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A Labor of Love: Women's Perspectives on Gender and Identity in Informal Caregiving

By

Kirby Hurd

A Thesis Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master in Science

In

Human Services Planning and Administration

Minnesota State University, Mankato

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A Labor of Love: Women's Perspectives on Gender and Identity in Informal Caregiving

Kirby Hurd

This thesis has been examined and approved by the following members of the student's committee.

Dr. Emily Boyd

Dr. Barbara Keating

Dr. Judith Luebke

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“No one achieves anything alone.”

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Abstract

The elderly population (adults 65 and over) is larger than at any time in history, thanks to improved access to healthcare, advances in medical technology, and health services focused on addressing the needs of aging adults. However, support for this growing population remains insufficient; the costs of in-home and residential care are high, and consequently, family members often become providers of informal, unpaid care. Presently, there is inadequate literature regarding the academic study of family members providing informal caregiving, especially from a perspective that emphasizes sociological principles and theories. Existing studies of the family caregiver phenomenon show that middle-aged adult daughters comprise the vast majority of those physically caring for an aging parent(s). To better understand this social fact, sociologists can examine the role of the informal caregiver by discussing its relationship to gender and identity. Using a qualitative lens, this study explored the experiences of 12 women who provide informal caregiving services for an aging parent. Participants were recruited using online advertising, purposive sampling, and snowball sampling methods. A semi-structured interview format proved fruitful for gaining insight into the experiences of women caregivers; Charmaz's model of grounded theory (2010) was utilized to structure and analyze findings. The compiled data suggested two pervasive themes: 1) that caregiving is a gendered experience, particularly in the kinds of activities caregivers provide and in the expectations a caregiver receives from her family and herself, and 2) caregiving necessitates a great deal of identity work, particularly through the management of many social roles, role reversal of parent and child, and the degree to which a caregiver accepts or rejects the caregiving role and how that impacts the self-actualization of the caregiver role, especially as determined by positive or negative experiences with caregiving and with the care recipient.

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A Labor of Love: Women's Perspectives on Gender and Identity in Informal Caregiving

Family caregivers are the backbone of long-term care, with over 45 million Americans providing an average of 21 hours per week of unpaid care to impaired older adults. (National Alliance for Caregiving [NAC] & AARP 2009).

Globally, the population of adults aged 65 and over is larger than at any time in history (Pope, Kolomer, and Glass 2012). Advances in medical technology combined with increased access to and availability of healthcare providers, prescription medications, and specialized health services have resulted in extended lifespans, and physically vulnerable and disabled people are able to live longer than in every preceding generation. Despite greater awareness of healthcare needs for the elderly and subsequent longer life expectancies, support for this population remains inadequate. Consequently, decisions regarding the burden of caring for the elderly—who will pay for care, and who will provide it--often fall to the family.

It is a commonly-held belief that in contemporary society, older adults are abandoned by their families and left to the care of nonrelatives in institutional settings. However, this is not the case; changes in the composition of population demographics show that despite an increasing number of people aged 65 and older and a simultaneous decrease in child birth, the number of people caring for an aging parent in an informal setting is on the rise (Paoletti 1999; O'Connor 2007). Studies suggest that in the USA, families provide up to 80 percent of all in-home care to elderly parents, and therefore are the primary players in informal caregiving (Lee 1999; Neufeld et al. 2007; Pope et al. 2012).

What is caregiving? In common discourse and casual language, it is often unclear what is meant by the term, especially because for a long time, the work done by caregivers was largely unrecognized and taken for granted (Lee 1999). The “caregiver” was originally someone who provided end-of-life care at home for a terminally-ill parent or child when treatment or hospitalization was unaffordable or death was unavoidable; the caregiver was merely providing the sick person company and physical comfort in the dying process (Crooks 2001). With the advent of immunizations as preventative measures, advanced medical treatment for congenital disorders and terminal cases, and outpatient-based health management, the role of the caregiver has changed dramatically. In a modern context, caregiving is the term given to the act of providing unpaid support and assistance of varying kinds—physical, emotional, and financial—to family members and others with differing degrees of need. Modern caregivers are typically capable of providing a wide range of services to care recipients—caregivers often cook and clean for care recipients, assist them in their daily living activities (such as using the bathroom, showering, and eating), and accompany them to appointments. They are expected, at an increasing rate, to be capable of administering relatively complex at-home medical treatments like intravenous medications, catheters, and oxygen equipment (Turner and Findlay 2012). Lee summarizes this, saying “Caregiving covers a huge range of responsibilities and commitments, from occasional assistance with transport or shopping through to 24-hour-a-day invalid care, and thus average levels of care hide a huge degree of variability in commitment and responsibility” (1999: 31). The time commitment associated with this type of care is not insignificant, nor is the financial burden and emotional toll it puts on providers of care (O’Connor 2007; Turner and Findlay 2012).

Modern caregiving is a holistic, time-consuming, and unrecognized aspect of social reality (Paoletti 1999).

In this thesis, I explore the caregiving experience from the perspectives of 12 women who provide informal caregiving services for an aging parent, or have done so in the past, with a special attention to the ways that gender and identity shape their caregiving experiences. I find that women who provide informal caregiving services for an aging parent feel that their gender impacts the kinds of caregiving activities they perform and the expectations they have of themselves and from their families, and also that women caregivers engage in identity work through management of many roles, role reversal between parent and child, and self-actualization of the caregiver role.

First, I discuss some theoretical considerations that help to situate the study within a sociological framework. Next, I review the academic literature regarding gender and identity impacts on women caregivers. Then, I explain the specific research questions and the research methodology. These all lead to the presentation of the findings through analysis of collected data. Finally, I'll offer some concluding comments and suggestions for further research.

THEORETICAL ASSUMPTIONS

Research consistently indicates that informal caregiving is a field dominated by women; estimates show that women comprise nearly three-quarters of the number of informal caregivers (Lee 1999; Paoletti 1999; Navaie-Waliser, Spriggs, and Feldman 2002; Kramer 2005; Pope et al. 2012; Turner and Findlay 2012). In order to understand the complex nature of caregiving—how it has emerged as a field of (typically) unpaid work done primarily by women, and how it consequently impacts their lives and personhoods—we must first position the issue theoretically.

The Social Construction of Caregiving

To examine this issue from a sociological perspective, I am asserting that caregiving is a socially-constructed reality that we can better understand through the examination of social phenomena that are both real and possess meaningful yet intangible characteristics (Berger and Luckmann 1966). By socially-constructed, I mean that caregiving is a subject grounded in and shaped by social interactions, processes, and institutions. Based upon these assumptions, one could argue that the sociological lens best-suited to examining caregiving as a social process that occurs within a socially-constructed reality is symbolic interactionism. Symbolic interactionism suggests that individuals create, negotiate, and sustain the meanings of social objects—people, actions, and things—through interactions with others in their social worlds (Crooks 2001; Ritzer 2011). Thus, these meanings are highly fluid, variable, and contextually-situated. To understand caregiving, then, we must first identify and explore the context in which it

occurs, the interactions that are involved in caregiving, and the meanings caregivers and recipients of care create through their interactions.

Within the extensive field of symbolic interactionism lies standpoint theory, which broadly suggests that the individual members within a specific social context occupy a certain standpoint that gives them a unique perspective into a social experience; this “insider knowledge” may offer a deeper insight or diverse perspective than those looking at the same experience through the lens of the dominant discourse (Harding 2003). Furthermore, standpoint theory suggests that research should start from the experiences of those who have traditionally been left out of the production of what we accept as general knowledge in order to add to, and expand upon, what we consider to be “known” beliefs and understandings that have been taken for granted within a given context (Ritzer 2011). The role of informal caregiver is fundamentally different than that of professional caregiver, and consequently, the accounts given by those individuals in both settings are likely to differ greatly. Professional caregiving, unlike most informal caregiving, is paid work that requires formal training and education, and is therefore more often the point of view that is accepted and valued in discourse and scholarship regarding the caregiving experience. Examining the caregiving role through the less-validated and underprivileged viewpoints of informal caregivers would add to the body of knowledge about the caregiving experience, and would likely offer additional insights beyond those of the prevailing and governing opinions regarding caregiving. As the primary players in this social context, women caregivers can provide accounts that contribute to these understandings and thus to the greater body of knowledge about

caregiving as a social experience, validating the use of standpoint theory as a guiding model of research.

REVIEW OF THE LITERATURE

Gender in Informal Caregiving

To understand the complex nature of the caregiving experience, it is necessary to examine gender as a sociological phenomenon. A discussion of what gender *is* must also include the distinction of what it is *not*; it's common to hear people mistakenly use sex and gender interchangeably in everyday conversation. Sex refers to physiological differences between males and females that manifest in sex characteristics, such as the reproductive system and sexual organs (what makes a person biologically a female or male), while gender is the presentation of the behaviors, attitudes, and roles that we associate socially with femininity and masculinity (Butler 1998). In this paper, I'll focus solely on gender.

Social scientists understand gender to be a primary social force that determines a significant part of who we are and is acquired only through our interactions in the social world; by its very definition, gender is learned and practiced (Wood 2005). The feminist philosopher Judith Butler suggests that gender is not only a product of social interaction, but is best conceptualized as a performative accomplishment within a given context, stating that "Gender is in no way a stable identity or locus of agency from which various acts proceed; rather, it is an identity tenuously constituted in time—an identity instituted through a *stylized repetition of acts*" (1998: 519). Using this definition of gender as performance means that descriptions of women as "feminine" suggest not who or what women inherently *are*, but rather particular outcomes or effects of what women *do* (West and Zimmerman 1987; Cameron 1997). Butler is not the first to posit that gender is

socially constructed rather than intuitive; in Simone de Beauvoir's seminal work *The Second Sex*, she famously stated that "one is not born, but rather *becomes* a woman" (1949, emphasis added).

If we adopt the model of gender as performance, we acknowledge that gender is not something that you achieve once and for all early in life, but is a series of both intentional and subconscious decisions and actions that shape and reinforce social norms. Thus, the way we "do" gender is highly reflexive—we are constructing social norms through our various gender performances while simultaneously being formed by the very norms we construct, maintaining gendered activities, expectations, and roles.

Caregiving activities appear to be gendered (Navaie-Waliser et al. 2002). When I say that caregiving activities appear to be gendered, I mean that women caregivers report feeling that certain aspects of their caregiving responsibilities take precedence over others, and this hierarchy seems to be structured around "traditional" gender roles and expectations. Chappell, Dujela, and Smith (2015) agree, asserting that a person's gender impacts two major aspects of her caregiving experience: the kinds of caregiving activities she performs, and the expectations placed upon her by her family. These activities tend to be centered on the needs of daily living—meal preparation and delivery, and personal hygiene and grooming, both of which are often the responsibilities of women due to traditional gender norms (Lee 2009). According to some scholars, caring for the physical body of an ill or vulnerable person has traditionally been considered the work and responsibility of women (Navaie-Waliser et al. 2002; Pope et al. 2012; Chappell et al. 2015). A particularly salient example is described by MacKinnon (2009) as "body work," or the care of the physical body of the care recipient in assistance of activities of

daily living (the healthy body) as well as caring for the ill (unhealthy) body. Additional studies (Navaie-Waliser et al. 2002; Chappell et al. 2015) have found that women caregivers regularly assist with relatively complex tasks involving the physical body that in the past have been sequestered to institutional and hospital (professional) care, such as performing wound and dressing changes, administering and coordinating prescription and non-prescription medications, and aiding with the use of medical equipment. This work, while highly technical and precarious, is often performed with little or no direct training and almost always with no financial compensation, contributing further to the unpaid work done by women (Kramer 2005; Pope et al. 2012).

Scholars have posited that traditional gender roles and family structures encourage women to be responsible for particular tasks, many of which are associated with the caretaking of both younger and older relatives; thus, many expectations of women to be the “natural” providers of care originate in the actions and exchanges between members of a family (Navaie-Waliser et al. 2002; MacKinnon 2009). Women are often interpersonally characterized as having an innate “sensitivity to others” in their social worlds, and thus the responsibilities of caring for others is seen as reflective of both gender normativity and moral imperatives (Pope et al. 2012). Therefore, while the number of women working both outside and inside the home is higher than ever before (Turner and Findlay 2012), social pressure for women to attend to the needs of their families first (often at the expense of maintaining their personal and professional lives) persists (Lee 2009). Consequently, female family members are expected to deliver, often free of charge, the type of professional care that would otherwise function as paid

employment, out of duty and pressure to perform expected social roles (Kramer 2005; Lee 2009).

As long as this discrepancy and radical imbalance exists and produces inequalities and disadvantages for women, gender must be discussed as a fundamental aspect of the caregiving experience.

Identity, Roles and the Self

Women taking care of their aging parents in addition to balancing the challenges presented by their personal and professional lives engage in identity work (Coeling, Biordi, and Theis 2003; Miller et al. 2008; Ugalde, Krishnasarny, and Schofield 2012). By identity work, I am referring to the active process of creating and managing one's identity through constant development and evaluation of the self within a given social context. The identity work in which women caregivers actively engage arises alongside of and impacts the other roles they perform in their daily lives, and may result in dramatic role reversals as the relationships between caregivers and recipients of care inherently change.

More than half of women providing any kind of informal caregiving service are caring for their own parent or parents or their spouse or partner's parent or parents (Navaie-Waliser et al. 2002; Coon 2012; Turner and Findlay 2012). Being engaged in caregiving leads to challenges in embodying the traditional adult-child and adult-parent roles; these challenges can result in role changes and negotiations, impacting the identities of the adult parent and the adult child acting as caregiver (Coeling et al. 2003;

O'Connor 2007; Miller et al. 2008; Ugalde et al. 2012). Adult women who have previously conceived of themselves in the child role often find themselves renegotiating this role as the parent(s) they care for are less physically and mentally capable and therefore become more childlike in their needs and actions. Adult children assume a more parental role as their adult parents decompensate physically and mentally, bringing them closer to childlike states of limited functioning and increasing dependency on others; this role reversal proves difficult for both the women caregivers and their adult parents (Miller et al. 2008).

Additionally, the degree to which a woman has self-actualized the role of caregiver impacts the way she conceives of herself, her identity, and personhood. In this context, I use the term self-actualization to represent the connection between one's actions in the social world and the way a person conceives of herself in relationship to these actions. While many women caregivers readily acknowledge that they participate in caregiving activities, not all conceive of themselves as caregivers by title. Some of the literature suggests that women struggle to define their caregiving role in discrete terms due to significant overlap between activities they do as part of their everyday lives and those they do as part of their care provision (Kramer 2005; O'Connor 2007; Ugalde et al. 2012). Furthermore, some caregivers appear to have difficulty maintaining a sense of self due to the strong connection they feel to their recipient(s) of care (Ugalde et al. 2012). This difficulty can be intensified when the demands of caregiving require dramatic shifts in the caregiver's life, such as moving to a new home, deferring promotions, or even quitting a job, in order to be closer to or provide more or better care to the recipient (Coeling et al 2003; Pope et al. 2012).

MacKinnon succinctly emphasizes this point, saying, “When family members are called upon to provide care, they are often required to take on new roles in addition to those previously held...when these new roles are assumed, they are likely to affect the power dynamics of the relationship” (2009: 506). This is reflective of a major event that occurs within identity work—the merger between a role and a person, as discussed by Turner (1978). As he states, “By each individual, some roles are put on and taken off like clothing without lasting personal effect...other roles are difficult to put aside when a situation is changed and continue to color the way in which many of the individual’s roles are performed” (Turner 1978: 1). Thus, the role of a woman as caregiver often becomes so central to her self-conception that it forces a transformation and subsequent restructuring of the adult-child and adult-parent roles, especially when the context changes. As O’Connor states, “Positioning one’s self as a caregiver takes place when one develops a new framework, or story-line, for understanding and constructing meaning about one’s actions; until one begins to position one’s self as a caregiver it is difficult to see the work one is doing...this is not a simple process...the story-line that is used by family members to position themselves as a caregiver may result in inherent tensions between their needs and the preservation of the unique personhood of the family member for whom they are caring” (2007:173). Finding a balance between the mother’s need for both autonomy and connection through their communication was fundamental to the success of the caregiving relationship. The tendency for both parties to be attentive and responsive to the other’s needs and a desire to minimize conflict and tension were identified as contributing factors to a positive outcome; the ability for daughters to help

preserve their mothers' autonomy predicted a more constructive and positive relationship (MacKinnon 2009: 505).

In the same way that positive attitudes toward caregiving can result in self-actualization for caregivers, caregivers who feel warmly toward their care recipient(s) are more likely to feel positively about their caregiving experiences overall, while those who report more adverse feelings toward their care recipient(s) detail more feelings of stress or strain resulting from caregiving (Fudge, Neufeld, and Harrison 1997; Neufeld and Harrison 2003; Neufeld et al. 2007). This suggests that the more closely she identifies with her actions as a caregiver, and the more positive the relationship with the care recipient, the more a woman involved in caregiving has self-actualized this role, reinforcing the aspect of caregiving that contributes to her personhood (Neufeld and Harrison 2003, O'Connor 2007, Miller et al. 2008).). It seems that the more positively a woman feels about her caregiving experiences, the more likely she is to embrace the role or title of caregiver.

RESEARCH QUESTIONS AND METHODOLOGICAL PROPOSITIONS

Situating the Research Questions

My initial interest in women caregivers came from an informal discussion I had with customers at my job. On a regular basis, a group of six women in a book club regularly patronize the small business at which I work, and they are friendly with me and my coworkers. In a casual conversation, I discovered that three of the six women in the group had been involved in some aspect of caring for an aging parent, either currently or in the past. This surprising fact—half had cared for a parent in an informal setting, and in addition to working outside their homes and taking care of their families, no less—made me wonder if this particular small group was in any way representative of a larger population of women. This simple question built the foundation for my interest and research into this topic.

After reading just a bit into the topic, I learned that caregiving is a field overwhelmingly populated by women—women comprise the vast majority of both those providing and receiving care. I was curious how this came to be a seemingly normative reality, and what this meant about the caregiving experience. Primarily, does a person's gender affect the types of caregiving activities she performs, and if so, what caregiving activities are typically performed by women, and why? Also, what kinds of expectations do caregivers experience as a result of these social forces, and who or what imposes and upholds these expectations? I also noticed that women caregivers engage in a lot of role juggling—daughter, sister, spouse, mother, and worker are just a few of the proverbial hats women caregivers wear in addition to being caregivers. I wondered how these

constant role changes affect women engaged in caregiving. Finally, I was interested in learning about the ways in which the relationship with the care recipient impacts how the caregiver feels about her caregiving experience, and its impact on her personhood and self-conceptions—does a more positive relationship with the care recipient necessarily result in better feelings about caregiving generally for the caregiver? In what circumstances does the relationship with the care recipient produce a more stressful or negative situation for the caregiver? These are the questions that guide my research.

An Application of Grounded Theory

Grounded theory guides the methodology in this paper, particularly the approaches proposed by Charmaz (2010), Glaser and Strauss (1967), and Crooks (2001). In the case of qualitative research, grounded theory is especially advantageous—it allows the researcher to stay intimately connected to the data as theory develops from the analysis of information, instead of the reverse process (Charmaz 2010). Crooks (2001) says that an especially notable and significant aspect of grounded theory application in research about women’s issues is that it gives voice to the thoughts and actions of women from a “woman-centered perspective”—women’s stories are being told from their own points of view and in their own words. The grounded theory approach allows themes and topics to emerge organically and to initiate directly from respondents themselves. As themes emerge, they will be explored in subsequent interviews; themes may carry over from one interview to the next, establishing patterns as well as nuances. Thus, data

collection and analysis occur simultaneously and are intrinsically connected, a strength of this kind of methodology (Glaser and Strauss 1967).

Methodological Procedures

To further examine and understand caregiving as a social phenomenon, I conducted semi-structured interviews with qualifying participants, who were recruited using three methods (see appendix D for semi-structured interview guide). The first was open advertising using a “Call for Volunteer Participants” flyer posted on a website (www.craigslist.com, see appendix C for “Call for Volunteer Participants” flyer). Under the “Volunteers” section of the website, I asked for study participants; if an interested respondent met the listed criteria for the study, she was encouraged to contact me via email or phone. The second method was purposive sampling. Through routine interactions with people in my daily environment (at my jobs, at school, in my recreational time), I announced my goal of obtaining interviews with adult women taking care of their aging parent(s) with the hope of finding participants. Individuals who expressed interest in participation and who qualified per the study criteria were invited for an interview. Some interactions and interviews revealed an additional potential interview (someone “knew of” another woman who met the study criteria); subsequently, my contact information was passed along and the third party was invited to contact me if she wished to participate, a variation of snowball sampling, the third research method.

To best accommodate possible study participants, I planned to conduct interviews in person and over the phone if necessary. When participants were able to meet in person,

coffee shops, libraries, public locations, and their homes as well as mine were utilized as locations for interviews. Interested and qualified candidates who were able to meet in person chose the dates, times, and locations for the meetings. When a candidate expressed interest in participation and qualified for the study but was unable to meet in person (typically due to physical distance constraints), a phone interview was conducted using the same set of semi-structured interview questions.

Ethical Concerns

Prior to the start of each interview, I reviewed the informed consent form (see appendix B for the Informed Consent Form) with the participant by reading its content aloud and asking the participant if she agreed to its terms. If she confirmed her consent, I obtained the printed name and signature of the participant, as well as the date. The participant got a copy of the same informed consent form for her own records and purposes. When physical distance required the interview take place over the phone, I reviewed the informed consent form in the same manner—by reading it aloud and asking for confirmation of its terms—to obtain verbal consent; after the interview had taken place, I mailed a copy of the informed consent form to the participant to sign, date, and return, along with a self-addressed stamped envelope and a copy of the informed consent form for her to keep as well.

As discussed in the informed consent form, harm to participants in this study should be minimal; any risks to participants would be psychological and emotional, as there is always the possibility of discomfort arising from sharing personal and sensitive

information. I ensured risks were minimized by reminding the participants that their participation was entirely voluntary, and that they could stop the course of the interview at any time should it become uncomfortable or distressing for them.

At the conclusion of each interview, I thanked the participant for sharing her story, and turned off the recorder. Each participant was given the opportunity to ask any questions pertinent to the interview, the project, and my intended use of the data. Most participants continued to talk with me for several minutes; quite a few participants mentioned that it was helpful to continue to chat in a casual manner after the “formal” questions to emotionally decompress.¹

Per the terms of the informed consent form, all consenting participants agreed to the use of a voice recorder for purposes of transcription of; those interviews that were conducted over the phone were recorded by using the speakerphone setting (with the participant’s permission, and assurance of privacy) and the voice recorder nearby. To ensure the confidentiality of participants and their responses, all transcription was performed immediately following the interviews, and all audio recordings were deleted after the transcription process was completed. Interview participants were assigned a pseudonym from the first stage of the interview process, so that the only location of a participant’s real name was on the informed consent form. All names used in the analysis section of this paper reflect those pseudonyms; any similarities between real names and characteristics of individuals are coincidental and unintentional. All materials—documentation, informed consent forms, identifying information of respondents, memos,

¹ After the initial conclusion of one interview, a participant asked me to turn the recorder back on, as she had remembered an additional story that she wanted to share; this provided about 7 more minutes of interview length. Additionally, one participant contacted me via email to share further details to an interview question she wanted to answer, but didn’t have the exact specifics at the time of the interview.

and the recorder—were secured in a locked storage container when not being used for analysis purposes. Each respondent was sent a thank-you note immediately following the interview.

Interview Outcomes

Eight interviews were held in person, and four interviews were conducted over the phone. The duration of the interviews depended on the depth of answers to the interview questions; additional or follow-up questions were asked as seen fit to gain greater insight into or clarification of a particular phenomenon or example, as in a typical semi-structured interview format.² Interview lengths varied; the shortest interview lasted 1 hour and 6 minutes, and the longest was 3 hours and 22 minutes; the average length was around 2 hours and 15 minutes (see appendix E for interview lengths). In-person interviews were almost always significantly longer than phone interviews, and thus proved to be the preferred method for obtaining the most information from the respondent. In most cases, actual interview times far exceeded the expected interview length of 45-90 minutes; however, this caused no problems for participants, who were given the freedom to answer questions in as little or as much depth as they preferred, and were encouraged to stop at any time for any reason, with no questions asked. Many respondents expressed surprised at how long the interview had lasted, and often remarked

² For example, one of the questions I asked in all interviews was ‘Can you take me through a typical day in your life?’ While a seemingly broad and ambiguous question with a possibility of potentially endless answers, most participants focused on their performance of only a few and sometimes only one role. In these cases, I would probe with further questions to obtain more information. This point is further discussed in the analysis section on women caregiver identity work through role management, in which I posit that women caregivers tend to minimize the amount of work they do and the many roles they perform in addition to their caregiving roles, both out of gender norm expectations to be self-effacing and modest and in some cases to distance themselves from the caregiver role.

they'd had more to say than they'd originally anticipated. This was a welcome surprise for me as the researcher, as well, because I was given a wealth of information through their extensive and insightful responses to my questions.

Interviews were conducted between September 22, 2014, and July 26, 2016 (see appendix E for the interview schedule). Over this time period, I conducted 12 interviews; the content of these interviews formed the analysis section of this paper. All respondents self-identified as women and described themselves using feminine pronouns, and were between 51 and 70 years of age. 10 women self-identified as heterosexual, and 2 women self-identified as homosexual. Of the 12 participants, 7 women were married, 4 women were in long-term relationships but not married, and 1 woman was single. 9 of the 12 participants had children. 10 participants identified as White or Caucasian, 1 identified as Asian-American, and 1 identified as European-American. All were employed or had been employed outside of the home at some point during their caregiving experiences (see appendix F for respondent statistics). Respondents represented three states in the upper Midwest United States.

Interviews were analyzed for content through line-by-line and focused coding methods. Using information obtained from the coding processes, I composed extensive comparative memos to establish themes and patterns in the data. These memos structured the final presentation of the findings.

The analysis of the data is organized into two sections that explore and answer my proposed research questions, and are as follows: *Caregiving as a Gendered Experience:*

Activities and Expectations, and Identity Work in Caregiving: Role Management, Role Reversal, and Self-Actualization.

ANALYSIS OF THE DATA

Caregiving as a Gendered Experience: Activities and Expectations

The assumption that women are available to care for family members, while men are only available if careers and personal aspirations permit, means that the resultant restriction of women's opportunities is positioned as natural and unalterable. (Lee 1999: 28)

The findings of this study suggest that a person's gender impacts two major aspects of her caregiving experience: 1) the kinds of caregiving activities she performs, especially in meal planning and preparation and in personal hygiene, grooming and health needs, and 2) the expectations placed on her by her family and corresponding role of the caregiver in relationship to her siblings, parent(s), and self.

Caregiving Activities as Gendered: Meals, Food and Nutrition

The work of preparing meals is disproportionately performed by women. Women have been and are expected to plan meals, go shopping for any necessary ingredients or items, bring groceries home and store them properly and functionally in the home, prepare meals, and serve meals (with great efficiency and aesthetic talent)—a multi-step process that takes time, money, effort, and energy. To be a particularly “good” cook is an honorable trait among groups of women and families, and is used often in common discourse to describe a woman; the title of “best” cook of a particularly popular meal or recipe is highly coveted and respected. Mothers are expected to teach their daughters to prepare “special” foods—family favorites, traditional holiday meals, and family recipes

that have been passed down through generations. Women who lack either skill or interest in cooking have been considered undesirable as spouses and mothers, and are often socially diminished by their families, peers, and the media through teasing and chastisement. Therefore, we understand the preparation and serving of meals, and a concern with substantive and balanced nutrition, to be correlated with femininity and the experience of being a woman in social systems across most cultures, religions, and ethnic groups throughout history to the modern era.

When asked about the single most important caregiving activity they perform for their care recipients, every respondent answered that meal preparation and cooking took primary concern. As previously discussed, cooking is an activity primarily performed by women, so this is not a revelation; however, it is an important point for both its implications regarding gender expectations and its centrality in the caregiving experience. Because they saw meal preparation and delivery as the most important function they performed as caregivers, it served as the fundamental activity of caregiving around which all other caregiving activities were centered: meals came first, and all other activities came after. Provision of meals, frequency of providing meals, and quality and quantity of food they provided were all major concerns for respondents. Many respondents discussed the ways in which they planned their work days, their free time, and even their vacations around meals for their care recipients.

Caregivers often provide meals for their care recipients, whether they are cooking the meals in person, bringing already-prepared food to the care recipient's home, or taking the care recipient out to eat. This is no small task, even for those who find cooking pleasurable; between meal planning, shopping for groceries, cooking, and presenting

food at her own home or her care recipient's home, a caregiver may spend hours engaged in meal preparation and delivery. For some caregivers, the hours are weekly; for most, they are daily.

Cindy, a single woman in her early 60s, visits her mother every night, and their evening routine begins with an elaborate dinner together.

I work until about 4. I love cooking and making new food, and to my mom's credit, she is always happy to try something new or weird (laughs). If I don't have everything I need to make dinner, I'll stop by the grocery store on my way home, otherwise I go straight there. It usually takes me about an hour, maybe two, to make dinner. We eat a lot and have a few cocktails too (laughs). Then I clean the dishes and we talk about the news or something, and then we watch a TV show together. Lately it's been reruns like *Mary Tyler Moore*, things like that... we love *The Golden Girls* (laughs). She thinks streaming shows is the most amazing thing! (laughs) When we get bored, we play cards. Then I help her get ready for bed, and she goes to bed and I leave. We do that every night, for over seven years, since my dad passed.

Cindy is somewhat unique to the study sample in that she leads a very independent lifestyle—she is unmarried and works for herself—but this does not negate the considerable amount of time she spends caring for her mother on a daily basis, or the emotional and physical significance of their shared meals over the better part of a decade.

Alice sees her mother nearly every day and makes sure that between her and her sister, someone is consistently bringing food to their mother:

I go over just about every day and my sister as well, or we, ya know, tag team, she'll bring food or I'll bring food, you know, she works on the yard, I work on the house. Like yesterday, for example... I went to the dump... came home, got some things together, went to my mom's, made her lunch, took her out... did some errands with her, and then went to work at 4. I do that just about every day.

Alice shows us that providing meals is often a major part of the daily routine of caregiving for a parent, and usually one task of a list of services provided by caregivers.

Joanne, too, carried the burden of being responsible for her mother's meals, at least part of the time:

My dad would get caregivers in the morning, but my weeknights and my weekends were my responsibility to, you know, check and see that [my mother] ate, check and see that she was gonna have something for dinner. I basically couldn't work late hours unless I scheduled it way ahead of time, and I wasn't good at doing that.

Joanne was therefore accountable for planning ahead to ensure that her mother had a daily evening meal, and was also expected to schedule her hours and her own needs around making dinner for her mother each night.

Several respondents discussed that while they typically don't mind or even enjoy some degree of cooking, meal preparation that arises out of caregiving isn't the simplest or most fulfilling—it often requires extra attention to ingredients that accommodate stricter diets and are easier for the care recipient to ingest and process in the body.

Jackie discusses the special meals she has to prepare for her mother:

Because she's diabetic and has heart disease, we have to watch how much she gets of everything—sugar, salt, fat, that kind of stuff. She's lost a lot of weight since she got sicker and can't make food for herself, which I guess is good (laughs) but somebody has to pick up that slack and it's me and my sister 'cause my dad doesn't cook. If it were up to them, they'd just keep eating junk and probably would be even sicker than now. So I'm careful with what I put in things and kinda cater recipes to fit her diet.

Without complaining, Jackie acknowledges the extra thought she must put into meal preparation as a noteworthy part of her caregiving work, as well as the point that if she wasn't putting in the extra effort to ensure healthy meal delivery, no one would.

Lisa visits her mother nearly every day and meal preparation and cooking are a large part of her everyday caregiving experiences:

I make lunch and usually dinner for her. I like to make a lot of something at a time so she can have the leftovers the next day in case I can't be there. Soup or casserole or something, sometimes a big pot of mashed potatoes (laughs). She really likes if it's something sweet, like a dessert, apple pie or muffins or something (laughs). I'll put stuff in containers so she can just heat it up herself pretty easy, or just eat it cold. She's not too picky.

Here we see that Lisa, too, plans meals ahead, and even makes special accommodations to ensure that her mother can easily access food in the case of her absence.

Celeste makes a similar point, discussing how she planned her mother's meals ahead of time when she and her family were going to be on vacation:

I made a couple of (my mother's) favorite things that she could warm up in the microwave in her apartment so I knew she would have food to eat while we were gone. I showed her how to heat each bowl and for how long so she knew what to do every time...it was good to not worry about her and what she was eating while we were gone...to at least not worry about even just that.

We see that for Celeste, it was important to have the peace of mind that her mother would have access to food while she and her family were gone, and also for the food she made ahead of time to be familiar and special for her mother, providing an extra layer of comfort and security in Celeste's absence. This is a poignant example of the mental toll

caregiving takes; worrying about food availability was even the least of Celeste's concerns in planning for her mother during her absence.

A few respondents mentioned that they worried that without meal assistance, their care recipients would simply choose foods that were convenient or tasty but were not necessarily well-balanced or nutritious, and that providing more substantial and well-rounded meals was an important part of their caregiving experiences. Monica was concerned about the lack of nutrition her mother had been receiving in her previous placement at a nursing home:

I'm after her to eat better. She would eat candies and cookies all day long, and an egg once in a while and a slice of bread and cheese, but...ya know...and she survived on that forever, but truthfully, um, that was one of my main problems or concerns with her living at this assisted living place. She had to pay a monthly fee for the apartment...and there was a five or six hundred dollar food bill that she had to pay, whether she used it or not. So she used that to invite all her friends, so she'd go two, three times a month or maybe more, with a bunch of friends, and eat and use up her money that way. Which meant that she didn't use her money for herself to go eat there, with the result that she would buy...uh...yogurt and juices and...an occasional something, cheese, cookies, booze.

Without her influence, Monica worried that her mother wouldn't be getting the proper meals or making the best choices about her health and nutrition. By being highly involved in food preparation for her care recipient, Monica could have a sense of fulfillment knowing her mother was eating regularly, and consuming healthier foods.

Like Monica, Jillian recognized a sort of importance in not only providing food, but healthy food in particular; she expressed a sense of satisfaction at being able to provide what she perceived to be more nutritionally-sound food for her mother:

I just put a plate of food in front of her and she eats it, you know? It's that simple. And it has been more work for me. It isn't that I didn't cook for [my husband] but there would be times I'd say, you know, do it yourself (laughing). And not that I couldn't say that to my mother, but I don't want to, because I want to make sure that she gets good food, healthy stuff. Vegetables and so on, meat and some cheese, and some fish.

This exemplifies that caregivers care not only about providing food for their care recipients, but that the food is substantive and nutritionally balanced. As adults age, their metabolisms slow, their appetites decrease, but their needs for healthy and well-rounded meals stay the same, and many caregivers feel strongly about providing nutritious food, and plenty of it.

Celeste echoes this point, stating that:

One thing I did for my mom all the time was to give her a lot of food, make sure she was eating enough, and good stuff, because she didn't like to cook and didn't think it was important for her to eat so much at the end. But I knew it was something she needed so it was just something I did.

Celeste shows us how caregivers not only acknowledge their care recipient's need for "good" or healthy food but the general need to eat regularly, a notion that many of us take for granted but is not as common sense for some, especially for care recipients who have memory loss, dementia, and other ailments that affect recall, or conditions and medical interventions that may decrease appetite.

A recurring theme throughout Joanne's interview regarding food and cooking was remembering her mother as having been a good cook, and that her Alzheimer's kept her from being able to make even something simple much less put together elaborate meals.

This kept Joanne's focus on being sure her mom was able to have access to something that had previously been a non-issue in terms of health/thriving:

She had quit cooking, she used to be a great cook...mentally, she just can't do it anymore. She was a great cook, and she, um...people with Alzheimer's, they can't organize their thoughts enough to do something like put together a sandwich, so she just couldn't do these tasks that were second nature to her.

Thus, the importance of her mother having access to food was important to Joanne not only because of her mother's health needs, but because her mother had placed a lot of value on good food. Her mother had formerly had the coveted title of being a good cook, and in the loss of that identity, Joanne helps to pick up the pieces and help "repair" some of that broken or lost identity.

Heather expressed a similar point, saying:

My mom was such an amazing cook. She made everyone's favorite thing, like, ya know, my son's favorite cookies were Grandma's cookies, and that made her feel really good, ya know, so I try to make her old things to make her happy and keep the family favorites going. There's a lot of pride there, even if she won't admit it.

Again, we see that helping a care recipient to retain a sense of identity is significant for caregivers; Heather shows us that it was important to her as a caregiver to maintain the traditions established by her mother, and that she recognized the value of these traditions for both her mother and her family.

Caregiving Activities as Gendered: Hygiene, Grooming, and Health

A second type of caregiving activity that seems to take precedence over others and aligns with traditional gender roles is assistance with personal hygiene, grooming, and physical health needs. Historically, the work of maintaining clean bodies, orderly clothes, and proper hygiene within a family system has disproportionately fallen to women; in contemporary times, it is typically performed in addition to the daily demands of work outside of the home, and is almost always unpaid. Within the daily routines of caregiving, the activities associated with this kind of work include direct assistance with bathing, toileting, and care of the intimate physical body, help in daily beauty rituals, such as styling hair and applying cosmetics, as well as semiregular physical and bodily maintenance needs, like providing haircuts or nail trimming. Additionally, some care recipients need assistance with elements of outpatient physical therapy, such as exercises that target repetitive movement of joints and limbs, or that work to strengthen particular parts of the body, such as the hands. If the caregiver is not the one providing the service, it is typically she who makes arrangements for the care recipient to receive a particular service; she may schedule an appointment at the hairdresser, or bring a physical therapist into the home. This is a salient point; it's women caring for women, because women understand women's grooming needs and preferences far more than men, who weren't socialized into womanhood—this phenomenon is not by accident, but rather by design.

Beth discusses her role in helping her mother with activities of daily living that involved hygiene and grooming:

I'd go over there every morning and help her with everything she needed for the day—brushing her teeth, giving her a bath, combing her hair, helping her pick out

clothes, getting dressed...all that stuff, daily, and at nights too. Some days I'd take her to the hairdresser, she had a friend who styled her hair, or I'd paint her nails, or we'd get our nails done together like we used to do sometimes when I was younger. It felt like the least I could do, help her look good, because she was a beautiful woman and she deserved to look good even when she wasn't feeling great or able to do [hygiene] herself.

Beth understood the value of "looking good" as fundamental to helping her mother retain a sense of pride through her physical appearance, and spent a considerable amount of time and energy engaged in the rituals of hygiene and beauty upkeep on a daily basis.

Lisa performed similar caregiving activities for her mother, and discusses the significance of physical contact through caregiving activities that involved caring for another's body:

When I visited her, I did her nails a lot. And her hair. She really liked that. I think too it was the only time she really had a lot of physical contact with another person by that point, especially someone who wasn't a nurse or someone she didn't really know very well, so she liked the touch of my hands on her hands or in her hair, like it was comforting to her or something to have that touch from someone she knew. I guess for me it got emotional sometimes because I thought about her being a mom and doing that for me when I was a child...I felt honored...to be the one to do that for her, make her feel good about how she looked and how she felt. It was very special looking back, having that time with her and those little things like painting her nails. She really loved to have nice nails. She'd show her friends at dinner and everyone who came in her room. Her favorite color was this lilac purple that I thought was pretty ugly (laughs), but she really loved it.

For both Beth and Lisa, helping their mothers maintain a sense of pride from their physical appearances, even through the "little things" like hairstyling and nail painting, gave them a sense of pride and satisfaction as well. Furthermore, Beth and Lisa were able to connect fond and salient memories of past experiences with their mothers in which they participated in beauty rituals together, or had been the recipients of physical hygiene care, with their present experiences as providers of this kind of care.

Maureen elaborates on some ways in which these caregiving activities reinforce a kind of bond between women:

It's not like I was the only one who could help her with baths or...her hair or whatever. But there was something special and kind of...unspoken, like it would just be me because I was her daughter and a woman and I know the things that are important to women, like looking nice, smelling good, looking put together, all of that, because they're values that women just...understand, in a way that men don't, probably because they don't have the same expectations of themselves or from society or each other. Women just get it, ya know? (laughs)

This excerpt is significant, because Maureen is relating these particular caregiving activities—assistance with bathing and grooming—not only to the experience of being a woman (the things women do to retain a certain standard or image in regards to their appearance), but also to societal expectations of womanhood and femininity. The expectation that women who care for other women through paying mind to their looks because they “just get it” was not only stated by caregivers like Maureen, but also those in the periphery of the care recipient's life, and those not providing care.

Joanne asserted this point, saying:

My dad would get really upset if my mom looked like, disheveled or something, or if I didn't make doing her hair or whatever my number one priority when I was over there. He'd say, put some rouge on her cheeks, she looks so pale, or do something with her hair, she looks like she just woke up...it was so maddening. I don't even wear makeup myself, and it was like, he didn't even pay attention to that fact, and he just assumed that I should do those things for her because what, just because I'm a woman or something? And of course it was always when I was making them breakfast or doing laundry or something, and that wasn't more important than her how her goddamn hair looked? I'd have to stop making eggs or whatever, drop everything, and take her to the bedroom to curl her hair...it just made me so angry.

Joanne's statement reflects several poignant themes—that caregiving activities should be performed by women, that women should intuitively “just know” how to do things like apply makeup and style hair, and that it was a bigger priority to her father that her mother

“look good” than to eat a meal. These points remind us of the very gendered nature of this kind of work; why women perform these activities for other women, and the role of social expectations of males and those outside the caregiver-care recipient relationship.

Those people around a caregiver who aren't participating in the provision of care for the care recipient are often quick to point out any inadequacies they observe on the part of the caregiver to sufficiently perform caregiving activities.

Jackie discusses this point regarding comments from her siblings when she would take her mother to family events:

I was the one doing all of her [care], so they'd blame me if she was wearing the same clothes, or if her teeth hadn't been brushed really well, or if she smelled a little bit off, or something...one time my brother pointed out that my mom had worn the same outfit the last time he had seen her a couple months or so before that, at Easter supper maybe, and I thought, what the hell do you care? She wears that shirt a lot because it's easier for me to button things up on her, you know like a cardigan sweater, rather than pull things over her head like sweatshirts or something, because it's hard for her to lift her arms after her shoulder—her rotator cuff surgery, and of course he just doesn't know any of that, because he's not the one who was there for her during any of that so he has no clue. You're not the one who is there for her, and you have no idea what I do for her, you know nothing.

Jackie's brother, who doesn't participate in the daily activities of caregiving for their mother, is clueless both in the kinds of activities Jackie does for their mother as part her caregiving work, as well as her reasoning in performing some activities in specific and deliberate ways, yet feels the need to point out small and insignificant observations that feel diminishing for Jackie, the sole provider of care.

Women who spend a considerable amount of time performing direct actions on the physical body are more aware of the care recipient's body and health needs, and are often the ones to identify and contact further or more specialized service providers. It's

typically caregivers who first notice a change in the care recipient's immediate physical wellbeing, such as recognizing an unusual mental state or observing hearing loss, and can make emergency medical arrangements as necessary. The burden of either providing these services or finding a professional to do so, or some combination of the two, leaves caregivers with overwhelming feelings of frustration at the amount of work involved in the care of the physical body, especially those who see themselves as expected to do this kind of work simply because they are women.

Celeste, who was caring for her mother even while her father was still alive, explains her acute awareness of her mother's unintentional weight loss, and its implications:

I was doing all of the cooking, so I knew it wasn't because of her not eating, it had to be something else. My dad would be there most of the time, and always for meals, and so he thought she was eating enough too and didn't really notice very much. She just started looking a lot thinner pretty quickly, and I couldn't figure out what it was. Then one day I gave her a bath and all of a sudden you could count her ribs, and I knew something was wrong, because she just looked so...frail and delicate, like she could just break in half, ya know, and when I asked my dad about it, he said she looked fine to him and that I was worrying too much. Maybe he liked that she looked thin, too, I don't know, I didn't ask about that, but he made me feel like I was making too big a deal or overthinking, or...like, obsessing, I guess. Then not that much after that she was sick, coughing a lot, so I took her to Urgent Care and she had bronchitis, and she had lost 17 pounds in less than two months, and she didn't have much weight to lose to begin with, so we knew something was wrong, and I get mad at myself sometimes because I knew it from the beginning, that something was wrong, just because I was with her so much and could tell she was sick, but didn't do anything about it as early as I should have.

As an active caregiver, Celeste was very familiar with her mother's habits and her body, so she was the first to notice change, while her father, who wasn't doing any caregiving activities, not only didn't notice her mother's weight loss, but also insisted Celeste was overthinking the situation and somehow caring *too much* when she expressed concern.

This shows that those who are physically and emotionally removed from the acts of caregiving are automatically less aware of the care recipient's health and wellbeing than the women actively involved in the daily routines dictated by caregiving.

Before becoming a psychologist, Beth had worked as a nurse in an intensive care unit, where she spent a lot of time caring for older adults with significant health needs and severe or terminal medical conditions. Because of her training and experience, Beth had high expectations of herself and her skills when she took on the responsibilities of caregiving for her mother, and subsequently found it challenging to admit to herself that there were limits to her own caregiving abilities, and that she should solicit professional help when it was needed:

I felt like there was nothing I shouldn't be able to do for her. I had the interest, not really the time, I guess, but it was something that was important to me to do for her, so I felt like I owed it to her to be the one to do it all, especially since my dad and brothers did so little, at least at that time. For a long time, I was able to help with just about everything—cooking, cleaning, doing their laundry, helping Mom with her baths and her hair and all of that, all while going to school...my days were just nonstop. It got to the point where I felt like I had a good flow of everything going, and that's when she became...basically incontinent, she couldn't go more than an hour without needing her clothes—her pants to be changed. And I realized, I can't do this alone, because I can't be there every waking moment—I still have to go to school, I still have to be at home with my husband occasionally, and find time to keep myself going...that's when I gave in and saw it was time to get another person to help with the things I couldn't always do. And then just when I had convinced myself—because it took me years, *years* to come to this conclusion, that I was ready to ask for help, that's when she had her first big fall and we decided, well, I decided, it was time for her to go to a nursing home so she could get all the help she really needed, and honestly, even though I was in denial at the time, it was the best thing for her, ultimately, and probably the best thing for me too by that point.

Beth had high expectations of herself as a caregiver because of her education and experiences in nursing, and the degree to which she considered her caregiving work to be morally important only reinforced these expectations. Acknowledging that she needed

help, when she felt like there was nothing she shouldn't be able to do for her mother, was perhaps the biggest challenge of all her caregiving experiences.

Safety and security are also overriding concerns for women caring for an aging parent. These concerns are especially evident in regards to activities of daily living, particularly those that include hygiene and grooming—bathrooms are small spaces with uneven and slippery surfaces, and using a toilet requires the ability to move from a crouched to standing position with relative ease. Many caregivers worry that without their help, their care recipients would try to bathe or use the toilet alone, which could result in injury from an unforeseen slip or fall. Similarly, those care recipients who have physical ailments like sensitive knees or who those who require the use of a wheelchair for mobility have additional safety concerns while bathing or using the toilet, and the work of ensuring protection in these special circumstances often falls to caregivers.

Joanne discusses performing some of these tasks of basic daily living for her mother out of a concern for her safety:

She hasn't really been able to dress herself, or get herself to bed. Now she's at the point where...going to the bathroom on her own...sitting down, I'm always afraid...and everyone who's with her is afraid she's gonna miss the seat, and is she gonna be able to get herself up...she's so fragile...so she needs help with that. She needs help with that, and to get dressed in the morning and bathed.

We see the amount of worry Joanne has for her mother's safety in mobility in performing seemingly simple movements, like getting up and down from the toilet, movements that able-bodied people and those not involved in caregiving take for granted.

Jillian expressed a similar feeling about helping her mother with bathing due to safety concerns:

It was important for me to do it, because it wasn't something she could do on her own. She had a hip replaced after a fall already...when my dad was still there and she fell out of the bed one night...but she didn't learn from it and she'd just keep going or try to do everything herself. I would wake up from nightmares sometimes thinking about her trying to do that again, and falling and hurting herself all over again, so it was easier to just do it myself with her.

Jillian was helping her mother with bathing to make it easier and safer for her mother, and to give herself the peace of mind that her mother would be okay. The fact that she was waking herself up from nightmares about scenarios in which her mother had hurt herself from a misstep or a fall shows us how stressful caregiving was for her; it occupied her time and thoughts, even when she was asleep.

Alice, too, expressed a sense of fear for her mother's safety that presented itself at inopportune times, like during her work as a caterer, and manifested in dreams:

I'd be in the middle of moving dishes around or...arranging dinner rolls or something...decorating cupcakes (laughs)...whatever it was! And I'd suddenly have this like, nightmare vision of my mom in the bathtub, like that whole 'I've fallen and I can't get up' thing from the commercials, and I would just obsess about it, couldn't get it outta my head. And then I'd be asleep and I'd wake up from some dream—same thing, she fell in the bathroom or in the kitchen or whatever, and that's—that's when I thought, enough, I can't always be there for every situation that can go wrong. I mean, I was already helping her with her baths, but what if she just wanted to take one for whatever reason and I couldn't be there? It was...unnerving, you know? I was like, it's time to get her one of those tubs where she doesn't have to stand up or climb in. And she didn't like it at first, but now she does, and I feel much better about it when I can't be there, it's a huge relief and I can get some sleep now (laughs).

Alice reminds us that the mental burden of caregiving is not a switch that can be turned off when leaving for work or going to sleep for the night and back on only when it's convenient or necessary; rather, it's a constant awareness of and an innate sensitivity to the needs of another person, and that feeling never really goes away.

Gendered Expectations of Caregiving Within Families

In the previous section, I discussed the ways in which gender impacts the kinds of caregiving activities women perform, and how certain caregiving activities seem to be built around traditional gender roles. In this section, I'll expand upon the discussion of these activities to explore the expectations placed on a caregiver by her family and the corresponding role of the caregiver in relationship to her siblings, parent(s), and self in regards to these specific and also more general activities of caregiving.

All of the women I spoke with regarding their caregiving experiences have siblings. A few shared some caregiving responsibilities with another sibling either previously or currently, but most of the women caregivers in this study found themselves the sole providers of care for their aging parent(s) among their siblings. This fact seemed to be the source of a lot of stress and negative feelings surrounding caregiving. Sibling relationships seem to face a significant amount of strain when the responsibilities of caregiving fall to only one sibling in a family of several children, a point that seems to relate directly to gender.

Beth, who grew up in a “good Catholic family”, felt abandoned by her five brothers when her parents were in a position of needing help. For her, it was a true paradigm shift—she went from feeling that her family was somewhat close prior to her mother's illness to describing their present relationships as estranged. The lack of support and assistance from her brothers throughout the time she spent caregiving for her parents ultimately changed the relationships she would have with her brothers from that point

forward, and the amount of distress this situation has caused her feels insurmountable.

She discusses these feelings:

I was raised with the notion that you honor your parents, and...so when my brothers weren't around in the ways that I thought they could be or should be, or when it seemed so easy for them to see my parents struggle and still not step up, in my opinion, in the way they should have stepped up they didn't, but seeing them, just sort of—my imagined family just came crashing down around me, and I thought...these people aren't at all who I have...imagined them to be. They're not...we are...we are blood family, but I grew up a lot through that experience; any sort of idyllic notion I had of who we were as a family unit definitely dissolved. I think that's largely why...I don't have a lot to do with any of them today. I mean, I love them, and I will always love them and they are my brothers, but they are not people...that I...respect or that I see life the same way as, um...I think so when my idyllic notion of who were as a family unit crashed...for a long time there was nothing but grief and sorrow and anger toward them that I felt inside. And disbelief.

Therefore, Beth was not only grieving the loss of mother as an independent and healthy parent, but the loss of her ideas of what “family” meant; she had to reconfigure everything she thought she knew, and cope with the feelings that left her.

Jackie, who cared for her mother after her father passed away, described difficulties among she and her five siblings in regards to the division of caregiving labor:

You got a little bit frustrated where...you wanted people to maybe, you know...volunteer to do things, and like my oldest brother, the one who was the farmer, he would go trucking, and we would say you know, even just small jobs...can someone do this, or you'd ask someone point blank can you do this, and the first thing out of their mouth would be no, and it was like, you know we all have jobs too, and granted yours takes you away sometimes, but you should at least have the willingness to try to contribute instead of relying on three of the kids, when there's six of you. Just to volunteer, “I'll do that,” or...I just don't think someone should be asked to do something all the time.

Therefore, for Jackie, coordinating the care for her mother, or trying to share that responsibility, became yet another duty that fell to her.

Physical proximity seems to be a reason many women are caring for their parent(s) alone—when siblings live far away, they have the excuse of physical distance to keep them from having a perhaps more direct role in caregiving for their parents, as Alice explains:

I have an older sister that lives out of town. And when she comes into town, it's kind of like, there's a little bit of a struggle sometimes. She comes in and she knows everything. She calls my mom, and she sends her books and information, but like I said, she lives out of town.

Not only does Alice have to deal with the lack of assistance on her sister's part, she must also cope with the attitude her sister takes and her opinions about the kind of care their mother should be receiving.

Heather shared a similar concern regarding her siblings' lack of participation in their mother's caregiving needs due to physical distance:

My brother and sister both live in Milwaukee, so they'd come to visit together, like once or twice a year, maybe three times if there was a wedding or baptism, or something, and I'd start to dread their visits because they wouldn't be helpful at all, they would just make things harder and more complicated. Like they'd criticize me for not cooking better meals for Mom, or not taking her out enough, or for old food in her fridge, or this or that or this or that... whatever they could possibly find to complain about, they would. And I'd just think, at least I'm here for her, and you can't be here for her because you're...*there*. You can't be here if you're there! It just felt really selfish to me, to have them use the distance as an excuse not to come here or see her, and then also make me feel bad when I was the one who was here and was seeing her, ya know? It made me really mad and it probably still does, to tell you the truth.

As we see from these comments, Alice and Heather both acknowledged a lack of participation on their siblings' part, but also suggested that perhaps their absences are preferable, because they contribute to the stress of caregiving rather than helping to relieve it.

Cathy also had issues negotiating with her sister about care, but in her case, a rift in the relationship between her mother and her sister meant a change in her mother's living arrangement:

[My mother] went to live with my sister in a different state, and lived there for about 5 years together, and that didn't work out very comfortably, and I did sort of a...a rescue operation, go to her house and end that situation a couple of years ago when she came back to live with us. She and my sister are on pretty good terms now which is great, but it's long distance.

This provides us another example of an additional responsibility taken on by a caregiver—in addition to caregiving, Cathy is now facilitating the relationship between her mother and her sister.

However, even when all members of a family reside physically near one other, that doesn't automatically result in a sharing of the caregiving responsibilities for the adult parent(s) in the family. Joanne, who is the sole caregiver for her mother who suffers from Alzheimer's and has performed some caregiving activities for her father as well, feels the burden of caring for her parents alone without any assistance from her brother, who lives in the same town as she and her parents:

My brother and his ex-wife, who is...they just don't do anything for my parents, you know my brother will bring my parents a meal every once in a while but he'll just leave it with them, he never sits down and eats with them. And the only time my brother eats with them, and that his kids see them, is when my parents take them out to dinner, and my mom can't, like, really hold a fork anymore, so she doesn't see them hardly at all, and they never come by, really...they, they're...it all makes me sick.

As Joanne has suggested before, the smallest gesture from her brother could go a long way—even the simplicity of sitting down to have a meal with their parents rather than leaving them to eat on their own.

Beth discussed a similar point regarding her brothers, who all lived somewhat near her mother, yet took no part in her care, and how their lack of participation had lasting impacts on their relationships:

It was whatever excuse you could put on having it be a woman's job, and that's very much my brothers. So in the end, (I have) much less respect for my brothers. I think that's largely why...I don't have a lot to do with them today. I mean, I love them and I will always love them and they are my brothers, but they are not people...that I...respect or that I see life the same way as. I want to say I was forgiving of my brothers, but I don't think I really am...I'm not sure I've ever put peace...with them.

The gravity of her statement shows the significant and permanent effects that unequal caregiving responsibility loads within a family can understandably cause.

Jackie asserted a similarly unequal workload among her and her siblings, but was comforted knowing she was available for her mother when she needed it, and wouldn't live with guilt over time missed with her mother:

The best part was just spending time with her, and like my husband said, you know, later on, you will never regret...you won't have any regrets because you did everything you could, where some of the other siblings might have regrets because they didn't make as much effort. So in that aspect, to know I did as much as I could for her, I mean I always think could I have done things differently, but at least I did it.

Jackie was unique in this expression of gratitude at the expense of being the sole provider of care. Her perspective is positive—"at least I did it" and offers hope for a future lived without regrets.

The caregivers in this study who had a second living parent were still the sole providers of care a vast majority of the time; fathers of caregivers who were spouses of the care recipients played little or no role in caregiving activities and instead relied on their adult daughters to perform all duties necessary to the caregiving experience. As I

mentioned previously, women caregivers spend an inordinate amount of time engaged in caregiving activities that involve meal planning and preparation and in personal hygiene, grooming, and health. Many women engage in these activities of caregiving because, as they point out, their siblings and fathers are often reluctant to do it.

Referring to herself as her mother's "protector", Joanne seems to carry the burden of ensuring that her mom has access to meals, especially because of the lack of effort on the parts of her brother and father to do the same:

[My dad] could go without eating lunch, or he could fix himself lunch, because he's the kind of person who would forget to get my mom something, or think that she's getting fat and just needs dinner...and then he'll get her...ahhhh...and then he, um...and then dinner was always an issue, and when I came back I was making dinner for them, because my mom just quit cooking, she couldn't even make a sandwich for herself, I would just, you know, make sure she'd get lunch and dinner and that maybe she'd get some kind of a social life, you know? And yet my brother's a really good cook, and, um...and my...you know I don't know if he's ever really, like...I should use that to help out.

Therefore, despite her brother's and father's physical ability to help with preparing meals, and her brother's apparent skill and enjoyment of cooking, Joanne still found herself the sole procurer of meals for her mother.

It also seemed that while Joanne didn't necessarily mind preparing meals and cooking for her mother and parents, the fact that her father seemed to expect her to do it and didn't show any appreciation for her work in that area kept her from being able to gain much satisfaction from meal preparation and cooking, especially when she went to extra lengths to make mealtimes enjoyable and socially stimulating:

So, and for, you know, for dinner, I'd invite their friends and stuff...and (sighs), but then I just got burnt out because my dad just expected me to do all this stuff and on top of it he'd never really compliment me.

In this case, perhaps even a small gesture of gratitude would have been enough to make up for the pressure Joanne felt to make meals not only means of providing physical sustenance, but opportunities for fulfillment of social needs through camaraderie and fellowship.

Within a family, caregiving activities involving hygiene and grooming are often expected to be the duties of adult daughters, many of whom are working outside the home and taking care of their own families as well. Jillian described going to her mother's house to assist her with a bath twice a week.

At that time, I was working a whole 40 hours a week, and I'd still drive to Le Center to visit (my mom). I'd go three or four times a week to see her...two of those times I would make sure we got her in the bath. I never understood why my brothers would never go over more than maybe once a month or so and they never even offered to help with any of that. They both live in town and the one doesn't even have kids or nothing and he still...wouldn't help get her a bath or anything. It really pissed me off. I was working a lot and still doing that and they never offered to help with it.

Jillian's situation was common; she was a daughter making time to visit and care for her mother, while her brothers, who even lived much closer to their mother, offered little help or care of their own. They seemingly just assumed she would take care of it, and this functioned quite well for them, as it appeared to them that she didn't ask for their help.

Lisa, too, performed grooming and toileting activities for her mother, especially considering her father's unwillingness to do so:

I would be the one to bathe her, or, you know...all that stuff. Brush her teeth. And she was starting to be incontinent. I would do her hair—this was in the days when you ratted and backcombed and all that business, and washed it once a week or curled it, so...I would do that, or do her hair, or pick out clothes for her, or help clean the house or do laundry, my dad didn't really do that.

Lisa shows us those activities that have frequently been viewed as “women’s work” are often invisible or taken for granted, and become the work of adult daughters rather than husbands and fathers.

Even in families where a male family member participates in some aspects of caregiving, there seems to be an expectation of women to do the majority of the caregiving work, and an undercurrent of assumptions that the work of caregiving is somehow more “natural” for women. Beth discusses the ways in which her father helped when her mother became ill, but how despite his assistance, he maintained the expectation that she, as the lone female child, would logically be the one to take care of her mother:

My father also was there in spades. He was uh, it was really beautiful, how he took care of my mom. My father, um, took care of my mom not because he saw it was a man’s role but because it was the role of a partner, so I mean for him it was duty and obligation, and even when my mother was in a nursing home he went down there every day and fed her lunch, so it was...you take care of the people that you love, that’s what I was raised, and then secondarily, if you’re a female, that must come...there’s something on the X chromosome that makes you a caretaker. It was whatever excuse you could put on having it be a woman’s job. We were the stereotypical family, you know...very...women are dependent, a woman’s place is in the home, the man runs the show outside the home. I think that’s the mental frame that everybody had, it was somehow easier for me because I was a female, or because I was the youngest, I was the baby of the family, I was Mom and Dad’s baby, but I think very much the...my family is very stereotypically, um, gender placed, and I hated it as a kid growing up, and I hated it very much when my mom got ill.

Beth so poignantly describes an idea that was echoed by many respondents, that male family members believe the work of caregiving is or should be “naturally” the work of women.

Beth also explains her frustration at feeling that the entirety of the responsibility of caring for her mother was placed on her, even when she had to move temporarily for an internship and her brothers and their families still lived close by her parents:

It was the weekend I came back home that my dad announced to me that he was gonna put Mom into the nursing home. And I think...I, I was devastated with that. I felt bad because I was thinking...had I not had to move to Ohio, I don't think she'd be going to the nursing home yet. I was thinking, had I been here, we would have continued to take care of her at home but he just couldn't do it alone. And I think that speaks to, too, I mean I had four of my brothers live in the same town that my parents did, and they're all married, and they all had grown teenage children, but yeah, the gender piece was there with my mom clearly, when the daughter moves away, now we have to put Mom in a nursing home, because we've got four sons and four wives and a whole bunch of kids but no one can do anything.

Here, we see several psychological phenomena occurring for Beth: a double standard in expectations (she was expected to stay to take care of her mother, but her brothers were not), a despondency at feeling like no one besides her was responsible for doing anything for their mother, and extreme feelings of guilt and self-blame for her mother being moved to a nursing home. She shows us that for a caregiver, there may be recognition of the injustice of differing expectations, but also overriding feelings of guilt, shame, and deficiency—acknowledgment that the situation is unfair, but being unable to ignore regretful feelings.

Joanne describes a parallel expectation of her as a daughter by her father, and similarly nonexistent expectations of her brother:

I heard my dad say, this is what women do. It's good to have sons for some reasons, but it's good to have daughters because they will take care of you. My friend Jamie, we're both caretakers of our mothers, and she even more so than me maybe, and she has a brother also, and we both just laugh at how our brothers can do something and it's such a big deal and we can do everything and it's taken for granted, you know? It's just expected for us. There's something about when a guy does it, whatever it is, if they just show up for dinner, they can just show up for

dinner and it's a big deal...where you can make the whole goddamn dinner and no big deal.

As a daughter, then, Joanne feels taken for granted—being a daughter and caregiving is “no big deal”—and this impacts the way she sees herself, and believes she is seen by others.

Heather listed a similar reasoning for stepping in to help her mom when needed.

My dad would take her, but if it was something that my dad wasn't going to, you know, a bridal shower, or some whatever...a woman thing...it would be me. And then when my parents did go somewhere, I would always go with them, to help take care of her, or if she had to go to the bathroom or something and my dad wouldn't be able to help her with that, I would always go.

Thus, Heather shows us that activities of caregiving that are especially intimate or personal are often performed by women, perhaps out of necessity or convenience, but also because of baseless excuses made by male family members that they were somehow unable to help with certain activities or responsibilities, despite having no evidence to support these claims.

Beth is the lone daughter and only member of her “very blue collar” family to have a college degree, and several graduate degrees at that. She describes her frustration at her father's lack of recognition of the importance of her career, and how being a daughter first and foremost always overshadowed her work obligations and commitments:

My dad probably had, I don't know, seven or eight doctors caring for different body systems. I would always take him to appointments, but I was a psychologist in private practice at the time, and I remember one time I couldn't—I had a conference or something, something I couldn't, you know, usually I just canceled with my client but whatever this was I couldn't, so I had asked him if he could ask my other brother, this other brother who lived locally, and that other brother was also self-employed, and I remember asking Dad, you know, well I can't do this

particular appointment, do you think we could ask him to take you? And my dad looked quizzically at me and said, well, (your brother) has a job, he can't just take off. I thought god...this is the epitome of how my father sees me. So here I am as a psychologist—not that that makes me better, but in the pecking order of society...one would think that would be looked upon as a high thing—nope, in my dad's eyes that wasn't even a job, 'cause you're not a man, so anything you'd do isn't serious. I think it was a way to reduce me...I think the fact that I as the only female in this family and as the youngest child and went on to school and got this fancy degree and...I think it was kinda threatening in that scheme of, where men are really supposed to be the men, and so it was also simultaneously happening at the same time my mom's illness came, but I think a lot of that came crashing down...I think I broke some unspoken rule in my family, when I surpassed the males, in terms of educational achievement.

Therefore, even though Beth attained many personal achievements, her gender is still an albatross around her neck; care is still demanded of her—regardless of her accomplishments—because she is a woman. Furthermore, her success was used against her when she became more prosperous and achieved a higher status than the rest of her male family members; she was resented rather than celebrated for her accomplishments.

In the case of a few caregivers, the care recipient had moved into the caregiver's living space, either out of necessity or convenience. Monica sensed that she was the only sibling in her family who would accept her mother's asking to move in with one of her children:

My mother asked to live with me because I'm the only one who would say yes. My sister wouldn't do it and my brother wouldn't do it either. She would never ask, she would never even ask. My brother lives in a very small house in the Netherlands and has no money. My sister is very into her job and doesn't have time for other people. We don't really ever talk. My sister has a huge house, so my mother could be there, but it would drive my sister crazy. And I don't think my mother would wanna be there...we are much more easygoing here, and she gets to say what she wants to say without being yelled at, and she says a lot of things.

Monica felt that she had both the physical space and personality traits to comfortably cohabit with and accommodate her mother, where her sister had little time and interest

for their mother and her brother was financially unable to take on the responsibility of housing another person.

Cathy expressed a similar sentiment when discussing her mother's move into the home that only she and her partner had shared for many years:

It wasn't exactly ideal for me. [My mother] wasn't living anywhere nearby, so the move alone was pretty inconvenient and labor-intensive. It took about four trips between me and [my partner's] cars, over three hours each way, so it wasn't anything we could do in a day or even in one weekend, it took a lot of time. Then there was the actual moving things around... [my partner] and I hadn't moved anything around hardly at all, not even really to clean (laughs), so it took a lot of time and moving things around to figure out how to fit all my mom's stuff, because she has a ton of stuff and she wanted to keep most of it, and it was all about where would it go, and how she wanted it to look, and blah blah blah. That caused a lot of fights actually, because she wanted to keep everything and I put my foot down and made her get rid of a few things that we just couldn't fit or that we had more than one of, and she said that my sister wouldn't have made her throw away special or precious belongings, and I said it didn't matter, because she was living with me, not my sister, and my sister never would have let [my mom] live with her to begin with. I was still working a lot and commuting over three hours every day, so it definitely wasn't—isn't ideal for her to be here, but now that she's all moved in and settled, it's okay, and it's better than her fighting with my sister or having nowhere to go.

While this is a familiar concept—Cathy's mother moved in with her because her sister wouldn't accommodate her—what's even more notable is the point that goes unsaid:

Cathy has a brother, and it was never even a consideration that their mother would live with him. It was just assumed that their mother would live with a daughter and not a son, regardless of the fact that her son was a single man who lived alone in the same town as their mother. Instead, Cathy moved her mother away from home and in with her, because it was easier than worrying about her mother's living arrangements, and expected of her by her mother and her siblings.

People outside of the caregiving relationship are not the only ones to have the expectation that caregiving is women's work—in a few cases, caregivers themselves suggested that they too thought caregiving work came more naturally to women, or that they would prefer daughters take care of them rather than sons. For Monica, embodying her current role as a caregiver forces her to speculate about eventually needing care herself, and who would be the person to step up to take care of her when the time arrived:

I think there is a big difference in being a daughter and taking care of your mother and being a son and taking care of your mother, and my sons would be fine...but if I had to choose I'd have a daughter to take care of me. It would be more natural and easier for a daughter to take care of me than to expect that of my sons.

This is a notable point: Monica is acknowledging both that she is the only one to take care of her mother, because it's expected of her as a daughter, and also that maybe that's okay, because she wouldn't expect her sons to take care of her in the event she needed caregiving of her own.

Maureen asserted a similar point, stating:

I guess it makes sense that I'm the one to do [caregiving], because if I think about myself, I'd rather have my daughter take care of me than my son, because she would just...understand my needs better, and wouldn't be uncomfortable or judgmental about things, because she's a woman too.

Again, we see the idea that it's considered simply logical for women to perform this kind of work, because they inherently are aware of women's needs, and therefore are more understanding and less critical than their male counterparts would be within the context of caregiving.

All of this evidence suggests that caregiving is a gendered experience, and a person's gender impacts the kind of caregiving activities she performs, particularly in

meal planning and preparation, and those that involve hygiene, grooming, and health needs, and the expectations a caregiver holds from herself and her family in her role in caregiving. We can acknowledge that these kinds of activities and expectations are structured by gender norms, and are created and maintained through social interactions and the performance of gender.

Identity Work in Caregiving: Role Management, Role Reversal, and Self-Actualization

Sociologists understand identity to be not a fixed and permanent set of personal characteristics, but an active and fluid process that involves constant renegotiation of one's self. Caregiving thus occurs in a context; caregivers' lives are often filled with other roles such as worker, spouse, parent, and/or volunteer. (Coon 2012: 232)

Women taking care of their aging parents in addition to balancing the challenges presented by their personal and professional lives engage in identity work. As mentioned earlier, identity work is not a fixed task within a given timeframe, but rather an ongoing and constantly evolving process. This process forces a dynamic relationship between actions, thoughts, feelings, and emotions; each inherently affects and is affected by the others in a perpetual cycle of renegotiation of the self within a given social setting, in this case that of caregiving. The previous discussion of some of the activities that are typically performed by women caregivers, especially those that are structured by gender norms, gave us a glimpse of some of the actions of caregiving and corresponding thoughts of women caregivers in regards to these actions and the expectations they sense. In this section, I explore some of the feelings and emotions that can result from these caregiving, which provide additional detail to the actions of caregiving described above,

and provide a sense of the kind of identity work in which women caregivers engage. First, I discuss the many roles women caregivers occupy and their strategies for managing these roles. Next, I examine the ways in which adult parents and adult daughters experience role reversal and how it impacts their sense of self and relationship with the care recipient(s). Finally, I analyze the impact of the positive or negative nature of the caregiving experience on a caregiver's negotiation and self-actualization of the caregiver identity.

Role Management: "Doing it All," Achieving Balance, and "Missing" Roles

Women caregivers express a wide variety of feelings and emotions when discussing their caregiving work. Some assert mostly positive feelings—pride, altruism, and a sense of satisfaction that comes from helping another person; others are quicker to highlight the more negative feelings resulting from caregiving—frustration, irritation, and especially stress. According to several women caregivers, the ultimate cause of stress can result simply from wearing so many proverbial hats—worker, daughter, mother, sister, and partner, to name a few. Juggling these many roles, and doing it *well*, is challenging enough for the average woman; adding the role of caregiver, and the responsibilities it brings, further strains the workload for women caregivers. Consequently, management of all the roles becomes yet another duty for women caregivers.

Maureen, who is married, has two children, and has worked for 25 years as a special education teacher in an elementary school, discusses this managing of roles:

There were days when, and I was getting up around 5 am to do this, I'd be making breakfast for [my kids and husband], driving them to school, going to work and sometimes staying late to do paperwork or clean up, otherwise picking them up from school and usually making dinner too, and I'd go right to my mom's house to make dinner for her too, maybe give her a bath or watch some TV or something, and be getting home at 8 or 9 just to go to sleep to wake up and do it all over again.

On any given day, Maureen was managing the work of being a mother, a wife, a daughter, a teacher, and a caregiver, all roles which involved many actions and responsibilities, and often management of multiple roles at a time.

She asserts a further salient point, stating:

And then there'd be days where there were soccer games or choir concerts or whatever, and I just couldn't do everything, and I'd feel really bad about having to miss something but caring for Mom was always more important, ya know? I couldn't miss that.

Here, Maureen shows us how one role and its corresponding responsibilities were always taking a proverbial back seat to another—there was a kind of a hierarchy of roles, and the caregiver role took priority over other roles.

Maureen also mentioned feeling badly about missing things, saying “I just couldn't do everything” when describing her attempts to manage all of her roles. The idea of wanting to “do everything” or “do it all” was a recurring theme throughout the interviews. Not being able to do it all lead to feelings of guilt and stress for women caregivers, and also created a conceptual ideal: balance. Women caregivers who discussed an attempt or desire to “do it all” often mentioned balance in the same sentence, either as a goal or a maxim; balance was both an objective and a measure of success. If a caregiver felt like she was successfully “doing it all,” she had achieved balance, or if she accepted that she *couldn't* “do it all,” at least she was *trying* to achieve

balance. Most respondents expressed a desire for balance but an ongoing struggle to achieve it.

Cathy, whose mother lives with her and is mostly physically independent and capable, describes this general feeling, and the guilt she experiences from her frustration in trying to “do it all”:

I commute most days of the week, by choice really, and then coming home and being sort of, um...this is probably one of the pressure points of my day...coming home and finding my mom hasn't had anybody to talk to all day other than, you know, she'll have phone calls and emails and so forth so she'll tell me about what she's done, but the main thing is a sense of...communication needs on the part of my mom and feeling responsible for, you know, can I give her some of the mental energy right at the time when I'm thinking, okay, now I have to cook for a crabby eater, and the cats are meowing, and my mom is just talking...and it's really just me to do it all.

Cathy shows us the stress that results from being someone's “everything”—along with her own responsibilities (working, commuting, cooking, feeding her pets), she has to accommodate her mother's needs—making particular food and fulfilling her mother's social needs through communication—as well. This exemplifies the difficulty of trying to do it all while managing a multitude of roles.

Heather describes having a tough time with balancing her roles, using exactly that language:

Balancing things is hard. I love my job, I'm so grateful for it, most people hate customer service but I love helping people with their problems. Maybe that's why I'm a natural caregiver too. But to have so many other things to do is hard. I love my husband, but he's not always the most helpful with [my mom] or even some things around the house and he worries about the money we have to spend on my mom. One of my daughters is a single mom with two kids, so I try to spend a lot of time with them too. And some days I don't even want to do anything, I just want to stay at work and not have to do anything for anyone but me...it causes a lot of strain, trying to do everything all the time.

Here, we see that for Heather, balance is a goal, although an admittedly difficult one; she feels like she must “do everything all the time” even when she feels incapable of doing anything for anyone beyond herself. The mental burden of caregiving is significant for caregivers like Heather, who feel the pressure to do it all.

Balance was described by many not only as a goal, but also as an ideal to achieve.

Beth discusses the concept of balance as an ideal:

I was always trying to find a balance, but looking back I don't know if I balanced anything really at all. I'm not sure I balanced it as much as I just plowed through it, I did what had to be done. Because I was in graduate school, I wasn't working at the time, just going to school, and so...but that literally was my time. I remember I would go to school, I would take care of Mom and Dad, I would study, I would sleep, I would go to school, I would take care of Mom and Dad, I would study, I would sleep...my every moment...was consumed with my parents. So I guess it wasn't balance as much as, um...just, perseverance I guess.

Again, we see how the idea of finding balance is the desired goal, but a caregiver may be both reluctant to admit that she has achieved balance and more likely to define it differently than her peers; some gave a different name to what others might define or measure as achieving balance. In this case, Beth used the word perseverance while others could interpret her situation and say she was doing nothing if not balancing her roles as student, daughter, and caregiver.

Cindy was one of only two caregivers in the study who felt they had achieved a balance in managing their roles, and discusses this as fundamental to having a positive experience with caregiving:

There was a time when I realized I was doing everything, and doing it well, and I thought, hey, I got this. I'm working, I'm taking care of Mom, she's healthy, I'm healthy, and all the bills are paid, food on the table, all that...I felt like there was a real balance there and it felt good. Once I felt that, everything was fine and I felt like we were in a good place, and it was so natural and...just in a groove I guess

(laughs). I was lucky to have that good of a time with it 'cause I know it's not that way for a lot of people doing [caregiving].

The peace of mind Cindy describes was clearly connected to her feeling that she had found or achieved a kind of balance by her own definition.

This excerpt also highlights another important point: that women caregivers do a lot of comparing their actions and abilities to others, as if there is a need to acknowledge that while caregiving work may be challenging for them, it's even more difficult for others. This kind of self-minimizing and comparative language is a gendered phenomenon—women are socialized to be humble and self-effacing in their assessments of themselves and their achievements—and was another common thread throughout the interviews in regards to discussion of the self and the caregiver identity, and the concept of “doing it all” or achieving balance.

Joanne discusses the ways in which she compared herself to several peers who were also performing caregiving activities for their parents:

[My friend] was also caregiving for his dad when I started taking care of Mom, and I remember watching him with his dad—and he did so many things with him, so much more than I was doing, and I just thought, he's so natural with him and amazing and gentle and patience and I just wasn't any of those things...I was always losing my temper or getting frustrated or pissed at my dad and I'd think, why can't I be like [my friend] and have all the time and patience in the world, 'cause it's not my mom's fault, my dad would just set me off and I'd take it out on her. And my neighbor, she does it too, caregiving I mean, and she has kids and a full-time job and I don't have either of those things, so I'm just amazed at what she can do, and I think, I could never do that if I was her, because she was just so busy and had so much going on all the time. She and I got coffee one time...and all I was doing was complaining about my mom and dad...and then I had this a-ha moment and I was like, I am such an asshole, she is doing the same thing as me but has way more going on in her life...what right do I have to complain?

Anyone on the outside of Joanne's situation could assess the work Joanne was doing as mentally and physically difficult, and appreciate the challenges it brought to her life; however, she was inclined to minimize the amount of work she was doing, feel guilty for talking about it (calling it "complaining"), and compare her own perceived caregiving abilities and skills to those of her peers, who she deemed as more competent or busier than she.

Jackie expressed a nearly identical feeling:

There were days when I felt like I was just doing so much, that there was no one around who understood the amount of work I was doing...between work and taking care of my mom and then making dinner and being with my husband, and sometimes having the girls over for dinner too...but then I knew of people who were having to do even more than that, and had no help at all—at least my sister was there every once in a while, like if I couldn't take Mom to an appointment she'd fill in, or something—so I'd feel really bad for acting like I was so busy and stressed all the time when there were other people around me...doing even more but having, not being supported in any ways, so I shouldn't be complaining about anything.

Jackie acknowledged the amount of work she was doing in managing so many roles—worker, mother, spouse, daughter, home keeper—but was inclined to be dismissive of her workload in comparison to her peers, who she believed must surely be doing more and with less support, and that any discussion of her feelings about juggling her roles must qualify only as "complaining" rather than ordinary conversation.

Many of the women caregivers in the study also commented on "missing" roles—roles they may have had in addition to the others if they had not been so actively engaged in the activities and responsibilities of caregiving. This was especially significant for women who spent many years, sometimes even decades, building their lives around the demands presented by their caregiving. These women speculated who and what they

“could have been” had it not been for their time and energy spent caring for their parent(s). For a few caregivers, it was the role of mother, and for the others, it was the role of employee or worker. Both of these roles are central to a woman’s self-concept and identity; even women who don’t have children, either by choice or not, have an innate awareness of the social expectations of women to want to be mothers, and feel the need to discuss or explain their childlessness as a matter of identity. Similarly, many women, especially those who feel the pressure to “do it all,” feel compelled to work both in and outside of the home, and sense a failure to meet social expectations if they’re not working for an outside employer as well as in their homes for their families and for their parent(s).

Beth describes feeling limited by her caregiving responsibilities in her choices about becoming a mother:

Prior to getting married, I wasn’t sure that I wanted children, but I remember, um... I think the possibility of that could have changed along the way had we not been grappling with this, but during all of those years that I would have been potentially childbearing, first my mother became ill and I was very involved and then my father became ill and... I think I didn’t want the burden of another somebody I needed to take care of. And it was a point of sadness, that realization that [having children] probably just wouldn’t happen for me, and something I always had to come to terms with and explain to people.

Not only did Beth sense the physical and emotional load of hypothetically caring for yet another person, she felt the need to justify the fact that she probably wouldn’t have children not only to herself—a challenge itself—but also to other people.

Earlier in her relationship with her partner, and before the demands of caregiving took center stage in her life, Joanne had envisioned becoming a mother.

We met when we were in our 30s, but she’s a few years younger than I am, so she could have [become pregnant] even if I couldn’t. But then my mom started

declining, and it was clear Dad wasn't gonna be the one to help to her and neither was anyone else, so that whole idea pretty much went out the window. [My partner] would have been a great mom, and I think I would have done okay with it too (laughs), so sometimes I have a lot of regrets about that and I can't help but think how things coulda been different, ya know? But I know I would have felt worse if we'd have had kids and I couldn't help out as much as I wanted or could handle because of all the things I was doing for Mom. I'm lucky that [my partner] wanted to be with me anyway even if we couldn't have kids and that she supported me through all that, but it's hard to not think about at least sometimes, what being a mom would have been like.

We see how complex the feelings surrounding this “missing” role are for Joanne—she feels both guilt and relief, and she is resolved yet questioning; this duality causes a chasm between her ideal and actual selves, and an intrinsic doubting of the full “potential” of her identity through the lack of fulfillment of some of her desired roles.

As a young woman, Jillian trained to become a nurse, the career she had envisioned for herself since she was a little girl. After only three years working on a pediatric intensive-care unit, she had to give up her dream job to assume full responsibility of caring for her mother, who was suffering from early-onset Alzheimer's disease, when her father died suddenly.

It was heartbreaking, really, to have to give that up. I worked really hard to get where I was, and to have to give it up was...just...heartbreaking. My mom had been a nurse, and she was my hero, I wanted to be just like her. So it was hard enough that she couldn't see me achieve my dream, because she didn't really know what was going on by then, and then to have to give it up and move in with her, provide all that care because [my dad] left her with next to nothing, so couldn't put her in a home, it damn near...it just broke my damn heart, it really did! And I felt so bad, cause she lived her life to take care of people, sick people, my dad, and me and my brothers and sisters, and here I was complaining about having to take care of her, but it just felt so damn unfair, ya know, and looking back it's funny, because the whole time I was actually being a nurse, my mom's nurse, and I never thought of it that way at the time, cause all I could really think about was not being able to really work, and I just felt...short-changed. Eventually I accepted it, and I was happy to be the one doing it for her, because she was so far gone...and she just needed me so much.

Again, we see a complexity and range of emotions—frustration that she had to give up a career she had always wanted and worked so hard for, and one that was a special source of pride for Jillian, who had followed in her mother’s footsteps, but also a recognition of all her mother had done and a satisfaction of giving back to her in her neediest time.

It’s also notable here that despite caring for her mother and operating as her mother’s nurse, Jillian remarks that she didn’t conceive of herself in the “worker/nurse” role because she felt like she was “not able to really work.” This suggests that the labor involved in caring for a parent, which is typically informal, unpaid, and demanding, is not always identified or assessed as “real” work, and is less personally and economically valuable or respectable to the caregiver than a professional and waged job—even when the profession, such as nursing, entails similar tasks.

Lisa, who also sacrificed a career to take care of her mother when she became ill and incapable of caring for herself, echoes a similar point, stating:

Sometimes I felt lazy, or kind of worthless. Like when I was talking with my friends or old coworkers and they all sounded so busy, I felt like I should be doing more, like I wasn’t even really working or anything but yet I felt all this stress all the time, and it made me feel like I was making a big deal out of nothing. My sister, she’s a lawyer, and I’m sure she was way busier than I was, but at least she had money to help with medical bills and stuff and that’s more helpful, and I had nothing to contribute to my own family because I wasn’t working. That made me feel really guilty for a long time, even though my husband didn’t complain. He worked two jobs for a few of those years, and my kids were understanding too, but I just felt like I was always missing doing something, not doing as much as I could or being a great mom or a great...employee or something. Especially since my mom, in her generation women had to fight really hard to have jobs, and to not do that felt like I was, like...betraying her or maybe she was ashamed or disappointed of me.

As discussed earlier, caregivers often feel they need to “do it all.” Lisa felt that pressure to be doing more as well as guilt at not contributing monetarily to her own family or to

the care of her mother, and while Lisa was doing the active work of daily caregiving, she viewed her sister's financial contribution to her mother's care as more helpful than hers. She feels inadequate due to her lack of formal employment, and speculates about the ways she might be different if she was "really working"; her feelings of inferiority due to her "missing" role negate a positive self-identity.

Role Reversal: Caregiving Activities and Shared Spaces

As discussed earlier, adult women who care for aging parents perform a variety of tasks for their care recipients, especially those that involve the needs of daily living—meal preparation and delivery, and personal hygiene and grooming, both of which are often assumed to be the responsibilities of women. In this section, I focus on the implications of caring for one's own parent and assuming the role of responsible adult daughter as well as caregiver.

Being engaged in caregiving leads to challenges to the traditional adult child and adult parent roles; these challenges can result in role changes and negotiations, impacting the identities of the adult child and the adult parent. Adult women who have previously conceived of themselves in the child role often find themselves renegotiating this role as the parent(s) they care for are less physically and mentally capable and therefore become more childlike in their needs and actions; this role reversal poses challenges for both the women caregivers and their adult parents. Adult children assume a more parental role as their adult parents decompensate physically and mentally, bringing them to states of limited functioning and significantly more dependency on others. This role shift is

particularly visible within certain caregiving activities, especially those that involve food preparation, cleaning, and hygiene maintenance, and also in circumstances where the adult parent moves into the adult child's home, creating additional concerns over shared space, time, and responsibilities. First, I address role reversal in caregiving activities specifically, and second I turn to role reversal within shared spaces.

Alice discusses the challenges that arise out of maintaining traditional child-parent roles when engaging in particular caregiving activities for her mother:

I think...you know, there's some times when I become a little more...controlling. Like I'll go and clean her house, or make her dinner, and she's like, I don't want you to do it like that, and then I'll be like, well, this is the way I wanna do it, and I'll have to step back and say, it's her house, you know, so I get a little bit...controlling. So I have to step back and let her be, let her be her own woman and my mother and she can tell me things and I will listen and step back.

A salient point here is that it's important to Alice to help her mother retain her sense of identity, to be "her own woman" who can function with autonomy and authority, thus maintaining a kind of motherly presence and role.

Celeste also regarded the ways in which she intentionally helped her mother "still feel like a mom" as an important part of her caregiving duties, despite the necessity of a dramatic role reversal during particular caregiving activities:

I think it was hard for her to accept that was declining so much, especially mentally, so when she'd forget to turn on the oven when we were making dinner, I'd never call attention to it, or I went out of my way to ask her for help or with things that I knew she could still do. Like for example, she was incontinent by that time, so I was basically having to help her with clothing—with changing her clothes when she had accidents, or if we could catch it ahead of time, just with going to the bathroom or whatever. But she could still do laundry, could fold clothes really nicely, iron, things like that, so I'd ask for help on purpose, even though I didn't need it, because I knew it would make her still feel like a mom, and like she was taking care of the household things...and the ironic part was that she didn't, couldn't really understand that it was her own clothes that she was

having to wash because of her accidents, or that I was the one turning the iron on and off in case she forgot...and that was good, I think, because then she didn't have to feel...embarrassed, or ashamed I guess, and it's not like I thought she should or anything, but you know, when you've been the one doing all the things for your family for all those years and then to be the one who needs the help eventually, that must be really hard and I felt so sad for her, and that was the best way I could help her still feel...important, I guess, and like she was still taking care of us, and that things weren't that different from before.

Celeste was functioning very much as a mother would overseeing a young child—predicting and assisting with toileting mishaps, supervising household activities for safety purposes, and helping with the daily needs of maintaining a home, such as preparing meals and doing laundry—but she was also acting in a parental fashion by caring for her mother's mental wellbeing through reinforcing aspects of her identity and encouraging her self-efficacy, thus maintaining the mother-child relationship.

These excerpts also remind us that these are not problems that family members who don't perform caregiving have—they don't have fights over how things should be kept or cleaned, or by whom, because they aren't physically there engaging in caregiving activities, and they don't have to make special efforts to help parents maintain their identities and parental roles. Thus, in performing the daily activities of caregiving, women caregivers are opening up the potential for difficulty in their relationships with their care recipients simply out of the challenges of maintaining the parent-child role, whereas those people not actively involved in caregiving perhaps don't struggle with these issues.

The activities of daily living that a healthy and functioning person may take for granted as basic and fundamental for adults, like bathing and grooming, are reconsidered when looked at from a caregiver's perspective; a woman caring for her mother may find

it difficult to dictate the performance of an activity without feeling frustrated at its necessity of role reversal, as Beth describes:

I remember when she really started to decline. The caregiving of her was very involved at that point... I think I had just given her a bath and washed her hair and stuff or something, and I pulled her dentures out to have her brush her teeth and she didn't understand anymore the concept of brushing her teeth, so I would brush her teeth. But I gave her mouthwash to rinse her mouth, and she just sat there with the mouthwash in her mouth and didn't do anything, so I would try to mimic, you know, with my own mouth, you know, Mom, try to do this and see if something would trigger kind of her memory and it wouldn't and I remember pushing her head down over the sink to just try and just like, spit it in the sink, but I remember pushing—either I pushed her head down rough, I didn't hurt her or anything, but I did something in a way that surprised myself, my own irritation at that she just didn't understand this and it was so hard every day.

Again, Beth is describing a situation that is unique to the caregiving experience—only adults who are active caregivers would find themselves in a position where they are brushing a parent's teeth for them. She acknowledges her feelings of annoyance and difficulty that arose from her caregiving activities on a daily basis.

Heather expressed a similar frustration that stemmed from helping her mother bathe, an act common in children's experiences caregiving for their parent(s):

She hated to do [bathing]. She just hated it. It was so hard for her to let someone see her be so vulnerable. She knew she couldn't do it alone, but that meant that she was never gonna do it, not that someone should ever help her. And because she hated it, she was really unpleasant during those times. She'd get angry and fight me and one time she hit my hand when I tried to move her in the tub. I'd get angry too and I hated to feel that way, because she was really having a hard time and I just felt like I was making it worse by making her do it since she didn't want to. I'd surprise myself at how frustrated I'd get with her, like she was my kid or something, and it was so...disheartening to feel that way.

This situation is very similar to a child's response when they are asked to do something they don't want to do—they protest the action, respond with strong emotion, and may physically resist or fight back—and the parent is expected to respond with patience and

understanding. In the caregiving context, the child who has stepped into the role of the parent experiences the challenges of role reversal. Even though Heather showed great empathy and understanding for her mother's feelings, she acknowledged that the reversal of roles was both difficult and frustrating for her.

Joanne asserts a similar point regarding the importance of practicing compassion in acts of caregiving that necessitate a reversal of the child-parent role:

Caretaking is...cleaning up people, and you know, just being kind to them during their vulnerable times like when they have an accident and they're all wet and they need to be cleaned up.

Though a simple statement, the message is profound; women caregivers feel the need to demonstrate patience, kindness, and empathy in the same ways their parent(s) had shown them when they were children.

Lisa discusses her memory of the time she first acknowledged a role reversal between her and her mother:

I remember saying to her, C'mon Mom, time to put your shoes on, 'cause we're gonna be late meeting everyone if we don't leave soon, and she just looked at me like I had three heads, and I realized that she didn't know what I was saying. Or if she did know what I was saying, she couldn't connect the words to her...actions, or what I was asking her to do physically. She'd been starting to have memory loss but that was when I first noticed how...severe, I guess, it was...and I realized I had to put her shoes on for her because she couldn't do it anymore, and I thought, wow, it's like I'm the mom, because this is something she must have done for hundreds of time when I was a kid, and it was this total complete mental...like, shift or something for me. Everything pretty much changed after that day, and I never really thought about it like that until then.

We see here that it was the action of helping her mom with her shoes that forced the recognition in Lisa's mind that a role reversal had taken place; this symbolic incident was

indicative of a drastic change to previously-held roles and a point in time from which things would no longer be the same.

Women who open their homes to a live-in care recipient face the additional challenge of sharing space. This negotiation of space can result in a reconfiguration of traditional child-parent roles. When caregivers find themselves in the position of having a parent move in with them, they often must make changes to the physical spaces in their homes to accommodate changing physical needs inherent to aging, particularly in small spaces like bathrooms. This is not unlike the changes parents make to their homes to accommodate infants and children, such as turning a spare room into a nursery, or building a playroom to store books, toys, and other items for children, or adding safety features to household appliances and structures, like covers on outlets and gates to stairways.

Monica's mother moved in with her when she was no longer able to live independently. Monica discusses the changes she and her husband made to their home to make toileting easier for her mother when she moved in with them:

The move itself was a pain in the neck, and all the remodeling that hasn't been finished yet. I wouldn't do any of this stuff that's happening downstairs, nothing would have happened if it hadn't been for her. Thankfully it's possible to make another bathroom, so—and actually it's a good idea because she can use the little bathroom right next to her bedroom to go to the bathroom if she needs to, but the other bathroom I made...what do you call that, wheelchair accessible for the shower, so I can roll her around, and that's another reason we did the marble everywhere, so there wouldn't be any dips or anything like that. It has been so expensive to do but it had to get done.

Here, we see the complexity of the changes necessary for Monica to accommodate her mother's move; she was managing the renovations and disruptions caused by the move,

and footing the significant bills, just as parents traditionally do for their children within the spaces of their homes.

Since her 91-year-old mother moved in with her, Cathy describes the shared kitchen space as being representative of this shift in roles:

I think one of the things that's hard for both her and me to adjust to, living together, is sharing space, sharing kitchen space...it's hard for us to not end up in the kitchen at the same time. She was a very good cook growing up, as a mom, she spent a lot of time doing that...so I'm surprised at how possessive I can be in that space...this is MY kitchen! She probably has thought for so long that the kitchen is just her realm, and so I guess I should back off a little bit and let her have more control there. It's hard though, you know? It was just mine for so long so I'm not used to her thinking she's still my mom, making all the food and trying to do everything in the kitchen, and I just want to say, Mom, let me do that...I can do all of those things now, because I'm a grownup (laugh). But I have to be careful with that approach with her, because it's satisfying to her, I think, to still be able to help with things like that, at least as much as she can.

Cathy acknowledges that a large part of her mother's role as a mom had been dictated by her having been a good cook, which likely meant that she had spent a lot of time in the kitchen space, asserted control over where and how cooking utensils, appliances, and ingredients were stored, and prepared a lot of meals for her family; she was used to a certain way of doing things that satisfied her role as a mother. As a grown adult child, then, Cathy had to recognize these qualities in her mother, interpret them as important to her sense of identity as a mother, and consider the ways she could help her mother to maintain that identity.

The Self-Actualization of the Caregiver Identity

In the same way that caregiving involves a juggling of many roles, the labor of caregiving is multifaceted and complex—a caregiver can provide needs related to food and nutrition, hygiene, grooming, and health, and assistance within homes and living spaces, among other things; in addition, caregivers often fulfill social and communication needs for care recipients, particularly when they are the sole providers of care.

While all of the participants in the study readily acknowledge that they participate in caregiving activities, not all conceive of themselves as caregivers by title. As previously discussed, some caregiving acts create a shift in the roles between adult children and their parents. Caregivers who express warmer feelings toward their care recipient(s) are likelier to feel positively about their caregiving experiences overall, and those who report more adverse feelings toward their care recipient(s) detail more feelings of stress or strain resulting from caregiving. It seems that the more positively a woman feels about her caregiving experiences, the more likely she is to embrace the role or title of caregiver. This suggests that positive attitudes toward caregiving create a stronger likelihood of self-actualization. In this context, I use the term *self-actualization* to represent the connection between one's actions in the social world and the way she conceives of herself in relationship to those actions. The more closely she identifies with her actions as a caregiver, the more a woman involved in caregiving has self-actualized this role.

For those caregivers who reported positive feelings toward the care recipient and positive caregiving experiences overall, a significant theme emerged as particularly

relevant as contributing to self-actualization of the caregiver role: the general safety of the care recipient and mutual enjoyment of shared hobbies and activities between the caregiver and care recipient, and how these contributed to the perceived relative ease of the caregiving experience.

Jackie discusses the positive feelings she had about caregiving that arose from her satisfaction in providing her mother safety:

Honestly, looking back, I didn't really think about it that much at the time, but when I think about it now, I think it was better that I was doing [caregiving] for my mom, because I didn't have to worry about someone else doing it for her. I didn't have to wonder if they were doing a crappy job—like if they were being too rough with her, or not making sure she got enough food, or had her—the books she liked around, or her room just a certain way, or whatever. If I was the one doing it, I knew she had things the way she liked, and also that she was safe, ya know, that she had someone who knew her physical abilities and...limits and...the things that she didn't feel safe herself doing. I was happy to be the one caring for her, because I knew that I could do it and she was getting all the things she needed and that she was as happy as she could be, at least as much as I could hope she was. And that made me feel really good, to be doing what she needed and what I could for her.

Jackie shows us how important it was to her for her mother to feel comfortable and secure in her space, and that knowing she was safe and well cared for was particularly gratifying for her.

Monica emphasizes the fact that having her mother in her home is pleasurable primarily because she can be physically closer to her, therefore giving Monica peace of mind that her mother is safe:

I absolutely enjoy having her here. And it's kinda nice to...you know, to be here for her, because, um...yeah. It was frustrating for me to be so far away, when she lived across the country, you know, cause I couldn't take care of her. It makes it easier, because then I don't have to worry about it. We have tough times, yes, but mostly it's really good. And I know how she is, how she is feeling, how she is sleeping, all of that, and it's just...easier this way.

This point is simple, but profound—it was “easier” and more desirable for Monica to be an active caregiver than not, because worrying about her mother was worse than taking care of her; the potential mental toll was that significant.

Alice, who has been employed as a caregiver professionally in addition to taking care of her own mother, discusses how the nature of her relationship to the care recipient affects her self-actualization as a caregiver:

When I look back, I guess I have, I mean I guess I kind of think about myself...um...and I hear more about caretakers, and I think, you know I am a caretaker, I never really thought about myself in that respect. I guess I did when I worked for the family in Lakeville, but um...not really with my mom as much, but now I see myself as a caretaker. People ask me what I do, and I say catering, but also caretaking, part-time work. But yeah, caretaking is definitely a...a skill and a job. But I'm happy to do it, because I love my mom and she's pretty easy to be with.

Alice's comment is informative—when she was employed as a professional caregiver, she thought of herself as a caregiver by title; initially, she was more reluctant to call herself a caregiver when she was caring for her mother, but that has changed with time. She also describes more positive feelings about caregiving because she has loving feelings toward her care recipient, and describes her as easy to be with.

Lisa describes a similarly positive relationship with her mother, and enjoyment at spending time together during certain activities:

And it's, it's great to be able to distract her, and be with her at the same time, you know, and see a change, and have her say, yes, that was great, I feel better, and work through it with her. We go to Walgreen's, and we'll go do errands. We...um...she really likes to shop. And um, we've been to lunch a couple times. Um...or we'll take walks, we'll walk up and down the street...oh, you know...I don't know, just being together, yeah. It's good to know I'm able to be that person for her, caring for her and helping her with the things she needs and also just spending time.

For Lisa, being able to see the influence of her care and to “just be together” was important to her as a caregiver and vital to her ability to self-actualize her caregiver role.

Cathy has a mother who moved in with her. She says that she enjoys her mother’s personality and that they share some hobbies and interests, and this makes it pleasant for them to spend time together:

I enjoy very much the fact that, you know, she appreciates the pets and the garden and the physical world and she’s a great observer and commentator on, on things she can see are happening, so it’s always fun to get her feedback, so I would say those kinds of things. She’s also a pretty voracious reader of the same type of material I read, so yeah, I really enjoy hearing what she’s liking and why she’s liking it, and mostly taking care of her, too. It makes it a lot easier.

Again, we see that when the caregiver conceived of the duties of caregiving or the relationship with the care recipient as “easier,” the burden of caregiving was minimized or seen as lesser by the care recipient.

If we can conceptualize that caregiving stresses are significantly lesser for caregivers who feel that their relationships with care recipients and experiences with caregiving work are more positive or easier, it’s logical then that women who face more struggles with their care recipients and caregiving experiences report challenges in their ability to self-actualize the caregiver role. This is especially apparent when women caregivers discuss the ways in which their caregiving burdens leave them feeling shortchanged on the time they are able to spend on themselves—time spent working, with their families and spouses, or on leisure activities.

Cathy discusses the implications of being the only person available to provide a social life for her mother, and imagines that her mother would feel more fulfilled if she had a peer community beyond the walls of the home they share:

Ideally she wouldn't be living with us; she'd be living in a place that had other people around because this woman is a real social butterfly. She loves being with people. When I take her in, you know, shopping with me, we usually stop at a couple stores, the library or something, and she will talk everybody up, and it's just so sweet, but it can be embarrassing, and you know, she'll be telling all sorts of stuff, and I'm like, Mom, these people have a job to do! I don't want to say that, but yeah, I would just love for her to be in a more physical place where she would have people to talk to, because she really enjoys it. She doesn't complain about being out here, I think she really wants to be out here and she tries very hard to be useful to us...she takes care of the pets, she washes the dishes, she contributes X dollars to the grocery bill, so yeah, she's holding up her part of the bargain, I just feel bad that she doesn't have more social contact, and my sister, she is nowhere to be found.

Cathy shows us the complexity of her feelings here. She has empathy for her mother, and recognizes her various contributions within the household, but she still feels a lot of guilt, and expects herself to meet all of her mother's needs—even those beyond Cathy's ability within her home—and to do so alone, since no other family members offer any help.

Joanne, who expresses strain in her relationship with her care recipient, struggles to find positive aspects of her caregiving experiences. She feels obligated to spend time with her mother, sometimes at the expense of time spent alone or working:

I have a lot of anger toward her for not taking responsibility for her situation. Mentally, she just can't do it anymore...the whole thing is just so awful, I'm just going nuts right now. There's still all this guilt during the day and feelings like I have to take my mom for a walk and bring her over to my house while I do work so I do that still. I can't concentrate when she's with me, because she always needs something, you wouldn't believe it. She's constantly fidgeting, needing something, asking the same question over and over...you can't get things done. And I can't help but think, I didn't sign up for this, you know. This is not what I saw for my life, for my...journey, or story, or adult...experience. Whatever you want to call it. To have to be the grownup in this situation, between my dad who doesn't give a shit, and my mom who can't do anything for herself but can't help it, either. And I just try to remember that, that it's not her fault, that she can't help it, and there's nothing I can do about it so I should just try harder to empathize, to be kind and nice and...just...better.

Like Cathy in the passage above, Joanne experiences a range of emotions—anger, guilt, a lack of concentration, and feelings of frustration and being overwhelmed—as a result of

her caregiving experiences, and her resistance to acceptance of the caregiver role as a result.

Joanne takes this point further, and deliberates on the sacrifices she and her partner have made due to the burden of her caregiving responsibilities since they began dating many years ago:

I feel like [caregiving] has taken up so much of our time, like on weekends for so long since we've been together...have been...taken up by, you know, trying to do activities with my mom, trying to provide her with some kind of social life that I don't have one of my own. I don't really miss out on that much, I mean with work or outside of my relationship with [my partner] but I wish I at least had time to give to [my partner] because she deserves it and she's put up with so much, as much as me pretty much, and that's not something just anyone could do.

Here, Joanne is giving credit to the patience and constancy of her partner throughout the duration of Joanne's years spent caring for her mother, acknowledging that not all spouses or partners would be willing to sacrifice the time and energy that has gone to caregiving activities over more enjoyable or relaxing recreation.

Beth discusses her complex feelings about her caregiving experiences and what they meant for the sacrifices she had to make in her personal life:

There was this point where all I was doing was just studying and going to class and taking care of my mom. I don't think I was sleeping hardly at all, and I never saw my husband, I mean really never, except when he was with me helping with my mom. We'd probably go weeks without spending more than ten minutes together, at least awake, and it was just miserable, and I remember not being able to get past that, that I was just miserable all the time and it felt like it would never stop. I remember having this icky self-awareness, that in a forgiving way, yes, I'm human, there's a limit to what I can endure here...but also not liking to see that, you know, 'cause at, no matter how tiring it was to take care of her, I always felt this tremendous compassion. My mother was such a giving soul. And...so that I would feel impatient was really, um...sad for me. I didn't like that about myself.

Beth's acknowledgement that she was "human" and therefore could only handle so much didn't negate her feelings of guilt at being exhausted and overwhelmed all the time, especially considering Beth's observation of her mother as a generous person. She noted her despair at missing out on time with her husband, and even on basic human needs like sleep, as a result of her caregiving responsibilities, and felt badly when admitting these emotions to herself.

Joanne confessed similar negative feelings that resulted from the demands presented by her daily caregiving responsibilities:

I'm surprised at how much anger I have. Because I feel like I, I am revisiting anger that I had growing up that I didn't have as an adult, like I'm in my own little world, and um...and it scares me. I mean, I don't like...the person I become when I'm pushed to the limits and nobody pushes me to the limits like [my family]. Including my mom.

Joanne's comment is insightful on both micro- and macro- levels of sociological theory. To admit that you "don't like the person you become" reminds us of the flexible and complex nature of identity; that identity is again not a fixed or permanent state of being, but rather an ever-changing process of evaluating the self within various social contexts. It suggests a change from the state of being a person you accept and like to someone you don't accept and dislike. To "not like" your conceptualization of your personhood within a given context, such as caregiving for an aging parent, then, is to reject the qualities ascribed to the particular role, and to ultimately fail to self-actualize the caregiver role.

Another situational force that kept caregivers from self-actualizing their roles was the amount of discontent they expressed regarding the metaphorical weight that their caregiving responsibilities held, and the limits they imposed for the caregiver's lives.

Beth describes this idea using the analogy of a car running on empty to reflect her feelings about the intense demands of caregiving for her mother:

I remember being painfully aware when my mom was sick and I was...so grief-stricken for so long, just every day was an absolute drain on me, but I remember thinking on many occasions that I just wish I knew when this was going to end so I could pace myself. I just had that sense of, I am running on empty, and empty, and empty, and empty, and something is going to break...and I don't know if I can keep putting in enough fuel to keep the car going, so to speak, til something breaks. I hated feeling that way, that it would have been easier to just know when she was going to go, when it would all be over and I'd be able to have a life again. But it was the truth, and that thought just consumed me for such a long time. It made me hate that part of me that couldn't handle this anymore...I know I just wanted my freedom back and rationally I knew that was not so much to ask for, but it felt like the shittiest realization, you know? And selfish, just really selfish.

The gravity of this statement is undeniable. The analogy of feeling so exhausted that you're like a car running on fumes, while not necessarily shocking or novel itself, is particularly salient in this case; Beth is making a bold statement admitting that she felt ready for her mother to die, or at the very least, ready to know it was going to happen, so she could intentionally limit the amount of energy and resources she was giving through her care. By having an end in sight, Beth felt she could pace herself and not be in the position of speculating when she might get her life back.

Lisa echoes very similar feelings when detailing her feelings of the burden imposed by her caregiving responsibilities:

I remember talking about my mom and I said to [my therapist], I said I feel as though...I am...I don't know the proper term for these things, but...a, a box, you know, like a pallet or something, uh...slats of wood, and people keep putting more and more weight on this box, and the box on the outside looks just fine, and it's always smiling, and I'll do what you ask me to do or need me to do, but at some point, this box is going to break, and it's gonna surprise everybody, because nobody realizes...the weight that's on this box.

Lisa takes the concept of the metaphorical weight of caregiving a step further by mentioning how unaware others around her were of the toll her caregiving duties took from her, and the degree to which she was practicing impression management through smiling and being dutiful and devoted at all times despite the heavy burden her caregiving responsibilities caused.

Joanne expressed a parallel awareness very succinctly, stating:

I remember talking about I feel like I'm a fridge and at some point they keep going in and pulling out, and keep going in and pulling out, and they keep going in and pulling out, but I'm not restocking the fridge, and they're not restocking the fridge and at some point this is going to be empty.

Not only does Joanne feel that she's approaching a breaking point (the "fridge is about to be empty"), she acknowledges a failure to keep "restocking" the fridge, which is the only logical solution to keep herself (the "fridge") going.

Using these analogies—a car running on fumes and approaching breakdown, a pallet weighed down by heavy boxes, a fridge that doesn't get restocked and is nearly empty—seems to be a deliberate strategy caregivers utilize to distance themselves from the very complex human aspects of the delicate yet intensive nature of caregiving work, and to help others to understand what it feels like to be so heavily burdened by the expectations on the caregiver by herself, her family, and her social world. When she feels overwhelmed by her duties and unsupported by other people, the heaviness of caregiving responsibilities and expectations contribute to a caregiver's inability to self-actualize her role as a caregiver.

As this section has shown, women taking care of their aging parents in addition to balancing the challenges presented by their personal and professional lives engage in

identity work; their stories have shown us that identity is not fixed or stable, but rather an ongoing and constantly evolving process that forces a dynamic relationship between actions, thoughts, feelings, and emotions. The actions, thoughts, and feelings produced by caregiving demand renegotiation of the self. Consequences of identity work for women caregivers include the management of many roles, such as mother, daughter, sister, worker, and caregiver, among others, and often require a reversal of roles, particularly in certain caregiving activities and within shared spaces of homes. Feelings about the caregiver identity result in either an acceptance or rejection of the caregiver role; more positive experiences with caregiving and with the care recipient suggest a greater likelihood for the caregiver to self-actualize the caregiving role.

CONCLUDING COMMENTS

The analysis of the data collected from this study shaped two prominent themes. The first theme is that caregiving is a gendered experience, and a person's gender impacts two major aspects of her caregiving experience—the kind of activities she performs, particularly in meal planning, hygiene, grooming, and health needs—as well as the expectations a caregiver holds for herself and her family in her role in caregiving. These kinds of activities and expectations are structured by gender norms, and the previous discussion of the actions of caregiving and corresponding thoughts of women caregivers in regards to these actions and the expectations they sense demonstrate that caregiving is a gendered experience.

The second theme that emerged was that women taking care of their aging parents in addition to balancing the challenges presented by their personal and professional lives engage in identity work. In sociology, we understand that identity is not fixed but rather an ongoing and constantly evolving process that forces a dynamic relationship between actions, thoughts, feelings, and emotions. Caregiving identities can be discussed in exploration of three capacities—role management, role reversal, and self-actualization. Women caregivers occupy many roles and express a desire to “do it all” while achieving balance in their roles, and they sometimes acknowledge a “missing” role they've had to sacrifice for their caregiving responsibilities. Adult daughter caregivers also experience role reversal through the routines of active caregiving, especially those that are dictated by the needs of everyday life, and through shared spaces. Finally, I discussed the impact of the positive or negative nature of the caregiving experience on a caregiver's negotiation and self-actualization of the caregiver identity.

The purpose for this research was to gain a greater understanding of the sociological processes and dynamics underlying the experiences of women taking care of their aging parent(s). Interviewing women who actively engage in caring for their adult parent(s) helps to gain greater insight into how caregiving is a gendered experience, the ways in which women caregivers engage in identity work, and the impact of the caregiver's relationship with the care recipient on the caregiver, her personhood, and her experiences in caregiving.

SUGGESTIONS FOR FURTHER RESEARCH

This study focused solely on women who engage in active caregiving. As I mentioned earlier, women comprise the majority of those people providing care for a growing elderly population; nearly three-quarters of those caregiving for an aging parent are women. In this study, I have examined the gendered activities and expectations that shape this phenomenon as a social norm, and discussed the kinds of identity work in which women caregivers actively engage.

A logical comparative study would examine the experiences of men who are caregivers for their aging parent(s). The more I investigated the experiences of caregivers and expanded my network of connections of people providing informal caregiving, the more men I became acquainted with who were performing some of the same caregiving activities and services for their aging parent(s) as their women counterparts³.

A primary question guiding my research considered the possible effects of gender on the type of caregiving activities women often perform—specifically, does a person's gender affect the types of caregiving activities she performs, and if so, what caregiving activities are typically performed by women, and why? The results of this study suggest that gender indeed plays a role in the kinds of activities caregivers perform, and for women, those activities align with traditional gender roles and expectations, particularly those that involve the needs of daily living such as meal preparation and hygiene. Therefore, logic would suggest that asking this same question of men performing caregiving would likely indicate that men, too, perform specific activities within

³ My paternal uncle, Peter Hurd, is one of these men; he has been providing various aspects of informal caregiving for my grandparents for the better part of a decade, increasing the scope of his caregiving activities with the level of need.

caregiving that correspond with expectations based upon their gender identification and presentation.

Similarly, it's likely that men performing caregiving would face struggles to manage many roles in comparable ways reported by their women counterparts. Men too often fulfill the roles of father, husband, son, and worker, among others, simultaneously, and any additional role, such as that of caregiver, would add to the pressure to balance multiple roles and attempt to do everything, and do everything well.

Utilizing identical research methods of open advertising, purposive and snowball sampling to locate respondents and holding semi-structured interviews would help obtain information about the experiences of men caregivers, and would provide content suitable for comparative qualitative analysis.

An additional study that would prove fruitful for comparative analysis would involve a cross-cultural study of women caregivers. In many ethnic groups and cultures around the world, it is not uncommon for multiple generations of families to be living together under the same roof in a system where many people are communally caring for one another in various ways, from sharing the cooking, cleaning, and laundering loads, helping to raise children, and operating family farms and businesses. This has been the arrangement and lifestyle of family structures in managing households for hundreds of years in many places around the globe. Caregiving that occurs typically outside the home of the caregiver is a Western world phenomenon, both in situations where the care recipient remains in his or her home or relocates to a facility that specializes in senior living.

I would be curious to conduct a study that would explore the lives of women for whom caregiving is a cultural way of life, where it isn't the exception but rather the rule, particularly in regards to their opinions of the role of gender and identity in their caregiving experiences. The two participants I interviewed who didn't identify as White-Caucasian (one identified as Asian-American, and one identified as European-American) both believed that they didn't really feel that gender played a significant role in their caregiving activities or the expectations of them as caregivers, and that even when it did, they considered it acceptable or appropriate, stating opinions that seemed to suggest, *This (caregiving) is just what women, and women in my family, do, and that's okay*. This was particularly notable because it contrasted entirely with the opinions expressed by all of the other caregivers in the study (ten women who identified as White-Caucasian), who felt that gender played a role in their caregiving activities and expectations, and a highly substantial one, at that. This remarkable contrast could be an anomaly, but I would imagine it is likelier reflective of a larger trend, one that is perhaps rooted in cultural expectations of gender roles in regards to caregiving activities and expectations. Gathering a significantly larger participant pool would almost certainly result in a more representative sample and would provide for fascinating comparisons and conjecture about the roles of gender and identity in cross-cultural caregiving experiences.

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Appendix A

**Minnesota State University, Mankato Application for the Conduct of Human
Research**

ADD YOUR INPUT AND LEAVE EVERYTHING ELSE ON THIS FORM AS IT IS

University policy requires that all research involving human participants be reviewed by the Institutional Review Board (IRB). In completing the application, be aware that the persons reviewing it may be unfamiliar with the field of study involved. Present the request in non-technical terms. Incomplete proposals will be returned without review. Data collection may not begin until approval is received from the IRB.

To facilitate a timely review, please make sure all spelling and grammar are correct. After you complete this form, please upload it on IRBNet, electronically sign it (click “Sign this Package”), and submit it (click “Submit this Package”).

1. **Project Title:** A Labor of Love: Women’s Perspectives on Gender and Identity in Informal Caregiving
2. **Key Personnel:**
 - a. **MSU Faculty/Staff (NOT ADJUNCT) Principal Investigator (PI) Name:** Dr. Emily Boyd
Department: Sociology and Corrections
Campus Mail Code: AH 113 (Office Q)
Phone Number: ext 1375
Email: emily.boyd@mnsu.edu
PI is a salaried MSU Employee (not adjunct): Yes No
 - b. **Co-PI Name:**
Department:
Campus Mail Code:
Phone Number:
Email:

- c. **Student PI Name:** Kirby Hurd
Department: Sociology and Corrections
Campus Mail Code: AH 113
Phone Number: 507.351.6668
Email: kirby.hurd@mnsu.edu

3. Project Information

- a. **Has this project previously been approved by the MSU IRB?** Yes,
 IRBNet ID#: No
If yes, please submit a revision rather than a new application.
- b. **Has this proposal been submitted to another human subjects committee?**
 Yes No
- c. **Has this proposal been approved by another human subjects committee?**
 Yes No
If yes, please include a copy of approval letter.
- d. **Will results be presented beyond class presentations (e.g., submitted for presentation or publication including thesis, Alternate Paper Plan, dissertation or presentation)?**
 Yes No
- e. Do you wish to use an MSU email distribution list (e.g., send a survey to all students) to recruit participants? Yes No
 If you responded yes, please indicate whether you have access and permission to use this distribution method.
- f. **Funding Source**
 MSU Funding Source:
 Non-MSU Funding Source:
 No Funding
- g. **Provide a concise statement of the purpose for the research.**
 The purpose for the research is to gain a greater understanding of the sociological processes and dynamics underlying the experiences of women taking care of aging parents.

4. Archival Data

a. **Is archival data being used? If yes, please complete the remainder of section 4 and then continue to section 8. If not please go to section 5.**

Yes No

b. **Describe the source of the data.**

c. **Describe how the identity of participants will be protected.**

5. Potential Participants

a. **Will participants be under age 18?** Yes No

b. **Are you specifically recruiting participants because they are pregnant women?**

Yes No

c. **Are you specifically recruiting participants because they are people with cognitive impairments?** Yes No

d. **Are you specifically recruiting participants because they are prisoners/incarcerated people?** Yes No

e. **Are you specifically recruiting participants because of their membership in marginalized populations (e.g., ethnic minority, low socioeconomic status, differently abled; if yes, explain what populations and why they are chosen)?** Yes: No

f. **Do any of the researchers have a pre-existing relationship (e.g., supervisor, instructor, coach, advisor) with the potential participants?**

Yes No

If yes, please explain the relationship and how the participants will not feel pressure to participate.

6. Procedures

a. **Where will the research be conducted? If data will be collected online through another organization or off campus, obtain a dated, signed letter indicating permission from the institution/organization (on official letterhead) to allow the data to be collected at that location after you receive IRB approval, then upload it to IRBNet.**

The research will be conducted through off-site interviews of qualifying participants. Coffee shops, parks, libraries, and other public spaces will be

utilized as locations for interviews; every effort will be made to accommodate the candidate's first choice in meeting location provided it meets the boundaries and agreements of the consent form. If a candidate expresses interest in participation and qualifies for an interview but is unable to meet in person due to distance or time restraints, a phone interview would be conducted using the same set of interview questions; subsequently, consent forms will be mailed, emailed or faxed and reviewed by the student investigator prior to the start of the phone interview.

b. Describe how participants will be recruited, including how researchers will first contact potential participants (including how their contact information will be obtained, if applicable), script and/or recruitment materials.

Participants will be recruited using the following three methods:

- 1) The student PI will post a flyer (see attached document Flyer A) on www.craigslist.com. Under the “volunteers” section of the website, the student PI will ask for study participants; if an interested respondent meets the listed criteria for the study, they will be encouraged to contact the student PI.
- 2) Purposive Sampling—The student PI will be looking for women who have experiences in taking care of their aging parents. She will announce this goal in routine interactions with others in her daily environment with the hope of finding participants; should an individual express interest in participation, she will be evaluated for the study criteria. Individuals who meet study criteria and voluntarily offer to participate will be invited for interviews. If interactions or interviews revealed an additional potential interviewee (someone “knows of” another woman who would meet the

study criteria), the student PI's contact information would be passed along and the third party would be invited to contact the student PI if she wished to participate.

- 3) Snowball Sampling—When a participant has been found, consented, and completed an interview, the student PI will ask that participant to pass along the student PI's contact information and flyer to any other women she may think fit the study criteria. These potential respondents then may choose to contact the student PI if they wish to participate in the study.

c. What exactly will participants be asked to do? Include participants in any control condition, a description of research procedures, data collection tools, time commitment, and anything else that might be pertinent.

Participants will be interviewed by the student PI under the supervision of the PI. Prior to the start of the interview, the student investigator will review the consent form with the participant by reading its content aloud, asking the participant if she agrees to its terms, and obtaining a signature and printed name of the interviewee. The interview will likely last between 45-90 minutes depending on the depth of answers to interview questions; additional or follow-up questions may be asked as seen fit to gain greater insight into or clarification of a particular phenomenon, as in a typical semi-structured interview format. Per the terms of the consent form, all consenting participants will agree to the use of a recorder for transcription of dialogue purposes; all transcription will be performed by the student investigator post-interview to ensure the confidentiality of participants. Additionally, the student investigator will use paper and pen for note-taking purposes. All written recordings and notes will be destroyed after the completion of the project to ensure participant confidentiality; audio recordings will be deleted after the transcription process is finalized.

- d. If this study will involve deception, is a clinical trial, or might otherwise have an ambiguous end time, how will participants know when the study has ended?**

[X] Not applicable

- e. What are the potential risks participants may encounter, and how will you ensure these risks are managed and minimized (risks can include but are not limited to physical or mental harm, stress, discomfort, undesirable social, economic, and/or financial consequences)?**

Potential harmful risks to participants in this study would be minimal. Talking about sensitive and personal information always carries the possibility of psychological discomfort. The student investigator will ensure risks are minimized by reminding the interviewee that participation is entirely voluntary, and that the interviewee may stop the course of the interview at any time should it become psychologically distressing or uncomfortable.

- f. What are the potential benefits to the participants of participating in the study?**

Potential benefits to the participants in this study include but are not limited to sharing deeply meaningful and important experiences with a student researcher, mutual expression of interest in the important issue of caregiving, and reinforcing the value of caregiving to self, family, and society.

- g. What are the potential benefits of this research for society?**

Potential benefits to society are plentiful. Interviewing women caring for their adult parents would help to gain greater insight into how women balance their personal lives with their caregiving responsibilities, how it affects them and their families financially, and the kind of identity and emotion work that is

done by women caregivers. This research is especially important at a time in which the “baby boom” generation is aging and needing more assistance in all realms of their lives, assistance that often becomes the responsibility of adult children.

- h. Will compensation be given to participants (e.g., money, extra credit, gift cards; if yes, please describe)?** Yes: No
- i. How will the privacy, confidentiality, and/or anonymity of participants will be protected?**

Confidentiality of participants will be maintained at all times, from the beginning of the research process to the academic presentation of findings. Participants will be assigned pseudonyms within both written transcripts and all presentation of findings, including publications. All written and audio recordings will remain in the possession of the student investigator at all times throughout the duration of the study. Audio recordings will be deleted immediately after they have been transcribed, and all written recordings will be kept in the PI’s office for three years and then destroyed via shredder. This information will be presented in the consent form, which will be recognized and signed by the participant.

7. Consent

- a. Will you be seeking a waiver of consent (i.e., research will be done without seeking the consent of persons whose records/tissue are analyzed)? If yes, please explain why.** Yes, because:
 No
- b. Will you be seeking a waiver of documented consent (i.e., consent obtained but there is no signed consent form)? If yes, please explain why.**
 Yes, because: No
- c. When and how will you obtain informed consent?**

The student investigator will obtain informed, written consent prior to the start of all interviews. The student investigator will read the consent form aloud to the participant, while the participant follows along with her own matching sheet. The participant will be asked if all information is understood and if there are any questions prior to the beginning of the interview; if questions should arise, they will be addressed before commencing the interview. The participant will be reminded that participation is entirely voluntary, and that she may choose to end the interview or skip a question at any time, without any questions asked or any ramifications, and that if the participant at any time becomes uncomfortable or distressed, to make the student investigator aware so that she may end the interview in an appropriate manner. The interview will not begin until the consent form is signed with a printed name; without a signed consent form, an interview will not be conducted.

- d. The Principal Investigator will ensure that signed Informed consent/assent records of the participants are kept in a secure location at Minnesota State University, Mankato or satellite site for at least three years after the completion of the research. Where will they be kept?**

Not applicable

Name of Person Responsible: Dr. Emily Boyd

Location (Campus address or other university site): Armstrong Hall 113,
Office Q, Minnesota State University, Mankato

8. Attachments (check and include at the end of this document all that apply)

Approval from another IRB

Consent Form/Statement

Assent Form/Statement

Cover letters, recruitment scripts, flyers or other information that will be given to participant prior to participation in the study

Any other relevant or supporting documentation, including questionnaires:

Permission Letter from Cooperating Agency (after approval from IRB)

The electronic signature of the PI is required before the IRB can review the submission. On the left side of the page in IRBNet you will find the link “Sign this Package.” Click the link, “Sign this Package,” answer the questions that appear, and submit it. By electronically signing the IRBNet proposal, I agree to the following:

“In making this application, I certify that I have read and understand the Minnesota State University, Mankato IRB Manual, and that I intend to comply with the letter and spirit of the University Policy. Changes in the protocol will be submitted to the IRB for approval prior to these changes being put into practice. Informed consent/assent records of the participants will be kept by the Principal Investigator in a secure location at Minnesota State University, Mankato for at least three years after the completion of the research.”

Appendix B

Informed Consent Form

I freely and voluntarily give my consent to be a participant in this research project, “A Labor of Love: Women’s Perspectives on Gender and Identity in Informal Caregiving.” This research is being conducted by Kirby Hurd, a graduate student, under the supervision Dr. Emily M. Boyd, a sociologist at Minnesota State University, Mankato. I recognize that the purpose of the research is to understand how women balance their personal lives with their caregiving responsibilities, how it affects them and their families financially, and the kind of identity and emotion work that is done by women caregivers. My decision whether or not to participate in this research will not affect my relationship with Minnesota State University, Mankato.

Potential risks that could arise would be stress related to an honest interview about the personal issues underlying caregiving experiences. Potential benefits include honest reflection on my experiences and contributing to a greater understanding of how caregiving affects women.

I understand that I will be interviewed about my experiences by Kirby Hurd, who will keep my responses confidential. I understand that nothing I say will be associated with my name or used in any way that will identify me. I understand that I will be asked to participate in a 45-90 minute one-on-one interview that will be recorded on a secure audio device. I understand that I may refuse to do either or both. I understand that any recordings of my comments will be transcribed for research purposes only and then destroyed; a pseudonym will be used instead of my name in written transcripts. Interview transcripts will be stored on Kirby Hurd’s password protected, encrypted professional computer for the duration of the research, upon which time they will be deleted or otherwise digitally wiped from the machine. This consent form will be kept on file in Dr. Boyd’s faculty office for 3 years and then destroyed through a shredder.

I understand that I may withdraw from participation in the research without penalty or loss of benefits at any time by saying I wish to stop, withdraw, or refuse to answer a particular question.

If I have questions, I understand that I can contact Dr. Emily Boyd by phone (507-387-1375) or by email at emily.boyd@mnsu.edu. If I have any questions or concerns regarding the treatment of human subjects, I should contact: Dean Barry Ries, Vice President of Research, at Minnesota State University, Mankato, 115 Alumni Foundation, (507) 389-2321.

In checking the following categories, I indicate my willingness to participate in Kirby Hurd's research project under the supervision of Dr. Emily Boyd:

- I agree to be interviewed one-on-one.
- I agree for my interview(s) to be audio-taped.
- I have received a copy of this consent form for my records.

Interviewee signature: _____

Date: _____

Researcher signature: _____

Date: _____

Appendix C

Graduate Student Seeks Adult Women Volunteers for Interview Study



My name is Kirby Hurd and I'm a graduate student at Minnesota State University, Mankato. I am seeking volunteers for a sociological study about women who are caregivers for their adult parents. I will be conducting the research under the direct supervision of Dr. Emily Boyd, a tenured faculty member in the Department of Sociology and Corrections at Minnesota State University, Mankato. I am looking for adult volunteers who meet the minimum following criteria:

- 1) You are a woman who currently is or previously has been responsible for some aspect of caring for your adult parents as part of your regular lifestyle.
- 2) You perceive your caregiving responsibilities have affected your life in some manner.
- 3) You must be able to meet with me, the interviewer, in person, or have access to a phone to use for the duration of the interview.

The interview will last approximately 45-90 minutes and will be conducted in a public place that both the student interviewer and the interviewee will agree upon, or over the phone as necessary. Your name and any additional identifying information will be kept confidential during the interview process and in the final presentation of findings.

If you are interested in participating in this study, please contact me directly at kohurd@gmail.com or 507.351.6668.

Thanks for your time and consideration; I look forward to hearing from you.

Appendix D

Semi-Structured Interview Guide

- 1) I'm most interested in your caregiving experiences, but may I have a bit of background information about your life? Anything and everything you'd like to share.
- 2) Can you tell me about the people with whom you currently live?
- 3) Are you in a romantic relationship/s (dating, marriage, partnership, civil union, etc.)? Can you tell me a bit about that relationship (how long you've been together, how you view the state of your relationship/s, how you perceive your relationship/s to be affected by your caregiving responsibilities, etc.)?
- 4) Do you have children? Can you tell me about your children (their ages, sex/gender, personality characteristics, how you view the state of your relationship/s, how you perceive your relationship/s to be affected by your caregiving responsibilities, etc.)?
- 5) What are your educational and professional backgrounds? Are you currently working outside the home? If so, can you tell me a bit about your job (what you do, how long you've been working there, what your hours are like, etc.)? How do you feel about your job?
- 6) You are involved in caregiving, correct? Can you tell me about the person you care for? (Don't assume it's a parent/spouse's parent.) What is your role in their care (what do you do for them)?

- 7) Can you take me through a typical day in your life?

- 8) Is balancing work/family/caregiving hard for you? Can you give me an example?
What would you say is most challenging for you?

- 9) How do you “deal” with managing these responsibilities? Do you have particular strategies for managing stress that results from caregiving in particular or the challenges presented by your everyday life?

- 10) Are your current caregiving responsibilities different from those of the past? If so, in what ways?

- 11) Do you anticipate your caregiving responsibilities to change in the future, in terms of having to take on either more or fewer responsibilities?

- 12) What would you say is different about you before you started caregiving? After? Have there been changes in how you see yourself? Have others expressed seeing you change? How does this make you feel?

- 13) Did you anticipate the feelings that would arise from your changed responsibilities as a caregiver, or did they surprise you? In what ways?

- 14) What about how you generally feel—can you compare your emotions “before” caregiving and “now” as a caregiver? What emotions have changed? Have any increased, or decreased?
- 15) What, if anything, do you feel you have learned from or discovered about your feelings, emotions, and self-identity that have resulted from your caregiving responsibilities? Do you think of yourself in different terms now than you did in the past? If so, in what ways?
- 16) Have your caregiving responsibilities impacted or changed the major relationships in your life (those with your children, your romantic partner, your friends, other family i.e. siblings, coworkers, etc.)? If so, in what ways?
- 17) Are there things you enjoy about being a caretaker? If so, what things? Are there things that are especially hard about being a caretaker? If so, what things?
- 18) What, if any, kinds of skills do you feel you have developed through your caretaking responsibilities? (For example—increased empathy, navigating healthcare systems/insurance plans, becoming familiar with federal initiatives such as Social Security, etc.)
- 19) Do you feel like you have social support networks in your current life? If so, can you tell me about them (who they are, in what ways you perceive them to be supportive, how often you see them)?

20) Do you feel that social norms and expectations regarding gender play a role in your caretaking responsibilities? If so, in what ways? Have you always felt this way or has your opinion changed with time?

21) Is there anything that I haven't asked you that you'd like to share with me?

Appendix E
Interview Schedule

Date of interview, respondent name

Type of interview (phone or in-person), length of interview

9/22/14: Joanne
Phone interview, duration 2 hours, 25 minutes

10/6/14: Monica
In-person interview, duration 2 hours, 12 minutes

10/27/14: Cathy
Phone interview, duration 1 hour, 32 minutes

11/3/14: Alice
Phone interview, duration 1 hour, 16 minutes

11/14/14: Beth
In-person interview, duration 2 hours, 50 minutes

11/20/14: Heather
Phone interview, duration 1 hour, 6 minutes

2/15/16: Lisa
In-person interview, duration 3 hours, 22 minutes

3/5/16: Jillian
In-person interview, duration 2 hours, 45 minutes

3/6/16: Cindy
In-person interview, duration 2 hours, 37 minutes

4/10/16: Celeste
In-person interview, duration 2 hours, 16 minutes

5/22/16: Jackie
In-person interview, duration 1 hour, 56 minutes

7/26/16: Maureen
In-person interview, duration 2 hours, 35 minutes

Appendix F
Respondent Statistics

Respondent name, respondent age, respondent occupation, care recipient(s)

Joanne, 51, self-employed store owner, both parents

Monica, 68, retired, mother

Beth, 52, psychology professor/therapist, both parents

Alice, 58, caterer, mother

Cathy, 70, medical sociologist, mother

Heather, 64, customer service manager, mother

Lisa, 55, office administrator, mother

Cindy, 64, social worker, mother

Jillian, 67, at-home parent, mother

Celeste, 69, teacher, mother

Jackie, 55, medical technician, mother

Maureen, 54, teacher, mother