Background

Providing care to a family member or friend is a new societal role for older men and their informal caregiving experiences are not well understood. Although the majority of participants in caregiving studies have been female, 30-40% of informal caregivers are men. More information is needed about their experiences to provide appropriate support to this growing group of caregivers.

Purpose

The aim of this study was to explore older men’s perceived meaning of the informal caregiving experience, transitions to and within the caregiver role, and perceived preparation for caregiving events.

Framework

The Middle Range Theory of Transitions by Meleis provided a framework to examine elements of the caregiver role.

Method

This phenomenological, mixed methods study consisted of initial interviews with 13 older men, mostly Caucasian. Instruments used were a demographic questionnaire, structured interview guide, and the Preparedness Scale of the Family Care Inventory.
Findings

Participants described caregiving as a familial, reciprocal responsibility. They viewed caregiving as a natural part of the life cycle and took pride in their work. Previous caregiving experience, supportive marriages, and skills acquired in their former work life were discussed as helpful in preparing them for their current caregiving experience. Men shared advice for others including asking for help, learning needed skills, and practicing self-care strategies. Implications for practice, education, systems, and technology were discussed. Due to the level of interaction with patients and families, nurses are uniquely positioned to support older male caregivers in this new role. Knowledge gained from this study will contribute to developing strategies to assist men in adapting to the informal caregiving role.
To my husband, Jim Taylor,
whose steadfast belief and support helps me achieve my dreams.

To my parents, Walter and Ilona Striplin,
who encouraged my love of learning.
This dissertation has been approved by the following committee of the Faculty of The Graduate School at The University of North Carolina at Greensboro.

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CHAPTER I

INTRODUCTION

Informal caregiving is a centuries old responsibility usually assumed by family, friends, or other individuals in the community. Informal family caregiving is highly valued by much of society, with an estimated 80% of long-term care being provided in the home (National Family Caregivers Association, 2009). Yet, it is an unpaid job often with little recognition unless care is not adequately given. The estimated cost of this unpaid job was $375 billion per year in 2007 which compares to the spending of Medicare ($345 billion in 2005), Medicaid ($300 billion in 2005), nursing home and home health care ($206.6 billion in 2005), and the U.S. budget deficit in 2006 ($248 billion) (American Association Of Retired People, 2007; Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009).

Without this unpaid and informal care, more costly services such as paid home health aides, assisted living facilities, and nursing homes would be used or older adults would go without care. Most informal caregiving is not paid for by traditional health care system reimbursement or insurance coverage. However, caregiving is not without cost to the caregiver. Lost productivity at work, lost benefits or promotions, unpaid leave or premature retirement, and declining mental and physical health are challenges for family caregivers (Metlife Mature Market Institute & National Alliance for Caregiving, 2006; Rubin, 2002). Thus, understanding the past and current needs of caregivers is important.
as we move into the future, which will bring different challenges with increasing longevity, economic constraints, and diversity in the older adult population.

**Purpose**

The meaning of the informal caregiving experience for men is not well understood. Men’s role as caregiver is relatively new and often men’s care work is unrecognized, which may present additional challenges for the male caregiver (Russell, 2007). Since caregiving is not readily apparent unless it is left undone, this invisible work combined with a new role for men may present challenges different than or not experienced by female caregivers.

Men, especially older men, typically have fewer social networks than older women and underutilize community services. This may increase men’s sense of isolation and decrease their effectiveness in the caregiving role (Russell, 2004). Supporting men in the caregiving role is necessary to increase the number and effectiveness of informal male caregivers. Therefore, the purpose of this study is to examine older men’s perception of the informal caregiving experience, how they transitioned to and within this role, and their level of preparedness.

**Relevance**

There is an unprecedented increase in the older population, due to the aging of the baby boomer generation. It is predicted that by 2030, 70 million Americans will be older than 65 years of age and 8.5 million persons will be older than 85. Older adults 85 years
old and older are the fastest growing group (Bennett & Flaherty-Robb, 2003). While the number of people over 65 years of age is expected to increase by 2.3%, the number of family members able to care for them will only increase by 0.8%, thereby producing a shortage in the number of available caregivers (National Family Caregivers Association, 2007). Family caregiving ability is an important predictor of institutionalization. A decline in the health of caregivers rather than the care receiver is a principal risk for institutionalization (Talley & Crews, 2007). Therefore, considering both caregiver and care receiver needs are important in allowing the care receiver to age in place.

As people live longer, the incidence of chronic disease will increase. Some chronic diseases present moderate health problems while other chronic conditions lead to increasing disability and dependency. This combination of increasing care needs and the fact that there will be fewer available family caregivers indicates that informal caregiving for older Americans is a growing need and an emerging public health issue (Talley & Crews, 2007).

The estimated cost of informal caregiving services for 2007 was $375 billion (Robison, Fortinsky, Kleppinger, Shugrue, & Porter, 2009). In 1997, older Americans used 30% of all health care resources. Use of healthcare resources is expected to increase to 50% by 2030 (Center for Policy Alternatives, 2006). Nearly 25% of older Americans require some form of assistance with daily living tasks and only a small fraction (3%) live in nursing homes (Bennett & Flaherty-Robb, 2003). Thus, the majority of older Americans who require assistance is in community settings and depend on family and friends.
Both the rising cost of health care and the lack of available informal caregivers present a concern in terms of dollars available to provide services. Providing caregivers with resources to manage their care recipient’s chronic conditions will potentially decrease the inappropriate use of medications or treatments, number of visits to the doctor’s office, emergency room use, and hospital admissions, thereby reducing overall health care costs. Today more than ever, families are struggling to find resources to care for older Americans who require more intense non-institutional care or informal caregiving for longer periods of time. Thus understanding the male caregiver experience and his needs will assist in supporting the growing numbers of men in this role.

**Background**

While informal caregiving has been traditionally perceived as a family responsibility, caregiving in the 21st century presents new challenges: 1) persons are living longer and have greater levels of disability and disease; 2) a mobile society presents geographic barriers to providing care so that family members may not be immediately accessible; 3) increasing health care costs, fixed incomes, and a poor economic climate; and 4) increasing numbers of women are employed outside the home thus reducing the number of traditional, full time caregivers. In addition, Bennett and Flaherty-Robb (2003) identified four critical issues for family caregivers: 1) insufficient resources to help individuals and families manage multiple chronic conditions, 2) lack of health care providers educated in broad based geriatric care, 3) high cost of health care, and 4) inattentiveness to the needs of older adults. To address the complex issues
surrounding the provision of informal care to a growing elderly population, innovative strategies are required. These strategies may be provided by both formal and informal means. One strategy is to provide support for older male caregivers, which may add to the overall availability of caregivers and their effectiveness.

Support for informal caregiving may be found in national initiatives. One of the goals of Healthy People 2010 is to “increase quality and years of healthy life” (US Department of Health And Human Services, 2007). For most older Americans, having care provided in a home environment by people known to them would improve the quality of their lives. The mission for the National Institute of Nursing Research (NINR) focuses on promoting and improving the health of individuals, families, communities, and populations. The research focuses on health promotion and disease prevention, quality of life, health disparities, and end of life issues ((National Institute of Nursing Research, 2006). In each of these focus areas caregiving is an important consideration. With these two initiatives as a backdrop, studies on caregiving may provide nursing with a foundation to develop strategies that address particular needs faced by caregivers, especially males.

Traditionally, the majority of informal caregivers have been women, though the number of men is increasing. This may be due in part to a projected decrease in numbers of caregivers and projected increase in numbers of care receivers (National Family Caregivers Association, 2007). This imbalance between numbers of caregivers and care receivers may encourage men to accept a new role. In addition, society’s definition of masculine responsibility is changing, which may persuade more men to consider
providing care to loved ones. Russell (2007) reports that approximately 30% of men are providing care in the home to an ill family member or friend. Campbell and Carroll (2007) found the largest group of male caregivers consisted of older men. In looking at spousal caregiving, men comprised 30-50% of caregivers. Support for and assistance with this evolving role for men may encourage additional men to provide informal care.

Male-female caregiving differences are reported. One measure of the intensity of the caregiving experience is the number of hours providing care. Male caregivers spend an average of 18.9 hours per week providing care, which is lower than the average of 21 hours per week for both male and female caregivers (Gibson, 2006; National Alliance for Caregiving & AARP, 2004). Caregivers providing 40 or more hours of care per week tend to be 65 years of age or older, with husband and wife caregivers spending equal amounts of time providing care (Levesque, Ducharme, Zarit, Lachance, & Giroux, 2008). Fifty four percent (54%) of those providing 8 hours or less each week are male (National Alliance for Caregiving & AARP, 2004). Also, caregiving is not a short-term activity, with caregivers expected to spend an average of 4.5 years providing care (Washington State Department of Social And Health Services, 2007). While some men report fewer hours of care than women, increased health risks and adjustment to a new societal and personal role may produce stress comparable to that experienced by women caregivers.

**Theoretical Framework**

The theoretical framework used in this study is the Middle Range Theory of Transitions (Meleis, 2007). Transition is described as a change in health condition, roles
and relationships, expectations, or abilities. This framework captures the nature of transitions, facilitators and inhibitors, patterns of response, and nursing therapeutics. The characteristics of transitions include types, patterns, and properties (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Use of this framework illustrates the fluid nature of the caregiving experience and identifies areas of crisis and opportunity.

Types of transitions included developmental, situational, health-illness, and organizational. Developmental transitions involve defined roles such as parent or spouse. Situational transitions refer to changes in a life situation such as homelessness or family caregiving. Using a health-illness approach to transitions focuses on specific acute and chronic disease states. Finally, organizational transitions refer to changes in an organization related to the broader social, political, or economic environment (Meleis, 2007).

Patterns of transitions include single, multiple, sequential, simultaneous, related, and unrelated. Identifying the transition pattern helps determine the level of complexity and overlap for a particular individual. When various events that may contribute to the transition are recognized, exploring the relationship between these events may yield important information in assisting the individual to adjust to the transition. Understanding the pattern assists the caregiver in reaching a positive outcome (Meleis, Sawyer, Im, Messias, & Schumacher, 2000).

Properties of transitions include awareness, engagement, change and difference, transition time span, and critical points (Meleis, 2007). While awareness is a key property of transitions, lack of awareness does not prevent the transition from occurring.
Therefore, preparing for transitions in the caregiving experience necessitates awareness of need by the caregiver. Being prepared for the complex nature of transitions in caregiving may improve outcomes for both the caregiver and care receiver. Understanding how male caregivers are or are not prepared provides a foundation for intervention.

Engagement is the level to which an individual is involved in a process. Searching the internet for information or modifying activities may reflect engagement in the caregiving process. Change is an alteration and may cause disequilibrium or alterations in roles. When men change roles from involvement in the outside world to the more isolated world of caregiving, a period of adjustment may be required to assume a very different role for which men may or may not have been prepared. Differences may include unmet expectations, feeling or being perceived as different, or seeing life in a different way. Male caregivers may feel different from women about assuming a traditionally female role, or men may have different perspectives of the caregiving experience, which may include caregiving strategies not used by women and not previously identified or explored (Meleis, 2007).

The property of time span indicates the different phases of transitions, which may vary from individual to individual. Critical points are those events in the transition process that offer opportunity and crisis. Recognition of common caregiving critical points such as diagnosis of an illness, initiation of treatment, change in health status, or cessation of treatment assists the caregiver to prepare for possible events in order to potentially improve the outcome (Meleis, 2007). The period of time between critical
points in the caregiving process is uncertain and may be difficult for the individual to navigate without support. Awareness of common critical points will assist health care providers in planning support for the caregiver. While this was not the focus of this study, critical points for male caregivers were elucidated as a secondary outcome.

Transition facilitators and inhibitors incorporate personal, community, and societal factors (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). The meaning of an event may either facilitate or inhibit the person’s adaptation to a transition in care. Thus understanding the meaning of caregiving to older men will lead to development of strategies to facilitate adaptation to the caregiver role. Since many older men may not have experienced a caregiver role earlier in their lives, exploring older men’s perceptions of preparedness for caregiving may reveal ways to facilitate their recognition of, preparedness for, and successful adjustment to the role.

Patterns of response include process and outcome indicators. Process indicators allow for early identification of those activities that could positively influence the caregiver or put them at risk. These indicators consist of feeling connected, interacting, location and being situated, and developing confidence and coping. Outcome indicators include mastery of skills and behaviors needed for a new situation as well as integration of a new identity (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). By framing older men’s perceptions of preparedness within the concept of transitions, needed resources, behaviors, and skills can be identified at each transition point. Identification of influencing factors as well as necessary resources and skills may lead to improvement in caregiving skills and thus increase the perception of being prepared.
Nursing therapeutics involve elements of nursing practice that support positive responses to transitions. These elements may include assessment, creation of health environments, or mobilization of resources (Meleis, 2007). Nurses embrace the role of patient advocate and are recognized in public opinion polls as the healthcare provider with the highest credibility on health care issues (Massachusetts Nurses Association, 2010). Additionally, due to the considerable amount of time spent with patients and families, nurses are uniquely positioned to assist caregivers.

The transitions theory guides nurses in identifying patterns, properties, and nursing practices that assist with developing strategies to support male caregivers as men adjust to the new role. Understanding the uniqueness of men's caregiving experience and how they are or are not prepared for the role allows nurses to anticipate critical transition points where men may need additional support. By considering aspects of the transitions framework, nurses may improve caregiving outcomes through an approach centered on individuals within the context of their environment.

**Operational Definitions**

Informal or family caregiving was defined as providing care or assuming the responsibility of having care provided to loved ones in the home or an extended care facility. This is an unpaid job involving significant amounts of time and energy for months or years. Caregiving tasks may include those related to finances, transportation, medical, and personal care.
Primary caregiver was defined as one who accepts the main responsibility of either giving or providing care related to physical, emotional, or daily living tasks. The caregiver may or may not be related to the care recipient or may or may not live with the care recipient. Informal caregivers do not stop providing care when the care recipient moves to an extended care facility. Perhaps due to staffing issues or a sense of purpose, the informal caregiver may continue to provide physical, emotional, and medical care in the institutional setting.

Preparedness was viewed as readying for a specific reason, event, circumstance, or situation. Schumacher et al. (2008) defined preparedness as “perceived readiness for multiple domains of the caregiving role” (p.51). These domains include physical care, emotional support, in-home support services, and caregiving stress. Thus in order to prepare, the person must identify with the caregiver role, have some awareness of what the role entails, and possibly identify areas where additional resources or support are required.

The caregiving experience was defined as a series of transitions in which many events take place over a period of time in relation to the illness progression or increased dependence of the care recipient. These events may require various resources at differing points. Skills and abilities may need to be modified or learned in order to cope with the changes brought about by the transitioning nature of illness and dependence of the care receiver. Caregivers may assess their preparedness for the caregiving experience in order to identify capabilities and required resources and support.
Research Questions

The aim of this study was to explore older men’s experiences with the informal caregiving role. Four questions examined older men’s experiences of informal caregiving, transition to and within the role, and preparation for the informal caregiving role.

1) What are older men’s experiences of informal caregiving?
2) What are transitions to and in the informal caregiving role?
3) How well prepared do older men feel for the informal caregiving experience?
4) What would help prepare older men for the informal caregiving experience?

Outcomes

By exploring older men’s perception of their caregiving experiences, transitions, and preparation for the role, new knowledge was developed which will serve as a foundation on which approaches may be identified, interventions developed, and community strategies enacted that support successful and effective male informal caregiving. Specific information from this study will be useful in development of education and resource strategies specific to older men’s learning styles and needs through the transitions accompanying an informal caregiving experience.

Also, findings revealed that men use caregiving strategies that women caregivers would find useful or effective. In addition to identifying themes central to the male
caregiving experience and preparation, study findings offered strategies for both male and female caregivers.

Assumptions

A basic assumption of this study was that men might have unique experiences in societal roles and in the role of informal caregiver. It was assumed that men might have different experiences of caregiving at differing ages. Also, the same man may experience caregiving differently at varying times in his life.

Additionally, it was assumed that men would be able to fully discuss their caregiver experiences. Some men were and some were not able to talk at length about their caregiver experience. This may be related to an unwillingness to discuss their experience or not being aware of the influence the caregiving role had on their lives. The intensity of the caregiving experience may decrease men’s ability to fully participate as they are consumed by caregiving responsibilities or may feel talking about it is too personal.

Delimitations and Limitations

This study was limited to those older men who were in a primary caregiver role for at least 6 months during the past 3 years, which may not reflect or represent other male caregiver experiences. Six months was determined to be an adequate time period for men to recognize the role, establish a daily routine with their care recipient, perceive the meaning of their caregiving experience, and acknowledge preparation or lack thereof.
for the role. Potential subjects may have been unwilling to participate due to unfamiliarity with studies. Men who are not aware of research studies or choose not to participate may have different experiences.

**Summary**

The number of men in the caregiving role has been steadily increasing over the last 2 decades. This increase is expected to continue in order to meet the informal care needs for the escalating numbers of older Americans. The type of home care has changed with older Americans having a greater level of disability and disease than previous decades due to early diagnosis, lifesaving treatments, and increased life expectancy. Strategies and resources are needed to prepare and assist the increasing number of male caregivers for transitions to the caregiver role.

Meleis’ middle range Theory of Transitions assisted in framing the caregiver experience, transitions encountered, and preparation for the caregiving role. By understanding male caregivers’ needs and perception of being prepared, strategies and resources can be identified and developed to support these caregivers. Findings added to the knowledge of male informal caregivers, identified critical decision points for this group of men, and offered strategies that will be useful to both male and female caregivers.
CHAPTER II
LITERATURE REVIEW

Development of Caregiving Knowledge

Over the past four decades, the informal caregiving literature has grown to include areas related to theory, concepts, and practice. The wide variety of concepts have included both positive and negative aspects of caregiving with burden being the concept most studied and preparedness being one of the least studied. Also, the majority of previous studies have used female caregivers. In order for society to ensure that caregiving is provided in ample amounts and quality, including the acceptance by men of a new role, knowledge development of this critical role is required. This study included both the meaning of male caregiving, transition to and within the role, and level of preparation for the role. Using a transitions framework, the concept of preparedness in the context of the male caregiving experience was the focus of this study.

The body of caregiving knowledge within the last 30-40 years included costs and benefits to the caregiver-care receiver dyad, measurement of positive and negative aspects of caregiving, and interventions to support both the caregiver and care receiver. Each decade added to the structure of caregiving knowledge and a foundation for new information and ideas. These contributions refined concepts, methods, and gaps in the knowledge base.
In the 1970’s, the need for caregiving research became apparent following the implementation of new Medicare programs, increasing life expectancy, and the increasing older population. Policy makers were concerned that the new healthcare benefits would encourage families to abandon informal care with expectations that the government would assume these costs. This concern was not realized as many families assumed caring for members as an integral part of being a family (Berg-Weger & Tebb, 2004). Caregiving responsibilities were described as skills inherently attributed to women (Thompson, 2005). Health care providers were interested in caregivers as an important part of the patient’s welfare. However, research studies were largely anecdotal descriptions with little use of theoretical frameworks that linked findings with strategies to implement caregiving interventions (Berg-Weger & Tebb, 2004).

In the 1980’s, caregiving research focused primarily on negative aspects of caregiving. Zarit and colleagues investigated the effect of caregiver burden on relatives and others who had primary responsibility for caregiving (Zarit, Reever, & Bach-Peterson, 1980). The term caregiver burden became a common focus of caregiving research.

Research studies began using theoretical frameworks and explored mental and physical effects of caregiving on the caregiver-care receiver dyad, meaning of the caregiver role, and strategies to support caregivers (Gallagher, 1985; Hinds, 1985 Hunt, 2003; Lobchuk, 2006; Robinson et al. 1998). Primary independent study variables were limited to age, gender, and socioeconomic status. Gender was largely being used for
descriptive information rather than in the context of relationship to the care recipient or to
compare differences between male and female caregivers (Berg-Weger & Tebb, 2004).

In the 1990’s, research added the concept of caregiving as a process with
identifiable transitions (Lindgren, 1993; Pearlin, Mullan, Semple, & Skaff, 1990).
Studies increased in size and complexity to include positive aspects of caregiving
(Hogstel, Curry, & Walker, 2005; Kaye & Applegate, 1990), cultural influences (Cox &
Monk, 1990; Macera et al. 1992), gender roles (Ford, Goode, Barrett, Harrell, & Haley,
1997; Marks, 1993; Wolff & Kasper, 2006), relationships (Deimling & Bass, 1986;
Neufeld, 1998), and more organized strategies for caregiver support (Berg-Weger &
Tebb, 2004; Knight, Lutzky, & Macofsky-Urban, 1993). In examining men’s roles, older
male caregivers tended to be underserved as a group and not as visible to health care and
service providers (Thompson, 1994). Common limitations for research with male
caregivers during this decade cited by Houde (2002) include small, self-selected sample
sizes, limited cultural diversity, and few studies that identified husband and son groups.

Moving into the 21st century, caregiver research built on previous decades of
caregiving research exploring both positive and negative influences of caregiving.
Recent research foci included caregiver-care receiver relationship, role of male caregivers
and other diverse groups, health consequences of caregiving, caregiving as a career,
coping, and quality of life (Ekwall & Hallberg, 2007; Gaugler & Teaster, 2006; Glasser,
Evandrou, & Tomassini, 2005; Lauderdale & Gallagher-Thompson, 2002; Lingler,
Sherwood, Crighton, Song, & Happ, 2008). While the number of studies including and
focusing on male caregivers has increased, there remains minimal knowledge on which to
develop, implement, and evaluate interventions for preparing both the male caregiver and his care receiver for this transition.

**Concepts**

Common concepts in caregiving studies include burden and stress, caregiver esteem and satisfaction, reciprocity, help seeking, caregiving skill, caregiver appraisal, and making meaning of the caregiving experience (Ayres, 2000; Calasanti & King, 2007; Ekwall & Hallberg, 2007; Gillon, 2007; Hunt, 2003; Lopez, Crespo, & Zarit, 2007; Schumacher et al. 2008;). Though the majority of caregiving research focuses on the caregiver, studies have included concepts related to the care recipient, such as the meaning of receiving family care and satisfaction with the delivery of care (Ayres, 2000; Crist, 2005).

**Burden and stress**

Negative concepts such as caregiver burden and stress have been the most frequently studied. Hunt (2003) defines caregiving burden as subjective and objective consequences encountered when providing care to others who are not able to care for themselves. These consequences may include physical, psychological, social, and financial problems coupled with a belief that current and future resources are inadequate to meet the healthcare demands (Ankri, Andrieu, Beaufils, Grand, & Henrad, 2005). Burden may be increased by multiple, competing demands that engulf the caregiver (Faison, Faria, & Frank, 1999; Honea et al. 2008; Lopez, Crespo, & Zarit, 2007). Male
caregivers experience greater burden than non-caregivers but less burden than female
caregivers (Wallsten, 2000). This may be due to a traditional management approach to
caregiving tasks employed by male caregivers (Russell, 2007). Also, women commonly
provide care to more ill family members, which entails more personal care and household
chores than men traditionally perform (Pinquart & Sorensen, 2006). The number of
caregiver burden studies has decreased since the 1980s, but caregiver burden continues to
be an important concept. Providing informal care is a stressful process even with
adequate resources. When uncertainty about finance and ability to provide care arise,
caregiving may impose greater physical and psychological effects on caregivers (Pinquart
& Sorensen, 2007).

Measurement of caregiver burden has been primarily by qualitative description
and tools (Houde, 2002; Hunt, 2003). Zarit’s Burden Interview is one of the most widely
used measures of caregiver burden. The tool has been translated into multiple languages
and used with diverse populations such as the Pueblo Indians (John, Hennessy, Dyeson,
& Garrett, 2001; Zarit, Reever, & Bach-Peterson, 1980). Although other burden scales
have been developed, the Zarit Burden Interview has shown good reliability and validity
across various populations and disease states (Vitaliano, Young, & Russo, 1991).

Role strain

Studies examining predictors of role strain are older (Archbold, Greenlick, &
Harvath, 1990) and those focused on caregiver outcomes (Hunt, 2003) are more recent.
Factors that influence role strain are mutuality, preparedness, and demand (Archbold,
Greenlick, & Harvath, 1990; Schumacher et al. 2008). Being prepared may be seen as a
proactive step toward either assuming the caregiver role or weathering the transitions in care as the health of the care receiver changes. Since preparedness is the least studied of these predictors, additional exploration of preparedness in caregiving transitions is needed.

**Esteem and satisfaction**

Studies exploring the positive aspects of caregiving have increased over the past decade. Caregiver esteem and satisfaction are used to investigate the perception of well being gained from participating in the caregiver experience (Carpenter & Miller, 2005; Ekwall & Hallberg, 2007). Many caregivers find the assumption of the caregiver role to be challenging but over time may find it a rewarding experience (McGuire, Anderson, Talley, & Crews, 2007; Sandberg & Eriksson, 2007). Hunt (2003) described uplifts or daily events encountered in the caregiving experience that positively affected the caregiver’s spiritual, social, or intellectual state. Caregivers may experience satisfaction from a job well done, even when facing adverse circumstances.

Role satisfaction for male caregivers has been associated with higher level of education, satisfaction with social participation, use of problem solving skills, investment in the caregiver-care receiver relationship, and a sense of mastering a difficult situation (Carpenter & Miller, 2005; Ekwall & Hallberg, 2007; Russell, 2001). Male caregivers are reportedly more satisfied with their ability to deliver care than female caregivers. Some influencing factors may include use of a problem solving approach, view of caregiving as a shared process, receiving reward and recognition for performing a non-traditional role, and success in mastery of difficult transitions (Sandberg & Eriksson,
2007). As further studies of male caregivers are conducted, additional information may be discovered about their skills and behaviors that will assist male and female caregivers in achieving greater role satisfaction.

**Reciprocity and responsibility**

Reciprocity has been shown to provide positive reinforcement for the complex relationship between caregivers and care recipients (Neufeld, 1998). In partnerships, each member usually performs those tasks, which they feel they have the ability to do (Calasanti & King, 2007). Lingler, Sherwood, Crighton, Song, and Happ (2008) described the interdependence of mentally challenged adult children and their aging parents. Other authors discuss the marriage partnership in relation to caregiving reciprocity and responsibility (Thompson, 2005). In traditional marriages, reciprocity can be seen as a husband’s role being the primary financial provider, auto mechanic, and doing yard work while the wife does the household tasks, contributes to family finances, and functions as the gatekeeper for the family’s health care and social activities. In later years, men may see caregiving as a way to reciprocate for the years of homemaking provided by their wives or companions (Calasanti & King, 2007). Some men may see caregiving as a demonstration of their marriage vows and a way of being faithful to their wives or companions (Russell, 2001). Often, older couples use an interdependent style to take care of each other during their chronic illnesses. Together they supplement each other’s abilities. The quality of the marital, companion, or significant other relationship will influence the feelings produced by the caregiving experience (Ciambrone & Allen, 2005; Sandberg & Eriksson, 2007). Therefore, reciprocity may be seen as a positive
influence to do a difficult job well or it may be seen as a burdensome obligation, which will have a less positive impact.

**Help seeking**

Help seeking may be defined as asking for or actively seeking assistance, which may be problematic for a man who accepts the hegemonic masculine ideal that asking for help is a weakness (Gillon, 2007). This concept has not been widely studied among male caregivers. Seeking help is related to the meaning of different types of help available. Both women and men use formal services such as adult day care, housekeeping services, and sitters; men use these services more often than women (Russell, 2001). Men use informal resources such as support groups less often than women (Brown, Chen, Mitchell, & Province, 2007). Men may be accepting of interventions such as coaching or the opportunity to be an expert for another male caregiver which more closely conforms to the hegemonic masculine ideal (Gillon, 2007). Conditions, which influence help seeking, include attitudes and values, relationships with family and those outside the family, cost, availability, time, knowledge, and past experiences in obtaining help (Brown, Chen, Mitchell, & Province, 2007). Men may be less likely to seek help if they feel they cannot return the favor due to their increased caregiving responsibilities (Neufeld, 1998).

The reluctance to seek help by caregivers may be influenced by beliefs, attitudes, and the context for caregiving (Laditka, Pappas-Rogich, & Laditka, 2001; Mansfield, Syzdek, Green, & Addis, 2008). This reluctance may be more detrimental to older men than older women because men are more prone to physical and mental illness earlier than
most women. Men have lower utilization rates for health care services, increased morbidity and mortality rates, under diagnosis of suicide and other psychological illness, and increased incidence of substance abuse (Addis & Cohane, 2005). When older men seek help, they usually ask their primary health care provider first. If men have a negative experience with health care providers, they are less likely to ask for help again (Mansfield, Syzdek, Green, & Addis, 2008). Further exploration of older men’s experience in help seeking would provide valuable information to health care providers in planning, developing, and implementing caregiving services and programs.

**Caregiving skill**

Family caregiving skill is the ability to participate effectively and efficiently in the following core caregiving processes 1) monitoring, 2) interpreting, 3) making decision, 4) taking action, 5) making adjustment, 6) accessing resources, 7) providing hands-on care, 8) working together with the care recipient, and 9) negotiating the health care system (Schumacher et al. 2008). As informal and home care have increased in complexity, caregiving skill is important to assist caregivers in adapting to their specific situation. Caregiving skill may be achieved by combining existing skills with identified needed skills, incorporating care recipient information with knowledge of the illness or health condition process, and allowing time and experience to develop the skills. Often caregiving skill is thought of as a caregiver following a structured procedure rather than synthesizing knowledge and resources to deliver the care required by the care recipient. Schumacher et al. (2008) offer examples of skills such as noticing subtle changes in the care receiver, interpreting the seriousness of the change, deciding on a course of action,
and implementing and evaluating the change. These examples highlight the complexity of the caregiving skill concept and the subset of skills necessary to provide quality care and adjust to the daily changes in the care recipient’s health.

**Appraisal and perspective-taking**

Caregiver appraisal is the process of a caregiver assessing his or her own strengths and areas for improvement. This process involves subjective, cognitive, and affective evaluation of the potential challenge and how well coping strategies are used (Hunt, 2003). It can be positive, negative, or neutral. Caregivers appraise a situation by incorporating their abilities, feelings, and environmental concerns into a plan to best deal with the caregiving demands.

Complementing caregiver appraisal is the concept of perspective taking. Lobchuk (2006) defined perspective taking as an empathetic process, which affects communication competence, accuracy of perceptions, and increase in caregivers’ ability to attend to their loved ones’ needs. Perspective taking may be used to explore the understanding of the illness experience from a dyadic viewpoint (Coeling, Biordi, & Theis, 2003). This understanding may improve communication between the caregiver and care receiver (Lobchuk, 2006). Both caregiver appraisal and perspective taking allow caregivers to prepare for challenging work of providing care to a loved one.

**Meaning of caregiving**

Making meaning of caregiving offers a way for caregivers to incorporate the caregiving events into their life story. Positive meaning may offset the perceived burden
of caregiving. Thus, the meaning of particular tasks can explain the caregivers’ perception of burden (Ayres, 2000). Meaning may be described as an interconnected process consisting of expectations, explanations, and strategies. Expectations may predict what will happen. Explanations offer reasons for events and strategies are action plans to fulfill the desired expectations (Ayres, 2000).

This process allows caregivers to make sense of what is usually an unplanned and undesirable event. The meaning of caregiving may symbolize a spouse’s or partner’s love and commitment, a life purpose, or a sense of connection to both the care recipient and others who assist the caregiver (Crist, 2005; Doka, 2004; Thompson, 2005).

Also, the meaning of caregiving may be viewed from the care recipient’s position. While relatively few studies reflect the care recipient’s view of caregiving, themes that emerged included loss of individualism and indebtedness to care providers (Crist, 2005; Parsons, Cox, & Kimboko, 1989). Crist (2005) found some elders felt they maintained their autonomy and receiving care was a positive experience when relationships with family caregivers were positive.

**Gender issues**

Most studies have compared men to the traditional caregiver role identified with women instead of with other caregiving and non-caregiving men (Russell, 2007). In a meta-analysis of 229 studies of caregiver health, stressors, and social resources, Pinquart and Sorensen (2006) found that husbands and wives’ caregiving experience is similar, while sons and daughters’ caregiving experience is different. Sons providing care are outnumbered by daughters three to one compared to husbands who provide 30-50% of
spousal care (Campbell & Carroll, 2007). However, once sons accept the caregiving role, their behaviors and emotions are similar to daughters’ and wives’ behaviors and emotions (Pinquart & Sorensen, 2006).

Previous studies indicate women experience more hours of care, caregiving tasks, burden and depression, and lower social well being and physical health (Ekwall & Hallberg, 2007; Pinquart & Sorensen, 2006; Sandberg & Eriksson, 2007). These findings may reflect that more women provide care for sicker people than men. Men report more stress when they provided psychosocial care rather than physical care (Sandberg & Eriksson, 2007). Men generally report a higher sense of self-esteem than women, which may be due to perceiving the caregiver role as one of accomplishment rather than sacrifice (Kim, Loscalzo, Wellisch, & Spillers, 2006).

Wolff and Kasper (2006) reported that men might feel discomfort in the informal caregiving role if they perceive that the caregiver role is in opposition to the traditional masculine role. When caring for a spouse, caregiving responsibilities are incorporated into the couple’s expressions of intimacy and commitment. A strong sense of commitment has been reported as a key reason for men providing care (Black, Schwartz, Caruso, & Hannum, 2008; Boeijji & Ven Doorne-Huiskes, 2003; Russell, 2001). Overall, more exploration of gender role influence on informal caregiving is needed (Brazil, Thabane, Foster, & Bedard, 2009).
Characteristics

Characteristics of men who are informal caregivers include: 1) being an only child, 2) having no female siblings, 3) having adolescent sons, 4) close geographic proximity to care receiver, and 5) having a wife who provides care (Campbell & Carroll, 2007). In a 2004 study of 1,247 U.S. caregivers, 39% were men. This reflects the increasing number of male caregivers over the past 20 years. These male caregivers (60%) were more likely than female caregivers (41%) to be working full time. Men juggling full time employment with caregiving responsibilities may encounter different levels of stress than women who are employed part time or work solely in the home. Also, a large percentage of male caregivers (35%) were providing care to men than their female counterparts (28%) (National Alliance for Caregiving & AARP, 2004).

Challenges

Health

Older spousal caregivers are in poorer health than non-caregivers with fewer resources to support them in the caregiving role (Levesque, Ducharme, Zarit, Lachance, & Giroux, 2002; Wallsten, 2000). Men with greater health risks are those with low socioeconomic status; men of color, especially those with low socioeconomic status; middle class, African-American men; older men; and those with lower levels of informal support (Pinquart & Sorensen, 2007; Williams, 2003). Men’s health behaviors may be a reflection of their interpretation of masculinity. Men’s reticence to express their
emotions or talk openly about difficulties may relate to the hegemonic masculine ideal (Gillon, 2007).

Decreases in function and health may conflict with men’s ideas of masculinity (Kaye, Crittenden, & Charland, 2008). Men access health care services at a lower rate than women and may view seeking health care as a weakness (Mansfield, Syzdek, Green, & Addis, 2008). Not only do men have higher mortality rates than women, male caregivers have greater increases in blood pressure and cortisol levels, as well as unfavorable lipid profiles as compared to female caregivers (Adler, Patterson, & Grant, 2005).

Social networks provide support in dealing with isolation and depression, though some older men may have difficulty in establishing such a network (Russell, 2004). Men may receive encouragement from family and friends to participate in social activities. Many older men choose to form social networks with other men as a continuation of their working career or to conform to socially acceptable standards (Russell, 2004).

Financial

Older male caregivers provide care to spouses and parents who may have a greater incidence of chronic illness and cognitive disorders (Russell, 2001). Changes in Medicare reimbursement have resulted in shifting care that is more complex from hospital to home (Wolff & Kasper, 2006). Men leaving the workforce prematurely to care for a spouse results in lost productive years of employment. This may reduce not only current but future retirement income (Metlife Mature Market Institute & National Alliance for Caregiving, 2006). Hiring part-time nurses and non-professionals to manage
personal or bedside care during hours a caregiver is at work or away from the home is economically and emotionally costly (Rubin, 2002). Changes in health insurance coverage due to a change in employment status may increase out of pocket medical care expenses. Yabroff & Kim (2009) list costs to employers as retraining new workers, absenteeism, and work interruption. Therefore, financial costs should be evaluated when developing an action plan for the caregiver.

Summary of Current Knowledge of Male Caregivers

Informal caregiving has been a significant focus of research for the past four decades. Attitudes and beliefs about the value of informal caregiving as well as policy initiatives such as Healthy People 2010, strategic research at NINR, and Medicare requirements have contributed to understanding of caregiving. Early studies focused on burden and negative aspects of the caregiving experience. This focus progressed to include positive aspects of caregiving such as satisfaction and skill development. More recently, studies have begun to address the experience of those receiving care. While caregivers in early studies were predominately women, the percentage of male caregivers in 2004 was reported as 39% (National Alliance for Caregiving & AARP, 2004).

A snapshot of male caregivers includes a diverse group of men who may be providing care alone or as part of a family or group of friends. Care receivers may be family, friends, or community members. The largest group of male caregivers is older men providing care to their spouses or partners. Men are often drawn into the caregiver role at varying ages by the women in their lives. The level of care provided by men
encompasses assistive activities to full participation in tasks and skills. Some men provide a great deal of personal and medical care while others manage or coordinate the provision of care through others. Men in the caregiver role report higher burden and stress than men in a non-caregiver role. Asking for help for both the care recipient and themselves can be difficult for men and may lead to poor health outcomes for the caregiving dyad.

Satisfaction of the caregiver role among men is associated with higher levels of education, use of social networks, use of problem solving skills, strong commitment to the relationship with the care receiver, and pride in mastering a difficult situation. Men typically use a managerial, task focused approach to providing care, which may offer a protective benefit as men face burden and stress associated with the caregiver role. Calasanti and King (2007) describe the following ways that men approach caregiving: 1) identify and master the task, 2) complete the task using strategies to suppress negative emotions, and 3) minimize effects of caregiving on their lives. Strategies that achieve this approach include manipulating or coercing care receivers, separating emotions from tasks, keeping routines as normal as possible, and using distracting activities. This provides a basic description that male caregivers have a pragmatic view of caregiving with the ability to adapt and master needed skills while maintaining interests that minimize the negative effects of caregiving.
Current Knowledge of Gaps and Limitations

Studies involving men compare male caregiving experience to females. Since women traditionally have been recognized as primary caregivers that experience has been used as a benchmark for the male caregiving experience. However, there is insufficient validity to use women’s experience as a benchmark (Russell, 2001). More importantly, the focus of most studies has been related to concepts identified from female caregiving experiences with little or no translational foundation for male caregivers.

Past research with male caregivers is limited due to 1) small sample size, 2) men’s reluctance to participate in caregiving studies, 3) lack of participant diversity, 4) a wide range of ages, 5) limited reporting of relationship of caregiver to care receiver or type of care provided, 6) lack of clear inclusion and exclusion caregiver criteria, 7) difficulty in recruiting caregiving sons, 8) men’s unwillingness to talk about negative emotional experiences or ask for help, 9) tendency of men to underreport mental health problems, and 10) use of predominately Caucasian men (Ducharme, Levesque, Zarit, & Lachance, 2007; Houde, 2002; Lauderdale & Gallagher-Thompson, 2002).

Areas that need further exploration are: 1) the meaning of caregiving, 2) how caregivers adjust to caregiving transitions, 3) non-gender biased outcome measures, 4) caregiver diversity, 5) role relationship of caregiver and care receiver, 6) use of a wide range of care receiver illnesses, 7) help seeking, 8) preparedness, and 9) strategies and interventions specific to male caregivers (Campbell & Carroll, 2007; Kramer, 2005). This study contributes to knowledge of caregiver meaning, transitions and preparedness.
Summary

Men of differing ages have moved into the traditionally feminine role of informal caregiving. Findings from previous studies indicate men may take on caregiving as a reciprocal commitment to family or as an obligation. Men may not ask for help or may not use community resources. Men may not want to discuss the emotional aspect of caregiving. However, men may want to discuss their caregiving accomplishments. The last forty years of caregiving research revealed that men of all ages provide care, with spousal caregiving being the most common, and that men manage the role differently than women. Many studies compared men and women but the literature provides incomplete and inconsistent information about male caregivers and less that are theoretically grounded in the male perspective.

This study explored older men’s perception of informal caregiving. Uncovering information about the meaning of the caregiving experience, transitions into and throughout the role, and examining men’s perception of being prepared for this role contributed to knowledge of male caregiving.
CHAPTER III
METHODOLOGY

Design

This study used a mixed methods approach to explore older men’s experience of informal caregiving, transitions to and within the caregiver role, and men’s level of preparation for the role. A phenomenological approach allowed examination of a common lived experience through accounts from several individuals (Creswell, 2007). By gaining a deeper understanding of a common experience, support for those individuals, such as policy, services, and education, are delineated.

Both the act of caregiving and the context in which it occurred was examined through a simultaneous process incorporating the caregivers’ environment, time span, mind-body connectedness, and relationships to demonstrate the interconnectedness of caregivers and the world in which they live (Munhall, 2007). Use of the bracketing technique decreased the researcher’s bias in order to see the experience from a new vantage point. Phenomenological reduction assisted in producing a rich description to recognize the essential structure of older men’s caregiving experience. By recognizing both the participants’ and the researcher’s views, a clearer picture of the phenomenon was revealed.

Phenomenological inquiry allowed a detailed description of caregiving by older men who were in the informal caregiver role for at least 6 months within the last 3 years.
Phenomenology does not lend itself to a series of rigid steps (Creswell, 2007). These steps may not always progress in a linear fashion but may occur concurrently or move back to a previous step then move forward. The flexible give-and-take of this process allowed a holistic view of the participants. After collecting accounts from 13 men, common themes were identified and the data were synthesized to capture the essence of their perceived experience.

The Preparedness Scale of the Family Care Inventory provided a quantitative measure of the participants’ perception of preparedness to augment the qualitative data gathered through interviews (Archbold, Greenlick, & Harvath, 1990). Three follow up questions addressed preparation for caregiving and advice they had for other male caregivers. The aim of this study was to provide new knowledge of men’s perceived experiences of informal caregiving, transitions to and within the caregiver role, and level of preparedness for the role.

One of the assumptions of this study was that men might be unwilling to discuss their experience, as this is a new societal role for them. Therefore, a pilot study was conducted to explore issues related to sampling, recruitment, and data collection strategies. Four men were recruited and three were interviewed. Modifications from the pilot study included an increase in the size and types of recruitment sites to obtain an adequate sample, and the addition of a question about caregiving advice participants would offer other male caregivers. In qualitative studies, the researcher is part of the study and must be aware that beliefs and biases will affect the results. The pilot study
offered practice with interviewing and bracketing techniques to reduce researcher bias, as well as men’s understanding of the quantitative tool.

Setting

The setting for this study was the southeastern United States. This area has both multigenerational and transplant families that provide caregiving. North Carolina was well suited for this study as it has the fourth fastest growth rate in the elderly population, 28% minority population, both rural and urban areas, an active aging network statewide, and a generational demographic balance (Department Of Health And Human Services, 2009; North Carolina Division Of Aging And Adult Services, 2009). Large metropolitan areas attract considerable numbers of people from outside the state and rural counties. North Carolina is also a prime retirement site that attracts a large number of older adults and a large military veteran population (North Carolina Division of Aging and Adult Services, 2009). Forty two percent of the 65 and older population is male. There are an estimated 840,345 caregivers in North Carolina providing 900 million caregiving hours per year (Family Caregiver Alliance, 2004). These characteristics offered a good laboratory for this study.

Sample

A purposive sample of older men in two counties in central North Carolina was recruited through a continuing care retirement community, two churches, a congregational nurse program, two social organizations, and social networking. Male
caregivers were recruited through a variety of formal and informal organizations. Formal organizations, such as churches, provide structured resources to assist caregivers and often have specific offerings for men. Inclusion criteria for participants were: 1) self identification as male; 2) age 60 years or older; 3) being a primary caregiver for at least 6 months; 4) providing care to an adult with a chronic illness within the last 3 years; and 5) willingness to participate in an interview for 45 minutes and a 15 minute follow up interview two weeks after the initial interview. For the purpose of this study, primary caregiver was defined as one who accepts the main responsibility of either providing or coordinating care related to physical, emotional, or daily living tasks. Exclusion criteria were: 1) female; 2) younger than 60 years old; 3) functions in a secondary caregiver role; 4) provides care to an adult with an acute illness; 5) non-English speaking; and 6) unable to complete the interviews due to scheduling conflicts or desire to withdraw from the study.

Since data saturation determines the number of participants in qualitative studies, sample size was increased until no new themes were identified (Zuzelo, 2007). A wide range, 1-324, of participants in qualitative studies has been described by Creswell (2007). The estimated sample size of 10-15 for this study was chosen based on similar qualitative guidelines and studies (Archbold, Greenlick, & Harvath, 1990; Brown, Chen, Mitchell, & Province, 2007; Calasanti & King, 2007; Sandberg & Eriksson, 2007). An adequate sample allowed experiences to be explored in great detail to more fully illuminate the phenomenon of interest. Interview length was determined by reports of saturation being reached in 30-120 minutes (Mapp, 2008).
Recruitment

Recruitment strategies included working with recognized community organizations and social organizations that address caregiving concerns. By conducting the study in respected community or social organizations, participants may have been more confident in the credibility of the research. Sharing sensitive information may be more comfortable through an organization that is familiar rather than through postings in public places. Drawing a sample from informal organizations, such as social groups and social networking, provided an opportunity to identify men who did not seek out structured resources and therefore may have a different experience than men who belonged to support groups or participated in caregiver programs. A snowball sampling method was used with all participants to maximize the sample size and diversity of the group.

The identified contact persons in the organizations distributed study information through communication methods commonly used in their organizations, which included flyers, bulletin announcements, newsletters, in-house television announcements, or shared information with a group. The researcher offered to talk with a group about the study at each site. One site invited the researcher to present to a group of interested participants. The contact persons asked men, who indicated they were willing to participate, to contact the researcher by phone or email.

An initial phone conversation between the researcher and participants confirmed that the inclusion criteria were met. Participants not meeting the criteria were thanked for their interest and not included in the study. For those who met the criteria, the researcher
briefly explained the study and answered questions, asked if they wanted to participate, and then identified a mutually agreeable site for the first interview. Each potential participant was asked to communicate the opportunity for study participation to other older male caregivers who fit the study criteria and share the investigator’s contact information with those men. Although a variety of sites was used for recruitment, the majority of participants were from a single continuing care retirement community. This site offered opportunities to participate in research studies on an ongoing basis. One site was undergoing staffing changes, which may have influenced recruitment efforts.

**Data Collection**

Prior to beginning the interviews, the researcher conducted a literature review to establish a baseline understanding of male caregiving. In addition, personal feelings and beliefs about caregiving were examined to identify biases and preconceived notions about male informal caregivers. This process of epoche offered an open environment for the researcher to see the information with new eyes.

To create a comfortable interview environment, a brief social conversation was conducted. Then the researcher read the informed consent aloud to each participant. An opportunity was provided for participants to ask questions about informed consent or other aspects of the study. Reading the consent aloud and asking for questions allowed adequate clarification to augment participants’ understanding of the consent. Once the participant signed the consent form, a copy was given to the participant and a copy retained by the researcher. Demographic data were collected and an audio taped, person-
A face-to-face interview pertaining to the caregiving experience was conducted using a structured interview guide.

To assess the level of preparedness, the researcher gathered participants’ responses to the Preparedness Scale and three open ended questions about preparation for the caregiver role and advice they would offer other older male caregivers (Archbold, Greenlick, & Harvath, 1990). The total time for the session was 26-80 minutes.

Two weeks after the first interview, the researcher contacted participants by phone to provide a brief review of the initial interview, clarified any questions from the interview and asked for additional thoughts about their caregiving experience. At the conclusion of the phone conversation, participants were thanked for their time and offered a $20 gift card of their choice to a department, home improvement, restaurant, or grocery store. Thank you notes containing the gift cards were mailed to participants within one week following the final phone conversation.

Face-to-face interviews allowed the researcher to clarify understanding of men’s perception of the caregiving role through both the spoken word and observed non-verbal communication. Most of the interviews occurred in the caregivers’ homes, with two interviews at local restaurants. Having a choice of interview location allowed the men to discuss sensitive information in a setting they deemed safe and comfortable. Field notes were taken during the interviews and follow-up calls to document the researcher’s observations, environment, and flow of communication. These notes were reviewed during the data analysis phase.
Measurement/Instrumentation

Instruments used were a demographic questionnaire, a structured interview guide developed by the researcher and reviewed by nursing faculty with expertise in caregiver research, and the Preparedness Scale of the Family Care Inventory (Archbold, Greenlick, & Harvath, 1990). The demographic questionnaire consisted of questions about the caregiver such as age, race/ethnicity, working or retired status, length of time as a caregiver, relationship to care recipient, hours of care provided and reason for caregiving. Questions about the care recipient included age, chronic illnesses, and where they lived. This questionnaire took approximately 5 minutes to complete. The researcher completed the questionnaire by asking the participant for information.

The interview guide began with a broad question about the meaning of the caregiving experience and used a series of prompts to explore the participant’s responses. Areas that were explored by prompts included beginning of role, previous caregiver experience, description of a typical day and routine, getting help from others, effect of caregiving on self and care recipient, and responsibilities. An open-ended question at the end of the interview allowed the caregiver to add thoughts not covered by the questions asked.

The Preparedness Scale of the Family Care Inventory is an 8-item tool using a five-point response format related to the multiple domains of caregiving including physical, emotional, stress, and resources (Archbold, Greenlick, & Harvath, 1990). The five-point response format potential responses were 0 (not at all prepared), 1 (not too well prepared), 2 (somewhat well prepared), 3 (pretty well prepared), and 4 (very well
prepared). Scoring was achieved by summing the item responses and averaging them for a total score. A higher score indicated a higher perception of preparedness.

Internal reliability has been demonstrated with Chronbach’s alphas of 0.88-0.93 ((Hudson & Hayman-White, 2006; Silver, Wellman, Galindo-Ciocon, & Johnson, 2004; Carter et al. 1998). Construct validity has been demonstrated through repetitive correlations between preparedness and caregiver worry and lack of resources (Schumacher et al. 2008). The researcher read the scale to participants who indicated the number of the answer that matched their perception of preparedness. The Flesch-Kincaid grade level for the tool is 7.9 and the Flesch Reading Ease level is 72.9. Three open-ended questions followed the eight items to capture specific needs related to caregiving preparedness and advice to others (Schumacher et al. 2008).

**Protection of Human Subjects**

Ethical considerations included honest representation of the study to participants, uncoerced informed consent, modest compensation of participants’ time, review of available literature, and use of accurate citations. Confidentiality was protected by using coded respondents’ information so that only the researcher was aware of the source. No personally identifiable health information was collected. One participant withdrew from the study and his information was shredded.

Maintaining confidentiality can be challenging in a qualitative study due to small sample size and detailed descriptions. Participants received a verbal explanation of how information would be used and protected as part of the informed consent process. To
address literacy concerns, the informed consent, demographic questionnaire, and Preparedness Scale were read aloud to all participants. The participant signed two copies of the consent form. One copy was retained by the researcher and the second was given to the participant.

Recruitment strategies designed to increase representation did not offer incentives that might encourage participation when the participant is hesitant or unwilling (Speziale & Carpenter, 2007). A $20 gift card to a department, home improvement, restaurant, or grocery store was offered to recognize the value of the participants’ time. Not all study participants accepted the gift card. This study was approved by the Institutional Review Board at the University of North Carolina at Greensboro.

**Data Analysis**

Both qualitative and quantitative data were used to answer the research questions and describe the context of the caregiving experience. The quantitative data complimented the qualitative data and provided a self-rating of the participants’ perception of preparedness. The following research questions were answered:

1) What are older men’s experiences of informal caregiving?
2) What are transitions to and within the informal caregiving role?
3) How well prepared do older men feel for the informal caregiving experience?
4) What would prepare older men for the informal caregiving experience?

Research questions 1, 2, and 4 were answered using qualitative data gained from the structured interview and follow up questions. Information for research question 3 was
collected using the quantitative data from the Preparedness Scale of the Family Care Inventory. A sample description was developed using measures of central tendency with information from the demographic questionnaire.

Use of the following recognized verification guidelines for phenomenological research strengthened validity and reliability of the study and assisted in identifying perceived caregiver experiences and transitions associated with the caregiver role (Creswell, 2007; Moustakas, 1994). The bracketing method was used prior to and during the interviews to control researcher bias. The interviews were transcribed verbatim using a transcription service. One participant was referred by the transcriptionist consequently, that interview was transcribed by the researcher. After completion of the interviews, the researcher listened to all tapes to ensure consistency with transcripts and the use of code names. A faculty member listened to selected excerpts from tapes D3, D5, and D7. She then compared them with the transcribed version to confirm the dependability of the transcription. Two faculty members reviewed the transcripts to confirm identification of significant statements. Three doctorally prepared scholars reviewed the transcripts to ensure adequate and ample data had been gathered for saturation and description. Data were checked by two researchers thereby adding to the credibility and confirmability of the data. Use of a transcription service and checking transcripts with interview tapes contributed to reliability of the study.

Validity was addressed through a period of careful reflection by the researcher to identify attitudes, beliefs, and biases that may negatively influence the data analysis. This reflection period included remembering and discussing personal and professional
experiences of caregiving to identify areas of potential bias or sensitive areas that might stimulate emotion. The researcher was immersed with the data to fully explore and understand the meanings offered by participants. To further maximize study rigor and trustworthiness of findings, an audit trail was maintained throughout the process. Shortly after each interview, the researcher reflected on the data gathered, made notes on participant responses, and identified specific areas that evoked personal responses. Careful descriptions of participants, inclusion criteria, context, and data analysis methods provided a foundation for limited generalizability to similar populations in similar settings and context (Brown, Chen, Mitchell, & Province, 2007; Priest, 2002).

The researcher used a coding strategy to ensure consistency in identifying important statements. Following Creswell’s (2007) qualitative analysis process, in the first step, horizontalization, transcripts were read for important statements, which provided an understanding of how the participants perceived their caregiving experience, and transitions encountered. Secondly, clusters of meaning were identified from the important statements and coalesced into themes and subthemes. A crosswalk of the themes, subthemes, and research questions was compiled to identify common points between the themes/subthemes and the research questions (Table 1). The crosswalk enhanced the credibility of the interview information derived by providing a structured way to check the themes/subthemes with the research questions. Third, these important statements and themes were used to write a textual and structural description of the participants’ experience. Finally, the perceived experiences, with context, were used to provide a description of the meaning of caregiving, the transitions experienced, and
Table 1. Themes/Subthemes and Research Questions Crosswalk

<table>
<thead>
<tr>
<th>Themes/Subthemes</th>
<th>RQ 1 Informal Caregiving Experience</th>
<th>RQ 2 Transitions</th>
<th>RQ 3 Prepared for caregiving experience</th>
<th>RQ 4 Preparation for other men</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Meaning/purpose</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1a. Role assumption/awareness</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>1b. Relationship</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>1c. Providing</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Assistance/resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2a. Professional</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2b. Community</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>3. Feelings</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3a. Positive</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>3b. Negative</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>3c. Other’s impressions</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Confidence</td>
<td></td>
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</tr>
<tr>
<td>4a. Application to new situation</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. Behaviors</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5a. Self care</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5b. Skill acquisition</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5c. Information seeking</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5d. Planning</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5e. Prior experience</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Beliefs</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6a. Moral</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6b. Faith based</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Change</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7a. Condition/function</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7b. Relationship/role</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7c. Loss</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7d. Living space</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7e. Planning/adapting</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Challenge</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8a. Privacy</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8b. Effectiveness</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8c. Financial</td>
<td>x</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
preparedness for the role to present the essence of the informal caregiving experience for this group of older males.

Even with guidance of linear steps, data analysis was an iterative process with multiple concurrent phases of the student and dissertation committee members reading and re-reading transcripts, selecting important statements, determining clusters of meaning, developing themes, and identifying subthemes. Similarly, the textual and structural description of participants’ experiences was recompiled, revised and rewritten to ensure depth and breadth of context. Using multiple readers to review the data confirmed the accuracy of the themes identified and transcription of the interviews.

A statistical software program, Statistical Package for the Social Sciences (SPSS\textsuperscript{TM}), was used to analyze the quantitative data. Descriptive statistics were used to examine sample characteristics and scale responses. Total scores were computed for each participant and an average total score computed for the sample.

**Summary**

A mixed methods approach was used to explore older men’s experience of informal caregiving. Phenomenology was well suited to explore the male informal caregiving experience where little is known (Donalek, 2004). The Creswell guidelines provided a clear path to elicit and develop a description of the male informal caregiver experience. The following steps promoted validity for study findings: 1) identification of phenomenon of interest, 2) bracketing, 3) collecting data from several older men who had experienced the phenomenon, 4) using iterative analysis of data through identification of
significant statements and coalescing them into themes and subthemes, 5) using multiple researchers, and 6) development of a textural and structural description to describe the essence of the phenomenon.

The setting and sample were chosen to explore this experience from the view of older, male caregivers. Recruitment sites were selected to provide a diverse and adequate sample. Data collection tools included a demographic questionnaire, structured interview guide, and the Preparedness Scale of the Family Care Inventory. These tools assisted in the description of older male caregivers, delineated their experience in the role, identified transitions, and measured their perception of being prepared for the role. This information adds to the body of caregiver knowledge from the perspective of older men.
CHAPTER IV
FINDINGS

This chapter will provide a discussion of findings related to older men’s perceived experiences of the informal caregiving role. Specific areas of interest were: 1) understanding how older men described their caregiving role, 2) transitions to and within the role, 3) preparation for the caregiving experience and how well prepared men were for the caregiving role, and 4) what advice men would offer to other men who anticipate or find themselves in the caregiver role.

Through analysis of the interviews, in which older men described their caregiving experience, the following eight areas emerged: 1) meaning/purpose of the caregiving experience, 2) feelings about caregiving, 3) confidence in caregiving ability, 4) caregiving behaviors, 5) caregiving beliefs, 6) assistance and resources for caregiving, 7) changes related to caregiving, and 8) challenges of caregiving. The following information collected from a group of predominately spousal caregivers describes the men, their caregiving experiences and their perception of preparation for the caregiving role. The four research questions are presented with accompanying themes and subthemes followed by a summary of the overall caregiving experience described by this group of older men.
Sample Characteristics

A total of 13 men, predominately Caucasian, were included in the study. The men were retired, at the mid to upper income level, and had completed some years of college. Their ages ranged from 61 to 90 years with a mean age of 78.3 years. The care receiver ages ranged from 61 to 104 years with a mean age of 79.5 years. Years of current caregiving experience varied from 1-29 years with a mean of 8.6 years. There were 12 spousal caregivers and 2 caring for parents (Tables 1 & 2). One man was simultaneously caring for his wife and mother.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Min</th>
<th>Max</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>13</td>
<td>61</td>
<td>90</td>
<td>78.3</td>
<td>8.95</td>
</tr>
<tr>
<td>Years of current caregiver experience</td>
<td>13</td>
<td>1</td>
<td>29</td>
<td>8.62</td>
<td>9.07</td>
</tr>
<tr>
<td>Age of care receiver</td>
<td>13</td>
<td>61</td>
<td>104</td>
<td>79.54</td>
<td>11.76</td>
</tr>
<tr>
<td>Hrs/wk resources &amp; personal care for care receiver</td>
<td>13</td>
<td>11</td>
<td>124</td>
<td>56.62</td>
<td>35.28</td>
</tr>
</tbody>
</table>

The range of hours per week that men provided resources and/or personal care was 11 to 124 with a median of 56 hours per week. Six men stated that the caregiving responsibilities were either 24 hours a day/7 days per week or during waking hours. Men related that they thought constantly of what needed to be done to care for their loved one and to keep them safe. These men spent more time providing resources and personal care than both the average (18.9 hours) reported by male caregivers and the average (21 hours) reported by both male and female caregivers (Gibson, 2006; National Alliance For
Caregiving & AARP, 2004). This reflects the high intensity of the caregiving experience for this group of male caregivers.

**Table 3. Sociodemographic Characteristics of Older Caregiving Men**

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Race</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian = 12</td>
<td>12</td>
<td>92</td>
</tr>
<tr>
<td>African American</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td><strong>Retired</strong></td>
<td>10</td>
<td>77</td>
</tr>
<tr>
<td><strong>Income level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$51 K+</td>
<td>9</td>
<td>69</td>
</tr>
<tr>
<td>$21 – 50 K</td>
<td>4</td>
<td>31</td>
</tr>
<tr>
<td><strong>Education level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-4 years college</td>
<td>7</td>
<td>54</td>
</tr>
<tr>
<td>Graduate education</td>
<td>6</td>
<td>46</td>
</tr>
<tr>
<td><strong>Prior informal caregiving</strong></td>
<td>4</td>
<td>31</td>
</tr>
<tr>
<td><strong>Relationship to current care receiver</strong>*</td>
<td>12</td>
<td>92</td>
</tr>
<tr>
<td>Spouse</td>
<td>12</td>
<td>92</td>
</tr>
<tr>
<td>Parent</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td><strong>Lived with care receiver</strong></td>
<td>10</td>
<td>77</td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>77</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>23</td>
</tr>
</tbody>
</table>

*1 participant simultaneously caring for parent & spouse

The majority of the men lived with the care receiver. For those who did not, the care receiver lived in their own home, assisted living, or skilled nursing care facilities. No one else lived in the home with the caregiver and care receiver. Four care receivers died 4-16 months prior to the men’s participation in the study.

Information on the general health of the men and their care recipients was collected. (Table 4) The majority (46%) of the men rated their health as very good. The next largest group (38%) rated their health as fair. While 15% of the men rated their
health as excellent. Participants stated their satisfaction with their health as very satisfied (38%), satisfied (38%), or not satisfied (23%). The majority of caregiver health conditions were heart and vascular disease (38%) and cancer (38%). Four men (31%) stated they had no major health issues. Reasons for providing care were mainly heart and vascular disease (38%) and neurologic disease (38%). Given the mean age of the group (78.3 years), the health ratings and expressed satisfaction with health was higher than expected.

Table 4. Health Ratings

<table>
<thead>
<tr>
<th>Ratings</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>General health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Excellent</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Very good</td>
<td>6</td>
<td>46</td>
</tr>
<tr>
<td>Fair</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Satisfaction with health</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very satisfied</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Satisfied</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Not satisfied</td>
<td>3</td>
<td>23</td>
</tr>
<tr>
<td>Caregiver major health issues **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart/vascular disease</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Cancer</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Neurologic disease</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Diabetes</td>
<td>1</td>
<td>8</td>
</tr>
<tr>
<td>Vision disorders</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>None</td>
<td>4</td>
<td>31</td>
</tr>
<tr>
<td>Reasons for providing care **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Heart/vascular disease</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Cancer</td>
<td>2</td>
<td>15</td>
</tr>
<tr>
<td>Neurologic disease</td>
<td>5</td>
<td>38</td>
</tr>
<tr>
<td>Musculoskeletal disease</td>
<td>2</td>
<td>15</td>
</tr>
</tbody>
</table>

** More than one disease reported for caregiver or care receiver
Research Question 1

What are older men’s experiences of informal caregiving?

Meaning/purpose of caregiving

Some men gave concise answers about the meaning/purpose of caregiving such as taking care of or providing for the care recipient’s needs. Other men’s descriptions expanded beyond providing care to expressing that caregiving was a family responsibility.

It means she got to a point that she could not take care of herself, and she needed assistance. (Art C)

Well, I was taking care of my wife…like a man’s supposed to. (Richard B)

You provide as best you can for her needs. Particularly those that are identified by the attending physician. (James S)

Participants described their caregiving activities in the context of family responsibilities and the need to provide care. Caregiving grew out of established relationships and was seen as a natural progression of those relationships. Men discussed reciprocity as one factor influencing their decision to provide care. When relationships began, an initial pattern of responsibilities for each partner was established. Over time, these responsibilities evolved so that the partner who was able, became the primary person who carried out the responsibilities. While caregiving may be unplanned, these men expressed that caring for their loved one was a way to reciprocate for all the years of
care previously provided. Others added that it was an expression of marriage vows or filial responsibility.

It’s something that I cannot walk away from, because in the vows, you say “for better or for worse” and we happen to have the worst. (Van H)

Oh, it means that I’m looking after her and seeing after all of her needs. I guess it’s an expression of love, after 63 years of marriage. (Robert M)

It means everything. I mean to do it for her to live a pretty normal life. That’s the gift to make them as normal as possible with giving my care. (David N)

So far as I’m concerned, my caregiving to her, for whatever I can do, is just a continuation of what I consider to be an excellent married life. (Art C)

I became more of a friend to him than I ever had been before. It’s just kind of like an equalizing, because as a child, he was the boss and now I was sort of the boss, in a way. (Clark G, caregiver to father)

Participants had strong opinions about providing care to family members recognizing that caregiving is part of a life together. Caring for a loved one was seen as a natural part of their relationship and they embraced it. When the need for caregiving arose, the decision was not if they would provide care but how they would provide care. One man shared what he saw as an example of men not living up to their marriage vows.

And heaven forbid, and I’ve heard of this happening – men who have wives that get into Alzheimer’s situation, I’ve actually heard of some actually divorcing the wives and throwing – turning them over to something else rather than having to put up with it. (Art C)
He was incredulous that a man could yield the primary responsibility for caring for a wife. Being a provider and living up to his marriage vows was a way to express his love for his wife.

Participants shared various tasks they performed ranging from personal care to supervising care.

I do the cooking…I do the pills, which is a major thing since she takes 28 pills a day. (Robert M)

The things I could do best was cleaning up after her (personal and household care). (Dan K)

I help her with undressing and hanging up the clothes, making the beds…a portable potty chair close to the bed. (Frank S)

I felt that was an important role for me to sort of keep the continuity of his care. Coordinating things with his doctor. To sort of be an interpreter between him and his doctor, between him and the professional caregivers at the assisted living place. (Clark G)

These men had little prior experience with housework but learned what needed to be done and did the household chores or had assistance with some cooking and cleaning tasks. As personal care was required, they learned those skills. Men taking care of their wives did not express embarrassment about performing personal care. The men caring for parents found personal care somewhat embarrassing or awkward, but were able to overcome these feelings to perform needed care. Overall, participants identified care needs, learned new skills, and accepted the majority of responsibility for providing care as an expression of their committed relationship with the care receiver.
Feelings about caregiving

In exploring the older men’s caregiving experiences, strong positive and negative feelings arose. The statements shared indicate the emotional duality of the caregiver role.

When she falls, it’s distressing. I get quite upset about that. (Henry F)

It’s frustrating. Sometimes rewarding, but not often. You have to learn that they’re sick and you’re well and there’s resentment. (Van H)

It’s either funny or totally pitiful. (Art C, talking about Alzheimer’s disease)

It’s (caregiving) really not all that bad, Particular…if you’ve been closely associated with the person all your life. You just can’t do as many things as you used to. (Henry F)

I found it mostly rewarding. Just knowing that he had somebody that he could really share his life with. Someone he could talk to…that he could feel very free with. I felt like I had found a friend. (Clark G)

It’s a hidden closet secret; things are in the closet and hiding. I think people need to be more expressive. People don’t know how to comprehend somebody that’s disabled. They don’t and friends leave you. (Van H)

I’m strong willed and don’t mind cussing them (healthcare providers) out if they need to be cussed out. (James S)

There is an emotional exchange. You receive an appreciation for what you do. There is a demand on your time. (Frank S)

The statements focus on feelings generated by concern for the caregiver, changes in the caregiver-care receiver relationship, and limitations placed on the caregiver.
Another area mentioned by the men is the reaction of others to the care receiver’s illness and subsequent changes in relationships between the caregiver dyad and others in their social network. Others may feel uncomfortable interacting with a chronically ill friend or family member. This may lead to distancing from the caregiver dyad and loss of social relationships.

A participant with a previous caregiving role related that it was easier taking care of his parents and in-laws than taking care of his wife. He assisted his wife with caring for his parents and in-laws while he was the sole caregiver for her. Having a partner to share caregiving responsibilities may be useful as the caregiving role is learned. Being the sole caregiver facing all the responsibilities and decisions alone or with minimal input can be daunting.

Confidence in providing caregiving

Overall, men expressed confidence in how they provided care.

I’m proficient in them all (caregiving responsibilities). I really am, I mean, because it’s been ongoing. (Van H)

Oh, most all of it, I feel pretty comfortable. (David N)

I felt that (caregiving) was something that I could do and that I do easily. (Clark G)

I guess I feel fairly comfortable with all of it. We’ve been married now for 64 years so we know each other fairly well (Frank S)

I think I always had them (caregiving qualities), I think it helped me perfect them (Van H)
I’ve been able to help several people that I work with. (Richard B)

As new skills were needed, these men employed a practical approach to learn how to take care of priority tasks. For those men who had a previous caregiving role, lessons learned from that experience allowed them to prepare for changes in their current caregiving experience. Richard B felt confident in using his new skills to assist other caregivers. This demonstrated confidence in his abilities to apply learned skills and resources to help others with similar needs. Participants expressed confidence in the skills they learned and felt they were using inherent caregiving qualities or drawing on their professional skills. This blend of nurturing and management skills assisted in accommodating transitions in care.

**Caregiving beliefs**

The men’s beliefs about caregiving supported multiple meanings including faith based principles, moral responsibility, and family responsibility. Men described their beliefs as an important reason for caregiving and were emphatic in stating their beliefs.

I was brought up in a Christian atmosphere where there’s a certain amount of responsibility you had to help them give. Christianity is a very strong part of my life, my existence. (Van H)

You do things because you feel its right. (James S)

Well, I get up in the morning and say, thank you, Lord it’s another day. I’m going to do the best I can with it. (Art C)
I didn’t feel like I was sacrificing by helping to take care of him. I felt like this was just a natural thing. What else would...I mean...why should I be doing anything else instead, other than that. That is what I’m supposed to be doing, I mean, not as an obligation but because it’s just a natural scheme of things. (Clark G)

I felt like that was my place that I should be at that time. (Dan K)

The men expressed pride in their ability to do a good job. Some men used the term obligation, but stated it was not a burdensome feeling. Rather they described it as a responsibility to be faced as part of the normal scheme of life.

**Caregiving challenges**

Caregiving challenges that men encountered included providing personal and incontinence care, medical issues, working with the healthcare system, Medicare, and financial concerns. Men described varying levels of challenge depending on the care required and to whom they were providing care. They described tasks performed that included both personal care and managing care. While some participants expressed discomfort in providing personal or incontinence care, many men performed a variety of tasks including dressing, bathing, and urinary catheter care. Some men found maintaining privacy boundaries while delivering care uncomfortable but learned skills to deal with their discomfort.

When she (mother) had a catheter…and there was no way to check it without exposing it. That was very uncomfortable. We’re taught not to look at your mama. (Van H)

She does not like me in the, with her hygiene, in the bathroom. (Peter L)
Dealing with incontinence…I learned a lot here, watching the aides work with her and all that kind of thing. That was very informative. (Glen F)

Other men found dealing with medical skills and uncertainty about the care receiver’s diagnosis challenging.

When I had to give shots. You had to give her morphine and all that the last couple of days, three days, and that was a chore more than doing what I’ve done. (Dan K)

I felt least comfortable about doctoring the wounds on her, on her foot. (James S)

We went through about 15 years of not knowing her condition. (James S)

Only one man had prior medical experience, which he found helpful in knowing the questions to ask. Other men dealt with periods of uncertainty about the diagnosis by using online medical resources to learn more about the disease. When medical skills needed to be learned, the men approached it with a “just do it” attitude.

Another area of concern for the men was their perception of being effective during transitions in the care recipient’s condition. This concern led to their either obtaining temporary or permanent help in the home or transferring the care receiver to a long-term care facility.

I was getting very troubled when we were having the fall down period. I feel when I wasn’t being effective enough and keeping that from happening, but we’ve gotten over that. (Robert M)

And that’s when I let her fall twice just trying to get her from the bathroom to the bed. (Art C)
Also, financial responsibilities and dealing with the healthcare system presented problems.

At the present moment, I’m dealing with a problem of finances. (Frank S)

The heaviest responsibility, and most responsibility that I have in caring for her, is writing a check to pay for her care. (Art C)

I think the hardest problem is trying to work in the system today with Medicare, and the healthcare restrictions, and knowing what’s legal, what the rules are, and knowing how to deal with it. Because every medical practice treats it differently. (Peter L)

While caregiving presents many challenges, participants discussed those relating to privacy, perception of their effectiveness, and financial concerns. Some men considered themselves a team with their care receiver, using the word we when referring to challenges faced. Men addressed these challenges with an attitude of “do the best you can”.

**Research Question 2**

What are transitions to and within the informal caregiver role?

**Meaning/purpose**

All participants indicated that their loved ones’ change in health condition was the starting point for providing care. Some of these changes began acutely with a hospitalization and other changes had a more gradual onset as with changes in mental
status. This awareness of the caregiver role, a property of the transition framework, was the beginning of their evolving caregiving experience.

When she got sick, I just fell into the job. (David N)

It became pretty obvious that as things began to get to the point that she was having trouble, somebody had to help her. And that’s how I became her caregiver, ‘cause I was there and the most logical one to begin to heal her. Then several years after that, I finally hired somebody to come in and give me assistance. (Art C)

It (caregiving) came slowly…my caregiving experience came over a slowly building, long period of time. And fortunately, I think, I was able to accept it. (Art C)

That was one of the reasons we moved back to North Carolina…because I knew the health care here and I knew the networking. (Van H)

Caregiving has been described as a career with a series of transitions related to changes in the care recipient’s condition (Gaugler & Teaster, 2006). Identifying transition pathways leads to common decision points, which can provide a road map for the male caregiver beginning his journey, as well as those men who are further along in the journey. Transitions noted in this theme were beginning of care, increase in care provided, move to long term care, and bereavement. Decision points included change in health status, availability of caregiver, change in relationship, and impending death.

Role assumption, a property of the transition framework, began with the illness of the care receiver. Some participants were able to identify change early and have time to prepare appropriate resources to deal with the change. Other participants described a gradual process of awareness leading to decisions about care. Not all men felt prepared for the caregiving role and some relied on advice from family members or other
caregivers. Several of the men who felt prepared for caregiving had been previously involved in caring for a family member.

As the care recipient’s condition declined, the decision was made to either continue care in the home or move the care receiver to a skilled nursing facility. This reflects a critical point in the transition framework property of time span. In making this decision, men faced challenges related to changes in function and health; need to acquire more caregiving skills, change in relationship, and recognition of the importance of self-care. In dealing with these challenges, men expressed feelings of frustration, pride, sadness, and satisfaction. Each decision point offered an opportunity or a challenge.

Four men related their preparation as changes were anticipated or occurred.

She had a heart attack. Then I got a van because her knees weren’t in real good shape. I felt like someday she may be in a wheelchair. (Dan K)

I just reworked the bathroom because she was complaining about getting in and out. (Van H)

We jointly made the decision that we were going to a full care place. I’d been doing a lot of looking into it. (Robert M)

Because 3…2 and a half years ago, when she got her diagnosis, I made the decision. We’ve got to figure out what we’re going to do because ultimately she’ll need nursing care. (Glen F)

I have a son that came over several times and helped to do that (lifting). (Dan K)

When change is anticipated, even well before an illness event, there is more time to develop strategies that address concerns presented by illness or aging conditions.
Participants considered alterations in house design, professional care, or being near family in case assistance was needed with declining function.

**Changes associated with caregiving**

Changes in roles and relationships, part of the engagement property of the transition framework, were seen by men as being frustrating, sad, and satisfying. Several participants described a continued deep relationship with some limitations in shared activities. Other men described a decrease in the quality of relationship due to illness or personality changes. Relationships outside the caregiver dyad were depicted as diminished due to family and friends’ reluctance to visit or offer help.

To adapt to these changes in roles and relationships, men reported self-care strategies such as exercise, writing, computer games, and meeting with other men on a regular basis to talk about various subjects including caregiving.

Now it seems like that everything I want to do, she’s against because of her Parkinson’s disease. (Peter L)

We were very active people…we did a lot of traveling…we played tennis. You get reconciled to the fact that you’ve gotten old and you’ve got problems, and you’ve got to deal with them. (Robert M)

It’s a matter of realizing there in the last year or two that she wasn’t going to get well and this thing was deteriorating. (Dan K)

I think it gave me sort of a new dimension to my own life. Relating to him in a different way was something very satisfying to me. (Clark G)
I believe I have more compassion. I realize her limited abilities to do things. (David N)

I spend 30 minutes to an hour on the computer…that’s my time to do that. (Van H)

I continue to play tennis…I did my writing. Well, you know you need something else. You can’t just do that or you’ll go nuts. (Robert M)

The changes discussed included recognition of limitations imposed by illness and aging, change in the care recipient’s condition, and continuing strategies such as exercise or writing to reduce stress. Two men reported meeting regularly with other men, who were not all caregivers. The purpose of these informal meetings was to discuss a variety of issues. Caregiving was a topic discussed but it was not the primary reason for the group meeting or membership. Rather it arose as a member desired to talk about the issue or situation. This allowed those in a caregiver role to have an identity other than as a caregiver. The men expressed that having conversations about topics other than caregiving was a welcome reprieve from their focus on caregiving.

Three participants also spoke about the end of the caregiving experience. Two men expressed uncertainty about the ending of the caregiving role. One man discussed the dying process with his wife.

What do you do when it’s over? You know somewhere there’s going to be a big empty hole. (Van H)

What happens when I go before her? (Robert M)
She adjusted to that (declining health) pretty well, I think. And we talked about that a lot. She made the statement that she felt like she ought to…going out, she wanted to go on out. (Dan K)

Because afterwards (death of wife) is where if it’s going to be done, I’m the only one. I wasn’t really prepared. It’s harder. I feel like doing the job of two people. (Dan K)

The statements focus on the effect of the care recipient’s death on the caregiver, recognition that the caregiver may die before the care receiver, and the care recipient helping the caregiver deal with her impending death. The end of the caregiving role and move to the bereavement phase was the final transition. Van H discussed continuing his community work as a way of filling the time after his wife’s death. Robert M worried about the possibility that he might die before his wife and was planning a talk with his daughter about transferring caregiving responsibility to her if that occurred. Dan K had several discussions with his wife over a period of time to prepare for her death so that her wishes would be met. After she died, he felt prepared for the event of her death but not for continuing daily tasks after she was gone. He missed having her companionship and input in making decisions. The men’s strategies indicated the caregivers’ anticipation of changes and a plan to continue care. Adjusting to abrupt changes, such as being alone, may be difficult at first. As strategies are incorporated to bring about a sense of stability, changes may be easier to accept.
Caregiving behaviors

To address the care receivers’ declining abilities, participants either anticipated the change or dealt with it as it occurred. Dan K talked about how he and his wife decided to use universal design principles when they began building their house, 15 years before her illness, in the event one of them became ill. His wife enjoyed cooking. Once she became confined to a wheelchair, he lowered the cabinets so that she could continue enjoying food preparation. He stated that she dropped food on the wheelchair and floor which created more to clean for him. However, he felt it was important to keep her enjoying the things that she could and he enjoyed spending time with her in the kitchen.

David N encouraged his wife’s independence by having her use a walker instead of a motorized wheelchair. Also, he insisted that she go to a chair exercise class to maintain her strength and mobility. Robert M discussed periods when his wife was prone to falling and that he needed to be strict and set rules about moving around to keep her safe. He did not like placing restrictions on her but felt it was imperative to keep her safe. These examples highlight the desire to keep things as normal as possible for as long as possible for both the care recipient and caregiver. During caregiving transitions, what is normal shifts in response to changes in the illness process, personality, and environment. Behaviors that these participants employed to move to the “new normal” included altering the environment, encouraging exercise to preserve function as long as possible and setting boundaries for safety purposes.
Most men shared that they felt comfortable doing daily household chores and providing personal care. Also, men accepted and received help from family, friends, and professional caregivers.

The relief I had was when I had one of my sons come…when I had to go out for meetings with others. (Dan K)

It began to get to the point that I just couldn’t do it all myself. My daughter called me up one day, and a friend of hers had called her up and knew of somebody that did that kind of work. (Art C)

My sister was always anxious to check on his clothes and to look at his toilet articles to make sure that things were as they should be. (Clark G)

We have a very giving church and a lot of our families provided food for us a lot of times. (Richard B)

Our church group, we arranged for people to be with her, including myself, around the clock for about 5 days (during hospitalization). (Fred A)

Home health came and did help for her…almost 2 months, bathing her, dressing her, helping with the wounds on her feet. (James S)

Assistance provided included varying levels of help directed toward the caregiver dyad, the care recipient, and the caregiver. Art C recognized his need for help through his daughter’s insistence on using paid assistance. Other participants discussed their families providing weekly dinners, visiting to help with care, and providing respite for short periods of time for them to participate in an activity unrelated to caregiving.

Two men discussed the pressure they felt from healthcare providers to use home health or skilled nursing care.
The medical people make quite a case for the fact that you’d be better off to yourself, as well as to your patient, by either getting other people to do it, home care, or letting them stay in a nursing home where they can be taken care of. (Robert M)

They (nurse practitioners) are more concerned about the caregiver and making sure the caregiver gets some time off and so forth. It was kind of interesting how much emphasis they put on that. (Glen F)

While they understood healthcare providers’ concern for them, both men felt they were handling their wives’ care very well and did not need help at that time. They indicated it was important to keep their wives’ in the home environment as long as possible to meet her desire to stay in the home and his desire to remain the primary caregiver. Caring for their wives at home indicated to men that they were doing all they could to provide the best care in a way that was acceptable to both them and their wives. Each man expressed uncertainty about their role once their wives moved to a long-term care facility.

Understanding the importance of maintaining the care receiver in a home environment is useful to healthcare providers as they discuss strategies with the caregiver to deal with increasing care needs. The transition phase from home to long-term care will require preparing the men for a new role as a central contributor to the caregiving team instead of being the sole care provider.
Research Question 3

How well prepared do older men feel for the informal caregiving experience?

The Preparedness Scale of the Family Care Inventory was used to measure men’s perception of being prepared to take care of physical and psychosocial needs of the care receiver (Schumacher et al. 2008). The mean scores for the individual questions ranged from a lower preparedness score of 2.15 to a higher preparedness score of 2.92. The overall mean score was 2.44, which indicated being somewhat well prepared.

Questions that had mean response scores falling below 2.44 included 1, 2, 4, and 5. These questions dealt with physical and emotional needs, stress, and making caregiving activities pleasant. The question, “how well prepared do you think you were for the stress of caregiving”, had the lowest mean score (2.15) indicating being somewhat well prepared. For this transition, there were nine men who had no previous informal caregiving experience. Three men stated that they were not at all prepared. One man indicated he was somewhat well prepared. Four men stated they were pretty well prepared and one man stated he was very well prepared. For the four men who had prior informal caregiving experience, two stated they were somewhat well prepared and two stated they were pretty well prepared.

Questions that were equal to or above the mean score of 2.44 included 3, 6, 7, and 8. These questions dealt with knowledge about available services, handling emergencies, getting help and information, and overall preparedness. The question “how well prepared do you think you were to respond to and handle emergencies that involve him or her”, had the highest mean score (2.92) which approached the pretty well prepared response.
Six men used a score of 2 or above (somewhat well prepared to very well prepared) for all the questions. The other seven men used responses lower than 2 (not at all prepared to not too well prepared) for some of the questions indicating they were not well prepared for the areas related to knowledge, emergencies, getting help, and preparedness. Both of these groups were composed of men who had and did not have previous caregiving experience. One participant declined to answer question number 2 about dealing with emotional needs. He said he could not address his wife’s emotional needs, as she was unresponsive due to her illness process.

Being prepared for and transitioning to the caregiver role includes awareness of a need, identifying with the caregiver role, and understanding what the role entails. With an acute event, such as an illness, there is usually little time to prepare. While some participants had discussions about caregiving prior to the illness event, most began their preparation when care receiver symptoms began to occur. Recognition that caregiving may be a common role in older populations will encourage older men to prepare for this critical role and the accompanying transitions throughout the caregiver career.

**Research Question 4**

What would prepare older men for the informal caregiving experience?

After completing the Preparedness Scale, the following three questions were asked 1) is there anything specific you would like to be better prepared for? 2) what prepared you for this caregiving experience? and 3) what advice do you have that would
help prepare other men? Areas related to meaning/purpose, caregiving behaviors, and assistance/resources for caregiving were identified from the men’s responses.

Meaning/purpose

Men discussed other experiences that prepared them for caregiving including supportive marriages, career skills, and knowing their partner’s wishes.

It was a wonderful, loving marriage…in which there was no conflict…we mutually took care of it. (Art C)

As a result of my vocation…I had been with people in many different situations…so that I have dealt with emotional needs and physical needs…so that I’m comfortable with the fact that all of us need help. (Frank S)

Maybe that’s just my personality, or it may be my profession. If you have a problem, you come and hire me to help you solve it. I just adapt. (Art C)

One thing that she wanted to die at home and that worked out. When we built that house, I had that in mind. We had the bedroom and it had double doors going into the living room and all. The house was wheelchair friendly to start with. (Dan K)

The relationship between caregiver and care receiver provided support for facing difficult situations. Communication within the caregiver dyad allowed the care receivers to express their wishes about end of life and strategies to accomplish the wishes. Also, men acknowledged applying the skills acquired through their work life to the caregiver situation. Difficult situations arose at transition points, which presented challenges. These men addressed the challenges through the strength of their relationship with the
care receiver, open communication, and adapting skills learned in their work life to the caregiving experience.

**Caregiving behaviors**

Participants indicated they would like to be better prepared for the death of their loved one, understanding the illness process, handling financial issues, acquiring skills, and knowing about available services.

I got in touch with home health care and that helped a lot. So we could figure some kind of a time when it was time to call them. (Dan K)

We had a plan and that’s one thing when you’re going through that kind of situation…where you don’t know what, exactly, what’s going to occur and what you should do about it. (Dan K)

I can see a change in her, you know, gradually. She’s not as lively now, flexible. She has a tendency to sleep a lot. (David N)

We got help towards the last with the home health care. (Dan K)

Listen to the doctors. Go with the person you’re providing care for to their doctors’ appointments, to the nurse practitioners’ appointments. Listen to what they have to say and abide by it. (James S)

I probably would like to have understood more about what was happening to my first wife. (James S)

In talking about experiences that prepared them for caregiving, four men stated that they were involved in informal caregiving prior to their current experience. One man provided episodic care to his brother. Another provided care to his first wife. Two of
these four men participated in caregiving with their wives. Men may be drawn into caregiving by assisting the women in their lives. This experience may prepare them for being the primary caregiver if the woman becomes the care recipient or unavailable to provide care.

One thing involved in it would be the fact that my mother lived with us for about 15 years. My wife, in turn, provided some hands on caregiving for her parents. So both of us have seen situations and therefore are able to respond to caregiving as a very natural part of life. (Frank S)

Men discussed taking care of themselves through exercise, meeting with other men to talk on a regular basis, and asking for help. One man had an agreement with his brother-in-law, who also had health problems, to call each other every day at 9:30 AM to check up on each other.

You know you have to keep the spirit up. Keep up your own life…keep that going as much as you can because it helps divert the attention and it keeps you encouraged about other people’s lives. Because you get to doing that kind of thing and nothing else day in and day out, you could wear yourself out or burn out. (Dan K)

Just get all the help you can. (Richard B)

On Saturday mornings, I have a group of men that meet…and I try to get there as much as I can. We call ourselves the old grumps club because everybody is grumpy. (David N)

I think that physical activity is very important. If you can have some type of outside activity, that is good. (Frank S)
Areas that men identified to prepare other male caregivers were understanding the illness process, handling financial issues, acquiring skills, knowing about available services, and preparing for the death of their loved one. Caregiving behaviors that participants identified as being helpful to other men included planning ahead for a caregiving episode, recognizing changes that may signal the need for more resources, using assistance when needed, and talking with the health care team to understand the plan of care. These men repeatedly stressed the importance of asking for help. With the increase in the aging American population, being prepared for caregiving transitions and willingness to accept help are key behaviors to develop in male caregivers.

**Caregiving assistance/resources**

The final question asked about advice men would provide to assist in preparing other men (see Table 5). Suggestions to prepare for caregiving transitions were doing the best you can, having a positive attitude, and recognizing that caregiving is part of the life scheme. Formal and informal support groups were recommended by the men including professional counseling.

> Grow with the situation…it’s a bad hat to have to wear; wear it with honor. Do the best you can. (Van H)

> It’s not a devastating experience. You make out all right. It’s not going to rob them of everything they’ve been accustomed to. They can still do a goodly number of things. (Henry F)

> Just be prepared and take it when it happens, and be happy to do it, and do a good job. (David N)
Men stated that learning new skills before you need them would decrease the difficulty of learning household skills as well as physical caregiving skills. They employed a matter of fact approach to the caregiving experience.

Well, if they (male caregivers) don’t know how to cook, they need to go ahead and learn how. (Glen F)

It’s going to be your responsibility if she gets to where she’s sick. She’s got to realize that from you too. It’s good to, in the place that you’re living, to try to look at what can be done to help facilitate the physical part of caregiving. All those things should be looked into before you actually have to do it because a lot of times you don’t have the time to put into it. (Dan K)

Do realize that it is a situation that they could conceivably become involved in, observe what situations are and continue to train themselves to try to keep their cool. Don’t get excited and go off, you know, about it because if it happens, it happens. (Art C)

Dan K mentioned that the caregiver and care receiver should understand each other’s role in the caregiving experience. This may lead to clearer communication about each other’s desires and abilities as they face changes in the caregiving experience. Art C talked about facing the situation realistically and controlling emotions. The benefits and burdens of the role were acknowledged but the men focused more on the pride and satisfaction they felt in doing a good job.
Table 5. Categories of Advice for Caregivers

<table>
<thead>
<tr>
<th>Clusters of Meaning</th>
<th>Caregiver Advice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do the best you can</td>
<td>Run like hell, good enough. Grow with the situation…it’s a bad hat to have to wear; wear it with honor. Do the best you can.</td>
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<tr>
<td></td>
<td>It’s not a devastating experience. You make it all right. It’s not going to rob them of everything they’ve been accustomed to. They can still do a good number of things.</td>
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<tr>
<td></td>
<td>Just be prepared and take it when it happens, and be happy to do it, and do a good job.</td>
</tr>
<tr>
<td>Self care</td>
<td>So, I keep repeating what they told me, so, look after yourself.</td>
</tr>
<tr>
<td></td>
<td>Look after yourself, don’t try to do it all yourself.</td>
</tr>
<tr>
<td></td>
<td>You know, you have to keep the spirit up. Keep up your own life…keep that going as much as you can because it helps divert the attention and it keeps you encouraged about other people’s lives. Because you get to doing that king of thing and nothing day in and day out, you could wear yourself out of burn out, or whatever.</td>
</tr>
<tr>
<td></td>
<td>I think that physical activity is very important. If you can have some type of outside activity, that is good.</td>
</tr>
<tr>
<td>Accepting help</td>
<td>You’re preparing yourself to just live and enjoy the life. Don’t be reluctant to accept help.</td>
</tr>
<tr>
<td></td>
<td>Just get all the help you can.</td>
</tr>
<tr>
<td></td>
<td>To have some type of support group is important, individuals you can talk to.</td>
</tr>
<tr>
<td>Learning basic skills</td>
<td>Well if they (male caregivers) don’t know how to cook, they need to go ahead and learn how.</td>
</tr>
<tr>
<td></td>
<td>Find out as much as you can about caregiving.</td>
</tr>
<tr>
<td></td>
<td>Try to learn from women who do a good job.</td>
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</table>

Summary

The informal caregiving experience was described by 13 older male caregivers and reflected in 8 themes and 24 subthemes across the areas of meaning, transition, and preparedness. Descriptions focused on caregiving in terms of a loving act, accepting responsibility, and reciprocity for the actions the care receiver had taken for them earlier.
in their relationship. The men viewed assuming the caregiver role as a natural part of their relationship with the care recipient. They described the ability to provide for their loved ones and keep them safe as important components of the meaning of caregiving. Meaning was attached to changes in relationships. One man described the change in relationship with his father as becoming more of a friendship than a relationship where the father was in charge. Men who were caring for wives with altered mental status stated they felt sad to see the gradual decline of their loved one but still felt a strong commitment to their marriage.

Common transitional decision points were anticipation of aging changes, changes in care receiver health status and function, role changes including the assumption of more responsibilities, and acquiring skills or assistance. Also, many of the men’s feelings, beliefs, and confidence in their caregiver role were discussed in the context of change in the care receiver’s condition. Adapting to changes in the relationship between the caregiver and care receiver focused on issues such as reliance on solid marriages, resentment for the care receiver who was perceived to be refusing to do daily tasks when they were capable, and discovery of a new satisfying relationship.

One of the challenges and changes shared was social relationships and support offered by friends and family. Participants were aware, after a period of time following the care recipient’s initial diagnosis that friends and family members spent less time with them. Husbands in this study had professional networks and social networks, which were largely maintained by their wives. After retirement, with the deaths of colleagues and their wives’ inability to maintain the social networks, support from these networks
declined. Compounding their isolation was the assumption of the non-traditional male caregiving role.

Some men formed new support relationships with other caregivers or relied more on the friends and family members that remained. Self-care and respite were employed by a majority of the men to deal with caregiving challenges. Two men mentioned informal meetings on a regular basis with other men to discuss a variety of issues. Caregiving, while discussed, was not the primary reason for the group meeting. The men expressed that having conversations about topics other than caregiving was a welcome reprieve from their constant focus on caregiving.

Men had varying levels of preparedness for the informal caregiving role. Planning ahead and adapting to events as they occurred characterized how men transitioned to and within the caregiver role and were prepared for caregiving. Some men sought help early in the experience while other men had family members who told them they needed help and assisted them in identifying resources. Since most of these men had not experienced caregiving before, they were unfamiliar with events to anticipate as well as knowing about available resources. Some men expressed that they would like to have been more prepared for certain aspects of the caregiving experience such as dealing with medical issues. Other men were able, either through previous caregiving experience or lessons learned from other situations, to be proactive in their thought and planning process.

All the men shared advice for other male caregivers. Participants who had been providing care for longer periods of time provided the most advice. Some men felt that
support groups, either formal or informal, were helpful as a self-care strategy. Several men emphasized the importance of accepting help. Also, men shared their feelings, behaviors, and beliefs about caregiving with the confidence that they were doing a good job.
CHAPTER V
DISCUSSION, CONCLUSIONS, AND IMPLICATIONS

Discussion

The middle range theory of transitions provided a guiding framework to explore older men’s experience of informal caregiving (Meleis, 2007). Descriptions provided by the 13 older men indicated that the caregiving experience was a situational type of transition. Several critical transition points were identified during the experience. These points included change in care receiver’s health, decisions about providing care, learning new skills, change in relationships to care receiver due to illness or memory deficits, change in relationship to others due to the care receiver’s illness, end of the caregiving role, and bereavement. Many of these points have been reported in previous caregiving research though not specific to male caregivers (Fraser & Warr, 2009; Silva-Smith, 2007; Gaugler & Teaster, 2006).

Some decision points were identified early in the illness event and some occurred much later, reflecting the ebb and flow of caregiving transitions. This ebb and flow was reported by Sandberg and Eriksson (2007) in their narrative study on male caregivers entering and adapting to a new, unfamiliar role. Coleman et al. (2004) described a care transitions intervention providing caregivers with tools and support to encourage participation in the transition from hospital to home. This intervention also resulted in decreased readmission rates. High levels of confidence in managing care,
communicating with the healthcare team, and understanding medication regimens were reported by patients and caregivers. For the current study, the transition process indicator, confidence, was conveyed by participants’ descriptions of their ability to perform caregiving responsibilities. Men in this study provided care (8.6 years) longer than the national average (4.5 years) for caregivers. This may explain their confidence in providing care (Washington State Department of Social And Health Services, 2007).

Transition outcome indicators described by men were skills and behaviors acquired to deal with the evolving role of caregiver. Each time the care recipients’ level of care increased, these men rose to the challenge by learning new skills, modifying the care environment, and identifying resources to assist in providing care. Changes were part of the transition process and often caused discomfort, even when that change was seen as positive.

Participants demonstrated preparedness for caregiving in the following areas: role assumption/awareness, assistance/resources, strategies, activities, and limitations. Husbands assumed new responsibilities with decreased support from their spouses. This is similar to new role assumption among middle-aged female and male caregivers reported by Schumacher, Stewart, Archbold, Dodd, and Dibble (2000). New responsibilities were based on changes in the role as well as the need to acquire skills and strategies to adjust to the changes in levels of care. Men in this study felt they were somewhat well prepared for the caregiving role, though there was variation in reported preparedness.
Areas where men felt least prepared included lack of basic care skills, uncertainty about the care receiver’s condition, financial concerns, and adjusting to some degree of loneliness and isolation. These findings are common reflections of caregiving and transition (Calasanti & King, 2007; Kaye & Crittenden, 2005). When entering the caregiver role, older men typically faced a dual challenge of learning new skills and dwindling social networks (Calasanti & King, 2007; Russell, 2004). Men in this study participated in formal and informal support groups, were involved in group activities, and received support from family and friends. These interactions provided relief from the constant presence of care demands as well as support to focus on evolving needs as has been shown by Thompson (2005).

Advice for future male caregivers focused on assistance/resources, strategies, activities, and limitations that relate to meaning, transitions, and preparedness. Also, advice offered to other men included understanding the caregiving role and accepting that caregiving is part of being connected to another person. Transition framework process indicators include connectedness, developing confidence, and coping with the caregiving experience. Men were interested in providing advice to other men to assist them in coping with the many transitions encountered in the caregiver role.

Participants shared their thoughts and experiences about the meaning of the caregiver experience, weathering the transitions as the care receivers’ condition changed, and their level of preparation for the role. Men were thoughtful in their descriptions of the caregiving experience, incorporating both positive and negative feelings as well as their beliefs about caregiving. The men shared their success and frustrations with the
ever-present responsibility of providing care for their loved ones. Overall, men in this study felt they were somewhat well prepared for the caregiving role. Two factors that prepared men for this role were a supportive relationship with the care recipient and their ability to transfer work skills to the caregiving role.

Most of the participants were involved with personal care in addition to management activities. These men applied a “just do it” attitude in acquiring new skills to adapt to their new role. The men’s descriptions of caregiving are consistent with other studies that portray men’s style of caregiving as a blend of nurturing and management styles (Thompson, 2005; Russell, 2004).

Conclusions

Providing informal caregiving to a loved one was described as a natural extension of being part of a loving relationship. Men responded to meet the needs of their loved ones by learning new skills throughout caregiving transitions. Their candid responses indicated that even though caregiving is challenging and frustrating, they faced their responsibilities and felt pride in doing a good job.

Most of the male caregivers were involved with personal care and care management activities. As the men became more adept with caregiving skills, using approaches from their work life seemed to provide a sense of control over what may be an overwhelming situation. Their overall approach was to do whatever was necessary to provide excellent care. Finally, advice that men offered to other older male caregivers
related to facing the situation, knowing your abilities, and getting help emerged and were validated by their own experiences.

Most men indicated they would like to be better prepared for the caregiver role. Those who felt prepared still faced challenges for which they would like to have been better prepared. Identified areas of concern were help seeking, building and maintaining social networks, providing personal and medical care, and housekeeping activities. Preparation for the caregiver role continues to be an area where older male caregivers require support.

Older male caregivers would benefit from programs that cover topics ranging from anticipation of the caregiver role through the bereavement process. Developing specific topics that address the critical points in caregiving transitions will assist older men as they adjust to this new role. Applying gender specific methods to a variety of approaches including workshops, discussion groups, and online offerings will provide information and resources in ways acceptable to men. Incorporating men’s belief that caregiving is grounded in relationship will provide a context for the purpose of caregiving and development of programs.

Limitations encountered in this study include a homogenous sample, which limits the generalizability of the findings. Even though a variety of agencies was involved, recruitment efforts were hampered by staffing changes at one agency. Participants were included who provided care within the last 3 years. Four of the participants were no longer providing care at the time of the interview due to the death of their care receiver. However, this time may have allowed time for reflection on this challenging journey.
This period of reflection offered an opportunity for the caregiver to explore his thoughts and feelings on a deeper level thereby yielding rich information.

Implications

Practice

Nurses are the largest healthcare professional group and are trained to practice across settings of care. Therefore, they are ideally positioned to support older male caregivers adjusting to a new role. The transitions framework may be used to identify critical points that assist men in the caregiver role and adjusting to the changes in their care recipient’s condition.

Nurses in various healthcare settings and nurse practitioners in primary care practices are positioned to assess needs and establish a plan of care for these men, facilitate access to programs and services, and coordinate the healthcare team to maximize services. Services that are offered in many communities are eldercare management and consulting to assist in coordination of care; caregiver handbooks that offer information on aging, stress, and community resources; and American Association of Retired Persons caregiver training programs. Since caregiving is a new role for many older men, they may welcome guidance in identifying and selecting programs suited to their needs.

Nurses can implement gender sensitive strategies designed to elicit health information and issues that male caregivers may be reticent to discuss. Active listening and communication skills can be used to conduct gender sensitive health assessments.
focusing on areas of strength and vulnerability as well as examining important roles in men’s lives in anticipation of transitions that occur with the caregiving experience (Kaye & Crittenden, 2005). Exploring these areas will assist nurses in developing a plan of care with the caregiver dyad that incorporates men’s health needs.

Incorporating gender sensitive strategies into programs for men might include gender appropriate language when advertising the program and using problem solving and task oriented activities. Further interventions would include providing opportunities for caregiving men to be an expert for other men, incorporating ritualized expressions of emotions into group activities, and setting outcome oriented goals (Kaye, Crittenden, & Charland, 2008). Lauderdale and Gallagher-Thompson (2002) report that men see caregiving tasks as part of their marital responsibility and they prefer a task-oriented approach to caregiving. Advertising that the information will be shared in classes instead of a support group emphasizes a task-oriented approach to caregiving and reduces the emphasis on supportive elements of the program, which may be more appropriate for men.

**Education**

In order to effectively screen and assess the health needs of older male caregivers, nurses need preparation in gerontology. The John A. Hartford Foundation and the American Association of Colleges of Nursing provide strategies to improve care for older adults through the Geriatric Nursing Education Project. These strategies include enhancing gerontology content in the curriculum, developing faculty expertise in gerontology and delivery of gerontological subject matter, increasing student interest in
gerontology, and providing scholarship opportunities (Hartford Institute for Geriatric Nursing, 2010).

Incorporating basic gerontological principles into Associate Degree and Bachelor of Science in Nursing programs as well as encouraging growth in masters’ level gerontological programs may provide nurses with appropriate preparation. If there is not a stand alone geriatric course, faculty can infuse gerontological principles into existing courses such as assessment, nursing practice foundations, community health, pharmacology, and medical-surgical nursing using learning modules and case studies that highlight needs of the geriatric patient. Applying best practices and gerontological principles, nurses can develop and implement patient and family education to address caregiver needs across the lifespan.

Education of the healthcare team through staff development would incorporate evidence-based approaches. This information can be shared through both formal and informal educational methods. Implementing workshops for healthcare providers regarding older caregiver issues in general and older male caregivers specifically, may improve support by healthcare providers as they care for the caregiver dyad.

The Nurses Improving Care for Healthsystem Elders (NICHE) program teaches nurses to use a systematic approach in the care of the elderly to create organizational change across disciplines. Using national benchmarking measures, training resources, and evidence-based clinical protocols, over 280 hospitals with NICHE programs aspire to improve clinical outcomes; enhance nursing competencies in geriatric care; and increase patient, family, and staff satisfaction (Hartford Institute for Geriatric Nursing, 2010).
Educational workshops based on this program can be offered to healthcare providers from varying disciplines to improve care to geriatric patients across inpatient and community settings.

Educational programs that incorporate gender specific learning for male caregivers provide information in a format that is comfortable to men. One area to consider is that older male caregivers are faced with generational taboos and perceptions of men caring for women’s hygiene. In addition, when adult children provide personal care for their parents, both the child and parent may be concerned about privacy issues. For these personal care trainings and preparations for older male caregivers, a program such as Bootcamp for New Dads™, used to train new fathers how to care for their child, could be tailored for older male caregivers (Bootcamp for New Dads, 2010). A similar format using coaching techniques with men teaching men to provide personal care may create an optimal learning environment for male caregivers.

**Systems**

In order to deal with the health care needs of the rapidly expanding older population, programs and services targeted to older male caregivers must be provided. The current, fragmented healthcare system is in need of reform and well-informed policy will provide a framework for delivery of care and assistance to male caregivers. With the current focus on changing healthcare policy, a unique opportunity exists for nurses to contribute to the reform of caregiving services. On the federal level, the National Family Caregiver Support Program’s goals are distribution of information to caregivers,
organization of support groups, provision of individual counseling, training, respite care, and other supplemental services (Wolff & Kasper, 2006).

On the state level, the Area Agencies on Aging (AAA) develop comprehensive, coordinated services for older adults to address health and should be consistent with the local community plan on aging. In North Carolina, the purpose of the AAAs is to help older adults remain in their communities in the least restrictive environment with maximum dignity and independence. Strategies to achieve this purpose include providing feedback to the state on aging issues and service delivery, strategic planning, technical assistance, education, training, advocacy, and program administration. The AAA Family Caregiver Support Program assists groups and agencies to coordinate provision of services to leverage resources. One way to provide older men information regarding caregiving is through the Full Circle of Care caregiver website. This website includes a variety of topics in areas such as legal, financial, housing options, medical issues, support groups, and web resources (North Carolina Department of Health Human Services, 2010).

State and local agencies can assess the needs of communities in order to provide resources that are useful. Targeting areas in the community that men are likely to visit will offer information to men already in the caregiving role as well as increase awareness for those who may not have considered caregiving as a future role. Strengthening partnerships between communities, caregivers, families, and healthcare providers will assist in providing a network of information and services to assist male caregivers.
Additionally, development of strategies to strengthen these partnerships between healthcare providers, families, and communities will improve both formal and informal care in a cost effective and customer friendly manner (Kaye, Crittenden, & Charland, 2008). If men have a negative encounter with health care providers, they generally will not use that group of providers again (Brown, Chen, Mitchell, & Province, 2007). Men may use words sparingly to describe their caregiving experience and understate their health issues (Russell, 2007). Therefore, healthcare providers should implement strategies such as active questioning and listening that are designed to elicit health information and needs that male caregivers may be reticent to discuss.

In order to keep men engaged with the healthcare system, the healthcare team should have an understanding of preferred communication and learning strategies to support older male caregivers in their role. Assessing preferred communication and learning styles during the health interview will assist providers in tailoring information in a way that is acceptable to men. Effective methods of advertising male support groups include using gender specific language, listing agenda items to include presentation topic and time for discussion, and using male group members in recruitment efforts (Kaye & Crittenden, 2005).

Parish ministry programs that provide support to caregivers may strengthen opportunities for early recognition and provision of resources for male caregivers in an environment that is known to them. These structured programs may provide an outreach component to connect the isolated male caregiver to needed resources. For churches that
do not have a parish ministry program, employing group care concepts such as circles of care will assist in early identification and support of male caregivers.

Providing information in a natural, community area where men may gather, such as barbershops, sports related businesses, and service groups, may increase awareness and accessibility of information and services by male caregivers. Neighborhood advocacy groups targeted to caregiving in the home may provide outreach services to those caregivers with limited knowledge of or means to access services. Other groups may serve as gatekeepers to identify high-risk elders through non-traditional sources such as bank tellers, property managers or appraisers, pharmacists, telephone company personnel, postal carriers, and utility meter readers (Kaye, 2005).

Investigating use of technology to improve monitoring of homebound elders by health care providers and family as well as providing assistive devices to support home care may improve outcomes and satisfaction for both caregiver and care receiver. Devices such as computerized health monitoring equipment, audio monitoring equipment, personal emergency response systems, and home robotics provide support to the caregiver during waking and sleeping hours. As many older caregivers do not feel able to leave their care receiver, providing information, skills training, and social support through online, synchronous and asynchronous resources may offer a time and cost efficient way to receive skills, knowledge, and support.
Recommendations for Research

Information about male caregivers is limited and inconsistent, thus understanding the meaning of the caregiver role for older men will assist in development of strategies to support men. Understanding caregiving transitions will promote insight to new models of care to support older male caregivers. Concepts of masculinity portray men as strong, in control, and capable (Calasanti & King, 2007). Being prepared may restore a sense of control and competence in an uncertain situation, which may support the man’s view of masculinity. Professionals should assess their own gender competencies to provide appropriate assistance for older male caregivers. Valid measures to assess these competencies should be developed. Effective education for gender appropriate strategies will prepare a competent workforce.

Male informal caregivers are a diverse group providing care across the life span. Information about the differences among male informal caregivers will provide knowledge to develop programs and services to support these men at varying stages of their lives. Determining differences in the way men provide care may uncover strategies that would be useful to all caregivers.

Past studies mostly compared men to women caregivers instead of comparing men to other male caregivers. Investigating male caregiver skills, knowledge, transitions, and preparedness in different life stages and roles may assist in developing a model for male caregiving. Providing informal care as a young adult may be very different from providing care at middle age while juggling family and job responsibilities or providing care in retirement years.
Further investigation of less commonly studied areas in male caregiving such as help seeking and preparedness may result in new practice guidelines to support and prepare male caregivers. Understanding caregiving transitions will assist family members, health care providers, and men in preparing for caregiving by acquiring skills and knowledge prior to a crisis. Knowing where and to whom male caregivers are providing care will offer information to tailor services that meet differing needs across the life span. Exploring differences in care receivers, effective caregiving strategies for persons of differing ages, or with different health needs is required. Studies that compare older caregiving men to older non-caregiving men may discover strategies, traits, or strengths for effective caregiving. Those discoveries may be used to prepare future older male caregivers.

Summary

Male informal caregivers are an increasing group and provide a critical service to family, friends, and society. Men in this study described the meaning of the caregiving experience, identified behaviors that assisted them in adapting to transitions in caregiving, and offered advice to prepare other men for this important role. As the population ages, healthcare in the community increases in intensity, and resource allocations diminish, men will play an important role in providing informal care. Expanding knowledge of the older male caregiver meaning, transition, and preparedness will address issues and meet needs encountered by other caregiver-recipient dyads.
REFERENCES


