

**THE LIVED EXPERIENCE OF WOMEN PROVIDING  
CARE FOR THEIR HUSBANDS WITH SEVERE  
COPD IN RURAL SASKATCHEWAN**

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By

**SHELLY HUTCHINSON**

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## **ABSTRACT**

The incidence of Chronic Obstructive Pulmonary Disease (COPD) is expected to rise in the coming years. Presently, in health care there has been a shift of the provision of care to the home therefore, the major burden of care falls on informal caregivers. The challenges that these caregivers face may be compounded by residing in a rural area where the provision of health care services has been increasingly compromised. In the literature, there has been an abundance of information looking at the experiences of caregivers of people with other chronic illnesses. However, the information on the lived experience of caregivers of people with severe COPD has been minimal. The purpose of this study was to explore the lived experience and meaning of that experience for spousal caregivers providing care to a person with severe COPD living in rural Saskatchewan. Face-to-face, conversational interviews, along with observations of the caregivers and their spouses' interactions and environment, were utilized to collect information from five women caring for their husbands with severe COPD living in rural Saskatchewan. Hermeneutic phenomenological reflection, as guided by the works of van Manen, utilized writing, collaborative discussion, life world existentials, and imaginative variation to illuminate themes and the overall essence of this experience. Five overlapping themes identified stemmed from the essence of unrelenting responsibility: 1) Assuming additional roles; 2) Ongoing vigilance; 3) Unfulfilled expectations; 4) Emotional burden; 5) Intermittent reprieve. This study assists in understanding the challenges faced by COPD caregivers and further aids in our understanding of how COPD patients manage their condition. In addition, it will facilitate the identification of strategies and actions to meet the needs sensitive to this population.

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## Chapter 1: Introduction

*Mr. W. was a seventy-two year old gentleman who had been admitted to hospital with an acute flare-up of his chronic obstructive pulmonary disease (COPD). His COPD had gradually worsened for several years; however, the last couple of years were particularly hard for him, and his wife said, it seemed that he had been sick more times than he was well.*

*It is difficult to describe Mrs. W. Her presence conveyed a strong confidence as she was not frail in appearance and she was very assertive when she spoke. She sat for hours watching her husband, listening to his breathing, and tending to his every need.*

*I had been a nurse for several years and I took pride in consciously being in the moment with all the patients that I cared for. I took great pride in treating everyone with respect and trying to understand the mediating circumstances that brought them to this point. But, there was something about Mrs. W. that impacted me greater than anyone I had ever provided care for. My heart wept as I watched her anxiously sit beside her husband as he struggled to breathe. I imagined that it must be difficult to watch and listen to someone struggle to breathe while all the time realizing that every breath may be his last. As a nurse, I knew that the road from diagnosis to the present time may have been long and full of experiences that altered the way that she dealt with the world; I could only imagine what Mrs. W. was experiencing. I wondered what it was really like to live and care for someone with this devastating disease, day-after-day, year-after-year?*

## **Background**

The World Health Organization (WHO) (2006) calls chronic obstructive pulmonary disease (COPD) a “major public health problem” of which “the prevalence and burden are projected to increase in the coming decades due to continued exposure to COPD risk factors and the changing age of the world’s population” (p. 8).

COPD is presently the fourth leading cause of death in Canada (Statistics Canada, 2003) and while deaths from other major diseases are leveling off or even decreasing, those from COPD are rising at an alarming rate (Canadian Thoracic Society [CTS], 2004). By 2020, Murray and Lopez (1997) project COPD will be the third leading cause of death worldwide.

COPD is a slowly progressive disease that is characterized by extreme shortness of breath, and limitations in activity that results in varying levels of disability increasing as the disease progresses. It is further characterized by frequent ‘flare-ups’ or periods of worsening symptoms which often leads to hospitalization for the sufferer. These flare-ups increase in severity and frequency as the disease advances (CTS, 2004). In addition to physical disability, people who suffer from this disease are often unable to work or leave the home and have significant emotional anxiety (Cain & Wicks, 2000).

Due to the disabling qualities of this disease, many people with advanced COPD require assistance at home (Bourbeau, Siok, Nault, & Borycki, 2002) with various tasks of daily living. In addition, the current trend in healthcare is to shift the provision of care to the home (CTS, 2004) so many who are ill are treated at home or discharged early, when they are hospitalized, resulting in greater care needs at home. Therefore, the major burden of care falls on family or friends who provide care at home (Cross, 2004).

In the literature, Herbert and Schulz (2006) found the impact of providing care is affected by the type of illness of the care recipient. An abundance of research exists on caregivers who provide care for people with other illnesses such as cancer, mental-illness, Alzheimer’s disease or those caring for someone with a physical disability (Bergs, 2002; Carter & Acton, 2006; Health Canada, 2002; Health Canada, 2005; Morgan & Laing, 1991; Osse, Vernooij-Dassen, Schade, & Grol, 2006; Secker & Brown, 2005). However, little research exists looking at the experiences of caregivers of people with COPD (Bergs, 2002; Cain & Wicks, 2000) and even less looking at the experiences of those

with advanced COPD (Simpson & Rucker, 2008). Due to the nature of the illness with its constant threat of ‘flare-ups’ and fear of respiratory failure (Bergs), caring for a person with COPD may differ from caring for someone with another chronic illness.

Further, a population that has received little attention is caregivers in rural areas. Thirty-six percent of Saskatchewan’s population is considered rural (Statistics Canada, 2001a) and rural communities have seen many changes in recent years; hospitals and nursing homes have closed, respite and homecare services have been centralized, and fewer family physicians reside and practice in these areas (Blakley & Jaffe, 1999). In addition, residents often have to travel many miles to receive healthcare and often the children of the elderly no longer reside in these communities, leaving the aged with little support. Due to the disparity of services in these rural areas, the aging population, and the ‘house-bound’ nature of this population, rural caregivers may find it particularly difficult to cope.

### **Purpose of the Study**

There is a need to understand and support caregivers of people with COPD, especially in rural areas, to further understand the challenges that they may face. To do this however, we must understand everyday experiences and the meaning of these experiences. The purpose of this study is to explore the meaning of the lived experience of female spouses providing care in their homes for their husbands with severe COPD in rural Saskatchewan.

### **Study Objectives**

In order to achieve the study purpose the following two objectives have been identified:

- To describe the lived experience of informal caregivers caring for someone with severe COPD in their homes in rural Saskatchewan.
- To explicate meaning from the lived experiences of those caregivers.

### **Definition of Terms**

**COPD.** Chronic obstructive pulmonary disease (COPD) is a slowly progressive respiratory illness characterized by extreme shortness of breath and limitations in activity that results in varying levels of disability, increasing as the disease progresses. It is further characterized by frequent ‘flare-ups’ or exacerbations which worsen as the disease

progresses as well as, systemic manifestations such as right heart failure, pulmonary hypertension, skeletal muscle dysfunction among others (CTS, 2007).

**Informal caregivers.** Informal caregivers are described as nonprofessional, unpaid, family, friends, or neighbors, providing long-term care for a person in their home or the care recipients' home (Schumacher, Beck, & Marren, 2006).

**Rural.** If a researcher is interested in a rural focus, Statistics Canada (2001b) suggests that the definition of “rural and small town” be used (p. 11). This definition includes all people outside the commuting zone of centers of 10,000 or more population. The definition of the commuting zone is taken from the Alberta Cancer Foundation (2003) and is described as greater than 35 kilometers from the outer boundary of an urban center.

## Chapter 2: Literature Review

There is a large body of literature available on caregivers with the majority focusing on those providing care for people with cancer, mental-illness, Alzheimer's disease or those caring for someone with a physical disability (Bergs, 2002; Carter & Acton, 2006; Health Canada, 2002; Health Canada, 2005; Morgan & Laing, 1991; Osse, Vernooij-Dassen, Schade, & Grol, 2006; Secker & Brown, 2005). Until recent years, little has been known about the experiences of those caring for someone with COPD (Bailey, 2004; Bergs; Booth, Silvester, & Todd, 2003; Cain & Wicks, 2000; Caress, Luker, Chalmers, & Salmon, 2009; Pinto et al., 2007; Seamark, Blake, Seamark, & Halpin, 2004) and even less known about the experiences of those caring for someone with advanced COPD (Simpson & Rocker, 2008; Simpson, Young, Donahue, & Rocker, 2010).

In this literature review, I will examine the characteristics of informal caregiving in Canada along with, the physical and psychological effects experienced by people who are providing care. In addition, the experiences of COPD patients will be examined to enhance the understanding of their caregivers. Further, I will also examine the most recent literature available on COPD caregivers and caregivers in rural areas.

While a modified literature review was completed to write the proposal it was not revisited for two years until the analysis of the current study was complete. At which time a more extensive review was conducted, including the review of four new studies in this subject area. The findings were then integrated into the analysis during the completion of the final draft. This assisted in protecting the results of the present study from being influenced by past results.

### Caregivers

**Characteristics.** According to the *National Profile of Family Caregivers*, 3.9% of adult Canadians are informal caregivers of whom 77% are women, 70% are over 45 years of age, 25% are more than 65 years of age, and 38% of caregivers are providing care to a spouse. Of the daily tasks performed by these caregivers 48% reported providing medications daily, 36% reported paying bills, 30% reported driving the recipients to appointments, and 29% reported assisting with lifting and moving. In addition, 10% of informal caregivers also provide care to a second recipient. This profile of informal

caregivers reported that nearly half of caregivers provide care out of necessity, as there was no one else to assume the responsibility and homecare was unavailable. Further, this study found that less than 23% receive any type of homecare services, leaving 77% to manage independently (Health Canada, 2002).

A recent report commissioned by the Canadian Institute for Health Information (CIHI), entitled *Supporting Informal Caregivers: The Heart of Home Care* (2010), found that of 131,000 adults receiving home care, only 2% were able to manage without an informal caregiver. In addition, 16% of all caregivers of home care clients reported some type of distress; a figure that increased significantly to 28% if they spent more than 21 hours per week providing care and to 32% if the recipient of care had depression. This report further purports that if caregivers are unable to continue in the caregiving role, the risk of institutionalization of the care recipient and of the caregiver is increased.

Informal caregivers provide care for individuals with a variety of medical problems including chronic diseases such as Parkinson's disease, chronic obstructive pulmonary disease, renal disease, or diabetes to mention only a few (Bergs, 2002; Carter & Acton, 2006; Osse et al., 2006; Secker & Brown, 2005). The recipients of care may also have mental illnesses or dementia such as schizophrenia or Alzheimer's disease, cancer or infirmity due to increased age as well, as physical disabilities (Health Canada, 2005). The lists are endless and thus so are the stresses and the resultant needs.

**Physical effects of providing care.** Many studies have identified the adverse physical effects experienced by informal caregivers (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glaser, 1995; Schulz & Beach, 1999; Segerstrom & Miller, 2004). Schulz and Beach compared 392 caregivers to 427 non-caregivers and found care giving to be an independent risk factor for early death. Those caregivers who were experiencing strain had a 63% greater early mortality than either those caregivers who were not experiencing strain or the non-caregiving controls.

Kiecolt-Glaser et al. (1995) found chronic caregiver stress was associated with decreased immunity and slower wound healing. This was supported by Segerstrom and Miller's (2004) meta-analysis of 300 empirical studies finding chronic stress, such as being an Alzheimer's caregiver, negatively affects all measures of the immune system,

leaving caregivers more vulnerable or susceptible to contracting other diseases or illnesses.

**Psychological effects of providing care.** In addition to the effects on their physical health, many studies have identified the psychological strain or burden which caregivers experience: depression, perceived stress, diminished subjective well-being, anxiety, and feelings of loss and isolation (Pinquart & Sorenson, 2003; Roland, Jenkins, & Johnson, 2010; Yee & Schulz, 2000). Further, some have suggested the disease of the care recipient impacts the degree of burden which the caregivers experience (Herbert & Schulz, 2006; Yee & Schulz).

In a meta-analysis of 84 studies examining the differences in perceived stress, depression, and subjective well-being between caregivers and non-caregivers, Pinquart and Sorenson (2003) found caregivers' experienced greater stress, depression, and had a general well-being that was lower than their non-caregiving cohorts and the caregivers reporting the greatest level of strain were women and spousal caregivers.

Yee and Schultz (2000) looked at psychiatric morbidity in caregivers of people who were considered to be frail, physically ill, or demented. In their narrative analysis caregivers across the recipient groups were found to have greater levels of depression, anxiety, and other general psychiatric symptoms than the non-caregivers. In this study, the women caregivers experienced greater levels of all of the above symptoms. The authors suggest the gender differences may be a result of the greater amount of time that women provide care and the type of care that women provide; women generally provide more day-to-day hands on personal care.

Other studies too have identified depression to be a result of caregiving and some have suggested that the characteristics of the informal caregiver such as personality and coping skills were significant predictors in the development of depression (Carter & Acton, 2006). Still other research has shown that caregiving puts added strain on other relationships, which causes "overload, burn-out, job-stress, and life-stress" (Saskatoon Caregiver Information Center, 2005, p. 3) all possible contributors to depression.

Roland et al. (2010) used phenomenology to explore the burden of five spousal caregivers of people with Parkinson's disease and found the caregivers reported the burden of isolation due to the unpredictability of the care recipients' illness. As the

disease progressed the recipient of care became more disabled resulting in increased social isolation.

Some have suggested that providing care is different depending upon the disease and disability of the care recipient (Health Canada, 2005; Kim & Schulz, 2008). Health Canada (2005) reported that caregivers experiencing the greatest strain were those who needed to adapt and provide care over a long period of time, such as those caring for an individual with mental illness. Kim and Schulz looked at 606 caregivers of people with cancer, dementia, diabetes, and the frail elderly and found that cancer caregivers experienced comparable burden to those caring for someone with dementia. However, in this study the degree of recipient disability was not reported so the reader was unable to determine if equal comparisons were being made.

Others have suggested that providing care is very individual because caregivers and recipients are diverse; however, there are many commonalities in providing care (Carter & Acton, 2006; Öhman & Söderberg, 2004). Carter and Acton compared the burden of cancer caregivers to those providing care for someone with dementia and suggested there were more similarities than differences between these caregivers. Öhman and Söderberg explored the lived experience of 13 spouses and one daughter caring for a family member with a chronic illness (lung disease, cancer, heart failure, and dementia) and identified common themes that were shared by all the caregivers (a) a shrinking life, (b) forced to take responsibility, and (c) struggling to keep going.

Even though there are similarities, there is little known about caregivers of people with COPD (Bergs, 2002; Cain & Wicks, 2000; Pinto, Holanda, Medeiros, Moto, & Pereira, 2007) and even less known about those with advanced disease (Simpson & Rucker, 2008).

### **People with COPD**

In recent years, researchers have begun to examine the effects of living with COPD from the perspective of the patient or their caregivers (Barnett, 2005; Elkington, White, Addington-Hall, Higgs, & Edmonds, 2005; Elkington, White, Addington-Hall, Higgs, & Pettinari, 2004) in order to assist in the understanding of this disease.

Breathlessness has been overwhelmingly described as a major symptom that people with COPD experience. It has the greatest impact on their lives and is the major

cause of disability (Barnett, 2005; Elkington et al., 2005; Elkington et al., 2004). In fact, the Canadian Thoracic Society (2007) uses breathlessness as one way to classify disease severity. A person with severe COPD according to disability will be too breathless to leave the house or is breathless when dressing and undressing.

Other symptoms described by patients and their proxies are fear of choking or suffocating but also anxiety, depression, panic attacks, fear of being alone and of dying (Barnett, 2005; Elkington et al., 2004) all contributing to diminished quality of life. Leidy and Traver (1996) found the level of belligerence, social withdrawal, helplessness, nervousness, and confusion to be similar to those suffering from moderate psychiatric disorders. Gore, Brophy and Greenstone (2000) found the symptom burden associated with emotional and social functioning to be equal or greater to those who have unresectable non-small cell carcinoma.

As COPD progresses patients are often restricted to their homes; venturing out only for medical appointments, receiving minimal assistance from formal home health care supports, and relying on their caregivers for ever increasing levels of support and care (Gore et al., 2000; Elkington et al., 2005).

### **COPD Caregivers**

In recent years researchers have begun to explore the experiences of informal caregivers of people with COPD (Bailey, 2004; Bergs, 2002; Booth, Silvester, & Todd, 2003; Cain & Wicks, 2000; Caress, Luker, Chalmers, & Salmon, 2009; Kühl, Schürmann, & Rief, 2008; Pinto et al., 2007; Seamark, Blake, Seamark, & Halpin, 2004; Simpson, Young, Donahue, & Rucker, 2010; Spence et al., 2008).

Seamark et al. (2004) found COPD caregivers assumed multiple roles which they found to be overwhelming. In addition, the caregivers in this study experienced losses that were similar to the patient; social life, shared experiences, and future dreams. However in this phenomenological study, the caregivers and recipients of care were interviewed simultaneously resulting in findings which were reported in one article. This made the reader question if the caregivers felt comfortable enough to disclose their experiences as well, the results were difficult to interpret due to the combined results of the caregivers and the recipients of care.

Bergs (2002) looking at the lived experience of six female spousal caregivers in Iceland too found the women experienced losses; of husband, intimacy, personal freedom, and self-identity. They noted their husbands' breathlessness caused communication difficulties and their husbands' anxiety prevented them (the caregivers) from expressing their feelings, in fear of upsetting their spouse and worsening the anxiety. The caregivers in this study also found their husbands to be overly self-centered and found themselves missing the husband they once knew. Further, the women were hyper-vigilant and found they listened and watched their husbands day and night. They felt there was no escape and they were becoming "mentally worn-out" (p. 618). However, in this study three of the six caregivers still were able to work outside of the home and the degree of disease severity of the recipient of care was not reported, making it difficult to interpret the context in which the results were reported.

Spence et al. (2008) explored the experiences and needs of family members caring for COPD patients and identified three themes which were (a) impact of family caregiving, (b) unmet support needs, and (c) carers' perceptions of patients. The caregivers in this study noted they lived in constant fear and were afraid to leave the recipient of care alone at home because of the unpredictability of the disease; fearing something would happen when they were gone. The caregivers also noted they were constantly fatigued and found their ability to concentrate was diminished due to their vigilance and the patients' needs throughout the night. In addition, the caregivers in this study felt helpless, frustrated, isolated, and experienced a lack of personal time. As well, they identified assuming a multitude of additional roles including that of feeling like they were a "nurse" (p. 370). Further, the caregivers voiced that they felt ill-equipped to make the decisions they were making regarding whether their recipients required professional interventions when they were having increased symptoms. Most voiced concern about the deteriorating condition of the care recipient and were unsure of what to expect and what services were available or where to access the services. Although this study identified the recipients as being 'advanced,' criteria to define this concept were not reported. In addition, the caregivers in the study were not a homogenous group but consisted of men, women, spouses, siblings, and children to the care recipient; making it difficult for the reader to determine if the results could be applicable to another context. Further, the

authors reported that the semi-structured interview guide was based on the current literature on caregivers' experiences; decreasing the credibility of the results due to leading of the participants.

A recent interpretive descriptive study exploring the 'burden' of COPD patients in rural New Brunswick, Canada found the caregivers of patients with advanced COPD lived one-day-at-a time (Simpson et al., 2010). More specifically, the authors' unearthed three themes (a) relational impact, (b) disease-related factors, and (c) coping-related factors. The caregivers noted ongoing relationship loss which heightened as the disease progressed; the relationship interactions that they once were accustomed to now either diminished or in some cases ceased altogether. As a result, the caregivers experienced anger, frustration, guilt, loneliness and many voiced the feeling that their relationship with the recipient of care was now very "one-sided" (p. 144). One participant likened it to "caring for a child" (p. 144). The caregivers were burdened by shifting roles; they now found themselves bearing the weight of the responsibilities that once belonged to the recipient of care.

The disease-related factors related to the increased responsibilities and care giving which they were now providing as a result of the recipients' inability or unwillingness to manage. As well, these caregivers too experienced and voiced hyper-vigilance which led to anxiety and fear.

The third theme of coping-related factors related to either the facilitators that assisted them in their capacity as caregivers such as interactions with family, friends, disease-specific knowledge, and self-care. However, there were also identified barriers that hindered the caregivers such as lack of respite, accessible peer-support, and disease-specific knowledge and skills that the caregivers thought were lacking.

Correlates of burden in COPD caregivers have also been explored (Cain & Wicks, 2000; Pinto et al., 2007). Cain and Wicks found no difference in burden noted between male and female care givers; however, those less than 55 years experienced greater burden, perhaps due to multiplicity of roles. While this study provides a look at correlation of burden, it does little to increase our indepth understanding of the day-to-day living and caring for someone with severe or very severe COPD at home.

A recent cross-sectional study done by Pinto et al. (2007) showed a negative correlation between relationship satisfaction and caregiver burden. No correlation was shown between female gender, spousal relationship, or caregiver health to affect burden. In addition, disease severity was not shown to correlate with caregiver burden. The authors of this study suggested this was in part due to the subjective nature of the measurement instrument used. The results from this study must be interpreted cautiously as the caregivers in this study were caring for recipients who had mild, moderate, severe, or very severe lung impairment; all with varying degrees of disability. CTS (2007) suggest that lung impairment measured by spirometry does not always correlate with functional severity and thusly care requirements.

Kühl et al. (2008) examined mental disorders and quality of life of COPD patients and their caregivers and found that caregivers of people with COPD had increased prevalence rates of depression and anxiety as compared to their non-caregiving cohorts. This study also identified that anxiousness in the caregivers significantly impacted the quality of life of the care recipient; however, the caregivers' well-being was also closely related to the recipients' health.

Two studies exploring the impact on caregivers of breathlessness in COPD patients identified that the caregivers experienced severe helplessness, anxiety, and fear as they watched the patients struggle to breathe (Bailey, 2004; Booth et al., 2002).

Caress, Luker, Chalmers, and Salmon (2009) conducted a narrative literature review on the needs of COPD caregivers along with interventions to support them and found few studies were available that identified needs of caregivers and no research was available that identified interventions.

While ten studies have been identified which looked at some aspect of providing care for COPD patients, the results of several of the studies made it difficult to determine if the results could be utilized with an alternate group of COPD caregivers. Seamark et al. (2004) interviewed both the caregivers and the recipients' of care simultaneously which may have affected the disclosure of both participants. As well, the results, from both the caregivers and the recipients' of care, were reported together which made interpretation difficult. A phenomenological study of woman spousal caregivers (Bergs, 2002) did not report the level of disability of the recipients' of care, making the results difficult to

interpret within the context from which they arose. CTS (2007) reports that COPD is a slowly progressive disease and someone can live with it for many years before becoming disabled. Therefore, the amount of care provided, by the caregivers in Bergs' study, was difficult to determine. Another study by Spence et al. (2008) must also be interpreted cautiously because they reported that their interview guide was developed from the current literature which would lead the participants in their answers. Both studies by Bailey (2004) and Booth et al. (2002) just examined the effects of breathlessness on COPD caregivers which did little to advance our understanding of the everyday experiences of this phenomenon.

Even though the ambiguous context that has been reported, within several of the current studies, made it difficult to transfer findings to another group of COPD caregivers, there were several similarities reported. Caregivers identified assuming multiple roles (Seamark et al., 2004; Simpson et al., 2010; Spence et al., 2008) as well as, watching the recipients' of care with vigilance day and night (Bergs, 2002; Simpson et al.). Several studies have reported emotional burden; however, the type of emotional burden was different with only a few similarities reported between studies and several of the similarities were drawn from the study using the interview guide developed from the current literature. Therefore, while there are several studies on COPD caregivers few similarities are reported and when they are reported a clear context is not provided, which makes it difficult for the reader to transfer findings to another group of COPD caregivers.

### **Rural Caregivers**

Little is known about caregivers who reside in rural areas as peer-reviewed studies on this topic are minimal and the concepts that have been studied are varied therefore, drawing conclusions is difficult (Goins, Spencer, & Byrd, 2009). Further, these authors note that it is difficult to determine if there is a difference between area of residence and the level of burden, stress, or depression experienced by caregivers.

Dwyer and Miller (1990) compared caregivers in rural areas in the United States with those who resided in urban areas and found rural caregivers to have greater mean stress levels but lower mean burden levels than their urban cohorts. Similarly, Butler, Turner, Kaye, Ruffin, and Downey (2005) found burden was not found to be related to

demographics but to isolation, task difficulty, knowledge of caregiving tasks, and family support.

Blakley and Jaffe (1999) found that the caregivers' social life, work outside the home, and health were impacted by providing care in rural Saskatchewan. The caregivers in this study either stopped participating in social activities or participated by themselves but decreased that participation. The authors attributed this to the caregivers either not wanting to leave the care recipients alone or because the added demands placed on the caregiver left them with little energy to participate. These authors also found that the caregivers' employment was also affected. The caregivers retired early in consideration of providing care or had to adjust their work to accommodate their caregiving responsibilities; increasing their burden, as all their spare time now revolved around providing care.

Further to this study, half of the participants felt their health had deteriorated since they assumed the role of care provider. They reported more stress, depression, chronic physical pain, and fatigue. Interestingly, a greater number of caregivers who continued to work outside the home reported less deterioration in their physical health than those who remained at home. Also, the caregivers who reported having help from their family members were found to report less worsening of their health.

Another study in rural Saskatchewan looking at the barriers to the use of formal healthcare services found that rural Alzheimer's caregivers were reluctant to use support groups and formal services for several reasons among which were their beliefs and attitudes (Morgan, Semchuk, Stewart, & D'Arcy, 2002). These caregivers did not accept services because it was a public admission that they couldn't look after their relatives. Further, they felt guilty because they saw caregiving as their duty and responsibility.

The studies on rural caregivers that were found have looked at either generalized caregiving in rural areas or have focused on dementia care. To date an in depth study looking at the lived experiences of caregivers of people with severe COPD in rural Saskatchewan is yet to be published.

### **Chapter 3: Methodology**

Morse (1991) noted that qualitative research is appropriate when little is known about a phenomenon or when a well-known phenomenon has not yet been explored with a certain group of people. Although there has been an abundance of research on caregivers with various illnesses; mental illness, dementia, cancer, or those with disabilities (Bergs, 2002; Carter & Acton, 2006; Health Canada, 2002), there is little understanding of caregivers of people with COPD (Bergs; Cain & Wicks, 2000) and even less understanding on the challenges faced by those residing in rural areas. For this reason I chose a qualitative inquiry method, applied hermeneutic phenomenology, to look at the experiences of people caring for someone with severe COPD living in a rural area in Saskatchewan.

In this chapter, I will review the general characteristics of qualitative inquiry and provide a brief history of the phenomenological movement. Van Manen's (1997) applied hermeneutic phenomenology was the methodological approach that guided this project and this approach will also be discussed. Further, I will review the design procedures used in this study including participant selection, data generation, analysis, ethical considerations, and criteria used for trustworthiness.

#### **Qualitative Inquiry**

Research in the health sciences has largely been quantitative over the years in order to “measure, analyze, replicate, and apply knowledge” (Streubert-Speziale & Carpenter, 2007, p. 2). While this approach is very useful in advancing our knowledge of phenomenon that can be objectively measured, such as the effects of medications or procedures on the body, it has been long recognized that it has been insufficient in measuring, or measuring with satisfaction, human behavior. The desire to understand, in a fuller or deeper way, human values, culture, and relationships, spurred by the social sciences, has advanced the tradition of qualitative inquiry (Streubert-Speziale & Carpenter).

Qualitative research is defined as “the investigation of phenomena, typically in an indepth and holistic fashion, through the collection of rich narrative materials using a flexible research design” (Loiselle, Profetto-McGrath, Polit, & Beck, 2004, p. 481).

Streubert-Speziale and Carpenter (2007) note all qualitative research has some common attributes. To begin, there is a fundamental belief that multiple realities exist. Qualitative researchers believe that because of their varied backgrounds and experiences, individuals come to understand and live experiences in a unique way. Secondly, qualitative researchers are committed to multiple ways of understanding. The question directs the research method chosen in qualitative research rather than the method directing the inquiry. Thirdly, there is a commitment to the view points of the participants and this is reflected in the selection of the participants, the generation of data, and the analysis and writing of the findings that are generated. Fourthly, information is collected from participants in their natural setting; interviews and observations are very often collected in the participants' homes. Fifthly, qualitative researchers acknowledge that they participate in the research process; the researchers collect the data, observe the participants, and analyze and interpret the results. For this reason, they openly reflect on their thoughts, experiences, and understandings of the phenomenon and attempt to *bracket* or set aside these beliefs in order to remain open to the data as it is revealed by the participants. However, even though the researchers attempt to set their understandings aside, there is an acceptance that qualitative research is conducted and influenced by the researcher to some degree. Subjectivity, according to Heidegger (1962), actually enhances our understanding of the phenomenon (as cited in Ahern, 1999) as it helps the researcher maintain an alertness in the development of themes that may be part of a "broader human experience" (Ahern, p. 408). Finally, qualitative research is commonly reported in a literary style that is rich with descriptions and grounded with stories and quotes by the participants (Streubert-Speziale & Carpenter). The aim of qualitative research is not to predict or generalize but to provide the audience with understanding and interpretation within the context that it is conducted (Streubert-Speziale & Carpenter, 2007).

I was drawn to qualitative inquiry for many reasons. First, I believe that our experiences shape us and influence both our understanding of the world around us and our world itself. For example, I believe that I view, interpret, and act differently because of my life experiences and therefore I have shaped my life, all-be-it not always consciously, as a result of my understandings and actions. Secondly, as a nurse, the

individual is extremely important and while experiences of the whole can guide our assessments and understandings, I believe that everyone and their situation is unique. Lastly, through my experience as a research assistant, I have found that questionnaires do not always reflect the participants' situation; the choice of answers are not always reflective of the participants' reality.

There are many qualitative research designs to choose from and a researcher chooses a method depending on what research question they wish to study. I chose van Manen's (1997) applied hermeneutic phenomenology in order to study the lived experience of rural caregivers of people with severe COPD.

### **The Phenomenology Movement**

The method of phenomenology draws heavily from phenomenology philosophy (Cohen, Kahn, & Steeves, 2000; Streubert-Speziale & Carpenter, 2007) and for that reason, I believe it is important to provide a brief historical account of the development of phenomenology over time in order to help with our understanding of van Manen's (1997) method of applied hermeneutic phenomenology.

Phenomenology is often referred to as a 'movement' as the concepts and ways of thinking within the philosophy have changed over time, both within the movement and within individual philosophers (Cohen et al., 2000; Streubert-Speziale & Carpenter, 2007). Cohen et al. identified three phases to the phenomenological movement; the preparatory phase, the German phase, and the French phase.

The preparatory phase involved two people, Franz Brentano and Carl Stumpf. Brentano (1838-1917) sought to reform philosophy so it could answer the questions that he felt organized religions were unable to answer. He engaged in descriptive psychology and he endeavored to make psychology more scientific. Carl Stumpf (1848-1936), his student, was noted to be the founder of experimental phenomenology, using experiments to discover the relationships in the perceived elements of individuals (Cohen et al., 2000).

The second phase, or the German phase, involved two influential philosophers; Edmund Husserl and Martin Heidegger. Husserl (1859-1938) is often referred to as the 'father of phenomenology' (Cohen et al., 2000). His approach was descriptive in nature and he endeavored to make phenomenology a rigorous science (Streubert Speziale & Carpenter, 2007). Several important concepts in the phenomenology movement were

introduced by Husserl especially the life-world or lived-experience, essences, and phenomenological reduction. The central concept in phenomenology is lived experience which is described as pre-reflective experiences; those day-to-day experiences that are so common-place that we take them for granted (Cohen et al.; Koch, 1995; van Manen, 1997). Another important concept is that of essences, which are described as the qualities that something has that makes it what it is and without them, it would no longer be the same (van Manen). Finally, phenomenological reduction or bracketing is another important concept, described as setting aside ones' assumptions and beliefs in order to allow the meanings of the participants to be illuminated (Cohen et al.).

Martin Heidegger (1889-1976) was Husserl's student and he introduced hermeneutics to phenomenology and questioned many concepts that he studied under Husserl (Dowling, 2007). While Heidegger also explored lived experience, he felt greater importance should be placed on interpretation and understanding (Dowling). He purported that through describing lived experiences the participant, has to some degree, already interpreted those experiences and they are further interpreted as the researcher recounts the experience and writes about the experience (van Manen, 1997). Heidegger also questioned whether researcher bracketing was possible or even beneficial as he felt that the subjective thoughts of the researcher are actually beneficial to identifying themes that are common to the human experience (Ahern, 1999).

The third phase of the phenomenological movement was the French phase and the three key players were Gabriel Marcel (1889-1973), Jean-Paul Satre (1905-1980), and Maurice Merleau-Ponty (1908-1961). The phenomenology of the third phase typically studied perception (Caelli, 2000) and worked on the premise that actions are a result of perceptions (Streubert-Speziale & Carpenter, 2007). Merleau-Ponty's work utilized the four existentials of lived time, space, body, and relationship (Dowling, 2007).

Caelli (2000) noted that the phenomenology that is utilized in North America has underpinnings in the above periods but yet has developed quite differently. Caelli identified differences between European and North American researchers using phenomenology. First, European phenomenology is often utilized to study abstract phenomena such as 'being' while American phenomenology is utilized for more practical applications and tends to be more concrete. Secondly, American phenomenology does

not describe experiences as being universal or unchanging but rather describes experiences within the context of culture. Thirdly, American phenomenology does not rely solely on the pre-reflective experience, as does the European approach, but also includes the thoughts and interpretations of the participants.

Van Manen (2002) suggests that professional practitioners from the human sciences, who are interested in explicating meaning of the everyday experiences of people, should use an eclectic approach to phenomenology, or what he refers to as applied hermeneutic phenomenology. This is the approach that I have chosen to use.

### **Applied Hermeneutic Phenomenology**

Van Manen (1997), an educator at the University of Alberta, notes that he was introduced to both phenomenology and hermeneutics while he was studying in the Netherlands. He states his approach, applied hermeneutic phenomenology is grounded in the lived experience and utilizes features from both the interpretive German school of hermeneutics and from the Utrecht school of descriptive phenomenology which evolved from Heidegger's approach.

Van Manen's (1997) applied hermeneutic phenomenology is respectful of both hermeneutics and phenomenology. This approach aims to be descriptive or phenomenological by unearthing the meaning behind our everyday lived experiences. It further aims to be interpretive or to use hermeneutics through deep, rich texts which helps to transport the reader to a place where they can not only cognitively understand what the experiences may be like, but where they can feel the experience and relate to certain aspects of those experiences. Van Manen describes the outcomes of this research as "ideally producing action sensitive knowledge" (p. 21), where the individual engaging in the text will be moved to act in a more thoughtful manner due to a greater understanding. In this approach, research and writing are inseparable and van Manen states that "hermeneutic phenomenological research is fundamentally a writing activity" (p.7).

Van Manen (1997) notes a researcher engaging in this methodology must have the "ability to be reflective, insightful, sensitive to language, and constantly open to experience" (p. xi). Applied hermeneutic phenomenology does not provide the researcher with a specific set of procedures to follow but rather, suggests six interplaying activities

be used in a dynamic, non-linear process. According to van Manen (p. 30-31) these inter-playing activities are:

1. “Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it;
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and re-writing.
5. Maintaining a strong and orientated relationship to the phenomenon;
6. Balancing the research context by considering the parts and the whole.”

### **Study Design**

**Participant selection.** The purpose of this study was to explore the meaning of the lived experience of family members providing care in their homes for people with severe COPD in rural Saskatchewan. In using applied hermeneutic phenomenology, the experience was investigated as it is lived rather than as we conceptualize it (van Manen, 1997) and therefore purposeful sampling was used to recruit participants who were experiencing this phenomenon.

**Setting.** The participants in this study lived in a rural area in central Saskatchewan and resided farther than 110 kilometers from an urban center; falling within the chosen definition of rural as defined by Statistics Canada (2001b). The interviews took place in the participants’ homes without the recipient of care present in the same room.

**Participants.** In order to gain an understanding of the phenomenon of interest, I turned to the people who were experiencing it and who would be able to provide descriptions of their experience. Two Registered Nurses, from two different rural areas participated in recruiting; one worked for the rural home care services and the other was a COPD nurse clinician. The recruitment consent is attached (see Appendix A).

The two recruitment nurses used purposeful sampling to recruit family members caring for someone who had a diagnosis of COPD. Even though the participants were thought to have COPD, objective data to confirm the diagnosis was not available. A spirometry was preformed at the initial interview to objectively confirm diagnosis as defined as a post-bronchodilator forced expiratory volume in one second (FEV1) to forced vital capacity (FVC) predicted ratio of less than 70%. In addition, the participants

were required to be providing care for a person who demonstrated severe functional disability from COPD as measured by the Medical Research Council's (MRC) (CTS, 2007) scoring of 5; too breathless to leave the house or breathless when dressing or undressing. Further, the participant needed to be identified by the recipients of care as their primary care provider, be unpaid, and a nonprofessional. Although all the recipients of care also had co-morbid conditions, they identified COPD as being the most bothersome. At the time of the interviews, the recipients had not had an exacerbation of their COPD in the previous six weeks.

The intended size of the project was six to ten participants. Morse (1991) proposes phenomenology studies designed to explicate meaning should include about six participants. Creswell (1998) said phenomenology should have a maximum of ten participants. Examination of previous phenomenology studies in this area revealed Bergs (2002) explored the lived experience of six participants in her study of female spousal caregivers providing care in their homes for a husband with COPD. Barnett (2005) utilized ten participants in exploring the lived experience of patients with severe COPD.

For this project, five female spouses and one male spouse were recruited who were providing care for their partner with COPD. All the participants who were recruited met the eligibility criteria and agreed to continue in the study when I contacted them and arrangements were made to meet them in their homes.

**Data collection.** As the activities of hermeneutic phenomenology are interconnected and dynamic (van Manen, 1997), data collection and analysis were simultaneous activities. Interviews, observations, and field notes were utilized to collect information for this project. As well, personal experiences, which were "immediately accessible" (p. 54) were used as a starting point to assist in my understanding of the phenomenon of providing care.

**Interviews.** Van Manen (1997) noted that interviews can serve two purposes in phenomenology. First, it is a means of collecting expert narrative from the people who are experiencing the phenomenon in order for the researcher to develop a "richer and deeper understanding of a human phenomenon" (p. 66). Secondly, it is a means for the researcher to develop a conversation with the participants or co-researchers, as he calls them, about the meaning of an experience.

Two digitally-recorded, conversational, face-to-face interviews were utilized to explore this phenomenon. The initial interviews occurred between December 2008 and February 2009 and the follow-up interview occurred in August 2009; all taking place in the participants' homes. The purpose of the first interview was to inform the participants and the recipients of care about the study, to collect signed consents, to perform spirometry with the recipient of care to determine if they had COPD, and to obtain a narrative from the caregivers who were living this phenomenon. The initial introductions, signing of consents, spirometry, and generally getting to know the participants lasted approximately 45 minutes. The interviews with the caregivers followed and were 45-60 minutes in length and were done in private without the recipients of care present. The purpose of this was to ensure that the caregivers would feel comfortable with disclosing their experiences without worrying about the impact on their spouse. The recipient of care and caregiver information letters, patient and caregiver consent forms, and demographic forms are attached (see Appendix B, C, D, E, & F) respectively.

The purpose of the second interview was to gain the caregivers' perspectives of the meaning of their experience, with the summary of the initial interview being used to initiate conversation. The first and second interview guides are attached (see Appendix G & H) respectively.

Of the six caregivers who were recruited, Joseph was the sole caregiver who did not agree to the second interview because he felt he had nothing more to add. The second interview was crucial in gleaning the essence of the experience. Each caregiver was provided with their initial summary and further questions were asked along with, the caregivers providing comments on the accuracy of the summary and the meaning that they attributed to the experience. Due to Joseph's inability to contribute to this dialogue, his interview was withdrawn from the analysis.

***Close observation and field notes.*** Close observations allow the researcher to become part of the environment (van Manen, 1997) and involve writing complete descriptions of the physical and social environment, observations of interactions, non-verbal communications, notations of things that are notably missing, and anything else the researcher feels pertains to the experience (Patton, 2002). Van Manen notes that the researcher who engages in close observation is really a collector of anecdotes and must

maintain an alertness allowing them to continually step back and reflect on the meaning of the situation.

Field notes were also used and recorded the most basic of information; their descriptive nature allowed the researcher to cognitively return to the interview at a later date of analysis (Patton, 2002). Ongoing field notes in the form of journaling, records the researcher's own experiences, insights, feelings, and reflections at the time they are experienced (Patton), and is part of the initial analysis process (van Manen, 2002).

The observations and field notes that I collected, not only focused on the communities and environments where the participants lived but also on their yards, acreages, farms, houses, homes, and of course interactions and non-verbal communication that were noticed either between the spouses or with the participants individually. I remained sensitive to the language that was used by the participants and I tried to maintain an attitude of openness; as if this experience was one that I was seeing for the first time. In addition, throughout the project, I recorded my insights as they became apparent whether it was on my daily walk or when I would awaken during the night.

Following the interview process when I returned to my vehicle, I took a moment to reflect on the interview and everything I noticed. I immediately wrote down all my observations and initial thoughts and feelings that were noted. These observations were helpful in analyzing the data because when I re-read them, I immediately returned to that moment in time with the participants.

**Data analysis.** In order to immerse myself in the data, assist in my understanding, and provide me with an overall feel for the interviews, I transcribed the digital recordings verbatim and then reviewed the recordings and the transcripts simultaneously to check for accuracy. I further reviewed the transcriptions and removed any identifying features such as names or geographic locations. In addition, the observations and field notes were also typed and attached to the corresponding transcripts. As insights emerged, they were recorded and a record was kept throughout the process of data collection and analysis.

Prior to beginning the analysis process, I reflected on my understanding of the phenomenon of caregiving and used that as a starting point. In addition, I maintained an attitude of attentiveness, which van Manen (1997) refers to as *reduction*. Further, to assist

in the illumination of the meaning of this experience, four interplaying techniques were utilized; writing as analysis, guided existential reflection, imaginative variation, and collaborative reflection.

*Personal experience as a starting point.* Van Manen (1997) suggests that often the researcher knows too much about the phenomenon they are exploring and simply trying to ignore their assumptions can result in our thoughts eventually coming forth and influencing our analysis. Rather, it is important to reflect on our understandings, experiences, and presumptions in order to attempt to “hold them deliberately at bay” (p. 47). However, Heidegger (1962) noted that this inability to completely suspend our understandings can actually assist the qualitative researcher in their understanding of the phenomenon because it provides alertness that those without the same experiences may not be aware (as cited in Ahern, 1999).

The experiences that I have had as a nurse and the people I have met in that capacity have influenced me greatly in wanting to explore this topic. However, the engagement I have for this topic comes from my personal experiences of providing care for family members.

Mrs. W. (the woman in the introduction) was a person who had an impact on me and I wondered why she moved me in such a way. Perhaps it was because I had been a nurse for many years and had spent a great deal of time caring for people in hospital who had COPD. I always felt COPD was a devastating disease, as I watched people struggle for breath and watched as they were isolated; either because they couldn't visit because of breathlessness or because they sometimes seemed to be ill-tempered or impatient.

I lived in a rural community for many years, where I would care for these people while they were hospitalized and then when they were well, I would see them struggling to get their oxygen tanks out of their vehicle as they walked up the long ramp to the post office to get their mail. As a nurse, I often thought about who cared and helped these people at home when they were discharged from hospital.

I had my first taste of being a caregiver when, as a teenager, I helped my father care for my mother who was dying of cancer. This was my first experience of caring for someone who was ill and required help. The operative word here was ‘help’. I was helping my father and therefore was not solely responsible for caring for my mother; I

still could go about and live my life and come and go at will. My father was there to provide care and support to my mother and I just provided assistance when I could. I remember feeling grief and sadness but more than anything, I remember feeling empathy for her in her pain; that which she suffered with, at a time of experimental cancer therapy and pain management. I remember the unending pain that seemed to go on-and-on and the creak of the rocking chair and the quiet sobs of someone who was unable to get relief from her new found partner, the pain. I remember praying for it to end, not just for her but because it was so painful to watch and hear. So, while I really wasn't the sole care provider, I do remember the on-going suffering that my mother experienced. However, because my mother had cancer we knew our time was limited, so the strain on us was inconsequential and we made the most of every remaining minute. This was my first recollection of my recognition of the day-to-day suspension of time that people who are not busy in the world can experience and perhaps this was one of the reasons that I was drawn to phenomenology.

At the time of my mother's death it was unbeknownst to me that we would once again be repeating the same process in three years when my father became ill. However, the time when he was diagnosed with cancer to the time that he died was short, so the care that I provided was minimal. So while the seeds and questions of providing care for a person with an illness had been planted, I still did not have a real understanding of what it may be like. At this point, I didn't understand the impact that the type and length of the illness trajectory would have on someone who either had the illness or the people who were caring for them. However, my time of providing care was not over and I would find out what it was like to care for someone who had a chronic illness.

Our son was diagnosed with a chronic illness in his early twenties. There is not a moment that goes by when he is not on my mind. He was the happiest child with a smile and a sparkle in his eye that, not only pulled on the strings of your heart, but ignited warmth that amplified life. He was a caring brother, a loving son, an appreciative grandson, a thoughtful friend, a scholar, an athlete, and a very compassionate being; someone who had a wonderful future to look forward to. Many difficult years passed, following his diagnosis, where he would have periods where he was so debilitated by his illness that he found it difficult to participate in life, as the rest of the world knew it. For

me, it was difficult to think of the possibilities that could have been but even more difficult to forget about them and live and work with the present. There have been times throughout the process, of coming to where we are today, that I have felt sadness for him and for our family. I have been angry because of his lack of insight and the decisions he has made. I have been paralyzed with depression because of the thoughts of what could have been and what now presently are. I felt unsure of the decisions that I was making in trying to seek help for our son and more than anything when he was unwell and making poor decisions, I felt an overall sense of helplessness and grief, yet an extreme sense of responsibility for his actions.

Perhaps, this most of all brought me to the heartfelt understanding that there is a difference between caring for someone who has a terminal illness and someone who has an illness that gradually worsens over time, interspersed with periods of acute illness, and with no expected certainty of termination. It also made me realize that the relationship that one has to the person with the illness can also impact what you as the caregiver experience.

Since I am working on my thesis towards my Master's of Nursing degree and I work with respiratory patients, where I am often confronted with the challenges they experience, it was natural for me to wonder about what the spouses of COPD patients experience when they are providing care to their loved one suffering from this devastating disease.

***Phenomenological reduction.*** Van Manen (2002) notes that the researcher, doing hermeneutic phenomenology, should adopt an attitude that brings them in closer contact with the emerging data. In order to adopt this attitude, van Manen suggests that the researcher engage in various forms of reduction in order to be mindful in the discovery of experiences of the life-world. He suggests five levels of reduction are necessary: (a) Heuristic reduction, allowing oneself to experience and be awakened by a sense of wonder and amazement; (b) Hermeneutic reduction, being open to new interpretations; (c) Phenomenological reduction, a state of concreteness or 'seeing' phenomenon as they are rather than theoretically; (d) Eidetic reduction, is looking past the concrete experience to see the universal meaning or essence; (e) Methodological reduction, or allowing the meaning to unfold in a non-linear, flexible manner without rigid adherence to method.

In analyzing this data, I assumed an attitude that I carried with me throughout the project. I continually took a step back and looked at it as if I was seeing it for the first time. When I thought I had come to a plausible interpretation, I would once again reflect on it from a different angle and always ask myself the question “what if?” I tried to see the lived experience as if it were new and had never previously been experienced by anyone. In addition, even though each caregiver’s experience was unique, I tried to find the common meaning which made this experience what it was and without it, it would not exist. Further, while initially I longed for some type of linear methodological approach, I soon came to realize and appreciate the dynamic process that was necessary in order to unearth the meaning of this phenomenon.

*Writing as analysis.* Van Manen (1997) states “hermeneutic phenomenological research is fundamentally a writing activity” (p. 7). In this methodology, writing is not merely a way to report findings but is considered to be part of the research activity and analysis. Through writing the researcher puts thoughts and reflections down on paper and through continually writing, reflecting, and re-writing, the thoughts transform into an interpretation of the phenomenon of interest. Further, this transformation is intended to “show rather than tell” (Nicol, 2008, p. 316), unlike other research styles where the findings are rationally reported. Its intent is to engage the reader in the text; to make them feel the experience as something they may have experienced or possibly could experience and to move them affectively.

Following the transcription of the interviews, I read each interview in its entirety in order to grasp the content and meaning. I then identified the meaning-units in each participant’s transcript and integrated them into individual summaries, incorporating stories and direct quotes as much as possible. I then read each transcript again in a selective approach in order to highlight phrases or statements which may have been particularly poignant in describing the experience and integrated these into the individual summaries. Finally, the summaries were then scrutinized line-by-line in order to identify what each one brought to the phenomenon of interest. These individual summaries were once again re-written and summarized as new insights became apparent, and eventually themes and meanings began to unfold.

***Collaborative reflection.*** New and deeper insights can develop and emerge when the researcher engages in collaborative discussion with a research group (van Manen, 1997). Following the completion of the individual summaries, the participants received their summary in the mail to read and reflect upon prior to the scheduling of the second interview. At the second interview, the participants were asked to clarify points from the initial interview and asked to provide their insights into what the summaries and their experiences meant to them. At this time, the participants provided valuable insight into the essence that unfolded from this experience.

In addition to the above collaboration, my supervisor and a member of my research committee, who is well versed in this methodology, read the summaries and provided their insights into the meaning of this experience; an integrated summary followed. This integrated summary was re-written several times until the themes that were illuminated began to reveal an overall essence about the experience.

***Imaginative variation.*** Imaginative variation involves looking at something from a different angle which helps to enhance or expand the themes already identified (Patton, 2002). Once the themes were identified, I dissected each one and asked two questions. The first question was “what would this experience look like if you were a different caregiver?” The second question was “how is this experience similar or different to another experience?” For example, when the caregivers talked about vigilantly watching their spouses I wondered how it would be different or similar to being a mother. Through this process new insights developed and it further assisted in teasing out the essence that was being sought.

***Guided existential reflection.*** Van Manen (1997) suggests there are four life-world themes or existentials that are common to the human experience and can be useful in explicating meaning of the lived experience. These lived themes are all pre-reflective: lived space, lived time, lived body, and lived relationship. Lived space refers to the felt space; that space that we do not put into words but which affects us. Lived time is not the measured objective time but the subjective feeling of moving of time. Lived body is our physical or bodily presence in the world; those feelings that are projected merely by our physical presence. Lived relationship is the lived relation that we experience with others in the space we share.

While these existentials were not the predominant analysis approach used in this study, they nevertheless were helpful in mining meaning and developing themes. For example, I experienced a feeling of vastness while driving to the caregivers homes in rural Saskatchewan. This feeling further led to the feeling of isolation which was reflected and identified in the stories that the caregivers shared.

Van Manen (1997) further suggests that the life-world existentials may be one way of organizing the phenomenological study in writing, especially if they were emphasized as the research approach. As these existentials were only used as a guide and other methods of phenomenological reflection, such as imaginative variation, were emphasized in this study, the themes that were explicated did not overtly reflect the lived existentials and therefore are not reflected in the organizational structure of the writing.

**Ethical considerations.** Ethical approval to conduct this study was granted by the University of Saskatchewan Behavioral Research Ethics Board and the Saskatoon Health Region.

Access to the potential participants was obtained through rural nurses in two different areas of the Saskatoon Health Region. Potential participants who met the study criteria, and who were willing to participate, were asked by the nurses to sign consent; to allow their names to be provided to me. I then further contacted the prospective participants by phone to provide them with a verbal description of the study and asked for verbal consent. At this time, when they agreed to participate, a meeting was arranged in their homes at a time that was convenient for them.

At the initial meeting, an information letter explaining the study was provided (see Appendix B & C). This easy, comprehensible letter included the purpose, procedures, risks and benefits as well, the contact information of the researcher and the researcher's supervisor. In addition, the participants were asked to sign a consent form (see Appendix D & E) after they were provided with the opportunity to read the letter and ask questions. The information letter and a copy of their signed consent were left with the participant for their records.

In anticipation that re-telling their stories may unearth unpleasant emotions, possible follow-up counselling was arranged with a counsellor in each of the prospective areas. Although two of the participants became emotional throughout the interviews and

emotional abuse was recognized as being experienced by another, all declined a referral to a counsellor when it was offered.

To maintain confidentiality, any identifying information was removed from the transcripts and pseudonyms were assigned. The information has been stored safely in a locked cabinet in the researcher's supervisor's office at the University of Saskatchewan and will remain there for five years.

**Criteria for evaluation.** Criteria for evaluating the trustworthiness vary depending on the philosophical underpinnings and purpose for conducting the research (Patton, 2002). Postmodern qualitative researchers value subjectivity (Patton) and therefore, rigid criteria are not congruent with their philosophy (Lietz, Langer, & Furman, 2006). However, researchers still must engage in activities to increase the readers' confidence that the meanings put-forth are representative of the participants' experiences (Lietz et al.). Patton suggests criteria for evaluating research utilizing social construction and constructivist philosophies are: subjectivity, reflexivity, authenticity, trustworthiness, and validation.

**Subjectivity.** Participants are recruited for their knowledge and experience with a particular phenomenon (Patton, 2002). The subjective stories of the participants' become the object of focus for the researcher (van Manen, 1997).

Through producing interpretative insights and staying true to the object of focus, the researcher becomes a co-creator with the participants sharing their stories (van Manen, 1997). The researcher, even though utilizing reductive methods, is unable to totally bracket all their previous experiences and understandings (van Manen) thus, injecting themselves into the meaning of the phenomenon.

Through explicitly stating how and why the participants were chosen to tell their stories and identifying my experiences and pre-understandings with this phenomenon, I have provided the reader with a basis upon which my findings were grounded. Through utilizing thick descriptions, I have enhanced the ability of the reader to evaluate possible subsequent application of the findings to similar situations. In addition, through reporting the limitations of this study, I have further allowed the readers to critically analyze the results.

**Reflexivity.** Reflexivity is the understanding and active acknowledgment, by the researcher, that the actions and decisions made will affect the meaning and context of the phenomenon (Horsburgh, 2003). By using the ‘first person’ throughout the writing process, I hopefully have assisted the reader to evaluate the extent of which my involvement has affected the findings. In addition, an audit trail describing the research findings and including reflexivity throughout has been especially important to allow consistent use of procedures by the researcher and to allow for the research community to critique the findings (Lietz et al., 2006).

**Authenticity.** Authenticity is being aware of one’s perspective, appreciating that of other’s, and reporting them with fairness (Patton, 2002). Throughout the study I have not only reflected upon my perspective but have remained open to competing or different constructions and have reported them openly and honestly.

**Trustworthiness.** In qualitative research, trustworthiness is not a rigid set of criteria but rather undertaking efforts to increase the confidence that we are representing the meanings put forward by the participants’ experiences (Lietz et al., 2006). To ensure greater depth in stories and provide me with a deeper understanding of the participants’ experiences, I spent significant time with the participants to develop trust and learn the ‘culture’ of caregiving. In addition, observations were used to ensure that I was able to identify those elements of the situation that were most relevant to the purpose of the study. To ensure data were accurate as provided, interviews were transcribed verbatim. In addition, phenomenological writing and re-writing returned and kept me immersed in the data throughout the analysis process.

**Validation.** The language of the phenomenological text can awaken the recognition of a shared lived experience with the reader (Ray, 1994). Through writing and re-writing, hopefully the themes have been transformed into experiences that ‘speak’ to the reader (van Manen, 1997). The “phenomenological nod” is what I was seeking as an end result of the process (van Manen, p.27); when the reader recognizes the essences put forth as an experience they may have had, or one that they could have.

## Chapter 4: Findings

*He hasn't been able to do anything for three years  
I have to do it all  
He won't even try to help himself  
I get frustrated  
You know, you have to watch what you say  
If I'm upset-he's upset  
I listen for his breathing  
I worry  
It feels like everything is closing in on me  
I'm lonesome  
Maybe I didn't try hard enough  
It upset me  
It feels like I'm giving, giving, giving  
It goes on-and-on  
When you love someone  
You do it  
It's not easy living with someone with COPD  
But you know that's your responsibility and if you don't do it-there's nobody else.*

A Compilation of Caregiver Quotes

The objectives of this project were to describe the experience of caring for someone with COPD and interpret the meaning of that experience, in order to more deeply understand what these caregivers are going through in providing care for a spouse with COPD. The caregivers, who I interviewed, shared their experiences which became the foundation for the findings, enhanced by the observations and field notes that were obtained by visiting the caregivers and the recipients of care in their homes. Even though the stories shared by the caregivers were different due to individual circumstances, there were commonalities that flowed throughout the stories that they shared. As mentioned in the previous section, the information that the lone male participant provided was not utilized, as he did not complete the second interview where the essence of the experience became apparent.

Using hermeneutic phenomenology reflection, I identified five overlapping themes of the phenomenon. The themes were overlapping because the stories shared by the women were rich in meaning and appropriately represented different themes. For example, the theme of *Unfulfilled Expectation* resulted in emotions that could also be

identified in the theme of *Emotional Burden*. Van Manen (1997) describes a theme as being “the structures of experience” (p.79) or meaning units which are used to help organize the experience. As well, themes can be thought of as tools that are used to help mine the deeper meaning of the experience, or the essence. The essence of the experience is what this methodology is really seeking. Van Manen notes that the essence is what makes an experience what it is and without it, it would no longer exist. After writing and re-writing and reflecting on the whole, the essence that seemed to permeate all of the caregivers’ experiences for me was that of unrelenting, ongoing, and sometimes overwhelming responsibility.

In order to understand this experience, the reader must first understand the context from which it originates. To assist with this, initially I have provided a description of a fictional person living with COPD and the challenges that are characteristic of this disease. I have then provided an introduction to the women caregivers, further enabling the reader to understand the context of the individual experiences. The caregivers have been provided with pseudonyms to protect their identity. I chose an alternate name for each of the caregivers while I was writing their interview summaries and at the second interview provided them with the opportunity to change the names, which no one did. The demographic information in table form is attached (see Appendix I).

Following the introduction to the caregivers, I have provided a table of the overlapping themes which have been identified as well, as illustrative quotes to assist the reader in organization when reading the findings. I have then described the essential themes utilizing direct quotes and anecdotes taken from the transcripts of the caregivers’ interviews. Within the themes, I have used imaginative variation to assist in illuminating the meaning of this experience. In addition, I have incorporated the knowledge gained from reviewing the literature on COPD caregivers into each theme in order to compare the findings from this study to that of previous studies.

Finally, I have reflected on the meaning that has been illuminated in the themes in order to explicate the essence that I perceive. Throughout the reflection, I often thought of the life-world existentials of lived space, lived body, lived time, and lived relation. However, they were used only as a guide to reflection and were not explicitly reflected in the summary.

I was unable to relay all the experiences that were shared by the caregivers, due to the vast amount of information that was provided as well, some of the experiences did not reflect the purpose of this project. For that reason, I have relayed only those caregivers' experiences that were most helpful in shining a light on understanding the essence of providing care for someone with COPD. My goal in writing this analysis was to touch that place within each one of us that makes us say "hmm" or "ahh..." when we understand something more deeply while at the same time representing the voices of the caregivers with respect. I want you to feel what it is like to care for someone who has COPD.

### **The Context**

While I have provided a definition of COPD along with the current literature describing symptoms, I don't think I have provided a look into the lives of people living with this disease. In order to assist the reader in understanding what the caregivers are experiencing, they first have to understand the context in which they live. The following story is about William, a gentleman in his early seventies with COPD who lives at home with his wife. Although William is a fictional character, his experience is drawn from the many people I have come to know who are living with COPD.

William was told many years ago that he had COPD but the words did not resonate with him at the time because, back then, it really didn't impact his life. You see, William was a farmer and besides having a persistent cough, which he attributed to his cigarette smoking, and a little more shortness of breath than usual, he was still able to manage to walk across the long yard several times a day to water and feed the cattle. He was still able to mow the grass in the yard, which seemed like it was the size of a football field, and he still tilled the garden for his wife and hauled water and garbage; all the chores that are required to maintain a farm on the rural prairies.

William began to become more short of breath as time went on and last winter, it seemed like he had one 'cold' after another, with little discernable difference in the periods in between. In fact, he dreaded the long cold winter months that are characteristic of prairie winters because he found it even more difficult to catch his breath in the outside air. During those cold months of winter, he was grateful for his home which seemed like an oasis, set apart from the bitterness of the outside elements; the endless snow drifts and

the temperatures so low that the air seemed to be heavy with crystals, making it even more difficult to breathe if he ventured out. His home was a place where he could close the door and not think about the work that still needed to be done or the cattle that, even more than ever, needed tending. However, this oasis also felt like a prison; a place he was trapped and unable to leave and a place which reminded him, of the life he was unable to live.

William can not really remember how long he has been bothered by his breathing, because it has gone on for so long, nor can he remember when his cough became persistent, producing thick, yellow phlegm that he spewed into tissues by the handfuls throughout the day. He also can not remember when the oxygen tubing, which he carried in fistfuls wherever he went, became his constant companion. But more than anything, William can not remember the moment in time when his breathing became a conscious act. In reflecting, he took breathing for granted, it did not even cross his mind when he was well but now, he thinks about every breath as he would every step, if he was walking on a tight-rope. He is cautious not to over exert himself, as anything more than a couple of steps can make it difficult to breathe. To him, it feels like his lungs are full and there is no room to add a thimble-full of air. He knows that he panics when he can not breathe, which makes it even worse, because that makes it even more difficult to get his breath. He imagines it must be like drowning; unable to fill your lungs and fighting to bring in air all the time realizing what is happening. He also knows that when he gets upset, he gets anxious and that too results in the same panic and breathlessness. William was once a strong man, capable of anything but now, he is someone who finds it difficult to carry his own weight across the room. He finds it difficult to do the things that he used to do, in fact, getting dressed is an overwhelming task. If the truth were to be known, there are days that he does not even bother. It just seems that everyday is hard interspersed with days that are even worse. William is exhausted.

### **Meeting the Participants**

All of the female spouses who agreed to be interviewed, to assist in our understanding of the lived experience of providing care for a person with COPD, lived in small communities in a rural prairie province. The initial meetings and interviews took place between December 2008 and January 2009; it was bitterly cold and this area had

received an abundance of snow. The drive to their homes was long and each drive seemed to be on an overcast, bleak day with snow drifting across the highway. While driving to their homes, I had an overwhelming feeling of being alone; I met few vehicles on the highway, and even fewer vehicles on the streets within their communities. I thought the barrenness was due to the extreme weather; however, I noted little activity on the highway or in the communities on my second visit in mid-August. I hadn't planned to visit the participants at these strategic times within the year but it was interesting to talk and see them both in the winter-time, when people with COPD are housebound, and in the summer-time when they are able to venture outside with greater ease.

I would like to introduce you to the people who were gracious enough to let me into their lives; they told their stories, and shared their feelings.

**Myrtle.** Myrtle was a friendly, warm, talkative woman in her mid-seventies; short in stature but tall, strong, and capable in presence. Myrtle told me that she had completed grade eight in school and had worked for many years as a healthcare aide at the local nursing home. Her husband, for whom she provided care, was in his late seventies; a tall frail man, who I imagined was a shadow of his former being. Myrtle's husband had very severe lung impairment, severe disability, and used oxygen continuously throughout the day and night; he carried a fist full of green oxygen tubing wherever he shuffled.

Myrtle and her husband lived on a large, well-maintained acreage on the outskirts of a small rural community in central Saskatchewan. Their children had all dispersed to various areas of the country and therefore, were not available on a daily basis to assist Myrtle in her caregiving role but, were available by telephone to provide support.

**Bea.** Bea was a friendly woman in her early seventies who, in her early life, was a school teacher but resigned to raise a family, and help her husband on the family farm. Bea had a strong, capable physical presence. She spoke openly but sobbed quietly while telling her story about providing care for her husband; it seemed as though she was relieved to have someone listen to her experiences. Bea's husband was a tall, frail gentleman in his late seventies who had moderate lung impairment but severe disability. Bea noted that her husband also suffered from some periodic confusion and heart failure and it seemed obvious to me, that he would not be living at home if not for the care and help that he received from his wife.

When their son moved onto the family farm, Bea and her husband moved to a small bungalow in this small rural community. Even though their son lived near by, Bea was reluctant to ask for help as she felt he had his hands full with the work on the farm and his own family to care for.

**Betty.** Betty was a short woman in her late sixties who was quick to smile and portrayed the appearance of being strong and capable. Betty left school after grade eight and spent her life on the family farm; helping her husband and raising their children. Her husband was in his early seventies; a tall, thin, frail gentleman who wore oxygen and carried the green tubing with him where ever he moved. Betty's husband seldom left the house, in fact, he hadn't helped with the outside work in three years because he became winded with any activity; he had very severe lung impairment.

Betty and her husband no longer grain-farmed and they were in the process of selling their herd of cattle. Their children had all moved away but they had a son that lived in a neighboring community; an hour away. Betty too, said she would only ask her son for help when she could not handle a situation on her own.

**Vivian.** Vivian was a quiet woman in her late seventies who appeared strong and capable. She quit school after grade eight when her father died, to help support their family. After marrying her husband, she stayed at home to raise their children; until recent years when she started working as a janitor at a local business. Vivian's husband was a small, frail man with moderate lung impairment who found that he became short of breath with the littlest of activity and, in the winter, seldom left the house.

Vivian and her husband lived on a small, well-maintained acreage in this rural community and most of their children had moved away, with the exception of their son who assumed ownership of the family trucking company. Vivian knew she could call her son for help, if required, but she too was reluctant to ask.

**Darlene.** Darlene was a woman who appeared somber. The stories that she told reflected a woman that was also strong and capable but because of her melancholy appearance she did not emit the same confidence that was obvious with the other female caregivers. Darlene was in her early sixties and talked openly, without reservation of her experiences of caring for her common-law husband with COPD. Her husband was a large, gruff, imposing man in his late sixties who remained in bed the majority of the time

that I was at the house; with the exception of once when he shuffled to the kitchen table to have a cigarette, wearing only his soiled underwear without functioning elastic. Darlene noted that he seldom left his bed; often eating his meals lying on his side, and he seldom left the house. Darlene's husband had very severe lung impairment.

The overlapping themes and illustrative quotes are shown in the following table:

Themes	Illustrative Quotes
<b>Assuming Additional Roles-</b> "I've got to do it all"	<ul style="list-style-type: none"> <li>- "He used to cut all the grass and stuff like that...I never had to do anything like that"</li> <li>- "But some things like...financial...he just throws up his hands and says 'you handle it'."</li> </ul>
<b>Ongoing Vigilance-</b> "You can just tell when he's not feeling good"	<ul style="list-style-type: none"> <li>- "You listen if it's normal or if it's raspy"</li> <li>- "So I took him to the doctor"</li> <li>- "For his medications...I have to tell him when to take them"</li> <li>- "Trying to get him to eat is the biggest problem"</li> <li>- "If you don't try...you'll lose what you could do"</li> <li>- "You've got to hide a lot of your feelings"</li> <li>- "I don't think it's fair to have him sit alone"</li> <li>- He likes to go on tours"</li> </ul>
<b>Unfulfilled Expectations-</b> "I can't get him to do anything"	<ul style="list-style-type: none"> <li>- "It upset me a little bit because I knew he needed help and (he) just wouldn't (go)"</li> <li>- "I get frustrated because I got to do it"</li> <li>- "Because he doesn't seem to want to help himself"</li> <li>- "I know sometimes I get short...I lose my patience"</li> </ul>
<b>Emotional Burden-</b> "It's hard...it's hard to live that way"	<ul style="list-style-type: none"> <li>- "It's changed"</li> <li>- "It just feels like everything is closing in on me"</li> <li>- "(I'm) very lonesome...very lonesome"</li> <li>- "I think that's the biggest...I think that's the biggest worry"</li> <li>- "Just sad to see him that way"</li> <li>- "It upset me because I tried"</li> <li>- "I don't know if he's playing games with me or not"</li> <li>- "You're like his maid"</li> <li>- "I get tired...I don't know how long I can deal with this"</li> </ul>
<b>Intermittent Reprieve-</b> "I can have piece of mind"	<ul style="list-style-type: none"> <li>- "I'll say smarten-up"</li> <li>- "We usually go up everyday"</li> <li>- "I had to get to my walking"</li> <li>- "It seemed like I could relax"</li> </ul>

### **Theme 1. Assuming Additional Roles: “I’ve got to do it all”**

A predominant theme that arose from the caregivers stories was assuming additional roles. They talked about all the additional work that had fallen on their shoulders because their spouses had COPD. They assumed the jobs that were once the responsibility of their partners; mowing grass, tilling gardens, shoveling snow, and tending cattle. These jobs, although sometimes familiar to them, were physical and were burdensome because there was no one else to share the load; it was solely their responsibility. To make these jobs even more difficult was the fact that these women were all aging and these jobs sometimes involved demanding manual labor, requiring them to lift and haul heavy loads; throw bails and handle equipment. However, they also needed to reach beyond the roles that were simply physical and take on roles that they may not have been accustomed to, like the role of decision-maker, especially those decisions involved in managing their finances.

**“He used to cut all the grass and stuff like that...I never had to do anything like that.”** I first met Myrtle when it was blustery, cold, and the area where Myrtle and her husband resided, had already seen a great accumulation of snow. I found their large acreage on the outskirts of town and as I drove into their yard I noted that their long driveway had been completely cleared of snow and the sidewalk that led to the house had been shoveled and swept. Although the snow was deep, you could see reminders of summer past; wooden lawn chairs sitting serenely under large Maple trees, a raised pond surrounded by stained glass stepping stones that had been strategically arranged for viewing, were all among the reminders that assumed their place, scattered throughout the yard, under a blanket of snow.

Myrtle, in an exhausted voice, sadly shared with me, that her husband had once been able to help with all the work that was required for the upkeep of their large acreage. Now, she is responsible for everything, everyday; the ongoing upkeep and maintenance. She continues to do what she did in the past; making meals, cleaning house, and buying groceries. However, now she has assumed those tasks that her husband once did. She said,

*I think the hardest is him not being able to do anything. He used to cut all the grass, and stuff like that...I never...did anything like that.*

Betty too shared similar experiences; she also assumed extra duties and took on additional responsibilities. Betty and her husband lived on a semi-operational farm; they rented their land to a neighbor and, at the time of our first interview, were in the process of selling their cattle herd. However, her husband had not been able to help with the chores for three years; Betty did it all. Not only had she been feeding and doing all of the cattle related chores but, she was responsible for helping with the calving; 30 the winter previous to my visit. In addition to tending to the cattle and their livelihood, Betty also did all the remainder of the outside work. She described some of the additional work that she did:

*He can't do anything and I got to do it all. Well, like...hauling garbage, we haul water, and there's a lot of that he can't do; so that falls onto me. I do all the yard work in the summer; cut the lawn, do the garden, run the garden tiller and the whole thing. In town, I do the running around; I pick up the mail, I go to the drugstore, I do the grocery shopping, whatever (there is).*

**“But somethings like... financial...he just throws up his hands.”** Like Myrtle and Betty, Bea too assumed all of the responsibility for the work both inside and outside their home. However, she noted the most distressing was learning how to manage their finances. Along with his COPD, Bea's husband has occasional bouts of confusion and as a result she has taken on the responsibility for their financial affairs. This has been new for Bea because when her husband was well, while they discussed their affairs, he made all the decisions. Bea said,

*There's a lot of things we can talk about, but some things like...financial...he just throws up his hands and says, 'you handle it.' You know, it's just too much for him...it gets too confusing for him. He just can't seem to get it figured out.*

Shoveling snow, hauling garbage, tilling garden, tending to the cattle, looking after financial affairs; the women had assumed the duties as if they lived by themselves. I couldn't help but think how similar this must be to being single; managing everything on your own. However, these people had lived a lifetime working, farming, and raising families. They had accumulated a lifetime of responsibility that they could manage in partnership whereas, a single person would only accumulate for one; making things much easier to manage without a shift in duties. No, while this has similarities to being single it was different.

Do you think it might be like losing a spouse? I imagine when you lose a spouse you immediately assume responsibility for everything. Much like a woman assuming the financial responsibilities when her husband dies; she has to step in and make decisions that may be foreign to her. This is similar to what these women have assumed but it is still different. While these caregivers have assumed the duties and responsibilities, and sometimes heavy work of two, their spouses are still alive. They still have a presence in their home, someone to talk with and share things with, someone to think about and do things for, someone who needed them. No, I think it is different than losing a spouse.

This theme has previously been described in other COPD caregiver studies (Seamark et al., 2004; Simpson et al., 2010; Spence et al., 2008). The caregivers in these studies have identified being overwhelmed with all their new responsibilities and have associated this as an additional burden (Simpson et al.; Seamark et al.). The caregivers in Spence et al. felt there was a loss, or at least a questioning, of their own identity as a result of assuming new and different roles of caregiver, counsellor, and nurse. In the present study, the theme of assuming additional roles was pervasive and pronounced throughout the texts and reflected the responsibility the caregivers assumed everyday. The women in this study assumed the role of caregivers but also the roles that were once occupied by their husbands. Due to living on the rural prairies where they lived on large, spacious, acreages and farms there was ongoing, over-whelming upkeep and in many cases heavy, manual laborious tasks. In addition, the caregivers in this study found that many of the tasks in their new roles were new and unfamiliar; ones they needed to learn and adapt to their abilities. Living on the rural prairies, where the work was sometimes all consuming, increased the responsibility and thusly, the burden of assuming these additional roles.

**Theme 2. Ongoing Vigilance: “You can just tell that he’s not feeling good.”**

In addition to the sometimes heavy tasks that they were solely responsible for, in order to maintain their lives as they once knew, the caregivers supported and watched their spouses with vigilance. They watched and waited and tried to act in order to stave off their spouses’ anticipated illness; trying to prevent them from needing hospitalization, trying to keep them alive. In addition, the caregivers in this study provided support and took responsibility for their spouses’ ongoing health; they made sure their spouses

received their inhalers and monitored their diet. They also understood that their spouses needed to remain active in order to maintain some strength, so they encouraged their partners to continue with some activities and whenever possible, the caregivers kept their partners busy by entertaining them.

**“You (listen) if it’s normal or if it’s raspy.”** Every hour of everyday the caregivers stood guard; they watched and listened. They asked themselves the questions; is he more short of breath than yesterday, is he coughing more, why is he so sleepy today, I wonder if he’s getting sick? At times this vigilance had become an unconscious act but at other times it was very obvious and deliberate. Nevertheless, they were always on guard, and always noticed when their spouses’ breathing had become more labored or the sound had changed. Myrtle listened for her husband’s breathing but she also noticed other subtleties that would suggest he was not feeling well;

*Just about a week I can tell that...he’s feverish and he’s coughing more and he doesn’t want to eat and you can just tell that he’s not feeling good. When he’s not feeling good then he’s grouchy...very on edge.*

She further noted that the listening is more obvious at night. She said,

*You (listen) if it’s normal or if it’s raspy or whatever you call it. Usually during the day, we’re together...he’s up and around...you don’t really (listen). But I say more in the evening or early morning... you know...during the night. He kind of breathes...kind of whistles...like I don’t know how to explain it but...he’s got a kind of a whistle when he’s letting his air out. But he always has had that...and you listen for that hey? (At night) then sometimes I’ll say, ‘are you o.k.’ ...you know...and then he kind of wakes up from his sleep.*

**“So I took him to the doctor.”** The caregivers in this study told the story of vigilantly watching their spouses but also when they noticed that something had changed that might indicate their spouse had become ill, they assumed the responsibility of seeking medical care. Bea told the story about when her husband was ill, even though he didn’t realize or admit it.

*He was getting weaker and one day he was really bad, he just couldn’t seem to function; like he couldn’t walk from...say the bathroom to the living room without stopping and just really breathing hard. So I took him to the doctor and they said, ‘we have to get you some help.’ So they sent him by ambulance to X (a city hospital)...in there he had a heart doctor and he had a respirologist looking after him...and he did have pneumonia they said, and also...atrial fibrillation. When he came home...he was tired and pooped-out again for quite awhile...I*

*would say...close to a month before he really got better. (When he first comes home from the hospital), he's really just wiped...and he does a lot of sleeping...and I have to do more things for him. Like instead of him getting up to get something...well, I would probably do it, because it just makes him puff so much...it's so hard on him.*

Even though the caregivers were aware their spouse was becoming ill and needed to see the doctor, for most of the caregivers, it was not an easy task to convince their spouse to seek medical help. Vivian said that her husband would not go to the doctor soon enough when he got a cold and then he became so sick that she had to rush him to the hospital.

*Well, there's times when he can't breathe too good and I've had to rush him to the hospital. But we have a 50 mile drive to get there and you pretty near have to phone ahead to say that you're coming...so I try and keep the numbers handy to phone. Figured it was time to get him to the hospital not just his family doctor.*

**“For his medications...I have to tell him when to take them.”** The caregivers not only expected that their spouse would get ill and vigilantly watched for that, but they had taken on the responsibility of trying to maintain their spouse's health and intercept that illness. The women talked about ensuring their husbands took their medication. Bea said,

*You do have to tell him...for his medications...I have to tell him when to take them. We were a little rushed for time (this morning) because I had to get to my walking. So...usually he takes his Spiriva at breakfast. By the time he had his breakfast...and I had to go...there wasn't time to take his Spiriva...but I said to him 'you can take this while I'm gone'...cause he knows what to do ... y'know...how to. I said, 'you can take this while I'm gone...but when I came home it was still there...y'know...he hadn't done it...and I said, 'you didn't take your Spiriva' and he said 'No, I thought I'd wait until you got home because I might not do it right.*

Darlene also noted that her husband needed to be reminded to use his medication;

*I can hear him get up. I don't get right out of bed...I just lay in bed. But the bed squeaks so I can hear when he's getting out of bed. So when he says, 'I can't breathe'...I say 'put your nebulizer on...or take your puffer.*

As well, when her husband became short of breath, he would often use an empty nebulizer or sometimes, he would only use it momentarily; for less time than what was

required to provide him with relief. Therefore, Darlene had to often fill his nebulizer and watch over him while he was using it to ensure that he took it for the required time in order for it to be beneficial.

**“Trying to get him to eat is the biggest problem.”** In addition to watching and encouraging their spouses to take their medication, the caregivers talked about the difficulty they had in getting their spouses to eat. Betty noted that her husband had no appetite and was becoming very thin and continued to lose weight. Both Betty and her husband drank *Ensure*; a nutritional meal replacement provided to people who are unable to eat their meals. Betty provided support by suffering along with her husband; drinking a drink that most people would rather not drink.

*Trying to get him to eat...to gain weight...is the biggest problem I've got. Because a lot of the times...he doesn't eat. You go to cook a meal and (he says) 'don't cook anything for me.' So we're on ensure.*

**“If you don't try, you'll lose what you could do.”** The caregivers also understood the importance, to their spouses, of maintaining some physical activity. Most of the women said they encouraged their husbands to help make meals, do the dishes, or make the bed. Betty said,

*In the house I get him to set the table and get him to empty the dishwasher...cause he does need some exercise.*

Myrtle said,

*You know, (when) I can see that he really isn't feeling good then I get it. Otherwise, I try and make him do things for himself. (I say) 'well, you have to try because if you don't try, you'll lose what you could do'.*

**“You've got to hide a lot of your feelings.”** Hiding their feelings was common for the caregivers as they found that when they were upset, then their spouses became upset and their breathing became worse.

Myrtle said,

*(when he's) not feeling good then he's grouchy...very on edge...you've got to be careful what you say. You've got to hide a lot of your feelings, that's cause...if I'm upset then he's upset.*

**“I don’t think it’s fair...to have him sit here alone.”** The women worried about their spouses if they left them alone and therefore, seldom left them for longer than an hour. Myrtle was healthy and still capable of participating in organizations and visiting friends but she would not leave her husband alone; not that her husband was not capable of managing on his own but she felt sorry for him;

*I don’t feel it’s fair...to have him sit here alone just because he’s sick.*

Bea too did not like to leave her husband alone both because she felt empathy for his situation but, more importantly, she worried that something would happen when she was away;

*I worry sometimes when I go somewhere...you don’t really know what he might...well, he does turn on the stove for when he’s going to steam (himself)...y’know...like he uses a pot on the...on the stove...and sometimes he does forget to turn it off.*

**“He likes to go on tours.”** When their spouses were feeling well and wanted to venture out of the house, the caregivers would drop everything to accompany them; most often going for a drive. Myrtle noted that often she would be busy when her husband would want to go for a drive and she would abide. Bea also noted that her husband liked to go for a drive and she would drop what ever she was doing when he wanted to go. She said,

*He likes to go on tours. Well, (on) different days...he’ll say ‘where are we touring today?’ So we just go out and we just drive...look at the crops you know or....drive out to the lake...yeah...and he really likes that kind of stuff.*

Not only do the caregivers take responsibility for the tasks that are required to maintain their lives, but they all seemed to take or share in the responsibility of their spouses’ health; vigilantly watching if their spouses’ symptoms had changed, taking them to the doctor, or rushing them to the hospital. While at the same time, the caregivers encouraged their spouses to do things that would help to sustain them like taking their medications, ensuring they eat, encouraging them to remain active and providing them with a change of scenery.

I imagined earlier how this might be similar to losing a spouse but after listening and hearing what the caregivers do for their spouses, I can see that it is much different. In addition to becoming solely responsible for all aspects of their lives, the caregivers in this

study bear a great responsibility for ensuring their loved one remains as healthy as they can. However, I couldn't help but think of how this is similar to a relationship that a mother would have with a child. A mother also assumes responsibility for her child; watches them for illness, takes them to the doctor or hospital if needed, ensures they receive their medication and proper nutrition, and provides endless encouragement and entertainment. Always wanting them near and not leaving them for long to ensure that nothing happens to them; feeling responsible for their well-being and happiness. However it is not quite the same, as a parent, a mother is building a foundation and looking towards the future; not wanting anything to happen that will affect their child later in life. While our caregivers were sustaining; hoping to keep their spouses well for as long as they could, really only looking at the moment; trying to keep them alive a little while longer.

This theme too has been found in other studies (Bergs, 2002; Simpson et al., 2010; Spence et al., 2008). Caregivers have been found to watch and listen to the recipients' breathing, often day and night (Bergs). They ensure the patients get their medications, take them to their medical appointments, and struggle to make sure they get the proper nutrition (Simpson et al.; Spence et al.), even though the recipient of care does not feel like eating. The caregivers talked often about not wanting to leave the recipients at home by themselves for fear something would happen when they were gone. When they were required to leave, the caregivers often timed the moments away and most times were gone for less than an hour (Bergs; Simpson et al., Spence et al.). However, in the present study, in addition to the above vigilance, the caregivers identified the encouragement they provided to their spouses to maintain their level of functioning, such as walking and getting up and retrieving items for themselves, within their limits. Further, the caregivers in this study, even though they were overwhelmed with their other duties, would drop everything when their spouses felt well enough to go for a ride in the country; to ensure their spouses' would experience some joy and participate in some activity. Throughout I have imagined that this is very much like the actions of a mother caring for a child. In fact, Spence et al. identified a caregiver who said "it's like having another child sometimes because you are sort of responsible" (p. 370). Again, the responsibility that the caregivers assume permeates this text but also texts of others.

### **Theme 3. Unfulfilled Expectations: “I can’t get him to (do anything)...”**

Maintaining their lives and monitoring and watching their spouses vigilantly have become the work of each of the caregivers. While doing this, or because of doing this, the caregivers have expectations of both themselves and their spouse with COPD. They have expectations that their spouse will seek medical attention when they are ill, or at the very least, listen to their suggestions to see the doctor. The caregivers also have expectations that their spouses will attempt to help and do minor chores when they are well or do things that will help to maintain their own health. But more than anything, the caregivers have expectations of themselves; they expect that they will be tolerant and patient without ever losing their tempers. Very often these expectations are unfulfilled and result in conflict and disappointment; conflict with their spouse or being upset and disappointed in themselves.

**“It upset me a little bit because I knew he needed help and (he) just wouldn’t (go).”** The women watched, listened, and monitored their spouses’ health. They ensured that their spouses got their medications and nebulizers and they took them to the doctor or rushed them to the hospital when needed. They would wake up at night and lie quietly listening for their spouses’ breathing and worry; wondering if they could still hear the rhythmic movement of air in and out of their lungs. Due to the time and energy they devote to maintaining their spouses’ health, along with the ongoing concern for their spouses’ lives, they got upset and frustrated when they were unable to convince their spouses with COPD to seek medical help sooner rather than later. Myrtle relayed an experience of when her husband became ill.

*Myrtle and her husband were fishing in northern Saskatchewan and the air was thick with smoke from forest fires. Myrtle could see that her husband wasn’t feeling well but he refused to go home; she knew he was ill and needed to see a doctor. The next morning when he finally agreed to go home, Myrtle wanted to stop at a hospital in a town they drove through, but he refused. When they finally arrived home, she wanted to take him to the local doctor; he once again refused. She said, I didn’t want to argue because he was so sick and we came home and he still wouldn’t go in (to the hospital)...and I was getting a little bit upset because I knew he needed medical attention. The next morning he couldn’t get out of bed...we had to get the ambulance out to take him in...and it upset me because I tried, and then I thought well maybe, I didn’t try hard enough...but what do you do...you know...they won’t go they...you can’t force them. I can’t*

*carry him in there. The doctors didn't think they were going to pull him through.*

**“I get frustrated because I got to do it.”** There seemed to be an understanding of the permanent changes that their spouses have experienced as a result of their chronic illness as well, as the characteristics of the illness itself. The caregivers seemed to understand that there was a new ‘normal’ for their spouse, interspersed with periods of illness. During these periods of illness, when their spouses had difficulty rising from their chairs, the caregivers did as much for them as humanly possible. However, it was during those times when the acute illness passed and the caregivers could see that their loved-one with COPD had regained some strength, that there were expectations. Yes, they may be short of breath but they should be able to do some things to help around the house. Betty talked about trying to get her husband to help with simple chores;

*I get frustrated because I got to do it. In the house I get him to set the table and get him to empty the dishwasher...cause he does need some exercise. But he doesn't seem to think so...and then I'll get upset and then he will do it.*

Darlene also noted that her husband did very little for himself. Even though her husband became short of breath with any activity, he was still able to get up to the bathroom and he would walk out to the kitchen table to have a cigarette, or fix himself a sandwich during the night when she was in bed. However, she noted

*He's a very demanding man. He wants you to do everything for him. He'll lay in bed and yell at me, 'come and bring me a pepsi...oh, bring me my supper in here'...and he doesn't even want to walk from the bed to the table to eat (anymore).*

**“Because he doesn't seem to want to help himself.”** To improve endurance, decrease shortness of breath, and increase quality of life in COPD it is important to exercise as well, it is important to continue to live your life and do as much as you can. The caregivers seemed to understand this as they expected that when their spouses were feeling well, they would take the initiative and do things to improve or maintain their health. Betty said,

*I just get mad sometimes when he doesn't try to do anything...because he doesn't seem to want to help himself.*

Myrtle expressed the same concerns;

*Well, you have to try because if you don't try, you'll lose what you could do. I said, the biggest problem we have is that I can't get him to do...even like walking or something...you know...trying to make him walk...even if he can't go far...do it many times...I can't get him to. Then he gets angry...and then you just drop the subject hey? I can understand that sure he's short of breath or something, I could see even myself panicking when you...you know, don't have any air. But it's the effort is not there to try and do anything.*

**“I know sometimes I get short, you know, I lose my patience.” COPD**

generally progresses over many years and a person with this disease can be severely disabled for a long period of time. When a spouse is healthy and the division of labor is uneven, conflicts arise. However, when the caregivers have been carrying the load to maintain their lives and have vigilantly watched and monitored the health of the person with COPD, even though they do not seem to help themselves, it is easy to understand why the caregivers may lose patience. Unlike losing patience with a healthy spouse, losing patience with someone who is ill and has difficulty breathing, causes the caregivers to feel guilty and regret that they opened their mouths or even more, that the thought even crossed their minds. They expect that this should not happen and that they should be continually calm and patient and laboriously try to manage their responses. Myrtle describes this labor;

*“I know sometimes I get short, you know, I lose my patience. It seems even the littlest task...I feel that he should be able to do, or trying to do, and he just doesn't; he just (says), ‘I can't, I can't’.” Myrtle said she often gets resistance and this leads to conflict, which makes her angry at times and at other times, she finds that she gets discouraged and just walks away. “Well, I know I get sometimes a little bit short...where I never did before hey? Well...you never had things like that (responsibilities of care) and I want to do something and...you can't do (it)...and you know it kind of bugs you a little bit...you just have to stop to think, maybe count a thousand and one, a thousand and two...until it passes. You know...and I say...I can...if I get a little bit upset or something on edge...I just go outside...even in winter. I just pretend I'm shoveling snow or do something...I'll putter outside.” Further, “(when he's) not feeling good then he's grouchy...very on edge...you've got to be careful what you say. You've got to hide a lot of your feelings, that's cause...if I'm upset then he's upset.” When this becomes too much, Myrtle said it bothers her and she'll lament for a short while but then picks herself up and says “smarten-up, don't feel sorry for yourself. I know that's the way things are and I just have to learn to accept the way it is.”*

Once again I thought of how this was similar to a parent-child relationship. Parents too have expectations of their children and of themselves. However, because parents come from a position of authority, parents have the ability to influence the decisions their children make. If their child is ill and needs medical attention, parents expect their child will not struggle when they take them to the doctor. When a child is growing older, a parent expects that they will gradually assume more responsibility for their own well-fair. As well, parents also expect that when conflict ensues, they as parents will rise above the situation and remain patient.

While the caregivers had similar expectations, they felt powerless to influence their spouses to seek medical care, help with minor chores, or do things to maintain their own health. They helplessly had to sit and wait, knowing their spouses were becoming ill but not knowing if this would be the illness that their spouses would not recover from. They had to wait until their spouses relented and accepted help. So while being a caregiver for someone with COPD has similarities to parenting a child, another important difference is that our caregivers had little control and were helpless in being able to influence their spouses and affect the outcome.

The caregivers in previous studies have voiced frustration because the recipients were not motivated to help themselves as well, frustration in having to do everything (Bergs, 2002; Simpson et al., 2010; Spence et al., 2008), which was also prevalent in this study. In addition, Spence et al. identified that the caregivers felt helpless and had little control over their lives because of their lack of personal time. Simpson et al. also identified feelings of helplessness due to the recipients' deterioration, breathlessness, increasing dependency, and their negative behaviors and attitudes. In the present study, the caregivers too felt helpless, lacked control, and became frustrated but it was a result of not being able to affect the decisions made by the recipients when they were ill. The caregivers in our study said they realized the recipients were ill and needed medical attention but the recipients were unwilling to listen and seek help. Further, they said they knew from experience the results of delaying treatment and this further aggravated the frustrations and feelings of helplessness. The caregivers further identified being upset with themselves because of losing their patience. This study identified these feelings as resulting from *unfulfilled expectations*. The caregivers expected certain things from the

recipients of care and from themselves and became frustrated when it wasn't achieved; other COPD caregiver studies have not identified this as unfulfilled expectations.

**Theme 4. Emotional Burden: “It’s hard...it’s hard to live that way...”**

As a result of their spouses' condition and the added responsibility of assuming additional work, monitoring and trying to maintain their spouses' health, and having expectations that are unmet, the caregivers experience emotional burden. They spoke of the many losses experienced; loss of partner, relationship, personal freedom, and loss of the future. In addition, and as a result of the losses and not wanting to leave their loved one alone, the caregivers shared their experiences of isolation and feeling house-bound, especially in the winter months; loneliness ensued. Due to their spouses' illness and ongoing symptoms, the caregivers worried about their spouse and felt empathy for them. As well, there were times they felt regret, uncertainty, and felt inconsequential. All these emotions that were experienced by the caregivers were a result of their spouses' disease and the physical burden, but they also compounded the overall burden by increasing the work needed to be done in order to either manage or accept reality.

**“It’s changed.”** A common theme for all the participants was loss. Their experiences reflected the loss of a partner to share in the many responsibilities and tasks required to maintain their lives; the upkeep and maintenance of their homes and yards, someone to help make decisions, and someone who looked after and took responsibility for their own health and happiness. However, the caregivers also experienced the loss of a partner to share in relational experiences. For the recipients of care, every moment was a struggle to breathe and perhaps for that reason were no longer interested in participating in any type of activity that required them to exert themselves; often meaning simple things that other people take for granted, like talking or eating meals together. The caregivers in our study no longer had someone to talk to about their day or discuss what will happen tomorrow. Darlene reflects on a typical day;

*In the morning it starts...I get up...I make coffee...and I'll tell him... 'the coffee's ready' ...sometimes he'll get up...sometimes he doesn't. I'll bring it in there. So I have my coffee and smoke and then he says, 'well, I'm really getting hungry' ...so I make him his bacon and eggs and his milk...sometimes he'll get up...sit at the table, eat it...sometimes he says 'well, bring it in here' ...if I tell him 'well, why don't you come up and sit at the table and eat it?' (He'll say) 'cause I don't feel like it, bring it in here.' So then he eats his breakfast...he'll have a half a smoke*

*(and if he has gotten up) he says, I've gotta go back to bed'. So he goes to bed...then he'll get up about 12. Then he'll say 'oh baby...I'm really hungry, make me some soup'. So I'll make him soup. So he eats his soup and then he sits there maybe five minutes and (says) 'I've gotta go back to bed, I've gotta go to sleep'. And then about three o'clock again, he'll yell from the bedroom, 'can you bring me something to eat? I'm hungry'. So I'll make him a sandwich and take it into him...and I'll say, 'supper's on'. (He'll say) 'well, I'm hungry right now'. So then he gets up about five o'clock and I ...have supper ready for him...he'll eat his supper...another five, ten minutes after he's eaten...he goes to bed. So he's in bed 75% of the day. I think we've grown further apart...cause we don't do things together anymore.*

Bea also noted that their relationship had changed as a result of her husband's illness. She said they were close and spent a great deal of time together prior to her husband becoming disabled by his disease. They used to travel in the winter months; golfing and visiting with friends. But now, things are different. Her husband's medical needs have made it difficult to travel, so consequentially they are no longer able to leave the country. As well, even the time they now spend together has changed. Bea talks about the period of time that her husband sleeps after supper but she also noted that he naps throughout the day.

*It's changed; you just don't do the same things together. He sleeps a lot. I'm surprised that he can sleep that much, like I said, after supper he'll sleep a couple of hours and then he just gets up for maybe an hour or what ever. (He then) takes his medication and maybe has a cup of tea and will see what the weather's going to be tomorrow and back to bed he goes.*

As well as the losses of a partner and the changes in a relationship, Myrtle's experience spoke of her personal loss of freedom and the realization that this was ongoing.

*Well, I say I just got to know that he can't do what he'd like to do and what I would like to do. You know, we can't do it and it is a little bit discouraging sometimes you know that you can't do anything...can't go into a café and eat...which we used to do...because he can't...get his air in there...So usually (we) have to buy a sandwich and if we're longer in (town)...we have to eat in the truck. You know we just can't go into a building...which is a little...sometimes bothers (me) a bit but then I'll say...smarten up...that's the way things are hey?" She also said, "I was used to being on the go outside...you know...I did whatever I wanted, when I wanted to hey?"*

**“It just feels like everything is closing in on me.”** Due to their vigilance and not wanting to leave their spouses alone, along with their spouses’ inactivity and not wanting to leave the house, the caregivers spoke of feeling isolated, especially in the winter months when the cold, windy weather aggravated their spouses’ shortness of breath, making it even more difficult for them to breathe.

For Bea there was a difference between the windy, cold months of winter and the warm freeing months of summer. In the winter, Bea’s husband would only venture outside when he was ill and needed to see the doctor or go to the hospital. He was weak and sometimes confused so Bea would never leave him alone for longer than it took for her morning walk.

In contrast the summer provided freedom; they no longer had to warm the car, put on winter clothes, struggle with the oxygen tank as they walked through the drifts of snow to the car, or worry about the frosty cold air that bothered her husband’s breathing. In the summer, they could go for long drives in the country to watch the crops as they grew and matured. They could sit in Adirondack chairs, which were strategically placed just outside their front door, under large spruce trees listening to the birds. The summer made it easier to stay connected to their surroundings and community.

*Oh, in the summer, you know, we can get out...and so we do visit and other people visit us too. We sit out there (pointing at the chairs under the spruce trees) and watch the birds. Ah... summer is fine like, we can go anytime. He likes to go on tours. Well, on different days...he’ll say ‘where are we touring today?’ So we just go out and we just drive...look at the crops you know, or...drive out to the lake....he likes that kind of stuff. Winter is not good you know...for getting out. He only goes out when he has to go to the doctor. You know, or what ever other kind of things because...the cold air bothers him so much...and he just doesn’t...you know...doesn’t like to go out in the cold at all.*

Myrtle said it the best when she said,

*It just feels like everything is closing in on me. I just have to...have some place where I can go and just work it off...you know...to get over that feeling. That’s why I said...like that’s why I’m more...just as much outside as in the house. Cause I am too used to being on the go constantly...I know I have to change...my lifestyle hey? But it takes a little while...it’s hard to tell myself that.*

**“(I’m) very lonesome...very lonesome.”** As a result of the losses and the isolation the caregivers in our study were lonesome. The companionship and mutual support that they once knew had changed. Darlene described her experience;

*(I’m) very lonesome...very lonesome. I think of the farm...I think of my first husband. Yeah, it’s hard. Cause when I met him...he was completely different...he was an outgoing guy. He liked driving early in the morning...going listening to the birds and stuff...ah...he really enjoyed the outdoors...(to) go fishing, go driving...go on a holiday, go camping...go to rodeos. He never missed a rodeo, but now it’s just like he...just...shut himself off from everything...and even me. I think he’s in a depression. His personality has really changed. To me it feels like I’m giving, giving, giving...and yet...I’m not getting anything back.*

**“I think that’s the biggest...I think that’s the biggest worry.”** Due to their spouses’ disease and their difficulty breathing, and as a result of previous experiences, the caregivers worried about their spouses. Earlier we heard Myrtle talk about how she watched her husband and how she wakes and listens to him breathe at night and wonders if he is still alive. She said,

*(I’m) scared that you’re going to wake up one morning and there’s not going to be (any sound). I think that’s the biggest...I think that’s the biggest worry.*

Darlene too worries about her husband and tells about a time when he had pneumonia:

*His breathing was so short...like he’s fighting to breathe. I’d lay in bed and I could...hear that whistle in his chest and it brought back memories of my (first) husband with lung cancer; and I think that’s what I’m scared of. One day they’re going to tell me that.*

**“Just sad to see him in that way.”** In addition to worrying about their spouses, some of the caregivers expressed empathy for them. Bea seldom talked about how difficult it was for her; mostly expressing her concern for her husband. It was very difficult for Bea to see her husband deteriorate. With tears in her eyes and an overwhelming sadness in her voice, almost like her heart was weeping, she said,

*(It’s) just hard to see (it) happening to him. It’s so hard on him. (It’s) just sad to see him in that way.*

Myrtle too felt bad for her husband. Even though she is in good health and could still get out and participate in different activities, she chooses not to go out very often, not because her husband can't stay by himself for short periods but because she wants to keep him company. She said,

*I don't like to go away and know that he's sitting here alone all the time; so I just don't. I don't feel it's fair...to have him sit here alone just because he's sick. I don't like him sitting alone.*

**“It upset me because I tried.”** The experiences that the caregivers disclosed often reflected regret. Many of the caregivers shared their difficulties in getting their spouses to access medical care when they were becoming ill and many of them expressed regret when they just did not take control and take their spouse to the doctor or the hospital.

It was upsetting for Myrtle when her husband became sick while fishing in a northern area of the province. She regretted not making a decision and taking her husband to the hospital.

*It upset me because I tried, and then I thought well maybe I didn't try hard enough...but what can you do...you know...they won't go...you know... (you) can't force them. I can't carry him in there.*

**“I don't know if he's playing games with me or not?”** Several aspects of uncertainty were expressed by the caregivers. Myrtle expressed uncertainty in how or when she was going to get her husband to seek medical help and Darlene expressed uncertainty in her husband; whether his expressed breathlessness was genuine.

Myrtle had difficulty getting her husband to the doctor or hospital. While this was upsetting, she questioned whether she should be doing something different. Although her statement reflects feelings of being ineffective or helpless, it also reflects that she is unsure of what she should be doing and if there is anything that can be done. She said,

*But what do you do?...you know, they don't want to go they...you know...can't force them. I can't carry him in there.*

Darlene too expressed uncertainty about the care she was providing. She said,

*He doesn't shower himself anymore...the nurses shower him...he won't do it...and if I went to do it for him...he would be yelling at me...(he would say) 'Oh, get out of my way I can't breathe, I gotta get out of here'. So...then the nurse took*

*over (and) he doesn't yell when they do it. It makes me feel like I'm not doing things right for him. I don't know what I'm doing wrong?*

Along with uncertainty in the care she was providing, Darlene occasionally wondered whether her husband was telling her the truth about his symptoms and, for that reason, was sometimes unsure how to react.

*I get nervous; I get scared ('when he says I can't breathe'). I say, 'put your nebulizer on.' He says 'that's not going to help' ...and all of a sudden he'll sit there and the thing is...I don't know if he's playing games with me or not...I don't know if he's telling me the truth that he can't breathe. Because...all of a sudden he'll go 'ahah...ahah (breathing sounds)...I can't breathe, I can't breathe'...and all of a sudden he'll start talking normal. So is he putting this on...to scare me?*

**You're like his maid."** As well as feeling regret in not asserting themselves and taking their spouse to the hospital or doctor sooner and feeling uncertain in what they could do different and feeling ineffective in what they did do, they also felt inconsequential. It was common for them to express that their spouse did not respect or validate their attempts to help. In addition, because their spouses were often demanding and wanted the caregiver to do everything for them, they felt their relationship had changed and felt their spouse only valued them for the care they provided.

Myrtle expressed her inability to get her husband to see the doctor when he was ill. She found this frustrating and even though these episodes of illness were happening more often, her ability to persuade him to seek help had not changed; however, the way she managed it had. Myrtle understood she could not effect her husband's decisions so she now elicited the help of her daughter; whom her husband would listen to. While Myrtle appreciated that her daughter was able to convince him to seek help, it upset Myrtle that her husband ignored her when she had been asking, suggesting, and trying to get him to the doctor; while his daughter needed to make one statement, and he was ready to go. Myrtle talked about when her husband was ill and wouldn't go to the hospital.

*I didn't want to argue because he was sick...sick and we come home and ...he still wouldn't go in...and I was getting a little bit upset because I knew he needed medical attention hey? The next morning he couldn't get out of bed...he had to get the ambulance out to take him in and it upset me because I tried, and then I thought well maybe I didn't try hard enough...but what do you do...you know, they won't go they...can't force them. I can't carry him in there. It upset me a*

*little bit because I knew he needed help and just wouldn't (listen). Well, he won't listen...he doesn't listen to me...but then I'll just phone my daughter in (the city) and...like she's an RN and she'll talk to him and he listens to her. But like just... he just doesn't want...well, maybe he thinks I don't know anything. It kind of upsets me because it seems he doesn't trust my opinion or anything, you know?*

Myrtle thought that her husband did not trust her opinion and she felt that she was only important for the care that she provided. As well, she felt like she was alone. She said,

*he's very demanding when he's not feeling well. When he's not feeling good you're...like his maid...you know, do everything...hey? You know like...it's just like you...sometime feel... get the feeling that... are you here just to sit alone in the sand?*

When Myrtle felt like “she’s alone in the sand” it made me think of a child playing alone in a sandbox with no one to play with. If what I say is unimportant and I feel subservient and no one wants to play with me, then I’m going to feel like I’m inconsequential.

Darlene too expresses the same feelings;

*I'm trying to help...and yet...it's not enough. I'm not...it seems like...what am I doing wrong like...I'm trying to...make him breathe...like...get his medication...waiting on him.... A lot of times he'll put his...nebulizer machine on and...he won't have nothing in it...so I'll say... 'well, your nebulizer's empty'. (He'll say) 'well, why didn't you tell me sooner?' ...So then I go and I fill up his nebulizer for him and he puts it on...and then he says 'thank you'. But it's hard...it's hard...to live that way. I'll sit in the (living room)...here and watch T.V. or something and I'll cry and cry because...I don't know what I'm doing wrong. Like...I try to do everything for him that I can and ...ah...it just doesn't seem like enough...and it's just...it's hard...it's hard. It's not easy living with someone with COPD. I feel like...he doesn't want me as his partner...he wants me as his nurse. Someone (to) just take care of him and he wants me to do everything for him. Sometimes I feel like he...just wants me here...to look after him...not as companionship like we used to be...we used to be close.*

**“I get tired...I don't know how long I can deal with this.”** There was heaviness to the quality of the caregivers' voices, as though they had walked for miles carrying a heavy load. These women have been maintaining their lives and managing their spouses'

illness. They have been watching, listening, and waiting, seldom getting a break. There has been little reprieve. Darlene said,

*All night long...he's up every...three hours...two hours. Like...he gets up and he'll get something to eat by himself. He'll get up and...I'll hear him going in the fridge or making a sandwich for himself...and then I hear him lighting up a smoke and then putting his machine on and then I (hear) him... 'I can't breathe'. Then he'll go back to bed and then he'll lay there and he'll cough and then he'll go back to sleep... a couple (of) hours...he's up again...and he does that all night...all night long... I get tired; every time I can hear him get up. I don't know how long I can deal with this. But I can't see myself leaving him because...he can't look after himself...I know that. I know it's not good for me, but I'm scared to leave him...because there's nobody here to look after him. But I would feel really bad if I did leave and something...and then I'd hear something happened to him."*

I could not help but wonder how these emotions that the caregivers spoke about were different than those of most people. Many people are empathetic for friends or loved ones that are having difficulties. Just like many people worry or are regretful that they did not act in a certain manner. Everyone at some point, whether they are a caregiver or not, will experience loneliness, worry, empathy, regret, uncertainty, and even sometime feel like what they do does not matter. However, these feelings very often resolve with time or when the situation is resolved or in some cases with a small amount of emotional work or cognitive reframing.

In contrast, for someone caring for a person with COPD whose disease lingers over many years and is characterized by highs and lows, these experiences seem to go on-and-on, improving at times only to once again become worse; never seeming to resolve. What the caregivers experience when their spouses' are ill is intensified but when they are well, they still have ongoing and lingering worry for their spouse, regret that they didn't act differently, loneliness even though their spouses are with them, uncertainty how to act, and sometimes feel like they are "always giving, giving, giving." These are all compounded by the many nights of lost sleep, listening for their loved one, and the burden of caring the load. I could not help but imagine that the constant bombardment of these unrelenting emotions day-after-day, year-after-year would lead the caregivers to feel like they were sometimes in a 'war-zone'; tired and wondering, 'will this never end?'

Other COPD caregiver studies have also identified similar emotional burden. The caregivers in our study identified many losses; loss of self, relationship, the person their husband once was, their social life, and their lives in general which was similar to other studies (Bergs, 2002; Simpson et al., 2010; Spence et al., 2008). In addition, they were continually worried and fearful (Simpson et al.). They felt lonesome (Bergs; Simpson et al.; Spence et al.) and often felt trapped (Bergs). There was remorse; they felt regret for some of the decisions they made and often blamed themselves when the consequences were unfavorable (Simpson et al.; Spence et al.), such as when they did not insist on medical intervention in the early stages of their spouses' worsening symptoms, resulting in life-threatening exacerbations. However, the caregivers also voiced feelings of being unappreciated and feeling like their husbands thought of them as their "maids" which has not been discussed in previous COPD caregiver studies.

**Theme 5. Intermittent Reprieve: "I can have piece of mind..."**

The additional tasks, ongoing monitoring, unmet expectations, and resultant emotions all contribute to the ongoing burden that these caregivers experience. In order to lessen the load, the caregivers not only labor at acceptance and working through their emotions but they do things that help them escape for a moment; to feel normal and forget their responsibility and concerns. However, sometimes reprieve was just given to the caregivers; when their spouses were hospitalized and they could take a rest from the everyday burden and responsibility.

**"I'll say, smarten-up."** Myrtle talked often about how she tried to reframe her situation so it was easier to bear. She often engaged in self-talk to get herself through;

*I'll say... smarten up... that's the way things are hey? Don't feel sorry for yourself.*

While Bea too talked herself through the situation, she also deliberately would not let herself worry about the future, or for that matter, even think about the future. Her children and her have discussed how her husband is deteriorating and becoming weaker, as time goes on. However, she knows that worrying about the future is futile and she sobbingly says,

*A person's not supposed to think too far ahead, I guess.*

**“We usually go up everyday.”** As well as talking themselves through what they are feeling, many of the caregivers deliberately maintained a routine. I can imagine that for someone who is healthy and active, a routine may seem monotonous, confining, and boring; something to avoid and strive to change. However, to someone who is living from day to day, the order that routine brings might provide security; something to look forward to, something that doesn’t change, and something to help propel the day forward. Not to mention that it provides security in knowing that everything is completed and nothing gets missed. Betty and Bea talked about maintaining a daily routine.

Every morning when Betty and her husband started their day, there was security and anticipation that they would make a trip to town before lunch; an activity that they could still do together. Their morning revolved around planning where they would go and what they would need. They got ready, started the car, and drove six miles to town everyday; rain, snow, or shine. Betty said,

*We usually go up everyday to get the mail. He likes the driving so...it's the one thing he can do that doesn't bother him too much...and he'll let me know if he's played out and then I take over.*

**“I had to get to my walking.”** In addition, the caregivers tried to escape the house and their situation for short periods of time. Bea and her husband also had a daily routine; however, more importantly, Bea made sure she got out for a daily walk with her friends and then stopped for coffee at the local café.

*We get up about seven in the morning...then he does his trip to the bathroom and comes back to the bedroom and gets...dressed for the day. Then we have breakfast...and he takes his medication...under my directions. We were a little rushed for time (this morning) because I had to get to my walking...*

Darlene and Myrtle also sought short periods of respite. Darlene noted that once a week she traveled to a neighboring community to play bingo. When she first started to attend she didn’t know anyone, but it has now become an outing where she can forget her worries and visit with her new found friends. She said,

*It's not that I really enjoy going...but it's just that...it seems like a relief...I'm sitting there and I'm playing bingo and...I'm not listening to somebody saying 'get me this and get me that...and do this and do that.' And it's just amongst people and I've met quite a few people at the bingo. So it's an outing for me. I like doing it every Wednesday...but it's just that it's a get away, I think. It's just so...I can have piece of mind for three hours, four hours during the week.*

Volunteering at the local nursing home twice a week helped Myrtle take her mind off of her husband's illness. Before Myrtle retired she worked at the local nursing home, and now she goes back twice a week to "call bingo" for the residents, an activity that not only provides her with something to look forward to but it provides her with the opportunity to reconnect with friends. She said that she does not like to leave her husband alone for long and is only gone for a couple of hours in the afternoon.

**"It seemed like I could relax."** In addition to the activities that they initiate and can control, the situation that brought the most relief to their voices was talking about when their spouses were in hospital. While they worried about their spouses and wondered if this was the time when their spouse would not make it home, they could relax knowing someone else was shouldering the burden and taking care of them. Darlene talked about a recent hospitalization of her husband;

*...So then I drove him back to the hospital and got him signed in and that...and sat there for...I'd sit with him until about six...because I don't like driving on that highway at night time. So, I'd sit with him until six o'clock and I'd come home...and then I'd go everyday and see him over there. I was worried about him. But actually, I did have good sleeps when he was gone...cause it seemed like I could relax...go to sleep. A couple of times I'd wake up and realize that he wasn't in bed...I'd just close my eyes and I'd go right back to sleep. I had...I had good sleeps because I knew he would be looked after...you know?*

Knowing someone else was caring for her spouse was such a relief. When I spoke to Darlene I could hear a long sigh and then her voice relaxed as she talked about that experience; it was as if a cloud had just been lifted. However, I do not think it was just someone else providing for her husband's physical needs and wants but, it was a rest from the continual, ongoing, unrelenting feeling that she was responsible for him. While her husband was in the hospital, she was provided with a gift; she could step down for a moment, from her job as caregiver and her obligations to her husband, and rely on someone else to watch, and worry. She could take a hiatus from the constant bombardment of feelings that followed her wherever she went; things were almost normal. When she woke at night, when her husband was in the hospital, she did not stay awake and worry about how he was but, she closed her eyes and went back to sleep and boy - did she sleep.

Finally, intermittent reprieve was identified by other studies. The caregivers in this study took moments in time for themselves; whether it was gardening, volunteering, or going to bingo. This too was noticed in other studies. Bergs (2002) noted the caregivers in her study, who worked outside the home, thought of it as an escape. Simpson et al. (2010) identified ‘intrapersonal facilitators’ or the things they did that made providing care easier; reading, walking, or taking personal time.

**Essence: “That’s (my) responsibility and if you don’t do it, there’s nobody else”**

I’ve imagined all along how caring for a person with COPD was similar or different to other experiences and I’ve wanted to know what made this experience what it is and without it, it would no longer be.

Whether they were discussing the additional duties they assumed, the monitoring or care they provided, the disappointment in unmet expectations, the emotional burden they experienced, or the quest to steal moments for themselves, there was an overwhelming pervasive sense of responsibility in their words. Their words had a heavy feeling, spoken without excitement in a monotonous tone, interspersed with sobs and wiping of tears.

I imagine that caring for a person with COPD would be similar wherever you lived but because these caregivers lived on the rural prairies, the degree of the labor they assumed was as vast as the never ending horizon which the prairies are renowned. These women assumed the roles which were once the responsibility of their husbands in order to maintain their lives, as they knew it, but also out of necessity. The consequences of not assuming the tasks were greater than the muscle strain associated with the heavy labor itself. Clearing snow from the long, winding driveways and vast yards was not done for esthetics but because it was a connection to the outside world and a reassurance that they could get help for their husbands if required. What if they needed to get their husbands to the doctor or what if they needed the ambulance? If their driveways and yards were snow blown, it would have been much more difficult to seek help and may have caused life-threatening delays.

The other duties that the women assumed were also not cosmetic but ones that required ongoing attention in order to maintain their lives. They were responsible for draining the septic tank, removing garbage, feeding the cattle, tilling the gardens, and

hauling drinking water. The women assumed these duties because their husbands were no longer able to leave the house and help with the things that they once had done. These were not tasks the women could 'let slide' if they felt tired, nor were they rare tasks but, they were ongoing, unrelenting, necessary tasks involved in living daily life in a rural area.

The women engaged in ongoing vigilance which stemmed from the responsibility that they took and felt for their husbands. They were familiar with the symptoms that their husbands' had on an ongoing basis: respirations that you could not only hear but could feel because of their visual laborious quality; the continual hacking, productive cough, for sometimes copious amounts of phlegm; and the shortness of breath with the least bit of activity. They watched and listened and they knew that if these symptoms changed than something was awry, requiring them to act in order to intercept a potential life-threatening episode of illness. They often drove miles over narrow, snow-blown, gravel roads to get their husbands to the hospital. Roads that you could travel on for hours without meeting another vehicle. Roads that in the dark of night were only lit by the light of the moon and the flicking lights of the vehicle, as it bumped and swerved over gravel and the hard, packed snow that looked liked fingers reaching across the road. When they drove their spouses to see the doctor, they were not assured of seeing a familiar face or driving to a clinic in their own communities because the doctors in these communities shared the time they were on-call for emergencies. In order to know where to seek help, these women kept notes by their phone reminding them which doctor was available in which community in the event of an emergency.

In addition to their attempts to intercept illness, the women tried to ward it off through the care they provided. They ensured their husbands received their medications, which not only involved supervision but also making arrangements for renewed prescriptions, taking the prescription to the pharmacy, and ensuring there were funds available to purchase the medication; all jobs that the recipients of care were unable to do because of their inability to walk more than a few steps without becoming extremely short of breath. Also, to maintain their husbands' health the women catered to their husbands' dietary wishes, trying to coax them to eat 'just one more mouthful' in order to add half-an-ounce to their already bony frames. But more than anything, the women were

conscious of hiding their feelings, as they realized their husbands' laborious breathing got even worse, if they became upset. So, they suffered the burden in silence, trying to hold on and not rock the already capsizing boat.

Due to assuming additional roles and the vigilance that they keep, they have expectations; of their spouses and of themselves. The women do not understand why their spouses do not want to help themselves and why at times they construct barriers to the life-lines which they have provided. However, most of all the women have expectations of themselves to remain patient and understanding throughout all the trials they have experienced.

The caregivers discussed the emotions they experienced as a result of their spouses' long-term illness, ongoing symptoms, and the resultant strain that has been placed on them because of the enormity of the additional tasks they have assumed. They have picked up the load which sometimes becomes heavy and difficult to carry. It seems to be endless and all consuming amidst the loneliness and sometimes felt isolation from their friends and communities, without the freedom that they once knew and with a partner that is consumed with every breath. They have learned from past experiences and they worry when their partners are alone or when they are getting ill. They regret some of the decisions they have made and they feel uncertain about others. Very often the caregivers feel like they do not matter and their spouses do not respect their opinions, along with the feeling that they are forever giving. However, there is a part of them that understands, and they feel empathy for their loved one. Compounding all these feelings is the fact that it seems like it has gone on forever. These caregivers seldom get a break, day-after-day, year-after-year, they go on; asking themselves 'will this never end?'

Occasionally, the caregivers took short, snippets in time in an attempt to refuel, in order to continue with their arduous roles. However, the responsibility they felt was forever tugging at them, pulling them back, and making them wonder if their husbands were alright. In these mere moments in time, the scenery may have changed but, they could not escape the heavy burden of the responsibility they felt.

These are not glamorous lives but lives of 'digging down' and trying to get by. The caregivers labored hard to hold on tight to what they had built and that which they were not yet ready to give up. They were not yet ready to concede. They tried to maintain

their independence; not asking for help because after all, it was theirs' and therefore, their responsibility.

## **Chapter 5: Discussion**

The women in this study assumed additional roles, maintained a constant vigilance, had expectations of their spouses and of themselves, experienced emotional burden, and sought moments in time as a reprieve from the ongoing demands of providing care for their husbands' with COPD. While there were many similarities to past studies, there were also noted differences as outlined in the themes. The most noticeable difference however, was the essence of this study as being ongoing, unrelenting responsibility.

This chapter will briefly discuss the burden of responsibility and put forth implications for practice and suggestions for future research. In addition, the limitations and strengths of this study will be discussed along with my personal reflections.

### **Responsibility as Burden**

The themes that were identified in this study, stemmed from the essence of ongoing, unrelenting responsibility. Being responsible as defined by Webster's New World Dictionary (2003) is being expected or obliged to account for something or someone or involving obligation or duty. The word responsibility is used often within text but little is known about the concept of responsibility. The burden of responsibility was identified in a qualitative study looking at caregivers of people with a multitude of chronic conditions (Öhman & Söderberg, 2004). This burden was related to being forced to take responsibility for aspects of their lives they were unfamiliar with. Another study, looking at family caregivers of people with a cardiac condition described the burden of responsibility (Kaan, Young, Cockell, & Mackay, 2010); they felt ill-equipped to make the decisions they were required to make. The caregivers in our study have also identified lack of confidence in making decisions about seeking professional help, or unsure if they were caring for their loved one in the proper way. As well, all the themes stemmed from the responsibility that the caregivers assumed. In addition, because these women lived in rural areas the responsibility they assumed was heavy and laborious; characteristics not mentioned in previous research. I suggest the essence of responsibility defines this experience as burdensome, obligatory, and an experience that our caregivers felt ill-equipped to manage.

## **Implications for Practice**

Interventions focused on assisting COPD caregivers in alleviating the burden which they experience are required. However, their needs are great and a single-focused intervention will undoubtedly not meet the requirements of everyone (Herbert & Schulz, 2006). The caregivers in this study have a need for respite from the additional heavy burdensome roles they assume and the ongoing vigilance they engage in. The unending responsibilities and the ongoing burden they experience is great and may eventually result in 'burnout.' By providing respite for the caregivers it will ensure they are rejuvenated and able to continue in their roles without becoming ill themselves. While these rural caregivers have access to home care nursing, many voiced the desire to be able to hire someone to come and stay with their spouse to provide the opportunity for a break. In addition, many noted having access to respite services would be beneficial to assist for extended periods of time.

In addition, the caregivers were overwhelmed with the roles they have assumed out of necessity and having access to someone to assist in the heavy laborious tasks would be beneficial, further lessening the burden they experience. While hiring someone to do these tasks seems like the logical solution, this may not be practical due to financial concerns. In addition, the women often voiced their reluctance to ask for help but perhaps if help was offered, for example, from volunteer organizations, it would be utilized and appreciated. Therefore, building partnerships between health care and community organizations may benefit caregivers.

Further, because of the unfulfilled expectations and the emotional burden experienced, these caregivers have a need for information and skill development to assist in their roles as caregivers. Information regarding the disease including the symptoms, exacerbations, management, treatments, and the outcomes would help to alleviate the anxiety that these caregivers are experiencing due to their feelings of uncertainty. Even though most had an understanding that their spouse would have ongoing symptoms, they felt uncertain and even guilty about encouraging them to do more within their limits, that which would be beneficial in decreasing their symptoms and increasing their endurance (Bourbeau et al., 2002). As well, most were aware when their spouse was becoming ill but being informed about what specific symptoms to monitor and the appropriate time to

treat those symptoms would assist the caregivers in seeking early treatment and provide them with the power to affect change in their spouse. The Canadian Thoracic Society (2007) notes that COPD is characterized by intermittent exacerbations, or periods of sustained worsening symptoms, resulting in deterioration in lung function, decreased quality of life, increased hospitalizations, and even death. These periods can be identified early and, if treated within 48 hours of the initial change in symptoms, can impact the course of exacerbation and the resultant effects.

In addition, building capacity and independence in the COPD patient themselves would assist in addressing the unfulfilled expectations experienced by the caregivers. Programs that provide education and support would assist in decreasing the burden on the caregiver. For example, by understanding that maintaining a walking routine in COPD can actually decrease shortness of breath and increase endurance (CTS, 2007), the recipients of care may be inclined to walk for exercise and assist with simple chores around the house which could decrease the burden on the caregivers.

As well as interventions focused on the practical aspects of assisting someone with COPD, interventions, such as cognitive-behavioral counseling, which could assist the caregivers to cognitively reframe the negative aspects of their experience would be beneficial in alleviating the emotional burden they experience. Caregiver support groups can also be utilized to assist in breaking the isolation and providing information and support, either within the community or through a web-based medium.

In addition, clinicians from all disciplines need to be aware and appreciative of the assistance that these caregivers are providing and include caregivers in consultations and decision-making, not only to alleviate the burden on the caregiver but also to assist in the management of their spouses' disease; as often, the caregiver is carrying the load.

Further, the clinician should also be aware that often the appointment that the dyad has in the office, may be the only outing they have for days or even weeks therefore, appropriate interventions to alleviate burden and provide support should be utilized. For example, the use of multi-disciplinary teams to assess and provide support, education, and counselling at routine physicians appointments may assist in building capacity, in both the caregiver and the recipient of care, in order to assist them in managing the disease and the challenges they face in everyday life.

## **Suggestions for Future Research**

Future COPD caregiver research focusing on the needs of this group, utilizing a mixed methodology approach, is required. While all the studies with this population have identified the COPD caregivers' experiences, their presumed needs have just been extrapolated and to date, few studies exploring the identified needs of this group have been done. A mixed methodology approach combines and utilizes the strengths of both qualitative and quantitative research and enhances both depth of understanding and generalization (Creswell, 2009). This will assist in broadening our overall understanding of this population and further assist in the development of interventions to support rural COPD caregivers. Further, studies examining developed technological interventions, such as internet support and DVDs, that would be accessible to this population with compromised services and resources, will assist in their modification and enhancement to further build capacity and decrease the burden for caregivers.

In addition, research to understand the degree of burden, which rural caregivers' experience, at all stages of disability would further assist in shining a light on this phenomenon. Further, because of the drawn out trajectory of the disease, understanding the processes the caregivers' experience, through the utilization of grounded theory, could be beneficial in guiding future interventions. Finally, there may be a difference in how men versus women experience this phenomenon. Therefore, studies examining these differences may be beneficial in illuminating this experience further.

## **Limitations**

The results of this study were obtained from the information that was provided by five women caring for their husbands with COPD who resided in communities in rural Saskatchewan and therefore can not be generalized to the entire population of COPD caregivers but rather, must be interpreted within the context of which it has been done.

In addition, the strategies that I used to gather information on the experiences of providing care for someone with COPD were through both interviews and observations; both which are not without their limitations. While the observations of the researcher can help to situate the information in the context of which it has been collected by describing the setting, the people, the interactions, and everything that is present but also missing (Patton, 2002), it also has some limitations. Even though I am a keen observer that pays

particular attention to detail, not everything can be observed. For example, I could only observe what was available for observation at the point of interaction and not what had happened in previous situations. However, meeting with the participants a second time helped to minimize this limitation. In addition, thoughts, feelings, intentions, and meanings also cannot be observed (Patton). For this reason the second method of information gathering was chosen; interviews.

Interviews too have their limitations of which one of the greatest is having the participant trust the interviewer enough to discuss their experiences in an open fashion without fear of being judged. In order to help minimize this, I ensured there was time available to visit with the caregiver and the recipient of care prior to the interview to assist in putting them at ease. In addition, interviews with the caregivers were done in private, without the recipient of care present, to ensure they felt safe in disclosing experiences; something which may have hindered them if the recipient was present.

A further limitation was through the method of recruitment. All the caregivers that were recruited for this study were either receiving home care services or were enrolled in a COPD self-management, supportive program both which may have influenced their reported experiences. Perhaps, caregivers who were not receiving any services may have shed a different light on the lived-experience.

### **Strengths**

Maintaining the study to five participants enabled me to examine the data in-depth and appreciate the richness that was put forth. In addition, I transcribed the interviews verbatim which allowed me to become more familiar with the information but also, by listening to the digitally-recorded transcripts over and over, I began to feel the essence of the experience through the spoken word.

In addition, conducting two interviews during two opposing seasons assisted me in illuminating the essence of this experience. Because of the nature of this disease, winters are extremely difficult, for COPD patients and their caregivers, which was probably magnified by living in a rural area where the need to do outside work was more important. Therefore, by also seeing them in August, it assisted me to understand the ongoing challenges of providing care.

Further, as an individual I am naturally very reflective, insightful, and sensitive to language, all qualities which van Manen (1997) purports are necessary to participate in this methodology. I was reflective and aware of my past experiences; illuminating them and using them as a starting point. This allowed me to ‘hold them at bay’ so I could see this experience as if it was something new; something that I had not seem before. However, it did provide me with the insight to understand that responsibility is not just a word to be worked into text but it is actually an understudied phenomenon in itself.

### **Personal Reflections**

I began this process of exploration into the lived-experience of COPD caregivers with naiveté on so many levels. To begin with, I was unprepared for the process of hermeneutic phenomenology and the ambiguity in which it is done. However, I have come to appreciate why there is not a procedural template and why van Manen (1997) proposes six interplaying activities; all which are needed to unearth the meaning of the lived-experience.

In addition, gathering the experiential information through interviews and observations had its challenges of which the greatest was how they emotionally touched me. I found these five female spousal caregivers to be so openly honest with their disclosures that it pulled on my heart strings, leaving an imprint that has impacted my ongoing interactions with COPD patients and their caregivers. I was grateful to these caregivers for opening their homes and their hearts and providing me with a glimpse into their lives; lives that aren’t glamorous but that are filled with ongoing challenges in day-to-day living.

Finally, I was unprepared for, what seemed like, a never-ending process of phenomenological reflection, to extract meaning from the transcripts and convey that meaning in a fashion that would move you to the same place that I experienced in entering their lives and hearing their stories. These women’s experiences are reflected in those stories of assuming additional roles, watching their loved-ones vigilantly, having expectations that are unfulfilled, being emotionally burdened, and seeking intermittent reprieve from the ongoing, unrelenting responsibility which they carry with them every minute of every day, day after day, month after month, and sometimes year after year.

## References

- Alberta Cancer Foundation. (2003). Palliative care network initiative. Retrieved August 2010, from [http://www.cancerboard.ab.ca/maco/pdf/hpcn\\_infosheet\\_rural\\_03-02-xx.pdf](http://www.cancerboard.ab.ca/maco/pdf/hpcn_infosheet_rural_03-02-xx.pdf)
- Ahern, K. J. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9(3), 407-411.
- Bailey, P. H. (2004). The dyspnea-anxiety-dyspnea cycle- COPD patients' stories of breathlessness: "It's scary, when you can't breathe". *Qualitative Health Research*, 14, 760-778.
- Barnett, M. (2005). Chronic obstructive pulmonary disease: A phenomenological study of patients' experiences. *Journal of Clinical Nursing*, 14, 805-812.
- Bergs, D. (2002). 'The hidden client' - women caring for husbands with COPD: Their experience of quality of life. *Journal of Clinical Nursing*, 11, 613-621.
- Blakley, B., & Jaffe, J. (1999). *Coping as a rural caregiver: The impact of health care reforms on rural women informal caregivers*. Retrieved June 2010, from <http://www.cewh-cesf.ca/PDF/pwhce/coping-rural-caregiver.pdf>
- Booth, S., Silvester, S., & Todd, C. (2003). Breathlessness in cancer and chronic obstructive pulmonary disease. Using a qualitative approach to describe the experience of patients and carers. *Palliative and Supportive Care*, 1, 337-344.
- Bourbeau, J., Siok, M. A., Nault, D., & Borycki, E. (2002). Optimizing medical care delivery. In J. Bourbeau, D. Nault, & E. Borycki (Ed.), *Chronic obstructive pulmonary disease* (pp. 1-18). Hamilton, Ontario: BC Decker Inc.

- Butler, S. S., Turner, T., Kaye, L. W., Ruffin, L., & Downey, R. (2005). Depression and caregiver burden among rural elder caregivers. *Journal of Gerontological Social Work, 46*(1), 47-63.
- Caelli, K. (2000). The changing face of phenomenological research: Traditional and American phenomenology in nursing. *Qualitative Health Research, 10*, 366-377.
- Cain, C. J., & Wicks, M. N. (2000). Caregiver attributes as correlates of burden in family caregivers coping with chronic obstructive pulmonary disease. *Journal of Family Nursing, 6*(1), 46-68.
- Canadian Institute for Health Information. (2010). *Supporting informal caregivers: The heart of home care*. Retrieved September 03, 2010, from [http://secure.cihi.ca/cihiweb/dispPage.jsp?cw\\_page=media\\_20100826\\_e](http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=media_20100826_e)
- Canadian Thoracic Society. (2004). State of the art compendium: Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease. *Canadian Respiratory Journal, 11*(Suppl. B): 3B-59B.
- Canadian Thoracic Society. (2007). Canadian Thoracic Society recommendations for the management of chronic obstructive pulmonary disease – 2007 update. *Canadian Respiratory Journal, 14*(Suppl. B): 1B-32B.
- Caress, A. L., Luker, K. A., Chalmers, K. I., & Salmon, M. P. (2009). A review of the information and support needs of family carers of patients with chronic obstructive pulmonary disease. *Journal of Clinical Nursing, 18*, 479-491.
- Carter, P. A., & Acton, G. J. (2006). Personality and coping: Predictors of depression and sleep problems among caregivers of individuals who have cancer. *Journal of Gerontological Nursing, 32*(2), 45-53.

- Cohen, M. Z., Kahn, D. L., & Steeves, R. H. (2000). *Hermeneutic phenomenological research: A practical guide for nurse researchers*. Thousand Oaks, California: Sage Publications Inc.
- Creswell, J. W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage.
- Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3<sup>rd</sup> ed.). Thousand Oaks, CA: Sage.
- Cross, S. (2004). The worldwide burden of COPD is on the increase. *British Journal of Nursing, 13*(18), 1066.
- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies, 44*, 131-142.
- Dwyer, J. W., & Miller, M. K. (1990). Determinants of primary caregiver stress and burden: Area of residence and the caregiving networks of frail elders. *Journal of Rural Health, 6*(2), 161-184.
- Elkington, H., White, P., Addington-Hall, J., Higgs, R., & Edmonds, P. (2005). The healthcare needs of chronic obstructive pulmonary disease patients in the last year of life. *Palliative Medicine, 19*, 485-491.
- Elkington, H., White, P., Addington-Hall, J., Higgs, R., & Pettinari, C. (2004). The last year of life of COPD: A qualitative study of symptoms and services. *Respiratory Medicine, 98*, 439-445.
- Goins, R. T., Spencer, S. M., & Byrd, J. C. (2009). Research on rural caregiving: A literature review. *Journal of Applied Gerontology, 28*(2), 139-170.

- Gore, J. M., Brophy, C. J., & Greenstone, M. A. (2000). How well do we care for patients with chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax*, 55, 1000-1006.
- Health Canada. (2002). *National profile of family caregivers in Canada- 2002: Final report*. Retrieved August 2010, from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2002-caregiv-interven/index-eng.php>
- Health Canada. (2005). *The cost of effectiveness of respite. A literature review*. Retrieved August 2010, from <http://www.hc-sc.gc.ca/hcs-sss/pubs/home-domicile/2005-keefe/index-eng.php>
- Herbert, R. S., & Schulz, R. (2006). Care giving at the end of life. *Journal of Palliative Medicine*, 9(5), 1174-1187.
- Horsburgh, D. (2003). Evaluation in qualitative research. *Journal of Clinical Nursing*, 12, 307-312.
- Kaan, A., Young, Q. R., Cockell, S., & Mackay, M. (2010). Emotional experiences of caregivers of patients with a ventricular assist device. *Progress in Transplantation*, 20(2), 142-147.
- Kiecolt-Glaser, J. K., Marucha, P. T., Malarkey, W. B., Mercado, A. M., & Glaser, R. (1995). Slowing of wound healing by psychological stress. *Lancet*, (346), 1194-1196.
- Kim, Y. & Schulz, R. (2008). Family caregivers' strain: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20(5), 483-503.

- Koch, T. (1995). Interpretive approaches in nursing research: The influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21, 827-836.
- Kühl, K., Schürmann, W., & Rief, W. (2008). Mental disorders and quality of life in COPD patients and their spouses. *International Journal of COPD*, 3(4), 727-736.
- Leidy, N. K., & Traver, G. A. (1996). Adjustment and social behaviour in older adults with chronic obstructive pulmonary disease: The family's perspective. *Journal of Advanced Nursing*, 23, 252-259.
- Lietz, C. A., Langer, C. L., & Furman, R. (2006). Establishing trustworthiness in qualitative research in social work: Implications from a study regarding spirituality. *Qualitative Social Work*, 5(4), 441-458.
- Loiselle, C. G., Profetto-McGrath, J., Polit, D. F., & Beck, C. T. (2004). *Canadian essentials of nursing research*. New York: Lippincott, Williams, & Wilkins.
- Morgan, D. G., & Laing, G. P. (1991). The diagnosis of Alzheimer's disease: Spouse's perspectives. *Qualitative Health Research*, 1(3), 370-387.
- Morgan, D. G., Semchuk, K. M., Stewart, N. J., & D'Arcy, C. (2002). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science and Medicine*, 55, 1129-1142.
- Morse, J. M. (1991). Approaches to qualitative-quantitative methodological triangulation. *Nursing Research*, 40(1), 120-123.
- Murray, C. J. L., & Lopez, A. D. (1997). Alternative projections of mortality and disability by cause 1990- 2020: Global burden of disease study. *Lancet*, 249(9064), 1498-1504.
- Nicol, J. J. (2008). Creating vocative texts. *The Qualitative Report*, 13(3), 316-333.

- Öhman, M., & Söderberg, S. (2004). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research, 14*(3), 396-410.
- Osse, B. H., Vernooij-Dassen, M. J., Schade, E., & Grol, R. T. (2006). Problems experienced by the informal caregivers of cancer patients and their needs for support. *Cancer Nursing, 29*(5), 378-388.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. (3rd ed.). Thousand Oaks: Sage Publications.
- Pinquart, M., & Sorensen, S. (2003). Differences between caregivers and non-caregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging, 18*(2), 250-267.
- Pinto, R. A., Holanda, M. A., Medeiros, M. M., Mota, R. M., & Pereira, E. D. (2007). Assessment of the burden of caregiving for patients with chronic obstructive pulmonary disease. *Respiratory Medicine, 101*, 2402-2408.
- Ray, M. A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), *Critical issues in qualitative research methods*, (pp. 117-133). Thousand Oaks: Sage.
- Responsibility. (2003). In M. Agnes (Ed.), *Webster's new world dictionary* (4<sup>th</sup> ed., p. 549). New York: Wiley Publishing, Inc.
- Roland, K. P., Jenkins, M. E., & Johnson, A. M. (2010). An exploration of the burden experienced by spousal caregivers of individuals with Parkinson's disease. *Movement Disorders, 25*(2), 189-193.
- Saskatoon Caregiver Information Center. (2005). *Report to the Federal labor review commission*. Retrieved August 2010, from

[http://www.hrsdc.gc.ca/eng/labour/employment\\_standards/fls/submissions/formal\\_briefs/brief22.shtml](http://www.hrsdc.gc.ca/eng/labour/employment_standards/fls/submissions/formal_briefs/brief22.shtml)

- Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The caregiver health effects study. *JAMA*, 282(23), 2215-2219.
- Schumacher, K., Beck, C. A., & Marren, J. M. (2006). Family caregivers. *American Journal of Nursing*, 106(8), 40-49.
- Seamark, D. A., Blake, S. D., Seamark, C. J., & Halpin, D. (2004). Living with severe chronic obstructive pulmonary disease (COPD): Perceptions of patients and their carers. *Palliative Medicine*, 18, 619-625.
- Secker, D. L., & Brown, R. G. (2005). Cognitive behavioral therapy (CBT) for carers of patients with Parkinson's disease: A preliminary randomized controlled trial. *Journal of Neurology, Neurosurgery, and Psychiatry*, 76, 491-497.
- Segerstrom, S. C., & Miller, G. E. (2004). Psychological stress and the human immune system: A meta-analytic study of 30 years of inquiry. *Psychological Bulletin*, 130(4), 601-630.
- Simpson, A. C., & Rucker, G. M. (2008). Advanced chronic obstructive pulmonary disease: Impact on informal caregivers. *Journal of Palliative Care*, 24(1), 49-54.
- Simpson, A. C., Young, J., Donahue, M., & Rucker, G. (2010). A day at a time: Caregiving on the edge in advanced COPD. *International Journal of COPD*, 5, 141-151.
- Spence, A., Hasson, F., Waldron, M., Kernohan, G., McLaughlin, D., Cochrane, B., & Watson, B. (2008). Active carers: Living with chronic obstructive pulmonary disease. *International Journal of Palliative Nursing*, 14(8), 368-372.

- Statistics Canada. (2003). *Mortality, summary list of causes-2003: Deaths by selected grouped causes, sex, and geography-Canada*. Retrieved October 06, 2007 from [http://www.statcan.ca/english/freepub/84F0209XIE/2003000/t001\\_en.pdf](http://www.statcan.ca/english/freepub/84F0209XIE/2003000/t001_en.pdf)
- Statistics Canada. (2001a). *Population urban and rural, by province and territory: Saskatchewan*. Retrieved October 6, 2007, from <http://www40.statcan.ca/101/cst01/demo62i.htm>
- Statistics Canada. (2001b). *Rural and small town Canada analysis bulletin*. Statistics Canada Catalogue no. 21-006-XIE. Retrieved October 6, 2007, from <http://www.statcan.ca/english/freepub/21-006-XIE/21-006-XIE2001003.pdf>
- Streubert-Speziale, H. J. S., & Carpenter, D. R. (2007). *Qualitative research in nursing*. Philadelphia: Lippincott Williams & Wilkins.
- Van Manen, M. (2002). *Phenomenology on-line*. Retrieved August 2010, from <http://www.phenomenologyonline.com/>
- Van Manen, M. (1997). *Researching lived experience: Human science for an action sensitive pedagogy* (2<sup>nd</sup> ed.). London, Ontario: The Athlone Press.
- World Health Organization. (2006). *Global initiative for chronic obstructive lung disease: Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease*. Retrieved October 1, 2007, from [http://www.who.int/respiratory/copd/GOLD\\_WR\\_06.pdf](http://www.who.int/respiratory/copd/GOLD_WR_06.pdf)
- Yee, J. L., & Schulz, R. (2000). Gender differences in psychiatric morbidity among family caregivers: A review and analysis. *The Gerontologist*, 40(2), 147-164.

Appendix A  
Recruitment Consent

Shelly Hutchinson, a Master's of Nursing student at the University of Saskatchewan, is conducting a study on informal caregivers providing care in their homes to a person with severe or very severe chronic obstructive pulmonary disease in rural Saskatchewan.

I, \_\_\_\_\_ agree to have the researcher contact me to provide me with further information about the study. At that time if I do not want to participate, I can withdraw without any consequences to me or the recipient of care.

\_\_\_\_\_  
(Signature of Participant)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature of Recruiter)

\_\_\_\_\_  
(Date)

Appendix B  
**COPD Patient Information Letter**

Code Number: \_\_\_\_\_

Your caregiver is invited to participate in a study entitled: The lived experience of informal caregivers providing care for a person in their homes with severe or very severe chronic obstructive pulmonary disease (COPD) in rural Saskatchewan. Please read this letter carefully.

**Researcher:** Shelly Hutchinson. I am a Registered Nurse completing my Masters of Nursing degree from the University of Saskatchewan. My phone number is (306) 955-4466. If you have any questions regarding the study please feel free to call me collect. If you would rather, you may contact my supervisor Dr. Donna Goodridge, College of Nursing, University of Saskatchewan at (306) 966-1478.

**Study Purpose:** The purpose of this study is to explore the lived experience of informal caregivers providing care in their homes in rural Saskatchewan.

**Procedures:** At the first meeting, the researcher will conduct a simple breathing test on you, to determine the severity of COPD. The information collected by this breathing test may not qualify your caregiver to participate in the study; at that time, no further information will be collected. In addition, your caregiver will be asked simple information about them.

Further information will be collected in two to three conversational interviews, lasting 45 to 60 minutes, about their experience of providing care. The interviews will be in a place the caregiver chooses. The interviews will be recorded on a digital recorder. In addition, the researcher will ask you to sign a consent form to have your caregiver participate.

**Confidentiality:** All the interviews will be digitally-recorded and written down on a form. All the information collected will be kept completely confidential. Your name will not appear on any information. At no time will any connection be made between you or the information. The information collected is valuable and direct quotes may be used in reports or presentations. If quotes are used, your caregiver will be given a different name and your place of residence will not be used, to ensure that you cannot be identified.

**Storage of Data:** The material will be kept in a locked cabinet in Dr. D. M. Goodridge's office at the University of Saskatchewan for five years. Only the researcher and the supervisor will be able to look at the information. The consent forms will be kept separate from the interviews.

**Ethics:** Approval to conduct the study was given by the University of Saskatchewan Behavioral Sciences Research Ethics Board on (\_\_\_\_\_). Any questions regarding your rights as a participant may be addressed to the Office of Research Services at (306) 966-2084. Out of town participants may call collect.

**Risks:** You are not participating in the study so there are no anticipated risks to you.

**Benefits:** The information collected will assist health care providers in developing programs to help people just like you. The results of this study will be shared with Home Care nurses in the rural Saskatoon Health Region and a copy will be mailed to all the participants. My Master's thesis will be based on this research and the information will be published in health care journals and presented at education in-services and meetings.

**Right to Withdraw:** Participation is voluntary, and your caregiver may withdraw from the study for any reason or at any time without penalty or judgment; any material they contributed will be destroyed at their request.

Please read and sign the attached consent form if you agree to have your caregiver participate. The researcher will keep one copy and you will keep the other.

Sincerely,

Shelly Hutchinson R.N., B.S.N.  
Graduate Student  
College of Nursing  
University of Saskatchewan

Appendix C  
**Caregiver Information Letter**

Code Number: \_\_\_\_\_

You are invited to participate in a study entitled: The lived experience of informal caregivers providing care for a person in their homes with severe or very severe chronic obstructive pulmonary disease (COPD) in rural Saskatchewan. Please read this letter carefully.

**Researcher:** Shelly Hutchinson. I am a Registered Nurse completing my Masters of Nursing degree from the University of Saskatchewan. My phone number is (306) 955-4466. If you have any questions regarding the study please feel free to call me collect. If you would rather, you may contact my supervisor Dr. Donna Goodridge, College of Nursing, University of Saskatchewan at (306) 966-1478.

**Study Purpose:** The purpose of this study is to explore the lived experience of informal caregivers providing care in their homes in rural Saskatchewan.

**Procedures:** At the first meeting, the researcher will conduct a simple breathing test on your loved one, to determine the severity of COPD. It may be possible, that this breathing test may not qualify you to participate in the study, and at that point we will not proceed further. In addition, simple information about who you are will also be collected. Further information will be collected in two to three conversational interviews, lasting 45-60 minutes each. The place of the interviews will be in a place of your choosing, with the researcher. The interviews will be recorded on a digital recorder. In addition, the researcher will record her observations. The researcher will ask you to sign a consent form if you decide to participate.

**Confidentiality:** All the interviews will be digitally-recorded and written down on a form. All the information collected will be kept completely confidential. Your name will not appear on any information. During interview three, you will be given the opportunity to provide your insights into the meaning of the earlier information. Direct quotes may appear in the final work; if at anytime after the interviews you change your mind about what was said in the interviews, you can contact the researcher and that information will be destroyed. At no time will any connection be made between you or the information.

**Storage of Data:** The material will be kept in a locked cabinet in Dr. D. M. Goodridge's office at the University of Saskatchewan for five years. Only the researcher and the supervisor will be able to look at the information. The consent forms will be kept separate from the interviews.

**Ethics:** Approval to conduct the study was given by the University of Saskatchewan Behavioral Sciences Research Ethics Board on (\_\_\_\_\_). Any questions regarding your rights as a participant may be addressed to the Office of Research Services at (306) 966-2084. Out of town participants may call collect.

**Risks:** An anticipated risk in participating in this study is emotional upset; some people may become emotionally upset when recalling the lived experience of caring for a loved one with COPD. If counseling should be required, a counselor in your district will be available to talk with you.

**Benefits:** The information collected will assist health care providers in developing programs to help people just like you. The results of this study will be shared with home care nurses in the rural Saskatoon Health Region and a copy will be mailed to all the participants. My Master's thesis will be based on this research and the information will be published in health care journals and presented at education in-services and meetings.

**Right to Withdraw:** Your participation is voluntary, and you may withdraw from the study for any reason or at any time without penalty or judgment; any material you contributed will be destroyed at your request. If you should choose to participate, please read and sign the attached consent form. The researcher will keep one copy and you will keep the other.

Sincerely,

Shelly Hutchinson R.N., B.S.N.  
Graduate Student  
College of Nursing  
University of Saskatchewan

Appendix D  
**COPD Patient Consent**

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to my caregiver participating in the study described above. I understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

\_\_\_\_\_  
(Name of Participant)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature of Participant)

\_\_\_\_\_  
(Signature of Researcher)

Appendix E  
**Caregiver Consent**

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above. I understand that I may withdraw this consent at any time. A copy of this consent form has been given to me for my records.

\_\_\_\_\_  
(Name of Participant)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Signature of Participant)

\_\_\_\_\_  
(Signature of Researcher)

Appendix F  
**COPD Patient and Caregiver Demographic Form**

Code Number: \_\_\_\_\_

**Patient:**

1. Patient's Spirometry:

FEV1/FVC: \_\_\_\_\_

FEV1: \_\_\_\_\_

2. Who is your primary caregiver: \_\_\_\_\_

3. When were you told that you had emphysema or COPD? \_\_\_\_\_

4. What other medical conditions do you have? \_\_\_\_\_

5. How would you describe your breathlessness?

(a) Breathless with strenuous activity? \_\_\_\_\_

(b) Breathless when hurrying on the level or walking up a slight hill? \_\_\_\_\_

(c) Walks slower than other people the same age or stops for rests while walking at own pace on the level? \_\_\_\_\_

(d) Stops for breath after walking 100 meters or 300 feet? \_\_\_\_\_

(e) Too breathless to leave the house or breathless when dressing? \_\_\_\_\_

(CTS, 2007).

**Caregiver:**

1. What do you feel the patient's primary medical condition is?

\_\_\_\_\_

2. Age of Caregiver: \_\_\_\_\_

3. Gender of Caregiver: M \_\_\_\_\_ F \_\_\_\_\_

4. Relationship to patient: \_\_\_\_\_

5. Where do you provide care? \_\_\_\_\_

6. Years of Education Completed? \_\_\_\_\_

7. Does your current income meet your needs?

(a) Well? \_\_\_\_\_

(b) Fairly well? \_\_\_\_\_

(c) Poorly? \_\_\_\_\_

(d) Not at all? \_\_\_\_\_

Appendix G  
**Interview #1 Guide**

The overall purpose of this interview is to gather information to help me understand the experiences you go through in providing care for your family member with COPD.

Although I understand and can appreciate how difficult the experiences are for your (mother/father/sister/brother/wife/husband); what I am interested in at this time is your experience, the stories you have to tell, and how it affects you. I want you to reflect on the experiences you have had; good and not so good; happy and sad; hard and easy.

**1. Take a moment to recall any strong memories you may have about your care giving experience. Choose one and describe it for me in a way that would make me feel like I was experiencing it myself?**

- How did it start?

- What happened next?

**2. Recall a recent typical day in caring for your (mother/father/sister/brother/wife/husband), and tell me about it from the beginning to the end?**

(Prompts)

- How did it start?

- What happened next?

**3. Recall a recent evening in caring for your (mother/father/sister/brother/wife/husband), and tell me about it from the beginning to the end?**

-How did it start?

- What happened next?

**4. Take a minute to recall a particular experience that really brought home the physical impact of caring on you? Once again, tell me about it, from beginning to end, like a story.**

**5. Recall a recent experience for you that aroused strong emotions in you? Tell me about it in story form, from the beginning to the end.**

**6. Can you give me a different example of an experience that aroused different emotions in you?**

Appendix H  
**Interview #2 Guide**

Once again, thank you for participating in this interview. If at anytime, you'd like to stop the interview please feel free to let me know.

**1. At the first interview I noticed several things involved in caring for someone with COPD that we didn't discuss. I would like you to think and comment on how you live and experience the different equipment and sounds associated with COPD.**

- The sound of the oxygen concentrator?
- The sound of your partner's breathing/coughing?
- The oxygen tubing?

**2. Have you ever provided care for someone, other than your partner, who had a chronic disease or a serious illness?**

- What was your relationship with this person?

**3. How does the experience of caring for someone with COPD differ from caring for this person?**

- How is it the same?

**4. How is caring for someone who is your intimate partner different than caring for a child, another family member, or a stranger?**

- How is it the same?

**5. How has the experience of caring for someone with COPD affected your relationship?**

**6. Tell me about the experience of seeking medical help in this rural community?**

**Thank you!**

Appendix I  
Demographic Table

<b>Name</b>	<b>Age</b>	<b>Gender</b>	<b>Location of care</b>	<b>Edu- cation (grade)</b>	<b>Income Met needs?</b>	<b>Spouse's Spirometry</b>	<b>Spouse MRC</b>	<b>Spouse's OMC</b>
<b>Darlene</b>	62	F	Home	8	Fairly Well	FEV1/FVC 62.39% FEV1 28.34%	5	Past CA of eye
<b>Myrtle</b>	77	F	Home	8	Fairly Well	FEV1/FVC 38.54% FEV1 31.01%	5	None
<b>Bea</b>	72	F	Home	1 yr Uni- versity	Well	FEV1/FVC 64.51% FEV 54.09%	5	Atrial Fibrillation Aortic Aneurysim
<b>Betty</b>	68	F	Home	8	Fairly Well	FEV1/FVC 35.6% FEV1 21.9	5	Hypertension
<b>Vivian</b>	76	F	Home	8	Fairly Well	FEV1/FVC 61.5% FEV1 59.4%	5	Osteoporosis Benign prostatic Hypertrophy