RURAL MALE CAREGIVERS:
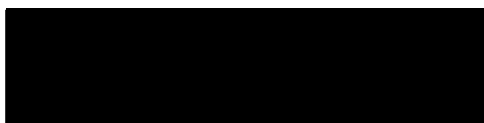**EXPERIENCES, MEANINGS, AND PROCESSES**

By

Chad E. O'Lynn

A Dissertation

Presented to
Oregon Health & Science University
School of Nursing
in partial fulfillment
of the requirements for the degree of
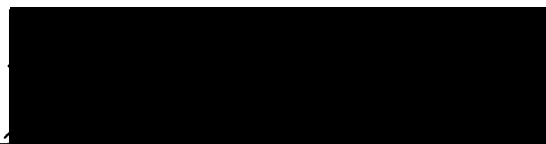Doctor of Philosophy

September 10, 2006

APPROVED:

Deborah Messecar, MPH, PhD, RN, CNS,   Dissertation Chair

Judith Kendall, PhD, RN, Committee Member

Helen Lee, PhD, RN,   Committee Member

Saundra Theis, PhD, RN, Dean, School of Nursing

Acknowledgements

I wish to sincerely thank the members of my dissertation committee for their encouragement, interest, support, and mentorship to me throughout this project. In addition, I wish to thank the faculty of the College of Nursing, Montana State University-Bozeman, Missoula Campus for their patience with me while developing and implementing this study, as well as for inspiring me to pursue research with rural populations. And most importantly, I want to thank the men who participated in this study. I will always remain in awe at their candor, openness, and eagerness to help other men caring for loved ones at home.

ABSTRACT

Title: Rural Male Caregivers: Experiences, Meanings, and Processes

Author:

Deborah Messecar, MPH, PhD, RN, CNS

Considering the realities of an aging American population, the anticipated

growing need for informal caregivers, the substantial numbers of men caring for loved

ones at home, and the challenges of health and human service delivery in rural areas,

nurses should be concerned that virtually nothing is known about how rural men

implement caregiving. The paucity of knowledge regarding this group of caregivers may

mask a looming men's health issue, which if not explored, will affect these men and their

care recipients. This qualitative study used constructivist grounded theory methods to

explore the experiences and process of caregiving for rural men. Twelve male caregivers

residing in frontier areas of Montana and Oregon, recruited from newspaper

advertisements, provided interviews lasting from 45-120 minutes in total. The

participants had provided care to female family members for between 1-28 years. From

the data, a theoretical model was constructed proposing how rurality and rural

masculinity influence caregiving. For these participants, challenges attributed to

caregiving, rural masculinity, and rurality increased stress and pushed caregivers toward

crisis. Resources attributed to financial sources, rural masculinity, and rurality reduced

stress. Increased caregiver demands required participants to adopt perspectives and

behaviors inconsistent with constructed gender. With increased levels of stress,

participants negotiated conflicts with constructed gender in one of three ways: gender

conflict preservation, which facilitated movement toward caregiver crisis; gender

compromise, which facilitated a state of accommodation in which men tolerated gender

conflicts in order to achieve completion of caregiver tasks; or gender reconstruction,

which facilitated a change in individual constructed gender and led to a state of

resiliency. This latter process instilled a realization of the importance of the affective

quality of the caregiving experience. Participants did not negotiate rurality attributes in a

similar fashion. A generic model was proposed for transferability to other caregiver

populations. Uniquely, this study considers gender and culture as holistic contexts and

offers a theoretical explanation to the behaviors and perspectives involved with male

caregiving over time. Health and human service providers should examine attributes of

constructed gender and culture for the appropriateness of fit of caregiver support services.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER 1: INTRODUCTION

Americans are getting older according to the U.S. Census Bureau, with 20% of all Americans expected to be over age 65 by 2030. Associated with increased age is the increased incidence of chronic health conditions requiring caregiving services. Most of this caregiving is provided by family members, especially for frail elders living in community settings. It is anticipated that with the increased number of elderly Americans, the importance of caregiving will increase for families and health professionals.

Researchers have responded to the growing importance of family caregiving to society by studying many aspects of this phenomenon. However, family caregiving in rural communities remains poorly understood. Health care resources and support in rural communities are stretched thinly. Since certain subgroups of family caregivers have been understudied, the growing number of intervention studies based on current descriptions and theoretical models of caregiving may not generalize to all caregivers groups, and particularly may not be applicable to existing resources in rural communities.

Of all subgroups of caregivers, perhaps the most understudied are rural male caregivers. In order to help address this problem, the purpose of this study was to explore caregiving provided by an understudied group of caregivers, namely rural men and to generate theoretical concepts applicable to this caregiver group. The hypotheses and concepts generated from this study were used to support and/or critique existing theoretical models of caregiving, particularly in how robust these models are in explaining the caregiving experiences of rural men. This critique is requisite in order to

develop appropriate, acceptable, and efficacious caregiver support strategies and interventions for this population.

The importance of female family caregivers as a resource to older adults is well-documented historically. However, within the large body of caregiver literature, relatively less attention has been given to the unique conditions, needs, and experiences of male caregivers. Although less than the prevalence of female caregivers, estimates of the percentage of male caregivers have been variable, but cluster around 30% of all family caregivers. Conservatively, over 12.5 million American men are caring for dependent adults. The overall number of male caregivers is expected to increase as the number of elderly Americans increases and the number of female family members traditionally filling caregiver roles decreases. Just as with women, caregiving is associated with negative health changes for men. Consequently, increasing numbers of men providing caregiving may present a growing men's health concern.

The concern for men's health as a result of caregiving is magnified in rural communities, since rural dwellers already experience more health problems than do non-rural dwellers. This disparity in health is primarily due to barriers in accessing health services and information as a result of distance and/or lack of available resources in rural communities. Thus, rural male caregivers may be at higher risk for negative health changes and poorer caregiver outcomes than are non-rural male caregivers.

Virtually nothing is known about rural male caregivers, since previous studies have rarely used rural men in their samples. This point is important in that rural men may desire and require different caregiver support services than their non-rural counterparts. For example, in a preliminary study completed by the researcher, hunting was a major

leisure activity and the requested form of respite. This activity has thus far not been discussed in the caregiver literature. In addition, the men in the preliminary study noted that due to the importance of self-reliance, independence, and masculine hardiness in their peer groups, these caregivers felt that they could not share their problems and concerns with local peers. These men viewed themselves as solitary soldiers in their struggles, which were magnified by their distrust of local health care providers.

Given the lack of knowledge of caregiving provided by rural men, exploratory research is needed to understand the experiences of these men and the processes they employ in addressing caregiving responsibilities. Exploratory research is necessary to provide a valid and grounded theoretical base for future meta-analyses, quantitative inquiry, and intervention studies with rural male caregivers. As such, this study adopted a qualitative and exploratory approach.

The specific aims of this study were as follows:

1. to explore the meanings and experiences of caregiving from the perspectives of male caregivers in rural communities;

2. to explore the processes used by rural male caregivers as they progress through the caregiving experience;

3. to explore the effects of caregiving on caregiver health and ability to provide on-going caregiving from the perspectives of rural male caregivers;

4. and, to develop a theoretical understanding of how male gender and rurality affect caregiving by initially examining rural male caregivers.

Significance to Nursing

As a holistic and applied health profession, nursing is concerned with all aspects of internal and external environments that might affect the health of individuals and communities. Considering the realities of an aging American population, the anticipated growing need for caregivers, the substantial number of men providing care to loved ones in home settings, and the challenges of health and human service delivery in rural areas, nurses should be concerned that virtually nothing is known about how rural men implement caregiving work. The paucity of knowledge about this group of caregivers may mask a looming men's health issue, which if not addressed, will affect not only these men, but their care recipients as well.

Nurses are frequently the first point-of-contact with the health care system for many individuals. As such, nurses must have practical and community-appropriate information to address health and quality of life issues for their clients. This study will assist rural nurses in detecting potential problems, identifying existing client strengths, and in working with other health and human service professionals to develop strategies that will be appropriate and acceptable to rural male caregivers as these men strive for optimal caregiver outcomes.

CHAPTER 2: REVIEW OF THE LITERATURE:

BACKGROUND AND SIGNIFICANCE

Introduction: General Approach to the Literature Review

The dominant knowledge base supporting this study is the informal caregiver

literature. Although the exact description of who is an informal caregiver and who is not

an informal caregiver has been lacking in the literature (Barer & Johnson, 1990),

'informal' generally refers to an unpaid status. Informal caregivers are frequently family

members of the care recipient, and usually provide a variety of assistive and protective

tasks for the care recipient in a home setting. In addition, informal caregivers have been

defined as adults caring for other adults, thus does not include the usual parental or

spousal relationship (MetLife Mature Market Institute, National Alliance for Caregiving,

& Center for Productive Aging, 2003; National Alliance for Caregiving & American

Association of Retired Persons, 2004; Stone, Cafferata, & Sangl, 1987). Heretofore, the

term *caregiver* will refer to an unpaid provider, and *caregiving* to the services they

provide.

The caregiving literature is voluminous. Scores of manuscripts and reports

examining caregivers and their work have been published over the past four decades. An

exhaustive critique of each of these works would be a gargantuan task that would not

necessarily strengthen the conceptual foundation or the need for this study. As such,

several published reviews will be included to summarize the general caregiver literature

to be followed by a more in-depth discussion of the caregiver literature pertaining to

selected variables common to many caregivers.

The rural environment is the context in which the caregiver actions of interest occur and is the naturalistic setting which frames this study. Consequently, examination of the literature examining rural life is also requisite in providing a foundation for the proposed study. Aspects of rural life that are particularly germane include culture, health disparities, caregiving in rural settings, and rural health policy and financing that affect caregiver realities for rural dwellers.

The cord that connects these two bodies of literature together in a unique and understudied fashion is the thread of male gender. One end of this cord will be evident in the selected focus of the caregiver literature review on male caregiving. Prefacing the discussion of male caregiving will be an examination of theoretical considerations of masculinity as it applies to caring. The other end of this male gender cord will be presented in a discussion of masculinity as it applies to rural culture. The summary section and the significance section will tie the two ends of the gender cord together, linking these two seemingly disconnected bodies of literature. This chapter will also include a discussion of a preliminary study interview conducted in 2004 with a husband caregiver residing in rural community. Findings from this interview and how the interview affected the development of the methods of this study will be detailed.

Summary Review of the General Caregiver Literature

Prevalence of Caregiving

The precise number of caregivers in the USA is unattainable since a universal definition of a caregiver is not available (Barer & Johnson, 1990). Even though Stone, Cafferata, and Sangl (1987) have proposed that the term 'primary caregiver' be limited to

caregivers providing most of the care given to the care recipient with other caregivers being classified as 'secondary caregivers', no agreed upon parameters are provided in the literature as to how many assistive tasks or what type of assistive tasks makes one a caregiver at all. Most reviews and studies have used self-identification as a caregiver as the criteria for enumeration or study inclusion. It is likely that individuals classify the assistance they provide to others as constituting caregiving in a highly variable fashion. Consequently, estimations of the number of caregivers are based on inexact methods. Not surprising then, estimations of the prevalence of caregiving in the USA are not consistent. Published prevalence estimates come from telephone and mailed surveys. Using the National Survey of Families and Households 1987-88, Marks (1996) estimates that 14.3% of all adults are caregivers. The National Alliance for Caregiving and The American Association of Retired Persons estimates that 21% of all adults are caregivers, with 16% of all adults caring for someone over age 50 years (2004); whereas the National Family Caregivers Association estimates that 26.6% of the adult population are caregivers (2002). Using the 21% estimation as closer to a mid-range value, approximately 44 million adults are caregivers in the USA based on the 2000 US Census (US Census Bureau, 2002). These caregivers provide an estimated contribution of over $257 billion in labor (National Family Caregivers Association, 2002).

Estimates of the percent of caregivers who are male are also variable. Estimates from the above sources indicate that between 28.5% (Stone et al., 1987), to 34% (Marks, 1996), and to 44% (National Family Caregivers Association, 2002) of all caregivers are men. Others have noted an increase in the percentage of male caregivers from 27% in 1996 to 39% in 2003 (National Alliance for Caregiving & American Association of

Retired Persons, 1997, 2004). The number of male caregivers varies along racial/ ethnic

lines, with 54% of all Asian caregivers being male and 33% of all African-American

caregivers being male (National Alliance for Caregiving & American Association of

Retired Persons, 2004). Using 39% as a mid-range figure, there may be over 17 million

male caregivers in the USA (US Census Bureau, 2002).

The prevalence of spouse, and more specifically husband caregiver, has been

reported less frequently in the literature than the total number, gender, age, and race/

ethnicity of caregivers. However, Marks (1996) estimates that 2.9% of the adult male

population are husband caregivers. Using this estimate, there may be 2.73 million

husband caregivers (US Census Bureau, 2002). It is unclear whether or not the

prevalence of husband caregivers varies along racial/ethnic or geographic lines.

Published Reviews of the General Caregiving Literature

Several large reviews of the caregiving literature have been completed by others

and are discussed here. These reviews have been cited by a number of researchers in

their published reports. As such, these reviews may be considered classic summaries. A

number of published studies discussing male or rural caregivers are included in these

reviews. Key studies of male or rural caregivers will be detailed in subsequent sections

of this chapter.

Perhaps the most comprehensive of the reviews is one completed by the National

Institute of Nursing Research (NINR) (1994). The NINR provides a state of the science

report covering the caregiving literature from 1969-1990 and included over 150

references. The focus of this review was informal caregivers of the elderly. In this

review, five major categories were identified from the literature: 1) caregiver

characteristics and the services they provide; 2) consequences of caregiving activities for

the caregiver; 3) quality of caregiving; 4) ethnicity and caregiving; and 5) nursing

interventions designed to assist and support caregivers.

The services provided by caregivers are broadly classified into two types:

instrumental services and personal care services (National Institute of Nursing Research,

1994). Instrumental services are those assistive tasks targeting the environment and

context in which the care recipient lives and may includes tasks such as shopping,

running errands, managing the household finances, scheduling health appointments, and

transportation services. On the other hand, personal care services are those that that

address the physical body of the care recipient and may include tasks such as feeding,

dressing, toileting, medical treatments and moving the body. Different studies have

broken down these two categories of tasks further based on the intensity of a task and the

physical or emotional work required to complete these tasks. Montgomery, Gonyea, and

Hooyman (1985) suggest that caregiving intensity is determined by the variety of tasks

performed rather than the duration of the caregiving task itself.

It is the performance of any of these tasks that may make one a caregiver,

although as mentioned earlier, it is not clear at what level of performance one becomes a

caregiver (Barer & Johnson, 1990). Others have used the list of caregiving tasks and

have developed classes of caregivers defined by the frequency certain tasks or clusters of

tasks are performed and/or the amount of time spent with tasks (Stone et al., 1987).

Archbold (1983) classifies caregivers into whether or not caregivers actually perform the

tasks (care providers) or delegate tasks to others (care managers). Frequently, researchers

have classified caregivers by the familial or social relationship they have to the care recipient. Other methods of categorizing caregivers are by gender, by the coping strategies used to adapt the challenges of caregiving work, or by the chronic illness affecting the care recipient (National Institute of Nursing Research, 1994). Regardless of how researchers have classified caregivers, caregivers themselves define their roles more broadly than most researchers have described in their reports (National Institute of Nursing Research, 1994).

The NINR (1994) reports that the literature discusses two major types of consequences of caregiving: negative and positive consequences. Researchers have focused much more attention to negative rather than positive consequences of caregiving. This emphasis on negative consequences has been criticized (Acton, 2002; Archbold, Stewart, Greenlick, & Harvath, 1992; Kramer, 1997b; Lawton, Kleban, Moss, Rovine, & Glicksman, 1989) and has been problematic in developing an understanding of how positive caregiving consequences may ameliorate negative consequences and improve caregiver outcomes (Acton, 2002; Kramer, 1997b; National Institute of Nursing Research, 1994). Regardless, the evidence that the negative consequences of caregiving creates stress is strong and unequivocal (National Institute of Nursing Research, 1994).

The NINR reports that the literature supports best the following sources of stress from caregiving: limitations placed upon the caregiver's life due to caregiving responsibilities, competing roles and demands for caregivers, and the demands placed on caregivers stemming from the care recipient's emotional and physical needs. Less consistently documented sources of stress include the lack of social support for caregivers, living arrangements with the care recipient, and the nature of the relationship

between the caregiver and the care recipient (National Institute of Nursing Research,

1994). Stress from these sources provides strain to caregivers, which is the primary

negative consequence of caregiving. This strain is most often referred to as *caregiver*

burden, a term that is poorly defined, but is clearly multi-dimensional. Four major

dimensions of caregiver burden (or strain) identified in the literature are emotional,

physical, financial, and familial (National Institute of Nursing Research, 1994).

Emotional strain is the best supported domain in the literature, and has been most

frequently operationalized as depression. However, other reported outcomes for

emotional strain have been emotional exhaustion, anxiety, helplessness, and low morale.

Physical strain has also been frequently examined and has been generally operationalized

as caregiver health. However, the evidence for physical strain has been weak and

equivocal. Financial strain has been poorly studied. Financial strain has been

operationalized as lost wages, increased medical costs, and time interrupted at work due

to caregiving responsibilities. The evidence is equivocal on financial strain, but it

appears to be less than one might assume. Family strain pertains to negative influence on

the relationships caregivers have with other family members and with the care recipient.

Evidence for family strain has also been equivocal (National Institute of Nursing

Research, 1994).

In terms of the positive consequences of caregiving, the literature suggests that

most caregivers report that they feel useful and needed. Positive consequences have been

described as personal affirmation and personal meaning (National Institute of Nursing

Research, 1994). Included within personal affirmation are constructs such as caregiver

satisfaction. Satisfaction may be a result of an accumulation of daily uplifts that

caregivers string together to appraise their situation as generally positive (Lawton et al., 1989). Personal meaning is possibly associated with constructs such as reciprocity, mutuality, affection, filial obligation, and attachment (National Institute of Nursing Research, 1994).

The NINR reports that research on caregiver needs has been scant, and that the findings thus far have been inconsistent. Unfortunately, service providers have developed caregiver support interventions without a solid empirical base for those interventions. This mismatch may account for the reported non-use of and attrition from currently used caregiver support interventions (National Institute of Nursing Research, 1994). In addition, how the ever-changing health care system affects caregivers and their work has also been neglected as a topic of research.

The NINR notes that most studies have focused on caregivers of persons with dementia and/or Alzheimer's disease. The evidence that caring for persons with dementia is burdensome is strong. Burden results from managing antisocial and problematic behaviors which caregivers often report as unpredictable and progressive. The need for managing personal daily care activities has also been noted as burdensome. Less is known about caregivers of elderly care recipients with other illnesses, particularly those elders with chronic mental illness or mental retardation. Of importance to this study, the reviewers state that caregivers in rural settings are in particular need of study (National Institute of Nursing Research, 1994).

In terms of the quality of the care provided by caregivers, the literature suggests that care recipients are receiving less than optimal care. Understanding the level of quality is difficult in that no external regulatory mechanism exists to define and monitor

the informal care received in non-institutional settings. As a result, researchers have used the absence of neglect and abuse or hospital readmission as the default indicators of care. The NINR notes that operational definitions of abuse and neglect are inconsistent due to various legal definitions, as well as a reluctance to question the assumed good intentions of caregivers. In addition, since there is no alternative to informal home care, a lower quality of care may be tolerated by health and regulatory professionals. The reviewers note that this topic is in need of research (National Institute of Nursing Research, 1994).

In concluding this state of the science report, the reviewers provide a number of recommendations for research on caregiving. Several of these recommendations pertain to improving methods and designs of quantitative studies to yield more consistent results, examining the effects positive consequences and a changing health care system have on caregiver outcomes, examining the quality of caregiving provided in non-institutional settings, and examining outcomes from the elderly care recipient's perspective. However, of particularly relevancy to the proposed study, the reviewers recommend that research is needed to examine the processes of caregiving, focusing on the caregiver's perception of their needs and the meaning they ascribe to their caregiving experience. The reviewers note that examination of caregiving processes is particularly germane to nursing since nursing itself is a process, and nurses have demonstrated their ability to manipulate processes in order to affect outcomes. In addition, the reviewers note that research is needed on subgroups of caregivers, particularly those in rural settings (National Institute of Nursing Research, 1994).

All of the other reviews and meta-analyses of the caregiving literature located focus on a particular aspect of caregiving. For example, Kramer (1997b) examined 29

caregiving studies through 1996 that examined the positive consequences of caregiving, otherwise described as 'caregiver gain' (as opposed to caregiver strain). Kramer notes that gain has been further described as satisfaction, uplifts, rewards, enjoyment, gratification, and growth and meaning. Kramer notes that many of the studies reviewed lacked a clear theoretical or conceptual base for caregiver gain, but that gain has been usually conceptualized as an aspect of caregiver appraisal. This appraisal of gain has either been operationalized as event-specific (uplifts) or as role-specific (satisfaction). Kramer notes that the findings from the studies suggest that the predictors of gain and strain are unique, and may be influenced from a number of psychological and sociocultural variables. In addition, Kramer reports that the effects of gain on caregiving outcomes may be dependent upon individual caregiver characteristics. From these studies, Kramer proposes a conceptual model for caregiver adaptation, which includes caregiver gain as well as the well-documented caregiver strain.

However, Kramer (1997b) notes a number of methodological shortcomings from the reviewed studies including: 1) an over-reliance on convenience samples; 2) an inattention to differences of subgroups of family caregivers; 3) an inattention to male caregivers; 4) an inattention to confounding variables; 5) an over-reliance on quantitative and cross-sectional study designs; and 6) an over-reliance on bivariate analyses. Based on these methodological limitations, Kramer offers the proposed conceptual model as tentative and in need of further evaluation.

Another review focuses on caregiver depression as an outcome of the negative consequences of caregiving for care recipients with stroke (Han & Haley, 1999). These reviewers examined 20 quantitative studies, noting that between 34-52% of stroke

caregivers are clinically depressed. Various instruments were used in the studies to evaluate depression. The studies suggest that the most likely predictors of caregiver depression are poor caregiver health, behavioral problems from the care recipient, and care recipient depression. Han and Haley also note a number of methodological limitations from the reviewed studies including: 1) selection bias in the samples; 2) small sample sizes; 3) an over-use of cross-sectional designs; 4) an over-use of simple statistical analyses; 5) lack of comparison groups; 6) lack of ethnic diversity in the samples; 7) lack of analysis of the positive consequences of caregiving and how these might affect caregiver depression; and 8) inconsistent time frames post-stroke used for measurement. Interestingly, most of the studies reviewed contained mixed-gender samples, yet the reviewers do not address the lack of analysis of depression by gender in their critique.

However, Yee and Schulz (2000) focused their examination of the caregiving literature of psychiatric morbidity among caregivers by gender. These reviewers examined 30 quantitative studies published between 1985 and 1998 in which male and female caregivers were compared on outcomes such as caregiver burden, role strain, and the level of support received. Care recipients in these studies were generally elderly with physical illness and/or dementia. Studies with care recipients with mental illness were excluded, though the reviewers did not explain this exclusion criterion. Due to the variety of methods used in the studies, the reviewers report their findings in a narrative format.

From this review, the literature suggests that female caregivers report higher levels of depression, anxiety, lower life satisfaction and general psychiatric

symptomatology than male caregivers, even when compared to gender-matched controls. The reviewers surmise that the greater number of caregiver tasks performed by women may account for this difference in psychiatric morbidity. Another reason offered by the reviewers is the evidence that men seek assistance with caregiving and employ preventative measures earlier than women when caregiving. Personal caregiver characteristics and selection of coping/ adaptation styles may serve as modulators of psychiatric outcomes, though the evidence of gender differences in the latter is equivocal (Yee & Schulz, 2000). In critiquing the studies, the reviewers note a lack of controlling for variables, such as socioeconomic status or caregiver health, that are believed to affect psychiatric morbidity. In addition, there was a lack of analysis in the studies on how positive aspects of caregiving might affect psychiatric morbidity.

In their review of the literature, Dilworth-Anderson, Williams, and Gibson (2002) focused on race, ethnicity, and culture. Fifty-nine articles published between 1980 and 2000 were reviewed. Similar to Yee and Schulz (2000), the reviewers summarized their findings in a narrative format due to the variable methods used in the studies reviewed. The reviewers examined the studies in terms of four domains: social support, negative consequences, coping, and cultural effects. Within these four domains, varying numbers of studies provided conceptual or theoretical frameworks, used comparative sampling, or used established measurement tools.

Among the findings, Dilworth-Anderson et al. (2002) state that "...caregivers to older ethnic minorities use more informal support..." and that "...close and distant family members provide that support" as compared to non-minority caregivers (p. 266). In addition, they note that some of the studies indicate that this family support lessens the

negative consequences of caregiving, though findings of outcomes such as depression are inconsistent. The studies reviewed provide a number of reasons why formal support services are used less frequently by minority caregivers, including possible shame for using assistance, sense of obligation for family to care for their own, or a perception that formal services are not culturally sensitive or relevant (Dilworth-Anderson et al., 2002).

Dilworth-Anderson et al. (2002) point out a number of limitations of the studies reviewed. Few studies examined other caregiver domains such as positive consequences of caregiving and caregiver health. Studies rarely used conceptual or theoretical frameworks sensitive to cultural differences and cultural-historical backgrounds. Theoretical perspectives such as symbolic interactionism, social constructivism, or anthropological approaches would better provide this sensitivity (Dilworth-Anderson et al., 2002). Another limitation is the use of race as a proxy for culture. The use of race as a defining characteristic fails to discern the diversity in cultural backgrounds and influences within a given race. Still another limitation is the lack of gender analysis in the studies. The reviewers note that although many of the studies reviewed included both men and women in their caregiver samples, few of the studies had enough of each to complete statistical comparisons (Dilworth-Anderson et al., 2002).

Dilworth-Anderson et al. (2002) provide a number of recommendations for researchers who examine minority caregivers, particularly when comparisons are made among racial/ ethnic groups. First, since minority caregivers utilize other family members for caregiving more than non-minority caregivers, researchers may need to examine caregiver groups rather than individual primary caregivers. Second, researchers must consider the cultural relevancy of measurement tools. And third, researchers must

do a better job of dissecting socioeconomic status when using it as a study variable, since race or ethnicity is intrinsically interwoven with it (Dilworth-Anderson et al., 2002).

Two other reviews examined the caregiving literature in terms of caregiver interventions (Acton & Winter, 2002; Sorensen, Pinquart, & Duberstein, 2002). Acton and Winter (2002) examined 73 studies of interventions for caregivers caring for persons with dementia published between 1991 and 2001. Only studies that included a treatment/ control group or a pre/post-test design were reviewed. Interventions were classified into six categories: educational interventions; support and education; counseling; respite; case management; and multicomponent interventions. Interventions described in the studies were effective in significantly changing study outcomes (such as caregiver burden, depression, knowledge, etc.) in the desired direction only 32% of the time. Of the types of interventions, educational interventions were the most frequently used and were the most effective, improving 36% of the studies' outcomes. The least effective intervention types were support and education interventions and case management interventions (Acton & Winter, 2002).

Acton and Winter (2002) report that the overall effectiveness rate of 32% for the interventions studied is less than optimal. Reasons provided by the reviewers for the poor effectiveness include the lack of intervention specificity; diversity in the length, intensity, and duration of the intervention; poor match between the intervention and the outcome evaluated; lack of baseline evaluation of caregivers on outcome variables; lack of matching caregiver needs to the interventions studied; use of small sample sizes; and lack of sampling homogeneity. The reviewers note that many of the studies reviewed contained samples of mixed caregiver types (spouses, children, and friends) who likely

have very different needs and resources. The reviewers recommend that researchers investigate homogenous samples in order to better understand their unique characteristics and outcomes (Acton & Winter, 2002).

In a relatively similar process, Sorenson, Pinquart, and Duberstein (2002) reviewed 78 caregiver intervention studies on how effective interventions were in changing caregiver burden, depression, subjective well-being, satisfaction, ability and knowledge, and symptoms of the care recipient. These reviewers categorized interventions into the following types: psychoeducational interventions; supportive interventions; respite; psychotherapy; interventions designed to improve care recipient competence; multicomponent; and miscellaneous interventions. According to Sorenson et al. (2002), although many of the interventions were effective at significantly changing the outcome variables in the desired direction, the effect sizes of the change were relatively small (between 0.14 and 0.41 standard deviations). Psychoeducational interventions and psychotherapy were the most effective types of interventions of the six outcomes evaluated. The reviewers provide additional insights on the findings from the studies reviewed. With the exception of improving symptoms of care recipients, interventions provided to groups of caregivers were less effective than interventions provided to individual caregivers. This finding suggests that individual caregiver resources, characteristics, and needs are crucial in determining the effectiveness of any given intervention. Interventions targeting spouse caregivers were less effective than those targeting child caregivers. According to the reviewers, this finding may have resulted from the fact that spouse caregivers are better prepared for caregiving than child caregivers, thus, a ceiling effect may have been present. The same is true for gender.

Female caregivers are more stressed and depressed than male caregivers at baseline, thus, showed greater improvement in the six outcomes than did male caregivers. In addition, interventions for caregivers caring for persons with dementia were less effective than those caring for persons with other illnesses. This finding may have resulted from the additional personal care and behavior management needs such persons require from caregivers (Sorensen et al., 2002).

Several large prevalence studies include additional information on caregiving. Much of the information provided in the reports from these prevalence studies, as well as findings from smaller caregiver studies, includes gender comparisons. Discussion of the differences in outcomes and in experiences between male and female caregivers will be provided in subsequent sections of this chapter. However, much other caregiving information not directly framed by gender is available in these studies, and is summarized here.

Two large studies were conducted by the National Alliance for Caregiving (NAFC) in conjunction with the American Association of Retired Persons (AARP) in which minority groups were over-sampled in order to provide enough participants for analyses of findings among racial/ethnic groups (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004). Both studies used telephone surveys to locate and interview caregivers in the continental USA. In the first study, 1509 caregivers were interviewed in English in 1996. In the second study, 1247 caregivers were interviewed, mostly in English with some initial interviews conducted in Spanish, in 2003. Findings were categorized similarly in the studies, allowing for comparisons and trending.

In both studies, caregivers were categorized using the Level of Burden Index, a tool based on "an index derived from the activities of daily living (ADL's), instrumental activities of daily living (IADL's), and the amount of time devoted to caregiving" (National Alliance for Caregiving & American Association of Retired Persons, 2004, p. 3). Categories of caregiver burden ranged in levels from one to five, with Level 1 representing the category of least burden, and Level 5 representing the category of most burden. No reliability data for the instrument are provided in either study, though tool development information with derivation of categories from a factor analysis is provided in the first report (National Alliance for Caregiving & American Association of Retired Persons, 1997). In both studies, roughly a third of all caregivers provided care at the two highest levels (36% in 1996 vs. 31% in 2003).

In comparing caregivers with higher and lower levels of burden, findings were generally consistent between the two reports (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004). In both 1996 and 2003, elderly caregivers (those over age 65) were more likely to be providing Level 5 care than any other level, though a substantial drop in percentages was noted (30% in 1996 vs. 22% in 2003). In both reports, Level 5 caregivers provided the most number of caregiving hours per week. However, the mean number of hours per week provided by these caregivers rose sharply, with 56.5 hours per week in 1996 and 87.2 hours per week in 2003. An explanation for this substantial difference was not provided. Not surprisingly, Level 5 caregivers were more likely to live with the care recipient than other caregivers. In terms of caregiver health, the two reports discuss slightly different measures, with physical strain reported in 1996 and health status in 2003. Regardless, Level 5 caregivers and

older caregivers reported poor health/ more physical strain than less burdened or younger caregivers. Caregivers over age 65 were more likely to be caring for a spouse than other types of care recipients. In 2003, older caregivers were more likely to have provided care to the care recipient for more than 10 years than younger caregivers, with 18% of caregivers over age 65 providing this duration of care. The combination of older caregivers in poorer health, providing higher levels of intensity of care and for a longer period of time has significant implications for health care providers (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004).

In terms of race/ ethnicity, the two studies report findings on Caucasian, African-American, Hispanic, and Asian-American caregivers. In both studies, minority caregivers were more likely to be younger than Caucasian caregivers, Asian-American caregivers had higher levels of education and higher household incomes than other caregiver groups, though the researchers noted that recent Asian immigrants were not included in the sample due to their lower ability to speak English (National Alliance for Caregiving & American Association of Retired Persons, 1997). The two studies differed in who was most likely to live with the care recipient, with Asian-American caregivers more likely in 1996 and Hispanic caregivers more likely in 2003. In both studies, Asian-American caregivers were least likely to report emotional stress. To cope with stress, Blacks and Hispanics were more likely to use prayer than Caucasian or Asian-American caregivers. Asian-American caregivers were more likely to use the Internet for caregiving information. Hispanic caregivers were the least likely to use support groups and are the group most likely to report unmet needs (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004).

In both studies, the main problem of the care recipient which required caregiving services was aging. Also, between 22-25% of all caregivers were caring for someone with Alzheimer's disease or dementia. Most of the care recipients were female, and most were over age 50. Care recipients with dementia and/or stroke were more likely to require higher levels of care than those with other illnesses (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004).

The two studies address the issue of unmet caregiver needs differently. In 1996, caregivers were asked what kinds of help/ services they would use; whereas in 2003, caregivers were asked whether or not they needed help with various items. As such, comparison of the findings is not facile. However, in both studies, the most common need identified was *finding time for myself*. Interestingly, in the 1996 sample, 38.1% of the respondents stated that they didn't know what supportive service they would use (National Alliance for Caregiving & American Association of Retired Persons, 1997, 2004).

Germane to my study, the 2004 study analyzed findings based on the rurality (urban, suburban, and rural) of the caregiver residence (National Alliance for Caregiving & American Association of Retired Persons, 2004). Unfortunately, findings based on rurality of residence were reported in only a few of the categories and outcomes identified in the study. Rural caregivers were less educated, more likely to be a primary caregiver, and were more likely to be Caucasian than their non-rural counterparts. Rural caregivers were less likely to use services identified in the survey (particularly financial services, transportation services, and adult daycare) than non-rural caregivers. In addition, rural caregivers were less likely to identify a need for help in talking with or

obtaining information from health professionals or to use the Internet for caregiver information than non-rural caregivers. It is not clear in the report as to whether or not rural caregivers were unaware of their information needs or had fewer needs than non-rural caregivers.

Marks (1996) completed a secondary analysis of the National Survey of Families and Households, a survey conducted of 13,017 households in 1987-88. Marks notes that many of the caregiving studies to date have examined variables in a bivariate fashion. Thus, the purpose of her analysis was to examine the influence of multiple demographic variables. Most of her findings are framed in terms of gender, since gender interactions were significant. As such, gendered findings will be presented later in this chapter. However, Marks does report several findings independent of gender.

Marks (1996) reports that Hispanic Americans are less likely to be caregivers than non-Hispanic Whites. This finding may seem unexpected due to the importance of family in Hispanic cultures, though Marks explains the finding may be a result that Hispanic Americans are more likely to be recent immigrants, whose elders may still be living abroad. Marks also reports that separated or divorced individuals are less likely to be caregivers than those in their first marriages. No explanation is provided for this finding. Not surprisingly, those who worked full-time were less likely to be caregivers, but for those working more than 45 hours per week, only men were less likely to be caregivers. Marks also reports that those in poorer health are more likely to be caregivers. The analysis of this variable does not indicate causality, but Marks suggests that caregiving leads to poor health rather than poor health leads to caregiving.

The MetLife Mature Market Institute (2003), in conjunction with the National Alliance for Caregiving and the Center for Productive Aging surveyed 1386 caregivers employed at three Fortune 500 companies. Again, most of the findings are reported in terms of gender. However, some general findings include the following. Those who had not expected becoming a caregiver had more difficulty balancing work and family responsibilities than those who anticipated becoming a caregiver. There was no gender difference in those who were considering changing jobs due to their caregiving. Predictors of those considering job changes were being a primary caregiver, feeling that a supervisor was not supportive of caregiving demands, and feeling that a stigma to caregiving was present in the workplace. In all, 27% of all caregivers were considering a job change. This latter finding is interesting in that a third of the caregivers were not aware of eldercare benefits that were available at all three companies.

Specific Knowledge of General Aspects of Caregiving from Quantitative Studies

Numerous quantitative studies have been completed shedding light on various aspects of the experiences, processes, and outcomes of caregiving with associated correlates and predictive factors. Over 40 non-demographic variables were identified in the review of quantitative caregiving studies for this chapter. The distinction among certain variables is not always clear. For example, the differences among negative responses (Given, Stommel, Collins, King, & Given, 1990), negative mood (Bakas & Burgener, 2002; Blake & Lincoln, 2000), and negative feelings toward the care recipient (Cantor, 1983) are not conceptually clear. Researchers have not used consistent

terminology for variables which may represent the same concept. In addition, researchers have used the same or similar variables either as independent or dependent variables.

In order to discuss the findings of caregiving studies, an organizing framework for variables is in order. Although frameworks for classifying caregiving variables and/or constructs have been proposed (Brown & Stetz, 1999; Clark & Rakowski, 1983; Hasselkus, 1988; Kramer, 1997a; Lawton et al., 1989), it is perhaps the framework proposed by Lawton et al. (1989) that is most comprehensive in scope and has, at least partially, been supported by factorial analysis.

Lawton et al. (1989) note that caregiving research to date has focused mostly on the distress felt by caregivers as a result of the caregiving services they were providing. This distress has been commonly referred to as caregiver 'burden', a term advocated by Zarit (Zarit, Reever, & Bach-Peterson, 1980). Lawton et al. proposes that caregiver burden is too narrow in scope to fully capture the conceptual description of caregiving. Using Lazarus' stress theory in which potential external stressors are assessed (appraisals) and coping processes are then mobilized (reappraisals), Lawton et al. propose the term *caregiver appraisal* in order to "include all cognitive and affective appraisals and reappraisals of the potential stressor and the efficacy of one's coping efforts", which would allow for the provision of all "...forms of appraisal that reflect all degrees of subjective response to the potential stressor: positive, neutral, and negative." (Lawton et al. 1989, p. P61-P62).

Using several psychosocial instruments with additional survey items developed by the researchers, Lawton et al. (1989) interviewed 632 caregivers in two groups: those receiving respite services and those who had recently placed their care recipient into

institutionalized care. Three domains were identified through exploratory and confirmatory factor analyses: subjective caregiver burden, perceived impact on the caregiver, and caregiver satisfaction. Other domains that trended toward significance included: caregiver mastery, caregiver reappraisal, and caregiver assessment of the care recipient's characteristics and relationship with the care recipient. The researchers conclude that a larger and more representative sample may have confirmed the latter three domains.

It should be noted though that there is some overlap of items during factor loading between subjective caregiver burden and impact of the caregiver. Lawton et al. (1989) note that it is primarily social items that load into the impact on the caregiver factor. This contradicts Cantor (1983) who notes that the impact on caregivers is multifaceted, including areas of impact to caregiver health, activities, and finances. Items used by Lawton et al. that loaded into the six domains do not clearly describe caregiver health or finances.

For the purposes of this chapter, the six domains proposed by Lawton et al. (1989) provide a conceptually sound, albeit imperfect, framework to organize a summary of the multitude of variables discussed in the caregiver literature. Cantor's (1983) multifactorial description of impact on the caregiver domain will be used to supplement the domains proposed by Lawton et al. A number of studies examined more than one of these domains within one study, and as such, may be discussed in multiple sections.

Subjective Caregiver Burden

Burden

Caregiver burden has frequently been studied, particularly following the development of the Zarit Burden Interview (Zarit et al., 1980). In the initial study, Zarit et al. (1980) note that earlier researchers had reported that family caregivers were burdened when caring for elders with senile dementia. However, at that time there was not a clear understanding of the sources of that burden. Zarit and his colleagues interviewed 29 family caregivers, mostly women and mostly spouses, of persons with senile dementia. The interview tool developed contained 29 items, developed from clinical experience and the findings of previous researchers about the areas of burden for caregivers. These areas include problems with caregiver health, psychological well-being, finances, social life, and with the relationship between the caregiver and care recipient. Each item contained a statement anchored by the responses of "not at all" to "extremely". Total scores were calculated representing the respondent's total level of burden.

Zarit et al. (1980) report a mean burden score of 30.8, out of a possible range of 0-84, which the investigators felt were unexpectedly low due to the substantial dependency of the care recipients. In examining correlations between burden scores and level of impairment of the care recipient, duration of illness, frequency of memory or behavior problems, impairments in ADL and IADL's, and frequency of visits from other family members, only the latter (family visits) were significantly correlated. The investigators note that when visit frequency increased, burden scores decreased. There were no significant differences in burden scores between wife and daughter caregivers, nor

between husband and wife caregivers (no son caregivers were included in the sample).

The investigators note that they did not inquire about the nature of the visits (social visits

or respite), but it may be possible that the visits offered social support to the caregivers.

The small sample size may have prevented the ability to find significance differences

among subgroups of caregivers.

A handful of other investigators have used the Zarit Burden Index (ZBI), or have

used portions of it to develop new tools (e.g. Lawton et al., 1989). In one study,

(Goldstein et al., 2004), a shortened version of the ZBI was used to investigate the factors

leading to caregiver burden. The investigators noted that others had found the shortened

ZBI to have high internal validity (Cronbach's alpha ranging from 0.78-0.92), but added

three additional items to the shortened ZBI in order to capture rewarding aspects of

caregiving. The investigators surveyed 206 caregivers of persons with cancer with the

shortened and revised ZBI, as well as collected demographic data, self-reported

frequency of caregiving tasks and limitations caregiving placed upon them, self-reported

health, and social support as measured by the Social Network Index (a tool categorizing

the social networks available for caregivers). Using both bivariate and logistical

regression analyses, the investigators note that lower social network scores, increased

restrictions of caregiver activities due to caregiving, and younger caregiver age were

significantly correlated with increased caregiver burden. It is unclear from the

investigators how the quality of the social networks available to caregivers may have

influenced the findings. The number of caregiver tasks or type of tasks was not

correlated with burden, nor was whether the caregiver was the child or spouse of the care

recipient. Gender was not discussed.

In another study (Roberts et al., 1999), investigators evaluated the effectiveness of a counseling intervention on psychosocial health (as measured by the Psychosocial Adjustment to Illness Scale). A variety of other variables were evaluated, including caregiver burden as measured by the ZBI, at baseline and post-intervention times. The investigators randomly assigned 77 caregivers of persons with cognitive impairments into an intervention group and control group. The groups did not vary significantly on any of the variables at baseline except for levels of education. The intervention consisted of up to ten nurse counseling visits over six months. At six and twelve months, there was no significant change in caregiver burden, and only those with poor logical-analysis coping skills at baseline showed significant improvement in psychosocial health. Subgroup analysis consisted of only examining the coping styles of the caregivers and whether the caregiver was a spouse or child of the care recipient. Possible gender differences were not discussed.

Well-Being

In a twist on caregiver burden, George and Gwyther (1986) note that the factors of caregiver burden (physical, psychological, emotional, social, and financial problems) are the same as the factors for well-being. As such, caregiver burden and caregiver well-being are but just opposite anchors on the same continuum. George and Gwyther believe the two terms to be interchangeable. They also note that measures of caregiver burden and caregiver strain examine the same factors. The limitations of these measures are that they have an explicit focus on caregivers, and thus, cannot be used for comparisons with other highly stressed individuals (such as single parents). In order to better understand the factors of caregiver burden (or caregiver well-being), the investigators surveyed 510

caregivers with measures for physical health, mental health, financial resources, and social participation, and compared the findings with those of various control samples. A variety of tools were used to measure these factors, though the investigators intentionally used tools appropriate for a non-caregiver sample. Hence, the ZBI was not used in this study. Compared to controls, caregivers had significantly higher levels of negative mental health and reduced social participation compared to controls, but not on physical health or finances. Among caregivers, spouse caregivers had significantly lower scores on the four factors than non-spouse caregivers, even when controlled for age. Care recipient duration of illness was not significantly related to caregiver well-being, and care recipient severity of illness was only significantly correlated with a few measures, though the strength of the correlation was low ($r \leq .20$). Possible gender differences were not evaluated. Although this study provides an informative comparison between caregivers and non-caregivers, interpretation of findings is limited since it is unclear how well control samples were matched to the caregiver sample.

Acton (2002) examined well-being, measuring caregiver well-being with the Index of Well-Being, a scale designed to measure both cognitive and affective dimensions of well-being (Acton, 2002). The purpose of Acton's study was to examine the health-promotion activities of 46 caregivers and a sample of demographically matched controls, and how those activities affected stress and its mediating effect on the dependent variable of well-being. Acton noted that caregivers who practiced health-promotion activities were significantly protected from stress and its affect on caregiver well-being. No possible gender differences were discussed.

Others have examined caregiver well-being also, but not in the global fashion as George and Gwyther (1986). In one study (van den Heuvel, de Witte, Schure, Sanderman, & Meyboom-de Jong, 2001) examined a number of aspects of caregiving for caregivers of persons with stroke. Although their primary outcome of interest was caregiver strain, they also investigated well-being in terms of psychological well-being, as measured by mental health subscale of the Short Form 36. The investigators note that mental health well-being was significantly lower for caregivers in poorer health, those caring for persons with severe emotional-cognitive-behavior problems, those who had poor confidence in their knowledge about stroke, and those who used confrontative coping strategies infrequently, were less satisfied with their levels of social support or were female.

Hodgson, Wood, and Langton-Hewer (1996) also examined psychological well-being in 50 caregivers caring for persons with stroke as measured by the General Well-Being Index. Caregiver appraisal of caregiver stress, caregiver health, and the level of satisfaction with formal caregiver services were found to be predictive of psychological well-being. No possible gender differences were discussed.

Caregiver Stress

Hodgson, Wood, and Langton-Hewer (1996) measured stress with one survey question, "Do you find caregiving stressful?" Response options ranged from "No, I have no problem coping" to "Yes, very stressful—I feel I cannot cope with caring." As mentioned above, caregivers' appraisals of their stress was a significant predictor in well-being. Confidence in this finding may be shaky due to the simple measure of stress (one question). Also, the responses to the question focused on coping. The self-reported

ability to cope is only one aspect of overall stress, thus, may not reflect a valid measure of stress. Acton (2002) addresses caregiver stress, noting that health promotion activities of the caregiver reduced stress and mediated caregiver well-being.

Blake and Lincoln (2000) surveyed 222 spouse caregivers of persons with stroke. A number of variables, including stress, were examined for correlations with caregiver strain. Stress was measured with the Perceived Stress Scale. Stress was not found to be significantly correlated with strain, although it should be noted that much of the sample had relatively low stress scales (mean score 25 out of a possible range of 0-56).

Miscellaneous

Another variable examined in terms of subjective caregiver burden is negative mood. Blake and Lincoln (2000) measured negative mood with the General Health Questionnaire-12 in 222 spouse caregivers of persons with stroke. Of 12 variables examined, negative caregiver mood was the best predictor of caregiver strain. Bakas, Austin, Jessup, Williams, and Oberst (2004) examined which tasks provided by 116 stroke caregivers best predicted negative caregiver mood. Tasks most predictive were managing finances, managing problem behaviors, and providing emotional support to the care recipients.

Bakas and Burgener (2002) examined caregiver self-esteem in 104 stroke caregivers. Self-esteem was measured with the Self-Esteem Scale and was noted to be a significant predictor of caregiver emotional distress (as measured by the Profile Mood States Short Form), which in turn was a significant predictor of caregiver outcomes (as measured by the Bakas Caregiving Outcomes Scale). Interestingly, these investigators also evaluated caregiver appraisal, akin to the definitional discussion of Lawton et al.

(1989). Caregiver appraisal was measured by the Appraisal of Caregiving Scale (Oberst, Thomas, Gass, & Ward, 1989). High threat appraisal was a significant predictor of emotional distress and caregiver outcomes. Neutral or beneficial appraisals did not significantly predict emotional distress.

Impact on the Caregiver

Strain

The precise distinctions between caregiver burden and caregiver strain are unclear, although the replacement of burden with appraisal by Lawton et al. (1989) might indicate that caregiver strain is less broad of a construct than burden. This characterization of strain is confirmed by Robinson (Robinson, 1983), who developed the Caregiver Strain Index (CSI). Robinson used the definition of strain as proposed by Pearlin and Schooler (1978), who define strain as "…those enduring problems that have the potential for arousing threat, a meaning that strain and stressor as interchangeable concepts." (p. 3). Using this definition, strain is an inherently negative consequence of threat appraisal, and requires mobilization of some sort of coping response.

In developing the CSI, Robinson (1983) created a 13-item questionnaire identifying common stressors of caregivers identified in the literature. Robinson surveyed 85 caregivers of elderly patients who had fractured a hip and received post-hospitalization care at home. Internal consistency of the tool was estimated with a Cronbach's alpha of 0.86. Construct validity was proposed by three factors: care recipient characteristics, self-perceptions of the relationship caregivers had with the care recipient, and emotional health of the caregivers. Interestingly, physical and mental

health disabilities of the care recipients did not factor in. However, only one of the care recipients in the sample experienced cognitive problems.

Other researchers have examined caregiver strain. Blake and Lincoln (2000) note that 37% of their sample of stroke caregivers was significantly strained (as determined by a CSI score of seven or higher). The investigators also note that significant predictors of caregiver strain were low caregiver mood, increased dependency of the care recipient as defined by increased extended activities of daily living, and increased negative affectivity (as measured by the Positive and Negative Affect Schedule). In bivariate analyses, strained caregivers had significantly lower self-esteem, decreased positive affectivity, lower optimism, and lower perceived support from informal support persons. Strain was not significantly correlated with age of the care recipient, or with the time since the onset of the stroke.

Van de Heuval et al. (2001) also used the CSI in evaluating caregivers of persons with stroke. These investigators note that strain was significantly predicted by younger age of the caregiver, severity of the stroke, decreased cognitive-behavioral-emotional functioning of the care recipient, and decreased satisfaction with social support. Decreased cognitive-behavioral-emotional functioning was the strongest of the predictors. These findings are generally consistent with those from Blake and Lincoln (2000).

Blake (2000) reports that 57% of a sample of caregivers caring for persons with reflexive sympathetic dystrophy was significantly strained as measured by the CSI. Significant correlates with strain included increased handicap of the care recipient,

increased levels of negative caregiver affectivity, poor caregiver mood, and poor adjustment of the caregiver to the care recipient's illness.

The above studies examining strain used a cross-sectional design. In order to further examine the relationship between care recipient disability and caregiver strain, Blake and Lincoln (2002) surveyed 130 spouse caregivers of persons with stroke three and six months post-stroke. Only two items were predictive of strain: if the care recipient had aphasia and if the caregiver was younger in age. However, these items lost significance at six months. This study may indicate that the influence of care recipient disability on caregiver stress may lessen in time.

Other researchers have examined caregiver strain with tools other than the CSI. Cantor (1983) interviewed 111 caregivers of elderly care recipients. Cantor does not describe clearly how strain was measured. However, she reports that the closeness of the bond to the care recipient accounted for the largest proportion of the variance in strain (37%), so that spouse caregivers had the most strain in total, followed by children, then other relatives, then friends and neighbors. However, there were some differences noted in the types of strain. Spouses reported the highest levels of physical and financial strain; whereas all caregiver groups reported similar levels of emotional strain.

Schulz et al. (2001) surveyed three groups of spouses of persons who died from cardiovascular disease over a four-year period: one group of non-caregivers, one group of non-strained caregivers, and one group of strained caregivers. Strain was defined as having to assist the spouse with at least one ADL or IADL which resulted in self-reported physical or emotional strain. Caregivers with strain had significantly higher levels of depression, which became non-significant after the death of their spouses. Caregivers

with strain did experience a significant increase in the frequency of health promotion activities after the death of their spouses compared to the other groups.

Archbold, Stewart, Greenlick, and Harvath (1990) surveyed 103 caregiver-care recipient dyads at six weeks post-hospital discharge and 78 dyads after nine months using the Family Caregiving Inventory. This tool contains subscales for caregiver role strain, as well as the Mutuality Scale and the Preparedness for Caregiving Scale. In this study, the investigators controlled for variables previously identified as being correlated with caregiver role strain (caregiver gender, whether or not the caregiver is a spouse to the care recipient, the cognitive and physical impairments of the care recipient, and the amount of direct care provided), and noted that high mutuality and high preparedness scores significantly reduce caregiver role strain. Specifically, low mutuality scores were associated with the following aspects of strain: feeling manipulated, global strain, mismatched expectations, tension in the relationship, role conflict, and strain from direct care. However, low mutuality scores were not associated with three other aspects of strain: strain from lack of resources, economic burden, and worry. For preparedness, caregivers who felt low levels of preparedness reported high levels of strain in all areas except economic burden and role conflict. Based on these findings, the investigators later suggest that "...caregivers who have a positive relationship with the care receiver experience less strain because they find caregiving inherently meaningful" (Archbold et al., 1992, p. 331).

Depression

Depression, as an outcome variable, has been frequently evaluated in caregivers. Kramer (1993) surveyed 72 wife caregivers of men with Alzheimer's disease in order to

examine whether a number of variables would predict caregiver depression and quality of life, as measured by the Center for Epidemiological Studies-Depression Scale (CES-D) and the Quality of Life Index. Kramer was particularly interested in the effect the quality of the relationship prior to onset of Alzheimer's disease had on subsequent depression and quality of life. With bivariate analyses, Kramer notes that caregivers who had been married only once had significantly higher levels of quality of life and less depression than caregivers with prior marriages. In addition, caregivers married just once were also more satisfied with their social involvement and reported better health. Caregivers who had reported poorer quality of the relationship with their spouses prior to the onset of Alzheimer's disease were significantly more depressed and had lower levels of quality of life. The same relationship to depression and quality of life was also noted with caregiver physical and social resources and appraisals of stress with IADL's and memory-behavior problems (MBP's). Financial strains and appraisals of stress with ADL's were not significantly correlated to depression and quality of life. Using multivariate analyses, the strongest predictors for caregiver depression included increased MBP's of the care recipients, shorter duration of caregiving, previous marriages, and appraisals of stress with IADL's. Kramer suggests that the love and commitment present in long-term marriages have a modulating effect on caregiver depression. No male caregivers were included in this study.

In a similar vein, Brody, Litvin, Hoffman, and Kleban (1992) examined different groups of daughter caregivers based on their marital status. In total, 492 daughter primary caregivers of spouseless elderly parents were surveyed for a variety of dependent variables, including depression, psychological well-being, personality, strength, health,

and caregiver satisfaction. Depression was measured using the CES-D. Using covariate analyses, married daughters were significantly less depressed, were more satisfied with family life, and experienced less financial strain than their unmarried counterparts. The investigators noted that although the demands to caregiving and to husbands and children are often in conflict for married daughter caregivers, the increased socio-emotional support, instrumental support, and economic support with marriage more than offsets the burdens, resulting in less depression.

Schulz et al. (2001), assessed caregivers who lost their spouses to cardiovascular disease and report significantly higher levels of depression with strained caregiver. However, this significance disappeared after the death of the spouse. The investigators also note that African-American caregivers were less depressed than Caucasian caregivers. There was no significant difference in depression in the sample based on age, sex, or education.

Wright, Hickey, Buckwalter, Hendrix, and Kelechi (1999) followed 42 couples over 12 months, representing equally couples experiencing early Alzheimer's disease, ischemic stroke, and well controls for evidence of depression. Depression was measured with the Short Zung Interviewer Assisted Depression Scale. Caregivers of persons with Alzheimer's disease or stroke were significantly more depressed than well controls, with caregivers of persons with Alzheimer's disease the most depressed. Half of all Alzheimer caregivers had scores indicative of moderate to severe depression in 12 months. For caregivers of persons with stroke, depression for Caucasian caregivers increased over time; whereas depression decreased for African-American caregivers. Cognitive and

functional impairment of persons with stroke, but not with Alzheimer's disease, were significantly correlated to depression for caregivers.

Burton, Zdaniuk, Schulz, Jackson, and Hirsch (2003) followed 818 elderly spouses from the Caregiver Health Effects Study over five years to evaluate trends in depression, physical health and self-mastery of caregivers. Depression was measured with the CES-D. Participants were categorized into three groups: non-caregivers, moderate caregivers (assisting spouse with at least one IADL, but no ADL), and heavy caregivers (assisting spouse with at least one ADL). Those who stayed or transitioned in to the heavy caregiving category had significantly higher levels of depression than the other groups.

Two sets of investigators describe caregiver depression within a broader context of mental health outcomes. Cossette and Levesque (1993) surveyed 83 French-Canadian wife caregivers of men with COPD on the effects of caregiving work and informal social support on mental health and the number of psychotropic medications taken by caregivers. Mental health was measured by the French version of the SCL-90, and included the dimensions of depression, obsession-compulsion, somatization, anxiety, hostility, and interpersonal sensitivity. Caregiver work was measured by a new tool developed for the study, the Caregiving Task Index. This index measured the number of tasks performed as well as the subjective disturbance of each task. The investigators report that the number of tasks performed explained between 18-23% of the variance in all of the mental health dimensions except somatization, with supervision tasks the most influential. In addition, subjective disturbance scores of the tasks explained 15-25% of all of the dimensions except somatization and interpersonal sensitivity. Tasks of difficult

emotional support were particularly influential. The provision of two or more tasks in any task category increased the level of psychotropic drug use, but not to the level of significance. The adequacy of informal social support had no significant effect on mental health or on the use of psychotropic medications. Baillie, Norbeck, and Barnes (1988) surveyed 87 family caregivers of elders on how caregiver demographics, perceived stress, and satisfaction with social support affected psychological distress. Psychological distress was measured with the Profile of Moods States scale, which identifies six dimensions: anxiety, depression, anger, vigor, fatigue, and confusion. Using multiple regression analysis procedures, only the duration of the caregiving and the mental functioning of the care recipient significantly predicted psychological distress. However, when perceived stress was removed from the prediction models, satisfaction with social support accounted for 19% of the variance in psychological distress and 22% of the variance in the depression subscale. From these findings, the investigators suggest that caregivers with unsatisfactory social support, caring for persons with poor mental function for longer durations of time are particularly at risk for psychological distress and depression.

Caregiving Work and Tasks

As mentioned earlier, Cossette and Levesque (1993) note that supervision tasks and tasks of difficult emotional support significantly impair various dimensions of mental health. Other researchers have examined the tasks caregivers provide. Cantor (1983) notes that spouse caregivers are more likely to provide personal care than non-spousal caregivers. Using a new tool to examine tasks predictive of negative mood and outcomes (The Oberst Caregiving Burden Scale), Bakas et al. (2004) note that the most time

consuming caregiving tasks are providing emotional support, providing transportation, managing finances, and household tasks. However, tasks most difficult for caregivers were managing problem behaviors, providing emotional support, carrying out household tasks, and managing finances. As noted earlier, managing finances, providing emotional support, and managing problem behaviors significantly predicted negative caregiver mood and outcomes.

Given, Stommel, Collins, King, and Given (1990) surveyed 159 spouse caregivers of elderly care recipients on how the caregiver environment (tasks) and caregiver and care recipient health affected caregiver reactions. Reactions were measured using a new tool that identified four types of reactions: negative responses, role responsibility, family abandonment, and impact on daily schedule. Negative reactions pertained to how the caregiver viewed their lives, their futures, and the emotional impacts of caregiving. Role responsibilities pertained to the importance and meaning caregivers placed on their caregiving work. Family abandonment pertained to the isolation caregivers felt from lack of support from other family members. Impact on daily schedule pertained to the demands caregiving work placed on the caregivers' schedules. The investigators note that spouse caregivers were more involved with providing IADL's than ADL's. Neither the number of hours spent completing tasks nor the level of involvement with IADL's nor ADL's were significantly correlated with negative responses, role responsibility, or family abandonment. Only number of hours and involvement with ADL's had a significant correlation with impact on the caregiver's daily schedule.

Other researchers have provided other typologies for classifying caregiver tasks other than the standard ADL/ IADL groupings. Albert (1991) used a pile-sort method

with child caregivers to develop groups of tasks. Results from the pile-sort procedure were then confirmed by qualitative comments from the participants. Twenty-five caregiver tasks were grouped by type of impairment leading to the task (cognitive vs. physical), location of the task (home vs. outside the home), and response to parental dependency (autonomy-fostering vs. guardianship of the parent). Albert notes that the participants made little distinction between the cognitive and emotional needs of parents, and notes that they lumped them together as one category contrasting with tasks resulting from physical impairment. This categorization indicates that caregivers may conceptualize tasks differently than researchers using the IADL/ADL grouping, or the grouping system of Archbold (1983) of caregiving vs. care managing. It is unclear, though reasonable to presume, whether or not different conceptualizations of types of tasks has affected the findings in other caregiver studies.

Caregiver Health

A number of researchers have looked at self-reported health as a consequence of caregiving. Kramer (1993) examined a number of caregiver variables, including health, and their effects on depression and quality of life. Kramer measured health as a self-reported item on a four-point scale, ranging from 1 = excellent, to 4 = poor. Kramer notes that this measure has been a strong correlate to mortality in other studies. In bivariate analyses, caregiver health was significantly correlated caregiver depression, quality of life, and satisfaction. In multivariate analysis, caregiver health was a significant predictor of caregiver depression and quality of life.

Strawbridge, Wallhagen, Shema, and Kaplan (1997) used longitudinal data from the Alameda County Study, which surveyed a sample of non-institutionalized adults from

1974 to 1994. Four groups were examined: 44 grandparent caregivers, 44 spouse caregivers, 130 child caregivers, and matched non-caregivers for age and education. Caregivers were self-identified in 1994. Physical health was self-reported as "poor, fair, good, or excellent". The investigators note that grandparent caregivers had significantly poorer health ratings, more depressive symptoms, were less happy, and had more activity limitations than controls. Spouse caregivers had significantly more depressive symptoms and were less happy than controls, but had no difference in health or activity limitations. Adult caregivers were significantly less happy, but no differences were reported in other variables when compared to controls. Since the caregiver samples were not drawn from support groups or service providers, the investigators contend that the results may have greater generalizability than the findings of other studies which used non-representative caregiver samples.

From studies mentioned previously, findings regarding caregiver physical health include the following. Goldstein et al. (2004) measured physical health as the number of chronic health conditions caregivers were told they had from their physicians. These investigators found no significant correlation between caregiver health and caregiver burden. Burton et al. (2003) measured caregiver health as "poor, fair, good, very good, or excellent" per self-report. Over a span of five years, caregivers had significantly more health deterioration than non-caregivers. Wright et al. (1999) measured caregiver health with the Multilevel Assessment Inventory and report that there were no significant differences in health among Alzheimer's caregivers, stroke caregivers, and controls. Given et al. (1990) measured health with a single item survey question in which respondents rated their perceived physical health. Physical health was a significant

predictor of caregiver responses to role responsibility, but not to the other responses of negative reactions, family abandonment, or impact on daily schedules. Unlike these investigators who examined physical health as an independent variable, Bakas et al. (2002) examined physical health as a dependent variable, measured by the Short Form-36 Health Survey. These investigators report that caregiver physical health was significantly predicted by lower income, living apart from the care recipient, and appraisals of threat.

Social Involvement

Kramer (1993) examined the role of self-reported satisfaction with the frequency and quality of social and recreational involvement per self-report of the caregivers. In both bivariate and multivariate analyses, Kramer notes that satisfaction with social involvement was significantly correlated with and predictive of caregiver depression, quality of life, and satisfaction. The strongest correlations and predictive strength was for quality of life. Brody et al. (1992) measured social involvement with a subscale of the Multilevel Assessment Instrument. They note that daughter caregivers who were either in their original marriages or were widowed were significantly more satisfied with their social involvement with friends than daughter caregivers with other marital statuses. Married and widowed daughters were more satisfied with social involvement with their families than separated/ divorced or single daughter caregivers.

Goldstein et al. (2004) measured social involvement of the caregiver with the Social Network Index (SNI). In bivariate and multivariate analyses, low social involvement was significantly associated with higher levels of caregiver burden. Similarly, Van de Heuval et al. (2001) note that the amount and satisfaction with social support, as measured by the Social Support List-Interaction/ Distribution, was a

significant predictor of caregiver strain. In contrast though, Hodgson et al. (1996) did not find social involvement to be a significant predictor of caregiver well-being for stroke caregivers.

George and Gwyther (1986) examined a variety of social activities including telephone contacts and visits with family/ friends; frequency of church attendance; frequency of club attendance; time spent with hobbies, time spent relaxing; and overall satisfaction with social activities as part of an comprehensive evaluation of caregiver well-being. These investigators note that caregivers had significantly lower levels of social involvement in all of the listed activities except church attendance than a non-caregiver comparison group. In addition, spouse caregivers demonstrated significantly less well-being, in part, due to differences in social involvement. Compared to adult or other relative caregivers, spouse caregivers had significantly fewer visits with family/friends, less frequent club attendance, less time spent relaxing, and less overall satisfaction with social activities.

Given et al. (1990) measured affective (emotional) support for caregivers using eight items from the Social Provisions Scale, which asked about people that caregivers could rely upon for support. Improved support was significantly predictive of positive role reactions from caregivers and decreased family abandonment and decreased impact on daily schedule reactions from caregivers.

Brennan, Moore, and Smyth (1995) used a computer-based support group intervention for caregivers of persons with Alzheimer's disease to evaluate changes in social isolation. A total of 102 caregivers participated, with half of the sample placed in a computer intervention group and the other half in a control group. Groups did not differ

in demographic or dependent variables. Participants were evaluated over twelve months. Social support was measured with the Instrumental and Expressive Social Support (IESS) Scale. Participants entered the computer program on average twice a week, mostly for information-seeking or emotional support purposes. However, the investigators note no significant differences in social isolation between intervention and control groups. The investigators propose that the IESS Scale may not have captured differences, since the scale focuses on sources of known support (such as from friends and relatives) and not new sources of support.

Caregiver Satisfaction

Another of the domains of caregiver appraisal described by Lawton et al. (1989) is caregiver satisfaction. Satisfaction has been examined by several of the investigators already mentioned. Kramer (1993) examined caregiver satisfaction as a dependent variable, along with caregiver depression and quality of life. Satisfaction was measured with the Caregiver Satisfaction Scale. In bivariate analysis, satisfaction was significantly and positively correlated with the number of ADL's provided to the care recipient and satisfaction with social involvement, and was negatively correlated with the duration of caregiving and the quality of the relationship with the care recipient prior to the onset of Alzheimer's disease. In multivariate analysis, satisfaction was significantly predicted only by the quality of the prior relationship when stressors were controlled for. Brody et al. (1992) note no significant difference in caregiver satisfaction among daughter caregivers of varying marital statuses.

Two sets of investigators examined caregivers' satisfaction with formal services provided to them. Hodgson et al. (1996) measured satisfaction with services with a yes/no response question and found that satisfaction of services (along with caregiver stress and caregiver physical health) were significant predictors of caregiver well-being for caregivers of persons with stroke twelve months post-stroke. Mudge and Ratcliffe (1995) surveyed 244 caregivers in England. Of the sample, over 90% were satisfied with physician services for their care recipient and 85% were satisfied with respite and/or day care services they were receiving. However, half of the respondents rated their satisfaction as poor or very poor with occupational and speech therapy services. Interestingly, even though one of the investigators (Ratcliffe) is identified as a nurse, no data on satisfaction with nursing services was provided.

Caregiver Mastery

Lawton et al. (1989) note that caregiver mastery is an aspect that had been neglected in the previous literature. From the stress model proposed by Pearlin and Schooler (1978) in which mastery is an element of personal resources that facilitates coping with challenges, Lawton et al. describe caregiver mastery as

...[representing] a positive view of one's ability and ongoing behavior during the caregiving process. Inasmuch as caregiving mastery is a self-perception conditioned by what happens during the course of caregiving, we suggest that it represents another facet of caregiving appraisal. (p. P62)

Consistent with the conceptual framework of Pearlin and Schooler, mastery has been most frequently examined in terms of coping styles and processes. However, Lawton et al. note that mastery is defined as a relatively stable personal trait with multiple dimensions. Some of these dimensions also include preparedness, self-efficacy, and caregiver needs, and are discussed below.

Coping Styles

Van de Heuval et al. (2001) examined how coping style influenced caregiver strain, mental well-being, and vitality in 212 stroke caregivers in the Netherlands. The investigators assessed coping styles with the Utrecht Coping List. Only the confrontative coping style and coping by seeking social support items were used, though the investigators' report does not provide an explanation for this limitation. Through multiple stepwise regression analysis, coping style was not a significant contributor to caregiver strain or vitality. However, poor use of a confrontative coping style was significantly associated with lower caregiver well-being.

Picot (1995) examined how caregiver appraisals related to coping styles in 83 African-American female caregivers. Picot assessed coping style with the Jalowiec Coping Scale, which categorizes respondents into one of three styles: confrontative, emotive, and palliative. Confrontative coping focuses on solving problems constructively by confronting them directly. Emotive coping focuses on the expressions of emotions as a release and a ventilation of feelings. Palliative coping focuses on strategies that reframe and modulate problems and ease stressors without directly confronting them (Picot, 1995). Within this framework, a confrontative style in which problems are addressed and behavioral actions are undertaken, has been suggested as the most

effective (Picot, 1995). Picot notes that the palliative strategies of prayer/ divine trust were the most frequently used in the sample, followed by the confrontative strategy of maintaining control over a situation. The emotive strategies of drinking alcohol and taking drugs were the least commonly used. Use of confrontative coping was significantly correlated with increased social support quality and increased income. Use of emotive coping was correlated with increased perceived caregiver costs (negative consequences), caregiver demands, and increased household income. Use of palliative coping was correlated with increased perceived caregiver costs, rewards, and demands. In addition, younger and employed caregivers were significantly more likely to use emotive coping; and married caregivers were more likely to use confrontative coping. Through hierarchical multiple regression analyses, the investigator notes that increased social support quality was the only significant predictor of confrontative coping; increased rewards significantly predicted palliative coping; and increased caregiving demands and costs and decreased quality of the relationship with the care recipient significantly predicted emotive coping. The investigator notes that confrontative coping strategies were used less than other strategies, consistent with findings from other researchers that minorities use confrontative coping less than Caucasians (Picot, 1995).

Related to coping strategies, Brennan et al. (1995) examined whether a computer-based support and information group would improve decision-making skills, decision confidence, and perceived social isolation for Alzheimer caregivers. Decision confidence and decision-making skill were evaluated by methods developed and piloted by the investigators. After one year of the computer service, caregivers did significantly

improve their decision confidence, but did not improve decision-making skill when compared to a matched-control caregiver group.

Preparedness

Archbold et al. (1992) define caregiver preparedness as "…how well prepared the caregiver believes he or she is for the tasks and stress of the caregiving role" (p. 328). These investigators surveyed 103 caregivers over nine months with the five-item Preparedness for Caregiving Scale, a subscale of the Family Caregiving Inventory (Archbold et al., 1990). After controlling for the influence of gender, whether or not the caregiver was a spouse, cognitive and physical impairments of the care recipient, and amount of direct care provided (known predicators of caregiver strain); lower preparedness significantly predicted increased caregiver strain from direct care, worry, increased tension, feelings of being manipulated, mismatched expectations, lack of resources, and global strain. The investigators suggest that nurses who evaluate caregiver preparedness would be better able to anticipate who is at risk for increased caregiver strain and (Archbold et al., 1992).

Self-efficacy

Acton (2002) examined caregivers and a comparison group on health promotion behaviors, using the premise that caregivers used fewer strategies to care for themselves than non-caregivers, and thus, had poorer health. Acton measured self-efficacy with self-care of health promotion with the Self-Rated Abilities for Health Practices Scale. Acton notes that caregivers expressed significantly lower self-efficacy for self-care than did non-caregivers. This finding was important in that Acton reports that caregivers who did

practice health promotion self-care were better protected from stress and had improved well-being than caregivers who did not practice self-care.

Caregiver Needs

Several researchers have examined the expressed needs of caregivers. Needs are related to mastery in that the identification and meeting of needs by caregivers is one aspect of meeting the challenges of caregiving work. Mudge and Ratcliffe (1995) surveyed 255 family caregivers in England. The investigators report that 47% of the sample needed information and advice (23% of which wanted information and advice on benefits, followed by 16% on medications); 33% wanted to join a support group, 23% needed training, and 22% needed reference books or equipment.

Bakas, Austin, Okonkwo, Lewis, and Chadwick (2002) interviewed 14 female family caregivers of persons with stroke on their needs during the first six months after the stroke. Interestingly, the investigators report that one male caregiver was initially included in the sample, but since his needs were so different than the other 14 female caregivers, his data were excluded. The sample of 14 included eight African-American caregivers. After collecting the data, the investigators conducted meetings with each other in order to reach consensus on the list of needs, eventually coming up with 32 needs in five categories. The most common type of need expressed was assistance with managing problem behaviors and providing emotional support to the care recipient. Next most common were informational needs, particularly information regarding signs and symptoms of stroke and future strokes. Needs for assistance with instrumental care, then with physical care were next most common. The least common type of needs was that pertaining to the emotional, social, and physical impact of caregiving on the caregiver.

One of the limitations of the above study was its cross-sectional design. Hanger, Walker, Paterson, McBride, and Sainsbury (1998) also studied stroke caregivers, as well as stroke patients, but prospectively over 24 months. Participants were interviewed at six and 24 months post-discharge from the hospital, while a subgroup was also interviewed two weeks post-discharge. The topics of questions were tabulated. Although the report does not distinguish totals on the types of questions asked by the caregiver versus the care recipient, the investigators note that the most common type of question asked at two weeks were those pertaining to the basic mechanisms of stroke. Fully 50% of the participants asked about the causes of stroke at two weeks, with this percentage dropping to 15% at six months and 14% at two years. At two weeks, 23% of the participants asked questions about stress and work, which also dropped at subsequent visits (4% at six and 24 months). At both six and 24 months, the most prevalent question pertained to the risk of stroke recurrence. At six weeks, 12% of the participants asked about medications. Fewer than 10% of the participants asked questions at six and 24 months pertaining to health management and rehabilitation.

Hileman and Lackey (1990) interviewed 15 persons with cancer and their caregivers on their needs. The participants provided 192 caregiver need statements, which were then Q-sorted into eight categories previously established by the investigators. These categories included information needs, household management needs, caregiver physical needs, caregiver psychological needs, spiritual needs, legal/ financial needs, respite needs, and miscellaneous needs. Caregivers reported that their greatest needs were in the psychological, informational, and household duties categories.

In a follow-up study, Hileman, Lackey, and Hassanein (1992) surveyed 492 caregivers of persons with cancer on their needs and investigated correlates of those needs. Needs were evaluated using the Home Caregiver Needs Survey, developed by one of the investigators, which contains 90 needs statements and evaluates the importance and satisfaction with each need. Caregivers were also surveyed two and four months later, though only 44 of the original 492 caregivers completed the survey at four months. Through factor analysis, the investigators identify six types of needs: psychological needs, patient care needs, personal needs, household needs, informational needs, and spiritual needs. At baseline, informational needs were the most common, particularly those pertaining to current and future symptoms. Next most common were psychological needs, then patient care needs. Correlations were calculated between caregiver variables and types of needs. The investigators note that caregivers caring for persons in poorer health had significantly higher psychological, patient care, and household needs than those caring for persons in better health. Caregivers living with the care recipient had significantly more personal needs. Younger caregivers had significantly more psychological and personal needs than older caregivers. The investigators report that correlations among needs between times two and three were largely non-significant, indicating that there was a change in needs over time. However, the investigators' report does not detail the nature of those changes.

Caregiver's Assessment of the Personal Qualities of the Care Recipient

and Relationship with the Care Recipient

As was previously noted, Kramer (1993) reports that wife caregivers who had been married more than once were significantly more likely to experience depression, and have decreased satisfaction and quality of life. She surmises that the love and commitment found in long-term marriages protect wife caregivers from these negative consequences. Other researchers have examined the quality of the relationship between caregiver and care recipient in terms of caregiver outcomes.

Blake (2000) used the Positive and Negative Affect Schedule to measure positive and negative affectivity of caregivers toward their care recipients. In caregivers of persons with reflexive sympathetic dystrophy, negative affectivity was significantly correlated with psychological distress in caregivers. Positive affectivity had no such correlation. However, Blake and Lincoln (2000), again using the Positive and Negative Affect Scale, note that decreased positive affectivity and increased negative affectivity both significantly correlated with increased caregiver strain. Robinson (1983) states that caregivers' satisfaction with how well the care recipient understood their work and caregiver perception on how well they got along with the care recipient had a negative significant correlation with caregiver strain. In her prevalence study, Cantor (1983) reports that 60% of spouse caregivers reported getting along very well with the care recipient, compared to 53% of child caregivers. Furthermore, spouse caregivers were more likely to report understanding the care recipient and report being treated well by the care recipient than were child caregivers.

Archbold et al. (1990, 1992) examined mutuality in relation to caregiver and strain. These investigators note that mutuality contains four dimensions: love and affection, shared pleasurable activities, shared values, and reciprocity. In their study, Archbold et al. measured mutuality with the Mutuality Scale, a 15-item subscale of the Family Caregiving Inventory. High scores on the Mutuality Scale reflect high levels of the four mutuality domains. Surveying 102 caregivers, the investigators report that mutuality was significantly and negatively correlated with caregiver strain. The investigators suggest that caregivers with high mutuality are less strained because they find caregiving meaningful. The investigators propose that mutuality assessments would be important for health providers, in that caregivers with very low mutuality scores may not be the ideal caregivers for their care recipients.

Caregiver Cognitive Reappraisal

Lawton et al. (1989) report that the term *cognitive reappraisal* stems from one the major coping mechanisms proposed by Lazarus, and refers to reinterpreting the meaning of a particular stressor. However, in the factor analysis completed by Lawton et al., items falling into this domain of caregiver appraisal pertained to the meaning caregiving had to the caregiver and the reasons the caregiver embarked upon caregiving. These aspects of caregiving have been discussed less often in the caregiver literature than other aspects of caregiving, and have been discussed more often in studies pertaining to male caregivers and in qualitative studies. One notable exception includes the study of mutuality by Archbold et al. (1990) discussed previously.

Characteristics of the Care Recipient

Although characteristics of the care recipient were not addressed as items factored

into the caregiver appraisal dimensions by Lawton et al. (1989), they have been

prominently featured in caregiver studies, primarily as an independent variable. Care

recipient gender, age, type of illness, illness severity, dependence level, depression, and

overall health have been used in studies. Generally, physical and mental health

characteristics of the care recipient have been most frequently addressed, particularly as

they relate to caregiver work and caregiver health. However, the findings of the studies

have been variable, probably due to differences in samples, measurements, and study

designs. Summary findings from several examples of these studies are highlighted

below.

Baillie et al. (1988) report that increased duration of illness and increased

cognitive impairments in elderly care recipients were significant predictors of caregiver

depression. Likewise, Kramer (1993) notes that memory and behavior problems and

increased duration of Alzheimer's disease significantly predicted caregiver depression

and decreased caregiver quality of life. Interestingly, caregivers caring for persons with

increased physical limitations had significantly higher caregiver satisfaction. In terms of

duration of illness, Van de Heuval et al. (2001) report contrasting findings that duration

of illness of persons with stroke was not significantly correlated with caregiver strain or

well-being. However, a high level of emotional, cognitive, and behavioral changes after

stroke was predictive of increased caregiver strain and lower caregiver mental health and

vitality. Likewise, Robinson (1983) reports that decreased care recipient mental

functioning and ability to complete ADL's were significantly correlated with caregiver

strain. Blake (2000) reports that increased handicap of the care recipient was correlated with caregiver strain. Blake and Lincoln (2000) state that decreased ability of the care recipient to complete extended activities of daily living (also known as IADL's) after experiencing a stroke was a significant predictor of caregiver strain. The same group of investigators notes in a subsequent study of persons with stroke that the only cognitive impairment significantly predictive of strain was aphasia (Blake & Lincoln, 2002).

In contrast to these findings on strain and mental health, Zarit et al. (1980) report that memory/ behavior problems, decreased cognitive function, and decreased physical functioning with ADL's and IADL's were not significantly correlated with caregiver burden. Likewise, Cantor (1983) did not find that care recipient health was significantly related to caregiver strain, and George and Gwyther (1986) found that care recipient illness characteristics were not significantly related to caregiver well-being. Hodgson et al. (1996) did not find care recipient physical and cognitive impairments 12 months post-stroke to be a significant predictor of caregiver well-being.

Given et al. (1990) reported that negative care recipient behaviors were significant predictors of negative reactions, family abandonment, and impact on daily schedule caregiver responses; whereas positive care recipient behaviors predicted positive role reactions from caregivers. Deteriorating care recipient health was negatively predictive of negative reactions and family abandonment and positively predicted role reactions. Dependency with ADL's was not predictive of any of the four types of caregiver reactions.

General Qualitative Findings

Although the studies reviewed thus far have provided important information on general caregiving characteristics, they are limited to specific variables. As such, only a limited perspective of caregiving can be derived from them. Several qualitative studies which did not focus specifically on male caregivers were located and are reviewed below. These studies provide a more comprehensive view of general caregiving.

Hasselkus (1988) notes in her review of the literature that few studies examined the experiential aspect of informal caregiving. Thus, Hasselkus used an ethnographic approach in interviewing family caregivers in order to "...elicit data on the meaning of the caregiving experience and on the patterns of formal learning embedded in that meaning" (p. 686). Hasselkus conducted a series of four one-hour interviews with 15 caregivers, one of whom was male and nine of which were spouse caregivers. Although the process of data analysis was not clearly detailed, Hasselkus notes that early in the analysis, a concept of learning emerged characterizing the caregiver as a reflective practitioner. Further analysis was conducted using the reflection-in-action model as an organizing framework.

From the reorganized data, Hasselkus (1988) identifies five themes of meaning. First is a sense of self, a concern of one's health and capabilities. Second is a sense of managing, focusing on organizing and conducting the caregiving work. Third is a sense of the future, which was usually characterized as a feeling of doom and pessimism. Fourth is a sense of fear and risk, exemplified by a fear of change or loss of stability and the risk of leaving the care recipient alone or for respite; and last, a sense of change in role or responsibility caused by the adoption of the caregiver-care recipient dynamic.

A sixth, but uncategorized theme of tension, is also reported by Hasselkus (1988). Tension occurs in a variety of relationships: between caregiver and care recipient, between caregiver and other family members, and between caregiver and health professionals. This latter tension is discussed most at length by Hasselkus, who notes that caregivers often felt stuck in the middle between care recipient demands and health professional instructions. Also, caregivers frequently feel a tension as they jockey for control of the caregiving, sometimes in conflict with health professionals' advice or even at the expense of the relationship with the health professional itself. Hasselkus concludes her discussion by emphasizing the need to reconceptualize the family caregiver as a reflective practitioner. In doing so, and in recognizing sources of tension, health professionals will work better with caregivers in a collaborative, rather than a hierarchical, fashion.

The issue of control of the caregiving situation was the focus of a study completed by Szabo and Strang (1999). These investigators completed a secondary analysis of qualitative data from interviews of 17 caregivers (four of whom were men) of persons with dementia in Canada. These investigators note that the literature suggests that perceived control has been linked to improved caregiver satisfaction and mental health, and that taking control of a situation was an aspect of action-oriented coping. The purpose of the study was to explore the experience of control as perceived by caregivers of relatives with dementia.

Using grounded theory methods, Szabo and Strang (1999) identify two dimensions of control: maintaining control and lacking control. Maintaining control was characterized by actively engaging in the control process and contained the properties of

using confident language, identifying positive internal resources, recognizing a need for help and asking for it, anticipating the future, and taking action if it was perceived that control was being lost. Lacking control was characterized by the inability to cope with demanding situations and contained the properties of identifying negative internal resources, being unable to recognize needs and/or ask for them, and being unable to anticipate the future.

The investigators also note a movement between maintaining and lacking control. Moving away from maintaining control was identified as losing control; whereas moving toward maintaining control was identified as regaining control. The investigators surmise that movement may be common over the trajectory of the caregiving as exceedingly stressful or new situations arise. The implications for these findings might be to understand better why some caregivers may have difficulty with caregiving work and why cross-sectional study designs may provide different information based upon movement during the caregiving trajectory (Szabo & Strang, 1999).

In striving to understand the comprehensive experience of caring for a relative with Alzheimer's or related diseases at home, Butcher, Holkup, and Buckwalter (2001) conducted a secondary analysis of in-depth interview data from 103 family caregivers, 29 of whom were men. The investigators used a 12-step psychophenomenological method, developed by van Kaam, to identify 2115 descriptive expressions which were categorized into 38 preliminary structural elements. From these preliminary elements, the investigators note eight essential themes of caregiving: being immersed in caregiving, enduring stress and frustration, suffering through the losses, integrating [dementia] into

our lives and preserving integrity, gathering support, moving with continuous change, and finding meaning and joy.

In summarizing their findings, Butcher et al. (2001) suggest that the method they used allowed for a more comprehensive picture of dementia caregiving than had been noted previously in other studies. The investigators comment on their wonder at how these caregivers, despite the daily and enduring burden of caregiving, were able to find ways to preserve self and find meaning. The eight essential themes identified allude to the dynamic trajectory of caregiving, and represent the domains of caregiver appraisal identified by Lawton et al. (1989).

Brown and Stetz (1999) also describe this dynamic trajectory of caregiving. These investigators conducted in-depth interviews over a four-month time span with 26 family caregivers (four of whom were men) of persons with AIDS or terminal cancer. The purpose of the study was to examine how a potentially fatal illness influences caregiving over time. Data came from a larger, mixed methods intervention study generated from participants in a cancer caregiver support group and an AIDS caregiver support group. Analysis of data was completed through a thematic analysis of transcripts using a constant comparison technique.

From the data, the investigators propose a substantive theory of informal caregiving for persons experiencing potentially fatal illnesses centered on the core theme of the labor of caregiving. The investigators define this core theme as the ongoing cognitive, emotional, and physical toil of caregiving. From this core theme, four phases suggestive of a trajectory process were identified: becoming a caregiver, taking care,

midwifing the death, and taking the next step (Brown & Stetz, 1999). Embedded within each phase were multiple sub-themes.

In becoming a caregiver, the investigators note that caregivers must first face the present reality, choose to become a caregiver, and develop caregiver competency. In taking care, caregivers provide the caregiving work and struggle with its inherent stressors. In midwifing the death, caregivers wait for the inevitable and hope that the death is peaceful. In taking the next step, caregivers grieve and then move on with the rest of their lives. In summarizing their findings, the investigators note that this study provides a broader perspective than just the caregiving work itself and provides a trajectory perspective essential for health professionals to use when supporting these caregivers (Brown & Stetz, 1999).

In adopting a more focused perspective of caregiving, Schumacher, Steward, Archbold, Dodd, and Dibble (2000) examined the process of family caregiving skill development. These investigators analyzed interview data collected from two larger studies in which 29 family caregivers (11 of whom were men) of persons with cancer were interviewed. Using grounded theory methods of open coding, constant comparison and memoing, the investigators identified the properties, dimensions, and indicators of caregiving skill. In total, 63 indicators of skill were noted, which were then categorized into nine caregiving processes: monitoring, interpreting, making decisions, taking action, making adjustments, providing hands-on care, accessing resources, working together with the ill person, and negotiating the health care system.

The investigators analyzed their findings in light of earlier theoretical analyses (Schumacher, Stewart, & Archbold, 1998) to derive a conceptual definition of family caregiving skill. They note that

> Family caregiving skill [is] defined as the ability to engage effectively and smoothly in nine core caregiving processes. Caregiving [is] effective when it [leads] to the best possible outcomes of care.....Caregiving [is] smooth when it [flows] with the seemingly effortlessness of actions honed through experience and practice. (p. 199)

The investigators note in their discussion that the findings provide an initial conceptual base that can move research from examining caregiver burden and tasks to evaluation of the caregiving role. The findings will assist in tool development aimed at evaluating caregiver skill.

Another focused study examined the home modifications made by family caregivers of elders as a strategy to facilitate caregiving work (Messecar, Archbold, Stewart, & Kirschling, 2002). These investigators note that although previous categorizations of home modifications had been presented, it was not clear that these categorizations matched the perceptions of the family. In this study, 24 family caregivers (seven of whom were male) were interviewed and 17 were observed in their home environments. Transcripts of interviews, field notes and memos were analyzed by open coding procedures, and then by clustering of codes into categories. In total, 44 home modifications were identified and organized into seven purposes: organizing the home

physical environment to facilitate caregiver tasks; modifications to supplement or optimize the care recipient's functioning; modifications to ensure the elder's safety; modifications to work around limitations of the home environment; and actions of transitioning to a new home environment. Some caregivers elected to make no modifications in the home environment. The investigators propose that their findings address a previous gap in the literature, and will assist future caregivers and health professionals in implementing strategies to improve the success of caregivers.

In light of the demands placed upon caregivers, Caron and Bowers (2003) were interested in examining why some caregivers continue to provide care and what might lead other caregivers to relinquish their caregiver roles. Such examination is significant in that it would better enable the provision of appropriate caregiver support. Using grounded theory methods, Caron and Bowers interviewed 16 caregivers (six of whom were men). Data from transcripts were analyzed using methods described by Glaser and Strauss (1967), Strauss and Corbin, (1998), and Schatzman (1991). From the data, the investigators propose a dimensional matrix of caregiving purposes. These purposes fell into two main categories: interrelational caregiving and pragmatic caregiving.

Caron and Bowers (2003) note that interrelational caregiving was used most often when the care recipient experienced cognitive deficits. Caregivers using this type of caregiving "...engaged in efforts to bolster the care recipient's sense of self and to preserve the caregiver-care recipient relationship" (p. 1258). Processes of this type of caregiving acted to protect and maintain the care recipients' views of themselves that the caregiver felt was positive and important. Caregivers using interrelational caregiving made decisions designed to pursue interrelational goals.

On the other hand, pragmatic caregiving focused on making the care recipient physically or emotionally comfortable as well as minimizing the costs of caregiving. Caregivers using this type of caregiving often tapped into formal care providers to take over tasks and also to provide for interrelational care. Care recipients receiving this type of care may be in the home or institutional setting.

Caron and Bowers (2003) propose a substantive theory of caregiving from the findings, which focuses on the purposes of caregiving. The investigators note that caregivers may shift from interrelational to pragmatic caregiving, or vice versa, in a non-linear fashion, but that understanding the purposes of caregiving and their subsequent anticipated and perceived caregiving consequences will better enable providers to understand why caregivers elect to maintain or relinquish the caregiver role.

In order to better understand how caregivers cope with the stress and demands of caregiving for a non-Caucasian population, Shyu, Archbold, and Imle (1998) completed a grounded theory study on the caregiving processes used by Taiwanese family caregivers. Fifteen family caregivers (two of whom were men) of elderly care recipients were interviewed. Using open coding and constant comparison methods, the core category *finding a balance point* emerged early in the analysis, and was substantiated with further interviews. Finding balance involved three processes: anticipating competing demands on the caregivers, weighing competing needs and making judgments about them, and choosing and implementing balancing strategies. Balancing strategies included actions taken to ameliorate or modify the demands of the caregiver environment and engaging in self-care. Caregivers who found balance reported better quality of care and satisfaction. Those who failed to find balance had difficulty anticipating and recognizing needs,

tended to implement ineffective and fixed strategies, and reported less satisfaction and success with caregiving.

Grant and Nolan (1993) note the preponderance of caregiver literature focusing on caregiver burden and hoped to redress the imbalance by examining caregiver satisfaction. The investigators analyzed qualitative comments from an open-ended question pertaining to caregiver satisfaction from the Association of Carers survey of English households. Qualitative data were taken from 522 caregivers (130 of whom were men) and analyzed with content analysis procedures. Several sources of satisfaction were discerned, the most frequent source deriving from the satisfaction caregivers received through the act of giving to the care recipient. Another source of satisfaction came from expressions of appreciation from the care recipient to the caregiver. Other sources of satisfaction came from a perceived improved affinity between the dyad as a result of caregiving, repayment for past caring and/or honoring wedding vows, knowing that the care recipient was being well-cared for, pride in caregiving accomplishments, altruism, religious convictions, and pride in that the caregiving prevented the care recipient from being placed into institutionalized care.

The decision of whether or not to place an elderly care recipient into a nursing home was examined by Hagen (2001). Hagen interviewed five co-resident family caregivers of persons with dementia who were considering placing their care recipient into a nursing home in Canada. Interviews were analyzed using open coding, constant comparison, memoing, and coding for categories methods. From the data, Hagen proposes a theoretical model of this decision-making process. The process included six factors: independence in the relationship between caregiver and care recipient; perceived

level of support from others; fear of loneliness; negative nursing home attitudes; sense of existential self (having distinct meaning and purpose in life apart from caregiving); and guilt. Hagen suggested that this model indicates that the decision to place a relative in a nursing home is rarely a simple or rational process. How significant these factors are in any given individual may explain the differential decisions and timelines individual caregivers use in placing relatives in nursing homes.

Two studies from the United Kingdom addressed a specific type of caregiver satisfaction, namely satisfaction with caregiver services. In both studies, researchers interviewed participants with open-ended questions, and categorized comments into themes. Seddon and Robinson (2001) interviewed 64 caregivers (25 of whom were men) of persons with dementia, as well as service providers and case managers on satisfaction with and needs for services. Five themes emerged. The first was *recognition*, pertaining to the need caregivers have to be recognized as individuals with individual needs, talents, and skills. Second was *information*, noting that caregivers wanted more information on disease processes and on available services. Third was *parameters of assessment*, pertaining to the need expressed that assessments should be sensitive to the caregiver and not to the needs of the service provider. Fourth was *monitoring and review*, pertaining to the need to review caregivers' needs on a periodic basis as they may change. Fifth was *staff training and development*. Although conducted in Wales, the information from these caregivers' perspectives of formal services may have universal implications.

In the other study, investigators interviewed eight English caregivers of persons with stroke about the formal home services they were receiving (Simon & Kumar, 2002). Four themes emerged from the analysis. First, caregivers wanted more information and

education about stroke and caregiving. Second, caregivers wanted multidisciplinary involvement at home as they had received when the care recipient was in the inpatient rehabilitation unit. Third, caregivers wanted services that were convenient, coordinated, and flexible. Fourth, caregivers wanted to be included as collaborators in the care planning process. Again, these findings most likely have universal implications.

The previous sections have highlighted a number of general caregiving studies. Before a summary is provided, examination of what is known about caregiving provided by men is requisite. A review of the literature on male caregiving follows.

Men and Caregiving

The previous sections of this chapter have focused on the prevalence of caregiving and general knowledge about the processes, experiences, variables, and outcomes of caregiving relatively free of the context of gender. However, before examining and critiquing what is known about male caregivers, a brief discussion of the theoretical perspectives of male caregivers is needed. An exhaustive review of the literature on gender will not be provided. Instead, how gender, particularly male gender, intersects with care and caregiving will be the focus.

Three disciplines have contributed the bulk of the conceptual literature on care: nursing, sociology, and psychology. In terms of the gendered nature of care, sociology has focused more on the differences of how men and women approach care, and has better contributed to the knowledge base on the causative factors of those differences than has nursing. This may be due to the overwhelming prevalence of women in nursing (Spratley, Johnson, Sochalski, Fritz, & Spencer, 2001) and of women conducting nursing

research. As such, women in nursing have provided a knowledge base derived from a primarily female perspective (MacDougall, 1997). These theoretical perspectives of caring by nurses are discussed next.

Theoretical Perspectives from Nursing

Care and caring, as a construct, has been elusive to definition (Morse, Bottorff, Neander, & Solberg, 1991; Morse, Solberg, Neander, Bottorff, & Johnson, 1990; Paley, 2001; Phillips, 1993). As such, no one has yet to explain caring comprehensively. Given this, three major theories of caring have come from nurse researchers: Watson's Theory of Human Care, Leininger's Theory of Transcultural Care Diversity and Universality, and Orem's Self-care Deficit Theory (Morse et al., 1990).

Watson's Theory of Human Caring proposes that caring is derived from the development of a humanistic-altruistic value system and a cultivation of sensitivity to self and to others (Watson, 1979, 1985). Caring is an attitude that is learned and not passed down through genes. This value system and caring attitude results in caring behaviors, which can be effectively demonstrated and practiced only in an interpersonal manner. Watson approaches caring from a phenomenological-existential and spiritual level, in which internal caring ethics lead to behaviors characteristic of caring. As such, human care is a moral ideal and not a task. Human care as a moral ideal is universal. Watson further delineates a difference between caring and curing, in which caring behaviors are aimed to maintain/ preserve health or promote a peaceful death; whereas curing behaviors, based in positivist perspectives, are aimed to problem-solve illness/ disease. Although Watson does not emphasize the gendered nature of care, Watson does provide a

perspective that is consistent with the assumption that caring and female gender are naturally paired.

Leininger (1991) adopts a broader perspective to human caring. Although Leininger believes that caring is universal among cultures, she proposes that multiple sociocultural factors influence how caring is perceived, valued, and implemented within a cultural group. Hence, caring is universal yet diverse. Within this framework, care cannot be operationalized into universal concepts and definitions, but instead, must be perceived as embedded within the sociocultural context in which the caring takes place. Although gender is addressed by Leininger, gender is but one of many influencing variables that shape care and caring behaviors.

According to Morse et al. (1990), Orem's Self-care Deficit Theory focuses on the phenomenon of self-care, in which individuals exhibit behaviors that promote self-maintenance and self-regulation. When individuals cannot perform these self-modulating behaviors, caregivers provide assistance, with the goal of restoring an individual's capability to return to as many self-care behaviors as possible. Orem's theory has been criticized as being incongruent with the value systems on non-Western cultures. Orem does not address gender directly.

None of these theories provides a comprehensive depiction of caring since they do not fully address the definition of caring, the motivations for caring, the different ways to exhibit caring, and the different outcomes for caring. As such, empirical evidence from studies examining caring have yet to fully support any one theoretical approach to care (Morse et al., 1991; Morse et al., 1990; Phillips, 1993; Stoller, 2002). Yet, several nurse

theorists have proposed that caring is the defining characteristic of nursing as a

profession (Boykin & Schoenhofer, 2001; Leininger, 1991; Watson, 1979, 1985).

Several important reviews of the nursing literature have been completed that

focus on proposed definitions and theoretical models of caring. The most comprehensive

is probably the review conducted by Morse and colleagues (Morse et al., 1991; Morse et

al., 1990). Morse et al. examined the definitions and models of caring from 35 authors

published between 1976 and 1989. Morse et al. organized these works into five

categories based on epistemological perspectives of care. Although the categories are not

rigid and multiple authors had perspectives encompassing several categories, the

categories include: caring as human trait; caring as an affect; caring as a moral

imperative; caring as an interpersonal interaction; and caring as a therapeutic

intervention. The outcomes of care focused on the patient's subjective experience of the

care and the patient's physical response to the care, though some authors also discuss the

effects of care on the nurse (Morse et al., 1991; Morse et al., 1990).

Authors who discuss caring as a human trait propose that caring is an essential

component of being human, that is universal, long-lasting, and necessary for human

survival. However, caring ability is not uniform among individuals, and may vary based

on the context of the caring environment. Authors who discuss caring as a moral

imperative note that caring is the foundational ideal for nursing, which guides care

decisions by determining what is right or what should be done in order to preserve a

patient's dignity. Caring from this perspective is nurse-centered. Authors who discuss

caring as an affect interaction also provide a nurse-centered perspective. These authors

propose that caring is derived from compassion and empathy in which optimal care

results from interpersonal intimacy between nurse and client. This intimacy may be negatively limited by workplace structures and technology that separates the nurse and the client (Morse et al., 1991; Morse et al., 1990).

Similar to the authors defining caring as affect interactions are those who define caring as interpersonal interventions. However, these latter authors emphasize the relationship between the nurse and the client and the mutual exchanges that occur within that relationship. In this perspective, caring may also be shaped by the client's desires and needs regarding the level of intimacy within the relationship. Last of the categories described by Morse et al. include those authors who define caring as therapeutic interventions. These authors focus more than the others on the actual work of nurses in meeting the needs of patients. As such, it is the only category that is patient-centered. From this perspective, effective care occurs when patients improve, regardless of how the nurse feels or whether or not the relationship between the patient and the nurse is characterized by mutuality, respect, or trust (Morse et al., 1991; 1990).

Related to the caring perspective of therapeutic interventions are those authors who focus not on the caring itself, but on outcomes as an indicator that care occurred. These authors propose that care is defined by its results (such as improvement in a patient's condition, prevention of problems, and/or satisfaction). However, Morse et al. note that some authors represented in the previous categories propose that care will lead to desired outcomes, indicating that care is purposeful and process-driven. Unfortunately, many of the authors do not provide a theoretical link between caring and outcomes, which seems inconsistent with the view that nursing is an applied discipline focused on outcomes (Morse et al., 1991; 1990). Since caring is so elusive to define,

perhaps the reconceptualization of caring as a subcomponent of comfort may provide for better assessment of the outcomes of caring behaviors.

Morse et al. also note that whether authors propose that caring is a uniform trait among humans, or whether caring is a learned skill, most theoretical models do little to explain the empirical evidence that care is implemented differently, even within the same nurse. For example, any given nurse may deliver different care to different patients within the same day. Research is greatly needed in examining different styles of caring and factors related to providing different types of care (Morse et al., 1990).

Morse et al. (1991) note that although caring is universally accepted as a central construct for nursing, few nurse authors have examined the issue critically. Several subsequent authors have provided some level of criticism. Phillips (1993) notes that nursing has over-emphasized the affective nature of caring to the detriment of outcomes research. Phillips suggests that some of the over-emphasis stems from the care versus cure dichotomy discussed by Watson and by others. Phillips suggests that this dichotomy is false, in that carative actions can be curative and curative actions can be caring. In addition, Phillips reviewed studies that suggest that patients rank skill and competence above affective factors as desirable in nurses. Although, affective factors have desirability, patient's safety and physical needs are a priority, consistent with Maslow's hierarchy of needs. Stated as a reflective question, does the nurse provide good care if the nurse demonstrates empathy and compassion but lacks competent bedside skills? Phillips' critique suggests that nursing has emphasized the affective and interpersonal interaction aspects of caring, but has overlooked the question as to whether or not patients want or need intimate relationships with their nurses.

Sourial (1997) echoes some of the comments provided by Phillips (1993). Sourial notes that the literature doesn't rectify the instrumental versus affective nature of care. Sourial references several studies that suggest that caring cannot occur without instrumental competence, yet quotes Pepin, who feels that nursing has placed an over-emphasis on the physical aspects of caring over the affective (in contrast to Phillips). In recognizing the need to propose theoretical models that address all aspects of caring, Sourial suggests that care be subsumed under holism, since holism is more clearly understood than caring and is scientifically-based (Sourial, 1997).

Scotto (2003) repeats the theme of the lack of comprehensiveness of conceptualizations of caring. As such, Scotto proposes a new definition for caring as an "…offering of oneself. This means offering the intellectual, physiological, spiritual, and physical aspects one possesses as a human being to attain a goal" (p. 290). However, this proposed definition, although holistic in nature, does not address either the motivations of caring, differences in implementing caring, nor the outcomes of caring.

Boykin and Schoenhofer (2001) propose a new theory of caring which they claim is more holistic. They introduce their theory and define caring in this way:

…all persons are caring. Caring is an essential feature and expression of being human….Caring is a process. Each person, throughout his or her life, grows in the capacity to express caring….Although persons are innately caring, actualization of the potential to express caring varies in the moment and develops over time. The development of competency in caring occurs over a lifetime. (p. 1-2)

Most of the studies identified in Table 2.1 have been discussed previously. Additional studies identified in Table 2.1 are discussed next.

Fitting, Rabins, Lucas, and Eastham (1986) surveyed 28 wife caregivers and 26 husband caregivers of spouses with Alzheimer's disease in order to compare burden, psychological adjustment and feelings about dementing illnesses by gender. A variety of measures were used, including the Zarit Burden Scale (Zarit et al., 1980), the Family Environment Scale, and the Minnesota Multiphasic Personality Inventory. The groups were similar demographically and had similar levels of impairment in their spouses. The researchers note no significant difference in caregiver burden. However, wife caregivers had significantly higher levels of depression than husband caregivers when age and level of impairment were factored in. Wife caregivers became more depressed as the severity of dementia increased; whereas depression remained stable for husband caregivers. In addition, wife caregivers were significantly more likely to report a deterioration of the marital relationship than were husband caregivers. Both wife and husband caregivers had equal levels of social support.

In another study (Jutras & Veilleux, 1991), 294 male and female French-Canadian caregivers of varying familial relationships of elderly relatives were surveyed on the level of ADL assistance they provided and the amount of caregiver burden Men made up 30% of the sample. The women in the sample were older, less educated and less likely to be employed than the men in the sample. The researchers note that female caregivers provided significantly higher levels of assistance with personal care ADL's than male caregivers, but there was no difference in the amount of household ADL's provided. Female caregivers were significantly more likely than male caregivers to use formal

services. There was no significant difference in the level of burden between male and female caregivers. There was no significant difference in the amount of care provided between employed and non-employed caregivers.

However, other researchers did find that female caregivers experience significantly more burden than male caregivers. Zarit, Todd, and Zarit (1986) surveyed 33 wife caregivers and 31 husband caregivers of persons with Alzheimer's disease at baseline and then again two years later for caregiver burden and social support. The male caregiver sample was significantly older than the female caregiver sample. The researchers note that at baseline, wife caregivers reported significantly more burden than husband caregivers. Burden was most closely associated with memory and problem behaviors. Also, burden was significantly reduced for caregivers who had placed their spouses in nursing homes during the study. However, burden was not significantly different two years later between husband and wife caregivers. The researchers concluded that wife caregivers were better able to adapt and cope with problems and/or the level of memory and problem behaviors declined over time. There was no significance difference in the amount of support from other family members for husband and wife caregivers. Both types of caregivers reported relatively low levels of support and need for respite services.

Thompson et al. (2004) compared 45 wife caregivers with 16 husband caregivers of spouses with Alzheimer's disease on a number of psychological and biological variables. Using a general stress-response framework, the researchers examined how stressors (perceived stress, caregiver burden) were mediated (by sense of coherence, coping, and social support) resulting in varying levels of outcomes (depression, quality of

life, immunocompetence, relaxation response). Burden was measured by the Screen for

Caregiver Burden scale. Quality of life was measured with the SF-36. In summary,

husband caregivers had significantly lower stress levels, less anxiety, less anger-hostility,

and somatic symptomatology than wife caregivers. In addition, husband caregivers had

significantly higher levels of mental health, sense of coherence, and social and physical

functioning than wife caregivers. The results on immune system function were

inconclusive, in that various immune system markers differed between men and women

suggesting negative impact. However, the researchers note that wife caregivers had

significantly higher levels of NK immune cells than husband caregivers and female non-

caregiver published controls, suggesting that the chronic stress resulting from caregiving

negatively impacts the immune system of wife caregivers.

Kramer and Kipnis (1995) examined non-spousal employed caregivers of elderly

care recipients for burden. In total, 413 caregivers were surveyed with an investigator-

designed questionnaire exploring the amount of type of caregiving provided, role strains

with work roles, resources available, and caregiver burden. Men comprised 35% of the

sample. The researchers note that after controlling for household size, female caregivers

reported significantly higher levels of burden, more distractions at work and having to

use sick leave due to caregiving responsibilities than did male caregivers. Female

caregivers were significantly more likely to provide personal care tasks than male

caregivers, but there was no difference in the amount of care management tasks provided

between men and women. There were no differences in perceived resources among the

caregivers. For all the caregivers, burden was predicted by younger age, less resources,

providing higher levels of care, and having more work role conflicts.

Young and Kahana (1989) examined 183 caregivers of persons with myocardial infarction six weeks after hospital discharge on a variety of psychological and well-being measures. Men comprised 20% of the sample. For all caregivers, burden was greatest within the first four weeks post-discharge, with lesser amounts noted over time. Between male and female caregivers, women reported significantly more burden (as measured by the Zarit Burden Scale), provided more hours of care per week, had greater role conflict, reported worse health and more psychological distress than did male caregivers. In addition, female caregivers were significantly more likely to provide personal care and male caregivers were significantly more likely to provide instrumental care. However, when husband caregivers were compared to wife caregivers, there was no significant difference in the number of caregiving hours provided. Daughter caregivers reported significantly more negative consequences of caregiving than did wife caregivers. No comparisons between son and husband caregivers were provided.

Horowitz (1985) interviewed 131 adult child caregivers of elderly parents, 24% of whom were son caregivers. Son caregivers were significantly different than daughter caregivers with higher levels of education and being more likely to be employed full-time. Using an in-depth survey developed by the researcher, no significant differences were noted in the amount of time son or daughter caregivers spent with the care recipients or with various caregiver tasks, except for personal care and household chores. There was no difference between the amount of assistance sons or daughters received from family members; however, sons were more likely to call on spouses for assistance than were daughters. Daughter caregivers were more likely to report increased levels of stress and negative impact on their lives from caregiving than were son caregivers.

Arber and Ginn (1995) surveyed over 2700 caregivers in England (exact totals were not provided), approximately 35% of whom were men. Women, as a group, provided more hours of care than did men. However, among spouses, the difference in hours of care was quite small. Nearly 50% of husband caregivers and 60% of wife caregivers provided over 35 hours per week of caregiving to their spouses. Husband and wife caregivers were just as likely to provide personal care. For child caregivers, cross-sex personal care was less likely to occur than same-sex personal care, with sons providing the least amount of personal care to mothers. The researchers conclude that social taboos inhibit sons from providing intimate care to their mothers (Arber & Ginn, 1995).

In an earlier study, Arber and Gilbert (1989) used the 1980 General Household Survey from Britain to examine the contribution male and female caregivers make in caring for 4553 elderly people living in the community. Over one-third of all caregivers were men, 75% of whom were co-resident husbands of the care recipients. Among spouse caregivers, 9% of all husband caregivers utilized formal services compared to 1% of all wife caregivers. Daughter caregivers were the least likely to use formal services.

Joseph and Hallman (1998) interviewed 1149 employed Canadian caregivers who travel to provide care for elderly relatives. Men comprised 47% of the sample. The researchers note that female caregivers were significantly more likely to provide personal care and household care, and male caregivers were significantly more likely to provide home maintenance care. For both male and female caregivers, the amount of time spent with caregiving was negatively correlated with the distance traveled to the care recipient's home. However, as distance increased, the drop in hours provided by female

caregivers did not significantly decrease but did for male caregivers. The total mean hours per week provided by female caregivers was significantly higher than for male caregivers, at 4.55 hours versus 3.14 hours.

Almberg, Jansson, Grafstrom, and Winblad (1998) surveyed 52 caregivers of persons with dementia and compared them with 66 non-caregivers who had elderly relatives. Men comprised 15% of the caregiver group. In comparing the two groups on aspects of strain, the only differences noted to be significant were family role conflicts, positive outlook on life, and social support, with caregivers having more conflict, less optimism, and less support. The researchers note that just being a relative of an elderly person may elevate strain, regardless of whether one is a caregiver or not. In examining gender as a comparison variable, female caregivers reported a higher negative impact of caregiving when compared to female non-caregivers, which was greater than the difference between male caregivers and non-caregivers. For the men, male caregivers reported a significantly lower positive outlook on life and less social support than their non-caregiver counterparts.

DeLaune and Brown (2001) surveyed eight husband caregivers and nine wife caregivers of persons with stroke on marital roles, using the Marital Roles Questionnaire. Participants were surveyed twice, once at baseline while the spouse was housed in an inpatient rehabilitation unit and again one week post-discharge. Participants were instructed to answer the items on the questionnaire at baseline based on perceptions prior to the spouse having the stroke. All subscales of the survey showed significant change at the second administration, with both wife and husband caregivers assuming roles in the family previously held by their spouses. Both types of caregivers reported decreased

satisfaction with these new roles and increased marital unhappiness. Both also reported

decreased time with social activities, though husbands (but not wives) reported that they

continued to spend the same amount of time with hobbies. Since the caregivers were

surveyed only one week after returning home with the spouse, the findings suggest

changes pre and post-stroke rather than describe a longitudinal perspective of caregiving

for someone with stroke.

Only eight quantitative studies were located that included exclusively male

caregiver samples. These studies provide insight into the experiences and variation of

male caregiving. Bowers (1999) examined the gender role identity and caregiving

experience in men by sampling 200 elderly widows. The participants, selected from

obituaries and death notices of their wives, had been widowed for 12-16 months at the

time of the study. From the sample, 102 men had provided caregiving to their wives for

at least one month (mean duration was three years). The caregiving sub-sample and non-

caregiving sub-sample did not vary in health, income, education, or length of time since

retirement. Gender role identity was measured with the Bem Sex Role Inventory (BSRI)

and psychological well-being was measured with the Affect Balance Scale. Contrary to

socialization theory, male caregivers scored significantly higher on the masculine

dimension of the BSRI than did male non-caregivers. In addition, masculinity was a

significant predictor of psychological well-being for all the men. The findings refute the

proposals of Hirsh, who suggest that men turn away from caregiving due to its feminine

characteristics (Hirsch, 1996).

Campbell and Martin-Matthews (2003) conducted a study to examine predictors

for sons providing care to elderly parents. From their review of the literature, Campbell

and Martin-Matthews propose three reasons why sons provide care: a) filial obligations, b) the availability of legitimate excuses (such as competing work or family responsibilities) or c) by default due to the unavailability of female family members to provide caregiving. Dependent variables of the study were the gendered types of care: a) traditionally male care, b) gender neutral care, and c) traditionally female care. Traditionally male care was defined as financial management and home maintenance tasks. Gender neutral care was defined as assistance with IADL's. Traditionally female care was defined as assistance with ADL's. Although the gendered definition of care tasks is consistent with assumptions in the literature, the researchers did not provide theoretical or empirical evidence to support these definitions. A number of independent variables were evaluated in terms of these types of care using regression analyses. Traditionally male care was significantly predicted by geographical distance (men who live closer provide more care), education (more education correlated with more traditionally male care) and by men who were without siblings. Gender neutral care was significantly predicted by an increased sense of filial obligation, geographical proximity, having no siblings, having children of older rather than younger ages, increased number of relatives needing care, and older ages of parents. Traditionally female care was predicted by geographic proximity, having no siblings, having lower income, having children of older rather than younger ages, increased number of relatives needing care, and older ages of parents. Marital status and the number of employment commitments of the men had no significance in the type of care provided. In terms of the reasons why men care, filial obligation was significantly correlated to gender neutral and traditionally female care only. The researchers conclude that sons adopt traditionally male care as part

of their roles as sons, whether or not they have a sense of filial obligation to caregiving. Legitimate excuses were only partially supported, in that men with younger children were less involved in care. However, marital commitments and employer commitments were not significantly related to care. Caring by default was partially supported. Men without siblings provided more care, whether or not sisters or brothers were available. Of all the variables, geographic proximity and the availability of either brothers or sisters are most significant to sons providing care.

Fuller-Jonap and Haley (1995) surveyed 52 husband caregivers of wives with Alzheimer's disease and a comparison group of 53 elderly husbands. All men were Caucasian. The groups were matched by age, education, income, length of marriage, and sex role identity (as measured by the Bem Sex Role Inventory). The men were evaluated on their physical health (as measured by the Cornell Medical Index), psychotropic drug use, self-reported health, number of physician visits in the past year, and mental health (as measured by the Brief Symptom Inventory). The husband caregivers had significantly poorer physical and mental health, but only in the domains of depression, respiratory symptoms, and health habits, compared to the comparison group. The researchers note that inconsistent findings in the caregiver literature may be due, in part, to the use of assessment measures that do not capture multiple domains of a concept such as physical health.

Kaye and Applegate (1995) interviewed 178 male caregivers, 70% of whom were husbands caring for their co-resident wives. Interviews sought both qualitative and quantitative data. Generally, only summary findings were provided in the report. The researchers note that the men generally rated their physical health as 'fair', but over 40%

of the caregivers reported that their physical health limited their ability to provide care. The men provided only mid-range assessments of their emotional health in terms of loneliness, frequency of worrying, general perceptions of life, and overall satisfaction with life. In terms of tasks provided, the men reported that personal care was the most stressful and least satisfying of all tasks. However, the researchers state

> On the other hand, a mixture of affective and instrumental forms of assistance including the provision of emotional support and companionship, shopping, providing transportation, and dealing with behavioral problems were rarely mentioned as stressful caring activities….In contrast to the stereotype that male caring is primarily instrumental in nature, these men reported performing tasks associated with the provision of social and emotional support most frequently, most competently, and with the greatest degree of satisfaction. (p. 211)

The researchers continue by stating that contrary to Gilligan, these men provided caring from an ethic of caring, and not by an ethic of justice or obligation. Using the Zarit Burden Scale (shortened version), the researchers noted that men with higher levels of burden were most likely to use formal services, were less financially secure, more likely to live with the care recipient, were more heavily engaged in caregiving, and provided care to persons who were disoriented. Over half of the men in the sample were providing over 60 hours of caregiving per week.

Yielding similar findings, Mathew, Mattocks, and Slatt (1990) interviewed 12 male caregivers of elderly relatives with dementia and eight male caregivers who had

placed their loved ones with dementia into nursing homes. The researchers note that those still caring for loved ones at home averaged 7.2 hours of care provision per day. 90% of all the men stated that they felt close or moderately close to the care recipient. The most common reason the men gave as to why they provided care was love, followed next by marital responsibilities. Using the Zarit Burden Index, the researchers found no significant difference in burden between those still providing care in the home to those who had placed care recipients. All the men fell into the mild to moderate categories of burden. Most of the men reported a lack of family support for their caregiving.

Kramer (1997a) surveyed 74 husband caregivers of wives with dementia for predictors of negative appraisals (caregiver strain) and positive appraisals (caregiver gain). A number of tools were used to assess caregiver and care recipient characteristics, caregiver health, satisfaction with social participation, coping styles, and caregiver appraisals (strain and gain). Using multiple regression analyses, Kramer reports that strain was significantly predicted by higher levels of memory and behavior problems in the care recipient, less satisfaction with social participation, poorer health, and use of an emotional-focused coping style. On the other hand, gain was significantly predicted by better health, more satisfaction with social participation, use of a problem-solving coping style, and less education. Caregivers with less education appraise gain more readily since education may be associated with high paying employment and marketplace status (Kramer, 1997a).

In answering the criticism by some of the lack of longitudinal studies on caregiving, Kramer contributed two additional studies. In the first study, Kramer and Lambert (1999) followed 288 husbands, none of whom were caregivers at baseline, but

26 of whom had become caregivers for their wives within five years. Participants were selected from those participating in the National Survey of Families and Households in 1987-88, who were then followed longitudinally. Dependent variables included household tasks, social integration, quality of the marital relationship, and psychological well-being. The caregiver sub-sample was older, had lower incomes, and was less likely to be employed than the non-caregiver sub-sample, but did not differ in level of education, race, duration of the marriage, or changes in living arrangements. Compared to the non-caregiver group, caregivers had significantly increased the amount of time spent doing household tasks, reported significantly less emotional support, less marital happiness, less overall happiness, more depression, and were more likely to perceive that their marriages were in trouble. There was no significant difference in the amount of time spent with social activities and recreation, though caregivers significantly increased their church attendance compared to non-caregivers. The researchers note that husbands who transitioned into a caregiver role had higher psychological morbidity than their non-caregiver counterparts.

In the second study, Kramer (2000) surveyed 74 husband caregivers for wives with dementia at baseline and one year later. At the time of the second interview, 14 husbands had placed their wives in nursing homes. The samples were compared based on time and nursing home placement. Those who had placed their wives did not differ from those that did not place their wives based on age, education, income, duration of wife's illness, duration of caregiving and duration of the marriage. The men were surveyed on the care recipient's health and needs, financial worries, caregiver self-reported health, satisfaction with social participation, and depression (as measured by the

CES-D). Kramer reports that spousal dependency on ADL's significantly increased over the year (more so for those in nursing homes), but dependency on IADL's and level of memory and behavior problems did not increase. There was no significant change in worries about finances, though the men who had placed their wives were more worried than the men caring for wives at home. Perceived health and satisfaction remained stable for home caregivers, but increased significantly for those men who had placed their wives in nursing homes. Stress from the increased dependency and memory and behavior problems significantly decreased for both groups of men. Depression did not change for either group significantly. However, Kramer notes that depression levels decreased for the men caring for wives at home; whereas depression levels increased for the men who had placed their wives in nursing homes. Kramer also noted that even though depression decreased for men home caregivers, 32% were still above the cut-off for diagnosis of clinical depression. The finding that men who had placed their wives had become more depressed was an unexpected finding, especially since this group had significantly higher levels of satisfaction with social participation and reported better health. Kramer surmised that these men may have begun the grieving process and/or were suffering from diminished exposure to their primary source of companionship and emotional support.

Findings from Qualitative Studies of Male Caregiving

Eleven qualitative studies were located that either focused on gender with caregiving or included only male caregivers in the samples. Hirsch (1996) interviewed 32 male caregivers, 34% of whom were son caregivers, 22% of whom were husband caregivers, and the rest were of varying relationships to the care recipient. The purpose

of the study was to further explore how cognitive dissonance theory might explain the caregiving behaviors of men, as opposed to socialization or social structure theories. The men were categorized by gender role identity using the Bem Sex Role Inventory. Hirsch then used a case-study model to explore how each category of gender role implemented caregiving. Hirsch provided examples of how men used alternative ideologies to counter-balance the cognitive dissonance created by gender role stereotypes and caregiving. This perspective was later questioned by the study completed by Bowers (1999) discussed earlier.

In order to examine gender stereotypes of caregiving in conjunction with race stereotypes, Miller (1996) interviewed 215 husband and wife caregivers of persons with dementia. 36% of the caregivers were African-American, the rest were Caucasian. The interview contained mostly closed-ended questions, which were used in another study. However, this study focused on three open-ended questions asked during the middle of the interview. Responses to these questions were coded using thematic analysis. Miller notes that many of the caregivers described their caregiving in terms of emotional characteristics, household and childcare tasks, and physical strength. Also, Miller notes that male caregivers and African-American caregivers were more likely to state that there were no differences between male and female caregivers. Perceptions of gendered differences were more prevalent among Caucasian female caregivers. In addition, African-American caregivers of both sexes minimized gender differences in household and childcare tasks. Miller suggests that men may view caregiving as a new role and skill to learn and acquire; whereas women view caregiving as an extension of previously held roles, thus continue to see gender differences. African-American differences in

perceptions of gender-roles are consistent with previous findings of how family labor is manifested and valued differently in these families (Miller, 1996). As such, both gender and race are significant influences in how caregiving is perceived.

Chappell and Kuehne (1998) examined differences in congruence among husband and wife caregivers in Canada. Affect congruence was defined as the emotional similarity in which caregivers and care recipients within dyads responded to several open-ended questions about caregiving; whereas content congruence was defined as similarity in the content of the responses. Analysis of interviews with 54 spouse-spouse dyads were completed using mixed methods, although the researchers do not provide details on the process used to analyze the qualitative data. The researchers report that most couples demonstrated positive affect congruency; however the trend was for husband caregivers to report positive affect to responses more than wife caregivers. In fact, few husband caregivers reported negative affect compared to one-third of wife caregivers. Fewer couples provided content congruency. The researchers propose that the gender differences may be due to the perceived choice that husband caregivers have in providing care opposed to the perception of wife caregivers that obligation has forced them into caregiving.

Neufeld and Harrison examined obligation as part of a study of reciprocity for male caregivers (1998). These researchers defined reciprocity as a dimension of social support, which is vital in maintaining relationships. They note that equity theory would predict that non-reciprocal relationships would result in termination of the relationship. Using grounded theory methods as described by Strauss and Corbin, the researchers interviewed 22 male caregivers (most of whom were husbands) of elderly persons with

dementia three times over 18 months. After coding the data, categories and proposed interpretations were validated with a focus group of seven of the participants. The researchers note three types of reciprocity: waived, generalized, and constructed. Waived reciprocity occurred when men waived any expectations of reciprocity from the care recipient due to his or her illness. Generalized reciprocity occurred when men assumed that reciprocity would be received from others as part of contributing to the 'good of society' or altruism. Constructed reciprocity occurred when men interpreted untypical comments, gestures, and behaviors from the care recipient as indications of positive feelings toward them. Men who employed generalized or constructed reciprocity reported positive feelings about their caregiving. Men who employed waived reciprocity had mixed feelings about their caregiving. Men who employed none of the types of reciprocity generally explained caregiving as a task of obligation. The men also reported that their caregiver responsibilities diminished their ability to experience reciprocity from other family members and friends, which led to feelings of anger, frustration, and depression. However, some men made special efforts (such as regularly visiting senior centers) in order to develop new avenues for receiving reciprocity. The findings from this study are generally consistent with a similar study conducted by the researchers which focused on female caregivers. However, the researchers note that female caregivers were able to use a wider range of behaviors in order to develop a constructed reciprocity than did male caregivers. Some men moved from constructed reciprocity to obligation over the course of the study, perhaps due to the continued deterioration of their loved one's health.

The importance of reciprocity for male caregivers was also examined in a study by Russell (2004). Russell examined the social networks of 30 elderly husbands caring for their wives with dementia through open interviews which were then analyzed for themes. Three major themes emerged from the data: in retrospect, need to lessen burden, and need to socialize with other men. With the first theme, *in retrospect*, men talked about the employment-related social networks they had in the past before retiring. The men were surprised how important these networks were, realizing their significance only after they were no longer present. Men often sought out information about former co-workers and tried to maintain contact with them, but found the lack of common employment a barrier in maintaining these networks. Men also recounted how their previous work accomplishments were visible to their co-workers. However, since their caregiving work was done in the private sphere, few friends could recognize their caregiving accomplishments.

With the second theme, *need to lessen burden*, men realized that seeking outside social contacts was necessary in reducing the stress from caregiving. This realization was not always self-discovered. Some of the men reported that family members insisted that they *get out of the house* and maintain involvement with the outside world. Some of the men, not accustomed to participating in social outlets outside the work setting, found themselves seeking outlets that they perceived to be out of character for themselves. For example, one of the men joined a book club and another started frequenting a shopping mall. However, these men recounted how beneficial these new outlets were for them in terms of respite.

The third theme, *need to socialize with other men*, proved to be the dominant theme among all the men. Men, for the most part, avoided caregiver support groups as they were dominated by women. Although platonic female companionship was appreciated, the men reported that they felt uncomfortable talking about caregiving challenges and/or relationship issues with other women. For others, there was a worry about perceptions of impropriety if they socialized with women. For most of the men, previous social networks consisted primarily of males, and as such, men felt comfortable socializing with other men. In addition, the men did express a need to socialize with other male caregivers. This type of socialization usually involved an acknowledgement of the challenges they shared without dwelling on caregiving discussion. The men enjoyed a break from caregiving by discussing other topics, yet felt supported that other male caregivers understood them. Russell notes that the findings from this study are important in planning gender-appropriate supports for husband caregivers.

Hilton, Crawford, and Tarko (2001) interviewed ten Canadian husband caregivers of wives with breast cancer. Using thematic analysis, the researchers note two major themes of coping: focusing on their wives' illness and care and focusing on keeping the family going. In the first thematic pattern, men actively sought information to assist with decision-making, assisted their wives with medical treatments and negotiated the obstacles in the health care system. In the second pattern, men focused on activities and tasks to normalize the family as much as possible. This included taking over all tasks formerly performed by the wife in order to avoid any disruption to the family's routines. Most of the men felt unprepared for the role as caregiver and struggled to maintain a positive attitude by putting themselves and their own needs on hold. It is unclear how

these men used the patterns over time or whether or not men changed patterns during the course of their wives' illnesses.

Archer and MacLean (1993) used a thematic analysis of six case studies to explore the experiences of male caregivers. In this study, three husband caregivers and three son caregivers of elderly family members were interviewed. From the analysis, three themes emerged: maintaining outside interests, relationship changes, and personal emotional gratification. All of the men expressed the desire and importance of taking time to pursue interests outside the caregiving environment. The men viewed this as vital in maintaining their health and in conserving their strength so that they could continue to provide optimal levels of care. All of the men reported changes in their relationships with others, with all reporting abandonment from other family and friends. The men reported that this led to great emotional pain. This abandonment prompted most of the men to seek support from alternative sources such as new social outlets and support groups. Some of the men also reported a deepening of the relationship with their care recipient as a way to gain additional support. The third theme, personal emotional gratification, pertained to the men's reports of satisfaction and gratification with their caregiving roles. The men reported feelings of reciprocity and noted that love, and not duty, was the source of their caregiving.

Using a phenomenological approach, Parsons (1997) examined the lived experiences of five husbands and three sons caring for wives or mothers with Alzheimer's disease. From the interviews, eight themes emerged, with one additional theme provided by the son caregivers. The first theme was that of enduring. This referred to the patience and persistence the caregivers needed to meet the challenges of

caregiving. The second theme was that of vigilance. Vigilance meant providing supervision, safety-proofing the house, and keying in on behaviors. The men viewed this theme in positive terms in that vigilance allowed them to discover new insights to the needs of the care recipient and to devise and revise caregiver strategies. The third theme was that of a sense of loss, of losing the person that they once knew and loved and of losing a full wife or parent. The fourth theme was that of aloneness and loneliness. As the health of the care recipient deteriorated, the men felt increasingly lonely as their previous relationships were lost. Also, the men felt very alone in their caregiving, noting that they received very little support from other family members and friends. The fifth theme was that of taking away. This theme was tied to that of vigilance, in that the men had to continuously remove items from the environment (such as car keys) that would endanger the care recipient. The sixth theme was that of searching to discover. The men described a need for and actions of seeking information about Alzheimer's disease and caregiving. This information was crucial in solving problems and developing strategies. The seventh theme was that of needing assistance. The men reported a great need for help and the relief they experienced when formal or informal help was provided. The last theme was that of reciprocity. The men discussed that their caregiving provided a return favor for all the love and nurturing that they had received in the past from the care recipient. However, the men also described how caregiving had enriched their lives and that they were better able to give back to others in general. Son caregivers identified an additional theme, that of overstepping boundaries. This theme referred to the discomfort sons felt by crossing social taboos when they had to provide intimate care to their

mothers. The men reported that these themes intensified over time as the disease progressed. The men also acknowledged their own suffering as caregivers.

Harris (1993) also interviewed male caregivers of persons with Alzheimer's disease, but focused only on husband caregivers (n = 15). Harris used guided interviews to collect data, which were analyzed using a thematic analysis approach. A variety of themes emerged from the data. A dominant theme was that of commitment. The men expressed a desire to continue caregiving, noting that their wives would be committed to them if they were ill. None of the men expressed resentment of caregiving. Another theme was that of social isolation, especially from family and friends. Loss of female companionship was another theme. The men did not report a need for sexual relations, but rather missed interacting with women on a conversational level. However, men also reported that they needed and sought other men to discuss personal matters with. Some sought clergy to fulfill this need. Still another theme was that of strategies. Men used a number of strategies including trying to maintain control of the caregiving environment, problem-solving coping, and seeking respite from caregiving.

From these themes, Harris (1993) proposes four types of male caregivers: the worker, the labor of love, the sense of duty, and the one at the crossroads. The worker caregiver modeled their caregiving after their previous market sector work. These men adopted caregiving as a new employment role, with some even setting up offices in their homes to manage and coordinate caregiving. The labor of love caregivers were those who expressed that love, not duty, motivated them. These caregivers reported providing much emotional care, and often would hold hands with their wives in order to comfort them. These caregivers felt that love saw them through caregiver challenges. Caregivers

funding in order to have the financial resources to serve a local rural area (Centers for

Medicare & Medicaid Services, 2004). Generally, these hospitals receive cost-based

reimbursement as opposed to usual prospective reimbursement (Bushy & Bushy, 2001).

These hospitals must provide 24-hour emergency services. Most of these hospitals

transfer complex or highly acute patients to larger facilities, since the average length of

stay of the hospital population must not exceed an average of 96 hours.

Conversion of an existing rural hospital to a CAH must take into consideration the

benefits and detriments of conversion (Bushy & Bushy, 2001). Participation in the CAH

program may require a complete restructuring of the hospital's business plan and

administrative framework, and requires development of an integrated rural emergency

service plan, collaborative referral agreements with larger hospitals, and adherence to

quality assurance programs (Bushy & Bushy, 2001). However, participation in the CAH

program has afforded rural communities continued access to emergency care and low-

acuity hospital care in familiar facilities that might have otherwise been forced to close

due to low cash flows from small patient volumes and prospective payment

reimbursement. Rural nurses have noted that rural communities placed high levels of

trust and took great pride in their local CAH (O'Lynn, 2006a).

Many CAH's have diversified their product lines horizontally by offering

adjoining long-term care facilities, home-based care services, and adult day care services.

Such diversification not only allows for improved financial stability, but also addresses

recommendations of integrated and collaborative service delivery and expansion of

existing services as noted previously. However, some have criticized these

diversifications in that the new services offered are implemented within a medical/ illness

framework rather than within a social service framework (Magilvy, 1996; Rowles, 1996). It is unclear from these critics whether health and human services can be delivered from one provider using a blending of seemingly different frameworks.

Rural Culture

Leininger (1991) defines culture as "...the learned, shared, and transmitted values, beliefs, norms, and lifeways of a particular group that guides their thinking, decisions, and actions in patterned ways" (p. 47). Although culture has been defined as including large groups of diverse individuals (for example, *Western culture*), characteristics of Leininger's definition are perhaps more clearly demonstrated when applied to smaller numbers of groups with numerous shared lifeways. A relevant consideration for my study is whether or not there is a *rural culture*.

Before elaborating on the consideration of a rural culture, it is important to point out that many individuals may have membership in more than one culture concurrently. For example, an individual may be a member of a group characterized by its geographical location, another group characterized by its ethnicity or race, and yet another group characterized by its religious beliefs and practices. Gender and sexual orientation may also be considered cultures (Jarviluoma, Moisala, & Vilkko, 2003). Some may consider some of these cultures as sub-cultures in that they are molded by a primary or dominant culture. So, whether an urban, heterosexual, African-American Muslim male considers himself primarily African-American or Muslim may be an individually-made decision that may vary over time and context.

The question as to whether or not there is a rural culture is not new (Bigbee, 1993). Clearly, rural dwellers are highly diverse, not only with the USA, but internationally. But do rural dwellers have shared beliefs, values, and lifeways that shape their thinking and behaviors (accepting that sub-cultural aspects may create different nuances in rural thinking and behaviors)? Based on her review of the literature, Bigbee suggests that there *is* a rural culture.

According to Bigbee (1993), rural culture is characterized by relatively close and long-term relationships with families and neighbors which results in a lack of anonymity and a blurring of social roles. Rural dwellers tend to be more morally and politically conservative and more closely adhere to traditions than their urban counterparts. Rural dwellers value individualism and self-sufficiency. They tend to be more family and community-oriented, religious, and work-oriented than non-rural dwellers. Traditional sex-based roles within families tend to be more visible than in non-rural families. In addition, rural elders place value in hard work, independence, a faith in God, and love of the rural landscape (Running, 1998). Bigbee also notes that isolation, both social and geographic, substantially shapes rural culture. This isolation may enhance the visibility of other attributes associated with rural dwellers, such as a keen perception of and distrust of outsiders (Bailey, 1998; Lee, 1998a), ethnocentrism (Dybbro, 1998), and a reliance upon non-formal, yet readily accessible, health resources to manage health and illness (Buehler et al., 1998; O'Lynn, 2006b).

In his review, Wagenfeld (2003) echoes the summary provided by Bigbee (1993). However, Wagenfeld notes that some scholars feel that the cultural divide between urban and rural dwellers is narrowing. Wagenfeld states that empirical evidence of this may

stem from the unique characteristics of the specific towns included in studies that demonstrate this narrowing divide. On the other hand, how improved communication technology, exposure to outside cultural influences, and changing demographic patterns might influence rural culture is not yet clear. Despite rural adherence to traditionalist stances as described by Bigbee, Leininger (1991) notes that cultural characteristics are dynamic. As such, rural culture, however describable, cannot be considered essentialist or static. Regardless of the importance of the previous statement, further exploration of rural culture is requisite to provide a beginning foundation for understanding the significant contextual role that rural living has in the proposed study.

In order to explore and delineate theoretical relationships relevant to nurses practicing in rural settings, Long and Weinert, in collaboration with graduate students and faculty in the 1970's and 1980's, employed a number of research methods to describe the perspectives of rural dwellers, particularly in terms of health (Long & Weinert, 1998). The result was the articulation of three relational statements, the first being as follows.

The first statement is that rural dwellers define health primarily as the ability to work, to be productive, to do usual tasks...Rural persons place little emphasis on the comfort, cosmetic, and life-prolonging aspects of health. One is viewed as healthy when able to function and be productive in one's work role. Specifically, rural residents indicated that pain was tolerated, often for extended periods of time, so long as it did not interfere with the ability to function. (p. 10)

This statement has been widely quoted by others (Lee & Winters, 2004), yet may need some revision in light of more recent studies. Rural elders in Alabama reported that health was also defined in terms of being able to work, but also in terms of being able to do what one *wants* to do and in terms of having a sense of well-being (Davis et al., 1992). These last two caveats may be highly individualistic. Also, Lee and Winters (2004) note an emphasis on ability to function in work roles, but note that health was defined also in terms of one's ability to function with leisure activities. Lee and Winters report that their participants described health more holistically in that health implied physical, mental, and emotional fitness. This holistic perspective of health is supported in a study of rural Canadians as well (Thomlinson, McDonagh, Crooks, & Lees, 2002). How this emphasis on the ability to work and function and how the more holistic perspective of health from rural dwellers compare with urban dwellers is not clear.

In terms of the second relational statement, Long and Weinert (1998) note

> ...rural dwellers are self-reliant and resist accepting help or services from those seen as 'outsiders' or from agencies seen as national or regional 'welfare' programs. A corollary to this statement is that help, including needed health care, is usually sought through an informal rather than a formal system. (p. 11)

There appears to be a substantial level of support for this statement, though like the first, there may be need for some changes and caveats (O'Lynn, 2006b).

This second relational statement includes a number of concepts. The first, self-reliance incorporates a number of characteristics, but generally refers to an aspect of self-

sufficiency and independence from the need of assistance of others (Chafey, Sullivan, & Shannon, 1998). Chafey et al. note that self-reliance is learned from personal life experiences and from observing self-reliance in others. Self-reliance is also the ability to make, and then to implement, choices that affect one's life. Chafey et al. note that self-reliance incorporates self-confidence and skills of functional competencies. The importance of self-reliance to rural dwellers is also described by Lee and Winters (2004).

The ability to be self-reliant and the value placed in self-reliance is interwoven with other stated values and behaviors of rural dwellers, including autonomy, efforts at maintaining independence, and hardiness (Chafey et al., 1998; Koehler, 1998; Leipert & Reutter, 2005; Wirtz, Lee, & Running, 1998). Some may view hardiness as the ability to endure the obstacles and challenges of rural living. Wirtz et al. (1998) interviewed men and women who were identified by others as possessing hardiness. Although there were some differences in the descriptions of hardiness between the men and women participants, there was general agreement that hardiness required that one be adaptable, enduring/ having fortitude, and has a positive attitude. In addition, hardiness was developed and maintained by learned and lived experiences. Wirtz et al. note that the women felt that spirituality facilitated the achievement of hardiness. In somewhat similar findings, Leipert and Reutter (2005) report that developing resiliency required that one becomes hardy, defined as "...an increased feeling of confidence and the ability to carry on in spite of adversity" (p. 56). Becoming resilient requires self-reliance, adaptability, and a positive attitude to challenge. Similar to Wirtz et al., Leipert and Reutter note that women felt that spirituality facilitated the process of becoming resilient.

Another concept in the second relational statement offered by Long and Weinert (1998) is the aversion to outsiders. Outsiders are characterized by differentness and an unfamiliarity and unconnectedness to a contrasting group (Bailey, 1998; Lee, 1998a). Outsiders are considered to not share cultural values and meanings with the group, and as such, may lack credibility and influence. Although the length of time needed to shed the outsider label may be highly variable and contextually bound, outsiders may be excluded from local knowledge and may not be trusted with decisions that might affect local residents and institutions (Bailey, 1998). Evidence for this aversion to outsiders is provided, albeit indirectly, from authors discussed previously who note that urban programs don't work in rural settings. The action to implement a program designed by non-rural dwellers into a rural area exemplifies the unfamiliarity and unconnectedness characteristic of the outsider label. The outsiderness and seemingly disinterest from many policy makers in the local rural culture is so apparent that it prompted one source to state, "The view of rural America by urbanites and suburbanites seems to be one of incredulity" (Kane & Ennis, 1996, p. 4).

Yet another concept presented in Long and Weinert's (1998) second relational statement is that of national or regional welfare programs. However, Long and Weinert do not provide a definition of what constitutes these types of programs. Resistance from rural dwellers to the acceptance of direct assistance in the form of cash payments and food stamps to help sustain families may seem congruent with the concepts of self-reliance, independence, and hardiness as noted earlier. Earlier in this chapter, it was noted that rural areas have higher near poverty rates than non-rural areas and higher poverty rates for rural elderly than non-rural elderly. Also, it was noted that rural areas

have less stable, more seasonal employment than in urban areas. It is not clear then how rural dwellers perceive and/or utilize assistance programs, including unemployment insurance, or how they perceive reliance upon Medicare/ Medicaid. Perhaps, these programs are not viewed as 'hand-outs' since all employed workers support these programs with taxes. And to extend this discussion further, it is not clear whether rural communities view large subsidies from the government to rural industries which allow logging, mining, and grazing on public lands as welfare. Without a clearer understanding of how welfare is perceived by rural dwellers, it is not clear whether or not this portion of the relational statement is supported empirically.

Long and Weinert (1998) provide a corollary to the second relational statement, stating that needed health care is usually sought from informal, rather than formal sources. They note that this corollary had empirical support from the extant literature at the time. After this corollary was presented, Buehler, Malone, and Majerus (1998) conducted a grounded theory study which produced a theoretical model depicting the use of informal health sources, which they named the Symptom-Action Time Line (SATL). Briefly, the SATL process begins with the recognition of a negative health symptom, followed by self-care for resolving that symptom. If resolution does not occur, rural dwellers then employ the assistance of lay resources, and then employ the assistance of professional (formal) health resources only as a last step in the process. The time allotted to progress through the process is dependent upon the interpretation, intensity, and duration of the symptom. In addition, in certain situations, such as symptoms involving children or symptoms interpreted as life-threatening, phases of the process may be by-

passed and professional resources are contacted directly. However, typical progression through the process varies from four to fourteen days (Buehler et al., 1998).

O'Lynn (2006b) completed a review of the extant rural literature to determine the level of empirical support for this proposed theoretical process. The keywords of rural, rural health, rural environment, and rural populations were combined with terms such as self-care, decision-making, self-assessment, alternative therapies, complimentary medicine, and home remedies to search the CINAHL, MedLine, and PsychInfo databases from 1966-2004. After removing review articles, foreign studies, and dissertations, 36 relevant studies were located for review. Of the studies reviewed, eight supported, at least minimally, the tendency to use self-care and lay resources before going to a health professional for non-emergent adult symptoms (Congdon & Magilvy, 2001; Davis et al., 1992; Grubbs & Frank, 2004; Horner et al., 1994; Johnson, 1994; Lee & Winters, 2004; Roberto & Reynolds, 2002; Sellers, Poduska, Propp, & White, 1999). However, none of these studies described or tested a comprehensive process of symptom identification and action.

Many of the 36 studies describe some sort of self-care intervention used by rural dwellers, though with the exception of the eight noted above, most of the studies did not relate the implementation of self-care in relation to the stated phases of the SATL process. Some of the interventions used were similar to those discussed by Buehler et al. (1998), including the use of over-the-counter medications, herbal remedies, family remedies, publicly-available printed information sources, and physical treatments (e.g. heating pads, stretching, yoga). However, several reviewed studies discuss the use of prayer and spirituality (Arcury, Bernard, Jordan, & Cook, 1996; Arcury, Quandt,

McDonald, & Bell, 2000; Bennett & Lengacher, 1999; Congdon & Magilvy, 2001; Gaskins & Lyons, 2000; Roberto & Reynolds, 2002; Wallace, Tuck, Boland, & Witucki, 2002), an intervention not noted by Buehler et al. In support of the SATL process and the corollary statement, several studies note that rural dwellers were more likely to use self-care strategies to treat symptoms than were non-rural dwellers (Boyd, Taylor, Shimp, & Semler, 2000; Ganther, Wiederholt, & Kreling, 2001; J. F. Moore & Johnson, 1993; Rabiner et al., 1997).

The use of lay resources in managing symptoms is also supported from the literature review (O'Lynn, 2006b). Generally, these lay resources consist of soliciting the assistance and support of friends, family, and support groups. However, only a few of the studies discuss the progression to lay resources after self-care interventions had failed to resolve the symptom, or discussed the use of lay resources prior to using professional health resources (Davis et al., 1992; Horner et al., 1994; Lee & Winters, 2004; Roberto & Reynolds, 2002; Sellers et al., 1999). None of the studies reviewed provided specific timeframes for obtaining services as suggested by Buehler et al. (1998), though there is support for the assertion that professional sources are sought quickly if symptoms are deemed life-threatening or involve children. In addition, several studies note that professional services are sought more quickly if individuals belief the symptom will require a prescription (Johnson, 1994; Lee & Winters, 2004), or if the symptom will result in the individual missing work (Lee & Winters, 2004; T. Sullivan, Weinert, & Cudney, 2003). The literature also notes that several types of resources may be used concurrently by individuals.

Based on the literature review, O'Lynn (2006b) recommends the following

revisions to the SATL process:

1. expand the definition of symptom to include psychological symptoms,

2. expand the definition of symptom to be more reflective of a health need, so that

   measures one may take to prevent illness and/or promote health are included,

3. recognize that the intentional disregard of a symptom is a type of self-care action,

4. embed the SATL model within an environmental context external to the decision

   tree in order to account for variables such as gender, race/ethnicity, socio-

   economic status, family or social role, residential location, etc.,

5. identify the time line aspect of the SATL model as a descriptive outcome, rather

   than as component of the action itself, and

6. depict the model to be more circular, rather than linear, in nature.

Based upon the initial study by Buehler et al. and the literature review by O'Lynn, there

appears to be support for the Long and Weinert's (1998) corollary statement that rural

dwellers tend to use informal, rather than formal, resources initially to meet health needs.

The third and final relational statement offered by Long and Weinert (1998) states

that "...health care providers in rural areas must deal with lack of anonymity and much

greater role diffusion than providers in urban and suburban settings" (p. 11). Although

this statement does not address the culture and behaviors of rural dwellers directly, the

lack of anonymity is a reality in rural communities for non-health care professionals as

well (Lee, 1998c; R. Levant & Habben, 2003; Wagenfeld, 2003). In addition, lack of

anonymity and greater role diffusion may influence the recruitment and retention of

health professionals to rural areas, thus influencing the availability of health providers to

local residents. The third relational statement is supported, at least in part, from studies of rural nurses (Bushy, 2002; O'Lynn, 2006a; Rosenthal, 1996; Scharff, 1998; Vukic & Keddy, 2002) and rural physicians (Jones et al., 2004a; Richards, Farmer, & Selvaraj, 2005), and health care providers in general (Casarett, 1991).

Although none of the cultural characteristics described in this section can be attributed uniquely to rural dwellers, it is perhaps the combination of these characteristics and the high value placed on these characteristics that distinguishes rural dwellers from non-rural dwellers. The sources referenced in this section represent study participants from nearly all geographic regions of the USA and included, albeit minimally, voices of minority communities. In addition, consistent findings were present in studies from Canada. As such, there is a reasonable level of support for Bigbee's (1993) assertion of the presence of a rural culture.

Rural Masculinity

Little research was located on how masculinity is manifested in rural communities. Perhaps much of what is believed to be true about rural masculinity comes from popular literature and films. Nevertheless, the recognition of multiple conceptualizations of masculinity is relatively new, and has only been explored with seriousness since the mid-1980's with the advent of men's studies programs (Levant & Habben, 2003). Some of these newer conceptualizations of masculinity have been previously discussed in this chapter, with further discussion in the assumptions section of the following chapter.

Although recognizing the complexity of gender and the reality of multiple masculinities within individuals and within groups, Levant and Habben (2003) provide some general considerations about rural men. Levant and Habben propose that rural men tend to be more traditional in their masculine ideology. As such, compared to urban men, rural men may adhere more tightly to the belief that masculinity is characterized by toughness, self-reliance, homophobia, avoidance of behaviors perceived as feminine, avoidance of emotionality, and an importance placed on accomplishments and work. This ideology may impede men from seeking health care or assistance for self-care and self-health maintenance (Courtenay, 2000; Levant & Habben, 2003).

Due to the lack of anonymity typical in rural communities, the actions and reputations of men are highly visible and carry more weight than for men in non-rural communities (Levant & Habben, 2003). "As a result, rural men are more likely to try to adhere to a higher moral code or else keep their problems very private" (p. 177). This reality might explain why rural men are very unlikely to seek mental health services, as such action might reveal a weakness of masculine character.

However, rural men have some character strengths in comparison to their urban counterparts. Despite the value of self-reliance among rural men, some community and work projects cannot be done in a solitary fashion. Consequently, rural dwellers are highly interdependent upon each other in order to accomplish large tasks such as harvesting, clearing roads, construction projects, and such. Levant and Habben (2003) note

As a result of higher visibility and more interaction with a larger percentage of the entire community, rural men interact more intimately with the people in their communities. This lends itself to a code of being a 'good neighbor'.... As a result, 'the good neighbor doctrine' interacts with masculinity ideology in a way that men are more likely to 'pitch in and help' a relative stranger. (p. 177)

Due to this good neighbor doctrine, rural men may establish trust more readily with others than do urban men. This trust establishment may be necessary to facilitate the interdependence and interconnectedness among rural dwellers. How these perceptions of rural masculinity offered by Levant and Habben affect rural men's desire and ability to provide caregiving have yet to be explored.

Rural Caregiving

Of all the caregiver studies reviewed for this proposal, only eight studies were located that included a focus on rural caregivers. Five of these eight studies were conducted in the USA. The small number of studies located supports the obvious conclusion of Cuellar and Butts (1999) that there is a paucity of rural caregiver literature.

Beginning with the American studies, Burman and Weinert (1997) surveyed 294 persons with cancer and their family caregivers residing in Montana with a researcher-developed inventory. Of the caregivers, 57.5% were men, and all caregivers were Caucasian. Burman and Weinert note no significant difference between male and female caregivers. However, women tended to report more relationship difficulties than did

men, particularly with spouses. The percentage of caregivers, male or female, reporting relationship and other affective problems was less than 20%.

Conley and Burman (1997) completed a thematic analysis of semi-structured interviews focusing on informational needs with 14 caregivers whose care recipient had died within the previous 12 months from a variety of medical conditions. All the caregivers lived in Wyoming, all were Caucasian, and 36% of the caregivers were male. Several themes emerged from the data. Caregivers reported their caregiving experience as all-consuming and exhausting. Caregivers noted that family members and friends offered frequent advice, but offered little assistance with caregiver work. In terms of informational needs, caregivers wanted information on their loved ones' medical conditions and on available services. Informational needs were met using one or more of four approaches: assertive seeking and asking, self-reliance, common-sense strategies, and obtaining information from informal services. The researchers note that although caregivers were satisfied with the information they received from professional sources, information from these sources was received only after very assertive requests.

Reed and Weicherding (1999) interviewed 20 caregivers of veterans in order to explore factors related to caregiver reports of social isolation. Of the sample, 5% were male, 85% were Caucasian, and 90% lived in rural areas of Illinois and Indiana. From the interviews, the researchers reported that the high sense of responsibility to the veteran accounted for the social isolation of the caregivers. Caregivers reported guilt about taking assistance from others or seeking respite services. However, nearly all the caregivers reported that God provided well for them and did not give them more than

they can handle. A few of the caregivers reported that assistive and respite services were not available in their local areas.

Ladner and Cuellar (2002) collected demographic data and data from the Center for Epidemiological Studies Depression Scale (CES-D) from 30 caregivers receiving hospice services in rural Mississippi. Of the sample, 27% were male, 80% were Caucasian, and 37% were age 59 years or older. The researchers report that 40% of the sample was clinically depressed (evidenced by a CES-D score of 16 or higher), but that only 17% of the sample was receiving any treatment for depression. The researchers report that Caucasian caregivers were significantly more depressed than African-American caregivers. Caregivers married to the care recipient were more depressed than the other caregivers, and male caregivers were more depressed than female caregivers.

Pierce, Steiner, Govoni, Hicks, Cervantez-Thompson, and Friedemann (2004) interviewed nine caregivers of persons with stroke via telephone and via posted entries to a Web-based caregiver support group. Of the sample, 55% were male, 89% were Caucasian, and all lived in rural areas of Ohio and Michigan. Texts from interviews and postings were analyzed for themes using QSR N 5, a computer-based program designed to code qualitative data. The researchers report that five themes were present in the data, but only one theme was presented in the published article, that caregivers pulled together and felt connected with family members as they provided caregiving to loved ones.

As mentioned, three of the eight studies were conducted outside the USA. Wengner, Scott, and Seddon (2002) examined qualitative and quantitative data from the larger Gwynedd Study, a study which examined 2600 people over age 65 living in rural North Wales. Within the database were 40 caregivers of persons with dementia, who

provided the sample for the presented research study. Of these 40 caregivers, 22.5% were male. The researchers report that the most common stressor for these caregivers was the intense supervision requirements of the care recipient, with 35% of the sample stating that they could not leave the care recipient alone. In addition, 50% of the caregivers stated that they had given up social activities due to caregiving, and 23% of the sample had not received any formal assistive services in the previous 12 months. The researchers note that the caregivers, by in large, received much informal support, with 80% reporting receiving assistance from family members and 65% reporting assistance from neighbors. Interestingly, the researchers report that the findings were similar to the findings from a previous and similar study conducted in Liverpool, so inferences about the effect of rural residence could not be made.

Morgan, Semchuk, Stewart, and D'Arcy (2002) facilitated two focus groups of health providers and family caregivers to explore a perceived low utilization of assistive services by caregivers of persons with dementia in rural Saskatchewan. Participants included 13 allied health providers, seven physicians, and nine caregivers. Of the caregivers, 85% were female. Transcripts from the group meetings were analyzed for themes using constant comparison technique and coding. Six barriers to using formal services were identified including the stigmatization of dementia, lack of privacy, perception that use of services would indicate failure of self-reliance, lack of awareness that services were available, lack of accessible and/or acceptable services, and difficulty obtaining services in remote locations.

Harris, Thorpe, Dickinson, Rorison, Barrett, and Williams (2004) interviewed 20 patient-caregiver dyads who had traveled great distances from remote areas in Australia

to a tertiary hospital. A total of 80 interviews were completed during the hospitalization and post-hospitalization periods to explore the effects of early discharge of patients from the hospital to remotely rural communities. Demographic details of the sample were not provided in the published report. The researchers report that the major theme identified in the data was that of high financial and emotional costs as the participants negotiated an unfamiliar health care facility far from home. Participants reported high and non-reimbursed expenses for travel and for lodging and meals for the caregiver. While at the hospital, participants were far from supportive family members and friends. Upon return to their communities, participants reported great difficulty in accessing needed post-hospitalization home services. Participants stated that these costs exacted a great toll, including bankruptcy and marital strain.

Clearly, the eight studies briefly reviewed in this section do not provide a large enough body of literature to make comparisons with the general, non-rural caregiver literature. However, these eight studies do provide some nuances consistent with aspects of rural demography and rural culture discussed previously. Within these eight studies are nuances of self-reliance, lack of anonymity/ privacy, isolation, spirituality, use of informal health resources, barriers to accessing services, and the centrality of family and interdependence upon others for large tasks. Whether or not these nuances are true characteristics of rural caregiving cannot be determined. As such, there is a clear need for further exploration of rural caregiving. In addition, gender influences on rural caregiving is virtually unexplored. Only two of the studies examined male and female caregivers as distinct groups (Burman & Weinert, 1997; Ladner & Cuellar, 2002), and no study examined rural male caregivers exclusively.

Gaps in the Literature

As noted previously in this chapter, the general caregiver literature provides ample evidence of the complexity of caregiving. Caregiving work clearly provides stress that can lead to negative physical and psychological consequences. However, studies have yielded conflicting evidence on how, when, and to whom do these negative consequences occur. In addition, caregiving may likely lead to positive consequences, though these consequences are less well-described in the literature.

In terms of rural caregivers, the adjective paucity may not be strong enough to describe the lack of studies contributing to the knowledge base for this population. This clear gap in caregiver knowledge is significant when one considers rural health disparities and the realities of rural living noted earlier.

In terms of male gender, a number of the studies reviewed do provide important, albeit limited, information on the unique experiences, process, and interpretations of male caregivers. However, only two studies generated theoretical concepts grounded in a male (non-rural) sample (Coe & Neufeld, 1999; Harris, 1993). When considering all of the reviewed studies that included men in their samples, several methodological and study design features have resulted in noteworthy limitations, and thus, gaps in our knowledge of male caregiving. These features include a) folding data generated by men into a larger female data pool, b) blending all men into perceived homogenous samples, and c) emphasizing data from women as the caregiver norm.

Specifically, a number of studies reviewed combine data generated by men and women into one analysis pool (Albert, 1991; Butcher et al., 2001; Chappell & Kuehne, 1998; Conley, 1993; Grant & Nolan, 1993; Hardy, Young, & Wistow, 1999; Hasselkus,

1988; Mant, Carter, Wade, & Winner, 2000; Messecar et al., 2002; Morgan et al., 2002; Mudge & Ratcliffe, 1995; Oberst et al., 1989; Perry, Hsu, Brooks, & Cherry, 1999; Roberts et al., 1999; Schumacher et al., 2000; Seddon & Robinson, 2001; Shyu et al., 1998; Simpson, 1997; Szabo & Strang, 1999; Wenger et al., 2002; Wright et al., 1999). Combining men and women into one data pool does not clarify our understanding of the possible influence gender has on caregiving, nor of the possible uniqueness of male caregiving as a phenomenon (Houde, 2002; Thompson, 2002). Combining data from both men and women may likely be a significant design flaw. Jarviluoma, Moisala, and Vilkko (2003) state

> Gender is an important criterion in identifying ourselves and is central to the way we perceive and structure the world and events in which we participate. It influences all aspects of our being....Gender must be taken seriously in every kind and at every level of research, from practical choices to methodological questions, as well as at every stage of the research process....In our opinion, the duty of researchers is not only to explore but also to question the cultural patterns relating to gender in all human actions and its products. (p. 1)

When data unique to men are folded into the data of a sample of predominately women, men become invisible (Houde, 2002; Thompson, 2002) in a fashion similar to combining data from minorities into a predominately Caucasian data pool (Burlew, 2002; Porter & Villarruel, 1993). This invisibility may promote the interpretation that the experiences, meanings, processes, and behaviors of male caregivers are similar to their female

counterparts (Kramer, 2002). Invisibility of men in caregiving studies may lead practitioners to develop support strategies and interventions that are not applicable or acceptable to male caregivers (Gwyther, 1992).

Another feature creating a gap in our knowledge about male caregivers is the practice of blending all men into one sample or group, regardless of key demographic variables. Such a practice infers that men of varying demographic variables experience and implement caregiving similarly. Some authors have criticized researchers for combining men of differing familial relationships to the care recipient into one sample (Harris, 2002; Houde, 2002; Thompson, 2002). Most of the studies reviewed which include men in the samples do not examine possible differences between husband and son caregivers (Almberg et al., 1998; Archer & MacLean, 1993; Blake, 2000; Burman & Weinert, 1997; Butcher et al., 2001; Cantor, 1983; Coe & Neufeld, 1999; Conley & Burman, 1997; Hagen, 2001; Hardy et al., 1999; Hodgson et al., 1996; Kaye & Applegate, 1995; Mant et al., 2000; Mathew et al., 1990; Mays & Lund, 1999; Messecar et al., 2002; Mudge & Ratcliffe, 1995; Neufeld & Harrison, 1998; Parsons, 1997; Wenger et al., 2002). However, the styles of caregiving, and the needs, strengths, actions, and experiences among caregivers who are sons, husbands, brothers, or friends are likely very different (National Family Caregivers Association, 2002; Thompson, 2002).

Carpenter and Miller (2002) note that the age of the caregiver and the length-quality of the relationship with the care recipient are particularly relevant, thus, findings may be confounded by mixing husband and sons within samples. From studies comparing husband and son caregivers, sons express more difficulty staying in the caregiver role, experience more stress in balancing job and caregiving responsibilities,

are more likely to believe that formal support services are acceptable, experience less emotional loss as the care recipient's health deteriorates, are more comfortable setting limits, and feel that they are overstepping relationship boundaries when providing intimate care to care recipients than do husband caregivers (Kaye, 2002; Matthews & Heidorn, 1998; Mays & Lund, 1999; Parsons, 1997). Thus, threats to external validity and reliability may result from such combined samples. For example, if replication studies are conducted using a sample with a different mix of husband and son caregivers than the original study, findings may vary widely. Also, interpretation of findings from data generated from primarily husband caregiver samples may not generalize or transfer well to son caregivers.

The third limitation feature leading to a gap in our knowledge of male caregivers is the practice of emphasizing findings from female data as being the caregiver norm. Thompson (2002) notes that this practice stems from assumptions that any male difference noted in studies is couched as an aberration or is summarily dismissed. This practice is apparent in the discussion or implication sections of published reports, in which findings from female-generated data are highlighted and/or are used as the basis for recommendations for interventions for the generic caregiver (as seen in (Arber & Ginn, 1995; Beck, Jijon, & Edwards, 1996; Blake, 2000; Horowitz, 1985; Joseph & Hallman, 1998; Mudge & Ratcliffe, 1995; National Alliance for Caregiving & American Association of Retired Persons, 1997). For example, although Arber and Ginn (1995) note that men provide substantial caregiving, they state that resources should focus on women caregivers since they experience more caregiver burden. With this practice, the

contributions made by male caregivers, and the burdens and rewards they experience uniquely are downplayed and possibly not addressed (Thompson, 2002).

Some studies report statistically significant differences between male and female caregivers, but do not discuss the clinical significance or effect sizes of those differences (Miller & Cafasso, 1992). For example, one study reports that female caregivers provide significantly more hours of caregiving per week than do male caregivers, with a mean of 18.8 hours versus a mean of 15.5 hours per week (National Alliance for Caregiving & American Association of Retired Persons, 1997). However, these researchers do not discuss whether the difference of 3.3 hours per week leads to a notable difference in stress or other caregiver outcomes, nor do the researchers explain why there is a difference. In other words, do women complete more tasks, or are men more time-efficient at completing tasks? Still other studies do not provide standard deviations or ranges in their results. This exclusion may mask a possibly wide variability among male caregivers on the variable measured (Miller & Cafasso, 1992).

Although examination of gender differences in caregiving is important in understanding how men provide care, examination of gender differences as the only caregiving variable is of questionable clinical value since caregiving is a multi-dimensional phenomenon (Miller & Cafasso, 1992). Of greater benefit to the existing knowledge base would be a more comprehensive examination of how gender may shape the experiences and meanings of caregiving for men (Kramer, 2002; Miller & Cafasso, 1992; Thompson, 2002; Young & Kahana, 1989).

In summary, despite the large number of studies on caregiving, very little is known about rural male caregivers. Most of the quantitative studies reviewed examined

caregiving relatively unidimensionally and without serious consideration of the context (especially sociological context) in which the caregiving was occurring. Despite efforts at rigor, many of the quantitative studies have yielded contradictory findings. Most of the qualitative studies reviewed did not examine gender holistically and/or did not generate theoretical findings that could be developed, tested, and/or used to expand current theoretical models of caregiving. In addition, very little is known about caregiving in rural environments, though these studies suggest that rural culture may have an influence on caregiver phenomena.

Preliminary Study

Under the supervision of faculty at Oregon Health & Science University School of Nursing, I conducted a preliminary grounded theory study of rural husband caregivers (O'Lynn, 2003). The specific purpose of the study was to explore caregiving experiences and salient concepts for rural men caring for their wives at home. The preliminary study used grounded theory methods as described by Glaser (1978; 1998; 2001), in which a transcript from a recorded interview was analyzed using open coding and constant comparison methods. The interview lasted approximately 90 minutes. The interview was conducted in the participant's home. The participant was the primary caregiver for his wife who had chronic illness and disability. An interview schedule similar to the schedule located in Appendix A was used, though additional questions and topics were explored consistent with grounded theory method. Field notes from the interview were taken and analyzed as well.

The preliminary study did not yield saturation of topics, nor generate enough data for the derivation of categories and their associated properties. As such, theoretical relationships were not discerned, nor did a critical comparison with the extant caregiver literature occur. However, the overall purpose of the preliminary study was to provide me with mentored practice with grounded theory methods, as well as to pilot potential topics for future interviews. Findings from the preliminary study offered several new perspectives. For example, *being a bull*, a term offered by the participant, refers to a self-reliant, committed, and stubborn approach to caregiving. This participant stated, "I can do just about everything she needs without help from nobody." Another perspective offered was an overall distrust of allied health professionals, namely therapists, who did not focus their rehabilitation activities toward vocational goals. It is possible that these perspectives are reflective of rural values of self-reliance and the perception that health is defined in terms of being able to work (Lee, 1998b; Long, 1998; Long & Weinert, 1998). In addition, the participant discussed coping strategies, such has prayer and relying upon support from family members that have been previously discussed in the literature, but these participants discussed the implementation of these strategies as accomplishments in which they had great pride. Interestingly, despite his strongly stated self-reliant attitudes, this participant expressed a loneliness and isolation from his friends. The participant stated that he was not necessarily seeking assistance from others, but instead, sought validation and praise from others for his problem-solving skills and accomplishments with caregiving. Also, this participant was emphatic that it was love, and not duty, that motivated him to persist in the caregiver role. This latter finding suggests a contrast with the more traditional gendered perspective of caring discussed earlier in this chapter.

From this preliminary study, I had some fertile ground to explore during the first few interviews of my study. Namely, the *being a bull* approach to caregiving, pride in accomplishments, need for validation of caregiving work accomplishments, and love as a motivation for caregiving were potential categories ripe for exploration. These perspectives served as initial questions for subsequent interviews and provided me a theoretical curiosity.

CHAPTER 3: METHODS

Assumptions of the Researcher

Research Philosophy

Unlike quantitative researchers who utilize a positivistic or post-positivistic paradigm characterized by uniform and well-known philosophical assumptions, qualitative researchers approach inquiry from a variety of paradigms. As such, qualitative researchers have a responsibility to convey their assumptions in order for consumers of their research to evaluate the quality, usefulness, and applicability of the rendered findings (Annells, 1996). The purpose of this initial chapter section is to convey the assumptions of the researcher on the nature of inquiry, as well as to provide chosen conceptualizations of gender and rurality, two of the major contextual aspects underlying the proposed study.

I assume a relativist ontology, more specifically, an ontology in which persons construct their perceptions of reality from the meanings they attribute to the phenomena in their lives. In tandem with this assumption is the assumption that knowledge is created from meanings which arise from transactions one has with oneself (reflection) and with others (interaction). Meanings are constructed mutually from individual and shared interpretations of phenomena that are then shared and agreed upon in varying degrees. Since transactions are innumerable, and since meanings are dynamic, reality is not only relative within individuals, but also dynamically relative among individuals over the course of time.

Consistent with these assumptions, qualitative research is a systematic and prolonged process of the development of shared meanings, as opposed to a quest for a singular truth, or a version of a truth that imperfectly represents a real, or solitary truth. As such, research should employ processes that capture interaction between researcher and participant, between researcher and data, and make transparent reflection and construction of findings. The outcomes of research should enhance the understanding of shared meanings, the creation of new meanings, the rectification of mutually misunderstood meanings, and/or expand the boundaries of limited meanings. The outcomes of research should produce growth of both researcher and participant, and should yield information that has pragmatic applicability. Consistent with these assumptions, I assume definitions of gender and rurality that are interactional and that recognize the breadth of influence these contextual aspects have on caregiving.

Gender

Much has been written about gender, how it is determined, and how it influences a variety of social phenomena. A full summary of the gender literature is beyond the scope of this chapter section. Suffice it to say, some authors have noted that earlier discussions of gender have focused on biological determinants and socialization processes as the source of gender (Bohan, 1993; Courtenay, 2000; Pleck, 1995; West & Zimmerman, 1987). These discussions have produced an essentialist perspective of gender. However, Bohan notes that essentialism does not assume that gender is pre-determined, but rather gender is singular in its location. Bohan notes that an essentialist stance assigns specific characteristics or traits to gender. This stance has been

demonstrated in the previous chapter with assumptions by researchers in the caregiving literature and by those, such as Gilligan, who have conceptualized caring from an essentialist perspective.

On the other hand, Bohan (1993) describes a constructivist perspective on gender. Constructivism assumes that gender is defined in the interactions people have with one another, in that these interactions have shared meanings as to what is appropriate and/or expected in terms of biological sex. Bohan provides a helpful analogy. She notes that the difference between an essentialist perspective and a constructivist perspective is similar to the difference in identifying a person as friendly and a transaction as friendly. In the former, friendliness is a trait inherent within that individual. In the latter, friendliness is understood to be present by how an interaction with shared meanings occurs and progresses between two individuals.

Courtenay (2000) supports a constructivist perspective of gender, and suggests that this perspective reveals much about how men approach their own health care. Courtenay notes that previous essentialist perspectives have proposed a singular male sex role which does not account for the variability of gendered characteristics seen empirically. Citing support from the literature, Courtenay proposes that gender is not determined by psychologically or biologically determined traits, but rather by culture and social interactions. Gender is socially constructed, produced by dialectical and constructivist processes, resulting in a highly dynamic social structure. As such, persons have some influence on changing perspectives of gender and how it is manifested. He states

From a social constructionist perspective, however, men and boys are not passive

victims of a socially prescribed role, nor are they simply conditioned or socialized

by their cultures. Men and boys are active agents in constructing and

reconstructing dominant norms of masculinity. (p. 1387-1388)

Viewing gender as an active, rather than static, phenomenon has been proposed

by authors such as West and Zimmerman (1987). These authors suggest that gender

should not be so much viewed as a noun, but rather as a verb. Gender is something

people *do*, not something people are (West & Zimmerman, 1987). As an active and

dynamic structure, gender is constructed variably, resulting in multiple types of

femininity and masculinity (Beynon, 2002; Bohan, 1993; Courtenay, 2000; Thompson et

al., 1992). Despite this dynamic nature, however, gender has shared meanings between

individuals and among members of a group. Persons shape behaviors and perspectives to

be congruent with these shared meanings. Consequently, although gender may be

dynamic and socially constructed, gendered constructions result in norms that may at

times appear static, hegemonic, and essentialist in nature (West & Zimmerman, 1987).

Negotiating possible conflicts resulting from the hegemonic aspects of gendered

constructions may lead to psychological stress (Good et al., 1995).

As such, I assume the following about gender. *Gender is not pre-determined by*

biology or socialization, but rather, is constructed from shared meanings derived from

social interactions. These constructed meanings are dynamic and contextually

influenced. However, these meanings may lead to hegemonic and normative

constructions. Individuals who must redefine gender meanings due to life events or new

contexts engage in psychological and social labor and risk social consequences as

meanings are renegotiated. The intensity of hegemonic gender constructions will

influence the amount of labor and type of risks experienced by individuals.

Rurality

Rurality, as a concept, is not defined, but only implied in the literature. As noted

in the previous chapter, a number of governmental and organizational bodies have

developed different definitions of rural. Most of these definitions focus on population,

geographical, or economic data. However, the term *rurality* has been used by only a few

authors to vaguely indicate how distant a place is from some sort of population center

(Glynn, Byrne, & Murphy, 2004; Lago, Stuart, & Ahern, 1993; Ryan-Nicholls, 2004).

Weinert and Boik (Weinert & Boik, 1995) go further in defining rurality, but use

population and geographic data in a quantitative manner to develop a rurality index.

However, in the previous chapter, it was noted that a number of authors have described

the sociocultural aspects of rural dwellers and the influence rural residence has on other

phenomenon, such as health. However, I was able to locate only one reference that

combined these geographical demographics and sociocultural perspectives of rural

residence into a solitary concept. Wagenfeld (2003) notes that rural is a state of mind and

that simply having a rural mailing address does not make one rural. Wagenfeld questions

whether an urban individual who relocates to a rural area is truly rural. This

consideration may be congruent with the concept of insider/ outsider among rural

dwellers (Lee, 1998a). Wagenfeld notes that rurality incorporates rural values and a

sense of 'rusticity', though he does not define rusticity in his discussion. Such a

combination of place of residence and culture is not unheard of in other contexts, particularly when one considers the colloquial terms of *Westerner* or *New Yorker*. Each term not only indicates place of residence, but also indicates shared cultural and life experiences.

As such, I suggest that numerical perspectives of rurality are not sufficient in capturing the influence that the rural context might have on caregiving. For example, some rural caregivers could be geographically isolated and have limited access to services. However, this challenge could be just as difficult for urban caregivers, who for reasons of poor knowledge, lack of resources, or limited transportation options could be just as isolated and limited to services as their rural counterparts. Therefore, *I assume that what makes the rural context unique is the holistic blend of the population-numerical perspectives and the sociocultural perspectives of rural. I name this blend 'rurality' for the purposes of my study.*

This definition of rurality is consistent with constructivism. Sociocultural aspects of rurality are borne from interactions-based meanings that are shared and agreed upon by social members. These meanings have historical origins and longevity within communities, yet are dynamic and malleable. These meanings provide the foundation for the values, beliefs, and actions of rural residents. These meanings also provide the foundation for identification and self-identity for persons experiencing rurality. In addition, the numerical aspects of rurality are also constructed, though more prescriptively, among researchers, service providers, and bureaucrats. Based on this perspective, I assume that individuals can *do rurality* in a similar vein as individuals *do gender*. As noted in the beginning of Chapter Two, male gender is a cord that becomes

the central area of interest that connects and intersects rurality with caregiving. The intersections among gender, rurality, and caregiving, all dynamic phenomena, remain uncharted territory in the literature.

Background on the Method

Introduction

Included within the stated aims detailed in the first chapter are the exploration of the experiences, processes, and meanings of caregiving, as well as the exploration of theoretical relationships among identified concepts present within the data. Exploration of meaning could be accomplished with phenomenological or ethnographic methods (Creswell, 1998). However, it is the latter aim, that of exploring theoretical relationships, that required a method that goes beyond qualitative description. My study required a method that could produce qualitatively derived theory. Grounded theory is such a method (Creswell, 1998; Glaser, 1978, 2001; Glaser & Strauss, 1967).

Grounded theory, originally described by Glaser and Strauss in the 1960's, has undergone revisions that have led to contentious arguments among grounded theorists (Charmaz, 2000; Glaser, 2001, 2002; Kendall, 1999). These arguments focus mostly on the application of various analysis procedures or on the use of differing ontological and epistemological assumptions for approaching inquiry with grounded theory methods. As such, a researcher interested in using grounded theory must select from the various genres of grounded theory (Annells, 1997). This chapter section will briefly review these genres and provide a rationale for the genre selected for use in the proposed study. However, a brief discussion on the origin of grounded theory is in order.

Symbolic Interactionism: The Origin of Grounded Theory

Authors have associated the origin of grounded theory with symbolic interactionism as developed by the Chicago School of Sociology (Annells, 1996; Charmaz, 1994a, 1994b, 2000; Kendall, 1999). However, Glaser and Strauss (1967) and Glaser (1998) note that the blend of thoughts from both the Chicago School of Sociology and Columbia University were instrumental in the origin of grounded theory. Strauss was trained at the Chicago School of Sociology in qualitative approaches to inquiry. Glaser was trained in quantitative methodology at Columbia University. Traditional scientific approaches of post-positivism characterized Glaser's training. These approaches are well-known, and thus, will not be described in detail here. However, symbolic interactionism theory deserves some discussion since its definition and implications are particularly relevant to my study.

It is difficult to precisely define symbolic interactionism, as no singular perspective on symbolic interactionism exists (Meltzer, Petras, & Reynolds, 1975). Blumer (1969) identifies symbolic interactionism as a "...distinctive approach to the study of human group life and human conduct" (p. 1). Numerous social psychologists and sociologists, such as William James, Charles Cooley, John Dewey, W. Thomas, and George Herbert Mead, contributed to the development of symbolic interactionism through their writings and teaching. However, it was Herbert Blumer who coined the term *symbolic interactionism* and provided the three premises of the theory that are now well-known (Blumer, 1969; Meltzer et al., 1975).

Blumer's (1969) three premises are a) that humans act toward things on the basis of meanings that the things have for them, b) that the meanings of things are derived from, or arise out of, social interactions, and c) that these meanings are handled in and modified by an interpretive process used by individuals in dealing with the things encountered. The implications of these premises have been variable, but Meltzer et al. (1975) note that symbolic interactionism

...is the interaction that takes place among various minds and meanings that characterize human societies....that the individual and society are inseparable units....that the complete understanding of one demands a complete understanding of the other...In the interactionist image, human beings are defined as self-reflective beings....The behavior of men and women is 'caused' not so much by forces within themselves (instincts, drives, needs, etc.), or by external forces impinging upon them (social forces, etc.), *but what lies in between, a reflective and socially derived interpretation of the internal and external stimuli that are present.* (p. 1-2, italics added)

This perspective ran counter to the assumptions of the time that humans and their behaviors were functionalist and deterministic in nature.

Since the development and articulation of symbolic interactionism in the mid-20th century, various sociologists have differed in the application of symbolic interactionism to inquiry. Meltzer et al. (1975) note two major approaches: one attributed to the Chicago School of Sociology and to Blumer, the other attributed to State University of

Iowa and to Kuhn. The differences between the two approaches focus primarily on methodology. Blumer strives to "...make modern society intelligible. Kuhn seeks universal predictions of social conduct" (Meltzer et al., 1975, p. 57).

Blumer takes a more phenomenological approach to examining humans and advocates for participant-observation and intimate placement within the participants' environments. Blumer also advocates for a sensitizing approach to concepts so that the researcher has directions on where to look, instead of using an operational approach to concepts that informs researchers prescriptively on what to look at (Meltzer et al., 1975). Blumer (1969) states

...the four customary means [of inquiry methods] –adhering to scientific protocol, engaging in replication, testing hypotheses, and using operational procedure—do not provide the empirical validation that genuine empirical social science requires...Very simply put, the only way to get this assurance is to go directly to the empirical social world—to see through meticulous examination of it whether one's premises or root images of it, one's questions and problems posed for it, the data one chooses out of it, the concepts through which one sees and analyzes it, and the interpretations one applies to it are actually borne out. (p. 32).

Opposing this perspective, Kuhn advocates for operationalization of concepts and use of quantitative instruments as key components of inquiry (Meltzer et al., 1975). It is the approach of Blumer that is most closely associated with symbolic interactionism

(Meltzer et al., 1975), and is the approach most influential to Strauss and to Glaser (Glaser, 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1998).

Original/ Traditional Grounded Theory: Glaser and Strauss, Glaser

As noted earlier, grounded theory arose from a blending of traditions from both Glaser and Strauss. Although symbolic interactionism may have been the source for some of the assumptions of grounded theory, such as the need to obtain data from the natural world in which phenomena occur, Glaser (1998) is clear that the procedural methods of grounded theory came from his training at Columbia University. Glaser notes that grounded theory has its roots in qualitative math. According to Glaser, Lazarsfeld (one of his professors at Columbia) stated that any qualitative hypothesis or concept could be expressed in terms of a mathematical formula, and that any mathematical formula could be expressed qualitatively. As such, qualitative research could generate theories that could later be tested mathematically (quantitatively). The challenge then was how to generate theory systematically from qualitative data.

This challenge led to the articulation of several research processes now associated with grounded theory. Glaser (1998) reports that constant comparison technique came from the process used at Columbia to generate concepts from qualitative data that were to be later used in questionnaires and surveys, as well as from inductive processes of reducing data to more general categories. Line-by-line comparison technique came from *explication de text,* a procedure Glaser learned at the University of Paris. (In this technique, texts are examined line-by-line for meanings and concepts.). Theoretical coding and conceptualization came from the teachings of Merton at Columbia. Glaser

then combined these research processes with Strauss' background of symbolic interactionism, with its importance of meanings to lives of people, to create the approach they later termed *grounded theory* (Glaser, 1998).

Glaser and Strauss (1967) note that at the time of their original text on grounded theory, there had been discussions for some time about the gap between theory and empirical research in sociology. They note that Blumer provided an explosive commentary on this gap with his 1939 critique of Thomas and Znaniecki's manuscript, *The Polish Peasant in Europe and America.* This gap was also discussed by many others including Merton. However, Glaser and Strauss note that many addressed this gap by further refining processes focused on the verification of theories, which did little to actually close the theory-research gap.

Glaser and Strauss (1967) wrote their initial text to explain the method they used in their collaborative study examining the dying experience of hospitalized patients. Glaser and Strauss, and later Glaser (1998), are emphatic that the method they called grounded theory was discovered, not created (though they do not explain well why it was discovered as opposed to created). Nevertheless, Glaser and Strauss (1967) operated with the assumption that "...the adequacy of a theory for sociology...cannot be divorced from the process from which it was generated" (p. 5). Thus, quality theory must be derived from rigorous and inductively-derived social research. The purpose of grounded theory was to generate theory that fit the reality of persons situated in the natural environment (Glaser & Strauss, 1967). Grounded theory would also produce theory that was workable (since it reflected the way things really worked) and relevant (since it pertained to the major concerns of participants rather than to the concerns of researchers) (Glaser, 1998).

Through conceptualization and theoretical sampling, *grounded* theories would produce various levels of hypotheses and theoretical constructs that could then be verified and applied deductively.

Some readers found their original discussion of grounded theory to be vague and difficult to follow (Glaser, 1978). Glaser went on to publish his 1978 text, in which he further explicated the methodology of grounded theory. In this text, Glaser focuses much attention on the analytical stance of the researcher, the use and role of the researcher's previous knowledge when using grounded theory, procedures for coding data, and conceptualization. It is this 1978 text that many continue to use as the basic primer for traditional grounded theory.

Over the years, various researchers, including Strauss, have added their own perspectives on grounded theory, some of which will be addressed shortly. These other perspectives have encouraged Glaser to write additional papers and texts to further explain grounded theory methodology (for example, Glaser, 1998, 1999, 2001, 2002). In these subsequent writings, Glaser insists that researchers should engage in inquiry without a priori conceptualizations regarding the phenomenon, should passively listen to informants and not inject researcher perspectives in interviews, should code data with a theoretical stance, and should have the goal of conceptualization from the data instead of deep description of the data. Glaser has remained consistent over the years that the approach to grounded theory as he describes it is the only legitimate approach to grounded theory. Glaser describes other approaches as remodeled versions that weaken grounded theory as a methodology, and as such, do not meet the rigorous standards of the grounded theory title. Many of his more recent writings have taken a rather arrogant and

contentious tone (Bryant, 2003; Charmaz, 2000). Nevertheless, grounded theory as proposed by Glaser and Strauss (1967) and later by Glaser (1978, 1998, 2001, 2002) adopts ontological and epistemological assumptions consistent with post-positivism (Bryant, 2003; Charmaz, 2000; Patton, 2002).

Revised Grounded Theory: Strauss and Corbin

After the introduction of grounded theory by Glaser and Strauss, Strauss continued to teach the method to students at the University of California, San Francisco (Strauss & Corbin, 1998). Many students and researchers new to the method found the procedures difficult to understand. Consequently, Strauss completed an additional text on the method in 1987, and then teamed up with Juliet Corbin for additional texts in 1990 and 1998 (Strauss & Corbin, 1998). These texts by Strauss, and later in collaboration with Corbin, revised some of the analysis procedures from the original grounded theory method, primarily in how data are coded (Kendall, 1999). Strauss and Corbin (1998) note that the differences in their approach were not intentional, but rather arose out of growth of the method, a growth they felt enabled researchers to more systematically derive theory from qualitative data, and a growth that brought the method closer to its symbolic interactionist roots.

In terms of coding, Strauss and Corbin (1998) propose a coding process they had discussed in their previous 1990 text. According to their method, the open coding process, in which data bits are coded into categories that emerge directly from the data, is followed by a coding process called *axial coding*. This process is so named due to the resemblance of the process to a wheel, in which relationships among categories are

delineated as radiating from a central core concept. During axial coding, the researcher

examines the coded data using a coding framework, which assists the researcher in

examining the conditions, contexts, actions, and consequences of the categories. This

framework provides a skeleton of the relationships for the emerging theory. This process

then is followed by selective coding, in which further data collection and analysis is

completed to refine and provide depth to the core category and its related peripheral

categories in order to better capture the theoretical aspects of the phenomenon under

study (Kendall, 1999; Strauss & Corbin, 1998).

Numerous authors have discussed the merits and limitations of these revisions to

grounded theory. Several authors have commented that Strauss and Corbin move closer

to a more subjective epistemology, in that Strauss and Corbin recognize the contribution

and role of the researcher's interpretive actions (Annells, 1996; Charmaz, 2000). Strauss

and Corbin (1998) note

> Analysis is the interplay between researchers and data. It is both a science and
>
> art. It is science in the sense of maintaining a certain degree of rigor and by
>
> grounding analysis in data. Creativity manifests itself in the ability of researchers
>
> to aptly name categories, ask stimulating questions, make comparisons, and
>
> extract an innovative, integrated, realistic scheme from masses of unorganized
>
> raw data. (p. 13).

From this quote, it is possible to argue that Strauss and Corbin are moving grounded

theory into a more interpretive, and possibly constructivist, approach. However, it could

be also argued that this quote is simply referring to a slightly revised perspective on Glaser's discussion of theoretical sensitivity. However, throughout their 1998 text, Strauss and Corbin describe theory generation as discovery. They state, "Remember, our primary purpose is discovery" (p. 280). Although they also discuss the importance of researcher sensitivity to capture the nuances and multiple perspectives in the data, they also emphasize that objectivity is crucial in discovering theory that most accurately reflects the reality in the data. They state

> Objectivity is necessary to arrive at an impartial and accurate interpretation of events. Sensitivity is required to perceive the subtle nuances and meanings in the data and to recognize the connections between concepts. Both objectivity and sensitivity are necessary for making discoveries....What is important is to recognize that subjectivity is an issue and that researchers should take appropriate measures to minimize its intrusion into their analyses. (p. 42-43).

It is this emphasis on objectivity and discovery of reality has led some to describe grounded theory as articulated by Strauss and Corbin as having a critical realist ontological perspective and a positivist epistemological perspective, though less so than Glaser (Annells, 1996; Charmaz, 2000).

Perhaps the harshest criticism of Strauss and Corbin has come from Glaser himself (Charmaz, 2000). Glaser (1998) states that in an effort to simplify grounded theory procedures, Strauss and Corbin have "...thrown the baby out with the bathwater" (p. 39). Glaser notes that the revised coding procedures are conducive to forcing data

into a pre-determined framework. As such, Glaser feels that theory will not emerge from the data accurately. In addition, Glaser rejects the more interpretive stance taken by Strauss and Corbin. Although theoretical sensitivity provides the researcher the ability to view data with an open mind (Glaser, 1978), Glaser states that the findings will emerge from the data, on its own, without interpretation on the part of the researcher.

Dimensional Analysis: Schatzman

Dimensional analysis has been described as an alternate method for generating grounded theory (Kools, McCarthy, Durham, & Robrecht, 1996; Robrecht, 1995; Schatzman, 1991), but has received little attention due to Schatzman's minimal discussion of the method in publications (Kools et al., 1996). I have not found any comment from Glaser on dimensional analysis, unless one assumes it can be included in the generic "remodeling of grounded theory" of which Glaser is quite critical (Glaser, 1999, 2002). Perhaps the lack of comment is due to the fact that Schatzman does not identify his method as a type of grounded theory, but rather a "...methodological approach to the grounding of theory in qualitative research." (Schatzman, 1991, p. 303). However, others have identified dimensional analysis as a type of grounded theory (Kools et al., 1996; Robrecht, 1995).

Schatzman was a colleague of Strauss at the University of California, San Francisco and worked with graduate students who were attempting to use grounded theory techniques as presented by Glaser and Strauss, and later taught by Strauss (Schatzman, 1991). Schatzman was critical of the lack of clear guidance on how to analyze collected data, and that the approach taught by Strauss was taking students too

far away from the symbolic interactionist roots of grounded theory with his coding plan and a priori coding framework. As a result, Schatzman developed dimensional analysis in order to assist student researchers arrive at theory more systematically. Schatzman bases dimensional analysis on a process he termed *natural analysis*, a process in which humans examine attributes and properties of phenomena they encounter (Kools et al., 1996; Schatzman, 1991). As with other forms of grounded theory, dimensional analysis does not detail methods for data collection. Rather Schatzman's description of dimensional analysis instructs the researcher on the theory-generation aspect of grounded theory, the aspect Glaser identifies as *conceptualization*.

Briefly, in using dimensional analysis, a researcher analyzes bits of data by designating (naming) *dimensions* of the data bit. Dimensions include the data bit's context, conditions, processes, and consequences. Once a critical mass of dimensions is collected, the dimension with the greatest explanatory power is lifted to the status of a *perspective*. Other dimensions become part of the background context (Kools et al., 1996; Robrecht, 1995; Schatzman, 1991). With dimensional analysis, the researcher is able to explain what all is going on with data, rather than identify the basic, or primary, social process derived from traditional grounded theory method (Kools et al., 1996).

Although one might consider the matrix used to identify dimensions and determine a perspective to be less prescriptive than the coding framework as described by Strauss and Corbin (1998), dimensional analysis does employ relatively prescriptive and researcher-oriented description of what constitutes a dimension. As such, it is not clear whether Schatzman has moved grounded theory closer to symbolic interactionism as he claims. However, the key difference with dimensional analysis from the previously

described approaches to grounded theory is with its epistemological assumptions (Kools et al., 1996; Robrecht, 1995; Schatzman, 1991). With dimensional analysis, the researcher's prior knowledge and interpretations are used in identifying dimensions and perspectives, in contrast to Glaser's and Strauss and Corbin's more objectivist stances.

Constructivist Grounded Theory: Charmaz

Naturally, constructivist grounded theory adopts a constructivist paradigm and represents a more extensive reformulation of grounded theory than those presented by Strauss and Corbin or by Schatzman. Patton (2002) notes that *constructivism* and *social constructionism* are terms that are interchangeable, and pertain to the belief that persons construct reality from the meanings assigned to phenomena. However, Patton states that Crotty distinguishes between the two terms in that constructivism describes the meaning-making within the individual; whereas social constructionism describes the meaning-making among individuals. This paradigm of construction assumes a relativist ontology and a subjective and transactional epistemology (Lincoln & Guba, 2000). A simplistic analogy of this paradigm follows. A group of individuals wish to construct an office building. Each has an idea of what the building should be. Collectively, they determine how the building is to be constructed. Artistic and utilitarian aspects are incorporated in the design and ultimate construction of the building. Once completed, the group occupies the building and carries out their office work within its walls. Another group, also wishing to construct an office building, goes through a similar process. Upon completion, the second office building appears different than the first. Despite similarities of doors and windows and such, the two buildings differ in appearance and

utilitarian features (such as conference rooms in one and amphitheaters in the second). The question of which building is the *real* office building becomes irrelevant. Both are real, yet very different, based upon the meanings, contexts, and needs of the two groups. As such, the buildings represent separate realities, constructed transactionally among group members. Truth then, differs based upon which building one is located.

In answering the critiques by postmodernists of postpositivist approaches to inquiry (such as the previous presentations of grounded theory), Charmaz has developed *constructivist* grounded theory (Charmaz, 1994a, 1994b, 2000, 2006). In explaining this approach, Charmaz notes

> Constructivist grounded theory celebrates firsthand knowledge of empirical worlds, takes a middle ground between postmodernism and positivism, and offers accessible methods for taking qualitative research into the 21st century. Constructivism assumes the relativism of multiple social realities, recognizes the mutual creation of knowledge by the viewer and the viewed, and aims toward interpretive understanding of subjects' meanings. (p. 510)

Charmaz notes that despite the prescriptive approaches to grounded theory offered by Glaser, Strauss and Corbin, and Schatzman, constructivist grounded theory offers a heuristic approach.

Patton (2002) also notes that deconstruction is an analytical process that is inherent with constructivism/ social constructionism. Deconstruction refers to the process of taking apart text in order to examine hidden meanings, assumptions, and

power relationships. Deconstruction affords the researcher the opportunity to examine who is served by the constructions of meaning for phenomena. Charmaz's approach incorporates deconstruction, evidenced by her emphasis on the examination of the meanings hidden in codes. For the most part, Charmaz advocates procedures of data analysis similar to those described by Glaser; however, Charmaz incorporates constructivist foundations to the procedures. Further details of how Charmaz incorporates a constructivist approach are discussed in subsequent sections of this chapter.

<div align="center">Selection of a Grounded Theory Method</div>

Annells (1996) provides a number of considerations for researchers to examine in selecting a method of grounded theory. First and foremost is the appropriateness of the method to the research questions or aims. According to Annells, the focus of grounded theory is to explore a social process, structure, and/or interactions. The aims of my study, as discussed earlier, seek to identify social processes and interactions. Thus, grounded theory is an appropriate method.

Second, Annells (1996) raises the question of feasibility. Grounded theory often requires a great deal of time and resources in order to reach saturation of topics. In addition, mentors are requisite for novice researchers to conduct quality grounded theory research (Glaser, 1978, 1998). For my study, I used school faculty, a grounded theory learning group at the University of Alberta, and the literature to provide guidance on the method. At the outset of the study, it was not known whether enough time would be available to fully saturate concepts. However, Strauss and Corbin (1998) note that

preliminary theoretical constructions are possible with abbreviated studies, which can be strengthened later with further research.

However, the most important consideration offered by Annells (1996) in selecting the approach of grounded theory is my personals philosophical stance. Annells notes that the approach taken must match the assumptions of the researcher. Based on these considerations, constructivist grounded theory, as described by Charmaz, is the most appropriate grounded theory approach for my proposed study.

Rural Location for My Study

My Assumed Definition of Frontier

As noted in the previous chapter, various categorizations of population centers have been proposed by organizations and been used be researchers and service providers. Currently, there is no agreement on the population, geographic, and economic parameters for rural. However, there is more consistent agreement on the characteristics for the most rural of categories, that is, frontier. *For the purposes of my study, frontier residence was defined as residence in a county of less than six persons per square mile and location in a community under a population of 15,000.*

Location

The location of the participant residence for this study was a 12-county area in north central Montana and a 10-county are in eastern Oregon. According to the 2000 US Census, each of the counties meets the population density requirement for frontier county designation (US Census Bureau, 2004, 2006). In fact, most of the counties far exceed the

density requirement for frontier designation. Table 3.1 below identifies each of the counties and population data.

According to the US Census Bureau (US Census Bureau, 2004, 2006), all of the counties are more sparsely populated than the state as a whole, and 19 of the counties have a higher percentage of senior citizens than the state average. The majority of residents, as is with the state as a whole, are Caucasian per self-report. In Montana, Native Americans comprise the largest minority subpopulation; whereas in Oregon, Hispanic/ Latinos comprise the largest minority subpopulation. Havre is the largest Montana town within the study location, with a 2000 population of 9621 (US Census Bureau, 2004). Ontario is the largest Oregon town within the study location, with a 2000 population of 10,915 (US Census Bureau, 2006).

The counties in the study area have a shared history of American Indian forced displacement, ranching, forestry, mining, and homesteading with the advent of railroad infiltration in the 19th and early 20th centuries. In addition, in nearly all of these counties, residents have relatively low median household incomes and higher percentages of individuals below living in poverty than the remainder of the state, rural America, and the United States as a whole (US Census Bureau, 2004, 2006) (Table 3.2).

Table 3.1 Year 2000 Population Data of Counties in Study Location

County	Population	Population density (per mile²)	% of Population over age 65	% of Population that is one-race Caucasian
			Montana	
Blaine	7009	1.7	12.9%	52.6%
Choteau	5907	1.5	17.5%	84.0%
Fergus	11,893	2.7	19.9%	97.1%
Hill	16,673	5.7	12.8%	79.5%
Judith Basin	2329	1.2	17.2%	98.6%
Liberty	2158	1.5	19.7%	99.2%
Petroleum	493	0.3	17.0%	99.2%
Phillips	4601	0.9	17.6%	89.4%
Pondera	6424	3.9	16.3%	83.7%
Teton	6445	2.8	16.6%	96.3%
Toole	5267	2.7	15.9%	93.9%
Valley	7675	1.5	19.0%	88.1%
			Oregon	
Baker	16,741	5.5	19.0%	95.7%
Gilliam	1915	1.6	19.1%	96.8%
Grant	7935	1.8	16.8%	95.7%
Harney	7609	0.8	15.0%	91.9%
Lake	7422	0.9	17.7%	91.0%
Malheur	31,615	3.2	13.7%	75.8%

Table 3.1 Continued

County	Population	Population density (per mile^2)	% of Population over age 65	% of Population that is one-race Caucasian
Morrow	10,995	5.4	10.6%	76.3%
Sherman	1934	2.3	18.3%	93.6%
Wallowa	7226	2.3	18.9%	96.5%
Wheeler	1547	0.9	23.3%	93.3%
Montana	902,195	6.1	13.4%	90.6%
Oregon	3,421,399	35.6	12.8%	86.6%
Rural USA	55,440,227	n/a	14.7%	84.8%
USA	281,421,906	79.6	12.4%	75.1%

Table 3.2 Year 2000 Economic Data of Counties in Study Location

County	Median Household Income (1999 US dollars)	% Individuals Living in Poverty
Montana		
Blaine	25,247	28.1%
Choteau	29,150	20.5%
Fergus	30,409	15.4%
Hill	30,781	18.4%
Judith Basin	29,241	21.1%
Liberty	30,284	20.3%
Petroleum	24,107	23.2%
Phillips	28,702	18.3%
Pondera	30,464	18.8%
Teton	30,197	16.6%
Toole	30,169	12.9%
Valley	30,979	13.5%
Oregon		
Baker	30,367	14.7%
Gilliam	33,641	9.1%
Grant	32,560	13.7%
Harney	30,957	11.8%
Lake	29,506	16.1%
Malheur	30,241	18.6%
Morrow	37,521	14.8%

Table 3.2 Continued

County	Median Household Income (1999 US dollars)	% Individuals Living in Poverty
Sherman	35,142	14.6%
Wallowa	32,129	14.0%
Wheeler	28,750	15.6%
Montana	33.024	14.6%
Oregon	40,916	11.6%
Rural USA	33,687	14.6%
USA	41,994	12.4%

In terms of medical services, ten hospitals are located in the Montana counties, six of which are critical access hospitals (Montana Area Health Education Center, 2002). The region is serviced by two major medical centers, though neither is located within the region. One medical center is in Great Falls, approximately 20 miles from the southwest border of the Montana study location; whereas the other is located in Williston, North Dakota, approximately 80 miles from the eastern border of the region. In Oregon, the study location is serviced by six hospitals, five of which are critical access hospitals (Oregon Health & Science University, 2006). However, the Oregon region is served by larger hospitals in Bend (near the western edge of the region), Pendleton (on the northern edge of the region), and by large urban hospitals in Boise (approximately 60 miles from the eastern edge of the region).

Rationale for Selection of the Study Location

As noted earlier, various definitions of rural have been developed and used by researchers and policy makers. As such, rural participants of previous studies and programs may have been classified as rural under one definition and non-rural if another definition was used. All of the commonly used definitions for rural employ categories of population demographics, though rural population is likely more accurately expressed as a falling on a continuum. One may view a very densely populated area such as New York City as one anchor of this rural continuum and frontier areas as the opposite anchor. It is likely that the structural, social, and economic aspects of rurality have a large influence on the health care barriers present for rural dwellers, and on the cultural development of rural communities (Wagenfeld, 2000, 2003). Logically, frontier areas

may best exemplify the unique characteristics of rurality. Data in Table 3.1 indicate that the counties selected exceed the criteria for frontier areas.

Field Placement

Although I was tangentially familiar with the 12-county Montana region from previous studies with rural residents of Montana, I did not have first-hand knowledge of the lifeways of the area's residents. As such, I was an 'outsider'. Outsiders are characterized by a differentness to and unfamiliarity with the social norms of the local community, as well as an unconnectedness with the community and its concerns (Lee, 1998a). In addition, rural participants may be reluctant to consent to interviews conducted by researchers that they clearly perceive as outsiders (Lee, 1998a).

Unfortunately, having a familiarity with the lifeways of the community is essential in order to better understand the meanings and interpretations of rural dwellers. Becoming an insider to the community may require a great deal of time, and may never occur unless one is born and raised in the community (Lee, 1998a). As such, field placement may not completely eliminate the negative consequences of having an outsider status. However, within the time constraints of my study, a field placement afforded me the opportunity to become enmeshed in a rural community. Field placement allowed for the direct and extended observations of the everyday activities of the rural frontier community, as well as allow for the improved ability to make contacts with human service and health providers in the community.

As such, I resided in Fort Benton, Montana for approximately four months. Fort Benton has a population of 1594 (US Census Bureau, 2004), and is located between

Great Falls and Havre, Montana. Although Fort Benton is not in the geographical center of the 12-county Montana region, Fort Benton is within a five-hour drive to all portions of the region. A critical access hospital, a long-term care facility, an adult day care center, and a home health agency are located in Fort Benton.

Sample

Size and Inclusion/ Exclusion Criteria

The key data source for my study came from interviews with participants. Ideally, in order to avoid the limitation of blending men of various relationships to care recipients in one sample as mentioned earlier, husband caregivers were specifically sought for participation. However, due to the feasibility concerns, some son caregivers may also be included in the sample. Initially, I anticipated enrolling 20 participants in the study, each receiving a minimum of two interviews. Thus, data was expected to come from approximately 40 or more interviews. The exact number of participants was not determinable at the onset of a grounded theory study, since the method employs theoretical sampling and efforts to reach content saturation. (These strategies will be discussed later). However, the proposed sample size was consistent with the guidelines provided by Morse (Morse, 2000).

The study region has a total adult male population of approximately 66,384 (US Census Bureau, 2004, 2006). Since the States of Montana and Oregon do not record the number of caregivers, an estimate of the number of husband caregivers in the study location must be estimated from national caregiver prevalence data. Current estimates of the prevalence of husband caregivers were not located. However, using survey data from

1987-1988, Marks (1996) estimates that 2.7% of all US males are husband caregivers. It is possible then, that there may be 1792 potential study participants in the region.

Inclusion criteria for my study were:

1. Fluency in English

2. Over 21 years of age

3. Husband (legal or common-law as defined by the State of Montana) or other male relative of the care recipient

4. Provide, or provided, daily ADL and/or IADL assistance to the care recipient per self-report

5. Live in a community of 15,000 persons or less within a county of population density of less than six persons per square mile

Exclusion criteria for the proposed study are as follows:

1. Inability or unwillingness to provide consent

2. Reside on an Indian reservation

The exclusion criterion of residing on an Indian reservation is noteworthy. The 12-county Montana region includes all or part of three Indian reservations, each with their own tribal culture and tribal government. In order to include reservation residents, an inter-tribal agreement must be obtained for the study, and a participatory action study design would be required (personal communication, Dr. Patricia Holkup). Such requirements were not be feasible or compatible with my study. Thus, reservation residents were excluded.

Although the inclusion criteria and the demographic realities of the region would likely promote a relatively homogenous sample in terms of race, social norms, and socioeconomic history, variability in the sample was expected in terms of caregiver experience, tenure, intensity of caregiving, and characteristics of the care recipient. For example, it is possible that one care recipient would be able to physically complete ADL's, but require constant cuing and supervision due to cognitive impairments; whereas another care recipient would be cognitively intact but physically unable to complete ADL's due to weakened or terminal condition. Variation in the sample in terms of care recipient diagnosis and disability and in the length of care provision from the caregiver would provide a feasible approach to diversity allowing for greater depth of caregiver experiences and trajectories in this population.

Recruitment of Participants

Access to participants occurred in a variety of ways. Advertisements were placed in 18 different rural newspapers serving the region. Each advertisement ran for a minimum for two issues in each newspaper. In addition, I made personal visits to 11 different home health agencies serving the region. During these visits, I reviewed the study with intake and nursing personnel and left recruitment flyers for distribution to potential participants served by the agencies. Recruitment flyers were also posted in two local post offices and five local senior centers. In addition, nursing faculty at Montana State University-Bozeman College of Nursing, Great Falls Campus and Oregon Health & Science University, La Grande campus were informed of the study and asked to inform potential participants of the study. Participants were also asked to inform any other

potential participants about the study. Examples of advertisement text and flyers are located in Appendix B.

Data Collection

According to Charmaz (2000, 2006), grounded theorists have been rather silent on providing prescriptive guidelines on data collection procedures. A possible exception is the emphasis on theoretical sampling as discussed below. Grounded theory has much of its emphasis on data analysis and how theory is generated from the analysis of the data, although Glaser (Glaser, 1998) does discuss the non-necessity of tape recording interviews. (Glaser prefers shorthand note taking during interviews instead.) Consequently, grounded theorists seek data that will inform the researcher on the phenomenon of interest. Multiple strategies may be used to collect data. It is in the data analysis phase that distinguishes grounded theory from other qualitative methods.

In my study, potential participants were contacted via telephone and informed of the details of the study's purpose, their responsibilities as participants, and the benefits and possible risks of participating. If participants were agreeable, a date, time, and place for an interview was scheduled according to the preferences of the participant. Initial interviews with Montana participants were conducted face-to-face; while subsequent and Oregon interviews were conducted via telephone. Consent forms were reviewed with the participant and signed and returned to me prior to starting any interviews. Permission was also sought from the participants to tape-record interviews. As a token of appreciation, I mailed a $35 (thirty-five) gift card from a local retail store or gas station to participants at the conclusion of their interviews.

Quality and depth of the responses will depend, in part, on the establishment of rapport with participants (Fontana & Frey, 2000). In order to facilitate the establishment of rapport, efforts to reduce power hierarchies is important (Fontana & Frey, 2000). Therefore, I made efforts to minimize my role as an academic. In introducing the study, I discussed the value I place in the caregiving work provided by the participants. I informed participants that, as a nurse, I understand the subtleties and challenges inherent in caregiving. I presented myself as a learner, eager to understand caring behaviors as perceived by and implemented by this group of men. As a man, I expected to be able to facilitate the provision of gendered perspectives offered by the men (Fontana & Frey, 2000). When necessary, topics unrelated to caregiving (such as sports or the weather) was engaged in order to initiate conversation or segue into other conversational topics. In order to show gratitude and respect, written and verbal appreciation was given to all participants for their time and for sharing their personal information.

Initial interviews were semi-structured and sought demographic information, including questions on participant and care recipient health and health resources. In addition, grand tour questions will be asked. These questions are broad, opening questions such as "Describe your typical day as you look after your wife." Grand tour questions open up a topic of conversation, from which the conversation can take a number of directions. The use of broad questions at the onset of the study is essential in grounded theory (Charmaz, 1994a). A list of some of the grand tour questions used is located in Appendix A. Responses to opening grand tour questions directed me toward subsequent follow up questions. In order to decide on the nature and content of subsequent questions, I listened attentively to discern the meanings, both overt and

covert, imbedded in the responses (Charmaz, 2000). Over the course of the interview, questions became more focused. In addition to demographic and grand tour questions, I asked each participant to describe their caregiver trajectory. Such an approach provided a feasible option for examining caregiver processes longitudinally. Each interview lasted between 45-90 minutes.

As categories became apparent with the data analysis that occurred during data collection (discussed more fully later), I became aware of further questions and gaps in the developing qualitatively derived theory. These gaps guided me topical areas of the phenomenon in a process called 'theoretical sampling' (Glaser, 1978). Theoretical sampling is essential to grounded theory. Glaser notes

> Deductive work in grounded theory is used to derive from induced codes conceptual guides as to where to go next for which comparative group or subgroup, in order to sample for more data to generate the theory…..deduction is in the service of further induction and the source of derivations are the codes generated from comparing data, not deductions from pre-existing theories in the extant literature. (p.38)

Theoretical sampling allows the researcher to examine emerging theory conceptually in contrast to strategies employed in quantitative approaches designed to verify a priori hypotheses. In many studies, theoretical sampling also occurs with selection of subsequent study participants. However, due to feasibility concerns with passive recruitment restrictions, and due to the fact that all participants experienced the

phenomena (caregiving, rurality, masculinity) deeply, theoretical sampling in this study

recruitment was not done.

Consistent with the recommendations of Charmaz (1994a; 1994b; 2000),

theoretical sampling of topics occurred after interviews were completed with several

participants in order to avoid missing vital concepts prematurely. Charmaz recommends

that the researcher should wait until conceptual categories have been identified and

developed from the data so as to allow for the development of theoretical questions by

the researcher before sampling becomes too focused.

Observations of the immediate context and environment of the participants during

the times of interviews were recorded in field notes and as soon as was feasible following

interviews. These data were included with interview transcripts for analysis, and were

examined similarly. In addition, reflections about the interviews and environment were

recorded in environmental notes which were used to assist in interpretation. Theoretical

notes were taken to document the development of the study findings. Data analysis

methods used and the use of environmental and theoretical notes are described below.

Data Analysis

Constructivist Approach to Data Analysis

The constructivist grounded theory approach to data analysis employs the general

procedures of coding, constant comparison, writing theoretical memos (memos), and

theoretical sampling as initially presented by Glaser and Strauss (1967) and later

described by Glaser (1978; 1998; 2001) and Strauss and Corbin (1998). Similar to other

genres, constructivist grounded theory analysis begins immediately with the first

interview, and continues concurrently with data collection. Charmaz (2000; 2006) states that constructivist grounded theory could employ data analysis procedures from any of the earlier grounded theorists. However, it is clear from Charmaz that data analysis using constructivist grounded theory does differ in some aspects from the other approaches. For example, Charmaz (2000; 2006) does not advocate the use of a coding framework as discussed by Strauss and Corbin (1998). Charmaz recommends a different perspective on coding than that of Glaser (1978; 1998; 2001), in that the researcher's voice and perspective is recognizable and is utilized in the analysis. In addition, Charmaz recommends a step she calls *rendering through writing*. Each of these steps is detailed below.

Coding Plan and Derivation of Findings

According to Charmaz (1994a; 2000; 2006), coding serves as the vital foundation for inductively generating categories and concepts from data. Coding begins with a line-by-line process called open or initial coding. With open coding, each line of the transcript is analyzed from multiple perspectives in order to generate as many codes that might fit the events occurring in that transcript piece (Glaser, 1978). It is vital that pre-conceived codes or catchy phrases not be used in open coding (Charmaz, 1994a, 2000; Glaser, 1978). Codes should reflect the actual events in the data, as opposed to forcing data into a priori codes. Open coding is a painstaking process, but it is essential in discovering emerging concepts and in directing the researcher in theoretical sampling; however, open coding becomes more facile as the study progresses as categories become saturated (Glaser, 1978).

During open coding, the researcher asks questions of the data (Charmaz, 1994a, 1994b, 2000; Glaser, 1978, 1998; Glaser & Strauss, 1967; Strauss & Corbin, 1998). These questions primarily focus on the social processes occurring in the data. The researcher must have a theoretical sensitivity when coding and planning future data collection. This sensitivity comes from the researcher's prior knowledge of the phenomenon and the discipline (Glaser, 1978). However, this sensitivity is used as a guidepost, rather than a defining theoretical framework, during data analysis and theoretical sampling (Charmaz, 1994a; 1994b; 2000; 2006; Glaser, 1978).

Despite the instructions of Glaser and of Strauss and Corbin to ask questions of the data and employ theoretical sensitivity, Charmaz (1994a; 1994b; 2000; 2006) places these grounded theorists squarely within an objectivist paradigm. Charmaz states that these theorists propose that categories and concepts will emerge from the data without over-interpretation from the researcher. In other words, an astute researcher will discover findings in the data through systematic analysis procedures. In contrast, Charmaz states that the researcher must have a relationship with the participants and the data. The researcher develops codes from the data in a creative process, in which the researcher's theoretical sensitivity and perspective unavoidably shape the findings as provided by the participants. Charmaz notes that Glaser, Strauss, and Corbin focus their analyses on overt data, but fail to probe with their questions hidden assumptions and meanings in the data. As such, Charmaz states that other (objectivist) grounded theorists provide descriptions and conceptualizations too far removed from the experiences of the participants. Charmaz (2000) notes

Different questions can flow from objectivist and constructivist starting points. These questions can be concrete...or abstract. Concrete questions are revealed in their [Strauss and Corbin] discussion of two categories—pain experience and pain relief....Here the categories take on an objective, external character—objective because these questions assume answers that reflect 'facts'; objective because the answers assume that the researcher discovers what being in pain 'really is all about'; objective because the topic of pain now takes on an external character that can be identified, addressed, and managed. In contrast, I start by viewing the topic of pain subjectively as a feeling, an experience that may take a variety of forms. Then I ask these questions: What makes pain, pain? ....What defining properties or characteristics do ill people attribute to it? When do they do so? (p. 526)

Charmaz contends that these constructivist questions lead to a different set of findings, findings constructed from the participants and from the researcher. As such, Charmaz recommends that the researcher probe for meaning of the processes in the data, not just a description of the processes themselves. Such probes become evident in memoing, a process described shortly.

In addition to searching for meaning imbedded in the data, Charmaz (2000; 2006) recommends the use of action codes during the coding process. Action codes are simple verb-noun terms that provide insight to what is happening in the data. An example might be a code termed "trading spaces" or "enduring pain". Although not all codes will be

action codes, these action codes will assist the researcher in identifying processes and relationships.

As codes recur during open coding, focused coding begins to take shape (Charmaz, 1994a, 1994b; Glaser, 2001). In this process, a line-by-line approach is no longer used, and data are analyzed more conceptually in terms of these recurring codes. In focused coding, the researcher takes recurring codes and reviews large amounts of data for presence or absence. Focused coding forces the researcher to collapse related codes into larger and more abstract categories and eventually to core categories that capture the processes relevant to the phenomenon of interest. At this point, subsequently collected data are no longer subject to open coding, but rather, are examined in terms of these developed categories (Glaser, 2001). Categories may retain in vivo titles, or may adopt an appropriate analytical title (Charmaz, 1994b). Attributes and properties of these categories are then further refined during subsequent analyses. The data may reveal that there are gaps in identifying attributes and properties of categories, thus directing the researcher to further data collection using theoretical sampling. The data may reveal that categories need to be broken down into sub-categories in order to better explicate the relationships within the social processes under study (Charmaz, 1994b). If additional data obtained provide no further clarification of the developed categories and their properties, saturation of the category has been provided.

Once categories have been identified, the extant literature is examined for further clarification, expansion, and delineation of the categories (Charmaz, 1994a, 1994b, 2006). Use of the extant literature also provides the researcher additional insight on the emerging findings during data analysis. Charmaz also notes that the extant literature

assists the researcher in outlining and comparing meanings for categories, but does not provide frameworks into which data are forced.

In addition to the examination of the properties of categories, relationships among categories are examined and defined. Both Glaser (1978) and Strauss and Corbin (1998) provide frameworks for relationship analysis (Glaser uses theoretical families; Strauss and Corbin advocate a process of axial coding and a framework of category relationships). Charmaz (1994b; 2000; 2006) does not recommend one approach over the other, although Strauss and Corbin's coding framework is not consistent with my study's constructivist assumptions, and thus, was not be used. In fact, Charmaz (2006) states that she has never used coding frameworks or families.

Near the conclusion of the data analysis, findings of my study were compared and contrasted with relevant theories in the extant literature. The purpose of this final step was to determine if the findings support or extend current theories, or whether the findings propose a unique conceptualization of caregiving by rural husbands. A graphic depiction of the coding plan that was used in my study, consistent with Charmaz's recommendations, is included at the conclusion of this chapter section.

Constant Comparison Method

Constant comparison method was initially introduced by Glaser and Strauss (1967), and has become a mainstay of all of the genres of grounded theory (Charmaz, 2000). With this method, the researcher analyzes data as data are coded, instead of analyzing data after coding has been completed. When analysis and coding occur simultaneously, the researcher is better able to capture emerging themes, explore

properties of concepts, and redirect theoretical sampling (Glaser, 1978; Glaser & Strauss, 1967). The researcher is also better able to theorize relationships and how well data fit emerging categories (Glaser, 1998).

As data are being simultaneously coded and analyzed, the researcher explores theoretical hunches by constantly comparing codes and categories between lines of text, between interviews, among participants, and among the various sources of data. The researcher searches for similarities and differences in the comparisons for delineating characteristics and properties of categories. In addition, Charmaz (1994a; 2006) notes that comparisons are made among the contexts, beliefs, values, and different accounts of similar events and situations offered by the participants. Constant comparison method occurred throughout the analysis phase of my study, starting with the first interview and eventually finishing with a final comparison of study findings with the extant theories of the literature.

Memoing

Memoing (theoretical memoing) is a vital process in grounded theory (Charmaz, 1994a, 1994b, 2000; Glaser, 1978, 1998). In fact, Glaser (1978) identifies memoing as the core stage of grounded theory. Glaser defines memoing as "…the theorizing write-up of ideas about codes and their relationships as they strike the analyst while coding" (p. 83). Charmaz (1994a; 2006) notes that the purpose of memoing is to allow for the researcher to have a dialogue with himself regarding the data and the analysis. Memos detail the researcher's actions of viewing the data from multiple perspectives; of trialing potential codes, concepts, and categories during data analysis; and will aid the researcher

in "...linking analytical interpretation with empirical reality" (Charmaz, 2000) (p. 517). Charmaz (1994a) notes that theoretical memos assist the researcher in asking questions of the data and in implementing focused data analysis steps. Since memos should be written as quickly as they come about in the researcher's thoughts, memoing slows down the coding and analysis process, thus allowing for more reflective conceptualization. Memos provide a written account of the analysis, and they explain how theoretical sampling and category emergence occurs within a study. Both Glaser and Charmaz note that memos provide a skeleton of the conceptualization process useful when the study's findings are presented in written form. Although not stated by Glaser or Charmaz, memos also provide an audit trail useful in enhancing the rigor of the study.

It is imperative to note the distinction between field notes and memos. Field notes record observations and perceptions of the context in which the phenomenon is occurring and/or the context in which the data collection is occurring. Field notes are considered a data source, and were analyzed as such in my study. Memos are not data, but rather a written account of the researcher's thoughts and conceptualizations. Data may be repeated in a memo, so that the source of the memoing thought is clear. And although memos should be reread, modified, and reflected upon by the researcher, they are not analyzed in and of themselves as data (Glaser, 1978).

Memoing begins as the first data are collected (Glaser, 1978). Memos are a place to examine the assumptions and meanings participants have and how those assumptions and meanings mesh with those of the researcher (Charmaz, 2000; 2006). This latter aspect of memos provides the constructivist nature to the interpretations, data collection, and analysis decisions made by the researcher. As such, my study included my

perspectives and assumptions in memos as they pertain to perspectives and assumptions embedded in the original data. In addition, thoughts about reflexivity and relationality were recorded within memos. Reflexivity refers to the influence the interviewer-participant interaction has on data collection and analysis; whereas relationality refers to the power and trust dynamics between interviewer and participant (Hall & Callery, 2001). Attention to reflexivity and relationality also depict the constructivist approach to grounded theory used in the proposed study.

Plan for Rendering Through Writing

According to Charmaz (2000; 2006), objectivist approaches to grounded theory advocate for clear delineation of findings devoid of context. These presentations of findings perhaps address the pragmatic aspects of the purposes of grounded theory, that is, to provide conceptualized accounts of social processes from which hypotheses and theory-testing endeavors could be derived. These types of conceptualized accounts strive for objectivity. However, Charmaz (2000) suggests that the constructivist approach provides conceptualized accounts of the phenomenon with which the reader is still able to encounter the findings experientially. Through linguistic style, Charmaz states that constructivist grounded theory

...removes the writing from typically scientific format without transforming the final product into fiction, drama, or poetry... [in which] key definitions and distinctions [are framed] into words that reproduce the tempo and mood of the experience. (p. 527)

Charmaz advocates for a mixture of concrete detail with analytical (conceptual) categories in order to connect the familiar with the unfamiliar for the reader. In order to remain consistent with the philosophical assumptions provided earlier, particularly those that pertain to the interactionalist nature of gender and rurality, the proposed study will present findings in a fashion consistent with the recommendations by Charmaz.

Other Sources to Inform the Researcher and Assist in Construction of Findings

Three other information sources assisted me in the interpretive process and my construction of the eventual study findings. First, I collected and analyzed ethnographic-styled notes throughout the data collection phase of the study, which I named *environmental notes*. These environmental notes were personal notes detailing my observations of the general local environment. These observations included notations on public behaviors and customs of local residents, descriptions of local events and history, discussion of local institutions and services, and descriptions of the geography of the study locale and context. These notes were of great assistance in providing me a better understanding of the contextual influences of locally constructed meanings of gender and rurality.

Second, I maintained a photographic journal. Photographs did not include any images that could potentially identify study participants. However, photographs served as a visual companion to my environmental notes. Photographs provided an aesthetic component to the notes which assisted me with reflection during data analysis. Photographs assisted me in writing the findings in a way that grounded them in the

gendered culture from which they arose, benefit noted in the literature (Denzin, 2000).

In addition, since the field placement was time-limited, photographs enhanced the sensual

aspects of the field site for data analysis after I had left the field site. Selected

photographs taken during the study are located in Appendix D.

Third, the extant literature was an additional source of information. However, use

of this information source occurred after much of the analysis of the study data has been

completed. Charmaz (1994a) states that examination of the literature at this point allows

the researcher to explore the data in new ways. This use of the extant literature is

requisite in developing theoretical relationships, models, and hypotheses robust enough to

expand current theory or propose new theory (Glaser, 1978, 1998, 2001; Glaser &

Strauss, 1967).

Summary of Data Analysis

Clearly, many of the analysis procedures advocated by Charmaz in her constructivist

approach to grounded theory are similar with those used by Glaser, as well as many of

those used by Strauss and Corbin. These procedures include using multiple sources of

data, open and selective or focused coding, constant comparison, and memoing.

Departures from the objectivist approach to data analysis are most evident in Charmaz's

recommendations for the use of action codes, in incorporating reflexivity and relationality

in memos, in including the search for constructivist derivations of meanings and

assumptions, and in rendering the findings through an experiential writing style. A

graphic depiction of the data analysis procedures that were used in my study are detailed

in Figure 3.1 below.

Figure 3.1 Graphic of Data Analysis Plan

Context of Theoretical Sensitivity:
Knowledge, reflection, reflexivity, analytical stance, standpoint of the researcher

Memos

Data

Field Notes

Data

Field Notes

Constant Comparison

Data

Field Notes

Theoretical Sampling of Interview Questions

Data

Field Notes

Coding

Interpretive Tools of environmental notes, photography, and extant literature

Focused Coding

Rendered Findings

Evaluation of Rigor

Much has been written in recent years regarding how to evaluate rigor in qualitative studies. According to Morse, Barrett, Mayan, Olson, and Spiers (2002), Lincoln and Guba laid much of the foundation for subsequent discussion of qualitative rigor by recommending use of the term *trustworthiness* in place of rigor. The reason for this was the assumed belief that rigor was limited to the evaluation of reliability and validity of quantitative research, and thus, incorporated evaluation methods non-applicable to qualitative research (Davies & Dodd, 2002). As such, a number of evaluative criteria were established for evaluating trustworthiness, which were further delineated by Lincoln and Guba (1985) and by others such as Leininger (1994). However, the creation of parallel sets of evaluation criteria has led to confusion. More recently, calls have been made to reclaim the term rigor as a generic term applicable to all types of research (Davies & Dodd, 2002; Morse et al., 2002), particularly when the term is used to differentiate between research of lesser or higher quality (Davies & Dodd, 2002). Yet those who call for the reclamation of rigor note that different approaches are needed when evaluating qualitative research.

Lincoln and Guba (2000) now suggest that the strides for validity (rigor) in qualitative research cannot be standardized into a simple set of procedures or evaluative perspectives due to the differing assumptions of the various paradigms. Lincoln and Guba differentiate between old and new paradigms, in that the post-modern turn has had great influence on paradigms such as constructivism and participatory. This influence has

had a significant effect on how researchers formulate validity. Lincoln and Guba state

that there are now two discussions of validity present. They note

> The first, borrowed from positivism, argues for a kind of rigor in the application
>
> of method, whereas the second argues for both a community consent and a form
>
> of rigor—defensible reasoning, plausible alongside some other reality that is
>
> know to author and reader—in ascribing salience to one interpretation over
>
> another and for framing and bounding an interpretive study itself. Prior to our
>
> understanding that there were two forms of rigor, we assembled a set of
>
> methodological criteria… [that] are still useful for a variety of reasons.…It is the
>
> second kind of rigor, however, that has received the most attention in recent
>
> writings: Are we interpretatively rigorous? Can our co created constructions be
>
> trusted to provide some purchase on some important human phenomenon? (p.
>
> 178-179)

This presentation of two types of rigor is compelling. If accepted, the researcher must

attend to at least two perspectives of validity in order to enhance rigor (much like, though

not analogous to, quantitative researchers attending to instrument validity and the internal

and external validity of studies). These two types of rigor address both a) methodological

soundness of the study and the philosophical/ paradigmatic coherence of the study and b)

the rendering of findings through reasonable interpretation.

In terms of methodological rigor, Lincoln and Guba (2000) continue to support

their previously described evaluations of trustworthiness. However, in terms of

interpretive rigor, Lincoln and Guba declare that there is no answer yet available for questions of evaluation. They note that postmodernists may indeed be anti-criteria, but note also that researchers adopting newer paradigms are considering a number of perspectives on ensuring rigor of interpretation. Lincoln and Guba note that poststructural forms of validity integrate ethics and epistemology. This view is supported by Davies and Dodd (2002), who recommend that the evaluation of rigor in qualitative studies derives first from the consideration of how well ethics has been integrated in a particular study. Davis and Dodd note that ethical conduct requires the researcher to involve "...trustfulness, openness, honesty, respectfulness, carefulness, and constant attentiveness" (p. 281). From this nexus, Lincoln and Guba identify a number of criteria appropriate for the constructivist paradigm.

Three criteria stemming from the ethics-epistemological nexus are voice, reflexivity, and textual representation (Lincoln & Guba, 2000). The interpretation of voice and how it is best presented varies among researchers. However, consistent with a constructivist paradigm with its relativist ontology and transactional epistemology, multivocality must be evident in research. This multivocality (voices of the researcher, the informants, and others) supports the assumption that knowledge is co-created from meanings and values derived from interactions, and should be evident in the study's methods and rendering of findings.

Reflexivity has been previously mentioned in this chapter and was defined as the influence the researcher-participant interaction has on the research process (Hall & Callery, 2001). However, Lincoln and Guba (2000) discuss reflexivity in greater depth.

Lincoln and Guba describe reflexivity as a process in which the researcher critically evaluates his or her role as the human instrument of research. They note

> It is a conscious experiencing of the self as both inquirer and respondent, as teacher and learner, as the one coming to know the self within the process of research itself....Reflexivity...demands that we interrogate each of our [multiple] selves regarding the ways in which research efforts are shaped and staged around binaries, contradictions, and paradoxes that form our own lives. (p. 183)

In simplistic terms, reflexivity encourages the researcher to grow with and from the research. This growth process forms a context within which meanings and insights are constructed with participants and data. Reflexivity, novel to the original postpositivist assumptions of grounded theory, supports the foundational assumptions of symbolic interactionism, and therefore, if evident, will enhance the rigor of grounded theory studies (Hall & Callery, 2001).

The third criterion recommended by Lincoln and Guba (2000), postmodern textual representations, has been previously discussed in this chapter in terms of Charmaz's approach to rendering of the findings through writing. Both Charmaz (2000) and Lincoln and Guba note that textual representations should disrupt the boundary between the scientific and the literary. This disruption, criticized by some for resulting in "messy texts", is necessary to "...create a social science about human life rather than *on* subjects" (Y. S. Lincoln & Guba, 2000) (p. 184, italics theirs). Ways in which these boundaries can be disrupted are continuously expanding. However, Charmaz

recommends that the literary rendering of findings should produce a story rich in context without creating drama, fiction, or poetry.

Despite the new and multiple perspectives on evaluating the rigor of qualitative work, Morse et al. (2002) note that evaluation criteria in and of themselves do not *ensure* rigor, since evaluation occurs on a post-hoc basis. Evaluation after a study is completed does not afford the researcher the opportunity to revise procedures in mid-stream in order to improve rigor before findings have been discerned. Morse et al. recommend incorporating rigor-enhancing strategies in the study itself. These strategies include investigator responsiveness, methodological coherence, theoretical sampling and sampling adequacy, incorporating an active analytical stance, and saturation. In relation to the previous line of discussion in this chapter section, one can view most of these strategies as those designed to enhance methodological validity or rigor. However, it may be naïve to assume that qualitative researchers interested in rigor do not incorporate procedures in their studies that would demonstrate rigor associated with qualitative evaluation criteria, or that post-hoc evaluators do not look for methodological evidence that rigor-enhancing strategies were employed (as Morse et al. seem to imply).

For my study, I adopted the perspectives of Lincoln and Guba (2000) in that two types of rigor, methodological and interpretive, must be addressed. Methodological rigor was addressed by incorporating the strategies recommended by Morse et al. (2002). Interpretive rigor was addressed by perspectives offered by Lincoln and Guba (2000), Charmaz (2000) and Hall and Callery (2001). Some of these strategies have already been discussed in previous sections of this chapter. Therefore, a brief summary is all that is necessary here.

In terms of methodological rigor, investigator responsiveness (defined as the researcher's sensitivity, insight, and flexibility by Morse et al. [2002]) is akin to Glaser's (1978) discussion of theoretical sensitivity, but also incorporates aspects of reflexivity and relationality. Evidence of my responsiveness was evident in research memos. Memos included questions I posed of the data and of me. Memos documented different perspectives I had in thinking about the data, and discussed new insights, changes in direction, rationales for pursuing new directions, and procedures for sampling theoretically. Memos included my perspective on power structures perceived and observed, and described my perception of the researcher-participant relationship. Thus, memos served as an audit trail, making my thinking, decision-making, and growth transparent.

Morse et al. (2002) define methodological coherence as the congruence between the research questions and the study methods used. I would add that methodological coherence should include congruence between paradigmatic assumptions and the study method employed. Although Glaser (2001; 2002) adamantly rejects the notion that constructivist assumptions are compatible with grounded theory, others, including myself, respectfully disagree (Charmaz, 1994b, 2000; Hall & Callery, 2001; Morse, 2001). Evidence of methodological coherence has been demonstrated in the earlier discussion of the rationale for the method selected for the proposed study. Incorporation of an analytic stance, in which data are analyzed from multiple perspectives and in which data are collected and analyzed concurrently, is inherent with grounded theory, both from the perspectives of Glaser and of Charmaz (Charmaz, 1994b, 2000, 2006; Glaser, 1978,

1998). Evidence of the analytical stance is demonstrated in the selection of the study method, and was also present in the study's memos and coding processes.

Interpretive rigor, evidence of voice, reflexivity, and the postmodern textual representation are more difficult to demonstrate at the onset of any study. Constructivist grounded theory, as detailed in earlier sections of this chapter, does take into consideration these evaluation criteria of interpretive rigor. Some evidence, particularly for reflexivity, was present in my study's memos as noted previously. However, it is also in the rendering of the findings through writing that evidence for voice and postmodern textual representation was also demonstrated.

Evidence of multivocality (voice) must be present in order to demonstrate the constructed nature of knowledge, though how multivocality is demonstrated is variable among qualitative researchers (Lincoln & Guba, 2000). The voice of the participant was evident by transcribing interviews verbatim, and coding directly from these transcripts. As recommended by Glaser (1978; 1998) and by Charmaz (2000), language of the participants was used to name codes during the open coding process. An example of this participant language was noted earlier from the preliminary study, in which the phrase "like a bull" was used as the name of a code. In addition, action codes, those that signify a process or participant activity (Charmaz, 2000), were also be used. Participant voice was also provided in quotations and exemplars provided in the written findings. Voices of others (others being local individuals not part of the study) were present in the ethnographic notes taken during the field placement. These ethnographic notes reflected the language, values, and beliefs of the cultural members of the study location. These types of notes generally allow a researcher to ground findings in the context of the study

and in the lives of those living among the study participants (Denzin, 2000). Articulation of these voices came through with the use of local colloquialisms, explanations of events and environmental objects, and discussion of the meanings of phenomena as recounted to the researcher. Articulation of these voices arose as I probed meanings in memos. Eventually, these voices will all the reader to experience the events through literary vehicles in the final written report (Charmaz, 2000).

Voices of others also include the voices of previous researchers. Articulation of these voices occurred as I compared and contrasted perspectives and conclusions from the extant literature with the findings from the study. Evidence of the recognition from all these other voices also was present in memos, as I engaged these voices in written discourse. My own voice is audible throughout the study, in ethnographic and field notes, memos, and in the process of focused coding. My observations, perspectives, reflections, and conversations were also evident. However, it is with the rendering of the findings through the written report that my voice is most audible (Charmaz, 2000; Denzin, 2000; Richardson, 2000). Charmaz notes that a researcher demonstrates voice as interpretive choices are made on how to present the written findings. Charmaz recommends using the grounded theory categories constructed in the study as signposts for the narrative report. Theoretical relationships of the processes occurring among categories become the narrative thread. How the thread connects a study's findings with the vivid accounts of the participants' stories reveals a researcher's voice.

Richardson (2000) expands further on writing as a demonstration of researcher voice, and suggests that writing is a vehicle for the discovery of knowledge. As such, writing should occur throughout the study, with the researcher experimenting with new

perspectives, new interpretations, and new ways of exploring the data. This writing-as-you-go activity is consistent with the discussion of memos provided by Charmaz (2000; 2006). A researcher's voice is demonstrated by how the researcher chooses to word the report and tell the story of the phenomenon as experienced by the participants (Charmaz, 2000, 2006; Denzin, 2000; Richardson, 2000). Richardson explains that the use of metaphor is the backbone of social science writing, as well as displays well the voice of the researcher. Metaphor, with its tools of comparison and analogy, becomes the frame upon which constructed meanings and findings are built. Together with the voices of others, the interpretive voice of the researcher constructs knowledge from the study, and then selects metaphor to convey that knowledge to the reader. Inherent in the metaphors selected are the "...philosophical and value commitments [of the author] so entrenched and familiar that they can do their partisan work in the guise of neutrality, passing as literal" (Richardson, 2000, p. 927). In my study, I have presented with this document a written report in which metaphors are clearly present in order to present findings clearly, yet grounded to the subjectivities of the participants and the researcher.

Reflexivity, the recognition of the effect of the researcher-participant relationship on data collection and analysis, has been discussed previously. Evidence of reflexivity was present in the study's memos, as I documented the questions I posed of the data as I searched for meanings. Such questions included the following:

1. "What does this phrase mean?"

2. "Why does he think/ believe this way?"

3. "What might be influencing his thinking/ behavior?"

4. "Why do I, as the researcher, find this phrase/ behavior/ observation interesting/ unusual/ compelling/ obvious, etc.?"

5. "What attitudes/ beliefs/ past experiences might be influencing how I interpret this information?"

6. "What have I learned, and what don't I understand?"

Evidence of postmodern textual representation is best demonstrated in a written report. Charmaz (2000) does not detail steps a researcher should take to address this criterion, except that the findings should be rendered in such a way that the reader is taken into the story without resorting to drama or poetry. However, Denzin (2000) and Richardson (2000) discuss textual representation in greater depth. Denzin notes that the movement to the literary by qualitative researchers is paralleled by, and should follow the lead of the movement in journalism toward intimate, civic journalism. In this type of journalism, stories are told rather than reported. These journalists, recognizing that social life and the reports about it are social constructions

.....use real-life dialogue, intimate first-and third-person voice, multiple points of view, interior monologues, scene-by-scene narration, and a plain, spare style....The writer may be invisible in the text or present as narrator and participant. (Denzin, 2000, pp. 899-900)

Denzin notes that such a writing approach never separates the theory the writer has on a phenomenon from the surface of the text.

Richardson (2000) notes that in contrast to quantitative research, with which the reader can interpret study findings from tables and graphs, qualitative research requires the production of rich, context-bound text from which the reader can interpret findings and discern the constructions provided by the researcher author. The use of metaphor for articulating the voice of the researcher has already been discussed, but the use of metaphor is one way Richardson suggests addressing the need for postmodern textual representation. Another way to address this need is with experimentation of writing format. Richardson (2000) notes that, historically, scientific writing has been separated from literature, with scientific writing perceived as being focused, objective, linear, and problem-centered. This approach to writing is consistent with a modernist perspective, and has held hegemonic symbolic power over social scientists (Richardson, 2000). Richardson states, "How we are expected to write affects what we can write about" (p. 927). As such, qualitative researchers must be free to explore and experiment with writing formats in order to address the postmodern context. Such experimentation includes freeing oneself from the convention of the third-person style of writing. Richardson advocates for a writing style that demonstrates poststructuralist principles, in which language, subjectivity, social organizations, and power relationships are linked and examined. Such an approach "...directs us to understand ourselves reflexively as persons writing from particular positions at specific times" (p. 929), and does not force the researcher to present findings in an objective and format-driven style in order to appear legitimate.

In summary, the study must demonstrate two types of rigor: methodological rigor and interpretative rigor. Methodological rigor was proposed prior to the initiation of my

study, and was demonstrated by the selection of the method and procedures planned for the study. An audit trail of memos and field notes documented the maintenance of methodological rigor. Committee members and fellow doctoral students (in OHSU dissertation seminars) were available for peer audits of methodological rigor. Interpretive rigor was evident in memos and notes. Memos and notes included discourses and experimentation of writing styles. The final written report (manuscript) will demonstrate attention to the criterion of postmodern textual representation. In a more simplistic view, much of the methodological rigor for the proposed study can be evaluated a priori (as suggested by Morse et al., 2002). However, much of the evaluation of interpretive rigor will occur on a post-hoc basis. Although Richardson (2000) uses the following criteria for ethnographic reports, readers of my study's report should ask the following questions:

1. Does the report provide a substantive contribution to the social phenomenon?

2. Does the report have aesthetic merit?

3. Does the report articulate reflexivity?

4. Does the report impact the reader emotionally and cognitively? Does it inspire the reader to ask questions, to write, and/or to action?

5. Does the report embody a fleshed out and credible account of the situated reality of the phenomenon?

Human Subjects Considerations and Research Ethics

Prior to the collection of data, ethical and procedural approval for the study was obtained from the appropriate human subjects committees at Oregon Health & Science University (OHSU), including the institutional review board (IRB). All requirements and

recommendations from these committees were followed. However, Davies and Dodd (2002) note that research ethics are more than receiving approval from oversight committees. Instead, ethics "…are integral to the way we think about rigor and are intertwined in our approach to research" (p. 281). As such, I made all possible efforts to foster trustfulness, respectfulness, constant attentiveness, and accountability with all individuals involved in my study, including myself. Such efforts required that I adopt procedures to protect participants from harm and to secure the data. Such procedures are detailed below.

Protection from Harm and Confidentiality

Once participants have contacted me expressing interest in the study, I reviewed the content of the consent form with the participant over the telephone. The content and the format of this consent form were already approved by the OHSU Institutional Review Board (see Appendix F). I informed the participant that interviews would be audio taped, unless otherwise declined by the participant. If the participant was still interested in participating in the study, an initial interview was scheduled, and if conducted face-to-face, a desired location was determined. I suggested private locations for face-to-face interviews so that the participant would feel free to speak frankly. However, where the interview occurred and whether or not the care recipient was also at the interview location was a decision made by the participant. No one, including anyone who had provided my contact information to the participant, was informed that the participant had expressed interest in the study. During the initial interview, I again reviewed the consent form to participate in the study with the participant, including consent to audiotape the

interview. All but one participant consented to have their interviews audio taped. The format and flow of questions varied from interview to interview. The researcher will not ask for any information that could potentially identify the participant to local outsiders.

Interview questions and topics could have resulted in discomfort or distress for the participant. As such, participants were informed at the onset of the initial interview that he could decline to respond to any question. In addition, I discussed my role during the interview before starting an interview. This role would not include the provision of professional counseling interventions should a participant express emotional distress during the interview. However, I informed participants that I would provide them contact information for local counseling services or other caregiver assistance services if necessary or requested. None required such information, though one participant was given website addresses pertaining to general caregiver information. Although care recipients were not participants in my study, my legal obligations as a nurse to report evidence of adult/ elder abuse was acknowledged and conveyed to all participants prior to the initiation of interviews.

I transcribed all interviews and field notes. Self-transcription enhanced confidentiality, since the possibility of finding a local transcriptionist who could not identify a participant from the audiotape was unknown prior to starting my study. I assigned initials to each participant interview and its affiliated field note. The assigned initials were linked to the participant's contact information via a code list. This code list facilitated the scheduling of follow-up interviews and in data analysis. The code list was available only to my committee and me. Telephone interviews were conducted in a private location, either in my personal office or residence. Written findings did not

include any identifying information that could be linked to any specific participant. Due to the extremely low population density of the study area, published reports resulting from my study will not include identification of the geographic area in which the study occurred. Instead, the study location will simply be referred to as "frontier areas of Montana and Oregon", which could potentially include large swaths of geography.

Data Management and Security

All data and contact information was kept under lock and key either at my residence or my office. During the study, data and contact information was available for viewing only by me and my dissertation committee. All raw data and notes will be destroyed five years after the completion of the study. During this time, data and identifying information will continue to be kept under lock and key. Members of the dissertation committee and of university human subjects committees were welcome to review study documents or visit the field site at any time.

CHAPTER 4: RESULTS

Description of the Sample

Eighteen interviews were conducted with 12 men living in frontier counties in north central Montana and eastern Oregon. In addition, one participant letter providing additional comment was received. The age of the men at the time of the interview ranged from 45 to 87 years, with a mean of 58.9 years. At the time of the interview, participants had been caregivers between one to 28 years, with eight of the 12 participants providing care for five years or less. Nine of the 12 participants were caring for their wives. Three participants were caring for, or had cared for, more than one family member at the same time. All participants reported providing the bulk of the physical and instrumental care. Although newspaper advertisements inviting men to participate in the study were printed in newspapers from communities located near Indian reservations, all men in the sample were non-Hispanic Caucasian. Additional demographic data are presented in Table 4.1.

Ten of the participants have been life-long residents of rural communities, with the other two participants residing in rural communities for the past seven and 15 years respectively. The population densities of the participants' counties of residence range from 0.9 to 2.3 persons per square mile (US Census Bureau, 2004, 2005a). Two participants currently live on farms or ranches, outside of any incorporated town. The remainder of the participants live in small towns with populations ranging from 150 to 12, 228. For half of the participants, the nearest hospital services were located at critical access hospitals; whereas the remainder of the participants was served by small community hospitals. Although all participants visit primary care providers locally,

TABLE 4.1 Selected Demographic Data of Study Sample

Participant	Relationship to Care recipient	Years of Caregiving	Occupation	Employment Status
RO	Son, father	5 yrs/21 yrs	Rancher	Employed
JG	Husband	6 yrs	Farmer	Employed
CS	Husband	1 yr	Logger	Retired
GB	Son, brother	2 yrs/4 yrs	Newspaper deliverer	Employed
GF	Son	2 yrs	Fence installer	Employed
DP	Husband/grandson	1 yr/2 yrs	Mill worker	Employed
JGil	Husband	19 yrs	Health aide	Employed
BW	Husband	1.5 yrs	Logger	Retired
JM	Husband	1 yr	Logger, soldier	Retired
MC	Husband	3 yrs	Mechanic	Semi-retired
KH	Husband	3 yrs	Electrician	Semi-retired
JK	Husband	28 yrs	Store owner	Employed

all care recipients of the participants required routine specialty services, such as neurology, cardiology, or orthopedic surgery, which were located from 58 to 228 miles one-way distant from their homes.

Participants reported that their care recipients were diagnosed with a number of ailments. Five care recipients experienced significant cognitive impairments, though only one participant reported that his family member had Alzheimer's disease. Most care recipients experienced more than one chronic illness. The type of illnesses reported by the caregivers is detailed in Table 4.2. Of the fifteen care recipients cared for by the sample of men, 11 were still living at the time of the interview. All care recipients required assistance with multiple activities of daily living; no care recipient could live independently without live-in care services during the time this sample of men provided care.

Generally, the men in the sample reported that they themselves were free of chronic medical conditions. One participant reported multiple conditions, including arthritis, stroke, diabetes, heart disease, and shingles. Another reported that he had diabetes and atrial fibrillation. Two participants reported that they were diagnosed as being obese, one of which also reported having gastroesophageal reflux disease and the other reported having hypertension.

TABLE 4.2 Reported Illnesses of the Care Recipients of the Study Participants

Participant	Care Recipient	Illnesses of Care Recipient Reported by the Caregiver
RO	Mother	Stroke, cognitive decline
RO	Daughter	Cerebral palsy
JG	Wife	Rheumatoid arthritis, COPD, obesity
CS	Wife	Fractured hip, arthritis
GB	Mother	Alzheimer's disease
GB	Sister	Cerebral palsy, psychiatric disorders
GF	Mother	Multiple strokes, dementia
DP	Wife	ALS
DP	Grandmother	Hypertension, failure to thrive, "old age"
JGil	Wife	Spinal cord injury, quadriplegia
BW	Wife	Osteoporosis, multiple fractures, liver failure
JM	Wife	Arthritis, liver failure
MC	Wife	Spinal cord injury, paraplegia
KH	Wife	Arthritis, dementia, fibromyalgia, Type I diabetes mellitus, obesity
JK	Wife	Spinal cord injury, multiple brain surgeries, multiple cognitive deficits

Findings

Introduction: Derivation of a Model

After completing the first four interviews, I noted repetition in many of the open codes. Using constant comparison methods, exploration for subtle differences in the data was completed, resulting in the refinement of repeating open codes. After eight participants had been interviewed, I collapsed open codes into focused codes and then into categories. Again, interview transcripts were laid side-by-side to examine the categories for redundancy and to explore possible theoretical relationships among categories. I developed a rough model in which categories were clustered graphically (Charmaz, 2006). This model was then compared to the data resulting in further refinement. A core category, ultimately named *gender negotiation*, emerged in the model of clustered categories as the primary explanatory and action category to account for differences in the perspectives of caregiving among the eight participants. This preliminary revised model reminded me of a buffalo jump. Since a buffalo jump provided an interpretative and geographically relevant analogy, I used it as a visual inspiration for the model and the theoretical processes constructed. This visual inspiration will be discussed later.

Four additional participants were interviewed after the initial development of the revised model. I interviewed these participants in a much more focused fashion, specifically exploring topics relevant to the model. The participants provided data that further supported the model. Several open-ended questions were asked of the participants, allowing for the introduction of new categories. However, none of the four participants provided data representing new categories relevant to the aims of the study.

At this point, I re-examined all 18 interviews for cohesiveness and further refinements were made to the model.

In the following sections, categories constructed from the data will be discussed. The core category, gender negotiation, will be discussed last, as its relevance is best understood after discussion the other categories depicted in the model. Excerpts from participant interviews will be provided in order to illuminate discussions of the categories. At the conclusion of this section, I will present the model holistically. This will be followed by a three participant exemplar narratives. In the next chapter, comparisons of the study's findings to those of the extant literature will be presented, as well as how the study's findings address the aims of the study. The next chapter will conclude with the implications to health care providers and directions for further research.

Categories

Initially, 21 focused codes were constructed from 285 open codes. A list of open codes, focused codes, and categories is located in Appendix F. The focused codes generally depicted actions and were deeply imbedded in the comments of the participants (Charmaz, 2006). A situational map was made with the focused codes in order to discern relationships. Using the methods described in the previous chapter and earlier in this section, four categories were constructed from these codes: rurality, rural masculinity, caregiver challenges, and negotiating gender.

Rurality

The division between rurality and rural masculinity is fuzzy at best, since both gender and culture are socially constructed phenomenon and are intertwined in derivation and manifestation. Indeed, my findings indicate that both categories share some similarity in their attributes. Nevertheless, from the data provided by the participants and through the interpretive lens of my pre-knowledge, some distinctions were made. In general, attributes of rurality apply in varying degrees to all members of highly rural communities; whereas the participants reported that the attributes of rural masculinity apply in a more predominant fashion and notably stronger in rural men as compared to rural women.

Isolation. From a structural perspective, geographic isolation is a key attribute of rurality. The sparse population in rural areas does not provide an economy of size for many of the health care services needed by the participants and their care recipients. Although all of the participants lived within 50 miles of an emergency department (often a critical access hospital), none lived close to medical specialists and comprehensive durable medical equipment providers. As such, participants were required to drive their care recipients long distances in order to access care. The participants' communities are surrounded by wide expanses of prairies and high deserts, broken occasionally by mountain ranges intersected by roadway passes high in elevation. Driving such distances placed great financial, time, and comfort hardships on these caregivers and their loved ones. Some participants noted that urban dwellers have little understanding or appreciation of such geographic realities. For example, one care recipient in Montana

required a pain pump. The nearest facility to place this pump was located in Billings, a round trip of 450 miles. After the pump was inserted, the participant noted

> ...we were told, I said, "Where do you get this filled?"
>
> "Well, the people will come right to your home and do it. The home health service or you can go to the hospital in Havre."
>
> The first time [she] needed it filled, [she] had to go to Billings. I don't know how many times we went to Billings....There wasn't anybody, we found out. The only two places in Montana that they would fill this pump were Kalispell and Billings. (Participant 2)

After some time, this participant pleaded with his personal physician to arrange to have a provider in Great Falls fill the pain pump. Although Great Falls is a 300-mile round trip, the participant considered this change to be a major victory in advocating for services for his wife.

In order to drive these distances, two of the participants depleted their savings to purchase specially equipped vans in order to transport their care recipients in a comfortable manner. One participant reported that he had become a member of newly-formed ambulance service, in which an annual fee is paid to have a helicopter land in his community and transport his wife to an urban hospital over 100 miles away.

Self-reliance/ hard work. Several cultural aspects of rurality were evident in the data. These aspects are likely multi-factorial in origin, yet some may be derived from the reality of geographical isolation. For example, if one is not close to services, one may be

forced to rely upon oneself to meet needs. Although most of the participants discussed self-reliance in terms of themselves as men, all of the participants noted that rural women and men work equally hard, contributing as much as they could before seeking assistance from others. For example, after describing how hard they work in providing care, all of the participants were asked how their female care recipients would care for them differently if the roles were reversed. All of the participants stated that women would work just as hard as they themselves. The tone of these statements was not of glowing admiration, but rather, a tone of matter-of-factness. Much work is involved in maintaining rural households. The men believed that anyone would work hard to accomplish necessary tasks. Also, the men noted that male or female caregivers would only ask for help if they could not accomplish tasks on their own. Another participant noted that hard work and self-reliance are historically derived. He noted that his family and his wife's family were "Oregon Trail people" (Participant 12), which fostered values of self-reliance and behaviors consistent with ruggedness and independence.

Community support. Another consequence of geographical isolation is the necessity for rural dwellers to assist each other when faced with large tasks and challenges. Such necessity created an interdependence that was necessary for survival in earlier generations and perhaps has been best exemplified by the stereotypical image of an old-fashioned barn-raising. Whether or not a willingness to help neighbors is truly unique to rural communities, the participants described pervasive community support as an essential and beneficial characteristic of rurality. One participant, in responding to a question about the difference between rural and urban communities, commented

...on the good side, there's a lot of community support. Everybody's willing to

help. You know, everyone takes an interest. People don't balk at being asked to

help in anyway. (Participant 6)

After being asked about whether or not he had concerns for privacy, this participant

replied

No....the fact that people knew what was going on is not an issue. In fact, I rather

enjoy it. [It is good] that people asked "How's it going?" because it was always

followed by a "Well, how can I help?" (Participant 6)

Another participant commented on rural community support by saying

Well, it's....it's so much different than in even a medium-sized town, because

here in [name of town], there's only 150 people. And it, and to tell you the truth,

I wouldn't admit to all of them [starts laughing]...it's like a large family.

Uh....anything I needed, I could holler for, somebody would help. (Participant 8)

In discussing how the community provides assistance, this participant stated

Oh, the food would come in if I wanted, and sometimes when I didn't want it

[laughing]. Oh, I had acreage outside of town, and I had people come in and do

the hay and haul and help, and just general all-around help. (Participant 8)

This participant noted that he rarely ever had to ask for something in particular. He would just answer the door and neighbors would be there with food or he would get a telephone call from neighbors volunteering to do farm work. It was as if should the neighbors have to wait until being asked for help, some cultural norm would have been violated; that if one perceives that a neighbor has a need, one has a cultural expectation to offer assistance. This sense of assumed reciprocity was supported by another participant who stated

Neighbors are nice. They help each other [and] share back and forth pretty freely. I help him [his neighbors] out with things and they help me out....I lend him over some tools and he helps us with the computer, and we do, you know, that neighborhood barn-building...barn-raising kind of stuff. (Participant 5)

Participants perceived that rural dwellers look out for each other and for each other's welfare in a fashion they perceive does not happen among urban dwellers. One participant, who had grown up in a suburb of a large Midwestern city but has lived in rural northeastern Oregon for 15 years, described the differences in community support he's experienced this way:

I'll give you an idea. Just the question alone, the hair is standing up on my arm. I mean, I find it so profoundly different, so profoundly different, that I think the major difference has just been the sense of community. My two examples....if

you had your hood open on your car in the [store] parking lot [back in home town] and you were working on your car and you were a beautiful young woman, you would get no help. If you were a young kid and vulnerable, you would get no help. If you were an old guy, you would get no help. No one would ever stop and help you. If you were on the side of the road, not even in a parking lot....I'll give you an idea. I had car troubles at 11:30 at night....I opened my hood, and right away some guy from the Forest Service and a retired mechanic comes over. One sheriff guy comes over. Then one other person. I have no idea who he was, but he comes over....Yeah, if I pull over, these people see my car, they pull over! I have two log trucks blocking the traffic saying, "Hey buddy! You need any help?"....I mean everybody [here] sticks their finger up in the air when they wave to you and drive along, you index finger goes up like a peace sign or whatever....In [home town], it's the MIDDLE finger that goes up [laughing]...With that said, my mom [his care recipient] walked past the government building...one time and I got this phone call from somebody....gosh, I can't remember the department, but it was out of the DA's office. And they said, "Oh, we saw your mom. She carries that little dog with her, a terrier, right?"

"Yeah, that's my mom."

"Well, she's standing on the street corner for 15 minutes looking totally confused."

I would get a report back like that and I would make a phone call to [family member] to go check on grandma and redirect her back home. (Participant 4)

This participant felt assisted and reassured, that while he was at work, people in town would keep an eye on his mother as she went out for walks and notify him if there was trouble. Such communal caretaking was unheard of back in this participant's hometown.

Faith communities. Many of the participants discussed a special type of rural community support: faith communities. Although faith communities are present in both rural and non-rural communities, rural communities lack the diversity and number of social organizations found in urban communities. For many rural towns, the church is the most visible and viable social organization, and a source of great support. Although members of faith communities provide assistance with tasks and provide companionship similar to neighbors and friends, some of the participants reported that faith communities meet higher emotional and spiritual needs. In describing the difference in support between co-workers and church members, one participant who was also a father of teen-aged girls stated

I guess the [people from work] were more analytical, or "What can we do to help?" Church people were there not only to help with the physical things, but spiritual. And the concerns about the twin girls. Here's twin girls going through this. The deep concern that our church family had for that, that they tried, not to protect them, but to make sure that they were OK with what was going on. (Participant 6)

Another participant, who is Catholic, is caring for a wife who attends a Protestant church. This participant expressed gratitude for receiving support from multiple faith communities in his rural town.

> It kind of elevates you, and I'm not certain how to describe it. It...uh...really uplifting you know. You depend upon prayer chains from denominations in this community. That's a really nice thing about being in a small town, is you know, you're not known in just your [faith] community. You're known in many groups. And, so, you know, I'd meet folks in the grocery store who'd say, "I'm praying for you, your wife and you." Which, you know, is humbling and uplifting, and...uh...it's sustainable. (Participant 12)

Even for the participants who did not attend a specific church, the powerful support available in rural faith communities was recognized. One participant reminisced about the faith community of his youth in another town from which he felt a family-like love. He has spent his adult years in the town of his current residence, but has not yet joined a local faith community that he has found to his liking. However, he invited members of a church over to visit with his care recipient. He found value in the respite they provided, as well as the emotional-spiritual care they offered to his care recipient. The participant noted that there were two tight knit families in rural towns: the church family and the bar family, meaning that both churches and bars have members that regularly spend time together, socialize, and look out for each other. (I will discuss more about the bar family in Chapter 5.)

Outsider. However, one participant noted that accessing rural community support was difficult. This participant had lived in a rural community the least amount of time (seven years). He viewed himself very much as an outsider to the community. He commented

> Support...unfortunately, that's one thing that is lacking up here is any kind of support. Um...and I don't know, you know, there used to be some kind of spouse caregiver support association some years ago, but they've disbanded.
> (Participant 7)

Importantly, this participant was seeking a formal service that did not exist in this rural community, yet did not seek informal (non-professional) support from community members. Also, this participant was seeking support for his emotional needs, rather than seeking support for physical tasks. He lacked a recognition that emotional support in rural communities may come packaged differently (e.g. faith communities, sharing hobbies and recreation with others) than in urban communities. This participant reported difficulty in warming up to local residents. Later, after discussing how the local business community had resisted changes to their accustomed practices, this participant categorized rural dwellers as resistant to any change, including starting a caregiver support group. He stated

> The mentality out here is just that they're afraid to change....It seems that the long-timers rule this area. They commonly refer to, you know, themselves as

[Name] County natives. I mean, even though I'm a native Oregonian, they don't

really see you as belonging out here. (Participant 7)

However, the difficulty this participant had in accessing rural community support

or in misinterpreting the actions/ beliefs of rural dwellers cannot be solely dismissed as

stemming from a lack of cultural competence. Participant 11 had lived his entire life in

rural communities, most of his adult life spent in one small town in Louisiana. This

participant described community support in rural towns positively, similar to other

participants. However, this participant had lived in rural Oregon for only five years and

said the following about making new friends

Not as many as I would like, but it's tough getting out to go see people and, uh,

it's a little tough getting people to come in. They're kind of clannish in a sense.

This participant considered his physician, priest, and daughters as his main sources of

informational, emotional, and physical support. Interestingly, via Internet and web cam,

he maintains close contact with his old friends and neighbors from Louisiana and

considers them as valuable resources.

Faith. For most of the participants who did not attend church regularly, faith

itself was important to them and their families. One participant stated that although he

didn't attend church services himself, church attendance was important to his care

recipient wife. Before she required his help, she would take herself to church while he

went trap shooting. However, she is no longer able drive. Since attending church was so

important to her, he gave up trap shooting so he could drive her to church. He stated, "I thought it was better for her to go to church than it was for me to shoot" (Participant 3). Although he did not attend church himself, he described himself as a Christian. Another participant stated

> Well, we belong to a church, but we don't go because, uh, like she gets too tired. So we just don't go. We're both believers in Christ and God and all that. We both have a very religious belief. (Participant 9)

Another non-church going participant reported that he prayed frequently to help him with stress. Still another participant noted that rural dwellers place a high value on church and the church community and said, "Yeah, I know that is different [than in urban communities] because most folks in town are real involved in the church" (Participant 5).

Along with a strong sense of faith, participants offered platitude-like comments that expressed a fatalistic perspective on life's challenges. It might seem that such fatalism runs counter to a sense of self-reliance. However, remembering that rural dwellers have long been at the mercy of uncontrollable natural events such as hailstorms and droughts, fatalism, as expressed by these participants, seems less a sign of defeat but more an acknowledgement that no human can overturn what God sends. And even though God may send adversity, God provides humans with strength to survive. One participant stated, "God plants us the seeds to be strong and get us through tough times and so we have to nurture that seed and let it grow" (Participant 6). Two of the participants commented that, although caregiving is hard work, "God never sends us

more work than we can handle." Participant 11 commented, "We're both satisfied with the fact that God will take care of us." Still another, in discussing how fate has treated him commented, "We said that we married for better or for worse. We just happened to draw the worse card" (Participant 12). Similarly, Participant 3 commented, "You take life as it comes."

Care for one's own. Several of the participants reported that rural dwellers had family values that dictated that family members take care of each other. This perspective was discussed in response to inquiries as to why the participants were taking on the hard work of caregiving. The men did not describe an unwanted duty or obligation; rather caregiving was an expectation, a cultural norm. It was simply something one is supposed to do. One participant commented that caring and relationships are important to rural dwellers, and that one learns to take care of family and animals. He noted that although this value is not discussed much, rural dwellers are always there for their families. Three participants noted that they cared for their wives at home because their wives would do the same if the roles were reversed. One stated, "She'd be doing exactly what I'm doing because we both believe in the same things, the same kind of principles" (Participant 9). Later, this participant commented about how someone approached him and gave him compliments for taking care of his wife. The participant found these compliments perplexing and stated, "...the way I take care of her and the attention I give her, and I figure that's part of it, that's what I'm supposed to do. I told her [his wife] a long time ago that that's why she hired me on forty years ago." However, this same participant believes that this principle for caring for your own is generational, commenting that

younger men he knows would not do the work he does in caring for his wife. He continued

> There's no way shape or form they'd do it because they don't know how to begin with and they wouldn't do it just because the wouldn't do it....because the way they were raised. Like the word here is that when the stuff comes down, they don't want nothing to do with it. The first they want to do is stick them in a nursing home....'Cause I was born like back in 1941. And we lived on a farm...and so we were, we weren't really isolated, but we had family values that came out of the Depression, out of the 30's, and uh, families stuck together and they did what they did at that time...But nowadays, these kids that's coming up, that's 35...40 years old, there's a hell of generation gap, that they don't have the core values that I've had the opportunity to have....and these guys coming up now...these 40-45 years olds, couldn't handle it and most of them don't know where to get help. (Participant 9)

Participant 4 reported that this value was instilled in him as a child. He noted

> I think it's how I was raised, 'cause from the time I was born up until I was 18 and in the service, my dad and my granddad, they had in place a partnership that when granddad and grandma go up there in their years, then my dad and my mom both took care of my grandfolks up till they passed away. So that was instilled in me from day one.

Rural Masculinity

Another category constructed from the data is rural masculinity. The participants described rural masculinity attributes in very personal terms. Instead of describing rural communities, families, or other groups, the participants used these attributes to describe themselves, their perspectives, and their rationales for choices made and behaviors enacted. In addition, the participants used these attributes in describing how they perceive other rural men.

Self-reliance. Perhaps no other rural masculinity attribute was as pervasive, intense, and detailed in the data as self-reliance. The self-reliance described by the participants was more than just willingness to work diligently or a sense of ingenuity. Rather, this self-reliance was described as a compilation of characteristics. On one hand, the participants described self-reliance as a rugged hardiness that spurned a deep sense of independence, an unwillingness to turn to others for assistance, which shaped the very way these participants viewed themselves as men. For example, Participant 1 commented, "This self-reliance thing....well men just have to get over that [in order to be good caregivers]." Participant 6 commented, "You know, I'm macho, and I'm a guy, and I figured I could do it all."

On the other hand, several of the men gave additional characterizations of self-reliance in describing themselves as being "hands-on" kind of men with "can-do" attitudes. These men were eager to roll up their sleeves and confront challenges as they arose. Consequently, none of the men balked at the daunting amount of work that often is involved with family caregiving, even if caregiving required creative strategies. For example, one participant, although having access to physical therapy services and durable

medical equipment, saw no need to access services or purchase equipment when he could provide these items himself. After his wife with paraparesis returned from the hospital, he noted

> I started manufacturing different things to get her up and walk, and even had her up in the shop...used the engine hoist to get her up in the walker. Yeah, we had all different kinds of things....And when she goes to the potty, why, I got an overhead...uh...wench that I run on a rail that I transfer into the bathroom and the shower. The reason I had to do it, we live in an older 1966 double wide mobile home, and the doors were only two feet wide and weren't quite wide enough [to get a wheelchair through]....I fixed her up a [exercise] walker right off the bat...kind of like a cross country skiing. Sometimes she'll go on it for an hour and a half or maybe two hours a day. And then I fixed her an exercise bike and put a pair of shoes on them so she could put her feet right in the shoes, and she can take a ride for an hour and a half." (Participant 10)

All of the men were primary caregivers. As such, they completed household chores as well as personal care tasks for their care recipient. This work was in addition to the necessary farm/ranch work that had to be completed, or for five of the participants, in addition to full-time jobs. When asked about how they felt about the amount of work they were doing, most of the participants paused and stammered to provide a response. It was a perplexing, almost non-sensical question, as if asking the farmer how he feels about getting up early to tend to the animals. How one feels about necessary work is

almost irrelevant; the work has to get done. Participants 5 and 6 both summed up the responses for the group by concisely stating, "Well, you do what you gotta do."

Several of the participants noted that a can-do attitude and tackling hard work was something they learned growing up. According to the participants, if men needed something done, they just did it. It did not always matter if the task was something generally attributed to one gender or another. Participant 12 commented

Well, first of all, my family, they came over the Oregon Trail. The short story is that they were ranching people in Eastern Oregon. And so, men cooked. You know, nothing fancy, but my dad always cooked. And so did my mother. But because of that, I've always cooked. And that was no big deal...it's nothing to fix a pot roast or a stew, or, uh....do just about anything I set my mind to do.

And for Participant 4, a can-do attitude for any task was something that he learned from and admired in his father. He commented

[He was] just a doer, you know, washing dishes, making dinner and everything. All my life it was like that. If mom worked at the hospital, her shifts, I mean, how many Thanksgiving dinners this man made? You know, I mean, changing the kids diapers, I mean, he was just a hands-on kind of guy from that direction, and at the same time, he'd be underneath the car pulling the transmission. You know, I mean, he was just...he worked every day of his life. I mean, every day...I could

take lessons from him, no question about it. But with that said, my goal was always to kind of fill his shoes.

Supporting the sense of self-reliance was value placed on independence. Several of the participants noted that they were independent men, even if that independence, in retrospect, was detrimental (such as in not seeking assistance). The value of independence (or perhaps, avoidance of dependence) was exemplified in how two of the participants promoted the independence of their care recipients. Participant 5 had a mother and an adult sister who required care. Initially, his father was the primary caregiver for both, but upon his father's death, the participant assumed care. The participant had two adult sisters who advocated that the mother and sister be placed in a formal care facility. The participant balked at this option, stating that his family members would not have independence in a care facility. Consequently, he built an addition to his home to accommodate his mother and sister, and refused to lock the doors in the home. He felt it important that his mother and sister have the ability to independently walk about the neighborhood. He stated

In this case, we allowed her to have access. I think being in this [rural] community has allowed her, allowed my mother to live a more free life and be more independent when the disease probably called for more interference or more involvement from her caregiver.

Likewise, Participant 10 commented on how important he felt it was for his wife to remain as independent as possible. One way he minimized her dependence on him was to *intentionally* fumble at something so as to motivate her to do it herself. He shared

> ...and it gives her more incentive to do more for herself. And I'm a firm believer in that 'cause it's just the way it seems. If you do everything for them...she really don't expect it. She gets in the habit of it, but if you drag your feet, well, she'll figure out a way of doing it. I used to dress her up until about four or five months ago, and now she says, "I'll do it myself." And, thank God, she does a pretty good job of dressing herself. I don't know how she does it, but she does it.

Independence, as an aspect of self-reliance, contributed to some level of unwillingness, or possibly aversion, to asking for assistance in accomplishing caregiver work. For some of the men, asking for help was akin to admitting defeat or countered their sense of pride in their individual ability to produce caregiver results. Participant 6 noted that he was "...too independent for [his] own good." Participant 8 stated, "I've always been too damned independent for my own good." For some of the participants, this unwillingness to ask for help was described in terms that nobody could care for their family member better than they could. Participant 7, in commenting why he doesn't seek others to help in order to provide himself respite, stated

> ...it's hard for me, for me to have someone else doing for her....She was in the hospital here last week with a kidney infection, and you know, I was there on and

off, still doing the things for her that I do for her here at home. The fact that the people in the hospital really don't know how to do it, transfers and things like that, and…you know, she just feels more comfortable with me doing it.

However, for some of the participants, not reaching out for help was additionally influenced by the lack of resources. Only two participants had adult children or siblings that lived close by. Consequently, few of the men could ask for family assistance, even if they felt compelled to do so. Although the access to rich community support was noted previously, it is likely that few neighbors and friends could provide physical caregiving on a long-term basis. In fact, the men described assistance from the community mostly as emotional/ spiritual assistance, not in providing on-going physical or respite care. For this type of care, most of the men relied upon professional home health services when they did reach out for assistance. Two of the participants commented that they could not afford these services, and so used them only sporadically and only when absolutely necessary. Two other participants commented that home services were putting a significant strain on their family budgets.

Focus on outcomes. For the participants, hard work was less a process to be described and analyzed, but instead, was a process that simply yielded results. For Participant 10, hard work resulted in equipment that allowed his wife to maintain strength and obtain optimal independence. For Participant 1, hard work resulted in his daughter's ability to fill out her own insurance forms. For Participant 5, hard work resulted in meeting the physical needs of his mother. This outcome-focused perspective of hard work is likely a carry-over from how rural men view the fruits of their occupational work.

In commenting about how rural men view work and changing economic times, Participant 8 stated

> Most men worked at a job that had a product at the end of the shift. Something they could point to and say, "I did that or made that." Such as falling trees, cut them into logs, made the lumber at the mill, used it to build homes...putting up hay that was fed to cattle, taken to market, made into different cuts of meat...Miners and fisherman have all suffered the same fate, being put out of work by the changing times. Most of all the resource industries have gone now and the transition has hit many men very hard. It's difficult to put into words the real feelings of these changes to a total lifestyle. Some cope, but there are some that can't accept it.

What's important in this comment is the statement "I did that or made that." This participant did not use the pronoun 'we', even though the industries he mentions are not solitary endeavors. Rather, men need to point to something that they, as individuals, have produced or contributed to. There is no mention of teamwork. This individual work was played out in the data, as men rarely discussed teamwork with caregiving, even for those men who received some type of assistance. Individual work was something that promoted the self-reliant aspect of their identity as men who work hard to produce something very tangible.

Tangible results of their individual caregiving work were a source of pride for the participants. Participant 2 stated that being able to do the laundry was the thing he was

most proud of as a result of caring for his wife. Several other participants commented how proud they were of being able to complete all the work asked of them. Participants 4 and 5 reported that they were most proud that they were able to keep their care recipients out of care facilities. Participants 7 and 12, men who had cared for their wives the longest, were proud that their marriages were still intact. Few of the participants mentioned items of which they were proud that were abstract in nature.

Resistance to relinquish control. Related to self-reliance, independence, and an aversion to seeking help for some of these men was a resistance to relinquish control and allow others to come in and complete some of the caregiving work. The very act of relinquishing control was a frank admission that they, as men, were unable to complete the work and somehow had failed as caregivers. Participant 7 commented

(Participant): We've [he and his wife] have been doing this together [he taking care of her] for so many years that it's hard for me, for me to have someone else doing for her...

(Interviewer): Tell me why is it hard to have somebody else do these activities? Is it not having the availability for someone to do it, or is it that you have difficulty allowing someone else to do it?

(Participant): That in a combination of both. It's just hard for...someone else to do the, uh...stuff with the catheter, or bowel care, or things like that. I mean, it bothers me for someone else to do it.

This theme emerged several times during the two interviews with this participant. Although he commented that is just easier for him to do things because he has done them so often, he kept commenting on how having others help would be uncomfortable for him.

For those men who initially resisted assistance but then accepted assistance, relinquishing control was viewed as a painful change in their behaviors, which in retrospect, turned out to be very beneficial and should have happened sooner. Participant 1 commented that this was an important lesson that he had learned. As an individual, he eventually realized in time that he could not complete all the caregiving work and his work on the ranch. He related his sense of control as being "macho". He stated that the best advice he could give to other men would be to "give in" and seek help. Participant 6 recounted that he and hospice butted heads initially. This battle over control was particularly intense in that the participant did not request or seek hospice services. Hospice was obtained, without his knowledge, by his neighbors.

I guess the only time I felt intruded upon was when I had to bring hospice in. And, and, not knowing how that process worked. I mean, they just swooped in here. It was four or five of them that come in and they said, "OK, we're going to do this and this." I said, "Wait a minute! I don't know none of this." In retrospect, knowing what I know now, they were right on. They were doing what they had to do.

Later, in reflecting upon this significant event, Participant 6 noted that he felt he was

typical of most men, in that they feel they need to be in control of things, but that men

need to let go of a little bit of that control. He stated he would advise other men with the

following:

> Don't be afraid to ask for help. And....uh, and to just know that here are
>
> resources out there. I guess that just goes with the 'don|t be afraid to ask for
>
> help.' But there really is. There are...I never even really used all the resources
>
> that were out there...I mean, don't be as fussy as I was....There is always
>
> somebody. Uh, and you don't know who that is. It might be somebody you don't
>
> expect. (Participant 6)

For others, relinquishing control of one's schedule in order to accommodate the

needs of the care recipient has been difficult. Participant 5 commented that he was

always at the beck and call of his mother, and felt quite "repressed" that his schedule was

not his own. He commented that she required much time to complete ADL tasks due to

her stroke which intruded on the time he had for other chores and work. Participant 10

also commented on no longer being in control of his time. However, this participant had

come to accept this life change, though somewhat reluctantly.

> I was always a guy who was gun-ho to get things done, and she [his wife] was
>
> too, and you come to an abrupt stop like that. Well, I was just used to getting
>
> everything yesterday. I wanted to get it done yesterday. It's hard to get the

patience to let enough to kind of lay back and let stuff take its course, 'cause there ain't nothing you can do about it anyway. It gets damned frustrating.

Reluctance to meet emotional needs. For some of the participants, there was a clear distinction made in their discussions about asking for assistance with the physical work of caregiving and asking for emotional support, though asking for either counters the idea that one can do the work on one's own. Many of the participants recognized the need for emotional support, yet few sought assistance due to discomfort with asking, lack of male caregiver peers, and/or a loner mentality. Few men noted that they discussed their problems with others, especially with male friends. Participant 10 noted that he had a lot of friends and enjoyed visits from them. However, visits were not used to share personal troubles, but rather to get his mind off of his troubles. He stated

(Participant): They [his friends] joke and laugh...they're really good people.
(Interviewer): Do you feel comfortable confiding with them?....Do you talk about emotional stuff, when you're angry about things?
(Participant): I never bring up anything like that. If anything happens when they're there, I just make a joke of it and they laugh. But they understand. No, I don't give them any hard luck stories, because it wouldn't do any good. Besides, when they're here, they're enjoying it here and they don't want to stir anything up.

Ten of the participants noted that they did not know any other male caregiver with whom they could share their problems. For some, such a peer was desirable in that the men felt that others (women or male non-caregivers) did not understand their struggles. Participant 7 discussed this issue at length.

(Participant): What I think I really need is another male that is in the same situation that I am that can really understand what I'm going through. People are here that we try to talk to, but I don't think that unless you're in the situation, you really, really truly understand what I really go through.

(Interviewer): Are you saying that most of the people that you do talk to are women, or are they men that don't do the kind of work that you're doing?

(Participant): Most of them are women, and um, they're maybe a couple of men, but even what you say [to them], they really don't understand what I do. I think that women are a little more understanding and can at least understand the emotional side of what's going on.

(Interviewer): If you had such a man to talk to, who was in a similar kind of situation, what kind of topics do you think you'd be talking about? What might be different than with the men that you're currently talking with?

(Participant): Well, just how to deal with the…the…the fact of taking care of their wife, and you know, what they do in a situation, like if she's upset or there's something going on with her body, how he deals with, you know…doing some of the very personal things for their wives.

Later in the interview, this participant reported that he had attended a caregiver support group when he and his wife had lived in the city. However, he did not find the group helpful since most of the attendees were women and what few men were there were elderly. The importance of connecting with a peer that had similar challenges was echoed by Participant 5. This participant did know of a man in his town who had recently cared for his father who suffered from Alzheimer's disease. Participant 5 reported much stress in caring for his mother, who had cognitive deficits following a stroke. When asked if he talked to this other man about stress and being overwhelmed, Participant 5 replied

Uh, no. And I don't think that that was part of his personality to be overwhelmed. Being overwhelmed tends to be depressive more. I tend to be that way. When I get overwhelmed, I tend to get into a depressive attitude. He…he was…he never really ever talked like that. He always seems to be very active. And he was a genius and creative and a very active person.

However, a few men did report having a close friend with whom they confided in about their emotional struggles. These men found that sharing with a friend was essential in helping them meet the demands of caregiving. Usually, this sharing took place outside the home and during some sort of recreational activity. Participant 12 stated

I have one very close friend who has shared my burdens with me. You know, he would actually come get me from time to time when things were a little bit over

the top....Depending upon the time of year, sometimes we would just go out for a drive. Sometimes, we might go out for a drink. Or we would go hunting, or, you know, it depends upon the daytime and the nature of the weather.

Participant 12 also reported that he had met another husband caregiver in his town who is Hispanic. This gentleman was having a hard time at first, and Participant 12 felt he could help him as a peer.

(Interviewer): Do you see...do you guys have some struggles in common?

(Participant): Yes....I would say that we do. He's another guy just because we share the same burden...It's been harder for him I suppose culturally, because in their culture...uh...you know, there is...uh...maybe doing what I've done is not always done by men in the Mexican culture. And yet, he has really swallowed his....uh...cultural standards, and done the same thing. And now, his wife is responding and she's getting better.

(Interviewer): Do you guys swap horror stories or tips from the trenches or whatever?

(Participant): Yes.

(Interviewer): Do you find that important and helpful?

(Participant): Yeah, I would suppose that anytime anyone walks in your moccasins, you know, it's easier...in a sharing group, in AA, whomever, when

there is some commonality of discourse, uh....at least people have an understanding.

Other participants reported spending time with friends playing golf or going hunting or fishing.

Still other participants revealed a loner-type approach to meeting their emotional needs, and thus, did not reach out and connect with others. Participant 5 described himself as a loner, who likes to be alone when emotionally stressed. When asked if he talked to anyone about the stress he felt, he replied

No. I don't talk a lot. I talk to myself a lot when I think. And I go on walks...I'm a walker. I like the solitude. You know, when your legs are in motion, your body is moving, your mind isn't.

Participant 8 also believed in self-talk.

(Interviewer): Did you feel overwhelmed at times?

(Participant): Oh...a number of times!

(Interviewer): What did you do at those times?

(Participant): Just mostly sat down and talked to myself, and explain to myself that I just had to do it....There was times, like anything else, you know, you'd loose your temper a little bit, and had to, like I said, sit down and talk to myself, and "You got to get over this and get through it."

Participant 7 shared the following perspective.

> (Participant): Well, you know, we [he and his wife] have fights just like
> everybody else, but ...being mad at each other doesn't last as long, I mean, if I get
> mad, I still do what I need to do, but I'll be silent. I'll go out to my shed or
> something like that for half an hour, 45 minutes or something like that, and cool
> down that way. I mean, it takes less time to cool off from that because, you
> know, because I have to transfer her to bed every night, you know, so we still
> have to hug....We still have our fights, but I can take my time by myself that I
> need, but not like the whole day or something....I mean, we can still be angry
> with each other, but I still have to do things. I always play the silent treatment.
> (Interviewer): Does that [place] another layer of tension on what is perhaps
> already a tense situation?
> (Participant): Sometimes (long pause). Yes, it does.

Although solitude and cooling off may have clear benefits, particularly in the short-term,

these three participants spent or sought little time with friends. Interestingly, these three

participants were the ones who most readily described their stress and admitted to

feelings of resentment and bitterness, so much so that Participant 5 stated that he was

looking forward to his mother's eventual death, and that he would feel "liberated" once

he was no longer caring for her. Perhaps the worst consequence of loner-type behavior

was described by Participant 6. This participant described a man in his church who was

caring for his wife who was terminally ill. The participant, as well as others in the church, made repeated attempts to provide assistance of any kind, but all attempts were rebuffed by this gentleman. The man's wife died recently, and now the man refuses to leave his house. The participant and the people in town all fear that this man will commit suicide.

For men displaying loner-type behavior, there was a common approach to stress management. This approach was characterized by a general stoicism, in which action was only taken when the stress became unbearable. This approach incorporated the seeking of solitude and the use of changes of scenery, employment, and "puttering around the shop" as diversions. Self-talk was also used as a method of reframing perspectives and problems (as noted above). Participant 8 illustrated this stoicism in discussing how rural families often now live far apart due to the reality of economic conditions in rural communities. He stated

> Family gatherings are always a high point in their [rural men's] lives. Families used to live close together, but now there are many miles between. Visits are great, but in the end when the visit ends, the worst thing is, everyone goes their separate ways. Many men don't show it if they can help it, but it really bothers them a lot.

Later, in noting what he was most proud of in caring for his wife, this participant stated, "Just suffering through it." This approach of suffering in silence was not always perceived as beneficial. Participant 5 noted that stoicism made him stay focused inward,

which made him feel "repressed and depressed." Participant 12 reported that his stoicism

to the stress made him depressed to a point where he actually sought treatment. He

commented

> (Participant): I'm still on Lexapro. This has been a year and a half.
>
> (Interviewer): And how's that going?
>
> (Participant): I...you know, I feel much better. Obviously, men aren't supposed
>
> to get depressed, or there's a rumor about that.
>
> (Interviewer): Where do you suppose that rumor comes from?
>
> (Participant): I...you know, I'm not certain about that, but I'd like to strangle that
>
> guy.

Two of the participants reported consuming higher amounts of alcohol since becoming a

caregiver. Alcohol was described in terms of reducing their stress; however, the alcohol

was consumed in solitude, as opposed to going out with friends for a few beers.

Participant 10 admitted, "Well, I tell you, I've always like my beer, and I'm not proud of

it, but it's that drinking beer, 'cause it relaxes me and it helps me overlook what's

bothering me I guess is what it is."

Neglecting personal health. The majority of the men in the sample reported that

their own physical health was good, having no conditions requiring on-going medical

care. However, when physical ailments were present, little priority was given to them

until symptoms became severe. Participant 2 suffered from a previous stroke, significant

arthritis, type 2 diabetes mellitus, and recurrent bouts of shingles. Over the past year, the

culmination of these illnesses was making it increasingly difficulty from him to function as the sole laborer of his farm and the sole caregiver for his wife. He commented that he rarely sought medical attention, as an appointment would require four or five hours away from this farm and wife in order to drive to town, be seen, and return. Such an appointment would require that he spend some of his limited funds to pay for someone to watch his wife. Interestingly, he made such journeys once or twice a week to purchase farm supplies, groceries, or complete other such errands, yet never combined these errands with medical appointments. This participant only sought medical attention when his symptoms prevented him for working for more than a day or two. Two other participants reported significant joint or back pain resulting from their physical work as caregivers. Neither sought medical attention, stating that they were still able to complete the caregiving work. Two participants reported significant sleep disruptions which they attributed to the stress of caregiving. Neither participant took sleep medication. Only one participant reported being attentive to his physical health care needs while serving as a caregiver. This participant was diagnosed with atrial fibrillation, which he stated worsened while he was a caregiver. His unstable condition served as a catalyst for him to seek caregiver assistance from a home health agency.

Hobbies. Another approach to lessen stress used by a number of men was to engage oneself in hobbies. Often these hobbies served as a conduit for maintaining social engagement with friends. As such, men spent time together hunting, fishing, golfing, or playing softball, or in attending clubs such as gun clubs, the Masonic Lodge, or the Knights of Columbus. Men engaged in hobbies described the stress-relieving benefits and how they felt more stress when they could not engage in hobbies due to time

constraints. One participant described how he had given up his Sunday trap shoots in order to have time to get his wife ready and take her to church. Another participant described how he could no longer attend gun club meetings in the evenings due to his caregiving responsibilities. The importance of maintaining involvement with hobbies was reflected in the advice some of the participants stated they would give to other men. For example, Participant 12 suggested, "Get a hobby for one thing."

Valuing common sense. Another attribute prevalent among the participants was a value on common sense. This attribute revealed itself in various contexts. For example, Participant 2 commented that his neighbor didn't have enough common sense to keep his truck filled with gas, so if his neighbor ran out, it was "his own damned fault." This participant also provided several examples of how it was common sense to tend to cows that had gotten loose on the highway before tending to the caregiving needs of his wife. Three of the participants commented on the lack of common sense they perceived in health care providers. Participant 2 recounted a situation in which his wife needed hospitalization. He told the ambulance that they would have to take her to Billings, but the ambulance company's protocol dictated that they first go to the local rural hospital. This frustrated him because he saw the duplication of services as a waste of time and money. He reported

> (Participant): Now that's another thing. When we had to go to Billings with the
> ambulance, the ambulance comes out of [name of local town], picked us up, and I
> said, "We got to go back to Billings." No….they had to stop at [nearby hospital].
> Go into the hospital over there. The doctors, they poked around, an hour and a

half, two hours...they took x-rays and everything. Then we had to go to Billings.

And that didn't make a bit of sense to me. Then we took her to Billings.

(Interviewer): And in Billings, did they have to re-do everything that they did

in....

(Participant): Oh yeah!

Participant 5 expressed frustration at the red tape and inefficiencies that plagued a local

senior service agency. He noted

The lady down in [name of local town] that's in charge of it...she doesn't know

how to think I don't think. I was trying to get clarification on things, and the

manual, the little book they gave us, was not very clear. I mean the flyer that

explained what was available and what we could use. And then, the rules that

comes, that comes...what the caregivers are looking for. They were telling us

that the rules weren't compatible with what they were saying. And I called for

clarification on it, and she was quite bureaucratically tied down and said, "Well,

that's just the way we do it here."

However, the value of common sense was also described in terms of how the men learned

how to perform caregiving and household tasks. None of the men reported that they ever

received formal instructions from any nurse or home health provider on how to complete

caregiving tasks such as transferring techniques, medication administration, and hygiene

tasks. The men stated that they learned how to perform caregiving tasks either by asking

other family members, observing how things were done by nurses or aides, and by

"common sense".   Participant 9 described it this way:

> (Interviewer): Now, who taught you all the stuff that you need to do?
>
> (Participant): Common sense.
>
> (Interviewer): Common sense? How did that work out at first?
>
> (Participant): Well, uh…when I first started taking care of her, I got a little bit of
>
> help and a few ideas from my stepdaughter….and myself, I got a lot of common
>
> sense. I figure myself pretty smart. I've watched other people, picked up a few
>
> things here and a few things there. And I'm the type you show me something
>
> today, I'll remember ten years from now…..I do what's necessary, and most of it
>
> to me is common sense.

The only explicit education or instructions provided by health professionals described by

the participants came from hospice workers after the death of Participant 6's wife, and

from a hospital physician caring for the wife of Participant 10. This participant recounted

> When we were two and half months in Boise, over at [name of hospital], one
>
> doctor there, she come in and [name of wife] at that point wasn't laying straight
>
> there in the bed, and she tells me to get her straightened up or she'd do it. She
>
> was big enough she could lift both of us. She was very critical about keeping that
>
> spinal cord straight when you're lying there in bed. [Name of wife] was always

lying to one side.…But the gal come in and she says, "Well, you're not doing too

good of a job there. You better help me keep that gal straight."

Interestingly, none of the men provided any negative comments about not receiving any

formalized instructions. In fact, the men expressed pride in being able to figure things

out on their own and accomplish the caregiving work.

Role as provider. Another attribute of rural masculinity for these men was value

in being perceived as a provider for their loved ones. This value was expressed variably.

As noted earlier, several men commented that they were supposed take care of their loved

ones, and that family members take care of each other. However, Participant 1 was more

explicit. In commenting that men need to be willing to ask for help, I asked him if asking

for help was a way of providing. At this, his facial expression changed. He perked up

with recognition and commented, "Yes it is! Men want to be good providers for their

families." For some, the provider role was most evident in the advocacy actions several

of the men took in order to ensure that the needs of their care recipients were met. Often,

advocacy was levied against an antagonistic health care system. Participant 1

complained about years of battles with insurance companies and doctors in order to meet

the needs of his daughter. Participant 2 recounted numerous battles with health

providers. For example, as his obese wife's mobility and health deteriorated, she was

unable to use a walker for mobility due to the weakness in her arms. When seeking an

electric wheelchair, providers insisted that his wife should use a manual wheelchair

instead. In describing the encounter, he stated

And they put her in the wheelchair and they had a carpet on the floor, and she couldn't move it two feet. And they said, "Well, she'll build up her arms." And I said, "There's no way in God's world that she can run that wheelchair, 'cause I've been around her and I know." Oh, they insisted, and that was all the help I could get. We had to go for a wheelchair. Got a manual one.

For Participant 5, battles with city hall took much of his energy. He wanted to move his mother up from California so that he could look after her, but he did not have enough room in his home. He wanted to place a small mobile home on his property, but the city would not change the zoning law which required only permanent structures in town. This participant solicited the support of his friends and many of the citizens in town and was eventually successful in his petition for a variance. Participant 4 experienced a similar experience. The city would not allow him to build onto his home in the fashion he wanted in order to have the room to take care of his mother and his sister. So, he obtained a licensed to convert his home to an assisted living facility, and then was able to obtain the financing and permits to remodel and enlarge his home to allow for separate apartment-like living quarters for his care recipients.

For three of the participants, the value they placed on their provider roles prompted them to make employment sacrifices. Participant 4, an accountant with a newspaper, took a lower-paying position as a newspaper deliverer in order to have the flexibility in hours to be a caregiver. Participant 5 worked as a fence installer so that he would have the flexibility to leave work to tend to issues at home. Participant 7 worked only part-time due to his caregiving responsibilities. At the time of his second interview,

he reported that his employer had let him go because he would not work more hours. These employment decisions resulted in financial hardship. Yet, these men expressed that these decisions were required in order for them to be caregivers.

Caregiver Challenges

Another category constructed from the data was caregiver challenges. The participants discussed at great length about the work they did and the struggles they had in caring for their care recipients. The challenges described by the men were characteristic of caregiver challenges described in the literature including struggles to obtain services, financial hardship, lack of sufficient respite, taking on new tasks in the home, giving up hobbies and activities, fatigue, marital stress, lack of time, poor sleep, disruptions at work, changes in levels of intimacy with care recipient wives, and physical disruptions in health due to caregiving. These challenges can be roughly categorized as role change, physical, emotional, and financial challenges.

Most of the men talked about the struggles they had to get all the work done. For example, Participant 3 noted

It is quite a chore to try and do what has to be done. The washing, cooking, cleaning. By the time you get breakfast, do the dishes, maybe vacuum, and a few other chores, it is time for lunch. After lunch, doesn't seem long 'till you have to fix dinner. When the weather is good, some outside work had to be done....It is difficult and some things just don't get done.

Participant 2 commented on his numerous competing demands. He shared the following:

The day before yesterday, somebody went into my place and left the gates

open....And the cows, and I got two horses, they were out at 6:30 in the morning.

Sheriff's department calls and says, "Your horses and cows are on the highway."

And then she [his wife] says, "Get me up." And I say, "Well, we usually stay in

bed." And she says, "I don't care. When I get up and lay there a little bit, I got to

pee. What am I supposed to do? Go in the bed?" I told her, I says, "I ain't gonna

be gone but 15-20 minutes to get the cows and that in."

He decided ultimately to put a towel under her and went off to get the animals off the

highway. He recounted how angry she was, particularly since this conflict between her

needs and the farm chores was a daily occurrence.

Most of the participants noted that these challenges resulted in a high level of

psycho-emotional stress. Only one participant denied any stress resulting from his work

as a caregiver. He noted, "I think that's [emptying the commode] the only challenge I

really got. My wife is very easy to take care of. Very easy!" (Participant 9). Otherwise,

the men described a pervasive caregiver stress. Yet, these men described this stress in

relatively few, though powerful, words. Participant 11 commented, "It [the stress] gets

pretty tough. (Long pause) It can be real tough." Participant 12, in discussing the time

he spent with his wife when she was hospitalized, stated, "Well, what I had to do in Boise

was pour myself out of the car to go up and see her. It was a pretty miserable time."

Participant 8, a man of few words, simply commented, "It was very stressful, very

trying." The men dealt with stress variably, as discussed earlier.

For two of the three men who cared for family members other than their wives, caregiving responsibilities had pretty much destroyed their marriages. Both men were caring for their mothers. Both men reported that their wives did little, if any, of the caregiving work. One of the wives was a licensed practical nurse, yet both men reported that the wives only provided emergency back-up. Usually, when their mother-in-laws required assistance, these wives contacted their husbands to come home and provide the needed care. Participant 1 was also caring for an adult daughter with cerebral palsy. He shared that his wife did help with his daughter's care, but for many years, his wife worked outside the home. Since he was home working on the ranch, he would meet any of his daughter's needs after she had come home from school. This participant shared that the stress of the years of caregiving had "...really affected the marriage. We're still together, but we just seem to share the same household."

When asked what he would like to be different about his caregiving situation, Participant 5 commented

Well, I could probably name one thing right now...the relationship with my wife and her support and involvement in this and the tenor of our relationship overall....I have to be very careful or I'll stress her out and that will be the end of everything you know....An ideal relationship wouldn't be stressed so much, but sometimes we're not ideal....When we got mom, mom was living with us for awhile, which is not what she wanted....My wife knew my mom and she said that she would be happy to have her come live with us, but stability is not my wife's

strongest point....kind of back and forth. I mean, she and my mom get along, but it's kind of delicate.

For several of the participants caring for their wives, stress had negatively affected the quality of their marriages. Participant 8 described how his wife's personality had changed prior to the fall that broke her pelvis which required him to become a caregiver. He stated

A couple of years really before she passed away, she started, sort of, withdrawing within herself. She didn't want to go anywhere. She wouldn't go out after dark and just sort of drifted away from everybody. Mentally, she was still fairly good, but like I said, she let herself drift and sort of had given up on life.

These changes in his wife were not evaluated medically, so it is not clear as to whether she had developed a true dementia-type condition. Participant 12, who has cared for his wife for some 28 years, noted that his wife's condition precluded her from many activities they could enjoy together socially. He commented, "...it's been a long lonely trip. And, it's not her fault. It's not my fault. It's nobody's fault. It's just the way it is. But that doesn't make it any easier." Participant 7 described difficulty dealing with his wife's emotional labiality, which seems to have worsened over the past few years. This participant believed his wife's emotions were due to her disability, that she had been in a dependent role for so long that chronic stress was taking a toll on her. He commented, "And you know, some of the emotional stuff, 'cause it gets real difficult dealing with her

emotions, just the daily problems of being disabled. So it takes a toll on my emotional being also." This reality was a major reason this participant longed to find other male caregivers, to discuss how they contend with the emotional needs of their wives.

Interestingly, Participant 7 was the only participant who discussed role conflicts. Although other participants discussed how the quality of their relationships had changed with their care recipients, they discussed their caregiving as consistent with their roles as husbands and sons. However, Participant 7 shared

(Participant): ...I still have, constantly finding the fact that, you know, what is my role sometimes. Is it, you know, caretaker, is it husband, is it provider? ....Even after 19 years, I still struggle with the fact of trying to separate, you know, trying to be caregiver and husband. It's something....you never get used to....That's something, you know, is always going to be hard to separate.

(Interviewer): That's interesting. Tell me, what are the differences in your mind between the roles of caretaker and husband?

(Participant): Well....(pauses)....Husband is offering probably more emotional support, and, 'cause when I'm doing stuff for her, catheter care, bowel program and stuff like that, I almost approach it like, you know, from a caregiver aspect rather than from a husband. I think a husband needs to offer more financial support and emotional support, which, you know, has always been hard for me in life. It almost seems more difficult trying to separate those things right now. And offering that support she needs when something is wrong...I don't know which

way to approach it. Either, from like a caregiver aspect or husband. It's still real difficult to separate the two.

No other participant reported any need to separate caregiving from their relational roles with their care recipients, even those participants who were specifically asked about this issue. However, this participant's history is like none of the other participants. Participant 7 has had a career as a certified nurse's assistant and rehabilitation aide. He discussed his professional approach to client care on the job as having an emotional distance. As such, he had established formal caregiver perspectives and behaviors prior to becoming a caregiver to his wife. In addition, he met his wife when she had already had quadriplegia. He never had a husband relationship with his wife without also having a caregiver relationship with her. Over the 19 years of their marriage, he has not learned how to infuse the two relationships into one, nor learned how to differentiate between a family caregiver role and a professional caregiver role.

Negotiating Gender

Negotiating gender became the final and core category constructed from the data, in that most of the men underwent a process in which various attributes of rural masculinity had to be rectified with caregiving responsibilities. This process was not always done in a self-reflective manner; indeed, for most men, this process occurred in a reflex-like response to changes and during periods of increased caregiver stress.

Caregiving required that the men confront new situations, adopt behaviors, and complete tasks to which they were unaccustomed. For one participant, these changes produced no reported stress. For the rest of the men, new behaviors and tasks ran into

conflicts with their individually constructed gender roles. For a few men, these conflicts were mild or infrequent since their caregiving responsibilities requiring such changes were mild in nature. For these few men, attributes of rural masculinity (such as a self-reliant/ can-do attitude) were utilized to accomplish caregiving work. However, for many of the participants, the intensity of caregiving responsibilities was significant enough to create a notable non-congruence with their constructed gender roles, contributing to and correlating with overall levels of stress. This non-congruence has been described in the literature as gender role conflict (Good et al., 1995). Gender role conflict is defined as psychological stress that stems from restrictive gender roles resulting in negative behaviors and experiences that restrict self-potential or the potential of others (O'Neil, Good, & Holmes, 1995). For most of the men, caregiving responsibilities required behaviors and perspectives that conflicted with various attributes of rural masculinity. How the men resolved this conflict varied. However, three general patterns of addressing this conflict through gender negotiation were constructed from the data: gender compromise, gender conflict preservation, and gender reconstruction.

Some men incorporated a compromise in the conflict to needed behaviors and one or more rural masculinity attributes. This gender compromise constituted an adaptive process, relevant to the context of caregiving, which allowed men to *tolerate* any psychological stress created from conflicts with rural masculinity so that they could successfully complete caregiving tasks. With success at task completion, the majority of the participants perceived themselves as getting by, as making do with the challenges presented to them. The labor involved with compromise was deemed acceptable due to the benefits and personal satisfaction obtained from success with completing the work of

caregiving. In this sample, attributes that were involved with compromise included the sub-attributes associated with an overly independent self-reliance, namely an unwillingness to ask for help and resistance to relinquish control. Gender compromise, however, led to eventual congruence with other attributes of rural masculinity, namely the attributes of focusing on outcomes and adopting a provider role.

For a few of the other men, gender compromise was minimal or non-existent. These men seemed to preserve the tension of the conflict between caregiving and gender constructions by a relentless clinging to specific attributes of rural masculinity, namely over-independent self-reliance and a reluctance to meet emotional needs. These men expressed directly or indirectly the emotional stress that resulted from their inability and/or unwillingness to resolve gender role conflict. Consequently, these men periodically disengaged from caregiving and disengaged emotionally from others. Disengagement hampered their ability to complete the work of caregiving, potentially jeopardizing the health and safety of their care recipients. This preservation of gender role conflict put these men at increased risk for caregiver crisis.

Still other men were not only successful in modifying behaviors to complete caregiver work, but were also able to *reconstruct* their personal perspectives on rural masculinity itself. This reconstruction changed the dynamic from one of *tolerating* psychological stress (compromise) for the benefit of accomplishing caregiving work to one of *changing* beliefs so that new caregiving behaviors were consistent with their new perspectives on gender. In other words, these men were able to determine that certain attributes of rural masculinity were the origins of conflict itself. By reconstructing their own self-construction of gender, they were able to minimize or eliminate the

psychological stress created from gender conflicts, and thus, reduce their overall caregiver stress. The attributes deemed most problematic, and consequently reconstructed, were the same as those mentioned for the other two patterns of gender negotiation. In addition, through the process of gender reconstruction, these men understood the value of tending to one's emotional health. According to these men, this reconstruction allowed them to improve the *quality* of their caregiving work. Although these men reported that they did not experience less physical work from this reconstruction, reconstruction provided them some resiliency and allowed them to experience rewards of serving as a caregiver. These men negotiated gender through gender reconstruction. Each of these three responses to negotiating gender is described further below.

Gender compromise: Accommodation. Although most of the men described large amounts of stress and other caregiver challenges, the general and initial perspective was to buckle up and work harder to accomplish caregiver tasks when challenges increased in number and intensity. How each participant met their challenges was variable. Nevertheless, the men viewed themselves as successful caregivers since caregiver tasks were being completed. In other words, success with caregiving was generally perceived in terms of task completion.

For these men, maintaining one's self in a state of "making do", or accommodation, required a battle of sorts in which caregiver challenges were countered with adaptive strategies employed by the men. During periods of increased challenge strength or quantity, the men increased the strength and/or the number of their strategies. These strategies varied, but included behaviors such as partaking in a hobby, using a trial-

and-error approach to figuring out how to accomplish a task, prayer, spending time with friends, and even asking for help. Despite the variability in the strategies employed, one thing was nearly universal in the sample; men employed strategies so as to accomplish caregiving tasks independently. If these strategies did not allow for independence with task completion, then and only then was outside assistance sought. For many of the men, asking for outside assistance runs counter to the attribute of self-reliance and an unwillingness to reach out. However, this conflict was tolerated in order to accomplish caregiving work. An analogy might be the farmer, who staunchly completes farm work independently until help is necessary at harvest time. At harvest, one farmer is not likely enough to accomplish the needed work. However, asking for help at harvest time does not negate the value of self-reliance. Simply, the farmer tolerates and accepts help until it is no longer needed. The emphasis here is on task completion. So it is with men who negotiate gender through gender compromise. They reach out for help only when necessary and with the focus of only to get the work accomplished. For example, Participant 3 offered the following as advice to other men based on a retrospective look at his gender compromise:

> The advice I would give anyone taking care of someone is to evaluate the amount of care, then decide if you are able to do the job. Sometimes the care required can be more than one person can give.

What is important to note is that help was sought out only to complete those tasks for which he could not perform himself. Assistance was not sought for respite purposes

or to free him up to fully pursue self-enhancing activities such as hobbies or increased time with social contacts. For these men, there was a strong pragmatic perspective. Gender compromise occurred only if task completion was jeopardized. If help was needed to pick up the slack, then help was sought. Participant 10 commented

> And it's just, I don't know…a funny thing, we raised eight kids. So we, we always had a strong backbone between the two of us. So we got things done, no matter what it was, we got things accomplished.

Usually, men who sought help sought professional services, such as those provided from home health agencies, or from adult children when the health of the care recipient had deteriorated significantly. Most of the men using gender compromise did not actively seek assistance from neighbors and friends, possibly in order to maintain a sense of independence within their peers. However, if help was volunteered (such as with the occasion of neighbors volunteering to cut one of the men's hayfield), help was not turned away. For these men, caregiving and gender negotiation was not viewed as an internal and self-reflexive process. Rather, caregiving and gender negotiation was external and outcome-focused.

Gender conflict preservation: The cliff's edge to caregiver crisis. Another pattern of gender negotiation is that of gender conflict preservation, which pushes the caregiver to a dynamic and highly individualized cliff's edge to caregiver crisis. I define crisis, in short, as coming to a point in which strategies employed by the caregiver are insufficient to counteract the challenges of caregiving, resulting in an inability to complete the work

of caregiving. By nature, crisis implies a shift in the caregiver dynamics that occurs quickly and rather unexpectedly. Crisis results, or is likely to result if not reversed, in significant health disruptions for the care recipient that will require institutionalization.

None of the participants used the term "crisis" specifically, but a number of the participants described events in their caregiver trajectories that depicted crisis or near-crisis. Generally these events were precipitated by sudden health disruptions in their care recipients that increased their level of dependence requiring increased caregiving labor, or by health disruptions in the men themselves. When these events occurred, the men described how they were no longer able to complete the work. However, these events were generally viewed as temporary setbacks to which they struggled to resolve. For example, Participant 2 recounted

And then when I had the heart operation, they was checking me, and they was giving me insulin. And I had to put her [his wife] in a nursing home in Great Falls when I had to leave the heart operation. Then after I had got out of the hospital there, I had to go to a nursing home because they wouldn't let me come home and take care of her....Two weeks I think it was. The trouble was that if I would have come home, there was nobody to take care of me. She couldn't take care of me. So, I stayed in the nursing home over there. And I had to talk like hell to get out of the nursing home, to get back home. They didn't want me to come home.

What is unique about the men who negotiated gender with gender conflict preservation is that they did not seek and did not accept help willingly in order to accomplish the work of caregiving, either during crisis or in between crisis episodes. Instead, these men clung stubbornly to their independence from others and to their belief in their own self-reliance and ability to accomplish all necessary work. Help for these men only occurred when forced upon them by health care providers or only very infrequently and under extenuating circumstances. These men were unable and/or unwilling to relinquish control of the caregiving to others. Participant 7 described his discomfort with others providing any hands-on assistance for his wife, even when she was hospitalized and cared for by hospital employees. His insistence on completing all work independently cost him his job, as he could no longer work the required hours at his place of employment. Participant 5 only accepted outside services that were requested by his care recipient (such as the librarian providing of audio books). Participant 2 only allowed outside help after his care recipient complained enough times that he was not able to complete her bath and hygiene to her liking.

For these men, the conflict that occurred between their adherence to an overly independent self-reliance and control over the caregiving context, as well as the neglecting of their own emotional needs created stress that was manifested by self-reports of feeling depressed and bitter and with excessive disengagements from their caregiving responsibilities. Disengagement occurred when men felt overwhelmed by multiple demands which led them to physically remove themselves from their highly-dependent care recipients for up to hours at a time without providing for someone else to fill in for them. Disengagement was also evident in their loner-type behaviors. During periods of

stress, these men did not seek support from social contacts which were available to them in their communities. Instead, these men went off by themselves. Although it is unrealistic to expect social availability for each stressful episode, these men rarely, if ever, sought the support of others. As noted earlier, times of solitude may be a successful stress reduction strategy in the short term. However, these participants did not reveal awareness of how negative emotions and actions *cumulatively* served as a force that was actually pushing them closer to the cliff's edge of caregiver crisis. Men who negotiated gender with gender conflict preservation were unable and/or unwilling to negotiate rural masculinity attributes in order to effectively accomplish caregiver tasks on a consistent basis.

Gender reconstruction: Resiliency. This transformational process represents the third pattern of gender negotiation. Although men using this pattern experienced different caregiver trajectories with unique constellations of caregiver challenges, these men had important similarities. These men had experienced trajectories in which the intensity of the caregiver challenges had eventually overwhelmed them, overloading any gender compromise they may have been using, and pushing them uncomfortably close to crisis. However, unlike the men negotiating gender with gender compromise or gender conflict preservation, these men accessed the support of friends, neighbors, and faith communities. These social contacts provided the physical and/or emotional/spiritual support for these men to avert crisis in the short-term. In addition, these social contacts encouraged and supported these men to seek professional services. These men noted that once help was received and the caregiving work was again being accomplished, they had the energy to reflect upon the recent changes in the caregiving dynamic. For these men,

reflection allowed them to see the benefits of receiving assistance in enhancing the quality of the caregiving work itself, the improvement in their emotional health, and the quality of themselves as caregivers. They acknowledged that the value they had placed in being independent, self-reliant and in control was excessive and was making them ineffective caregivers. They realized that letting go of control and asking for help when needed was essential for caregiver success and avoidance of crisis. Importantly, these men identified these attributes of overly-independent self-reliance, control, and neglecting their own emotional needs as something that men have in common, not as something that was unique characteristics to themselves as individuals. As such, these attributes of rural masculinity actually serve as a source of gender role conflict, a source that could be minimized or eliminated. Participant 1 noted that self-reliance was a "macho thing" that had to be tossed. Participant 6 commented that men like to be in control, but that men need to relinquish that control and ask for accept help. Also of importance, these men did not equate this new perspective and resulting behavior change as an emasculating process. Rather, these men reported that in forgoing their sense of excessive independence and control, they were actually strengthening congruence with their values of being good providers for their families. In contrast to the other men, the participants displaying gender reconstruction perceived caregiving as both an external and an internal and self-reflexive process. These participants had developed an understanding that how they *felt* about the caregiving work and how they *interpreted* themselves as caregivers were important to caregiver success. These men realized that they had needs for emotional support and took actions to meet those needs. Addressing

any qualms the second time around in accessing resources and taking care of themselves

by ameliorating their stress. These men described themselves as more resilient to new

caregiver challenges and as more successful in their caregiver roles. In particular,

Participant 6 noted that as he started caring for his terminally ill grandmother, his new

perspective made him more accepting of the inevitable. Also, he was comforted in

knowing that his friends, neighbors, and church would support him "...every step of the

way, there for me whenever I needed, for whatever I needed."

The men who used gender reconstruction reported a new and palpable sense of

altruism. They commented that they chose to participate in my study to help other men.

Participant 6 went even further. His second recipient (grandmother) had died just a few

weeks before he provided an interview. Although sad about his grandmother's death, he

described how his caregiving had changed him. He noted that his caregiving experiences

had made him more insightful and had strengthened his faith. He said

> You know, I'm doing good. When my grandmother died, it was like a blow, like
> "Why does this keep happening to me, this death in the family?"....But God
> plants us the seeds to be strong and get us through tough times, and so we have to
> nurture that seed and let it grow.

Participant 6 described that the way to let this seed grow is to help those who had helped

him. He felt that his new perspective was a gift—a gift he hopes to use with his faith

community. He noted that he is even considering going to the seminary.

Gender-Cultural Model of Caregiving: Rural Male Caregivers: The Buffalo Jump

A model was developed to illustrate the proposed theoretical relationships among the categories constructed from the data. As noted earlier, this model was inspired by the dynamic processes that move in a buffalo jump. Before presentation of the model, a brief discussion of a buffalo jump is necessary.

Prior to the reintroduction of horses to North America by Europeans, Native Americans hunted on foot. Large animals, such as buffalo, were difficult to hunt due to their size and speed. However, through human ingenuity and natural geographic features, groups of hunters were able to kill large numbers of buffalo, providing much food and hides to their tribes. Such feats were accomplished using a buffalo jump (*Ask Dr. Dig: Questions about Native Americans*, 2006; Thomas, 1993).

A buffalo jump was comprised of a steep cliff or embankment, which fell abruptly from an expanse of prairie. The canyon below the cliff was usually U-shaped, which allowed humans to construct a corral on the canyon floor, the fence stretching from cliff face to cliff face. Such geographical features are actually quite rare on the high plains. On the prairie, above the canyon, humans constructed driving lines made up of brush and rocks that extended from the cliff's edge out onto the prairie. These driving lines served as bumper guides, funneling approaching buffalo to the cliff's edge. These driving lines were sometimes quite long. One of the most famous buffalo jumps, the Heads-Smashed-In Buffalo Jump, located in present-day Alberta, Canada, had driving lines that extended eight miles out onto the prairie (*Ask Dr. Dig: Questions about Native Americans*, 2006; Thomas, 1993).

In order for the process to work, groups of hunters would slowly coax a herd of buffalo to move towards the jump. Movement of the herd was accomplished by allowing the animals to see one or two hunters, making the animals nervous causing them to move away. Other hunters would don buffalo hides and mingle with the herd. These imposter buffalo were familiar enough to the herd as not to startle them, but somehow were not perceived as quite right, which coaxed the herd to move away from the imposter animals. This process necessitated patience and time, as startling the herd would cause a premature and uncontrolled stampede. To prevent this from occurring, much prayer was offered and close coordination among hunters was dictated by the hunting party leader. As the herd moved closer to the jump, they were guided to graze in between the driving lines. When the herd had sufficiently migrated into the driving lines, large numbers of hunters would come up from behind the herd and startle them into a stampede, driving them further into the arms of the driving lines and toward the edge of the cliff. If the buffalo attempted to run in a direction lateral to the cliff's edge, hunters hiding behind the driving lines of brush and rocks would suddenly jump up, yelling and shaking hides to frighten approaching buffalo to change direction and head toward the cliff. In this fashion, the herd was funneled to the precipice. As the buffalo became more frightened, they picked up speed. Those animals at the head of the stampede were unable to stop when they noticed the approaching cliff due to the pushing force of the animals behind them. Consequently, continuing rows of animals plummeted off the cliff's edge to the canyon below. Any animals that survived the fall were trapped in the constructed corral. Injured and confused, these surviving animals were easily slaughtered (*Ask Dr. Dig: Questions about Native Americans*, 2006; Thomas, 1993).

The buffalo jump serves as an appropriate analogy for the developed model (Figure 4.1). The model is embedded in the contexts of gender and culture, contexts similar to the driving lines of a buffalo jump. Located at the center level of the model is the rural male caregiver. In the model, the rural male caregiver is not particularly close to the edge of the cliff, representing caregiver crisis and located near the top of the model, nor is he particularly close to the bottom of the model representing caregiver success. Affecting the caregiver are challenges associated with rurality, rural masculinity and caregiving, as well as resources associated with rurality, rural masculinity, and other resources (e.g. financial resources). The balance between challenges and resources affects the stress level of the caregiver. Specific attributes of gender and culture that serve as resources and those that serve as challenges are listed in Table 4.3.

Figure 4.1 Gender-Cultural Model of Caregiving: Rural Male Caregivers
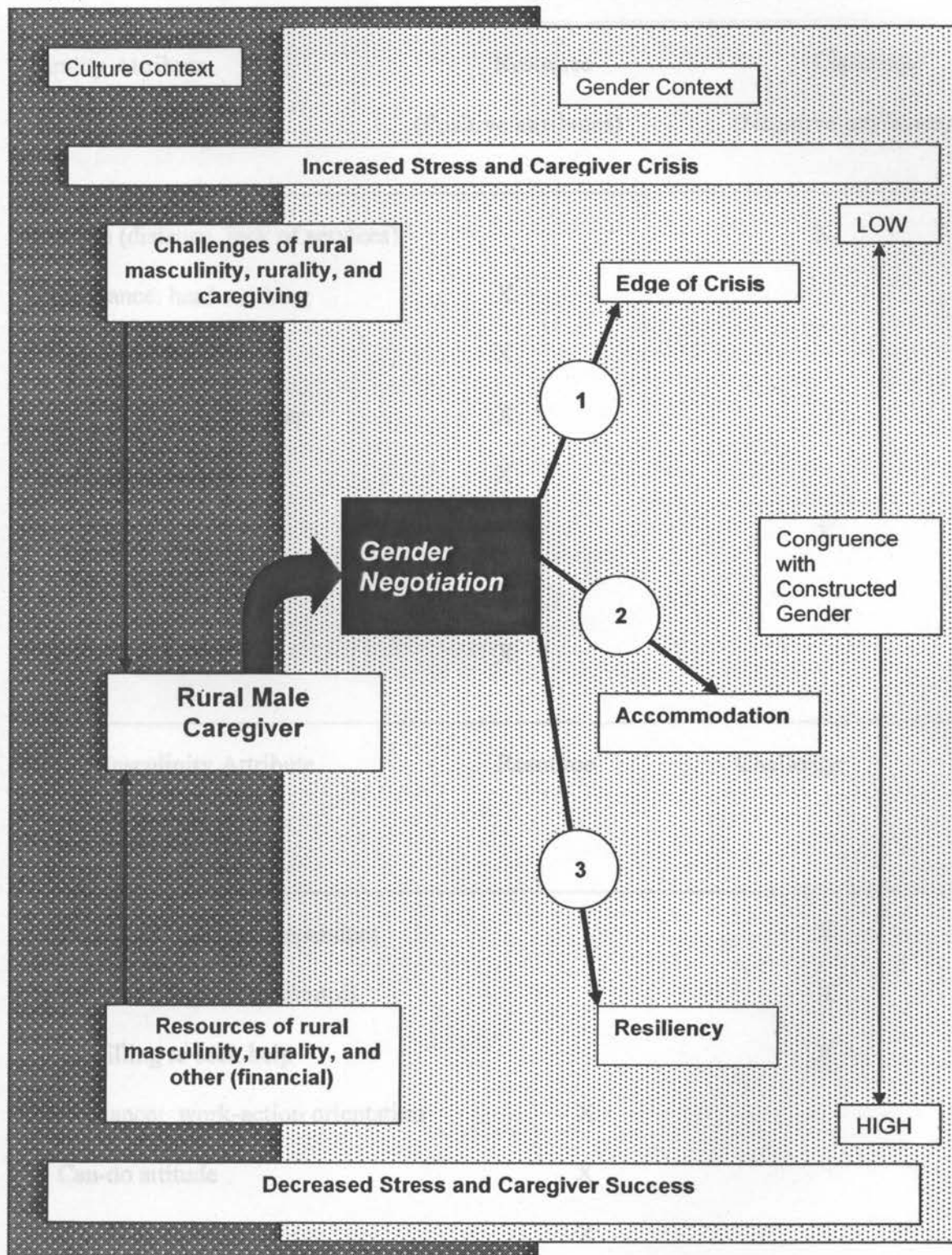
1= Gender Conflict Preservation; 2= Gender Compromise; 3= Gender Reconstruction

Table 4.3   Challenge and Resource Attributes of Rurality and Rural Masculinity

Rurality Attribute and sub-attributes	Resource (Positive attributes)	Challenge (Negative attributes)
Isolation (distance, lack of services)		X
Self-reliance: hard working	X	
Community support	X	
Look out for one another	X	
Faith communities	X	
Outsider status		X
Faith	X	
Care for one's own	X	

Rural Masculinity Attribute and sub attributes	Resource	Challenge
Self-reliance: overly independent		X
Resists relinquishing control		X
Unwilling to seek help		X
Self-reliance: work-action orientation	X	
Can-do attitude	X	
Focus on outcomes	X	
Will do all work necessary	X	

Table 4.4 Continued

Rural Masculinity Attribute and sub attributes	Resource	Challenge
Reluctance to meet emotional needs		X
Loner perspective/ stoicism		X
Isolation from male caregiver peers		X
Neglects personal health		X
Values outdoors/ hobbies	X	
Values common sense (foresight, ingenuity)	X	
Role as a provider	X	

Inherent to the role and demands of caregiving of are conflicts with attributes of rural masculinity. If the challenges (role changes and demands) are of sufficient quantity, men respond to this conflict and stress through a process termed gender negotiation. Caregivers negotiate the conflict between gender and caregiving in one of three patterns. Caregivers may cling to and preserve gender constructions, which intensify the conflict. Intensification of conflict intensifies the stress of caregiving and inhibits caregivers from taking full advantage of possible resources. This intensification and inhibition increases the risk of the caregiver to approach crisis. Caregivers may respond to this conflict through compromise with their gender constructions. This compromise allows them to tolerate the psychological stress inherent in adopting behaviors and roles that conflict with their gendered constructions. The costs of psychological stress are outweighed by the satisfaction and benefits of being able to accomplish the instrumental work of caregiving. This provides a state of accommodation to the conflict. Or, caregivers may reconstruct their perspectives on gender. These caregivers reconstruct or redefine specific gender constructions deemed counterproductive to caregiving through a process of reflection. Reconstruction allows these men to avert or minimize the experience of gender role-related psychological stress when adopting caregiver roles and behaviors. These caregivers develop a relative resiliency to increased caregiver challenges compared to other caregivers. Reconstruction allows men to experience possible rewards of caregiving, such as a renewed sense of altruism.

Returning to the visual inspiration of the buffalo jump, stress from increased caregiver challenges and gender role conflict must exceed resources. This imbalance is the catalyst in pushing men to the emotional and psychological labor involved with

gender negotiation. This catalyst is akin to hunters starting the buffalo stampede into the driving lines of the buffalo jump. Stress is worsened when men negotiate gender by preserving the conflicts. Conflict preservation keeps men moving in a dysfunctional direction, driving these men to the cliff's edge of caregiver crisis, similar to hunters driving buffalo to the cliff's edge. Negotiation through compromise leads men to a state of accommodation. Conflict is tolerated. This is akin to the buffalo herd stopping themselves before the cliff's edge in order to hold their ground. Conflict is not removed, but rather kept at bay. Negotiation through gender reconstruction would be akin to one of the driving lines falling apart. The shape of the driving line is altered. Buffalo are allowed to escape laterally, avoiding increased stress and movement toward the cliff's edge.

Exemplar participant narratives may best illustrate how this model works. The next section provides brief narratives of three of the participants from my study. One participant described a state in which he is clearly clinging to the edge of crisis. Another participant described a state in which he is making do (accommodation). And yet another participant described gender reconstruction, and how that reconstruction has transformed his caregiving experience.

Exemplar Participant Narratives

John: Gender Conflict Preservation: The Edge of Caregiver Crisis

John is a farmer and has been all his life. He works still even though he is approaching 80 years of age. For all but the first three years of his life, he has lived in the small house he calls home. The house is small, just four rooms. It sits in a cluster of

trees, the only protection it has from the sun and from an endless wind that flows across the prairie. Clinging to the clapboards like late summer berries are sporadic paint chips, sharing a secret of a long-ago whitewash. Littered about the yard lies a collection of rusting parts to long forgotten automobiles and farm equipment. In describing his home, John shares that he sees no point in fixing the place up, as he believes the State will buy the land on which the house squats when it gets around to widening the highway. John points to the barn. "I'll be sad to see that go. It sits closer to the highway than the house, so I guess it'll come down too." The barn, an oblong Quonset hut of gleaming corrugated metal was built where an older wooden barn once stood. This barn seems an odd companion to the short and squat house. From the highway, one might notice the farmhouse. The house, with only a lean-to roof and small square windows facing the highway, might easily be mistaken for a large chicken coop. But this odd coupling of buildings, gleaming barn and dilapidated house, characterizes a deep pragmatic streak within John, a streak he calls common sense. After all, the barn is essential to the economic vitality of the farm. The house is really nothing more than a bunkhouse if you think about it.

John and his wife have worked this farm for over 50 years. They never had children, so have relied on each other to complete all the chores. John states that he's used to tending to the work independently, usually relying only on the labor of himself and his wife. He has hired help only during harvest time. In his younger days, John grew multiple crops, herded both sheep and cattle, and even tried raising poultry. Now though, he leases much of his land to others. He still keeps a small herd of cattle and tends to hay field and irrigation equipment himself.

John has been a caregiver to his wife for about six years now, as severe arthritis, chronic pain, and COPD gradually made her unable to tend to her needs independently. For two years now, John's wife has been totally dependent upon him for most of her activities of daily living. Once in her wheelchair, she is able to brush her teeth and hair. On days when she feels particularly energetic, she can wash a few dishes or fold some clothes, but those days are very infrequent now. John describes his caregiving work in great detail. Everything adheres to a schedule, timed to coordinate with farm chores. At the time of my interview, John and his wife were able to start the day a little later as it was not yet harvest time and the cattle were in pasture.

The caregiving work is physically demanding. John must lift his wife during transfers as she is able to provide only minimal assistance with her arms. Yet John suffers from his own physical ailments. He has significant arthritis in his back and shoulder. Also, a previous stroke has left him with a weakened right arm. He does not complain. It is only after coaxing from his wife during my interview that he discloses his own health issues. Even still, John expresses little concern about his ailments since the farm work and caregiving work are getting done. Instead, John focuses most of his health discussion on the lack of common sense he finds among health care providers. He details how every encounter he and his wife has with doctors and hospitals is filled with conflicts over insurance restrictions, lack of access to desired services, or bureaucratic procedures. In John's mind, these conflicts would be minimized if providers had the common sense to streamline policies and procedures to meet the needs of clients. On top of this frustration are the long distances he and his wife must travel to access services, requiring time away from farm duties.

John rarely reaches out to anybody. Neighbors and people in town have offered assistance, especially when John's wife or John has required hospitalization, but John has usually turned them down. When questioned, John states that the neighbors are too old and decrepit to help much. Besides, he gets all the work done if his wife would be patient. This lack of patience, as he perceives it, is a constant source of irritation. During my interview, John's wife explains at length John's inability to meet her needs. She provides details of numerous incidents in which she was left sitting on a commode or in bed for minutes to even hours while John was outside doing chores. She shares that she gets frightened, that she will become hurt waiting for John to come in and assist her. She becomes upset during her talk, the pitch and cadence of her voice quickening and her eyes welling with tears. I look at John. No visible emotion cracks his poker-face. Instead, John sits in a chair, eyes blank, shoulders stooped, and an overwhelming fatigue permeating from his core. When his wife takes a breath, he changes the subject to details of his farm work, his ingenuity at addressing unexpected crises with the farm animals or crops, or his savvy business decisions with those who lease his land. John's face becomes more animated as he provides his case that he is, indeed, a self-made man.

John is a loner. He says he knows everyone in town, though he wishes that some people he didn't know. John says he has some old friends, but has too much work to do to spend much time with them. Before his wife got sick, he used to belong to a local gun club, even serving as club president. Membership had dwindled down though, so much so that John and one other man were the club's only official members. Both men decided to fold the club some time ago, neither wanting to foot the electric bill for the club house. John shrugs his shoulders at my inquiries about the benefits of confidants. Instead, John

shares his disappointment with a recent event. Several weeks prior to the interview, his 60th year high school reunion had taken place. He wanted to go and see "some of the old timers…" It was a three-day affair. He knew he couldn't spend three days away from the farm and his caregiving work, but thought he could go at least for one day. He made arrangements to have a health aide from the local home health agency come and watch his wife. At over $10 per hour, he could only afford to hire her for an afternoon. It turned out that Friday afternoon was her only available slot. John agreed and attended the reunion only to find out that most of the attendees arrived in town on Saturday, the next day. This time, John's face shows genuine pain. He spent a significant portion of their weekly budget on this aide and did not see many of his old high school friends. Since he lived only four miles out of town, I ask if he stopped by the next day for a quick visit. John shakes his head, "No, too much work to do here at home."

At this, John's wife seems to take offense, stating that it wasn't her fault she needed so much care. She proceeds to detail how John gets tied up with farm chores and doesn't come into the house to tend to her needs. John remains silent. I ask John if it is difficult juggling farm work and caregiving. John perks up. "Well, not really." John describes how he goes out to the barn expecting to complete a quick chore and sees that something else needs to get done. He looses track of time and forgets that his wife might need something. "That's the way I've always been," he comments. "The work has to get done." I ask him if changing himself to think about caregiving was like teaching an old dog new tricks. He chuckles and nods his head in agreement.

At the conclusion of this interview, John tells me that he'll walk me out to my car. As we get up, his wife asks how long he'll be. "I'll be just a minute," he tells her.

"Good," she replies. "I have to go to the bathroom." As we stand out by my car, John and I have a few moments of privacy. Squinting in the afternoon sun, I look across the flat, dry fields, nourished only by rainwater and a thin ribbon of irrigation water. John tells me about a small herd of cattle off in the distance. We turn and look at his fields on the other side of the highway. The view is partially blocked by a dirty and slightly dented van. John tells me that he completely drained their life's savings to purchase this used van two years ago. "But we had to have something that could take her and her wheelchair and oxygen tanks to the doctor's." He explained that he had tried to get a loan, but felt that the interest rate was too high. So, he used their life savings to pay off some bills and purchase the van with cash. John stands a bit taller as he explains how he has no debt. I ask him if that was a source of pride. John nods his head and smiles, "I ain't beholding to nobody." Thinking of the time, I give John a quick thank you and say my good-bye. As I pull down the driveway, I look into my rearview mirror for a last look at John. Instead of returning to the house, I see John pick up a couple of buckets and begin walking to the gleaming silver barn.

Glen: Gender Compromise: Accommodation

Glen is an energetic man in his late 40s. He speaks with incredible speed on the telephone, almost as if he is in a manic frenzy. He says that he has so much to tell me. I check to see that I have an extra cassette for the tape recorder just in case.

Glen grew up in an outer suburb of a large Midwestern city. He moved to rural Oregon 15 years ago. He claims to be very much an insider of his community, being active in numerous town organizations over the years. His self-described gregarious

nature has facilitated him becoming close to most of the people in town. He says he understands how people think in town and that he shares their values. Since I am not planning to interview non-caregivers who reside in his town, I cannot validate his insider status. I take him at his word.

Glen became a caregiver four years ago. His mother had Alzheimer's disease and his sister was dually diagnosed with cerebral palsy and bipolar disorder. Until he assumed their care, Glen's father was the sole care provider. Upon his father's death, Glen's two other sisters, both nurses, recommended that their mother and sister be placed in facilities. Glen wouldn't hear of it, and against the wishes of his sisters, Glen moved his mother and sister to Oregon to assume their care. Glen initially sought a permit to add an addition to his home to accommodate his mother and sister, but the city would not grant a permit due to zoning restrictions. Glen then applied to convert his home to an assisted living facility and was then able to receive the appropriate permits and funding to build two small apartments attached to his home.

Prior to assuming care of his mother and sister, Glen worked as an accountant. It became clear to Glen that his caregiving responsibilities would conflict with his work commitments. Glen took a lower paying and lower status job that provided much greater flexibility with hours. At first, this bothered Glen, but shares that he decided that he was not defined by his job, but defined instead as a member of a family. With his flexible hours, he and his wife were able to coordinate caregiving, work, and sleep schedules.

Glen describes the intense day-to-day caregiving work and juggling of schedules he has performed over these past four years. I ask him where he learned how to do the things he does. He replies

My father...he was just a doer, you know, washing dishes, making dinner and everything. All my life it was like that. If mom worked in the hospital, her shifts, I mean, how many Thanksgiving dinners did this man make? You know, I mean, changing the kids diapers. I mean, he was just a hands-on kind of guy from that direction, and at the same time, he'd be underneath the car pulling the transmission. You know...he worked every day of his life. I mean, EVERY DAY....I mean, I could take lessons from him, no question about it. But with that said, my goal was always to kind of fill his shoes.

Glen proceeds to tell me how he is a hands-on guy himself, never balking at hard work and the need to roll up his sleeves to get the job done. However, as the interview proceeds, the discussion subtly turns to issues of control. At first Glen talks about control rather indirectly, disguising his need to be in control by his willingness to be in the thick of the caregiving work. However, with my questions, Glen discusses control more directly. Glen admits that he didn't want to place his family members in facilities because he didn't feel that the services provided by these facilities met his standards. He acknowledges that facility employees are highly trained and caring, but economic constraints prevent them from doing their best. Glen states that he would be a nuisance, directing the care down to the minutia. He says that he would probably come in daily telling the nurse's aide that even though orange juice is more expensive than apple juice, his mother prefers orange juice. His need to be in control of the caregiving was apparent with the aides he had come into his home to help with caregiving.

For several hours a day, during the afternoon while he slept (he would get home from work about 0900), he had an aides keep an eye on his mother and sister. He gave the aides strict instructions on what he wanted and didn't want. One aide was particularly problematic in that she stole some pocket change from his mother. Despite this, he noted how good she was with his mother. She seemed to be the only one that could make her laugh. The walks this aide took with his mother energized his mother and stimulated her to become engaged in conversations and games. Although he couldn't keep this aide after she stole some money a second time, he realized that others involved in the caregiving contribute talents and skills that he did not possess.

Glen shares that shortly after this incident, his mother died. That was two years ago now, and he has continued taking care of his sister. He has learned to accept the fact that he has to occasionally let go of some of his control and allow others, namely his sister, to become more involved in the care decisions. Sometimes, this hasn't always worked out satisfactorily. He shares a story of how he let his sister do her own laundry, and in the process, ruin a set of brand new towels when she poured in a whole bottle of fabric softener. Nevertheless, Glen states that he realizes now that others, such as those in an assisted living facility, could provide his sister good care. Although a facility may not do everything the way he might, Glen says that he could still be involved in her care and still provide input, just not on a 24/7 basis. Glen has not made the decision to place his sister, but shares that after four years, he and his wife are nearing exhaustion. Glen ponders what his role might be should he place his sister. He surmises, "And you know, she would appreciate, I think, if I came by every Friday or so to take her to Wal-Mart or Bi-Mart or something. Shopping is her savior." Four years ago, Glen would never have

dreamed about placing his sister in a facility. He's not quite sure why, whether it was a sense of familial obligation or not. Glen says he might have just thought that nobody could care for them as well as he could, and if you love someone, you want the best for them. Yet, Glen acknowledges, he's accepted the fact that others can provide good care too. Somehow, knowing this fact, Glen states he feels the caregiving is easier. Glen adds, "You know, if and when the time comes to place her, I'll be OK with that."

Dan: Gender Reconstruction: Resiliency

Dan is a 52-year old man who has spent his whole life in a rural community and his whole career working in a mill. Ten years ago, Dan and his wife were struck with horrific news: his wife was diagnosed with amyotropic lateral sclerosis (ALS). Dan explains that at first, her symptoms were fairly mild. Dan would only have to help her sign her name to checks or assist in opening jars. He says that her right hand was affected first, then her arm and then her left hand grip. Within a year, she was wheelchair-bound. Six months after that, she became bed bound.

At the time of her diagnosis, Dan and his wife had two twin daughters, 13-years old, and a toddler son. Dan was working the graveyard shift. Shortly into her illness, Dan would come home just as the girls were leaving for school. Dan looked after his wife until his daughters returned home. He would then get some sleep while his daughters took over the caregiving and taking care of the toddler. He would get up in the early evening and resume care while the kids got ready for bed. Dan and his family kept this schedule for over a year. Over this year, Dan's wife required more and more assistance with toileting, hygiene, and feeding. The workload increased exponentially.

Dan admits that work was a respite. It gave him an opportunity to focus his mind and energy on something other than his family (although Dan admits that he dreaded getting a call at work from his daughters that his wife had died. "She passed away on one of the nights I was home," Dan recalls. "I'm glad things turned out that way.") Dan says his co-workers were supportive from the start. They asked how they could help, and his boss let him take a vacation day whenever he wanted. Dan learned everything he could about ALS, and shared this information with his co-workers. At first, he did this so that his co-workers realized that he wasn't exaggerating the seriousness of his wife's illness just so that he could get some extra time off. But Dan noted that their continued offers to help convinced him that their concern was genuine.

Dan then discusses his church family. He says that they were a Godsend, that without them, he could never have made it through his wife's illness. In discussing the difference in support, Dan says, "I guess work was more analytical, or 'What can we do to help?' Church people were not only to help with physical things, but spiritual." For Dan, one of the greatest services they provided was emotional and spiritual guidance to his daughters. Dan recounts how draining it was to tend to the grieving needs of his wife, his kids, and himself all at the same time.

As his wife grew more ill, volunteers from the church provided more in-home assistance. Dan says that this did not bother him at all. He was comfortable with friends and neighbors at work and at church checking in with him on how they could help. He says he still felt in control because all volunteer time was cleared with him. His resistance to relinquish control was tested, however, when hospice was brought into the picture. Dan says to this day he is not sure how hospice got involved. He suspects that

one of the church ladies called hospice to come in. All he knows is that he got a telephone call from hospice asking him if it would be OK to stop by. Dan says when they came, five or six of them swooped in and took charge. He says, "They came in and they said, 'OK, we're going to do this and this and this.' And I said, 'Wait a minute! I don't know any of this.'" Dan chuckles. In retrospect, he knows now that they knew what they were talking about. Dan comments, "If they had waited for me to call and give the OK, it would have been a ways down the road. And they could see the stress."

I ask Dan about the stress. "How did they know that you were stressed? What did they see?"

Dan answers that they could see that he was in denial that she was as close to death as she was. But more important than that, Dan notes, they could see that he wouldn't let them help him. Dan shares that he fought them at first, but his church family helped him learn to let hospice do their job. Once he was able to do that, he was able to see how his clinging to control was hurting him and his family. Dan says

You know, I'm macho, and I'm a guy and I figured I could do it all. So, in retrospect, you know, I could have had hospice in here two or three months sooner. Not that they would have been able to do a whole lot, but it would have been nice.

A few years after his wife died, Dan's grandmother's health began to deteriorate. She lived next door, so Dan did not move her into his home. Dan says he cared for her for two years until she died, just a few weeks prior to this interview. I ask Dan to

compare the two experiences. Dan says that his grandmother's death was easier on him. She was 92 years old and had lived a full life. Dan says that he also knew what to expect, how to pick cues that the body was shutting down in preparation for death. But more than that, with his grandmother's illness, Dan reached out for help much sooner and without reservation. Dan states that he didn't feel he needed to always be in the driver's seat. Although his grandmother did not belong to his church, his church family was there for him and his family, his grandmother included. Dan says that he accepted support wherever he found it, and accepted it with enthusiasm. Dan takes off on this message in giving advice to other caregivers. Dan says

> Don't be afraid to ask for help. And, uh, to just know that there are resources out there. I guess that just goes with the 'don't be afraid to ask for help.' But there really is. There are...I never even really used all the resources that are out there. So, that's what I would say. Don't forget that there are people out there who can help you. I mean, don't be as fussy as I was....There is always somebody, and you don't know who that is. It might be somebody you don't expect.

I ask Dan how he's doing now. "You know, I'm doing good." Dan reflects on how he's changed after caring for these two women. Dan says he's gained a lot of insight. Dan says he's never too proud to ask for help and understands how important others can be in providing emotional support. Pushing others away because of pride or because you think you can do it all robs you the benefit of receiving the love of others. Dan shares a story of a gentleman in his church who recently lost his wife. This

gentleman has not learned Dan's lessons, and pushes fellow church members away. Dan says he's worried. This man refuses to leave his house. Dan fears he will commit suicide.

Dan returns to the topic of receiving love from others. He shares how this support really saw him through tough times, but only came after he learned how to accept the help of others. Now Dan wants to return the favor. At first, Dan thought he would become a hospice volunteer. But now, Dan is considering the seminary. His caregiver experiences and the deaths of his family members have strengthened his faith. Dan believes his insight is a gift that he can share with others.

CHAPTER 5: DISCUSSION

Introduction

In the previous chapter, the key process constructed from the data, gender negotiation, was defined and discussed. Briefly, this process is activated when caregiving responsibilities push men to adopt new behaviors and perspectives. In order to push men to negotiate gender, caregiving responsibilities must result in stress of sufficient frequency and intensity to conflict with self-perceived constructions of rural masculinity. Attributes of rural masculinity that most readily conflict with caregiving responsibilities are an overly independent self-reliance (especially a resistance to relinquish control and an unwillingness to ask for assistance) and neglecting of one's emotional health. If these attributes are strongly held constructions and conflict with caregiver responsibilities, men experience a psychological stress stemming from a gender role conflict. Men might address this gender role conflict in one of three ways. First, men may stubbornly cling to these gender attributes resulting in intensification of the conflict, its inherent stress, and movement toward caregiver crisis. Second, men might make a compromise between the conflict and the benefits of caregiver task completion, leading to a state of accommodate. Third, men might reconstruct their masculinity by redefining or reprioritizing the attributes that construct their personal masculinities. Gender role conflict, thus, is minimized by gender reconstruction, resulting in a relative resiliency. Positive attributes of rural masculinity that are pervasive in an individual's gender construction may trump or direct attention away from gender role conflict and the need to negotiate gender.

In this chapter, relevant findings from the extant literature will be used to compare and contrast to the findings of my study. In particular, theoretical models from other grounded theory caregiver studies will be examined in order to explore how they are bolstered by the current findings or how they may conflict with the current findings. Following this, implications for rural providers will be presented. Also in this chapter, discussion of how my study's theoretical model might be transferred to other populations will be provided, as well as limitations of my study and recommendations for further research. In the chapter's conclusion, study findings will be summarized in terms of each of the study's aims presented earlier in Chapter 1.

Comparisons to the Extant Literature

Rurality

A number of attributes of rurality were constructed from the data as they relate to caregiving. All of these attributes are supported by discussions of rurality in the extant literature. Consistent among the men was a geographical separation from large population centers, one aspect of the rurality construct (Bigbee, 1993; Wagenfeld, 2003). Along with distance from population centers, all of the men discussed large physical distances between their communities and comprehensive health services. Although most of the men lived relatively close to emergency care services, care recipients required specialists that were sometimes 250 miles away. Travel to these specialists placed emotional, financial, and physical stress on caregivers and their recipients. The hardship encountered with traveling for services is characteristic of many rural dwellers (Bales, 2006; Findholt, 2006; Henson, Sadler, & Walton, 1998; Winters et al., 2006).

Another attribute of rurality that was pervasive in the data was self-reliance. Self-reliance was attributed to members of the rural community at large and included related categories such as hard-working and hardiness. These characteristics of self-reliance were evident in descriptions of how both men and women would work hard at caregiving and would value independence from the assistance of others. Self-reliance was described as pervasive with historical roots, such as in the characterization of rural dwellers as "Oregon Trail" people (Participant 12). Self-reliance among rural dwellers are well supported in the literature (Bales, Winters, & Lee, 2006; J. Bigbee, 1991; Bigbee, 1993; Chafey et al., 1998; Koehler, 1998; Lee & Winters, 2004; Leipert & Reutter, 2005; K. Long & Weinert, 1998; Wirtz et al., 1998).

Seemingly paradoxical to self-reliance and independence is the attribute of community support, although this support belies the interdependence among rural dwellers to come together for completion of large work projects or to provide social support. Community support was described by the men as coming not only from their neighbors in general, but also from work settings and from faith communities. The pervasiveness of support in rural communities was particularly evident in the few participants who had lived in urban communities, places perceived as having little if any community support (Participants 4 and 7). Community support was identified by a number of the men as essential to the well-being of caregivers. The high level of community support available in rural areas is also supported in the literature (Bales et al., 2006; Bigbee, 1993).

However, access to this community support may be dependent, in part, upon an insider status. This attribute was noted by two participants who were new to their

communities. Both of these men noted that their communities were "clannish" in some ways, which made them feel that obtaining social support was more challenging. The idea of being an insider or an outsider to a community is also discussed in the literature. Although some of the references in the literature focus on the insider/outsider status of service providers, the concept has been used in general terms to people new to a community or possessing values/ beliefs not prevalent in a local rural community (Bailey, 1998; Findholt, 2006; Kane & Ennis, 1996; Lee, 1998a).

Another attribute of rurality identified by the participants was that of faith. Although the men did not necessarily tie faith to church attendance, they described themselves, their families, and their neighbors as believing in God, trusting that God would see people through hard times, and that some things that God sends us cannot be overturned by hard-working and self-reliant individuals. Faith and fatalistic perspectives are less supported in the literature as unique attributes of rurality than are some of the other attributes constructed from the data. Nevertheless, the centrality of faith and the use of prayer by rural dwellers has been noted (Arcury et al., 2000; Bennett & Lengacher, 1999; Congdon & Magilvy, 2001; Gaskins & Lyons, 2000; Koehler, 1998; Running, 1998; Wallace et al., 2002).

One additional attribute of rurality that was constructed from the data is that of caring for one's own. The participants were explicit that rural dwellers had family values that encouraged, even expected, family caregiving and discouraged placement of family members in institutions unless absolutely necessary. This attribute was described as general to rural dwellers and not unique to the participants themselves. Participants noted that their care recipients would be just as willing to care for them at home if they

themselves were in need of care. Also, in the case of one participant (Participant 2), there was condemnation of a family member by the townspeople when she was resistant to assist with family caregiving. Several of the participants commented that this value was instilled upon them from an early age, though one of the participants commented that this value is less prevalent in younger generations. It is possible that this value of caring for one's own might be related to the attribute of community support. Participant 8 noted that his small town was "like a family" and Participant 6 referred to his faith community as his "church family". However, this value was most explicitly described as a motivator for keeping the care recipient in the home setting. I was unable to find direct support for caring for one's own as a rural attribute which would support family (and possibly, community) caregiving However, indirect support could be drawn from literature references of the importance of family support and family health in rural communities (Bigbee, 1993; Meiers, Eggenberger, Krumwiede, Bliesmer, & Earle, 2006).

Rural Masculinity

As noted earlier, rural masculinity and rurality are intrinsically intertwined since they are both socially constructed phenomena. As such, it should be no surprise that some of the attributes of rural masculinity constructed from the data overlap somewhat with attributes of rurality. However, the participants identified several attributes that they ascribe as particularly strong or prevalent in rural men. Hence, these attributes are used as defining characteristics of rural masculinity. The academic literature is relatively void of any discussion of how masculinity might be constructed differently among rural men than among non-rural men, nor of empirically-derived characterizations of what a rural

masculinity or gender ideology might be. However, the literature provides substantial

support that, in theory, masculinity ideology among rural men is likely different than

masculinity ideology among non-rural men (Beynon, 2002; Bohan, 1993; Courtenay,

2000; Good et al., 1995; Levant & Habben, 2003; Levant et al., 1992; O'Neil et al., 1995;

Pleck, 1995; West & Zimmerman, 1987). It is in terms of characterizing rural

masculinity, especially in terms of caregiving, that may be the most unique contribution

of my study.

As noted in Chapter 2, Levant and Habben (2003) note that rural men tend to be

more traditional in their masculine ideology. Pleck (1995) defines masculine ideology as

> Beliefs about the importance of men adhering to culturally defined standards for
>
> male behavior....The construct of masculinity ideology derives most directly from
>
> research on what is generally termed 'attitudes toward masculinity'....Masculinity
>
> ideology also connotes better the superordinate, organizing nature of these beliefs,
>
> at both the individual level and social-structural level....There is clearly not a
>
> single masculinity ideology, but many. The concept refers to a variety of
>
> component beliefs that may be endorsed to different degrees and related to each
>
> other in varying ways, both in individual and in different social subgroups. (p. 19)

Traditional masculinity ideology has been characterized by toughness, self-reliance,

homophobia, avoidance of behaviors perceived to be feminine, avoidance of

emotionality, non-relational / objectifying attitudes toward sexuality, and an importance

placed on accomplishments and work (Good et al., 1995; Levant & Habben, 2003; O'Neil

et al., 1995). In addition, Levant and Habben suggest that rural men may initially be more trusting than non-rural men, consistent with a "good neighbor doctrine" (p. 177).

Characterizations of a rural masculinity ideology, particularly rural *Western* masculinity ideology, are nearly non-existent in the available academic literature. As such, evidence of a rural masculinity ideology must be supplemented from other sources such as the popular literature and from my field experience. The popular literature tends to portray rural men as noted above, with possibly the additional characterizations that rural men are unrefined, poorly educated, and cling to common sense as a source of logic and knowledge.

The male characters in the film *Brokeback Mountain* (McMurty & Ossana, 2005) display a number these characterizations. In the film, key tensions that comprise the plot stem from homophobia, restrictive emotionality, and the centrality of work. The centrality of work serves as the overt *raison d'etre* for the early experiences of the two main characters and the separation between the characters over time. However, homophobia and restrictive emotionality serve as the undercurrent, sometimes overt but often covert, for the pathos in the film. Even minor male characters in the film are depicted as tough, stoic, homophobic and self-reliant individuals. Tenderness and gentleness emanating from any male character are generally limited to remote and private mountain hideaways.

Michael Martin Murphy sings about rural masculinity in his song *Cowboy Logic* (Cook & Rains, 1990). The lyrics describe how cowboys solve problems and dilemmas, namely with approaches based on common sense, a focus on outcomes, hard work, and simplicity. Murphy sings

...When the times are hard and the chips are down, he [the cowboy] knows just what to do. Now the cowboy's got a set of rules that he lives by day to day, and if you ask him for his advice, he'll more than likely say...

Murphy then proceeds with a set of maxims that illustrates how cowboys think and act. For example

...If it's fence, mend it. If it's a dollar bill, spend it.....If it's load, truck it. If it's a punch, duck it. If she's a lady, treat her like a queen. If it's a job, do it. Put your back into it. 'Cause a little bit of dirt's gonna wash off in the rain. If it's a horse, ride it. If it hurts, hide it. Dust yourself off and get back on again.

These maxims highlight values of hard work, toughness, and simple functionality. Murphy then sings how these maxims are well-known to the point of universality. He sings in the refrain

...That's the cowboy logic. Every cowboy's got it. It's in the way he lives his life and the songs he sings. That's the cowboy logic. Every cowboy's got it. He's got a simple solution to just about anything.

Martin sings many other songs, many of which are traditional Western songs and ballads. In these songs, men are depicted similarly. Notably however, in many of his songs, men

experience heartache due to restrictive emotionality and inattention to the emotional needs of one's love interest. It is as if music is the only acceptable place to discuss and to teach other men about intimate emotions.

Far too many popular books and novels have been written about rural Western men and their possible masculinity ideologies to summarize here. Quite possibly, many of these written accounts present an overly dramatic or stereotyped depiction of rural men. An historical and notable exception is likely the stories written by Charles (Charlie) M. Russell. In my conversations with both men and women during my field placement and my residency in Montana, Russell was identified most frequently as the best source for understanding both rural men and rural Western culture. Russell was a renowned Montana artist and storyteller, whose life spanned the transition of the Wild West into an industrialized and increasingly urbanized region. Although he lived nearly a century earlier, Russell's stories of rural men adapting to changes of the 20th century mimic the experiences of today's rural men adapting to increased technology and changing economic realities (Cristy, 2004), as evidenced by the wistful account provided by Participant 8 in Chapter 4.

The popularity of Russell's stories is that they resonated with people, depicting the realities of their values and their lives, though often with humor. Russell is better known for his paintings and sculptures, though he preferred his storytelling. Cristy (2004) notes

Russell was unenthusiastic about his paintings because rendering stories through paint daubed on canvas was hard work, and the results seldom satisfied him as the complete story or as acceptable art. (p. 9)

Despite his years of storytelling, few of his stories were written down. One text, *Trails Plowed Under*, published after his death, is one of the few surviving texts where one can read Russell's stories, minus the foul language that usually sprinkled his tales (Cristy, 2004). In reading Russell's stories, one notes the similarities in the thinking and actions of his characters to the cowboy logic described by Murphy. The basic plot in many of Russell's stories centers on a rugged, tough, and self-reliant man who is out working at the beginning of the story. The work may be ranching, cowboying, hunting, or some other endeavor. While working, the main character comes across a surprising, and often dangerous, problem which requires swift and creative thinking. Unfortunately, the character relies upon a seemingly common sense reaction, but a reaction that doesn't quite fit the dangerous new problem. Some calamity or unexpected series of events results, informing the reader that the character did not really have the common sense he thought he had. Russell twists this plot with humor to help drive home his point while entertaining his audience at the same time. Sometimes, the story character shares a story with his friends about such a calamity. For example, Russell (1927) tells a story about a group of rural schoolboys that were so much trouble that the school couldn't keep a teacher. The boys were violently unruly, led by a ringleader nicknamed Mix. The parents did not want their sons to go uneducated, so they hired a prize fighter from New York to come teach the children. On the first day of class, the boys go into their

accustomed pattern of physically driving the teacher out. However, this time, the teacher has one up on the boys. Russell writes

When the school room quiets down the new teacher pulls up a nice little talk.

"Boys," says he, "I ain't huntin' for trouble, but it's been whispered around that this bunch is fighty, an' I'm here to tell you as a gentleman that if there's any battle pulled, you boys is goin' to take second money." [The last word ain't left his mouth till one of the big kids blats at him.

"Come here," says he, kind of pleasant, to the kid that did it. The kid starts, but the whole bunch is with him. The teacher don't move nor turn a hair, but he kind of shuffles his feet like he's rubbin' the rosin. The first kid that reaches him, he side steps and puts him to sleep with a left hook. The next one he shoots up under a desk with an upper-cut, and the kid lays there snorin'. They begin goin' down so fast, Mix can't count 'em, but the last he remembers he sees the big dipper an' the north star, an' a comet cuts a hole through the moon. When he comes to, it looks like the battle of Bull Run, an' the teacher is bendin' over, pourin' water on him from a bucket....

When he gets through bringin' his scholars back to life, teacher tells the boys to get their song books an' line up.

"He makes us sing every mornin'," says Mix. "We was sure broke gentle." (pp. 66-67)

Aspects of a rural masculinity ideology that permeates Russell's stories include self-reliance, hard work, toughness, a focus on outcomes, and the value of common sense. Also permeating Russell's stories is the centrality of liquor in the lives of men, both as a means for socialization and as a reward at the end of a hard day or hard work.

Yet another source of information stems from my field experience. The details and rationale for the field experience are detailed in Chapter 3. In conversations I had with men and in listening to conversations among men around me, work was the most common topic of conversation or was the topic that was used as an entrée to other conversation topics. When conversations covered multiple topics, much greater detail and explanation was used when discussing work than with discussing other topics. Themes of self-reliance and hard physical labor permeated discussions of work. Interestingly, I noticed a generational difference in how men communicated. Younger men were much more verbose, providing much more detail in the topics they discussed. Older men were more likely to communicate messages through shared meanings and non-verbal communication. As an illustration, in discussing a fishing trip, a young man might provide the details of the drive to the fishing spot, the bait used, the techniques he used, how the day went, etc. The transcript of such a conversation might be relatively lengthy. Whereas the same conversation between two older friends might go something like the following:

"Went fly fishing up past Choteau." (Long pause.) "Got there early, before the heat." (Long pause. Listener nods head slightly.) "Cast my red corker in an eddy. In no time, I had my limit." (Long pause.)

"Good day then?" asks the listener.

Slight smile. "Yep, best ever." Both nod their heads slightly.

During these long pauses, there is not an absence of communication. Instead, there is a near telepathic exchange of shared meanings and experiences. The listener receives a story full of information. The listener understands as he has been fishing before, knows the speaker well, and can visualize and possibly viscerally experience the fishing trip in great detail. With older men, I discerned a pattern of economy of words, a parsimonious functionality to communication. This pattern was evident in many of the interviews I had with participants. Frequently, responses to open-ended questions were brief, concise, yet filled with meaning.

Attributes of rural masculinity constructed from my study's data are generally consistent with the attributes of rural masculinity ideology from the academic and non-academic sources listed above. However, not all source attributes were identified (e.g. homophobia) as the interviews were centered on a caregiver context.

Perhaps no other attribute was as pervasive in the data as self-reliance. Within this broad attribute, I constructed various sub-attributes, characteristics that related to a self-reliant nature. These sub-attributes included having a can-do attitude toward work, doing all the work that is necessary to accomplish a task, and focusing on outcomes or the end-product of work. Other sub-attributes included a resistance to relinquish control, an unwillingness to seek assistance, and for some of the men, a loner-type or self-induced isolationist behavior. For many of the men, this overall self-reliance mirrored the non-academic source characteristics mentioned above. These men, by in large, approached

caregiving work with an outcome-focused and self-reliant perspective. They tackled new challenges, at times with previously learned maxims or rules for task accomplishment. Like some of the characters in Russell's stories, at times these challenges required swift and creative thinking. However, like some of Russell's characters, this swift and creative thinking didn't always lead to desired outcomes, and sometimes, led to calamity. Unlike the characters in Russell's stories, these negative outcomes were not viewed with humor.

Similar to the characteristics found in the literature and from the field experience, constructed attributes from my study include the tendency to value common sense and the tendency to neglect one's emotional and physical needs. Neglect of physical needs projects a toughness, a resiliency to illness and injury. This neglect was overtly described by some of the men, though most of the men denied physical ailments or complications from caregiving work. Medical records/ histories were not examined, so it is unclear if the participants were really as healthy as reported or if possible ailments were denied. More clearly discussed by the participants was the neglect of their emotional needs. This attribute has some relation to restrictive emotionality, an attribute mentioned by the academic sources. Restrictive emotionality was noted in the stoicism of some of the participants and the stated reluctance to share emotional pain and stress with others. For some of the participants, this reluctance was exacerbated by their perception that their friends would not understand them since they were not caregivers themselves. A couple of the men felt that talking with other male caregivers would be very beneficial. These men felt that other male caregivers would provide a mutual insider status, a shared experience that could be discussed. Interestingly, this mutual insider status resembles the sanctity of the mountain hideaways in *Brokeback Mountain*; a separation from the usual

social network so that emotionality could be expressed in a safe and supported environment. Nevertheless, except for those participants exhibiting significant loner behaviors, most of the men recognized that they had emotional needs and most advised that male caregivers should address those needs. For some of the men, this recognition actually did result in action, usually by spending time with friends or faith communities.

One attribute constructed from the data not noted in the academic and non-academic sources is that of serving as a provider. A sense of serving as a provider, along with the related attribute of rurality of caring for one's own noted earlier, was prevalent in most of the participant transcripts, primarily as the rationale for enduring the work of caregiving. One reason that this attribute may not be supported in the non-academic sources is that rural men are often characterized as lone outdoorsmen. Although perhaps romantic in thought, the lone cowboy, miner, or trapper in the rural West is not typical of today's reality. Instead, farmers, ranchers, loggers and the like living in rural communities are members of families. The importance of families and caring for one's own has likely permeated rural masculinity. The sense of serving in the provider role likely has yet to permeate the popular literature.

Caregiver Challenges

The participants provided much detail on the challenges encountered during their caregiving work. Although challenges were not quantified among the participants using available tools which measure caregiver burden, strain, depression, and the like, the participants described multiple challenges that have been described in the literature at length. These challenges include fatigue, stress, strain in personal relationships, role

conflicts among multiple demands, time management challenges, difficulty in accessing resources and respite, disrupted sleep, and negative consequences to their personal health. Of importance though, the participants provided variation in how they interpreted the effect of these challenges. Some participants provided detail of the great amount of time spent doing hands-on personal care. Some participants described great amounts of stress resulting from caregiving work; whereas others minimized the characterization of the work as toil, commenting very instrumentally that "you gotta do what you gotta do." Many of the men described how the affective consequences of caregiving (such as stress) changed over the course of time, either intensifying as caregiver work intensified, or lessening as caregivers became accustomed to the work. This variation among the 12 participants over a trajectory of caregiving supports the criticism made of the numerous quantitative caregiver studies which have examined caregiver phenomenon using cross-sectional study designs, and thus, do not capture the experience of caregiving over time or from a trajectory perspective (Coe & Neufeld, 1999; Harris, 1993; Kramer, 2000). Indeed, the findings of my study suggest that men experience caregiving in a dynamic, multi-directional process. Measurement of various caregiver challenges among these men at the time of their interviews would have likely yielded highly variable results based, in part, on where the participants were in the process of gender negotiation and their individual caregiver trajectories.

In contrast to caregiver challenges, few of the men described experiencing caregiver rewards, even when specifically asked. For most of the men, rewards were described in terms of work. The men noted that they were satisfied and experienced pride that they were able to keep their care recipient at home, or that they were able to

accomplish certain caregiver tasks. These rewards served to strengthen or validate pre-existing rurality or rural masculinity attributes. Of notable exception were the men who used the gender reconstruction pattern of gender negotiation. These men described rewards much more characteristic of personal growth, such as a strengthening of faith, a new and more balanced perspective on life, or a more accepting perspective of one's personal strengths and limitations.

Gender Negotiation

Gender negotiation is the central process constructed from the data. This process has been described in detail in Chapter 4 and in the introductory section of Chapter 5. In returning to the available extant literature, virtually nothing is written about the negotiation of gender as a process of caregiving. As detailed in Chapter 2, gender in the caregiver literature is discussed in terms of gender differences in the provision of care, gender differences in the consequences of caregiving, or theoretical propositions to explain these gender differences. Little was found discussing how an individual caregiver is influenced by an individually constructed gender ideology while providing care.

Two studies were located, and previously reviewed, that explored how men might negotiate gender in their caregiving (Bowers, 1999; Hirsch, 1996). However, both of these studies assume a gender identity paradigm and use the BEM Sex Role Inventory as a measure of gender identity. The gender identity paradigm proposes a fixed masculine ideal in a culture, and that men strive to meet this ideal with various levels of success. This paradigm has generally been disregarded by researchers, particularly by those in the

field of men's studies, since the 1980s. The gender ideology paradigm is better accepted today and is better supported empirically (Good et al., 1995; O'Neil et al., 1995; Pleck, 1995).

Pleck (1995) initially introduced gender ideology and its resulting gender role discrepancy-strain (when attitudes and behaviors conflict with ideology) as an alternative to gender identity/ orientation paradigm in 1981 by providing ten research-based propositions:

1. Gender roles are operationally defined by gender role stereotypes and norms.

2. Gender role norms are contradictory and inconsistent.

3. The proportion of individuals who violate gender role norms is high.

4. Violating gender role norms leads to social condemnation.

5. Violating gender role norms leads to negative psychological consequences.

6. Actual or imagined violation of gender role norms leads individuals to over-conform to them.

7. Violating gender role norms has more severe consequences for males than females.

8. Certain characteristics prescribed by gender role norms are psychologically dysfunctional.

9. Each gender experiences gender role strain in its paid work and family roles.

10. Historical change causes gender role strain.   (p. 12)

Pleck notes that a gender ideology is made up of various standards (attributes) and expectations of behaviors to conform to those standards. As individuals, men may ascribe to some or to all of those standards. These gender ideology standards and expectations are socially derived, though constructed within and among individuals. Hence, many possible individual gender ideologies are present within a culture. Despite this, Pleck states that within a culture, there is usually a constellation of standards and expectations of gender ideology that are highly prevalent and particularly strong among men. Such a constellation has been termed as *traditional* or *conservative*.

Gender ideology provides strong paradigmatic support for the findings of my study. The derivation of attributes of rural masculinity is consistent with the derivation of a constellation of standards and attributes. The fact that individual participants prioritized (ascribed to) some attributes over others is also supported by gender ideology paradigm. Pleck's propositions support the findings that a given attribute (such as self-reliance) can lead to different sequelae, and that men who engage in the gender conflict pattern experience psychological distress and over-conform (in other words, cling to negative / challenge attributes). Perhaps most importantly, Pleck's discussion of gender role strain provides strong support for the concept of gender negotiation constructed from the data in my study.

Pleck (1995) suggests that men engage in psychological labor in response to gender role strain, which leads to various behaviors and processes of accommodation. Exploration of these processes remains on-going, though a sizeable body of knowledge is coming together. In terms of gender role discrepancy strain, Pleck notes

A second theoretical issue is that discrepancy-strain may not be a static outcome, but a process. When individuals experience gender role discrepancy strain, they probably do not remain frozen in this state for extended periods of time. *Rather, they cope with or adapt to it by changing their behaviors, by changing their perception of gender roles norms or disengaging from them, or by changing their reference group.* Thus, gender discrepancy's impact on psychological well-being may not persist in a way that will be evident in cross-sectional studies. (p. 14, emphasis mine)

Pleck's suggestion of an adaptive process to discrepancy strain is remarkably similar to the processes constructed from my data; namely that men change their perception of gender role norms (gender reconstruction), change their behaviors (gender compromise), or change their reference group (gender conflict preservation/ loner). The gender conflict preservation pattern may also represent those that have yet to adapt while in the meantime continue to have escalations in psychological distress. Therefore, the process of gender negotiation constructed from the data in my study has little support from the caregiving literature (most likely because few have looked at caregiving from this perspective) but does have paradigmatic support from the men's studies literature.

Comparison of Findings to the Qualitative Caregiver Literature

Since potential variables within the data were not quantified or measured, direct comparison of my study's findings with the numerous quantitative studies in the literature is not possible. However, as noted earlier, the participants described many of the

challenges and many of the strategies to confront those challenges that have been described in the general literature. It is more feasible to compare my study's findings with those of other qualitative studies for similarities and contrasts.

Most of the qualitative studies that have examined male caregivers in part or exclusively have been descriptive in nature, in which researchers used study methods including phenomenology or variations of thematic analyses. Fewer studies used methods that generated a theoretical model or proposition. In addition, researchers in these studies used undefined, mixed, or non-rural samples. Nevertheless, my study's findings support many of the themes noted in previous studies. Themes *not supported* by my study are summarized in Table 5.1 and are described below. (Greater review of these studies is located in Chapter 2.)

Russell (2004) examined the social needs and networks of elderly male caregivers and identified three themes: in retrospect, the need to lessen challenge, and the need to socialize with other men. The latter two themes were supported by my study, particularly the need to socialize with other men. Except for the participants engaging in loner-type behaviors, the participants of my study commented on the importance being able to talk with other male caregivers and the isolation they felt in not knowing other male caregivers in their area. The first theme, in retrospect, referred to the realization that previous employment social networks were important to the men who were now retired. This theme was not supported in my study's findings, possibly due to the intersections among social networks in rural communities. The participant's co-workers (present or former) were likely members of their faith communities, members of their recreational

activities, or were likely to be encountered as participants ran errands in town; whereas in urban settings, various social networks are more likely to be mutually exclusive.

Hilton et al. (2001) identified two themes among men caring for their wives with breast cancer: focus on their wives' illnesses and keeping the family going. These themes were supported by the findings of my study in that many of the participants were very much in tune with the physical needs of their care recipients. Participants 6 and 12 were particularly engaged in learning about the medical and prognostic details of their care recipients' illnesses, and then sharing that information with co-workers, friends, and neighbors. The desire to keep the family functioning as smoothly as possible despite the disruptions of caregiving was described by Participants 1, 6, 7, and 12, all of whom had minor children in the household while they were caregivers.

Table 5.1 Continued

Theme	Source
6. *Lack of privacy*	Morgan et al. (2002)
7. *Sense of fear/ risk* (at taking on the challenges of caregiving)	Hasselkus (1988)
8? *Loss of female companionship* (losing both intimate *and* social interactions with all women)	Harris (1993)

Archer and MacLean (1993) identified three themes: maintaining outside interests and hobbies, relationship changes, and personal-emotional gratification. The first theme was supported by the findings of my study in that most of the participants discussed how they continued to engage themselves in hobbies and/or advised other male caregivers to maintain hobbies. The second and third themes had less support. Archer and MacLean note that their participants experienced abandonment from their families and friends when they became caregivers. The participants of my study expressed the opposite. Although family members may have lived some distance from the participants or disagreed with the decision participants made to keep care recipients at home, family members (with the exception for Participant 2) willingly came to provide assistance or respite when called upon. More importantly, friends seemed to rally behind the participants, almost providing too many offers of help and support. This contrast is likely due to the supportive nature of rural communities, particularly among insiders. The third theme, personal-emotional gratification was partially supported by the findings in my study. The participants in my study expressed gratification in terms of work/ task accomplishment only, unless participants reconstructed gender (as noted above.)

Parsons (1997) identified eight themes among male caregivers: vigilance, loss, taking away, searching to discover, needing assistance, reciprocity, aloneness/ loneliness, and for son caregivers, overstepping boundaries (in terms of providing personal care to their mothers). Generally, the findings of my study support these themes. However, Parsons defines aloneness/ loneliness in terms of a lack of family or community support. Again, the participants in my study described an opposite experience, although some of the participants expressed a desire and need to interact with other male caregivers. In my

study, three son caregivers provided interviews. None of these son caregivers mentioned any discomfort or role conflict with providing personal care to their mothers. It is possible that the participants in my study maintained a focus on accomplishing necessary tasks. Discomfort at seeing and handling the private parts of their mothers seemed to be secondary to task accomplishment.

Harris (1993) identified four themes: commitment, the need to talk with other men, loss of female companionship, and social isolation from family and friends. The findings in my study support the first two themes, but support less the last two themes. Harris identifies the loss of female companionship not only in terms of a loss of intimate relations with wives, but also in terms of loss of social interactions with women (Namely, that her participants' primary social contacts with women was with their wives.) Two of the participants in my study noted that sexual relationships had ceased with their wives as their illnesses progressed. Others described a maintaining of intimacy through hugging and kissing (without mentioning directly the cessation of sexual intercourse). However, these men did not describe this change necessarily as a *loss*, per se, but more as an acceptance of an illness trajectory. None of the participants in my study mentioned a lack of social contact with women as a whole, likely since women were instrumental members of the social networks in their rural communities.

From the themes noted above, Harris (1993) proposes four types of male caregivers: the worker, the laborer of love, the sense of duty, and being at the crossroads. Harris notes that men may shift back and forth among these caregiver types depending upon the caregiver trajectory. The participants in my study did not fall out concisely into these caregiver types. In my study, the participants possessed characteristics of multiple

caregiver types described by Harris concurrently. For example, many of the participants possessed characteristics of the worker and the laborer of love, while at the same time, espoused values of commitment to their care recipient. As such, the findings from my study do not support the caregiver classification proposed by Harris.

Mays and Lund (1999) identified three themes among caregivers of mentally ill relatives: expressions of hardship, commitment, and role affirmation. The findings of my study support these themes. Participants provided evidence of the theme of role affirmation when they discussed the value of caring for one's own and pride in accomplishing caregiver tasks.

Four qualitative studies were located that examined rural caregivers. Conley and Burman (1997) identified three themes: caregiving as being all-consuming/ exhausting, a desire for information, and little physical assistance received from family and friends. Reed and Weicherding (1999) identified three themes: God provides, lack of services, and feelings of guilt when asking for help. Again, the findings in my study do not support the theme of little assistance from family and friends. Also, none of the participants expressed guilt when assistance was sought. In fact, participants in my study were much less affective, noting that assistance should be sought if work was not getting done. Several of the participants in my study noted that, in retrospect, assistance should have been sought earlier in their caregiver trajectories. Reluctance in seeking help stemmed from gender role conflicts with self-reliance and independence, not in terms of expressed guilt. It is important to note that the samples used by Conley and Burman and Reed and Weicherding were predominately women. It is likely that these female caregivers desired greater assistance from families and friends than what was desired by

the participants in my study. Also, it might be possible that the female caregivers were more likely to experience feelings of guilt and/or express feelings of guilt than were my participants due to the differing gender ideologies between rural men and rural women.

Two other studies included Harris et al. (2004), who identified the high financial and emotional cost of traveling long distances for services (also noted in my study), and Morgan et al. (2002), who identified six reasons why caregivers caring for family members with Alzheimer's disease don't access formal services. These reasons include: self-reliance, lack of awareness of existing services, lack of available services, residing in remote areas, stigmatization of dementia, and lack of privacy. Codes constructed from the data in my study were consistent with only the first four of these six themes. The participants in my study did not indicate any stigma related to the illness experienced by their loved ones, though few participants reported caring for family members diagnosed with Alzheimer's disease. None of the participants in my study, even those exhibiting loner-type behaviors, expressed a concern for privacy. In fact, two of the participants stated that they felt supported by others in their communities when they asked questions about their caregiving. One participant expressed gratitude at questions townspeople had regarding their care recipients and their status with caregiving, as such questions implied caring and concern rather than busybodiness. For the loners in the sample, privacy concerns were not offered as reasons for not seeking services. Rather, a value in solitude and a belief in their individual self-reliance were provided as reasons for not seeking assistance.

Three additional qualitative studies were located in the general caregiver literature that used mixed-gender samples. As with the rural studies, it is unclear how strongly the

experiences of male participants contributed to the derivation of these themes. Butcher et al. (2001) identified eight themes for caregivers caring for family members with Alzheimer's disease: being immersed in the caregiving, enduring stress and frustration, suffering through the losses, preserving care recipient integrity, gathering support, moving with continuous change, finding meaning and joy, and integrating dementia into their lives. Grant and Nolan (1993) identified eight themes in terms of what caregivers found satisfying in their caregiver work: act of giving, expressions of appreciation, improved affinity with the care recipient, returning the favor, knowing that the care recipient is well-cared for, pride, religious convictions, and avoidance of institutionalization. Although not all these themes were present in all of the participants in my study, open codes were constructed from the data in my study which were consistent with these themes. Hasselkus (1988) identified six themes: sense of self, conducting the caregiving work, sense of pessimism of the future, sense of change in roles, jockeying for control, and sense of fear/ risk. The findings of my study support all of these themes, with the exception of sense of fear/ risk. None of the participants in my study expressed fear at taking on the caregiver role or confronting the challenges of caregiving. In addition, none of the participants expressed feeling fearful as their care recipient's health worsened. All of the participants accepted challenges and bad health news with a matter-of-factness or with a fatalistic perspective. For some, a sense that God would provide what was needed to endure challenges was present which quieted any expressed fears they might have had.

A handful of qualitative studies that included male caregivers in their samples yielded new proposed theoretical relationships or models of caregiving. Some of these

studies examined highly focused components of caregiving, such as reciprocity (Neufeld & Harrison, 1998), making the decision to access formal services (Coe & Neufeld, 1999), caregiver purpose (Caron & Bowers, 2003), and the process of psychomotor skill development (Schumacher et al., 2000). The theoretical model I propose, with its process of gender negotiation, is more global in perspective, and hence, is more difficult to compare to these highly focused studies. However, Coe and Neufeld note that men go through phases of resistance and giving in as they progress to a point of seeking formal services to assist with caregiving. These phases include initial resistance, giving in, opening the door/ looking for help, and making the match (finding the appropriate service provider). Conflicts with rural masculinity ideology and gender negotiation as I propose in my model may provide an explanatory basis for the phases described by Coe and Neufeld.

Schumacher et al. (2000) propose nine core processes that caregivers must adopt in order to optimally acquire caregiver skills (and supposedly, caregiver success). These processes include monitoring, interpreting, making decisions, taking action, providing hands-on care, working together with the care recipient, negotiating the health care system, and accessing resources. The participants in my study generally adopted all of these processes at some point in their caregiver trajectories, with the notable exception of accessing resources. This was a process delayed, and by those who employed gender conflict preservation as their pattern of gender negotiation, actively fought against. The model I propose facilitates the need to understand conflicts with gender ideology as an explanatory basis as to why rural men may not access resources.

Three other studies provide a more global perspective, yet it is important to note, none of these studies examined men exclusively. Szabo and Strang (1999) examined issues of control in caregiving relationships, and propose that caregivers struggle with gaining and keeping control. They hypothesize that caregivers in control are actively engaged and have improved coping over caregivers who lack control. Although the findings of my study address control, namely the sub-attribute of resisting relinquishing control, Szabo and Strang characterize control very differently. These researchers describe being in control as being action-directed and proactive; whereas lacking control is being reactive and unaware of changes. In my study, control was characterized as the desire to be the sole decision-maker of caregiving decisions and was maintained by not allowing others to routinely provide hands-on caregiving work or provide emotional support. Due to these different characterizations of control, it is not clear how the findings of my study compare to those of Szabo and Strang.

Brown and Stetz (1999) identified a core theme of caregiver toil and described the changes in that toil and caregiver needs as the care recipient progresses through an illness trajectory until death. Their model emphasizes that the experience of caregiving is dynamic and follows a trajectory. The findings of my study partially support this model, though only three of the participants had provided caregiving through to the death of their care recipients. Nevertheless, most of the participants were clear about how caregiving had changed over time. The process of gender negotiation may provide an explanatory basis for how rural men may or may not change their caregiving approach as the care recipient transitions through their illness trajectory.

Shyu et al. (1998) examined Taiwanese caregivers and propose a process of finding balance between caregiving and the outside lives/ needs of the caregivers. The concept of balance, as defined by these researchers, was not evident in the data from my study. Instead, participants either tolerated imbalance in order to accomplish the caregiving work or negotiated gender role conflicts in order to reduce the need for finding balance. Generally, the participants in my study gave very low priority to their own emotional and spiritual needs, and as such, did little to seek an inner balance or peace. It is likely that the concept of balance has greater cultural relevance for Taiwanese caregivers than for rural male caregivers. The importance of cultural differences is highlighted by Participant 9, who noted that a Hispanic friend of his who was a caregiver to his wife was struggling with having to do dishes and housework that he perceived as "women's work." Participant 9 commented that this conflict was something attributable to his friend's Hispanic culture. Participant 9 noted that Caucasian men he knew didn't really perceive these duties as "women's work", but simply as work that needed to be done. Participant 9 believed that farmer, hunting, and ranching men were comfortable with cooking and cleaning, whether it occurred in the field or in the home. As such, my proposed model, with the importance of culture and its interconnection with gender in shaping the experiences and processes of caregivers, suggests that caregiving must be explored and understood within the context of culture.

Lastly, the findings from my preliminary study described in Chapter 3 are consistent with the findings of my study proper. The participant in the preliminary study described a work-outcome focused approach to caregiving, ingenuity with designing and

implementing caregiving work, a value in hard work, and a desire to interact with other

male caregivers. All these themes were noted in many of the participants of my study.

Implications for Health and Human Service Providers

The process of gender negotiation and the Gender-Cultural Model for Caregiving

as a means to understand and explain caregiving processes for rural male caregiving is

unique and illustrates various points in the caregiver trajectory where health and service

providers could intervene in order to improve caregiver outcomes. Much of the caregiver

literature has focused on caregiver challenges and has suggested that providers should

implement strategies to lessen the quantity and intensity of those challenges to promote

caregiver success. The model constructed from the data of my study supports this

perspective. It was noted that when challenges are small in scope or frequency, rural

male caregivers employ simple strategies in order to accomplish caregiver work without

much stress or negative sequelae. However, this traditional focus on caregiver challenges

is far from comprehensive, and fails to capture how gender ideology and culture

influence the caregiver experience, caregiver perspectives, and caregiver behaviors. With

the model constructed by my study, providers are afforded additional entry points for

planning assistance.

Specifically, providers working with rural men should assist these caregivers

accentuate positive (or resource) attributes of rurality and rural masculinity, namely self-

reliance (having a can-do attitude, willing to work hard, remaining outcomes focused),

caring for one's own, faith, common sense, and valuing the provider role. At the same

time, providers should assist men to reframe their perspectives on relinquishing control,

asking for help, independence/ loner attitudes, isolationism, and how they address their own physical and emotional needs. In order to accomplish this effectively, providers must be knowledgeable of typical cultural and gender ideologies prevalent in their communities, as well as conduct an assessment on their clients' individual attitudes and conflicts with those ideologies. The necessity of this type of assessment is supported by Levant and Habben (2003) in their recommendations for mental health providers working in rural communities. Such information will better guide the provider in incorporating gender and culturally appropriate assistive strategies.

Based on the findings of my study, I recommend the following additional approaches for providers working with rural male caregivers:

1. Promote "positive" self-reliance. The sense of self-reliance is prevalent in rural men and can be a source of great strength and accomplishment. Providers can empower men to be successful with caregiver tasks by praising caregiver creativity and motivation in the self-development of strategies, as well as providing focused teaching on how to accomplish tasks safely and efficiently. It is noteworthy that with the exception of Participant 6 (who worked with hospice), no participant reported receiving formal instruction by health care staff in hospitals, clinics, or home health agencies on how to complete caregiving tasks. It was only by common sense, trial-and-error, observation, and asking lay resources that participants were able to learn much of the caregiving work, especially those caregiving tasks associated with medication management and personal care. Instructions from health providers would have greatly enhanced the men's ability to complete tasks effectively from the start. Providers should

inform caregivers how their instructions will enable them, as caregivers, to complete tasks independently, without injury to themselves or the care recipient. For example, a nurse could say to a caregiver, "Let me show you how you can transfer your wife to the commode safely if you don't have a hospital bed at home."

2. <u>Don't wrestle control away from caregivers</u>. Rural men are generally resistant to relinquish control, particularly of the caregiving work and decision-making. As such, blatant taking over of caregiving work by providers could likely backfire, leading to increased stress, distrust, and confrontations, even if the caregiving is taken over for one-hour-a-day visits by a home health aide. Taking over caregiving, in effect, removes the sense the caregiver has that he is self-reliant and may damage the pride the caregiver has in his ability to accomplish work. This recommendation is consistent with the advice from Levant and Habben (2003), who state, "…it will be much more beneficial to help the rural man *build on* his self-reliance than to attempt to *strip it down*" (p. 179, emphases theirs). As such, providers should ask caregivers how they want assistance and what kind of assistance they prefer. Providers should remind caregivers that while care is being provided by them, caregivers are free to complete other work or are free for respite. In addition, if desired on the part of the caregiver, providers should encourage caregivers participate in the service provision. Such participation would allow providers to evaluate caregiver skills and allow opportunities for education as discussed above.

3. Anticipate and respect "appropriate" solitude. Some rural men will display loner-type behaviors. Episodes of solitude may be a necessary and healthy stress-reduction strategy for these caregivers. However, as noted earlier, excessive solitude and a pushing away of offers of help or other resources can eventually lead to caregiver crisis. For these men, providers should first ensure that caregivers are aware of available services and resources. Then, providers should inform these men what changes might indicate a warning that services should be accessed (for example, an increase in the frequency or intensity of feelings of bitterness or anger). Providers should contact these male caregivers periodically. These contacts might not yield information on caregiving status if these men are reticent; however, these contacts allow providers to reinforce information on how and when to access services. Since many community providers may be left out of the loop if a caregiver is a loner, it becomes incumbent upon staff discharging a care recipient from a hospital to initially provide the caregiver this resource information and for staff at primary care and specialty clinics to reinforce this information on an on-going basis.

4. Solicit the assistance of community support systems. The participants in my study noted the value and benefit of community support, both from the community at large as well as from faith communities. These support networks served as a safety net of sorts for some of the men. The support networks were sources of emotional support for the men who engaged in gender reconstruction. Health and service providers should inform faith communities, parish nurses, and civic organizations how to reach out and support male caregivers in general.

Providers should ensure that these groups are familiar with available services and how they can be contacted, as well as general warning signs of increased caregiver stress and crisis. In addition, providers should not forget about the social networks found in local bars. Although none of the participants in my study indicated that their primary social network was a group of drinking buddies, Participant 5 commented that in rural communities, there are the church families and the bar families that serve as the cornerstone for social networks. In my field experience, I observed and learned about close-knit friendships among men who were regulars in a given bar. I conversed at length with two male caregivers I met in local bars. Neither of these caregivers consented to participate in my study. As such their data were not included. However, both these men described incredibly stressful and engaging caregiver experiences. Both men stated that they relied heavily on the love and support they received from the locals at their bar. The importance of social networks for men in rural bars and the sharing of health information and experiences in rural bars is supported by an unpublished master's thesis (Jorgensen, 2006). Consequently, providers should not ignore these places of social support. Providers could advertise services with flyers posted in men's rooms or print service information on drink coasters. Providers should also consider writing occasional articles about rural caregivers, needs, and services in local rural newspapers.

5. <u>Acknowledge when common sense is lacking</u>. Rural men value common sense. Frequently, from the perspectives of rural men, rules and regulations governing services lack common sense and serve as a barrier to service access when rural

men are ready to ask for assistance. Providers should acknowledge the complexity of the rules and regulations and freely admit when they do not best serve the needs for caregivers in a rural context. Providers should then aggressively seek ways to minimize the presence of rules-generated barriers. Providers should adopt the approach of "Despite these crazy rules and restrictions, let's see how we figure out how to get the things you need."

6. <u>Explore ways to minimize peer isolation.</u> Most of the participants in my study reported that they knew of no other male caregiver. For some of the men, this left them with a sense of peer isolation. Although these men had friends and neighbors and knew of female caregivers, they stated that these contacts did not and could not understand their circumstances and concerns. This need to interact with male caregivers for information and support was noted elsewhere in the literature (Harris, 1993; Russell, 2004). Providers may be limited in bringing male caregiver peers together, particularly when such peers are separated by great distances. Fortunately, most of the participants reported that they have access to and use the Internet. Providers could advocate for larger agencies (such as area offices on aging or national caregiver organizations) to provide electronic chat rooms/ postings exclusively for male caregivers. Feasibility and acceptability of electronic communication as a source for information and peer support has been demonstrated in at least one group of rural dwellers, namely women with chronic illness (Cudney, Winters, Weinert, & Anderson, 2005; Weinert, 2000; Weinert, Cudney, & Winters, 2005).

Limitations

Several limitations of the study are noteworthy, foremost is the small sample size. Much has been written about the appropriate sample size for qualitative studies, though the consensus is generally to include enough participants to get the necessary information on the phenomenon of interest. In terms of grounded theory studies, only one source was located that suggested a number of participants, that being of at least 20-25, to adequately provide data (Morse, 2000). The key determinant of appropriateness of sample size is often considered the achievement of saturation of concepts, though saturation is an ideal that may never be truly reached (Charmaz, 2006). Instead, researchers using grounded theory should strive to collect enough data to support well-flushed out theoretical propositions (Charmaz, 2006; Glaser, 1998). In my study, the basic theoretical model was constructed from the first eight participants. The remaining four participants contributed data that further strengthened the model, yet offered no new concepts and provided no contradictions to the model. Although further attempts to obtain additional participants were made, legal requirements for passive recruitment of participants and the general difficulty in recruiting rural study participants (Cudney, Craig, Nichols, & Weinert, 2004) hampered success.

Glaser notes that all is data (1978; 1998). Therefore, examination of the academic and popular literature and the notes from my rural field experience was made for support or non-support of the theoretical model constructed in my study. By in large, despite the paucity of research of rural caregivers and male caregivers in general, strong support for the attributes of the concepts of caregiver challenges, rurality, and rural masculinity constructed from the data was noted. Attributes from the literature not present in the

study findings are likely due to the gender and cultural differences between the study sample and the literature samples. Most importantly, the core category of gender negotiation has strong paradigmatic support from the men's studies literature. As such, the model constructed is grounded in the experiences of all of the participants and has empirical and theoretical support from outside sources.

Another limitation is that the sample lacked ethnic and racial diversity. Measures were taken at the onset of the study to encourage diverse participation, though all eventual participants were non-Hispanic Caucasians. Within any culture exist various sub-cultures (Leininger, 1991). Rural areas contain much cultural and sub-cultural diversity, as noted in Chapter 2. In rural areas, various sub-cultures likely would contribute differing aspects of culture, and consequently, of gender. As noted earlier, evidence of this was provided by the participant who knew a Hispanic male caregiver. As such, the specific findings of my study are applicable only to Caucasian rural men of the inter-mountain West. However, diversity was evident in the sample in terms of relationship to the care recipient, illness experienced by the care recipient, length of time in the caregiver role, and in various socioeconomic data.

The lack of ethnic and racial diversity creates a limitation of transferability. Specific recommendations may only be applicable to rural Western male caregivers. However, the concepts and processes constructed from this study do have widespread applicability, as all caregivers have a gender and are a member of some cultural group. In consideration of transferability of my study's findings, the general Gender-Cultural Model of Caregiving depicted in Figure 5.1 is a proposition based on the findings of my study. The general model directs users to evaluate relevant gender and cultural

ideologies and how individual caregivers may or may not subscribe to those ideologies. Attributes of gender and culture that may create barriers to successful caregiving could be evaluated, and if problematic for an individual caregiver, strategies to assist caregivers in negotiating those constructed attributes could be employed.

Figure 5.1 Hypothesized General Gender-Cultural Model of Caregiving
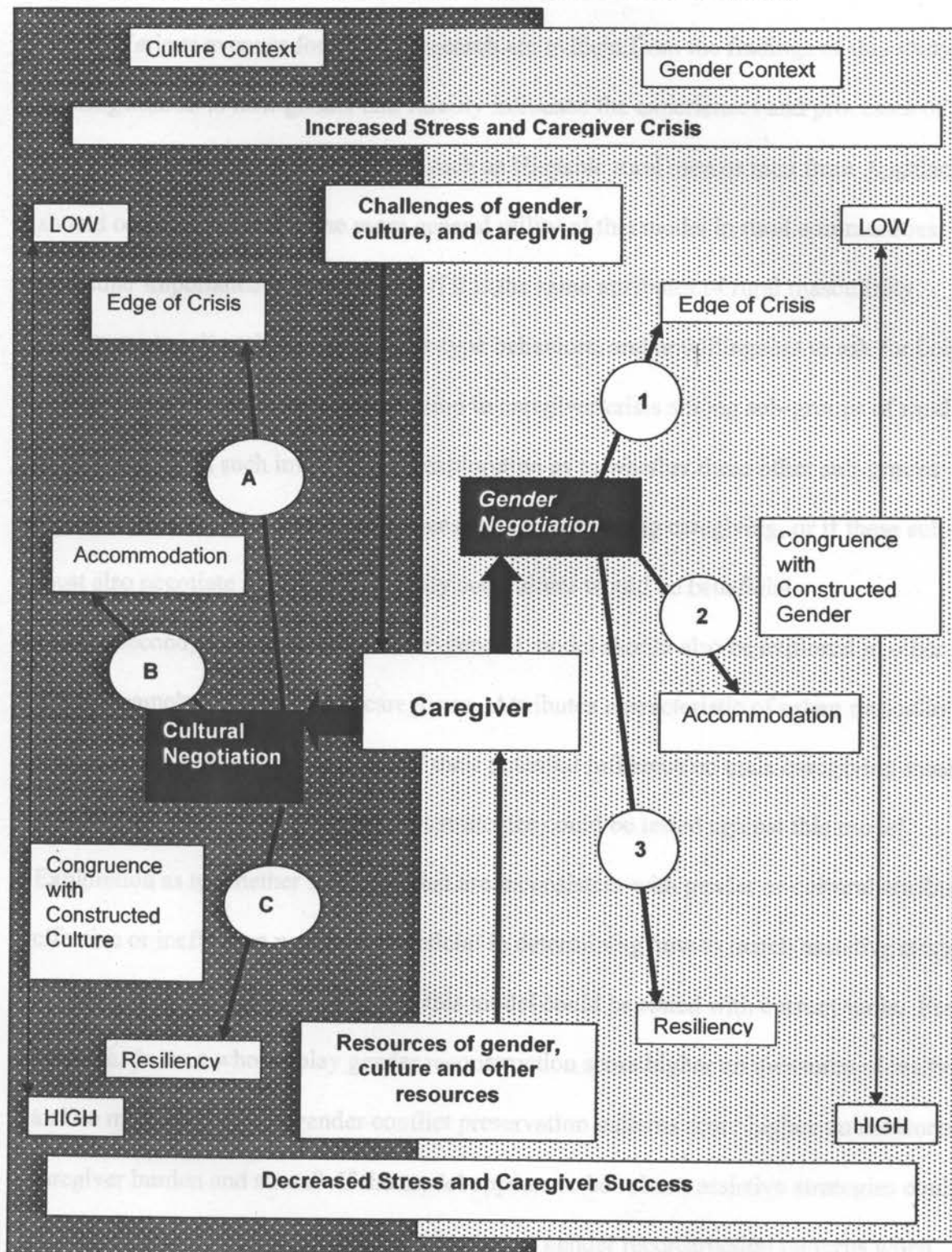
1= Gender Conflict Preservation; 2= Gender Compromise; 3= Gender Reconstruction
A= Cultural Conflict Preservation; B= Cultural Compromise; C= Cultural Reconstruction

Implications for Further Research

Various avenues for further research are evident from the findings of this study. First, investigation as to how gender and rurality influence the experiences and processes of rural men representing other sub-cultures (such as Hispanic rural men or men from Appalachia) should occur to determine the more general utility of this model in rural communities. Of particular importance is to determine if it is the same attributes of rural masculinity (resistance to relinquish control, loner-type behaviors, and unwillingness to ask for help) that are problematic and promote progression to caregiver crisis among sub-groups of rural male caregivers. With such investigation, exploration as to whether these other sub-groups negotiate gender only as a central process of accomplishing caregiving, or if these sub-groups must also negotiate attributes of rurality sub-culture would be beneficial.

Second, the applicability of the general model should also be explored in other groups of men, namely non-rural male caregivers. Attributes characteristic of urban masculinity/ gender ideology may be different and their potential influence on male caregiving must be investigated. Third, caregiver support strategies could be tested against this model. Exploration as to whether strategies that are inconsistent with gender or cultural attributes are effective or ineffective would be beneficial in determining how to match assistive strategies to individual caregivers. And fourth, this model could be tested with current tools. For example, do men who display gender reconstruction score higher on measures of resiliency, and do men who employ gender conflict preservation patterns score higher on measures of caregiver burden and stress? If the model appears to be robust, assistive strategies could be developed and tested to facilitate the adoption of gender reconstruction patterns when needed.

Conclusion

This study explored a virtually unexplored phenomenon: rural male caregiving. Critiques were given at the outset of the study that the current body of knowledge was insufficient to guide health and service providers in understanding the experiences and needs of these caregivers. Such knowledge is necessary to best assist caregivers in optimizing success. This study yielded a new and unique theoretical model constructed from participant interviews and the literature that considers the centrality of gender and culture in the context of caregiving.

The aims of this study were to explore the meanings and experiences of rural male caregivers, to explore the processes these caregivers use in providing care, to explore the impact caregiving has on self-reported health, and to develop a theoretical understanding of how gender and culture influence caregiving (see Chapter 1). The first three aims of this study were met through analysis of rich interviews from 12 male caregivers residing in highly rural communities. The fourth aim, developing an initial theoretical understanding, occurred through the construction of a model, in which the process of gender negotiation was the central process for this sub-group of caregivers. The model was bolstered by interviews from four additional participants, from comparisons to data from the academic and popular literature, and from the notes from my field experience. No other model was located from previous sources that presented gender and culture together in the context of caregiving. Previous research has primarily focused on the differences between male and female caregivers and how they provide caregiving differently. This limited focus is surprising considering that everything is gender (Jarviluoma et al., 2003) and people *do* gender (a verb) in all their actions (West & Zimmerman, 1987). One could easily make the same statement

regarding culture. Few have examined how men, as gendered and cultural beings, experience caregiving and *do* caregiving. As such, the findings from this study constitute a unique contribution to the body of caregiver knowledge.

REFERENCES

Acton, G. J. (2002). Health-promoting self-care in family caregivers. *Western Journal of Nursing Research, 24*(1), 73-86.

Acton, G. J., & Winter, M. A. (2002). Interventions for family members caring for an elder with dementia. *Annual Review of Nursing Research, 20,* 149-179.

Adler, K., Patterson, T., & Grant, I. (2002). Physiological challenges associated with caregiving among men. In B. J. Kramer & E. Thompson (Eds.), *Men as caregivers: theory, research, and service implications* (pp. 127-150). New York: Springer Publishing Company.

Albert, S. M. (1991). Cognition of caregiving tasks: multidimensional scaling of the caregiver task domain. *Gerontologist, 31*(6), 726-734.

Almberg, B., Jansson, W., Grafstrom, M., & Winblad, B. (1998). Differences between and within genders in caregiving strain: a comparison between caregivers of demented and non-caregivers of non-demented elderly people. *Journal of Advanced Nursing, 28*(4), 849-858.

Annells, M. (1996). Grounded theory method: philosophical perspectives, paradigm of inquiry and postmodernism. *Qualitative Health Research, 6*(3), 379-393.

Annells, M. (1997). Grounded theory method, part II: options for users of the method. *Nursing Inquiry, 4,* 176-180.

Arber, S., & Gilbert, N. (1989). Men: the forgotten carers. *Sociology, 23*(1), 111-118.

Arber, S., & Ginn, J. (1995). Gender differences in informal caring. *Health and Social Care in the Community, 3,* 19-31.

Archbold, P. G. (1983). Impact of parent-caring on women. *Family Relations, 32,* 39-45.

Archbold, P. G., Stewart, B. J., Greenlick, M., & Harvath, T. A. (1992). The clinical assessment of mutuality and preparedness in family caregivers to frail older people. In S. Funk, E. Tornquist, M. Champagne & R. Wiese (Eds.), *Key aspects of elder care: managing falls, incontinence, and cognitive impairment* (pp. 328-339). New York: Springer Publishing Company.

Archbold, P. G., Stewart, B. J., Greenlick, M. R., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health, 13*(6), 375-384.

Archer, C., & MacLean, M. (1993). Husbands and sons as caregivers of chronically ill elderly women. *Journal of Gerontological Social Work, 21*(11/2), 5-23.

Arcury, T. A., Bernard, S. L., Jordan, J. M., & Cook, H. L. (1996). Gender and ethnic differences in alternative and conventional arthritis remedy use among community-dwelling rural adults with arthritis. *Arthritis Care Research, 9*(5), 384-390.

Arcury, T. A., Quandt, S. A., McDonald, J., & Bell, R. A. (2000). Faith and health self-management of rural older adults. *J Cross Cult Gerontol, 15*(1), 55-74.

Ask Dr. Dig: Questions about Native Americans. (2006). Retrieved February 14, 2006, from http://www.digonsite.com/drdig/native/8.html

Axmaker, L. (2003). *What men need to know about depression.* Retrieved May 11, 2004, 2004, from http://menanddepression.nimh.nih.gov/infopage.asp?id=18

Bailey, M. C. (1998). Outsider. In H. J. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 139-148). New York: Springer.

Baillie, V., Norbeck, J. S., & Barnes, L. E. (1988). Stress, social support, and psychological distress of family caregivers of the elderly. *Nursing Research, 37*(4), 217-222.

Bakas, T., Austin, J. K., Jessup, S. L., Williams, L. S., & Oberst, M. T. (2004). Time and difficulty of tasks provided by family caregivers of stroke survivors. *Journal of Neuroscience Nursing, 36*(2), 95-106.

Bakas, T., Austin, J. K., Okonkwo, K. F., Lewis, R. R., & Chadwick, L. (2002). Needs, concerns, strategies, and advice of stroke caregivers the first 6 months after discharge. *Journal of Neuroscience Nursing, 34*(5), 242-251.

Bakas, T., & Burgener, S. C. (2002). Predictors of emotional distress, general health, and caregiving outcomes in family caregivers of stroke survivors. *Topics in Stroke Rehabilitation, 9*(1), 34-45.

Bales, R. L. (2006). Health perceptions, needs, and behaviors of remote rural women of childbearing and childrearing age. In H. J. Lee & C. A. Winters (Eds.), *Rural nursing: Concepts, theory, and practice* (Vol. 2nd, pp. 66-78). New York: Springer.

Bales, R. L., Winters, C. A., & Lee, H. J. (2006). Health needs and perceptions of rural persons. In H. J. Lee & C. A. Winters (Eds.), *Rural nursing: Concepts, theory, and practice* (Vol. 2nd, pp. 53-65). New York: Springer.

Ballantyne, J., & Buehler, J. (1998). Experiences of HIV-infected men with rural health care. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 366-377). New York: Springer Publishing Company.

Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. *Gerontologist, 30*(1), 26-29.

Beck, R. W., Jijon, C. R., & Edwards, J. B. (1996). The relationships among gender, perceived financial barriers to care, and health status in a rural population. *Journal of Rural Health, 12*(3), 188-189.

Bennett, M., & Lengacher, C. (1999). Use of complementary therapies in a rural cancer population. *Oncology Nuring Forum, 26*(8), 1287-1294.

Beynon, J. (2002). What is masculinity? In J. Beynon (Ed.), *Masculinities and culture* (pp. 1-25). Philadelphia: Open University Press.

Bigbee, J. (1991). The concept of hardiness as applied to rural nursing. In A. Bushy (Ed.), *Rural nursing* (Vol. 1, pp. 39-58). Thousand Oaks, CA: Sage.

Bigbee, J. L. (1993). The uniqueness of rural nursing. *Nursing Clinics of North America, 28*(1), 131-144.

Blake, H. (2000). Strain and psychological distress among informal supporters of reflex sympathetic dystrophy patients. *Disability and Rehabilitation, 22*(18), 827-832.

Blake, H., & Lincoln, N. B. (2000). Factors associated with strain in co-resident spouses of patients following stroke. *Clinical Rehabilitation, 14*(3), 307-314.

Blake, H., & Lincoln, N. B. (2002). Cognitive impairments following a stroke: the strain on caregivers. *British Journal of Therapy and Rehabilitation, 9*(9), 334-337.

Blewett, L. A., Smaida, S. A., Fuentes, C., & Zuehlke, E. U. (2003). Health care needs of the growing Latino population in rural America: focus group findings in one midwestern state. *Journal of Rural Health, 19*(1), 33-41.

Blumer, H. (1969). *Symbolic interactionism: perspective and method.* Englewood Cliffs, NJ: Prentice-Hall, Inc.

Bohan, J. S. (1993). Regarding gender: essentialism, constructivism, and feminist psychology. *Psychology of Women Quarterly, 17*, 5-12.

Bookwala, J., Newman, J., & Schulz, R. (2002). Methodological issues in research on men caregivers. In B. J. Kramer & E. Thompson (Eds.), *Men as caregivers: theory, research, and service implications* (pp. 69-98). New York: Springer Publishing Company.

Bowers, S. (1999). Gender role identity and the caregiving experience of widowed men. *Sex Roles, 41*(9/10), 645-655.

Boyd, E. L., Taylor, S. D., Shimp, L. A., & Semler, C. R. (2000). An assessment of home remedy use by African Americans. *Journal of the National Medical Association, 92*(7), 341-353.

Boykin, A., & Schoenhofer, S. O. (2001). *Nursing as caring: a model for transforming practice*. Sudbury, MA: Jones and Bartlett Publishers.

Brennan, P. F., Moore, S. M., & Smyth, K. A. (1995). The effects of a special computer network on caregivers of persons with Alzheimer's disease. *Nursing Research, 44*(3), 166-172.

Brody, E. M., Litvin, S. J., Hoffman, C., & Kleban, M. H. (1992). Differential effects of daughters' marital status on their parent care experiences. *Gerontologist, 32*(1), 58-67.

Brown, M. A., & Stetz, K. (1999). The labor of caregiving: a theoretical model of caregiving during potentially fatal illness. *Qualitative Health Research, 9*(2), 182-197.

Bryant, A. (2003). A constructive/ist response to Glaser. *Forum: Qualitative Social Research, 4*(1), [25 paragraphs].

Buckwalter, K. C., Davis, L., Wakefield, B., Kienzle, M., & Murray, M. (2002). Telehealth for elders and their caregivers in rural communities. *Family Community Health, 25*(3), 31-40.

Buehler, J., & Lee, H. (1998). Exploration of home care resources for rural families with cancer. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 299-317). New York: Springer Publishing Company.

Buehler, J., Malone, M., & Majerus, J. (1998). Patterns of responses to symptoms in rural residents: the Symptom-Action-Time-Line process. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 318-328). New York: Springer Publishing Company.

Bull, C. N., Krout, J. A., Rathbone-McCuan, E., & Shreffler, M. J. (2001). Access and issues of equity in remote/rural areas. *Journal of Rural Health, 17*(4), 356-359.

Burlew, A. (2002). Research with ethnic minorities: conceptual, methodological, and analytical issues. In G. Bernal, J. Trimble, A. Burlew & F. Leong (Eds.), *Handbook of racial and ethnic minority psychology* (pp. 179-197). Newbury Park, CA: Sage.

Burman, M. E., & Weinert, C. (1997). Concerns of rural men and women experiencing cancer. *Oncology Nursing Forum, 24*(9), 1593-1600.

Burton, L. C., Zdaniuk, B., Schulz, R., Jackson, S., & Hirsch, C. (2003). Transitions in spousal caregiving. *Gerontologist, 43*(2), 230-241.

Bushy, A. (2002). International perspectives on rural nursing: Australia, Canada, USA. *Aust Journal of Rural Health, 10*(2), 104-111.

Bushy, A., & Bushy, A. (2001). Critical access hospitals: rural nursing issues. *Journal of Nursing Administration, 31*(6), 301-310.

Butcher, H. K., Holkup, P. A., & Buckwalter, K. C. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research, 23*(1), 33-55.

Campbell, L. D., & Martin-Matthews, A. (2003). The gendered nature of men's filial care. *The journals of gerontology. Series B, Psychological sciences and social sciences, 58*(6), S350-358.

Cantor, M. H. (1983). Strain among caregivers: a study of experience in the United States. *Gerontologist, 23*(6), 597-604.

Caron, C. D., & Bowers, B. J. (2003). Deciding whether to continue, share, or relinquish caregiving: caregiver views. *Qualitative Health Research, 13*(9), 1252-1271.

Carpenter, E. H., & Miller, B. H. (2002). Psychological challenges and rewards experienced by caregiving men: A review of the literature. In B. J. Kramer & E. H. Thompson (Eds.), *Men as caregivers: Theory, research, and service implications* (pp. 99-126). New York: Springer Publishing Company.

Casarett, D. (1991). Elders and neighborliness: implications for rural health care. In A. Bushy (Ed.), *Rural nursing* (Vol. 1, pp. 243-255). Thousand Oaks, CA: Sage.

Center on an Aging Society. (2003, January 2003). Data profile: rural and urban health. *Challenges for the 21st century: chronic and disabling conditions,* 1-6.

Centers for Medicare & Medicaid Services. (2004, May 2004). *Fact sheet: critical access hospital program.* Retrieved December 18, 2004, 2004, from http://www.cms.hhs.gov/providers/cah/default.asp

Chafey, K., Sullivan, T., & Shannon, A. (1998). Self-reliance: characterization of their own autonomy by elderly rural women. In H. J. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 156-176). New York: Springer Publishing Company.

Chappell, N., & Kuehne, V. (1998). Congruence among husband and wife caregivers. *Journal of Aging Studies, 12*(3), 239-254.

Charmaz, K. (1994a). 'Discovering' chronic illness: using grounded theory. *Social Science in Medicine, 30*(11), 1161-1172.

Charmaz, K. (1994b). The grounded theory method: an explication and interpretation. In B. Glaser (Ed.), *More grounded theory methodology: a reader* (pp. 95-115). Mill Valley, CA: Sociology Press.

Charmaz, K. (2000). Grounded theory: objectivist and constructivist methods. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509-536). Thousand Oaks, CA: Sage.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Thousand Oaks, CA: Sage.

Christman, L. P. (1988). Men in nursing. *Imprint, 35*(3), 75.

Clark, N. M., & Rakowski, W. (1983). Family caregivers of older adults: improving helping skills. *Gerontologist, 23*(6), 637-642.

Clifford, C. (1995). Caring: fitting the concept to nursing practice. *Journal of Clinical Nursing, 4*(1), 37-41.

Coburn, A. F. (1996). Health reform and rural long-term care. In G. D. Rowles, J. E. Beaulieu & W. W. Myers (Eds.), *Long-term care for the rural elderly: new directions in services, research, and policy* (pp. 156-169). New York: Springer.

Coe, M., & Neufeld, A. (1999). Male caregivers' use of formal support. *West J Nurs Res, 21*(4), 568-588.

Congdon, J. G., & Magilvy, J. K. (2001). Themes of rural health and aging from a program of research. *Geriatric Nursing, 22*(5), 234-238.

Conley, F. K. (1993). Toward a more perfect world--eliminating sexual discrimination in academic medicine. *New England Journal of Medicine, 328*(5), 351-352.

Conley, V. M., & Burman, M. E. (1997). Informational needs of caregivers of terminal patients in a rural state. *Home Healthcare Nurse, 15*(11), 808-817.

Cook, D., & Rains, C. (1990). Cowboy Logic [Recorded by M. M. Murphy] [Music]. New York: Warner Bros. Records.

Cossette, S., & Levesque, L. (1993). Caregiving tasks as predictors of mental health of wife caregivers of men with chronic obstructive pulmonary disease. *Research in Nursing and Health, 16*(4), 251-263.

Courtenay, W. H. (2000). Constructions of masculinity and their influence on men's well-being: a theory of gender and health. *Social Science & Medicine, 50*(10), 1385-1401.

Creswell, J. (1998). *Qualitative inquiry and research design: choosing among five traditions*. Thousand Oaks, CA: Sage Publications.

Cristy, R. J. (2004). *Charles M. Russell: The storyteller's art*. Albequerque, NM: University of New Mexico Press.

Cudney, S., Craig, C., Nichols, E., & Weinert, C. (2004). *Recruiting an adequate sample in nursing research*.Unpublished manuscript, Bozeman, MT.

Cudney, S., Winters, C., Weinert, C., & Anderson, K. (2005). Social support in cyberspace: lessons learned. *Rehabilitation Nursing, 30*(1), 25-28; discussion 29.

Cuellar, N., & Butts, J. B. (1999). Caregiver distress: what nurses in rural settings can do to help. *Nursing Forum, 34*(3), 24-30.

Davies, D., & Dodd, J. (2002). Qualitative research and the question of rigor. *Qualitative Health Research, 12*(2), 279-289.

Davis, D. C., Henderson, M. C., Boothe, A., Douglass, M., Faria, S., Kennedy, D., et al. (1992). Health beliefs and practices of rural elders. *Caring, 11*(2), 22-28.

Davis, M. T., & Bartfay, W. J. (2001). Men in nursing: an untapped resource. *Canadian Nurse, 97*(5), 14-18.

DeLaune, M., & Brown, S. (2001). Spousal responses to role changes following a stroke. *MEDSURG Nursing, 10*(2), 79-88.

Denzin, N. K. (2000). The practices and politics of interpretation. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed. ed., pp. 897-922). Thousand Oaks, CA: Sage Publications, Inc.

Dilworth-Anderson, P., Williams, I. C., & Gibson, B. E. (2002). Issues of race, ethnicity, and culture in caregiving research: a 20-year review (1980-2000). *Gerontologist, 42*(2), 237-272.

Dobalian, A., Tsao, J. C., & Radcliff, T. A. (2003). Diagnosed mental and physical health conditions in the United States nursing home population: differences between urban and rural facilities. *Journal of Rural Health, 19*(4), 477-483.

du Plessis, V., Beshiri, R., Bollman, R. D., & Clemenson, H. (2001). Definitions of rural. *Rural and Small Town Canada Analysis Bulletin, 3*(3).

Dybbro, J. A. (1998). Ethnocentrism. In H. J. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 287-296). New York: Springer.

Eberhardt, M., Ingram, D., & Makuc, D. (2001). *Urban and Rural Health Chartbook, Health, United States, 2001* (No. 76-641496). Hyattsville, MD: National Center for Health Statistics.

Edelman, M. A., & Menz, B. L. (1996). Selected comparisons and implications of a national rural and urban survey on health care access, demographics, and policy issues. *Journal of Rural Health, 12*(3), 197-205.

Egeland, J. W., & Brown, J. S. (1988). Sex role stereotyping and role strain of male registered nurses. *Research in Nursing and Health, 11*(4), 257-267.

Ekstrom, D. N. (1999). Gender and perceived nurse caring in nurse-patient dyads. *Journal of Advanced Nursing, 29*(6), 1393-1401.

Findholt, N. (2006). The culture of rural communities: An examination of rural nursing concepts at the community level. In H. J. Lee & C. A. Winters (Eds.), *Rural nursing: Concepts, theory, and practice* (Vol. 2nd, pp. 301-312). New York: Springer.

Fitting, M., Rabins, P., Lucas, M., & Eastham, J. (1986). Caregivers for dementia patients: a comparison of husbands and wives. *The Gerontologist, 26*(3), 348-252.

Fontana, A., & Frey, J. H. (2000). The interview: from structured questions to negotiated text. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 645-672). Thousand Oaks, CA: Sage.

Fuller-Jonap, F., & Haley, W. E. (1995). Mental and physical health of male caregivers of a spouse with Alzheimer's disease. *Journal of Aging and Health, 7*(1), 99-118.

Ganguli, M., Mulsant, B., Richards, S., Stoehr, G., & Mendelsohn, A. (1997). Antidepressant use over time in a rural older adult population: the MoVIES Project. *Journal of the American Geriatric Society, 45*(12), 1501-1503.

Ganther, J. M., Wiederholt, J. B., & Kreling, D. H. (2001). Measuring patients' medical care preferences: care seeking versus self-treating. *Medical Decision Making, 21*(2), 133-140.

Gaskins, S., & Lyons, M. A. (2000). Self-care practices of rural people with HIV disease. *Online Journal of Rural Nursing and Health Care, 1*(1).

George, L., & Gwyther, L. (1986). Caregiver well-being: a multidimensional examination of family caregiversw of demented adults. *The Gerontologist, 26*(3), 253-259.

Gilligan, C. (1982). *In a different voice*. Cambridge, MA: Harvard University Press.

Given, B., Stommel, M., Collins, C., King, S., & Given, C. W. (1990). Responses of elderly spouse caregivers. *Research in Nursing and Health, 13*(2), 77-85.

Glaser, B. (1978). *Theoretical sensitivity*. Mill Valley, CA: The Sociology Press.

Glaser, B. (1998). *Doing grounded theory: issues and discussions*. Mill Valley, CA: The Sociology Press.

Glaser, B. (1999). The future of grounded theory. *Qualitative Health Research, 9*(6), 836-845.

Glaser, B. (2001). *The grounded theory perspective: conceptualization contrasted with description*. Mill Valley, CA: The Sociology Press.

Glaser, B. (2002). Constructivist grounded theory? *Forum: Qualitative Social Research, 3*(3).

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: strategies for qualitative research*. New York: Aldine de Gruyter.

Glasgow, N. (2000). Rural / urban patterns of aging and caregiving in the United States. *Journal of Family Issues, 21*(5), 611-631.

Glynn, L. G., Byrne, M., & Murphy, A. W. (2004). The effect of rurality on patients' satisfaction with out of hours care provided by a family doctor cooperative. *Rural and Remote Health, 4*(320), 1-12.

Goeppinger, J. (1993). Health promotion for rural populations: partnership interventions. *Family & Community Health, 16*(1), 1-10.

Goins, R. T., & Mitchell, J. (1999). Health-related quality of life: does rurality matter? *Jouranl of Rural Health, 15*(2), 147-156.

Goldstein, N. E., Concato, J., Fried, T. R., Kasl, S. V., Johnson-Hurzeler, R., & Bradley, E. H. (2004). Factors associated with caregiver burden among caregivers of terminally ill patients with cancer. *Journal of Palliative Care, 20*(1), 38-43.

Good, G. E., Robertson, J. M., O'Neil, J. M., Fitzgerald, L. F., Stevens, M., DeBord, K. A., et al. (1995). Male gender role conflict: psychometric issues and relations to psychological distress. *Journal of Counseling Psychology, 42*(1), 3-10.

Grant, G., & Nolan, M. (1993). Informal carers: sources and concomitants of satisfaction. *Health and Social Care, 1*, 147-159.

Grubbs, L., & Frank, D. (2004). Self-care practices related to symptom responses in African-American and Hispanic adults. *Self-care, Dependent-care, and Nursing, 12*(1), 4-9.

Gwyther, L. (1992). Research on gender and family caregiving: implications for clinical practice. In J. Dwyer & R. Coward (Eds.), *Gender, families and elder care*. Newbury Park, CA: Sage.

Hagen, B. (2001). Nursing home placement. Factors affecting caregivers' decisions to place family members with dementia. *Journal of Gerontological Nursing, 27*(2), 44-53.

Hall, W. A., & Callery, P. (2001). Enhancing the rigor of grounded theory: incorporating reflexivity and relationality. *Qualitative Health Research, 11*(2), 257-272.

Han, B., & Haley, W. E. (1999). Family caregiving for patients with stroke. Review and analysis. *Stroke, 30*(7), 1478-1485.

Hanger, H. C., Walker, G., Paterson, L. A., McBride, S., & Sainsbury, R. (1998). What do patients and their carers want to know about stroke? A two-year follow-up study. *Clinical Rehabilitation, 12*(1), 45-52.

Hardy, B., Young, R., & Wistow, G. (1999). Dimensions of choice in the assessment and care management process: the views of older people, carers and care managers. *Health and Social Care in the Community, 7*(6), 483-491.

Harris, N. M., Thorpe, R., Dickinson, H., Rorison, F., Barrett, C., & Williams, C. (2004). Hospital and after: experience of patients and carers in rural and remote north Queensland, Australia. *Rural and Remote Health, 4*(246), 1-10.

Harris, P. B. (1993). The misunderstood caregiver? A qualitative study of the male caregiver of Alzheimer's disease victims. *Gerontologist, 33*(4), 551-556.

Harris, P. B. (2002). The voices of husbands and sons caring for a family member with dementia. In B. J. Kramer & E. Thompson (Eds.), *Men as caregivers: theory, research, and service implications* (pp. 213-233). New York: Springer Publishing Company.

Hartley, D., Korsen, N., Bird, D., & Agger, M. (1998). Management of patients with depression by rural primary care practitioners. *Archives of Family Medicine, 7*(2), 139-145.

Hasselkus, B. R. (1988). Meaning in family caregiving: perspectives on caregiver/professional relationships. *Gerontologist, 28*(5), 686-691.

Hegney, D., McCarthy, A., Rogers-Clark, C., & Gorman, D. (2002). Why nurses are attracted to rural and remote practice. *Australian Journal of Rural Health, 10*(3), 178-186.

Henson, D., Sadler, T., & Walton, S. (1998). Distance. In H. J. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 51-60). New York: Springer.

Hermanova, H. M., & Richardson, S. K. (2001). Conclusions and recommendations for policies on rural aging in the first decades of the 21st century. *Journal of Rural Health, 17*(4), 378-382.

Hewitt, M. (1992). Defining 'rural' areas: impact on health care policy and research. In W. Gesler & T. Ricketts (Eds.), *Health in rural North America: the geography of health care services delivery* (pp. 25-54). New Brunswick, CT: Rutgers University Press.

Hileman, J. W., & Lackey, N. R. (1990). Self-identified needs of patients with cancer at home and their home caregivers: a descriptive study. *Oncology Nursing Forum, 17*(6), 907-913.

Hileman, J. W., Lackey, N. R., & Hassanein, R. S. (1992). Identifying the needs of home caregivers of patients with cancer. *Oncology Nursing Forum, 19*(5), 771-777.

Hilton, B., Crawford, J., & Tarko, M. (2001). Men's experiences of coping with their wives' breast cancer involved focusing on the cancer and treatment and focusing on family to keep going. *Evidence Based Nursing, 4*(1), 31.

Hirsch, C. (1996). Understanding the influence of gender role identity on the assumption of family caregiving roles by men. *International Journal of Aging and Human Development, 42*(2), 103-121.

Hodgson, S., Wood, V., & Langton-Hewer, R. (1996). Identification of stroke carers 'at risk': a preliminary study of the predictors of carers' psychological well-being at one year post stroke. *Clinical Rehabilitation, 10*, 337-346.

Hopkins, M., & Domrose, C. (2001). *Remote control*. Retrieved January 11, 2004, 2004, from http://www.nurseweek.com/news/features/01-04/rural.asp

Horner, S. D., Ambrogne, J., Coleman, M. A., Hanson, C., Hodnicki, D., Lopez, S. A., et al. (1994). Traveling for care: factors influencing health care access for rural dwellers. *Public Health Nursing, 11*(3), 145-149.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: differences in role performance and consequences. *Gerontologist, 25*(6), 612-617.

Houde, S. C. (2002). Methodological issues in male caregiver research: an integrative review of the literature. *Journal of Advanced Nursing, 40*(6), 626-640.

Howard, S. (1998). Invisible youth: gay, lesbian, and bisexual youth in rural Montana. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 352-365). New York: Springer Publishing Company.

Ira, P. C. (1992). The magic of caring. In D. A. Gaut (Ed.), *The presence of caring in nursing* (pp. 257-267). New York: National League for Nursing Press.

James, N. (1992). Care=organisation + physical labour + emotional labour. *Sociology of Health and Illness, 14*(4), 488-509.

Jarviluoma, H., Moisala, P., & Vilkko, A. (2003). *Gender and qualitative methods*. London: Sage Publications.

Johnson, J. E. (1994). Sleep and alcohol use in rural old-old women. *Journal of Community Health Nursing, 11*(4), 211-218.

Johnston, D., & Jones, B. N., 3rd. (2001). Telepsychiatry consultations to a rural nursing facility: a 2-year experience. *Journal of Geriatric Psychiatry and Neurology, 14*(2), 72-75.

Jones, E. D., & Beck-Little, R. (2002). The use of reminiscence therapy for the treatment of depression in rural-dwelling older adults. *Issues in Mental Health Nursing, 23*(3), 279-290.

Jones, J. A., Humphreys, J. S., & Adena, M. A. (2004a). Doctors' perspectives on the viability of rural practice. *Rural and Remote Health, 4*(305), 1-11.

Jones, J. A., Humphreys, J. S., & Adena, M. A. (2004b). Rural GP's ratings of initiatives designed to improve rural medical workforce recruitment and retention. *Rural and Remote Health, 4*(314).

Jorgensen, K. P. (2006). *Health beliefs and practices of 'regulars' at the rural bar.* Unpublished Master's, Montana State University-Bozeman, Bozeman, MT.

Joseph, A. E., & Hallman, B. C. (1998). Over the hill and far away: distance as a barrier to the provision of assistance to elderly relatives. *Social Science & Medicine, 46*(6), 631-639.

Judd, F., Jackson, H., Davis, J., Cockram, A., Komiti, A., Allen, N., et al. (2000). Improving access for rural Australians to treatment for anxiety and depression: the University of Melbourne Depression and Anxiety Research and Treatment Group-Bendigo Health Care Group Initiative. *Australian Journal of Rural Health, 9,* 92-97.

Jutras, S., & Veilleux, F. (1991). Gender roles and care giving to the elderly: an empirical study. *Sex Roles, 25*(1/2), 1-18.

Kane, C. F., & Ennis, J. M. (1996). Health care reform and rural mental health: severe mental illness. *Community Mental Health J, 32*(5), 445-462.

Kaye, L. W. (2002). Service utilization and support provision of caregiving men. In B. J. Kramer & E. Thompson (Eds.), *Men as caregivers: theory, research, and service implications* (pp. 359-378). New York: Springer Publishing Company.

Kaye, L. W., & Applegate, J. S. (1995). Men's style of nurturing elders. In D. Sabo & D. Gordon (Eds.), *Men's health and illness: gender, power, and the body* (Vol. 8, pp. 205-222). Thousand Oaks, CA: Sage Publications.

Kendall, J. (1999). Axial coding and the grounded theory controversy. *Western Journal of Nursing Research, 21*(6), 743-757.

Koehler, V. (1998). The substantive theory of protecting independence. In H. J. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 236-256). New York: Springer.

Kools, S., McCarthy, M., Durham, R., & Robrecht, L. (1996). Dimensional analysis: broadening the conception of grounded theory. *Qualitative Health Research, 6*(3), 312-330.

Kramer, B. J. (1993). Marital history and the prior relationship as predictors of positive and negative outcomes among wife caregivers. *Family Relations, 42*, 367-375.

Kramer, B. J. (1997a). Differential predictors of strain and gain among husbands caring for wives with dementia. *Gerontologist, 37*(2), 239-249.

Kramer, B. J. (1997b). Gain in the caregiving experience: where are we? What next? *Gerontologist, 37*(2), 218-232.

Kramer, B. J. (2000). Husbands caring for wives with dementia: a longitudinal study of continuity and change. *Health and Social Work, 25*(2), 97-107.

Kramer, B. J. (2002). Men caregivers: an overview. In B. J. Kramer & E. Thompson (Eds.),

    Men as caregivers: theory, research, and service implications (pp. 3-19). New York:

    Springer Publishing Company.

Kramer, B. J., & Kipnis, S. (1995). Eldercare and work-role conflict: toward an

    understanding of gender differences in caregiver burden. *Gerontologist, 35*(3), 340-

    348.

Kramer, B. J., & Lambert, J. D. (1999). Caregiving as a life course transition among older

    husbands: a prospective study. *Gerontologist, 39*(6), 658-667.

Krausz, M., Kedem, P., Tal, Z., & Amir, Y. (1992). Sex-role orientation and work adaptation

    of male nurses. *Research in Nursing and Health, 15*(5), 391-398.

Krout, J. A. (1996). The role of senior centers in rural long-term care. In G. D. Rowles, J. E.

    Beaulieu & W. W. Myers (Eds.), *Long-term care for the rural elderly: new directions*

    in services, research, and policy (pp. 85-108). New York: Springer.

Kumar, V., Acanfora, M., Hennessy, C. H., & Kalache, A. (2001). Health status of the rural

    elderly. *Journal of Rural Health, 17*(4), 328-331.

Ladner, C., & Cuellar, N. (2002). Depression in rural hospice family caregivers. *Online*

    Journal of Rural Nursing and Health Care, 31(1).

Lago, D., Stuart, B., & Ahern, F. (1993). Rurality and prescription drug utilization among the

    elderly: an archival study. *Journal of Rural Health, 9*(1), 6-16.

Lawton, M. P., Kleban, M. H., Moss, M., Rovine, M., & Glicksman, A. (1989). Measuring

    caregiving appraisal. *Journal of Gerontology, 44*(3), P61-71.

Lee, H. (1998a). Concept comparison: old-timer/ newcomer/ insider/ outsider. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 149-155). New York: Springer Publishing Company.

Lee, H. (1998b). *Conceptual basis for rural nursing.* New York: Springer Publishing Company.

Lee, H. (1998c). Lack of anonymity. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 76-88). New York: Springer Publishing Company.

Lee, H. J. (1991). Definitions of rural: a review of the literature. In A. Bushy (Ed.), *Rural Nursing* (Vol. 1, pp. 7-22). Thousand Oaks, CA: Sage.

Lee, H. J., & Winters, C. A. (2004). Testing rural nursing theory: perceptions and needs of service providers. *Online Journal of Rural Nursing and Health Care, 4*(1).

Leininger, M. (1991). *Culture care diversity and universality: a theory of nursing.* New York: National League for Nursing Press.

Leininger, M. (1994). Evaluation criteria and critique of qualitative research studies. In J. Morse (Ed.), *Critical issues in qualitative research methods* (pp. 95-115). Thousand Oaks, CA: Sage.

Leipert, B. D., & Reutter, L. (2005). Developing resilience: how women maintain their health in northern geographic isolated settings. *Qualitative Health Research, 15*(1), 49-65.

Levant, R., & Habben, C. (2003). The new psychology of men: application to rural men. In B. Stamm (Ed.), *Rural behavioral health care: an interdisciplinary guide* (pp. 171-180). Washington, DC: American Psychological Association.

Levant, R. F., Hirsch, L. S., Cozza, T. M., Hill, S., MacEachern, M., Marty, N., et al. (1992). The male role: an investigation of contemporary norms. *Journal of Mental Health Counseling, 14*(3), 325-337.

Lincoln, Y., & Guba, E. (1985). Establishing trustworthiness. In Y. Lincoln & E. Guba (Eds.), *Naturalistic inquiry* (pp. 289-331). Thousand Oaks, CA: Sage.

Lincoln, Y. S., & Guba, E. (2000). Paradigmatic controversies, contradictions, and emerging confluences. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 163-188). Thousand Oaks, CA: Sage.

Lishner, D. M., Richardson, M., Levine, P., & Patrick, D. (1996). Access to primary health care among persons with disabilities in rural areas: a summary of the literature. *Journal of Rural Health, 12*(1), 45-53.

Long, K. (1998). The concept of health: rural perspectives. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 211-222). New York: Springer Publishing Company.

Long, K., & Weinert, C. (1998). Rural nursing: developing the theory base. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 3-18). New York: Springer Publishing Company.

Long, K. A., Scharff, J. E., & Weinert, C. (1997). Advanced education for the role of rural nurse generalist. *Journal of Nursing Education, 36*(2), 91-94.

MacAvoy, S., & Lippman, D. T. (2001). Teaching culturally competent care: nursing students experience rural Appalachia. *Journal of Transcultural Nursing, 12*(3), 221-227.

MacDougall, G. (1997). Caring--a masculine perspective. *Journal of Advanced Nursing, 25*(4), 809-813.

Magilvy, J. K. (1996). The role of rural home and community-based services. In G. D. Rowles, J. E. Beaulieu & W. W. Myers (Eds.), *Long-term care for the rural elderly: new directions in services, research, and policy* (pp. 64-84). New York: Springer.

Magilvy, J. K., & Congdon, J. G. (2000). The crisis nature of health care transitions for rural older adults. *Public Health Nursing, 17*(5), 336-345.

Mant, J., Carter, J., Wade, D. T., & Winner, S. (2000). Family support for stroke: a randomised controlled trial. *Lancet, 356*(9232), 808-813.

Marks, N. (1996). Caregiving across the lifespan: national prevalence and predictors. *Family Relations, 45*, 27-36.

Mathew, L. J., Mattocks, K., & Slatt, L. M. (1990). Exploring the roles of men. Caring for demented relatives. *Journal of Gerontological Nursing, 16*(10), 20-25.

Matthews, S. H., & Heidorn, J. (1998). Meeting filial responsibilities in brothers-only sibling groups. *The journals of gerontology. Series B, Psychological sciences and social sciences, 53*(5), S278-286.

Mays, G. D., & Lund, C. H. (1999). Male caregivers of mentally ill relatives. *Perspectives in Psychiatric Care, 35*(2), 19-28.

McLaughlin, D. K., & Jensen, L. (1993). Poverty among older Americans: the plight of nonmetropolitan elders. *Journal of Gerontology: Social Sciences, 48*(2), S44-S54.

McMurty, L., & Ossana, D. (Writer), & A. Lee (Director) (2005). *Brokeback Mountain* [Film]. In D. Ossana & J. Schamus (Producer). USA: Focus Features, LLC.

McNiven, C., & Puderer, H. (2000). *Delineation of Canada's North: an examination of the north-south relationship in Canada* (Government report No. 92F0138MIE, no. 2000-3). Ottawa, Ontario: Statistics Canada.

Meiers, S. J., Eggenberger, S. K., Krumwiede, N. K., Bliesmer, M. M., & Earle, P. A. (2006). Rural family health: Enduring acts of balance. In H. J. Lee & C. A. Winters (Eds.), *Rural nursing: Concepts, theory, and practice* (Vol. 2nd, pp. 110-126). New York: Springer.

Meltzer, B. N., Petras, J. W., & Reynolds, L. T. (1975). *Symbolic interactionism: genesis, varieties and criticism*. London: Routledge & Kegan Paul.

Messecar, D. C., Archbold, P. G., Stewart, B. J., & Kirschling, J. (2002). Home environmental modification strategies used by caregivers of elders. *Research in Nursing and Health, 25*(5), 357-370.

MetLife Mature Market Institute, National Alliance for Caregiving, & Center for Productive Aging. (2003). *The MetLife study of sons at work: balancing employment and eldercare* (Report). Westport, CT: MetLife.

Michalak, E. E., Wilkinson, C., Hood, K., Srinivasan, J., Dowrick, C., & Dunn, G. (2002). Prevalence and risk factors for depression in a rural setting. Results from the North Wales arm of the ODIN project. *Social Psychiatry and Psychiatric Epidemiology, 37*(12), 567-571.

Miller, B. (1996). Beyond gender stereotypes: spouse caregivers of persons with dementia. *Journal of Aging Studies, 10*(3).

Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: fact or artifact? *Gerontologist, 32*(4), 498-507.

Montana Area Health Education Center. (2002, November 5, 2002). *The critical access hospital resource center*. Retrieved March 1, 2005, 2005, from http://healthinfo.montana.edu/cah/maflist.html

National Alliance for Caregiving, & American Association of Retired Persons. (1997). *Family caregiving in the US: findings from a national survey* (Report). Washington, DC.

National Alliance for Caregiving, & American Association of Retired Persons. (2004). *Caregiving in the US* (Report). Washingon, DC: National Alliance for Caregiving.

National Family Caregivers Association. (2002). *Family caregiving statistics*. Retrieved December 30, 2003, 2003, from http://www.nfcacares.org/NFC2002_stats.html

National Institute of Nursing Research. (1994). *Family caregiving*. Retrieved April 8, 2003, 2003, from http://www.nih.gov/ninr/research/vol3/FamCare.htm

National Institute of Nursing Research. (1995). *Chapter 2: Rural America: challenges and opportunities*. Retrieved April 9, 2003, 2003

National Institutes of Health. (2001, May 15, 2001). *Depression can differ in men and women*. Retrieved May 11, 2004, 2004, from http://www.nih.gov/news/NIH-Record/05_15_2001/story08.htm

National Rural Health Association. (1999). *Mental health in rural America*. Retrieved April 22, 2003, 2003, from http://www.nrharural.org/dc/issuepapers/ipaper14.html

National Rural Health Association. (2001a). *Long-term care in rural America*. Retrieved April 22, 2003, 2003, from http://www.nrharural.org/dc/issuepapers/ipaper21.html

National Rural Health Association. (2001b). *The need for responsive rural health delivery systems* (Issue Paper). Washington, DC: National Rural Health Association.

National Rural Health Association. (2003a). *Quality of rural health care* (Policy brief): National Rural Health Association.

National Rural Health Association. (2003b). *What's different about rural health care?*

    Retrieved February 13, 2004, 2004, from

    http://www.nrharural.org/pagefile/different.html

Neufeld, A., & Harrison, M. J. (1998). Men as caregivers: reciprocal relationships or

    obligation? *Journal of Advanced Nursing, 28*(5), 959-968.

Nichols, A., Worley, P. S., Toms, L. M., & Johnston-Smith, P. R. (2004). Change of place,

    change of pace, change of status: rural community training for junior doctors, does it

    influence choices of training and career? *Rural and Remote Health, 4*(259), 1-8.

Nolan, M., Keady, J., & Grant, G. (1995). Developing a typology of family care:

    implications for nurses and other service providers. *Journal of Advanced Nursing,*

    21(2), 256-265.

Oberst, M. T., Thomas, S. E., Gass, K. A., & Ward, S. E. (1989). Caregiving demands and

    appraisal of stress among family caregivers. *Cancer Nursing, 12*(4), 209-215.

O'Lynn, C. (2003). *The process of male caregiving in rural areas* (unpublished paper).

    Portland, OR: Oregon Health & Science University.

O'Lynn, C. (2006a). The experiences and perspectives of men working as rural nurses: land

    of opportunity. In H. J. Lee & C. A. Winters (Eds.), *Conceptual Basis for Rural*

    Nursing (2nd ed.). New York: Springer.

O'Lynn, C. (2006b). The Symptom-Action Time Line: a literature review and

    recommendations for revision. In H. J. Lee & C. A. Winters (Eds.), *Conceptual basis*

    for rural nursing (2nd ed. ed.). New York: Springer.

O'Lynn, C. E. (2004). Gender-based barriers for male students in nursing education programs: prevalence and perceived importance. *Journal of Nursing Education, 43*(5), 229-236.

O'Neil, J. M., Good, G. E., & Holmes, S. (1995). Fifteen years of theory and research on men's gender role conflict: New paradigms for empirical research. In R. F. Levant & W. S. Pollack (Eds.), *A new psychology of men* (pp. 164-206). New York: Basic Books.

O'Neil, J. M., Helms, B. J., Gable, R. K., David, L., & Wrightsman, L. S. (1986). Gender-role Conflict Scale: college men's fear of femininity. *Sex Roles, 14*(5/6), 335-350.

Oregon Health & Science University. (2006). *Oregon rural critical access hospitals.* Retrieved August 30, 2006, 2006, from http://www.ohsu.edu/oregonruralhealth/rurhospcah.htm

Paley, J. (2001). An archaeology of caring knowledge. *Journal of Advanced Nursing, 36*(2), 188-198.

Parsons, K. (1997). Male experience of caregiving for a family member with Alzheimer's Disease. *Qualitative Health Research, 7,* 391-407.

Paterson, B. L., Crawford, M., Saydak, M., Venkatesh, P., Tschikota, S., & Aronowitz, T. (1995). How male nursing students learn to care. *Journal of Advanced Nursing, 22*(3), 600-609.

Paterson, B. L., Tschikota, S., Crawford, M., Saydak, M., Venkatesh, P., & Aronowitz, T. (1996). Learning to care: gender issues for male nursing students. *Canadian Journal of Nursing Research, 28*(1), 25-39.

Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.

Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behavior, 19*, 2-21.

Perry, S. I., Hsu, R. T., Brooks, W., & Cherry, D. (1999). Perceptions of community services among Asian and white stroke survivors and their carers: an exploratory study. *Ethnicity and Health, 4*(1-2), 101-105.

Phillips, P. (1993). A deconstruction of caring. *Journal of Advanced Nursing, 18*(10), 1554-1558.

Picot, S. J. (1995). Rewards, costs, and coping of African American caregivers. *Nursing Research, 44*(3), 147-152.

Pierce, L. L., Steiner, V., Govoni, A. L., Hicks, B., Cervantez-Thompson, T. L., & Friedemann, M. (2004). Caregivers dealing with stroke pull together and feel connected. *Journal of Neuroscience Nursing, 36*(1), 32-39.

Pleck, J. H. (1995). The gender role strain paradigm: An update. In R. F. Levant & W. S. Pollack (Eds.), *A new psychology of men* (pp. 11-32). New York: Basic Books.

Porter, C. P., & Villarruel, A. M. (1993). Nursing research with African American and Hispanic people: guidelines for action. *Nursing Outlook, 41*(2), 59-67.

Preston, D. B., Forti, E. M., Kassab, C., & Koch, P. B. (2000). Personal and social determinants of rural nurses' willingness to care for persons with AIDS. *Res Nurs Health, 23*(1), 67-78.

Rabiner, D. J., Konrad, T. R., DeFriese, G. H., Kincade, J., Bernard, S. L., Woomert, A., et al. (1997). Metropolitan versus nonmetropolitan differences in functional status and self-care practice: findings from a national sample of community-dwelling older adults. *Journal of Rural Health, 13*(1), 14-28.

Reed, D. M., & Weicherding, M. (1999). Factors of caregiver isolation in a rural midwest area. *Home Health Care Service Quarterly, 17*(4), 13-24.

Richards, H. M., Farmer, J., & Selvaraj, S. (2005). Sustaining the rural primary healthcare workforce: survey of healthcare professsionals in the Scottish Highlands. *Rural and Remote Health, 5*(365).

Richardson, L. (2000). Writing: a method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (pp. 923-948). Thousand Oaks, CA: Sage Publications, Inc.

Ridgeway, C. L., & Smith-Lovin, L. (1999). The gender system and interaction. *Annual Review of Sociology, 25*, 191-216.

Roberto, K. A., & Reynolds, S. G. (2002). Older women's experiences with chronic pain: daily challenges and self-care practices. *Journal of Women & Aging, 14*(3-4), 5-23.

Roberts, J., Browne, G., Milne, C., Spooner, L., Gafni, A., Drummond-Young, M., et al. (1999). Problem-solving counseling for caregivers of the cognitively impaired: effective for whom? *Nursing Research, 48*(3), 162-172.

Robinson, B. C. (1983). Validation of a Caregiver Strain Index. *Journal of Gerontology, 38*(3), 344-348.

Robrecht, L. (1995). Grounded theory: evolving methods. *Qualitative Health Research, 5*(2), 169-177.

Rosenthal, K. (1996). *Rural nursing: an exploratory narrative description.* Unpublished

Dissertation, University of Colorado, Denver, CO.

Rost, K., Williams, C., Wherry, J., & Smith, G. R., Jr. (1995). The process and outcomes of

care for major depression in rural family practice settings. *Journal of Rural Health,*

11(2), 114-121.

Rowles, G. D. (1996). Nursing homes in the rural long-term care continuum. In G. D.

Rowles, J. E. Beaulieu & W. W. Myers (Eds.), *Long-term care for the rural elderly:*

new directions in services, research, and policy (pp. 109-131). New York: Springer.

Running, A. (1998). Health perceptions of rural elders: "landscapes and life". In H. J. Lee

(Ed.), *Conceptual basis for rural nursing* (pp. 223-235). New York: Springer

Publishing Company.

Russell, C. M. (1927). *Trails plowed under.* Lincoln, NE: Univeristy of Nebraska Press.

Russell, R. (2004). Social networks among elderly men caregivers. *The Journal of Men's*

Studies, 13(1), 121-142.

Ryan-Nicholls, K. (2004). Health and sustainability of rural communities. *Rural and Remote*

Health, 4(242), 1-11.

Scharff, J. (1998). The distinctive nature and scope of rural nursing practice: philosophical

bases. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 19-38). New York:

Springer Publishing Company.

Schatzman, L. (1991). Dimensional analysis: notes on an alternative approach to grounding

of theory in qualitative research. In D. R. Maines (Ed.), *Social organization and*

social process (pp. 303-314). New York: DeGruyter.

Schulz, R. (1990). Theoretical perspectives on caregiving: concepts, variables, and methods. In D. Biegel & A. Blum (Eds.), *Aging and caregiving: theory, research, and policy* (pp. 27-52). Newbury Park, CA: SAGE Publications, Inc.

Schulz, R., Beach, S. R., Lind, B., Martire, L. M., Zdaniuk, B., Hirsch, C., et al. (2001). Involvement in caregiving and adjustment to death of a spouse: findings from the caregiver health effects study. *Jama, 285*(24), 3123-3129.

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (1998). Conceptualization and measurement of doing family caregiving well. *Image Journal of Nursing Scholarship, 30*(1), 63-69.

Schumacher, K. L., Stewart, B. J., Archbold, P. G., Dodd, M. J., & Dibble, S. L. (2000). Family caregiving skill: development of the concept. *Research in Nursing and Health, 23*(3), 191-203.

Scotto, C. J. (2003). A new view of caring. *Journal of Nursing Education, 42*(7), 289-291.

Seddon, D., & Robinson, C. A. (2001). Carers of older people with dementia: assessment and the Carers Act. *Health and Social Care in the Community, 9*(3), 151-158.

Sellers, S. C., Poduska, M. D., Propp, L. H., & White, S. I. (1999). The health care meanings, values, and practices of Anglo-American males in the rural midwest. *Journal of Transcultural Nursing, 10*(4), 320-330.

Shyu, Y. I., Archbold, P. G., & Imle, M. (1998). Finding a balance point: a process central to understanding family caregiving in Taiwanese families. *Research in Nursing and Health, 21*(3), 261-270.

Simon, C., & Kumar, S. (2002). Stroke patients' carers' views of formal community support. *British Journal of Community Nursing, 7*(3), 158-163.

Simpson, R. G. (1997). Carers as equal partners in care planning. *Journal of Psychiatric and Mental Health Nursing, 4*(5), 345-354.

Slifkin, R. T. (2002). Developing policies responsive to barriers to health care among rural residents: what do we need to know? *Journal of Rural Health, 18 Suppl,* 233-241.

Smith, J. L., Rost, K. M., Nutting, P. A., Elliott, C. E., & Duan, N. (2000). A primary care intervention for depression. *Journal of Rural Health, 16*(4), 313-323.

Sommers, C. H. (2000). *The war against boys.* New York: Simon & Schuster.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *Gerontologist, 42*(3), 356-372.

Sourial, S. (1997). An analysis of caring. *Journal of Advanced Nursing, 26*(6), 1189-1192.

Spratley, E., Johnson, A., Sochalski, J., Fritz, M., & Spencer, W. (2001). *The registered nurse population March 2000: findings from the National Sample Survey of Registered Nurses* (Report). Washington, DC: U.S. Department of Health and Human Services, Health and Resources and Services Administration.

Sprouse, D. O. (1996). Message from the president. *Interaction, 14*(3), 1-2, 4.

Statistics Canada. (2005). *Definitions of rural.* Retrieved March 18, 2005, 2005, from http://www.statcan.ca:8096/bsolc/english/bsolc?catno=21-601-M2002061

Stimpson, D., Neff, W., Jensen, L., & Newby, T. (1991). The caring morality and gender differences. *Psychological Reports, 69,* 407-414.

Stoller, E. (2002). Theoretical perspectives on caregiving men. In B. J. Kramer & E. Thompson (Eds.), *Men as caregivers: theory, research, and service implications* (pp. 51-68). New York: Springer Publishing Company.

388

Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: a national

profile. *Gerontologist, 27*(5), 616-626.

Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: techniques and*

procedures for developing grounded theory (2nd edition ed.). Thousand Oaks, CA:

Sage.

Strawbridge, W. J., Wallhagen, M. I., Shema, S. J., & Kaplan, G. A. (1997). New burdens or

more of the same? Comparing grandparent, spouse, and adult-child caregivers.

Gerontologist, 37(4), 505-510.

Sullivan, E. J. (2000). Men in nursing: the importance of gender diversity. *Journal of*

Professional Nursing, 16(5), 253-254.

Sullivan, T., Weinert, C., & Cudney, S. (2003). Management of chronic illness: voices of

rural women. *Journal of Advanced Nursing, 44*(6), 566-574.

Szabo, V., & Strang, V. R. (1999). Experiencing control in caregiving. *Image Journal of*

Nursing Scholarship, 31(1), 71-75.

The National Advisory Committee on Rural Health and Human Services. (2004). *The 2004*

report to the Secretary: rural health and human service issues (Report). Washington,

DC: Department of Health and Human Services.

Thomas, C. (1993). De-constructing concepts of care. *Sociology, 27*(4), 649-669.

Thomas, D. H. (1993). Part one: The world as it was. In B. Ballantine & I. Ballantine (Eds.),

The Native Americans: An illustrated history (pp. 23-110). Atlanta: Turner

Publishing, Inc.

Thomlinson, E., McDonagh, M. K., Crooks, K. B., & Lees, M. (2002, October 3-5, 2002). *Health beliefs of rural Canadians: implications for practice.* Paper presented at the Charting the Courses for Rural Health in the 21st Century, Bingingham, NY.

Thompson, E., Pleck, J., & Ferrera, D. (1992). Men and masculinities: scales for masculinity ideology and masculinity-related constructs. *Sex Roles, 27*(11/12), 573-607.

Thompson, E. H. (2002). What's unique about men's caregiving? In B. J. Kramer & E. H. Thompson (Eds.), *Men as caregivers: Theory, research, and service implications* (pp. 20-50). New York: Springer Publishing Company.

Thompson, R. L., Lewis, S. L., Murphy, M. R., Hale, J. M., Blackwell, P. H., Acton, G. J., et al. (2004). Are there sex differences in emotional and biological responses in spousal caregivers of patients with Alzheimer's disease? *Biological Research for Nursing, 5*(4), 319-330.

Tong, R. (1993). Carol Gilligan's ethics of care. In R. Tong (Ed.), *Feminine and feminist ethics* (pp. 80-107). Belmont, CA: Wadsworth Publishing Company.

University of Pittsburgh Center for Rural Health Practice. (2004). *Bridging the health divide: the rural public health research agenda* (Report). Pittsburgh, PA: University of Pittsburgh.

US Census Bureau. (2002). *US summary: 2000* (Census profile No. C2KPROF/00-US). Washington, DC: US Department of Commerce.

US Census Bureau. (2004, January 14, 2003). *Summary File (SF) 1 Demographic profiles (Montana).* Retrieved February 28, 2004, 2004, from http://ceic.commerce.state.mt.us/SF1demogProfiles.html

US Census Bureau. (2005a). *Census 2000 Summary File 1 (SF 1)*. Retrieved July 21, 2005, 2005, from http://factfinder.census.gov

US Census Bureau. (2005b, March 17, 2005). *Question and answer center: definitions: urban and rural*. Retrieved March 18, 2005, 205, from http://ask.census.gov/cgi-bin/askcensus.cfg/php/enduser/std_adp.php?p_sid=IR4euOAh&p...

US Census Bureau. (2006). *Census 2000 Demographic Profile Highlights*. Retrieved August 30, 2006, 2006, from http://factfinder.census.gov/home/saff/main.html?_lang=en

van den Heuvel, E. T., de Witte, L. P., Schure, L. M., Sanderman, R., & Meyboom-de Jong, B. (2001). Risk factors for burn-out in caregivers of stroke patients, and possibilities for intervention. *Clinical Rehabilitation, 15*(6), 669-677.

Vargas, C. M., Dye, B. A., & Hayes, K. L. (2002). Oral health status of rural adults in the United States. *Journal of the American Dental Association, 133*(12), 1672-1681.

Villeneuve, M. J. (1994). Recruiting and retaining men in nursing: a review of the literature. *Journal of Professional Nursing, 10*(4), 217-228.

Vukic, A., & Keddy, B. (2002). Northern nursing practice in a primary health care setting. *Journal of Advanced Nursing, 40*(5), 542-548.

Wagenfeld, M. O. (2000). Delivering mental health services to the persistently and seriously mentally ill in frontier areas. *Journal of Rural Health, 16*(1), 91-96.

Wagenfeld, M. O. (2003). A snapshot of rural and frontier America. In B. Stamm (Ed.), *Rural behavioral health care: an interdisciplinary guide* (pp. 33-41). Washington, DC: American Psychological Association.

Wallace, D. C., Tuck, I., Boland, C. S., & Witucki, J. M. (2002). Client perceptions of parish nursing. *Public Health Nursing, 19*(2), 128-135.

Watson, J. (1979). *Nursing: the philosophy and science of caring.* Boston, MA: Little, Brown and Company.

Watson, J. (1985). *Nursing: human science and human care: a theory of nursing.* Norwalk, CT: Appleton-Century-Crofts.

Watson, J., & Smith, M. C. (2002). Caring science and the science of unitary human beings: a trans-theoretical discourse for nursing knowledge development. *Journal of Advanced Nursing, 37*(5), 452-461.

Weinert, C. (2000). Social support in cyberspace for women with chronic illlness. *Rehabilitation Nursing, 25*(4), 129-135.

Weinert, C., & Boik, R. J. (1995). MSU Rurality Index: development and evaluation. Montana State University. *Research in Nursing and Health, 18*(5), 453-464.

Weinert, C., Cudney, S., & Winters, C. (2005). Social support in cyberspace: the next generation. *Computers, Informatics, Nursing: CIN, 23*(1), 7-15.

Wenger, G. C., Scott, A., & Seddon, D. (2002). The experience of caring for older people with dementia in a rural area: using services. *Aging and Mental Health, 6*(1), 30-38.

West, C., & Zimmerman, D. H. (1987). Doing gender. *Gender and Society, 1*(2), 125-151.

Winters, C. A., Thomlinson, E. H., O'Lynn, C., Lee, H. J., McDonagh, M. K., Edge, D. S., et al. (2006). Exploring rural nursing theory across borders. In H. J. Lee & C. A. Winters (Eds.), *Rural nursing: Concepts, theory, and practice* (Vol. 2nd, pp. 27-42). New York: Springer.

Wirtz, E., Lee, H., & Running, A. (1998). The lived experience of hardiness in rural men and women. In H. Lee (Ed.), *Conceptual basis for rural nursing* (pp. 257-274). New York: Springer Publishing Company.

Worley, P. S. (2004). Good health to rural communities? *Rural and Remote Health, 4*(292), 1-4.

Wright, L. K., Hickey, J. V., Buckwalter, K. C., Hendrix, S. A., & Kelechi, T. (1999). Emotional and physical health of spouse caregivers of persons with Alzheimer's disease and stroke. *Journal of Advanced Nursing, 30*(3), 552-563.

Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: a review and analysis. *Gerontologist, 40*(2), 147-164.

Young, R. F., & Kahana, E. (1989). Specifying caregiver outcomes: gender and relationship aspects of caregiving strain. *Gerontologist, 29*(5), 660-666.

Zarit, S., Reever, K. E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist, 20*(6), 649-655.

Zarit, S., Todd, P., & Zarit, J. (1986). Subjective burden of husbands and wives as caregivers: a longitudinal study. *The Gerontologist, 26*(3), 260-266.

Appendix A Grand Tour Questions and Subsequent Probe Questions

Aim #1: Meanings and Experiences of Caregiving: What is it like looking after your wife [or parent]?
1. When someone looks after their wife **[or parent]**, there can be challenges. What kinds of challenges do you have?
2. What kinds of things do you experience when looking after your wife **[or parent]**?
3. How is your life different now that your wife **[or parent]** needs your help?
4. Why have you taken on this role instead of having someone else do it?
5. If the roles were reversed, that your wife **[or parent]** was looking after you, what would she do differently than you?

Aim #2: Processes of Caregiving: How do you look after your wife [or parent]?
1. What kinds of thinks do you do for your wife **[or parent]** to help her out?
2. Tell me about your typical day as you look after your wife **[or parent]**.
3. Are there things at night that you have to do for your wife **[or parent]**?
4. What kind of help do you get or need to get things done?
5. What was it like when you first started looking after your wife **[or parent]**? What is it like now?

Aim #3: Self-perceptions of Health: How are you getting along?
1. Do you have people to lean on if you need it?
2. How do you take a break?
3. How's your health been since you've been looking after your wife **[or parent]**?

Aim #4: Theoretical Understanding (To be determined by theoretical memos and data analysis).

Appendix B Text for Newspaper Study Recruitment Advertisement

Men: Are you looking after a sick or disabled wife or parent at home? Nurse researcher seeks to interview men caring for their family members at home in order to help health care workers provide better support. Participants will receive a $35 gift card for granting two or three interviews lasting as long as one hour each. If interested or desire further information, please contact Chad O'Lynn, RN at 503-943-7357. (D. Messecar, PhD, principal investigator, eIRB# 1329.)

Appendix C Study Recruitment Flyer

Men---

Are you helping a sick or disabled wife or parent at home?

Chad O'Lynn, RN, a professor from the School of Nursing at the University of Portland, is seeking to interview men in rural communities who are helping their wives or parents at home with personal tasks due to illness or disability. These interviews are part of a study conducted through Oregon Health & Science University School of Nursing.

The purpose of this study is to help health care workers better understand the experiences and needs of men who look after family members at home in rural communities. The information gained from this study will help health care workers support the success of men providing this assistance to their wives.

Interviews will be conducted individually over the telephone at a convenient time and date. Men who participate will receive a $35 gift card for granting an initial interview and a second brief interview if there are any follow-up questions. The initial interview lasts about one hour.

If you are interested in participating, or would like further information, please contact Chad O'Lynn, RN directly at 503-943-7357, or email address olynn@up.edu . (D. Messecar, PhD, principal investigator, eIRB# 1329.)

Appendix D   Selected Photographs From My Photo Journal

Grain silos: Carter, MT

Idle farm equipment: Loma, MT

Cattle ranching: Teton Co., MT

Critical access hospital: Ft. Benton, MT

High plains: Big Sandy, MT

A local bar: Chinook, MT

Appendix D   Continued

Wheat fields: Geraldine, MT

Field site: Ft. Benton, MT

A prayer for rain: Carter, MT

A lifetime of hunter's pride: Loma, MT

Community pride: Joplin, MT

Wildflowers and prairie: Hilger, MT

Appendix D Continued

Running errands: Ft. Benton, MT

Family time: Ft. Benton, MT

Resting at the rodeo: Ft. Benton, MT

Outdoor hobbies: Choteau Co., MT

Old friends: Ft. Benton, MT

Small town life: Joseph, OR

Appendix D Continued

Oregon Trail People: Prairie City, OR

Hauling hay: John Day, OR

Solitude: Wallowa Co., OR

Faith in God: Zortman, MT

Appendix E   Consent Form Used in Study

OHSU **Oregon Health & Science University**
Consent & Authorization Form

eIRB#: 1329
Protocol Approval Date: 6/12/2006

OREGON HEALTH & SCIENCE UNIVERSITY
Consent & Authorization Form

TITLE: Rural Male Caregivers: Meanings, Experiences, and Processes

PRINCIPAL INVESTIGATOR: Deborah Messecar, PhD, RN (503) 494-3573

CO-INVESTIGATOR: Chad O'Lynn, MS, RN (503) 943-7357

This form contains important information about the study in which you are being invited to participate. Please read the form carefully, ask questions of the investigators or others who are obtaining your consent to participate in the study, and take time to think about your participation. You may want to discuss the study with your family or friends before agreeing to be in the study.

What is the purpose of this study?

The purpose of this study is to learn more about how men who live in rural areas care for their adult family members at home.

What is required to participate in this study?

To qualify for this study, you must meet the following criteria:

1. Be over 21 years old
2. Speak English fluently
3. Be the legal husband or son of the person receiving care
4. Help with at least one daily personal task used to do by her/himself
5. Live in a town of less than 15,000 people

What can I expect as a study participant?

You will be interviewed at least twice by the investigator. The first interview will be done in person. This interview will last between 45-90 minutes, and will take place when and where you want. Other interviews may be done in person or over the telephone.

Interviews will be tape-recorded so that the information gathered is accurate. You may choose not to have the interviews tape-recorded.

This study requires at least two interviews. The investigator may call you to clarify any answers up to six (6) months after your first interview.

If you have any questions regarding this study now or in the future, contact Deborah Messecar at (503) 494-3573 or Chad O'Lynn at (406) 622-5863.

What effect will this study have on my care?

Being in this study will not affect any care that you might receive at any of your health care providers, or any future care that you might receive at OHSU.

How will my privacy be protected?

We will protect your privacy in the following ways:
Your name or other protected information will not be used. Instead, we will identify you by a code so that we may contact you by telephone if needed. Only information that you provide us during interviews will be recorded and used in this study.

Only the OHSU Institutional Review Board, the Office for Human Research Protections and the research team will be able to access your personal information. No written work or presentation from this study will have information that could identify you as a participant in this study. During the study, all information will be kept under lock and key. Audiotapes of the interviews will be transcribed (written down) and the tapes themselves will be destroyed at the end of the study.

This authorization will expire and we will no longer keep health information that we collect from you in this study when the study is completed.

What are the possible risks of participating in this study?

Although we have made every effort to protect your identity, there is a minimal risk of loss of confidentiality. In addition, some of the questions asked during the interview may be of a personal nature and may cause some discomfort. You may refuse to answer any question for any reason. If your interview is audiotaped, you may ask that the tape recorder be turned off at any time.

Since the investigators are nurses and are bound by Montana law, any suspected abuse must be reported to local authorities for investigation.

What are the possible benefits of participating in the study?

You may or may not benefit from being in this study. However, by serving as a subject, you may help us learn how to benefit patients in the future.

Will it cost anything to participate?

Participating in this study will cost you nothing except your time. You will be provided a gift card or certificate worth $35 for your time when you have finished the study. If you participate in only one interview, you will be given a gift card or certificate worth $20.

What if I am harmed or injured in this study?

If you believe you have been injured or harmed while participating in this research and require immediate treatment, contact Deborah Messecar at (503) 494-3573.

The Oregon Health & Science University is subject to the Oregon Tort Claims Act (ORS 30.260 through 30.300). If you suffer any injury and damage from this research project through the fault of the University, its officers or employees, you have the right to bring legal action against the University to recover the damage done to you subject to the limitations and conditions of the Oregon Tort Claims Act. You have not waived your legal rights by signing this form. For clarification on this subject, or if you have further questions, please call the OHSU Research Integrity Office at (503) 494-7887.

What are my rights as a participant?

If you have any questions regarding your rights as a research subject, you may contact the OHSU Research Integrity Office at (503) 494-7887.

You do not have to join this or any research study. If you do join, and later change your mind, you may quit at any time. If you refuse to join or withdraw early from the study, there will be no penalty or loss of any benefits to which you are otherwise entitled.

You have the right to revoke this authorization and can withdraw your permission for us to use your information for this research by sending a written request to the Principal Investigator listed on page one of this form. If you do send a letter to the Principal Investigator, the use and disclosure of your protected health information will stop as of the date she receives your request. However, the Principal Investigator is allowed to use information collected before the date of the letter or collected in good faith before your letter arrives. Revoking this authorization will not affect your health care or your relationship with OHSU. However, once data is analyzed, your identification will be stripped from the information. At that point, your information will be impossible to remove from the study findings.

If the researchers publish the results of this research, they will do so in a way that does not identify you unless you allow this in writing.

You may be removed from the study at the investigator's discretion.

You are free to withdraw from the study at any time.

To participate in this study, you must read and sign this consent and authorization form. If you withdraw your authorization for us to use and disclose your information as described above, you will be withdrawn from the study.

We will give you a copy of this form.

SIGNATURES:

Please show your wishes by initialing one sentence below.

_____ I will allow the interview(s) to be audiotaped.

_____ I will NOT allow the interview(s) to be audiotaped.

Your signature below indicates that you have read this entire form and that you agree to be in this study.

> **OREGON HEALTH & SCIENCE UNIVERSITY**
> **INSTITUTIONAL REVIEW BOARD**
> **PHONE NUMBER (503) 494-7887**
> **CONSENT/AUTHORIZATION FORM APPROVAL DATE**
>
> **Aug. 30, 2006**
>
> **Do not sign this form after the**
> **Expiration date of: 6/11/2007**

Signature of Participant: _____ Date: _____

Signature of Investigator: _____ Date: _____

Name of Investigator: _____

Appendix F   List of Open and Focused Codes and Categories Constructed from Data

<u>Open Codes</u>

Advanced directives
Advices is to do the best you can
Advice is to get support
Advice is to let go of control
Advice is to accept help from anyone
Advice is to accept your limitations
Advice is to ask for help
Advice is to tap into faith
Advocating for wife
Age
Allows wife to be present with interview
Always on call
Asking & accepting help
Assist with spirituality
Becoming keenly aware of wife's needs
Busy schedule
Can't stay angry too long
Can't stop working
Caregiver less than 5 years
Caregiver more than 5 years
Caregiving aggravating husband's health
Caregiving is time-consuming
Caregiver tasks are hard
CG always on his mind
CG demystified death
CG denies his own health problems
CG down to an art
CG during the day
CG hard emotionally
CG hard on the body
CG hard on the marriage
CG interrupts work
CG more difficult over time
CG need to ask for help
CG negative effect on the marriage
CG prepared hem for future CG
CG role more instrumental
CG several hours per day
CG should be caring
CG should be hard working

CG should be knowledgeable
CG should be on call to help
CG should be patient
CG should be physically fit
CG transforms him
CG work gives you insight
CG work helps you help others
CG work trumps worrying
Church friends can help
Church help physical & spiritual
Church helped daughters emotionally
Church not intrusive
Clinical talk with co-workers
Common sense is important
Co-workers don't understand
Co-workers offer to help
Co-workers showed interest
Denial of gravity of wife's illness
Denies his own health needs
Denies hobbies due to CG
Did not miss much work
Didn't believe co-workers' concern
Difficulty giving emotional support
Difficulty obtaining proper DME
Difficulty reflecting beliefs
Difficulty with reflection on roles
Distrusts government
Distrusts hospice at first
Distrusts the HCP and system
Do what you gotta do
Does cooking
Does housework
Doesn't use HH
Doesn't want to disclose to co-workers
Doesn't want wife as CG
Double caregiver
Easier to be family CG
Easy to describe work/ procedures
Educating co-workers
Emotionally distant

Appendix F   Continued

Employed at a hospital
Faith important
Faith is stronger
Family gives lukewarm assistance
Farmer
Fatalism
Feared wife would die when at work
Feels discounted & angry with HCP
Fighting battle with HCP
Financial difficulties with services
Finding respite in golf
Focus on problem-solving
Food is comfort for stress
Found support group comfortable
Frequent attention to wife
Friends don't understand
Friends willing to help
Frustrated with caregiving demands
Frustration when can't fix things
Gained 80 lbs after death of wife
God gives us strength
Goes to be alone when angry
Grandmother next door
Grandmother wanted to die
Grief pamphlet helpful
Hard to deal with wife's emotions
Hard working
Hardship fosters self-disclosure
Has DME
HCP discounts husband
Help from teen-aged daughters
Helps mother with IADLs
Helps wife with bathing
Helps wife with dressing
Helps wife with IADLs
Helps wife with positioning
Helps wife with ROM
Helps wife with toileting
Helps wife with transfers
Helps with everything
His grief identical to grief pamphlet
Hobbies important respite
Home health doesn't serve husband

Hospice did case mgmt
Hospice helped him with control
Hospice is hard work
Hospice provides respite
Hospice recognized family stress
Hospice respectful of your beliefs
Hospice took control
Hospice very knowledgeable
Husband has chronic illness
Husband role as provider
Husband role more affective
Husband should be caring
Husband should be patient
Husband should do housework
Husband should have leadership
If not spiritual, tap into science
Importance of faith
Inadequate case mgmt
Interplay between weather and work
Irritability
Irritated when wife interrupts
Isolated from HC services
Isolated from other male CG
It could be worse
Kept co-workers updated
Lack of CG support
Lack of family
Lack of help from friends/neighbors
Lack of pride in CG work
Lack of respite services
Lack of specialists
Land rich, house poor
Learned CG at work
Likes people to take interest
Logger
Loners attached to wife
Loners have trouble
Loners may be suicidal
Long distances
Long-term rural
Lost job due to CG
Making concession with HCP
Making room pleasant for wife

Appendix F   Continued

Managing his own health self-care
Married long-term
Men less likely to talk emotion
Men will talk if trust
Men will talk if stressed
Misses time with his friends
Mother next door
Mother with chronic illness
Moved to rural to raise kids
Multiple deaths are difficult
Needs validation for decisions
Neglects own health due to CG demands
Negotiating roles
Neighbor willing to help
Never gets used to role problems
NHP for respite services
No help from family
No heroic measures
No trouble juggling roles
Nobody's like me
Not giving up control sign of stress
Not knowing trajectory fearful
Not retired
Outsider to rural
Over age 65
Overwhelming fatigue
Perceives HCP as greedy for money
Perceives wife doesn't understand him
Perception that living in city would be easier
Perseverance
Plan the work
Plans to join seminary
Poor sleep
Pride
Pride at staying out of debt
Pride in his marriage
Priest understands death
Privacy not a concern
Prof CG gives less emotional support
Protects wife from worry
Provides ADLs at night
Provides ROM for wife
Rancher

Reaching a desperation point
Reaching out for help
Realizing he needs help
Realizing wife's wishes
Received grief pamphlet
Reflection not practical
Relinquishing control
Resistance to move
Resistant to give up control
Retired
Role as a provider
Rural community support
Rural don't forgive and forget
Rural folks offer help easily
Rural resistant to change
Self-pays for services
Some overlap with roles
Someone else called hospice
Stress
Support group mostly women
Taking on more tasks
Talks frankly
That's the way I've always been
The buffalo jump
Thinks he can do better
Traveling distances difficult
Trouble with roles
Trumping roles/ tasks
Trumps roles
Trying to help other CG
Unable to obtain services
Underestimating work
Understands hospice
Uses home health
Uses prayer
Values common sense
Values family
Values hard work
Values self-advocacy
Wants male CG his age
Wants male CG to talk to
Wants to go to urban setting
Wants to live close to family

Appendix F   Continued

Wants to live closer to resources
Went to support group after death
Wife active in decision-making
Wife CG would ask for help sooner
Wife CG would have trouble physically
Wife comfortable with rural
Wife has friends for support
Wife is homebound
Wife would be more attentive CG
Wife would have it easier as CG
Wife's chronic illness
Wife's deteriorating health
Wife's self-care
Women CG don't understand
Women understand emotions
Work is close to home
Work (farm) takes toll on body
Work was a respite
Worked nights
Works as a farmer
Works farm/ranch
Would CG all the time if possible
Would compare notes with other CG
Would compare notes with other men CG
Would prefer a female CG
Would talk to men about emotions
Would talk to men about roles
Would talk to men over Internet
XX Demographics
Young aren't supposed to die

Appendix F   Continued

Focused Codes

Approaching the Buffalo Jump
Battling finances
Battling for control
Battling the health care system
Contending with rural isolation
Dealing with caregiver burdens (challenges)
Denying/ Neglecting his needs
Doing the caregiving work
Enjoying rural support
Exploring positive strategies
Expressing my emotions
Gaining insight and transformation
Giving advice
Miscellaneous
Negotiating roles
Nobody helps me
Nobody understands me/ isolation
Taking pride
Talking about rural
That's the way I've always been
Thinking about gender

Categories

Caregiver challenges
Negotiating gender*
Rural masculinity
Rurality

*core category