

EXPERIENCES OF FAMILY CAREGIVERS FOR ADULTS WITH OXYGEN  
DEPENDENT COPD

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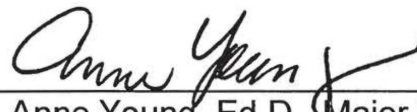
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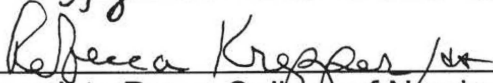
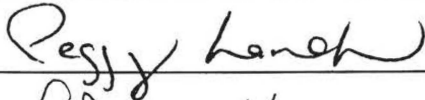
To the Dean of the Graduate School:

I am submitting herewith a dissertation written by Ann Warner entitled "Experiences of Family Caregivers for Adults with Oxygen Dependent COPD." I have examined this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy with a major in Nursing.



Anne Young, Ed.D., Major Professor

We have read this dissertation and recommend its acceptance:



Associate Dean, College of Nursing

Accepted:



Dean of the Graduate School



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My mother-in-law, Pauline Warner, had no idea when she started smoking as a young woman how her health would be affected years later. My sister-in-law, Jessie Warner, while experienced as her own mother's caregiver, could not have anticipated the challenges she would have in caring for Pauline. These women were the inspiration for this project because I wanted to understand their experiences as caregiver and care recipient.

My husband, Paul, has always been there for me from the very beginning when he told me I couldn't quit something I hadn't started to the very end through family illness, death, and hurricanes. I would not have completed this dissertation without him and I love him very much.

My children, Beth, Thomas, and Katie, have grown up during this process and have learned many things. Hopefully, they have learned to value education and the perseverance an education requires. I love them very much and am very proud of them.

## ABSTRACT

ANN WARNER

### EXPERIENCES OF FAMILY CAREGIVERS FOR ADULTS WITH OXYGEN DEPENDENT COPD

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This study investigated the caregiving experiences of family members who care for oxygen dependent adults with chronic obstructive pulmonary disease (COPD). A grounded theory design was used with a sample of 13 English speaking primarily non-urban caregivers who provided uncompensated care for oxygen dependent family members. Interviews using a semi-structured open-ended interview guide were audiotaped and analyzed using constant comparative analysis to develop the caregiving model. Findings suggest that caring for a family member with COPD was like taking a journey. The three step model starts with *Learning to Drive* where caregivers learned about COPD and the required care regimen while care recipients remained independent. The second stage, *Navigating the Bumps*, where caregivers learned to balance care recipients' need for independence despite increasing care requirements, was very difficult for caregivers. During this phase caregivers learned to use strategies to help them that included *Negotiating*, *Getting Help*, *Watching*, and *Coping*. *Negotiating* involved mutual decision making by care recipients and

caregivers in order to maintain the care recipients' independence and the caregiver's lifestyle as care recipients required more assistance. *Getting Help* described strategies caregivers used to get assistance from others. *Watching* referred to the constant vigilance most caregivers employed to assess their family members. *Coping* included the emotional responses and personal health strategies caregivers used. The final phase of the caregiving model, *End of the Road*, described how caregivers and care recipients faced death and how the caregiver was often able to find comfort and satisfaction from the caregiving experience. Findings suggested that caregivers may not ask for assistance with caregiving and may not recognize changes in their health. Additionally, continued tobacco use by the care recipient may be very distressing and confusing to the caregiver. Further study is needed to investigate the experiences of male, non-Caucasian, and rural caregivers so that nursing interventions can be developed to meet their needs. Interventions enabling caregivers to effectively intervene when care recipients continue to use tobacco need to be identified as well.

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## CHAPTER I

### INTRODUCTION

Chronic bronchitis and emphysema are included in the group of respiratory diseases called Chronic Obstructive Pulmonary Disease (COPD) that are characterized by non-reversible airway obstruction that leads to progressive dyspnea, wheezing, hypoxemia, and cor pulmonale (Brashers, 2002). In 2001, over 11 million Americans reported being diagnosed with chronic bronchitis and 3 million reported being diagnosed with emphysema sometime in their life. The highest prevalence rate, 67.3 per 1,000 people, occurred in individuals over the age of 65. COPD is the fourth leading cause of death in the United States and for the first time more women died of COPD than men (American Lung Association [ALA], 2003). In Calcasieu Parish, Louisiana, the ALA (2003) estimates that there are nearly 2,000 adults who have emphysema and nearly 6,000 who have chronic bronchitis

Caring for large numbers of adults with COPD is complicated by the morbidity associated with the condition. Dyspnea (Baker & Scholz, 2002; Gift & Sheperd, 1999) and fatigue (Small & Lamb, 1999; O'Neill, 2002), both of which may be severe, are the most commonly reported symptoms of COPD and often occur with physical activity (Theander & Unosson, 2004; Yuet, Alexander & Chun, 2002). Significant depression may occur with COPD and often is not

treated (Lacasse, Rousseau & Maltais, 2001). People with COPD suffer from physical disability, memory impairment, mood changes and behavioral changes (Cain & Wicks, 2000). Family members perceive that people with COPD have significant difficulty with social adjustment (Leidy & Traver, 1996). The Disability-Adjusted Life Year (DALY) is the sum of years lost because of premature mortality and years of life lived with disability adjusted for the severity of disability. While COPD ranked 12<sup>th</sup> in DALYs lost worldwide in 1990, by 2020 it is projected that COPD will rank 5<sup>th</sup> in years lost as a result of disability (Global Initiative for Chronic Obstructive Lung Disease [GOLD], 2003). In fact, Eisner et al (2002) attributes 1 in 17 cases of current non-participation in the labor force among people of employable age to COPD or asthma.

As COPD becomes increasingly severe, supplemental oxygen is added to individuals' treatment regimens. Supplemental oxygen increases survival and improves hemodynamic functioning, hematologic outcomes, mental status, exercise capability, and lung mechanics in people with Stage IV COPD. The goal of oxygen therapy is to raise PaO<sub>2</sub> to 60 mm Hg at sea level and the SaO<sub>2</sub> to 90% (GOLD, 2003).

The demands of caring for increasingly disabled adults with oxygen dependent COPD are affected by changes in our society and health care system. The national nursing shortage, shorter hospital stays for acute illness, increasingly sophisticated treatment technologies used in the home setting, changes in family structure and nature, and the growing preference for older



people to be cared for and to die in their homes all impact caregivers for adults with COPD (Poirier & Ayres, 2002). As family members and significant others close the caregiving gap by providing and monitoring care given to aging family members with COPD (Orem, 2001), they cope with a wide variety of challenges that affect their quality of life.

Despite the significant prevalence of COPD with its resultant disability, research describing the caregiving experience of family caregivers for adults with COPD is sparse. Knowledge about the caregiving experience of caregivers for people with COPD is limited primarily to urban female Caucasian caregivers who are providing care following acute illness and who describe negative aspects of caregiving. Studies of caregivers for people with other chronic health conditions have demonstrated that there are racial differences (Janevic & Connell, 2001; Sander, High, Hannay, & Sherer, 1997), gender differences (Northouse, Mood, Templin, Mellon, & George, 2000; Nijboer, Tiesmstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000) and positive aspects (Nijboer et al., 2000) in the caregiving experience. No studies could be found that reported the COPD caregiving experiences of caregivers who live in non-urban areas.

### Problem of Study

The purpose of this project was to explore rural multicultural caregivers' experiences of caring for family members who have oxygen dependent COPD. The goal of this study was to develop a theory that describes the caregiving experience from the perspective of the caregiver for an adult with oxygen

dependent COPD. Emphasis was placed on recruiting caregivers from groups who have not been adequately studied – African-Americans, males, and those who live in non-urban areas.

### Rationale for the Study

While several different authors (Cain & Wicks, 2000; Leidy & Traver, 1996; Sexton & Munro, 1985; Sexton & Munro, 1988; Xiaolian, Chaiwan, Panuthai, Yijuan, Lei, & Jiping, 2002; Cosette & Levesque, 1993) have studied caring for a person with COPD, no study has focused on caregivers who live in non-urban settings and few studies (Cain & Wicks, 2000) have included significant numbers of either African Americans or men in their samples. Non-urban populations have higher rates of health behaviors that increase their risk of disease. For example, *Women's Health USA* (Health Resources and Services Administration [HRSA], 2002) data for the period of 1997-1998 indicates that 27% of non-urban women smoke cigarettes as compared to 20% of urban women. In addition, *The Urban and Rural Health Chartbook, Health, United States* (National Center for Health Statistics [NCHS], 2001) reports that physical inactivity during leisure time is reported by 56% of women and 47% of men in the most rural counties of the southern United States. While people with physically active occupations, common in non-urban areas, may choose sedentary leisure time activities, the high rates of physical inactivity are not completely explained by this demographic factor (NCHS, 2001). The numbers of older Americans (45 – 64 years, 65+ years) living in non-urban areas are projected to increase as a percentage of

population from 21.4% and 17.2% respectively in 1996 to 25.6% and 23.1% respectively by 2020 (HRSA, 2002). These older non-urban Americans will be caregivers and care recipients in the years to come.

It is important to investigate the caregiving process that occurs in non-urban settings since access to health care for both routine and emergency services is different than what is found in urban settings (HRSA, 2002). For example, two important determinants of access to health care are health insurance and physician availability. Rural adults under 65 years regardless of poverty status are less likely to have health insurance than their urban counterparts (NCHS, 2001). In addition, the number of practicing primary care physicians per 100,000 people decreases steadily as counties become more rural (NCHS, 2001).

Differences in access to care affects the caregiving process as caregivers incorporate strategies to receive care, manage emergencies, and obtain support into the caregiving process that are likely different than strategies employed by urban caregivers. For example, *The Urban and Rural Health Chartbook, Health, United States* (NCHS, 2001) reports hospital discharge rates (excluding maternity hospitalizations) for rural adults under 65 years as 92.6 discharges per 1,000 population while rates for corresponding metropolitan inhabitants ranged from 65.0 discharges per 1,000 population to 70.8 discharges per 1,000 population depending upon the size of the metropolitan area. The authors speculate that rural inhabitants are more likely to delay seeking ambulatory care

until their conditions become severe enough to warrant inpatient care (NCHS, 2001).

Men who care for family members with COPD have not been adequately represented in existing studies describing the COPD caregiving process. As the prevalence of COPD in women increases (ALA, 2003), it is likely that more men will care for their family members with COPD. Men may respond to COPD caregiving differently than women and may be consistent with reported caregiving experiences of men caring for their wives with cancer (Northouse, Mood, Templin, Mellon, & George, 2000; Nijboer, Tiesmstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000).

People who have COPD pose unique challenges for their caregivers. For example, symptoms of the disease include dyspnea (Baker & Scholz, 2002) and fatigue (Theander & Unosson, 2004) and may lead to psychological consequences like depression (Lacasse, Rousseau & Maltais, 2001), physiological consequences like decreased physical activity (Yuet, Alexander & Chun, 2002), problems with social adjustment (Leidy & Traver, 1996) and problems maintaining employment (Eisner, Yelin, Trupin, & Blanc, 2002). The combination of these issues challenges caregivers for people with COPD in different ways than caregivers for people with other chronic conditions such as dementia or stroke.

The disease trajectory for COPD is characterized by exacerbations followed by periods of relative health that may result in distinctive responses from

COPD caregivers. In the United States, COPD is likely to have resulted from tobacco abuse (GOLD, 2003). Caregivers of people who have COPD as a result of tobacco abuse may respond to caregiving differently than a caregiver caring for a person who has a lung disease that did not occur as a result of substance abuse.

It is important for nurses to study the caregiving experiences of men, African-Americans and non-urban residents who care for individuals with oxygen dependent COPD because this is an increasing caregiver population that has not been studied. An understanding of this caregiving experience may help nurses assist caregivers to successfully cope with caring for a family member with oxygen dependent COPD.

### Theoretical Orientation

Symbolic Interactionism, which provides the theoretical orientation for this study, is an approach in the study of human group behavior and conduct that is most closely associated with Herbert Blumer. Blumer, a sociologist, drew heavily on the works of George Herbert Mead as well as John Dewey, William James and other turn of the century pragmatists to develop a theory of human behavior that emphasizes the meanings individuals place on their social interactions with others (MacDonald, 2001). Individuals' actions are based upon their interpretation of meanings. In order to understand human behavior it is important to understand the meaning that individuals' social interactions have to themselves (Milliken & Schreiber, 2001). Symbolic interactionists view humans

as active participants in their world who create a society that is composed of people acting and interacting continuously (MacDonald, 2001).

George Herbert Mead's philosophical views of the nature of human society were the basis for Blumer's development of symbolic interactionism (Blumer, 1969). Mead's theoretical scheme as described by Blumer (1969) included the self, the act, social interaction, objects, and joint action. According to Mead, humans are unique because they possess a self. The self is separate from the physiological organism and develops as a result of social experiences. The self is able to respond to itself as well as to others (Mead, 1934). Humans act as a result of their interpretations of the world in order to actively cope with the demands of life.

Social interactions are either symbolic or non-symbolic. Non-symbolic interactions occur at the response level without conscious interpretation. Symbolic interactions, on the other hand, require conscious thought and are conveyed through the symbols of language (Mead, 1934). Symbolic interaction then is an ongoing process applicable to a full range of human relationships.

The fourth component of Mead's framework was the concept of object. An object is any construct to which the organism "physiologically and chemically responds" (Mead, 1934, p. 77). The importance of an object is based upon the meaning the object has for an individual—meaning is not intrinsic to the object itself. People organize their actions toward the objects in their lives based upon the meanings these objects have for them (Blumer, 1969).

Finally, Mead described joint action as a “social act” which is defined as “a complex organic process” (Mead, 1934, p. 7) that requires more than one individual. Individuals identify specific social acts and then interpret and define each other’s acts so that the individual can decide on a course of action.

Mead’s framework is clearly evident in Blumer’s three premises underlying symbolic interactionism that inform this study of caregiving experiences. First, Blumer (1969) believed that humans act toward the people, objects, institutions, ideals, activities of others and everyday life situations based upon the meanings each has for the individual and that these meanings are central to the individual. Caring for a family member with COPD requires individuals to act toward the person being cared for as well as with objects such as oxygen and nebulizer equipment, and with health care institutions. Caregivers act upon their ideals about such issues as chronic illness and death as they care for their family member. Everyday life situations and the activities of other family members and friends also require caregiver action.

Blumer’s (1969) second premise is that the source of meaning for individuals is the social interaction the individual has with people, objects, institutions, ideals, activities of others and everyday life situations. Meanings are social constructs that grow out of the activities of individuals as they interact. The meaning of caregiving for an individual grows out of the ways that others including the care recipient see caregiving and respond to the individual caregiver.



Finally, Blumer (1969) postulated that the use of meaning by an individual is a process where meaning changes as an individual's interpretation of meaning evolves. Blumer believed interpretation of meanings was a two-step process. First an individual determined what things had meaning and then communicated those meanings internally. Caring for a person with COPD is a process that changes over time as a result of disease progression. The caregiver must continually determine where meaning lies and reinterpret it as the disease process progresses.

#### Assumptions

The major assumption underlying this investigation was that the meaning the caregiver assigns to the object of caregiving for a person with oxygen dependent COPD is an important and valuable perspective worthy of investigation. Another assumption was that the caregivers' perspective about caregiving can be determined through the analysis of symbolic interactions; that is, that the words of the informants are an accurate reflection of the meanings caregiving has for caregivers.

#### Research Question

The following research question was explored in this study:

1. What are the experiences of family members who care for an adult with oxygen dependent COPD?



### Orientational Definitions

1. Family caregiver – An English speaking adult family member who reported that they gave uncompensated care to the person with oxygen dependent COPD on a regular, ongoing basis.
2. Care Recipient – A person who was diagnosed by a physician as having COPD and who was oxygen dependent for the majority of the day.
3. Oxygen dependent COPD – Severe obstructive respiratory disease that required supplemental oxygen in order to maintain the care recipient's oxygen saturation above 90%.

### Summary

COPD has significant morbidity associated with it and caring for a person with oxygen dependent COPD has not been sufficiently studied. The perspectives of COPD caregiving are lacking from several significant groups of COPD caregivers, namely African-Americans, men, and those who live in a non-urban setting. It is important for nurses to study COPD caregiving experiences from these groups' perspective so that a more complete picture of COPD caregiving can emerge. Symbolic interactionism is the theoretical perspective that best guides this investigation because of its view that humans are active decision-makers who interact with the people, objects, and situations in their changing circumstances in a thoughtful manner.

## CHAPTER 2

### REVIEW OF THE LITERATURE

Chronic Obstructive Pulmonary Disease (COPD) is a major chronic illness that results in disability and ultimately death. Individuals with COPD struggle with dyspnea, fatigue, depression, and other psychosocial and physical problems on an ongoing basis. Families of these patients are affected by their loved ones' struggle and provide task-oriented and emotional assistance to dependent family members (Travis & Piercy, 2002). However, caregiving is a very complex construct and few studies have investigated the experiences of family caregivers of individuals with COPD.

This chapter will begin with a discussion of the effects of COPD on an individual and then describe the impact of COPD on family members. Pertinent caregiving research will be reviewed with an emphasis on caring for family members with COPD. Finally, the research describing the experiences of family members providing care for adults with COPD will be addressed.

#### Overview of COPD

COPD is characterized by airflow limitation that cannot be reversed with medications. The underlying pathological process in COPD is chronic inflammation that occurs as a result of exposure to inhaled particles that cause physiological changes in the airways, lung parenchyma and pulmonary blood

vessels. COPD is usually progressive in its course despite cessation of exposure to inhaled particles because of decreases in pulmonary function that occur as a result of normal aging, although periods of remission and exacerbation often occur (Global Obstructive Lung Disease [GOLD], 2003). Chronic activation of inflammatory cells results in the release of mediators that damage lung structures and maintain the inflammatory process. Other factors thought to play a role in the development of COPD include imbalances in proteinases and antiproteinases in the lungs, which may have a genetic basis, and oxidative stress that is a consequence of inflammation (GOLD, 2003).

Chronic inflammation of the large airways increases the size and number of mucous glands and goblet cells which make up the epithelial lining of the airways and results in hypersecretion of thick viscous bacteria trapping mucous (Brashers, 2002). Mucous hypersecretion overwhelms the cilia and compromises the removal of entrapped bacteria. As mucous clearance becomes increasingly impaired airway narrowing occurs which limits airflow (Brashers, 2002).

In the smaller airways (internal diameter less than 2 mm) chronic inflammation causes repeated cycles of injury and repair that ultimately increases collagen content and scar tissue in the airway wall. Airway scarring narrows the bronchiole lumen which limits airflow and results in a less distensible airway (GOLD, 2003).

Chronic inflammation as well as genetic factors causes an imbalance in



the proteinases and antiproteinases in the lung and results in destruction of the alveolar septa. Destruction of the alveolar septum eliminates portions of the pulmonary capillary bed, compromises the ability of the alveolar walls to support and hold open the airways and results in loss of alveolar elastic recoil (Brashers, 2002). The resulting picture is one of large, hyperinflated alveoli that cannot effectively empty and which have less surface area for gas exchange.

Pulmonary vasculature is also affected by chronic inflammation as inflammatory cells infiltrate vessel walls causing smooth muscle proliferation and thickening of the intimal layer of the blood vessels. Narrowed vessels contribute to the resultant hypoxemia and hypercapnia and in severe cases pulmonary hypertension and cor pulmonale (GOLD, 2003).

Key indicators of COPD include cough that is present every day often throughout the day; chronic sputum production; dyspnea that is progressive, persistent and worsens with exercise and respiratory infections; and a history of exposure to tobacco smoke, occupational dusts and chemicals or smoke (GOLD, 2003). Diagnosis of COPD is confirmed with pulmonary function tests that measure airflow. Forced expiratory volume in 1 second ( $FEV_1$ ) which is the amount of air expired in the first second after a deep breath expressed as a percentage of the expected value based upon the individual's age, size and gender is an example of a commonly used pulmonary function test used to diagnose COPD (Schnell, van Leeuwen, & Kranpitz, 2003).

Disease severity ranges from stage 1 mild COPD with a FEV<sub>1</sub> of 80% of predicted value to stage 4 very severe COPD with a FEV<sub>1</sub> less than 30% or FEV<sub>1</sub> less than 50% plus chronic respiratory failure. A person who has stage 1 mild COPD usually has a chronic cough and sputum production, but may not be aware that lung function is abnormal. As the disease progresses to stage 2 moderate COPD, patients often first seek medical care for dyspnea on exertion. Stage 3 severe COPD is characterized by progressive shortness of breath and repeated exacerbations that impact quality of life. Finally, stage 4 very severe COPD is accompanied by chronic respiratory failure and repeated life threatening exacerbations.

Treatment of COPD progresses in a stepwise fashion through the stages of the disease with the goals of symptom management, exacerbation and complication prevention, and improvement of health status (GOLD, 2003). For example, people with mild COPD benefit from risk factor reduction strategies especially smoking cessation and influenza vaccination coupled with short acting bronchodilator therapy as needed. As the disease progresses long-acting bronchodilators, pulmonary rehabilitation, and inhaled glucocorticosteroids will be added. Finally, very severe COPD requires the initiation of long-term oxygen therapy in order to maintain the patient's PaO<sub>2</sub> at least 60 mm Hg and SaO<sub>2</sub> greater than 90% (GOLD, 2003).

## *Patient's Responses to COPD*

### *Dyspnea*

Dyspnea is a subjective sensation that occurs when an individual feels short of breath. Other descriptions of dyspnea include breathlessness, air hunger, labored breathing or a preoccupation with breathing. Dyspnea is often exacerbated by exertion or a recumbent position such as during sleep. Causes of dyspnea include alterations in ventilation, gas exchange, or ventilation-perfusion ratios (Brashers, 2002).

Dyspnea has been reported to be the most commonly occurring symptom in multiple studies of people with COPD (Baker & Scholz, 2002; O'Neill, 2002; Sexton & Munro, 1988). All of the participants ( $N = 21$  women,  $M = 67$  years) in a descriptive qualitative study using the Common Sense Model as a framework reported dyspnea as the most common and most distressing symptom (O'Neill, 2002). In a descriptive correlational study of pulmonary rehabilitation patients ( $N = 51$ ), Baker and Scholz (2002) also found that dyspnea was the most common symptom reported. Gift and Sheperd (1999) in a descriptive study of outpatients with COPD designed to compare women ( $n = 48$ ;  $FEV_1 = 20\%$ ) and men ( $n = 56$ ;  $FEV_1 = 24\%$ ) in regard to their COPD symptoms found all subjects reported dyspnea in the week prior to data collection that did not differ between genders in frequency, severity, or distress. A convenience sample of patients drawn from a sub acute hospital in Hong Kong ( $N = 54$ ;  $M = 73$  years,  $SD = 10.91$ ;  $M$  length of



illness = 11.6 years,  $SD = 13.2$ ) reported severe or very severe dyspnea an average of 10 times a month and that the most dyspnea producing activities were “walking on inclines”, “walking on bumpy terrain”, and “climbing 3 stairs” (Yuet, Alexander, & Chun, 2002). In fact, people who are subsequently diagnosed with COPD commonly initially present for medical care with the chief complaint of dyspnea (GOLD, 2003).

### *Fatigue*

Fatigue is also common in people with COPD but has been described and measured differently by various researchers (Theander & Unosson, 2004; Trendall, 2000). In a recent concept analysis based upon Walker and Avant's framework (1995), Trendall (2000) defines the attributes of fatigue associated with COPD as follows: “a subjective internal and unpleasant feeling; affects physical, mental and emotional dimensions; does not resolve with rest and nutrient; an overwhelming desire to rest and sleep; decreased motivation and interest in surroundings; decreased capacity for physical and mental work” (p. 1129). Trendall further identifies the antecedents of fatigue to include a situation where individuals are conscious and able to evaluate their feelings about an illness or treatment. Consequences of fatigue include weakness, reduced vigor, decreased performance of nonessential activities, difficulty in attending to and understanding instructions, feelings of concern, frustration, irritability and fear (Trendall, 2000).

Characteristics of fatigue described by Trendall (2000) are supported in several studies describing fatigue in people with COPD (O'Neill, 2002; Small & Lamb, 1999). For example, in a qualitative study designed to describe participants' subjective experiences of fatigue people with COPD ( $n = 17$ ) and asthma ( $n = 19$ ), who lived at home, described fatigue as general feelings of tiredness that occur intermittently throughout the day as a result of their inability to obtain enough oxygen (Small & Lamb, 1999). These participants who had physician diagnosed COPD or asthma believed their fatigue was fundamentally different from fatigue occurring as a result of ordinary conditions or other health problems because of the associated dyspnea that was always present during fatigue (Small & Lamb, 1999). Likewise, women ( $N = 21$ ) in O'Neill's (2002) descriptive qualitative study that explored how women recognized and responded to symptoms of COPD described fatigue as being "tired beyond belief" (p. 298) and rated it second only to dyspnea as their most distressing symptom.

Fatigue challenges COPD patients because of its prevalence and debilitating effects. In a descriptive comparative study Theander and Unosson (2004) investigated the prevalence, duration and severity of fatigue and the impact of fatigue on cognitive, physical and psychosocial functioning in Swedish COPD patients ( $n = 36$ ;  $M = 68$  years) recruited from a pulmonary outpatient department and a sex and aged matched control group ( $n = 37$ ) selected from



the regional populations register. Significant numbers of these COPD patients identified fatigue as being a daily occurrence ( $n = 17$ , 47%), which lasted between 6 and 24 hours per day ( $n = 19$ , 53%), and was either the worst or one of the worst symptoms ( $n = 16$ , 44%) with which they had to contend. Although 40% of the subjects in the control group reported having a chronic illness that was not COPD, control group subjects reported less daily fatigue ( $n = 5$ ; 14%) that lasted between 6 and 24 hours per day ( $N = 7$ ; 19%), which was statistically significant when evaluated using Mann-Whitney U ( $p < .001$ ). In addition, the COPD patients reported significantly higher scores on the Fatigue Impact Scale indicating they had more functional limitations (cognitive, physical, psychosocial) than the control group when evaluated using t-test ( $p < .001$ ) (Theander & Unosson, 2004).

The extent of fatigue identified by Theander and Unosson (2004) is consistent with that identified by Yuet et al. (2002) in a descriptive, correlational study designed to describe functional status and symptoms of COPD and their influence on psychosocial adjustment. A convenience sample of patients drawn from a sub acute hospital in Hong Kong ( $N = 54$ ;  $M = 73$  years,  $SD = 10.91$ ;  $M$  length of illness = 11.6 years,  $SD = 13.2$ ) all reported fatigue and reported severe or very severe fatigue an average of 10 times a month. In addition, fatigue, as measured by the fatigue component of the Pulmonary Functional Status and Dyspnea Questionnaire, was significantly and positively correlated with

psychosocial adjustment ( $r = 0.54, p < .01$ ), as measured by the Psychosocial Adjustment to Illness Scale—Self Report, indicating that as fatigue scores increase psychosocial adjustment deteriorates.

Gift and Sheperd (1999) reported gender differences in the fatigue experience in a correlational study of outpatients with COPD designed to compare women ( $n = 48$ ;  $FEV_1 = 20\%$ ) and men ( $n = 56$ ;  $FEV_1 = 24\%$ ) with regard to their COPD symptoms. While there were no differences in the amount of fatigue that men and women reported,  $t = 0.81, p < .42$ , women found their fatigue to be more severe,  $t = 2.4, p < .05$ , and more distressing,  $t = 2.5, p < .01$ .

Fatigue has been strongly correlated with dyspnea and physical activity. In a pilot study with a descriptive correlational design Woo (2000) investigated the relationships between dyspnea, physical activity and fatigue in community dwelling patients with COPD ( $N = 22$ ;  $M = 67$  years,  $SD = 10.55$ ;  $M FEV_1 = 48\%$ ,  $SD = 13.63\%$ ). Fatigue was measured using the fatigue subscale of the Profile of Mood States which has reported internal consistency reliability (0.93), test retest reliability (0.74), and face and content validity. Dyspnea was measured using the Vertical Visual Analogue Scale which has been positively correlated with the horizontal visual analogue scale and negatively correlated with peak expiratory flow rate. Physical activity was measured as the distance achieved during a 6-minute walk on a flat surface. Woo (2000) not only found fatigue and dyspnea to be positively correlated,  $r_s = 0.69, p < .0001$ , but also found fatigue,  $r_s = -0.63, p$

$< .005$ , and dyspnea,  $r_s = -0.62$ ,  $p < .005$ , to be negatively correlated with physical activity leading to the author's conclusion that higher levels of dyspnea resulted in more fatigue and shorter walking distances.

Fatigue is also correlated with negative mood states in people with COPD. In a cross sectional descriptive correlational study Oh, Kim, Lee, and Kim (2004) investigated the multidimensional characteristics of fatigue in a group of Korean outpatients with COPD ( $N = 128$ ). The sample consisted of 73 men and 55 women who were older than 45 years with physician diagnosed COPD who had not had an exacerbation in the last 2 months and who did not have other major medical illness that could cause fatigue. Dyspnea, FEV<sub>1</sub>, pulmonary symptoms (shortness of breath, wheeze, cough, and chest tightness), mood state, stress levels, and sleep quality were measured and correlated with fatigue using the Pearson's correlation coefficient. Patients reported moderate levels of fatigue, mild dyspnea, a relatively negative mood state, poor sleep quality, and mild stress. While fatigue was significantly correlated with all of the study variables the correlation to dyspnea was the strongest,  $r = -0.55$ ,  $p < .01$ . Stepwise multiple regression analysis revealed the significant determinants of fatigue were dyspnea and negative mood state,  $R^2 = 0.484$ ,  $F(2,101) = 47.39$ ,  $p < .001$ , which explained 35% and 13.5% of the total variance respectively.

Fatigue is a multidimensional concept that is commonly found in people with COPD (Theander & Unosson, 2004; Yuet et al., 2002) and that has been



correlated to dyspnea (Oh et al., 2004; Woo, 2000), physical activity limitations (Woo, 2000), negative mood states (Oh et al., 2004) and poorer psychosocial adjustment (Yuet et al., 2002). While there seem to be no differences in the amount of fatigue men and women report, women find fatigue more distressful (Gift & Sheperd, 1999; O'Neill, 2002). In addition, people with COPD perceive their fatigue as unique because it is always associated with dyspnea (Small & Lamb, 1999).

### *Depression*

Depression has been commonly reported as occurring in patients with COPD (Eisner, Yelin, Trupin, & Blanc, 2002; Lacasse, Rousseau, & Maltais, 2001; O'Neill, 2002; Sexton & Munro, 1988). O'Neill (2002) conducted a descriptive qualitative study of 21 women enrolled in pulmonary rehabilitation to determine how women recognized and responded to symptoms of COPD. These women reported anxiety, depression and sleep disturbances as the most difficult disease symptoms after dyspnea and fatigue (O'Neill, 2002).

Likewise, in a cross sectional descriptive study Lacasse et al. (2001) investigated the prevalence of depression in COPD patients registered in a respiratory care home service and its consequences on health related quality of life (HRQOL). The Geriatric Depression Scale, which has been used to screen for depression in elderly populations and has reported reliability and validity, was used to measure depression. The Medical Outcome Survey—Short Form 36 (SF-

36), which has been used to assess HRQOL in people with COPD and which has reported reliability and validity, was used to evaluate HRQOL. Significantly, out of 109 study participants ( $M = 71$  years, *mdn* FEV<sub>1</sub> 34%), 105 used continuous oxygen therapy (*mdn* months of therapy = 19; range 9-32 months). Lacasse et al. found that 82 (75%) of these patients had significant or severe depression and more importantly, only 6% of those meeting the criteria for depression were receiving treatment for depression.

Depression is even evident in people with COPD who are not recruited from clinical agencies. Eisner et al. (2002) examined the impact of asthma and COPD on health status and work disability using a population-based sample of people ( $N = 3805$ ) with COPD ( $n = 172$ ), asthma ( $n = 297$ ), other chronic conditions ( $n = 1747$ ) and no chronic conditions ( $n = 1589$ ) recruited from the California Work and Health Study. Logistic regression analysis indicated that compared to those without chronic health conditions people with COPD had greater risk of depressive symptoms,  $OR = 10.05$ , 95% *CI*; poor sleep quality,  $OR = 5.51$ , 95% *CI*; fair or poor general health,  $OR = 10.95$ , 95% *CI*; and activity limitation,  $OR = 10.44$ , 95% *CI* after controlling for covariates. Among the people of employable age, those with COPD as compared to those without chronic illness were at higher risk of being unemployed,  $OR = .41$ , *CI* = 95%; as having prolonged labor force non-participation (>5 years),  $OR = 2.92$ , *CI* = 95%; and as perceiving themselves either as unable to work  $OR = .19.5$ , *CI* = 95%; or having

limited work capacity due to health status,  $OR = 12.90$ ,  $CI = 95\%$ . Based upon these data, authors attribute 1 in 5 cases of both diminished general health and depression to asthma and COPD and 1 in 17 cases of current nonparticipation in the labor force to COPD or asthma (Eisner et al., 2002).

### *Social Adjustment*

People with COPD are perceived to have problems with adjustment to social situations. Leidy and Traver (1996) in their secondary data analysis explored family perceptions of patient adjustment and social behavior in older adults with COPD ( $N = 51$ ) with patient self-report and published norms. The Katz Adjustment Scale for Relatives, which has reported reliability (.41- .89) and validity as well as reported norms of adjustment and social behavior for older adults, was used by the families to assess adjustment and social behavior of COPD patients. The Sickness Impact Scale, which has reported reliability (.85 - .94) and validity, was used to evaluate the functional abilities of the COPD patients. Family member ratings of social behaviors indicated that COPD patients had higher levels of belligerence,  $t(134) = 2.97$ ,  $p < .005$ , one-tailed; negativism,  $t(134) = 3.48$ ,  $p < .001$ , one-tailed; helplessness,  $t(134) = 2.69$ ,  $p < .005$ , one-tailed; withdrawal,  $t(134) = 3.12$ ,  $p < .005$ , one-tailed; nervousness,  $t(134) = 4.90$ ,  $p < .001$ , one-tailed; confusion,  $t(134) = 2.82$ ,  $p < .005$ , one-tailed; and general psychopathology,  $t(134) = 4.92$ ,  $p < .001$ , one-tailed, than the general population. However, socially expected activity performance and



free-time activity performance as reported by family members did not differ between patients with COPD and the general population (Leidy & Traver, 1996).

### *Individual Coping with COPD*

In a recent concept analysis of coping and stress, Keil (2004) concludes that coping is a response to stress whereby individuals confront internal or external events with various levels of success. Research describing individuals' responses to COPD have focused upon identifying strategies used to cope (Frey, 2000; O'Neill, 2002) and correlating coping strategies with other indicators of well being (Herbert & Gregor, 1997; Yuet et al., 2002). Women ( $N = 21$ ) in O'Neill's (2002) descriptive qualitative study that explored how women recognized and responded to symptoms of COPD identified multiple strategies used to control symptoms. For example, behavioral strategies revolved around medication administration practices, breathing techniques, energy conservation, and avoidance of airway irritants. Cognitive strategies used to manage their symptoms of COPD included distraction, self-talk, prayer, relaxation, being with positive people and living day to day.

Herbert and Gregor (1997) used a descriptive correlational design to study coping and quality of life (QOL) in 39 patients (33 = male; 6 = female) with severe COPD. Participants were interviewed in their homes using the Jalowiec Coping Scale (JCS) to assess frequency of use and degree of helpfulness of coping strategies, the Sickness Impact Profile (0 – 100%; higher scores = lower QOL) to

assess objective QOL and Cantrell's Ladder (Step 1 = worse possible QOL; Step 10 = best possible QOL) to assess subjective QOL. The JCS is composed of 60 coping strategies that the participant identifies as to use (ranging from 0 = never used to 3 = often used) and effectiveness (ranging from 0 = not helpful to 3 = very helpful). Individual coping strategies are assigned a coping style group based upon the qualities of the coping strategy so that a group score could also be obtained. The eight coping style groups are supportant, confrontive, palliative, emotive, evasive, fatalistic, optimistic and self-reliant.

Herbert and Gregor (1997) found the participants' frequency of use of coping strategies scores ranged from 49 – 115 (possible range 1 – 180) with a mean of 87.0 (*SD* not reported). Participants' perceived effectiveness of coping strategies scores ranged from 24 – 109 (possible range 1 – 180) with a mean of 72.1 (*SD* not reported). Participants identified the optimistic coping style as most beneficial followed by the supportant and confrontive. The participants in this study did not experience significant impairment in their objective QOL ( $M = 8.1\%$ , range 0 – 30.7%) and had high subjective QOL ( $M = 6.25$ , range 2 - 10). Finally, there were no statistical correlations between coping scores on the JCS and the objective QOL scores,  $r = .08$ ,  $p < .05$ . Authors attribute the low use of coping strategies to one or more of the following: decreased energy levels, not perceiving their lives to be stressful, use of coping strategies not included on the JCS, successful adjustment to illness (Herbert & Gregor, 1997).



The JCS has also been used by Frey (2000) to compare coping styles and effectiveness between male ( $n = 66$ ) and female ( $n = 88$ ) lung support group participants who were mailed a copy of the JCS to complete and return to the investigator. There were no statistically significant gender differences in either use of coping style or in their perceived effectiveness. Participants in this study used the optimistic coping style most often and found it most effective in coping with COPD.

In a descriptive correlational study Yuet et al. (2002) examined the relationships between perceived use and effectiveness of coping strategies and psychosocial adjustment in Chinese COPD inpatients ( $N = 54$ ) from a sub acute hospital. A Chinese language version of the JCS (.78 perceived effectiveness; .92 perceived use) was used to measure coping, the Psychosocial Adjustment to Illness Scale – Self Report (PAIS-SR) was used to measure psychosocial adjustment and the Pulmonary Functional Status and Dyspnea Questionnaire was used to measure severity of illness and functional status. In this study, participants' frequency of use of coping strategies scores ranged from 38 - 143 (possible range 1 – 180) with a mean of 86. Participants' perceived effectiveness of coping strategies scores ranged from 36 - 128 (possible range 1 – 180) with a mean of 76.5. The most commonly used coping styles were fatalistic, palliative and supportant. The three most effective coping styles were identified as supportant, palliative, and evasive. There were no significant relationships

between use of coping strategies and psychosocial adjustment or between perceived effectiveness of coping strategies and psychosocial adjustment. However, age was negatively correlated with perceived use of coping strategies,  $r = .34, p < .05$ , leading the authors to suggest that younger people use a greater variety of coping strategies.

Several authors have described the experience of coping with COPD; however, attempts to correlate coping with QOL (Herbert & Gregor, 1997) and psychosocial adjustment (Yuet et al., 2002) have not identified significant relationships. Descriptive studies using the JCS to measure coping have had various results perhaps because of cultural influences. According to Keil (2004) abstract terms are understood through language and usage—both of which are culturally defined. Therefore, it may be difficult to draw conclusions about coping strategies across cultural groups even if the same research tool is used. In studies of Americans (Frey, 2000; Herbert & Gregor, 1997) the optimistic coping style is identified as most commonly used and most effective for both men and women. Neither Frey (2000) nor Herbert and Gregor (1997) identified participant ethnicity in their studies.

#### *Family's Responses to COPD*

The impact of COPD on families has been explored in several studies most of which describe the experiences of wives responding to their husband's illness (Bergs, 2002; Sexton & Munro, 1985). Kanervisto, Paavilainen, and

Astedt-Kurki (2003) in their descriptive, comparative study of the impact of COPD on family functioning did not identify which family members participated.

Bergs (2002) conducted a phenomenological study of the experience of quality of life of women ( $N = 6$ ) who cared for their husbands who had COPD. Quality of life was defined as “the satisfaction . . . with their [the wives’] lives and surroundings as well as the values they attach to varied aspects of their lives” (Bergs, 2002, p. 616). Seven of the thirteen themes that emerged during the unstructured personal interviews seemed to describe the wives’ responses to their husbands’ illness while the remaining six themes addressed caregiving. Themes describing the wives’ responses to their husbands’ illness included no time to worry about my physical health, having employment was important, being on the alert even at night, weakening of the marital relationship, the emotional straitjacket of living with him, becoming mentally worn out, and the feeling of isolation. Bergs believed the women in this study had lost their self-identity as they became so involved in their husband’s care. In fact, successfully delivering the care their husbands needed was these wives’ main value at this point in their lives (Bergs, 2002).

Several of the themes identified by Bergs (2002) are evident in Sexton and Munro’s (1985) comparative descriptive study that investigated the differences in stress and life satisfaction reported by wives of COPD patients ( $n = 46$ ) and wives whose husbands did not report chronic illness ( $n = 30$ ). Sexton



and Munro identified roles and responsibilities the wives of COPD patients assumed, the major day-to-day problems these wives addressed and the activities the COPD wives gave up because of their spouses' illness. The wives of COPD patients reported higher stress,  $F(1) = 4.800, p = .032$ , and lower life satisfaction,  $F(1) = 8.104, p = .006$ , than the wives whose husbands did not have chronic illness. In addition, the wives of COPD patients indicated they had taken on additional roles and responsibilities,  $F(1) = 5.297, p = .025$ , and rated their health lower,  $F(1) = 7.333, p = .009$ , than the wives of men who did not have chronic illness. The main problems reported by the wives of COPD patients were related to their husbands' condition and symptoms (22%), their husbands' attitude and irritability (20%), and the loss of the wives' personal freedom (20%). Wives of COPD patients were more likely to talk over problems with their children (46%) than with their husbands (33%) and relied on their children (70%) or physician (46%) for assistance. In contrast, wives whose husbands did not have chronic illness talked over problems with their husbands (70%) or friends (53%) and relied on their friends (73%) and children (63%) for assistance (Sexton & Munro, 1985).

The sample in the Sexton and Munro (1985) study was a convenience sample of community dwelling COPD patients and their wives most of whom had moderately (24%) or markedly (35%) restricted activity. Bergs (2002) studied women whose husbands were disabled as a result of COPD but who still lived at

home. Kanervisto et al. (2003) studied caregivers caring for much sicker people when they compared the level of family functioning between families of community dwelling oxygen dependent patients with COPD ( $n = 36$ ) and families of inpatients ( $n = 29$ ) who had been hospitalized at least 3 times in the past year. The Family Dynamics Measure 2 that was designed using Barnhill's framework for healthy families and which was tested for use in family nursing research was used to evaluate family functioning. While the overall family functioning scores for both family groups fell within the functional level, families of the oxygen dependent patients displayed higher levels of independent thought,  $t = -1.98$ ,  $p = .052$ , had higher levels of mutuality and emotional closeness,  $t = -2.19$ ,  $p = .032$ , and were more flexible in their responses to change,  $t = -2.24$ ,  $p = .029$ , than the families of the inpatients (Kanervisto et al., 2003).

While family responses to COPD have been studied from the perspectives of several different cultural groups (Bergs, 2002; Kanervisto et al., 2003; Sexton & Munro, 1985), wives who have husbands with COPD have been the primary informants (Bergs, 2002; Sexton & Munro, 1985). These wives report changes in their family roles (Bergs, 2002; Sexton & Munro, 1985), social isolation (Bergs, 2002; Sexton & Munro, 1985), emotional fatigue (Bergs, 2002; Sexton & Munro, 1985), and loss of self-identity (Bergs, 2002). However, some families of very ill COPD patients function at high levels despite oxygen dependence and hospitalization (Kanervisto et al., 2003).

### *Caregiving*

Families have always cared for each other, but family caregiving has evolved due to changes in health care and societal expectations. For example, a decreased mortality rate from acute illness has resulted in greater numbers of individuals with increased life spans but dealing with chronic illnesses such as COPD (Lubkin & Larsen, 2002). Successful treatment of chronic illness often requires complicated care regimens with which caregivers often assist. In addition, at a time when hospitals care for only the most acutely ill, many elderly and disabled prefer to be cared for in their homes often by family members (Poirier & Ayres, 2002).

Understanding caregiving research is complicated by various conceptualizations of caregiving. Initial descriptions of caregiving as “onerous work done by beleaguered or saintly women” (Poirier & Ayres, 2002, p. xi) have given way to more balanced views of caregiving (Hunt, 2003). Hunt (2003) in her recent concept analysis of caregiving describes the negative conceptualizations of caregiving as burden, hassles, strain, and stress; the positive conceptualizations as esteem, uplifts, satisfaction, finding meaning and gain and the neutral concept of caregiver appraisal.

#### *Caregiver Appraisal*

Caregiver appraisal occurs when caregivers assess stressors, the affective and cognitive responses to stressors and coping responses (Hunt,



2003). Since appraisal is neither positive nor negative, it may prove to be the most useful construct from which to view caregiving. For example, caregivers are expected to consider the needs of the care recipient over their own needs and provide care without compensation—a situation that is imbalanced and which over time may be perceived as a burden. However, as Hunt (2003) points out, not all imbalanced situations are inherently negative such as parent-child or teacher-student relationships. So, different caregiving situations may be perceived by different caregivers as positive, negative, or neutral depending upon the individual caregiver's appraisal of the situation. Caregiver appraisal has been measured using the Caregiver Reaction Assessment Scale (CRA) and used to study caregivers for several groups of people with chronic conditions including those with cancer (Nijboer, Triemstra, Tempelaar, Mulder, Sanderman, & van den Bos, 2000), those who have had stroke (Teel, Duncan, & Lai, 2001), and those who care for elders after acute hospitalization (Bull, Maruyama, & Luo, 1995).

### *Caregiving Stress*

Caregiving stress is derived from the relationships among the individual caregiver, the caregiver's individual characteristics, and the environmental event perceived as stressful (Hunt, 2003). Events perceived as stressful to caregivers for people with COPD include the challenges of providing emotional support (Cossette & Levesque, 1993). Stressors of caregiving may be perceived

differently depending upon individual characteristics such as race or ethnic group (Cain & Wicks, 2000).

The difficulty in providing emotional support as a task of caregiving figured highly in Cossette and Levesque's (1993) cross sectional study of French speaking wives ( $N = 89$ ) who cared for their husbands with moderate to severe COPD. The study was designed to determine if the relationships between categories of caregiving tasks and the mental health of the wife caregivers differed according to the number of tasks or amount of disturbance caused by the task. In addition the influence of informal social support on the wives' mental health was determined. Regression analysis indicated that providing difficult emotional support was predictive of somatization, depression, obsession-compulsion, anxiety, and hostility. The amount of disturbance generated by health care tasks was a significant predictor of depression. Depression was the most important predictor of psychotropic drug use that in this sample included 40% of the wives. Wives who received respite support were 3 times more likely to use psychotropic drugs.

While female caregivers may be particularly vulnerable to the stressors of caregiving, race and cultural group are also influencing factors in perceptions of caregiving stressors. Cain and Wicks (2000) examined the differences in subjective burden by caregiver age, race, gender, educational level, family relationship and financial adequacy in a secondary analysis of 138 family



caregivers for patients with COPD. Caucasian caregivers reported significantly higher levels of burden,  $t = -3.10$ ,  $p = .002$ , than African American caregivers. Caregivers younger than 55 years reported significantly more burden,  $t = 1.97$ ,  $p = .05$ , than caregivers older than 55 years. In this sample, subjective burden did not differ based upon gender, educational level, family relationship (spouse, non-spouse), or financial adequacy, although significantly more African American caregivers reported inadequate income,  $\chi^2 = 3.64$ ,  $df = 1$ ,  $p = .05$ . Cain and Wicks (2000) question whether “race is a proxy measure for culture or social class and which of these factors potentially mediate the experience of caregiver burden” (p. 63).

#### *Coping with Caregiving*

Caregivers respond to the stress of caregiving by confronting internal and external events (Keil, 2004) and research describing caregiver coping has identified coping strategies used by caregivers for people with COPD (Bergs, 2002). Bergs (2002), in her phenomenological study of the experiences of quality of life of women ( $N = 6$ ) who cared for their husbands with COPD, identified themes that reflected their caregiving experiences including being too proud to ask for help, having to walk the road to the very end, weakening of the marital relationship, the dreadful prospect of a single life, positive aspects of caregiving, spiritual help, and the need they had for increased social support. Factors increasing the quality of life of the women in Bergs' study included having close

relationships with their children and grandchildren, being able to please their husbands and care for them until the very end, getting to know their husbands better, and doing more things together.

### *Social Support*

Caregiver support provided by family members (Xixolian, Chaiwan, Panuthai, Yijuan, Lei, & Jiping, 2002) has been investigated to determine care recipient outcomes. In their study of Chinese COPD out-patients ( $N = 98$ ), describing and correlating family support to self-care behaviors, Xiaolian et al. (2002) found that cultural norms of family intimacy and cohesiveness may account for high levels of perceived family support. Using the Perceived Social Support from Family Scale (MPSS-Fa), that had been modified and used in several studies with Chinese respondents, patients responded either yes or no to 15 questions (15 = high family support; 1 = low family support) designed to measure the extent to which moral support, emotional support, intimacy and the need for information and feedback were perceived as being provided by their family members. Self-care was conceptualized using Orem's Model and measured using the Self-Care Behavior Scale for COPD patients (COPDSC), a researcher developed 32-item Likert scale measuring universal self-care requisites and self-care behaviors for meeting health deviation self-care requisites. Respondents were primarily married ( $n = 76$ , 78%) men ( $n = 65$ , 66%) with stage I or II COPD ( $n = 86$ , 88%) who reported that their spouse was their

most available support person ( $n = 69$ , 70%). Family support scores were very high ( $M = 10.43$ ,  $SD 1.99$ ) and correlated positively with both total self-care behaviors,  $r = 0.252$ ,  $p = 0.012$ , and self-care behavior for meeting health deviation self-care requisites,  $r = 0.216$ ,  $p = 0.032$ . The authors concluded that COPD patients with higher levels of family support would likely perform more self-care behaviors.

### *Summary*

Knowledge about family caregiving has exploded in the past twenty years as family members have learned how to care for individuals with chronic illnesses in the home for longer periods of time. While traditional COPD caregiving research has focused on the white urban female caring for an ill spouse, research about male caregiving and caregiving by members of other racial and ethnic groups is ongoing. Non-urban caregivers have not been represented in the literature and may have special caregiving challenges. For example, non-urban residents are typically older with less healthy lifestyles. Caregivers for people with COPD struggle to care for individuals who likely have dyspnea, fatigue, depression, and problems with social adjustment. The role of tobacco in the development of COPD is clear, but as tobacco use becomes more socially unacceptable it is unclear how caregivers for people with COPD will be affected.



## CHAPTER 3

### PROCEDURE FOR COLLECTION AND TREATMENT OF DATA

A grounded theory approach was used to develop substantive level theory that explained the caregiving experiences of caring for a family member with oxygen dependent COPD. Grounded theory is a qualitative research methodology developed by Strauss and Glaser (Strauss & Corbin, 1998) using the theoretical perspective of symbolic interactionism. The purpose of grounded theory is to develop theories, which explain human behavior. These newly discovered theories are verified by systematic data collection and data analysis that occur simultaneously throughout the study. Data are collected in a naturalistic setting where the researcher tries to identify patterns of behavior and then discover relationships among the patterns. The end result is a substantive level theory that describes a process (Morse & Field, 1996).

Grounded theory was particularly suited to this investigation for two reasons. First, the process of caregiving for an adult with oxygen dependent COPD has not been extensively described. Qualitative methods are used either when little is known of an event or when what is known is thought to be incomplete or biased (Morse & Field, 1996). Grounded theory, because of its theoretical basis in symbolic interactionism, focuses on processes individuals use to make sense of their life situations (Milliken & Schreiber, 2001).

Second, the purpose of this investigation was to develop a theory that explained the caregiving experience from the perspective of the caregiver. Qualitative methods including grounded theory are especially valuable in describing an emic perspective (Morse and Field, 1996). Grounded theory has been used to enlighten how people “deal with what has happened to them through time and in changing circumstances” (Schreiber, 2001, p. 57). Since a major strength of grounded theory is its ability to identify and analyze complex processes, grounded theory is an effective method to use to understand the experiences individuals have in responding to a life events, in this case caring for a family member with oxygen dependent COPD (Morse, 2001).

### Setting

The setting for this investigation was Calcasieu Parish in southwestern Louisiana. According to 2000 Census records, there were 183,577 people living in Calcasieu Parish most of whom were Caucasian (135,113; 74%) or African-American (44,058; 24%). In 1998, the primary sources of employment for Calcasieu Parish residents were manufacturing (13%), retail (13%), health care (12%), government (12%), and accommodation and food services (11%). In 2001, when the national unemployment rate was 5%, Calcasieu Parish reported an unemployment rate of 6%. In 1999, Calcasieu Parish residents reported a \$17,710 per capita income which is significantly less than the \$21,587 per capita income reported nationally for the same year. Not surprisingly, 15% of the parish population fell below federal poverty guidelines and 25% reported being

medically uninsured. While the overall parish had adequate numbers of primary care physicians and dentists, there were several areas within the parish that have been designated as health professional shortages areas (HPSA) by Federal Bureau of Shortage Designation (Chapman & Nichols, 2003). These areas included the towns and surrounding areas of Vinton in the far western section of the parish, DeQuincy in the northern section of the parish, and the northern section of Lake Charles which is primarily African-American. The parish is served by 6 hospitals all of which are located in Lake Charles except West Calcasieu-Cameron Hospital located in Sulphur and DeQuincy Memorial Hospital located in DeQuincy which carries the designation of a critical access hospital. The parish has 2 public health units—one in Lake Charles and one in Sulphur as well as a rural health clinic in Iowa, a small town in the eastern portion of the parish (Chapman & Nichols, 2003).

Interviews were conducted in public areas, for example, public libraries, which are usually centrally located within the community and have private, quiet rooms that can be used for audio taping conversations. Settings away from the caregivers' homes were chosen so caregivers could discuss their caregiving experiences without distraction from the care recipients, who often lived in the same home, other household members, or other distractions. The rationale for choosing a primarily non-urban setting was that caregivers in these settings have not been sufficiently represented in existing studies.



## Population and Sample

A purposive sample of caregivers of people diagnosed with oxygen dependent COPD was recruited via local physicians and nurse practitioners who routinely saw oxygen dependent COPD patients in their practice. The physicians and nurse practitioners asked patients for their permission to give their name, address, and phone number to the nurse researcher who was studying caregiving for people with COPD.

In this study caregivers were English speaking adult family members who reported that they provided uncompensated care for the person with oxygen dependent COPD on a regular, ongoing basis. Multiple caregivers from each family as well as caregivers who did not reside with the person with COPD were interviewed. The sample was composed of female and male caregivers including Caucasian and non-Caucasian caregivers living in urban and non-urban settings in Calcasieu Parish in Louisiana.

Theoretical sampling guided participant selection as data analysis yielded categories of data. Theoretical sampling is a technique described by Strauss and Corbin (1998) where study participants are chosen for their ability to enlighten how “a category varies in terms of its properties and dimensions” (p. 202). As the properties and dimensions of each category become clearer no new data will emerge and the relationships among categories will be established. At this point, which Strauss and Corbin (1998) call theoretical saturation, data collection will

cease. For this investigation it was anticipated that theoretical saturation would occur after 15 to 20 participants had been interviewed (Creswell, 1998).

### Protection of Human Subjects

After approval from the Institutional Review Board at Texas Woman's University (Appendix A) prospective participants were recruited from local physicians and nurse practitioners who cared for patients with oxygen dependent COPD. The physicians and nurse practitioners asked their patients who had oxygen dependent COPD for their permission to give their name, address, and phone number to the nurse researcher. If the patient agreed to release contacting information, the nurse researcher contacted the patient and asked them to recommend a family caregiver for possible inclusion in the study. If the patient did not agree, the physician or nurse practitioner did not release contact information to the researcher. If, after talking to the nurse researcher, the patient did not recommend a caregiver for participation the patient was not contacted further.

Written informed consent (Appendix B) was obtained from each caregiver who agreed to be a study participant. All questions were answered prior to having the participant sign the consent form and initiating interviews. In addition, the researcher offered to read the consent to the participant and gave each participant a copy of the consent.

Several risks existed for caregivers who agreed to be interviewed. For example, improper release of data could have resulted in loss of confidentiality.

Data, both computer disc and hard copy, were kept in a locked file that only the investigator has access to as recommended by Creswell (1998). Pseudonyms were used to protect participant privacy (Creswell, 1998). If family members or physicians had inquired about interview information they would have been told caregiver responses could not be shared without the participant's permission. When an interview was interrupted, the tape recorder was turned off and if necessary the interview would have been rescheduled.

Interviews could have been anxiety producing for caregivers or cause physical or emotional discomfort as well as take up their valuable time. Participants were told they could refuse to answer any questions without penalty, that they could end the interview at any point, and that interviews would be scheduled at their convenience. There was no risk of injury to the participants, but they were told that any descriptions of potentially abusive behaviors would be reported.

#### Instrument

A semi structured open-ended interview guide which included demographic data (Appendix C) that was used in the pilot study was used with minor modifications to explore caregiver experiences since their family member's diagnosis with COPD, the challenges the caregivers have experienced, and what role nurses had in helping caregivers cope. Questions and probes were used as indicated to encourage closer examination of the caregiving process and to help the investigator understand the caregiver's experiences. The interview guide was



modified as new information emerged to ask more specific questions about the caregiving process as recommended by Milliken and Schreiber (2001).

Demographic data about the caregiver including age, gender, ethnic group, employment status, and length of time caregiving was elicited at the beginning of the interview. Caregiver information about living arrangements was also obtained including whether the caregiver resided with the care recipient, others living in the care recipient's home, and the location of the home. The length of time the care recipient had been receiving home oxygen was also assessed.

#### Data Collection

Caregivers who met the study criteria were identified and referred to the investigator by physicians and nurse practitioners. The physicians and nurse practitioners asked patients for their permission to give their name, address, and phone number to the nurse researcher. Letters were then sent to the patients describing the study and asking the patient to recommend a caregiver who might be interested in participating. The researcher followed up one week later with a phone call to the patient asking for the name and contact information of the caregiver who was then contacted by the researcher. If the caregiver was interested in participating, a meeting at a convenient time and location was scheduled. If the caregiver was not interested in participating, the researcher did not contact the caregiver again.

Audiotaped interviews occurred in a private room with only the investigator and the caregiver present. Interviews lasted approximately one hour each. Two tape recorders were used with staggered start times.

After the participant left the interview the investigator audiotaped a memo describing her impressions about the interview, any thoughts about the data that needed specific analysis, and any procedural issues that needed to be addressed. Memos are valuable for recording the “progress, thoughts, feelings, and directions of the research and researcher (Strauss & Corbin, 1998, p. 218). Additionally, immediate memoing prevents the loss of data that might otherwise occur (Milliken & Schreiber, 2001). Data transcription occurred as soon as possible after the interview and the investigator checked the transcriptions of the audiotaped interviews to verify accuracy.

### Treatment of Data

Data collection and analysis occurred concurrently so emerging patterns and categories could be identified. Data was analyzed using constant comparative analysis so conditional propositions could be derived. Data gathered from subsequent interviews was analyzed by comparing it to earlier interviews. Core concepts were identified by identifying themes that described caregiving for oxygen-dependent COPD patients (Creswell, 1998).

Initially, open coding of the interviews identified categories of information. Categories were phenomena that the study participant described such as a problem, issue, event or happening (Creswell, 1998). Open coding was used



early in the study to “discover, name, and categorize phenomena according to their properties and dimensions” (Strauss & Corbin, 1998, p. 206). Properties are the characteristics of the phenomena while data dimensions refer to the location of the property on a scale. As the analysis continued, data were placed in existing categories when possible (Milliken & Schreiber, 2001).

Axial coding began when the researcher discovered similarities and differences of the categories and began linking dimensions and properties. The goal of axial coding was to understand the interrelationships between the categories and subcategories. These interrelationships were visualized through a paradigm that helped the investigator integrate structure and process (Strauss & Corbin, 1998).

Selective coding began when the investigator identified a single category as central to the investigation that reflected the main concern of the study participants (Milliken & Schreiber, 2001). The endpoint of selective coding was a theory that encompassed a “central phenomenon, causal conditions, strategies, conditions and context, and consequences” (Creswell, 1998, p. 58). For this investigation a visual diagram identified the central phenomenon of caregiving, strategies the caregivers use for caregiving as well as contextual and intervening conditions that affected caregiving and consequences of using the caregiving strategies.

Memoing was the main technique by which analysis decisions were documented. Memos provided a mechanism for the investigator to record her

thoughts, ideas and understanding of the participants' meanings related to caregiving (Milliken & Schreiber, 2001). Actually, memos provided tangible evidence of the symbolic interaction between the data and the researcher.

## CHAPTER 4

### ANALYSIS OF DATA

The purpose of this grounded theory study was to explore the experiences of family members who care for an adult with oxygen dependent chronic obstructive pulmonary disease (COPD). Grounded theory studies are done to develop substantive level theory to explain the process of human behavior (Morse & Field, 1996). Data were gathered using audio-taped interviews which were subsequently transcribed and analyzed. This chapter will present a caregiving model that describes the process of caregiving for family members who have oxygen dependent COPD.

#### Description of the Sample

The purposive sample contained 13 caregivers of adults diagnosed with COPD that were chosen from the patient lists of three physicians—one family practice physician, one internist, one pulmonary medicine specialist—in southwest Louisiana. Caregivers were English speaking adult family members who reported that they provided uncompensated care for the person with COPD on a regular, ongoing basis. Audiotaped interviews were conducted in private areas usually in public libraries or at a local hospital near the caregivers' homes. In one instance the spouse and daughter of one care recipient were interviewed simultaneously. The majority of caregivers ( $n = 8$ ) lived in towns with populations

of 5,000 or less while four lived in a town of 20,000 and one lived in a town of 72,000.

The sample consisted of 6 wives (age range 57 – 75 years,  $M = 66.6$  years,  $SD = 7.40$ ), 2 husbands (age range 70 – 72 years,  $M = 71$  years,  $SD = 1.41$ ), 3 daughters (age range 47 – 53 years,  $M = 50$  years,  $SD = 3.00$ ), 1 son (34 years) and 1 longtime female friend (66 years) who reported providing care for the prior 6 months to 20 years ( $M = 7.9$  years,  $SD = 7.00$ ). All care recipients were oxygen dependent as a result of COPD ranging in duration from 6 months to 10 years ( $M = 3.74$  years,  $SD = 2.81$ ) and most ( $n = 8$ ) had other chronic illnesses such as osteoporosis, fibromyalgia, diabetes mellitus, atrial fibrillation, coronary artery disease. Caregivers reported that five care recipients continued to smoke, five care recipients had quit smoking one as recently as in the prior 6 months, and two did not discuss the care recipient's smoking history. According to published obituaries, three of the care recipients died within 6 months of the caregiver interviews.

All caregivers were Caucasian except for one African-American and five also reported significant personal illness such as coronary artery disease, oxygen dependent emphysema, arthritis severe enough to require joint replacements, recent pneumonia, and atrial fibrillation. Four caregivers either reported personal tobacco use or were seen smoking by the investigator, three caregivers reported previous smoking but had quit the habit, one was currently a nonsmoker but it



was unclear whether she had smoked in the past, and five caregivers did not discuss their personal smoking habits.

All the spouses lived with the care recipients in single family homes. One couple's college aged granddaughter lived with them at the time of the interview. One daughter was staying temporarily with the care recipient and one daughter, who worked full-time, had recently moved her mother to her brother's home as her mother's care requirements increased. One daughter lived in the same town as the care recipient. The son lived with his wife and three children approximately a mile from his parents. The friend who was a caregiver maintained her own home in another town and only stayed with the care recipient if he was having difficulties.

All spousal caregivers were retired although three reported flexible part time jobs or volunteer commitments. One daughter continued to work full time as a hospital unit clerk. Two daughters reported that they were homemakers. The son worked two part-time jobs. Three caregivers reported they had worked as nursing assistants and one was a retired registered nurse.

Five caregivers reported that in addition to caring for their family member with oxygen dependent COPD they had significant responsibilities caring for additional family members. For example, one daughter had adopted her granddaughter and had been caring for her for 8 years; one caregiver had an adult daughter who was nursing home bound; three reported responsibilities for elderly, incapacitated siblings; and, the son reported daughters with chronic



illness. Three caregivers reported significant family caregiving in the past. One had cared for her mother who also had oxygen dependent COPD; one cared for her bed ridden husband and mother simultaneously for years prior to their deaths; and one cared for her brother-in-law, sister-in-law, and mother in the last months of their lives.

Hurricane Rita, which hit southwest Louisiana September 24, 2005, occurred during data collection. Four interviews were completed prior to Hurricane Rita and the remaining interviews occurred afterward. Data collection was temporarily suspended during the immediate recovery period. Interviews resumed 3 months after the hurricane and were completed the following summer. Of the 29 care recipients contacted to recommend caregivers for inclusion in the study, 12 recommended caregivers who ultimately participated. Five care recipients refused saying they were too busy, one was no longer using oxygen, and two care recipients died before interviews could be scheduled. Three care recipients indicated caregivers were too ill to participate while two caregivers stated they could not leave their family members long enough to be interviewed. Four caregivers did not offer reasons. Fifteen of the refusals occurred after the hurricane as families recovered from the hurricane's effects.

### Findings

The diagnosis of COPD began what is often a long and difficult journey for caregivers and their family members. Caregivers and their families moved through three stages as the caregiving process became more complicated and

time intensive. The caregiving process for oxygen dependent COPD patients was akin to taking a journey (see Figure 1). While each phase of the journey required unique knowledge and skills the phases often overlapped as caregivers progressed in their caregiving journey. The caregiving process changed over time as caregivers and care recipients aged and matured. Finally caregiving was affected by the caregivers' previous experiences with caregiving as well as by their previous relationship with the care recipient.

The initial stage of caregiving was conceptualized as *Learning to Drive*. Following diagnosis of COPD, caregivers began a process of education where they learned about the disease, medications, breathing treatments and they started observing the care recipient's responses to the disease. During this stage care recipients remained independent in both managing their care regimen as well as with activities of daily living (ADLs). The process became more complex as the disease progressed and oxygen therapy was added.

The second stage, *Navigating the Bumps*, was the most challenging for caregivers as they learned to restructure their lives to accommodate increasing restrictions in their family member's activities. Caregivers used a variety of strategies to manage this stage including *Negotiating*, *Getting Help*, *Watching*, and *Coping*. *Negotiating* involved mutual decision making by the care recipient and caregiver in order to maintain the care recipient's independence and the caregiver's lifestyle as care recipients required more care and supervision. Caregivers and care recipients negotiated solutions to a variety of issues

**Caregiving Model**

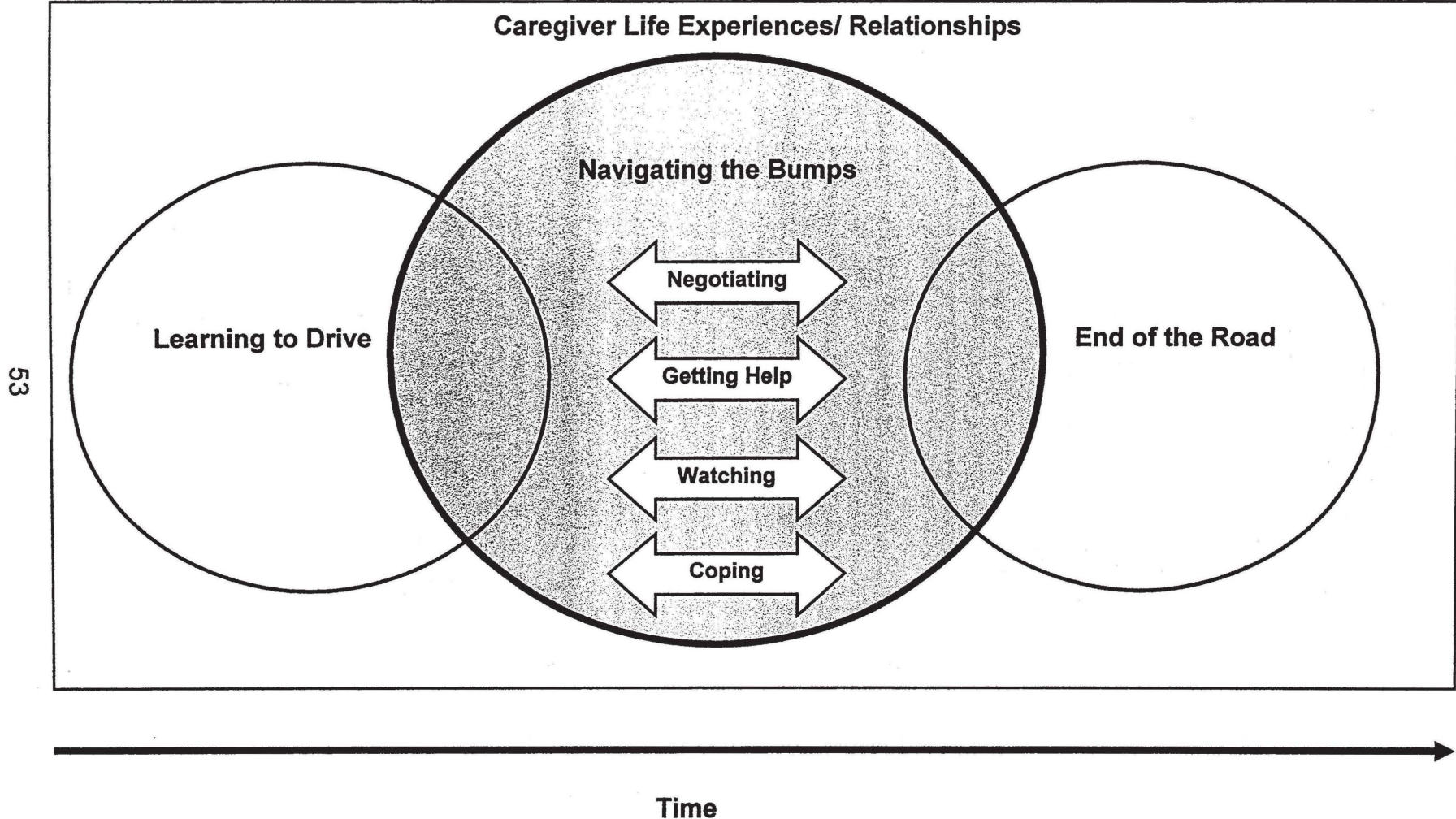


Figure 1. Caregiving Model



including continued tobacco use, adherence to the medical regimen, activities of daily living and the need for hospitalization. *Getting Help* were activities that some caregivers did to draw others—family as well as health care providers—in to assist with caregiving decisions. *Watching* referred to the vigilance almost all caregivers employed to assess and monitor their family member's status. *Coping* included the emotional responses and strategies for maintaining personal health caregivers use as they acknowledge their frustrations of caregiving even as they fear for their care recipient's well-being.

Finally, as the disease reaches the terminal stage which is called *End of the Road*, caregivers and their family members confront issues related to the end of life. By this point caregivers are often able to reflect back on the caregiving experience and report satisfaction with their caregiving journey.

### *Learning to Drive*

A common mark at the beginning of the journey was the unknown nature of COPD. At the initial COPD diagnosis most caregivers did not know what to expect and this unknown created a drive to find out more information. As one spouse whose husband died of COPD complications 4 years after initial diagnosis explained, "It was just a COPD name." Her daughter further explained their learning process saying, "... it just sounded really bad...and as his illness progressed on, of course, I started doing some reading on it and as his illness progressed on he was doing everything that I had read". One African-American daughter described her actions while her mother was hospitalized, "...I just listen



and kind of like learn from the nurses.” A 70-year-old spouse caring for his wife who had COPD as well as fibromyalgia used his 90-year-old sister who had been a nurse as a resource saying, “there’s a whole lot of things that I don’t know, but talking to somebody who’s been in the profession helps out.” Caregivers were diligent in finding information from the internet, from family members who were nurses, from the news media and by watching and learning from nurses who cared for their family members.

Not all caregivers were present for the initial diagnosis. Those beginning their caregiving roles after marked disability was already present had a harder time understanding COPD and the limitations placed upon care recipients. Starting later in the journey increased frustration. One daughter, who moved in with her mother after she was already oxygen dependent, struggled with understanding her mother’s care regimen and responses to illness. An example of this daughter’s frustration with her mother was evident when she said

All she does is grab her a quick something to eat. ... She gets a piece of toast or something like that and she’ll sit in that chair, and that’s it. She doesn’t do anything. She won’t bathe herself. She won’t pick up in her house. She will not do anything....Momma can do lots of things when she wants to. But she won’t.

During the initial phase care recipients managed their own care regimens including medications, nebulizer treatments, and the oxygen delivery systems. However, with disease progression caregivers became experts on strategies to

help manage care regimens. Increased responsibilities took extra planning – particularly for oxygen management. Equipment was heavy and difficult to handle, requiring extra planning. Resource levels also limited options. For example, one African-American daughter who cared for her mother and her 8-year-old granddaughter wished her mother could have had an oxygen delivery system that would have been lighter weight saying,

I try to keep her at least one 8-hour tank for her to go to the doctor on, and I have the little portable tanks. They're for 2 ½ hours for her to go to church when she used to go to church. But you know they got that little helium tank and it's so lightweight. That would have been so much better for her, but they said Medicaid don't (sic) pay for that.

Once oxygen was routinely needed there was concern about how to manage in order that the oxygen would always be available. A caregiver, a spouse who was also a retired registered nurse, commented,

People who are on concentrators and have the cylinder gases tend to isolate themselves. I remember once, taking his sister [who also used oxygen] out to lunch, and she worried the whole time we were gone that her oxygen was going to give out while we were gone.

Medications posed challenges for several caregivers. For some caregivers the large number of different medications was confusing; other families had difficulties with side effects of medications, and still others struggled with care recipients who did not take medications as prescribed. For example, three

siblings learned their parents' medication regimens when they suddenly found themselves caring for both their dad who had oxygen dependent COPD and their mother recently discharged from the hospital after having had pneumonia. One of their daughters described how unknowledgeable they were.

We need to be prepared. ...we should have been prepared more. It was like we were doctors and nurses and we knew nothing...I called ... we'd all call the separate floors and talk to the nurses and say, "Is this this?" and they'd say "Okay now and blahblahblah". I said "Okay, Okay." Treatments, I had never mixed up a treatment. I didn't even know how to do a treatment. We all learned.

Wearily this daughter concluded, "It was always so much medicine, medicine, medicine." Subsequently, their dad died at home with his children present while his wife who had been rehospitalized with respiratory failure heard of her husband's death from her hospital bed.

Medication side effects were a source of stress for some caregivers. A husband whose wife had only been recently placed on oxygen reported, The biggest problem she has had is the reaction to the medication the doctors would give to her. It was frustrating to her and the side effects caused such things as diarrhea ...even to the point of suspected Crohn's disease ...

One son who assisted his mother in caring for his 84-year-old oxygen dependent dad reported marked behavior changes due to medication side effects that occurred when his dad was hospitalized saying



... it's a medicine that they give him, and I've seen him and I've had momma call me crying, telling me I need to come down here [to the hospital] 'cause he would get rough with her. So I'd come down here, and you'd think he's losing his mind. He's just going crazy. He get up in the bed and jerk the IVs out of his arms. And tell them he's leaving. And she just go in and get hysterical. I come down here and try to make him...As long as I was around, he won't do nothing like that.

How caregivers managed difficulties with medications tended to reflect how they managed the whole caregiving process. This son, who assisted his mother in caring for his dad, worked part time at night and was the minister of a small church in addition to caring for an elderly aunt and his wife and three children. He summed up how he and his sister approach their parent's care saying, "...when my daddy's in the hospital or my daddy's at home, either way it goes, we're gonna be with him. That's just. . That's how we are."

Other families struggled with care recipients not adhering to prescribed medicine regimens possibly because of medicine side effects or advanced illness. One daughter, who recently moved in with her mother to help care for her, describes their family's situation as follows:

... she's on like 15 different types of medication, and she chooses the one she wants to take...she was supposed to be taking one for Alzheimer's because she gets in like a dementia form. She has bad memory loss. She does. She forgets things she says and repeats it like twenty times a day,



and stuff like that. So, she chooses her medications. So, she doesn't stay like she should be. You know, she goes to a pain doctor also. So, she never forgets her pain medication and stuff like that, but her other medicines. She'll say "Oh that makes me sick. I don't think I need to take that." And she won't take it because she chooses them.

This care recipient would place her oxygen tubing under her leg while she smoked and attempted to hide her continued tobacco use from her home health nurse and physician with perfumes. Thus far, her daughters have not discussed these issues with their mother's health care providers.

As caregivers began learning their caregiving role they began watching their care recipient carefully and they gradually began to learn what behaviors indicated a deteriorating condition. This vigilance continued throughout the caregiving process to the very end. In addition to observing care recipient behaviors, caregivers became very observant of care recipient daily routines and care regimens and learned to respond accordingly. For example, one wife caring for her husband for 20 years describes how she responded to her husband when he comes in from his beloved yard. "...if he runs out of oxygen, or he's low on oxygen, when he comes in, then he can't talk. I can tell ...you don't talk to him because he can't answer." Her husband died several months after the interview after 43 years of marriage.

A daughter, who had recently begun her caregiving experience with her mother's advanced illness, learned to assess her mother's worsening condition

saying, "...when she's really sick, you see the paleness in her and she can't breathe." Even caregivers who were also nurses learned specific signs of deterioration in their family members as this wife who is a retired RN explains, "The thing that took me most by surprise was not being aware enough that he had oxygen deprivation and wasn't thinking good."

Caregivers not living in the same home as the care recipient relied on either the care recipient or their caregiving parent to call them in the case of emergency. A son relates how he knew when his dad's condition worsened.

...momma tells me, you know, he'll be in the bed and he'll take chills, and he'll go to shaking. And that's the first sign that something's really fixin' to start happening. When he start running chills and fever, he always asks his momma [wife] to get up and go make him a pot of coffee. And when she's gotta get out of bed to made him a pot of coffee... They'll call me and, you know, momma says, "Well, your daddy is sick." And I'll go over there.

Gradually the caregivers learn about COPD—the disease process, the medications, oxygen delivery systems and they start seeing their family member responses. As the caregiving process continues to the second stage, caregivers face new challenges.

### *Bumps in the Road*

*Bumps in the Road* reflect the middle phase of caregiving. Caregivers have obtained essential information about COPD and the daily management

process. The disease has progressed so that the care recipients are less able to manage their own care and their independence becomes compromised. Greater responsibility now falls on the shoulders of the caregivers. This phase of caregiving is characterized by role renegotiation as independence decreases and caregivers now often have to ask for assistance from other family members. Observant behaviors caregivers learned in the first stage intensify as they become increasingly watchful of their family member. Continued tobacco usage was a concern for some both from a health and safety perspective. The ability to continue activities outside the home during this phase was variable – some dyads experienced greater isolation while others figured out how to overcome disease restrictions. Hospitalization modified the caring routine – giving a decreased or increased sense of burden to caregivers. All caregivers identified coping strategies and most identified the value of patience and verbalized caregiving frustrations that they managed in various ways—both constructive and destructive. Maintaining the caregiver's health became important in this stage especially for the older caregivers as the demands of caregiving multiplied.

*Negotiating.* As caregiving progresses there is constant role negotiation. Care recipients focused on maintaining their independence especially in the areas of employment, driving, hobbies, and daily activities. Caregivers found it difficult to determine what aspects of care they should be responsible for and if they made efforts to curtail care recipients' activities they were often met with overt hostility. For example, one husband, whose wife had very recently started



using oxygen, chose to give his wife space as she learned to deal with her oxygen dependence saying,

I left her alone most of the time...not from the standpoint of neglecting her, but I just felt like she needed to be by herself to work through this and right now she is potting. She is a potter...and nothing stands in her way.

Another spouse who was not able to determine when her help was no longer needed to get the daily donuts described the experience saying,

...for five days, I did it [got the donuts]. And the next day I was getting ready to go and he got mad because we didn't want him to do anything. He was okay, so he went...he doesn't want to give up. He doesn't want to depend on somebody else to do something. But he'll give me a tough time.

Caregivers were impacted in multiple areas by care recipients increasing disability and desire to maintain independence. One spouse described the difficulties they had when her husband, an electrician, had to retire at 58.

Accepting that [retirement] was literally the hardest thing we dealt with for awhile, because he was no longer the bread winner, and he was used to being very active, and he couldn't do things without getting fatigued very easily or short of breath.

Despite his oxygen dependence this care recipient later added a room to their home himself. His wife says, "He just got a longer piece of tubing and tried not to



get tangled up". Ten years after beginning to use oxygen this couple is still able to take out of state car trips although the care recipient no longer drives.

Many care recipients continued to use tobacco to the distress of their caregivers who worried about health effects and fire safety issues. The problem was compounded if caregivers reported smoking themselves or had family members who smoked. Caregivers struggled with wanting to be supportive of the care recipient while knowing that continued tobacco use was dangerous. One daughter, who had been a nonsmoker for three years and resumed her habit after moving in with her mother, described her situation,

She continues [smoking] and she even lies about it, because my husband smokes and he gives her like two to three packs a week. So she lies about it because she knows she's not supposed to be smoking....I could kick myself [for resuming smoking], but my nerves have been so....It's been such a challenge this last six months, it's just...and it's because I love her, and I'm scared that she's in her last days, I really am, because at times I see that, that I try to just overlook it all.

Another caregiver who thought her husband had quit smoking caught him smoking when she returned from shopping. He had been able to coax a workman who was repairing their hurricane damaged home to get him cigarettes. Another caregiver who had recently been diagnosed with coronary artery disease worried about the effects of second hand smoke on her health. Her husband continued to smoke three packs per day despite using oxygen. This caregiver

had cared for her oxygen dependent mother several years prior and relates how she addressed the smoking issue with her mother

...sometimes I feel bad about it, but she didn't smoke the last year I had her, because I wouldn't give her the cigarettes. But like he [the daughter's husband] said, "Look, she's eighty something years old. She's dying. Why not let her have cigarettes.' And I didn't do it. She never asked for them though, but one time I found... a bunch of cigarettes butts that she had got out of an ashtray, I guess, and put in her pocket or something. But she never asked me for them. And she could talk. But she never asked me for them...

A daughter who had quit smoking described the safety issues she had to confront in caring for her mother saying,

She's not supposed to smoke, but during the time she was staying at my house ...she was smoking. She even threatened to leave my house because I tried to talk her out of smoking and tried to keep people from bringing her cigarettes. I found out later that as we slept, she smoked in the house, in the room with her oxygen.

As the care recipients' independence becomes more compromised, the caregiver also limits activities that take them away from their family member. Not surprisingly, caregivers consistently reported their lives became more restricted as caregiving responsibilities consumed more of their time. One spouse, caring

for her husband who had been oxygen dependent for five years as well as a grown daughter who was a nursing home resident, described her feelings saying,

They [care recipients] put your life on hold ...because... if you're going to do what you've got to do, you don't have a life to a point. I mean I go grocery shopping, and I go to church every weekend, and I go to see my daughter, but it's not like when you can leave your house with your husband and go visit.

This wife subsequently described coming home to find her husband had inadvertently placed a paper plate on a lit stove and another time found him smoking when she had thought he had quit.

Some caregivers found it difficult to get out of the house with their care recipients while others traveled with minimal problems. One wife who was 5-feet tall had difficulties when her 6-foot anticoagulated husband fell in public. She describes her situation saying,

If there wouldn't have been two men in there he'd still be sitting on the floor. I can't pick him up. He loses balance. So, you're kind of leery about bringing him anywhere, and then sometimes he makes me feel like, "You don't want me to go?" I'm like, "it's not that I don't want ...." Well, I don't answer him. I just bring him. I mean; I say to myself, "Well, if he falls, he falls." It's like a guilt trip they put on you.

Other families are able to continue to travel with thorough prior planning. One couple was able to arrange an airline flight to visit family.



The decision to quit driving was also difficult for some families. Often care recipients limited their driving to rural roads while others sold their vehicles after maintenance costs seemed excessive. One daughter describes her father's feelings about driving,

...he would just tell us, he needed that [to drive].... Even if he would have gotten in a wreck, Daddy still needed to get behind that wheel for his manhood.... He was used to his freedom.

For other care recipients the car seemed to be a symbol of independence that was hard to give up even if they didn't really feel like driving anywhere. As one wife explained, "He finally sold the little truck. And I think he's regretted it a lot. Just the idea of it being out there in case he did want it." This couple had a second truck that the wife drove and which he could still use as well.

*Getting help.* During the second stage of caregiving caregivers often found that they needed assistance from others. Some caregivers made arrangements with their children or siblings to make sure care recipients were not left alone, but several caregivers had difficulty asking for assistance from others. A caregiver, who had been taking care of her friend for 19 years, explained her feelings about asking for help, "I'm supposed to do this. 'Cause he asked me to take care of him. And he's got his trust in me, to my best abilities to take care of him."

Caregivers would sometimes care for their family member to the detriment of their own health. One caregiver, a wife who also cared for her brother, describes how she put off going to her physician when she began having chest pain.



...they told me I had a mild heart attack.... I just walked the floor and when the pain eased off I just... 'cause I thought it was indigestion or something, because I have ...I call them hyena (sic) hernias. I have one of them so I thought it was just indigestion.... I thought I'd get better and I had things to do. And I didn't want to end up in the hospital because I knowed (sic) I had him [her husband] and my brother.... And I have to pick his medicine up because he takes it...this sheet of paper [holding up a sheet of paper] would hold his list of medicine.

On another occasion she developed light headedness and called her step children to ask them to pray for her. They came immediately and took her to the hospital where she was hospitalized with uncontrolled atrial fibrillation and was found to have had a myocardial infarction. This caregiver lives in a rural area that is about 15 miles from a rural hospital that has a physician on call. It was not clear who cared for her husband and brother during her hospitalization.

Even when caregivers report that there are other family members available to help they hesitate to call on them. One caregiver who uses oxygen herself at night who cares for her oxygen dependent husband now and who cared for her mother in the years prior to her death described their relationship with their two sons who live close.

They [her sons] call us all the time. "What'd you need done?" or "do you need me to do anything, mom? Do you need anything?" I mean it's constant. They're very good. But I always tell them "No, we good, you

know" .... And, 'course we lie to them a lot, you know, and we say "Aw, we fine, everything's fine." We may be sicker than two old dogs. But, you know, they got lives and like I say I took up my whole last, my mother's 11 years, her life, I took my life and just put it on hold for her...

In several instances caregivers reported not receiving help from family members, but it was often unclear if they asked for help. One husband's eyes welled with tears when he said,

I haven't received any help, you know. I just, I'm the type of person that... I'm going to work it out. They'll [other family members] just leave it up to you. You take care of it, and that's a problem, you know.

A daughter who commuted 30 miles to a full time job also had difficulties caring for her mother and perceived she didn't receive needed assistance from other family members. As her mother's condition deteriorated her mother moved in with a son whose wife was home during the day. This daughter described their family's situation

It's just a trying time, I tell you. And it's very stressful. And I mean I love my mom and if I had to do it all over again I would, but I mean you need help. You can't do it alone. Give me a break. Nobody gave me a break. It was just me.

Physicians and home health nurses were also generally helpful to these caregivers. Some caregivers voiced multiple frustrations with communicating with health care providers while others found supportive relationships with their

physicians and home health providers. It was not unusual for care recipients to lie or omit information, often about continued tobacco use, during health care provider visits which placed caregivers in tenuous positions. One wife caregiver who was also a registered nurse explained her biggest frustration as “getting this specialist to talk to this specialist that talks to this specialist. They all know it all. And I finally just threw a little fit ...” Another wife whose husband continued to smoke explained how she managed visits to her husband’s physician and how her husband responded.

Well, [the] Dr. is a good doctor and I always go in with my husband. And I sit there and grit my teeth when I know he’s not telling [the] Dr. the whole fact. And then sometimes, if it’s something I think he should know, then I’ll tell him [the physician]. He [her husband] just cuts his eyes and I go on. I know I’m gonna catch it when we get out of there, but I told him, “The doctor can’t help you if you don’t tell him the truth”.

This caregiver reports that her husband will not come to visit the physician without her being present. Neither will this care recipient consent to having home health visit his home to assist.

Another wife caregiver sheds light on how she chooses when to give her husband’s physician information her husband might not like her sharing. When her previously even tempered husband became very negative she asked her husband’s physician to prescribe a medication for him



[The] doctor had put him on the Effexor. I asked him to for the negativity and all. And it was helping him but then it got to where it didn't help him, so he [the doctor] doubled up on it. Well he ran out of 'em the other day and he didn't tell me he ran out, see. He says, "I quit taking them damn things." And I said, "No, you not gonna quit taking them." "Yeah I am, I ain't taking them no more." Well about 3 days later, I said, "Now dad, you're not doing me right, you're not doing yourself right, you're not doing those kids right." He went in there and he took him two of them and so he's been back on 'em, and he's, leveled back out.

This caregiver concluded, "I guess you speak up whenever it's kinda hurting you too."

Some caregivers reported receiving much needed support from home health caregivers in their homes. One wife and daughter described how a very perceptive physical therapist was able to help their spouse and father in his last days.

He got real depressed there one time and his physical therapist ... I called her and I said, "I don't know what kind of mood he's going to be in when you get here." But oh, he loved her. I said, "but he is real depressed, and he's wanting medication for it." She said, "I don't think he needs medication for that because he's already taking ..." So when she got out there he acted like everything was okay. And then after a bit, he was real irritated acting, and she said, "Mr. X is something bothering you?" And he



said, "Yeah, I'm tired of sitting in this chair, and I want to get out." She said, "Well I'll tell you what let's do, let's go for a walk. "So she got him the walker and she took him outside and walked him down the driveway, down the sidewalk. And thereafter, she would come, if the weather was presentable, she'd take him outside.

Another caregiver described how a home health nurse helped her care for her husband while they lived in a small camper trailer they had moved to after hurricane damage made their home uninhabitable. This care recipient developed a cyanotic foot during their 10 hour drive to evacuate and required subsequent hospitalization.

...she [home health nurse] checks his blood pressure, vital signs, and everything. She doctors the toe. That was a blessing when he had home health because then I didn't have to go everyday to the doctor. And plus he's on that Coumadin, that blood thinner medicine, where she takes his blood work for him when he needs it... that's a big help then I don't have to take him and bring him to the doctors.

This 5-foot caregiver had difficulties assisting her husband who is over 6-feet tall despite his using a wheelchair.

Hospitalization of the care recipient posed special challenges. Most care recipients resisted hospitalization vigorously and caregivers pleaded, threatened, and demanded their family members seek hospitalization. For some families

hospitalization was a welcome respite from 24 hour care. For most staying in the hospital with their family member added to the caregivers' work.

A son who lives near his parents often receives a call from his mother when his dad needs to go to the hospital. However, usually it is his sister who lives further away who convinces their dad to go to the hospital.

... he's hard headed. But, you know, he'll lie there and almost die before he goes to the hospital. And I just tell him, "Look, I'll just tell 'em you're losing your mind. But one way or another, you're going." And I'll call my sister and she'll come down. My sister's got a way, I guess since she's the girl and he's the daddy. She's got a way that she can, you know, she can go in there and cry a little bit and talk to him ... they gone [to the hospital]. But with me it's a different story... That's just him. And I mean, he's old and stern, and if you push him, he's liable to give you a few French words off the top of his head. You know, that's just him.

Another daughter took a different approach with her mother when making the decision to pursue hospitalization.

I guess the hardest thing is deciding when she is sick, and I need to be really concerned... because there for a while, I got to where, "Momma, if you're really sick, come on and we're going to go to the emergency room. I'm going to take you to the hospital. "But when I start threatening her like that, because I can take her to any emergency room. She's got Medicare and all that. When I start ... because she smokes and she knows she

can't smoke if she goes to the hospital. She, when we start threatening to take her to the hospital, then she'll come out of it... she don't want to go to the hospital unless she has to. Usually she's on her last leg when we take her, and you know they put her in. She knows that. Basically, anytime that she goes in the emergency room right now, they're going to put her in if the doctors didn't know her.

This daughter reports that when her mother is finally hospitalized that "she's a good patient and the nurses are good to her."

Once hospitalized most caregivers have added demands placed on them. As one wife, who cares for her husband and brother, related

... because he [her husband] has animals, I have to take care of 'em. And then I have to make sure my brother has his medicine. So I'm back and forth every day, and that's 34 miles roundtrip a day. Then up here [at the hospital] he's still dragging the IV with him to go outside and smoke. He wants coffee at 3 or 4 o'clock in the morning. He's used to getting up at that time...He gives these nurses a fit. They can tell you.

Other caregivers report that their care recipient will not allow hospital staff to help them with ADLs, but would wait for their family caregiver for assistance.

One family described a very special time in the hospital when both parents were hospitalized and they celebrated their mother's birthday.

We had a ...you could call it a fun time. I [mother] couldn't stay off the bed too long, but they'd bring me to his [her husband's] room, and to tell him



hello, and I'd stay maybe 10 to 15 minutes, and then they'd have to put me back to bed.

Their daughter describes the experience, "It was a week full of wonderful... it was memories". Both parents were discharged from the hospital together, but the wife returned several days later and her husband died at home several days after that.

*Watching.* Caregivers not only did not like leaving the care recipient, but also described being available within their homes if their assistance was needed. Despite caregiver gender, age, or time spent caregiving, these caregivers consistently described being vigilant in their caregiving responsibilities. This vigilance began in the first stage of caregiving, but intensified in the second stage as the care recipient required more assistance. For example, a husband caring for his oxygen dependent wife who also had fibromyalgia said, "You've got other chores you've got to do, but, too, you've got to keep in mind that the main aspect is taking care of someone—you've got to be close." A daughter who did not live with her parents but who was helping care for her father said, "I was just always there if they needed something. I was there." Even at night, the vigilance continues. A longtime friend who stays with her oxygen dependent significant other when needed says, "I don't really sleep when I'm there. I...catnap because I'm listening for him."

Some of the caregivers gave very detailed descriptions of the extent of their watchfulness. One wife, whose husband had had lung disease for 20 years



and who had been oxygen dependent for the 18 months prior to the interview, described how she watched her husband manage his oxygen and how she intervenes if there is a problem.

I usually go to bed later than he does. I happened to go in there and I couldn't hear it [the oxygen]. I put the light on and it wasn't bubbling. And I woke him and I don't think he had it on that night. He'd gone to bed without it and forgot to put it on. And I have to watch when he loads up his little tank from the big one. He forgets to turn the big one off when he goes somewhere else, so I've got to check the bedroom to make sure he's not wasting the oxygen... it's not going while he's not connected to it or that it doesn't run out or low before they [DME] come.

*Coping.* All the caregivers identified coping strategies that they used.

Nearly all recognized patience as a key attribute for caregiving and most described caregiving situations that frustrated them giving rise to feelings that included anger, fear, sadness, and guilt. A daughter helping her mother care for her dad said, "Yeah, it takes a lot of love and patience." Her mother agreed and added, "I'm short on patience."

Caregivers struggled with knowing when to respond to care recipients' comments and when not to. A husband whose wife had been oxygen dependent for three years describes his approach saying, "There's a lot of times you want to say this and you want to say that, but you need to hold your tongue and just try to do the best you can with what you've got." However, not responding can be

painful as a wife, caring for her husband of 42 years who died several months after the interview, describes

Well, I don't say anything, but it does affect me. What can you say? You know, a lot of that [his illness] is not his fault. And he gets upset, but I just don't say anything. Change the air conditioner. Give him another blanket or something. You know, it just depends.

Sometimes caregivers did voice their opinions with their care recipients with equally painful results. One wife explained,

... if they do something that they shouldn't, you tell them, and then they get mad at you. But you've got to go on, and say, "Well, it's okay. I didn't hear that..." Well, it don't (sic) make you feel too good, but I just ignore it. Because I know the brain's not right.

Caregivers reported a range of emotions as they tried to meet their care recipient's needs. Overwhelmingly, the female caregivers talked about being afraid for their family members while none of the male caregivers mentioned fear. Whether the female caregivers were afraid of running out of oxygen, of their care recipient's shortness of breath, of their care recipient's dying, or of not being able to help the care recipient in the event of a fall, caregiving was becoming a scary proposition for many of these women. One longtime caregiving wife talks about how they ran out of oxygen on the way home from an out of town doctor's visit approximately 40 miles from their home.

...when we went to leave to come home, neither one [oxygen cylinder] had oxygen. Of course that upsets him and I've got to race home with the air blowing in his face and him kind of gasping at it. It's pretty scary because you don't want to be speeding, but you don't want him to pass out. You know he's hurting for oxygen at the time. It hurts to see somebody like that. To know what they used to be able to do and what they're limited now.

Another caregiver described how she handles her fear about her husband's dyspnea.

I just ask him if he wants to go to the hospital. He always says, "No I'll be alright. I'll be alright." It scares me more than I think it does him. Like at night when he goes to bed. And you wonder, "Is he gonna wake up in the morning?" I don't know. I guess I'm tough or I'm crazy. One of 'em. I don't know. I just kind of try to keep it out of my mind really. [That] is what I try to do.

Fear isn't the only emotion caregivers describe. A daughter who moved home temporarily to help care for her mother described how angry some of her mother's behaviors made her saying,

I'm there doing most of everything with her, and then when I can't take so much, I'll call one of them [her sisters] and say, "Look you're going to have to deal with her for a few weeks, because I can't take it right now."



These sisters took turns caring for their mother and perceived that their mother's caregiving expectations of them were different than what she expected of her sons. As one daughter said, "When I'm around, she stays sick because she wants me to take care of her.... She thinks that her daughters owe this to her." Another daughter had a similar experience with her mother saying, "When I would go to work she'd get up and do little things in the house, but when I was there, she depended solely on me.... I just had to wait on her hand and feet." This daughter describes how she became the family caregiver, "I'm the only daughter, so I was the one that had to make the choice to bring her to my house." Interestingly, the son who helps care for his dad believed that his sister was more successful because of her gender in getting their dad to agree to hospitalization.

One caregiver reported frustrations with helping her mother adhere to a prescribed diet saying, "she's giving everybody the blues because she wants some salt." While a husband new to the caregiving role said not being able to identify what was bothering the care recipient was very frustrating for him.

Most caregivers reported good health even those who reported chronic illnesses. All were able to talk about stress relieving activities they enjoyed although several reported having to curtail leisure activities because of their caregiving responsibilities. For example, one husband who maintained a fishing lease at a lake 80 miles from his home has continued his lease even though he can't leave his wife as often to fish. Caregivers with grandchildren enjoyed seeing



them even when visits were short and activities simple. Most caregivers reported being active in church activities that provided both spiritual and social benefits.

While it is difficult to know how much caregiver stress is related to caregiving or to the ongoing hurricane recovery, several caregivers seemed unaware of their own health needs. For example, one 66-year-old caregiver described a pre hurricane event when she suddenly couldn't move her arms and her oxygen dependent friend had to take her to the hospital. She related what her physician told her, "it's nothing wrong, but exhaustion. You don't take heed when your body and your brain tells you it's enough... Relax or sit down. You push, push, push." After this experience the caregiver reported being more aware of her feelings. Another 69-year-old caregiver whose home was severely damaged in the hurricane and who was living with her husband in a camper reported that she had lost 24 pounds in the 8 months since the storm and that her physician had prescribed sleeping medication for her. She said, "He gives me something to help me rest.... What am I going to do tomorrow? How am I going to do this and what am I'm going to do? You've got to get some rest too." When asked about her health she said, "...there's nothing wrong physically, you know. I just don't have time to sit down and eat. I'm going to grab me two bites, and I'm gone." Finally, a 71-year-old wife whose husband died while she was hospitalized for pneumonia attributed her illness to being unaware of her needs saying, "I got tired toward the end. I guess that's why I took pneumonia. I got too tired and didn't know it."

### *End of the Road*

The final stage of caregiving is called *End of the Road*. By this stage most of the caregivers had been caring for their family member for years and some were able to identify how caregiving had enriched their lives. Caregivers that identified positive aspects were either caring for their parents or spouses at the end of their lives or were very experienced caregivers who had cared extensively for other family members.

Sometimes caregiving brought families closer together. For example, an African-American daughter describes how she and her mother became closer before her mother's death which occurred soon after this interview.

This is really kind of like a bonding time with my mom because she didn't raise me. I was raised by my grandmother, so I really didn't have all the momma daughter...you know. So all this time that she's spent with me it like I'm just really getting to know her.

This daughter went on to say "... we never really was (sic) a close knit family. And really I think this brought us as close as we've been, you know, mom being sick."

Two very experienced caregivers who had both worked as nursing assistants identified aspects of caregiving that were personally rewarding to them. A 66-year-old woman caring for her friend of 19 years said

...my best experience caregiving is to talk someone down to where they think they're dying and you can bring them out of it and make them have a

better look on life. It really makes me feel good. To make them care again... to not want to go, you know. And it just thrills me to see that.

A 57-year-old spouse who cared for her oxygen dependent mother prior to her death and was now caring for her oxygen dependent husband described her feelings about caregiving.

When you're taking care of somebody that can't take care of themselves, especially an older person, it made me feel good because I was helping somebody that couldn't help themselves.

Less experienced caregivers had difficulty identifying positive aspects of the caregiving experience—a typical response was to ask if there was anything positive about caregiving. Most caregivers in the midst of the caregiving process did not find caregiving a rewarding experience. As one 69-year-old wife caregiver said, "Well baby, there's not too much positive, you know. It's just when he has a good day, I have a good day."

Caregivers know that COPD is a progressive disease and that the situation will continue to deteriorate. Dying was a very real concern not only to spousal caregivers but also to the daughters and son. Two examples particularly illustrate the poignancy of the situation. In the first a wife who had been caring for her husband for 20 years related

I was in the bedroom with the door shut and he knocked on the door and I said "Who is it?" He said, "It's your husband". I jokingly said, "Which one?"



He said, "The one that's dying." It's answers like that that will really get to you.

Another wife caregiver who also had health problems shared

About two months before we both got sick and went to the hospital, we were sitting in the living room one day...he wouldn't say much and I said, "Do you feel bad?" And he said, "Well, I don't feel real bad," he said, "but I don't feel good." And I said, "Well, what's wrong?" He said, "Nothing. No more than usual." And he said, "I just know I'm not going to be here much longer." And I said, "You do not know that. Are you God or something?" It was hard, but the way I responded...I said, "No, you don't know that." You know, gave him a face. He said, "I do know that." I said, "Tell me how you know it." He said, "I just know my body." Now when he said that, that gave me a start. And I said, "Well, Honey, I don't have your body, and I don't know, but you look good, and you're eating good, so just don't even go there."

Both of these care recipients died within months of the interviews each after having been married for over 40 years.

The children of the care recipients also tried to come to terms with their parent's impending death. A daughter whose mother died soon after our interview talked with tears streaming down her face about how well intentioned advice did not help her.



And everybody been telling me, that I need to get her to sign a living will and you know this, that, and the other. You know, just keep beating it into my head that she's going to go. She's going to go. I guess, I have faith in God and I know God's able to do anything besides fail, but just listening to them keep telling me that over and over, you know, and I keep thinking it to myself [that] I'm just getting to know her. I don't want to let her go right now, you know. And it's like hurtful things for me.

Two caregivers caring for their parents talked about the need to "make memories" of their parents before they die. One son helping to care for his 84-year-old dad explains how he does that.

... like she [his mother] called me yesterday. They had a propane leak. I got up, went over there, and figured it was just a screw. I tightened it down and everything's all right. But you know, that's just little things in some ways, but everything that I do...everyday that I live...every time I go...everything I say...the times we sit down and drink coffee...the time we sit on the porch and talk...all I'm doing is making memories. You know, 'cause if he happens to slip off before I slip off, that's my memories. I'm writing my book and it ain't just me. It ain't something I'm writing in paper, but in my mind, I'm making memories. I've heard a lot of people talk about when their momma and daddy or so and so passes away...when they go look at 'em in that casket ...that's where your memories gonna be of what you've done and what you didn't do.

When asked what recommendations she had for anyone starting to care for a person with COPD, a daughter, who helped her mother care for her dad who had recently died, said, “Just help as much as you can. Be with them, for them, help Mother. Being with Daddy, just laugh and cut up and do everything you can to make memories.”

### Summary

The diagnosis of COPD starts families down a long road of caregiving that ends when the care recipient dies. In the initial step in the process, *Learning to Drive*, caregivers start to learn about the disease and the care their family member will need. In this stage the care recipient manages their care regimens and ADLs independently with no restriction on the caregiver’s activities. However, as the disease progresses families enter the second stage of caregiving, *Bumps in the Road*, where care recipients became more dependent upon their caregiver for assistance and caregivers found increasing restrictions being placed upon their lifestyles. This stage is characterized by struggle as both care recipients and caregivers try to figure out how to manage so that each individual’s needs are met. Finally, in the last stage of caregiving, *End of the Road*, caregivers and care recipients must face the care recipient’s death. By this time, sometimes decades after the original diagnosis of COPD, some caregivers can reflect on the caregiving experience with self satisfaction.

## CHAPTER 5

### SUMMARY OF THE STUDY

The purpose of this grounded theory study was to explore rural multicultural family caregivers' experiences of caring for family members who have oxygen dependent chronic obstructive pulmonary disease (COPD). COPD is characterized by non-reversible airway obstruction that usually leads to progressive dyspnea, fatigue, depression, difficulty with social adjustment, and, for those of employable age, non-participation in the workforce. Little is known about how caregivers for patients with oxygen dependent COPD experience caregiving. Most research has investigated COPD caregiving from the perspective of Caucasian urban wives caring for their husbands with COPD (Bergs, 2002; Cossette & Levesque, 1993; Sexton & Munro, 1985). No studies have investigated COPD caregiving in non-urban populations—a group likely to be more vulnerable due to increased age, poorer health practices, and less access to health care. The goal was to develop a theory of caregiving that described the caregiving experience from the perspective of the caregiver for an adult with oxygen dependent COPD.

This chapter contains a summary of the study and a discussion of findings as they relate to the current literature. Conclusions and implications of the study follow. The chapter closes with recommendations for further research.



## Summary

A grounded theory design was chosen to explore the COPD caregiving experience since grounded theory has been shown to be an effective methodology explain life situations, in this case, caring for a family member with oxygen dependent COPD. Care recipients diagnosed with oxygen dependent COPD were recruited from three physicians' practices. These care recipients were contacted by the investigator and asked to recommend a person who helped care for them who might participate in the study. Recommended caregivers were then contacted by the investigator who explained the study and, if the caregiver was interested, scheduled an interview time and place.

Audiotaped interviews were conducted with family caregivers using a semi structured open-ended interview guide that explored the caregivers' experiences with caregiving since their family member's diagnosis with COPD, the challenges the caregiver experienced, and the role nurses had in assisting caregivers. Data collection and analysis occurred concurrently so emerging patterns and categories could be identified. A theory of caring for a family member with oxygen dependent COPD was developed through the use of open coding, axial coding and finally, selective coding.

The sample consisted of 13 caregivers whose ages ranged from 34 years to 75 years. Eight spouses, four children and one longtime friend provided care for an average of eight years. Most caregivers were female ( $n = 10$ ) Caucasians ( $n = 12$ ) who lived in towns with populations of 5,000 or less ( $n = 8$ ) in single



family homes with the care recipient ( $n = 8$ ). Care recipients used oxygen for an average of 4 years even though some ( $n = 5$ ) continued to smoke and most had other chronic illnesses ( $n = 8$ ).

The process of caregiving occurred in three overlapping phases that was likened to making a caregiving journey. The first phase of the caregiving process was characterized as a learning time for both caregivers and care recipients. Families learned about COPD and incorporated new care regimens into their routines while the care recipient remained independent.

As the disease progressed, caregivers moved into the second phase of the caregiving process, Bumps in the Road, which was characterized by struggle. Care recipients struggled to remain independent while caregivers struggled to know when and how to assist. Caregivers used four strategies in this phase. The first, Negotiating, involved working with care recipients to determine what role caregivers would play. Examples of negotiated issues included employment, driving, tobacco use, as well as activities of daily living (ADLs). The second strategy, Getting Help, included the activities caregivers used to draw others—professionals and family—into the caregiving process. Watching was the third strategy caregivers used and was an intensification of the vigilance that started in the initial phase of caregiving. Finally, caregivers identified how they used Coping to deal with their feelings about caregiving.

The final phase of caregiving, End of the Road, described how caregivers approached issues surrounding the end of life. Some caregivers were able to

reflect upon the positive aspects of caregiving by this point while others could not. Factors that influenced caregiving throughout the process included the caregivers' previous experiences caregiving as well as their relationship with the care recipient.

### Discussion of the Findings

During the Learning to Drive phase of the care giving journey caregivers learned about COPD, the care regimens, and the care recipients' responses to the disease. Caregivers in this study recognized care recipient responses to COPD and all reported varying levels of care recipient dyspnea and fatigue which were consistent with previously reported COPD symptom descriptions (Baker & Scholz, 2002; O'Neill, 2002; Sexton & Munro, 1988; Small & Lamb, 1999). Other symptoms identified as commonly occurring in people who have COPD which were also reported by these caregivers included depression (Lacasse, Rousseau, & Maltais, 2001), difficulties in social adjustment (Leidy & Traver, 1996), and progressive disability (Eisner, Yelin, Trupin, & Blanc, 2002).

As COPD progressed caregivers restructured their lives using caregiving strategies they developed to manage caregiving responsibilities. For example, caregivers reported constant role negotiation as care recipients focused on maintaining their independence while caregivers tried to determine aspects of care to provide. These findings are similar to the family role changes reported in studies of wives caring for their husbands with COPD by Bergs (2002) and Sexton and Munro (1985).

Issues surrounding tobacco use surfaced repeatedly as caregivers and care recipients negotiated the role tobacco would play in their lives. Caregivers, who tried to restrict their family member's access to cigarettes, felt guilty for doing so or angry at the care recipient for smoking. Care recipients often continued to smoke in the same rooms where their oxygen was despite their caregiver's disapproval and the safety issues involved. Although continued tobacco use was a source of substantial tension in many families, literature lacks information regarding the frequency of occurrence or mechanisms for defusing this care giving problem.

Caregivers tried to determine when they needed assistance in the caregiving process. Several caregivers found asking family members for assistance was difficult as did the caregiving wives in Bergs' (2002) study. However, in this study it was not only the wives who struggled with asking for help; one husband and the children caregivers also had difficulties with asking other family members to assist in caregiving.

Despite this difficulty some of the children caregivers in this study were able to acknowledge that they felt closer to their siblings as a result of caring for their parent. These feelings of closeness were usually identified either after the parent's death or when the parent was very disabled as a result of COPD. Kanervisto et al., (2003) also found that families of community dwelling oxygen dependent patients had high levels of mutuality and emotional closeness as well as independent thought and flexibility.



Caregivers in this study reported being increasingly watchful of their family members as the disease progressed. Consistently, regardless of gender, relationship to the care recipient or experience caregiving, caregivers remained vigilant to small changes in care recipient's behaviors. The caregiving wives in Bergs' (2002) study described a similar phenomenon as "being on the alert".

A commonly reported strategy the caregivers in this study used to help them cope with COPD caregiving related to having strong religious faith. Bergs (2002) also reported that the wives in her study relied on their spiritual beliefs as a valued form of coping.

Caregivers identified situations that increased their stress with caregiving. Nearly all the caregivers in this study identified having patience as being key to caregiving. Examples the caregivers gave of situations requiring patience often revolved around providing emotional support to the care recipient or not responding to care recipient statements or actions that were argumentative. The difficulty wives had in providing emotional support their husbands with COPD has been identified in several studies (Bergs, 2002; Cossette & Levesque, 1993; Sexton & Munro, 1985). In this study all caregivers regardless of gender, relationship to care recipient, or time spend caregiving identified having patience as key to good caregiving.

It is possible that caregivers of family members with COPD appraise caregiving situations differently depending upon gender, relationship with the care recipient or other factors. For example, most of the female caregivers in this



study volunteered that aspects of the caregiving experience were frightening to them while the male caregivers, even when specifically asked, were not able to identify any situation that would be scary to them. In addition, most of the children—daughters as well as the son—interviewed in this study believed that their parent—whether mother or father—had differing expectations of and responses to their child's caregiving that were gender dependent. Cain and Wicks (2000) in their study of COPD family caregivers reported that while caregiver perceptions of caregiver burden did not differ based upon gender or family relationship greater amounts of burden were reported for Caucasian caregivers and caregivers younger than 55 years. While caregiver appraisal of caregiver situations has been studied in groups of people with chronic conditions such as cancer, stroke, and those recovering after acute hospitalization differences in how COPD caregivers appraise caregiving have not been reported.

Caregivers know that COPD is a progressive disease that will ultimately end in the care recipient's death and often begin preparing themselves for that eventuality. Bergs (2002) in her study of wives caring husbands with COPD identified the theme of "having to walk the road to the very end" that resonated with the experiences of some of the caregivers in this study. Three of the four children and two of the six wives that were interviewed spoke very poignantly of how they approached the impending death of their parent or spouse.

## Conclusions and Implications

The conclusions that were drawn from this study are as follows:

1. COPD caregiving is a three step process with overlapping stages that are not mutually exclusive and which change over time.
2. COPD caregiving is influenced by caregiver characteristics which include prior caregiving experience, the quality of the relationship with the care recipient, and personal characteristics such as age and gender.
3. Continued tobacco use by care recipients results in caregiver distress and markedly increases tension during care provision.
4. Caregivers often struggle with knowing when and how to assist care recipients as well as when and how to seek assistance from other family members.
5. Caregivers are very observant of care recipient responses to COPD.
6. While caregiving is very difficult for most caregivers, very experienced caregivers often describe psychological rewards they have received caregiving.
7. Caregivers can become so involved in the meeting the needs of the care recipients that they neglect their own personal health.

The implications for nursing practice derived from this study are as follows:

1. Caregivers may not ask for assistance with caregiving challenges from others. Nurses should explore with caregivers issues surrounding asking for and receiving help.
2. Caregivers may not recognize changes in their health or may adopt harmful health practices as coping mechanisms for caregiving. Nurses should be alert to changes in caregiver health and provide intervention as appropriate.
3. Continued tobacco use by the care recipient may be very distressful and confusing to the caregiver. Nurses need to assess ongoing tobacco use habits of COPD patients and develop strategies that support caregiver attempts to limit use.
4. Caregivers work very hard at helping care recipients manage COPD symptoms, medications, and ADLs. Nurses should listen to caregivers and support them in their caregiving.

#### Recommendations for Further Study

Research describing the experience of caring for a person with COPD is minimal and usually presents the perspective of a Caucasian wife caring for her husband. The recommendations for further study are as follows:

1. Research is needed to describe how men respond to care giving expectations of their family members so that nursing interventions can be developed to address their needs. As more women develop COPD, their husbands and sons will help care for them.

2. Investigate interventions to assist non-urban caregivers who tend to be older, poorer, and have health problems of their own.
3. Research needs to identify interventions that will enable caregivers to effectively intervene when their care recipients continue to use tobacco.
4. Test a long term intervention program that supports the caregiving process over the three phases of COPD caregiving.



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## APPENDIX A

### University Human Subjects Review Committee Approval



**TEXAS WOMAN'S UNIVERS**

DENTON DALLAS HOU

**Institutional Review B**

1130 John Freeman Blvd., Houston, Texas 77030 713/794-

**MEMORANDUM**

TO: Anne Young  
Ann Warner

FROM: IRB

DATE: June 20, 2005

SUBJECT: IRB Application

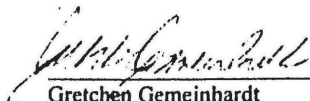
Proposal Title Experiences of family caregivers for adults with oxygen dependent chronic obstructive pulmonary disease (COPD)

Your application to the IRB has been reviewed and approved.

This approval lasts for 1 year. The study may not continue after the approval period without additional IRB review and approval for continuation. It is your responsibility to assure that this study is not conducted beyond the expiration date.

Any changes in the study or informed consent procedure must receive review and approval prior to implementation unless the change is necessary for the safety of subjects. In addition, you must inform the IRB of adverse events encountered during the study or of any new and significant information that may impact a research participant's safety or willingness to continue in your study.

REMEMBER TO PROVIDE COPIES OF THE SIGNED INFORMED CONSENT TO THE OFFICE OF RESEARCH, MGJ 913 WHEN THE STUDY HAS BEEN COMPLETED. INCLUDE A LETTER PROVIDING THE NAME(S) OF THE RESEARCHER(S), THE FACULTY ADVISOR AND THE TITLE OF THE STUDY. GRADUATION MAY BE BLOCKED UNLESS CONSENTS ARE RETURNED.

  
Gretchen Gemeinhardt  
Chairperson

## APPENDIX B

### Consents to Participate



College of Nursing  
Houston Center  
1130 John Freeman Blvd.  
Houston, TX 77030-2897  
713 794-2100 Fax 713-794-2103

TEXAS WOMAN'S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: Experiences of Family Caregivers for Adults with Oxygen Dependent Chronic Obstructive Pulmonary Disease (COPD)

Investigator: Ann Warner, M.S .....337/475-5831  
Advisor: Anne Young, Ed.D .....713/794-2109

Explanation of the Purpose of the Research

You are being asked to participate in a research study for Mrs. Warner's dissertation at Texas Woman's University. The purpose of this study is to learn about what it is like to care for a family member who has chronic obstructive pulmonary disease (COPD).

Research Procedures

For this study, the investigator will conduct face-to-face interviews with caregivers of people who have COPD. This interview will be done in a private location agreed upon by you and the investigator. You will be audiotaped during the face-to-face interview. The purpose of the audiotaping is to provide a transcription of the information discussed in the interview and to assure the accuracy of the reporting of that information. Your maximum total time commitment in the study is estimated to be approximately two hours.

Potential Risks

One risk to you is that you might worry that people will find out what we talked about. In order to prevent this from happening any names used during the meeting will be taken out of the typed transcript. If our meeting is interrupted, the tape recording will be turned off and if we both agree, we will meet at another time. If your family or physician asks the investigator what you said the investigator will tell them she cannot answer any questions unless you give her permission to do so. *Confidentiality will be protected to the extent that is allowed by law.*

Another risk is that you may become tired or anxious during the interview. You can refuse to answer any question and you can end the interview at any time without penalty.

Participant Initials

One final risk is loss of your time as a result of participating in this study. However, interviews will be scheduled at a convenient time for you and you may withdraw from the study at any time without penalty.

*The investigator will try to prevent any problem that could happen because of this research. You should let the investigator know at once if there is a problem and she will help you. However, TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.*

#### Participation and Benefits

Your involvement in this research study is completely voluntary, and you may discontinue your participation in the study at any time without penalty. The only direct benefit of this study to you is that at the completion of the study a summary of the results will be mailed to you upon request. \*

#### Questions Regarding the Study

If you have any questions about the research study you may ask the investigators; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research at 713-794-2840 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu). You will be given a copy of this signed and dated consent form to keep.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

The above consent form was read, discussed, and signed in my presence. In my opinion, the person signing said consent form did so freely and with full knowledge of its contents.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Date

\*If you would like to receive a summary of the results of this study, please provide an address to which this summary should be sent.

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

\_\_\_\_\_  
Participant Initials





College of Nursing  
Houston Center  
1130 John F. Kennedy Blvd.  
Houston, TX 77030-2897  
713-794-2100 Fax 713-794-2103

**Texas Woman's University**

**Experiences of Family Caregivers for Adults with Oxygen Dependent Chronic  
Obstructive Pulmonary Disease (COPD)**

The undersigned consent to have his/her voice be recorded by Ann Warner, acting on the date under the authority of the Texas Woman's University. The undersigned understands that the material recorded today may be made available for educational, informational, and/or research purposes and consent to such use.

\_\_\_\_\_  
Participant

\_\_\_\_\_  
Date

The above form was read, discussed, and signed. The person signing this consent form did so freely and with full knowledge and understanding of its contents.

\_\_\_\_\_  
Representative of the  
Texas Woman's University

\_\_\_\_\_  
Date

Think SUCCESS  Think F  
Page 16 of 16

## APPENDIX C

### Semi-Structured Interview Guide and Demographics Form

### Semi-Structured Interview Guide and Demographics Form

<b>Introduction:</b> (5 minutes)	Hello, my name is Ann Warner. I'm the one you spoke to on the phone and I am the one who will be interviewing you. Our purpose today is to discuss what it is like for you to care for a family member who has COPD. I am interested in learning about your experiences so there are no right and wrong answers—only what you have discovered in caring for your _____. I will be analyzing this conversation as well as others I am conducting so that I can get a better understanding of what it is like for family members who care for people who have COPD. It may take me awhile, but eventually I want to use this information to determine how nurses can better help families like yours.
<b>Acknowledgement</b>	Thank you for meeting with me today and fitting this in to your schedule.
<b>Disclosures</b> (5 minutes)	I will be audio taping our conversation so that I can write an accurate report of our conversation. (Get consent)
<b>Demographics</b> (5 minutes)	<p>First, I have some questions to ask you that will help me understand your situation a little better.</p> <ol style="list-style-type: none"> <li>1. What is your relationship to the patient?</li> <li>2. Do you live in the same home as your _____?</li> <li>3. Where do you live?</li> <li>4. What is your age? Gender? Ethnic group?</li> <li>5. Do you work outside the home? Full-time? Part-time? Retired?</li> <li>6. How many other people live in your home?</li> <li>7. How long have you been caring for your _____?</li> <li>8. How long has your _____ been dependent on oxygen?</li> </ol>

**Interview**  
(45 minutes – 1 ½  
hours)

**1. Please tell me what it has been like for you since  
\_\_\_ was diagnosed with COPD?**

Probe:

- a. How has your life changed?
- b. What did you expect when \_\_\_ was diagnosed?
- c. How was it when \_\_\_ was first diagnosed?
- d. How is it now?
- e. What has been your best experience with caregiving?
- f. Tell me about a typical day caring for \_\_\_\_.
- g. Several caregivers have told me that patience is very important in caregiving. Is that true for you?
  - o How do you know when to help and when not to help?
- h. Most of the caregivers I've talked to have talked about how closely they watch for changes in breathing. Is that true for you?
  - o How do you help him breathe?
  - o When do you know that he is not breathing well?
- i. Most of the caregivers I've talked to have talked about fear. Being afraid of different aspects of caregiving. Have you ever been afraid while caring for \_\_\_?

**2. What are the main challenges you have experienced as a caregiver since your  
\_\_\_ was diagnosed?**

Probe:

- a. Who has helped you with these challenges?
  - o What keeps you from asking for help?
- c. What helps you to be able to do \_\_\_\_\_?



	<p>d. What has been your worst experience with caregiving?</p> <ul style="list-style-type: none"> <li>o How do you handle emergencies?</li> <li>o Has he ever been hospitalized? How did that work?</li> </ul> <p>e. What advice do you have for other caregivers?</p> <p>f. How did you manage during the hurricane?</p> <p><b>3. Tell me about your health.</b></p> <p>Probe:</p> <ul style="list-style-type: none"> <li>a. What previous experiences do you have in caregiving?</li> <li>b. What do you do to relax?</li> <li>c. What do you enjoy doing?</li> </ul> <p><b>3. What do nurses need to do to help you care for your _____?</b></p> <p><u>Probe:</u></p> <ul style="list-style-type: none"> <li>a. What do nurses do that is not helpful to you in caring for your _____?</li> <li>b. What do home health nurses do to help you?</li> </ul>
<b>Closure</b> (5 minutes)	<p>That is all the questions I have to ask. Is there anything you would like to ask or add? I will be interviewing several people. Would you like me to send you a copy of my results? It will be nearly a year before they are available, but if you give me your address I will mail you a copy of them. Thank you very much.</p>