift into the car?" I said "Watch me." With that I drew on every bit of strength that I had or could find and lifted her into the car and took her home on my own. You have to take into consideration that my mother had pressure sores, osteoarthritis, high blood pressure, diabetes, as well as her other conditions. This very act itself was a monumental task. If I made a mistake, it could cause an untold amount of pain and possible further damage to her already delicate condition. It was imperative that she not stay in one place very long. When I explained this to the man at intake, it was as if what I said went right through him. I could see through this situation that a support system was not going to be available to me. I now felt that discussing issues related to Mum's condition was going to be difficult, if not impossible.

I was desperate when I had to take Mum home with no care or treatment because I had challenged these heterosexed spaces when confronted with subtle discrimination. We went home and I had to actively search to find someone who would see Mum. There had to be a way to get her in hospital and seen by someone. Once again I put my life out to be exposed in order to get the secretary at the specialist's office to call me. From my own perspective, I explained what had taken place at the ER and why. I then begged to have Mum

seen by this neurologist after not getting the care in the ER after the suspected stroke.

This is but one example of what I went through as a lesbian caregiver. I have to wonder: if I had been heterosexual, would I have to call into speculation issues surrounding my sexuality, sex life, sexual behavior, familial relationships and the family structure at home in order to receive treatment or care for my mother? Can I say that her care was affected by these factors? If I was required to have facts written down in black and white, I would have to say the answer would be 'no'. Nevertheless, the reactions and results of those I dealt with and the outcome speaks volumes to me. The devaluing and blaming for being ill, sick and disabled was connected to both Mum and me. For example, on one occasion one doctor asked, "What kind of things and activities are you and your mother doing to improve her mobility, strength and energy?" I then found myself listing in detail all of the things I did to try and keep Mum active. Interwoven into their questioning about our daily routines and activities were yet more questions about our household, who lived there, and what we did together. Care was in fact given, but I query the level of quality and timeliness. Some of the professionals I encountered claimed that they had never met a lesbian before. What I think they should have said was that they never met a lesbian who was out of the closet. Their focus seemed to be more on the novelty of meeting "the lesbian" and less on my mother, her care, treatment plan, and her needs.

The silence from others unwilling to let Mum and me be heard was not nearly as frustrating to me as was my own silence. I started this work with the notion in mind that there was, somehow, a particular moment in which I became an unpaid informal lesbian caregiver. I felt I had to identify that moment and looked initially to caregiver's age as the critical factor from which to begin my work. However, I now see that the focus should never have been on the age of the lesbian caregiver but rather on the process of the construction of her identities over a significant portion of her life. This idea drove me to create a forum in my thesis which opens the space for other lesbian caregivers to perhaps recognize themselves in this process and the journey of their caregiving roles. I wish to no longer be simply an add-on to a particular caregiving issue.

As an example of the ways that the experience of lesbian caregivers is still largely ignored and understudied and remains, to a large extent, invisible within the mainstream community, I refer to a study in which I participated as a subject. Conducted by researchers at Dalhousie University (Beagan, 2005), this study, titled "Caregiving Portraits: Narratives of 14 Women Caregivers in Nova Scotia, A Report of the Healthy Balance Research Program", focuses on the overall impacts of the caregiving process specific to the women who participated in the study. Since three of the fourteen women studied were lesbians, lesbian caregivers are one part of the study. While such a study does incorporate part of my story and is a reason why I have done this research, it also, in part, has given me a foundation wherein I start with my story not only as a caregiver but

as a lesbian woman. Even though some research is now being done on the caregiving experiences of some LGBTQ people within the Capital Health District here in Halifax, Nova Scotia, projects like this one perpetuate rather than disrupt the tendency to subsume the experiences of lesbians within the general category “women”. The experiences I document in this thesis help to illustrate the effects of oppression, discrimination and homophobia, in ways that are not yet captured, documented, or understood in other studies and other research.

As a lesbian caregiver I have, through my own experience, felt the impact of the kind of social control that Smith (1987) speaks of when she says

The critique of the institutions that alienate women from their experience has taken many forms in the women's movement and developed very rapidly: attacks on stereotyping in advertising and the media in general; the critique of sexism in school reading materials, of the exclusion of women's interests and news relevant to women from the historical traditions organized and maintained by men; the critique of theology and religious institutions, of the social practices such as Women's House in Los Angeles and also in teaching and writing. Another critical approach has focused on the professionally organized institutions of social control, the health care systems, law, and psychiatry in particular. The same line of fault is identified in their practices (p.53).

Such institutions as the health care system in Nova Scotia are no exception to the rule. While balancing on the fault line created by men, and still maintained to a large extent by them, it is hard for a woman who is also a lesbian to be effective as a full-time caregiver. Lesbians take risks everyday and we risk many things. I have found that by taking even some of those risks there may be attendant, and unexpected, risks for those you care for. Lesbian identity in this

caregiving process does not allow for complete healing and recovery from isolation, rejection, and open discrimination while being a caregiver. Systemic invisibility, exclusion, and marginalization often impede healing and recovery even when the caregiving process has ended.

There is no solace in your partner being of the same sex, which was a notion of one health care professional that we had to deal with in this caregiving journey. This particular health care professional felt it was, as he put it “like having a two for one sale and you two girls are nice and strong so I am sure you are up for the challenge that is ahead of you with her mother”. It seemed that they believed that two women being together can accomplish twice as much work, a sentiment also shared by my male siblings. They were always saying throughout the whole caregiving process, “you girls do such a good job with Mum”. Ironically, we were still viewed as traditionally feminine, embodying twice over the feminine qualities of nurturing and caring. However, the image of the lesbian as a “masculine woman” meant that we were also viewed as more physically capable, in effect removing our identities not only as lesbians but also as women.

The effects of heterosexism and homophobia take discrimination a step further. When I am forced to disclose who I am sexually, emotionally, and psychologically, and then become of clinical interest as unwilling research subject/novelty item, I and Mum, and her care, are forgotten or, even worse, ignored. I remember when Mum was placed onto the ward and the nurse came

in and told the three of us that only immediate family was allowed to visit at the same time. I told her we were all family so it was all right. The nurse looked at me, my partner and then at our roommate and friend and said "All right, which of you are really family?" I said "We all are members of the family". She said "Look I know that you are all 'friends' but I am going to need to know who is actually family." Finally I sighed and felt compelled to say what and who each of was and the connections, when it became clear that this particular nurse was not willing to let it go. So, I said "This is my partner and I am her biological daughter and this is our roommate and close friend." Her response was "Oh, I see, well I will write down your name as her daughter as family." My mother reclaimed some of that in a matter of seconds by acknowledging all of us as her daughters, not "just" her family, but her daughters. I think that is significant. Even though my mother was in the advanced stages of Parkinson's disease and cancer, which made her voice soft and low, and at times difficult to understand, this gesture spoke to me as eloquently as if she had shouted it out with perfect clarity. When I look back on that moment now, I realize that the acceptance of who I am as a woman and a lesbian was given back to me freely by my mother. There seems to be a common perception that because I am a lesbian/dyke, I am tough, hard, unloving, cold, and unfeminine; this then becomes understood to be a good thing because I can take and handle whatever has to be done to me or dished out to me.

My experience as a caregiver has helped me to recognize the development of the informal caregiver as a perfect unpaid and under recognized employee. My labor is a product that is produced for a society that, in many situations and circumstances throughout the health care system, deliberately or inadvertently reproduces oppression and discrimination. By utilizing me as a commodity that reduces the burden on the health care system and economy through my providing 24 hour a day care for my mother, there is removed the necessity for this system to have to provide or pay for such care.

Karen Henderson (2005) cites an "Advisory Council on Aging" report which indicates that there are four and a half million caregivers in Canada today who spend part or all of their lives in the caring for others. There are costs to many caregivers. This report points to such costs that many caregivers, such as people like myself, dish out of our own pockets. These extra expenditures are in the form of subsidizing the cost of services in what they term casual costs (food, laundry, gas, parking, car, medical products, etc). These "casual" costs can deplete the small financial resources that the caregivers have for their own expenses and needs. In the same article it is indicated that these extra expenses total in excess of over one-hundred million dollars a week, suggesting that caregivers spend about five billion a year in their roles as caregivers. The same article also points out that such economic value, accomplished through the work and labor done by those unpaid caregivers, is estimated to be equivalent to the work of 276,509 full time employees. Just imagine if those unpaid caregivers

were paid and had disposable income as well as taxes that were being generated into the economy. This is but a small portion of the economic value of informal unpaid caregivers; of the total number of workers, it would be interesting to have a percentage of the number that would be from the LGBTQ communities. Out of this number of unpaid caregivers, a separate analysis and sample of lesbian caregivers would have to be obtained in order to measure how many are women who are also lesbians providing the care that boosts the economy. I am overwhelmed by the value of myself as a product and an invisible commodity.

This social invisibility leads to varying impacts on the caregiving process that can lead to problems for those receiving your care. The interest in my sexual orientation often overshadowed my mother's health concerns in such a way that it was becoming crucial to her quality of life and mine. I am haunted by the memory of coming into the hospital after my mother's affirmation of our "status", my partner and I as lesbians, to find her sitting alone in the dark with her supper in front of her and no one to help her eat it. When I asked her why she was in such a state she said, "They just left me here, even when I told them I can't eat by myself. I tried and tried to move my hands but I just could not do it. I could not figure out why they had done this to me." Because of our reactions to the state in which we found her, the nurse came along and told me that, because we all were not family, if we did not settle down we might be asked to leave. It was at moments such as these that I wonder why it is even difficult for

others not to see that the nature of our own sexuality is viewed differently than for women and men of the heterosexual community. Again it is hard to find any hard facts or evidence to back up this claim except to say that when I observed other families take issue with the ways in which the staff was treating their loved ones, they appeared to get immediate attention from heads of departments or staff. One woman said to me that she did not like the fact that staff had not been in to check on her husband's medication drip for over an hour and the staff jumped to it when she spoke to them. She told me "all you have to do is speak up and then you get action." I cannot say the same happened for any of us.

Time and time again when we raised problems and concerns which we felt were not being addressed, our concerns were often ignored or pushed aside. One incident comes to mind: when I questioned one of the staff about whether or not Mum had a bath, the woman said to me, "If you were not as focused on your 'friends', you would have known that was taken care of quite some time ago." Some might suggest that this was simply a clash of personalities. However, when either I, or my partner, or our roommate, were making simple inquiries, these types of situations kept arising with different staff and not just one individual. These problems may not just have been connected to our sexuality because at times it appeared to be our gender that was a major factor. The fact that ours was a matriarchal family, without apparent heterosexual privilege, may have produced some of the tension. I observed that the responses and interactions between other families, that were not all female and who fit the

traditional notion of family, and the staff were different and far more positive. These more positive interactions may have diminished the levels of stress and pressure in the situation for the heterosexual caregivers. For me, the stress, pressure, and need to avoid conflict increased as a result of the staff responses to our situation. For those involved in this often heart wrenching journey, the constant battle to try and maintain the relationship between the caregivers and the one being cared for is a primary need. Denial of the expression of that need was devastating for my mother, my partner and other family members with us (see also Cruikshank, 1991).

As Brookes (1992, p.13) points out, the difficulties in undertaking autobiographical analysis are enormous. It demands that I confront my past and go beyond my own preconceived notions of what constitutes "serious academic" work. I work with what is not already there. Having the work and the experience as a caregiver acknowledged is being able to participate in controlling my own position, role and status as a caregiver, rather than being simply a passive participant in the construction of the reality of my experience as a lesbian caregiver by others.

I grew up in the late 1970s and 1980s and, in that time, being a lesbian was still considered a mental illness, abnormal, sick and depraved. It may be difficult for those who grew up in a different era to comprehend the complexities of the development and construction of my identity as a lesbian and as a caregiver, which dominated every aspect of my life and left little room for much

else. Through my life, I experienced changes in my attitude and beliefs which affected my development as a lesbian and also as a woman. A lot of my beliefs and attitudes came from the assumptions and presumptions of the dominant culture at that time.

I dealt with considerable indifference to my development as a young woman and the beginnings of coming to a realization that I was 'different' from other young women my own age. At that time I had no particular term for who I was, because I did not hear the terms lesbian, dyke, lezzie, butch, bull-dagger until much later on in my life. It was not difficult to suppress my lesbian identity, since, by my late teen years I was a full-time caregiver to my mother, my brother, and his wife. Caregiving was the identity that had taken hold for me. I looked after Mum's needs more and more. At this time it was starting to become clear that Mum's health was not as good as it used to be. For some time I did not consider that she might be becoming really ill. When she dropped things, I had to pick them up for her. I had taken over the family tradition of writing Christmas and birthday cards as she was having trouble writing. She was finding it hard to see the writing in her books, so I took to her to eye specialists. Even though I should have been able to see the shift in our relationship, from mother and daughter to more a caregiver and the one needing care, I could not. It was more than a matter of not realizing that the shift was occurring. This failure to see what was occurring in our relationship was also connected to my refusal to recognize my sexual orientation. I did not want to be abnormal. I worked extra hard at

maintaining the perfect public impression and to be really sensitive to the ways and behaviors of the “regular, normal” people around me. I was so good at hiding this part of myself that I, at times, could no longer tell the difference between the real me and the public persona presented to everyone else. The caregiving role was real to me and, in effect, had become me.

By the time I was almost eighteen, my life became consumed by my role as acting parent for my brother and his first wife. This role was taking over and was beginning to consume my life. It was, for me, a choice that was the right one, the normal one. I know now that I was seeking to hide from the condemnation of my friends, family, and my community. I knew that I must have done something wrong to be like I was but I thought I could make it right by taking care of everyone. My mother no longer took an active part in running and maintaining the household. She ignored and kept at arms length her role as mother and head of the household. I remember one incident that drove home my true role and position in the household. I came home from school and Mum was home on vacation from her paid job and the house was a wreck, the dishes not done and the bills sitting on the kitchen table unopened. Mum said to me, “Linda, the bills need looking at and you need to clean the house and I want to know when you are going to get groceries.” I looked at her in utter amazement. I said “Why don’t you take care of it? I have school work to do.” “Oh! You do it so much better than me. You know how to take care of everything.” For Mum it now seemed too hard to do anything else but go to her paid employment. The

rest of her life just appeared to be too much for her. At this time I had no idea that Mum was already ill with diabetes and high blood pressure. The rest of her chronic health problems would come later. My mother was enthusiastic of and really encouraged my role as the main caregiver. As her level of health and energy became worse, so did the level of care, workload, stress, and strain for me. The evolution of my caregiving role and identity moved ahead rapidly.

Through other people's reactions to me, I had been warned of the consequences of being perceived as weird, strange, or odd. I also recognized that there was a safety in being immersed in the caregiving role as surrogate mother and primary caregiver to my household. My sexuality was to remain hidden, in fact, to lie dormant for a long time, as the presentation of the acceptable public persona of dutiful daughter brought with it approval from those around me.

At times, when watching Mum immersed in yet another movie, book, crossword, knitting, or television program, I could see and feel that, in many ways, she was as helpless as me to escape our lives which had become entwined. The corridor between individuality and dependence was narrow for both of us, but at most times it appeared to be particularly so for me. At the time, I found that I had no words or definitions for the parallel closets of developing as an unwilling caregiver and a lesbian that I was very effectively creating for myself, that would stand as a testament to the rigidity of my own unwillingness to accept and explore the nature of my own sexuality. Each 'self' lived in closets of my own creation, lined and separated with my experiences as a caregiver, a

woman, and a lesbian. There was nothing there in my life that was equal or symmetrical and the only road to acceptance and validation was through my role as a caregiver. My identity was now multi-dimensional. Fragments and pieces of my independence, an individuality separate from my role as caregiver, continued to be stored and hidden away in the dark upon those shelves in my closet. I watched from the perimeter of my own life the intricate safety of what was, in many ways, a fantasy life; one that provided shelter and protection from what Mum could not or would not live with.

I had learned to live inside a role rather than inside my body, what Brookes (1992) describes as a safe, acceptable, normal status. I was a caregiver. Brookes also discusses shutting out feeling and emotion, and living inside her head. I transferred feeling and emotion into trying to live as the image of “perfection” in the form of the perfect caregiver. I moved away from my body and even further away from my sexuality and sexual orientation. The caregiving role allowed me to exchange feeling, emotion, and sexual desire, for a role and an image that was respected and normal. Brookes also says that, by living in her head, she found a way in which to live and cope within a male-organized world. I could utilize my own ability as the perfect caregiver, surrogate mother, and nurturer, as a means to remove myself from true emotion, feeling, or living.

This is a point at which I cannot help but comment further on what Brookes (1993) says, which is relevant to my discussion in this chapter.

Brookes defines for me what is in fact so important about work and research of this nature:

Feminism is not, however, some new kind of truth. Rather, feminism is a perspective from which to examine relations of power. To examine relations of power is, in my opinion, to examine how they differently organize, sexualities, genders, races, and classes. Because I start from the assumption that the focus of a feminist perspective is a critique of power and how people are differently organized by relations of power (p.48).

At that point in my life the multi-leveled layers of power relations were starting to control and consume the course and path of my life. I was constructed, at least in part, by the power differences between my male siblings and myself. At no time were my two brothers involved in the ever-increasing caregiving responsibilities for my/our mother. Both of them left Mum and me behind to go and pursue their own lives, careers, and relationships. It was not until almost the end of Mum's life that they reappeared in any capacity in our lives. Their reappearance did not in any way provide support or relief from my role as a caregiver. They altered the dynamics between my mother and myself, and the constant struggle with community and societal perceptions of what and who as a woman I was supposed to represent as a caregiver became a central focus of my life.

I now find myself coming to what most would presume is the end of my caregiving journey, but nothing could be further from the truth. This next portion of the thesis deals with the stories surrounding my mother's final illness, and her death. It was then that I came to realize how my past and my development as an

invisible lesbian affected my role as a caregiver. Earlier, I talked about taking my mother to the emergency room because we thought she had a stroke. This turned out to be the case. She had to be admitted to the hospital. Mum was filled with fear and terror at the prospect of not only of going into the hospital but also of never leaving it. At that point, the doctors were unsure what exactly caused the stroke. There followed what seemed to be an endless array of tests and examinations. In and through all of this, I tried to turn to my partner, and she to me, to seek solace in one another. On one occasion, drained completely by the situation, I leaned against my partner in sorrow in a waiting room, only to see others in the room staring at us and pointing and whispering. Even though we had not really been cognizant that our lesbianism was a secret, it was as if our secret was exposed. At a time when it was apparent that we both needed that closeness, both of us felt that we needed to separate and sit apart from each other. In that moment, I re-entered the role of what is perfect, normal, and straight.

Once again I accepted my title and role as the caregiver and accepted my title of the 'good' woman and left the lesbian in the closet. I realized that, in order to ensure acceptance and care for Mum, I had to be presumed heterosexual. When Mum was moved onto the ward, I moved in with her. I maintained my vigil, and my vigilance, knowing full well the terrible consequences for her if I was to cross the boundaries of my gender and sex role again. I told myself I did not need those other aspects of myself anyway. They

were not relevant to the situation as far as I was concerned. I pushed most of who I was so far down that I no longer recognized who I was becoming. I was living, breathing, and functioning for Mum; everything was now about her. I said to her one day, "The cancer was gone, you beat it and you were home free!" "Linda, don't you mean you beat it, and you were home free? My illness getting worse does not mean you failed, you know." I saw Mum's failing health as my failure as a caregiver and a woman.

I was the one designated to make all the decisions with regard to Mum's care. We received the results of all the tests, and the doctors came to me to tell me that the stroke had been caused by rapidly advancing cancer. The cancer had invaded most of Mum's vital organs and they told me that she would not survive. This was a devastating blow, one which I really was unprepared for, even though I thought I was. I now had to face telling my mother that she was going to die. As her caregiver for the last twenty years, I did not know how to provide this kind of assistance, support or advice. As I prepared myself to go into her room, to deliver the news, I was consumed with questions and thoughts. Did my being a lesbian have any bearing on this outcome? Would the doctors and medical staff have worked quicker and faster to diagnose and treat her if the specter of my sexual orientation had not been a distraction or more of the focus than Mum's illness? Had I killed my mother? All sorts of odd notions like this came into my head.

I had to ask myself if other people spent as much time wondering about such things at such a time, or was it specific to me. So many things were going through my mind. What will I say? How will she take it? How will I live without her? Who am I without her? Each step towards the ward and the room Mum was in filled me with guilt, shame, and sorrow. I entered, sat down and said, "Mum, you know the tests are back, and we have to talk about them, o.k." I looked into those kind eyes and held her hand and said, "Mum, we have done pretty well up until now haven't we, but this time we cannot win, I cannot win for you, we are not going to make it." Mum looked at me and said "It's o.k. I already know, I knew when everyone kept avoiding my questions about all of the tests." Mum was sitting straight up in that bed, her eyes were clear and she spoke perfectly clearly to me. In that moment I knew that she had chosen her own path, to complete her own courageous battle and remain the woman I had always known her to be. And I consciously chose to be with her: I was her daughter, another woman, and her caregiver. Yet in the midst of this conversation, as I chose to stand with my mother at the end of our caregiving journey, I had to ask myself: Is it possible to face the possibility of her death or will I crumble when she needs me the most?

When it became clear that Mum was not leaving the hospital, we had an uphill battle with the medical team assigned to her, to try to have her moved to a private room. The 'team' focused instead on what I considered a useless expenditure of time, re-explaining what Mum already knew, that her illness was

terminal. After much of a battle with timing, red tape, availability, and trying to negotiate a way to be able to take Mum home to die, we finally did get her into a private room. I stayed in this room with her and did not leave for the next fifteen days. It was then that I sought for places and people that could help to alleviate some of my burden. I was to find none. Everywhere I turned I could see nothing of myself or my life's experiences in any of the people or places in the medical/health care setting.

As I walked the floors of the hospital, I learned what it means to survive even when completely lost and separated from one's 'self'. When I saw the straight families and their networks of support, pouring not only from their own world but from the medical/health care world, I remembered a section on jealousy that Meigs (1981) wrote. She said, "[m]any women, particularly lesbians, having explored the nature and external presence of jealousy in their relationships, have attempted to eliminate it by sharing in a free exchange of love. But is it possible to release your rage and suppress your jealousy?" (p.214). While Meigs was not writing about caregiving, I was reminded of that passage in the midst of my grief, my loneliness, my rage, and my jealousy. I wanted the same support and caring to be offered to me and mine at this time. I wished I could rid myself of the jealousy, but I could not. I looked at the loving supportive nature of these other people's support systems and pondered the absence of my brothers, who told me that "I know that you and the girls are

taking good care of Mum, we're here if you need anything". I think what they meant was that they were safe and distant from the whole process.

As I sat by Mum's bed and listened to her quietly sleeping a fitful sleep, I considered that my brothers were lucky, or so I thought. Both my brothers were raised with the sense of freedom and right to an individual nature by virtue of their gender and their heterosexuality. Never once did either of them ever have to consider what life was going to be like as the primary caregiver for not one but five different households over their lifetime. Nor did they have to consider the loss of careers, identities, friendships, lovers, social connections, support networks, freedom, and opportunities. All of these considerations were always and continued to be far from their realities. My sexual orientation was a huge source of friction between us over the years. They had this perception that, because I was unmarried, had no children, and I was her daughter, naturally I would not mind being Mum's caregiver. It never occurred to either of them that, because of my role and duty as Mum's caregiver, I had no chance to have children of my own. In their minds the choice had already been made for me, by virtue of my gender which entrenched me in my role as caregiver for Mum and the household. This was a choice that I did not make for myself. It did not seem to matter that I might have wanted to have children.

Living beyond the death, grief, sorrow and loss of one loved so dearly is for the caregiver a long road, one that deals with many complexities and issues related to this journey. It is now ironic that, as the first anniversary of my

mother's birthday after her death came and passed, the only concrete measure that marked the passing was my own initiation into the world of illness and disease I have been diagnosed with diabetes. As I struggle to gain some control over my own disease, I cannot come to terms with the fact that I am now becoming part of a new generation, of those in need of care, and that my partner is now becoming part of the caregiving process yet once again; first helping me with the care of my mother and now at times a caregiver to me. It is an irony that is often bitter and hard to contemplate or even to accept. There is no mistake that my life as a woman is now truly paralleling my mother's life.

Auger (2003) in "Passing Through: The end-of-life Decisions of Lesbians and Gay Men", writes that

The extensive literature and research on end-of-life issues in Canada focuses primarily on the needs of heterosexuals, with very little mention being made of how these issues affect lesbians and gay men. When mention of our needs is made at all, it is normally with respect to the end-of-life, health related treatment options available to gay men with HIV/AIDS infections (p.10).

This also includes little or no options or choices for members of LGBTQ community who are caregivers and who are faced with having to deal with the end-of-life decisions for loved ones in a primarily masculine and heterosexual medical and health care environment. Our issues and concerns cannot surface in such environments because of fear, rejection, reprisals, and trying to remain closeted in an effort to protect those being cared for in their final stages of life.

Martin's (1993) assertion of the importance of lesbian autobiography underscores the significance of my story. There are issues of dealing with internalized homophobia while living immersed in the health care system. Some of the covert forms of discrimination, homophobia, and heterosexism were easy to identify when examining their operations in the context of my own life history. I clearly had to deal with aspects of my own feelings and behavior in an effort to quell the serious complications and limitations that there could be for my mother's care. I battled with the role and status of being "the caregiver" or being a "lesbian woman". The issues that are of concern to me become multi-layered and more complicated when I consider wanting to be part of the LGBTQ community, which is typically defined by geography, networks, social activity, and political activity. My communities are multi-leveled and are sub-divided, and connections to the rainbow community lack accessibility, which isolates me within the multiple communities in which I reside as a caregiver. There is a certain kind of status accorded to the caregiver in the mainstream, health care and medical world. My ability to pass so that there was no discrepancy between me and the woman who sat next to me holding her husband's hand in a waiting area of the hospital ER was critical in maintaining "caregiver status." My almost passing was to be as invisible as possible. To "hide back in the closet" meant adapting to the changes of not only my environment but the one which I shared with my mother as her caregiver.

The operations of heterosexism and homophobia informed my life as a caregiver. Although she was a heterosexual woman, my mother's life was also informed by these same operations. In this chapter, I have shared a few of the incidents that we experienced in our interactions with the health care community and its professionals. In this telling, I have toggled between actual story telling, on the one hand, and the requirements of academic writing, on the other hand. This is not an easy balance to maintain. I do not want to render our stories into a dry, emotionless prose but, at the same time, this chapter needs to exist within this thesis for a reason. I turn, in closing, to Ken Plummer (2001), who noted that "[m]ost social science somehow comes to be written as if the author is not there. Words glide across the page, but the composers of such words count as little. ...a small group...usually feminist-inspired are...fighting back. ...They are reasserting the importance of *the self in the text*" (p. 180, emphasis in original).

I am fighting back, against the health care professionals who either preferred me to be invisible, or who tried to make the novelty of the lesbian in front of them count more than their patient. I am, through this work, reasserting the importance of my self in the text that is my life, as well as this thesis.

Chapter Five: Discussion of Issues and Findings

Observation Notes (Toronto, Canada, February, 2003)

Upon first glance, the LGBTQ community of Toronto appeared to be a paradise for those seeking a place they could call home and community. But, as I walked the streets of this large and extensive community that runs through several blocks and other parts of the old part of Toronto, I began to see little in the way of a lesbian women's presence, particularly lesbian women who were over forty. The lack of lesbian presence was especially noticeable with regard to older lesbian women and those that were in the caregiving role. I could at no time see anyone who even resembled a similar situation to mine. At first it was not at all clear to me why this was the case; in fact prior to my arrival I believed that Toronto would have a vibrant older lesbian community in which I would be able to access more information about caregiving issues and the impact on members of the LGBTQ community who were in that role.

After going to the LGBTQ community center, I discovered that there are only two lesbian groups that meet; one meets regularly and the other only informally once a month. There were none that dealt with or provided support specifically for lesbian women who were caregivers. Taking into consideration the size of the Toronto LGBTQ community, these groups can hardly fulfill the need of its older lesbian women's population or its members who are also caregiving. In terms of getting around to accessible lesbian businesses, services and organizations, it is not all that easy, especially for older lesbian

women who are from out of the area and may be differently abled, or for those who may have to take those they are caring for with them and may not be able to get around easily. For an older lesbian caregiver seeking information and access to services and resources, the wait can be long and the journey difficult to get where the information is. GLAD Toronto, the oldest and possibly the largest LGBTQ book store, is up two flights of stairs that have walls lined with various pictures and portraits of gay and bisexual men, but little or no representation of the lesbian woman's experience. Over all, LGBTQ people in the community were very friendly and the one social club that appeared to have a larger group of over thirties was a really nice club called the "Looking Glass". It also was not accessible to those with physical limitations. There was little indication that many older lesbians even frequented the obvious male and youth orientated structure, style, and feel of this large LGBTQ community.

Visibility of lesbian women is quite low and even lower for older lesbian women. I asked one older woman why she thought there was such a small presence of older lesbian women and she said and I paraphrase here " the going out to clubs and socializing is for the younger ones and a lot of older women have a lot of other commitments and responsibilities and besides that I know a lot of older lesbian women who are recovering from alcohol or drug abuse". I would also add that many older lesbian women do not have the disposable income, resources and time that many of their gay male counterparts have. Also, older lesbian women like myself often have full-time responsibilities

in their roles as caregivers. After frequenting as many men's clubs and bars as I could, it was clear to me that the gay and bisexual men's clubs were nicer, larger and had a lot more to offer to entertain their patrons. Everything, from gay clubs, gay health clubs, social networks, the community center, literature, advertisements, clothing, to actual people, were primarily male.

While in Toronto, I spent some time discussing informally with a small group of older lesbian women with whom I came in contact during my visit, the issues that were important to them and what they wanted to see in the community with regard to changes. There appeared to be some concerns over lack of visible symbols of lesbian women's lives. Certainly nothing reflected my reality as a lesbian caregiver. Certain practices, language, socialization, and lack of visual representation of lesbian women may indicate to some lesbian women they are in an environment that will not address their needs and one in which they may not feel completely comfortable to express their needs. I know I did not as an older lesbian woman caregiver over forty.

Observation Notes (Golden Threads, Provincetown, United States, June 2004)

Upon arrival Provincetown seemed to be like a sun soaked paradise. My partner and I were not quite sure how to find our way to the hotel where the conference of older lesbian women was being held but we did not have to wait long, it just so happened that the organizers were there seeing off some friends of their's and offered to take us to the hotel. We got acquainted and they told me and my partner about the conference and its history. I spent some time

telling them why it took me so long to attend one of their gatherings; the cost, the time, the travel, the accessibility, and being able to find some one to care for Mum while I was away at this conference.

Going to Toronto was a very different experience than going to “Golden Threads”, especially considering that Toronto’s LGBTQ was more accessible in terms of cost and travel. The experience of getting to know all of those older lesbian women from the United States and other countries was a direct contrast to Toronto (and even Halifax); the journey to get there from beginning to end was quite difficult at times but was worth it. The flight was uncomfortable and not all that accommodating to me or my partner’s health concerns; the same was true of the fairly remote location of the hotel for this conference. It was a small plane and there was little in the way of services such as serving food or a small meal, which for both of us was important; Wendy and I both have health problems that require regular meals. The hotel was located on the far most part of Provincetown and was hard to get to. Another concern for me was the difficulty in actually being able to find that such a conference even existed or was available for me to attend. If I did not have access to the internet, have research skills, know LGBTQ groups/organizations here in Canada and the United States I may never even have found the “Golden Threads” gathering.

Once there and settled the organizers let me know that my presence as an observer from Canada would be to meet and get to know people; I was not prepared for the response to me and the work I wanted to do in Canada. When

the lesbian women at this gathering/conference found I was there and what I was doing, they wanted to really be a part of the research and were very willing to participate. Older lesbian women sought me out at every turn; I started to know what it might be like to be a celebrity. Lesbian women would stop me in hallways, after workshops, after seminars, and even came and knocked on my hotel room door wanting to tell me and talk about their experiences as lesbians and as caregivers. Some even brought along their partners that they were caring for and I was able to hear stories/experiences from the lesbian caregiver and some lesbian's who were being cared for. This was a very unique experience for me and after talking and listening to many different lesbian women, it became clear to me that these women wanted their experience's of becoming older lesbians and being a lesbian caregiver or being cared for to be told.

It was now clear to me that this group of lesbian women wanted this information to be available, to be accessible, to be visible and most importantly to be told. I knew that this was important research that needed to be done. The desperation of these older lesbian women to tell their stories/experiences of growing older and of caregiving underlines my contention how important this research on lesbian caregivers is. Many of the lesbian women there felt that this was an issue that no one cared about and some even found it funny that some young lesbian woman from Canada came all the way to Provincetown, U.S.A. just to find out what was like for them to grow older and be a caregiver and a

lesbian. Many found it hard to believe that I was really serious and wanted to hear their stories/experiences. Once they realized that I was serious I could not stop them from approaching me, at no time did I have to approach anyone. It was surprising to me that some were very disappointed that I could not interview them and use the data in my research. I had to explain that I was just observing and did not have approval to conduct formal interviews. Many volunteered to participate in anyway they could if I decided to do formal interviews.

Two older women in particular struck me because of the similarities between their life experiences as lesbians and as lesbian caregivers and mine. They had an age difference between them, and they were looking after one of the women's mother. They had given up their house and own life to move in with the mother. This short term arrangement turned into years. They stayed with the mother until she died. I paraphrase here that they both pointed out the toll it took on the life they could have had. They told me that I was too young to have that kind of burden and to make sure that I did have a life of my own before it was too late. They were together for over thirty years but after the mother died the years of strain, stress, and burden finally ended their relationship. I still keep in touch with them and they now live apart and in separate locations but are trying to work on re-building a friendship. This for me is a poignant story and why such research, travel, cost, and time is important as well as the importance of older lesbian women's own voices to be heard. This was but one group of

older lesbian who are also caregivers; there are many more out there waiting to be heard from.

Discussion of Issues

A major theme throughout this thesis has been invisibility and lack of representation of older lesbian women's voices and their experience of the caregiving journey as well as growing older inside and outside the LGBTQ community. Another strong issue for me was the severe lack of up to date material to draw on for this thesis. Many of the pieces of literature, as well as my own observations, indicate lack of resources or developed social networks for other older lesbian women caregivers, which continue to affect older lesbian women who are in the caregiving role, keeping them marginalized inside and outside the LGBTQ community.

Other considerations include loneliness, isolation, and lack of resources and services specifically geared towards the needs of older lesbian women caregivers. While many authors have noted that there are many similarities between lesbian women and heterosexual women in the aging process and through the caregiving journey, there are also differences in the forms of relationships, family units, types of socialization and interests, as well as a need to find a place within the LGBTQ community, that differ for lesbians from the experience of their heterosexual sisters.

Loneliness exists in many areas of both the LGBTQ and straight community for older lesbian women who are also caregivers, and can have

negative effects on the type and quality of the caregiver role that is experienced, which can vary from individual to individual. Throughout this thesis there have been examples of positive experiences that older lesbians have had with regard to aging and growing older that connects to the kind of quality of life that a lesbian caregiver can have. Many of the positive aspects of aging and growing older in this thesis have been related to freedom, being able to come out of the closet in a climate in society that makes it more acceptable to live life as an out lesbian woman who is getting older and who is also in the traditional role for women of caregiving. But, it is important to note that while there is a lot of information in this thesis that leads me to believe there are many positive aspects of growing older and caregiving for older lesbians, there are also negatives. Kehoe (1989) discusses some of the responses from her study in relation to the question about loneliness and isolation.

Those who participated in our study are survivors, coping with loneliness and the aging process rather well. But they are, as we have already noted, a select group. Many of the most vulnerable did not hear of the study, so could not be involved. Some of those who did fill out the questionnaire had poignant comments scribbled in the margin. In answer to "What is your present living arrangement?" a 70-year-old from a rural area in the Middle West wrote, "I live with my black-and-white cat," and that she travels more than 100 miles monthly to attend SOL meetings in the nearest city, just to have contact with people she can relate to (p.36).

Rusty Brown comments in the book "Long Time Passing: Lives of Older Lesbians", in an article "Always Me" (1989), on the importance of the LGBTQ community.

We had very few gay friends. There were very few places you could go to meet other lesbians. The gay bars in New York were mostly men. We were more or less isolated. When we went out men would often say things and harass us. Our getting involved in the gay community did not start until we came to Los Angeles. I'm very grateful for the gay friends I have here. I've never been in the closet; I've never pretended to be straight. It feels good and secure to be surrounded by lesbians. Also, when Terry got sick, those friends gave me a lot of support. I wasn't alone (p.151).

Many of the positive experiences of growing older for the lesbian in the caregiving role are connected to accessibility to their community of choice. Many older lesbians found on the pages of the literature included in this project who indicated satisfaction with retirement years lived in urban centers, had access to more LGBTQ services, more money, were white and were college educated. Almost all of the literature collected for this paper is of white and affluent older lesbians. The samples are usually small and don't represent the diversity among older lesbian women who may be in the caregiving role. Thus, there is no insight into lives of these lesbian women who are also faced with the challenges of day to day living as lesbian women and as caregivers. The comments above indicate the importance of a strong connection to the LGBTQ community for the lesbian woman who is a caregiver when growing older, as a positive influence on the quality of that caregiving experience.

Chapter Six: Implications and Conclusions

Implications

The purpose of this thesis was to look at issues and experiences of older lesbian women who are caregivers and the issues and concerns that may alter their ability to grow older in a healthy and positive way beyond the caregiving role, or if that role actually ends, and what type of ending it may be. The information gathered for this thesis has been gathered from various pieces of literature that dealt with many different issues of the caregiving and aging process for older lesbian women from different perspectives. Some of the lesbian women whose stories are in this research have experienced loneliness, joy, satisfaction, invisibility, isolation, and homophobia within mainstream society. I focused much of my attention on autobiographical, historical, archival, secondary literature sources and personal narratives in an effort to include those who may not have been willing or able to participate in a face-to-face interviewing process, as well as to bring to light the value of the written word from lesbian women's own perspectives when doing research that may otherwise be impossible to accomplish.

Assessments of older lesbian women's caregiving experiences in relation to growing older and being part of the mainstream society and culture are, for me, a theoretical question that could not rely on conventional means to access the needs and wants of these women after they either go beyond the role of caregiver or continue along in the role as they continue to grow older and age.

Traditional methods for this particular project ran close to the experiences of many older women who are caregivers, not just older lesbian women caregivers. However, much of the information collected did indicate that there is a strong indication from older lesbian women caregivers that sexual orientation and their needs are rarely considered inside or outside the LGBTQ community.

The older lesbian women's aging stories are related and connected to the role of the older lesbian caregiver and, in this thesis, I have indicated the strong variation in the different ways of growing older, aging, and caregiving that each of us has, and how different issues related to the LGBTQ experience is a strong factor in the quality of the caregiving experience for each of us. Gender and age are components that also must be given consideration, but overall it is clear that lesbian identity and lesbian sexuality figures prominently into every aspect of these women's lives as they grow older and live inside the role of the caregiver.

Myer, .M. K. & Raphael, S. M. (2000) point out that

Today's midlife lesbians are the post-Stonewall generation who, more often than not, disclosed their lesbianism at the same time that traditional values and ideology regarding gay people were being challenged in the courts, in the media, and in the streets. According to Brown (1988) and Strommen (1989), there is no uniform response to the disclosure of a gay or lesbian family member. But the increasingly positive social acceptance of lesbianism assists the family, over time, to come to terms with their lesbian children. Homophobia shapes both the process of the lesbian daughter's self acceptance of her gay identity and the family's reaction to disclosure of her sexual orientation (p.141).

It is time that older lesbian women feel free to disclose their identities, while challenging the myths, assumptions and stereotypes of the aging process and the retirement years of their lives. A more positive acceptance of the different forms of aging and dealing with the role of the caregiver for lesbian women will help to assist them and those who love them to deal with both the positive and negative aspects of becoming older and being the caregiver. If caregiving and issues for older lesbian women don't continue to be addressed it will continue the invisibility of a group of women who have largely been ignored by society and academia when looking at issues that affect aging, unhealthy, disabled populations in both Canada and the United States.

The experiences of women, whether they are straight, lesbian or bisexual, are not usually the central focus of concern in either research or traditional mainstream culture. The experiences of older lesbian women caregivers who have faced many obstacles and barriers in being able to have a life separate from their role and status as caregivers are still invisible and marginalized by being a sub-group of an already oppressed group because of their sex/gender. This also does not take into consideration even further sub-grouping with regard to class, race, economics, and religion. I wanted to provide some evidence of real experiences of lesbian women after they grow older and connect those experiences to the caregiving role that some have undertaken, and to hear some experiences through the personal narratives and autobiographical portion of this

thesis which I used, that allowed for my own voice as well as some of their voices to be heard.

Reflections and Conclusions

Some thoughts throughout this process continue to give me concern. The main thought is the presumption and assumption that the role and status of being a lesbian caregiver ends when those that are being cared for either die or go into LTC facilities. Often, within and outside the medical/health care setting, I sense a prevailing attitude at such a point of a job well done and carry on. There are no follow-ups for the caregiver in either a medical/health care fashion or in current mainstream research. There are also the uncounted costs of being a caregiver, financially, emotionally, psychologically, and socially. In my own situation, I have been left with the responsibility of being the executor of my mother's estate and having her creditors look to me to pay her debts, not to mention the untold number of hours, time, energy and strain this puts on me trying to put back the pieces of my own life. I now spend all of my time trying to figure out what my place is in the world, now that I have spent most of my life being created and constructed to be the caregiver, devoid of my sexuality and identity as a lesbian. Another thought I have is the uncounted and countless hours of unpaid labor that has not been paid for by society for my contributions. I reflect on the many years of non-paid work and development of skills that have not been viewed as marketable in the paid workforce. There is no place or

organization that I know of that can help assist me in adapting all of those skills I developed into recognized skills desired by the paid workplace.

I also spent some time considering that, for twenty of my most productive working years according to the traditional standard by western society and culture, I put nothing towards retirement. As an unpaid caregiver I have no RRSP's, GICS, Bonds or investments or money set aside for the day that I turn sixty-five and leave the paid workforce. There is also no medical plan to take care of my failing health to deal with my own illness and disease, and no life insurance to help me get by until I find 'paid employment'. I now live in poverty, unemployed and without the heterosexual privilege that comes from having a male partner. As a lesbian woman I am without the acceptance of my relationship with another woman, or understanding from others over our lack of monetary success. I never considered the devastation and loss of my lifestyle and way of living that would come with the loss to my mother's income of two-thousand four hundred dollars a month. Our intertwined lives and inter-connected roles as caregivers and providers proved to be devastating. It would be of note to go back to lesbian caregivers after a few years when the traditional form and sense of caregiving has ended and see what has become of the lives of these women.

More formal research needs to be done in forums for and with LGBTQ caregivers and elders, to discuss their most urgent needs by sharing their stories of isolation and discrimination to assist all communities concerned in being able

to provide advice and services that are more tailored to the needs of those who seek assistance. Development of a resource manual and other information could be made available to both urban and rural older lesbians in and out of the LGBTQ community. Non-discriminatory training programs could be developed and provided for those who work with older lesbian women caregivers in the medical/health care communities as well as in mainstream communities and those who work in the LGBTQ community. Such programs would address the diversity of its community members and would include the old and those who are caregiving. As well, we need to create an awareness, sensitivity to, and educate on the needs of lesbians who have grown or are growing older and are also caregivers, to help break down barriers that already exist for these women and develop support networks that extend beyond the traditional model, and the perception of the caregiver that will extend beyond the death of, or the transition into LTC facilities of those being cared for.

Research such as this should continue and some areas to examine may be as follows:

- ◆ Looking at the value of developing and creating interactive workshops between older lesbian women caregivers and members of their respective communities: mainstream (straight), medical/health, LGBTQ.
- ◆ Research on the development of websites that may assist an older lesbian woman who is caregiving in finding information on issues of concern to her.

- ◆ Research on areas related to connecting older lesbian women caregivers to larger established social groups such as “Golden Threads” from the United States and “Silver Threads” in Canada.
- ◆ More research that draws on the wealth and debt of the lifetimes of experience and knowledge before these remarkable lesbian women’s voices are gone.
- ◆ Development of a book that expands on my autobiography that would include resources, information, websites and groups and organizations that may be of assistance to lesbian caregivers.
- ◆ Explore ways in which to develop groups or organizations in Atlantic Canada that could serve members of the LGBTQ communities who are in caregiving roles.

This project was conducted to give voices to many older lesbian women caregivers who even today remain unheard. In a time when our population is rapidly growing older and aging, caregiving and other issues related to this phase of many women’s lives become a reality. It is important that older lesbian women have our concerns and needs considered in our ever changing society.

Ageism and sexism can be fought on many fronts but the battle to eradicate homophobia within LGBTQ communities presents new challenges. Work of this kind has to become more common place, to include a large group of people that up until now have had almost no consideration of how their communities will change to serve them in the aging and caregiving process.

Similarities between lesbians and their heterosexual sisters need to be researched more to find where common ground exists and where the divisions are, to better assist both groups in understanding and appreciating the diversity that exists in all groups of women.

Older lesbian women have written many pieces of literature in the eighties and nineties and now is the time for that work to continue. We of this generation must pick up the torch and go forward so that the caregiving journey and years of older lesbian women are happy, joyful, empowering, and a fulfilling experience. As researchers we must be able to look beyond the borders of mainstream culture, to include groups of women that have traditionally not been seen as important as other groups. As human beings we all are connected in one way or another. It is possible to benefit more than just the group being researched.

I hope that this thesis gives those who read it some insight into various aspects of the caregiving journey and its connections to the aging process that affect older lesbian women's older and aging years. Older lesbian women have to plan for their senior years the same as their heterosexual counterparts do, which may be further complicated by full-time roles as caregivers. The difference between us is the fight for equality and fairness. The hope is that lesbian women who are caregivers will no longer have to reject their older faces or lesbian identities but be free to embrace them.

Works Cited

Adelman, M. (1986). Long Time Passing: Lives of Older Lesbians. Boston: Alyson Publications, Inc.

Adleman, J. (1995). We Never Promised You Role Models. In Dyke Life: A Celebration of the Lesbian Experience. (Ed.) Karla Jay. New York, New York: Basic Books.

Angrosino, M. V and Mays De Perez, K. A. (2000). Rethinking Observation: From Method to Context. In Handbook of Qualitative Research, Second Edition. (Eds.) Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, California: Sage Publications Inc.

Aronson, J. (1994). Old Women and Care: Choice or Compulsion. In Gender, Aging and The State. (Eds.) P. Leonard & B. Nichols. (pp. 17-43). Black Rose Books.

Auger, J. (1990). Lesbians and Aging: Triple Trouble or Tremendous Thrill. In (Ed.) Sharon Dale Stone, Lesbians in Canada, (pp. 25-34). Toronto: Between the Lines.

Auger, J. (1992). Living in the Margins: Lesbian Aging. Canadian Women Studies 12(2): 80-84. York University. Ontario.

Auger, J. (2002). From the Inside Looking Out: Competing Ideas About Growing Old. Halifax, Nova Scotia: Fernwood Publishing.

Auger, J. (2003). Passing Through: The End-of-Life Decision of Lesbians and Gays. Black Point, Nova Scotia: Fernwood Publishing.

Bauer, M. W. & Jovchelovitch, S. (2002). Narrative Interviewing. In Qualitative Researching with Text, image and Sound: A Practical Handbook. (Ed.) Martin W. Bauer and George Gaskell. Thousand Oaks, California: Sage Publications, Ltd.

Bauer, M. W. (2002). Analytic Approaches to Text, Image and Sound: Classical Content Analysis: A Review. In Qualitative Researching with Text, image and Sound: A Practical Handbook. (Ed.) Martin W. Bauer and George Gaskell. Thousand Oaks, California: Sage Publications, Ltd.

Beagan, B. (2005). Caregiver Portraits: Narratives of 14 Women Caregivers in Nova Scotia: A Report of the Healthy Balance Research Program. Dalhousie University, Department of Occupational Therapy, Halifax, Nova Scotia.

Berger R. M. (1982). Gay and Grey: The Older Homosexual Man. University of Illinois Press: Chicago.

Berger R. M. (1982). The unseen minority: Older gays and lesbians. Social Work; 27(3): 236-242.

Berger, R. M. (1984). Realities of Gay and Lesbian Aging. Social Work, 29, 57-62.

Brookes, A. L. (1992). Feminist Pedagogy: An Autobiographical Approach. Halifax, Nova Scotia: Fernwood Publishing.

Brown, R. (1986). Always Me. In Long Time Passing: Lives of Older Lesbians. (Ed.) Marcy Adelman. Boston, Massachusetts: Lyson Publications, Inc.

Cahill, South & Spade. (2000). Outing Age: Public Policy Issues Affecting Gay, Lesbian, Bisexual and Transgendered Elders.

Charbonneau, C. & Lander, P. S. (1991). Redefining sexuality: women becoming lesbian in midlife. In (Eds.) B. Sang, J. Washow, & A. Smith. Lesbians at midlife: The creative transition (pp. 35 - 43). San Francisco: Spinster.

Code, L. (2002). Encyclopedia of Feminist Theories. New York, New York: Routledge.

Cooper, B. (1988). Over the Hill: Reflections on Ageism Between Women. The Crossing Press: California.

Cox, B. & Waller, L. (1991). Bridging the Communication Gap with the Elderly: Practical Strategies for Caregivers. American Hospital Publishing, Inc.

Cruikshank, M. (1991). Lavender and Gray: A Brief Survey of Lesbian and Gay Aging Studies in Journal of Homosexuality 20:34, pp. 77-87.

Deevey, S. (1990). Older Lesbian Woman: An Invisible Minority. Journal of Gerontological Nursing. Vol 16, Issue 5, pp. 35-37.

Dunker, B. (1987). Aging Lesbians: Observations and Speculations. In (Ed.) Boston Lesbian Psychologies Collective Lesbian Psychologies: Explorations and Challenges. Urbana, Illinois: University of Illinois Press.

Faderman, L. (1991). Odd Girls and Twilight Lovers: A History of Lesbian Life in Twentieth-Century America. New York, New York: Penguin Books USA, Inc.

Gallagher, K. A. (1995). Centering the Margins: What Can be Learned from Listening to the Voices of Lesbians Over the Age of 55. masters thesis (B.S.W.) University of Victoria.

Gamson, J. (2000). Sexualites, Queer Theory and Qualitative Research. In Handbook of Qualitative Research, Second Edition. (Eds.) Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, California: Sage Publications Inc.

Gilligan, C. (1993). In A Different Voice: Psychological Theory And Women's Development. Cambridge, Massachusetts: Harvard University Press.

Hash, K. (2001). Caregiving and Post-Caregiving Experiences of Midlife and Older Gay Men and Lesbians. A Dissertation Submitted in Partial Fulfillment of the Requirements of the Degree of Doctor of Philosophy at Virginia Commonwealth University.

Healey, S. (1995). RV Life Begins at Seventy In Dyke Life: A Celebration of the Lesbian Experience. (Ed.) Karla Jay. New York, New York: Basic Books.

Henderson, K. (2006). The Dichotomies of Caregiving: Mental Health Challenges Of Informal Caregivers. National Advisory Council On Aging, Government of Canada.

Herringer, M. and B. Isaac. (1998). Lesbian Passages: Invisible Lives and Issues of Community. Journal of Lesbian Studies, 2(1), 49-58.

Humm, M. (1995). The Dictionary of Feminist Theory, Second Edition. Columbus, Ohio: Ohio State University Press.

Keen, L. (1992). The Gay and Lesbian Liberation Movement. (Ed.) M. Cruikshank. New York, New York: Routledge.

Kehoe, M. (1986). A Portrait of the Older Lesbian. Journal of Homosexuality, 12(3/4), 157-161.

Kehoe, M. (1989). Lesbians Over 60: A Triple Invisible Minority. Journal of Homosexuality, Vol. 12, Issue 3 and 4, pp. 139-152.

Kehoe, M. (1989). Lesbians Over 60 Speak for Themselves. New York: Harrington Park Press.

Kerner, K. F. (1995). Health Care Issues In Dyke Life: A Celebration of the Lesbian Experience. (Ed.) Karla Jay. New York, New York: Basic Books.

Kimmel, D. C. (1978). Adult Development and Aging: A Gay Perspective. The Journal of Social Sciences: New York. 34(3), 113-129.

Laner, M. (1979). The growing older female: Heterosexual and Homosexual. Journal of Homosexuality, 4, 267-275.

Leighteizer, V. K. (1993). Other Than Other: An Autobiographical Analysis of the Presentation of Self Within a Socially Constructed Lesbian Culture. Master of Arts, Acadia University.

Macdonald, B. & Rich, C. (1991). Look Me in the Eye: Old Women, Aging and Ageism. San Francisco: Spinsters Ink.

Martin, B. (1993). Lesbian Identity and Autobiographical Differences. In (Eds.) Henry Abelove, Michelle Aina Barale and David M. Halperin The Lesbian and Gay Studies Reader. New York, New York: Routledge.

Meigs, M. (1991). Falling Between the Cracks. In Inversions: Writing by Dykes, Queers and Lesbians, (Ed.) Betsy Warland. Vancouver, BC: Press Gang Pubs.

Meigs, M. (1981). Lily Briscoe: A Self-Portrait an Autobiography. Vancouver, British Columbia, Canada. Talonbooks.

Meigs, M. (1994). Reflections of an Aged Lesbian. Rites. December-January. Toronto, Ontario.

Meigs, M. (1995). About Being an Old Lesbian in Love In Dyke Life: A Celebration of the Lesbian Experience. (Ed.) Karla Jay. New York, New York: Basic Books.

Murphy, M. (1991). Are You Girls Traveling Alone? Adventures in Lesbianic Logic. Los Angeles, California: Clothespin Fever Press.

Myer, M. K. & Raphael, S. M. (2000). Family Support Patterns for Midlife Lesbians: Recollections of a Lesbian Couple 1971-1997. In Midlife Lesbian Relationships: Friends, Lovers, Children, and Parents. (Eds.) Marcy R. Adelman. Binghamton, NY: Harrington Press.

Nelson, F. (1999). Queer Families, Common Agendas, Gay People, Lesbians, and Family Values. In Lesbian Families: Achieving Motherhood. (Ed.) T. Richard Sullivan. New York, New York: Harrington Park Press.

Noyes L. E. (1982). Gray and Gay. Journal of Gerontological Nursing(11): 636-639.

Onken, S. J. (1998). Conceptualizing Violence Against, Gay, Lesbian, Bisexual, Intersexual and Transgendered People. In (Eds.) Lacey M. Sloan and Nora S. Gustavsson Violence and Social Injustice Against Lesbian, Gay and Bisexual People. Harrington Park Press: Binghamton, New York.

Patterson, J. (1986). How to Mend a Broken Heart. In Marcy Adelman. Long Time Passing: Lives of Older Lesbians. Alyson Publications Inc.: Boston, Massachusetts.

Plummer, K. (2001). Documents of Life 2: An Invitation to a Critical Humanism. Thousand Oaks: Sage Publications.

Poor, M. (1982). Older Lesbians. In (Ed.) Margaret Cruikshank, Lesbian Studies: Present and Future, (pp.165-178). The Feminist Press and Margaret Cruikshank. New York.

Quam, J.K. and Whitford G.S. (1992). Adaptation and age-related expectations of older gay and lesbian adults. The Gerontologist, 32(3), 367-374 .

Quon, A. (2003). Bridging the Disability: Pride And Prejudice and Gay Communities. Abilities: Canada's Lifestyle Magazine for People With Disabilities, 57(Winter), 22-26.

Reinharz, S. (1992). Feminist Methods in Social Research. New York, New York: Oxford University Press.

Schoonmaker, C. V. (1993). Aging Lesbians: Bearing the Burden of Triple Shame. Faces of Women and Aging. Haworth Press, Inc.:

Smith, D. E (1987). The Everyday World As Problematic: A Feminist Sociology. 1987. Boston, Northeastern Press.

Tierney, W. G. (2000). Undaunted Courage: Life History and the Post-Modern Challenge. In Handbook of Qualitative Research, Second Edition. (Eds.) Norman K. Denzin and Yvonna S. Lincoln. Thousand Oaks, California: Sage Publications Inc.