VOICES FROM THE INSIDE:
GENDER AND THE MEANING OF CARE

By

REBECCA ANN SIDERS

Submitted in partial fulfillment of the requirements for the degree

Doctor of Philosophy

Department of Sociology

CASE WESTERN RESERVE UNIVERSITY

May, 2016
CASE WESTERN RESERVE UNIVERSITY
SCHOOL OF GRADUATE STUDIES

We hereby approve the thesis/dissertation of

Rebecca A. Siders

candidate for the degree of Doctor of Philosophy

Committee Chair

Dr. William Dale Dannefer

Committee Member

Dr. Gunhild Hagestad

Committee Member

Dr. Eva Kahana

Committee Member

Dr. Peter Whitehouse

Date of Defense

March 30, 2016

*We also certify that written approval has been obtained for any proprietary material contained therein.
DEDICATION

This project is dedicated to:

Robert Binstock, a mentor who cared about this project. Dr. Binstock envisioned potential challenges I could face in the course of this project and provided me insightful feedback, provocative questions, and ideas on how this project may improve care experiences of elders as well as address some of the ways in which we evaluate care practices. As a giant in the field of aging and health policy, I was very fortunate to have had the chance to learn from and be mentored by him.

Ben and Floretta Guancialle, whose circumstances first inspired me to begin thinking about what care is and what it means to the resident and family. My caregiving experience with Ben, both in the LTC facility and in his private home, was one of the reasons for the design of this study. I wanted to focus on and bring to the front stage, the voices of the resident. My friendship with Floretta remains strong to this day and I cherish it. She and her family knows, that when or if the time ever comes of when she needs a caregiver, I would do anything to be there.

St. Paul Homes Community, for whom I could not even begin to thank for the decade of multiple opportunities to care for, and be cared-for by the residents and St. Paul Homes staff and community. I learned so much while working here and I would not be where I am today, nor would I have had the rich experiences of care if it weren’t for this Community embracing me and allowing me to flourish under their employment.
# TABLE OF CONTENTS

DEDICATION ......................................................................................................................... 3

TABLE OF CONTENTS ........................................................................................................... 4

LIST OF TABLES .................................................................................................................. 6

LIST OF FIGURES ................................................................................................................ 7

ACKNOWLEDGEMENTS ....................................................................................................... 8

ABSTRACT ............................................................................................................................. 9

CHAPTER 1: INTRODUCTION .............................................................................................. 10

BACKGROUND .................................................................................................................... 10

My Personal Connection to Long-Term Care ................................................................. 11

Significance of the Research .............................................................................................. 14

Assumptions of the Current Study ..................................................................................... 15

CHAPTER 2: LITERATURE REVIEW ..................................................................................... 17

INTRODUCTION .................................................................................................................. 17

Definitions and Meanings of Care ..................................................................................... 18

Theoretical and Philosophical Discussions on Care ......................................................... 28

The Ethics of Care ............................................................................................................... 28

An Historical Review of Care: Feminist Frameworks ...................................................... 34

Care as Power and Dependency ....................................................................................... 36

Disability Activists’ Perspectives on Care ......................................................................... 38

Social Policy on Care .......................................................................................................... 40

Care as a Basic Society Need or Function ....................................................................... 41

Elder Residents’ Perspectives on Care ............................................................................. 42

Conclusion ............................................................................................................................ 45

CHAPTER 3: METHODOLOGY ............................................................................................ 48

INTRODUCTION .................................................................................................................. 48

Qualitative Method ............................................................................................................ 50

The Study Design .............................................................................................................. 52

Pilot Study to Refine the Interview Guide ....................................................................... 55

Sampling ............................................................................................................................... 56

Data Analysis ....................................................................................................................... 56

Research Setting ................................................................................................................ 58

Recruitment and Sample .................................................................................................. 60

CHAPTER 4: EMERGENT CARE THEMES ....................................................................... 65

INTRODUCTION .................................................................................................................. 65

Major Theme: Care as Control ............................................................................................ 66
LIST OF TABLES

Table 1.1  Historical Development of Standard of Care .......................... 22
Table 1.2  Facility Characteristics of Resident Sample .......................... 60
Table 1.3  Resident Sample ................................................................. 63
Table 1.4  MDS 3.0 Nursing Home Comprehensive (NC) Version ............. 117
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Figure 1</td>
<td>Interview Continuum</td>
<td>48</td>
</tr>
<tr>
<td>Figure 2</td>
<td>Care Area Assessment Summary</td>
<td>119</td>
</tr>
<tr>
<td>Figure 3</td>
<td>Preferences for Customary Routine and Activities</td>
<td>120</td>
</tr>
<tr>
<td>Figure 4</td>
<td>Behavioral Symptoms</td>
<td>122</td>
</tr>
<tr>
<td>Figure 5</td>
<td>Rejection of Care</td>
<td>122</td>
</tr>
<tr>
<td>Figure 6</td>
<td>EAWS Elder Questionnaire</td>
<td>125</td>
</tr>
<tr>
<td>Figure 7</td>
<td>EAWS Family Questionnaire</td>
<td>126</td>
</tr>
</tbody>
</table>
ACKNOWLEDGEMENTS

I want to acknowledge my committee members – my “Giants” whose shoulders I proudly stand. I can only hope to carry on your legacy as boldly and as remarkable as I enter into the next journey.

William Dale Dannefer, Chair – Thank you for choosing to take this journey with me, mentoring me from the beginning of my graduate experience to the end. You never gave up on me, even though I came very close to at times. I am proud to “prove you wrong” today.

Gunhild Hagestad – Thank you for my initial inspiration to pursue this line of inquiry. Your perspective and poignant questions continue to make me think in squiggly lines vs linear, and I although I have definitely followed the fox’s path to get to where I am now (vs the moose), and I know I have always had your continued support.

Eva Kahana – Thank you for your continued support and encouragement over the years. You became a confidant when I needed one most and I appreciate it more than you know. Your advice and mentorship has always been to make me a better student, a better academic, and a better scholar. I am one because of you.

Peter Whitehouse – Thank you for stepping in during the last stage of the process. Your thoughtful and provocative questions and passionate discussions have made this final product much better. I look forward to creating additional opportunities of collaboration between us in the future.
Voices from the Inside: Gender and the Meaning of Care

Abstract

By

REBECCA ANN Siders

In the current reality of care work, what gets counted as care is unilaterally imposed upon care-recipients. As passive consumers of care services, recipients are almost universally treated in the caregiving literatures as irrelevent to the systemic social processes that frame the discourse of care. This is paradoxical in that the recipient is the sole object of the care process. This dissertation is concerned with the relation of the meaning of care to the recipient, specifically, residents in long-term care (LTC). It departs from previous research by shifting the traditional resident as an “object of care” to a “human actor with expertise” in the matter of care. A central premise is that LTC cannot claim to understand care adequately without the perspective of residents. The purpose is to understand when residents are cared-for and identify what they mean when asked about care. Only then can care providers improve quality care.
CHAPTER 1: INTRODUCTION

BACKGROUND

The term “care” is widely used throughout the fields of gerontology, nursing, healthcare more generally, and in women and gender studies. It typically appears as a standard set of service delivery practices that are defined by professional and clinical experts, or in connection with the expanding range of issues and challenges surrounding the role of a caregiver. In these contexts, very little attention is given to what care is or what it means, particularly to care recipients, despite the fact that care is intended to be an act on behalf of them. As Alvan Feinstain (2001) notes, “the viewpoint…of the individual persons who receive care are seldom used” in evaluating quality of care issues (p.206).

In the current reality of care work, what gets counted as care is unilaterally imposed upon care recipients, and also upon frontline caregivers. As passive consumers of caregiving services and practices, care recipients are almost universally treated in the health care and caregiving literatures – as they are in everyday life – as irrelevant to the systemic social processes of everyday activity and discourse, and as objects of care. The lack of attention to the experience of being cared-for represents a significant gap in our knowledge concerning care. Too often, the idea of care is divorced from the practice of caring (Cluff and Binstock 2001). Even when it is not, the care recipient’s voice is still absent. This is the case, for example, in the writings of Nel Noddings, the venerated scholar of care who considers explicitly the meaning and the role of care recipients, recasting their relational position as the “one being cared-for”. Despite her exhortations for more attention to care recipients, Noddings (1984) imposes her own definition of care
and her own assumptions about care recipients’ needs and preferences in shaping her analysis of care. Applied specifically to long-term care, the same can be said of writings of Eden founder, Bill Thomas (1996) and other Culture Change advocates. This is paradoxical in that the care recipient is the sole object of the care process, and is a human being who may have insightful perspectives on care practices (see Stein and Dannefer 2001; Dannefer, Stein, Siders and Patterson 2008; Shura, Siders and Dannefer, 2009). It is remarkable that the question of what care means, and how it is experienced by the care recipient has not yet been critically considered.

Indeed, so far as I am aware, there has been little to no investigation into the meanings and experiences of care from the perspective of care recipients – the very individuals for whom care is being delivered. Therefore, the central premise of this research is that the field of long-term care cannot claim to understand care adequately without including the perspective of those who are its objects and purpose – the recipients of care.

My Personal Connection to Long-Term Care

The idea for this study developed as a result of my work experiences after high school and during my undergraduate years at Pennsylvania State University. I worked in a long-term care (LTC) facility for more than ten years as a certified nursing assistant (CNA), an activity aide, and a fitness/rehab assistant. It was early in my role as a CNA when I noticed there was a significant difference between the experience of being cared-for from the resident’s perspective and the way that care is understood and evaluated by healthcare professionals and state regulators. One of the well-known LTC ‘mantras’ of charting that we would hear from our nursing supervisors is, “If it isn’t documented, it
didn’t happen” (also see Diamond, 1996). CNA’s rarely have enough time to chart everything required at the end of each shift; therefore, there were many experiences related to care that did not get documented. In addition, most of CNA daily charting consisted ofinitialing next to the task or activity performed – a checklist – with very little room for longer explanations or descriptions of what care experiences occurred during that shift. Any “significant or unusual” events that occurred was to be reported to the shift nurse and they may document the event or not. If so, the event was typically documented in the shift turnover notebook. Such events would usually be when significant behavior exhibited by the resident was in the form of some kind aggression or angry outburst – a negative behavior. Not often was it documented when positive care interactions occurred. In fact, most of the positive everyday routine interactions between frontline staff and residents, or between residents themselves, that occurred and reciprocated was rarely qualitatively documented; therefore, such care interactions “did not happen”. Even if such interactions were written in the shift notebooks, regulators rarely reviewed these notebooks as a means to evaluate certain care practices.

From my perspective as frontline staff, including the long-term care (LTC) facility and Federal/State regulators, care was typically understood as the tasks of routine activities of daily living (ADLs). These activities included getting residents up and dressed for the day, bathed, toileted, fed etc. Furthermore, spending time visiting with residents or doing other activities (e.g. going outside for a walk, etc.) or participating in a scheduled activity (e.g. Bingo, sing-a-long) was viewed as a job for the Activities Department. Therefore, CNAs, who spent too much time with the residents doing something other than completing ADLs with the resident, were reprimanded for not
completing their job duties, especially if they had to stay after their shift to finish charting or taking out the trash. I was reprimanded several times for: 1) spending too much time with a female resident who was teaching me a new skill – crocheting; 2) escorting a male resident to the designated smoke area too many times during my shift; and 3) delivering pornographic materials for a male resident who requested it. It was these types of acts that the residents called the “little extra things” that made them feel extra cared-for. And I would know they felt cared-for because the residents themselves would articulate their many thanks and words of appreciation, or they would reciprocate in their own way of expressing their thanks. These “little extra things” are the experiences I wanted to capture and identify as “care”. These were the things that were typically not captured in the MDS or the resident’s chart as care, nor were they acknowledged as official forms of care despite that this activity occurred quite frequently between frontline staff and residents.

Yet, the type of care that seemed to matter to State regulators and therefore the facility itself, were those items on the MDS checklist. Moreover, what became clear to me, is that “quality care” or care in general – as defined by the medical profession (e.g. ADLs, treatment, rehab etc.) or the State – was not at all congruent with the resident’s perspective of what care means or when they feel cared-for.

Throughout my doctoral studies, I have been exposed to theory and research that validated my perception that the needs of elders living in LTC are not fully understood nor adequately assessed as care. Thus, the purpose of this study is to challenge the general conceptions of care and get inside the lived experiences of elder care recipients, listen to their stories and identify when residents of LTC feel cared-for. Furthermore,
take these accounts and compare them to the professional definitions of care in hopes to identify any gaps and improving current care practices in long-term care.

*Significance of the Research*

This exploratory study has significance for the disciplines of sociology, gerontology, for the caring professions and the enterprise of long-term care reform, and for health care more generally. The critical analysis into the *meanings* of care as experienced by care recipients offers unique and critical insights into the distinctive features of care – insights that are currently lacking within sociological literatures, and social and behavioral science literatures more generally. Additional knowledge about the care experiences of care recipients living in long-term care adds to the knowledge base in all of these disciplines.

Furthermore, the results of this study may stimulate further research about care from care recipient’s perspectives using larger and more diverse populations, thereby producing knowledge that would inform policy and care services that will best support residents living in long-term care. Beyond theory and policy, my hope is that this and future work on care will have implications for actual care practices within long-term care and across various health care providers to elders. For example, this research reveals gaps in facility-wide (and federal) initiatives to improve quality care; therefore, a subsequent study objective could be to develop a taxonomy of care as an evaluative tool for long-term care institutions that accurately reflect care delivered from the point of view of the care recipient.
Assumptions of the Current Study

One of the basic assumptions of this research is that elders who participated are experts on their own lives and their own experiences of care. I view them as accurate reporters of care in their lives, and I believe that what they shared is true from their perspective, despite any diagnoses or symptomology of cognitive impairment. Interviews with frontline staff were also gathered to validate, on a general level, some of the experiences and information shared by the residents. Frontline staff may have in-depth knowledge of some of resident care experiences since they interact with residents daily.

Another important assumption to note is that this project only addresses and includes the meanings of care of English speaking Western cultures. This is important because for many other languages, the word “care” may not exist. For example, on one of my trips to a conference, I was taking a taxi from the airport and noticed that my cab driver’s first language was not (American) English. I asked him what his native tongue was and he told me it was Farsi. I asked him if he knew what the word “care” meant and he looked at me with a blank stare. It was clear he did not understand this word. So, I tried to explain to him what it meant and asked if he could translate the meaning of care as we know it – having deep concern for someone and/or being responsible for or custody of another. His response left me speechless. He said that they have a phrase for that, “I give you my eyes”. He explained that they believe “your eyes are the windows to the soul, and so when you feel like that to your brother or your friend, you give them a part of you. But it’s not just your labor or a body part (like your hands or feet), it’s your eyes because you give them a part of your soul”.

15
I asked another graduate student in Sociology, whose native language is Arabic, the same question – how do you translate what we know of as “care” into Arabic, is there such a word in your native tongue? She explained that there was no one word to translate “care”, but the closest Arabic word would be *A’tani* which in English means, “to look after or responsible for”. However, this word does not necessarily capture the feelings we mean by care as well.

Another language that has no direct translation of care is Vietnamese. My friend explained that in Vietnamese language it depends on whom you are speaking to, specifically, their role and who they are to you. For example, the word(s) that would express the sentiment most similar to “care” in Vietnamese is, “I worry for you”, and is different depending on whether you are speaking to an elder or a peer.

In sum, it is important to note that this study does not address these various cultures or languages in which the term does not exist, and therefore, this study does not take into consideration these potential various meanings of care. A future study on care could address this same research question from a global and cultural perspective, which I discuss in my conclusion. In the next chapter, I review the care literature of various disciplines.
CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

Despite the importance and salience to literature on health, healthcare systems, families, and beyond, there have been very few, if any, rigorous theoretical treatments of care in the social science literature until recent years. Michael Fine (2005) notes that in mainstream sociology literature, care appears to have been taken for granted, often considered within alternative rubrics such as social support and family. For example, a large body of literature on caregiving exists in social gerontology, but seldom does this literature consider the question of what care is or what it means. Rather, in this body of literature, care is often implicitly reflected as a stress or burden on the caregiver (Zarit et al., 1980; Pearlin et al., 1990), leaving the actual nature and content of care and the way it is experienced by the care recipient unexamined. Furthermore, the term “care” has been adopted by multiple disciplines and groups that when the literature is reviewed, what is clear is that there is not a single, unified body of work, but rather care is understood differently by a series of parallel literatures wherein there lies a set of special interests (Cancian and Oliker, 2000; Fine, 2005). Such interests may be based on occupational specializations such as medical or nursing on health care concerns as well as general, yet distinct, social concerns from disability and feminist activists (Thomas, 1993; Daly, 2002; Barnes, 2006; Fine, 2007).

In sum, the term ‘care’ has often been taken for granted, inconsistently defined, if at all, and presented as comprehensive in its coverage of a caring activity or conceptualizations of care. However, what we see is that the meanings of care employed
are mere partial representations of the totality of care, and therefore, we are left with a fragmented understanding of what care is and what it means (Thomas, 1993).

In this chapter, I review the ways in which care has been defined and meanings commonly used throughout the literatures, including the various frameworks and theories by “care scholars”. In so doing, I highlight a gap in the literature that this study endeavors to address. The chapter is organized by first identifying the multiple ways in which care is defined and used by multiple disciplines in “Definitions and Meanings of Care”.

Secondly, in the section, “Theoretical and Philosophical Discussions of Care”, I discuss the different theoretical and philosophical frameworks of care posited by various disciplines. Finally, I discuss the long-term care (LTC) literature in which elder care-recipient’s viewpoints are considered in analysis. I conclude the chapter with the research questions and objectives of the present study.

Definitions and Meanings of Care

Many care scholars emphasize that care is centrally associated with and embedded in inter-personal and interdependent relationships between a carer and care recipient (Abrams, 1978; Gilligan, 1982; Noddings, 1984; Thomas, 1993; Tronto, 1993; Hochschild, 1995; Ruddick, 1998; Veatch, 1998; Bowers et al., 2001; Duffy, 2005; England, 2005). For example, Nel Noddings (1984) describes caring as “the engrossment of the carer to the needs of the cared-for” (13). Carol Gilligan (1983) describes care to “encompass the range of human experiences associated with feeling, concern for, and taking charge of the well-being of others” (51). Hochschild (1995) defines care as “a bond in which the caregiver feels responsible for others’ well-being and does mental, emotional, and physical work in the course of fulfilling that responsibility” (89).
Similarly, Joan Tronto (1993) describes caring as the “engagement of both thought and feeling, including awareness and attentiveness, concern about and feelings of responsibility for meeting another’s needs” (28). These definitions of care claim that not only is care relational, care has both an affective dimension and an action dimension. As another example, Carol Thomas (1993) states, “care is a concept and an ideal that refers to both intangible affective elements and to observable, material actions, which have clear consequences for each party involved…where the nature of care is defined as an activity state and/or a feeling state” (112). Additionally, both Hilary Graham (1983) and Clare Ungerson (1990) have described care as both “labor and love”, where ‘labor’ is the activity or the instrumental component while ‘love’ is the feeling state or the emotionality component. Similarly, Noddings (1984) and Tronto and Fisher (1990) describe these same dimensions as “caring for” and “caring about”. However, Berdes, and Eckert (2007) claim caring is more than a labor of love, and that those who provide care – the caregivers – get something out of it personally. Joanne Altschuler (2001) emphasized that caring activities provide a sense of meaning and continuity for women throughout the life course; therefore, it may be that by doing care, caregivers reinforce the image of themselves and their personal identity as caring people. Thus, satisfaction is derived from both the care work and affect, not simply from the relationship with the cared-for (Altschuler, 2001; Berdes and Eckert, 2007).

Initially, care was understood as simply the ‘labor’ dimension – specifically, household tasks such as washing, cleaning, shopping, cooking as well as nurturing children, the sick and the aged (Finch and Groves, 1980; Fine, 2005; Barnes, 2006). Others have used the term “tending” to describe the practical or physical labor of the
carer (Parker, 1981; Parsloe, 1989; Fine, 2005, 2007; Bowlby et al. 2010). Nicky James (1992) and Marion Barnes (2006) claim that the physical labor is the most visible element of care as the carer responds to the basic human requirements such as eating, sleeping, bathing/washing, dressing/undressing, defecating and urinating. Julia Twigg (2000) uses the term, “bodywork” to describe care work that is complex and multifaceted but as careworkers are constantly confronting “the entropy of leaking bodies…encounter the body’s materiality in its immediacy in the form of bodily wastes and fluids, while simultaneously negotiating nakedness” (212). Twigg (2000) also calls this the “hidden dirty work” of care, which covers the degrading tasks that are integral to society but that which modern society does not want to acknowledge with its ethic of material success and its emphasis on youth and glamour.

Francesca Cancian and Stacey Oliker (2000) further describe care not simply to include physical care (e.g. bathing or feeding) or emotional care (e.g. tender touch, supportive talk, empathy, and affection), but care also includes providing direct services such as driving someone to a store or adjusting the medications of a patient. Similarly, Marion Barnes (2006) describes care as a “service” – that which encompasses the instrumental aspects of care activities, such as making beds, cleaning rooms, or preparing meals. Mignon Duffy (2005) describes this type of care as “reproductive labor”, which she defines as the “activity necessary to ensure the daily maintenance and ongoing reproduction of the labor force such as cooking, cleaning, child care, and other women’s work in the paid labor force” (171).

Alongside the idea of care as a service, the medical field has adopted the term “care” and have applied it pervasively to almost every specialty in the medical
profession. One simply has to pick up a medical brochure in a hospital or doctor’s office to read the various types of care (i.e. service) offered, such as ambulatory care, respiratory care, emergency care, preventive care, etc. Specific to older adults, you may see services such as long-term care, in-home care, adult day care, respite care, dementia care, skilled nursing care, rehabilitative care, and hospice care. Perhaps it is because of these various services and specializations that care remains to have a broad and nebulous definition – according to the medical dictionary, care is “the responsibility for or attention to health, well-being, and safety” (http://c.merriam-webster.com/medlineplus/care). For legal purposes, the New England Journal of Medicine (2004) provides a definition for a “Standard of Care”:

“1. A diagnostic and treatment process that a clinician should follow for a certain type of patient, illness, or clinical circumstance. 2. In legal terms, the level at which the average, prudent provider in a given community would practice. It is how similarly qualified practitioners would have managed the patient’s care under the same similar circumstances. The medical malpractice plaintiff must establish the appropriate standard of care and demonstrate that the standard of care has been breached.” (NEJM, 2004)

Furthermore, Peter Moffett and Gregory Moore (2011) review the meanings of “standard of care” using legal cases and dictums, and its legal history and definitions in order to provide the working emergency room physicians with a practical and useful guide to daily practice. Table 1 displays the summary of the historical development of the standard of care definitions.
Table 1.1  Historical Development of the Standard of Care

<table>
<thead>
<tr>
<th>Definition</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Initial Definition</strong></td>
<td>Based on custom&lt;br&gt;That which is typically done is what is considered standard</td>
</tr>
<tr>
<td><strong>20th Century Definition</strong></td>
<td>That which is customarily done plus anything that seems reasonable even if not typically done</td>
</tr>
<tr>
<td><em>(Helling v. Carey; The TJ Hooper)</em></td>
<td></td>
</tr>
<tr>
<td><strong>The Modern Definition</strong></td>
<td>That which a minimally competent physician in the same field would do under similar circumstances</td>
</tr>
<tr>
<td><em>(Hall v. Hilburn; McCourt v. Abernathy; Johnston v. St. Francis Medical Center)</em></td>
<td></td>
</tr>
</tbody>
</table>

What is important to note is that these are the legal definitions of a standard care practice for a specified profession who provide “care” to patients. In addition, what I find most surprising, is the lack of specificity of what “care” is, especially since these legal definitions are used to help guide emergency room physicians in daily care practices to avoid malpractice action. This legal standard – whatever it may be – provides no clarification whatsoever as to the nature of care is nor what the nature of the standard of care should be.

The Institute of Medicine (IOM) attempts to define quality of care in terms of standards and initially defined “quality” (as opposed to “care”) as, “the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge” (Lohr, 1990). This definition led to a listing of quality indicators, which are expressions of the standards comprised of the Five Ds: death, disease, disability, discomfort, and dissatisfaction (Lohr, 1988). However, the most recent IOM (2001) work that identifies the components of
quality care is centered on the conceptual components of quality rather than measured indicators: quality care is safe, effective, patient centered, timely efficient, and equitable.

Avedis Donabedian (1988) tried to provide a standardized means to evaluate and define “quality care”. Donabedian (1988) divided the domains of quality care into three components: structure, process, and outcome. Each of these may then be subdivided into diverse constituents and standards could be set for evaluating the individual constituents (Donabedian, 1988). *Structure* refers to the personnel, facilities, and system involved in health care delivery; *Process* refers to the actions that emerge from those structural elements; and *Outcome* denotes the subsequent events that follow the process (Donabedian, 1988). Although this classification produced an excellent basic taxonomy for delineating the entities to be considered and evaluated, others found immediate problems with this model. Matthews and Feinstein (1988) argued that first and foremost, the three components occurred sequentially but were not consequential; thus, the effects could not always be attributed to or be associated with the causes making it very difficult to evaluate and measure quality care. Furthermore, because of the dissociations and uncertainties, there have been no consensus on such questions like whether structure/process is more important over outcome, or should evaluations also measure each of the constituents of all three and the interrelationships among them (Matthews and Feinstein, 1988; Feinstein, 2001).

Setting standards of evaluation is often regarded as the most difficult part of appraising quality care mainly because of the disagreements about how the standards should be set and applied (Feinstein, 2001). Furthermore, Feinstein (2001) proposes using care-recipient’s point of view or perspective in evaluating care despite arguments
against it. Most patients are regarded as “not qualified to make decisions about the
efficacy of a system, the competence of the personnel, the appropriateness of therapy, or
the appraisal of a clinical outcome” (Feinstein, 2001: 216). He further argues that the
omission of the patient’s viewpoint may seem to make evaluations more scientific, but
also tends to make curing, rather than caring, the main focus of evaluation (Feinstein,
2001). What is implicit in the much of the medical literature is that care is a service
provided – service that takes action or labor in the form of a curative treatment, process
or procedure – by a medical professional for or to their patient(s).

At the same time, numerous scholars emphasize that care is not simply
instrumental or an activity, it also includes an affective dimension. Cancian and Oliker
(2000) also define caring as “a feeling of affection and responsibility combined with
actions that provide responsively for an individual’s personal needs or well-being, in a
face-to-face relationship” (119). Similarly, other scholars describe “caring about” as
having concern for another, and this can be expressed through ways in which physical
care is provided as well as expressed through spending time with someone, holding
hands, stroking one’s hair, or giving gifts (Parker, 1981; Hochschild, 1983; Ungerson,
1987; Valentine, 1989; James, 1992; Sevenhuijsen; 1998; Barnes, 2006).

It is not simply enough to have caring feelings; feelings must be put into action,
which is often observable (Valentine, 1989). Therefore, care – which is embedded in a
relationship between a carer and care recipient – has certain characteristics, behaviors,
thinking and attitudes. These characteristics or what some scholars call, care virtues,
include: benevolence, compassion, attentiveness, empathy, comfort, faithfulness,
humaneness, and tenderness (Veatch, 1988; Tronto and Fisher, 1990; Sevenhuijsen, 2000; Bowers et al., 2001; Harris, 2002).

Many of these definitions of care derive from the professional expertise and in some cases the experiences of the scholars who offer them. By contrast, Debra Stone (2000) analyzed 24 qualitative in-depth interviews with caregivers – home health aides, home health nurses, physical and occupational therapists, social workers, and case managers in New England as well as 10 unpublished transcripts of a focus group with ten home health aides from the Picker Institute in Boston, MA. The interviews and discussions were centered on their concepts of “good care” including what their views of what factors contributed to or hindered good care. Stone (2000) found that caregivers distinguish between “doing the job” and “caring”, between the physical tasks and the emotional relationship, between the technical quality and the moral value of what they do, and that no matter how good the technical care, it is not good care if it does not include talking and listening, and most important, love (Stone, 2000). At some point, almost all caregivers use the word “love” to describe their feelings toward some or all of their clients. Furthermore, this deep affection that is taboo in the formal rules of caregiving organizations is both unavoidable and essential to caregivers, and thus, “love” is often a way that caregivers distinguish good care from mere technical care (Stone, 2000).

However, this calls into question whether or not one could consider the instrumental activities or care tasks is really care at all if love or the other virtues of compassion, empathy, tenderness, etc. are not present or demonstrated with the activity. Some scholars would argue that we should only refer to caring when the virtues of love
and affection are demonstrated alongside the tending (Leininger, 1984; Parsloe, 1989; Valentine, 1989; Sevenhuijsen, 1998). Joan Watson (1988) attempts to address this in her theory of human caring to the field of nursing as she describes care as “the highest form of commitment to patients – a moral ideal – as it becomes the ethical principle of standard by which treatments and interventions are measured” (38). Another nursing scholar, Kathleen Valentine (1989) claims caring is the interaction between nurse and patient on personal one-to-one basis, what she claims is “care in action” since she claims, it is not enough to just have caring feelings.

Bowden (2000) argues that limiting the definition and meaning of care to practical tasks and instrumental activities, excluding the affective dimension and the human relationship and interdependency, reduces the potential for providing a real framework of empowerment for the care recipients as well as carers. Furthermore, defining care in terms of “directly meeting of needs” differentiates caring from other activities that may foster survival – such as economic provision (Folbre, 2003; England, 2005). This definition recognizes that everyone needs care, not just those we consider incapable of caring for themselves. Often only children, elderly, the disabled, or chronically ill are seen as requiring care, while the need for care and receiving care by so-called independent adults is suppressed or denied (Glenn, 2000). Glenn (2000) proposes defining care as “practice” that encompasses an ethic of care (caring about) in creating a relationship. In a nursing home study with African American and immigrant nurse’s aides, Bowers, Esmond and Jacobson (2000) found that nurse’s aides and residents viewed their relationships to be the central determinant of quality care, using the term “family” to denote providing individualized care in a way that allowed residents to
maintain their sense of competence and dignity. They also found residents described care in the context of the closeness and caring they obtained in relationships with the staff (Bowers, Fibich and Jacobson, 2001). These findings also support Dannefer and colleagues’ (2008) nursing home work where they found care to be a “generative, interactive, and dialectic process” between carers and nursing home residents (116).

Researchers suggest that good care may be defined differently by people with different cultural backgrounds and social positions (Stone, 2000; Cancian and Oliker, 2000). A person’s relative power in the caring situation or in society may shape their view of caring. For example, nurses and other caregivers may define good care in terms of caregivers having the power and resources to provide the care they think is needed; while care recipients may emphasize the importance of defining their own needs and their connection to or relationship with their carer.

From the literature reviewed in this section, it is clear that no consensus exists as to a precise definition of care. As Carol Thomas’ (1993) review of the literature concluded 20 years ago, there still remains a lack of consensus about the meaning of the term care. She argues care lacks the ontological and definitional characteristics that make it possible to utilize it as a reliable social measure in its own right (Thomas, 1993).

Care remains a social phenomenon and what is understood as care seems to change over time, just as it is subject to cultural and political difference (Williams, 2001; Sevenhuijsen, 1998; Morris, 2001). It continues to be a slippery term, difficult to define precisely, subject to different interpretations and emphases. Michael Fine (2007) provides a good summary of care, “Care is not an object, nor is it a standardized or uniformed product. It is a concept and an ideal that refers to both intangible affective
elements and to observable material actions which have clear consequences for each party involved” (141).

**Theoretical and Philosophical Discussions on Care**

Several scholars have contributed theoretical and philosophical considerations to the study of care. In this section, I discuss some of these contributions as well as some the frameworks of care by various disciplines. I begin with the discussion of some original works on the *Ethics of Care*, which imply there is a moral significance in the fundamental elements of relationships and dependencies in human life. Next, I provide a brief historical review of how care has been conceptualized by some feminist scholars, in the *Brief Historical Review of Care: Feminist Frameworks*. In addition, disability activists responded to the feminist framing of care as I highlight these perspectives in *Disability Perspectives and Social Policies on Care*. Lastly, I review how social policy informs us on how to frame future discussions about care as basic societal and human needs.

*The Ethics of Care*

One of the original works of care ethics was Milton Mayeroff (1971) book *On Caring*, in which he describes care as “helping another grow and actualize himself” and further asserts that care is “…a developmental process that gives meaning and order to one’s own continuity of being or to care for something outside himself” (7). Mayeroff (1971) provides a fruitful way of thinking about the human condition using the concept of caring. However, in the 1980s, psychologist Carol Gilligan and philosopher Nel Noddings are credited with developing “the ethics of care” as a distinct moral theory. Both Gilligan and Noddings claim that up to this point, traditional moral theories and approaches were male biased. Carol Gilligan (1982) wrote her dissertation (later
published as the influential book, *In a Different Voice*, outlining a different path of moral development than the one described by her mentor, Lawrence Kohlberg. Gilligan (1982) argued that males and females are often socialized differently where females are more likely than males to stress interpersonal relationships and take responsibility for the well-being of others. Gilligan’s (1982) ethics of care include both a care-based morality and a justice-based morality. The care-based morality is based on 1) emphasizing interconnectedness and universality and 2) acting justly means avoiding violence and helping those in need. Gilligan (1982) claimed care-based morality was more common in girls because of their connections to their mothers, and furthermore, because they remain connected to their mothers, they develop a capacity for relatedness. On the other hand, justice-based morality is based on 1) views the world as being composed of autonomous individuals who interact with another and 2) acting justly means avoiding inequality. Gilligan (1982) claims this morality was more common in boys because of their need to differentiate themselves from their mother. This separation helps prepare boys for work in the public sphere that values single-minded efficiency and competitiveness. Furthermore, the importance of separation and autonomy for men often leads them to center discussions of morality around issues of justice, fairness, rules, and rights whereas the importance of family and friends for women leads them to center discussions of morality around people’s wants, needs, interests, and aspirations (Gilligan, 1982).

Nel Noddings (1984) uses a feminist approach, specifically a “mother’s voice” to the ethics of care and applied it to moral education. Noddings (1984) ethic of care is rooted in receptivity, relatedness, and responsiveness. She identifies two parties in a caring relationship – a “one-caring” and “cared-for” – and that both parties have an
obligation to care reciprocally although not in the same manner. The role of the one-caring comes across to the cared-for in an attitude. The caring relationship begins with the “engrossment” of the one-caring to the cared-for. Noddings (1984) describes this engrossment as:

“I set aside my temptation to analyze and to plan. I do not project; I receive the other into myself, and I see and feel with the other. I become a duality. I am not thus caused to see or to feel – that is, to exhibit certain behavioral signs interpreted as seeing and feeling – for I am committed to the receptivity that permits me to see and to feel in this way. The seeing and feeling are mine, but only partly and temporarily mine, as on loan to me” (30).

Receptivity is required of the cared-for also. The cared-for responds to the presence of the one-caring – “they feel the difference between being received and being held off or ignored…whatever the one-caring does is enhanced or diminished in the attitude conveyed to the cared-for” (Noddings, 1984: 61).

Noddings (1984) further distinguishes two stages of caring – “caring for” and “caring about”. Caring for is the direct face-to-face attempt to respond to the needs of the cared-for – the actual hands-on application of care tasks – while caring about is characterized by some distance – from the face-to-face of direct responsibility into the public realm. Her greatest contribution to care theory is the emphasis on the caring relationship – a relationship that contains another, the cared-for, and both the one caring and the cared-for are reciprocally dependent (Noddings, 1984).

Joan Tronto (1993) explored the intersections of care ethics, feminist theory, and political science. She identified four moral boundaries of care that served to privatize the implications of care ethics, and highlights the political dynamics of care relations:

1. Caring about – recognizing and being attentive to others
2. Taking care of – taking responsibility for action
3. **Care-giving – competently performing care tasks/work**

Tronto (1993) suggests these moral boundaries may act as a guide to varying forms of practice, but without prescribing a precise form of practice or defining procedural guidelines. This posits care as fundamentally a practice. Tronto (1993) also stresses that care requires a continual negotiation between caregivers and care-receivers based on the social relationships and reciprocity in the process of giving and receiving care.

Another scholar who has contributed to the ethics of care is Virginia Held, whose work moves beyond ideals of liberal justice, examining how social relations might be different when modeled with the premise on a fundamental non-contractual human need for care. In *Feminist Morality* (1993), Held describes feminist ethics as committed to actual experience, with an emphasis on reason and emotion. In *The Ethics of Care* (2006), she notes:

“*The small societies of family and friendship embedded in larger societies are formed by caring relations... globalization of caring relations would help enable people of different states and cultures to live in peace, to respect each other’s rights, to care together for their environments, and to improve the lives of their children*” (168).

Accordingly, the ethic of care is a cluster of practices and values, an approach to rethinking how we ought to guide our lives with the potential of being based on what she claims is “truly universal” (Held, 2006).

Selma Sevenhuijsen (2003) argues that for a long time it seemed natural for women to be responsible for care, in families as well as in social services. The modern women’s movement, however, has challenged the previously self-evident assumptions of women’s caring role. Feminists argued for a fairer distribution of tasks between men and women, and for a re-evaluation of care as an activity, identity and morality...
(Sevenhuijsen, 2003). However, the way in which these aims should be politically combined was not always clear and in social policies, emancipation was been interpreted simply as increased participation in the labor market, equal rights, and autonomy for women (Sevenhuijsen, 2003). The premise was that women needed to free themselves from the world of care. Recently, Sevenhuijsen (2003) claims a change has begun to take place, whereby care is now recognized as an important part of human existence and the idea that care does not necessarily have to be opposed to independence and self-realization is becoming more widely accepted. Sevenhuijsen (2003) argues for a re-evaluation of care, not only a redistribution of paid labor and caring tasks between men and women, but also a new approach to justice, morality and politics – an ethics of care with political perspectives and concepts – placing care within concepts of democratic citizenship.

Nursing scholars have also contributed to the theoretical development of care. Madeline Leininger (1991) recognized that human care is the central, unique and dominant phenomenon that characterizes and explains the discipline of nursing, specifically what she called, *transcultural nursing*. Leininger (1995) defines transcultural nursing as:

“A substantive area of study and practice focused on comparative cultural care (caring) values, beliefs, and practices of individuals or groups of similar or different cultures with the goal of providing culture-specific and universal nursing care practices in promoting health or well-being or to help people face unfavorable human conditions, illness, or death in culturally meaningful ways” (58).

Furthermore, Leininger (1991) coined the term, *culturally congruent care*, which is the primary goal of transcultural nursing practice. This type of care is possible when the following occurs between the nurse-client relationship.
“Together the nurse and the client creatively design a new or different care lifestyle for the health or well-being of the client. This mode requires the use of both generic and professional knowledge and ways to fit such diverse ideas into nursing care actions and goals. Care knowledge and skill are often repatterned for the best interest of the clients...thus all care modalities require co-participation of the nurse and clients (consumers) working together to identify, plan, implement, and evaluate each caring mode for culturally congruent nursing care. These modes can stimulate nurses to design nursing actions and decisions using new knowledge and culturally based ways to provide meaningful and satisfying wholistic care to individuals, groups or institutions” (Leininger, 1991:44).

The practice of transcultural nursing addresses the cultural dynamics that influence the nurse-client relationship, and due to its focus on this particular aspect of nursing, Leininger (1991) developed her Theory of Nursing: Culture Care Diversity and Universality. The goal of this theory was to provide culturally congruent wholistic care as well as provide care measures that are in harmony with an individual or groups cultural beliefs, practices, and values (Leininger, 1995). Central to her theory is the view that humanistic and scientific caring behaviors, values, and expressions exist in all human cultures, but they are expressed differently and often covert (Leininger, 1991).

Another nursing scholar, Jean Watson (1985) contributed a humanistic model of caring or a humanistic nursing theory. Watson’s (1985) nursing theory’s philosophical foundation are found in her claim that “caring calls for a philosophy of moral commitment toward protecting human dignity and preserving humanity” (1985: 31). She describes caring as a value and an attitude that has to become a will, an intention, or a commitment that manifests itself in concrete acts (Watson, 1985: 32). Furthermore, caring is an ideal that transcends caring in order to influence collective acts of the nursing profession, with important implications for human civilization (Watson, 1985). Thus, caring eventually becomes a philosophy of action to meet individual needs and to assist the welfare of others.
An Historical Review of Care: Feminist Frameworks

Feminist approaches to care begin from a quite different starting point. Feminist scholars have argued that care was initially understood as involving domestic household tasks and although it included giving love and personal support, it was not reducible to just nurturing children or attending to the sick or aged (Finch and Groves, 1980; Cancian and Oliker, 2000; Fine, 2004, 2005). Defined in this way, care was an unpaid duty of women, a burden that held women back from achieving careers in the paid workforce outside their home – the work of paid staff was, therefore, not seen in the same light as that of the unpaid work of carers (Parks, 2003; Fine, 2007). This changed over time. Discussions about care increasingly came to focus on the conditions of employment and career development. Like the burden of care in the domestic sphere, researchers typically sought to highlight the negative aspects of paid care work, including the low rates of pay, the moral exhortations towards compassion and responsibility, and the limited career prospects for most staff, whether it be in private domestic employment or more public services (England, 2005; Barnes, 2006; Fine, 2007). Yet, the “burden of care” which refers to the result of the impact of caring about and the range, intensity, and physical demands of care activities continues to be the topic of the bulk of caregiving literature (Finch and Groves, 1980; Glenn, 2000; Lloyd 2002; Barnes, 2006; Fine, 2007).

Feminists have argued that care has been and continues to be identified as work with “a woman’s face” since women typically are responsible for meeting the physical needs of children, partners, relatives who are sick or disabled, and therefore, seen as a “natural” province of women (Cancian and Oliker, 2000; Daly and Rake, 2003; Barnes, 2006; Fine, 2007). Selma Sevenhuijsen (1998) claims feminism, in the form in which it
arose at the end of 1960s, can be seen as a rebellion against this supposedly ‘female’ nature of care and the associated subordination of women to men. Hilary Graham (1982) claims that women’s place in man’s lifecycle has been that of nurturer, caretaker, and helper. The woman is the “weaver” of the care networks and relationships on which she in turn relies. However, while women have taken care of men, men have, in their theories of psychological development as well as in their economic arrangements, tended to assume or devalue care (Graham, 1982). When care is paid work, it is poorly paid, and much of the analysis of reasons for the devaluing of care has concentrated on the gendered and racialized characteristics of caregiving (Hochschild, 1995; Ehrenreich and Hochschild, 2002; Duffy, 2005; England, 2005; Barnes, 2006).

Clare Ungerson (1990), whose primary concern is with care policy and the possibilities that ensure the provision of quality care for recipients is provided without the exploitation of women. Ungerson (1990) argues that research on care reproduces this false dichotomy between the formal and informal spheres of care characteristics by fusing the meanings of “caring for” and “caring about” as well as drawing a conceptual division between the public and domestic domains (i.e. formal and informal care). Such division hampers care policies that can assist women in the public sector as the changing landscape of care continues to evolve. Additionally, Mary McIntosh (1978) argues:

“For the reproduction of labor power the state sustains family household system in which a number of people are dependent for financial support on the wages of a few adult members, primarily a male breadwinner, and in which they are all dependent for cleaning, food preparation and so forth on the unpaid work done chiefly by a woman. At the same time, the state itself carries out some of these functions of financial support and of servicing; yet it usually does so under such ideological conditions that it is seen as ‘taking over’ functions properly belonging to the family or as ‘substituting’ for work that ‘should be done by a housewife’ (264).
Thus, the state plays a part in the oppression of women through its support for a specific form of household: the family household dependent largely upon a male wage and upon female domestic servicing. Through this process, the state ensures that the household reproduces labor power through women’s unpaid work, and also takes on some of these “family” responsibilities itself because the family is inadequate in fully meeting this task. In maintaining women’s economic dependence on men, the state has also positioned married women as a reserve army of cheap labor, and reinforced women’s dependence through public policies such as social security and unemployment insurance, disability benefits, tax breaks for married, protective labor laws for women and children, and prenatal policies. Such interrogations of the relationship between the state, market, and family provided the foundation for modern conceptions of social reproduction.

**Care as Power and Dependency**

Sociologists argue the interpersonal relationship is typically discussed as unidirectional and typically representative of power differentials in which the disabled individual or the one in need of care are conceptually located as the “other”, powerless, and dependent (Noddings, 1984; Watson, 1985; Silvers, 1995; Lloyd 2000; Bowden, 2000). Even the venerated care scholar, Nel Noddings’ (1984) defines care as a “unidirectional relationship of power and dependency” (38), thus leaving the institutionalization of disempowerment and dependency intact, securing the cared-for in a position of passivity and objectified helplessness and the carer in a position of authority and power. What is ironic is that, in advanced societies, those most responsible for caring is disproportionately carried out by those who are least powerful in society: women, people from minority ethnic groups, migrants and older people (Ehrenreich and
Hochschild, 2002; Duffy, 2005). In a study of immigrant nurse’s aides working in nursing homes, Berdes and Eckert (2007) found that nurse’s aides distinguish their caring activities (instrumental care) from their affective care (caring about) in that they supply their affective care electively. In other words, they showed some residents affective care and some not. Instrumental care was the minimum, universal form of care, whereas any affective care tended to enhance the care for those lucky few recipients who received it (Berdes and Eckert, 2007). The researchers also suggested that nurse’s aides were also seeking to distinguish themselves from aides who do not make this effort of demonstrating affective care; therefore, the aides who did not provide affective care to some residents were simply not providing good care (Berdes and Eckert, 2007).

Joan Tronto (1993) proposes a contrasting approach to what we generally think of the caregiver as having the power in the relationship. Tronto (1993) argues that the care recipient or cared-for, even if subordinate and/or dependent, also has agency and power in the relationship. Tronto (1993) notes that for situations where the cared-for employs the carer or has social authority, the cared-for may have more power than the carer. Additionally, Dannefer and colleagues (2008) found that care recipients in a long-term care facility – nursing home residents – were very much active carers to each other, and when given the opportunity, they were active participants in defining and evaluating current care practices as well as providing suggestions and recommendations for changes. Therefore, all parties involved in the caring relationship have the capacity to be either carers or care recipients or both, and more importantly, they may change places as the need arises and has also been identified as “reciprocal care” (Tronto, 1993; Nolan et al., 1996; Dannefer et al., 2008; Shura et al., 2009). In a broader context, reciprocity
includes the idea that we should return care that others have given to us, or more broadly return to society, care that we have received through social relationships (Jaffe, 2009).

Sociologists tend to focus on care giving as a relationship in which individual feelings, needs, wants, and actions are influenced by society, the whole web of relationships in which the carer and cared-for live and how a private and personal relationship takes meaning and direction from the cultural beliefs, social institutions, human associations, and historical events (Cancian and Oliker, 2000; Barnes, 2006).

Disability Activists’ Perspectives on Care

Disability activists assaulted these negative portrayals of care, despite seeking to work within the social policy tradition as well. They fought to reject the depiction of people with disabilities as simply “burdens”; they attempted to reframe the debate to focus on the relationship between care recipient and caregiver (Fine, 2004; Beckett, 2007; Adams et al., 2009). This contributed to a reconceptualization of the interpersonal aspects of care, helping to shift understanding from care as a one-directional activity involving the provision of assistance by an active carer to a passive dependent, towards an understanding of it as a more complex mutual activity that takes place within a system of interpersonal relationships (Lloyd, 2000; Shakespeare, 2000). Disability activists also demanded that care recipients be able to make the decisions about the assistance they received and the care assistants who provided it (Fine, 2007). However, from the disability perspective, neither the individual nor social model of disability helps classify which tasks constitute care – to be caring or cared-for are not positions, attributes or roles that are necessarily oppositional or dualistic in practice, but are part of the weave of any social relationship (Beckett, 2007).
Bill Hughes (2005) argues that both disability movement and feminist perspective can strengthen the dominant heteronormative discourse of care by locating women’s primary positions as within care relationships and diminish disabled people’s rights to be treated equally regardless of their care needs. Care is thus potentially both a lifesaving necessity and a disempowering relationship. From a feminist perspective, care takes on specific relationship to the marketplace, expressed both through actual wages or lack of them and through conceptual relationships. Additionally, Bill Hughes (2005) associates care with institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion “…to be cared for is to be in deficit and to have one’s competence as a social actor denied or questioned (217). However, Sevenhuijsen (1998) argues for a re-evaluation of care and proposes a new political concept of an ethics of care that will integrate themes from feminist ethics and gender theories. This modern ideal of care as citizenship demands that citizens free themselves from dependencies and loyalties in their political judgment in order to arrive at free and autonomous choices (Sevenhuijsen, 1998). Although care may be ill defined, disability activists claim care has financial implications, policy makers are forced to prioritized some method of allocating funds and therefore, embedding care into a discourse of civil rights for disabled people is clearly an absolute need on the way to equality for disabled people, where the focus is not necessarily about human rights, but about resources (Barnes, 1990; Silvers, 1995; Hughes, 2005; Beckett, 2007). However, Joan Tronto (1993) argues that attentiveness is lacking from policy considerations and there is a sense that the notion of responsibility towards others is slightly embarrassing to acknowledge; thus, the assertion of rights, not care, reflects liberal notions of individual autonomy rather than recognizing
the universal human need for care. Tronto (1995) further suggests that modern political theory should locate care both “above and below” politics.

Furthermore, Marion Barnes (2006) claims that we need an approach to social justice capable of incorporating care as well as rights if we are to develop policies and practices encompassing circumstances both of disabled and older people and those who care for them – based on an understanding of the universality of human inter-relatedness, it is not solely concerned with addressing the welfare of needy others.

**Social Policy on Care**

Originally conceived as most appropriate to the private and intimate spheres of life, care ethics branched out as a political theory and social movement aimed at broader understanding of, and public support for, caregiving activities in social policy. Barnes and Brannelly (2008) argue that the development of practices grounded in the principles and ethics of care discussed above is necessary to ensure that care recipients needing care as a human right, can do so. To be both feasible and accessible, such practices need to be located within supportive social policies and service systems (Barnes and Brannelly, 2008). Many times social policies and service systems have not been adequate to support appropriate practices, leading to unnecessary marginalization and stigmatization of intellectually disabled offenders (Barnes and Brannelly, 2008).

An ethics of care that is political and critical must be grounded in the concrete activities of real people in the context of webs of social relations, and in turn, these webs are affected by politics and the structure of social policies (Sevenhuijsen, 2000). Social policy research previously focused on transfers – social insurance, child and family benefits, and social assistance. Earlier research was concerned to explain the rise of the
welfare state as a consequence of industrialization and urbanization, attention turned to accounting for differences in the pattern of welfare state expenditure (Barnes, 2006; Barnes and Brannelly, 2008). Building on the class-centered politics of power resource theory, Esping-Andersen’s (1990) *three Worlds of Welfare Capitalism* – liberal, social democratic, and conservative-corporatist – became the focal point of much of the debate. It was feminist researchers, however, who uncovered the silent gendered assumptions governing social reproduction via the unpaid work of women in the home.

Care contributes to capacity of states to meet the welfare needs of their citizens, and introduces notions that caregiving needs to be understood in terms of broader function than solely providing support for individuals; it must be understood as a force for social cohesion and a duty of citizenship (Barnes, 2006; Adams et al., 2009). Therefore, policies promoting care must go beyond the model of isolated family caregiver, to support and enhance the much wider range of social approaches that can ensure access to personal assistance and support when it is needed as well as the opportunity to provide support when it is required (Fine, 2005).

*Care as a Basic Society Need or Function*

Care pertains to intimate human relations, yet at the same time, general in the sense that it is integral to society. It is rooted in relations of personal involvement and to some extent, personal service wherein there is a moral element in care that distances it from usual boundaries of work (Kittay, 2001). Paula England (2005) describes care as “an understanding of the role of the carer that extends beyond meeting the immediate needs of the cared-for, but invests in the cared-for’s capabilities to the extent that the relationship enhances these capabilities, and the cared-for will become more independent
and productive…thus, care is a public good” (56). England (2005) further argues using “subtractibility” – that is the removal of caring would harm all members of society – would have a significant impact on the cost of state substitution of lay (informal) care and personal costs, which are not simply a loss of practical support, but also a loss of emotional support and significant contributions care can make to self-esteem and sense of personal value, not only to recipient but also to carers (England, 2000).

Elder Residents’ Perspectives on Care

Care recipients, especially dependent elders, are typically eclipsed from the processes of care planning and more generally determining how care should be provided, evaluated or understood, even though they are uniquely positioned to speak to the issue of their own care, operating with both immediate firsthand knowledge and with a lifetime of experience. Throughout the long-term care literature, elder resident perception of quality sometimes equates to satisfaction (Eriksen, 1987; Louden, 1989; Lowe et al., 2003; Walsh, 2014). Cleary and McNeil (1988) reviewed resident satisfaction as an indicator of quality care. Overall, they found the research to indicate that quality nursing care is related to residents’ perceptions of technical skills, intelligence, and qualifications of the nurse. Furthermore, their findings indicated that perceived interpersonal and communication skills of health care providers generally account for more of the variation in resident satisfaction than technical skills. Cleary and McNeil (1988) conclude that their findings support the importance of residents’ perceptions and the desirability of maximizing resident participation in research studies.

Kahana and colleagues (1985) describe their longitudinal study of the initial year of institutional living in which the researchers followed prospective residents from the pre-institutional stage through their initial adjustments and through the first year of life in the institution. The study encompassed self-reports of the elderly regarding life in the institution,
perspectives of staff, and interviewers’ observations about social interactions with respondents. What the researchers found was that elders living in institutions who receive frequent visitors from outside have generally pleasing interactions with other residents and staff and participate in activities available at the facility (Kahana, Kahana, and Young, 1985). For most elderly, the first year of institutional life is characterized by both relative psychological and social stability, and qualitatively portrayed the institutionalized aged as active participants in their social world, seeking to maintain interpersonal engagement interaction.

Bond and Thomas (1992) reviewed the use of elders’ perceptions of nursing care and found that data collected were usually used to influence service planning and improve public relations. Most data were used to measure the patient’s overall satisfaction, rather than the patient’s view of quality nursing care. In sum, their review of the literature reflected a belief that elders were not sophisticated or well enough educated to make decisions about quality care (Cleary & McNeil, 1988; Eriksen, 1987; Merry, 1987; Prehn, Mayo, & Weisman, 1989).

A study by Bliesmer and Earle (1993) collected resident perceptions about 17 different quality care indicators (QCI) that were identified in the National Citizen’s Coalition for Nursing Home Reform (1985). The researchers asked the residents to score them by importance. Of note, the QCI format did not allow the residents to freely define nor identify any component they considered as part of quality care. The specific QCIs were: a) good staff attitude, b) prompt attention, c) homelike atmosphere, d) privacy in room, e) variety in food, f) broad range of activities, g) daily activity choices, h) physician availability, i) privacy with physicians, j) room cleanliness, k) bathroom cleanliness, l) strong administration, m) opportunity to practice of religion, n) respect of rights, o) opportunity for community activities, p) vehicle transportation, and q) problem resolution. The results showed the top five QCIs found most important by 30 residents randomly selected from two different nursing homes were: 1) good staff attitude; 2) bathroom cleanliness; 3) privacy in room; 4) prompt attention, 5) opportunity to practice religion. In this study, the researchers also interviewed 15 staff – 5 each of each: RNs, LPNs, and CNAs –
from each home (n=30), and asked them to complete the same instrument as the residents. The
indicators found most important by staff were: 1) homelike atmosphere, 2) good staff attitude, 3)
opportunity to practice religion, 4) prompt attention, and 5) privacy in room. The researchers
stated the implication for nursing achieving an understanding of what are true indicators of
quality care to residents in order to ensure that residents’ perceived needs, not the needs of staff
are met.

Another example in which both staff and care recipients perceptions were taken into
consideration was a study to identify a meaning of “care dependency” that can be shared by both
caregivers and care-recipients (Boggatz et al., 2007). The authors used the concept analysis
method as proposed by Walker and Avant (2005) to: 1) identify all general uses of “dependence”
“care dependency” used in the Medline, CINAHL and Cochrane databases; 2) determine the
defining attributes; 3) construct model, related, unclear and contrary cases; 4) identify antecedents
and consequences of the concept, and 5) define the concept’s empirical referents. Boggatz and
colleagues (2007) also evaluated theoretical discussions about the concept of ‘care dependency’
or ‘dependency’ in general, qualitative nursing studies that attempted to understand the
phenomenon of dependency from either the care givers’ or care recipients’ perspective, and
nursing literature that claimed to measure care dependency. The findings of this study include
care dependency is a particular form of dependency and also shares defining attributes of
dependency and meaning in relation to care (Boggatz et al., 2007). In addition, care dependency
is defined as a need for support in at least one domain of care to compensate for self-care deficit,
and functional limitations and unmet needs are related but not similar concepts of care
dependency (Boggatz et al., 2007). This analysis allowed components of care dependency to be
identified upon which both care givers and care recipients agreed, and therefore, the authors’
claim should become the defining attributes of the concept of care dependency. In short, a
definition for care dependency would be, “a subjective, secondary need for support in the domain
of care to compensate a self-care deficit” (Boggatz et al., 2007: 568).
More recently, Kahana and colleagues (2009) offer a conceptual framework that focuses on “care-getting”, a proactive means of insuring responsive and high quality care that is necessary for maintenance of good quality of life during the final years of life. The authors propose an innovative model of proactive “care-getting” by recognizing that frailty and the need for care-getting can coexist with retaining agency and initiative. During a time in one’s life generally associated with dependency, residents can still exert control over the care received by proactively marshalling support (Kahana et al., 2009). This model calls for empowerment to insure that residents living in long-term care can choreograph their final years in a proactive manner. Furthermore, this model allows researchers the opportunity for empirical exploration that may support or falsify tenets of the theory and further move social gerontology toward acknowledging the last frontier of the lifespan.

In a research project based on action research, Dannefer and colleagues (2008; Shura, Siders and Dannefer 2010) found that many elders living in long-term care are not only capable of articulating their needs, but also of evaluating institutional care practices when given the opportunity to voice their concerns and observations (also see Dannefer and Stein 2001). In weekly meetings, residents were fully engaged in the meaningful activity of community and relationship-building as well as identifying strengths and weaknesses of the facility and its care practices, and how it affected their quality of life and quality of care while living in a nursing home.

Although the literature reviewed in this section provides many instances of resident perspectives on quality care, what is missing is the resident perspectives on what quality care means as well as qualitatively identifying when residents feel cared-for. The current study builds on this earlier work by asking residents directly about their care experiences as a care recipient, what care means, and when they feel cared-for.

**CONCLUSION**
In sum, from the review of literature, meanings of care encompass one or all of these three overarching themes:

1) Care is a form of work or activity providing assistance to another
2) Care is a social and personal and interdependent relationship
3) Care is a disposition or concern for others; and

Overall, the meanings of care depend on the discipline or context in which the term is being employed, therefore, we continue to have just a fragmented picture of what care is or what it means in today’s society. Thomas (1993) raises the questions whether it is possible to construct a single concept of care that suits all purposes and further argues that care is not a theoretical category, but rather it exists at the level of everyday familial and political discourse.

The literature on care is quite diverse and extensive. Yet, despite this, what is clear, across disciplines and across the diversity of scholars represented here, is that a gap exists between these conceptual and theoretical approaches to the subject of care and its application in the everyday work of healthcare professionals. I can recognize the value of the questions raised by the scholars reviewed here. Yet, at the same time, a review of their arguments makes clear that they share an even more fundamental limitation, and one to which the present study responds. A characteristic shared by virtually all of the scholarship reviewed is that for all these authors, care is defined primarily by those who are in positions of power – whether as professional experts or as health professionals who provide care. Therefore, the justification for the current research study is to address the gap in the literature that pays very little attention to the experience of being cared-for and the meanings of care from recipients of care.
The research questions for this study evolved from a culmination of my work experiences, research projects in graduate school, and the multidisciplinary courses in aging and critical gerontology. Although each component evolved separately, they have come together in what appears to be a good fit, especially for this research project. My journey through academia has led me to the cutting edge of current critical thinking about the life experiences of elders living in long-term care and the need for more meaningful studies specifically targeted to this population.

The purpose of this study is to add to the knowledge about what care means by elder care recipients living in nursing homes, and to highlight the incongruence of how care is measured and evaluated by LTC institutions and state/federal regulatory agencies. In response to my increased awareness of some of the gaps in the care literature, I designed this study to provide an opportunity for the voices of elder care recipients to be heard. The primary research questions include:

1. What does care mean and how is it experienced by elder care-recipients?
2. What does care mean from the perspective of providers and regulatory agencies?

Accordingly, the objectives of this research project are to identify what care means and how it is experienced by elders living in LTC, then compare these definitions of care to the official criteria and measures of care mandated by the nursing home facility and federal regulators.
CHAPTER 3: METHODOLOGY

INTRODUCTION

In this chapter, I describe the methodology used for this research study. This study draws on the general tenets of a naturalistic inquiry, more specifically, a qualitative descriptive approach. To address the primary research question of what care is from the perspective of the care-recipients, the primary data source is the data collected from the care recipients themselves in a face-to-face interview.

Interviews are typically placed on a continuum of structure, from “unstructured” to highly “structured” (RAND, 2005). Imbedded in this continuum is the idea of how much control the interviewer will have over the interaction.

![Interview Continuum](Image)

Figure 1: Interview Continuum

There are benefits to each of kind of interview. The researcher has a clear plan when conducting unstructured interviews, however has little control over the topics the respondents bring up since the conversation may go in many directions, and may vary by respondent (RAND, 2004). The interviewer does not exert much control over the course
of the discussion, but should follow topics and discussion with additional probing questions based on the topics from the respondent (RAND, 2004). The interviews would be relatively free-flowing and could provide very rich and nuanced data; however, interviews may take a long time.

For semi-structured interviews, a guide with questions and topics that must be covered is typically used during this type of interview. The researcher has some discretion about the order in which the questions are asked, but the questions are standardized, and probes may also be provided to ensure that the researcher covers the correct material (RAND, 2004). In this kind of interview, the data continues to be detailed information gathered in a style that is still somewhat conversational. Semi-structured interviews are particularly useful for pursuing in-depth information around a specific topic (Babbi, 1998).

The most controlled type of interview is structured because the questions are fixed and they are asked in a specific order (RAND, 2004). Respondents are asked identical questions, in the same order and typically resemble a survey being read aloud, without deviation from the script (RAND, 2004). These interviews are useful when one has a very large samples and looking for data that can be generalized to a large population.

The primary method of data collection for this research project is semi-structured interviews with care recipients living in long-term care and the frontline staff (aka CNA).

Qualitative research began its “coming of age in gerontology” (Gubrium, 1992) about four decades ago, when the qualitative approach to aging studies was effectively justified by social gerontologists (Murphy and Longino 1992). Since then, researchers have continued the effort to develop qualitative research in social gerontology, from
revisiting epistemological paradigms in theory to further expand applied research in hopes of guiding practice (Powell and Longino Jr. 2002; Dionigi, 2006; Pohlmeyer et al. 2009).

To address how care is defined and measured by long-term care regulators and facilities, I analyze and describe the federally mandated guideline used for evaluating long-term care, and the evaluative instruments this LTC facility used to measure care services.

This chapter is organized by discussing qualitative method which is the primary methodology used for this research project. Next, I describe the research design, which includes the pilot study I conducted in order to test and finalize the interview guide used to collect all the data needed for analysis. I discuss the research setting, recruitment strategies, and the final study sample.

**Qualitative Method**

Qualitative methods is appropriate for this research study because it seeks to describe the meanings of a central theme within the life world of the residents living in long-term care (Kvale and Brinkmann 2009). Major sources of contribution to qualitative research have ranged from constructionism to phenomenology, hermeneutics, and ethnomethodology (Chen 2004). Along with cognitive, idealist, and subjectivist approaches, they are given a general name of “interpretive social science”, which is often equated with qualitative research (Neuman 1997). Sankar and Gubrium (1994) claim that qualitative approaches are appropriate in situations where issues are unknown, ill defined, or argued upon by scientists. The goal of qualitative research is to consider meaning and the interpretive process of the those individuals involved in the social, cultural, and
situational contexts in order to provide a deeper understanding of the subject matter (Blumer 1969; Jaffe and Miller 1994; Sankar and Gubrium 1994). Using this method takes an interpretive, naturalistic approach to its participants and studying them in their natural settings, attempting to interpret accurately and make sense of the phenomena (Blumer 1969; Jaffe and Miller 1994).

Qualitative research is also informed by Alfred Schutz’s (1967) theory of social phenomenology as both a philosophical framework and a methodology. Social phenomenology generally posits that reality is socially constructed through individual or collective definitions of the phenomenon, and in order to understand the person(s) being studied, the researcher should try to grasp what phenomenologists call “meaning structure” (Asper, 2004). Meanings come in structures and attain meaning in relation to other meanings, rather than in isolation; therefore, the process of meaning constitution is largely a social process. For this research study, it is the subjective meaning of care experiences that is the topic for interpretation. Schutz (1967) formulated a method for studying social action involving two order constructs of verstehen – interpretive understanding. The first order construct is the process by which people make sense of or interpret the phenomena of the everyday world (Schutz, 1967). The second order construct involves generating “ideal types” through which to interpret and describe the phenomenon under investigation (Schutz, 1967). In addition, interpretive understanding requires a trail of evidence throughout the research process to demonstrate creditability, trustworthiness and integrity (Koch 1994; Aroni et al., 1999). The interpretive approach in social research is “the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at
understandings and interpretations of how people create and maintain their social worlds” (Neuman, 1997; p.68).

Qualitative methods play an important part in clarifying the values, language, and meanings attributed to people who play different roles in organizations and communities (Abel and Sankar 1995). This method allows people to speak in their own voice, rather than conforming to categories and terms imposed on them by others. In this case and in other qualitative studies, researchers find that they are giving voice to those who are otherwise rarely heard, who are far down the hierarchical chain of command. From Goffman’s classic study of mental hospital patients as “inmates” (1961) to Diamond’s study of nursing homes (1992), sensitivity to the ways in which realities and roles are socially constructed and reconstructed has helped illuminate the unspoken assumptions underlying relationships between institutions and people with relatively little power in society. The strength of qualitative research is the ability to determine, represent, and explain the meaning of something from the perspective of the actors involved (Sankar and Gubrium 1994).

Thus, it is for these reasons that the research design for this project uses qualitative method to extract the voices from those for whom care is meant – the care-recipient – providing insight into a vantage point that has not yet been systematically examined. The general aim of this research design is to be systematic in investigating and exploring the phenomenon of care experienced through the subjective meaning from residents living in LTC.

The Study Design
The first research question is addressed through the use of a constructivist approach. A semi-structured interview guide is used to elicit data. The interviewer begins with describing the research study and reviews the informed consent form if the recipient agrees to participating in the study. After completing the consent process, the interviewer begins the interview by first asking questions about their personal background. Questions such as, “Where did you grow up?” “Can you tell me about your family?” or “How long have you lived here?” These questions were used to begin the dialogue and get some context about the resident. The next topic the interviewer would cover is life at the facility. Sample questions include, “How would you describe your life here?” “What are things that you most like about living here?” or “What are things that you dislike about living here?” Once the rapport has been established between the interviewer and the respondent, the interviewer begins asking the questions about care. Some specific questions include, “Would you say you receive care?” If they answered “yes”, the interviewer would probe by asking, “Can you elaborate?” or “What kind of care do you receive?” If the resident answered “no”, the interviewer may ask, “Why not? Can you explain why you don’t think you receive care here?” Additional care questions include, “What exactly does care mean to you?” or “Can you give me specific examples of when you feel cared-for?” As the resident begins talking to each of these, the interviewer may ask more probing questions to ascertain more details. The interviews conclude with the questions, “If you were to suggest ways to improve your life and care received while living here, what do you recommend?” Also, “Are there any other topics you would like to talk about that we have not covered?”
Probing is one way to stimulate the interview. Interviewers may use probes when they do not understand what the respondent has said and need further clarification. In semi-structured interviews, the interviewer is sometimes asked to follow up on an issue if the topic does not come up in the response to the initial question. In addition, probing questions may be used when the interviewer may think that the respondent has not told them everything, or if the respondent has not understood the question. Sometimes an “I don’t know” response really means, “I need more time to think about this” or “I don’t really understand what you are asking”. In deciding whether or not to use probes, interviewers need to listen very attentively to the respondent’s answer in order to determine whether the answer is clear and complete. Understanding and being familiar with the purpose of the questions is vital for the interviewer to know when the answer is sufficient.

The design for this study also includes eliciting similar information from the frontline staff. The frontline staff are key informants in the sense that they may confirm or validate some of the anecdotal data gathered from residents who may be considered as suffering from dementia or other forms of mental illness or disease. The staff interviews were designed to understand care from the perspective of those who work with the residents on a regular basis and in more intimate ways than other nursing home staff. Understanding care from the frontline staff perspective may help bridge the gap between resident meanings of care and institutional definitions of care when under scrutiny. The interview begins with gathering personal background and context about the staff as well as information about their employment with this facility. Questions about care to the staff were framed similar to the resident’s in order to elicit the same information about
meanings of care from the staff perspective. The interviews also ended with asking frontline staff of recommendations to improve their work-life.

To address the second research question and objective, I examine and describe in detail the evaluative tools and measures from the federally mandated guidelines for LTC as well as the measures used by this facility to receive feedback from residents and family members.

Finally, I juxtapose the responses from residents with the professional and institutional definitions of care defined by regulatory agencies. Healthcare providers, particularly LTC institutions are heavily reliant on government payment system (e.g. Medicare/Medicaid) and most are licensed or certified by state entities. Therefore, many care providers are subject to a range of State/Federal regulatory requirements of care. Consequently, patient outcomes and patient/family satisfaction surveys have become the focus of attention as a means to measure quality care in order to improve care services. Thus, to adequately understand care and how better to improve quality care, we must understand from all levels and perspectives – the resident, the frontline staff, the LTC facility, and State/Federal agencies – what is meant by care.

_Pilot Study to Refine the Interview Guide_

The method of semi-structured interviewing is well suited to the goal of accessing these personal realities. The interview guide provides a series of topical areas to be covered, yet allows the flexibility to follow up on promising or serendipitous comments. While all topics identified in the guide are generally covered, the order in which they are covered may be altered by respondent’s comments. After a few meetings and discussions
with my mentors and advisors who have had extensive experience in qualitative methods, a preliminary interview guide was developed. This guide was then piloted with two residents at a LTC facility. The pilot study was constructive as it identified some modifications to the wording and order of the questions, which was then finalized (see Appendix 3.0). This interview guide was used unchanged throughout the data collection process.

**Sampling**

An important part of any research effort is determining the sampling. Sampling is structured in some studies so that the sample either does not over-represent certain groups. In other cases, study samples purposively oversample certain minority groups. For this research project, stratifying the facility bed numbers by the assigned resident’s gender was a *systematic* or *stratified* sampling method. Once the bed numbers were organized by gender, the bed numbers were set as parameters for the random number generator, which was then used to determine the assigned residents for the study sample. The stratified sampling approach was employed for this study simply to include as many male and female residents as possible since male residents are typically underrepresented in LTC facilities. I consider male resident perspective just as important as female residents to this research on care.

**Data Analysis**

When conducting qualitative data analysis, there are two basic approaches to analyzing data: deductive and inductive (Rice and Eddy, 1999). For the current study, I used an *inductive* approach to explore and assess any unexpected relationships from the data. This analysis includes reading thoroughly all the qualitative data from each
Thematic analysis is a search for themes that emerge as being important to the description of the phenomenon (Daly, Kellehear, & Gliksman, 1997). The process involves the identification of themes through careful reading and re-reading of the data (Rice and Eddy, 1999). It is a form of pattern recognition within the data, where emerging themes become the categories for analysis. Thematic analysis was chosen for this study to address the research questions by allowing the tenets of social phenomenology to be integral to the process, allowing for themes to emerge directly from the data using inductive coding. The coding process involved recognizing an important moment and encoding it or seeing it as something prior to a process of interpretation (Boyatzis, 1998; Tobin and Begley, 2004). Although it may appear to be a linear procedure, the research analysis was an iterative and reflexive process. The data collection and analysis in this study were undertaken concurrently, reading and re-reading the previous transcripts before undertaking further analysis to ensure that the developing themes were grounded in the original data. The primary objective for data collection was to represent the subjective viewpoint of care recipients who shared their experiences and perceptions of the meaning(s) of care.

In the process of thematic analysis used to summarize the data, categories were derived inductively from the data and then applied systematically. This was a reflexive process where the simultaneous collection and analysis of data mutually shaped one another. With new data came new insights as participants described their unique situations and reflected on their care experiences. Initially multiple themes were identified and what was clear from the initial analysis, is that the themes were gendered...
and therefore coded accordingly. I then reduced these into sub-themes by gender. Upon final analysis with my mentor, we identified the three major themes and ten sub-themes that emerged throughout the resident interviews.

The merit of qualitative research is tremendous. One can summarize patterns, themes, perspectives, and perceptions that provide rich descriptions and quotations unique to qualitative research. It is important to remember that the unit of analysis differs for qualitative data – to the extent to which the data can be either quantified or generalized to the broader population varies. For this research study, the qualitative data cannot be generalized to the broader population, nor even to the general LTC population. This study is exploratory and simply the first step in identifying meanings of care from the care-recipients’ point of view, and to see how it may differ from meanings of care from those who define and evaluate care.

Research Setting

The research setting for this project was part of a non-profit, faith-based, Continuing Care Residential Community (CCRC) that serves the needs of residents and older adults. It is located in the mid-west region of the United States. Currently, the CCRC encompassed 622 acres of farmland in rural Pennsylvania that included various levels of continuing care. The Villages (pseudonym) is the 192-bed skilled nursing facility, which is the LTC research setting for this research project. The Ridgeline is an aging-in-place Assisted Living facility that offers 40 studio style apartments. The Heritage is also an aging-in-place personal care facility that offers 80 studio and 1-bedroom apartments. The Colonies offers estate and woodland homes as well as 1-bedroom apartments. The total capacity of all areas is approximately 400 residents.
Over the past decade, *The Villages*, which is the primary research setting for this study, has been engaged in purposeful efforts to change the culture by implementing the principles and values of the Eden Alternative. The Eden Alternative is a non-profit organization dedicated to remaking the experience of aging and disability across America, making structural changes in the living accommodations and moving from a medical model to a social model with a sense of “home-likeness”. In addition, a core principle of the Eden Alternative is that aging not a decline, but rather a continuous stage of growth and development in human life. The administration of this CCRC strongly believed in and were fully committed to the Eden Alternative principles, implementing the changes – both structural and in delivery of practice – that were needed to improve the well-being of their elder residents, their living and working conditions of their staff.

This long-term care facility, *The Villages*, is not a national representation of LTC generally. However, the facility characteristics of the residents are not much different from other LTC facility characteristics in regards to gender, age, and payment sources. At *The Villages*, the majority of the residents are female (N=190, 76%) while only one-fourth are male (N=60, 24%). Most residents are aged 75 years and older with 92 (36.8%) aged between 75-84 and 140 (56%) residents aged 85 years or older. As a LTC facility, it is not surprising that Medicaid (43%) is the main payment source while private insurance (20%), Medicare (19%) and self or family out-of-pocket (19%) each constitutes about one-fifth of the payment sources. Finally, other resident characteristics include psychiatric diagnoses (N=10, 4%), mental retardation (N=3, 1%), and hospice (N=8, 3%). This information is displayed in Table 1.2 below.
Table 1.2  Facility Characteristics of Resident Sample

<table>
<thead>
<tr>
<th>Gender</th>
<th>N</th>
<th>%</th>
<th>Age</th>
<th>N</th>
<th>%</th>
<th>Payment Source</th>
<th>%</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>60</td>
<td>24</td>
<td>25-54</td>
<td>4</td>
<td>1.6</td>
<td>Medicaid</td>
<td>43.2</td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Female</td>
<td>190</td>
<td>76</td>
<td>55-64</td>
<td>3</td>
<td>1.2</td>
<td>Insurance</td>
<td>20.4</td>
<td>3</td>
<td>1.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>65-74</td>
<td>11</td>
<td>4.4</td>
<td>Medicare</td>
<td>19.2</td>
<td>8</td>
<td>3.2</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>75-84</td>
<td>92</td>
<td>36.8</td>
<td>Self/Family</td>
<td>19.2</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>85+</td>
<td>140</td>
<td>56</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Recruitment and Sample

Previous long-term care research (including other research projects I have been involved in) shows the difficulty in resident participation, particularly frontline care staff due to their place in the hierarchy of the institution. Many residents and staff fear retribution from staff or administration (in the case of staff) if found out that they participated in a study or project that produced negative results (see Diamond 1992). This research project includes interviewing residents and frontline staff. However, because of my previous relationships with some of the staff, I hoped I would get more staff participation than in previous projects. Frontline staff were very helpful in identifying and providing relevant resident information as well. In most cases, because many of the staff were familiar with me due to my history of volunteering, no one questioned why I was escorting a resident off the unit or to the privacy of their room for the resident interviews. Therefore, resident participation was still anonymous to most of the staff. Recruitment of residents started with the facility census list of each of the units that
included residents from *The Villages*. From this list, I stratified the bed numbers by gender. Then, using an online random number generator and the facility bed numbers as parameters, 40 random female bed numbers and 60 random male bed numbers were identified. The goal was to get an even number of interviews for each group (approximately 20/20), or until data saturation had been reached. Due to differential mortality for men and women in older populations, other researchers typically stratify their samples by sex, and oversample men, as I have done for this study.

During each visit to the home, I had the list of bed numbers and approached the resident assigned to that bed asking if they would participate in the research project. If the resident was not in their room, I would ask the staff about the resident’s whereabouts (e.g. residents could be at an activity onsite, activity offsite, or at a doctor’s appointment, with family, hospital, etc.). Depending on the resident’s whereabouts, I would either try to find the resident (if onsite), or move on to the next room number on my list and come back to this room at a later time or during my next visit.

Once a resident was located, I asked him/her if they had time for a visit with me. If they agreed, I proceeded to take them to their room or an area of their choosing that ensured privacy. Although the majority of interviews took place in the resident’s room, some took place outside on the patio or in the gardens depending on the elder’s preference. Once a rapport was established between myself and the resident, and I felt the resident was comfortable and capable of conversing with me, I explained the research project, its purpose, and asked if they would like to participate. If the resident agreed to participate, I proceeded to go through the informed consent process, which included asking them if I could audio record the interview. If the informed consent was signed, I
began the interview. However, if a resident declined, I continued visiting for a few minutes or until the resident was done visiting. I then went on to the next number on the list. For those who refused, nothing was recorded or noted about their refusal – I simply marked an “R” beside the room number on my list.

Participation for the study was open to all participants who were able to verbally consent and engage in a verbal interview with the interviewer. Given the potential for cognitive functioning to fluctuate (Borg, 2008; Blanchard-Fields, 2008) and the potential for individuals diagnosed as impaired to offer cogent and insightful commentary on their living arrangements (Dannefer, Patterson and Siders, 2007), cognitive status was not a criterion for inclusion or exclusion of this study.

The final resident sample for this study includes: a total of 39 resident interviews, in which 18 are from male residents and 21 from female residents. For this sample, the average age of men is 84 years and 86 years for women. All residents are Caucasian. The average length of stay (2.6 years) were the same for both male and female, as well as the average number of different medications (n=14). The payment sources were split between Medicaid (n=8) and private insurance (n=8) for men, with 2 residents using Veterans pay. For females, more used Medicaid (n=13) compared to private insurance (n=8).
### Table 1.3 Resident Sample

<table>
<thead>
<tr>
<th></th>
<th>Male (n=18)</th>
<th>Female (n=21)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age Range</strong></td>
<td>46-92</td>
<td>70-104</td>
</tr>
<tr>
<td><strong>Average Age</strong></td>
<td>84</td>
<td>86</td>
</tr>
<tr>
<td><strong>Race (Caucasian)</strong></td>
<td>18</td>
<td>21</td>
</tr>
<tr>
<td><strong>Length of Stay</strong></td>
<td>2 mos – 9 yrs</td>
<td>3 mos – 10 yrs</td>
</tr>
<tr>
<td><strong>Average Years of Stay</strong></td>
<td>2.6 yrs</td>
<td>2.6 yrs</td>
</tr>
<tr>
<td><strong>Average Number of Medications</strong></td>
<td>14.0</td>
<td>13.7</td>
</tr>
<tr>
<td><strong>Medicaid</strong></td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td><strong>Private Insurance</strong></td>
<td>8</td>
<td>8</td>
</tr>
<tr>
<td><strong>Veterans</strong></td>
<td>2</td>
<td>0</td>
</tr>
</tbody>
</table>

Frontline staff recruitment included asking the Certified Nurse’s Aides (CNAs), who worked in The Villages, if they would like to participate in the study. The staff who agreed to participate contacted me after their shift to discuss their best time to meet for an interview. Most staff interviews took place in a public restaurant at their request, but we sat in an area where we could have a private conversation without being too close to other people. I ensured the staff member felt comfortable during the informed consent process and asking permission to record the conversation. Two staff members were interviewed in the privacy of their home at their request. Similar to other research projects, frontline staff recruitment and participation in the study was difficult due to a sense of apathy because they felt that their voicing their concerns would be heard or no action would be taken by their administration. In addition, others refused participation due to a fear of reprisal. This lack of staff participation is arguably indicative of facility culture – the culture this facility was trying to change as they go through the Eden Alternative journey.
The frontline staff sample for study includes: a total of 11 frontline staff where 10 were females CNAs and one male CNA. Most frontline staff were not married, where five (n=5) were single, while two (n=2) were currently separated, and four (n=4) were married. The age categories included: 18-29 years (n=5), 20-39 (n=2), 40-49 (n=1), 50-59 (n=2), and 60-69 (n=1). The majority (n=7) frontline staff annual salary ranged between $20-29k; while two (n=2) had an annual salary range of $15-19k; and two (n=2) had an annual salary range of $30-39k. The average years of employment in this specific LTC facility was 8 years, while the average years of working in LTC generally for this staff sample was 10.5 years. Four (n=4) CNAs worked day shift; four (n=4) worked afternoon shift, two (n=2) worked midnight shift, and one (n=1) staff member was currently enrolled into nursing school and working only weekends. I asked what their future goals were or where they see themselves in the next 3-5 years and five (n=5) of the CNAs did not see any major changes to their current situation or employment, while four (n=4) wanted to go to Nursing school, and two (n=2) were planning to retire.

In conclusion, the total sample for this research study includes a total of fifty (n=50) participants with thirty-nine (n=39) resident interviews and eleven (n=11) frontline staff interviews. Of the 50 respondents, thirty (n=31) were female and nineteen (n=19) were male.

For the next three chapters, I will discuss the qualitative findings of the thematic analysis gathered from the elder care recipient and frontline staff interviews.
Chapter 4: EMERGENT CARE THEMES

INTRODUCTION

The process of extracting themes from the data, described in the previous chapter (Methodology), yielded a total of 13 themes related to the meaning of care. Of these, three (3) issues emerged as primary care-related themes based on the frequency of mention and the indications of their high importance to many residents. Five other issues can be regarded as relatively minor, but they were mentioned with enough frequency and/or force in relation to the topic of care to warrant inclusion.

The two major themes, “being able to do something for others” and “the need for more sexual intimacy” are the subject of the following two chapters. As it will become clear, both of these themes are sharply differentiated by gender. Following the presentation of data on these themes in Chapters 5 and 6, Chapter 7 will analyze the federally mandated evaluations of care as well as facility level of care measures. In chapter 8, I relate these care themes in relation to broader theoretical issues related to care and to other research on the needs of elders.

Before turning to this task, I report and briefly discuss a major theme and its subsequent sub-themes. While these themes warrant little further discussion beyond this presentation, it is important to report them as legitimate, even if minor, responses to the questions I put to my resident and staff interviewees about care. The overarching major theme is what I label, “Care as Control”. The three sub-themes are: (a) care as a threat to independence, (b) care as transparency, and (c) care as discipline.
MAJOR THEME: CARE AS CONTROL

SUB-THEME: A threat to independence

One of the ways in which the respondents, most notably female respondents, perceive care is receiving care was a threat to one’s independence. Nearly half (n=9) of the female residents interviewed identify themselves as being an “independent woman”. For some of these women, independence includes telling staff what they can or cannot do or not allowing staff to do certain physical care tasks. For these women, if residents can participate in their care in any way, they may feel they do not need care; however, this respondent not only identifies herself as independent because she does not allow staff to wash her, but recognizes that the time will come when she will not able to do these tasks.

“There are people here who are, I don’t know, backward I guess [i.e. staff]. They want to wash you whether you want them to or not. They want to tell you what to do, and I don’t let them. I think it bothers them that I tell them ‘no’. I’m too independent...an independent woman, you know. There may come a day when they will have to do that and I don’t want to get on the wrong side of them, you know, but I’m not an invalid yet, so I don’t let them care for me.” [Edith]

She goes on to describe how she reacts about other rules and demands of the facility.

“It’s hard to come in here and follow all the rules they make. And of course, I’m pretty mouthy and speak out and say, ‘no! I’m not doing this or that’. It’s something I don’t wanna do...like when they tell you its time to go to bed at 7:00 PM. I’ve been too independent too long that I feel when I’m paying the kind of money I do for this place, I’m gonna do things my own way.” [Edith]

Another female resident also expressed that part of her independence is in articulating to the staff what she wants or doesn’t want; however, learning that stating one’s wants and needs may result in other forms of unwanted treatment.
“For the most part, I don’t have no problems. If I do, I take care of it. The girls here are pretty good but if something does happen, I run my mouth off… but sometimes it gets me into trouble [laughing]. One time, I almost got in trouble when I wasn’t feeling good and the girl was bringing me some aspirin or Tylenol. Well, she was fumbling around, dropping things or something, so I just said, ‘Oh just give me the whole damn bottle already!’ And oh boy, did I stir up a hornets nest! She went right down and told the head nurse, and the head nurse went and called the psychiatrist. He was going to come see me and see if I needed to go into some crazy house because they said I made a suicidal comment! I told them. ‘If you send him up here, I’ll kick his ass right back out!’” He didn’t come up, but I watch what I say anymore or they’ll put you under suicide watch around here, you know. [Gertrude]

For some of these women, the ability to speak out and state what they want or do not want is an important way of maintaining their independence. As anticipated above, several residents claimed that it was the facility specifically, or living in this place, is what made them lose their independence, and therefore, needing care was a threat to their ability to perform daily functional movements or instrumental tasks without assistance.

One resident describes how fast her mobility declined after moving to this facility.

“It all seems like it just came on me really fast. I never used the walker or the wheelchair until I got here. There are some things I can still do, but I can’t get around very easy anymore. I can’t believe how fast its all happened. I think being here does that to you, you know – lose your independence”. [Ethel]

Similarly, another female resident expressed that living in this facility affected her mental well-being:

“I’ve always been an independent woman and I still have most of my wits but sometimes I feel like I’m in the nuthouse here and I’m just about to go off the deep end myself…these people, this place, will make you think you’re crazy even if you’re not! Who knows, maybe I’m the crazy one after all”. [Gertrude]
Not only is living in this type of care facility symbolic of their loss of independence, but to many residents, living in this facility and receiving care affects their independence negatively on both physical and mental health levels. However, one resident, the eldest of the female residents interviewed describes how her independence is stifled because of her age.

“I don’t like to complain, but I’m tired of living in this chair all day and that’s what I’m doing! They [staff] put me to bed, they get me up, put me in this chair. I could do all this myself, but because I’m over a hundred years old, they won’t let me do anything. I say, they’re trying to make an invalid out of me! I like to do things on my own and in my own time, but they want to do everything for you here”. [Elsie]

She goes on to describe how the staff reacts when she tries to do things on her own:

“I can get out of bed and get started in the morning. I’ve done it a couple of times but was reprimanded for it...they yell at you and say, ‘You’re not allowed to do that!’ So now they just put my walker and wheelchair over there [pointing across the room] at night so I can’t reach them and get up by myself”. [Elsie]

What is clear from Elsie’s account is that she views these actions by the staff not as an act of care (where staff could argue these actions are care in the form of taking safety precautions due to her “high risk for falls”) but rather, Elsie views it as quite the opposite – debilitating her further, stifling her independence and making her “an invalid” in the process. In sum, from the perspective of many elder female care recipients, care appears to be a major threat to one’s independence.

**SUB-THEME: Care as transparency**

Another theme that arose mainly throughout the male resident interviews was the need for being informed about any changes with their medical condition, medications, room, or finances. Specifically, some of the male residents felt un-cared for when they
were not informed of these changes, angry reactions often coupled with skepticism concerning facility motives or intentions were expressed. For example, one male resident claimed that he was moved from a private room to a shared room because another resident was willing to pay more money than he was paying for the private room.

“Well, I had a nice single, private bedroom. I went down to breakfast one day and they [a social worker] come and tell me ‘You’re moving today’. Just like that! It’s not like they ask you. You’re going and that’s it! So they moved me into this little cubby hole [spreads arms out to show current room]. So, I asked the lady who maneuvered that deal, she came to see me and I said, ‘Why pick on me? I’m not the only private room in this place.’ She said, ‘Well, he [another resident] has to be immune and has to be this, and has to be that, he’s gotta have a private room...’ so they put him in there. Now, I see he’s out there talking to everybody, walking around, he’s eating with everybody, and I say, ‘Where’s the immunity?’ So I don’t ask no more. Then, I found out he’s got the money, you know. Yeah, I could’ve kept the room if I would’ve paid another $800 a year! I said forget it.” [Jimmy]

When I asked him how he found this information out, he would not say specifically, just that he had his “sources”. I also probed and asked how it made him feel, he replied:

“Well, definitely not cared-for...I felt like punching someone’s lights out cuz it was such a nice room”. [Jimmy]

Jimmy was not laughing when he said this, and it was very clear he quite angry about it. Later in the interview, and after discussing some of his medical conditions, Jimmy recalls other instances in which he was not informed from the medical professionals at this facility:

“They don’t tell you shit around here. I don’t know how many X-rays I’ve had done since I’ve been here, and I never know how any of them come out, or if they
found anything, but nooooo, once they got their money, they don’t give a shit”.

[Jimmy]

Throughout the conversation Jimmy seems very skeptical and at times quite angry when he describes these practices of not being informed about room changes, finances, or medical test results. Furthermore, he suspects that such practices are financially motivated by the facility and/or the medical profession and therefore not true care practices.

Another male resident expresses similar anger and suspicion for not being informed on the prescription medication changes. One male respondent, who was previously in law enforcement, expressed threatening to call the police on the facility.

“I’ve never had a drink or a smoke in my whole life, but now they’ve got me on seven different medications and they won’t tell me what they are for! Maybe I’ll just call up my connections at the State Police and tell them what’s going on here”. [Alfred]

Although he later admitted he wouldn’t call the police, he did however articulate his frustration at not knowing what specifically his medications were for. I asked if he ever discussed these concerns with his nurses, he replied that he never got a straight answer from them. Interestingly, I observed such an interaction during our interview as the nurse came into the room to give him his medication. As she hands him the pills, Alfred asks, “What is this for [short pause], gonorrhea?” The nurse responds, “Oh, I don’t know, just take it!” As he puts the pills into his mouth, she hands him a cup of water and continues, “Yeah, it just might be for gonorrhea… from your latest conquests.” Additional interaction occurs between Alfred and the nurse, and both are laughing and joking with each other as the nurse walks out of the room. It was clear to me that the nurse never did directly answer his question about what the medication was or what it was for. After
this interaction, I also ask Alfred what the nurse meant by ‘‘conquests’’ and if he indeed had any lately. He replies:

“Nah, I’m a married man, but I’m not dead... there are some lookers around here. But if you can’t have a sense of humor around here, you might as well be dead!” [Alfred]

He further confirms that he honestly did not know what kind medication the nurse just gave him and said that it is one of the seven new meds he has been taking since moving into the facility. [SIDE BAR: This is an interesting interaction since the conversation went from the resident inquiring about the medication, albeit jovially mentions a sexually transmitted disease (STD), which then turns the interaction between nurse and male resident turns into a jovial banter about male “conquests” (sexual connotation). This interaction is indicative of what many male resident interviews will show in the next chapter.]

After the interview with Alfred, I stopped to talk to the same nurse, who was standing in the hallway with her medicine cart. I asked what the medication was that she gave Alfred. Nonchalantly, she said “Oh that was [states name of medication] for his blood pressure”. I continued, “Well why not just tell him that when he asked? She replies “Oh he knows what it’s for, he just likes to joke around like that all the time”. Although I did not interrogate the nurse further, Alfred had made it clear to me in the interview that he did not know what medications he was prescribed, nor what they were for. When I asked Alfred whether he felt cared for in this context, he replied:

“Well, I sure as heck would feel a lot more cared if I knew what the heck they were giving me! [Laughing]” [Alfred]
Alfred thus made clear that he wanted to know these things. Despite the jocular interaction between the nurse and male resident, the end result is that Alfred continues to experience the situation as one in which he is uninformed, and remains uninformed even when he specifically inquired about it.

Similarly, another male resident, Harold, expresses his anger about the staff changing his medications and that there’s a conspiracy to keep him crippled by using these meds.

“They switched my pills on me for no reason at all! They tell me its for my Parkinson’s and I asked them what was wrong with the other pills I was taking, but they don’t tell you shit around here! They are giving me these new pills now and I didn’t even know it. I mean, I used go to the bathroom and everything all by myself until all this started. Now, I can’t even piss without somebody coming and having to help me. See, even my legs, I can’t even kick somebody’s ass if I wanted to…and it’s these new pills that’s crippling me! They tell me they can’t change anything until the doctor does, so I’m stuck here like a cripple until the doctor changes it. So, I get mad and go off on them about it…how’s that for care?” [Harold]

It is quite apparent that Harold does not feel cared-for at the moment because of his physical decline, which he blames on the staff for switching his medication without awareness. He expresses his anger towards the staff and knows well enough to tell me that the staff deflects the blame onto the doctor.

“It’s all a blame game to all of them. They do this [change meds], and when I find out and start yelling at them, they just blame the doctor and say they’ll let him know, but they just keep giving me this shit day in and day out until I won’t be able to walk anymore! By the time the damn doctor shows up again, it’ll be too late. Those doctors don’t give a shit about you here.” [Harold]

What is unfortunate about Harold’s account is that I know all too well from more extended observations in LTC facilities that it is not uncommon to hear nurses and
doctors place the blame on each other to pacify the resident (briefly) for any medical changes that the resident may not like at the moment. And in Harold’s case, it appears that no one is willing to explain to him the reasons for the prescription change. And although he feels as if the medicine is further “crippling” him, there is nothing the staff or doctor can or will do until the next doctor’s appointment. Until then, he is left crippled, helpless, uninformed and ultimately uncared-for.

Room changes and medication were not the only topics in which residents felt they were deliberately kept uninformed. The cost of care and their financial situation appeared in several of the male and female resident interviews. For one male respondent, who appeared to be managing his own bills, expresses surprise and some skepticism at the costs being charged:

“Getting through that stack of mail every day is my goal, like paying those bills. I’ve got an ambulance bill and facility bill there, and boy, you should see how much they charge me! A pretty good penny for every little thing! I need to go downstairs and see what’s going on, but I know that without talking to anyone yet, they’ll have a pretty good story to tell me, explaining all of it, I’m sure”.
[Edward]

It is quite uncommon for a resident to still manage his finances while living in LTC. Typically, a family member or a power of attorney manages this responsibility. As such, a few (n=5) male residents who no longer manage their own finances specifically expressed feeling very isolated from this process and that the facility was purposefully them from it for a reason. This conspiracy is described by Cecil:

“I think there’s monetary problems here, but they isolate us from our expenses, so we don’t know anything about it. You know they wouldn’t let you in this place if you didn’t have money, and they’ll take everything they can from ya’. But sooner
Simply put, Cecil’s understanding (as well as other residents) was that the facility allows you to live here as long as you have money, and once the money is all gone, the residents are sent away to a different facility. I asked Cecil what he thought happens if you run out of money and the facility does not send you away, he replied:

“Well, I’m not quite sure since they don’t tell us anything about it. I guess you just die here, which that’s pretty much what most do…just die here”. [Cecil]

In sum, male residents express passionately that one form of care is being informed of changes to medications, rooms, and finances. Furthermore, that for most of these cases where they were not informed, it was conspiratorial whereby the facility or medical professionals were intentionally or deliberately not caring for them but rather keeping them uninformed for their own financial gain or to further cripple or debilitate their current state/situation.

**SUB-THEME: Care as discipline**

Throughout my work and research experience, it is quite common for residents to describe living in LTC like that of living in prison or some other type of restrictive institution. LTC falls under what Erving Goffman (1957) called a *total institution* as wherein its totalistic features include: 1) all aspects of life are conducted in the same and under the same single authority; 2) each phase of the members’ daily activity is carried out in the immediate company of the larger group of others, all of whom are treated fairly.
alike and required to do the same thing; 3) all phases of the day’s activities run on a tight schedule; and 4) the various activities are brought together as parts of a single over-all rational plan is designed to fulfill the official aims of the institution. Therefore, it was not surprising for this theme of institutionalization to emerge during my discussion about care with nursing home residents. For example, when asked if he felt cared-for here, Jimmy describes a common sentiment:

“This place is like the prison just without the bars. You gotta do what they say or you’re in trouble.” [Jimmy]

When I probed residents to explain these institutional analogies of their current situation, most described the routinization of everyday life in a nursing home:

“They serve me my meals, lunch, dinner and breakfast at certain times. I get my bath on certain days. They’re very routine here. It was very difficult for me to come in here and follow all the rules that they make. I don’t think they should tell you when you have to go to bed and stuff.” [Annie]

Jimmy and Annie, as with many other residents, spoke of such routinization not in a favorable light, but rather most residents described it negatively, and more importantly, that such routinization was not a form of good care, nor did they feel cared-for as they described having a difficult time adjusting to these routines, or getting in trouble because they did not follow or abide by facility rules.

However, what is most interesting is the perspectives from the male residents who served in the military, where care is viewed as discipline. Alfred, a Marine veteran, describes the facility and its routines similar to a Marine barracks:
“...this place is just like a Marine barracks, except that they do everything for you here...but we all have to do everything at the same time, every day, see the same people, you know. We go here, we go there, the same time, the same place, see the same people every time. It’s like clockwork you know. They have to run this place like that I guess. Just like the guys in the Marines, when you have that many people to deal with, you have to have a strict schedule; otherwise, no one would ever learn any discipline.” [Alfred]

When I probed Alfred to explain how such routinization teaches residents discipline and if he thought this was a form of care, he replied:

“Routines just teach discipline and you have to have that when you have this many people you are in charge of, you know. You can’t have everybody doing their own thing at their own time, you’d have mayhem around here...So yeah, routines is good thing. I like knowing when I’m getting up and going to eat, and going to this or going to that...now whether that always happens around is another whole other matter [chuckles].” [Alfred]

Similarly, Sam, a retired Sergeant in the Army, best describes these routines as discipline in training:

“We train each other. Teach each other how to survive together. It’s a good training program here. We do everything together, we eat together, develop the same habits, we have the same goals, we train how to get along with each other so we can live together in civility. We learn a lot of this ‘togetherness’ in the service and so we carry this into this life here.” [Sam]

This description of military life is common. A good friend of mine describes deployment similar to Bill Murray in the movie Groundhog Day. “We do the same thing, eat the same food, see the same people, day after day. That’s what life is like for the whole deployment however long it may be” (LCDR in the U.S. Navy). Similarly, Sam
seems to describe the same repetition and regimentation of everyday life on this unit and describe such repetition as training to live together in civility. Throughout the interview he spoke in this analogy and I asked what happened if he or someone did not adjust well to the routines here, and he replied:

“Punishment. You sit in isolation or what we call the ‘Jailhouse’ [chuckling] under strict regulations until you conform. You learn to adjust to this kind of lifestyle...but there’s more training here than there is punishment.” [Sam]

The ‘jailhouse’ he spoke of was a separate lounge area where one resident currently sat alone in a geriatric chair. It was clear throughout the interview, he views himself as a “good soldier” and one that not only has adjusted well to this institutional life, but also has the responsibility of playing a key role in training other residents and being a good example of a “good soldier” here on his unit. When I asked if he felt cared-for under this regime and he ecstatically replied:

“Oh yes, when you’re a good soldier, you get rewarded...I got the Good Soldier of the Month Award’ [smiling very proudly]. They posted a picture of me on the wall out there.” [Sam]

I asked what he did to earn that award, and he said:

“By following your training, doing everything the correct way, the right way, at the right time. You follow all the rules and conform to being the good soldier in training, and they reward you well. You get treated with respect.” [Sam]

I probed and asked Sam, “What about the other residents living here who are not yet “good soldiers”, do they still get rewards and good care too?”

“Oh yes, we continue to train them to be good soldiers. Care is in the discipline and the training. We train everyone here to be able to live with each other in
civility. We train each other every day, we work together as a whole, but until they follow the rules, they stay in isolation...It's a rigorous life here, but we enjoy it. If you follow the rules then life is good and easy. That's why guys like me get picked for good behavior and rewarded on that wall out there. The good thing is, once you're a good soldier, you become a good civilian when you move into civilian life.”

In sum, a unique care theme emerged from the military veterans interviewed in this sample, where routinization is viewed as a form of discipline and furthermore, a type of good care. To Sam, a regime in which everyone is doing the same thing, working and training together with one common goal – to live together in civility – care is the discipline and the training. Conformists to such regimes are rewarded while non-conformists are punished or isolated until they learn to or succumb to this training and conform (Kahana & Coe, 1969). This discipline, this training is a form of care for the whole community to live together in harmony.

Now that the full enumeration of identified themes is complete, it is time to turn to a more intensive examination of the major themes. Chapters 5 and 6 each consider two themes that are held in opposition to each other.

In Chapter 5, “Care as physical and intimacy and companionship” is discussed as the modal result that emerged from the male residents. It may not that obvious but these descriptors – physical intimacy and companionship – are in somewhat opposition from each other wherein males wanted physical intimacy and females wanted companionship. In addition, Chapter 6 will discuss the female modal result where they expressed care as “helping others” compared to the male response of “embracing the sick role”. In sum, readers may infer from the descriptors that these terms are strongly correlated with gender, which emerges a major organizing fulcrum in the following two chapters.
CHAPTER 5: Care as Physical Intimacy & Companionship

INTRODUCTION

This chapter focuses on the modal response of what care means from the male residents living in this LTC facility. As stated in Chapter 3, there were a total of 18 male residents who participated in this study. The ages ranged between 46 – 92 years with the average age of 84.24 years for this male sample. Considering most of the male respondents lived and worked in the surrounding small towns in rural Western Pennsylvania area, it was not surprising that the majority of the male residents’ former occupations were working and lower middle-class plant workers – such as foremen, engineers, welders, and truck drivers. There was one music/English teacher, and one Radiologist. As far as medical diagnoses, four of the 18 male residents had dementia or Alzheimer’s as a primary diagnosis, and another four had dementia as a secondary diagnosis. Other primary diagnoses included rehabilitation for various surgeries (hip fracture, heart surgery, subdural hematoma), pneumonia, congestive heart failure, COPD, and one male resident was a paraplegic. The average number of prescription medication for this sample was nearly 14 (n=13.53) different medications. Finally, twelve (n=12) of the 18 male residents needed significant (“2-person” as marked in their charts) assistance for transferring, dressing, and toileting.

In this chapter, I discuss the topic that was most frequently brought up and also implied in the context of what care is or when these men feel cared for. I label it as “Care as Physical Intimacy”; however, I organize this section by various sub-groups in which this topic was brought up: highlight a sub-group of male respondents whose meanings of
care are related by more explicit to the overall male care theme. Frontline staff responses are also included – “The Dirty Old Man Syndrome” – providing accounts of what they experience in the context of providing care to male residents and witnesses to other resident experiences of care as physical intimacy. The male resident and staff accounts are then contrasted with interview data from female residents on this similar theme – “Care as Companionship”. However, it is important to note that this care theme was not the modal response for female respondents. In fact, probing questions were asked to elicit responses related to this theme when women talked about missing specific people in their lives or certain relationships. The probing questions were adapted to female resident interviews since care as physical intimacy became an evident theme from the very beginning of the male interviews. The results for this chapter are obtained through the face-to-face interviews with male and female residents and the frontline staff.

**SUB-THEME: CARE AS PHYSICAL INTIMACY**

One of the biggest challenges during the interviews with male residents was how difficult it was to get a clear definition of and specific meanings of care articulated from male respondents. Asking directly what care means to them or even having them define what they meant when they mentioned “care” proved to be quite difficult. Therefore, multiple probing questions and allowing the time and space for men to articulate exactly when they felt cared-for proved to be key to delving into some of the deeper meanings of care. An example of how probing questions got to different meanings of care is noted below for one of the male residents. Note that in the interviews below, “R” stands for Researcher and all of the respondents’ names are pseudonyms.
R: Do you receive care here?

Mike: Sure, the girls take care of me.

R: How do the girls take care of you? What do they do?

Mike: You know, they take care of things I need.

R: Like what?

Mike: Like when I need to go to the bathroom.

R: What do they do?

Mike: They take me to the bathroom.

R: Is that what care means to you, when someone takes you to the bathroom?

Mike: Sure, if that’s what I need them to do.

R: Okay, so care means someone taking you to the bathroom when you need to go?

Mike: Yeah and they need to respect you.

R: What do you mean?

Mike: Well, they should tell you what you’re doing while they’re doing it.

R: So, care is when someone is telling you they are taking you to the bathroom while they are taking you there? Is that care or respect?

Mike: I’d say both... and it’s like when they’re pulling things down, and wanting you to sit... stuff like that.

R: So, telling you that they’re pulling your pants down and asking you to sit, while they are assisting you in doing these things, this is what you are saying care and respect is?

Mike: Yeah, like that.

R: Do you get that kind of care here?

Mike: [Laughs a little]... Not that often really.
In this interaction, Mike initially describes care as taking him to the bathroom, but in probing further, we find that that care is more than just the act of taking him to the bathroom, but rather includes demonstrating respect in which the caregiver tells him what they are doing while in the midst of doing the actual activity. Furthermore, Mike expresses that this type of care is not the type of care he receives often. Later, in the conversation, I ask for additional examples of care:

R: Are there other times that you feel cared for?

Mike: Sure...when the girls give me a hug, like the other day, this girl gave me a hug for doing a good job when I went to the specialist for this sore on my tongue [he sticks his tongue out to show me]. So she gave me a big hug, and then the other girl in the room said, “Oh, I didn’t give you a hug yet either!” She comes over and puts her arms around me. I got hugs from both them girls.

R: Why did that make you feel cared for?

Mike: I got hugs from them.

R: So, because they put their arms around you made you feel cared for?

Mike: Yeah that made me feel good. You don’t get hugs around here very often, and I got it from TWO girls that day!

By asking additional probing questions, he identifies care is more than taking him to the bathroom and respecting him by telling him what they are doing, but that the physical act of hugging made him feel cared-for because hugs were not given often and he received two of them from two different girls. Thus, to Mike, care includes the physical touch of affection, like a hug.

Code Words to Describe Different Meanings of Care

My interview with Mike was unusual in the sense that he was able to articulate and respond to my questions with some specificity. However, I learned that it was not as
easy to get other male residents to articulate exactly what they meant by certain
statements or phrases about care. For some male residents, they used “code words” to
imply certain meanings. For example, in my interview with Curtis, I asked:

*R: Can you give me some examples of when the girls provide care?*

*Curtis: Oh they do all the time, you know, I used to do a pretty good Jitterbug back in the
day. I was quite the catch for the ladies. Now, I’m just a useless old man, but the girls here will tell me, “Oh don’t say that, you’ve got lots of years still in you!” But I know they’re just saying that to be nice. They wouldn’t do any of that with me anyways, I’m pretty much useless now.*

*R: So, the girls provide care to you when they tell you those nice things?*

*Curtis: Partly, but they wouldn’t do THAT with me anyways, I don’t even know if I could at this point [laughing].*

*R: Do what exactly?*

*Curtis: [pauses] Let’s just call it the Jitterbug...[laughing]*

*R: Jitterbug, as in the dance?*

*Curtis: Well, not the dance per se, but you know, what dancing leads to after... a good time.*

*R: Is this how the girls provide care to you... doing the Jitterbug and having a good time?*

*Curtis: Well, I guess I’m saying they DON’T do this is more like it, huh [starts laughing].*

*R: If they did do the Jitterbug with you? Would you describe that as care?*

*Curtis: Sure if they could Jitterbug, but it's the good time too, you know.*

*R: What is the ‘good time’ exactly?*

*Curtis: Well I won’t go into all that...let’s just call it... Jitterbug.*

*R: Okay, but we aren’t talking about dancing? [He shakes his head no] Can you give me a clue as to what you mean?*
Curtis: Well, let’s just say, it’s lots of good moves [laughing] ... it’s all a good time.

I continued trying to get him to state exactly what he meant by “a good time”, but he wouldn’t provide a specific explanation and insisted on calling it “the Jitterbug” in a joking manner. It was clear that he did not mean the dance, but rather something more intimate or sexual. However, there are a few things important to note from this interview. First, Curtis initially states that the girls do provide care to him by way of telling him that he still many years left to live. This was immediately followed by a reflection of identity as a “useless old man.” As I interrogated him to explain what he felt the girls would not do to him, he appeared a little embarrassed and instead used the code words of “Jitterbug” to mean something more than just the dance. Thus, the meaning of care changed from the girls saying nice words, to something more intimate, perhaps even sexual. Finally, Curtis also acknowledges that this kind of care is what he does not receive from the staff.

Another resident, Jim, also used code words to describe a meaning of care. I asked:

R: What kind of care do you receive here?

Jim: Oh, the girls treat me real good here...feed me, bathe me, do all the stuff I need, you know.

R: So you’d say feeding and bathing you is care?

Jim: Sure.

R: ... Do you provide care back?

Jim: Oh no, I don’t do anything to them! I don’t monkey around with them or anything, you know.
R: What do you mean, “monkey around”?

Jim: You know... monkey around... touch them.

R: When you say ‘touch them’ are you meaning like how they touch you when they’re giving care to you, like a bath or feed you? You don’t touch them like that?

Jim: No, no. I don’t do that to them anyways.

R: ...meaning, you don’t feed or bathe them?

Jim: Yeah I don’t do stuff like that.

R: So what do you mean you don’t monkey around with them?

Jim: Oh, [laughing] I don’t touch them like THAT [uses hands just to show emphasis – no clear gestures]... Ah never mind. I’m just a dirty old man now, you know, but I don’t monkey around like that anymore [laughing].

Jim did not state exactly what he meant by “monkey around”, however, what is important in this interaction is that Jim initially agrees that he receives care from the girls such as feeding and bathing. Interestingly, when asked if he reciprocates care, he appears immediately defensive in expressing that he does NOT “monkey around” with the girls.

The important part to highlight here is the different meanings of care: the first is the care the girls provide to him by way of feeding and bathing; the second, is what he calls “monkeying around” which he clearly implies is not feeding or bathing. He doesn’t explain what this means, however, it is worth noting that he meant something related to touching intimately or sexually considering how he identified himself as “a dirty old man” as a way to re-direct the conversation. The identity of being “an old man” was rampant among the male residents; however, you will see there are several variations: Poor, Lonely, Dirty, and Useless.
How Medical Conditions Influence the Pursuit of Care

Some male residents felt that their medical condition influenced their care. For example, Harvey describes how his blindness was a significant reason why he became “useless.”

R: Would you say you receive care here?

Harvey: Losing my eyesight was the worst thing that ever happened to me. I could deal with my legs not working, but when you can’t see, you don’t see people. You can’t make friends. When I lost my eyes, I lost everything. I became useless.

R: So not being able to see or make friends, makes you useless?

Harvey: All I have to look forward to now is that it’ll soon be over.

R: Are you receiving care while you are here?

Harvey: Yeah, but I can only imagine what some of these girls touching me look like cuz I can’t see them.

R: What do you imagine?

Harvey: [pauses] …they’re young and blonde [laughs].

R: Do you feel cared-for or would you say you receive care when the girls are touching you?

Harvey: Well they don’t really touch me like THAT unfortunately. Like I said, I’m useless in that way.

R: They don’t touch you like what, how do you mean?

Harvey: You know...like THAT! [like how exactly?] ...like they, you know, they care.

R: So you don’t feel cared-for from how the girls actually touch you? Would you feel cared-for if they touched you in the way you imagine?

Harvey: Well, I wouldn’t be able to do anything back, you know. I’m blind. I’m useless. I can’t see anything let alone to do any of that kind of stuff.

R: What kind of stuff exactly?
Harvey: You know... touching and stuff...

R: Would you touching them back or if they touched you in the way that you wanted, is that what you mean by care?

Harvey: Isn’t that what you asked?

R: Yes, I was just trying to clarify

Initially, Harvey uses his blindness to explain why he is useless, but as the conversation moves along to discussing care, he implies a clear difference between how the girls touch him and how he imagines the girls touching him. And on the end, it’s the way that he imagines the girls touching him as well as how he would reciprocate care that is different from the reality of how he is experiencing care. It is important to note that he doesn’t describe explicitly how he imagines the girls touching him, despite the multiple ways I tried, but he clearly makes it known that the reality of care received is different from the care imagined. Furthermore, it is the care imagined that would make him feel cared-for.

Another resident, Pete, told me he was diagnosed with Alzheimer’s Disease at the beginning of the our interview. Although he did not reside on the Memory Support Unit (MSU), I would not be surprised if he had this diagnosis, but I was more surprised that he told me and that he used his medical condition to let me know that he may not be able to finish interview. Pete appeared very aware of his own condition, despite his diagnosis.

R: Do you feel cared-for here?

Pete: I used to worry about that kind of stuff, relationships and sex, but there’s no use for me to attempt it here. I did okay talking to girls back when I first came here, but because, you know [points to his head], it’s impossible to maintain a relationship with anyone. This is a crazy house in here, and if it’s not me whose crazy, then it’s these other people who are CRAZY...and believe me, there are some crazies in here! [Laughing]...But, if they had a hot blonde around here, I might attempt it.
R: So do you not feel cared-for because you can’t have a relationship or sex while you’re here?

Pete: Well I can’t because of my condition you know.

R: Do you think you can’t have a relationship or sex or both?

Pete: Well if you can’t maintain something like that then why… and I can’t do it [pointing to his head].

R: But you mentioned that if they there was a hot blonde around here, you might attempt a relationship with her here?

Pete: Well, sure! I said that huh [laughing]? I might attempt it...

R: What would you attempt exactly? What would make you feel cared for?

Pete: Oh you know... [uses his hand to make gestures around his crotch area]. I won’t be able to maintain it, but this old man can still hope, you know.

Interestingly, Pete uses his medical condition to initially state why he can’t pursue a sexual relationship in response to asking him if he felt cared-for. However, he changes his mind as an afterthought if there was a “hot blonde”, expressing that he would attempt to pursue something sexual – as gestured rather than articulated – and thus, his medical condition was not an issue except to maintain what he started.

Similar to Pete, another male resident, Donald, mentions sex explicitly when asked when he feels cared-for.

Donald: Sex always rears its ugly head with us men. We miss it when get this old. We’re just poor, old men.

R: So having sex makes you feel cared-for? [He nods affirmatively but doesn’t say anything more verbally].

R: Do you feel cared-for here?

Donald: No. Not like that.
Again, Donald refers to sex when asked about being cared-for as well as identifying as a poor, old man, and thus, does not feel cared-for.

Lee expresses that he’s afraid to ask or provide care to anyone simply out of fear of rejection.

*R: Do you provide care to anyone here?*

*Lee: I’d like to, but I’m afraid they’d just say no. They’d just laugh and reject me.*

*R: Who do you want to provide care to?*

*Lee: Oh there’s all these young girls here. I doubt any of them would even like me or not. What would they want with an old man like me?*

*R: You said you would provide care to them? How would you do that?*

*Lee: Oh, none of them would want anything to do with me, so I couldn’t do it. They’d just reject me.*

*R: What would you do if you could care for them?*

*Lee: Oh I know what I’d like to do, but no one would want this lonely old man.*

Lee never expressed what he would do to provide care, but what is clear is that he would not be able to provide care simply because he felt undesirable by the female staff (“girls”) he would want to provide care to. He feared rejection and identified very strongly with being a lonely, old man. Although he never states what care is if he were able to provide it, he strongly implied it was about desire and as such, he was undesirable.

*Marital Status Makes No Difference to Care*

Although the majority of male residents were widowed, marital status made no difference among this sample of respondents referring to care as some form of intimacy.
When I asked Pete:

*R*: Do you feel like you provide care to anyone here?

*Pete*: I can’t do much especially cuz I’m a married man. I have a few lady friends here, but there’s no love affair or anything like that going on here.

*R*: You can’t provide care because you’re married?

*Pete*: Yeah I’m a happily married man for 40+ years, but I’m not dead you know!

*R*: So would you say you provide care to your wife or any of your lady friends here?

*Pete*: Nah, I’m married. My wife comes in to visit once in awhile, so there’s no love affair going on. I don’t do that anymore.

*R*: So having some kind of love affair is what you’d consider providing care?

*Pete*: Well, to some of these ladies yeah. I may be married, but I’m not dead [laughing]. But I’m married, so there isn’t that kind of stuff going on here.

To Pete, being a “married man” was both what prevented him from being able to provide care – which means having some kind of “love affair” with the ladies [frontline staff]. Interestingly, he does not associate “providing care” in this way to his wife, and in fact, reiterates that there is no “love affair” going on with the other ladies because his wife visits periodically.

When another married male resident, Gil, was asked about when he feels cared-for, he mentions his wife immediately.

*R*: When do you feel cared-for?

*Gil*: I miss my wife, but we can’t do that kind of stuff here, you know.

*R*: What kind of stuff is that?

*Gil*: oh, you know...what married people do [laughs]... well, first I can’t do much in that area, so that’s the main thing. Second, look around, this isn’t the most private rooms. There’s just a curtain separating me and him [points to his roommate]. No the wife would not go for that around here. But if there was a little
youngin’ around who wouldn’t mind coming in here [pats the top of his bed laughing]…sure, I’d let her take care of me!

R: So do you think if you had a private room, would you and wife try to be intimate during one of her visits?

Gil: Well yeah another room would definitely help, but I don’t even know if I could do anything!

R: You mentioned if one of the young girls here were willing to take care of you in here, what did you mean exactly? Are you talking about the same kind of care as what you would do with your wife?

Gil: Well I am married, but if she wanted to take care of me in that way, I sure wouldn’t stop her [laughs]… but I don’t see any of these girls here doing that here. This isn’t that kind of place that would do that.

R: Well in what way would she take care of you? Could you give me an example?

Gil: Sure, in whatever way she wanted!

We went back and forth in trying to get some specific examples, but he wouldn’t specify anything, but what is important to note is that despite him proclaiming being married, he still “taking care of” as some form of intimacy, whether it was from his wife or some young girl. This is the only married respondent who mentioned not having privacy as a barrier to doing it.

Similar to Gil, Andrew was married and his wife visited often, but he also expressed being very lonesome and missing intimacy especially at night.

R: Do you feel cared-for?

Andrew: I’m awful lonesome. The staff tries to do their best here. Like they take me to all these activities during the day and it helps sometimes. My wife will come as often as she can, but only during the day when my son can bring her. But my worst times are at nights. That’s when I miss her the most.

R: why do you miss her mostly at nights?
Andrew: You know, I’ve got everything you could want. I have my phone, TV, activities, what else could you ask for? I’m not really saying I need anything, but I don’t expect them to furnish any call girls at night for us lonely old men or anything.

R: Is that why you’re lonesome? You need someone or your wife to come visit and stay with you at night?

Andrew: That would help. That’s when the loneliness hits me the most.

R: What exactly do you need to help you cared-for at night?

Andrew: Oh these girls are nice and everything here, and I probably can’t do much of anything, but I’d just want them to stay with me, lay with me.

R: Like sleep in the bed with you?

Andrew: Yeah. I know it’d be tight. These are small beds. But I just want to lie down with someone. I know I’m married and I miss her.

R: Is there anything else that would make you feel cared-for?

Andrew: Well, I don’t really care what else they’d want to do to me. I’d be okay with it as long as they’d stay with me all night. But I don’t expect this place bring in call girls for the night though. We’re just lonely old men in here.

Although Andrew was resigned to being a lonely old man, he expressed how lonely he became during the night. He acknowledged how the staff would keep him during the days and his wife would visit during the day, but that his loneliness was worst at night. He was also resigned to the fact that the facility was not going to furnish him call girls to meet his needs at night. This intimacy at night was what Andrew was referring to when I asked what would make him feel cared-for, and it was clear that he did not feel was cared-for.

Hot, Gorgeous Blondes

One of the surprising results of this project was how many times the mental picture of a “hot blonde” was raised by the male respondents. Although many of these sub-themes overlap, the fact that “hot blondes” were mentioned so frequently from a sub-group of male respondents, is also worth noting. There were a total of seven (n=7)
different male respondents who specifically mention “hot blonde” when referring to someone desirable. For example, when I ask Joe:

*R: What would make you feel cared-for?

Joe: An 80-year-old hot blonde full of ambition and a double bed! That’d make me feel cared-for all the way around [chuckling] …who knows, maybe she’ll come busting through that doorway, jump on my bed and surprise the hell out of me!

In another male interview with Rob, I asked, “What does care mean to you?”

Rob: Oh we don’t have to do nothing around here, these girls do it all for you. They take care of everything! If only there were more little hot blondes to flirt with…[laughing]

*R: What exactly do the girls do to take care of everything for you?

Rob: Well they don’t do THAT that’s for sure!

*R: What is THAT?

Rob: Oh, you know us old men, we just like to have a little fun. We like flirting and stuff like that. You gotta have a sense of humor around here otherwise, you might as well shrivel up and die!

*R: So providing you more hot blondes to flirt with is what care means to you?

Rob: Well sure that would help, and bring some excitement around here. But it’s not like they’re gonna bring in some hot blondes in here take care of us lonely old men.

Similar to Andrew, Rob is also resigned that this request won’t happen, but both expressed it as a form of care, despite not providing specifics as to the nature of the care itself, other than flirting with a hot blonde.

Andrew and Rob were not the only male respondents who appeared resigned to not having their physical intimacy needs met. When I asked Claude if there was anything else he would add about care and making his life better while here, he responded:

Claude: I don’t really have anything practical to say or add to make me feel cared for. You can say what you want around here, but if it’s not done, what’s the use of saying anything? You have to act on these things and they aren’t gonna do that here. When your money’s all gone, they’ll just kick you out if you can’t afford to
live here no longer. And in the meantime, they aren’t gonna bring in a bunch of hot blondes for us guys either.

R: So if you spoke up and wanted to say something about what would make you feel more cared-for, what would it be?

Claude: Like I said, they don’t care what you say around here, you could shout it from the rooftop here and they still won’t do anything.

R: You mentioned they’ll kick you out when you run out of money. Do you really feel this way?

Claude: Yeah, they can’t keep all of us in here when we don’t have the money to pay to live here. Either that or you’ll just die here.

R: Would bringing in “a bunch of hot blondes” make you feel more cared-for?

Claude: Yeah sure, but they aren’t gonna do that here... so there’s just no use in saying anything around here.

Throughout my interview with Claude, it was clear that he was upset with the lack of communication from the staff on multiple levels and about multiple topics such as finances and room changes. This exchange reveals his frustration and feels that his voice is not heard and does not matter to the facility. Although Claude’s main meaning of care is transparency or open communication from the staff and the facility, I use him here because this care theme is brought up at the end of the interview. Furthermore, Claude, agrees that care from “hot blondes” would make him feel more cared-for, despite acknowledging that it would never happen. Because he appeared to be getting upset again (as he was earlier in the interview when talking about he felt ignored), I did not try to further interrogate this line of questioning.
Another example of “hot blondes” as an afterthought is my interview with Ted who describing the differences in the women between the Assisted Living and the Unit he is living on now:

R: So would you say you receive care anyone else here?

Ted: You know when I was up there [i.e. Assisted Living], I noticed there was these women who were all dressed up, and I mean dressed to the tee. They had jewelry, makeup, the whole nine yards. These were women here don’t dress to come to dinner or anything. I mean, it doesn’t help that some of them are really goofy, if you know what I mean [Laughing]. But I would talk to those ladies up there, you know. I have to laugh because I didn’t come here to get mixed up a woman. Hell, I was just trying to get used to this pacemaker I had put in! I came here to get cured, not get mixed up with some hot blonde! BUT, it wouldn’t be such a bad thing if it was the last thing I saw! [Laughing].

R: So are you still friends with some of the ladies up there? Do you receive care from anyone there? Do they visit you here?

Ted: Oh no. No one from up there comes to visit here. This is the death trap down here. Just look at all them around.

R: You mentioned not wanting to get mixed up with a woman…?

Ted: Yeah, you know, getting mixed up with a woman.

R: Do you mean like having a relationship with her?

Ted: Yeah, like being with her and doing stuff together, you know, things like that.

R: Is being intimate part of this relationship you are talking about, is this what you mean by care?

Ted: Sure, sure! But I didn’t come in here for that you know. I had heart problems…[he goes on to tell me more about his heart issues]

R: So did you have an intimate relationship with any of the ladies up there in assisted living? Or with anyone down here?

Ted: Oh no! I wouldn’t have minded though, those were some nice ladies. That’s not the case here. Definitely none of these ladies...

What is interesting about Ted’s interview is that he distinguishes the differences between the ladies from Assisted Living and the ladies in the Skilled Nursing where he was now
residing – “ladies” meaning other female residents rather than the staff or nurses. He was clearly more impressed with and attracted to the ladies in AL; however, as an afterthought, stated that if a hot blonde was here, it wouldn’t be such a bad thing. The importance of Ted’s interview is that he discussed pursuing an intimate relationship in the context of receiving care.

The youngest male respondent interviewed, Wayne, had a slightly different account of a hot blonde intimacy than the other male residents:

*R: What does care mean to you?*

*Wayne: It feels like home, you know. You can do things, anything you want! Me, I like drinking my beer at night, staying up late, watching porn, and sleeping in in the morning.*

*R: So you feel cared-for here because you get to drink beer and watch porn here?*

*Wayne: Oh yeah! Debbie does Dallas, is my favorite. She’s a hot gorgeous blonde!*

Wayne goes on to provide details about the video and also what occurs with staff when he requests to watch the video. It is clear through his accounts that he has verbally expressed this need for sexual activity and one way the staff have addressed it, is to allow him to watch pornographic videos in the privacy of his room. It is important to note that this was one of the few cases where the male resident’s sexual need was satisfied, and the male resident expressed feeling cared-for.

The majority of the men discussed care as some form of touching, intimacy, or sex and for the most part, care that they were not currently experiencing. My final interview with Will summed up what many of these men were truly expressing:

*R: Can you tell me what care means to you, or give me an example?*

*Will: Yeah, being with a woman*
R: Tell me more

Will: Well you know, being with a woman… sexually.

R: That’s what care means to you – being with a woman sexually?

Will: Yes. I want to be with a woman so bad.

R: Why? Would that make you feel cared-for here?

Will: Oh yes!

R: Why does being with a woman sexually make you feel cared-for?

Will: Because I’ve without one for so long. It’d just make me feel cared-for. It just makes me feel more manly… touching a woman makes me feel like a man.

R: Does driving a big truck with big wheels and all that stuff make you feel manly?

Will: [Laughs] No! I used to drive truck – a big rig too. Plus, I owned many big trucks. That’s not what I want now. A young hot blonde to make me feel manly. Would you let me touch you? [He reaches out to grab my leg as I catch his hand and place it on his wheelchair arm].

R: Well I’m not really a hot blonde...[I stop his other hand which reaches out on the other side to try to grab my leg. I place his hand on top our other hands, and he seems calmed just stroking my hands as I hold them down for a few seconds until I know he isn’t going to continue trying to reach for me].

Will: That’s okay, you would do [laughing and still holding my hands].

R: Are you always this frisky with the ladies here?

Will: [laughs]... well the girls treat me like a patient here. They don’t touch me like I want them to... but I get to cop a feel once in awhile [laughs sheepishly]... I just wanna touch them all over.

We were able to finish the interview without him trying to grope me again, but what is key was already captured in his responses. Will desperately wanted to touch a woman and he is not afraid to try or openly express his need by reaching out and trying to touch me. I did not need to ask what he meant by “touching a woman”, he tried to show me and
where he would touch them! It is important to note that this was not unusual behavior for Will. I found out afterwards as I walked out of the room and the nurses aides were giggling when I exited the room, then they laughed out loud when they saw my face. They also told me they constantly fight him everyday because of that, and that they now double up so that one girl can hold him down while the other does what needs to be done. I will further discuss staff responses and accounts to other male residents since Will’s behavior of open sexual expression towards me may have been an outlier compared to the rest of the male resident’s reactions towards me; aggressive sexual expression toward staff was not unusual as I will discuss in the next section. However, the most important part about Will’s responses and behavior is that he clearly articulates what the men alluded to, but may not have said outright… that the lack of this kind of care, of being touched, of being able to touch and or perform intimately or sexually, all of it resonates deeply with their masculinity. Many of the men identified with being a poor, lonely, useless, old man, and what these responses demonstrate is that for these men, to receive and provide care is central to their masculinity and their identity.

The Dirty Old Man

Expressing sexual or simply some physical intimacy desires do not come without a cost for male residents living in LTC. One such cost is a negative stigmatizing general cultural negativity regarding old men’s interest in sex as captured by the familiar notion of the “dirty old man”. This cultural image was alive at this facility as articulated by the frontline staff in describing male resident’s who liked to verbally flirt with the staff, but especially when they discussed specific behaviors from some of the male residents. For example, in one interview with an older and more experienced staff member to explain
why she calls one of the male residents a ‘dirty old man’, she describes some of his behaviors directed at her during their daily routine:

“Well, like when he’s in bed his hands are down, but as soon as you do anything like start to change him or turn him over, he puts his hands over the edge of the bedrails and gets his fingers wiggling them like that... and if you’re not watching, he’ll go right for your crotch! He’s done it to me several times... like when you bend down to fix his legs before standing him up, he’ll reach down the front of my shirt and grab my boobs! He’ll say things like, ‘Gimme some of that!’ or ‘Why don’t you come here and play with my cock!’... he’s just a dirty old man.” [59-yr-old, CNA]

A younger CNA, who also describes another male resident as a “raunchy old man”, describes similar behavior:

“There’s one raunchy old man on my unit. He’d tell me and this other girl I was working with at the time, ‘My wife used to give me so many blowjobs a month...’ and says it like he expects us to do it to him too! So, I told him, ‘I’m not your wife and I don’t get paid enough to do that so you can find it somewhere else cuz I’m not doing that to you!’” [19-year-old CNA]

This young staff member goes on to describe how some of the male residents act like they expect them to do this kind of stuff for them.

“For example, there’s this other guy who calls me into his room late at night. Just rings his call bell to make me come in there and he just wants me to take the cover off of him, or fluff his pillow, or to move this over to the other side. I mean, really? Then, while I’m in there doing this, he’ll whisper to me and want me to come close to him, like he’s gonna tell me a secret or something. I made the mistake ONE time only of actually bending down cuz he said he wanted to tell me something, and he reached out and tried to kiss me! Stuck his tongue out and everything! So gross!” [19-year-old CNA]

In most of the accounts articulated by the staff about “dirty old men” when I asked how they responded to such advances, the most common verbal responses were: “We tell him
he’s not allowed to touch us like that” and “You can’t talk to us like that”. One staff member went as far as telling a male resident:

“We don’t do those things here, we aren’t prostitutes or anything like that and we aren’t here for your beck and call for things like that.” [38-year-old CNA]

The frontline staff also provided specific actions that they do as a response to some of these behaviors. Examples include positioning the male resident’s body or even their own body in certain ways so that the resident could not physically touch certain parts of them while they were helping them with daily care. Others include teaming up with other staff or their nurse if they are attending to a male resident known to be (sexually) aggressive. And another tactic was to simply ignore them.

“As long as they weren’t harming themselves or someone else, we sometimes ignore them.” [45-year-old CNA]

Male residents were not only sexually expressive towards the frontline staff; they were also just as expressive and aggressive towards other female residents. One staff recalls the most current incident that occurred between two residents on her unit:

“We have a female resident who is in a special chair and we had her sitting in the main lounge. Then this particular male resident was brought in there too. They were sitting beside each other in their own chairs. The female resident was hollering because she didn’t want to leave her room and she always makes these noises anyways. So, as the the staff went to go get more residents from their rooms, we realized later that this female resident got real quiet. So, when one of the girls returned, bringing another resident to the lounge, she found the male resident running hands through her hair and playing with her boob, and the resident was just laying there with a smile on her face, letting him do it! That’s why she got so quiet.” [59-year-old CNA]
Despite the appearance of mutual enjoyment by both residents as described by the CNA, the aide expressed that they did not encourage this type of behavior among the residents, and in fact discouraged it:

“We can’t have him doing that to her! He might do it to other women...and there’s a lot of women here. He’s just a dirty old man, and he tries to get away with it with her because she can’t speak, she just makes these noises. She can’t give consent to this, and we just can’t have that going on here. What if he approaches other women? No, no...we can’t have that.” [59-year-old CNA]

What is clear among in the accounts and descriptions by the frontline staff is that all sexually expressive and/or (sexually) aggressive behaviors are seen as “problematic”, as articulated by one staff member (but also confirmed by others) and when I asked how she responds to some of the behaviors she described:

“Oh we report everything. We tell our nurses and it’s all documented in their chart. Then it gets discussed in their next care plan meeting with the social worker and the family and everybody. Sometimes we’ll call the head nurse in or the social worker to come up and talk with the resident right away, and they’ll usually tell him that he can’t act that way. It doesn’t do much, so we have to deal with it on a daily basis you know.” [59-year-old-CNA]

Moreover, so not only are sexual expressions and aggressive behaviors seen as problematic behaviors, they are discouraged and reprimanded on a regular basis. It is important to note that the frontline staff who described sexual expressions and aggressive behaviors by male residents towards them, varied in age, body weight, marital status, and shift worked. Therefore, not only were the male residents sexually aggressive towards the younger, more attractive staff, they were also sexually aggressive towards the older, middle-aged and even heavy and
obese frontline staff members. In addition, this behavior was also directed towards older female residents living at the facility.

The staff describing male residents as “dirty old men” included verbally flirting with the staff, calling them certain names (both non-derogatory and derogatory names) or whistling out loud as they walked by, to aggressively trying to touch private parts of the staff or female residents. The frontline staff viewed all of these behaviors as problematic behaviors that many of the nurses and social workers wanted to be documented and formally addressed in care plan meetings.

The cultural notion of “dirty old man” was not only alive and well among the frontline staff. It was alive and well among the male residents as they too identified with this cultural notion. Throughout many of the male resident interviews, such comments recurred, indicating an internalization of their low status of a nursing home resident. Male respondents frequently described themselves in these terms: “a poor old man”, “a lonely old man”, or simply “an old man” – a role in which they can embrace and be taken care of by others. However, in doing so, their masculine identity as a (hetero-) sexual being simultaneously is heightened as they are now surrounded by women – female residents and young female nurses and aides taking care of them – are squashed because as a “poor, lonely, old man” you are not likely to get a woman – young or old – to meet your sexual needs. From these results, we can see how prevalent the need for sexual desire or simple physical touch and intimacy is among male residents, and perhaps the reason for it is because it reaches to the core of their masculine identity. Because of this, men articulating and acting out their sexual desires may be at risk for double jeopardy: not only are they not being cared-for, but their needs and desires are not regarded as
legitimate and are therefore punished for expressing their needs with a negative stigmatizing identity.

**SUB-THEME: CARE AS COMPANIONSHIP**

As the care theme of “care as physical intimacy” emerged for the male respondents during the interview process, I wanted to contrast it with some female respondents who articulated that they missed certain companionship. However, it is important to note that different from the male residents, female residents were responding to probing questions about their current and past relationships, and not about what care means to them or when they feel cared-for.

There were several instances in which I observed a male and female resident having a friendly conversation in one of the lounges or at the dinner table. During one of my visits I had seen one of the female respondents visiting with another male resident, and so during our interview when I asked about relationships formed while living at this facility, Sarah replied:

“We have some older men here that sometimes tell us stories about their life. It’s kinda nice. I talk to them a little, not very often. I’ll sit and talk with ones, like Barney, but his mouth goes on for hours, you know...[laughing]. I miss my husband. There will be no other man, except my brother and the kids now... I miss him terribly, but I wouldn’t ask for him back. He couldn’t walk, couldn’t talk in the end you know. He had Parkinson’s for 15 years.” [Sarah]

I probed to see if she would like to talk to some of the men more often, and she replied:

“Not really. I know he’s [husband] gone and he’s okay now. I’m not interested in anyone else. It would never be the same as when you’ve been married for so many years, you know.” [Sarah]
Similarly, I witnessed Maxine visiting with a male resident just before our interview, so I asked about if this was a new relationship forming between them. She replied:

“Oh no [laughing]... I met him last year when I was on the 2nd floor. He likes sports and my husband liked sports, you know. And he knows all the fellows that my husband played ball with, he played for Sharpsville, so they played against each other, way back then. We couldn’t believe when he’d start talking about some people and I was like, oh my I know all of them! ...He’s a nice guy but he’s no one special to me, you know.” [Sarah]

Missing their husbands, who were deceased, was the typical response when asked about male relationships; however, what is different than the male responses, the women expressed they missed their husbands for other deeper, personal connections rather than for meeting their sexual needs. For example, Jessie reminisces about missing her husband during a specific time of day:

“Yes, I miss [him] sometimes. He died in 1997, so I’m used to him being gone now. The time I really miss him most is when we’d kneel down before bed and say his prayers...” [Jesse]

She went on to describe that even through their struggles and hard times as he suffered with Alzheimer’s Disease while she cared for him at home, prayer time was the one time she knew he would always be calm. It had become a very intimate and personal time for them. She went on to say that she had no interest in other male relationships:

“I’m so busy with my sons and daughters and their kids and my friends here, I don’t have time for all that nonsense. I’m not interested in any of that anyways, that part of my life is over.” [Jesse]

For Ruth, friendship was what she missed:
"I just miss my husband...I haven’t had a need for anything more except friendship – real friendship, you know. The staff are friendly, but we aren’t friends, like I am with close friends... I don’t really need anything more.” [Ruth]

For most of the female residents, when I specifically asked if they had any desires for sexual or physical intimacy with a man, many of the responses were similar to Mary’s response:

“...not at my age, I don’t need anymore of that!” [Mary]

Other responses were also similar to Betty’s response:

“No. I never wanted that again after my husband died. I could never do that... we were married 60 years.” [Betty]

In sum, most female residents expressed that they did miss male companionship – specifically, their deceased husband’s companionship – but they no longer had the need for sexual intimacy or activity as compared to their male counterparts. These results could be explained in part by the cultural notion that women, particularly from these cohorts, do not typically talk about their sexual or erotic desires with others, much less with a young lady or student researcher, whom they view young enough to be their grandchild. What is interesting, are the contrasting accounts from the staff that describe some female residents making sexual advances toward other male residents. A staff member, Susan, describes how several female residents on her unit flirt with male residents:

“...A couple women do this to the men all the time... they’re always trying to sit beside them, reaching over to hold their hand, straightening their clothes, shirts or something and some will reach over and try to kiss them!” [42-year-old CNA]
Frontline staff gave some accounts where female residents flirted with or made advances towards a few of the male staff. Jennifer, describes an instance where she witnessed a female resident running after a male nurse:

“I’ve seen where a female resident chased, Joe, down the hallway... but this was more like a high school crush chasing, you know. More like just to get his attention. She didn’t grab him in private areas or anything, like how some men do to us girls, she just was just chasing him to get his attention.” [22-year-old CNA]

In this instance, Jennifer highlights the difference of how female residents make advances (or tries to) towards the male staff compared to how male residents make advances towards female staff. From the accounts of the frontline staff interviews, and resident interviews, it appears that male residents are more verbal in expressing their sexual needs, and more aggressive and more successful in touching the female staff or residents during their sexual advances.

On the other hand, female residents denied having any current sexual desires or need for physical intimacy, but rather missed their husband’s male companionship or friendship, despite that for some female residents, this was in contrast to some of the staff accounts.

**CONCLUSION**

In conclusion, this chapter highlights the modal response of the male residents interviewed when asked about care or when they feel cared-for. These results show that nursing home male residents feel cared-for when they can express their sexual needs or desire for physical intimacy. However, in doing so, male residents are at risk for a double jeopardy: they are negatively stigmatized as a “dirty old man” from the staff as
well as internalized by the men as they too viewed themselves as poor, useless, dirty old men and furthermore, the men were truly cared-for. This was not a deviant. Rather, it is quite pervasive among this sample of male residents interviewed and appeared to be the standard operating procedure of these men. Moreover, their behaviors are seen as problematic, and as such, they were reprimanded – charted as if a deviant – and also treated by staff in such a way that reinforced the degradation of their masculinity and ultimately not being cared-for.
CHAPTER 6: HELPING OTHERS vs THE SICK ROLE

INTRODUCTION

This chapter focuses on the modal response of what care means and how one feels cared-for from the female residents living in LTC. It is contrasted with accounts from male residents on the same theme; however, it was not the modal response for male residents. Staff accounts along this theme are also discussed. Results for this chapter are obtained through my semi-structured interviews with male and female residents, frontline staff, and researcher field notes. In this chapter, I describe in detail the most frequent care theme identified among the female resident interviews. The theme, “helping others” is the modal response to the questions about what care is or what it means to the female residents. Interestingly, male respondents responded in a very different, often oppositional way to this very same care theme.

SUB-THEME: CARE AS HELPING OTHERS

Among the female residents interviewed, care was described as an activity with the purpose of helping another. As I tried to derive meanings of care from respondents, I asked, “What does care mean to you?” or “What makes you feel cared-for?” And many of the women immediately responded not in terms of their own immediate needs, but rather in terms of their limitations in helping or assisting someone else. For example, Sarah describes how she currently helps others by completing what she calls her “job”:

“I’m happy for the steady job. I enjoy the routine here. This is like my office here [laughing], it’s where I do my chores...like water plants, make my bed, clean my room to some extent you know...clean up, that sort of thing to help out around here.” [Sarah]
Similarly, Norma describes the opportunities for care given to her by the staff as “volunteering”:

“They call it volunteering...like when we’re waiting for a meal or something, I’ll be visiting with the other people around. If you go into our dining room then I’m helping people if they allow me to because most of them don’t have a mind, you know. And I’m a social person. Like there’s a guy I help out at the end of the table. There’s mustard sauce that somebody made, and I give him some on his plate...I’ve taken him out with his wheelchair too, and other times he wants to do it himself, and I let him. I volunteer to do this cuz I enjoy it. I’d call this care, right?”

The dining room appears to be a common area where care opportunities are given to (female) residents. Socializing or visiting with other residents, assisting with set up, and pouring water are just a few examples described by female residents of opportunities for care in this facility.

However, such opportunities were not always encouraged by staff, and for some residents duties were forbidden. In fact, this is not necessarily about what women considered “being cared for” but rather how the facility resists their efforts to do so. For example, Myrtle describes what she is allowed to do and what she would like to do if she were allowed:

“In the dining room, I’m always helping everyone, like with their bibs or turning their plates so they can reach them, or moving their desserts closer to them...little things like that. I’m not allowed to escort any of the residents, but I would help if I were allowed because sometimes these people are waiting for a long time to get pushed in.” [Myrtle]

Interestingly, Myrtle sees a need – a caring opportunity – in which she could assist both the residents and the staff by escorting some of the residents in wheelchairs into the
dining room. However, she was told by the staff she is “not allowed” to escort. A similar experience of staff discouraging a resident to help another was shared during my interview with Madeleine:

“I try to provide care to others but I usually get in trouble more than anything. I have a friend down the hall and she’s getting to the point where she can’t go anywhere on her own, so I push her wheelchair and take her where she wants to go. They don’t like that cuz they don’t want me pushing her anywhere and they tell me to leave here there even though she’s asking me to take her out. I don’t know why, I think they think I can’t do it right or something, but I do it anyways... then they’ll just yell at me and tell me to go to my room”. [Madeleine]

In this case, not only are the staff discouraging the resident, the resident expresses she is reprimanded for trying to care for her friend. Despite getting in trouble, she continues to help her friend.

Escorting residents in wheelchairs was one of the activities where staff and residents appeared conflicted as an opportunity for care or helping. However this was not consistent throughout the facility. Throughout many visits I observed several occasion in which residents were both encouraged and discouraged by staff to escort other residents in wheelchairs throughout the facility. During one informal conversation with a frontline staff, the CNA told me that according facility rules, residents were not allowed to escort other residents in wheelchairs. During my staff interviews, I asked about this “rule”, and it was evident this facility “rule” was not stated clearly to many of them. Most claimed that it was not a rule per se, but what they would tell a resident who wanted to escort others and they (staff) did not feel they should escort them for whatever reason (e.g. they weren’t strong enough, they were too unstable, etc.). As a follow up on facility policy, I spoke informally with the Administrative staff who is part of the training staff, and she
stated that it is NOT a facility policy per se, but agreed with some of the staff interviewed: escorting other residents was dependent on various factors such as the resident’s medical and physical condition, their desire to help, and the staff working at the time. In sum, it is left to the unit staff discretion to encourage or discourage residents to care for other residents by escorting them throughout the facility.

This lack of opportunity or discouragement of care opportunities also pertained to some domestic activities as articulated by some female residents. In my interview with Rhonda, she expresses how having any responsibility provides purpose and meaning to helping others:

“The days seem so long, and that’s because I don’t have any responsibility. I don’t have to sweep, dust or clean windows. It’s important, you know. I’ve always had responsibility. It makes you feel like you’ve accomplished something, or helped somebody or something. Just being helpful is what it (care) means.” [Rhonda]

Additionally, there were other residents who claimed they did not have any responsibility simply because the staff no longer asked them to do anything. For example, Kathy said:

“I’m not doing much of anything anymore, not because I don’t want to, just because they [staff] haven’t told me there was something I could do. They don’t come and say, we’re working on some crafts or cooking or something, come with us. No, they haven’t done that lately, so I just haven’t gone. It isn’t that I don’t want to, or because I don’t feel I can…they just don’t ask me anymore. If they did, I’d go.” [Kathy]

There were several accounts in which female residents expressed an association of domestic or instrumental activities as a way of helping others, as such, a form of care. Therefore, the lack of such opportunities implies a lack of care.
On the other hand, there were several ways in which the staff recognized the need to provide domestic work to some residents. For example, when I interviewed the staff, a common instrumental responsibility given to female residents is folding linens. Cecelia says:

“Some of my women like to help pass linens with me, and the other day, I just had laundry bring down two big carts of towels and there were four of them who sat at the table and folded all the towels and washcloths for me.” [Cecelia]

In sum, a true concern with caring about and meeting the majority of female resident’s needs would seem to require providing some sense of instrumental or productive participation in their daily activities of living. However, care is not simply providing them with an activity, for female residents’, the purpose and meaning is driven from knowing that it is helping an “other”, whether it is another resident or the staff. And when these opportunities are denied them, many express feelings of boredom, isolation, incompetence, and therefore, they are not cared-for.

**SUB-THEME: EMBRACING THE SICK ROLE**

While most of the female residents expressed the need for work or responsibility, several male residents explicitly stressed that one of the reasons why they enjoyed living in LTC was because they no longer have any responsibilities. One male resident who had lived alone before moving to the facility expressed how happy he was not to have to do any housework.

“I don’t have to do nothing – no cooking, no cleaning...I’ve lived alone since my wife died 5 years ago I’m glad to not have to do any of that stuff anymore”.
[Edward]
All of the male residents who indicated they enjoyed not having domestic responsibilities anymore stated that they could not do any of these tasks simply because of their current physical condition(s) which have been debilitated by a stroke, Parkinson’s Disease, blindness, etc.; therefore, it appears that for male residents, taking on the role of a care recipient provides them permission to not want any domestic responsibility, allowing them to be ‘lazy’ as expressed by the following male respondent.

“I can sit in my recliner, sleep and be lazy all day. Of course, I can’t do anything anymore. I can’t walk due to my stroke and so my whole left side is shot. And I can’t see much either, so the girls do everything for me”. [Claude]

One Marine veteran, contrasted his current responsibilities to when he lived in the Marine barracks:

“Here we don’t have to do anything really. They make your bed for you, clean your room, do your laundry. See, all of that you do yourself in the Marines. And everything had to be done a certain way – clothes folded this way, beds made up that way, hair shaved short...you know, all of that kind of stuff. Here, we don’t have to do anything. Hell, we don’t have to dress ourselves, comb our hair, or anything...we don’t even have to take ourselves to that main room, where we eat, if we don’t want to...these girls will come and do everything for you!” [Alfred]

When I asked him if he wanted more responsibility now, he stated:

“Well, not really [laughing]. That’s why I’m here though, I can’t do that stuff no more. I’m stuck in this wheelchair for now. I mean, I’ll dress myself when I can, but that’s what these girls are here for...that’s why we pay them the big bucks [chuckling]”. [Alfred]

I asked if he thought the girls got paid “big bucks”, and he replied:

“Do you know how much it’s costing me to live here? Somebody’s getting all that money, that’s for sure...probably not the girls. Nah, the little guys never get the big bucks, that’s true but I shouldn’t have to do that kind of stuff, you know. I’m sick and that’s why I’m here.” [Alfred]
Alfred highlights a financial component linking the work the female residents needed to feel cared-for to services paid for due to their illness. In other words, since Alfred is sick and living in long term care now, this status gives him the right to “be lazy” since he is paying these services. On a similar note, Harold views similar activities (e.g. getting dressed, etc.) as helping the staff do their job, and since he was a patient, he was not going to help the staff while he was still sick. During my interview with him, he expressed anger as he shared an incident that occurred the night before:

“... I’m not doing anything for anybody anymore! I’m not an employee here! I used to brush my teeth, help get myself ready for bed, and stuff like that, but the last couple of nights I haven’t done it. So when the girl says, ‘You go and brush your teeth now and get ready for bed’ [in mocking high-pitch tone]. I told her, ‘I’m not going to do it by myself. I’m in a wheelchair!’ so she pushes me in there [pointing to bathroom] and I still said, ‘No! I’m not doing it until I get better!’” [Harold]

Both Alfred and Harold appear to identify with the “sick role” as described by Talcott Parsons (1975) as did many other male residents who expressed they should not have any responsibilities since they are sick and currently live in long-term care. Therefore, living in this facility due to their illness gives them permission to relax, be lazy, and not have any domestic responsibilities.

In sum, there is a stark gender difference in the meanings of care among men and women living in LTC. While most of the female residents in this sample articulated the need for some productive and instrumental responsibility with the intent to help others, male residents appear to adhere to the patterned social role of being sick or a patient living in a skilled nursing facility. Thus, to care-for female residents in this sample, is to
provide them with productive activities while granting male residents permission to be lazy and adhere to the sick role.

CHAPTER 7: OFFICIAL NARRATIVES OF CARE
INTRODUCTION

This chapter focuses on how care is regulated and evaluated in long-term care (LTC) facilities by the federal government and an example of how LTC facilities themselves may evaluate their own quality of care and care practices. Critical analysis of the federally mandated Minimum Data Set (version 3.0) resident assessment and care screening forms, as well as the Eden Alternative Warmth Survey (EAWS) in which this research setting used to survey their own residents and family members in 2009.

In the foregoing chapters, we have seen for residents, “being cared for” has specific meanings. While these meanings are sex-differentiated, for both men and women, being cared for involves relationships, intimacy issues, communication, issues of feeling competent, independent, and being able to do something useful. Let us now see how these residents’ views of care relate to the “official” approach to care that is defined and provided by the expertise of the formal system of care and its cadre of care professionals.

SUB-THEME: FEDERAL NARRATIVES OF CARE

Federal regulations require long-term care (LTC) facilities to complete, at a minimum and at regular intervals, a comprehensive, standardized assessment of each resident’s functional capacity and needs, in relation to a number of specified areas (e.g. customary routine, vision, and continence). The results of the assessment, which must
accurately reflect the resident’s status and health needs, are used to develop, review, and revise each resident’s comprehensive plan of care.

In accordance with 42 CFR 483.20(k) the facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident’s medical, nursing, and mental and psychosocial needs that are identified in the comprehensive assessment. The services that are to be furnished to attain or maintain the resident’s highest practicable physical, mental, and psychosocial well-being and any services that would otherwise be required but are not provided due to the resident’s exercise of rights including the right to refuse treatment.

The Minimum Data Set (MDS) is a standardized instrument used to screen and assess the health status of all residents admitted to a Medicare and/or Medicaid certified long-term care facility (CMS.gov). Overall, this tool is used to measure specific areas of physical, psychological and psychosocial functioning and steps the NH takes in providing care to facilitate functioning. More importantly, this tool used as the foundation of a thorough individualized care plan for each resident for as long as s/he resides in this LTC facility.

The MDS is separated into twenty (20) different sections. Table 1 provides a list of each section and their titles.
Table 1.4: MDS 3.0 Nursing Home Comprehensive (NC) Version

<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Identification Information</td>
</tr>
<tr>
<td>B</td>
<td>Hearing, Speech, and Vision</td>
</tr>
<tr>
<td>C</td>
<td>Cognitive Patterns</td>
</tr>
<tr>
<td>D</td>
<td>Mood</td>
</tr>
<tr>
<td>E</td>
<td>Behavior</td>
</tr>
<tr>
<td>F</td>
<td>Preferences for Customary Routine and Activities</td>
</tr>
<tr>
<td>G</td>
<td>Functional Status – includes ADL Assistance</td>
</tr>
<tr>
<td>H</td>
<td>Bladder and Bowel</td>
</tr>
<tr>
<td>I</td>
<td>Active Diagnoses</td>
</tr>
<tr>
<td>J</td>
<td>Health Conditions</td>
</tr>
<tr>
<td>K</td>
<td>Swallowing/Nutritional Status</td>
</tr>
<tr>
<td>L</td>
<td>Oral/Dental Status</td>
</tr>
<tr>
<td>M</td>
<td>Skin Conditions</td>
</tr>
<tr>
<td>N</td>
<td>Medications</td>
</tr>
<tr>
<td>O</td>
<td>Special Treatments, Procedures, and Programs (e.g. cancer treatments; PT; etc…)</td>
</tr>
<tr>
<td>P</td>
<td>Restraints</td>
</tr>
<tr>
<td>Q</td>
<td>Participation in Assessment and Goal Setting</td>
</tr>
<tr>
<td>V</td>
<td>Care Area Assessment (CAA) Summary</td>
</tr>
<tr>
<td>X</td>
<td>Correction Request</td>
</tr>
<tr>
<td>Z</td>
<td>Assessment Administration – Medicare Part D</td>
</tr>
</tbody>
</table>

Although the foundation of the care plan, it is not surprising that the majority of the MDS encompasses questions related to medical treatment or the resident’s physical and psychological functioning. These areas are clearly important; however, nowhere in the MDS is ‘care’ defined despite its use of the term throughout the instrument. In fact, there is one section (Section V) that is devoted specifically to “Care Area Assessment (CAA) Summary”, which is highlighted in Table 1. It is within this section that one might especially expect “care” to be defined and the measures identified different from the other sections. However, upon further review of the CAA section we find that it consists simply of a checklist of the functional areas – identified in the MDS as “care areas” – in which the resident has had a significant change (known as a “trigger”), and furthermore, whether or not this “trigger” is addressed in the care plan. The twenty (20) care areas
include: delirium, cognitive loss/dementia, visual function, communication, ADL functional/rehabilitation potential, urinary incontinence and indwelling catheter, psychosocial well-being, mood state, behavioral symptoms, activities, falls, nutritional status, feeding tube, dehydration/fluid maintenance, dental care, pressure ulcer, psychological drug use, physical restraints, pain, and return to community referral (see Figure 1).

The care plan identifies all the care areas including any potential issues, other related risk factors, and more importantly, how the staff addresses each of these care areas. What is clear from this checklist is that the care areas identified in the CAA does not come close to any of the definitions or meanings of care identified by the male or female nursing home residents.
After a closer review of each section in the MDS, a few sections that might arguably be claimed to capture some semblance of ‘care’ as articulated by residents in the previous chapters. One of these is Section F – Preferences for Customary Routine and Activities, wherein some of the questions address a few of the topics that some residents
articulated as examples of care, such as the ability to choose bedtime routines, involvement of family and close friends, and preferred activities in/outside the facility (see Figure 3). Although the strength of this section captures the importance of each preference question from the respondent’s perspective, which could be the resident or a family member/significant other, it is limited in capturing what care is or how it is defined from the resident’s point of view, first and foremost because the term care’ is simply not mentioned nor related to care in any of the preference questions.

Figure 3: Preferences for Customary Routine and Activities
Another section in the MDS that addresses or at least skirts around some of the care meanings articulated by the residents is Section E – Behavior. In this section, MDS items address two specific topics of care that were brought up by residents: care and intimacy (articulated by male residents), and care as a threat to independence (articulated by female residents). Let me first review how “Behavioral Symptoms” are coded (see Figure 4):

A. **Physical** behavioral symptoms directed toward others (e.g. hitting, kicking, pushing, scratching, grabbing, *abusing others sexually*)

B. **Verbal** behavioral symptoms directed toward others (e.g. threatening others, screaming at others, cursing at others)

C. **Other** behavioral symptoms not directed toward others (e.g. physical symptoms such as hitting or scratching self, pacing, rummaging, *public sexual acts*, disrobing in public, throwing or smearing food or bodily wastes, or verbal/vocal symptoms like screaming, disruptive sounds)

The care theme of needing, wanting female intimacy by male residents, is addressed in this section in the sense that “sexual acts” are considered *problematic*. In fact, if the resident is coded with exhibiting any of these behaviors, it would then be considered a “triggered care area” in the CAA Summary. What this means is male residents who may act out in such a way that displays their need for sexual intimacy. That is, care, according to male residents, is officially regarded as problematic and therefore must be addressed by a corrective plan. Is this really fair? It does say “public”
sexual acts, not sexual acts generically, does it?? If so, i.e. if it IS fair, consider adding something like the following:

Thus, it seems that the formal constraints of care planning may tend to restrict the expression of impulses or needs that, for many men, are integral to the issue of care.

<table>
<thead>
<tr>
<th>Behavioral Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>ED200. Behavioral Symptom - Presence &amp; Frequency</td>
</tr>
<tr>
<td>Note presence of symptoms and their frequency</td>
</tr>
<tr>
<td>Coding:</td>
</tr>
<tr>
<td>0. Behavior not exhibited</td>
</tr>
<tr>
<td>1. Behavior of this type occurred 1 to 3 days</td>
</tr>
<tr>
<td>2. Behavior of this type occurred 4 to 6 days, but less than daily</td>
</tr>
<tr>
<td>3. Behavior of this type occurred daily</td>
</tr>
</tbody>
</table>

| ED300. Overall Presence of Behavioral Symptoms |
| Enter Code |
| Were any behavioral symptoms in questions ED200 coded 1, 2, or 37 |
| 0. No → Skip to ED000, Rejection of Care |
| 1. Yes → Considering all of ED200, Behavioral Symptoms, answer ED500 and ED600 below |

Figure 4: Behavioral Symptoms

A similar paradox between residents’ care interests and those defined in the MDSxx exists for women.

| ED800. Rejection of Care - Presence & Frequency |
| Enter Code |
| Did the resident reject evaluation or care (e.g., bloodwork, taking medications, ADL assistance) that is necessary to achieve the resident’s goals for health and well-being? Do not include behaviors that have already been addressed (e.g., by discussion or care planning with the resident or family), and/or determined to be consistent with resident values, preferences, or goals |
| 0. Behavior not exhibited |
| 1. Behavior of this type occurred 1 to 3 days |
| 2. Behavior of this type occurred 4 to 6 days, but less than daily |
| 3. Behavior of this type occurred daily |

Figure 5: Rejection of Care

As can be recalled from previous chapters, female residents articulated that accepting care or assistance was a threat to their independence. In fact, there were several accounts of male and female residents who described instances of refusing assistance, disobeying the nursing staff, or simply refusing to take medications. These were ways in which residents felt they could continue to maintain their independence while living in LTC. However, such activity also runs into opposition and into the risk of a sanction,
because it contradicts the behavioral requirements laid out in the MDS. Specifically, in the Behavioral Symptoms section, is a ‘Rejection of Care – Presence and Frequency’ question, “Did the resident reject evaluation or care (e.g. bloodwork, taking medications, ADL assistance) that is necessary to achieve the resident’s goals for health and well-being?”

As a result, such behaviors are then officially deemed as a “rejection of care” and then considered a “triggered care area” that must be addressed in the resident’s plan of care. Thus, the logic of the MDS ironically confirms the female resident’s sentiment that needing care IS a threat to their independence. To the extent that the staff impose an additional care plan to enforce their version of care and deal with residents efforts to reject care, one could argue that the MDS imposes a regimen that runs directly counter to the resident’s idea of care. The paradox is sometimes care means “not doing” something for someone; however, when a resident tries to claim the space to act on her/his own, she risks being charged with noncompliance under the form of “rejection of care”.

In sum, although there are some sections and questions throughout the MDS that may address some of the residents definitions and meanings of care, it is clear that the MDS is in many ways incongruent with care interests that are does not accurately capture what care is or what it means from a care-recipient’s point of view.

SUB-THEME: FACILITY NARRATIVES OF CARE

While the MDS is used to assess the physical, psycho-social functioning of the resident in order to create a plan of care, LTC facilities may use other tools or methods to evaluate how or if they deliver care. When I asked the Administrator of this LTC facility
if they use other methods to evaluate their care services from a resident perspective, she provided me with data from their most recent surveys given to residents and family members (2009). In this section, I critically examine the instrument used by this facility to evaluate their care from the resident and family points of view.

In the facility, under study, St. Paul Homes, the instrument used for obtaining feedback from the residents and family members at the time of this research was the Eden Alternative Warmth Survey (EAWS). The facility chose this survey since it is going through the Eden Alternative culture change process. For readers unfamiliar with it, I will note that the Eden Alternative is “an international, non-profit organization dedicated to creating quality of life for Elders and their Care Partners…” (www.edenalt.org). The Eden Alternative vision is “to eliminate loneliness, helplessness, and boredom…to improve the well-being of the Elders and their Care Partners by transforming the communities in which they live and work” (www.edenalt.org).

Although the purpose of the EAWS is to measure organizational climate, or what Eden Alternative calls the “soil temperature” of the facility (www.edenalt.org). This tool also contains many items that address concerns about care. Figures 5 and 6 display the resident/elder and family questionnaires from the EAWS that includes twenty (20) questions where the answers are based on a 5-point scale ranging from Strongly Disagree, Disagree, Neutral, Agree, and Strongly Agree. For the elders and family, the questions are very similar except for just two (2) questions that pertain specific to residents or family members only.
There are a few questions on these surveys that may relate to or imply a similar sentiment of care as articulated by the residents. For example:

**Q1. I am allowed to participate in decision-making.**

This statement relates to resident’s meaning of care in the sense that male residents expressed being left out of decisions, such as the social worker switching his room from a private to a shared room.
Another example includes when male residents claimed they were unaware that the doctor changed their medication until the nurse tried giving it to them. Therefore, if male residents in this sample answered this question with a high level of disagreement, one could presume that these residents feel they are not being cared-for.

**Q3. The staff care about me.**

First, it is worth noting that this is the only question that mentions the term ‘care’ and implies a definition of an emotional feeling or connection between the two parties – in this case, staff and resident – from the perspective of the resident (or family member...
answering the question). Thus, this question could be but one way in which LTC facilities could measure the quality of care delivery and care practices from the perspective of care-recipients.

**Q18. Staff members take time to talk and listen to me.**

One could argue this question relates to or could be correlated with the previous question discussed (Q3) as well as residents meaning of care in the sense that many residents provided several anecdotes of enjoyment whenever staff went out of their way to do something for them, such as escort them outside for a walk. It is important to note that the residents in this sample are very aware of how busy the nursing staff are, and therefore, when they spoke of certain staff members taking extra time to do things for them, they felt special or valued by that staff member, stating things like, “they didn’t have to do that, you know.” Thus, if the residents agreed with this statement, they feel cared-for by the staff.

**Q9. I can choose what I want to eat.**

**Q10. I can get up and go to bed when I want.**

Both questions 9 and 10 could relate to meanings of care from the residents who expressed the ‘institutionalization’ or ‘routinization’ of living in LTC is not care, and so, for these questions, it could be argued that providing choice of these routines is a form of care.

**Q14. I feel helpless at times.**

**Q18. I am bored.**

Questions 14 and 18, could arguably relate to the majority of female residents who expressed wanting to help others or be provided opportunities with meaningful activity.
Thus, if female residents who answer these questions with a high level of agreement, one could argue they are not being cared-for.

For these reasons, it could be argued that the EAWS measure of care, that when compared to the MDS, is more closely aligned with resident concerns regarding care. This should not be surprising, since it has been developed by an organization whose goal is to make nursing homes more responsive to residents’ interests and concerns.

Nevertheless, if we want to measure care from the care-recipient’s perspective, it also lacks some key measures of care. First, similar to the MDS, ‘care’ is not clearly defined in the EAWS. Second, although the term ‘care’ is used in one question and implies the definition of “cares about”, the question is limited in the sense that it indicates that the staff are the only ones to care about the resident. However, it is clear in many resident accounts, that the residents themselves not only cared about other residents, but also provided care or wished to provide care to each other.

Finally, sexual behaviors and rejecting care were considered problematic areas that needed to be addressed in a special care plan in the MDS. The EAWS avoids addressing these two topics altogether. Nowhere in the EAWS does it address care as expressed by male residents’ of the need or desire for intimacy in any way. Additionally, the EAWS does not address the topic or idea in which care may be threat to independence, whereby residents who refuse assistance from staff or disobey some of the rules and regulations is one way in which residents themselves feel they are exerting their independence.

In sum, it could be argued that the EAWS does capture a semblance of what care is and the meanings of care as articulated by the residents living in this LTC facility,
especially when compared to the MDS. However, it is worth noting that the EAWS was created to measure the “warmth” of the facility going through the Eden Alternative culture change (www.edenalt.org), and furthermore, this instrument is not a standard for all LTC facilities to complete. This is simply an example of how this particular LTC facility measures the quality of care and care practices from the perspectives of their residents and family members, while on their Eden Alternative journey.

What is notably different is that the MDS is federally mandated for all LTC facilities regulated by the Centers for Medicare/Medicaid Services (CMS), and is the collection of resident health assessments that are used to provide data on the quality of care and care services provided by that facility (CMS.gov). What is clear, is that there is something of a disconnect between resident concerns and specifically those that fall into the care domain, and what both of these care evaluation documents focus on and define as care, particularly the MDS.
CHAPTER 8: INTERPRETIVE ANALYSIS

INTRODUCTION

The primary purpose of this research is to examine in detail the meanings of care from the perspective of care recipients by learning about their care experiences, or the lack thereof, within the context of living in long-term care. The primary method of this project was face-to-face, semi-structured interviews with elder care recipients living in the skilled facility of a Continuum Care Retirement Community (CCRC). After analyzing all the transcripts, I looked for themes relevant to understanding care from the perspective of the elderly residents. I then compared these meanings of care to the government standards for evaluating care in long-term care facilities as well as the evaluative measures this facility used to measure their company culture, which they considered somewhat related to delivering care services. To a much greater degree than I anticipated, I found that the meanings of care and how it is experienced by elders living in long term care are sharply differentiated by gender. I also found a dramatic mismatch between what residents found important in their own experiences of care and the nature of care that is conceived by professional expertise and in government regulatory requirements. In this chapter, I review the differences between what female elder residents considered as care compared to male residents considerations of care. I then put these results into context using a theoretical framework of self-determination theory (SDT). I conclude with my own reflections of this project and the challenges faced throughout the journey.
The Making of an Invalid and Being In Valid

Many of the female residents strongly identified with being an independent woman. They found their dependency inherent to living in the facility as a threat to their independence, and hence to their sense of personal integrity and identity. Some female residents made statements like, “Living in this place makes you an invalid!” and “They’re making an invalid out of me!” These are powerful statements with a double meaning. Not only were they dependent on the staff for some of their basic daily functioning (a loss of control of their own bodies), some felt oppressed by the staff since they were denied the ability to try to help themselves, thus, making them an invalid. Additionally, female residents felt they were denied opportunities to help others when they wanted and tried, which affected their identity in the sense of a caregiver and someone of significance and purpose. Thus, not only was their identity as an independent woman significantly impacted because they were made into invalids, but also because they were in valid.

Many female residents responded to the questions about care not in terms of their own immediate needs and dependencies, but mostly in terms of their limitations in lacking opportunities to provide help to someone else. Such a finding is consistent with the work of Kahana and colleagues (2013), who studied the impact of altruistic attitudes and prosocial behaviors such as volunteering and informal helping among retirement community elders. They found that altruistic attitudes, volunteering and informal helping behaviors make unique contributions to the maintenance of life satisfaction, positive affect and other well-being outcomes (Kahana et al., 2013). Similarly, researchers have studied the effect of helping behaviors and physical activity on mood states and depressive symptoms of elderly people living in long-term care and found that helping
behavior was positively correlated with cheerfulness and vigor and negatively correlated with depressive symptoms (Sarld et al., 2010). Such studies are consistent with the Deci and Ryan’s influential formulation of self-determination theory, which identifies the experience of competence as one of three basic human needs.

In sum, the modal response from the female residents of this exploratory study support previous LTC research that demonstrates when residents are provided with meaningful and purposeful opportunities of engagement, they have less depressive symptoms, increased autonomy, and positively impacts their overall well-being. Therefore, understanding that residents – especially female residents need opportunities to engage with others in such meaningful ways that they are helping others in some way, may also minimize the threat to their independence while positively affecting their experiences of being cared-for.

*Embracing the “Sick Role”*

For the male elders, in this sample, having opportunities to help others was not a desire or a need in order to be cared-for like it was for female residents. In fact, many male residents expressed they did not want any responsibilities, and that the main reason they were living in long-term care was because they were not able to maintain or keep up with the domestic responsibilities at home due to their illness; therefore, their illness and the fact they were living in the nursing home gave them permission to be cared-for by others. These responses relate to Talcott Parson’s (1951) sick role theory, which explains the particular rights and responsibilities of those who are sick. Parsons saw the sick role as a form *deviance* or going against societal expectations because the sick person has different patterns of behavior than the norm (Parsons, 1951). Generally, people of a
community are expected to be productive members of that community; however, if you fall sick are not able to carry out these normal duties, this deviant behavior is positively sanctioned or approved by the community or authority. For the male residents in this sample, the fact that they were diagnosed with an illness (many with multiple) as well as admitted into the nursing home, legitimates their illness, and therefore, allows them to embrace the sick role. Parsons’ (1951) sick role also points out the two main responsibilities of this role: 1) one must make it a priority to get better, and 2) one must seek appropriate treatment for the medical condition.

It is not my intent to critically examine Parsons’ theory of the sick role, but I use it to relate it to and explain some of the male responses. Many of the male residents expressed simply wanting to get better, not only so they could do the basic activities of daily living such as walking, bathing, and toileting, but they also anticipated moving back home. These male residents felt their admittance into the nursing home was temporary, as well as their current “sickness.” In addition, they were staying in a medical facility in which they were paying for the care services; therefore, they simply expected the nursing staff to do all the work for them, to care for them, and they had no responsibility except to follow the doctor’s orders of taking their medications and following the prescribed treatments. One male resident stated, “That’s what these girls are here for…that’s why we pay them the big bucks.” This response was in response to the question, “Do you provide care or wish you could provide care to others here?” Including probing questions that specified the way in which female residents meant by care, such as, “Do you get opportunities or wish you had opportunities to help others around here?” There was one instance in which male residents described the times in which he regularly assisted
another residents. He described when he used to escort the blind female resident staying at the end of the hall into the dining room. Although he himself was in a wheelchair, he would wheel himself down to her doorway and talk her through to where she could grasp a hold of his wheelchair handles. He would then resume to escort her back down the hallway into the dining room where the nursing staff would assist her into her chair at the table.

From my perspective, as researcher, this is a meaningful example of residents caring for each other. However, what is important is that the male resident did not relate this story to a definition of or a meaning of care. He did not share this engagement as an example of care, rather it was an example of when he helped or assisted another resident. This is an important distinction because it demonstrates the difference of what male and female residents considered as care. Where female residents counted similar opportunities (or the lack of opportunity) to help another as care, male residents – although experienced some opportunities in which they could help others – they did not consider them as care. In fact, most of the male residents’ meaning of care was quite different than how most female residents thought of care, which leads me to the next section.

“A Poor, Dirty, Useless, Old Man”

Overall, most all responses from male residents were dramatically different from the female residents. The most pervasive response from men was the need for some kind of physical intimacy. In fact, most or almost all of them directly or indirectly mentioned some kind of desire, want, or need for some kind of physical intimacy with a woman when asked about the meaning of care or when asked for examples of when they feel
cared-for (or when not cared-for). Some men used “code words” or phrases like “the Jitterbug,” “monkey around,” or “do a Big Ben” to describe the different ways in which they meant to describe an experience of physical sexual intimacy. In these cases, codes words may have been used because of my gender and age, which may have inhibited the men from comfortably articulating or expressing what they meant by these codes. In addition, although not all men were so specific, some mentioned a certain type of woman, specifically a “hot blonde” or “hot gorgeous blonde”. Furthermore, marital status did not appear to make a difference. The married men also expressed this need and desire for physical sexual intimacy. Of all the male residents expressing the need for care as physical sexual intimacy, it was clear that they were NOT currently cared-for in this manner, despite that some spouses visited regularly. The one exception was the male resident who described watching porn in his room to meet this need. However, it appeared that this was done in secret, facilitated by an arrangement between him and a few of the staff. I needed to assure him several times that I would not disclose this information to the nursing staff since it was clear to me that once he shared that information with me, he feared retribution.

The modal response from male residents is important for this research study because it identifies how these men think about care, what it means to them, and more importantly, how the need to be cared-for physically and intimately was related to their masculinity and identity. This theme was comparable in its dominance to what I heard female residents who associated caring with the ability to have their sense of independence affirmed.
It was also clear that many of the male residents’ who articulated caring as physical intimacy identified with being a “poor old man,” a “dirty old man,” or a “useless old man.” Although common vernacular terms, these words warrant some attention. A poor old man, “poor” not only meant lack of finances or the transparency into their finances (as some male residents discussed), it also meant they were full of pity – pitiful.

The few men who identified with being a dirty old man, were the men who talked about wanting physical intimacy with the young girls, the female staff. These men were also the male residents who flirted and joked around with the staff. The useless old man identity came from a few men who understood or recognized that they may not even be able to perform sexually if given the opportunity, and therefore they would be useless in the ability to reciprocate care with their partner. Male respondents often noted that their desires, while authentic, were beyond institutional parameters. Some stated explicitly that they did not expect the facility to bring in prostitutes or hot blondes to take care of them in this way.

The modal results from the male residents in this study highlight an enduring but often-hidden phenomenon in LTC facilities. Sexual aggression in nursing homes is not a new issue. In fact, many of the nurse’s aides interviewed for this study mention being a victim of such aggression from male residents. However, sexual aggression among nursing home residents, whether male or female, is typically treated as misbehavior and problematic in which action from the staff and the facility must show documentation and a planned corrective action. Additionally, disconcerting is that the sexual inclinations or actions exhibited by nursing home residents are at times deemed a result of the resident’s dementia or cognitive decline, or symptoms prescribed medication (Kettl, 2008). In such
cases, additional treatments such as changes to prescription medication are often taken in order to mitigate the sexual behavior (Harnett, 2004; Kettl, 2008). This is troublesome because at the root of these reactions, the evaluations, etc. is ageism – a denial that elders remain sexual beings even as they continue to age. These results show how the basic human needs for human touch, closeness, and intimacy do not disappear with age. And furthermore, that the male residents in this sample thought of this as a form of care and they were able and willing to articulate it.

Unfortunately, previous research on aging and sexuality indicates that current attitudes are negative just as the current societal myth is that sexual interest declines and disappears in old age (Aizenberg, Weizman and Barak, 2002). However, other research on older adults and LTC shows it is possible for older adults to maintain their desired level of sexual activity if the environment is accepting and accommodating for the adults’ needs (Miles and Parker, 1999; Doll, 2012). However, it is not surprising that those older adults who are institutionalized in nursing homes have fewer opportunities to meet these needs. Thus, long term care health care professionals, need to recognize that because of losses due to nursing home placement, declining health and lifestyle changes, the need for intimacy may even be greater (Doll. 2012). According to the Culture Change movement, the LTC facility or nursing home is viewed as the resident’s home. Home implies a place of choice, a place of pleasure and comfort, including a place where sexual expression can occur, and when such basic human needs are denied, residents – especially male residents in this case – are not being cared-for.
A Theoretical Framework: Men and Women, Plagues and Needs

According to self-determination theory (SDT), every individual has three basic needs – autonomy, relatedness, and competence (Deci and Ryan, 1985). SDT is a highly respected and highly influential framework in developmental and motivational psychology. Autonomy relates to a sense of control over our own lives, a degree of control and choice over one’s situation without undue constraints either on activities and the usage of time, and on space. Relatedness refers to a sense of meaningful connection to others. Competence refers to feeling like we can do something useful. It is important to recognize explicitly that these needs develop early in the life course, and there is no reason to suppose that they change with age. Indeed, there is much reason to suppose they do not change with age. They are just as important for centenarians as for teenagers. Dannefer and colleagues (2009) have suggested that the frustration of these basic needs aligns closely with the problems that Culture Change pioneer, Bill Thomas identified as the “three plagues” of nursing home life – boredom, loneliness, and helplessness (Thomas, 1996). Thus, SDT provides a systematic grounding for interpreting these plagues in terms of basic psychological deficits as well as provides one framework for achieving this clarity because it provides an established and respected theoretical basis in human development theory for identifying what human beings generally need to thrive.

Using SDT as a framework, I argue that the female resident responses in which care is a threat to their ability to help others directly relates to the basic human needs of autonomy and competence. Female residents expressed that living in LTC is a threat to their independence since they are robbed of their sense of control (autonomy) not just of
their bodies as they experience physical decline, but are also denied ways to maintain their current physical functioning – what female residents called *making of an invalid*.

As an Eden facility, they began changing from the traditional medical model of care to the model of “person-centered” or “resident-centered” care. This included training staff on all the Eden principles, shifting the culture in ways that the staff and the residents began thinking about aging, nursing homes, and care practices different from the traditional nursing homes. Resident-centeredness focused on reorganizing the staff’s routines, patterns and assignments by resident’s preferences, thus, providing residents more autonomy. Other examples of increased autonomy include changes in the structure of mealtimes like offering several times to eat throughout the day and offering bistro like kitchenettes on each unit, and more food choices.

The accounts from female residents highlights that this LTC facility needs improvement in providing female residents opportunities for meaningful activities that provide care to others (competence). The denial of such opportunities only reifies female residents as *objects of care* rather than their continued life role as carers, further rendering them as *invalid*.

It is worth noting here that there were several female and male residents who articulated several accounts in which they were provided “jobs” or “volunteer” opportunities. Specifically, some residents had “Eden responsibilities” that included taking care of the bird aviaries on the unit, or taking care of their personal birds. One resident (and also a staff, neither of whom participated in this study) was responsible for ensuring the facility dog had water in the dog bowl on every unit. These are just a few examples that were not highlighted in the findings of this study, but should be noted as

139
part of my knowledge about the facility and its progress along the Eden Alternative journey. However, the findings of this study clearly show that among the female residents interviewed, they wanted and needed more opportunities. One of the Culture Change principles is “the work is never done,” thus, this finding highlights an area in which this Eden facility can improve.

Dependency remains a defining characteristic of nursing home residents, even under a Culture Change mode of person- or resident-centered care. Resident-centeredness implies nothing about resident efficacy, empowerment, competence, or agency. If competence is a human need, delivering quality care must therefore include “delivering competence”. Researchers have provided one way this can be done by using participatory action research (PAR) in nursing home studies, inviting and enabling residents to use and regain their voices not just in asking for care, but in commenting on their individual and collective circumstances, their observations, ideas, visions and critical analysis (Dannefer et al., 2008; Shura et al., 2011). The fundamental premise is that the residents themselves are the “experts” of nursing home life and are also fully capable of observing, critiquing, evaluating and contributing towards their own provision or receiving care. They are the experts because of their 24/7 lived experience in such care settings, as well as the wealth of life experiences that often involve care, such as parenting, care giving, and for some, even previous professional skills. Thus, elder residents are uniquely positioned to identify strengths and ways to improve quality care in long term care facilities, and especially for female elders, finding ways to deliver competence will improve quality care.

Another study based on Culture Change principles, identified residents’ narrative history of activities – activities the resident enjoyed prior to admission to the LTC facility
– with the goal of recreating those opportunities or a reasonable comparable option for residents living in LTC (Alexander et al., 2011). Alexander and colleagues (2011) conducted a study based on the culture change philosophy of care in which nursing home life should be more akin to the life residents enjoyed while living independently in the community (2011). The authors interviewed 11 (5 male, 6 female) residents living in a 125-bed skilled LTC facility in New York, garnering resident information about their prior activities preferences (PAPs), and identifying the obstacles limiting their engagement in these PAPs. In each case, the interviewer was able to identify one or more PAPs and direct obstacles that hindered the resident’s ability to engage in PAPs. They found the obstacles most cited were lack of energy, limited mobility, pain, memory or health problems, worry about falling or injury, lack of materials, and lack of opportunity (Alexander et al., 2011). This study also included the researchers and an interdisciplinary team – that included the executive director, activities coordinator, a nursing staff, and physical therapist – to generate interventions that would be effective at re-engaging residents and feasible for the facility to implement (Alexander et al., 2011). The results of this study found that nearly all of the study participants demonstrated re-engagement in which residents were able to exercise their autonomy in unexpected ways, such as by positively influencing changes in their environment such as the creation of several new structural innovations that increased choices for many residents (Alexander et al., 2011). In each of these studies, the changes may have been small, however the fact that the researchers included the residents into the research process, and/or incorporating their voices into nursing home life represents a fundamental change in LTC practice and
Such positive responses from the LTC facility administrators, demonstrates to the residents that they truly value the resident’s input.

Finally, if care as physical intimacy and companionship addresses the human need of relatedness, then delivering quality care must also include “delivering relatedness”. In this sense, relatedness includes physical human touch, physical intimacy and affection, sexual intimacy, companionship, and friendship. One of the ways in which this facility and other Culture Change initiatives, addresses a way in which general relatedness and increased social interaction among staff and residents and residents themselves may be delivered, is to approach it from a structural perspective. Building or remodeling the facility from the traditional white long hallways of hospitals or institutions to more open and collaborative spaces, may enhance opportunities for engagement and social interaction. This Eden facility underwent a 4-million-dollar renovation to include structural changes where nurse’s stations were no longer hidden from resident lounges, resident dining is no longer in one cafeteria-like location, and residents lined up along the hallways waiting to go into the cafeteria during mealtime. Instead, each unit had its own dining room that was set up family style so that small groups of people could eat around a table and be able to talk and socialize. Nurses stations were in central locations to resident lounges so both nurses and residents could interact even while doing their work and lounge activities. Lounges and resident rooms were designed and decorated to be more “home-like”. In addition, the language began to change to include “family” and “team” when referring to both staff and residents on the same unit. And although these changes occurred in this Eden facility, it is not clear, nor was it the purpose of this study to measure whether these structural changes increased or enhanced relatedness between
the staff and residents or among residents themselves. Furthermore, such changes still do not address directly the human need of relatedness as articulated by the male residents that of physical sexual intimacy.

The findings of this study show that there is a need for increased awareness and acceptance that sexual expression and physical intimacy is a prominent need, especially among male residents, living in LTC. The men in the current study were expressive in identifying this need and but not without a stigmatizing cost. As the staff experienced the sexual aggression from male residents in their daily interactions, the male residents were able to articulate these needs in some way to me as I asked them about care means. However, as the findings show, the need for relatedness came at a stigmatizing cost for the male residents – they were identified as a “dirty old man” (from staff) and the internalization of the “poor, useless, old man” (male residents).

There are currently no rules regarding sexuality in long-term care (Doll, 2012). However, one facility has attempted to address this issue – the Hebrew Home, located in New York. They established a policy that provides guidance on an institutional approach to sexual expression, including a training video entitled, “Freedom of Sexual Expression: Dementia and Resident Rights in Long-Term Care Facilities” (Hebrew Home for the Aged Research Division). Their policy and training video presents both appropriate and inappropriate sexual expression and been sent to all LTC facilities in New York State to emphasize the importance of each facility having residents’ rights policies to sexual expression and the responsibility of staff in upholding them (Sisk, 2009).

In conclusion, based on SDT theoretical framework, the results of this study strongly suggest that when the needs for autonomy, competence, and relatedness are not
being met, the care recipient is not being cared-for. Furthermore, long-term care facilities must recognize these human needs are not the same for both male and female residents and thus, should be addressed differently for male and female residents.

A Reflexive Discussion

Finally, as I show the themes that emerged from both men and women, we can see that there are remarkable differences in the way men and women think about and talk about their meanings of care. I consider this an important finding from this work, and is significant to sociological literature (as well as other disciplines) because when we seek to understand what care might mean to care recipients, we must first recognize that the way men and women construct issues of care are quite fundamentally different.

Second, when resident meanings of care are compared to the federal guidelines of how care is measured, it is abundantly clear is that there is quite a dramatic mismatch between the dimensions of the care evaluated by the MDS and the dimensions of the operationalization of care as constructed by residents. As Alvin Feinstein suggests, perhaps the medical professionals and experts should evaluate the curing component of medical institutions, and let the caring component be evaluated by the care recipients. Therefore, to better improve how we currently evaluate quality care, we should include care recipient’s perspectives including the various experiences of care between men and women.

I have discussed in a previous chapter that sexual aggression is captured in the MDS. However, this behavior was considered problematic. Further, the rejection of care also seen as problematic according to the MDS, relates directly to the female’s response to care as a threat to their independence. The significance of this study highlight the
problem of how we evaluate care in LTC since the MDS – the instrument that provides information for individualized resident care plans – contrasts so dramatically and actually “punishes” what residents consider care.

As the researcher and interviewer, I was somewhat surprised that the male modal response theme emerged from the beginning of the male interviews. However, as a previous CNA, I knew that these and similar acts of sexual expression overtures and dialogue about the need for physical intimacy with male residents were not unique to this sample of male residents, nor did I deem it an interviewer effect since many staff provided similar anecdotal accounts.

Compared to the male results, I was not that surprised to find the modal theme emerged from the female residents: care as helping others. Historically, women provide care to others throughout the life course, from raising children and caring for the family as well as aging parents and spouses. Therefore, the need to continue this role as carer and participating in the daily activities of living was not surprising a surprising care theme emerged for these female residents. However, I was more surprised by the accounts that residents told me they felt they were deliberately being stifled by the staff from regaining their independence – in their terms, *the making of an invalid* – and further included denying them the opportunities to help others in the name of “facility policy” and/or “safety” (e.g. escorting residents in wheelchairs, assist feeding others). These findings may provide some insight to LTC facilities and frontline staff into understanding how these practices affect female residents’ identity as an independent woman. LTC facilities and frontline staff may then be able to address and improve care practices to
incorporate ways in which females are not only encouraged to remain independent but also as valid members to the home and community.

Unexpected Challenges

Explicating clear meanings of care from people who work and live in long-term care was much more difficult than I expected. Thinking back to my proposal defense, Dr. Robert Binstock, a member of my committee at the time, predicted this challenge. He was curious as how exactly I would get residents and staff to communicate or articulate clearly what I was seeking to get – clear meanings and definitions of care from their perspective. At the time, I did not fully understand what he meant and understood his concern to be more about the challenge of developing the trusting relationship and rapport needed among the residents and staff that would enable them to talk openly. That is, creating that much needed space in which they would share openly with me their care experiences, or lack thereof, without retribution from the staff, co-workers, or their supervisors. During the defense, I addressed Dr. Binstock’s concern by relaying my previous research experiences interviewing residents and staff, and also my rapport and previous relationship with this and other LTC facilities. In the case of the facility I studied, I had a developed relationship with the facility and received permission from the administrator to conduct the study with their residents and staff. Also, with my volunteer hours, I was not a complete stranger to the staff or residents, and was therefore had dispelled somewhat the initial threat of strangers coming and asking questions about life and work in this facility. However, what I found was that the challenge was not in creating the trusted relationships or the space in which care experiences could be shared. The challenge was forcing them to think about what they truly mean when they think
about what care is or what it is not; however, it was not simply to provide a definition, which was very difficult itself, but to get them to articulate what they meant by care. By asking residents the various types of questions regarding care.

During my staff interviews, it was clear they felt care was simply what they do – it was their work. ‘Doing’ care are was how their job performance was measured, and included what was part of their daily tasks or activities such as bathing a resident, assisting them to the toilet or cleaning them up while in bed, escorting them to an activity, filling up their water pitchers, taking out the trash, doing their laundry, and documenting each of these activities in the residents’ charts. Very few staff members articulated other meanings of care. One staff member described care as, “truly knowing your resident’s likes and dislikes.” For example, knowing when they liked to have their water pitcher filled with fresh water and ensuring there was a wash cloth underneath the pitcher so the pitcher wouldn’t sweat on her nightstand. One frontline staff member said that it wasn’t simply about knowing the resident’s likes and dislikes, but that care involved one’s feelings for the well-being of that resident; caring about that resident.

She further states:

“We can do what we do every day and still provide care. But when you really care about them, that’s when what we do really matters and the residents know it too. That’s how I know they are cared-for. And I try to do that for MY people.”

Many staff took possession of “their people” which was a form of endearment rather than power or control, when they made such statements like, “my people”, “my unit”, or “my residents”, which to me indicates that they took ownership of and were proud of them.

One of the most surprising results and disappointing findings was that reciprocal care did not emerge from the data. Reciprocal care in the sense that the staff felt cared-for
from the residents, turning the notion that the caregivers were only the CNA’s and the recipients of care were only the residents, upside down. In fact, when I asked the staff if they received care from others while at work, most responded in that they did not receive care or support from their peers or teammates (other CNAs and nurses working other shifts), nor from the administrative staff; therefore, the staff did not think of receiving care from the residents. This was very disappointing because in my personal experience as a CNA and employee working in LTC, reciprocal care – residents providing care to me – was what made my work most meaningful significant. I learned new skills from residents, like learning how to crochet and make beaded jewelry from different female residents. I grew an interest into classic cars from the male residents when I escorted them to our annual car show, and they explained what make and model and what kind of engine or unique features of each of the cars. I learned new skills, new interests, and developed close relationships with many of them and also with some of their families, I truly felt cared-for. I know and have witnessed it with other staff members as well, and I had hoped that this would emerge from my interviews with the staff. Unfortunately, true reciprocity of care did not emerge as a care theme in this study. There were a few staff members who shared experiences of how they were treated by residents, some of which were described in the data chapters; however, it was expressed as care provided to them from the residents.

Limitations

A major limitation of the current study is the issue of generalizability, which is inherent in many qualitative study designs, and more specifically to dissertations. Since this project is an exploratory study into understanding the meanings of care in a very
specific context – care recipients living in LTC – it was clear from the beginning that the design of this study was not going to be generalizable. Additional research sites were discussed at the beginning of the planning and design stages, however, the final study design that was presented and approved only included one research site. It was not until during the data analysis and reflection that the findings of this study might highlight the uniqueness of this particular research site – as a LTC facility as well as the lack of demographic diversity among respondents. This CCRC is located in a rural mid-western region of the United States. Therefore, the residents and staff are from the surrounding rural towns with little exposure to diverse cultures and people with different ethnicities. As mentioned previously, all respondents in this study were Caucasian. This CCRC was also unique in the sense that it was progressive in its adoption of the Culture Change principles and wanting to change the skilled nursing facility, the primary research site, into an “Edenized facility.” Therefore, the results of this study cannot be generalizable to LTC facilities more generally.

The lack of demographic diversity among the respondents may also highlight another limitation of the current study – the interviewer effect. At almost every presentation in which I have presented the findings of this study, questions of interviewer effect arise from the audience. I can respect these questions as they address data reliability and validity of this study. It is vitally important, as the researcher and main interviewer, to be reflexive in qualitative studies. This is acknowledged within social science research and there is widespread recognition that the interpretation of data is a reflexive exercise in qualitative designs through which meanings are made rather than found (Mauthner et al., 1998). The subjectivity of the interviewer in interpreting the data
may be called into question in qualitative studies particularly when there is a single interviewer. However, questions could be mitigated by explaining and describing in full detail the methodology and process used throughout the interviews, which I feel I have done in their respective chapters (see Chapters 3 and 5). In addition, another way to mitigate such questions of doubt is to build in the study design reliability testing with a secondary researcher or multiple researchers. In retrospect, this method would have been helpful in addressing the unanticipated questions of data reliability.

To address the concern of interviewer effect and the issue of validity, I turn to the social construction of reality (Berger and Luckman, 1966) in which people create their own form of realities through their actions and interactions with others. It is a shared reality that is both experienced objectively factual and subjectively meaningful. Berger and Luckman (1966) provide a theoretical framework of how knowledge is produced and co-produced through human interaction, which I will not go into detail here, but I mention this to help address the consistent question of the interviewer effect on the findings of this study. This theoretical framework informed my first assumption (see page 15) that stated, “…elders who participated are experts on their own lives and their own experiences of care. I view them as accurate reporters of care in their lives, and I believe that what they shared is true from their perspective, despite any diagnoses or symptomology of cognitive impairment.” Therefore, I must agree that as the interviewer interviewing the residents in this study, I most certainly had an effect on all the respondents – how they interpreted as well as responded to the questions on care. We were co-producers in the knowledge construction of what care means to them and how they experienced care. I created a space for these men and women to articulate and
express feelings and ideas about care that at a different time and space, and with another interviewer may not have otherwise been expressed. And it is for this reason that I stand by the validity of the data in this study, that the findings I have reported are true and valid as articulated by the men and women residents who participated.

**Future Research**

Were I to have the opportunity to replicate this study in the future, I would first redesign the study to include a team of diverse interviewers in which their demographics varied. In addition, the study design would include multiple LTC facilities with demographically diverse residents. Multiple LTC sites could include enrolling both “Eden facilities” and those that are more traditional nursing home models. Redesigning this study to answer a similar research question so that it is more generalizable will be important not only to the various bodies of care literatures (e.g. medical, nursing, long-term care, and general care scholarship), it may also have practical and policy implications on care practices. As new quality of care initiatives continues to grow in LTC and health care more generally, understanding what care means from the perspective of care recipients, may provide LTC providers and regulators opportunities for innovative ideas and initiatives to improve care policies and procedures including ways in which care is evaluated. In addition, the Eden Alternative initiative is part of the Culture Change movement, and as this movement continues to grow in the field of LTC, research studies that compare traditional facilities with “culture change facilities” will be important and valuable for both Culture Change and LTC more generally.

Another future study could include interviews of different cohorts of male and female residents. This may address the question of whether meanings or experiences of
care change for men and women over time. One suggestion of a pilot study is to interview multiple generations within one’s family, such as great-grandfather, grandfather, father, son, and grandson, asking them questions about care. The average male resident of this sample was born in the 1920’s and grew up into very traditional families with traditional gender roles in which men of this generation were not very expressive with their emotions or very affectionate outside of the privacy of their home or bedroom. The cultural changes of gender roles have changed since then and therefore may influence how men and women of the 1940’s, the ‘60’s, etc. think about and experience care.

Cohort studies are very useful because they reflect the societal changes over time. For example, Cherlin and Walters (1981) show progress has been made in moving toward the goal of widespread support toward women’s freedom and independence, and overall gender equality. Demographic studies show how structural changes reinforce economic and educational changes, wherein those with education, work, job and family characteristics predisposing society toward egalitarian views steadily become a larger part of the population, thus, the level of gender egalitarianism will rise as well (Pampel, 2011). Pampel (2001) emphasizes the structural position argument that highlights the importance of rising female education, labor force participation and dual career families for increasing gender egalitarianism. Other demographic studies compare diverse high-income nations, which researchers found evidence of cross-national consensus in gender attitudes including similarities the liberalization of attitudes (Alwin, Braun, and Scott, 1992; Treas and Widmer, 2000). However, the pervasiveness of shifting values suggests that gender norms also develop independent of social structural position wherein men and
women in varied positions of a society come to adopt more egalitarian attitudes with social and economic development (Pampel, 2011). Societal value shifts may raise questions about why groups in different positions and with different interests adopt similar egalitarian attitudes. Inglehart and Norris (2003) argue that economic prosperity and security foster a broad cultural shift toward quality of life values and emphasize self-expression and individualism. This shift tends to erode traditional beliefs, family authority, and communal obligations and lead to changing views of women’s roles towards a more gender equality in modern society. As these studies highlight the changes of society and gender roles over time, it calls into question how will men and women respond to similar care questions.

My final addition to further the sociological scholarship on care, I also envision a future study on the globalization of care and its impact on care practices generally and specifically, LTC practices. By generally, I mean exploring how the meanings of care might differ among careworkers who come from various cultures in which the term “care” may mean something different from the United States or even Webster’s dictionary definition. Care may not even exist, like the anecdotes I shared in the introductory chapter. Global careworkers work in many of our various health care institutions including caring for our children and elderly, even though they have left their own country and sometimes their own families to care for others. The field of global careworkers brings a whole new host of research questions relevant to care as well as personal struggles these careworkers face from a cultural perspective. Many global careworkers come from countries where they value their elders and therefore, it begs multiple questions of how cultural values transfer to the delivery of care practices.
Literature in the field of transcultural nursing can provide some insight on how global careworkers from various cultures may affect care practice. For example, Boggatz and Dassen (2006) studied how Egyptian caregivers experienced their work and how they conceived its meaning. This qualitative study took place in a geriatric home in Egypt with 10 staff members. The authors found that for these caregivers, they needed to learn to get over the initial experiences of fear, disgust, and sexual taboo while performing care, and overall perceived care to be laborious and repetitious (Boggatz & Dassen, 2006). Christian values allowed female caregivers coping with experienced problems and alleviated conflicts between traditional gender roles and care of male residents. The traditional values helped to adapt to the requirements of providing care; however sexual taboos may have reduced the willingness to provide care (Boggatz & Dassen, 2006).

In conclusion, for future research there is so much more to explore, more to learn, and so much more to contribute to the fields care, sociology, gender, long-term care, aging and ageism, and institutional culture change. This research study is only the beginning – a stepping-stone to expand the care and sociological scholarship.
December 17, 2009

Dear Isabel Sanchez:

St. Paul's is pleased to offer this letter of support for the proposal entitled, "An Interrogation into the Meanings of Care: Empowering the Silenced Voices of Care Recipients" submitted by Dr. Dale Danner and Rebecca Siders of Case Western Reserve University.

St. Paul's has been a leader in finding new and better ways for serving the needs of residents and older adults of western Pennsylvania for 140 years. Currently, St. Paul's encompasses 622 acres of farmland in Greenville, PA. The Villas is a 192-bed skilled nursing facility; The Ridgewood is an aging-in-place personal care facility that offers 40 studio style apartments; The Heritage, also an aging-in-place personal care facility, offers 80 studio and 1 bedroom apartments; and The Colony offers Estate and Woodland homes as well as one-bedroom apartments. The total capacity of all areas is approximately 400 residents.

Over the past decade, we have been engaged in purposeful efforts to change the culture of our Assisted Living and Skilled Nursing communities by implementing the principles and values of The Eden Alternative, a non-profit organization dedicated to reclaiming the experience of aging and disability across America. We have made structural changes in our living accommodations, such as moving from a medical model to a social model with a sense of "homeness", as well as adopting the core concept of The Eden Alternative that teaches us to see aging not as a decline, but as a continuous stage of growth and development in human life. We strongly believe this is a powerful tool for improving the wellbeing of our residents and their caregivers.

We believe that the goals and objectives of the proposed research project are innovative in developing a conceptual framework into the meanings of care from the perspective of care recipients. Understanding what counts as care as well as what it means to those in need of care and for whom care is intended is especially relevant and important for care providers of disabled older adults, especially considering the significant increase in the older adult population over the next 25 years.

We are committed to participating in the planning activities associated with this project and eager to offer our time and resources to ensure its success.

Sincerely,

Tammy J. Landger, N.H.A.
Administrator

St. Paul Homes
335 EAST JAMESTOWN ROAD - GREENVILLE, PA 16125
PHONE (724) 588-7610

G. BRYAN OROS, N.H.A.
EXECUTIVE DIRECTOR
APPENDIX B: Informed Consent (Residents)

CONSENT FORM FOR SKILLED NURSING RESIDENTS

PROJECT TITLE: Voices From The Inside: Gender and the Meaning of Care

You are being asked to participate in a research project about the everyday experience of care received while living in an Assisted Living facility. Your participation in this study is voluntary. Please read this form and feel free to ask any questions that you may have before agreeing to participate in the project. The researchers conducting this study are from CASE WESTERN RESERVE UNIVERSITY. The Principal Investigator (hereafter PI) is Dale Dannefer, Ph.D., Professor of Sociology and the Co-Investigator is Rebecca A. Siders, M.A.

PURPOSE: The purposes of this project are: 1) to identify how care is defined and experienced by disabled elder care recipients living in long-term care settings, 2) to identify how different types of care recipients may experience care differently, and 3) to identify how quality care is measured by Assisted Living and Skilled Nursing institutions. Only the first of these requires your voluntary participation.

PROCEDURE: If you decide to participate, you will be asked to engage in a one-to-one interview with a researcher to talk about your life experiences, your health, and your experiences of care received while living in a Skilled Nursing facility. Interviews usually last 30-60 minutes and may be tape recorded with your approval. If you do not want to be recorded, the researcher may take notes throughout the interview. All responses are completely confidential and will not be shared any facility staff or anyone else except the researchers.

PROTECTED HEALTH INFORMATION (PHI): If you give permission, the research staff may use health information, such as present health history, your diagnosis, what medications you are taking, general health status, and social activities. This information may be provided by you and your medical records at the Skilled Nursing facility to determine your dependency status or identify what type of care services are needed. If you prefer we not use your health information, you are still able to participate in the project. If you give permission then change your mind, you may withdraw your authorization at any time by giving a written letter stating your wish to withdraw to the researcher. If so, the researchers will not collect any additional information about you. You may also request to see the health information used for this study. The researchers are the only people who have access to your health information and this will be treated as completely confidential, and all information will be kept in locked cabinets in the PI’s office at CASE WESTERN RESERVE UNIVERSITY.

RISKS AND BENEFITS: In this study, the only known risk is the possibility of some social discomfort that could occur during the interview. Issues may come up that could make you feel uncomfortable about expressing your experiences of care (or the lack thereof) while living in an Skilled Nursing facility. If so, you do not have to say anything. What you share with the researcher during the interview is up to you; you will not be pressed for information if you do not feel like saying anything. It is also possible that, as a participant, you will benefit through the enjoyment of sharing experiences of care with someone else as well as knowing that your contribution is contributing to science.

CONFIDENTIALITY: All records of this research will be kept private. No information will identify you in any of the documents generated from this project. All materials, such as notes and
tapes or CDs of recorded interviews, will be kept in a locked file cabinet at CASE WESTERN RESERVE UNIVERSITY. Tapes and CDs will be labeled with a non-identifying ID# which you will be assigned. A master list connecting your name with this ID # will be kept in a separate locked file cabinet in the PI’s office at CASE WESTERN RESERVE UNIVERSITY. Access to these materials will be limited to the researchers, the University review board responsible for protecting human participants, and sponsors and funding agencies. Also, all materials collected will be destroyed within three years of the end of the project.

**VOLUNTARY:** As stated at the beginning, your participation is completely voluntary. If you choose not to participate, it will not affect your current or future relations with the University or the Assisted Living facility. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

**CONTACTS AND QUESTIONS:** The researchers conducting this study is Dale Dannefer and Rebecca A. Siders. If you have any questions, you may contact Dr. Dannefer at his office phone number (216) 368-2703 or by email at dale.dannefer@case.edu, or you may contact Rebecca A. Siders at her office phone number (216) 368-0112 or by email at rebecca.siders@case.edu. If the researchers cannot be reached, or if you would like to talk to someone other than the researchers about 1) concerns regarding this study, 2) research participant rights, 3) research-related injuries, or 4) other human subjects issues, please contact CASE WESTERN RESERVE UNIVERSITY Institutional Review Board at (216) 368-6925 or send a letter to their address at 10900 Euclid Avenue, Cleveland, OH 44106.

You will be given a copy of this form for your personal records.

**STATEMENT OF CONSENT:** I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research project. Please put an X on the line if you approve tape recording the interview.

_____ YES, I consent to being tape recorded.

PRINT Name of Participant ______________________________________________________

SIGNATURE of Participant ______________________________________________________

Date: ______________________

PRINT Name of Researcher ______________________________________________________

SIGNATURE of Researcher ________________________________________ Date: __________

**AUTHORIZATION for ACCESS to PHI (Protected Health Information)**

Please SIGN here ___________________ if you are authorizing use of your PHI for the purposes of this study.

Name of Researcher: _________________________________________________________

SIGNATURE of Researcher ____________________ Date: ___________________
APPENDIX C: Informed Consent (Staff)

CONSENT FORM FOR SKILLED NURSING STAFF

PROJECT TITLE: Voices From The Inside: Gender and the Meaning of Care

You are being asked to participate in a research project about the everyday experience of care received while living in an Assisted Living facility. Your participation in this study is voluntary. Please read this form and feel free to ask any questions that you may have before agreeing to participate in the project. The researchers conducting this study are from CASE WESTERN RESERVE UNIVERSITY. The Principal Investigator (hereafter PI) is Dale Dannefer, Ph.D., Professor of Sociology and the Co-Investigator is Rebecca A. Siders, M.A.

PURPOSE: The purposes of this project are: 1) to identify how care is defined and experienced by disabled elder care recipients living in long-term care settings, 2) to identify how different types of care recipients may experience care differently, and 3) to identify how quality care is measured by Assisted Living and Skilled Nursing institutions. Only the first of these requires your voluntary participation.

PROCEDURE: If you decide to participate, you will be asked to engage in a one-to-one interview with a researcher to talk about your life experiences, your health, and your experiences of care received while living in a Skilled Nursing facility. Interviews usually last 30-60 minutes and may be tape recorded with your approval. If you do not want to be recorded, the researcher may take notes throughout the interview. All responses are completely confidential and will not be shared any facility staff or anyone else except the researchers.

PROTECTED HEALTH INFORMATION (PHI): If you give permission, the research staff may use health information, such as present health history, your diagnosis, what medications you are taking, general health status, and social activities. This information may be provided by you and your medical records at the Skilled Nursing facility to determine your dependency status or identify what type of care services are needed. If you prefer we not use your health information, you are still able to participate in the project. If you give permission then change your mind, you may withdraw your authorization at any time by giving a written letter stating your wish to withdraw to the researcher. If so, the researchers will not collect any additional information about you. You may also request to see the health information used for this study. The researchers are the only people who have access to your health information and this will be treated as completely confidential, and all information will be kept in locked cabinets in the PI’s office at CASE WESTERN RESERVE UNIVERSITY.

RISKS AND BENEFITS: In this study, the only known risk is the possibility of some social discomfort that could occur during the interview. Issues may come up that could make you feel uncomfortable about expressing your experiences of care (or the lack thereof) while living in an Skilled Nursing facility. If so, you do not have to say anything. What you share with the researcher during the interview is up to you; you will not be pressed for information if you do not feel like saying anything. It is also possible that, as a participant, you will benefit through the enjoyment of sharing experiences of care with someone else as well as knowing that your contribution is contributing to science.
CONFIDENTIALITY: All records of this research will be kept private. No information will identify you in any of the documents generated from this project. All materials, such as notes and tapes or CDs of recorded interviews, will be kept in a locked file cabinet at CASE WESTERN RESERVE UNIVERSITY. Tapes and CDs will be labeled with a non-identifying ID# which you will be assigned. A master list connecting your name with this ID # will be kept in a separate locked file cabinet in the PI’s office at CASE WESTERN RESERVE UNIVERSITY. Access to these materials will be limited to the researchers, the University review board responsible for protecting human participants, and sponsors and funding agencies. Also, all materials collected will be destroyed within three years of the end of the project.

VOLUNTARY: As stated at the beginning, your participation is completely voluntary. If you choose not to participate, it will not affect your current or future relations with the University or the Assisted Living facility. There is no penalty or loss of benefits for not participating or for discontinuing your participation.

CONTACTS AND QUESTIONS: The researchers conducting this study is Dale Dannefer and Rebecca A. Siders. If you have any questions, you may contact Dr. Dannefer at his office phone number (216) 368-2703 or by email at dale.dannefer@case.edu, or you may contact Rebecca A. Siders at her office phone number (216) 368-0112 or by email at rebecca.siders@case.edu. If the researchers cannot be reached, or if you would like to talk to someone other than the researchers about 1) concerns regarding this study, 2) research participant rights, 3) research-related injuries, or 4) other human subjects issues, please contact CASE WESTERN RESERVE UNIVERSITY Institutional Review Board at (216) 368-6925 or send a letter to their address at 10900 Euclid Avenue, Cleveland, OH 44106.

You will be given a copy of this form for your personal records.

STATEMENT OF CONSENT: I have read the above information. I have received answers to the questions I have asked. I consent to participate in this research project. Please put an X on the line if you approve tape recording the interview.

_____ YES, I consent to being tape recorded.

PRINT Name of Participant ________________________________________________________
SIGNATURE of Participant _________________________________________________________
Date: ______________________

PRINT Name of Researcher _________________________________________________________
SIGNATURE of Researcher _________________________________________________________
Date: ______________________
APPENDIX D: Elder Semi-Structured Interview Guide

These questions comprise an interview guide, and thus supply starting points for discussion of the topic questions to which they refer. Quality interview responses depend not only on these questions, but on the skillful probing and follow-up by the interviewer.

**Personal Background:**
1. I’d like to hear a little about your life. Where did you grow up? Could you tell me a little about your family?
2. How long have you lived here at ____________?
3. What were the circumstances that precipitated you moving here?

**Facility Life:**
4. How would you describe your life at ____________?
5. What are the things that you most like about living here?
6. What are the things that you most dislike about living here?

**Care:**
7. As you know from our earlier talks about this study, one thing we are especially interested in is the topic of care. I have several questions about care. First, since you’ve been here at [facility name], would you say that you receive CARE?
   • If YES – What kind of care do you receive?
   • If NO – Why not? Could you explain?
8. What exactly does CARE mean to you? Can you give me some specific examples of when you feel cared-for here?
9. Do you receive that kind of care from anyone here at [facility name]? From whom?
   [Prompt for specific names/titles/roles]
10. Can you give me some specific examples in which [Use one of the above names] provided that kind of care to you?
11. Do all of them provide the same kind of care to you? In other words, do some of them provide a different kind/type of care to you?
12. You’ve mentioned these people whom you receive care from…do you know of or witness other people who provide care to others, maybe not necessarily to you, but anyone else here, such as to other residents, staff, visitors, etc?
13. Could you tell me more about what kind of care you’ve witnessed?
14. Do you think YOU provide care to others (residents, staff, visitors) here as well?
15. Could you tell me more about what kind of care YOU provide to others? How do you know when you or others are cared-for?

**Recommendations:**
16. If you were to suggest ways to improve your life and care received while living here what do you recommend?
17. Are there any other things you’d like to talk about, that we haven’t covered?
APPENDIX E: Staff Interview Guide

These questions comprise an interview guide, and thus supply starting points for discussion of the topic questions to which they refer. Quality interview responses depend not only on these questions, but on the skillful probing and follow-up by the interviewer.

Personal Background:
18. I’d like to hear a little about your life. Where did you grow up? Could you tell me a little about your family?
19. How long have you worked here at ________________?
20. What were the circumstances that precipitated you working here?

Facility Life:
21. How would you describe your work-life at ________________?
22. What are the things that you most like about working here?
23. What are the things that you most dislike about working here?

Care:
24. As you know from our earlier talks about this study, one thing we are especially interested in is the topic of care. I have several questions about care. First, since you’ve been here at [facility name], would you say that you provide CARE?
   • If YES – What kind of care do you provide?
   • If NO – Why not? Could you explain?
25. What exactly does CARE mean to you? Can you give me some specific examples of that?
26. Do you provide that kind of care to anyone here at [facility name]? To whom? [Prompt for specific names/titles/roles]
27. Can you give me some specific examples in which [Use one of the above names] received that kind of care from you?
28. Do you feel residents provide the same kind of care to you? In other words, do some of them provide a different kind/type of care to you?
29. You’ve mentioned these people whom you provide care to…do you know of or witness other people who provide care to others, maybe not necessarily to you, but anyone else here, such as to other residents, staff, visitors, etc?
30. Could you tell me more about what kind of care you’ve witnessed?
31. Do you think YOU receive care from others (residents, staff, visitors) here as well? From whom?
32. Could you tell me more about what kind of care YOU receive from others? How do you know when YOU are cared-for?

Recommendations:
33. If you were to suggest ways to improve your work-life and/or resident’s life while living here, what do you recommend?
34. Are there any other things you’d like to talk about, that we haven’t covered?
BIBLIOGRAPHY


Dannefer, D. and Stein, P. (2000). *Systemically changing the culture of nursing homes*. Final project report to funding agency, the New York State Department of Health.


Murphy, J. W., and Longino, C. F., Jr. "What is the Justification for a Qualitative Approach to


Phillipson, C., and Walker, A. "The Case for a Critical Gerontology." In Social Gerontology:


Stein, P. and Dannefer, D. (2001). From the Top to the Bottom, From the Bottom to the Top. Final project report to van Ameringen Foundation.


Veatch, R.M. Medical Ethics, Mississauga, ON: Jones and Barlett Publishers, 1997.


172