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A small body of research suggests that caregiver identity is an important construct that influences family caregiver behavior, especially their use of support services. The measurement of caregiver identity has been limited to a dichotomous construct- are you a caregiver, yes or no- rather than treated as a multidimensional construct with a number of different dimensions. A global measure of caregiver identity is needed to advance research and practice in the area of family caregiving. The purpose of this study was to develop and validate the Family Caregiver Identity Scale (FCIS), an instrument designed to measure an individuals' role identity as a family caregiver. The study aims were to 1) identify the factors that influence caregiver identity development; 2) create a pool of items that can measure the theoretical domains of caregiver identity development; and 3) pretest these items, resulting in a valid and internally-consistent instrument that measures caregiver identity. To develop the Family Caregiver Identity Scale, the process of instrument development outlined in the Standards for Educational and Psychological Testing was combined with Dillman's four stages of pretesting. This was a multi-stage, iterative process, including several revisions based on feedback from experts, focus groups, and pilot testing. Confirmatory factor analyses were performed to test the hypothesized model of caregiver identity development. The results of the study suggest five factors influence family caregiver identity development- role engulfment and reversal; loss of shared identity; family obligation and gender norming; extension of the

former role; and development of a master identity. A final FCIS consisting of 18 items resulted and demonstrated initial evidence of validity. Future confirmatory factory analysis will need to be performed to complete validity testing. This study contributes to the growing body of research involving caregiver identity.

MEASURING CAREGIVER IDENTITY:

SCALE DEVELOPMENT

AND VALIDATION

by

Elise K. Eifert

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Approved by

_____
Committee Chair

To my parents – Your love has allowed me to pursue my dreams. You believed, and never doubted, that I would accomplish this goal which kept me moving forward despite times of my own uncertainty. You instilled in me the importance of hard work and education, without which this work would have been unimaginable. This achievement belongs to you too.

APPROVAL PAGE

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CHAPTER I

INTRODUCTION

Background of the Study

By 2030, the number of people 65 and older is projected to increase significantly. This increase is mostly due to the "graying" of the baby boomer generation, those born between 1946 and 1964. As the proportion of older adults in our population increases, the prevalence of people with chronic illness or disability who need some type of intermittent or long-term care will also increase. Most of the responsibility for providing care will fall on family members, primarily spouses and adult children. In 2008, it was estimated there were 48.9 million family caregivers in the U.S. or one in five households providing care for a dependent adult [National Alliance for Caregiving (NAC) & American Association of Retired Persons (AARP), 2009]. This number is expected to more than triple by 2050 (Department of Health and Human Services and Assistant Secretary for Planning and Evaluation, 2003).

Providing care to a loved one, typically without any form of financial compensation, is commonly known as informal caregiving. Because the loved is more often than not a family member, it is more frequently called family caregiving. Family caregiving can be a stressful and time-consuming experience. Although caregiving has several positive aspects such companionship, fulfillment, and the satisfaction of meeting an obligation and providing quality of life to a loved one (Cohen, 2002), it can also be

detrimental to the caregiver's health and well-being. Caregivers often face stressful events and ongoing distress which complicates the burden of caregiving. Caregiver stress and burden has been associated with several harmful outcomes including depression (Wright et al., 1999), poor health (Farran et al., 2004), burnout (Yilmaz et al., 2009), early nursing home placement for the care recipient (Donaldson et al. 1998), increased caregiver mortality rate (Schulz and Beach, 1999), and elder abuse (Schiamberg and Gans,1999).

To prevent or ameliorate these negative outcomes, caregivers need adequate forms of support and relief such as support groups, information and referral, education, and respite. In the United States, a large network of public programs are available for family caregivers (Wacker & Roberto, 2008). In addition to government programs, there are numerous community-based programs that provide assistance for free or at a low cost. These program exist so that individuals are able to care for their family members at home for as long as possible and without it adversely affecting their mental or physical health. Despite the availability of these programs, they often go unused by family caregivers.

Underutilization of support services by family caregivers is considered an important but poorly understood issue (Brodaty, Thompson, Thompson, & Fine, 2005; Robinson, Buckwalter, & Reed, 2005). An understudied but important concept that has shown to influence a family caregiver's use of support services is caregiver identity. *Caregiver identity* is the "self-understanding, self-objectification, or integration of information about the self" as it relates to the caregiver role (Holland, 1997). The profound changes in the day to day lives of those who take on caregiving can reshape

self-concepts. Family members cease to be just a husband/wife/partner/significant other/son/daughter but begin to take on the role of "caregiver". This role may not come easily or comfortably and there is rarely a single event to denote the beginning of caregiving. The caregiver may not identify with the title of "caregiver" immediately, effectively denying themselves access to a myriad of support services available to them from the beginning of their caring career.

The disconnect between being a caregiver and self-identifying as a caregiver was illustrated in the American Association for Retired Persons (AARP, 2001) Caregiver Identification Study. The AARP surveyed 4,037 adults in order to better understand perception and identification of family members with the term "caregiver" as well as to establish incidence of caregiving and care related activities. This study provided two ways of identifying one's self as a caregiver. The first question directly asked the person if she or he had been a caregiver in the past year while the second question indirectly asked about the person's participation by providing a detailed description of activities typically associated with caregiving (help with personal needs or household chores including care of finances, arranging for outside services, or visiting regularly). Of the sample, 44% self-identified as a caregiver or participated in the caregiver activities. Of the 44%, 15% indicated that they provided the kind of assistance described in the second question but did not self-identify as a caregiver in the first question. In a prior study, O'Connor (1999) found a much higher percent with almost 50% of family caregivers not self-defining as a caregiver. Furthermore, Henderson (2001) found a reluctance to self-

identify as a caregiver among spouses who were providing care to a partner with severe depression.

Understanding the link between caregiver identity and support service utilization may offer vital direction for researchers and practitioners. Research has shown that identity plays a role in motivating human behavior. For instance, Resnicow and colleagues (2009) found a relationship between ethnic identity and fruit and vegetable intake and Strachan and colleagues (2010) found that physical activity identity is related to more physical activity, stronger self-regulatory efficacy, proximal intentions, and satisfaction with life than less strong identity counterparts. Furthermore, Szalavitz (2012) suggests that one of the best ways to change health behavior is to change a person's identity. For example, when a smoker begins to view himself as a nonsmoker, behavior change such as smoking cessation may be possible if the person's identity is altered. Once you see yourself as a nonsmoker, smoking becomes harder to do. In regards to caregivers and support service use, a caregiver is highly unlikely to pursue services that she does not perceive to be relevant or applicable to her situation. Once an individual self identifies as a caregiver, they will be more inclined to seek and use support services available for caregivers. The AARP study (2001), O'Connor (1999), and Henderson (2001) all found a positive relationship between self-identifying as a caregiver and the use of support services. The National Family Caregiver Association (NFCA) and National Alliance for Caregiving (NAC) (2002) found that over 90% of family caregivers became more proactive about seeking support services after they self-identified. The researchers also suggested that there was a serious gap in the understanding of the link

between self-identifying as a caregiver and willingness to use support services (NFCA & NCA, 2002).

Because caregiver identity may play a role in caregivers use of support services, it is an important construct to measure. Currently, the method to identify a caregiver is limited. For example, research like the AARP study (2001) utilize a two-question approach such as 1) Are you a caregiver?- yes or no; and 2) Do you provide any assistance to a friend or family member such as help with health or personal needs (bathing, feeding, etc), household chores, finances, or arranging for outside services? From the AARP study (2001) and others, we know there is disconnect between the label of caregiver and actually providing care because a portion of respondents will say no to the first question and yes to the second. This disconnect most likely results from the lack of universal definition for who a caregiver is but also because this method of caregiver identification is a functional or technical classification not a method to measure some deep-rooted aspect of an individual.

Despite this knowledge, little effort has been directed toward in-depth development and testing of scales designed to measure caregiver identity. A better way to measure caregiver identity is needed and presently, an instrument does not exist. A theory-based, psychometrically sound scale designed to measure caregiver identity would contribute to the understanding of this construct and its valid assessment.

Statement of Purpose

Identification of caregiver status has typically been done using a single yes/no question- *are you a caregiver*?- followed by a question regarding specific kinds of

assistance provided. A global measure designed to assess family caregiver identity could not be found in the review of the published literature. To address this gap, the purpose of the present study was to develop and validate the Family Caregiver Identity Scale (FCIS), an instrument designed to measure the extent an individual identifies with the family caregiver role.

Specific Aims

The first study aim was to identify the factors that influence caregiver identity development. The second study aim was to create a pool of items that can measure the theoretical domains of caregiver identity development. The final study aim was to pretest these items, resulting in a valid and internally consistent instrument that measures caregiver identity.

Rationale for Study/Significance

Caregivers need support services that are generally available, yet they are highly underused. Several studies have all found a positive relationship between self-identifying as a caregiver and the use of support services (AARP, 2001; Henderson, 2001; O'Connor, 1999). Thusly, caregiver identity is an important construct to measure to further research regarding caregiver identity and caregivers use of support services as well as to apply theory related to caregiver identity development to community and public health interventions. It is also important for health professionals and support service providers to have a method to determine where a caregiver is in his or her identity development.

Theoretical Significance

Interventions with family caregivers should always include sound theory. An understanding of factors that influence caregiver identity development is critical to informing interventions with family caregivers. This study will lay the groundwork for future projects including designing theory based interventions aimed at helping individuals transition into the caregiver role. Furthermore, although several studies have identified factors in caregiver identity development, none have suggested a theoretical framework. This study expanded on the work of others to categorize multiple factors related to caregiver identity and create a conceptual framework to understand those factors role in the development of caregiver identity.

Practical Significance

In addition to the potential theoretical significance of this study, there is significance for practitioners. It is imperative that support service providers reach out to family caregivers, self-identified or not; however, to successfully reach them, practitioners must have a method to determine where caregivers are in the self-identification process. Family members adopt the identity of caregiver to different degrees (Hughes, 2013). The development of an instrument that measures caregiver identity will enhance the ability of health professionals to identify individuals who do not fully realize they are caregivers and educate them on their options for support.

Study Overview

Summary

This study is presented in four chapters. Chapter 1 provides background to the importance of caregiver identity and the limitations in its measurement. It presents a case to develop an instrument that measures caregiver identity. Chapter 2 includes a review of the literature pertaining to family caregiving and the use of support services as well as identity. It provides a detailed review of the factors involved in family caregiver identity development and provides the theory and context of an instrument to measure caregiver identity. The item development and instrument pretesting methods and results were documented together in Chapter 3 because of the research design that involved multiple phases and steps which built upon each other. A comprehensive description of the development of items to measure caregiver identity is provided. The chapter also describes how these items were pretested. Chapter 4 includes a discussion of the findings, conclusions drawn from the study, and recommendations for practice and future research.

Delimitations

Cognitive interviews during step five of the study were delimited to (a) English speaking (b) informal caregivers who (c) live in North Carolina, and (d) were in long-term caring situations with a family member over the age of 50 who had a chronic illness. Pilot testing during step six of the study were delimited to (a) English speaking (b) residents of North Carolina who (c) had never been a paid, professional caregiver. Additionally, the study was delimited to the measurement of caregiver identity. Only

items approved during step four and step five of the study were included in the instrument during pilot testing. Furthermore, confirmatory factor analysis was used to determine which items to include in the final version of the instrument.

Limitations

While this study was intended to create a basic, global measure that was comparable to a whole variety of ascribed memberships like gender or race/ethnicity, the focus was restricted to the single category of caregiver. This restriction raised a few measurement issues. First, although a comprehensive and structured literature review exploring factors related to caregiver identity was performed, it is possible that certain factors have not been identified. Caregiver identity research is still in its infancy and there may very well be other factors not stated in the literature. Second, caregiver identity may not be universal across populations. Pilot testing on this instrument was done using convenience sampling because of the exploratory nature of the study as well as to increase sample size. Future efforts to pilot the instrument should be intentionally done with diverse and unique populations to determine the ability of the *Family Caregiver Identity Scale* to capture caregiver identity in multiple cultural contexts.

Key Words and Operational Definitions

Caregiver An *informal caregiver* can be defined as anybody who provides regular, ongoing help to an unwell person without payment (Spillman & Black, 2005). The majority of informal caregivers are family members such as spouses and adult children of the care recipient. Thusly, informal caregivers are often referred to as

family caregivers. The term caregiver is also referred to as *carer* or *care provider* in the literature. For the purpose of this study, any reference to "caregiver" was in the context of informal or family caregiving.

Care Recipient The *care recipient* is the person in need or receiving care from the caregiver(s). Typically this person is chronically ill or has functional limitations that require them to need assistance with day to day activities on a long-term basis. The care recipient is also referred to as the *care receiver* in the literature.

Caregiver Burden Caregivers often face multiple concurrent stressful events and experience stress that continues over time. The impact of this stress is known as *caregiver burden*. There is no singular or uniform conceptualization or definition of 'caregiver burden' in the literature (Bastawrous, 2012; Chou et al., 2003); however, *caregiver burden* can be thought of as a negative reaction to unchecked stress related to caregiving. Caregiver stress and burden has been associated with several negative outcomes including depression (Wright et al., 1999), decreased immune systems and poor health (Farran et al., 2004), burnout (Yilmaz et al., 2009), early nursing home placement for the care recipient (Donaldson et al. 1998), increased mortality rate (Schulz and Beach, 1999), and elder abuse (Schiamberg and Gans,1999).

Support Services Various programs and interventions are available to assist caregivers in keeping their loved one at home and to cope with the demands of caregiving. These services, generally referred to as *support services*, include assistance with caregiving or related tasks and emotional or educational support that is provided to family caregivers by health professionals and community service providers. Examples of support services can include information and referral, education, counseling, and respite.

Identity *Identity* is described by Burke (2006) as "the self-meanings that define who one is". Alternative terms for identity include *self-concept, self-referent label, identity status, or self-categorization.*

CHAPTER II

REVIEW OF THE RELATED LITERATURE

This chapter presents an overview of family caregiving, caregiver responsibilities, caregiver stress and burden, support services for caregivers, underutilization of support services, and role identity. These concepts were reviewed in the context of the relationship between caregiver identity and support service use. The chapter continues with a review of the literature on family caregiver identity. The review focuses on studies that suggest a component of caregiver identity or influential factor of caregiver identity development. The final section presents a theoretical framework of family caregiver identity. Combined, these sections provide the justification for a study to develop and validate an instrument to assess an individuals' role identity as a family caregiver.

Family Caregiving

Families in the United States play an essential role caring for family members with acute and chronic illnesses. Family caregivers provide an estimated 90% of long-term care in the United States (Institute of Medicine, 2008) with an economic value of unpaid work estimated between $196 billion (Arno, Levine, & Memmott, 1999) and $354 billion (Gibson and Houser, 2007). In 2008, it was estimated there were 48.9 million caregivers or one in five households providing care for a dependent adult [National Alliance for Caregiving (NAC) & American Association of Retired Persons (AARP),

2009]. This number is expected to increase in the next couple of decades due to a variety of factors, the most obvious being the growing population of people 65 and older caused by the baby boomers. In addition to the sheer volume of older adults, baby boomers are expected to have a longer life expectancy than previous generations. Unfortunately, they will live longer but not healthier. The average number of healthy years is slowly decreasing (Crimmins & Beltrán-Sánchez, 2011) and baby boomers are expected to have more morbidity than their elders (King et al., 2013).

Caregiving Responsibilities and Burden

Caregiving encompasses a wide range of activities from occasionally running errands to supervising regular activities to direct, day-to-day care. Traditionally, responsibilities include assistance with activities of daily living (ADL), such as bathing, dressing, and eating, as well as instrumental activities of daily living (iADL) such as money management or transportation (Davis et al., 1997). Caring for a person with dementia such as Alzheimer's disease is often complicated by symptoms of the condition, including a lack of judgment, communication difficulties, and behavioral symptoms such as aggression or wandering. The amount of time spent on caregiving can be a few hours a week to 24 hours/7 days a week, depending on the needs of the care recipient and/or the presence of other caregivers- formal or informal. The average duration of a caregiver's role is approximately 5 years (NAC & AARP, 2009).

Of growing concern is the increasing complexity of providing care. Many caregivers of individuals with chronic disease report "performing medical/nursing tasks of the kind and complexity once provided only in hospital" such as medication

management including administering IVs and injections, wound care, operating specialized medical equipment, and physical or medical therapies or treatments (Reinhard, Levine, & Samis, 2012). Much of the advanced care provided is done with little to no training (Goldberg, Solloway, & Rickler, 2011).

The large quantity of care needs and the amount of time required to carry out this care can be a major influence on the caregiver's life and health. Although there are many positive aspects of caring for a loved such companionship, fulfillment, enjoyment, and the satisfaction of meeting an obligation and providing quality of life to a loved one (Cohen, 2002), it often takes a toll on the well-being of the caregiver. Caregivers experience numerous stressful events that occur concurrently and continue over time. The impact of this stress is known as caregiver burden. There is no singular agreed upon definition of 'caregiver burden' (Bastawrous, 2012; Chou et al., 2003); however, caregiver burden can be thought of as a negative reaction to unchecked stress related to caregiving. One study by Papastavrou and colleagues (2007), estimated that 68% of caregivers reported being highly burdened**.** Caregiver stress and burden is a cause for concern because it is associated with several negative outcomes including depression (Wright et al., 1999), poor health (Farran et al., 2004), burnout (Yilmaz et al., 2009), early nursing home placement for the care recipient (Donaldson et al. 1998), increased mortality rate (Schulz and Beach, 1999), and elder abuse (Schiamberg and Gans,1999).

Support Services

Various programs and interventions have been developed to assist caregivers in keeping their family member at home and to cope with the demands of caregiving. These

services include assistance with caregiving or related tasks and emotional or educational support that is provided to family caregivers by health professionals and community service providers. Some examples of support services include information and referral, education, counseling, and respite. Organizations that provide support for caregivers vary in availability/location, size, funding, and offered services. Every community in the United States has a local Area Agency on Aging (AAA) to serve them, as mandated by the Older Americans Act. The AAA often provides information about the aging services available. Caregivers typically can find support services in their area through the phone book or Internet, including the AAA website. Many support services can be referred to the caregiver by medical staff.

Several studies have highlighted the importance of support services for caregivers and the improvement of coping skills in burdened caregivers (Clyburn et al., 2000; Gallagher-Thompson and Coon, 2007; Alma et al., 2007). Counseling and support can improve care recipient's and caregiver's opportunities to adapt to the challenges of caring and to maintain well-being (Sorensen, Waldorff and Waldemar, 2008). In a meta-analysis of caregiver interventions performed by Parker, Mills, and Abbey (2008), 26 of the 34 randomized controlled trials examined, indicated that the intervention had positive effects for caregivers such as an increase in use of support services, a decrease in depression and burden, as well as a subjective improvement in overall well-being and quality of life. One of the most popular and well supported caregiver interventions for those facing dementia, Resources for Enhancing Alzheimer's Caregiver Health (REACH), reported that caregivers had better self-rated health, sleep quality, physical

health, and emotional health, which was related to less burden and bother with their caregiving role than caregivers not receiving the intervention (Elliott, Burgio, & DeCoster, 2010).

One of the most significant benefits and probably practical rationales of support service use by family caregivers is the delay in the institutionalization of the care recipient (Gaugler, Kane, Kane & Newcomer, 2005). Considering that some couples make promises to each other about avoiding institutionalization, using support services may keep many caregivers from breaking that promise; presumably saving them from extreme guilt and more depression. In some circumstances, long-term care use is necessary to get the care the care recipient needs. However, when family caregivers are healthy and well supported, they can continue to keep their loved one at home for a longer period of time.

Underutilization of Support Services

Despite the established benefit of support services in decreasing or off-putting negative outcomes related to stress and burden, caregivers make limited use. Numerous studies have documented the underutilization of formal services such as day care, support groups, and home health services (Dorfman, Berlin, & Holmes, 1998; Strain & Blandford, 2002; Winslow, 2003). Wackerbarth & Johnson (2002) found that family caregivers bringing someone to a memory disorders clinic had delayed seeking help for an average of nearly two years after first becoming aware of symptoms in their loved ones. In a study of family caregivers by Brodaty and colleagues (2005), one in three were not receiving any services and one in four used only one service. Litwin & Attias-

Donfut (2009) reported in their study of family caregivers that one-half received no help at all, about one-tenth received care from a household member, and one-third were helped by formal (paid) caregivers from outside the household. The trend of caregivers to infrequently use support services is surprising in the face of what would seem to be appropriate relief in an often overwhelming experience.

There are a number of supports and obstacles to support service use documented in the literature including environmental, predisposing, and need factors (Mast, 2013). One understudied factor is caregiver identity. *Caregiver Identity* is the "self-understanding, self-objectification, or integration of information about the self" as it relates to the caregiver role (Holland, 1997). Montgomery, Rowe, and Kosloski (2007) state that over time, "caregivers not only change their behaviors, but they also change the way they see their role in relation to the care recipient- that is, their role identity" (p. 49). Caregiver identity may play an important role in support service use because a person is highly unlikely to pursue services that she does not perceive to be relevant or applicable to her situation. There is no single definition for caregiver or caregiving and the role can differ dramatically from one person to another. An individual may carry out the role of caregiving without realizing they are a caregiver. If an individual does not see herself as that role identity, she will not seek or access services for a person in that role. For this reason, it may be important to help individuals understand their role identity as caregivers in an effort to increase support service use.

Role Identity

Much attention has been given to the concept of identity in the past 20 years. Numerous disciplines and subfields have added to the literature on the definition and development of racial, religious, gender, national, and other identities. Identity is of particular interest because of its influence on behavior (Biddle et al., 1985; Stets & Burke, 2003). According to Thoits & Virshup (1997), people utilize socially meaningful categories to describe themselves including socio-demographic characteristics (e.g. gender), social roles (e.g. husband, parent), social types (e.g. runner) or personality traits (e.g. funny, kind). These identifications form a set of identity standards based on the meanings and expectations associated with these categories that guide identity- relevant behaviors. Identity and identification of others is necessary to understand the world. In order to successfully

> regulate and govern their lives, individuals need to develop a stable and meaningful identity structure, which enables them to maintain a sense of self-continuity over time and space and which provides a frame of reference for making decisions, problem-solving, and interpreting experience and self-relevant information (Berzonsky, Cieciuch, Duriez, & Soenens, 2011, p. 295).

Identity Development

Identity development is a complex phenomenon that is, for the most part, socially constructed. According to Cooley's theory of looking-glass self, we come to see ourselves as we believe other people see us (Shubert, 1998). Individuals attempt to interpret how they are viewed by others as well as the judgment being placed on that view, and gradually develop a self-image consistent with what they perceive. Identity

develops through the interaction among a person's "psychological and biological dispositions and one's social context" (Kroger, 2006, p. 82). Identity formation has two dimensions- self and social. The first is reflexive in nature and based on a person's own narrative. The second occurs if that "self" identity is acknowledged and supported by others. People come to know who they are by interacting with others and knowing how others see them (Erikson, 1968).

Identity is not fixed and continues to develop and evolve over time (Kroger, 2006). It is to be expected that life experience will cause identity to be examined, reconfigured, and changed (Cross & Markus, 1991). Banaji & Prentice (1994) suggest that identity change takes place in response to major changes in role and situational demands. Major changes may be related to family life like marriage or childbirth or it can be related to accomplishments like completing school or retiring. Significant life changes cause a person to restructure his/her roles which will often be associated with changes in identity (Burke, 2006).

Another theory to explain identity change is Hughes' (1945) "master status". "Master status", or "master identity" as it is called in contemporary research (Haworth-Hoeppner & Maines, 2005). refers to a role that has become more important than any other label or role at that time. This role often shapes a person's entire life, overshadowing all other roles. For example, racial and ethnic identity is one of the most common master statuses reported in the literature (Helms, 1990). Master status has serious significance in identity renegotiation as a single role grows and becomes more dominant than any other role.

Caregiver Identity

The term "caregiver" began as an operational or functional concept that described what a person does but has evolved into a distinct identity with cognitive and emotional dimensions. Caregiver identity, like all identities, does not develop overnight but is a process as the line between the current role the person holds, like husband or daughter, begins to blur with the caregiving role. Many people who are in the role of caregiver have yet to identify as a caregiver. The purpose of this section is to examine and summarize the literature related to specific aspects of caregiver identity and identify influential factors of caregiver identity development. Specifically, the following research questions were addressed:

1. What factors are related to caregiver identity?
2. How does caregiver identity develop?

A high-quality narrative review using a systematic procedure was conducted with the purpose of understanding the development of caregiver identity. The aim was to locate valid and reliable literature that explored the development of caregiving identity; to identify major conceptual and theoretical foundations for caregiver identity development; and to report on the findings with regard to their contribution to an instrument to measure caregiver identity.

Search Strategy

The first phase of the literature review involved an academic database search to identify literature which linked "caregiver" and "identity" within their title, abstract, or keywords. The process was undertaken in two stages. A generic database search for the

terms “caregiver” (or alternative forms) and “identity” (or alternative forms), using appropriately selected search engines, was conducted. The engines included were: Ebsco, PsycINFO, PubMed, Ageline, ProQuest, and Medline. Sources of information included books, dissertations, journal articles and other scholarly works. Furthermore, reference lists from the obtained articles were manually searched to obtain additional literature sources. The second phase included a general search of the Internet (using the same search terms) to locate any technical reports from reputable caregiving organizations or publications from governmental organizations such as the National Institutes on Aging (NIA).

Inclusion and Exclusion

The original years of review ranged from 1990 to 2013 This selection coincides with the 10 years prior to the AARP study on caregiver identity from 2011 which was the first large scale study specifically examining caregiver identification. The inclusion criteria for article selection encompassed all studies and articles from both refereed and non-refereed literature sources determined by the author to be relevant to this literature review. Literature was excluded if it did not contribute to answering one of the two research questions.

Results

The bulk of literature located was considered unrelated to this review. Ultimately, thirty-one sources were obtained to provide literature reference for this narrative review. Of the thirty-one sources, only twenty articles of variable quality specifically investigated or discussed caregiver identity development. Five of the sources specifically dealt with

linking caregiver self-identification and support service use. Two were from the same authors and were different applications of their caregiver identity theory or reported similar findings. The remaining four briefly mentioned caregiver identity but did not substantially contribute to the understanding of caregiver identity development.

A variety of perspectives, methodologies, and theoretical lens were used in the literature to examine the factors related to caregiver identity development. Five major themes emerged from the sources of literature (Table 1). The sources were categorized according to the major findings presented in them. It should be noted that some of the sources had multiple findings and could have been placed in several categories.

Table 1.

Factors and Supporting Literature Related to Caregiver Identity Development

Factor	Supporting Literature
Role Engulfment and Losing Self When the role of caregiver and responsibilities of caring begin to consume a person, leaving little time for other activities and behaviors that may have defined the person previously.	Miller, Shoemaker, Willyard, & Addison, 2008
	Sherrell, Buckwalter, & Morhardt, 2001
	Heward, Gough, & Molineux, 2011
	O'Connor, 2007
	Burton, 2006
Loss of Shared Identity Changes to a person's dyadic identity because the dyad is diminishing or lost.	Hasselkus & Murrary, 2007
	Coeling, Biordi, & Theis, 2003
	Hayes, Boylestein, & Zimmerman, 2009
	Adams, 2002
	Orono, 1990
Family Obligation and Gender Norming A system of assumptions, beliefs, and values created by a society that frame how a family should respond to a caregiving situation and who is expected to be the caregiver, especially females.	Paoletti, 2002
	Kirsi, Hervonen, & Jylah, 2000
	O'Connor, 1999
Extension of Former Role Caregiving is seen as a normal and natural part of being a spouse/partner or child.	Montgomery and Kosloski, 2012
	Goldsteen, Abma, Oeseburg, Verkerk, Verhey, & Widdershoven (2007)
	Karner & Bobbitt-Zeher, 2006
	Henderson, 2001
	Golden, 2005
Master Identity When the caregiver role becomes the dominate identity, replacing or overtaking any other important identity.	Skaff & Pearlin, 1992
	Dickson, O'Brien, Ward, Allan, & O'Carrol, 2010

Role engulfment and losing self. Role engulfment and losing self occurs when the role of caregiver and responsibilities of caring begin to consume a person, leaving

little time for other activities and behaviors that may have defined the person previously. The individual's identity gradually comes under pressure as the caregiver role intensifies. Individuals do not just gain a new identity as caregiver, but see previous identities fade away or become less relevant because of caring responsibilities.

Heward, Gough, & Molineux (2011) found in their study of partners of individuals with multiple sclerosis (MS) that identities were reshaped by the loss of former roles and the development of new roles. Respondents previously defined themselves as homemakers, part of a parenting team, or breadwinners and were now struggling with "running the home independently and, in some cases, acting as sole parents and "carers" while also providing financially for the family" (p. 27). This finding suggests that as the caregiver role intensifies, former identities began to erode.

O'Connor (2007) believes that initially caregiver identity is grounded within the bounds of the familial relationship but gradual, deterioration of their loved one prompts them to reconsider their identity. At first, most caregivers are too busy to "reflect upon their role" (p. 168) but recognition that he/she has taken over leads to the notion that he/she is a caregiver.

In a case study involving a female adult child caring for her parents, Sherrell, Buckwalter, & Morhardt (2001) briefly discuss the caregiver's 'age-role' identity and how no longer seeing her "parents as protectors, but rather as needing protection, they(she) must shift their(her) own identity…" (p. 387). This analysis of the caregiver's interview indicates caring for your parents can cause a shift in the way a person sees his/her parent which can impact the caregiver's identity.

Furthermore, Burton (2006) found when caregivers begin to care, they struggle with their own new role as well the role of social services and the person they care for. Their inexperience and the "cumulative effects of increasing isolation, additional responsibilities and the loss of the person's abilities…." (p. 500), make adjusting to their new role challenging. Many participants focused on "what they had given up to be a carer" (p. 500) and wished to maintain the life they had together before caregiving.

In their qualitative study with family caregivers of elderly parents, Miller, Shoemaker, Willyard, & Addison (2008) found that there were two structures that factored into the development of the participants caregiver identity. The first was the parent-child structure. The respondents discussed role reversal and having to "parent their parent". They drew upon "memories of their own childhood and of their experience in raising children in constructing their identities as caregivers" (p. 36). The second was the competence structure. The respondents expressed a "had to be done" attitude regarding caregiving. For most of the respondents, they were the only ones competent enough to be the caregiver and do it right. They spoke of having to play multiple roles including banker, physician, shopper, driver, chef, etc. to complete care tasks, often at the expense of their paying jobs. These two structures suggest that individuals perform a myriad of tasks that engulf them and often make them feel more like the parent than the child.

Loss of shared identity. As mentioned previously, many caregivers have a prior relationship with the care recipient. A person may have an identity based on that relationship or being part of a couple (i.e. "us" or "we" rather than "I"). This shared

identity is often referred to as “dyadic identity”. This identity cannot function or continue without the other person. For example, to be a daughter, you have to have a mother or father. If you lose one or both parents, what happens to your identity as a daughter? Caregiving often forces changes in well-established patterns of interactions which impact how that person sees him/herself in that pair. *Loss of shared identity* consists of changes to a person’s dyadic identity because the dyad is diminishing or lost.

Coeling, Biordi, & Theis (2003) attempted to conceptualize a dyadic identity and how caregivers and care recipients negotiate the dyad’s rules that influence how caregiving fits with their current relationship. This process involves joint decision-making based on long-established patterns of negotiation between the caregiver and care recipient. Various factors, such as learning the rules, ease of negotiation, and the need for renegotiation effects how dyadic structuring occurs. The process and results of this negotiation lead “to a mutually accepted identity” (p. 24).

Shared identity emerged as a major theme in the interpretation of caregiver narratives in a study by Hasselkus & Murray (2007). They propose that chronic illness (in this study, dementia) “caused disruption in their(caregiver) lives and forced major changes in their daily routines and ways of viewing their selves” (p.16). Interruptions in former patterns of interaction and reciprocity between the caregiver and the care recipient caused changes in the “caregiver’s biographical self that was embedded in the shared identity” (p. 16).

Orona (1990) suggest that being a member of a caregiver-care recipient dyad is a core category in understanding identity. Caregivers question their shared identity when

tremendous changes brought on my dementia, occur to their loved one. Orona identifies several themes related to identity loss including social structure, reciprocity, and temporality. *Social structure* is related to the multiple roles a person has and how identity may be different in each situation. Eventually, caregiver becomes the primary role and can impact each of the other identities. *Reciprocity* pertains to the contribution that each person makes in the relationship. This occurrence maintains and transforms the other's identity. Eventually, a care recipient may no long be able to reciprocate. Orona specifically addresses *temporality* by discussing the shared history, memories, and biographies that accompany relationships. The loss of the person's ability to participate in these shared experiences leads to an identity transformation.

Hayes, Boylstein, & Zimmerman (2009) examined identity changes of the care recipient due to dementia and how these changes alter how their spouses identify themselves within their marriage. Due to the loss of cognitive functioning, many spouses report diminished intimacy, feelings of closeness, and reciprocity. The changes in the person with dementia threaten their spouse's own sense of self. Wives are more likely than husbands to report that "perceived changes in impaired spouses' identity altered how they identified themselves in relation to their spouse, shifting from a wife and lover to a mother or constant provider" (p. 5).

Adams (2002) identified four forms of story within informal caregiver's accounts of caring for a loved one with dementia including pre-onset stories, recognition stories, searching stories, and dependency stories. More than stories, these are memories with special significance that demonstrate a strong connection between the caregiver and care

recipient. *Pre-onset stories* were references to whom or what the person was like before they had dementia. *Recognition stories* were related to early symptoms of dementia and how the caregiver recognized their loved one had dementia. *Search stories* pertain to the caregiver's efforts to "find out what was happening to their relative" (p. 247). Finally, *dependency stories* allow for the caregiver to describe the increasing dependency of their loved one. These stories allow for inference about the identity development process of caregivers and suggest that the shared relationship between the dyad is a significant factor.

Family obligation and gender norming. Family obligation and gender norming is rooted in societal expectations of role obligations and perceived moral expectations. Society has created a system of assumptions, beliefs, and values that frame how a family should respond to a caregiving situation and who is expected to be the caregiver. Females rather than males are often expected to take on the responsibility of caring because they are perceived as the more gentler and compassionate of the two genders.

O'Connor (1999) found that the responsibility of providing care to a spouse or significant other is assumed and related to being a "good" husband/wife/partner. If anyone challenged this expectation, he/she would be perceived as unloving or selfish by society. For most participants, the belief was "so strong that it generally went without question; 'of course' one assumed responsibility for overseeing the care needs of one's spouse…." (p. 218). This belief was particularly true for women, who O'Connor believes are socialized to care and to be concerned about the well-being of others.

From a feminist perspective, Paoletti (2002) proposes that caregiving is a gendered practice, furthermore, caregiving is a “central aspect of gender identification” (p. 808). Caregiving develops in relation to pairs, such as father-daughter, husband-wife, etc. which is clearly related to the reason for taking up cargiving duties. Many of the participants construct caregiving as a feminine practice. Caring is not something that the males of the family cannot do or will not do, but the expectation that they will does not exist. This finding suggests that caregiving is closely related to gender identity.

Gender was of particular interest to Kirsi, Hervonen, & Jylha's (2000) study of male caregivers caring for their spouse. Kirsi and colleagues examined “stories of himself as a caregiver and as a man”. Participants report a masculine obligation to care for their unwell wives with references to wartime and having to perform domestic duties, a traditionally female task. These findings hint that perceptions of “female and male ways of caregiving” (p. 159) exist.

Extension of former role. Similar to family obligation and dyadic identity, the *extension of former role* theme is related to societal expectations and relationships. Caregiving is seen as a normal and natural part of being a spouse/partner or child. In this situation, individuals do not feel obligated per se, but the act of caring is normalized and accepted in the current relationship.

Montgomery & Kosloski (2012) state that over time, “caregivers not only change their behaviors, but they also change the way they see their role in relation to the care recipient- that is, their role identity” (p. 136). They outline this process by identifying five possible “phases of accommodation” (p. 143). Phase one is the period of role onset

and occurs when the caregiver begins performing caregiving activities. Caregiving is a small portion of their relationship. The caregiver is rarely has awareness of their caregiver identity. Phase two begins when the caregiver realizes that his or her caregiving activities are beyond the scope of the initial family role. Caregiving is approximately 25% of the relationship. Identification as a caregiver starts to develop. Phase three occurs when the caregiver realizes that his or her caregiving activities are significantly beyond the scope of the initial family role. Caregiving now accounts for approximately 50% of the role relationship. This shift begins a true identity negotiation as the caregiver struggles with his/her initial identity and the new caregiver identity. Phase four continues to see an increase in care needs and a solidification of the caregiver identity. Caregiving now dominates the role relationship. Phase five is reached when the caregiver turns over primary responsibility for care to formal care providers (ie nursing home placement). Caregiving retreats back to 25% of the relationship. The caregiver may retain his/her caregiver identity or shift back to his/her primary identity.

Karner & Bobbitt-Zeher (2005) describe caregiving as a shift in identities and reconstructed relations. They suggest that when caregiving tasks are associated with their ongoing role as spouse or child, the individual may not identify oneself as a caregiver. When the care recipient is "unable to perform their previous role of spouse or parent, they can no longer meet the interactive expectation of their partner or child to maintain the relationship" (p. 13), and caregiver identity can develop.

Moreover, Goldsteen and colleagues (2007) provide a framework for caregiver identity development through normative expectations and ideas about responsibility.

They tell the story of a woman who is the caregiver of her mother and her identity shift from “daughter” to “caregiver”. In the beginning she resists being labeled a caregiver but as the situation with her mother gets worse and professional caregivers are not of assistance, her identity as a daughter changes and she is redefined.

In her dissertation, Golden (2005) examines the construction of identity in a support group, emphasizing how group members “position themselves, how other group members respond to those position, and the implication of positions.” (p. 44). Support groups confirm or deny a caregiver’s positioning of himself through the sharing and conversations that occur in open forums like a support group. Findings suggest that caregivers construct identity in relation to their spouses. "Spouse" and "caregiver" are simultaneously interacting identities- the identity of "caregiver" is rooted in the "spousal" relationship. In support groups, group members can be subjective “spouses” and objective “caregivers”.

Additionally, Henderson (2001) proposes that care takes place within relationships. In particular, caregiving involves a “process of negotiation and re-negotiation between partners” (p. 150). Unfortunately, the agreement between the caregiver and care recipient can be called into question when “…professionals assume that someone’s partner is their carer” (p. 155). ‘Caregiver’ may be an identity some aspire to be but for others an identification of caregiver “bears no similarity to their own construction of their role within a partnership” (p. 155). The findings suggest that the label of caregiver is negotiated between the couple and that the label is sometimes prematurely placed by professionals on the person without readiness or acceptance.

Master identity develops. As seen in role engulfment and losing self, caregivers are often consumed by their responsibilities. This engulfment can lead to the loss of other identities and the prevailing identity becoming "caregiver" which would fit with Hughes' (1945) "master status" or "master identity" theory mentioned previously. *Master identity develops* when the caregiver role becomes the dominate identity, replacing or overtaking any other important identity.

According to Skaff & Pearlin (1992), caregiver identity develops as a result of the loss of self and role engulfment. In their study, "...caregivers essentially expressed the sense that the only identity left to them is that of caregiver" (p. 658). In this context, caregiver self-identification is not so much a process of development but the result of "the main or sole surviving context for self-evaluation" (p. 658).

Dickson, O'Brien, Ward, Allan, & O'Carroll (2010) examined spousal caregiver's understanding of what it is to live with an individual with a spinal cord injury (SCI). Participants reported that "duties and responsibilities that they felt obliged to perform often prevented them from being able to engage in activities that they wanted or would choose to participate in" (p. 1112) such as taking a nap or getting a meal. The caregiver role claimed the vast majority of their time and left no time to partake in that activities that once defined her his/her sense of self. Many of the participants stated that their only value was as a caregiver and that "assuming the role of partner caregiver, resulted in them becoming 'invisible' to other people- that their well-being became secondary to that of their injured partner" (p. 1112). This statement indicates that the new role as caregiver has altered the way in which they as well as others perceive them.

Discussion

The aim of the literature review was to examine factors related to caregiver identity, to identify major conceptual and theoretical foundations for caregiver identity development, and to report on the findings with regard to their contribution to an instrument to measure caregiver identity. The results are discussed according to the research questions- 1) What factors are related to caregiver identity development? and 2) How does caregiver identity develops?

What factors are related to caregiver identity development? The literature indicated several factors related to caregiver identity construction including role engulfment and losing self; loss of shared identity; and family obligation and gender norming. It is not surprising that roles and responsibilities is a significant factor related to caregiver identity development. The sheer amount of responsibilities and time commitment leaves little time or energy for other activities that may shape a caregiver's identity. This rational contributes greatly to our understanding of "master" identity and provides a theoretical framework for how caregiver identity develops.

It is not unexpected that a shared identity and familial ties were contributing factors to caregiver identity development. As previously mentioned, the majority of informal caregivers are family members. Caregivers most often are aiding a parent or spouse (National Alliance for Caregiving & AARP, 2005). An existing reciprocal relationship with established obligations and expectations as spouse or child is probable. Each participant has an understanding of who the other is and agreed upon patterns of interaction. Shared identity and familial ties are central to identity.

How does caregiver identity develop? Findings suggested that there were several pathways for caregiver identity to develop. The first is as an extension of the former role and the second is through social interactions between the caregiver and others.

Given the aforementioned shared identity and familial ties, caregiving as a systematic process of identity change in which the caregiving role emerges out of an existing relationship is logical. Caregiver identity slowly develops as the needs of the care recipient increases in quantity and intensity and the previous relationship becomes less familiar.

Most of the literature sources referenced that identity is socially constructed. Individuals may be unaware of the label but through interactions with others, they develop an awareness and eventual identity related to caregiving. McCall and Simmons (1978) suggest that people seek legitimization of their identity. One's identity will be validated or invalidated through interactions with others. When the identity is invalidated, the person will re-evaluate and possibly change their identity. Even in Henderson's (2000) finding that prematurely placing the caregiver label on someone was distressing for some, the occurrence prompted others to reconsider their identity and adopt the caregiver identity.

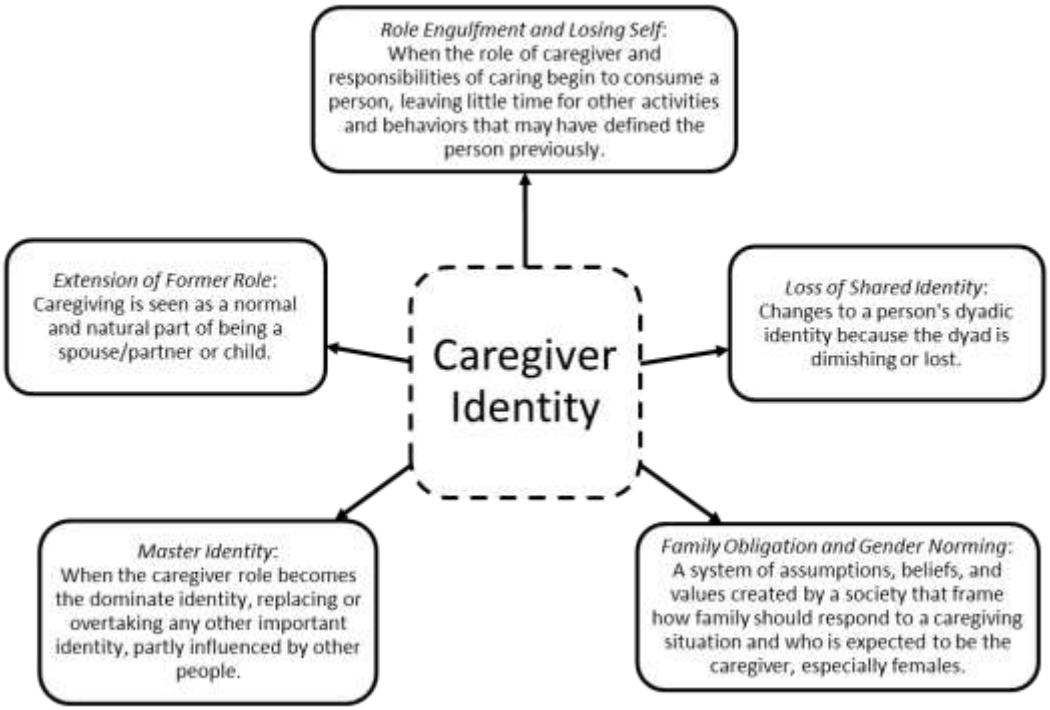
Theoretical Framework

Drawing upon the factors related to caregiver identity found in the literature, a theoretical framework was created (Figure 1). The theoretical framework explains the

key factors, concepts, or variables related to caregiver identity. The theoretical framework informed and guided the development of the *Family Caregiver Identity Scale*.

Figure 1.

Theoretical Framework to Explain the Key Factors Related to Caregiver Identity



CHAPTER III

METHODS & RESULTS

This chapter describes the research methods and results of the instrument development process for this study. It reviews the study purpose and aims followed by the study design, instrument development procedures, description of the sample, data collection, statistical treatment for pilot testing, and other study logistics. In addition, the chapter includes the results of each instrument development step. Because the study design included sequential steps where each step was based on the results of the prior step, the methods and results are reported in a combined chapter.

Study Purpose and Aims

The purpose of the present study was to develop and validate the Family Caregiver Identity Scale (FCIS), an instrument designed to measure the extent an individual identifies with the family caregiver role. The first study aim was to identify the domains that influence caregiver identity. The second study aim was to create a pool of items that can measure the theoretical domains of caregiver identity. The final study aim was to pretest these items to develop a valid and internally consistent instrument that measures family caregiver identity. The study was approved by the University of North Carolina at Greensboro's IRB and was exempted from full board review.

Study Design

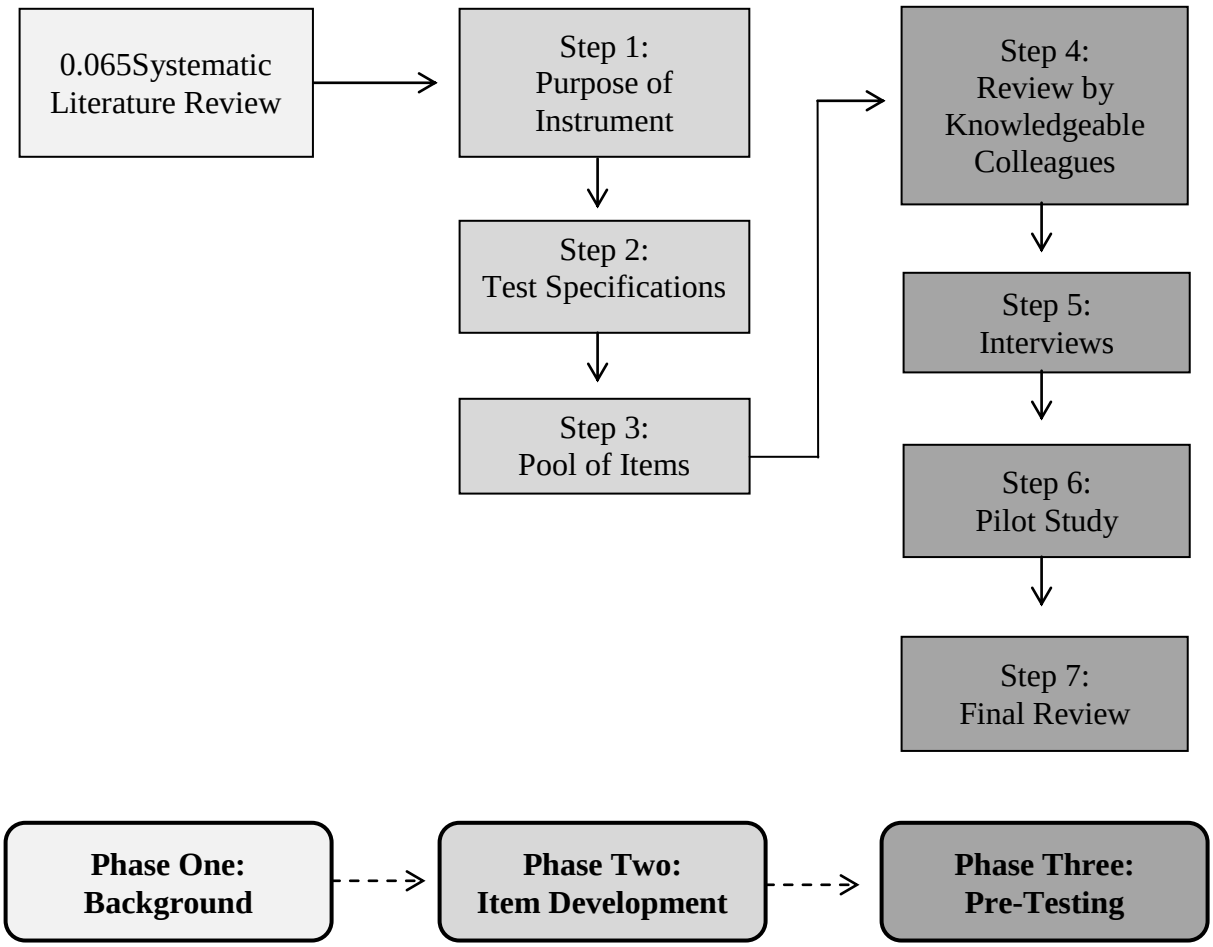
The steps to develop and validate the FCIS consisted of three phases and seven steps. *Figure 2* outlines the framework that was followed. The foundation for the instrument development process was theory-driven and based on the results of a systematic literature review which found five factors related to caregiver identity (Phase One). These five factors were; 1) role engulfment and reversal; 2) loss of shared identity; 3) family obligation and gender norming; 4) extension of the former role; and 5) development of a master identity. These findings provided the basis for the domains to be measured by the FCIS.

The development of the FCIS was guided by the *Standards for Educational and Psychological Testing* [American Educational Research Association (AERA), American Psychological Association (APA), and National Council on Measurement in Education (NCME), 1999], and Dillman's (2000) stages of pretesting. The *Standards for Educational and Psychological Testing*, also referred to as the *Standards*, provide criteria for the development of instruments used for measurement and testing. For this study, the *Standards* provided the guidelines for item development (Phase Two) including, develop the purpose of the instrument (Step 1), test specifications (Step 2), and a pool of items to measure one of the five domains of caregiver identity (Step 3). The items that resulted from Steps 1-3 of the study were pretested using Dillman's (2000) four stage process (Phase 3). Dillman's sequential stages include 1) review by knowledgeable colleagues and analysts (Step 4); 2) interviews to evaluate cognitive and motivational qualities (Step 5); 3) a small pilot study (Step 6); and 4) final review (Step 7). The methods included in

this instrument design framework are accepted practice in the health promotion field (Dilorio, 2005; Streiner & Norman, 2008).

Figure 2.

Framework to Develop and Validate the FCIS



Step 1: Purpose of Instrument

The first step of instrument design is to describe "the extent of the domains, or the scope of the construct(s) to be measured" (AERA, APA, & NCME, 1999, p. 37). For the *Family Caregiver Identity Scale*, domains to be measured were based on a systematic literature review that examined the literature related caregiver identity and identified influential factors on the development of caregiver identity. Five domains- role engulfment and reversal; loss of shared identity; family obligation and gender norming; extension of the former role; and development of a master identity- emerged from the literature (Chapter 2). They are listed and described in Table 2. These domains provided the instrument content and item objectives.

Table 2.

Constructs and Descriptions to be Measured in the Family Caregiver Identity Scale

1	**Role Engulfment and Losing Self**	When the role of caregiver and responsibilities of caring begin to consume a person, leaving little time for other activities and behaviors that may have defined the person previously.
2	**Loss of Shared Identity**	Changes to a person's dyadic identity because the dyad is diminishing or lost.
3	**Family Obligation and Gender Norming**	A system of assumptions, beliefs, and values created by a society that frame how a family should respond to a caregiving situation and who is expected to be the caregiver, especially females.
4	**Extension of Former Role**	Caregiving is seen as a normal and natural part of being a spouse/partner or child.
5	**Master Identity**	When the caregiver role becomes the dominate identity, replacing or overtaking any other important identity, partly influenced by other people.

Step 2: Test Specifications

The second step in the process was to determine the test specifications. According to the *Standards* (1999), "test specifications delineate the format of items, tasks, or questions; the response format or conditions for responding; and the type of scoring procedures" (p. 38). Test specifications contribute to improved reliability and validity of the assessment instrument and, therefore, must be developed deliberately and thoughtfully. The best format and design of items in the *Family Caregiver Identity Scale* was determined to be a continuum from completely agree to completely disagree because identity is a subjective state (Fowler, 1995). Participants were provided statements and asked to rate their level of agreement.

Additionally, issues of fairness and bias were examined during item construction. Items were intentionally created to lessen the likelihood of differences in measures and outcomes for respondents, regardless of gender, race, ethnicity, or any other characteristic or group membership. These issues are of particular importance due to well documented differences between male and female caregivers (Bedard et al., 2005; Pinquart & Sorensen, 2006), between caregivers of color and white caregivers (Navaie-Waliser et al., 2001; Pinquart & Sorensen, 2005), and between spouse and adult-child caregivers (Conde-Sala et al., 2010; Savundranayam, Montgomery, & Kosloski, 2010). In a later step, a panel was assembled to review instrument items and ensure content appropriateness. Furthermore, construct validity was examined during pilot testing in a later stage.

Step 3: Pool of Items

An item pool was compiled based on steps one and two and following Dillman's (2000) criteria for assessing survey questions. According to Dillman (2000), the goal of writing questions is to "develop query that every potential respondent will interpret in the same way, be able to respond to accurately, and be willing to answer" (p. 32). Initial items were created and intended to represent one of the five domains of caregiver identity development (Table 2). Items that measure the same domain were categorized together to create subscales and a table of specifications was created (Appendix A). A table of specifications classifies each item according to what domain it measures and can improve content validity (Fives & DiDonato-Barnes, 2013). Forty-seven items were created. A large pool of items was intentionally generated to address all of the domains with the knowledge that some items would not survive the pre-testing in the following steps.

Step 4: Review by Knowledgeable Colleagues and Analysts

Following the development of the pool of items, a group of individuals with various areas of expertise were asked to review the forty-seven items to obtain face validity and content validity. Items were entered into a Qualtrics survey and experts were provided with the link to complete the review. Experts examined items for clarity, strength, and precision. *Item Clarity* referred to the item's readability and logic. *Item Strength* referred to the item's quality including avoidance of bias, complexity, or insensitivity to groups of test takers. *Item Precision* referred to the item's articulation with the theoretical model constructs. To determine item clarity, strength, and precision, experts responded on a 5-star rating system: 1 star meaning *Very Poor*, 2 stars meaning

Poor, 3 stars meaning *Fair,* 4 stars meaning *Good,* and 5 stars meaning *Very Good*. Experts were also able to make a determination on item inclusion. *Item Inclusion* referred to the item being included in or removed from the instrument. To determine item inclusion, experts responded "yes" if he/she thought the item should be included or "no" if he/she thought the item should be removed. Experts also had a text box where he/she could provide any feedback, suggestions, or comments on the item. Furthermore, the expert panel had an opportunity to provide feedback on the format of the FCIS (likert & statement respond), scoring of the FCIS (summing across scores), and weighing of constructs (each construct is weighed equally). The FCIS review by knowledgeable colleagues took approximately 15 to 30 minutes to complete.

The members of the expert panel were recruited because of their "experience with previous surveys and knowledge of study objectives" (Dillman, 2000, p. 141). The panel consisted of professionals with various backgrounds and expertise from the University of North Carolina at Greensboro (UNCG) and across the country. Efforts were made to include the authors of published literature in the area of caregiver identity and experts in gerontology, in general. Additionally, experts in survey and instrument development were asked to participate. Eleven (11) experts were emailed an invitation to participate in the FCIS review. Eight (8) experts accepted the invitation and were emailed the link to the Qualtrics survey and an outline of the instrument content that included the purpose of the FCIS, theoretical framework, and descriptions of each domain to be measured.

Analysis of the Review by Knowledgeable Colleagues and Analysts

Upon completion of the review by all eight expert panel members, the Qualtrics survey was closed. Data was downloaded into an SPSS data set for analysis. Intra-class correlations (ICC) were performed to determine the level of agreement between experts (Hallgreen, 2012). Due to the lack of variability among experts, ICC results were not obtainable. A new strategy to reduce the item pool was developed. The criteria for deleting an item involved a systematic examination of the responses of the panel members. Means were calculated using SPSS. First, the responses of "should this item be included" were examined. If the majority (60% or above) indicated "no", the item was deleted. If the majority indicated "yes", the ratings of precision, strength, and clarity were examined. Items were considered for inclusion if the mean value of the expert ratings were 4.00 or above ("good" or "very good") on any of the three scales. If the mean value of the expert ratings fell below 4.00 ("very poor", "poor", or "fair"), the qualitative comments from the reviewers was assessed. If the item could be improved based on the feedback from the reviewers, the item was modified and included in the instrument. If the issues identified in the feedback could not be addressed or extensive modification of the item was required to adequately address the issues identified in the feedback, the item was deleted.

Results of the Review by Knowledgeable Colleagues and Analysts

The results of the expert review revealed that 14 of the items should not be included; reducing the item pool from 47 to 33. Twenty-three of the remaining 33 items did not meet the standards for precision, strength, or clarity and were examined for

modifications to improve the item based on feedback from the experts. Twelve items were determined to have issues that could not be addressed properly or were redundant; further reducing the item pool from 33 items to 21 items.

Upon compilation and review of the 21 items, it was determined that key dimensions of two constructs were not being measured due to the elimination of certain items. To address this issue, deleted items were reexamined. It was found that one of the items from *Family Obligation and Gender Norming* had been automatically removed due to inclusion criteria; however, the experts thought the item was important, just poorly written. Based on the panel's feedback, the item was rewritten and added back to the item pool, increasing the total number to 22. Two new items were created- one for *Family Obligation and Gender Norming* and one *for Extension of a Former Role*. These items were based on deleted items and feedback from the panel to fill the gap missing from the pool of items. This addition raised the pool of items to 24. Finally, it was found that one of the items removed from *Extension of Former Role* was due to the item measuring the wrong theoretical construct. It was added back to the item pool but moved to *Loss of Shared Identity*. The final item pool recommended by the knowledgeable colleagues resulted in a 25-item instrument including *five* items to measure the construct *Role Engulfment and Reversal*; *five* items for *Loss of Shared Identity*; *five* items for *Family Obligation and Gender Norming*; *five* items for *Extension of the Former Role*; and *five* items for *Development of a Master Identity*.

In addition to the item pool, the majority of the panel agreed that the proposed format of the FCIS was appropriate (100%, N=7), scoring of the FCIS was effective

(86%, N=7), and weighing of constructs equally was appropriate (83%, N=6). However, in the final comments section, one reviewer recommended the removal of the "neutral/uncertain" option from the agreement scale to force participants to respond. This change was made to the instrument. No changes were done to the planned scoring structure or construct weighing.

Finally, feedback from the panel suggested that participants may have difficulty with certain phrases used in several items. First, the phrase "loved one" was used to refer to the individual the person may be caring for. Attention was brought to the fact that just because a person is caregiving and they are family, they may not actually "love" the individual. Therefore, "loved one" was changed to "family member" and a description of what is meant by family was added to the beginning of the instrument. Second, the phrase "caring for" was used to refer to the actions of the caregivers. This phrase can be interpreted more as a feeling rather than an action. "Caring for" was changed to "providing care" throughout the instrument and a description of "providing care" was added to the instrument.

Step 5: Interviews with Family Caregivers

Step five involved conducting cognitive interviews with family caregivers to detect serious problems with individual items and the overall instrument. Caregivers were given a preliminary version of the FCIS and asked to complete it. Caregivers were instructed to read each item of the FCIS out loud and then to articulate or verbalize their thoughts when responding. This process provided an "understanding of how each question is (was) being interpreted and whether the intent of each question is (was) being

realized" (Dillman, 2000, p. 142). Concurrently, questions designed to elicit further information from the caregiver were asked by the interviewer. The probes were scripted as well as spontaneous and only done for clarification. The purpose of the verbal probing was to find out more about a particular aspect of the question-response process.

This type of interviewing explicitly focuses on the cognitive processes that the caregiver uses to answer questions and "has emerged as one of the more prominent methods for identifying and correcting problems with survey questions" (Beatty & Willis, 2007, p. 287). In theory, there are four actions that individuals take when responding to a question. They must 1) comprehend the question, 2) retrieve information related to the question, 3) make a judgment as to the information's relevance and accuracy as a response, and 4) respond to the question (Willis, 1999). Because this process is all done in the respondent's head, the interviewer cannot precisely understand how a person comes to their response. Using the think aloud method and verbal probing, as was done in this step, provides useful insight into the respondent's interpretation and decision-making processes. The cognitive interviews contributed to both the validity and reliability of the FCIS by providing feedback related to relevancy and clarity of items (Willis, 2005).

Sampling for the Interviews with Family Caregivers

According to Willis (2005), cognitive interviewing should be done with a small number of participants similar to those targeted in the final instrument. Therefore, the inclusion criteria included (a) English speaking (b) informal caregivers who (c) live in North Carolina, and (d) are currently or recently have been in long-term caring situations

with a family member over the age of 18 who has a chronic illness. Additionally, each participant had to identify him/herself as a caregiver, suggesting a strong caregiver identity has already formed. The sample size was ten (10) family caregivers (Fowler, 1995).

Recruitment of Family Caregivers to Interview

The study was conducted in partnership with local organizations that provide support services to family caregivers in North Carolina. These organizations were good places to recruit individuals who have strong caregiver identities because they have been caring for an extended period of time and sought support from the organization. The directors of these community organizations identified individuals who meet the inclusion criteria for cognitive interviewing. Potential participants were provided information about the study and asked to contact the principal investigator if he/she was interested in participating. Upon making contact, the cognitive interview process was explained and participants were screened for eligibility. If they meet the requirements and were interested in participating, a convenient time and location for cognitive interviews was set. To increase participation, gift certificates for $50 to local grocery stores or pharmacies were given to each person who completed a cognitive interview.

Analysis of the Interviews with Family Caregivers

All interviews were audio recorded. Additionally, notes were taken during each interview to record quotes and issues as the participant was talking. Because the intent of the interviews was to elicit data that could be used to evaluate the 25 items for relevancy and clarity, each item and not the actual caregiver was the unit for analysis. For this

reason, conventional transcription of the interviews was not done. Rather, recordings and notes were reviewed and summarized by each item. A document was created that listed the items. Under each item were verbatim quotes of respondent's interpretation of the item and any other relevant comments made regarding the item. Additionally, pertinent interviewer notes were listed.

Some background information regarding the caregiver was considered to understand responses in context of the caregiver's age, racial/ethnic identity, relationship to care recipient, and assistance from others in providing care. This contextual information was helpful in assessing the appropriateness of items for different caregivers. When a particular item presented contrarily among the caregivers interviewed, a possible relationship between the problematic aspects of the items and the characteristics of the caregiver or his/her situation was examined.

Analysis entailed examining the summarized data for each item in its entirety. The information was used to assess individual items and the instrument as well as a guide for decisions about keeping, deleting, or modifying items.

Results of the Interviews with Family Caregivers

The cognitive interviews led to the revision of multiple FCIS items. A review of the summaries resulted in 25 changes total. The majority of changes were minor and related to writing errors, grammar, or inconsistent usage of word or phrase throughout instrument. Several items had a word altered or small phrase added. Among the major changes, was the alteration of two questions due to poor word choice. Item #8 originally contained the word "obligated". The majority of interviewed caregivers expressed

displeasure over the word. To address this issue, the item was slightly modified in a way to appropriately capture the item's original intent. Similarly, Item #9 originally contained the word "responsibility". This word choice also caused unease by the majority of caregivers. To address this issue, the item was slightly modified in a way to appropriately capture the item's original intent. Finally, all interviewed caregivers completely disagreed with the item related to reminiscing with their ill family member. This outcome suggested that the item was not appropriate or did not capture the domain as intended. This item was kept in the final pilot study pool to confirm its unsuitability. It may be removed in the next step if it is found not to load onto the proper factor. Overall, the majority of items remained the same. A final instrument of 25 items, which was divided into five scales (domains of caregiver identity development) with five items each, resulted and was used in pilot testing during the next step.

Step 6: Pilot Study of the FCIS

The pilot study involved formally testing the FCIS (Appendix B) and was a critical step in the pretesting phase. This step involved simulating the actual data collection process on a smaller scale to further refine the instrument. Furthermore, the step was used to assess the adequacy of instructions to participants and ascertain instrument completion times. The result of the pilot study was used to provide a 'preview' of the results of the FCIS and to make additional revisions.

Sampling for the FCIS Pilot Study

According to Hertzog (2008), pilot testing with a newly developed instrument should be done with a large sample size to estimate internal consistency. Therefore, the

target sample size was five hundred (500). Eligibility was limited to (a) English speaking (b) North Carolina residents to ensure a diverse sample of caregivers and non-caregivers. Participants were excluded if they were currently or have ever been a paid caregiver to make sure the sample was not convoluted by different caregiver experiences.

Recruitment of Subjects for the FCIS Pilot Study

The study was conducted in partnership with local organizations that serve older adults or who provide support services to family caregivers in North Carolina. These organizations were good places to recruit a variety individuals including those who have yet to begin their caring careers, to those just beginning, to those who have been caring for a loved one for 10 years. A variety of recruitment strategies were utilized. Flyers were posted in each organization's building. A request for participation was placed in each organization's bulletin. Additionally, participation was solicited at appropriate events or services. Finally, a link to an online version of the FCIS was sent through the organizations mailing list/listserv so individuals could complete the instrument electronically.

In addition to utilizing local community organizations, snowball sampling was conducted via a variety of social media outlets. The link to the online Qualtrics FCIS was posted on the author's personal Facebook and Linkedin accounts and emailed to her entire contact list. The author's social and professional network was encouraged to complete the FCIS and share the link with their networks.

All potential participants were informed about the requirements and the risks and benefits of participating. Each individual interested in participating, was screened for

eligibility and provided with a consent form. If eligible, the participant completed the FCIS on the spot. If a participant could not complete the FCIS at the current time, he/she was encouraged to take the instrument home and return it upon completion to the local organization or mail it directly to the researcher. An envelope and postage was provided. To increase participation, each person who completed the FCIS was entered into one of five drawings for $100 gift certificates to local grocery stores or pharmacies.

Analysis of the FCIS Pilot Study

All data was entered into an SPSS data base. Descriptive statistics were calculated on demographic variables to determine frequencies. Confirmatory factor analysis (CFA) using M*plus* (Muthén & Muthén, 2004) was performed to evaluate the hypothesized-five factor structure of caregiver identity development formed in Phase One and to assess the validity of the 25-item instrument. CFA, a common form of structural equation modeling (SEM), is a theoretically driven analytic procedure used to analyze the relationships between latent and observed variables (Brown, 2006). The CFA process entails specifying a model by defining factor structures and characterizing the relationship between latent and observed variables, followed by testing to see if the data fits the model.

Performing CFA is common practice in validating psychometric tests and determining whether a psychometric tool measures what it claims to measure (Brown, 2006). In particular, CFA is commonly used for construct validation. Construct validation examines the relationships among unobserved and theoretical constructs. Determining construct validity requires specifying hypotheses about how the measure is

related to other measures based on theory. In this case CFA was used to determine the construct validity of the 25 items developed in the previous steps by verifying the pattern of factors and loadings that were suggested in the theoretical framework.

For analyses, robust weighted least squares (WLSMV) was selected as the estimation method. WLSMV is only available in the Mplus program and has the best options for handling categorical data. Given the Likert format of items and the relatively small number of scale points (e.g. completely agree, generally agree, generally disagree, completely disagree), it was decided that data should be treated as categorical, rather than continuous (Flora & Curran, 2004). This decision was done to address certain underlying assumptions regarding normal distribution and equal distance between scale points. A critical assumption associated with SEM is that the data are normal distribution and do not have significant skewness or kurtosis. If measures suggest significant deviations, it is reasonable to assume that the data come from a non-normal population which can cause over-rejection of adequately fit models (Flora & Curran, 2004). Although normal distribution is not a necessary for WLSMV, multivariate normality was evaluated before CFA analyses were undertaken. None of the items showed signs of skewness; however, one item (FaOblg5) showed evidence of kurtosis. This finding was determined to be an insignificant factor and the item was left in the model.

In this study, the purpose of performing CFA was twofold. First, CFA was used confirm the theory of caregiver identity development. Each of the 25 items (observed variables) was carefully developed to represent one of the five domains (latent variables) of caregiver identity development. The CFA determined if items loaded onto the

appropriate construct. Second, CFA was used to determine if instrument refinement was needed. Alternative factor structures were explored and items that did not contribute significantly to the model were removed to get a better fitting model and subsequent stronger instrument.

Results of the FCIS Pilot Study

Table 3 provides the demographic characteristics of the sample. Participants consisted of 513 predominately Caucasian (77%) females (77%) over the age of 45 (74%). Over half (52%) of the sample were working full-time with a total household income over $75,000 (29%). The majority of the sample had a family size under 10 (62%) and a household size of 1 to 2 (64%). Approximately two thirds of the sample (68%) identified themselves as caregivers. Table 4 provides characteristics of the self-reported caregivers. The majority of caregivers were providing care to a parent (47%) for five or more years (30%). Almost 60% were the person *most* responsible for providing care while only 21% were the *only* person responsible for providing care.

Table 3.

Characteristics of Pilot Study Participants (N=512)

		N (%)
Gender	Female	396 (77%)
	Male	99 (19%)
	Missing	17 (3%)
Age	Under 30	23 (4%)
	30-44	92 (18%)
	45-64	226 (44%)
	65 or older	155 (30%)
	Missing	16 (3%)

Race/Ethnicity	Asian or Pacific Islander	9 (2%)
	Black/African American	66 (13%)
	Caucasian/White	396 (77%)
	Latino or Hispanic	11 (2%)
	Native American	5 (1%)
	Other	4 (1%)
	Missing	20 (4%)
Employment Status	Full-time	264 (52%)
	Part-time	50 (10%)
	Retired	139 (27%)
	Out of work or unemployed	19 (4%)
	Other	20 (3%)
	Missing	19 (4%)
Household Income	Less than $24,999	57 (11%)
	$25,000 to $49,999	143 (28%)
	$50,000 to $74,999	135 (26%)
	$75,000 or greater	150 (29%)
	Missing	26 (5%)
Family Size	Under 5	161 (31%)
	5 to 10	157 (31%)
	11 to 15	92 (18%)
	16 or greater	82 (16%)
	Missing	19 (4%)
Household Size	1 to 2	328 (64%)
	3 to 4	136 (27%)
	5 to 6	27 (5%)
	7 or greater	3 (<1%)
	Missing	18 (4%)
Caregiver Status	Yes	346 (68%)
	No	149 (29%)
	Missing	17 (3%)

Table 4.

Characteristics of Caregivers (N=346)

		N (%)
Relationship to Care Recipient	Spouse/Partner	75 (22%)
	Parent	162 (47%)
	Other	106 (31%)
	Missing	3 (<1%)
Length of Time Providing Care	Less than a year	66 (19%)
	1 to 2 years	86 (25%)
	3 to 4 years	84 (25%)
	5 or more years	104 (30%)
	Missing	6 (<1%)
Person Most Responsible for Providing Care	Yes	205 (60%)
	No	133 (39%)
	Missing	8 (<1%)
Only Person Responsible for Providing Care	Yes	71 (21%)
	No	269 (78%)
	Missing	6 (<1%)

CFA utilizes more than one indices to determine the significance of the analysis and to determine the adequacy of the model fit to the data (Brown, 2006). Therefore, a range of goodness of fit statistics were examined including Chi-square (x^2), Comparative Fit Index (CFI), Tucker Lewis Index (TLI), Root Mean Square Error of Approximation (RMSEA), and standardized root mean-square residual (SRMR). A chi square probability value greater than .05 indicates acceptable model fit; however, chi square is sensitive to large sample sizes (Thompson, 2004). In studies with more than 400 cases, the chi square is almost always statistically significant. Because this study had over 500 participants, the chi square test had little bearing on determining model strength but was reported nevertheless. CFI and TLI values above 0.95 indicate a good model fit (Hu & Bentler, 1999), yet 0.90 is the conventional cutoff seen in the literature (Russell, 2002).

RMSEA values near 0.01, 0.05, and 0.08 indicate excellent, good, and mediocre fit, respectively (MacCallum, Browne & Sugawara, 1996). SRMR values equal or below 0.05 indicate a good model fit and equal or below 0.08 indicate a reasonable fit (Browne & Cudeck, 1993). Additionally, factor loadings were studied to determine the strength of the association between the latent variable and the observed variable. The process of using CFA to estimate construct validity as well as an item-reduction technique to reduce overlapping or under-performing measures is described below.

Initial model. A review of the hypothesized model produced a variety of concerns (Table 5). First, the overall model fit attributes did not meet common standards. The $\chi 2$ value, (1403; $p < .001$) was large enough to reject the null hypothesis of a good fit. CFI and TLI values were 0.573 and 0.813, respectively. In addition, the RMSEA was 0.229 and the SRMR was 0.149. Second, several of the item loadings were low (<0.20) or negative, suggesting that the items provided little contribution to the instrument, potentially leading to model misspecification. Therefore, review of the CFA for the initially proposed, 5-factor model led to the conclusion that a) items should be removed from the instrument and b) a CFA of the revised structure should be conducted to better assess the factors that the instrument was capturing.

Table 5.

Mplus Output and Fit Indices of CFA for Initial Model (Model 1)

Factor and item	Loading	SE	Est/SE
Role Engulfment			
I am the only person capable of providing care…	0.00	0.00	0.00
Because of providing care to my ill family member…	0.07	19.82	0.07
I often feel isolated because I am providing care to my…	0.07	20.00	0.07
There are activities that I use to do that I no longer…	0.08	18.39	0.08
I see myself more as a care provider than as a...	0.07	19.41	0.07
Loss of Shared Identity			
I feel less like a daughter/wife/husband/son/other…	1.00	0.00	0.00
The personal relationship I have with my family…	1.07	0.04	27.37
Since I began to provide care to my ill family member…	1.10	0.05	23.51
My ill family member and I no longer reminisce…	0.86	0.05	18.82
I wish my life would go back to the way it was before…	1.02	0.04	24.81
Family Obligation			
Providing care to others I part of a woman's role.	1.00	0.00	0.00
Others expect me to provide care to my ill family…	1.47	0.09	16.70
People in my family think that a woman, not a man…	1.15	0.06	19.95
It is the responsibility of the family to provide care for...	-0.48	0.08	-6.18
Being a part of a family means taking care of each other.	0.05	0.09	0.60
Extension of Former Role			
Being a daughter/wife/husband/son/other means…	1.00	0.00	0.00
I am responsible for providing care to my ill family…	5.21	1.38	3.77
Part of my role as daughter/wife/husband/son/other…	1.38	0.32	4.31
Being a good child includes caring for elderly parents…	0.63	0.21	3.03
Providing care to my ill family member is a natural…	4.54	1.21	3.75
Master Identity			
Being a caregiver is a significant part of who I am.	1.00	0.00	0.00
Providing care is only a portion of my life.	0.25	0.06	3.94
Others identify me as a caregiver.	1.10	0.04	26.60
Being a caregiver is the most important role I have.	1.01	0.04	25.84
My ill family member would consider me his/her...	1.08	0.04	25.12

Model Fit Indices: x^2 = 1403, df = 57, p=0.00; CFI= 0.57; TLI= 0.81; RMSEA= 0.23; SRMR= 0.15

Revisions and final model. To improve the strength of the model, individual parameter estimates were examined and alternative models were tested. First, the model was identified and latent variables were scaled to create "one less unknown" (Harrington, 2009, p. 26). An unidentified model is one for which it is impossible to come up with unique parameter estimates (Bollen, 1989). Without introducing some constraints any confirmatory factor model is not identified. One of the most common constraints is to set one of its factor loadings to one. For revised models, the unit of measurement was set to the indicator variable with the highest estimate. For example, all items for Factor 1 (Role Engulfment) were measured against RolEng4 due to its high estimate.

Furthermore, Item FamOblig4 was removed from the model due to its negative value. According to Byrne (2012), parameter estimates that are "not positive definite, as well as estimates exhibiting out-of-range values such as correlations > than 1.00" are unacceptable values (p. 78). Several other items (RolEng1, LosShrd4, MastID5) were dropped because they fell below an 0.80 cut off level of acceptability established by the researcher (Fornell & Larcker, 1981). Several items for Factor 3 (Family Obligation) also fell below this criterion but due to the factor needing at least 3 items to adequately capture the construct (Straub, Boudreau, Gefen, 2004), no other items were removed. Finally, Factor 4 (Extension of Former Role) had several low scoring items. The five items were examined more closely to determine if there were any issues. Two items (ExFmrRo2, ExFmrRo5) showed correlated error and were removed.

A revised model was run with the remaining 18 items (Figure 3). The overall fit of the model was improved dramatically and shown to be a better fit for the data than

Model 1 (Table 6). Chi-square was significant (x^2=259;df=52, p<0.001). CFI and TLI values were 0.929 and 0.977, respectively, suggesting an acceptable fit. The RMSEA was slightly outside of acceptable ranges at 0.093 but the SRMR was 0.056, indicating a good fit.

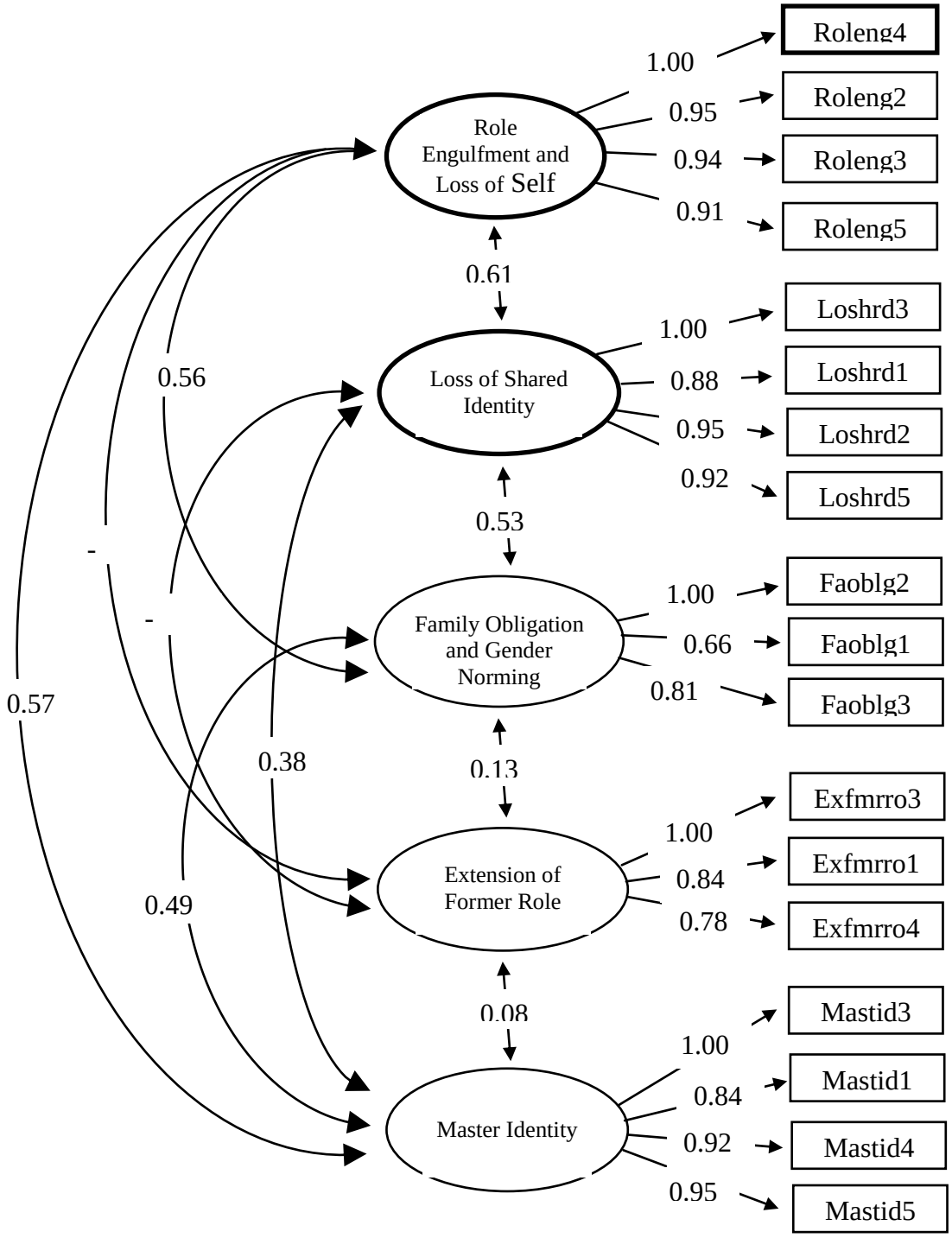
Table 6.

Fit Indices of CFA for Revised Model (Final Model)

Chi-Square	Value	259
	Degrees of freedom	52
	p-value	0.00
CFI/TLI	CFI	0.929
	TLI	0.977
Root Mean Square Error of Approximation (RMSEA)	Estimate	0.093
Standardized Root Mean Square Residual (SRMR)	Value	0.056

Figure 3.

Path Diagram of CFA for Final Model



Step 7: Final Check

The 18-item instrument that resulted from the pilot testing stage was reviewed a final time by three people who had no part in the development or revision process (Dillman, 2000). They were tasked with proofing the items for wording or content problems only. Several errors were found and the instrument was modified.

Conclusion

Using a systematic process and a variety of accepted practices, the Family Caregiver Identity Scale (FCIS) was developed and pretested. The Family Caregiver Identity Scale can be used to measure the extent an individual identifies with the family caregiver role. The version of the FCIS that resulted from this study consists of six parts. Part I includes describing key concepts related to caregiving including Providing Care, Ill, and Family. Part II consists of the actual 18 item FCIS. Part III is five general demographic questions while Part IV contains two questions regarding family. Part V and VI are only for people who have provided unpaid help to family members. They deal with care and support questions, respectively.

The final version of the FCIS will be made available after further CFA and validation testing is conducted. Since the initial CFA did not fit the data well, modifications were made and additional analyses were performed. The results helped to refine the instrument to 18 items and demonstrate adequate initial evidence of validity. Due to theoretical restrictions, these findings should be considered preliminary with further CFA work needed with other samples.

CHAPTER IV

SUMMARY, CONCLUSIONS, DISCUSSION, AND RECOMMENDATIONS

This chapter concludes the dissertation. It reviews the purpose of the study and summarizes the results. A discussion of the findings within the context of caregiver's use of support services is presented and implications for theory and practice are outlined. The final section examines the limitations of the current study and presents recommendations for further research.

Summary

Caregiver identity is emerging as an important but understudied factor in family caregiver's use of support services to manage caregiver burden. One of the challenges of understanding the role caregiver identity plays in caregiver's use of support services is the limited ability to measure it. The overall goal of this study was to develop and validate an instrument to measure the extent to which an individual identifies with the family caregiver role. Following a multi-step and phase framework guided by the Standards for Educational and Psychological Testing (AERA, APA, & NCME, 1999) and Dillman's (2000) stages of pretesting, a questionnaire that globally measures caregiver identity was formed. To begin, a comprehensive review of the existing literature was conducted to determine the factors that influence the development of caregiver identity. Secondly, a pool of items was created to measure different factors found in the review of the literature. Finally, these items were fashioned into a testable format and subjected to

evaluation. The first review was completed by a group of caregiving and instrument development professionals. Feedback from these experts was used to revise and improve items. The revised items were then examined by a small group of family caregivers using the cognitive interviewing technique. Feedback from the caregivers was used to revise and improve items for a second time. After making changes to the instrument based on the reviews, the instrument was pilot tested in North Carolina. The initial results confirmed the five factors theorized to influence family caregiver identity development (e.g. role engulfment and reversal, loss of shared identity, family obligation and gender norming, extension of the former role, and development of a master identity), but validation results were considered preliminary until further confirmatory factor analysis work can be done.

Discussion

Caregiver identity plays an important role in caregiver's use of support services. Non-use and underutilization of support services by family caregivers is a well-known fact but is poorly understood (Brodaty, Thompson, Thompson, & Fine, 2005; Robinson, Buckwalter, & Reed, 2005). Of critical importance is engaging caregivers early in their caregiving efforts so they are provided the information and support necessary to be healthy and successful caregivers. This early intervention provides caregivers with the resources they need before they need them by introducing them to support services that are available. According to Carpentier and colleagues (2008):

> Certain families manage to get organized, to mobilize resources, and to forge support ties with professional service providers. It is imperative to acquire a better understanding of the initial period, to identify the actors capable of playing important roles, and to gain a firmer grasp of the influence of attitudes and values likely to foster a more rapid acceptance of the disease and quicker access to and a more appropriate use of resources available in the community.

Understanding the transition to being a caregiver and the actual adjustment process for individuals is important because caregiver identity can begin to develop the moment a person begins providing care (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). Interventions aimed at helping individuals transition into the caregiver role and develop their caregiver identity may be warranted to encourage those providing care to engage in the support services available to them throughout their caregiving tenure.

According to Montgomery and Kosloski's (2009) *Caregiver Identity Theory*, a major source of caregiver stress is caregiver identity discrepancy or "a disparity between the care responsibilities that he or she is assuming and his or her identity standard" (p. 641, Montgomery, Kwak, & Kosloski, 2004). Montgomery & Kosloski (2009) suggest to reduce caregiver incongruence, one must: (1) Change their behaviors to bring them into line with their identity standard; (2) Change their self-appraisal or perception of congruence; or (3) Change their identity standard. When assisting individuals who are providing care to a family member, the first step may be helping that individual with the recognition of that role.

In an effort to address underutilization of support services by caregivers because of identity, the Caregivers and Professionals Partnership (CAPP) at Mount Sinai Medical Center in New York make a concentrated effort to increase efforts that "encourage

caregiver self-identification, while also helping families gain access to appropriate services" (Dobrof & Ebenstein, 2003, p. 36). CAPP offers a model for how to use caregiver identity theory in service and program efforts. They suggest the following guidelines:

(1) *Define caregivers broadly and often.* CAPP uses a definition that is all inclusive and speaks to those providing intensive care but also to those who are just beginning to worry about a family member.

(2) *Reach out to family caregiver and professionals.* CAPP acts as a direct resource for family caregivers who need information or support. In addition, they work with preparing professionals (ie hospital/medical staff) to identify and refer families who they recognize as needing support.

(3) *Proactively pursue the caregiver who does not self-identify.* CAPP employees purposively engage the general public and non-caregivers. They also accept medical and general referrals for people who may not have initiated contact otherwise.

(4) *Develop culturally sensitive services*. CAPP recognizes that cultures may define caregiving differently. They make an effort to have bi-lingual staff, materials, and education available. In addition, they engage community leaders who can refer families in need.

(5) *Include family caregivers in developing strategies.* Family caregivers have played key roles developing CAPP activities. CAPP recognizes that past and current caregivers can offer insight into identifying and assisting caregivers.

As a final point, to encourage those providing care to self-identify and utilize support services, more should be done to remove the stigma of caregiving and present caregiving in a positive light (Werner, Goldstein, & Buchbinder, 2010). Nobody wants to identify with something negative. Most of caregiving research has focused on the negative aspects of the caregiving experience compared to the positive aspects of caregiving (Carbonneau, Caron & Desrosiers, 2012; Cohen, Colantonio, & Vernich, 2002). According to Carbonneau and colleagues (2012), "Positive aspects should be considered when helping families since caregivers' support should not only reduce the difficulties they face but also enhance the positive aspects of their role" (p. 328). Moreover, there are many programs to help caregivers but rarely do these programs celebrate them. This perpetuates the myth that caregiving is undesirable and not something a person wants to be associated with.

Recommendations for Research and Practice

A valid and reliable measure of family caregiver identity was needed to advance research and practice in the area of family caregivers. Much of the prior research approached caregiver identity as a one-dimensional factor, rather than as a multidimensional construct with a number of different facets. This study contributes to the growing body of research involving caregiver identity; however, more research needs to be conducted in order to better understand the factors that influence the development of family caregiver identity and the influence of varying levels of caregiver identity on caregiver behavior. Likewise, this study contributes to the practice of community and

public health but practitioners need to determine how to apply caregiver identity theory and develop interventions to assist family caregivers transition into the caregiver role.

Recommendations for Future Research

Instrument development is a continuous process. Results from this study are preliminary with further research needed with other samples and influential factors. Within this study, the model was modified to achieve adequate fit. CFA must be repeated using the same measure as the latent structure of the 18-item FCIS across different samples or populations. The five factors of caregiver identity developed are related and could be argued to have significant item overlap. It is possible that factors could be collapsed and different dimensions captured. This notion needs to be examined in future theoretical models.

Additionally, future research should explore the relationships between caregiver identity development and other factors such age, gender, race, employment, income, family circumstances, relationship between caregiver and recipient, amount of responsibility to provide care, and level of caregiver support. Additionally, research needs to be conducted on the relationship between the development of caregiver identity and length of time providing care. As previously mentioned, identity is slow to develop and not an over-night occurrence. This process has implications for those who have been providing care a short time compared to those who have been providing care for an extended time. For example, caregivers of those with cancer may never develop the identity of caregiver because their caring tenure is brief or temporary once the care recipient goes into remission. For caregivers of a person with a slow progressing illness

such as Alzheimer's disease which can last 10-15 years, identity development would be different. Examination of diverse factors will provide a more complete understanding of how caregiver identity develops and different influences on that development. Furthermore, it would lay the foundation for a theory to explain the relationship between factors and a *process* for caregiver identity development.

Of utmost importance, future research should examine the relationship between caregiver identity and support service use. Health behavior theory such as the Social Cognitive Theory or Health Belief Model may be helpful in understanding the link between caregiver identity and support service utilization. A conceptual framework to explain the key factors, concepts, or variables related to caregiver identity development and support service use and the presumed relationships among them should be developed using a health behavior theory as a theoretical guide and the factors related to caregiver identity development used in the FCIS.

Recommendations for Health Education Practice

Very few community and public health programs have been designed to support caregivers at the beginning of their caregiving career (Ducharme, Levesque, Lachance, Kergoat, Legault, Beaudet, & Zarit, 2011). Most support services, taking a reactive rather than proactive approach, are intended for caregivers who are already dealing with caregiver stress and burden and possibly declining health. By offering intervention at the onset of the caregiving career, an opportunity to facilitate the transition to the caregiver role, develop the caregiver identity early, and introduce caregivers to support services begins to form. The FCIS can aid in the design, implementation and evaluation of

interventions that promote wellness for family caregivers who are just beginning their caregiving career.

Ducharme and colleagues (2009) created the *Learning to Become a Family Caregiver* program in Montreal Canada in an effort to assist caregivers in a successful transition to the caregiver role. The program focuses on the acquisition of skills and consists of the following modules: caregiver perceptions of the care situation, coping strategies for dealing with difficulties and averting psychological distress, how to communicate and enjoy time spent with the relative, how to use one's strengths and experiences to take care of the relative, how to get family and friends to help, knowledge of services and how to ask for them, and planning ahead for the future. The FCIS could be included in this intervention and others like it, to identify participants who have yet to develop the caregiver identity. They may have difficulty transitioning into the caregiver role (despite participation in an early stage intervention) and warrant additionally assistance.

Our current healthcare system depends on family caregivers to provide care for their loved ones, but does little to teach them how to do it and support them in this stressful role. Health education can offer caregivers the information, access to resources, and support they need to be successful. Health education interventions see the caregiver, not the care recipient, as the primary beneficiary and serve two main purposes. First, health education can provide support by directly reducing distress and improving their health and well-being. Secondly, health education can help the caregiver become more "competent and confident, providing safe and effective care to the patient, which can

indirectly reduce caregiver distress by reducing their load or increasing their sense of certainty and control" (Reinhard, Given, Petlick, & Bemis, 2008, p. 5). Considering the Seven Areas of Responsibility for Certified Health Education Specialists (CHES) (National Commission for Health Education Credentialing, Inc., 2010), several practical guidelines for health educators to use the FCIS were developed.

- *Plan Health Education*. The five factors that the FCIS measures can be used to develop theory based, health education. Health educators must understand how caregiver identity develops and incorporate it into their planning. It will be important for health educators to acknowledge the role that identity plays in behavior and, more importantly, behavior change. If health educators are encouraging support service use, they may need to examine caregiver identity as a barrier and plan accordingly.
- *Implement Health Education*. Caregivers are notorious for underutilizing programs and interventions, including health education. Health educators must assess a caregiver's openness and acceptance of interventions prior to implementation. The FCIS may play a role in determining if a caregiver is ready to utilize support services such as health education.
- *Conduct Evaluation and Research Related to Health Education*. Health education interventions may be more successful with caregivers who self-identify. Health educators may use the FCIS to evaluate an intervention for family caregivers who do not self-identify compared to those who do.

- *Serve as a Health Education Resource Person*. The FCIS is an easy to use and brief instrument. Health educators can train other health professionals on the use of FCIS and serve as a consultant on caregiver identity.
- *Communicate and Advocate for Health and Health Education*. The FCIS can be used to promote services for family caregivers as well as draw more attention to the needs of family caregivers. Health educators must engage in advocacy that emphasizes the crucial role that caregivers play in the care recipient's life, as well as the benefit to our healthcare system.

Moreover, the Patient Protection and Affordable Care Act of 2010 created several new Medicare programs intended to improve health care quality, using "pay-for-performance" payment strategies. Since its enactment, Medicare has offered physicians financial incentives to report performance on certain quality measures. Of importance would be physicians support for family caregivers, specifically their performance of a caregiver assessment. According to Feinberg & colleagues (2012), a caregiver assessment is a "systematic process of gathering information about a caregiving situation to identify the specific problems, needs, strengths, and resources of the family caregiver, as well as the ability of the caregiver to contribute to the needs of the care recipient" so they can continue in their caregiving role without being overburdened. Collins and Swartz (2011) state that a complete assessment "can be offered to any person who self-identifies as a caregiver" (p. 1311). Collins and Swartz acknowledge that many caregivers do not self-identify and recommend that a broad definition of caregiver be used to identify assessment candidates. Rather than identify caregivers by conjecture, the

FCIS could be used to determine who is in need of a caregiver assessment. Since a caregiver assessment can be performed not only by the caregiver's physician, but by other health care team members, including a social worker or case manager, it has implications for the community and public health professionals who may be called upon to perform said assessments (Collins & Swartz, 2011).

Limitations

The results and instrument produced from this study appear to be valid, but it is important to consider the limitations involved. First, a literature review and panel of experts attempted to reduce the likelihood that a factor related to caregiver identity development was omitted. However, it is still possible that a relevant aspect was not included. Caregiver identity research is still emerging and there may very well be other factors not stated in the literature and unbeknownst to professionals and caregivers. Therefore, the factors identified rely on the experience and judgment of the researcher and may be interpreted differently by others. Additionally, some of the literature included in the review would be considered dated by academic standards. Caregiver identity research is small but demonstrates continuity since its emergence in the literature. The limited, albeit dated, literature included in the literature review provides the only evidence available.

Second, there are some caveats to applying the results of this study to a wider population. Participants were recruited through community partner organizations in North Carolina and are therefore considered a convenience sample. The preferred sampling method would be to randomly select family caregivers from a nation-wide sampling

frame. Unfortunately, this method would be costly and beyond the scope of this study. Furthermore, North Carolina may have a regional belief system regarding family and caregiving that is different from other regions in the country (Kivett, 1976). This difference in the culture of family obligation should be taken into consideration when reviewing the results and examining the five factor structure of caregiver identity development. The sampling plan limits the generalizability of the study beyond the sample.

Confirmatory factor analysis has limitations as well. Alternative models are likely to fit the data equally as well as the one chosen. The choice of the appropriate model to understand the relationship between the latent variables was guided by theory and plausibility; however, it is possible that in future studies of caregiver identity development, variations in the structural relationships could be found. Furthermore, the sample used for the CFA consisted of both caregiver and non-caregivers to determine the FCIS' ability to discriminate between the two. The original model or an alternative model could work better with a sample of all caregivers. It may be beneficial to go back to the original 25 item FCIS and test the model again, possibly in an area like Florida that attracts large populations of people from other states. This strategy would not only check the theoretical underpinnings of the original model but test the FCIS on people with diverse backgrounds. Finally, because a number of modifications were made to the model, what began as a CFA ended as an exploratory analysis. According to Brown (2006), once a model is revised, it is no longer a confirmatory analysis. The instrument

in its current form will need to be confirmed in an independent sample before any formal validity conclusions can be drawn.

Conclusion

This dissertation research highlighted the current understanding of family caregiver identity development and the need for a more global measure of family caregiver identity. The results of the systematic literature review revealed that there are multiple factors that influence caregiver identity development. These factors- role engulfment and reversal; loss of shared identity; family obligation and gender norming; extension of the former role; and development of a master identity- cannot be captured in a single yes/no question. The five factors provide the background for an instrument called the Family Caregiver Identity Scale (FCIS) to assess the extent an individual identifies with the family caregiver role. The instrument development framework adapted from Dillman's steps of pretesting (2000) and the Standards (1999) resulted in an FCIS that was promising but needs further validation testing. This instrument will be available for future research and practice, and should be utilized in early interventions with family caregivers.

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APPENDIX A

ITEM SPECIFICATIONS

Item	**Construct**
Role Engulfment and Loss of Self	
1a. Caring for a loved one is overwhelming. 1h. Caring for my loved one keeps me from doing things that I enjoy. 1g. I often feel alone because I am caring for my ill family member.	Increasing isolation and additional responsibility (O'Connor, 2007)
1b. I am the only person that could care for my ill loved one.	Only one competent enough to care (Miller, Shoemaker, Willyard, & Addison, 2008)
1c. I often regret the time I spend caring for a loved one. 1f. To care for a loved one well, I need to give up other responsibilities.	Recognition of "giving up" something (Burton, 2006)
1d. My relationships with others are a very important part of who I am. 1i. I am afraid of losing myself to caring for my loved one.	Loss of former roles and development of new roles (Heward, Gough, & Molineux, 2011)
1e. Because of caring for my loved one, I do not have time to do things that I would normally do. 1j. There are many activities that I used to do that I no longer have time for because of caring for my ill loved one.	Loss of life they had previously (Burton, 2006)
1k. I see myself more as a care provider than as a child/spouse/other.	Role reversal (ie shift from daughter to motherly figure) (Miller, Shoemaker, Willyard, & Addison, 2008; Sherrell, Buckwalter, & Morhardt, 2001)

Item	Construct
Loss of Shared Identity	
2a. I feel less like a daughter/wife/husband/son/other because of caregiving.	Renegotiation of dyad's identity (Coeling, Biordi, & Theis, 2003)
2b. My relationship with my spouse/parent/other is a very important part of who I am. 2g. My ill loved one and reminisce about the past. 2f. My ill loved one and I no longer share important parts of our daily life.	Loss of shared history, memories, and biographies (Hasselkus & Murray, 2007) Decrease in joint decision-making; Decrease in reciprocity or the contribution that each person makes in the relationship (Orona, 1990)
2c. My relationship with my spouse/parent/other has changed since I have begun to care for him/her.	Changes in daily routine and interactions; Diminished intimacy or feelings of closeness (Hayes, Boylstein, & Zimmerman, 2009)
2d. I will never be the person I was before caring for my loved one. 2e. The relationship with my loved one will never be the same as it was before I began caring for him/her. 2h. I wish my life would go back to the way it was before my loved one became ill.	References to person before they became unwell (Adams, 2002)

Item	Construct
Family Obligation and Gender Norming	
3a. Caring for others is part of being a woman. 3d. If I fell ill, I would expect my daughter, not my son, to care for me. 3f. If I was/as a woman, my family would expect me and not a male family member to care for an ill loved one.	Assumption of care, particularly for women who are socialized to care and to be concerned about the well-being of others. (Paoletti, 2002)
3b. Females are more nurturing than males.	Caregiving is related to gender identity (Kirsi, Hervonen, & Jylha, 2000)
3c. Caregivers are considered good by other people. 3e. If someone falls ill, it is the responsibility of the family to care for him/her. 3g. If a family member fell ill, he/she would expect someone in the family to care for him/her. 3h. It is the responsibility of the family to care for unwell members. 3i. Being a part of a family means taking care of each other.	Related to being a "good" husband/wife/partner (O'Connor, 1999)
3a. Caring for others is part of being a woman. 3d. If I fell ill, I would expect my daughter, not my son, to care for me. 3f. If I was/as a woman, my family would expect me and not a male family member to care for an ill loved one.	

Item	Construct
Extension of a Former Role	
4a. I do not see my role of caring for my loved one as separate from being a daughter/wife/husband/son/other. 4h. It is natural for a spouse to care for his/her partner if he/she is unwell.	Related to ongoing role of spouse/child (Henderson, 2001)
4b. Caring for an ill loved one is part of being a good daughter/wife/husband/son/other. 4f. Part of my role as daughter/wife/husband/son/other includes caring for my loved one if he/she is unwell.	Caregiver identity is rooted in previous identity with person (Golden, 2005)
4c. It is my responsibility as a daughter/wife/husband/son/other to care for my loved one. 4d. I am happy to take care of my loved one. 4e. Taking care of an unwell family member is normal.	Normative expectations and ideas about responsibility to care (Goldsteen, Abma, Oeseburg, Verkerk, Verhey, & Widdershoven, 2007)
4g. Being a good child includes caring for elderly parents who are ill.	The identity of "caregiver" is rooted in the "spousal/child" relationship (Karner & Bobbitt-Zeher, 2005)
4i. Since I began to care for my ill loved one, our relationship has gradually changed.	Gradual process of development based on previous relationship (Montgomery & Kosloski, 2012)

Item	Construct
Master Identity	
5a. Being a caregiver is the most important part of who I am. 5b. Being a caregiver has very little to do with how I feel about myself. 5e. Being a caregiver is unimportant to my sense of what kind of person I am. 5h. I am proud to be a caregiver.	Only value is as caregiver (Dickson, O'Brien, Ward, Allan, & O'Carroll, 2010)
5c. Caregiving should be only a small part of one's life. 5i. Overtime, I have gradually gained a sense of who I am as a caregiver.	Caregiving claims majority of time (Hughes, 1945)
5d. I have a strong sense of being a caregiver. 5f. I believe that once a caregiver, always a caregiver. 5g. Others have referred to me as a caregiver. 5j. My ill loved one would consider me his/her caregiver.	Only identity left is caregiver (Skaff & Pearlin, 1992)

APPENDIX B

FAMILY CAREGIVER IDENTITY SCALE

Key Concepts

The focus of this questionnaire is in regards to people who provide care to an ill family member. Before you begin this questionnaire, please read the following descriptions to have a better understanding of what is meant by key concepts that you will read while completing the questionnaire:

1) Providing Care:

Providing care includes a wide range of tasks from occasionally running errands to supervising regular activities to direct, day-to-day care. Responsibilities can include assistance with activities of daily living (ADLs), such as bathing, dressing, and eating, as well as instrumental activities of daily living (iADLs) such as money management or transportation. The amount of time spent on providing care can be a few hours a week to 24 hours/7 days a week, depending on the needs of the ill person and/or the presence of other people providing care.

Some people provide care for free while others are employed as paid, professional caregivers. The majority of people who provide care for free are family members of the ill person such as spouses and adult children.

2) Ill:

Ill is a condition in which an individual is not well or healthy. The cause of them being ill may be related to Alzheimer's disease or another form of dementia, arthritis, cancer, diabetes, heart disease, or some other condition that causes a decrease in physical or mental function. It may also be caused by general aging or frailty. Some people who are ill can manage their symptoms and care on their own while others need assistance from friends or family.

3) Family:

Family is a group of people connected by birth, marriage, or affinity (feelings of closeness). Family can include immediate relatives such as parents, spouse/partner, siblings, or children and extended relatives such as grandparents, aunts/uncles, cousins, nieces/nephews, or in-laws. Additionally, family can include individuals that have no blood relation but whom you share a deep affection for or familiarity with.

Family Caregiver Identity Scale (FCIS)

Directions: Each item is a statement. Please indicate your agreement with the statement by marking the response that best fits with your thoughts. Response options will include completely agree, generally agree, generally disagree, or completely disagree.

(1) I feel less like a daughter/wife/husband/son/other because of providing care to my ill family member.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(2) Providing care to others is part of a woman's role.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(3) Being a daughter/wife/husband/son/other means providing care to my family member if he/she becomes ill.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(4) Being a caregiver is a significant part of who I am.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(5) Because of providing care to my ill family member, I do not have time to do things that I would normally do.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(6) The personal relationship I have with my family member will never be the same as it was before I began providing care to him/her.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(7) Others expect me to provide care to my ill family member.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(8) Providing care is only a portion of my life.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(9) I often feel isolated because I am providing care to my ill family member.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(10) Since I began to provide care to my ill family member, the dynamics or how we interact with each other has changed.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(11) People in my family think that a woman, not a man, should provide care to an ill member of the family.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(12) Part of my role as a daughter/wife/husband/son/other includes providing care to a family member if he/she becomes ill.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(13) Others identify me as a caregiver.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(14) There are activities that I use to do that I no longer have time for because of providing care to my ill family member.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(15) Being a good child includes caring for elderly parents who can no longer care for themselves.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(16) I see myself more as a care provider than as a child/spouse/other.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(17) I wish my life would go back to the way it was before my family member became ill.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

(18) My ill family member would consider me his/her caregiver.

- ○ Completely Agree
- ○ Generally Agree
- ○ Generally Disagree
- ○ Completely Disagree

Demographics

Directions: Please respond to the following questions by marking the circle next to the most appropriate response.

Are you a resident of North Carolina?

- ○ Yes
- ○ No

In which of these gender categories do you *most* identify:

- ○ Female
- ○ Male

In which of these groups is your age:

- ○ Under 30
- ○ 30 to 44
- ○ 45 to 64
- ○ 65 or older

In which of these racial or ethnic groups do you *most* identify:

- ○ Asian or Pacific Islander
- ○ Black/African American
- ○ Caucasian/White
- ○ Latino or Hispanic
- ○ Native American
- ○ Other-please specify: _____

What is your current employment status:

- ○ Full-time
- ○ Part-time
- ○ Retired
- ○ Out of work or unemployed
- ○ Other- please specify: _____

What is your total household income:

- ○ Less than $24,999
- ○ $25,000 to $49,999
- ○ $50,000 to $74,999
- ○ $75,000 or greater

Family

Directions: Please respond to the following questions by marking the circle next to the most appropriate response.

What is the size of your family, *including* you (number of members). It may be helpful to review the key concepts from the beginning of the questionnaire to understand what is meant by "family":

- ○ Under 5
- ○ 5 to 10
- ○ 11 to 15
- ○ 16 or greater

What is the size of your current household, *including* you (number of members living with you and having common income and expenditures):

- ○ 1 to 2
- ○ 3 to 4
- ○ 5 to 6
- ○ 7 or greater

Care

Directions: Please respond to the following questions by marking the circle next to the most appropriate response.

In the past *twelve* months, have you provided any unpaid help to a family member over the age of 18 such as assistance with health or personal needs, household chores, finances, or arranging for outside services (this person may live with you or somewhere else including another city)?

- ○ Yes
- ○ No

If you answered NO to the previous question, you have completed the questionnaire- thank you! If you answered YES to the previous question, please answer the following questions:

Please indicate the relationship you have with the person you most *recently* provided care to? He/She is my:

- ○ Spouse/Partner
- ○ Parent
- ○ Other- please specify: _____

Please indicate the length of time you have been providing care to that person?

- ○ Less than a year
- ○ 1 to 2 years
- ○ 3 to 4 years
- ○ 5 or more years

Are you the person *most* responsible for providing care?

- ○ Yes
- ○ No

Are you the *only* person responsible for providing care?

- ○ Yes
- ○ No

Support

Directions: Please respond to the following questions by marking the circle next to the most appropriate response.

Reflecting on your entire experience providing care, please indicate what support you sought to help you provide care? (Mark all that apply)

- ○ Educational presentations or program
- ○ Information and referral
- ○ Counseling
- ○ Support groups
- ○ Respite (short break or period of rest from providing care) including adult day programs or paid caregivers/companions
- ○ Assistance from other family members
- ○ Other- please specify: _____
- ○ I have not sought any help to provide care.

Please indicate what support you have used or received in the last *thirty* days? (Mark all that apply)

- ○ Educational presentations or program
- ○ Information and referral
- ○ Counseling
- ○ Support groups
- ○ Respite (short break or period of rest from providing care) including adult day programs or paid caregivers/companions
- ○ Assistance from other family members
- ○ Other- please specify: _____
- ○ I have not sought any help to provide care.

Thank you for your participation!