LIVING WITH LONG TERM OXYGEN TECHNOLOGY: INDIVIDUAL AND FAMILY PERSPECTIVES

By

DIANNE M. BROWN

A Thesis Submitted to the Faculty of Graduate Studies In Partial Fulfillment of the Requirements For the degree of

Master of Nursing

Faculty of Nursing
University of Manitoba
Winnipeg, Manitoba

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Recruitment of participants was facilitated through two Regional Health Authorities, their respective Home Care Managers and several Home Care Case Coordinators involved in direct service provision to this population. Without their interest and support for the research process, access of this target population would not have taken place with such ease. I greatly appreciated all the time and effort that was taken out of very demanding roles to foster home based research.

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This exploratory/descriptive study examines the experience of living on long-term in-home oxygen technology from an individual and family/support person perspective. The purpose of the study was to explore and describe individual and family/support person experiences of living on long-term oxygen, and to determine what assistive and restraining factors impact the management and quality of their lives as it relates to in-home oxygen therapy. Using person centered interviewing and observation, fifteen individuals living on long-term in-home oxygen therapy, together with their designated support persons (n=15), were conjointly interviewed for this study. Analysis of the data yielded six themes relating to the experience of living on long-term oxygen: the disease trajectory – journey toward oxygen, living with oxygen – a process of acceptance and adaptation, beyond the security of home, living with oxygen - effects on family/support persons, living with uncertainty – planning control and management, and the value of professional support and knowledge. The study also revealed that perspectives on health and quality of life varied among oxygen participants, but in general, it is possible to view health positively and attain an acceptable quality of life despite chronic illness and living with the limitations and uncertainties of living with in-home oxygen therapy.
CHAPTER ONE

STATEMENT OF THE PROBLEM

Introduction

Oxygen is a colorless odorless gas, present in the air that surrounds us. Despite the fact that it is necessary for life, it is taken for granted by the majority of us. This is not the case for older adults severely disabled with chronic respiratory disease. For those whose disease trajectory has progressed to the point where simply breathing in the air around them is no longer sufficient for them to function well or at all, the provision of supplementary oxygen in their homes becomes essential for their very survival. When this point is reached and to prevent or delay admission to a Long Term Care institution, living with oxygen delivered through in-home assistive technology becomes a viable and realistic alternative.

To date, the majority of research regarding the use of long term oxygen therapy (LTOT) has primarily focused on the measurement of mortality rates, functional status, forced expiratory lung volumes, and quality of life (Jansens, Rochat, Frey, Dousse, Pichard & Tschopp 1997; Lee, Graydon & Ross, 1991; Medical Research Council Working Party, 1981; McSweeny, Grant, Heaton, Adams & Timms, 1982; Nocturnal Oxygen Therapy Trial Group, 1980). Although these studies have provided valuable information upon which many home oxygen programs are based, only two studies have explored the actual day to day realities of the home oxygen experience (Borycki, 1996; Ring & Danielson, 1997).

To increase knowledge and understanding of the experience of oxygen use and the multiple affects this technology has on daily life, family members and quality of living, more research of a qualitative nature is required. To achieve enhanced understanding, perspectives from home oxygen users and their family/support persons must be sought. Their experiences and stories need to be heard. To meet the health care needs of this population and improve current programs and systems of service delivery, we must increase our awareness of the realities and challenges that accompany oxygen technology dependency (Borycki, 1996).
Purpose of the Study

Limited research findings regarding the experiences of individuals and family/support persons living with long-term oxygen technology in their homes provided the impetus for this study. Hence, the purpose of this research project was:

To explore and describe individual and family/support person experiences of living on long term oxygen, and to determine what assistive and restraining factors impact the management and quality of their lives as it relates to in-home oxygen therapy. Questions used to guide this study included:

1) What is the experience of living with in-home oxygen therapy from an individual and family/support person perspective? More specifically, what assistive and restraining factors impact quality of life and ability to manage their lives as it relates to home oxygen therapy?

2) What uncertainties does living with long-term oxygen bring to their lives?

3) How has living with long-term oxygen affected family life?

4) What is the nature of the participants’ relationships with health care and service delivery providers?

These questions were explored through the use of qualitative methodology. Local world (Kleinman, 1992) data were obtained through in-depth person-centered interviewing and observations (Levy & Hollan, 1998) with individuals using in-home long-term oxygen therapy and their family/support persons.

History of In-Home Oxygen Technology

The use of in-home long-term oxygen therapy (LTOT), sometimes referred to as domiciliary oxygen therapy, has gained popularity since the late 1970’s. This is a result of improved technology and evidence obtained from the Nocturnal Oxygen Therapy Trial
(NOTT) (Nocturnal Oxygen Therapy Trial Group, 1980) in the United States, and the Medical Research Council (MRC) (Medical Research Council Working Party, 1981) study in the United Kingdom. These two studies, which are discussed in greater detail in Chapter Two, were pivotal in the development of guidelines for prescription and the implementation of in-home long term oxygen programs in their respective countries (Stewart & Howard, 1992). Kira and Petty’s survey indicates that home-based oxygen provision has expanded and is now offered in many countries throughout the world. The highest prevalence rates of utilization occur in North America, with the United States indicating 241 users per 100,000, and Canada estimating 60 oxygen users per 100,000 (cited in O’Donohue & Plummer, 1995).

Based on these two major oxygen trials, goals of the therapy are to improve survival, improve quality of life, and reverse documented nocturnal hypoxemia. Patient selection criteria and eligibility for long-term oxygen therapy in Canada varies and is subject to provincial policies and jurisdictions. Based on selection criteria and eligibility, the cost of LTOT is covered under most provincial medicare plans; however, reimbursement ceilings may exist and direct patient expense can be expected (Hodder, 1988). The guidelines recommended by most authorities consists of stable patients receiving optimum medical therapy who consistently demonstrate any one of the following three features based on arterial blood gas analysis and subsequent measurements of partial pressure of oxygen (PaO2):

- \( \text{PaO}_2 < 55 \text{mm Hg} \) at rest breathing room air.
- \( \text{PaO}_2 < 60 \text{ mm Hg} \) at rest breathing room air plus one of the following; cor pulmonale, pulmonary hypertension or erythrocytosis (hematocrit >55%).
- \( \text{PaO}_2 < 60 \text{ mm Hg} \) or an oxygen saturation of < 90% during exercise or sleep documented by walking oximetry and nocturnal oximetry respectively.

The dose of oxygen prescribed to the individual should be sufficient to raise the \( \text{PaO}_2 \) to 65mm Hg or sustain an oxygen saturation of \( \geq 90\% \) (Findeisen, 2001; Hodder, 1988; Weg & Haas, 1998). To have an impact on the individual’s survival, the duration of oxygen
administration should be for at least 15 hours a day (Hodder, 1988; Nocturnal Oxygen Therapy Trial Group, 1980; Medical Research Council Working Party, 1981).

Individuals who most often meet the eligibility requirements are those experiencing chronic hypoxia as a result of end stage Chronic Obstructive Pulmonary Disease (COPD) (Stewart & Howard, 1992; Weg & Haas, 1998). Approximately 5.4% of Canadians have a diagnosis of Chronic Obstructive Pulmonary Disease (Wilkins & Park, 1996) with its incidence on the rise (Canadian Respiratory Review Panel, 1998). This statistic, coupled with Canada’s aging demographics, could have a direct impact on the number of LTOT users in the future.

History of the Manitoba Home Oxygen Program

The Manitoba Home Oxygen Therapy Program is a Provincial Program under the jurisdiction of the Regional Health Authorities of Manitoba (RHAM) and is delivered within the mandate of Regional Home Care Services. This program has been in existence since the late 1970’s and is available to children and adults who meet specific medical criteria (see Appendix A). In the early 1980’s designated physicians were established across Manitoba to act as Respiratory Consultants and determine eligibility onto the program based on the above mentioned criteria. Following approval by these Respiratory Consultants, care planning, ongoing supervision and arrangements for service provision is conducted by Regional Home Care Case Coordinators (N. Clark-Landry, Home Care Case Coordinator, personal communication, October 10, 2001).

At the time of the Home Oxygen Program’s inception and until 1997, oxygen concentrators, regulators, supplies and other equipment were purchased by the Manitoba Government and distributed to Home Oxygen clients through the Manitoba Health Equipment
Pool. Backup oxygen cylinders were obtained through private oxygen suppliers (N. Clark-Landry, Home Care Case Coordinator, personal communication, October 10, 2001). The costs of providing equipment, supplies, backup oxygen and maintenance services were covered under Manitoba Health, whereas mobility oxygen and its related paraphernalia were not. For example, portable oxygen cylinders, wheeled carts, wheelchair brackets and carry bags were obtained at the expense of the individual. Because oxygen is classified as a medication, it is partially reimbursed through the Manitoba Pharmacare Program.

In 1997, Manitoba Health contracted out the provision of the Home Oxygen Program’s equipment, service and backup oxygen supply components to one private oxygen supply company, RANA-Medical. During that same time period Manitoba’s Health Care System changed dramatically with the formation of Regional Health Authorities (RHAs). The transfer of health care programs and services from the Province to individual RHAs was mandated by legislation (Manitoba Health, 1997). In 1999, the contract for the Home Oxygen Program was re-tendered under the jurisdiction of the Regional Health Authorities of Manitoba (RHAM) with the successful supplier again being RANA-Medical (N. Clark-Landry, Home Care Case Coordinator, personal communication, October 10, 2001).

Since the inception of the Home Oxygen Program in Manitoba, the entrance criteria for the program has remained virtually unchanged and the Home Care Case Coordinator continues to remain pivotal in the initial coordination of service and supervision of the client and the family’s ongoing requirements for care in the home.
Limited qualitative research in the area of LTOT points to a need for individuals and family/support persons to disclose their personal perspectives on the difficult business of living, not only with a chronic illness, but also on supportive technology prescribed as a result of that illness. The experiential impact of using oxygen technology, has not been well examined. This lack of research may suggest that the presence of such devices improves quality of life for those individuals (Day & Jutai, 1996). Quantitative research refutes this assumption as it was found that LTOT imposes burdens on the individual’s quality of life (Heaton, Grant, McSweeny, Adams & Petty, 1983; Jansens, Rochat, Frey, Dousse, Pichard & Tschopp 1997; Nocturnal Oxygen Therapy Trial Group, 1980). Given the dynamic nature of family relationships one is left to conclude that in-home oxygen therapy must also have an impact on the family. The presence of this technology may affect motivation, compliance with the therapy, as well as socialization of the entire family unit (Stewart & Howard, 1992). The lack of assistive technology research from a qualitative perspective leaves the voice of the consumer and his or her family/support virtually silent. Their collective voices increase knowledge and understanding of their world and the positive and negative experiences encountered with long-term home oxygen.

The experience of living with home oxygen technology adds to a body of knowledge that, to date, has been primarily studied quantitatively with a morbidity and mortality focus (Heaton, Grant, McSweeny, Adams & Petty, 1983; Jansens, Rochat, Frey, Dousse, Pichard & Tschopp 1997; Lee, Graydon, & Ross, 1991; McSweeny, Grant, Heaton, Adams & Timms, 1982; Medical Research Council Working Party, 1981; Nocturnal Oxygen Therapy Trial Group, 1980). Naturalistic research in this area expands on the preliminary findings of Ring
and Danielson (1997) who explored the experiences of long term oxygen therapy on Swedish participants. The generation of new knowledge as it relates to the in-home oxygen experience will assist individuals, families, oxygen suppliers, and home care professionals to better understand both the debilitating consequences of chronic respiratory disease and the physical, social, and psychological effects of experiencing home oxygen technology.

**Significance of the Study**

Access to research information by oxygen dependent individuals and their support persons could be used to improve their understanding of how those in similar situations live with the consequences of oxygen technology. This research also has the potential to help oxygen users better understand the significant effects of their disease and the impact this technology has on their everyday lives. These modest findings provide home health care professionals with new insights into how to promote client and support person acceptance and adaptation during the initial stages of technology introduction and encourage their ongoing prescribed use of oxygen therapy. Oxygen suppliers will have access to new information that enhances their understanding of individual experiences. This knowledge can be integrated into enhanced in-home training and ongoing client support practices. Emerging themes with respect to the restrictive nature of oxygen use and difficulty in managing the technology, will be useful to the research and development departments of respiratory equipment manufacturers and will hopefully provide the impetus to develop more user-friendly technology. Policy makers and community program planners can use these research findings to support in-home and community respiratory program planning, education and service delivery. The findings of this study also support the promotion of health among individuals and families in relation to their physical, social and community environments. It also
supports theoretical perspectives in relation to the uncertainty of chronic illness. The rich descriptive voices of oxygen users and their families offer an understanding of their experiences and new perspectives regarding positive changes to home care programming, disease self-management education, nursing practice and ongoing research.

Although the intent of the study was not to be critical of the home care system and professional care providers, it would be unrealistic to think that criticisms and problem areas would not emerge from the data. Enhanced awareness channeled into progressive supportive strategies has the potential to change how professional care, services, and equipment are provided to this population. Although modest, the findings have the potential to improve the lives of those dependant on long term-oxygen technology. Knowledge is power and when shared and used by those working closely with this population it has the potential to benefit oxygen users, their family/support networks, community services and health care delivery systems.

Definitions of Terms

For the purposes of this study, the following terms are defined as follows:

Assistive Technology

Any item, product or equipment that is used to increase or improve functional capabilities and the survival of individuals with disabilities. Assistive devices may be categorized into the following types: mobility aids, communication aids, vision aids, personal care aids, home adaptations, respiratory aids, positioning aids, or miscellaneous (Watts, Erickson, Houde, Wilson, & Maynard, 1996). Given the compromised nature of the oxygen participants in this study many used more than one type of assistive device in their daily lives.
The assistive devices of interest in this study relate specifically to oxygen technology and include the following:

**Compressed-Oxygen Cylinders** - Steel or aluminum tanks that contain gaseous oxygen under pressure. A pressure reducing valve with a flow meter is applied to the oxygen cylinder to reduce the high pressure to a lower, safer pressure in order to deliver the oxygen from the tank to the individual requiring it at the prescribed rate of flow (Scanlan, Spearman, & Sheldon, 1990) usually ordered as liters per minute (L/m). Oxygen cylinders provide 100% oxygen and are available worldwide (Kacmarek, 2000) making them attractive to individuals capable of international travel. Compressed oxygen, or as users commonly call it “bottled gas”, is available in a variety of sizes for in-home use ranging from those that hold from 100 liters to those containing 7,000 liters of oxygen (AARC Times, 1998). Two main uses of compressed-oxygen are use as a backup supply and to provide oxygen for mobility outside the home.

**Backup Oxygen** – Available to all recipients of the Manitoba Home Oxygen Program. Backup oxygen provides the assurance of an alternate oxygen supply should a Home Oxygen client experience an equipment failure with their electrically powered oxygen concentrator or should their power supply be interrupted as a result of a power failure or electrical storm. Backup oxygen is not designed for mobility use as it is most often stored in large H sized cylinders weighing approximately 61 kg. These H sized cylinders, when full, are capable of providing a continuous oxygen flow of 2 L/min for approximately 2 days (Kacmarek, 2000).

**Mobility or Portable Oxygen** - Oxygen used for the purpose of meeting oxygen requirements while the oxygen user attends events or engages in activities outside of the home and away from the primary home oxygen source (oxygen concentrator). This mobility
oxygen may be provided in the form of small portable steel or aluminum cylinders or liquid oxygen canisters. Aluminum cylinders are 50% lighter than similar sized steel cylinders (Kacmarek, 2000) and thus are very popular for those wishing to enhance their mobility.

Many manufacturers have developed alternative sizes of small portable cylinders (Kacmarek, 2000). The size of cylinder chosen is often based on liter flow requirements, average length of mobility time, and physical strength of the individual. Financial capability is also a consideration, as mobility oxygen, carry bags, wheeled pull carts, wheelchair brackets, and conserving devices are a client expense. In Manitoba, oxygen is classified as a medication and therefore expenses specific to the oxygen itself are partially claimable under Pharmacare. E-sized aluminum cylinders weigh approximately 5.6 kg and last approximately 5 hours at 2 L/min (Kacmarek, 2000). Given their weight, this size of tank is often pulled or pushed in a 2 wheeled cart or stowed in a bracket or basket secured to wheelchairs, walkers or scooters. D-sized cylinders weigh just over 4 kg and provide 2 hours and 56 minutes of oxygen user time at 2 L/min (Kacmarek, 2000). Robust oxygen users may use a carry bag to transport this size of cylinder but commonly they are stowed in a bracket or basket on a assistive mobility device as listed above. One of the more common sized cylinder for carry bag use, is the M9 size. The M9 weighs approximately 3 kg and has the oxygen capacity to last 2 hours at 2 L/min. The smaller cylinders contain lesser amounts of oxygen and thus result in decreased time for mobility. Oxygen users may choose to use a demand oxygen system or conserving device when utilizing smaller cylinders with less oxygen capacity to increase the amount of mobility time available from each oxygen tank.

Conserving Devices or Demand Oxygen Systems (oxygen specific devices) –
Specially designed, battery operated regulators that sense a patient’s inspiratory effort and
deliver a ‘pulse’ of oxygen only when the individual breathes inward. Oxygen is conserved as it is delivered intermittently with each breath and allows the ambulatory oxygen user more time away from their stationary systems (Findeisen, 2001). These devices vary as to how the dose of oxygen is delivered; with every breath, every other breath, or other breath sequences. Several carry bag options accompany these devices such as shoulder bags, camera bags, and backpacks (AARC Times, 1998). Oxygen conserving systems and their related carry bags are not provided under the Home Oxygen Program and therefore are a personal expense.

Assistance to purchase these devices may be covered under private health insurance plans or Veteran’s Affairs where applicable.

**Oxygen Concentrator** - An electrically powered device that is capable of physically separating oxygen found in room air by passing air through a series of filters and molecular sieve beds. During this process other gases such as carbon dioxide and nitrogen are trapped and purged. The oxygen is then stored in an internal cylinder and is delivered to the patient through a flow meter on the concentrator (Findeisien, 2001; Kacmarek, 2000; Scanlan, Spearman & Sheldon, 1990). Most concentrators deliver up to 5 Liters per minute of oxygen. Newer models are capable of proving up to six Liters per minute in the 90 to 97 percent purity range. Concentrators generally weigh approximately twenty-four (24) kilograms and are approximately sixty (60) centimeters in height. As oxygen concentrators depend on electric power to operate, back up oxygen cylinders are also often provided in the home to ensure that an ongoing supply of oxygen is available in the event of mechanical failures or power outages (Findeisien, 2001; Kacmarek, 2000).

The focus of this study is on individual and family/support person’s experience using the oxygen concentrator technology as a stationary source of oxygen in the home with large
compressed oxygen cylinders for back up oxygen supply and portable cylinders used for mobility purposes outside the home.

**Family/Support Persons**

Family members or individuals who reside or have important and regular contact with the home oxygen participant and engage in the care and emotional/physical support of the individual and his or her oxygen equipment and related supplies. Family/support persons who participated in this study were identified and invited to participate by the oxygen dependent participant.

**Quality of Life**

Subjective expression of an individual’s perception of well-being and his/her ability to enjoy and partake in aspects of life that are important (Curtis, Deyo, & Hudson, 1994). Although one’s health and availability of health care strongly influence an individual’s quality of life, it is recognized that factors such as physical, psycho-social and economic environments also have a significant impact on well-being and quality of life (Curtis, Deyo & Hudson, 1994; Hancock, 1985).

**Home Care Case Coordinator**

Health professional charged with the responsibility of assessing, planning, coordinating home care services under the Provincial Home Care Program.

**Home Care**

Any form of health care services (private or publicly funded) provided in the home by physicians, nurses, respiratory therapists, direct service workers, and home oxygen technicians.
Home Oxygen Supplier

A home health care company contracted to supply oxygen and related oxygen equipment in the home, along with providing related training and client support and ongoing equipment repair and maintenance services as required. Fourteen oxygen participants received services under the Provincial Home Oxygen Program one participant paid for oxygen services privately.

Conclusion

Exploration into the local world experiences (Kleinman, 1992) of living with in-home oxygen technology from an individual perspective has not been widely studied to date. The voices of family/support persons to oxygen users remains unexplored and undocumented. As the incidence of chronic respiratory disease is on the rise (Brannon, Foley, Starr & Saul, 1998; Celli, Cosentino, Fiel & Petty, 1997a) and as medical treatment combined with life style adjustments have the potential to increase length of survival (Celli, Cosentino, Fiel & Petty, 1997b), the prevalence rates of oxygen technology in the home are likely to escalate as well. The provision of oxygen (assistive) technology in the home has been found to have a negative impact on the life experiences of individuals (Heaton, Grant, McSweeny, Adams & Petty, 1983; Jansens, Rochat, Frey, Dousse, Pichard & Tschopp 1997; Nocturnal Oxygen Therapy Trial Group, 1980) and has not been studied from a family/support person perspective and therefore requires further investigation. Home care professionals, oxygen suppliers, policy makers and health care program planners need to increase their understanding of the in-home oxygen experience with the view of improving programs and services based on consumer generated evidence so that programs and services clearly meet the needs of this specific
group. Uncovering answers to questions regarding the local world (Klienman, 1992) experience of this population necessitates “recording” their collective voices through qualitative research.
CHAPTER TWO
LITERATURE REVIEW

Introduction

This review of the literature commences with a brief discussion of the increasing use of assistive technology in the older adult population. Following this, research conducted specific to the use of in-home oxygen technology is examined. Most research in this area is quantitative and focuses on long-term oxygen’s effectiveness relating to morbidity and mortality. Two landmark studies with respect to the efficacy of long-term oxygen therapy (LTOT) provide a reference point for utilization criteria and ongoing research in this area. Reduced mortality rates documented in these studies is credited for oxygen’s worldwide popularity as an in-home treatment modality for stable hypoxemic (PO2 < 55mmHg) individuals with chronic respiratory insufficiency. However, there are limited studies examining quality of life in the area of LTOT. The sole qualitative study of this population is evaluated and its results are compared to similar findings revealed in chronic illness research. As the majority of individuals experiencing LTOT are also experiencing the additional burden of a chronic illness, a brief review of chronic illness literature is also addressed. As none of the home oxygen studies conducted to date have explored issues relating to the family and/or support persons, chronic illness and family care giving literature is appraised to provide insights into the experiences of families as documented by numerous researchers. The chapter concludes with a description of the conceptual frameworks chosen to guide this study and comments supporting their application to this research project.
Assistive Technology

Assistive technology can increase the function of an individual, manage a disability, prevent accidents and injuries and affects the person’s independence through modification of one’s environment. Assistive technology has many applications and there is increasing interest and recognition of the potential value in the area of technology and aging in Canada. This is largely related to advances in the treatment of illness, development of innovative technology, expansion of home-based services, health care cost containment, and growth in consumer demands for technological care (Chappell, 1994). As a result, there is a growing population of technologically dependent individuals receiving care in their homes (Mann, Hurren & Tomita, 1995; Watts, Erickson, Houde, Wilson & Maynard, 1996).

The goal of assistive technology is to bridge the individual’s functional limitations, reduce the impact of impairment and facilitate independence. Assistive technology varies from simple to complex including items for facilitating safety (bars and railings), mobility (wheelchairs, walkers, oxygen strollers), seating and positioning, bathing and toileting (hydraulic bath lifts, raised toilet seats), personal care activities, (Chappell, 1994; Gitlin, Levine & Geiger, 1993) nutritional replacement (infusion pumps), and the delivery of treatments (aerosol nebulizers, oxygen concentrators, in-home ventilators). They may be used in isolation or more commonly in conjunction with other assistive devices. Home-based elderly may use up to ten different assistive devices to promote independence and manage disability (Mann, Hurren & Tomita, 1995).

Although it is evident that the use of assistive technology can help disabled seniors and those with deteriorating health live independently, there has been limited research conducted in the areas of psychosocial impact of assistive devices (Day & Jutai, 1996),
effectiveness of these devices in meeting needs, and answering questions as to whether technology facilitates independence or creates dependency and isolation (Chappell, 1994). Despite the lack of evidenced based research, the literature indicates that there has been a general adoption of assistive technology use and an acceptance that these devices improve health, happiness and improve the advancement of civilization (Day & Jutai, 1996).

In-Home Oxygen Technology

For more than two decades, the use of in-home oxygen technology has become the standard and widely accepted method of treatment for stable hypoxemic (PO2 < 55mmHg) individuals with chronic respiratory insufficiency (Janssens, Rochat, Frey, Dousse, Pichard & Tschopp, 1997; Scanlan, Spearman & Sheldon, 1990; Stewart & Howard, 1992). The scientific evidence for the benefits of this treatment were demonstrated by two hallmark studies conducted in the early 1980’s. The Nocturnal Oxygen Therapy Trial (NOTT) (Nocturnal Oxygen Therapy Trial Group, 1980), which was a multi-centered study conducted in North America, and the Medical Research Council Trial (MRC) (Medical Research Council Working Party, 1981) of the United Kingdom demonstrated that long-term oxygen therapy for more than fifteen (15) hours a day significantly improves mortality and morbidity in a well defined group of individuals with chronic obstructive pulmonary disease (COPD).

In the NOTT study, 203 COPD patients met the eligibility criteria and were deemed to be free of exacerbations while managed on the maximum of bronchodilator therapy over a three week evaluation period. Following a one week hospital assessment and base line data collection, participants were randomly assigned to one of two groups: those receiving continuous oxygen therapy (average, 17.7 hours/day) and those receiving nocturnal oxygen therapy (average, 12.0 hours/day). The study participants were then discharged home and
followed every six months on an outpatient basis. After six months, the mortality rate for the continuous oxygen therapy group was 11.9% compared to 20.6% in the nighttime only group. After 24 months the mortality difference was 22.4% for continuous compared to 40.8% nighttime only. Although not statistically significant, an additional finding was that patients on continuous oxygen therapy tended to be hospitalized less often and had fewer hospital days than the nocturnal group (Nocturnal Oxygen Therapy Trial Group, 1980).

In the MRC (Medical Research Council Working Party, 1981) trial, 87 patients with COPD, experiencing an arterial oxygen tension (PaO2) between 40 and 60 mmHg, and one or more episodes of heart failure with ankle edema were randomized to receive oxygen for at least fifteen (15) hours a day or no oxygen treatment. At the end of five (5) years, the mortality rate of those receiving oxygen was significantly less than those who did not receive oxygen therapy, 45% compared to 66% respectively.

With respect to the evaluation of neuropsychological functioning, the NOTT (1980) study showed that individuals with hypoxemic COPD demonstrated impaired cerebral function. After six months of oxygen therapy patients on continuous oxygen appeared to be somewhat less impaired than those on nocturnal oxygen.

Quality of life data also collected during the NOTT study indicated relatively low levels of patient self-satisfaction, reduced physical and social capabilities, and increased levels of depression, anxiety, and hostility. There was no appreciable change in self-reported emotional status or general life quality following six (6) months of treatment. The researchers suggested that the apparent lack of improvement in life quality might have been related to the insensitivity of the self-report instruments used in the study (Heaton, Grant, McSweeny, Adams & Petty, 1983; Nocturnal Oxygen Therapy Trial Group, 1980).
Janssens, Rochat, Frey, Dousse, Pichard and Tschopp’s study (1997) revealed similar quality of life limitations when they examined the health related quality of life community dwelling individuals using LTOT. The participants (n=79) at baseline demonstrated major physical impairments with 46% walking less than 600 meters a day. Hospitalizations were frequent with an average of 51 days spent in hospital per patient per year. The results of the Hospital Anxiety and Depression questionnaire suggested a high prevalence of depressive and anxiety disorders (21 and 27% respectively). After one year, the researchers found that prevalence of emotional disturbance, physical impairment and resting dyspnea remained unchanged. The one year survival rate for this cohort was 69% (Janssens, Rochat, Frey, Dousse, Pichard, & Tschopp, 1997).

Thirty one (31) oxygen dependent individuals with limited lung function secondary to a diagnosis of COPD participated in a descriptive correlational study in which Canadian researchers Lee, Graydon, and Ross (1991) examined the relationship between psychological well being, physical status, social support, and level of functioning. Patients who experienced more physical symptoms, had lower lung functioning, or had poorer psychological well being, experienced more disruption in their level of functioning than those with fewer physical symptoms, higher lung function scores or better psychological well being. The symptoms with the greatest negative influence on physical functioning were dyspnea and fatigue. Level of social support was also found to be a significant factor in this study. Those indicating high levels of social support demonstrated significantly less disruption in their physical functioning. The researchers also found that this relatively small sample demonstrated a wide range of scores with respect to levels of physical functioning. This suggests that COPD has a
varied impact on individual lives, even for those whose lung function necessitates the use of supplementary oxygen (Lee, Graydon & Ross, 1991).

Utilizing phenomenological methods, Ring and Danielson (1997) explored ten (10) patients’ experiences of being dependent on continuous oxygen treatment and their views of self-managing their disease. Data were collected via audio taped interviews, which explored participants’ experiences of daily life, dependency on long-term oxygen treatment, and their specific thoughts about the future. In analysis of the data, the participants’ descriptions revealed four predominant categories; restricted to time and room, an advantage for the body, living on one’s own life rhythm, and put up with in order to live. The researchers found that the participants employed numerous day-to-day strategies, which revolved around the constant avoidance of perilous situations such as being away from their homes, which in turn affected their degree of social isolation. Not only was there a need to contend on a day to day basis with the work of being chronically ill, oxygen dependent individuals had the additional work of adapting to and managing the restrictions as a result of their long term oxygen therapy.

Participants in the study experienced social isolation while at the same time they indicated that having a close relationship with a significant other was of great importance to them. The respondents received support and security from these relationships and described them as a source of strength that enabled them to continue to struggle and to go on living. Phenomenology was the qualitative method used and the study did not explore the experience of long-term oxygen treatment from a family/support person perspective. During their discussion regarding the implications for nursing, the authors suggest that impact on the family would be a fertile area for further nursing research (Ring & Danielson, 1997).
These studies indicate that LTOT improves survival rates of individuals with chronic hypoxia associated with chronic obstructive pulmonary disease and other chronic lung disorders (Medical Research Council Working Party, 1981; Nocturnal Oxygen Therapy Trial Group, 1980). These promising results influenced a proliferation of home oxygen use throughout the world (O’Donohue & Plummer, 1995). A weak relationship between oxygen therapy and modest improvements in cerebral functioning has also been established (Heaton, Grant, McSweeny, Adams & Petty, 1983; Nocturnal Oxygen Therapy Trial Group, 1980).

Disappointingly, previous research has not demonstrated a positive relationship between long-term oxygen therapy and quality of life (Heaton, Grant, McSweeny, Adams & Petty, 1983; Janssens, Rochat, Frey, Dousse, Pichard & Tschopp, 1997; Nocturnal Oxygen Therapy Trial Group, 1980). Despite the oxygen therapy, immobility, dyspnea, anxiety, depression, (Janssens, Rochat, Frey, Dousse, Pichard & Tschopp, 1997) social and physical isolation, dependency on technology and avoidance of perilous situations (Ring & Danielson, 1997) were found to impact negatively on the quality of life for these individuals.

Although previous studies have examined the experience of living with technology from an individual and quality of life perspective, no study has been found which examines the impact of living with oxygen technology on families or primary support persons. Despite the fact that individuals have been using in-home oxygen technology for more than two decades and that there is documented evidence that LTOT lengthens life but does not necessarily improve the quality of life, it appears no research has been undertaken to explore the impact LTOT has on individual and support person quality of life. In addition, no studies were found that sought to understand clients’ perspectives on how existing systems and programs could be improved upon to enhance the oxygen technology experience.
Chronic Illness

Those requiring in-home long-term oxygen, in addition to the every day burden of dealing with and depending on complex technology, also experience the multiple burdens of chronic illness. To date, great strides have been taken to advance our understanding with respect to the chronic illness experience and in the area of family care giving research.

Chronic illness is a prevalent health care concern for Canadians with its demand on human, technological and financial resources, as well as its impact on quality of life for individuals and families. Very few individuals escape some form of contact with it, as it makes no age or sex distinction (Corbin & Strauss, 1984) with an exhausting list of disorders falling under the realm of chronic illness; heart disease, hypertension, diabetes, hepatitis C, AIDs, multiple sclerosis, cancer, arthritis and chronic obstructive lung disease to name only a few.

Older adults are more affected by chronic illness than other age groups. It is estimated that seventy-five percent (75%) of Canadians aged fifty-five (55) or over are living at home with at least one chronic condition (Wilkins & Park, 1996). Diagnoses of chronic illness are most often multiple and given that individuals are surviving longer, this equates into prolonged periods of disability, vulnerability to other health problems, financial concerns, and increasing health care needs (Curtin & Lubkin, 1995). Those seniors with disabling conditions are also at risk for institutionalization (Wilkins & Park, 1996). As a result, health care policy makers grapple with difficult decisions as to where to channel health care dollars and what programs meet the most needs – complex “high tech” treatment and institutional care, or community focused assistive technology and disease management care.
The encompassing nature of chronic illness is depicted in Curtin and Lubkin’s definition as, “the irreversible presence, accumulation, or latency of disease states or impairments that involve the total human environment for supportive care and self-care, maintenance of function, and prevention of further disability” (1995, p. 8). The onset of a disorder may be immediate, as in the case of a cerebral vascular accident, or insidiously with identifiable symptoms manifesting themselves only after decades of silent organ destruction, as in the case of COPD (Celli, Cosentino, Fiel & Petty, 1997a; Tiep, 1997). Diagnosis of a chronic illness in older adults does not often occur in isolation (Curtin & Lubkin, 1995). This means that individuals and families must accommodate the burden of more than one aliment and possible source of added disability into their daily lives.

The work of Anselm Strauss and other teams of researchers provided much of the early ground breaking and theory-building qualitative research surrounding the impact of chronic illness. Since the early 1980’s these researchers have examined chronic illness from the perspective of the illness trajectory, the work of being chronically ill and the impact of chronic disease on the family.

Illness trajectory is a term that refers not only to the physiological unfolding of a sick person’s disease but also to the total organization of work done over its course, plus the impact on those involved in that work and its organization. Most chronically ill individuals experience a downward nature to their trajectories even if long plateaus occur in between changes (Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984). In all chronic illnesses there is uncertainty regarding what lies ahead (Mishel, 1990, 1999). People need to constantly assess where they are now and readjust, as appropriate, based on changes they may need to come to grips with in light of lower levels of normal interaction and style.
"They strive valiantly and artfully to keep things normal at whatever level that has come to mean" (Strauss, et al., 1984, p. 86). When friends and relatives will not enter into new and more demanding roles, necessitated by lower levels of functioning, escape from the situation in the form of divorce, separation or abandonment may be sought. However, the chronically ill, as well as their spouses, relatives, and friends, are very capable of accommodating to increasingly lower levels of normalcy. According to Strauss, et al., (1984) this is accomplished either because of immense closeness to each other or because they are grateful for what little life and relationship remains.

With each phase of chronic illness, there are various types of work to be performed. The types of work include: symptom control and monitoring, preventing and handling crisis, carrying out regimens, organizing time, normalizing interaction and life, and preventing or living with social isolation (Strauss, 1984; Strauss, et al., 1984). White and Lubkin (1995) further expand on trajectory work as consisting of organizing and performing necessary tasks and actions that shape trajectories. This work moves from home to hospital and back to home, which adds crucial decision-making and managing the uncertainty of the illness trajectory to the types of work previously described by other researchers. How families share home health care tasks depends on the degree and kind of physical impairment, financial resources, and interpersonal relationships and communication within the family.

In search of data to answer the question of "what is the experience of those who live with a chronic illness in terms of the effect of the illness on an individual’s life and his or her ability to adapt to and manage that illness" Thorne and Paterson (1998, p. 174) conducted a meta-study of nearly two decades (1980-1996) of research in the field of chronic illness. In
their review of over 400 qualitative studies in the area of chronic illness, 158 reports met their inclusion criteria.

Using a seven stage meta-ethnography approach, members of a research team read, compared and analyzed the reports’ text and developed new interpretations. Their analysis found a shift over time in focus from a predominantly outsider research perspective to that of insider. Earlier studies (1980-1985) tended to be orientated by traditional biomedical frameworks and psychosocial theory. Emerging concepts of the chronic illness experience during that time period included: suffering loss, biographic disruption, and sick role. The loss and burden themes characterized during earlier studies were replaced with more optimistic perspectives of chronic illness during the analysis period of 1990-1995. More positive and hopeful results revealed in the meta-analysis incorporated concepts such as; being courageous, maintaining hope, restructuring, reframing, reconstituting self, regaining control, redefining health, finding meaning, managing self-transcendence, empowering potential, transformation, normality and discovery. The authors also found a preponderance of findings regarding the increased expertise of chronically ill in their health challenges, decision making, and in self-care management. In the 1980s very few questions were asked about relationships with health care professionals. Research in the 1990s began to demonstrate that many participants were engaged in partnerships with health care providers, which assisted them to live with chronic illness (Thorne & Paterson, 1998).

In the ensuing discussion of these findings, Thorne and Paterson articulated the need for caution regarding a blanket acceptance of the trends revealed in their meta-analysis (1998). They expressed that professionals should not overemphasize the cheerful, transformative, and powerful elements within the illness experience over the mundane and
difficult features such as pain, mobility impairment, anxiety or despondency as this would be a misrepresentation of the effects of disease on the lived experience. The authors reaffirm that the work of managing chronic illness can be overwhelming, that decision-making creates a burden of its own, and that some people still require the need for the knowledge and skill of an expert professional health care provider. They also note that as with all human beings living their own experience, people with chronic illnesses will differ in their abilities to spend time, energy and emphasis on their illness at varying points in their lives. Not to negate the importance for health professionals to involve the chronically ill as partners in their own care, it is as equally important to recognize the needs of those whose illness experience is intolerable and thus requires expert assistance for disease management control (Thorne & Paterson, 1998).

Jonsdottier (1998) conducted a phenomenological study to describe the experience of ten individuals with chronic obstructive pulmonary disease (COPD). The researcher conducted five in-depth interviews with each of the participants. During the interviews, participants were invited to express and discuss their life experiences by describing the most important events in their lives and the impact COPD had on their life patterns. Each of the participants (six males and four females) had experienced lung related problems for at least fifteen years. Audio taped recordings along with information from the researcher’s journal were transcribed and data collection and data analysis took place concurrently. The results demonstrated the participants’ dominant life pattern to be one of isolation and being closed in. Core themes that manifested from the analysis were (a) as it is resignation to the situation – a way to survive, (b) unsuccessful solutions to traumatic events, (c) difficulties in expressing oneself and relating to others, (d) conflict between internal needs and external expectations,
(e) few words for breathing difficulties, and (f) activity restrictions. The categories of resignation to the situation and activity restrictions were similar to those discovered by Ring and Danielson’s LTOT study (1997).

Areas not specifically explored in the study were family care giving issues and individual perspectives on interactions with healthcare professionals. Jonsdottier found that participants “repeatedly, and with deep concern, talked about not being understood by other people, neither close family members and friends nor people in society in general” (1998, p. 165). Although participants were not asked directly about their interaction with healthcare professionals, the results showed that the participants had not enjoyed the opportunity to meaningfully dialogue with knowledgeable professionals about important health experiences (Jonsdottier, 1998). These results indicate that impact on the family and partnerships with health care providers are important areas of further nursing research.

**Chronic Illness and the Family**

As revealed by Ring and Danielson (1997), the impact of in-home oxygen technology on the family and/or support person has not been studied and provides a fertile area of investigation. Given the incidence of COPD (Brannon, Foley, Starr & Saul, 1998; Chapman, 1992; Celli, Cosentino, Fiel & Petty, 1997a) and the prevalence of chronic illness in the over the fifty-five (55) age group (Wilkens & Park 1996), it can assumed that older adults (≥ age of 55) on long-term oxygen will be dealing with a minimum of one chronic illness, thus a review of chronic illness literature and its impact on family and caregivers is necessary to provide insights into possible commonalities that may face the participants in this study.

Affliction with a chronic condition is all encompassing as it affects an individual’s social, psychological, physical and economic lives, with an impact that is often cyclic in
nature (Curtin & Lubkin, 1995). Although it may be the affected individual who is the first to seek health care, assistance with chronic illness also comes from within the family context. Illness affects the family as a whole, and the family affects the individual's response (Hanson, 1987; Harmon Hanson, 2001). Using a systems perspective, the brunt of care and management of the illness trajectory reaches far beyond the individual, extending to family members and key support persons also affecting their social, psychological, physical and economic lives in a significant fashion. Successful management of the illness process and a high degree of family and support person involvement are essential components in the home care continuum. Without these, many older chronically ill persons would not be able to remain in the comfort and safety of their own home. Often with little or no job training, families are left with minimal equipment and no shift relief as they face the dual responsibilities of managing both the illness and the home environment (White & Lubkin, 1995). The ability of the family to maintain a normal life under the “abnormal” presence of chronic illness and heightened uncertainty is a fundamental task (Rolland, 1987). Social relationships are often disrupted or altered as a result of lessened energy, impaired mobility, body disfigurement, time spent on regimes and symptom control. As a result of symptom management or regimes being so time consuming and/or physically taxing, there may be a voluntary pulling away for both individuals and their families in having to make difficult choices about management of the disease verses maintaining social contacts (Strauss, et al., 1984).

The family, as a unit, experiences both rewards and losses throughout their chronic illness journey. As Bass (1990) describes, the constant demands of meeting another person's daily needs result in the loss of control over personal time. Complicated treatment regimes
leave very little time for relaxation, socialization or personal enjoyment of hobbies or other activities. Over long periods of time these demands may lead to feelings of anger and frustration (Bass, 1990).

Families may also experience chronic grieving with respect to the loss of the relationship with the ill person or the loss of normal family relationships as they once knew them. Costs for items such as special food or clothing, mobility aids, incontinent products, and the increased use of utilities combined with a fixed income or possible lost employment opportunities result in both actual and potential losses in the family’s financial picture (Bass, 1990). Despite the experience of these multiple losses, family care giving allows the individual to live at home with the hope of avoiding or delaying the threat of institutionalization. It allows families to provide care in the way their loved one desires, it offers the opportunity of satisfaction for a job well done and promotes family unity in working together for comfort and survival of an important loved one. As Curtin and Lubkin note, adapting successfully to chronic illness includes a conception that the quality of life for the individual is worth the struggle (1995).

Corbin and Strauss studied sixty (60) couples and found that successful management of chronic illness was the result of mutual coordination and working collaboratively. Coordination and collaboration assisted couples to circumvent problems and go on to do the illness and biographic work necessary to manage both the illness and their lives. The researchers discovered the opposite of collaboration to be disharmony with the negative consequences manifested in either partner as feelings of frustration, confusion, being overburdened, and worn out (1988).
Kuyper and Wester (1998) examined the impact of chronic illness on the patient’s partner and the role of the General Practitioner (GP) in a qualitative study conducted with thirty-one (31) partners and their family physicians. In order to obtain a broad view on the problems partners experienced, the sample was selected based on a number of characteristics, such as type of disease, duration of the illness, sex, age and social class. Partners of terminally ill patients were excluded from the study. Data were collected via in-depth interviews, reflection memos, and the completion of a well-being questionnaire. A pilot sample of three partners and their GPs was used to formulate the general research questions and develop the interview topics. The transcribed interviews were analyzed with the help of a computer program where text was analyzed in segments and coded with the use of key words.

The researchers found their partner sample scored lower on the well-being questionnaires compared to results of this questionnaire used in the general population and widow groups (Kuyper & Wester, 1998). From the data analysis, four problem domains emerged: biographical consequences, consequences for the patient-partner relationship, illness-related problems, and the everyday burden. Almost half of the partners had serious problems as a result of their spouses’ disease. They demonstrated signs of exhaustion, depression, or strain. For the other half, life went on normally. Problem severity varied with gender and the kind of disease. Female partners and partners of those experiencing more serious ramifications as a result of progressive chronic disease of the locomotor/nervous system or cancer revealed more severe problems. The disease classifications used in this study were cancer, n=11; myocardial infarction, n=9; and chronic or progressive disorder of the locomotor or nervous system, n=11(Kuyper & Wester, 1998). It did not appear that any of the participants’ partners suffered from chronic respiratory illness.
Scott (2000) investigated health-related quality of life (HRQOL) of 18 family members delivering care to community dwelling technologically dependent individuals with advanced heart failure. These caregivers felt positive about their role as caregivers and demonstrated higher ratings of HRQOL than care receivers. Caregivers derived their greatest satisfaction from their spirituality, friends and family. Areas of dissatisfaction were related to employment status, travel restrictions, lifestyle changes and the stress associated with caregiving. Using a variety of measurement tools and statistical analysis, Scott’s (2000) study examined the variables of caregiver preparation, health appraisal, bipsychosocial responses and their relationship to quality of life. In examining preparation it was found that when caregivers perceived they were unprepared for the caregiving role, they experienced more adverse effects. Adverse effects included difficulty in coordinating daily activities and maintaining their own health. The number of caregiving tasks also influenced a variation in quality of life for caregivers. The mental well-being of the caregiver, combined with the esteem of the caregiver, accounted for 49% of the variation in caregiver HRQL (Scott, 2000).

Summary

This review of relevant literature revealed that LTOT improves survival rates and cognitive functioning of individuals with chronic hypoxia associated with chronic respiratory disease. Despite wide spread use of LTOT as a treatment modality, the benefits long-term oxygen had not been found to extend positively into the area of quality of life. No studies were found to explore the family experience of LTOT, possible assistive or restraining factors affecting the quality of life of this population, or that examined ongoing relationships with health care professionals and service providers.
The chronic illness literature, reviewed for this study, accentuates the fact that the management of chronic illness is work, specifically in the areas of organizing and performing necessary tasks and actions to shape the illness trajectory. The work of being chronically ill, accompanied with feelings of uncertainty regarding the illness, has far reaching ramifications, which can impact on social, psychological, physical, and economic lives of every individual and family member it touches. Family caregiving, although often described as burdensome, can also have positive ramifications for the individual and family as a unit.

The literature specific to LTOT reveals that there is a need for additional research to augment our understanding of the experience through the exploration of individual and family/support person perspectives. Given what is already known about reduced quality of life for LTOT users, consumer input must be sought with the view of improving care and service delivery to this population with improving their quality of life to the greatest extent possible being the ultimate goal. The findings from this research project build on existing long-term oxygen and chronic illness research and expands our knowledge with respect to the specific uncertainties encountered by oxygen users and their family support persons and strategies they use to manage sustained uncertainty.

Conceptual Frameworks

The conceptual framework for this study includes elements from the Mandala of Health (Hancock, 1985) and the Uncertainty in Illness Theory (Mishel, 1988; 1990). These frameworks were chosen after reviewing numerous nursing theories and frameworks including The Roy Adaptation Model (Roy & Roberts, 1981) with respect to adaptation in chronic illness and the Calgary Family Assessment and Intervention Model (Wright & Leahey, 1984) which focuses on the relationships of
families, health and illness. The choice of a theoretical framework is difficult given
the complexities inherent in chronic illness experience which make it impossible to
capture through the use of one or even multiple theoretical perspectives (Thorne,
Paterson, Acorn, Canam, Joachim & Jillins, 2002).

The Mandala of Health was chosen as a framework for this at home population
as it is a community based model which reinforces that the health of individuals and
families is intimately bound with their physical and social environments and actions
within the community and broader social political culture act as important
determinants of health. This dynamic model encompasses a holistic view of health
and is particularly useful when working with high-risk community dwelling
populations (Hancock, 1985), such as individuals managing chronic illness.

When chronically ill are required to incorporate technology into their in-home
treatment regime there is a great deal of uncertainty surrounding the dependency of the
equipment and future of their illness experience. The uncertainty theory explains how
individuals cognitively process illness-related stimuli and construct meaning in these
events (Mishel, 1988). Individuals with chronic respiratory disease experience a
declining illness trajectory in conjunction with the potential for life threatening
exacerbations, which creates sustained levels of uncertainty for these individuals and
their families (Small & Graydon, 1993). The introduction of oxygen technology into
the home as a treatment therapy also increases uncertainty potential due to the
possibilities of equipment failure and/or fluctuations in oxygen supply. Enhanced
understanding of the stimuli and resulting impact of uncertainty assists nurses to
develop intervention strategies to help individuals and families adapt to a more
desirable state either through the reduction of uncertainty or through promoting probabilistic thinking, which fosters a new world view and alternative functioning (Mishel, 1990).

The Mandala of Health

The Mandala of Health was developed in the 1980’s by the Department of Public Health, for the City of Toronto. Its conceptualization of health has been influential in the evolving paradigm shift from the biomedical view of health as being the absence of disease or illness, to an expanded holistic view of health and health determinants. It has been widely used in educational and community health settings throughout Canada (Rootman & Raeburn, 1994).

As shown in Figure 1, the Mandala is a circular model, with the individual comprised of body, mind, and spirit positioned as the center and encircled outwardly by several influencing environments (Hancock, 1985; Rootman & Raeburn, 1994). For the most part, individuals exist within a family unit that plays a vital role in establishing health values, attitudes and habits (Hancock, 1985). Families are also influential in providing shelter, stability, security, and a setting for nurturance and growth (Murray & Zentner, 1993). Individuals and families exist within and are thus influenced by social and physical systems outside their family units including: community values, standards, health policy and social systems; prevailing culture; human made/built environments; and the physical (biosphere) world where life exists (Hancock, 1985; Rootman & Raeburn, 1994).
The model demonstrates that four broad factors influence the health of the individual and the family. These health-determining factors modified from the visionary work of Lalonde (1974) include: human biology, personal behavior, the psychosocial environment and the physical environment:

1. human biology: the genetic traits and predispositions; the competence of the immune system; and the biochemical, physiologic, and anatomic state of the person and the family;
2. personal behavior: dietary habits, including smoking and drinking; driving habits, including use of seatbelts; general risk-taking and preventive behaviors;
3. psychosocial environment: socioeconomic status, peer pressure, exposure to advertising, social support systems, and related factors;
4. physical environment: adequacy of housing and the physical state of the work
place and immediate environment (Hancock, 1985).

The Mandala of Health represents a systems model. A system is defined as consisting
of “interrelated parts functioning together to form a whole” (Conner, Magers, Watt, 1989, p.
310). As depicted in the mandala model, the individual comprised of body, mind and spirit is
located in the center of a circle symbolizing the universe. Although central to the model the
individual’s health and wellbeing is taken into context with the all other aspects of his/her
outside world which includes family, lifestyle choices, community, health care system, human
made/built environments and all other aspects of the living world (environmental air quality,
biosphere).

As a component of this system’s model individuals are in continual interaction with
their surrounding environments (physical, psychosocial, economic, political). Any change in
any one component within the system has the capacity to change the whole system by virtue
of their connectedness (Schneidirman & Trapp, 1985), thus individuals cannot be viewed in
isolation from their families and society (Hancock, 1985, Hanson, 1987). Family, family
nursing, and family health cannot be understood in isolation from the larger environmental
context (Hanson, 1987). The mandala reinforces that the health of individuals and families is
intertwined with their physical and psychosocial environments and is further affected by the
actions and policies of the health care system, the broader community and public policy, and
predominant culture. The interrelatedness of these factors form determinants of health and
wellness. Therefore, when exploring the health needs and experiences of individuals and
families with the view of providing programs and services to meet those needs, one must do
so by taking into consideration the family in relation to a variety of dynamic and interactive
components as depicted in the model. Any resulting interventions must address the social and political nature of health at the personal, family, community and societal level (Hancock, 1985).

The Mandala of Health model is compatible with family research as confirmed in Gilgun’s (1992) description of qualitative family research in that its “focus is on experiences within families as well as between families and outside systems” (p. 24). The model provides a holistic pictorial guide to the researcher’s exploration of the experience of in-home oxygen technology and the recognition that each family is a system within a system, which is affected by biological, personal, psychosocial and physical factors. The dynamic nature of the model dictates that any change in the health or experience of the individual may be influenced by one or all the factors in the model and that in turn, the individual can influence each factor alone or in concert with other family members. Families experiencing LTOT do not exist in isolation and therefore, are subject to factors external to their family unit. During the semi-structured interviews questions and probes were put forward to explore the individual’s relationship with family, lifestyle, community and community programs, health care system, human made/built environments and the broader living world (biosphere).

The presence or absence of community programs, type of air quality, availability of home care and institutional care, access to knowledgeable and credible health care providers, subsidized funding for the oxygen and related technology, predominant values and beliefs are all examples of external factors reflected in the Mandala of Health that have the potential to impact the LTOT experience for oxygen participants and family.
Uncertainty in Illness Theory

Uncertainty in illness is a theoretical approach positioning uncertainty as a significant variable (stressor) influencing the individual’s experience of illness, treatment and hospitalization (Mishel, 1981). Since its inception, components of the theory have been tested on populations such as: parents coping with childhood illness (Mishel, 1983), hospitalized medical patients (Mishel, 1984; Small & Graydon, 1993), adults with asthma (Sexton, Calcasola, Bottomley, Funk, 1999) adult females living with breast cancer (Nelson, 1996) receiving treatment for gynecological cancer (Mishel & Braden, 1988; Mishel, Padilla, Grant & Sorenson, 1991). Originally the theory had its strongest support with those experiencing the acute phase of illness or downward illness trajectories. However, with ongoing research and given that uncertainty is a constant variable in chronic illness, Mishel reconceptualized the theory to include theoretical perspectives regarding living with continual constant uncertainty as in the case of chronic illness (Mishel, 1990, 1999).

Uncertainty as described by Mishel (1988) is the inability to determine the meaning of illness-related events and occurs in a situation where the decision-maker is unable to assign definite values to objects and events and/or is unable to accurately predict outcomes. The uncertainty theory explains how individuals cognitively process illness-related stimuli and construct cognitive meaning of these events.

The primary antecedent variable to uncertainty is the stimuli frame. This frame has three components: symptom pattern, event familiarity and event congruence. Symptom pattern refers to the degree to which symptoms present with sufficient consistency to be perceived as having a pattern. Event familiarity refers to
the degree to which the situation is habitual, repetitive and contains recognized cues. Event congruence refers to consistency between the expected and experienced illness-related events. When present, these stimuli are inversely related to uncertainty (Mishel, 1988).

The three components of the stimuli frame are influenced by two variables: cognitive capacity and structure providers. Cognitive capacity is the information processing abilities of the person. Limited cognitive capacity will reduce the ability to perceive symptom pattern, event familiarity, and the congruence of events therefore, impacting negatively in the ability to reduce uncertainty (Mishel, 1988). The stimuli frame is further influenced by structure providers, the resources available to assist the person with interpretation of stimuli. Structural providers consist of the individual’s level of education, the presence of social support and availability of credible authority in the form of health care professionals or health information. According to Mishel’s (1988) theory, uncertainty results when a cognitive schema of the illness events cannot be formed.

In the illness experience, uncertainty manifests itself in four forms: ambiguity concerning the state of illness; complexity regarding the treatment and the system of care; lack of information about the diagnosis and seriousness of the illness; and unpredictability as to the course of the disease. Uncertainty is not inherently a dreaded or desired state until the implications of uncertainty are determined. The theory dictates that uncertainty can be viewed as either a danger or an opportunity. As uncertain disease related or illness related factors are introduced into the person’s life, the uncertainty competes with the person’s previous mode of functioning. If
individuals are able to contain the uncertainty it may not be sufficient to disrupt an ongoing life pattern. If uncertainty were to multiply and invade a significant aspect of the person’s being then the person would experience dis-equilibrium (Mishel, 1990).

For the most part, uncertainty is perceived as a danger. Coping and adaptation strategies are then put in place to reduce uncertainty and manage the emotion associated with a danger appraisal. Coping strategies described by Mishel are: mobilizing which is comprised of the strategies of direct action, vigilance and information seeking; and affect-management consisting of disengagement and cognitive support in the form of positive self talk (1988). How well a person copes with any situation is influenced by the ability to resolve uncertainty (Mishel, 1983).

As the uncertainty in illness theory evolved through ongoing theory testing research, it became evident that the long-term effects of many illness cause uncertainty to not only perpetuate, but also to change over time. As a result of recognizing this incongruence, Mishel (1990) went through the process of reconceptualizing various components of the theory in order to incorporate the experience of living with continual, perpetuating uncertainty.

When stimuli associated with illness, treatment and recovery are vague, ill defined, probabilistic, ambiguous and unpredictable, the sense of coherence by the individual may be lost (Mishel, 1990). If these states are experienced over long periods of time, as is the case with chronic illness, uncertainty becomes a foundation on which the new sense of order is constructed. Through the development of probabilistic thinking the nature of uncertainty is accepted as the natural rhythm to life. The expectation of continual certainty, control and predictability is abandoned as
a part of a new reality. In the new reality there is an enhanced ability to focus on multiple alternatives, choices and possibilities; to reevaluate what is important in life; to consider variations in personal investment and to appreciate the fragility and impermanence of life situations. Adaptation is psychosocial behaviors within the person’s normative level of functioning and is proposed as the end state achieved after coping with uncertainty (Mishel, 1990).

If this new orientation toward life is to be supported, both the social resources and the health care providers involved must believe in the probabilistic paradigm and assist the individual to use uncertainty as a positive force. Mishel posits that current nursing care of the chronically ill promotes probabilistic thinking. This is evidenced when nurses’ encourage patient consideration of multiple ways to accomplish valued activities, promote alternatives in adjusting to the changing nature of the illness, and foster learning about the varied human response to treatment (1990).

The population of interest in this study experienced uncertainty by virtue of their dependency on oxygen and the functioning of oxygen as well as the uncertain nature of their respiratory disease, fluctuating symptoms and exacerbations and their over all illness trajectory. Given our understanding of the dynamic nature of chronic illness, family systems and the components of the Mandala of Health, uncertainty experienced by the individual has the potential to affect the family unit as a whole. Uncertainty for both individuals and families may be further compounded by complexities of the broader social system such as, the intricacies, inconsistencies and the inadequacies of the health care system (Curtin & Lubkin, 1995; Small & Graydon, 1993). Since uncertainty has the potential to impact significantly on the quality of life
for individuals and their families living with LTOT the theoretical underpinnings of the Uncertainty in Illness Theory in conjunction of the Mandala of Health provide a valuable guide for the exploration, analysis, and discussion components of this study.
CHAPTER THREE
RESEARCH METHOD

Introduction

Nursing research involves implementing systematic approaches to problem solving issues of concern to nurses with the view of expanding nursing knowledge and improving professional service delivery. The methods and designs available to conduct nursing research are as numerous as they are diverse. The selection of an appropriate method often depends on the researcher’s personal taste and philosophy, the purpose and nature of the research question, the population of interest, and the setting of the investigation (Polit & Hungler, 1995). Qualitative methodology and more specifically, the method of person-centered interviewing and observation provides the basis for the design of this study. The selection of a purposeful sample and criteria for participation are outlined along with data collection strategies and methods of data analysis. Procedures to maintain trustworthiness and provisions to meet ethical requirements are also discussed. The concluding portion of this chapter identifies several limitations with respect to the application of this research design.

Research Design

To explore and describe the individual and family/support person’s experiences of living with long term oxygen therapy (LTOT), a qualitative methodology was chosen to guide this study. Naturalistic design provides a good fit with the researcher’s personal philosophy, the purpose and questions driving this research, the population of interest and the fact that the site of inquiry is the home environment. Qualitative methodology emphasizes the dynamic, holistic and individual aspects of the human experience in an attempt to capture those components to the greatest extent possible, and within the context of those sharing the
experience. Using a qualitative method, the researcher strives to shed light on the complex family experience of living with long-term oxygen, while at the same time, taking into consideration that there are always multiple interpretations of each reality (Polit & Hungler, 1997). To capture these expected multiple interpretations of reality, person-centered interviewing and observation, which is embodied within the ethnographic tradition (Levy & Hollan, 1998), is used as the method of inquiry and data collection.

Ethnography and person-centered interviewing and observation are derived from the field of anthropology (Levy & Hollan, 1998, Throne, 1991). Studies in this area reveal information about what is universal within human nature and what is dependent on coincidences of human logic and environments in dynamic interaction (Thorne, 1991). Many nurse researchers have used ethnography (Aamodt, 1991; Germain, 1986; Laskiwski, & Morse, 1993; Roper & Shapira, 2000) as a method of naturalistic inquiry. More recently, person-centered interviewing has been used to explore the experience of urban Aboriginal people living with type 2 diabetes (Gregory, Whalley, Olson, Bain, Harper, Roberts & Russell, 1999). Researchers explore and describe the perspectives of individuals and groups through the examination of their day-to-day local worlds and their subsequent felt experiences (Kleinman, 1992). Interviewing serves as an important means by which the participant’s interpretations inform the researcher’s analysis of meaning (Thorne, 1991).

Person-centered interviewing and observation, as a method, has typically focused on small-scale societies (Levy & Hollan, 1998) and to date has been more widely used in anthropology rather than nursing research. Person-centered interviewing engages the interviewee as a knowledgeable “informant” or expert witness who can tell the interviewer about culture and behavior in a particular setting. This is similar to other types of
interviewing, discussed in social science literature. The uniqueness of person-centered interviewing stems from the fact that it takes the process one step further in that it also engages the interviewee as a “respondent,” as an object of systematic study and observation. This mode of questioning explores what the participant personally makes of the phenomenon. The interviewee is also observed and studied during the interview process in order to note behaviors and reactions to various probes, questions and topic areas. The interviewing process moves back and forth between informant and respondent modes using both closed and open ended questioning and probes. Accounts of aspects of their lives are approached first descriptively, then with emphasis on the participants’ personal experiences and interpretations (Levy & Hollan, 1998).

Interviews are structured to elicit behavior that moves beyond role determined surface scripts portrayed in ordinary social conversations. In order to obtain a deeper understanding of the experience, hidden or latent dimensions of the individual and their sociocultural matrix must be revealed (Levy & Hollan, 1998). Specific to this study, individuals and their families living with in-home oxygen technology as the group of interest were interviewed in the oxygen participants’ homes. Their local communities and interactions with home care and other providers formed aspects of their sociocultural matrix.

Through the application of person-centered interviewing and observation, the researcher explored the experience of in-home long-term oxygen to obtain a rich understanding of this phenomenon of interest. The overall aim of this type of research is to learn about people by learning from the participants in an effort to understand their worldview as they define it (Polit & Hungler, 1995; Roper & Shapira, 2000).
This study was guided by a general topic of interest with no or minimal preconceived notions about the outcomes of the research (Roper & Shapria, 2000). The focus was on family/support person units within an identifiable group (those experiencing LTOT). I explored both experiences and feelings through a systematic process of informant respondent questioning, observing behavior, detailing, describing, documenting, and analyzing the particular patterns of experience, knowledge, and behavior using the participant’s environment as a backdrop and myself as instrument (Coffey, 1999; Sandelowski, 1995).

Data collection of the sample began with the completion of a short demographic and general information questionnaire (Appendix B). Following this, in-depth person-centered interviews were conducted using a semi-structured interview guide (Appendix C). To allow for the scope of the interview guide and to accommodate for variances in participant responses and physical capabilities, one to a maximum of two interviews were allowed for in the consent process. A second interview session was necessary with one participant dyad. Interviews were held conjointly. Although there are advantages to individual interviews, the interaction that took place during conjoint interviewing provided the opportunity to observe how family members act together, how they seek or help influence each other as well as, how they handle any disagreements that may arise in the interview situation (Morris, 2001; Racher, Kaufert & Havens, 2000; Sandelowski, Holditch-Davis & Glenn Harris, 1992). Person-centered interviews consist of topics of inquiry (Levy & Hollan, 1998). The framework for these topic areas and questions were derived from the research questions and the literature review and were reflected in the semi-structured interview guide. As qualitative methodology is inductive and discovery based rather than hypothesis testing (Hammersley, 1990), the interview questions and probes acted as a guide only. This permitted flexibility within the
method which promoted the revision of questions during the study as new discoveries lead to new directions of understanding (Germain, 1986).

Observations made during the interview sessions were recorded in the form of a field note guide (Appendix D). Personal thoughts, feelings and potential biases of the researcher were documented separately in reflective journaling (Roper & Shapira, 2000) to form introspective reflections of the research experience. Data collected from oxygen participants and support persons were combined to produce a rich qualitative data set.

Sampling

Qualitative research is based on the premise that knowledge about humans is not possible without describing the human experience as it is lived and defined by the actors themselves (Polit & Hungler, 1993). Sampling in qualitative research is not based on the number of interviews or events but rather on the fullness of the data (Germain, 1993). Mackenzie describes sampling as being conducted toward the view of developing and discovering categories on the way to developing theory (1994). Of primary concern is the selection of participants who can offer insight into the phenomenon under study, as well as taking into consideration sampling across time and place (Miles & Huberman, 1994).

Researchers therefore, rely on their judgment to select the most appropriate participants based on the nature of the research question (Fetzerman, 1989). Purposive sampling as a form of non-probability sampling occurs, as in this case, when the researcher has prior knowledge about the population of interest and its elements and uses this knowledge to select potential participants who are typical of the population in question (Polit & Hungler, 1993). As the target population for this study was older adults and their family support persons living with long-term oxygen technology, purposive sampling of this population was conducted through
Home Care Case Coordinators. Attempts were made to access both males and female oxygen participants who had been on long-term oxygen for varying lengths of time and a variety of support person caregivers including spouses, adult children and friends.

Participants

Inclusion criteria for the oxygen participant sample consisted of the following.

Individuals:

- treated with oxygen utilizing a oxygen concentrator (owned, rented, or provided by a third party payer) for a minimum of 4 weeks with the oxygen prescribed for at least 15 hours a day.
- who were able to read and understand English.
- fifty-five (55) years of age and older.
- who could understand and give written informed consent.
- not experiencing an acute exacerbation of their illness and therefore not hospitalized at the time of the interviews.

Oxygen dependent individuals who agreed to participate in the study designated a family/support person and requested their permission to participate in the interviews and provide insights regarding the impact of living with long term oxygen technology from a family/support person perspective. Oxygen dependent participants chose the interview location. All interviews occurred in the oxygen participants’ place of residence.

Inclusion criteria for the family/support group participants consisted of the following.

Individuals:

- family or support persons designated by the oxygen dependent participant as being a key provider of support to the oxygen user.
Recruitment of Participants

The participants for the study were drawn from a population of individuals living in a home environment who met the above selection criteria. Permission to access this population was sought from the urban Regional Health Authorities in a Province of Western Canada. Subsequent to obtaining permission to access this population, Regional Home Care Coordinators/Managers were approached to assist in identifying potential participants. A letter introducing the researcher and the intended research project was provided to the Regional Home Care Managers (Appendix E). The letter explained the purpose of the study, inclusion criteria for the sample, data collection methods and provisions for confidentiality. The managers arranged for Home Care Case Coordinators to assist in the recruitment of participants. When making initial contact with participants, Home Care Case Coordinators used a script that introduced the researcher and the proposed study (Appendix F). If individuals provided verbal consent to participate, the Home Care Nurse requested permission from the participant to release his/her name and phone number to the researcher. After obtaining notification of their agreement to participate, the researcher contacted potential participants in person via telephone, to further explain the study. If following this explanation they remained agreeable to an interview, an interview time and place was arranged. Prior to the commencement of the interview written consent from both the oxygen participant and family/support person was obtained (Appendix G & H).
Sample Size

The qualitative researcher usually works with small samples of individuals, nested in their context and studied in depth - unlike quantitative researchers who aim for larger numbers of context-stripped cases to seek statistical significance and generalizability (Miles & Huberman, 1994). Fifteen (15) oxygen participant/support person dyads participated in the study for a total sample size of thirty (30). This sample size provided rich description and multiple perspectives of the experiences of living on long-term oxygen. Sampling of participants concluded when a reasonable amount of data and insights had been collected in each of the study’s predominant topic areas.

Strategies for Trustworthiness.

The goal of this qualitative study was to explore and describe, in a trustworthy manner, the experience of living with long-term oxygen technology. My role as researcher was to represent the multiple realities of the participants as accurately and adequately as possible (Krefting, 1991). To be true to these participants and the stories they shared, a number of strategies were used to ensure that trustworthiness was maintained throughout the project.

To strengthen the credibility of the data and subsequently the findings, a process of in-depth person-centered interviewing using male and female oxygen participants and purposeful sampling to obtain a variety of caregiver types was implemented. The participants in this study had lived-experience with long-term oxygen technology and were chosen for their direct knowledge of the phenomenon (Morse & Field, 1995). The use of interviewing is a recognized method of generating empirical data about the social world by asking people to talk about their lives (Holstein & Gubrium, 1997). Systematic data collection occurred using a semi-structured interview guide (Appendix C), which reflected the study’s research questions and was grounded
in the conceptual frameworks. Question development was based on a thorough review of the literature and was designed to investigate previous findings and explore identified gaps. The interview guide was used consistently with each participant group although as themes emerged from initial interviews these areas were probed more extensively with subsequent interviews. Questioning was primarily open-ended and participants were asked questions posed in different ways in the same topic area in order to determine whether the responses generated were consistent (Brink & Wood, 1988; Dempsey & Dempsey, 1996). Audio taping of the interviews was conducted and verbatim transcription of the audio tapes was completed to capture data in its entirety. Any unclear or incomplete data from the interview were resolved during a follow-up phone call as provided for in the consent form (Brink & Wood, 1988). Reflective journal notes were recorded during the interview and analysis stage (Roper & Shapira, 2000). This documentation was reviewed periodically to assist in identifying and controlling for any biases or influences the researcher may have had (Krefting, 1991; Roper & Shapira, 2000).

The use of multiple data sources enhanced the trustworthiness of this study. The multi-stranded character of data collection provided the basis for triangulation in which data of different types were systematically compared (Hammersly & Atkinson, 1983: Robertson & Boyle, 1984; Roper & Shapira, 2000). The data sources were individuals and their key support persons. Data collection methods used for triangulation were short form questionnaires, interviews, and documented observations (field note guide). Truth-value was enhanced by continuous data analysis during the project to ensure that discontinuities, contradictions or unclear data was further explored in the field (Robertson & Boyle, 1984). I ensured that sufficient data were collected to develop a detailed and rich description of the phenomenon. Sampling was ceased when no new data emerged in the substantive topic areas (Morse & Field,
Generalizability is not the goal of qualitative study (Brink & Wood, 1988; Morse & Field, 1995), as this study was geared to examining a range of experiences rather than the average. Variability was expected, and in keeping with this, atypical or nonnormative situations were included in the findings to ensure that boundaries and outliers of the experience were identified and described (Krefting, 1991; Roper & Shaapira, 2000).

To ensure the confirmability of the findings, the findings are rooted in descriptive data (Brink & Wood, 1988; Guba & Lincoln, 1989; Krefting, 1991). All themes, assertions, and conclusions are supported by the short form questionnaire, verbatim textual excerpts from the participant interviews, and observational field recordings. A paper trail of my analysis was kept so that I can articulate the analytic strategies taken to reach the conclusions of the study (Brink & Wood, 1988; Roper & Shapira, 2000; Thorne, 1997). On a periodic basis I discussed preliminary findings and tentative analysis with my thesis chair as a method of debriefing. In addition, my thesis committee acted as external auditors by critiquing my findings and ensuring that they were deeply rooted in and supported by data and rich description (Guba & Lincoln, 1989).

Given my previous professional role in the delivery of oxygen services under the Provincial Home Oxygen Program, I brought experiential understanding and theoretical sensitivity to this research project. This also offers the potential for investigator bias. I maintained an acute awareness of how using myself as instrument could affect the data collection and analysis process. This awareness guided me to be objective throughout the data collection and analysis period (Walters, 1995). As Thorne observes, all knowledge is perspectival, and in order to provide assurance that the researcher’s interpretations are trustworthy, they must illustrate truths external to the researcher’s own biases and experiences (1997).
A key component for the assurance of good qualitative work is the establishment of trustworthiness. Through the application of the described strategies and techniques to the research design, an ongoing framework supporting trustworthiness was maintained.

Data Analysis

Based on Miles and Huberman’s (1994) recommendation of interweaving data collection and analysis, data analysis began with the first interview and progressed concurrently throughout the study. This assisted the researcher to think about the data, discover additional themes and generate creative strategies for pursuing alternative avenues as the investigation progressed. Given the vast amount of data that were generated from the short form questionnaires, transcribed interviews and written field notes of observations, a systematic and ongoing review of these documents was key to the data analysis process (Roper & Shapira, 2000). In addition to analysis of the transcribed data, results from the short form questionnaires were tabulated in the form of frequencies, ranges and percentages.

Audio taped interviews were transcribed into text as soon as possible after the interviews. The researcher re-listened to each tape in the presence of the transcribed text so that any transcriptional errors could be corrected, nuances in responses were noted and any gaps in data were addressed with participants (Levy & Hollan, 1998; Rank, 1992). The steps of analysis were based on Roper and Shapira’s (2000) eclectic approach and included coding of transcribed interviews and observations, sorting of the codes to identify patterns and themes, generalizing constructs and theories, and memoing throughout to note personal reflections and insights. To become familiar with the data, transcripts were read, coded, re-read and re-coded several times. Coding reduced the participant responses into meaningful units, patterns, categories and consistent themes. Copies were made of the coded transcripts. Coded originals were placed in
binders and kept in a secure location. Copies of the coded transcripts were used to cut written words/sections from the transcripts and in turn were grouped into meaningful segments or categories by way of colored file folders. The content of these folders was further analyzed to compare, contrast, and identify patterns occurring within the folders. Folders were collapsed into categories and subsequently into themes. Immersion in the written material was essential to gain insights and to connect themes within and between transcripts. As described by Roper and Shapira (2000), data analysis was not a linear process and moved back and forth between the steps.

Ethical Considerations

The researcher must ensure the rights of participants to privacy, dignity, confidentiality and care to avoid causing personal harm (Lipson, 1994). Ethical considerations in this study included; ensuring data collection methods protected participants from burdens and risks, establishing an informed consent process, maintaining confidentiality, and attending to participant symptoms such as, fatigue and shortness of breath. Protocols were put in place to address ethical concerns and approval for this research protocol was awarded by The University of Manitoba, Education/Nursing Research Ethics Board (Appendix I).

Data Collection Methods

In qualitative research data are primarily obtained through the human sense, with the researcher as the primary research instrument (Poilt & Hungler, 1997). As described previously, data were collected through a short demographic questionnaire, person-centered interviewing of participants and family/support persons, as well as observations documented during the interviews and recorded in a field note guide. I conducted all the data collection activities. Prior to the commencement of the interviews, a consent form was read to the participants (see
Appendix G & H) and was made available for their review and signature. A copy of this form was provided to each participant. Participation in an interview was considered agreement to take part in the project. An interview guide inclusive of standard questions and possible probes was used for the person-centered interviews. Interviews were audiotaped with the permission of the participants. Observations made during the interviews were recorded in a field note guide.

Audiotapes were transcribed verbatim into typed format. If an individual’s name or the name of a health professional or oxygen supplier was disclosed on tape, the typist was required to leave a blank space in the transcription. Transcribers (2) were briefed on the requirement for maintaining strict confidentiality of the data. Only the transcribers, my thesis chair and myself had access to the raw data. Each transcript was assigned a code and no participant names of the participants were revealed or recorded in conjunction with the raw data. These same codes were used as confidential identifiers on the field note documentation. Code identifiers and corresponding names were kept in a secured area separate from the transcribed material. All raw data were kept and will be kept in a secure locked area for at least seven to ten years.

Informed Consent

Each individual consenting to participate in this research project received verbal and written information regarding the project’s purpose and objectives. He or she was informed that participation was voluntary and that any information provided would remain confidential.

Informed consent was obtained by having the individual read and sign the appropriate consent form. The consent form reinforced that the participant’s involvement was voluntary, that he or she could refuse to answer any questions, and that he or she could withdraw from the interview at any time. Participation in interview sessions was considered consent to proceed with data collection.
I used techniques such as relaxed open posture and eye contact to make participants feel comfortable in telling their stories. I was aware of participants’ comfort levels and encouraged them to determine their own comfort level of disclosure by reminding them that they had the right to refuse to answer any question. On one occasion I was asked to turn off the tape so that the oxygen participant could make an “off-the-record” comment. This request was complied with and audiotaping was reestablished upon the direction of the participant. According to Lipson, (1994) a need may arise to remind participants that discussions are for the purpose of conducting research and that verbal reaffirmation of their consent for participation may be required. This necessity did not occur.

I informed participants of my status as a registered nurse and that I had previously been employed as a manager of clinical services and programs for an oxygen service provider. Participants were informed that their confidentiality would be strictly maintained and their participation in the study would not affect their care within the health care system. I was not in a position of power over the participants and was not a direct care provider, nor did I have influence over their service provision. I reinforced that their comments would be kept confidential and would in no way jeopardize their current or future oxygen service provision.

Confidentiality

Confidentiality was strictly maintained throughout the data collection, transcribing, analysis and report writing process. Given the unpredictability of qualitative research, the investigator has much less control over the process, which could undermine the spirit of informed consent and endanger the assurance of confidentiality (Ramos, 1989). Confidentiality was also ensured through the use of coded identifiers as previously outlined.
Burdens or Cost to Subjects

It is the responsibility of the researcher to inform participants of any potential positive and negative consequences associated with a study (Lipson, 1994). The participants were required to give their personal time with respect to the oxygen participant family/support person interview sessions. Their involvement time was approximately one to 1.5 hours for each session. From time to time it was necessary to reassure participants that their comments and opinions were important and only they could present their unique view of the experience of living on long-term oxygen (Domard & Bushmann, 1995). Interviews were held in participants’ homes thus providing a safe and comfortable environment. This also facilitated observation of their local worlds. Moreover home-based interviews alleviated these burdens with respect to energy expenditures of having to leave home, associated travel costs, and the requirement of mobility oxygen use.

Risks to Participants

As interviewing is a process of human interaction, there was the potential for evoking feelings of embarrassment, anger, misunderstanding, and conflicts in opinions and values to during the interviews (Antle May, 1989). During the interviews there were times when participants disagreed with one another but no major arguments or emotional upsets occurred. Tape recording was temporarily halted when oxygen participants became short of breath or experienced bouts of coughing. Participants were periodically consulted about their ability to continue. Participants, for the most part, preferred to complete the interview in one session and only on one occasion was a second interview required. Had participants exhibited sustained emotional upset I was prepared to encourage individuals to seek psychosocial support and the name and phone number of their Home Care Case Coordinator would have been provided. I
would have also used my twenty-five years of nursing experience and clinical judgment to determine the need for psychosocial support.

Participants were reassured that the information they provided would not have any impact on their future provision of oxygen services. Participants were provided adequate time to answer questions and fatigue and dyspnea were taken into consideration with respect to the length of the interview. Some participants may have felt obligated to participate in the study as a result of wishing to please the data collector and it was clearly stated during initial phone contact and in the written consent forms that they were under no obligation to participate.

Limitations of this Design

It is recognized that no qualitative study can provide a complete picture of the phenomenon of interest and that data collection is inescapably a selective process and it will not be possible to “get it all” (Miles & Haberman, 1994). According to Pishkin, no research paradigm has a monopoly on quality (1993). The following outlines several acknowledged limitations to this study.

The person-centered interviewing method depends primarily on verbal statements, the informant’s memory and story telling abilities, the experience of the researcher and the degree of trust obtained between the researcher and the informant (Levy & Hollan, 1998). These factors were relevant to this study. Some participants were better communicators and historians than others. One quarter (26.6%) of the oxygen participants had been on home oxygen for five years or more; therefore their ability to recall their feelings of what it was like when they were first started on oxygen may have been hampered by the length of time. As in any face-to-face dialogue, data have the potential for fabrication, exaggeration, distortion and are shaped by the forces of time and history. A longitudinal study of long-term oxygen use has the potential to
provide more in-depth understanding of the experience and the process of acceptance and adaptation over time.

It is known that differences exist between what a person says and actually does in different situations (Admi, 1995; Brink & Wood, 1988). Therefore, what is said may not be what in actual fact happened. According to Hammersly, (1992) we can never know with certainty whether an account is “true”, therefore we must judge the validity of claims on the basis of the adequacy of the evidence offered in support of them. It is recognized that the researcher was a novice and that the use of person-centered interviewing techniques may not have been as polished as a seasoned qualitative researcher. My comfort level and interviewing techniques improved as the interviews progressed. Participants demonstrated trust in me and were keenly interested in the outcomes of this study. Self-reporting format and the willingness to please the researcher can place a research project at risk for response biases (Polit & Hungler, 1995).

As confirmed by others, conjoint interviewing adds both methodological strengths and weaknesses to a study (Morris, 2001, Racher, Kaufert & Havens, 2000). Conjoint interviewing provides the opportunity for combining the intimacy of an interview with the public performance of a focus group (Morris, 2001). Although this interviewing technique was fundamental to the design of this study, it presented several data collection challenges. I found it important to reinforce that contribution by each participant was equally valuable to the study and there was a need to balance questioning so that both participants remained engaged in the dialogue. Positioning of both parties in close proximity to the tape recorder was vital to effectively capture their dialogue on audiotape. Oxygen participants, tended to have lower pitched voices as a result of their respiratory condition, which made their whisper-like speech difficult to perceive on
audiotape especially if there were any extraneous noises. The most common extraneous noise was simultaneous conversation by the other participant. Transcribed data were lost to inaudible voices on tape or the difficulty of capturing the content of two voices speaking at once. This proved to be more of an issue with particular dyads. For some couples, simultaneous conversation and interrupting one another was their usual pattern of communication.

Interruptions proved to be another potential area for lost data, as questions may not have been answered as completely as possible or explanations may not have been fully extrapolated. Other interruptions such as the phone ringing or people at the door required me to be skillful at bringing the conversation back to the interrupted topic area as soon as possible. Disagreements in answers or explanations also occurred periodically during this study’s conjoint interviews. This correcting of one another was a limitation at times as it was difficult to determine what was the correct or most pertinent response to the question. On other occasions correcting and/or corroborating stories lead to mutually negotiated dialogue with more complete answers or descriptions of the experience (Morris, 2001, Racher et al., 2000).

Limitations of data collection from family groups may arise as a result of adverse dynamics of the group process. On occasion discussions arose that were more related to side issues or the relationship of group members rather than the issues surrounding the experience of oxygen technology. When these diversions occurred I tactfully directed the participants back to the research topic.

Although conjoint interviewing provides strength to the study in expanding an understanding of living with oxygen from dyadic perspectives, conjoint interviews also have the potential to hinder credible data collection given participants need to protect one another from the truth (Racher et al. 2000). The significance of this limitation to the study findings is
unknown. Support persons were modest regarding the extent of caregiving and support they provided. It was also difficult to draw certain support persons out during the interview in an effort to obtain their rich descriptions. This poses the question did the caregivers in this study experience minimum caregiver burden or in some cases were they protecting the oxygen participant from their true feelings regarding the caregiving experience? As the majority of dyads in this study were family members and as families are one of the most closed and private of all social groups, it must be considered that certain secrets and loyalties will be deliberately hidden and thus inaccessible (Daly, 1992). A hesitancy of fully sharing their experiences may have also been a reflection of the caregiver’s relationship to the oxygen experience, in that they saw the oxygen participant as the dominant actor and therefore primary spokesperson to the illness experience (Morris, 2001). It is unknown if separate interviews would have revealed differing support person perspectives.

Another limitation was that only urban long-term oxygen users were examined in this study. The assistive and restraining factors affecting life on long-term oxygen for rural dwellers may be significantly different. The exploration of the experience for rural oxygen users would have broadened the perspectives and scope of this study.

Summary

In this chapter, I described the appropriateness of qualitative inquiry in understanding the phenomenon of interest and further outlined how person-centered interviewing and observation was implemented in this study. Inclusion criteria and strategies for acquiring the sample of fifteen long-term oxygen participants and their family/support persons (n = 15) were delineated. Data collection methods included a short demographic questionnaire, audio taped person-centered interviewing, and observations recorded in accordance with a field note guide. An in-
depth description of strategies and techniques used to ensure trustworthiness of the research process was outlined along with data analysis procedures, discussion of ethical considerations and strategies implemented to protect participants’ confidentiality and personal well-being. The chapter concluded with a discussion of the limitations encountered in using the chosen methodology.
CHAPTER FOUR

FINDINGS

Introduction

In this chapter, I present the qualitative findings of this study investigating individual and family perspectives of living on long term oxygen technology in the home. The first section of the chapter addresses characteristics and demographics of the sample. Findings include the experience of living with in-home oxygen and factors that impact on the participant’s quality of life, areas of uncertainty, family/support persons’ quality of life and the nature of relationships with community and health care providers.

Description of the Sample

Older adults (>55) utilizing long term in-home oxygen for more than 15 hours a day were recruited for the study. This was accomplished through the assistance of the Home Care Case Coordinators as previously described. Following a verbal telephone agreement to engage in the study, participants identified to the researcher family members or support persons they felt provided them with the most ongoing support. Interview dates were set in conjunction with the availability of the support person. A summary of the characteristic of the study participants may be found in Table 1.

A total of fifteen oxygen users, nine male and six female consented to participate in the study. Support persons (n=15) consisted of spouses, adult children and close friends. Twelve support participants lived with the oxygen user (11 spouses, 1 son). Three oxygen participants lived independently and designated a close friend (n=2) or in one instance a daughter as primary support persons. With the exception of one support person, all of the study participants were urban dwellers. Interviews took place in the
oxygen user's place of residence and for the majority of the study participants this was their home (n=7). Other interview sites consisted of condominiums (n=2), seniors housing (n=2), and apartment blocks (n=4). The age of oxygen participants ranged from 58 years of age to early 80's with seven participants being 70 years of age or older.

Support persons ranged in age from their mid-30s to their mid-80's. Eight of the oxygen participants obtained less than a high school education, two achieved high school education, two received post-secondary education and three achieved a university degree.

Lack of sufficient financial resources was a concern of one oxygen participant, citing low interest rates as a major factor to dwindling financial security. Seven (7) oxygen participants indicated that financial resources were sufficient some or most of the time, and seven (7) participants reported that financial resources were sufficient to meet their needs all of the time.

Fourteen (14) participants qualified for the Home Oxygen Program and received their in-home equipment and supplies as a component of their Regional Health Authorities' Home Care Program. One participant had not met the Home Oxygen Program arterial blood gas criteria after several assessments and therefore used equipment purchased privately. The length of time participants had used in-home oxygen therapy ranged from nine (9) years to two (2) months (> 5 yrs. n=4, 1-5 yrs. n=8, < 1 yr. n=3).

Participants' prescribed rates of oxygen flow ranged from 4 liters per minute to 1.5 (L/m) (median = 2, L/m) Six (6) participants had prescriptions that required them to increase their oxygen flows during periods of exercise (n=4) and/or sleep (n=3). All participants used their oxygen for greater than 15 hours a day and all utilized mobility oxygen for excursions outside the home. Four (4) participants were able to mobilize outside of the
home for short periods of time without the requirement of oxygen; however, they carried
mobility oxygen in their vehicles as back up.

Self-reported respiratory diagnosis included; asthma (n=1) brochiectasis (onset
infancy n=1), alpha 1 antitrypsin deficiency (onset age 38 n=1), lung cancer and COPD
(n=1), asthma/pulmonary infiltrates with eosinophilia (onset age 18 n=1), COPD (n=3),
emphysema (n=7). Three participants had experienced exacerbations that required
mechanical ventilation. All oxygen participants lived within close proximity to hospital
care. Although not part of the short questionnaire or interview guide, fourteen of the
fifteen oxygen participants revealed a smoking history. One oxygen participant
continued to smoke.

Table 1 Demographic Characteristics of the Sample Oxygen Participants (N=15)
Support Persons (N=15) Total Sample (N=30).

<table>
<thead>
<tr>
<th>Characteristics Oxygen Participants N=15</th>
<th>Range</th>
<th>Frequency</th>
<th>Percentage</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>55-59</td>
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</tr>
<tr>
<td></td>
<td>60-69</td>
<td>6</td>
<td>40%</td>
</tr>
<tr>
<td></td>
<td>70-79</td>
<td>6</td>
<td>40%</td>
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<tr>
<td></td>
<td>80-89</td>
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<td>Gender</td>
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<td></td>
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</tr>
<tr>
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<tr>
<td></td>
<td>Widowed</td>
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<tr>
<td></td>
<td>Divorced</td>
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<tr>
<td>Employment</td>
<td>Fully Retired</td>
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<tr>
<td>Financial status</td>
<td>Not sufficient to meet needs</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td></td>
<td>Sufficient some of the time</td>
<td>1</td>
<td>6.6%</td>
</tr>
<tr>
<td></td>
<td>Sufficient most of the time</td>
<td>7</td>
<td>46.6%</td>
</tr>
<tr>
<td></td>
<td>Sufficient to meet needs all the time</td>
<td>6</td>
<td>40%</td>
</tr>
</tbody>
</table>
The themes and categories revealed during the data analysis are presented in the following figure (Figure 2). Examples from data support the development of these themes and categories and are incorporated throughout this chapter.

Figure 2. Presentation of themes and categories

I  The Disease Trajectory – Journey Toward Oxygen
   Contributing risk factors - occupational hazards
   - smoking
   Hearing the news
   Hearing the news – the support person’s view
II  Living with Oxygen – A Process of Acceptance and Adaptation
    “Its my life” – positives of oxygen
    Trials and tribulations – restraining factors
    Living with oxygen – assistive factors
    View of health
    Quality of life – “It could be better but it’s not bad”

III Beyond the Security of Home
    People looking
    Air quality
    Built environments - barriers or blessings?

IV Living with Oxygen – Effects on Family/Support Persons
    Quality of life
    Strengths of supportive relationships

V Living with Uncertainty – Planning, Control and Management
    Uncertainty of living with chronic respiratory disease – “good days bad days”
    Uncertainty of living with oxygen technology – the dread of running out

VI The Value of Professional Support and Knowledge
    Specialists and medical practitioners
    Home care nurses
    Home oxygen providers
    “How do I know what I don’t know” – importance of disease management education

In this Chapter a letter and number coding system identify verbatim quotes.

Participant type is letter coded O = oxygen participant, D = daughter, F = friend, H = husband, S = son, W = wife; dyad groups are indicated by the number directly following the participant type code; the numbers following the dyad group number indicate the specific line(s) quotes were extracted from the transcribed raw data.
Findings

The Disease Trajectory - Journey Towards Oxygen

The journey toward long-term oxygen as an end stage treatment option is a long and arduous road. Often times, the onset of symptoms of chronic respiratory disease originated decades before and, in some cases, as far back as childhood (n=3).

He [physician] told me about the hanging over the bed and trying to cough stuff up [at age 12]. Have somebody pat my back and so on. But I was such ah it embarrassed me and I wouldn’t do it most of the time. So ah as I went along of course it got worse (O2, 17-20).

I got well, the first case, I got pneumonia at 18. And then every year I got pneumonia at least twice a year. Then I started getting pneumonia that was caused by an allergy to animals and you call it PIE, pulmonary infiltrates with eosinophilia...I didn’t always go to the hospital, I would refuse because I had young children at home. But I’d get pneumonia at least spring and fall, sometimes in the middle of the winter (O12, 17-21, 338-341).

I guess it would be about 85 [1985] I just started getting short of breath. I went to the doctor and he said you got the beginnings of emphysema and you can take these puffers and go home and quit smoking today, or next week you might not have to (O3, 7-10).

For some, the illness trajectory toward oxygen was a shorter duration. The need for oxygen increased insidiously and then erupting as a life-threatening event requiring immediate intensive care and weeks of monitoring and rehabilitation. The ability to return home from such a traumatic insult when “your lungs are wrecked” was precarious for these participants. Sometimes the remaining treatment option, in-home oxygen, was the only answer.

I had been having, been experiencing things that I didn’t realize were due to oxygen deprivation. I had trouble walking and I had very short fainting spells at the table, like one second duration. Enough to drop a cup of coffee...One day there was a home care worker over and was supposed to be helping me with things like having a bath and getting dressed and I keeled over. So I was taken to
the hospital. Later a nurse told me they almost lost me, but almost doesn’t count (O15, 156-164).

Spouse: He was having a hard time staying awake. He was hallucinating quite a bit, falling out of his chair. And I was out at the beach this last time and my daughter came over at 3 o’clock in the morning and found him sitting with the lid down on the toilet seat, passed out unconscious, so they called 911. And they had to put the what is it called? [pause] Trach right in the driveway (W31, 13-24).

I think this is the biggest scare a person on oxygen has, if you have lost it like I did…three weeks they had me on the machine (ventilator). You know that was the limit they had to take me off it… any longer I would have been dependent on it for life (O6, 839-843).

**Contributing Risk Factors – Occupational Hazards**

During their personal review of their respiratory disease trajectory, participants hypothesized about the possible causes of their disease. Some of their theorizing stemmed back to high risk occupations, which included firefighting, mining, farming, exposure to chemicals and furrier work.

I was in the fire department for 17 years and the oxygen masks for the breathing apparatus masks that they had in those days weren’t up to snuff. And of course they wouldn’t spend the money to get the proper ones and as a result we didn’t bother wearing them and you would spit smoke for 2 days afterwards (O9, 28-34).

I did ride a lot of tractors which probably didn’t help my lungs and of course we didn’t have any cabs on the tractors to do the farming. We’d come in, a there was dust on your face, your eyes and your teeth would be white the rest was dust (O12, 529-532).

Lack of knowledge regarding chemicals, proper masks and breathing apparatuses were felt to be contributing factors to the severity of their disease state.

**Contributing Risk Factors – Smoking**

All but one oxygen participant revealed a history of smoking. For many of them, their addiction began in their teenage years as they described 30, 40 and 50 year smoking
histories. Although implied in their descriptions, one participant articulated a very clear relationship between his smoking and his disease.

50 cigarettes a day. So I earned my emphysema didn’t I? (O15, 115-116).

Smoking was socially acceptable in those days and for those who served in the military smoking was fostered.

In the air force in 1941...the sergeant. I was in the kitchen and he said all those that smoke can sit down and have a cup of coffee and a cigarette. The rest can go clean shelves. So we all decided we were going to smoke. So we’d light a cigarette to puff when he was looking (O12, 521-526).

I started smoking at 16 or 17 like kids do...And then came the war and I went overseas and my high school and my family and my friends were sending me cartons of cigarettes. They were available to them for shipment to soldiers at a dollar a carton. I couldn’t possibly smoke them all but I started selling them. Anyway so I started smoking and I don’t want to be dramatic about it but there are moments of tension during the war when you feel like smoking (O15, 98-107).

After lengthy smoking histories, quitting smoking was a very difficult process and was often precipitated when distressing symptoms could no longer be ignored.

I was short of breath for a few years and ah was a heavy smoker 2 pack a day smoker. And then I just decided to, my shortness of breath was getting worse so I quit (O8, 7-9).

Interviewer: How did you quit smoking?
Oxygen participant: With difficulty. I smoked for 35 years. In 82 [1982] they diagnosed emphysema and I quit in 92, ten years ago. What finally did it was the patch. And by then I was so determined that I was not going to smoke anymore because I was really really my breathing, lots of coughing...(O14, 582-586).

For others, the reality of being prescribed long-term oxygen was the impetus for quitting.

As soon as they told me what I had and what I needed the cigarettes went out the window [laughing]. No more...Not patches not nothing. I said take these things it’s gone far enough. No more of these darn things. Cold turkey, forget it (O7, 139-150).
Daughter: But the oxygen. She quit and she quit cold turkey. She had no other choice because she was afraid of getting burned and whatever with her oxygen (D4, 787-789).

Methods to quit were attempted and many of these methods failed. For some, as previously described, the “cold turkey” approach proved to be the only effective method. Others quit using the “patch” (n=3) and acupuncture (1 participant with spouse). One individual developed his own cessation method, aversion therapy.

I had my own system, butt a cigarette and light it again. Do that about 5 times, tastes like poison. You give it up in no time (O11, 426-428).

Despite the volumes of research that supports the perils of smoking, the lived experience of an incurable chronic disease proved to be the most valuable lesson for oxygen participants. Realizing they were powerless to change their own smoking history and disease trajectory they expressed few regrets for themselves. They did, however, frequently express wishes and hopes for the future of others. Hopes for those they cared about and loved.

I hope [my grandchildren never start] and my kids quit. I hope. Cause I tell them now like I don’t know if I die, I don’t know who I am going to leave my oxygen machine to, cause I only got one machine but I got three kids that smoke (O8, 704-707).

In addition, concerns were expressed for smokers they did not know.

We didn’t know back in those days that it was dangerous. When I see young people smoking now. I mean I don’t preach to them, advice from me would be unwelcome. You can’t tell them anything. So I keep my mouth shut and bleed for them (O15, 116-119).

Hearing the News

Lengthy respiratory disease trajectories, abetted by occupational and lifestyle risk factors, journeyed participants to long-term oxygen as their last available treatment
option. Hearing the news of the need for long-term oxygen was a life-altering event for the participants. Although considered medication therapy, the prescribing of long-term oxygen had a much deeper and more profound effect on recipients than the ordering of steroids or bronchodilator treatment. The constant presence of equipment, the physical discomforts and side effects of being with or without oxygen and the restrictions oxygen imposes is an ever-present reminder that this is not only for life “it is my life”.

The majority of oxygen participants received their news of oxygen as a life-long treatment modality during a hospitalization. Four of the fifteen oxygen participants learned about their requirement for oxygen during a clinic visit following outpatient testing. Of these four, one did not meet the criteria for the Home Oxygen Program even though his sensations of shortness of breath debilitated him to the extent that walking across the street was challenging. His journey with long-term oxygen began at his own request for portable oxygen to supplement his breathing on an “as needed” basis.

And he [physician] was very reluctant to even give me that. And I got strict instructions once I closed the door and got over there [to his workshop] I was to take it off...I had to get down on my knees and beg for it (O9, 83-87, 112).

He now uses oxygen almost continuously but since he does not meet the requirement for Home Oxygen Program he uses an oxygen concentrator that he purchased privately and portable cylinders for backup supply. Just as his experience was unique for him so were the experiences, emotions and responses of the remaining fourteen oxygen participants.

Their broad spectrum of reactions and emotions ranged from:

Relief; “I was kind of happy about it” (O7, 161) “I knew it. I knew it. I had to have support” (O14, 62-63).

Acceptance; “If I have to have it. I have to have it” (O1, 95) “I accepted it because I knew it was going to happen eventually” (O6, 208-209)
Misgivings; “Kind of crummy” (O2, 50). “I wasn’t happy and I know, without it I would perish” (O15, 52-53).

Denial; “I just couldn’t visualize myself being on the damn thing” (O5, 97). “Well, I can’t be on it at work” (O3, 32) “Your not putting me on oxygen!” (O8, 113). “I just didn’t want to be handicapped. Carrying around all this garbage” (O11, 117-118).

Anger; “Mad. Sad everything at once” (O4, 127) “Mad. Furious. I said, I’m not going home on oxygen!” (O12, 60-61).

For some the news of home oxygen therapy offered a sense of relief, as oxygen at home was a positive alternative to frequent hospitalizations and relentless feelings of shortness of breath. Others accepted oxygen as another treatment modality. Their escalating symptoms created the awareness that long-term oxygen was inevitable.

Misgivings came as a result of not quite knowing what to expect or the reluctance to give in to the realities of the disease. One participant delayed the implementation of oxygen for almost a full year. Not wanting to give in to the disability of his disease and the stigma associated with joining the cultural group of oxygen users, he defied symptoms and his physician’s recommendation. Denial and anger are common emotions to those confronting a loss. Facing a life on long-term oxygen, participants grieved for present and future losses. The loss of meaningful work, loss of freedom, loss of independence, loss of retirement dreams, loss of not seeing their grandchildren grow up, the loss of ordinary things like yard care, baking and just generally the loss of the life they once knew. Losses of their own and losses shared with family/support persons.

He [physician] said I should be on it [oxygen] 24 hours a day. I was still working and ah so I said, ‘I can’t be on it at work. How am I going to carry an oxygen cylinder up a ladder.’ He said, ‘well you can’t go up a ladder you’ll fall off. You’ll be, your oxygen level will drop and you’ll fall off the ladder.’ (O3, 32-35).
Like being independent. I never used to ask for her [daughter] to come and pay the bills here and there. I would go walk...Get on the bus pay everything. Get my groceries and have them delivered. I never asked her to come (O4, 689-704).

A lot of it [anger at being on oxygen] was because John [husband pseudonym] was going to retire and just kind of, once I was diagnosed it just kind of here we are. We couldn’t do the things we had planned on doing. And I feel that I’m still angry and I’m sure he is too but he won’t say (O8, 229-232).

**Hearing the News – The Support Person’s View**

The emotional impact support persons expressed contained less intensity and range than those of the oxygen participants. Feelings about long-term oxygen varied between relief and acceptance.

Several support person participants’ relayed expressions of relief.

Friend: I was relieved because the times that I had been ah to see her prior to that and the number of times she had been in [hospital] before that ah her color was really bad. She was gasping so much for air and it scared me (F12, 75-78).

Spouse: Well I, I was all for the oxygen because as she said if she went down to the basement she would take a long time getting back up. And I knew that the oxygen would certainly improve her quality of life [she] would be much better with it (H8, 176-179).

Daughter: Actually for me it was a relief. Because I thought now we can maybe keep her at home rather than back and forth to the hospital. Because that’s what I was seeing was when we got to the hospital they just put her on oxygen. And until she felt better and then she would come home again. They really weren’t doing anything different for her, so that’s is why I suggested the Oxygen Home Program (D4, 200-204).

Witnessing their loved ones’ daily battle with the compromising effects of the disease was difficult. For these support persons, in-home oxygen therapy was seen as an important and necessary relief measure to counteract fatigue, chronic shortness of breath, anoxia and the revolving door of repeated hospitalizations.
Acceptance of the necessity of oxygen was also a prevalent initial feeling expressed by support persons during the interviews.

Friend: It didn’t bother me, well I was a nurse so I accepted it because I knew he had emphysema (F6, 266-267).

Spouse: No problem. I just said, ‘you got to have oxygen so we’ll do it’ (H2, 78-79).

Spouse: I ah thought it must be the best thing for him. I mean he had been in the hospital about 10 weeks at that time. And he certainly needs to be on oxygen, I can see that (W15, 1015-1017).

Although one support person participant expressed feelings of surprise at first, she also knew “it was going to happen sooner or later”. Taking the oxygen “in stride” and “learning to live by it” were necessary adjustments support persons were willing to make as they accepted the role of in-home oxygen in assisting with disease management and their loved one’s ability to live at home.

Living With Oxygen - A Process of Acceptance and Adaptation

Hearing the news launched participants into the cultural world of oxygen, which contained its own set of customs, rituals, language, artifacts and knowledge. They had to develop an acceptance of this new way of being. Acceptance was not simply the next stop in their learning journey with oxygen but accumulated by degrees along the way. The oxygen experience required ongoing acceptance as they encountered positive and negative changes, faced emotional hills and valleys, dealt with oxygen technology and managed the “good days and bad days” of their disease. As participants journeyed into the cultural world of oxygen the process of acceptance was interwoven with a parallel and complementary process of adaptation. As limitations and challenges presented, participants adapted and created new “normal” ways of being in the world.
Initial acceptance to a life with oxygen was reached through the realization that although oxygen created many trials and limitations, it provided beneficial symptom relief and was necessary for any hope of improved quality of life.

I made up my mind that I have to be on oxygen for the rest of my life and that’s all there is to it. I’m not fighting against it. What’s the use (O7, 244-246).

Well I think that you have to accept it. You have to accept your limitations and adjust to them. Once you get that in your mind it’s not so stressful (O14, 1385-1387).

I think you learn to live with the oxygen and learn to do, you know. This is this is me, my oxygen is me for the rest of my life. So therefore you can like it or lump it ehe. And I like to out with [husband]. I like to do things. I like to go out and putter in the garden or sit outside and watch him...But at first when I was diagnosed I think that was a lot of the anger too I just kind of ‘what kind of life is this?’ Can’t breathe. I can’t walk across the floor. But once I got on puffers and oxygen and certainly your whole outlook on life changes...And like I have told you the oxygen is me now for the rest of my life (O8, 864-875).

Acceptance for oxygen participants was a process that developed over time and in conjunction with adaptations to new ways of living their lives. Acceptance by support persons, although a process, was more immediate and in response to the objective improvements they witnessed in the oxygen users as a result of long-term oxygen therapy.

Two fairly new in-home oxygen recipients (< 3 months) had not yet reached initial acceptance of oxygen. This may be attributed to the fact that neither had experienced tangible physical benefits from their oxygen therapy and both continued to hope that home oxygen would soon be discontinued.

I really haven’t tried any length of time without it [oxygen] since. I feel I don’t need it but uh. Spouse: Your blood gas says you do. Participant: Well we’ll find out in the next day or two [follow up blood gas scheduled for that week]. (O31, 1047-1054).
Well I think it is the most horrendous experience that I have ever gone through. Everybody says it is doing me good. Okay it is doing me good, that’s why I keep on with it. At the same time I absolutely simple abhor it. Cause I feel like my life is over and it’s not going to get any better. And I I’m not ready to quit and yet it is making me. I haven’t got anything good to say about it. Except they say that it is doing me good. That’s the only good thing I can say everybody says it is doing me good. For myself I don’t feel any different now than I did before (O12, 1765-1774).

For these participants, the negative aspects of being on oxygen outweighed any positive effects and they held out on acceptance in the hope that oxygen would not be a life-long treatment. Adaptation strategies had not been fully developed as they may not be required if oxygen therapy were to be discontinued in the near future.

"Its My Life" - Positives of Oxygen

The positive effects, experienced by participants and witnessed by their support persons, promoted acceptance of oxygen and adaptation to the ongoing challenges oxygen presents. In-home oxygen was accepted as the “lesser of two evils” when taking into consideration the less undesirable options of institutionalization or death. Although bitter sweet, oxygen provided the breath of life into aging bodies suffering from years of debilitating respiratory disease. Enhanced ability to breathe was one of the most important gifts oxygen brought to the participants’ lives.

Well I think once I was on the oxygen I found such a difference in things I could do. My quality of life absolutely changed when I was on oxygen. There was things I could do now that if I wasn’t on oxygen I couldn’t do (O8, 125-128).

Oh there is a definite asset with having oxygen. Well I couldn’t do without it...Life was easier, you’re not sitting there huffing and puffing trying to get enough air, because the ah concentration that I’m breathing, with the oxygen, is a lot greater, richer than the air in the atmosphere. So it is definitely an advantage to me (O9, 160-174).
Reduced energy requirements for breathing provided strength to resume some of the activities they had found difficult prior to the addition of oxygen. One participant was able to resume her love of tap dancing and performed on stage with portable oxygen by her side as evidenced by a photograph of this accomplishment [field observation]. Not to be grounded by the requirement for continuous oxygen, one participant took flying lessons, obtained a private pilots license, and flew with her husband to international destinations. In addition to reduced feelings of shortness of breath and enhanced energy, other improvements identified by participants were improved “color’, being “less tired” and generally “more comfortable and at ease with self”.

Participants also spoke of the “life” giving qualities of oxygen. They identified that if it was not for the benefits of oxygen they might not be alive today and/or they might not had the ability to live at home. Thus, oxygen was life sustaining.

If I didn’t have it I would be dead (O6, 920).

Well it’s my life. Oxygen is my life. No oxygen, I wouldn’t be living (O7, 1212-1213).

Oh yes I feel a lot better on oxygen. I certainly do. I ah it has really put me, put my well it has given me life it’s as simple as that simple as that. If it weren’t for the oxygen I wouldn’t be here today. And I know that for sure (O5, 598-601).

Oxygen also allowed them to be at home as opposed to the alternative of living in an institution.

Going into a personal care home your finished. Say well my life is over (O7, 1290-1291).

I don’t think I could survive in an institution. I don’t, cause I am too independent (O12, 1466-1467).

Yes it is well worth it and I am glad of it. No that’s um anything is better than spending my years in Deer Lodge hospital, any time in Deer lodge hospital
listening to other war veterans bull shit. Conversely it does give me independence. It is a two-edge sword (O15, 674-676).

Oxygen held a place of importance in the lives oxygen participants. Oxygen reduced symptoms, enhanced well being and allowed them to live more comfortably at home.

Despite challenges, limitations and discomforts it was deemed “essential” for their existence.

Conversely, one oxygen participant could not think of anything positive attributes of his oxygen treatment even though his wife reminded him that he was “alive”. To which he replied,

Well I know that but I was alive before I was on oxygen. I can’t say this is a positive thing (O31, 899-900).

The lack of identifiable benefits from the oxygen made its presence more difficult to accept. His wife felt that oxygen was beneficial for the fact that it had kept him out of hospital and mechanically ventilated. Support persons reported other observed improvements in oxygen participants, such as less purplish skin tone, increased energy and reduced anxiety.

Spouse: I think it has made him more relaxed, you know what I mean. He knows that he can fall back on the oxygen when he needs it (W11, 674-675).

Spouse: Even I can tell just in his face. At one time there you didn’t know what was going to happen you know. Because he looked poorly before he had it [oxygen]. But he’s looking really good so. I’d say his health and of course that improved my health too. I don’t have to worry as much (W14, 658-662).

For support persons the justification for oxygen was demonstrated by the positive improvements they saw in their loved one’s health and state of mind. This enhanced well being had a reciprocal positive effect on the care providers by reducing their burden of worry.
Trials and Tribulations – Restraining Factors

On a leash.

Living on oxygen was a restrictive experience. Drawing oxygen from the oxygen concentrator gives the individual the sense of always being tied to the equipment. They referred to the connecting tubing as a “string” “tail”, “leash”, or “chain” hanging on them. The length of tubing attached to equipment signified the maximum distance they could travel in the home.

Well I don’t think it [oxygen] brought anything [to my life], except having a tail all the time...always being attached to something (O1, 587-600).

It bugs me to no end, running around here on a leash like a house broken puppy, or a wild colt or something. I don’t like it (O12, 500-502).

Like a dog on a leash, you can only go so far. That’s how you feel because you can’t; you can’t go any further on a tube. You can’t and ah, you know what I mean, from the concentrator (O4, 3-8).

In order to defy the restrictive perimeter of their connecting tubing, participants described creative strategies they engaged in to lengthen the “leash”. Threading tubing out windows, down stairwells and through doorways allowed them to exercise in their yards, plant gardens and/or putter around in garages without disconnecting themselves from their in-home concentrators.

In fact my neighbors think this is just so funny. I hook another thing up [connecting tube] and have this thing tailing behind me and I go out in the summer and in the flowerbeds (O8, 1507-1509).

These creative adaptations lengthened the parameters of their “leash”.

The restrictive nature of living on oxygen and the need to always take portable oxygen with them created a reluctance for some participant to venture away from the convenience and security of home.
It is restricted. I just don’t go about too much and can sit here, I can be in here for 10 days before I go out. I’ve got to go out because I am getting bushed [laughs] (O6, 425-427).

Well the thing that I hate about the oxygen that I can’t go out on my own. Yeah that’s the biggest problem there is. See if I didn’t have that I could just open the door and go walking in the hall with my buggy [walker] or go outside. I can’t with that oxygen (O7, 962-966).

Well like I have the oxygen going day and night and that so. But you know, I often think of being able to step outside and go to the neighbors and I can’t go, without the oxygen...You got to think about it. You don’t have ah, how can I put it, just up and walk out of the house and your out. You got to plan ahead I found that out (O4, 27-39).

The freedom to just walk out of the house unfettered and go to the neighbor’s or to the corner store is gone forever.

One participant found undue restrictions were placed on her because of the perceptions of others regarding her capabilities given that she was now on oxygen. Out of concern, friends and family “cut the last thread” of her independence by eroding her hard fought for and difficult to maintain independence.

My life changed so fast, cause I was totally unprepared for it and it knocked me for quite a loop. And then when I got home my sister said now that I am on oxygen and won’t be getting out of my suite. She’s going to have to do all my shopping for me. That really knocked me for a loop (O12, 1827-1832).

This well-meaning relative planned to look after things for her now that she was on oxygen.

I think she thought she was picking me up instead she was plunking me right down to the bottom cause she had a different perception of two different people (O12, 1859-1862).

This individual was distressed with misplaced support in her life as the occupants in her senior’s block told her to “stop it, sit down, don’t do anything” when she attempted to resume her normal activities. Adding insult to injury, she was arbitrarily relinquished of
her previous responsibilities that included ordering supplies and keeping the books for the
apartment block’s common kitchen area.

I mean they are not helping me get back to my normal life. They are prohibiting
me from doing just exactly that….Like the kitchen, I had books, I had the cash
and I had all the receipts and she took them. They asked me how I did it and she
says you can’t do that anymore and she walked away with them. Well that kind
of put me down (O12, 1063-1073).

The restrictions of oxygen were compounded by the well-meaning comments and actions
of others based on their misconceptions of her dis-ability as it related to oxygen.

Every day reminders – discomforts.

Most of the home participants placed their oxygen concentrator in a central
location in their home. This placement permitted sufficient connecting tubing length
from the machine to the cannula they wore and enabled them to move fairly unrestricted
around their home. To ensure the correct liter flow at the cannula, the maximum
recommended length of the connecting tubing is fifty feet. Connecting tubing comes in 7
and 25 foot lengths and plastic connectors are used to join one length of tubing to the
other. As they move around their home environment, the clear coiled tubing trails behind
them like a silent shadow [field observations]. The cannula consists of nasal prongs that
fit in the nose and the tubing lays across the face over their ears. This tubing is joined
together under the chin lariat style with a plastic ring that tightens or loosens the cannula
tubing according to the size and comfort of the individual.

In addition, oxygen is a dry gas. The constant flow of oxygen into the users’
ostrils combined with the presence of plastic tubing against their nares and over their
ears causes irritation to the soft tissue of these areas.
I am always conscious of the mechanism. I get sores on the side of my nose, there are physical discomforts involved...And this is minor pain, but I have two small lesions caused by this [lifting his oxygen tubing away from his face] on each side of the nostrils. You see I am wearing pads [padding around the tubing resting on his ears] because of the abrasive quality of the [tubing] (O15, 85-87, 325-329).

Oxygen participants attributed irritating symptoms of “nasal dryness”, uncomfortable “sores”, “noses bleeds”, “nasal blockages” and the “loss of the sense of smell” to the irritation of the plastic and the constant flow of oxygen. Although they had tried various types of treatment preparations, few found measurable relief. One participant applied an estrogen cream, as ordered by a specialist, and another utilized a topical antibiotic, both participants found these preparations to be effective in healing their nasal lesions.

Stepping on or tripping over the connecting tubing was also a source of irritation for the soft tissue around the ears, in nostrils, and to the soles of their feet.

You have no idea how many times I have stepped on this thing [tubing] and yanked it out of my nose (O31, 232-234). Wife: Those connectors are hell on our feet. I’ll tell you [both laughing] (W31, 252-253).

As they went about their daily activities, their tubing would get tangled around wheels of walkers, under furniture, in bed linens and anything else that got in its way. This coiling and tangling of tubing has the potential to be a safety concern for both the individual on oxygen and the support persons with whom they live, especially if their health status is further compromised by other chronic conditions such as osteoporosis.

I have fallen so many times over that silly tubing (O12, 922-923).
Interviewer: You have actually fallen?
Yeah, flat on my face. I get tangled up in it [pause]. It was worse before... he [home oxygen technician] put a swivel on (O12, 927-934).

Placing a special swivel like plastic connector between lengths of tubing helps to prevent tangling and was a strategy several participants used to guard against potential injury.
As respiratory effort diminishes and breathing rates slow during the night, it is important that oxygen users have continuous administration during the night. Morning headaches and the fact that some use increased liter flow rates for sleeping supported this need for continuous night-time oxygen flow. Given the slippery nature of the tubing and cannula and natural body movements or “restlessness” during sleep, participants often found their cannula lying on the floor or in the bed beside them upon waking. For some, the lack of supplemental oxygen for a period of time was not problematic. Others described waking up with feelings of shortness of breath or “gasping for air”. Still others experienced varying degrees of “headache” with one individual describing their headaches as “splitting”. One participant felt she has a subconscious awareness that her oxygen was off and she would wake up to that discovery.

I don’t know whether it is just in the back of my mind to wake me up if this thing comes off my face or what it is. But I’ll wake up if it comes off (O8, 1098-110).

Her husband, conscious of the importance of oxygen for his wife, incorporated surveillance as part of his care taking role and described how he periodically checked her at night to ensure her cannula was securely in place.

I’d feel her ear and then follow it [the tubing] down to her nose and then. It might be up here [pointing to the forehead] or something. I would have to wake her up (H8, 1086-1089).

Other sensory irritations.

The oxygen concentrator is an electrical device that draws in room air and passes this air through a combination of dust and bacteria filters. The air is then delivered to molecular sieve beds where the oxygen is separated out from other gases. This oxygen is stored for use and the other gases, namely carbon dioxide and nitrogen, are trapped and
purged from the machine (AARC Times, 1998). As the oxygen concentrator operates it generates heat, its motor hums, and the separating and purging processes create an assortment of noises with varying intensities and the sounds become an aspect of home milieu [field observations]. One couple described the sound of the concentrator as “comforting” but also expressed a concern about the heat it generates.

You would think it would bother us. Mona [wife pseudonym] likes it and it doesn’t bother me at all. We did have it against that wall in the dining room. But it generates a fearful heat and I dread this summer (O15, 543-546).

For others, the noise of the concentrator was bothersome and sound of it required a period of adjustment. One partner commented that it took her over three months “to get use to the noise of the machine.” The level of noise of the oxygen concentrator generates was thought to be related to the need for servicing and participants commented that newer machines were much quieter than older models.

Hills and valleys.

Living every day with oxygen is not without its share of emotional “hills and valleys”. When questioned whether living on oxygen ever got them down, there was a general feeling that at times it did and perhaps more frequently early in its use. This finding also supports acceptance and adaptation as a process.

Well I mean I wish I wasn’t [on oxygen] but I am. I have faced up to that quite a long time ago. So I don’t really get myself down about it (O2, 277-278).

In general these feelings were short lived, curtailed with coping strategies such as a “good cry” calling family, keeping busy and focusing on positive thoughts.

Well I don’t let it get me down. No I don’t, I think about it getting me down no. I think positive. I think positive I ah never take it back I think about the good points, the good points. I’ve never thought of the negative parts. I don’t ever let
them get me down...I’ll do something to ah bring myself, bring my way of thinking up (O5, 613-620).

I have lived my life positively why should I change. You have to adjust to your systems and go ahead (O6, 942-944).

Yes there’s hills and valleys. You try to stay on top of the hill you know. And things happen and you think why that, and then you think it could be worse. If it wasn’t for the bad times we wouldn’t appreciate the good times. Positive attitude (O14, 1262-1265).

Adjusting to changing circumstances and maintaining a positive attitude assisted oxygen participants to stay on “top of the hill” emotionally.

**Equipment – a home invasion.**

One participant expressed his discontent with how the oxygen equipment and mobility paraphernalia had overtaken his tastefully decorated home. Upon completion of the interview he toured me to his den, which he described as at one time being “an attractive room”. His partner of 45 years had earlier excused herself from the interview and was quietly positioned on a love seat surrounded by curios and artwork they had collected together on their numerous trips around the world. Cherished literature and music were also evident. This tranquil room, filled with culture and fond memories of days gone by in contrast generated a sense of invasion. Occupying a good portion of the remainder of the space was myriad medical equipment; wheelchair, walker, mobility oxygen cylinders and large white backup oxygen tanks. The presence of this equipment, however, was vital to this participant’s ability to live at home. It suggested a cluttered hospital supply room rather than a place of aesthetic pleasure and contentment [field observations].
Although only one participant referred to the invasion of oxygen technology and medical equipment as an affront the atmosphere of the home, the presence of equipment occupation was noted to varying degrees in each of the participant’s homes. Oxygen related language “gauges”, “bottles” “cylinders” “conserver” “concentrator” and equipment paraphernalia were components of their sociocultural milieu. The hum and swoosh of the concentrator as it pushed out life-giving oxygen was a constant and audible presence. Ghostly white five foot high back-up oxygen cylinders armed for emergencies wait their calling, safely tucked away in hall or bedroom closets. Like mini-sentries, portable cylinders stood in readiness wherever they were needed at the front door, the back door, on a motorized scooter, in the garage and vehicles. Ready to mobilize on a moment’s notice, these cylinders assisted their owners to venture from the sanctity of home into the uncertainty of the outside world [field observation].

**Time in a bottle.**

Mobility oxygen was an important quality of life enhancer for oxygen users. So near and dear is portable oxygen that two participants called their mobility cylinders “my buddy”. Without their portable companions they would be restricted to home or institution. With the assistance of portable oxygen technology, individuals were able to continue many of the outside of home activities they had enjoyed previously.

We still drive up there to Edmonton to see our son. We still, we still do pretty well what ever we want to do. I just take all the oxygen things with me and go (O2, 155-157).

Oxygen is considered a medication under the Manitoba Pharmacare program and the cost of purchase is 100% claimable once a person has met their yearly Pharmacare deductible. Oxygen must be purchased from a supplier and receipts are then sent into
Pharmacare for processing and reimbursement. An E-sized cylinder of oxygen, which provides a 3 L/m user with less than four (4) hours of oxygen time, ranges in price from $22.00 to $26.00. The initial financial outlay can be prohibitive to those living on a limited fixed monthly income. Another restrictive feature of portable oxygen is the set amount of oxygen a cylinder will hold. Based on an individual’s prescribed rate of oxygen flow and the capacity of the cylinder used, the amount of available portable oxygen is measured by oxygen participants as time in a bottle.

Oh boy no. They [portable oxygen] don’t last very long, about 3 hours (O7, 203-204).

If I’m just going to be a little while I just take the one on my shoulder. Its going to be longer I take my bigger one, because its got a lot more oxygen in it. So that I don’t run out of oxygen before I’m finished (O2, 563-565).

Three and a half hours and then I carry a spare tank in the van all the time. I’ve got a wrench in there and the whole works (O9, 445-447).

To avoid running out of oxygen, a great deal of planning and preparation was engaged in prior to each outing and wherever possible a second tank was taken along for backup.

Early like in the morning instead of getting dressed for around the house I get dressed as if I am going out. And I don’t have to do it again, to conserve energy. And ah and then of course the day before I make sure my [portable] oxygen is ready. It’s full or half full what ever…If it is getting pretty low I’ll get my daughter to take and extra tank say one that’s almost empty just in case I need it (O4, 1212-1216, 1225-126).

Constant planning and the limitations of time in a bottle placed restrictions on social outings.

You would think 2½ hours would be enough. But don’t forget, turning the oxygen on here [at home] after putting my coat on going outside like we have to used the rear exit because there is not a [wheelchair] ramp in the front. And walk around the block and wait for the cab or my friends. By that time I could have used up 20 minutes worth of oxygen. So you get to the restaurant, if you have a drink that consumes more time. I don’t usually; I will have a glass of wine with
my meal. I don’t know, somehow you eat and you look at your watch and have half and hour left (O15, 373-382).

Planning ahead, the necessity of taking portable oxygen along, and the time restrictions based on cylinder capacity compromises pleasurable activities and places further limitations on what is an already restricted lifestyle.

**Living with Oxygen - Assistive Factors**

**Informal caregiver support.**

Thirteen of the support person caregivers in this study were family members and two were close friends. These individuals were behind the scenes supporters of oxygen participants speaking modestly about their caregiving roles and responsibilities. The extent of caregiving varied based on the physical endurance of the oxygen participant and the degree of home care and/or privately paid services that oxygen participants had in place. Wherever possible, oxygen participants and their support persons engaged in role sharing to promote independence of the oxygen person and reduce caregiving responsibilities of the support person. In sharing physically demanding tasks, support persons supplied the physical labor and the oxygen participant engaged in less taxing aspects of the activity and/or provided supervisory support.

Spouse: She does the washing [laundry] and then when it is done, then I bring it up [from basement] and she does the folding (H8, 989-990).

Spouse: He’d supervise and tell me how to do things. Like I can never remember how far corn is supposed to go apart. How many seeds are supposed to go in and things like that (W3, 1384-1386).

Food preparation was the activity study participants most frequently described as being a shared pursuit. Oxygen participants engaged in tasks, for which they could take their “time at” such as baking or “peeling potatoes.” Meal preparation also proved to be
something support persons and oxygen participants worked together at quite comfortably as a team, aware of one another’s capabilities and limitations.

When asked to estimate the amount of time they spent on caregiving, support persons found this question difficult to quantify, as care they provided was not something they thought very much about.

Spouse: I wouldn’t put it to hours yet. He’s pretty very self sufficient (W3, 1414).

Friend: It’s not even, it’s not even ah anything that you think about doing. Like I don’t think oh golly I got to go and do this for Jack [pseudonym] today or whatever. You just do it. Its something you are going to do. If I go up shopping I’ll just phone him up and say ‘I’m going shopping do you need anything’. Or ah it’s just, it just doesn’t affect me anything really (F06, 975-981).

Daughter: Umm not [hours] per say. I try and phone her if not everyday then every other day. I know if there is something on she will phone me for sure anyway. But I try to phone at least every day just to make sure she is doing okay and nothing is going on and ah. And then there isn’t any particular day or number of days that I do come and do things for her. If there is something that needs to be done then we make arrangements and I come and I do it (D4, 537-543).

Any new activities they assumed such as oxygen equipment care, vacuuming, gardening, running errands, grocery shopping and transportation duties were not seen as burdensome commitments, but rather natural aspects of relationships rich with a history of reciprocal giving.

Other types of caregiving encompassed three categories; monitoring, disease management care, and coaching. Monitoring activities of support persons took place in the home and while caregivers were outside the home. Caregivers periodically checked on the status of the oxygen user with the assistance of telephone or cell phone. One support person lived in a suite below the oxygen participant. Her monitoring strategies included listening for movements and/or the sound of the television from above. If she
had not heard noises for a period of time she would phone to check on him. This monitoring was reciprocal in nature as the oxygen participant also listened and watched for her as a give and take component of their supportive friendship. Support persons who lived with the oxygen participant incorporated watching and listening strategies into their daily activities. Monitoring included coordinating activities so that caregivers were home when oxygen participants were doing strenuous activities, such as showering. If oxygen users went out in the yard or garden they would listen and/or “keep an eye on him (or her)” out the window. Regulation of the oxygen flow was a monitoring task one spouse took very seriously. This support person spoke of how difficult it was for him and his wife to remember to turn up her liter flow (as prescribed) when she engaged in increased physical activity. He described how he would hear her working in the basement or in the bathroom about to bathe. He would then call out to her to see if she had increased her liter flow or go to the oxygen concentrator himself to verify her flow rate and increase it if necessary. Monitoring activities were put in place by caregivers as a way of preventing or responding quickly to untoward events.

Assistance with disease management was another role that support persons provided for oxygen participants. Two support persons assisted by providing regular chest physio (pummeling). During an acute episode, caregiver duties escalated as they assumed more of the household responsibilities, prepared “home made chicken soup”, and facilitated transport to medical appointments and more vigilant monitoring activities.

Another important role of support persons was that of coach. Coaching consisted of encouraging independence wherever possible, ensuring that oxygen participants got out of the house on social exertions, and the promotion of ongoing exercise.
Spouse: He has trouble putting on his shoes and socks and pants. Getting dressed is a bit of trouble. I help him sometimes. Maybe I should help him oftener. If he doesn’t ask me I don’t. (W15, 1038-1041).

Friend: I know that there are things he can’t do. But I also know there are things he should do. So that’s when I push him. Make him go and do a little more (F6, 964-967).

Spouse: Well I try to keep him walking and a little bit on the treadmill. One of the nurses at the day hospital showed him how to walk stairs and I think that would help. You know, little things like that (W9, 537-541).

The burden of chronic illness and the restrictions of oxygen requirements sometimes inhibited the oxygen participant’s willingness to engage in physical or social activities. The support person, as coach, ensured that oxygen participants engaged in meaningful and enjoyable activities and maintained independence to the greatest extent possible.

**Importance of family.**

Oxygen, personal health, pets and the ability to “wake up every morning” were cited as significant factors in the lives of oxygen participants. In addition, the importance of other family members was consistently conveyed throughout the interviews by way of story telling and pictures. Photographs of family adorned walls, buffets and fridge doors [field observations]. Oxygen participants and support persons proudly spoke of Sunday suppers, family gatherings, summer vacations and the accomplishments of sons, daughters and grandchildren both near and far. Grandchildren were especially significant, as the ability to see them grow up was a substantial motivator for persevering with life.

My health definitely ah would be intertwined with [the importance of] family. Let’s put it this way ah, is to be able to see them grow up and everything. Like my grandsons grow up and my children getting older and that (O4, 1291-1293).
If it wasn’t for him [husband] I don’t really think I would be where I am today because ah he does he encourages me on a lot of stuff I do (O8, 1366-1367).

Wife: But if I need them they’ll come. If he [oxygen recipient] is in the hospital they [children] are all there. I’ve got two sons who are really good and a daughter. She may not have a nickel in her pocket but she’ll come all the way from the States to come home to see her dad. She phones 2 or 3 times a week. Our son in Saskatchewan he phones and he is here every 2 months (W10, 1192-1198).

Wife: Doing the best I can with the help of the children. They are good; they do different things [to assist] (W11, 1064-1065).

Clearly the close bond of family was a significant assistive factor with respect to well-being, quality of life and additional support for oxygen participants and support persons alike.

Activities of enjoyment.

Carrying on with enjoyable activities was important for quality of life. As discussed previously, many activities had to be adapted or changed as a result of coping with the limitations of their disease and oxygen as treatment. In-home activities and hobbies consisted of craft making, crocheting, knitting, tatting, cross-stitch, “angel books,” woodworking, reading, internet searches and watching television. At the age of sixty-nine (69), one oxygen participant remained acutely involved in a father-son business operation. Using the benefits of the telephone, in-home fax machine, computer and internet the father remained actively involved in the family business. Another oxygen participant provided holiday relief for a storeowner.

The study participants proved that being on oxygen did not require one to be restricted to the boundaries of home. All participants engaged in some type of out of the home activity. Activities such as attending hockey and football games, shopping, craft
sales, visiting family, and traveling across Canada and the United States were some of the
activities undertaken by participants. Going to the mall provided dual benefits of being a
social activity and an amenable venue for exercise.

I go to the mall and I, you know, I start walking from one end and I walk back
again while my wife is shopping or what ever. I ah go to the food court meet up
with her there we have a coffee together (O5, 359-363).

Some participants described the shopping cart as a form of mobility device. Shopping
carts bore the weight of portable oxygen equipment and provided oxygen participants
with a means of wheeled support. Leaning forward on the shopping cart with their arms
and stopping frequently afforded them the ability to travel much further distances than if
they were walking independently.

The other day I went all over Wal-Mart and then took my stuff out and put in the
van. And then went to the other end of the mall and stopped at Safeway and went
all through Safeway and it took me three hours (O3, 350-352).

This is quite an accomplishment for a man whose exercise tolerance in the home is such
that he was unable walk from his bathroom to the kitchen without stopping to catch his
breath at least once on route [field observation].

Participants also engaged in other activities of interest. This same participant
remodeled the kitchen of his home with the help of his wife, son, and neighbor.

Oxygen Participant: I did the walls, I did the painting. I did all the electrical and
plumbing.
Spouse: But I did the things like sanding and ah wherever. It was dusty and that
he just stayed out of it. And ah I took the other tiling down where it was
dusty...But its pretty well all done.
Oxygen Participant: I put the floor down, its Purgo. Every square is glued down.
Wife: Which meant he was on his knees a lot. But he did one row a day. Just
one row and that’s that (O3 & W3, 388-404).
Accommodating the limitations of chronic disease and oxygen therapy, this project took over two years to accomplish. It was approached as a team effort that proceeded at the oxygen participant’s pace “one step at a time.” Another oxygen participant and her husband were determined that oxygen was not going to dictate their lives and keep them at home. Against the advice of physicians she learned how to fly and obtained her private pilots license.

Husband: She took up flying and became a hell of a pilot. The reason for it your lungs expand and this is what you need to do.
Oxygen Participant: I even became a pilot. I got my pilot’s license. And that was good and we flew all over everywhere down south....
Husband: If I had listened to the GPs we’d sat at home and died (O2 & H2, 62-70).

Independence and personal achievements, however great or small, are just as important to individuals living on oxygen as there are to any other human being. Engaging in activities of interest assisted participants and their family members live well within the limitations of their oxygen experience.

**Assistive devices.**

The study’s oxygen participants used a number of types of assistive devices to help them to control or adapt to the disabling effects of their disease and the limitations of oxygen. Disease management items, along with the home oxygen equipment and supplies, were artifacts of the home oxygen culture and were plainly visible in the milieu of participants’ homes. Disease management artifacts included circulating fans, air conditioners, conserving devices, nebulizers, aerochambers, vibrator/pummelers, vibrating recliner chairs, car generators and an electric bed. Also used were walkers, wheelchairs, and a scooter equipped with baskets or cylinder brackets to promote
mobility and support the weight of the portable oxygen cylinders. Bath benches facilitated energy conservation and safety during bathing. Stationary bikes and treadmills were used to enhance physical strength and endurance. Many of these assistive devices were not covered under the Home Care Program and therefore their availability to participants depended greatly on personal insurance programs and/or financial resources.

Table 2. Oxygen participants’ self-reported use of assistive devices

<table>
<thead>
<tr>
<th>Assistive Device</th>
<th>Participants using</th>
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<tbody>
<tr>
<td>Oxygen conserving device</td>
<td>8</td>
</tr>
<tr>
<td>Nebulizer</td>
<td>7</td>
</tr>
<tr>
<td>Wheelchair</td>
<td>5</td>
</tr>
<tr>
<td>Walker</td>
<td>4</td>
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<tr>
<td>Bath bench or stool</td>
<td>3</td>
</tr>
<tr>
<td>Exercise bike</td>
<td>2</td>
</tr>
<tr>
<td>Treadmill</td>
<td>2</td>
</tr>
<tr>
<td>Vibrating recliner chair</td>
<td>2</td>
</tr>
<tr>
<td>Scooter &amp; van with hydraulic lift</td>
<td>1</td>
</tr>
<tr>
<td>Electronic lift to second floor of home</td>
<td>1</td>
</tr>
<tr>
<td>Electric bed</td>
<td>1</td>
</tr>
<tr>
<td>Pummeler (hand held)</td>
<td>1</td>
</tr>
<tr>
<td>Generator – installed in vehicle</td>
<td>1</td>
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</tbody>
</table>

One oxygen participant had additional limitations placed on his life by virtue of being visually challenged. After consulting with a number of oxygen suppliers, he was able to source a special type of portable cylinder, which he called “Grab ‘N Go”.

One of the oxygen companies has a canister to open, it’s called grab and go and you don’t have to turn things. All you do is just turn it on to my consumption, 4 liters a minute (O15, 291-294).

In using the Grab ’n Go system the oxygen user does not have to change regulators from one tank to another. The Grab ’n Go system is an oxygen cylinder with a regulator and a contents gauge provided as a complete unit. The built in gauge allows the user to verify contents at a glance and the user-friendly regulator allows adjustment of oxygen flow.
with the turn of a dial. Although more expensive than conventional oxygen cylinder rental, the cost of these cylinders is covered under Manitoba Pharmacare (personal communication oxygen supplier, February, 2002).

Eight oxygen participants utilized oxygen conserving devices to assist in increasing the amount of time available from a cylinder of oxygen. A conserving device is a special regulator that operates under the principle of delivering oxygen only during inhalation whereas conventional regulators deliver oxygen continuously. There are many types of conserving devices on the market and generally the operation of these devices reduces oxygen consumption by at least one half. Oxygen conserving devices are not provided under the Home Care Program and individuals must purchase them privately or are compensated as part of a medical insurance plan.

That’s one thing John [husband pseudonym] did for me, ah he went out and got everything he could get me so that I could get outside instead of sitting in here with the concentrator (O2, 115-117).

We don’t have to drag along a whole bunch of oxygen when you go out for a few hours (O3, 920-921).

So I got that little one [cylinder in a carry bag] which I can put over my shoulder. I can carry I can carry it like a purse not a problem...That is about the only thing I can get out with (O12, 125-131).

The requirement for less oxygen means that oxygen users can carry smaller lighter weight cylinders in carry bags or backpacks. These lighter weight oxygen cylinders improve energy conservation for individuals compromised by respiratory disease and other chronic conditions. Smaller cylinders in carry bags or backpacks eliminate the need for dragging cumbersome pull carts.
Three participants and their support persons described their cell phone in a manner reflective of an assistive device. The cell phone was used as a safety feature and a constant means of communication when they were separated from one another. The safety feature of having a cell phone was portrayed by this oxygen participant’s unpleasant experience of not having a cell phone with him.

I was going to plant some onions. And get some onions. And ah I planned on going on further and cutting rhubarb. I was going, bound I was going to have rhubarb pie. And I planted the onions and I had a handful of them and I planted them all but one and the last one I threw on the ground. I couldn’t even plant it. And then I just had to stand there with my hands on my knees and probably for about 5 minutes. Cause I had to walk out about 10 feet out of the garden where I had left the walker so I had something to lean on…Normally I have the cell phone and if I am out of the house and Gay [pseudonym wife] is in the house. Usually have it so I could call for help but this time she was out when I went out so I didn’t take it and she was back in the house before I…[got back] (03, 1125-1144).

Oxygen participants and their support persons avoid unpleasant experiences, such as the one described above, whenever possible. This is done through a process of recognizing potential dangers and the adaptation of prevention strategies and assistive devices, like the cell phone, to ward off future unpleasant events or uncertainties.

**Assistive support services.**

Oxygen participants utilized a number of services that were privately paid for or covered under Veterans Affairs Canada for participants who were war veterans. These services included transportation, housekeeping, laundry, lawn and yard care, driveway and sidewalk clearing and Life Line services. One participant was able to receive assistance with heavy cleaning, at no charge, through community programming offered in her urban area. Participants who did not have independent forms of transport accessed delivery services for such things as mobility oxygen and other drug prescriptions.
Five oxygen participants were dependant on support people out side of the home or public systems for their transportation needs. Forms of public transportation used were taxi, city buses, and Handi Transit/Vital Transit. These various forms of public transportation permitted oxygen participants to attend medical appointments and social outings without having to draw on the assistance of family members or support persons.

Although convenient with respect to door-to-door service and availability, participants found taxis costly and difficult to enter and exit. Most taxis are not designed to accommodate people with disabilities. Two participants spoke of the difficulty they experienced getting in and out of taxies especially with the added necessity of oxygen paraphernalia and other assistive devices such as wheel chairs.

I feel that I could go without the wheel chair but it is easiest way to carry the oxygen. You should see the taxi drivers face when he finds he has to put it into the trunk after collapsing it. It is usually a battle. They don’t come back into the car immediately so I know he is having trouble (O15, 416-420).

The taxi is a little more difficult getting in and out of there. It’s not that easy for me. It’s not that easy for me. I find it quite quite ah quite hard. I don’t know if it is tight corners; see you can’t stretch your legs out (O5, 400-403).

This oxygen participant very much enjoyed city bus travel more than Handi Transit. He had little difficulty climbing up the steps of the bus with his portable oxygen as long as the bus driver did not “hurry” him.

I enjoy it [city bus] because it takes me out of the house and I can see other things what’s going on in the city. The Handi Transit is great but it only takes you to one from point A to point B and from that point B back to A again. You don’t see you don’t see anything (O5, 355-359).

Those oxygen participants who used Handi Transit found the costs to be manageable and the drivers to be courteous and accommodating. One participant spoke of how she was discharged home from hospital and did not have a personal supply of mobility oxygen
with her. She was faced with the dilemma of either calling her daughter from out of town to bring her portable oxygen and drive her home or arrange for Handi Transit and make further arrangements to return the hospital’s oxygen cylinder. Accommodating the client’s need, the Handi Transit driver returned the hospital’s oxygen tank at no extra cost to the participant. This gesture allowed the oxygen participant to be independent and eliminated an unnecessary trip for her support person.

Participants expressed two drawbacks to using Handi Transit for transportation. One drawback was the fact that trips had to be scheduled 24-48 hours in advance. This precludes Handi Transit as an option for short notice transportation needs. Secondly, high demand and tight schedules caused drivers to be in a hurry, thus individuals were required to be ready and waiting for drivers when they arrived.

For this population of urban dwelling oxygen users, a variety of public transportation options were available. Participants choose the most appropriate option to meet their needs, with cost and accessibility being the main factors for consideration. This enabled oxygen participants to travel outside their home independent of family or support person assistance.

View of Health

During the interview, I described health to oxygen participants as an individual experience. Oxygen participants were asked, “Overall how would you describe your health in general?” Following their description, they were then asked to rate their health on a scale of one to five, one representing poor health and five being the best they could be. Verbal responses ranged from “no good”, “not to great”, “I can be better than I am”, “good” “pretty good” to “wonderful”.
Oxygen participants’ ratings of health ranged from 1 poor to 5 being the best they could be (Figure 2). Greater than half (66%) of these oxygen participants rated their health as average or above (median rating = 3). Five participants (33%) described their health as less than good. Those that described their health in this way revealed complicating factors such as, compounding chronic illnesses (osteoporosis, coronary artery disease, arthritis) and having a “bad summer” “bad cold,” and “too many things wrong with me.” Independence was also a factor for three of these four participants. All of these factors compounded their underlying health burden of chronic respiratory disease.

Figure 2. Oxygen Participant’s View of Health

![Graph showing oxygen participant's view of health](image)

Six of the participants who rated their health as 3 or better described their health as good but added the disclaimer that if it weren’t for the “oxygen”, “my emphysema” and “bad lungs” they would be healthy. It appeared necessary for them to separate their deteriorating lungs from their views regarding health.
If I didn’t have this problem, I’d put the overalls on and get some work done. I figure my health, if I had my breathing, I’d be able to do something cause everything else is working good (O9, 251-254).

One oxygen participant described her health as “wonderful” and rated her health at 5, the best it could be. Interestingly, this participant was no more less compromised than the others, in fact, her 18 year history of asthma and COPD had left her with moderate shortness of breath, limited walking endurance, the need for ambulatory assistive devices (walker and motorize scooter). In addition, she was diagnosed with heart disease. One of the underlying factors that assisted this individual to live well with her chronic illness was revealed in her descriptions of the activities and benefits available to her in the senior’s complex she resided in.

I think I am the best I can be with my oxygen and that. And there is a lot of activity in here, which I like and ah that makes a difference, you know (O1, 212-213).

Without having to venture outside her building she had a wide variety of services and social activities at her disposal and could access them independently. She clearly enjoyed participating in bingo, card playing, entertainment programming, congregate meals and Nintendo. For this participant, the availability of social activities was a contributing factor to her positive view of health.

Quality of Life – “Could Be Better But It’s Not Bad”

During interviews with oxygen participants and their support persons, quality of life was defined as an expression of an individual’s feelings of well-being and his/her ability to enjoy and partake in aspects of life that were important to them (Curtis, Deyo, & Hudson, 1994). Given this definition, oxygen participants were asked to describe their
quality of life and rate their quality of life of a 1-5 scale, 1 being poor 5 being the best they could be (Figure 3).

Figure 3. Quality of Life Ratings Oxygen Participants and Support Persons

For the most part, their descriptions revealed awareness of limitations, re-evaluation of what was important and the acceptance that life could always be worse.

Ah could be better but it’s not bad. We could go out socially more but, I guess over the years, I have lost contact with a lot of friends. But ah, anything we really want to do we do (O3, 721-723 Quality of Life rating 3).

I’d ah it was, my life is good. I ah am happy...So far as my ah health, you know, it hasn’t slowed me down to a sense where I can’t do nothing. I still can do things, I’m slower but...(O5, 507, 516-518 Quality of Life rating 3).

I do the things I want to do. I live within my limitations. I strive for contentment. I believe the whole world revolves around being contented in your life and I strive for that. And mostly I am happy with what my achievements. Like, I can live within my parameters and I accept them (O14, 431-435 Quality of Life rating 4).

The nature of their quality of life has changed given the gradual debilitation of the disease and the added discomforts and restrictions that oxygen therapy brought to their lives.

There were many activities and interests that they have had to give up and over time these were replaced with other less physically demanding interests.
Yea the little things I never would have looked at before you know. Of course I like feeding the birds...I feed the birds in the morning and at night. I enjoy that you know. Little things that I never would have done (O5, 375-379).

Spouse: It [wife’s quality of life] has changed from what, she used to love her gardening, now she loves her computer (H8, 825-826).

I’ve got a wood working shop in the basement and I got plants in the basement and stuff. I usually go down there for a couple of hours a day and putter around (O3, 277-279).

Learning to live with their changed quality of life, again was a process of acceptance.

You can’t change it it won’t change it just makes it worse. So ah, so it is limited but you so you get used to it and you start accepting it (O4, 1043-1045).

Acceptance of limitations, adapting to these limitations and incorporating new interests into their lives assisted oxygen participants to maintain an acceptable level of quality in their lives.

Three of the 15 oxygen participants described their quality of life as less than desirable. Two of these participants had been on home oxygen less than three months. They, along with the third participant, struggled with reduced physical strength and other chronic illnesses. Their impaired physical condition coupled with the requirement of mobility oxygen to engage in out-of-home activities curtailed their independence. Their views of quality of life were less positive compared to other participants.

[Quality of life was] Very small now (O7, 1107, Quality of life rating 1).

Well right now I don’t have any quality, it [oxygen] just wrecked it completely (O12, 786-788, Quality of life rating 2).

The number of professional people including nurses and an orderly that visit me and a myriad of Doctors appointments including ophthalmology, cardiologist, respirologist. And then my frequent, what will be frequent stays in the hospital, which will probably be at three month intervals. I look at this and say well, what energy have I got left to pursue many type of life I would like or have enjoyed,
very little. Every thing seems geared to keeping me alive. I am not convinced it is worth it (O15, 27-34, Quality of life rating 4).

Complicating chronic illnesses, reduced physical strength, increased limitations and erosion of independence were factors shared by these three participants.

Beyond the Security of Home

The availability of mobility oxygen and the addition of assistive devices enhanced the oxygen users’ ability to move from their home environment and partake in activities and events in their communities and the world beyond. As they moved from the more controlled environment of their home, they were confronted with curious looks from others and additional factors and/or barriers to face. In order to reduce their uncertainty, expected consequences were anticipated and controlled and attempts were made to control any unexpected consequences as efficiently possible.

People Looking

Oxygen users were conspicuous to the general public, by virtue of the nasal cannula they wore and the oxygen paraphernalia carried with them. Although it was not felt people intentionally wished to cause embarrassment, there were times when people, especially young children, would “look a little longer than they should.” Most participants identified feelings of embarrassment were experienced early in their oxygen experience and over time these thoughts and feelings dissipated to the point where going out in public was now “second nature.” Pride of not wanting to appear handicapped in public continued to be an underlying factor for two participants who avoided using mobility oxygen whenever possible.

Oxygen Participant: Just my pride I think. No never having to have anything like that, then all of a sudden you are on it. You sort of like...
Spouse: Like everyone is staring at you (O11 & W11, 741-745).

Some participants described how they used interactions with curious children as opportunities to teach them about oxygen and to explain why they personally required it.

You always have little kids stare. But that’s about all. They wonder what it is, you tell them and they kind of like that...I tell them when you grow up don’t you dare smoke [laughing] (O7, 333-341).

Children are the ones. They will [stare] you know. The parents try to shut them up and I want to hear them out. I explain to them why I’ve got oxygen, that it helps me breathe (O5, 185-188).

Encountering curious observers when out in the public was a fact of life that oxygen participants recognized and adjusted to over time.

**Air Quality**

As discussed elsewhere in this Chapter, participants’ respiratory conditions caused them to be sensitive to environmental triggers. When questioned about the air quality of their city, eight oxygen participants did not feel that the air quality was a concern for them. Only one oxygen participant described the air quality of her neighborhood to be poor. Her street was a bus and truck route and her home was located in close proximity to a fertilizer manufacturing plant. The roar of frequent truck traffic was evident during the interview [field observations] and was clearly heard on the audiotape during transcription.

Ah well even my sister [visiting from Calgary last summer] said that this is a poor area. She was sitting out, she smokes. She was sitting out there [on the front step] having a cigarette ‘my gosh the fumes and the diesel from the bus, she says is terrible’ (O4, 466-468). Daughter: Well [fertilizer plant] is just over here and you can smell the ammonia coming out of there (D4, 470-471).
Other participants who had concerns regarding air quality discussed episodic factors such as "stubble burning," smoke from fires, pollen, and high humidity and environmental tobacco smoke.

Sometimes it [air quality] does. Well the obvious one is when the farmers burn stubble, I nearly go insane. But the air quality of the city I have no quarrel with. I never think about it. This is a city without any heavy industrial stuff, manufacturing (O15, 348-351).

Smoke. The other night I could hardly breathe. I said to my son, ‘what’s the matter with me’? And he opened the door and…went outside and he said you should see the smoke out there. No wonder you can’t breathe. Somebody is burning something. I am very sensitive to smoke (O7, 51-55).

If it is awfully damp or windy it bothers my asthma. Or if the pollen is flying in the air…(O12, 748-749)

Fumes from vehicles and environmental tobacco smoke were also influencing factors of concern when participants traveled outside their homes.

I really don’t go downtown that much but it [air quality] does. What bothers me is the fumes from cars. I never walk behind a car. Too many gases (O11, 496-481).

Yes I find on some of the streets if we go out ah or on the bus. When we get to their [bus] station in the city here, where they all gather, I find that quite hard if I have to get off the bus to go to another bus. That’s when I get the fumes. Other than that, no. I am inside a vehicle and the windows are closed so it doesn’t bother me traveling (O5, 447-452).

Eight oxygen participants discussed their difficulty encountering environmental tobacco smoke (ETS) in their homes, in public places and with close contact of smokers and the odor of their clothing. Their degree of aversion to ETS varied from mild to severe. All eight of the oxygen participants expressing concerns regarding ETS were previous smokers. These individuals smoked in the many of the same settings they now attempted to avoid as a result of the smoking habits of others.
My daughter, she smokes in the house. And you can smell it on her clothes when she comes up to you (O10, 807-808).

It does [meaning ETS]. I don’t notice it but if I sit. We went to ah retirement party for a girlfriend… and ah we were there for about 3 hours I guess. And she [his wife] said I was getting paler and paler. I didn’t notice it cause I couldn’t smell the smoke very much (O3, 291-294).

And they don’t have smoking in here [seniors’ apartment block]. Because they don’t let you smoke in here. Just up at the Keystone for the bingo, one half [is designated non smoking]. So that’s one thing, the smoke bothers me too. And I used to smoke (O1, 3890-384).

Participants with sensitivity to environmental tobacco smoke took great efforts to avoid it whenever possible. Often times this meant avoiding going to restaurants or social events they once enjoyed; thus creating further losses. This avoidance of ETS compounded an already restricted life style.

Socials yea and ah, there is always smoke there so… We only went for about 3 hours and it [ETS] was getting to me. We sat away from most of the smokers, there was enough of us at our table, we had a little group. But we used to go out to socials (O3, 876-880).

I drag myself out and I have to drag myself back in the house. And then sit in the smoky place where my friends went. I don’t go there anymore. If we go for coffee we go to where there is non-smoking. Not because it bothers me that badly but ah you know why put yourself in that, in that position (O6, 743-748).

Well when I was a smoker I didn’t think it was so crazy but now I think its crazy that this be non smoking and tables right across are smokers like. But I just can’t go into the restaurants if there is smoking. If I can smell it… (O8, 585-588).

Exposure to tobacco smoke is at times unavoidable.

I was at a craft sale and I went into the bathroom and they, there were people in there smoking. And I had to go to the bathroom so bad I thought I was going to croak. Oh my God, here I am. Oh it was just unreal (O8, 554-557).

This event occurred in a public building that had designated smoking areas for smokers to use. The smokers she encountered chose to ignore the regulations. Given that walking,
even short distances, is difficult for those on long term oxygen, this oxygen participant found herself in a situation of being unable to avoid this very unpleasant environmental trigger due to lack of respect by others of smoke free regulations.

**Built Environments - Barriers or Blessings?**

Maneuvering within built environments can be very problematic for individuals with a debilitating chronic illness. It is especially difficult for those with respiratory deficiencies who require supplemental oxygen. Difficulties are compounded by factors such as reduced energy and strength, shortness of breath and the weight and cumbersome nature of mobility oxygen paraphernalia (cylinders, carts or carry bags). Managing ramps and stairs were the two most frequently cited environmental barriers encountered by oxygen participants.

Ramps on public buildings are designed to assist those requiring access with wheelchairs. Interestingly, ramps designed to meet the accessibility needs of the wheelchair population conversely create a barrier for those individuals with debilitating chronic respiratory disease.

Actually I prefer stairs than to the ramps. I find ramps hard to climb up...is more difficult to climb. Cause you got to work to climb up. Whereas the stairs you take one step at a time (O4, 496,497,511,512).

I try not to use the ramp. I find our sidewalk here, there is a bit of a downward and I find it harder to come up there than to walk from the corner to here and its not much of a slant...It is difficult, it is difficult to climb an incline. Yes I did, I found that (O5, 1089-1091,1093-1095).

Stairs were another frequently encountered barrier.

I never climbed any stairs if I could avoid it. No I didn’t maybe 2 or 3 (O15, 170).
They are out [stairs]...I can make it but they are a killer...I try to avoid those stairs as much as possible (O31, 198, 202,212-213).

Even with the oxygen on. I can come up them but you know, by the time I get up them I got to stop so... (O8, 517-518).

Despite the difficulty stairs present, one oxygen participant cognitively reframes the eight steps from his apartment to the main floor to being a “blessing in disguise.” He used his stairs as a form of physical therapy in the exercise it provided. Psychologically, stairs were viewed as a conduit to the freedom of being outdoors and a barrier to be mastered.

...I take the stairs as a blessing in disguise. Because I ah exercise my breathing and I exercise my my body at the same time my legs and my knees. So I go down stairs and I go outside. And depending on the weather I stand on my doorstep. If not, if the weather is good and not much wind I can walk up, I can walk up to the drive up to the street. Or I can walk around the yard. I’ll spend sometimes half an hour walking about. And then I come back in again. I climb the steps. I take a step at a time. Breathe, lift the other foot, take a step at a time. I am not in any hurry. I take my time. But it is a blessing in disguise, cause it does strengthen me (O5, 323-334).

Difficulty climbing stairs can be problematic if an essential service is located at the top or bottom of a staircase. Despite accessible building legislation, one participant finds herself in the position of having her physician’s office located in the basement of a building without elevator services. Her support person described the difficulty of assisting her friend to appointments prior to the establishment of home oxygen.

We would go to the doctor and we would to down those stairs I was so worried for her cause she was weak and couldn’t get her breath and it was scary (F12, 78-81).

Even though this oxygen participant has been established on oxygen and is in a stronger physical state, stairs continue to be very physically taxing and something she wishes to avoid when ever possible.
...I told the doctor I couldn’t go down those stairs anymore and she said on Friday mornings she would come up and see me, but it has to be an emergency...forget it. If I have an emergency I’m not going to wait until Friday...that’s not going to work (O12, 202-204,208-209,218).

This family physician’s offer to make home visits on Friday mornings in the case of an emergency is unhelpful; in that it is unlikely an emergency would occur during that designated time frame and precludes the client from the benefit of ongoing routine care. From references made throughout the interview this oxygen participant had a positive rapport with her physician. The barrier of the built environment places her in a difficult situation. She faces a choice of continuing with her family physician at physical costs to herself or does she, at the age of 81, begin the arduous task of seeking a family physician for reasons of accessible office space.

Participants observed that many public buildings and senior’s housing had easier access because of push button electronic doors. If doors were not equipped with this feature, participants expressed that the general public were usually willing to assist someone with oxygen.

Of course they all got these pushes [electric door openers] now. If you go some place that hasn’t got a push button it is rather hard. But ah, somebody always opens the door for me (O1, 457-459).

Well the downstairs [apartment block] door is quite heavy but there is usually somebody around. They jump to help everybody (O12, 727-728). Interviewer: So you find that people help you? Oxygen Participant: Oh yeah (O12, 731).

Walking any length of distance can be difficult for oxygen dependant individuals. Support persons often drop them off at the door of public buildings to reduce energy expenditures. Participants who traveled with their own vehicles found handicapped packing areas and passes to be a beneficial public policy and service. One participant
spoke of a recent change in policy whereby only one parking pass is issued per household. This causes difficulties when families own more that one vehicle, as this requires transferring the pass from one vehicle to the other so that the oxygen dependant family member always has the disability pass available.

Living with Oxygen – Effects on Family/Support Persons

Quality of Life

Given a definition of quality of life, support persons were asked to reflect on their feelings about the quality of lives and then rate quality of life on a rating scale of 1 to 5. “One” indicated poor quality of life and “five” indicated the best they could be. Support person ratings ranged from 3 to 5 with the median rating of 4 (Figure 3 p. 104). This rating was slightly higher than that of oxygen users. Support persons had experienced changes in their quality of life but not all changes could be attributed to the introduction of oxygen technology as some support persons were experiencing their own health concerns (n=7).

Support persons felt able to enjoy and partake in activities that were important to them. They described “walking, “mountain biking” “played bingo”, “the gym”, “aquasize” “puttered around in the workshop”, “retirees club”, “traveled” “volunteering” “their family and “babysitting grandchildren” as things they continued to enjoy and participate in. One major change in the quality of life for marital caregivers was that activities outside the home were often carried out alone or in the accompaniment of other friends. When they did go out as a couple, support persons found they had to adjust their pace to that of the oxygen participant.
Spouse: Not as good as it [quality of life] used to be, I can say that. Um, I mean we did we used to have more fun...Well I wouldn’t say the quality of our life is bad but it is not as good as it used to be (W15, 1163-1164, 1167-1168, Quality of life rating 3.5). [Please note some participants used .5 ratings on their own accord].

Spouse: I’ve lessened it [volunteering] somewhat to be around a bit more. Especially when he was really at his worst. I do get back to it more now but not as much as I used to...We don’t go out as a couple but I have accepted that (O11, 518-520, 686-687, Quality of life rating 3.5).

Spouse: I am very active. I get out and do things, and still manage to keep the house up and if it needs dusting and I don’t feel like it I don’t do it. And so it uh, it’s changed mind you with him. I think if we want to go out it is about three or four times as long as it used to be and whereas I am already to go, I’ve got the keys, come on, come on...(W31, 727-733, Quality of life rating 4.5).

Guilt when participating in activities on their own outside their home was a feeling expressed by four caregivers.

Spouse: I do have guilt feelings about him sitting at home whereas I’m running in and out. And ah and that...There is a lot we can do as a couple but I have just sort of taken on more like a single person (W3, 808-810, Quality of life rating 3).

Spouse: If I go for dinner or something like that with the family then I feel bad (W10, 1215-1217, Quality of life rating 5).

Other caregivers did not experience feelings of guilt, expressing that the activities they participated in were not ones they had shared previously as a couple for example swimming or clogging (a form of dance). Their feelings were reflected as a concern for the oxygen participant. To allay concerns about the oxygen participant being home alone, support persons adapted monitoring strategies. If the oxygen participant was not feeling well or was having a “bad day,” support persons adjusted their plans and stayed home.

Spouse: I got a cell phone and I always know that I can phone him, but if he was having a real bad day I wouldn’t go (O31, 764-766).
Spouse: I don’t want to leave him when he’s not feeling good. Unless there is somebody that is qualified to be with him (W11, 1185-1187).

The support persons of this study rated themselves as having reasonable quality of life. They had significant relationships with family and friends and were able to partake in activities that were important to them, creating a positive sense of well-being. Support persons experienced some feelings of guilt and concern when perusing interests outside the home, however, they incorporated monitoring strategies to control these adverse feelings and stayed home when the oxygen user felt unwell.

Strength of Supportive Relationships

When support persons and oxygen participants were interviewed about the nature of their mutual relationships some that felt that their relationships had stayed the same, some indicated that felt their relationships had grown closer.

It’s just the same as it always was. It has always been strong (O2, 485).

I don’t think it has really changed it. We were good friends before that and we’re good friends now. We’re just friends. A beautiful relationship as far as I’m concerned (O6, 1307-1309). Friend: Good friends and neighbors that’s it you know. There’s not a problem, actually it hasn’t changed anything (F6, 1313-1314).

Maybe we are a little closer because these things [was mechanically ventilated twice] just about, you know, took my life. I guess you could say we are a little bit closer now that ah. Well we have been a close family. Well I guess it has changed a bit, I guess (O31, 1167-1169).

Spouse: I don’t know we’re sort of he’s always been slow moving, where as I’m impulsive and that so it works out good [laughing]. He pulls me back and I speed him up and ah. I don’t know, in a way I guess yea. I’m more considerate than, but before I would just take off, I’d decide I’m going somewhere, hey I’m going. Now I have to stop and think, hey what’s he doing before I do take off (W3, 1478-1483).
The participants in this study had lengthy relationships with one another, which had stood the test of time. Given the strength of their relationships, the introduction of oxygen therapy into their lives had minimal effects on their relationships. For some, the precarious nature of chronic respiratory disease and the ever-present potential of losing a loved one to the disease caused oxygen participants and family/support persons to view their relationships as closer.

Several of the support person - oxygen participant dyads discussed areas of tension in their relationships.

Oh we have little fights once in awhile. We're pretty much the same eh? [laughing] We're both hot tempered, but you know we bark at one another but it's over. There is no worry. Some people they don't talk for, with us, two minutes after, it's all gone (O7, 1312-1316).

Daughter: There's days that I get very frustrated and probably take it out on Mom more than I should. But in the end, but in the end I don't know. But I think if I didn't tell her how I'm feeling I'd be holding it back and I think I would be more resentful. I think I need to ah let it out and tell her what's going on. She doesn't always want to hear it but I have to because otherwise I take it home with me and I get mad at my husband and take it out on the kids (D4, 640-654).

Wife: You take one day at a time and there is nothing much else you can do, just take it and bear it. He gets grouchy once in awhile but I just don't, I just go and find something to do (W10, 1239-1242).

There are frustrating days for caregivers and care providers alike. Participants described episodes of tension as “natural” in their relationships and that one “can’t be perfect all the time.” Giving one another space and the healthy discharge of negative feelings were instrumental in releasing tension. In the case of one support person this reduced the chances of projecting displaced frustrations onto other family members at home.
Oxygen participants were conscious of the fact that they did not want to be a burden to their care providers. It was difficult for them to ask family/support persons to do things for them.

I say it still is hard to ask Ron [pseudonym for husband] to do something. I don’t know why but [laughing] we have been married 46 years so why would I be. It is just that I don’t know there is just something about putting people out (O8, 999-1002).

Just as equally difficult was watching care providers do the things they used to be able to do independently.

There’s things I can’t do that she’s gotta do and I gotta a sit here and watch her do it. That really burns my butt to think that you used to be able to do all those things and now you just sit and look out the window at it (O9, 495-499).

Role reversal was frustrating for oxygen participants and had the potential for creating tension in relationships. In general, dyadic relationships were supportive. Some study participants noted a strengthening of their relationship. Areas of tension were viewed as natural and managed with discussion of issues and acceptance of each other’s strengths and limitations.

**Living with Uncertainty – Planning, Control and Management**

Uncertainty was a common thread throughout the interviews. Two main antecedents of uncertainty for oxygen participants were the uncertainty of living with the inconsistent fluctuations of respiratory symptoms, and uncertainty regarding the dependency on technology to deliver a consistent supply of oxygen. Emerging from participant descriptions was the amount and degree of planning and controlled management they incorporated as a team into their lives to address these identified areas of uncertainty. Controlling uncertainty assisted participants to avoid undesirable states or
situations. For oxygen participants the most profound undesirable states were the inability to breathe and the fear of running out of oxygen. Oxygen users and their support persons expended a great deal of time and effort to avoid these undesirable states and management of these uncertainties became part of the individual and support persons’ cultural ways of being. Reduction of uncertainty was engaged in by implementing systematic planning, control and management strategies.

Uncertainty of Living with Chronic Respiratory Disease - Good Days Bad Days

Living with the variable and downward trajectory of chronic respiratory disease caused oxygen participants to feel uncertain about their future.

There is uncertainty certainly. Every day is an uncertainty, I would say (O31, 992-993).

Who could say a year from now what’s going to happen. Especially when you are like this (O8, 1348-1349).

The effects of emphysema does cause me to be uncertain about my future. Because again the curtailment of my independence, the parameters beyond which I can’t climb. The things I can’t do (O15, 217-220).

Oxygen participants described challenges and limitations and the fact that their disease varied from day to day. At rest they felt fairly healthy and able-bodied but when it came to getting up and getting on with activities of their daily living, things were different.

Well I am always short winded sitting here, I’m sitting here right now and I can take this oxygen off, you know. It probably wouldn’t bother me but as soon as I get up and I start the initial move that’s when everything’s shuts down (O31, 540-544).

Sometimes I’ll be out and have a good day and I can walk to the car up the steps come in here [into house] and forget to put my oxygen on. And then the next day I come here, I can’t get up the stairs as soon as I am at the door I have to put my oxygen on. So I don’t know whether it is a good day or bad day or what. But I have good and bad days (O8, 366-371).
It is hard to tell what you can’t do until you try to do it and all of a sudden you’ve got no poop there, you know, your just dragged right out and have to sit down (O31, 361-364).

Some participants viewed their chronic disease future as “right now” and they approached the uncertainty of their illness by “living one day at a time”.

Well as far as I’m concerned I haven’t got no future, at age 78 years old my future is right now [laughing] (O7, 1126-1127).

There is the knowledge that was made clear to us at the hospital that it will never get better, the emphysema. I will only get worse. That’s easy to read between the lines and people that I have known that have had oxygen didn’t have it very long, they died. So I know there is a question of mortality and that doesn’t bother me very much (O15, 205-212).

I always said I wanted to live to be one hundred but I don’t think. I know I won’t make it. You know what I mean? So ah it does [make you feel uncertain] and that but then I’m trying to start thinking to live one day at a time. That’s what somebody said, live one day at a time. Don’t think about tomorrow, just live that day and when tomorrow comes live that day (O4, 1190-1196).

Others approached disease uncertainty by looking forward to the future. Knowing that there was very little that could be done to prevent the inevitable outcome of death. They chose to look ahead, making plans for the future without dwelling on the finality of death.

No I ah don’t even think of it. I feel that I’m good for another twenty years yet. I got places to go for another twenty years. I [got] things to do. I I got no it [uncertainty] doesn’t bother me at all, no (O5, 797-800).

I am going to live another 20 years. What the hell, you know [laughing]. What ever happens happens. When the good Lord calls you upstairs or downstairs you go whether you like it or not [laughing]. But ah, you have no say in it. I mean why waste time thinking about that really you know cause you don’t have any say (O6, 1085-1090).

I don’t have a feeling of the end is coming. Like I don’t get up in the morning a say gee another day and I’m still here. I don’t do that. I don’t have a sense of finality or anything, when it comes it will come (O14, 469-473).
The oxygen participants in this study coped positively with disease uncertainty by accepting that the ultimate outcome of their disease was beyond their control. Some oxygen participants lived with the uncertainty of their disease by approaching it “one day at a time” while others preferred to not dwell on uncertainty or the finality of their disease and described their future in terms of years.

Disease self-management - controlling for the inability to breathe.

Uncertainty of chronic respiratory disease is heightened during times of exacerbations. Oxygen participants described uncontrolled anxiety, environmental triggers, ineffective clearance of respiratory secretions, acute illnesses and hospitalization as aspects of life they attempted to avoid. Exacerbations were to be avoided at all costs due to the potential for hospitalization and/or precipitating a downward spiral in their disease trajectory. More critically, disease exacerbations were avoided because of the link between exacerbation and the undesirable state of the inability to breathe.

When you tell somebody you’ve got fear, you can’t explain that to anybody. How do you, they understand if you can’t breathe, the fear...usually people say you shouldn’t fear. Well you just try try not breathing and tell me that you don’t fear (O8, 402-405).

When you can’t breath and you never get rid of that fear. It doesn’t matter how often it happens it’s still scary. So ah I I do go through experiences of scary when I can’t breathe (O5, 891-894).

It is the worse feeling you can get in your world. And you know you got to breathe. When you can’t breathe what are you going to do...I have to watch I don’t, I don’t loose my ability to breathe. That is what scares me more than anything is the loss of breathing ability (O6, 1581-1583, 1568-1570).

Avoidance of the inability to breathe, as a result of consequences or exacerbations, was an important component of the management of oxygen participants’ disease uncertainty. As a result, fairly rigid disease self-management routines and
assistive paraphernalia were incorporated into their cultural ways of being and home milieu. This was necessary to reduce potential exacerbations of their condition and to ward off the undesirable state of inability to breathe.

**Anxiety management.**

Uncontrolled anxiety can lead to shortness of breath and increased sensations of inability to breathe. Oxygen participants learned to recognize the potential causes of anxiety and took measures to reduce the adverse sensations when anxiety presented itself.

If you let yourself you do [become anxious]. You have to concentrate on not letting it get to you. If you don’t, that’s it your up (O6, 568-570).

You get upset, I think, I’m sure you stop breathing properly. But you have to sit down and think instead of getting excited (O11, 886-888).

I’m learning now not to be so anxious...If ah something comes up and I get sort of anxious II sit down relax and I manage...Relax take deep breaths (O4, 1133, 1153-1154, 1160).

To reduce feelings of anxiety this population of oxygen users implemented a combination of cognitive restructuring, reduced physical activity and relaxation techniques.

Participants were aware that even minor acute illness, such as the cold or flu, could cause a major set back or result in lengthy hospitalizations.

I got a cold and got the flu and it just knocked me on my backside for ah, it is close to three weeks. And it was just gradually getting worse and worse. He [physician] said I did have a touch of pneumonia (O8, 291-294).

When I had pneumonia I was so sick. Was in there [hospital] for 31 days and lost pounds a day. Every day I lost a pound. It was just depressing (O11, 759-762).

Once the acute stage of their illness was over, some oxygen participants expressed that they had been kept in hospital longer than was necessary.

I would say I stayed a week or better both times doing nothing, just as I am sitting here. I was sitting in a hospital bed with the oxygen on (O31, 1387-1390).
I don’t know if it was the convalescent [ward] but nothing seemed to be done for 3 weeks except that my oxygen would be looked at occasionally, ‘Oh yea you’re at 4 [L/m] (O15, 832-834).

Exposure to illness, unappetizing food and noisy ward environment made stays in hospital undesirable. Another detrimental aspect of hospitalization was their restricted activity. The ability of oxygen users to ambulate in their room was limited by the length of their tubing from the oxygen receptacles on the wall. Portable oxygen cylinders were in short supply making exercising outside the ward area field difficult to arrange.

Well you are limited to 25 feet of hose and if you want to go outside for a break in the sun you have to get a wheelchair and a portable oxygen and they are not easy to come by. One time we had to, they gave us an empty one, another one was good for 20 minutes. So you have to put in a reservation about noon for a two o’clock bottle. The nurses were good about trying to get us one but a lot of times there was not a bottle available. There is only four bottles for the whole floor or something (O14, 1503-1510).

They [hospital ward] had two tanks, well two portables and they were never available. So what we used to do was take it and put it in a corner of the room and then when I wanted to go for a walk again it was there. Spouse: And if they came and wanted to borrow it [for another patient] I would say sorry we’re just leaving [laughing]. It wasn’t very nice of me. Oxygen participant: Or else when we would get it back and it would be empty, damn near empty, well we can’t go anywhere. So they said oh well we’ll have to wait until they send it down and get a cylinder and we would wait, and wait, and wait, and wait (O31, 1432-1435, W31, 1441-1443, O31, 1445-1449).

Oxygen users concealed hospital cylinders in an attempt to secure enough hospital oxygen to engage in exercise, an important therapy for individuals with respiratory impairment.

In addition to causing a serious setback in their disease trajectory, acute illness could result in death.
They sent me home to die [post pneumonia]. My daughter wouldn’t accept it so she took me back [to hospital]. And she told them ‘now here is my dad, you fix him up and that’s it’. And they did (O11, 782-785).

Like I try to tell the kids, which the doctor told me, and you take this in that class, pneumonia the flu is something that’s really really bad for me so therefore you try to stay out of that situation...If I had it really bad or got sick really, my chances of getting better are next to nil to what it would be like for somebody else (O8, 1350-1355).

Cognizant of the adverse affects related acquiring an acute illness and subsequent hospitalizations, oxygen participants and their support persons incorporated health promotion strategies into their overall disease self-management plan. Additional strategies included participating in flu and pneumonia immunization programs, circumventing crowds during the flu season and avoiding individuals with acute illnesses. Two oxygen participants had treatment plans that incorporated preventative antibiotic therapy.

**Avoidance of environmental triggers.**

Avoidance of environmental triggers was also an important aspect of disease self-management for this group of oxygen users. Triggers identified as problematic included environmental tobacco smoke, humidity, cold air, wind, plants, strong odors, perfumes, vehicle exhaust, animal dander, dust, pollen and cut grass cuttings. The most frequently reported triggers were environmental tobacco smoke [previously discussed], humidity, cold air and wind. Despite the fact that participants had the benefit of supplemental oxygen, these triggers continued to create adverse symptom challenges. To reduce the uncertainty of symptom exacerbation, oxygen participants avoided triggers whenever and wherever possible.
Oh yeah the humidity is ah, I can’t stand that. You see, I used to shower before. Oh I love a hot shower and get in there. Now I can’t do that it just chokes me right up. So now I have to resort to tub baths. That’s for sure, a nice warm shower but if you can’t breathe you can’t breathe (O31, 306-311).

The cold in the winter, I just don’t unless I have to, put my nose out the door because I got no breath at all. Even now if it is cold out if the wind is blowing I can’t hardly make it to the car (O8, 383-386).

Dust ah heavy dew in the morning or heavy rain and grass. Ah one thing that really gets me if people cut their grass, their lawns the lawn mower stirs the dander up and it just hangs. Ah various cosmetics all bother me I can’t wear, I don’t use shaving aftershave lotion because it gets to me. Of course perfumes and some brands of perfumes are murder. And I can’t stand smoking any body that’s smoking. Exhaust of vehicles especially diesel vehicles are the worst (O5, 226-233).

Avoidance of triggers often resulted in forgoing public events and family gatherings, staying indoors on certain days, and giving up yard care, household plants, family pets and other possessions they loved.

**Secretion management.**

Secretion management was another area of routine care oxygen participants employed. This included activities such as regular administration of broncodilators, chest physio/pummelling, use of massage (a special feature in recliner chair), controlled coughing, warm fluids and regular exercise. For some this meant engaging in rigid daily rituals as part of a way of life.

Cold fluids and then warm fluids to loosen up the congestion. Cough it up, it’s not all, it’s not all necessary that I will cough it up but this is what annoys me. You have a hard time, you start coughing and you know it’s in your chest but you just can’t bring it up. So I go through that pretty well, I go through that every morning (O5, 289-295).

Participant: I start off at 7:00 [a.m.] in the morning. I do my chest [pummeling] first. Then I get on the chair [recliner chair with massage feature]. And then right after dinner, I do it again, and then I do it again right after supper, three times a day.
Interviewer: So do you find that you are able to bring your secretions up better afterwards?
Participant: Oh yah. You bring it [secretions] up on the chair there. After I do my chest and get on the chair there is a chance some will be coming up. Then I get out here [heated garage], I’ll show you afterwards, I do my walking and that is important (O9, 282-295).

Regular exercise was viewed as important to oxygen participants not only as an adjunct for secretion control, but also to build strength and endurance and to decrease the demand for oxygen.

But you have to exercise if you are on oxygen. The more you exercise the less oxygen you need. If you build up the strength you don’t need the oxygen (O11, 1139-1142).

Oxygen participants spoke of engaging in some type of regular exercise as a disease management strategy. Exercise primarily included walking about their home, in hallways of apartment blocks, on the street, or in climate controlled shopping malls.

In summary, individuals on long-term oxygen living with chronic respiratory disease, experience uncertainty relating to their disease and their requirement for oxygen. Reduction of disease uncertainty was important to study participants to avoid disease exacerbation the undesirable state of the inability to breathe. Oxygen participants in this study employed a variety of disease self-management measures to reduce this type of uncertainty.

**Uncertainty of Living with Oxygen Technology – The Dread of Running Out**

It’s a hell of a feeling [running out of oxygen]. It’s like someone putting their hand over your mouth and squeezing your nose and then stand there and watch it. It’s not nice (O9, 693-699).

As revealed in this chapter, oxygen held a significant place in the lives of study participants. Although oxygen users could manage for short periods of time without the
benefit of oxygen, the uncertainty of living with oxygen equipment was augmented by the dread of running out of oxygen. Prevention efforts to reduce opportunities for running out of oxygen controlled the level of uncertainly related to living with oxygen technology. Accomplishing this entailed planning ahead, control, and management practices that were incorporated into the daily lives of oxygen participants and their support persons.

**Uncertainty of oxygen technology in the home.**

Study participants experienced very little uncertainty related to the capabilities of their in-home oxygen technology. Equipment failure and power outages were infrequent and were not considered to be a significant concern. All of the oxygen participants had oxygen cylinders as a back up supply in the home should in the concentrator fail or a power outage occur. Upon installation of the equipment, oxygen suppliers provided individuals with verbal and written instructions regarding the operation of the backup oxygen supply. Oxygen supply companies ensured that backup oxygen cylinders were left user ready so the least amount of manipulation was required to initiate oxygen flow. The amount of backup oxygen left in the home by the home oxygen company was sufficient to provide the user with a minimum of 48 hours of oxygen. All oxygen participants were comfortable switching themselves over to the backup cylinder supply or onto their portable cylinders.

Spouse: That’s all hooked up [backup cylinder], all I have to do now is go open the tank and turn the dial [flow meter] to the pressure she is supposed to get and she can put the…hose on (H1, 660-663).

I have my backups [large oxygen cylinders beside his bed]. If the machine quits I got my backup… I got 2 big cylinders. It has happened the machine has quit.
There is a malfunction or ah electrical black out. We have had that. But ah I
have no worry there (O5, 824-828).

Spouse: No he’s got it [backup cylinder] hooked up that’s where he as long as he
knows before he gets too weak and can get down the stairs to switch it over from
the concentrator to the big tanks. But we have got oxygen tanks [portable
cylinders] all over the place...in the basement with the concentrator and there is
oxygen I guess it is in the van and there is some in the landing. We just keep
extra tanks around (W3, 688-690).

One oxygen participant revealed that she was concerned about equipment failure when
she was first on oxygen.

I did [worry] at the beginning but not so much now cause I know I can get onto
these [portable cylinders] and ah. I know like summer time ah you know
electrical storms and that but and also we’re on the list at the Hydro in case they
have to if we are off for a long period of time they would get a generator or
something (O4, 415-419).

This oxygen participant was not confident that she could connect to her large backup
cylinder but was comfortable with her portable cylinders which sat ready for use at her
front door [field observation]. Her portable oxygen supply would provide her with
oxygen until her Hydro was restored or until she could obtain assistance from oxygen
supplier or family. The electrical utility company had been made aware of her medical
requirement for electricity, providing this participant with the confidence that a
contingency plan would be put in place should there be a long term discontinuation in
electric power.

The provision and set up of oxygen equipment and supply in the home proved to
be a controlled environment in which oxygen participants and their support persons had
confidence. If equipment failed they had sufficient backup supply to last them until the
problem could be rectified. Participants were aware of whom to call should their
equipment fail and had a level of trust in their home oxygen supplier’s ability to respond efficiently and effectively to any in-home concerns relating to running out of oxygen.

**Beyond the home – “got to have backups”**.

Uncertainly related to a guaranteed supply of oxygen and avoiding the undesirable state of running out of oxygen escalated somewhat as oxygen participants left the controlled environment of their home. Participants were comfortable using their mobility oxygen for short excursions outside of their home although even short trips required preplanning and backup oxygen protection. Preplanning included ensuring that there was adequate oxygen available by confirming the amount of oxygen in their portable cylinder(s) (time in the bottle) and determining if it was sufficient for the length of outing planned. Backup planning required preparing for any events that could potentially lead to running out of oxygen.

**Spouse:** You’re a fool if you let that happen [run out of oxygen]. That’s why you have backups (H2, 323).

**Son:** Try to keep ahead of what is going on for sure (S7, 1185).

**Spouse:** Well, just in town he can just take this portable and he can go for coffee and stuff. Just go shopping or for coffee, just to get out of the house. **Oxygen participant:** I carry a spare tank in the van all the time (W9 436-438; O9, 445-446).

Those who traveled in a personal or support person’s vehicle made it a habit to carry extra oxygen cylinders as backup in the event that one ran out. Those who used public transit were limited to the amount of portable oxygen they could physically carry; thus the use of public transit shortened the time they could be out and the number of backup options they could employ. The wisdom of fortifying backup plans was sometimes the result of an unpleasant but educational experience.
You get a lot smarter [laughing]...Well, I’ve had to ride back home on a couple of different occasions without oxygen. Use the whistle breathing method. Take it easy (O9, 709, 719-721).

Even when oxygen participants or their support persons put the best of plans in place, unexpected glitches still occurred.

He [son] used to take me to the mall. He would leave me there for about an hour, hour and a half and I would do some shopping and he would come and pick me up. I can’t do that any more but at first that’s what we did. This one time he said I’ll leave an extra tank in there [basket of wheeled walker] in case that one runs low, we will have an extra tank, and he left me. By golly if that tank didn’t go dry and I couldn’t put the other one on at all. There was a doctor there in the mall and we even asked him and he didn’t know how to get it on. Nobody knew, the guards no body knew. So the guard said we’ll get a chair and you sit down and don’t move till your son gets here. That’s what I did. I didn’t move at all. So it didn’t take long [son] came along and oh was I glad to see him (O7, 290-302).

This participant’s son implemented a backup plan for running out of oxygen. What had not been anticipated was the fact that no one in the shopping mall had the expertise to assist her with switching the regulator from one portable tank to the other. As a result of this experience and the dread of running out of oxygen, this participant refused to venture out in public unaccompanied by a capable support person.

Travel – less control greater uncertainty.

The farther away from home oxygen participants traveled, the greater the uncertainty and the more preplanning and backup planning was required. For some study participants, the risk and effort required to mobilize outside of their community was more than they were willing to take.

I do worry ah, the reason I will not go for long trips with my cylinders, I’m scared of running out of oxygen. Getting into a car accident, maybe a break down and I’d be stuck there without oxygen. Ah it’s a terrible feeling to feel that way and I will not go on a long trip...It’s a thing I never thought of before but I think of it now, because I ah that’s [oxygen] my life. It’s keeping me alive so I got to be, I got to think of it (O5, 831-839).
For this gentleman, travel outside his comfort zone (city limits) brings with it too many uncertainties that he perceives are beyond his ability to control. Oxygen was his “life”; running out of oxygen compromises this important lifeline and therefore, he will not be willingly placed in a situation that lowers his control and increases his risk of this undesirable event.

Some oxygen participants, with the assistance of various sources of support, took additional planning and the associated costs in stride and engaged in travel to other Manitoba locations, other provinces and states. The planning variables participants had to prepared for with respect to motor vehicle travel included mapping out locations of oxygen suppliers along their travel route, calculating oxygen needs during changes in land elevation, and picking accessible accommodations preferably with parking outside the door.

Spouse: We don’t go away that often because, you know, you load up your oxygen tanks to take with you and get the address and wherever your going. You have to worry if you were to run out of oxygen all the arrangements would have to be made...Oxygen Participant: We used to go once a year, go down to Grand Forks for a weekend. We had to pack the trunk full of tanks and we stayed at the Super 8 motel and it was down a little ramp in the door and their handicapped room was right there (W3, 734-737; O3, 764-767).

Most airlines do not allow oxygen users to carry their own oxygen with them and are required to purchase the airline’s in-flight oxygen and make separate arrangements for oxygen supplies at each point of landing and final destination. One oxygen participant had provided for his oxygen requirements between flights by renting a portable oxygen concentrator and carried it on board the airline as cabin luggage. When he came to deplane, the crew had misplaced this (rented) oxygen concentrator. As a result he was
without this pre-planned oxygen source and had to make unexpected alternate oxygen arrangements while at the connecting airport.

But sitting in Chicago when I first asked for oxygen they wanted over $700.00 U.S. to supply me with oxygen while I was in Chicago, while I was going south and coming back. I said to the girl [airport personal], got a supervisor? I would like to talk to him I said. I don’t know how the hell you get a $25.00 bottle multiply it up to $700.00. It didn’t make sense. So they came up and he [supervisor] started explaining. I realize that, you know, it’s not that cheap when you stop and think the time it takes for a guy to come to the airport too and then has to stay with me for 3 to 4 hours. Well they dropped it down to $500.00 [laughing] (O6, 549-559).

As depicted in this scenario, air travel requires a great deal of prearranging and on-route problem solving some of which have costly implications. The combination of uncertainty, increased costs and intensive arrangements makes air travel prohibitive for most long-term oxygen uses.

In summary, oxygen users revealed two types of uncertainty throughout the interview discussions the uncertainty of living with the day-to-day affects of chronic respiratory disease and the uncertainly pertaining to dependency on technology for the delivery of a consistent oxygen supply. Disease self-management and health promotion strategies were put in place to reduce uncertainties related to chronic respiratory disease and reduction of the undesirable state of inability to breathe. Oxygen equipment uncertainly was managed with pre planning and arranging backup plans in an effort to avoid running out of oxygen. As participants moved further away from the security of home, uncertainly was less easily managed due increasing extraneous variables and decreased ability to control for the unexpected.
The Value of Professional Support and Knowledge

As a result of having lengthy disease trajectories, oxygen recipients came in contact with many health care providers such as family physicians, respiratory specialists, respiratory therapists, occupational therapists and physiotherapists, nurses and home care staff in the course of their treatment history. Oxygen participants and their support persons were generally pleased with the level care received from health care professionals. They were thankful for the ability to live at home on oxygen and, therefore had a strong appreciation for the care and support they received as a result of the Home Care and Home Oxygen Programs.

As far as the support we are getting it is good. From the nurse, the family doctor the specialist. And anything we ask for is there and we don’t need a lot of extras, but maybe some day. But I have no complaints about the program [Home Care Program] they are doing, especially these days under what they are going through with the health costs. They are keeping us going. I am glad they do (O14, 1396-1401).

Participants also expressed gaps and frustrations they had experienced with providers and the health system. Through their descriptions, it became apparent that no one health care discipline took a lead role in providing them with support and information about their respiratory disease or benefits of oxygen as a treatment. As a result, oxygen participants and their support persons experienced misconceptions and obtained much of their information in a “piece meal” fashion.

Specialists and Medical Practitioners

Participants receiving medical direction from a respirologist or internist observed that these specialists were competent but found appointments and examinations to be
frustrating because they were short in duration and little information or education about their condition was communicated.

I have a respiratory doctor, but he hasn’t done much. I had to go to his office after I, oh a month after I got out of hospital to see him. And all he did was look at me, I looked healthy, I still do. I had to poke this finger into a thing that looks like a thimble [pulse oximeter], ‘Oh 92 very good come back in three months’. Jesus, that could have been done by a home care person (O15, 700-706).

Spouse: I have been with Dan [pseudonym for husband] a few times when he has gone to see the specialist and I have said to him what is the point… He wasn’t saying anything. We were in and out the door and most of the time not even how are your feeling, he can tell by looking at him (W14, 1197-1206).

Specialists hold positions of influence within the health care system and their time with clients is limited. One support person was frustrated with being denied direct access to the specialist supervising her mother’s respiratory condition.

I wanted to talk to that doctor [specialist] myself and I was told I could not. I would have to speak to the family doctor, the family doctor would then in turn have to give the information to the the um specialist and then she would in turn give the info back to the doctor and the family doctor would come back to me and I though that is absolutely nuts (D4, 851-856).

As the primary support person and advocate for her mother, this daughter was denied the opportunity to ask questions and to receive direct information from the specialist about her mother’s respiratory condition. One oxygen participant was instructed by her specialist to do as he said and they would get along.

He said, ‘Don’t you waste my time cause I don’t have time for you to waste my time’. He said, ‘You do what I say you listen to what I say’...I like him but you do what he says or else (O8, 1795-1797, 18191-820).

Although oxygen participants respected the credentials and knowledge of respiratory specialists, their busy time schedules and lack of information shared with patients made appointments frustrating and uninformative for oxygen participants and their families.
All oxygen participants in this study had family physicians. Some saw their medical practitioner on a regular basis, monthly to every six months. Those oxygen participants who saw their family doctor on a regular basis described trusting relationships.

We got a marvelous doctor. He is a marvelous man. And he does help us a awful lot. He's not afraid, if I need to be in the hospital, if I need to be admitted to the hospital there is nothing of this maybe or nothing, it’s now. And he comes in every morning, during the weekdays he comes in to see you (O5, 1146-1150).

One participant received conflicting messages regarding the importance of regular medical care. One family physician encouraged continuing care, but another physician refuted this by indicating he only “wanted to see people that were sick”. A small number of participants preferred to make appointments to see their physician on an as-needed basis. Attrition of family physicians and the difficulty of finding another physician was the experience of three oxygen participants.

Providing concrete information about their lung condition was also a component that some oxygen participants and their support persons felt was missing from their family practitioner’s care.

Not trying to be miserable, the doctor is ah he’ll check my my lungs and shake his head [laughing]. That’s it you know. I haven’t seen the specialist since I came out [18 months ago] (O6, 1360-1362).

‘Well your lungs are gone’ that’s just about all your doctor says. ‘Your lungs are gone. I can’t make it better. That’s all I can do for you’. That’s about the size of it (O10, 132-1340).

One support person expressed discouragement with her mother’s medical care prior to being treated with long-term oxygen. This daughter felt her mother’s physician had
“gave up on her” because of her mother’s smoking addiction and her repeated unsuccessful attempts at quitting.

All she [physician] did was kept giving her more inhalers just to cover up that [worsening condition] okay well I can’t breathe. Here is another one, try this one and it kept going and going and then it came to where she was on oxygen (D4, 777-780).

In this daughter’s opinion, had her mother’s medical practitioner provided stronger encouragement and made a referral to a smoking cessation program, her mother’s lung condition may not have progressed to the state of requiring oxygen support.

Professional support and information about their respiratory condition and the current status of their lungs was important to individuals and their families, yet this type of information was not consistently provided by medical practitioners.

Like they [nurses] did explain things more but doctors and specialist tend not to answer a pointed question. Then they only answer the pointed questions and won’t say nothing (O14, 1156-1158).

See the trouble is that these people explain things to many times to so many people then assume that you know...I think to often the have repeated it so many times and they assume you know but you don’t. This is a new patient (O14, 1429-1430, 1436-1438).

Not receiving consistent information from medical practitioners caused oxygen participants to learn about their respiratory condition and their requirement for oxygen by asking questions and receiving information in a “piecemeal” manner.

**Home Care Nurses**

Home oxygen participants had access to nursing services through the Home Care Program. Most participants were in contact with their Home Care Case Coordinators at least once a year, usually by way of a telephone assessment. In general, participants were satisfied with the Home Care Program. Participants and their support persons were
unanimous in their belief that should an increased need for home care services arise, assistance to arrange service provision was only a “phone call away.” They were aware of how to reach their Home Care Case Coordinators and were confident that the Coordinators’ professional expertise and assistance were there for them when required.

If I needed anything I can get a hold of the, ah of her [Home Care Case Coordinator] and I would discuss it with her. I think she would do her best to see what she could do for me yea. Yea, I I have faith in her (O5, 1373-1376).

There is no question I would get it [Home Care]. There is no doubt in my mind. I would phone [Home Care Case Coordinator] and or [Home Care Nurse] the nurse that is doing it. There is no doubt I would get it (O14, 1290-1292).

One participant/support person dyad expressed that their Case Coordinator had changed four times since he had been started on oxygen making it difficult to establish a consistent client/provider relationship.

Oxygen participants and support persons highly valued the Home Care Program and were conscious of not wanting to abuse any privileges they received.

Spouse: It always seems if there is anything that we need we can get through Home Care, who happen to mention anything about it we don’t seem to have any problem with getting it. Like I say, I’m not the kind of guy that just because its there I should be using. That doesn’t enter my mind. I feel that it’s there the services are there to help you if it’s necessary. If it’s not necessary I won’t bother with it (H1, 910-915).

Nine participants received Home Care nursing services on a more frequent basis. One participant had nursing services every other day while the other oxygen participants received nursing assessments from every two weeks to once a month. The nursing services primarily included an assessment of respiratory system and vital signs. These home assessments did not include monitoring of the oxygen client’s oxygen saturation. Two participants spoke of how their nurses had them ambulate during the home visit in
order to assess the status of their exercise tolerance. Participants looked forward to these in-home nursing assessments and found them to be reassuring.

I enjoy her [home care nurse] visits cause she puts my mind to rest how my general health is doing (O12, 1707-1708).

They [home care nurses] are very good and ah they help me along. Any questions I’ve got to ask or if I have to ah phone you know. They’ll phone the doctor if they feel that they should (O4, 1309-13-11).

I guess it gives you sort of an assurance that somebody’s there...But they make you feel better, you know, somebody’s coming. Something you can fall back on. (O11, 1195-1201).

Oxygen participants and their support persons had a trusting relationship with their visiting nurses. Having their health status monitored in-home on a regular basis and the knowledge that questions would be answered and concerns would be communicated to the appropriate practitioner was a source of comfort and reassurance.

Two oxygen participants spoke of the benefits of receiving intravenous therapy while at home. This home-based service reduced their length of stay in hospital and allowed them to convalesce in the comfort of home, reduced their chances of acquiring a nosocomial infection, and allowed them more freedom to ambulate as desired.

In addition to receiving the home oxygen and nursing services under the Home Care Program, six oxygen participants received additional types of home care assistance with meal preparation (n=2), personal care (n=4), bed making/laundry (n=3), and/or respite care for caregiver (n=1). In general, these services were found to be beneficial although three oxygen participants expressed discontent in having assistance with bathing. One participant found the requirement for daily personal care embarrassing and
unnecessary especially since her physical condition had improved post discharge from hospital two months prior.

That is another thing that bugs me. The home care insists that somebody comes and helps me wash and dress in the morning. Well I get up at 7:00 [a.m.] o’clock, she [home care attendant] gets here about a quarter after eight. Nine times out of ten, I’m washed and dressed (O12, 573-577).

Two other participants received assistance with bathing once a week. They questioned the value of this infrequent assistance.

I get into the shower and he [home care attendant] stands there to make sure I don’t fall on my head. I have got the safety bars and bench to sit on and everything and then he helps me dress, which is not necessary. He dries me off which isn’t necessary. What are they doing once a week? Do they think a man just showers once a week? If they want to help me send one every day, but I don’t expect that. This is a token isn’t it (O15, 769-775)?

Assistance with personal care was embarrassing and was deemed to be unnecessary by three of the four oxygen participants receiving this type of service.

**Home Oxygen Providers**

Home oxygen suppliers are responsible for the provision and installation of Home Oxygen equipment, education of equipment use and oxygen safety, ongoing repair and maintenance of equipment and emergency service should the client experience an equipment failure or extended power outage. In general, oxygen participants and their caregivers were satisfied with all aspects of their home oxygen services.

He [oxygen company representative] was excellent. He told us all about the condenser [oxygen concentrator], the noise it’s going to make and how long it will last. Oh he is super, he went through everything. He told us how many of these [canula] and how much tubing we had. Yea he’s whoever trained him did a good job (W31, 1568-1573).

I appreciate it [Home Oxygen Program]. It works. It makes you feel a lot better and the service is good, you know. I could phone in the morning if I had something I needed and have it in the afternoon (O11, 816-819).
I think they got a good program and it’s nice that they do provide home oxygen. You know that concentrator is very valuable (O14, 1360-1361).

One oxygen participant felt her initial in-home training session regarding oxygen equipment was inadequate. This necessitated a call to the company a few days later to request a repeat education session.

So they came the oxygen people. And they went through a whole bunch of questions, I forget. I really don’t know what they all talked about but they were talking to them [other family members present at training]. And she [oxygen company representative] kept turning her back on me so I couldn’t hear questions...And ah then I called them again. And explained they went through all these papers and everything else and I didn’t have a clue what they had been talking about. Cause they were talking to them, and me with a hearing problem (O12, 1346-1350, 1356-1360).

During the initial education session the oxygen client was not included as an active participant and the trainer was not cognizant of possible hearing impairments. This oversight was especially significant in this case as oxygen participant lived alone and family members only provide backup support if required. The oxygen participant recognized she lacked important information and was empowered to call and ask for further training.

In summary, the Home Care services provided to oxygen participants were appreciated and valued. Should their need for Home Care services increase at any time, they were very confident that their respective Home Care Case Coordinators were a phone call away and that every effort would be made to provide them with necessary assistance. Oxygen participant’s were conscious of the importance of maintaining their dignity and independence and did not want to abuse the Home Care system by receiving services they did not require. Confidence and trust in home oxygen providers was also
evident. Participants viewed home oxygen supply company employees as knowledgeable and provided regular and emergency service in an efficient manner.

**How Do I Know What I Don’t Know? – Importance of Disease Management Education**

The majority (60%) of the study’s oxygen participants indicated that they had participated in some type of formalized pulmonary education and exercise program. A variety of health care professionals including nurses, respiratory therapists and physiotherapists and occupational therapists delivered these programs. These programs provided a combination of exercise and skill building such as pursed lipped breathing, physical strengthening exercises, energy conservation and the importance of regular physical exercise.

I was taught that [breathing exercises] at the Day Hospital. That sure was a great help because they taught me to breathe. They taught me how to cough control. And then they taught me how, what method to use to ah loosen up the lung, lung congestion and to exercise. How to go about easily and body motion and how to walk (O5, 57-62).

It was clear from descriptions of daily activities that these oxygen participants incorporated knowledge and skills into their disease management programs. Attending programs with other individuals experiencing respiratory problems provided an atmosphere of peer support.

Ongoing it was a support group and a refresher for us (W3, 1701).

It is a support group as well as a treatment you know (O5, 1116).

Participants also developed trusting relationships with the professional educators of these programs and these professionals were held in high regard.

They’re well schooled those people. They’re right up on the bit. You ask them a question and I tell you they’re not long flashing it back to you. They’re not stammering and stuttering around, trying to get it out of a book (O9, 1038-1042).
They are great nurses that look after us (O5, 1105-1106).

One support person spoke of how she continues to call nurses at the Respiratory Program staff for advice and in one instance a staff person was instrumental in getting her husband (oxygen participant) in to see a specialist.

The education programs and literature provided by the Manitoba Lung Association had not been well utilized by the study participants. When asked about the use of Manitoba Lung as an information resource, only two couples had attended “Easy Breathers” sessions and only one support person had phoned Manitoba Lung and requested information be mailed. One participant expressed that some disease education is more prominent than others.

Like I say they spend a lot of time explaining asthma. There are pamphlets that you pick up all over the place but I don’t see a lot of emphysema. The only thing they usually say is they talk about smoking. Smoking is not good for you, it could cause emphysema that is about all they provide (O14, 1481-1485).

The oxygen participants who had participated in pulmonary education and exercise programs had positive experiences with these programs and continued to use some of the skills they were taught such as pursed lipped breathing, stair climbing, exercises and energy conservation techniques. Six of the 15 oxygen participants had not benefited from attendance in pulmonary education programming.

Despite ongoing relationships with knowledgeable care providers and the availability of educational programs, several participants expressed gaps in the amount of information they received specific to oxygen. It was difficult to ask questions and gain knowledge about oxygen when participants did not know what they did not know.
So you go to these classes to be taught how to breathe and to do your pursed lipped breathing, you know, see how far you can go without. And the last one I went to I said why don't you sit down and teach people about oxygen. What oxygen does for you like you know...There isn't any body my specialist said you have to be on oxygen, went to the hospital they said you have to be on oxygen, I didn't know what the hell oxygen was. I knew what it was, but how important? (O8, 1547-1551, 1554-1557).

For this participant a vital component of her disease management education had not been addressed by her specialist or any of the other health care providers. The home oxygen supplier taught her and her husband specifics of the oxygen delivery systems and their care and maintenance. The community based education program she had attended was for individuals with respiratory disease and had not contained information specific to oxygen. This participant was not alone in her initial lack of understanding of why oxygen was required.

They said they were going [to put me] on two liters, what the hell is that? I didn’t know what 2 liters a minute was...Like I put them [pieces of information] together myself (O14, 14553-1455, 1459).

When I first came home the nurse that came here said that maybe you can work it where you can be off it for a couple of hours or whatever. I said yea I hope so so I don’t have to take it to bed with me. She jumps right up and says 'Oh no no no, that’s the last place you can be without it. You have to have it'. So I couldn’t figure it out. But I could see it now. I mean you are not working [at breathing] to get anything, that [oxygen] is keeping you alive (O10, 925-932).

Why am I on oxygen? Well to start with the head honcho in respiratory decided that’s what I needed according to my blood gasses and whatever else...(O31, 1209-1211).

From discussions with oxygen participants it was evident that there were some deficiencies in understanding why oxygen had been ordered for them despite the fact there were numerous of health care providers involved in their ongoing care. Even
participants who had benefited from community based respiratory management education lacked information about oxygen and why it was required as a treatment.

**Summary of Major Findings**

The implementation of long-term oxygen technology is most often an end-stage treatment option within the illness trajectory of chronic respiratory disease. Hearing the news that long-term oxygen is to be a component of an individual/support person’s lives launched participants into the cultural world of oxygen, inclusive of its own set of knowledge, language, artifacts, customs and rituals. How the oxygen experience was incorporated into the lives of these individuals was dependent on the ongoing processes of acceptance and adaptation to this new way of being. Oxygen users and their family/support persons faced many challenges and limitations. For most participants the introduction of long-term oxygen brought with it tangible reductions in symptoms and identifiable improvements to quality of life. These findings revealed that it is possible to live with chronic respiratory disease requiring long-term oxygen and still maintain a positive of view of health and experience an acceptable level of quality of life.

Oxygen participants experienced two prominent uncertainties in their lives. One uncertainty was related to living with chronic respiratory, variable symptoms and unpredictable exacerbation, which precipitated the fear of an inability to breathe. The other major uncertainty in the lives of oxygen users pertained to oxygen technology and the requirement of a consistent supply of oxygen, which resulted in the dread of running out of oxygen. Individuals and their families implemented planning, control and management strategies into their daily lives to ameliorate the effects of these ongoing uncertainties.
The personal relationships between oxygen participants and their family/support persons in this research project were stable. A strengthening in relationships as a result of the terminal nature of respiratory disease was reported by several dyads. Support persons did not express the care they provided as burdensome and incorporated caregiving responsibilities into their day-to-day activities as a reciprocal component of their existing relationship with the oxygen user.

Oxygen participants and their support persons were appreciative of the Home Care and Home Oxygen Programs. As a result of long illness trajectories, participants had interacted with a number of health care professionals throughout their disease and oxygen experience. Although participants spoke of trusting relationships with health care providers it was clear that no one provider directed their care and/or provided them with information about their disease and their requirement for oxygen as a treatment modality. As a result participants revealed some inconsistencies in knowledge and the ability to access services.

**Recommendations From Participants**

Prior to the conclusion of each interview, oxygen participants and their support persons were asked for their suggestions on improvements to the oxygen equipment or health services that they currently received. Their recommendations were categorized into two groups, oxygen equipment and system related improvements. These suggestions are summarized in the following statements:
**Oxygen equipment improvements.**

- Reduce the noise and heat produced by oxygen concentrators.
- Reduce the size of oxygen concentrators to make them more portable.
- Create custom made cannula that could be fitted much the same as glasses.
- Develop remote control devices or automatic liter flow adjustment capabilities compatible with oxygen concentrators so that flow rates can be adjusted without physically returning to the concentrator.
- Provide tubing connectors that are smooth so as not to catch on furniture.
- Improve cylinder regulators to make them user friendly and easier to change for individuals with reduced physical strength.

**System related improvements.**

- More information and education provided to individuals and support persons prior to the set up of oxygen equipment.
- Respiratory specialists and medical practitioners provide ongoing information to clients with respiratory disease.
- Pulmonary education/rehabilitation programs should be made available prior to requiring oxygen.
- More professional assistance and programming be made available for individuals who demonstrate the desire to quit smoking.
- Home intravenous programs for individuals with respiratory disease.
- Portable oxygen be readily available in institutions to enhance long-term oxygen users' ability to ambulate more freely during periods of hospitalization.

- Portable oxygen pricing be standardized and costs related to portable oxygen be directly billable to Pharmacare.

- That conserving devices be made available to individuals who benefit from such a device but cannot afford to purchase privately.
CHAPTER FIVE

DISCUSSION OF THE FINDINGS

Introduction

In this chapter I discuss findings that emerged from the study “Living with Long Term Oxygen Technology: Individual and Family Perspectives”. The experiences of oxygen participants and their designated support persons are discussed and compared to findings obtained from the literature. In the second section of the chapter, the relationship of the findings to the conceptual frameworks that guided the study, Mandala of Health and Uncertainty in Illness Theory, are examined for their relevance to this study. The chapter concludes with recommendations for education, practice, nursing research and health care systems based on the findings, recommendations from the study’s participants, and identified gaps in health care services.

Summary of the Findings

Six themes emerged as a result of data collected from 15 older adults on long-term oxygen and their designated support persons (n = 15) who participated in this study. These themes categories were:

- The illness trajectory – journey toward oxygen,
- Living with oxygen - a process of acceptance and adaptation,
- Beyond the security of home,
- Living with oxygen - effects on family/support persons,
- Living with uncertainty – planning control and management, and
- The value of professional support and knowledge.
Answers to the research questions are addressed within these themes. It is important to note that many of the experiences and feelings of living on long-term oxygen for these individuals and support persons are intertwined with their experiences of living with chronic illness; therefore literature to compare and contrast the findings is drawn from long-term oxygen therapy research as well as that of chronic illness.

Discussion of Themes and Categories

The Disease Trajectory – Journey Toward Oxygen

The oxygen participants in this study had respiratory diseases that were incurable and progressively debilitating. Respiratory disease seldom develops overnight and initial stages of the disease were insidious. Individuals often sought medical intervention during an exacerbation or when their dyspnea became undeniable and intolerable (Tiep, 1997).

Fourteen of the 15 oxygen participants (93%) in this study revealed an extended smoking history, which complicated their respiratory disease and contributed to their requirement for oxygen. This is consistent with the evidence that smoking is the major etiologic factor in the development of chronic bronchitis and emphysema (Brannon, Foley, Starr, & Saul, 1998; Canadian Respiratory Review Panel, 1998; Chapman, 1992; Editorial Board Respiratory Disease in Canada, 2001; Lacasse, Brooks, & Goldstein, 1999; Tiep, 1997). In the case of alpha1-antitrypsin deficiency, genetic susceptibility to respiratory irritants such as tobacco smoke can cause earlier onset (age 32) of this rare form of emphysema (Brannon, et al., 1998; Chapman, 1992).

Chronic respiratory disease is a largely irreversible disorder. Smoking cessation to prevent further lung damage is an essential when COPD is diagnosed. This form of secondary prevention slows the rate of decline of pulmonary function (Canadian
Respiratory Review Panel, 1998; Chapman, 1992). As revealed by the participants in this study, smoking cessation is difficult to achieve given the physical addiction to nicotine and multiple behavioural factors involved in the act of smoking (Brannon, et al., 1998; Chapman, 1992). Studies have demonstrated that primary care physicians can increase an individual’s chances of succeeding in quitting smoking (Canadian Thoracic Society Workshop Group, 1992) but many general practitioners neither ask patients about their smoking behaviour nor provide counselling; despite the crucial role smoking can play in a person’s health (Cunningham, 1996).

**Hearing the News**

Second only to long-term institutionalized care, oxygen therapy may be the most life-changing treatment option offered to individuals with end stage chronic respiratory disease. Hearing the news launched participants into the cultural world of oxygen with its own set of knowledge, customs, language and artefacts. This new life included the intrusion of technology and equipment into their homes, equipment and supplies to maintain, safety protocols to follow, physical and sensory discomforts to cope with, and accommodation to time and life style restrictions. This precipitated real and perceived losses for these individuals and therefore evoked a range of emotions. To date no other long-term oxygen researcher has explored the feelings individuals experience when they are first informed of their requirement for long-term oxygen.

Those participants who expressed feelings of relief and acceptance saw in-home oxygen as a symptom relief measure and a necessary option to avoid frequent hospitalizations or long-term institutionalized care. Acceptance was a resignation that
one must go along with the constraints of the illness because there were few alternatives (Jonsdottir, 1997; McBride, 1993; Small & Graydon, 1993).

Denial was a defence mechanism activated to protect individuals from being overwhelmed by the reality of the situation and provides time to assimilate the impact of the illness and its consequences (Kahn, 1995). Some of the oxygen participants could not “visualize” themselves living with oxygen and appearing as less than “normal”. These participants viewed oxygen therapy as an admission of being “handicapped”. Until the point of requiring oxygen therapy they may have been able to pass for “normal” by concealing the condition and symptoms from others (Joachim & Acorn, 2000). The visible nature of oxygen therapy gives rise to body image concerns (Borycki, 1996) and provides unspoken evidence of disability (McMahon, 2000).

The experience of loss is prevalent in the downward trajectory of chronic illness (Corbin & Strauss, 1988; Harmon Hanson, 2001; Miller, 2000). When any type of “bad news” is communicated, some individuals grasp the news and its implications immediately; others need time to absorb the information (Corbin & Strauss, 1988). The cumulative effect of multiple losses may create doubts in an ill person’s mind about their ability to maintain quality of life (Miller, 2000).

Oxygen participants who experienced anger were grieving the loss of freedom, which had implications for fulfilling role expectations and their ability to partake in social activities. Their feelings of loss were heightened and they had yet to arrive at the state of acceptance and the realization that even though many choices in life were now restricted, many activities remained within their level of functioning and new skills and strategies could be developed (Kahn, 1995). Sustained anger, as was the case with two oxygen
participants, kept them from confronting the sadness associated with the loss and they required time and effort to learn more appropriate ways to express the anger (Kahn, 1995).

This study’s findings indicate that individuals who receive oxygen as a life-long treatment will have a variety of feelings and perceptions based on the reality that home oxygen is a life-altering event with many ramifications for both individual and family/support persons. Health care professionals must provide opportunities for clients to explore fears and perceptions of in-home oxygen therapy to facilitate acceptance of this important treatment option.

Living with Oxygen- A Process of Acceptance and Adaptation

This theme explores the day-to-day positive and negative life experiences of living with long term oxygen and answers the research question, “What is the experience of living with in-home oxygen therapy from an individual and family/support person perspective?” This theme also explores questions regarding assistive and restraining factors of long-term oxygen and provides insights into how oxygen participants viewed their health and quality of life.

Study findings revealed that oxygen participants engaged in a process of acceptance and adaptation of oxygen into their lives. Together with supportive care providers, they adapted to ongoing challenges and limitations by incorporating new strategies and ways of being into their lives. Study participants experienced restraining factors such as the restrictions of space, physical discomforts, sensory irritations, emotional hills and valleys, and the limitations of “time in a bottle”. Assistive factors
manifested themselves in the form of caregiver and family support, meaningful activity, assistive devices, and community resources.

Acceptance was interwoven with the process of adaptation. As limitations and challenges arose, participants accepted new realities and adapted to the cultural world of oxygen through the creation of innovative ways to normalize their lives and to live in harmony with their oxygen experience. Acceptance and adaptation to a life with oxygen was assisted by the positive attributes oxygen brought to the lives of participants. Oxygen was deemed to be important to their lives as it “gave them life”.

Acceptance and adaptation experienced by the oxygen participants and support persons in this study validated previous home oxygen research conducted by Ring and Danielson (1997) and other chronic illness research (Baker & Stern, 1993; Borycki, 1996; Corbin & Strauss, 1988; Crigger, 1996; Pollock, 1992; Small & Graydon, 1993; Stuifbergen, Serahine & Roberts, 2000). Ring and Danielson’s (1997) study revealed acceptance of oxygen therapy as “an advantage for the body”, a requirement, and a necessity to live. The experience of well-being as a consequence of the treatment was important in their acceptance of the therapy. Adaptation to a life with oxygen was portrayed in the theme “put up in order to live”. Living with oxygen required learning alternate ways of doing things in order to adapt to limitations and new situations (Ring & Danielson, 1997).

Stuifbergen, Serahine, and Roberts (2000) reveal acceptance as a process of integrating of chronic disease into overall lifestyle with the realistic view that one must accept the illness in order to get on with living. Corbin and Strauss’ (1988) work supports acceptance as variable ranging from non-acceptance to full acceptance. Even
when the person is relatively accepting, an incident may cause the individual to grieve again for what has been lost as was evidenced by several participants in this study. Acceptance may suggest that a person has found a way of accommodating to an illness through altered or changed performance, and in doing so gives meaning to life despite ongoing or progressive body failure (Corbin & Strauss, 1988, p. 78). Acceptance to long-term oxygen therapy occurred more readily for support persons and for some oxygen participants more so than others. Acceptance to a life with oxygen was reached through the realization that although oxygen created many challenges and limitations, it provided beneficial symptom relief and was necessary for improvements in quality of life. Those oxygen participants who saw little or no improvement in their physical status and a subsequent deterioration in their quality of life had more difficulty achieving acceptance to the introduction of long-term oxygen in their lives. Acceptance ebbed and flowed and periodically required cognitive renegotiation when new challenges or limitations presented themselves.

Adaptation is a complex process involving numerous internal and external factors that influence responses (Pollock, 1992). Behavioural adaptation as demonstrated by this study’s participates included: selection, optimisation, compensation and receiving help (Gignac, Cott & Badley, 2000). “Selection adaptation” occurred when activities were performed less often such as gardening, avoided or given up altogether. Optimisation adaptation activities were aimed at augmenting or enriching reserves. Compensation was demonstrated when assistive devices were used or an activity was modified. Receiving help was most often from primary support persons but also came from other family members, home care providers and other service agencies.
Finding symbolic meaning in chronic illness by accepting its reality and re-framing its implications is no easy task (Baker & Stern, 1993); therefore it cannot be assumed that adaptation is a normal and expected outcome for everyone experiencing chronic illness (Baker & Stern, 1993; White, Richer & Fry, 1992). This was the case with two oxygen participants who had difficulty finding positive aspects in a life with oxygen. Non-accommodation to chronic illness decreases receptivity to the promotion of self-care activities and prevents individuals from integrating illness into their identity in a way that allows seeing themselves as being normal and having control (Baker & Stern, 1993).

Despite the positive aspects that oxygen brought to lives of oxygen users and support persons, long-term oxygen presents several restraining factors. Significant to the lives of the study participants was the sense of always being “on a leash” and attached to the oxygen concentrator or portable cylinder, which placed constraints on their space and time. The length of their oxygen tubing within their home represented parameters beyond which they could not travel and the capacity of portable oxygen cylinders contributed to limitations of “time in a bottle” and the ability to freely partake in activities outside the home.

The restraining nature of living with oxygen is consistent with Ring and Danielson’s (1997) theme of “restricted to time and room”. Participants in their study expressed similar issues of being confined to home, difficulties with mobility “apparatus”, hindrances caused by oxygen tubing, restrictions in being able to travel and limited time in portable cylinders. Boryki’s (1996) sub-sample of oxygen users described oxygen and its related equipment as an imposition and a restriction to their daily lives.
The amount of oxygen in their portable cylinders defined the distance within which an individual was able to move outside the home.

Multiple assistive forces helped oxygen participants live with the restrictions of oxygen. Collectively these assistive forces helped to overcome physical, psychological and social challenges inherent in living with long-term oxygen and chronic disease. Caregiver support, assistive devices, and community services were instrumental in providing day-to-day support and assistance with management of oxygen and their disease.

Support persons were modest in describing their contribution to care provision. Caregiving by support persons was considered one aspect of their reciprocal relationship with the care receiver and was based on familial or friendship ties. The importance of family/support persons and supportive systems is prevalent in the chronic illness literature (Abel, 1991; Corbin & Strauss, 1984, 1988; Gignac, Cott & Badley, 2000; Hanson, 1988; Harmon Hanson, 2001; Leidy & Haase, 1996; Lubkin, 1995; McMahon, 2000; Miller, 2000; Montgomery, 1999; Ring & Danielson, 1997; Small & Graydon, 1993; Stuifbergen & Rogers, 1997; Wright & Leahey, 1987). Although friends and neighbours constitute an essential source of support, family members deliver the majority of illness care in the home (Abel, 1991).

Families and support persons provide many social and psychological supportive care functions (Hanson, 1988; Harmon Hanson, 2001; Leidy & Haase, 1996; Stuifbergen & Rogers, 1997). Family and friends were important enablers for the participants. Enablers facilitated or made possible the performance or continuation of activities and day-to-day tasks. This was particularly important to those trying to remain in their own
homes (Leidy & Hasse 1996). The illness work that families engage in may be complex and labour intensive (Corbin & Strauss, 1984, 1988). Although, the two adult children in this study appeared to be the most affected by their caregiver role, neither described their caregiving activities as burdensome. For the caregiving daughter, travel issues (lived a 20 minute drive from her mother) and balancing the needs of a young family with those of her mother were expressed concerns. The caregiving son in this study lived with his mother and with the exception of home care assistance for her personal care needs he provided the remainder of her caregiving support. This son was not working due to his own chronic health issues and his mother’s caregiving requirements. The alternative to caregiving for his mother was to have her placed in a long-term care facility a option neither was in favour of. As was evidenced in this study, the supportive care provider and the chronically ill individual adapted to role changes and negotiated strategies for performing necessary tasks (Hanson, 1988). Contrary to Kuyper and Wester’s (1998) findings caregiver burden was not significant in this study as caregivers articulated few problem areas and demonstrated positive quality of life ratings. Burden in this caregiver sample may have been buffered by the availability and support of home care and community services. Limited evidence of caregiver burden may have also been as a result of sampling bias, in that only home oxygen participants in supportive and well functioning relationships agreed to participant in this study.

Assistive devices facilitate the functional performance of the chronically ill (Day & Jutai, 1996; Gignac, et al., 2000; Leidy & Haase, 1996). Artefacts of the oxygen culture such as concentrators, carts, carry bags, and cylinders were clearly evident in the participants’ homes. In addition to more conventional devices, shopping carts, cell
phones and oxygen conserving devices provided assistive support to oxygen participants. Oxygen-conserving devices were used by 53% of the study’s oxygen participants and played an assistive role in enhancing mobility, socialization and quality of life for those who purchased these devices.

The oxygen participants in this study used a variety of agency and community services to assist them to live with the restrictions placed on them by their requirement of oxygen and their chronic disease. Organizational and system sources offer a supportive role to individuals living with chronic illness (Stuifbergen & Rogers, 1997). Limited research in this area speaks to the need to explore the value of community-based support systems to those living with chronic illness in the community.

**Beyond the Security of Home**

Oxygen participants with the support of their caregivers generally managed well with the limitations of their oxygen and within the protected controlled environment of their home. Moving outside the security of their home exposed oxygen users to environmental factors and elements that sometimes caused difficulties beyond their control.

Air quality and other environmental factors such as exhaust fumes, stubble burning, smoke from fires, pollen, wind, cold and humidity were frequently cited triggers. Fifty-three (53%) of the oxygen participants in this study had an aversion to environmental tobacco smoke with reactions ranging from mild to severe. The significance of tobacco smoke as an environmental trigger for this population provides further support for healthy public policy regarding air quality control and smoke free environments. Environmental irritants including tobacco smoke, dust, mould, particulate
matter and strong odours cold air, humidity, and wind are problematic for individuals with respiratory disease. Prevention and avoidance of identified triggers are coping strategies used to reduce incidences of dyspnea (Borycki, 1996; Tiep, 1997).

Moving beyond the security of home placed home oxygen participants at the mercy of built environments. Long-term oxygen and respiratory disease researchers have not examined the implications of built environmental issues regarding this population. The physical effects of carrying oxygen paraphernalia was compounded by the effects of their debilitating disease and built environmental barriers. Stair climbing and ramps were the most frequently encountered challenges in the built environment. Oxygen participants avoided environmental barriers whenever possible, which at times resulted in the discontinuation of a favourite activity such as social clubs and attendance at church suppers. Similar to the findings of Stuifbergen and Rogers (1997), supportive factors within the broader environment promoted access in the community. These factors included: the provision of wheelchairs at entrances of public buildings, electric push button door openers and public policy regulations mandating designated handicapped parking.

**View of Health**

The self-reporting by the oxygen participants in this study indicate that it is possible to view health in a positive way despite the limitations of oxygen and the debilitating effects of chronic disease. Two research studies exploring the perceptions of health in chronically ill populations validate this finding. Perry and Woods (1995) found health could be experienced despite chronic illness and disability, as being healthy was a philosophy or way of living. Important characteristics to health were energy,
independence, and realistic optimism. McWilliam, Stewart, Brown, Desal, and Coderre, revealed that health was being able to do the things individuals wanted to do and required balancing between “want to dos” and “need to dos” (1996). Positive attitude, appreciation of life, energy conservation and balancing day-to-day activities were all strategies used by this study’s oxygen participants to maintain a positive perspective regarding their own health.

**Quality of Life – “Could be Better But Its Not Bad”**

Eighty percent (80%) of the oxygen users in this study rated their quality of life as being in a range between acceptable and the best they could be (Figure 3, p. 104). This positive quality of life rating for long-term oxygen users conflicts with previous findings (Heaton, Grant, McSweeny, Adams & Petty, 1983; Janssens, Rochat, Frey, Dousse, Pichard & Tschopp, 1997; McSweeny, Grant, Heaton, Adams, & Timms, 1982). McSweeny, et al. (1982) found that COPD patients receiving oxygen therapy reported more tension, depression, anger, confusion and fatigue and less energy than a matched group of healthy subjects. Their group reported a higher level of life disruption including recreational, home management, and sleep and rest. A follow up study conducted on 150 participants from this study found no appreciable change in self reported emotional status or general life quality after six months of supplemental oxygen treatment (Heaton, et al., 1983). Janssens, et al. found a high prevalence of depressive and anxiety disorders in long-term oxygen users. In a one-year follow up, quality of life index scores were low and the prevalence of emotional disturbance remaining unchanged (1997).

Emerging chronic illness research points to antecedent variables of quality of life and revealed that social support as a significant variable in assisting individuals to make
psychosocial adjustment to chronic illness and health outcomes (Stuifbergen, Serahine & Roberts, 2000; White, Richer & Fry, 1992). Strengthening mediating variables such as social support and health-promoting behaviours may enable individuals to maintain and perhaps even enhance quality of life (Stuifbergen, et al., 2000). Given what has emerged regarding antecedents to quality of life, it could be hypothesised that the long-term oxygen users in this study had higher self-reported ratings of quality of life because of their social support systems, their use of community services, and health promotion practices. Findings from this current study point to mobility oxygen and conserving devices as important variables in the enhancement of quality of life for long-term oxygen users. These factors, in addition to the availability of home care services, may not have been available to the oxygen users participating in the previous quality of life research conducted in this area.

Living with Oxygen – Effects on Family/Support Person

Family and support person experiences are reflected throughout this chapter. This theme provides information regarding the research question specific to the affects of long-term oxygen on support person quality of life and family life in general.

Support person quality of life ratings (see Figure 3, p. 104) were higher than their oxygen user counterparts. Seventy-three percent (73%) of support persons rated themselves as having an acceptable quality of life. Although they reported their quality of life had lessened over time, they felt this was related to family and work commitments, personal health problems, their own ageing, as well as the introduction of oxygen into their lives. Spousal caregivers felt that the long-term requirements and limitations of oxygen contributed to a decline in number of activities they engaged in as a couple.
Most long-term caregiver research has focused on burden, stress, and depression as outcomes of caregiving with little research in the area of caregiver quality of life (Canam & Acorn, 1999; Scott, 2000). Scott (2000) investigated family health-related quality of life (HRQL) in care providers of at-home technologically dependent individuals with heart failure (Scott, 2000). Similar to the findings of this study, caregivers in the Scott study felt positive about their role as caregivers and demonstrated higher HRQL ratings than care receivers, with caregivers deriving satisfaction from friends and family. Areas of dissatisfaction were related to employment status, travel restrictions, lifestyle changes and the stress associated with caregiving. The number of tasks influenced a variation in quality of life. Scott also found that when caregivers perceived they were unprepared for the caregiving role, they experienced more adverse effects (2000).

Areas of relationship tension identified in this study primarily occurred as a result of role discrepancies. Oxygen participants expressed concerns of not wanting to be a burden to caregivers and had difficulty watching care providers do things they could no longer do. Imbalances in illness and household management can be sources of stress for individuals and their care providers (Corbin & Strauss, 1988; Stuifbergen & Rogers, 1997). The role of family members (support persons) expands when the chronically ill persons’ roles diminishes, (McMahon, 2000). Successful role sharing and division of labour require a clear understanding and acceptance of how the tasks are to be divided. There must also be a perceived mutuality between the partners, a perception that each is doing a fair share or all that each is capable of doing under the circumstances (Corbin & Strauss, 1988). The caregiver - care receiver dyads in this study demonstrated successful
collaboration by coming to terms with the illness, demonstrating commitment to the relationship, compromising so that one does not seem to be doing all the work, taking time out from illness work to enjoy social activities and by sharing thoughts and feelings with one another (Corbin & Strauss, 1988).

**Living With Uncertainty – Planning, Control and Management**

“Uncertainty is a constant experience of chronic illness due to the unpredictable and inconsistent symptom onset, continual questions about recurrence or exacerbation, and an unknown future due to living with debilitating conditions” (Mishel, 1999, p. 269). Support for uncertainty as defined above was prevalent throughout this study. This theme addresses the question regarding what uncertainties does living with long-term oxygen bring to the lives of oxygen users.

Symptoms and exacerbations related to respiratory disease and the need for a consistent source of oxygen were not always predictable. As a result, two profound uncertainties were revealed in this population. These included the inconsistent nature of respiratory symptoms leading to the fear of the inability to breathe, and the uncertainty related to the dependency on oxygen technology and the dread of running out of oxygen. Recognizing that these uncertainties were sustaining and impossible to irradiate, oxygen participants and their support persons incorporated a “probabilistic paradigm” into their daily lives (Mishel, 1990, pp. 260) and as a result uncertainty became integrated into the oxygen users’ cultural way of being.

The unpredictable fluctuation of respiratory symptoms and experience of “good days and bad days” is a known and documented entity in chronic respiratory disease (Borycki, 1996; Leidy & Haase, 1996; Ring & Danielson, 1997; Small & Graydon,
Small and Graydon (1993) found that the unpredictable course of illness was a source of uncertainty in COPD. Other areas of uncertainty demonstrated in their study were the future severity of symptoms, efficacy of treatment, and extent of progression of the condition. Concern relating to the efficacy of treatment as revealed by Small and Graydon (1993) was not expressed by the oxygen users in this current study.

In general, oxygen participants coped well with the uncertainty of their chronic illness and fluctuating symptoms. Physiological coping was accomplished by either living their lives “one day at a time” or by recognizing that death was inevitable and actively planning for what future they had. These diverse strategies are examples of accepting the realities of illness and incorporating a new world view and ways of living as methods of coping with the uncertainties of chronic illness (Mishel, 1990; Small & Graydon). Those participants who planned for the future employed optimistic and self-initiating coping strategies to effectively manage their disease uncertainty through futuristic thinking (Baker & Scholz, 2002; Small & Graydon, 1993).

The inability to breathe was an unpleasant consequence of exacerbations and thus exacerbations were to be prevented and managed to reduce uncertainty. Disease self-management rituals and the paraphernalia associated with it become part of the individual and support persons’ home culture and customs. Disease self-management is a comprehensive and coordinated system of care that deals with the disease state, rather than acute episodes (Tiep, 1997). Its value and prevalence of use is well supported in respiratory disease literature (Boulet, Becker, Berube, Beverridege & Ernst, 1999; Cote, Cartier, Robichaud, Boutin, Malo & Rouleau, 2000; Kolbe, 1999; Rivington, 1997; Small & Lamb, 1999; Tiep, 1997).
Uncertainty of Living With Oxygen Technology – The Dread of Running Out

The dread of running out of oxygen was also a significant uncertainty for this population of oxygen users and has not been previously documented. The intrinsic importance of oxygen is contained in their rich descriptions and their expressions of oxygen as “a necessity”, “the ability to breathe”, “it is me now”, “my lung” and “its my life”. The uncertainty of running out of oxygen can only be fully understood by those who have experienced the sensation. Running out of oxygen was such an unpleasant experience that study participants incorporated extensive planning, control and management strategies into their daily routines in an effort to restrain the uncertainty.

Levels of uncertainty with respect to running out of oxygen were related to the individual’s physical location and the availability of backup oxygen. The uncertainty of running out of oxygen appeared minimal in the more predictable environment of their home and escalated as they moved farther away from home and community. Even short trips required preplanning, sufficient oxygen supplies, and backup plans for the unexpected. Careful monitoring of time in the portable cylinders dominated and often detracted from their social outings. The uncertainty associated with long distance travel was prohibitive to many of the study’s participants. Those who travelled bore the costs associated with additional equipment, complex planning and higher levels of uncertainty.

The Value of Professional Support – Relationships with Health Care Providers

This theme addresses the nature of the participants’ relationship with health care and service delivery providers. Given their long disease trajectory toward oxygen, participants interacted with a wide variety of health care professionals and services providers.
Specialists and medical practitioners were seen as the medical managers of the oxygen participants’ care. Specialist appointments were sometimes frustrating, as little information was provided or information was delivered in a “piece meal” fashion during brief appointments. Health professionals can be “intruders” in the management of chronic illness if they act busy and important and do not want to be bothered with simple questions or concerns. This can lead to situations where clients perceive a detached rather than collaborative relationship with care providers (Leidy & Haase, 1996).

Lack of understanding was evidenced by the fact that some home oxygen users were started on long-term oxygen without knowing why. Small and Graydon (1993) found that patients being discharged home on oxygen experienced feelings of uncertainty due to inadequate knowledge of oxygen and lack of skills in managing equipment. This speaks to the importance of effective communication and education by health care providers. Providers who communicate, listen, teach, and help to clarify diagnosis, treatments, and care at home are critical to quality health care for consumers (Oermann, 1999).

Participants in this long-term oxygen study recommended that specialists and medical practitioners provide more disease and oxygen related education to their clients and that other care providers such as nurses be designated to brief new oxygen clients on what to expect. One participant contrasted the limited information he received regarding his respiratory disease and requirement for oxygen to the thorough education that he was provided prior to a surgical procedure. As both situations had a significant impact on health, he postulated that both warranted similar levels of education and preparation.
Deficiencies in the health care system experienced by participants in this study are largely due to that fact that the traditional health care system is designed for treatment of acute illness. The system is inadequate in meeting the needs of the growing chronic illness population. This has the potential to encourage dependency on the system as individuals are often not given the information or tools they require to deal with disease management and daily living (Nodhtuft, Schneider, Hebert, Bradham, Bryant, Phillips, Russo, Goettelman, Aldahando, Clark, & Wagener, 2000). Lack of a cure for chronic illness results in health care professionals who fail to realize the important role they have to play in facilitating health promotion for those individuals with chronic illness (Stuifbergen & Rogers, 1997).

As most chronic illness is managed in the home, the relationship between recipients of home care, family members and the home care nurse is important in the fostering of wellness within chronic illness. Ward-Griffin and McKeever revealed that very little empirical analysis has been undertaken regarding the relationship that develops between nurses and family caregivers. Their research indicated that nurse-family caregiver relationships were complex, dynamic and multifaceted. Both nurses and family caregivers recognized and valued the separate contributions of each other’s caring work (2000). Participants in this study had trusting relationships with their nurses and expressed reassurance that their health status was being monitored given that home care nurses often act as the eyes and ears of other care providers.

Links with Conceptual Frameworks

The theoretical frameworks used for this study included the Mandala of Health model and Uncertainty in Illness Theory. The Mandala of Health is a holistic model of
the human health ecosystem. The individual is seen as the centre of the universe and cannot be viewed in isolation from family, community and broader society. The health of individuals is intimately bound with their physical and social environments and factors within community and broader social world are important determinants of health (Hancock, 1985). Uncertainty in Illness Theory is a mid-range nursing theory that explains how persons cognitively process illness-related stimuli and construct meaning in these events. Uncertainty concerning what will happen, the consequences of an event, and what the event means are important to persons with any illness (Mishel, 1988).

These theoretical frameworks proved to be relevant to this study of older adults and their support persons living with long-term in-home oxygen managing a chronic respiratory disease.

The Mandala of Health broadened the scope of the research, leading me to explore the experience of individuals and family/support persons within the context of broader physical, psychosocial, environmental, community and health care system factors that interact with their health and well-being. Exploration of these additional factors extends to what is presently understood about this client population.

Consistent with the Mandala of Health and its basis in systems theory, the individual’s experience of health and well-being changes as the result of being established on in-home oxygen. Any change in the individual has the potential to evoke changes for the family or support persons (Hancock, 1985). The findings of this study revealed that care providers experienced a parallel process of acceptance and adaptation as a result of the introduction of oxygen therapy and equipment into their lives. Additional caregiving such as care of oxygen equipment, increased household demands,
running errands, monitoring, coaching and assisting with disease management were incorporated into their sociocultural lives. Immediate and extended family were deemed important to the lives of oxygen participants. These findings reinforce the need for health professionals to incorporate family and support persons as essential components in the delivery of care. This research provides evidence that family and support persons impact on the health and well being of those they provide care for.

Personal health behaviours affected health and well-being. Long histories of smoking contributed to the extent of the oxygen participants’ chronic respiratory disease. Deterioration of the lungs eventually lead to the need for long-term oxygen therapy. Exposure to personal behaviours of others in the form environmental tobacco smoke had an impact on their well-being given the effect of smoke as a respiratory irritant and its potential to precipitate an exacerbation. With respect to health promotion behaviours, study participants incorporated positive health practices into their lives as a method of promoting health and well-being within the context of living with chronic disease. Those oxygen participants who choose to mobilize without the benefit of their portable oxygen because of the stigma of disability made a conscious choice that had the potential to put them at risk.

The effect of the pyschosocial and political environment on participants was demonstrated in the importance of the Home Care and Home Oxygen program to their ability to remain at home. The availability of community services such as public transportation allowed participants to access services outside of their home. Economic status was revealed as a factor in the ability to obtain mobility oxygen and services not covered under the Home Care Program. Oxygen conserving devices were assistive in
enhancing mobility options for oxygen participants who used them. Although beneficial, these costly devices were not covered under the Home Oxygen Program and therefore not accessible to individuals with limited financial resources.

Physical and built environment issues created barriers and placed limitations on individuals living with oxygen. Wind, humidify, air quality and pollution were environmental triggers that impacted on their well-being. Challenges of the built environment restricted access to community events and services.

The findings of this study emphasise that oxygen participants and their family/support persons managed their lives and chronic illness within their home and surrounding community. Personal health practices, social support, community-based services, and public policy serve to augment their health and well-being. We see from this research that professional care providers and the health care system are one component in a matrix of multiple factors affecting the health of individuals and families.

Mishel’s reconceptualization of the uncertainty in illness theory fits well as an additional theoretical framework for this study. This theory offers flexibility, in that it is not focused on one population, one age group, or one type of chronic illness (Mishel, 1999). Uncertainty in chronic illness as defined by Mishel, is a constant experience because of the unpredictable and inconsistent symptom onset, continual questions about recurrence or exacerbation, and unknown future when living with debilitating conditions (Mishel, 1999, p. 269). These factors were evident in the lives of the oxygen participants in this study. Oxygen participants experienced “good days and bad days” and lived with the constant threat of exacerbations and unpredictable futures. Uncertainties regarding the inability to breathe and the dread of running out of oxygen were profound realities in
their lives. Realizing the impossibility of complete elimination of uncertainty, oxygen users and their family/support persons integrated uncertainty into daily life (Mishel, 1999) and managed it by implementing planning and control as a way part of the day-to-day culture of living with oxygen.

Through the incorporation of a probabilistic paradigm, the participants accepted the reality of disease and oxygen uncertainty as sustaining realities. This paradigm was developed over time as participants described how they became more comfortable and less uncertain with the oxygen technology and the backup systems of support. Some participants demonstrated complex views of life that incorporated living one day at time. Others demonstrated acceptance of death and continued planning for their futures. This complex level of functioning, as an aspect of living with chronic illness uncertainty (Mishel, 1990), was evident in their strict daily routines, the degree of planning and control incorporated into their lives and ritualistic disease self-management activities. Assistance with the transition of incorporating uncertainly into their lives was provided by supportive relationships. Family and support persons collaborated with the management of uncertainty by monitoring disease status and assisting in the planning and control of uncertainty.

Adaptation to chronic illness and the requirement of oxygen was clearly evident throughout the findings. In the uncertainty of illness theory, adaptation consists of psychosocial behaviours within the person’s normative level of functioning and its achievement is proposed as the end state after coping with uncertainty (Mishel, 1990). In this study, all the participants demonstrated adaptation to new ways of being in varying degrees. Two oxygen participants struggled with adaptation and gave evidence of being
caught in a mechanistic paradigm where uncertainty (oxygen) was viewed as the enemy and must be eliminated. In long-term uncertainty, persons must live with enduring uncertainty acquiring a new state evolving from what previously existed (Mishel, 1990). It would be interesting to revisit these two oxygen participants in six months or year to determine if they eventually made the transition to a probabilistic paradigm.

Structure providers in the form of knowledge, social support systems and credible authorities (home oxygen suppliers and health care providers) were evident in this study. Those participants who were able to engage in pulmonary education valued and incorporated the information and skills they had learned into the management of their chronic illness. The deployment of social support services for tasks such as yard care and heavy housework assisted study participants to avoid activities that could precipitate an exacerbation. Regular appointments with medical practitioners and assessments by home care nurses tapered disease uncertainty through the knowledge that their illness state was being monitored. As outlined by Mishel (1999), care providers are particularly important in providing a diagnosis, promoting self-management and the interaction between illness and normal role function.

In summary, the Mandala of Health and the Uncertainty in Illness theory provided strong theoretical underpinnings for this study. Mandala of Health assisted in the holistic examination of an individual within the context of family and external community and environmental factors. Uncertainty in Illness theory guided the investigation and our understanding of adaptation to sustained uncertainty within the long-term oxygen experience. These theories lead the data collection and articulation of the findings in areas not previously examined in the long-term in-home oxygen population.
Recommendations

In conclusion to this thesis I offer recommendations specific to nursing practice, education, research and health care organizations. These recommendations are put forward as a compilation of findings, participant recommendations, noted disparities in services and identified opportunities for nursing research.

Nursing Practice

Several implications for nursing practice emerged from this study. The findings are of particular interest to nurses working with individuals experiencing chronic respiratory disease, with the recognition that nursing care for these individuals occurs across the health care continuum including public health, home and institutional care.

Given the strong evidence in support of the themes “the illness trajectory – journey toward oxygen” and “living with oxygen – a process of acceptance and adaptation, it is important that nurses are aware of the vital role they play in assisting individuals and their support persons to accept and adapt to long-term oxygen and the many life changes that ensue. Although establishing oxygen with nasal prongs in hospital is a common occurrence, establishing long-term oxygen in someone’s life is not. For that individual, no matter how debilitated they may seem, hearing the news that they will be on oxygen for the rest of their lives is a life-altering experience. As with any life changing experience, each client will receive and process the news in his or her own way. The process of acceptance and adaptation to a life on long-term oxygen begins with hearing the news. Nurses need to understand that an already restricted life has just became more restricted for these individuals and their families. It is important that nurses
empathise with the client’s sense of actual and potential loss, losses felt for themselves, and losses felt for their family and support persons.

When individuals learn that they are to be on long-term oxygen, whether it is arranged in hospital or out in the community, an assessment of their level of understanding and learning needs regarding their disease and oxygen therapy should be conducted. Although some clients may have been on oxygen many times as hospital patients, this may not be the experience of all long-term oxygen recipients. It also cannot be assumed that those newly prescribed on in-home oxygen are aware of why long-term oxygen has been ordered. Implementation of comprehensive oxygen therapy teaching protocols would be beneficial to enhance knowledge and correct any misconceptions. Although some institutions have excellent home oxygen teaching practices, teaching is not standard across institutions nor does institutional based protocols meet the learning needs of those prescribed home oxygen on an outpatient basis. Individuals who learn they are to be on long term oxygen in the community setting also require oxygen therapy education and opportunity for a question and answer session prior to the in-home set-up and training. As portable oxygen is important to the quality of life for these individuals, pre-home oxygen education should include an overview of the various mobility options.

Follow up visits from home care nurses should include a reassessment of the client and family’s knowledge and comfort level with oxygen therapy. Enhancing understanding of the need for oxygen treatment, clarifying misconceptions, teaching self-management strategies and allaying fears will foster acceptance and adaptation of oxygen therapy and the life style changes for home oxygen clients and their family/support persons that ensure.
Given the insidious nature of the disease, not all individuals with chronic respiratory conditions will have a clear understanding of their disease process. The theme identifying the value of professional support and knowledge indicates that nurses play a vital role in assessing learning needs, providing patient education and informing individuals and their families of community programming such as pulmonary education and rehabilitation programs and educational services available from Lung Associations.

As tobacco smoking is the major etiologic factor in COPD, many potential home oxygen recipients have been or currently are smokers. If the home oxygen client smoked prior to the establishment of home oxygen, a health care team approach that includes the client, key support persons, family physician, and home care nurse must be implemented to facilitate successful and sustained cessation. As demonstrated in this study, and documented by others (Canadian Thoracic Society Workshop Group, 1992; Chalmers, Cantin, Murnaghan, Shuttleworth, Scott-Findlay, & Tataryn, 2001; Chapman, 1992; Tiep, 1997) smoking cessation is often lengthy process fraught with numerous relapses. Smoking cessation programs must be multi-factorial and include counselling from the physician and other caregivers, in addition to the judicious use of adjunctive measures (Chapman, 1992; Tiep, 1997). Information regarding the availability of community based cessation programs should be made available. It is essential that nurses provide non-judgmental encouragement and support to clients during the quitting process.

The findings of this study indicate that individuals living on long-term oxygen experience disease and oxygen related uncertainties. Professionals must understand that the provision of supplemental oxygen does not diminish the uncertainty and fear of not being able to breathe. The oxygen participants in this study detested being admitted to
hospital. Going to hospital or an emergency department usually meant they were experiencing an acute exacerbation and that their self-management strategies were no longer working. In response, they turn to health care providers for clinical care and professional support. As one participant described, "even when you are tied to this (lifting his oxygen tubing) you still want to live". The fear of the inability to breathe is profound. When home oxygen clients present in respiratory distress it is important for the nurse to recognize the client’s uncertainty and treat the fear as well as the lungs.

Participants’ dislike for hospitalization was multi-dimensional in nature. Particular to this study, were the mobility restrictions placed on long-term oxygen users as a result reduced availability of portable oxygen in institutions. Participants spoke of limited ward supplies of portable oxygen and how difficult it was to secure a cylinder to ambulate to the cafeteria or enjoy the outdoors. As the importance of ambulation cannot be overstated for this population, nurses must strive for changes in unit policies that allow for sufficient supplies of mobility oxygen. Oxygen users would benefit from a portable supply at their bedside as part of their hospital treatment regimen. Several participants believed their stays in hospital were longer than required. Extra expenditures for oxygen and additional equipment such as regulators and carts would be quickly offset by the benefits of fostering exercise and independence thus reducing length of stays for this population.

Nursing Education

This research supports the work of other researchers in that wellness in chronic illness is not an oxymoron. As demonstrated in this study, it is possible to perceive health positively and have an acceptable, even wonderful, quality of life rating despite
living with debilitating chronic respiratory disease and long-term oxygen. More emphasis in nursing education needs to be placed on the role of the nurse in promoting health and wellness in the chronically ill population. Master of Nursing programs that promote practicum study and thesis research in the area of health promotion and disease self-management in chronic illness would assist in the reduction of chronic illness burden to individuals, family/supportive caregivers and the health care system as a whole.

Oxygen participants and their support persons valued Home Care services and the nursing care a supervision they received. Supportive Home Care allowed home oxygen users to remain in their own homes and helped to lessen responsibilities of informal caregivers impacting positively on quality of life. Nursing education needs to promote home care as an exciting and challenging aspect of nursing. Most individuals with chronic illnesses manage their disease with the assistance of family/support persons in their homes. This fact combined with Canada’s aging population will see a significant increase in nursing opportunities in the area of home care. The advancement of technology will also see increased numbers of individuals and families living at home with technological assistance. The diversity of care delivered in the home and the professional rewards of functioning with enhanced autonomy makes home care nursing an attractive area of practice. Nursing students must experience first hand what a special privilege it is to provide nursing care in the home. A home care nurse enters a stranger and emerges a partner in family care.
The following recommendations are presented as possible avenues for future nursing research. This research project revealed that individuals and their support persons embark on a journey of acceptance and adaptation with the addition of long-term oxygen into their lives. To better understand and facilitate this important process, further research needs to examine what factors promote and inhibit acceptance and adaptation to chronic illness and more specifically long-term oxygen therapy. Adjustment problems affect social relationships, health and life quality within the family, which in turn can influence the manifestation and trajectory of illness (Leidy & Traver, 1996). In-depth knowledge of potential problems is required to develop strategies to counteract areas of concern. As individuals living with chronic illness must continually adjust to their disease as it progresses and as their bodies and lives yield to accommodate changes, a longitudinal study of long-term oxygen users would provide a more complete knowledge base of the experience and the adaptation process (Russell & Gregory, 2000).

Although several researchers have measured quality of life for long-term oxygen users (Heaton, et al., 1983; Janssens, et al., 1997; McSweeny, et al., 1982), there is limited understanding of the specific variables that have an impact on quality of life for this population. The findings from this research project disclosed air quality and built environmental issues as barriers that exist “beyond the security of home” and that these factors that had a negative impact on the ability of oxygen users to mobilize and access services in the community. The importance of mobility oxygen and oxygen conserving devices were also revealed as factors in the enhancement of quality of life for individuals and their support persons. To develop strategies and improve equipment and systems that
enhance the quality of life for oxygen users and their family/support persons more needs to be known about the specific variables that impact on well-being and quality of life.

**Health Care Organizations**

Services and supports that keep individuals in their own homes and reduce the need for periodic hospitalization were revealed as important to this population. Study participants valued the Home Care and Home Oxygen Programs and offered suggestions for system improvements. One recommendation was that home intravenous therapy (I.V.) programs be made more available to home oxygen clients. The home I.V. program allows this population to convalesce at home reducing their exposure to nosocomial infections and institutional imposed restrictions on activities. Home I.V. therapy is an increasing trend in home care and is seen as an effective method of enhancing client comfort and decreasing costly lengths of stays (Sheldon, 1994).

Pulmonary rehabilitation and disease self-management programming were positive skill building and supportive experiences for the participants as evidenced by the theme, value of professional support and knowledge. Strategies learned from health professions and pulmonary education programs were used to counteract the effects of chronic illness uncertainty. At present, pulmonary education programs are not widely available in Canada (Brooks, Lacasse & Goldstein, 1999). Similar to diabetes and asthma education models, implementing COPD disease self-management education early in the illness trajectory would encourage healthy lifestyle changes, slow disease progression and thus reduce the incidence and related costs of hospitalization and future requirements for in-home oxygen therapy.
The ability to enjoy and partake in activities of interest was important to oxygen users. Mobility oxygen plays an invaluable role in promoting activity and enhancing quality of life for oxygen users and their supportive cargivers. Given the significance of mobility oxygen to this population, the health care system needs to ensure that Pharmacare and home oxygen programs and policies make portable oxygen and related equipment affordable and accessible to all oxygen users.

Conclusion

This study explored the experience of living on long-term oxygen technology from an individual and support person perspective and outlined assistive and restraining factors affecting the management and quality of their lives. The findings of this study address this purpose and supported and expanded existing research in the area of long-term oxygen therapy and the experiences of individuals and caregivers living with long-term illness. A dual process of acceptance and adaptation of long-term oxygen were important to living with this life changing therapy. Exploration into the uncertainties experienced by this population revealed that the fear of the inability to breathe and the dread of running out of oxygen were sustaining uncertainties in their lives. The study also revealed that perspectives on health and quality of life for individuals on in-home oxygen varied among participant; however it is possible to view health positively and attain an acceptable quality of life despite chronic illness and the limitations of oxygen. It was found that family/support persons enjoyed a higher level of quality of life than the oxygen users they supported. Caregivers incorporated caregiving into their daily lives as a reciprocal component of historically supportive relationships. Health care providers and community services assist individuals and their support persons to live well within
the confines of chronic illness. Education, information and skill building regarding disease and disease self-management are important components along the continuum of care provided to individuals and families living with long-term oxygen in their home.

The strength of this study lies in the rich descriptive voices of the participants. The combined experiential wisdom of in-home oxygen users and their supportive caregivers helps practitioners to better understand the nature of living with long-term in-home oxygen. Their voices literally, at times barely a whisper, reverberate in my memory their compelling stories are imbedded in my heart and are time honoured in the pages of this document. My deep appreciation for their commitment to this research project is impossible to express.
References


*Qualitative Health Research*. 11(4), 553-567.


Appendix A

HOME OXYGEN THERAPY - ELIGIBILITY CRITERIA

The Provincial Respiratory Program provides home oxygen therapy coverage for clients who have documented chronic hypoxemia. The following eligibility criteria must be met:

1. Diagnosis must be established.

2. The client must be clinically stable and an optimal medical treatment program must be in effect when assessed for eligibility for home oxygen coverage (To demonstrate stability, the client should first be clinically stable, i.e. ready for hospital discharge and then demonstrate persisting hypoxemia over the subsequent 3 weeks).

3. The INITIAL ASSESSMENT for home oxygen eligibility must meet one of the following criteria:
   *Documentation must include results of a minimum of 2 arterial blood gases performed on room air no sooner than 1 week apart.

   3.1 Arterial blood gas tests confirming hypoxemia at rest - PaO2 < 55 mmHg on room air.

   3.2 Arterial blood gas tests confirming a PaO2 in the range of 56-59 mmHg. at rest breathing room air, in addition to other evidence of 1. cor pulmonale or 2. secondary polycythemia. (1. P-pulmonale ECG pattern, increase in P-wave amplitude (> 2 mm) in leads II, III, and AVF; jugular venous distention; tender liver; peripheral edema. 2. erythrocytosis with a hematocrit > 55%).

   3.3 Arterial blood gas tests demonstrating PaO2 < 45 mmHg after maximum therapy and client cannot be stabilized without O2. Such clients are rare.

   3.4 An assessment which documents nocturnal or exercise desaturation (desaturation data summary must be provided) within the following guidelines:

   3.4.1 Nocturnal desaturation must be confirmed by polysomnography or nocturnal oximetry tests completed in a sleep laboratory or hospital setting. Typically a client prescribed continuous nocturnal oxygen should spend a significant portion of sleep time (5%) at or below an SaO2 of 85%. These clients usually exhibit severe episodes of arterial desaturation on 1 or 2 occasions per night, persisting for at least 5 minutes. Documentation must include evidence that oxygen improves saturation during sleep.
3.4.2 Exercise desaturation must be confirmed by oximetry testing. Exercise tests comparing performance on compressed air and oxygen should be conducted in a blinded fashion (that is, the client should be given air and oxygen in exactly the same manner without being told which is which). Documentation must include evidence demonstrating the client significantly increased exercise capacity and oxygen saturation while using oxygen.

3.5 Assessment for home oxygen therapy for palliative care clients should conform with the above criterion.

4. Reassessment for continued eligibility for home oxygen therapy is required. Reassessment should occur after 3 months of oxygen therapy and yearly thereafter. Data submitted must include:

4.1 Arterial blood gases which confirm continued eligibility according to the guidelines for initial assessment.

4.2 The prescribed litre flow for oxygen therapy including variations for exercise or sleep.

Oxygen should be given at least 18 hours a day preferably 24 hours when possible. The dose should be such that the PaO2 exceeds 65 mmHg, and this dose should be increased by 1 L/min during exercise or sleep.
Appendix B
Oxygen Dependant Participant Demographic Questionnaire

To be administered at the beginning of the first interview.

I have a short form that I would like you to complete. This will provide background information for my study. If you do not feel comfortable answering any of these questions you are under no obligation to do so. Simply let me know if there is a question you do not want to answer and I will move to the next one. Could you please answer the following:

1. Are you?
   a) retired _____ b) employed --- Full Time _____ Part Time _____

2. Are you?
   a) married _____ b) single _____ c) divorced/separated _____
   d) widowed _____

3. What family or support persons live with you and assist you with your oxygen equipment?
   a) spouse - husband _____ wife _____ b) son(s) _____ c) daughter(s) _____
   d) sister(s) _____ e) brother(s) _____ f) friend _____ other, please specify

4. What family or support persons live outside your home and assist you with your oxygen equipment?
   spouse _____ son(s) _____ daughter(s) _____ sister(s) _____
   brother(s) _____ friend _____ neighbor _____ building supervisor _____
   home care _____ oxygen supplier _____ other ____________________________

5. Who of the above would you say are your key support persons, please name?
   ________________________________________________________________
   ________________________________________________________________

6. How long have you been diagnosed with a respiratory disease?
   ________________________________________________________________

7. What does your doctor call your respiratory disease?
   ________________________________________________________________

8. How long have you been having respiratory symptoms?
   ________________________________________________________________

9. What symptoms do you experience?
   ________________________________________________________________
10. Who would you say has provided you the most information about your respiratory condition? Please mark 1st, 2nd and 3rd beside the appropriate source.

a) Respirologist ____ b) Family Doctor ____ c) Hospital Nurse ____
   d) Home Care Nurse ____ e) Respiratory Therapist ____ f) Lung Association ____
   g) Family Member(s) ____ h) Friend(s) ____ i) Support Group ____
   j) Respiratory/Day Program ____ Name of program ________________________

k) Reading Material (please name)

__________________________________________________________

11. How long have you been using oxygen? _____________

12. What is your prescription for oxygen? _____________ L/min.

13. What setting (L/min.) do you use your oxygen at? _____________ L/min. If different than what your Doctor has ordered have you adjusted this rate?

__________________________________________________________

14. Who would you say has provided you with the most information about your oxygen therapy? Please mark 1st, 2nd and 3rd beside the appropriate source.

a) Respirologist ____ b) Family Doctor ____ c) Hospital Nurse ____
   d) Home Care Nurse ____ e) Respiratory Therapist ____ f) Lung Association ____
   g) Family Member(s) ____ h) Friend(s) ____ i) Support Group ____
   j) Respiratory/Day Program ____ Name of program ________________________

k) Reading Material (please name)

__________________________________________________________

15. Do you use any other assistive devices (wheel chair, walker, bath tub lifts, reacher) other than your oxygen equipment? Yes ____ No ____
   If yes please list ________________________________________________

16. What home care services if any do you utilize? ___________________________

17. Are these services listed above provided by Manitoba Health?
   Yes ____ No ____

18. What, if any services do you pay for privately?

__________________________________________________________
19. What is your highest education level achieved?
   a) Less than high school diploma ______ grade achieved ______.
   b) High school diploma ______.
   c) Community College/Vocational School Certificate ______.
   d) Community College/University training ______.
   e) University Degree ______.
   f) Graduate Degree ______.
   g) Other, please specify ________________________.

20. Would you describe your financial resources as:
   a) Not sufficient to meet my needs ______.
   b) Sufficient some of the time ______.
   c) Sufficient to meet my needs most of the time ______.
   d) Sufficient to meet my needs all of the time ______.

21. What is your primary source of income?
   Salary ______  Pension ______  Investments ______  Other ______

22. Please check the age range you fall into:
   55-59 ______  60-69 ______  70-79 ______  80-89 ______  Above 89 ______

23. Please check the age range of your caregiver:
   18-29 ______  30-39 ______  40-49 ______  50-59 ______
   60-69 ______  70-79 ______  80-89 ______  Above 89 ______

24. Male _____  Female _____
Appendix C

Participant & *Family/Support Person Interview Guide
*Questions specific to Family/Support participants are in italics

RESPIRATORY HEALTH STATUS

I am interested in what happened to you and how you came to be on oxygen. Can you please tell me about your respiratory problem?

What does your Doctor call your respiratory problem?

What does your Doctor feel caused your respiratory problem? Do you agree? If no what do you believe caused your respiratory problem?

What feelings did you experience when you were first told you needed to be on long term oxygen? Family/Support person - describe your feelings.

How do your feelings about being on oxygen differ now?

Describe some of your first experiences of being on long-term oxygen. Are your experiences different now?

VIEW OF HEALTH

Health is an individual experience, overall, how would you describe your health in general?

How would you rate your health on a scale of 1 – 5? 1 being very poor health 5 being the best you can be.

QUALITY OF LIFE QUESTIONS

Describe to me what your typical day is like living on oxygen?
  - What is getting dressed like?
  - What is making meals like?
  - What problems do you experience in getting out of the house?
  - Do you ever experience anxiety? If yes how do you avoid/deal with anxiety?
  - Do you experience shortness of breath? How often? What is it like
  - Tell me about your energy level?

Do you experience any difficulties getting about in your home?
  Probes
  Placement of the oxygen concentrator
  Placement of the large back up oxygen cylinders
  Oxygen tubing
  Climbing stairs
Do you experience any difficulties as a result of your physical environment? Out in the community.

Probes
- Getting in and out of buildings
- Proximity to Medical Services
- Air quality

Quality of life is often described as an expression of an individual’s feelings of well-being and his/her ability to enjoy and partake in aspects of life that are important. Thinking about this definition, describe for me your quality of life?

*Family's description of quality of life?*

Describe some of the changes that have taken place in your life now that you are on long term oxygen technology.

Does living on oxygen ever “get you down”? If so what do you do about this?

What effect has being on long-term oxygen had on your quality of life?
  - Positive effects
  - Negative effects

*Family - What affect has being on long-term oxygen had on quality of life?*
  - Positive effects
  - Negative effects

Describe any unpleasant experiences (running out of oxygen, comments people made) you have had with the oxygen equipment? How did this experience make you feel?

What do you do to avoid experiences such as this?

What social activities do you engage in? What barriers are there to enjoying these activities?

In what ways has the social activity of the family changed?

How would you rate your quality of life on a scale of 1 – 5? 1 being very poor 5 being the best you can be.

*Family ----- How would you rate your quality of life on a scale of 1 – 5? 1 being very poor 5 being the best you can be.*
UNCERTAINTY

Does the symptoms of you respiratory disease cause you to feel uncertain?
   If yes, describe for me what those uncertainties are?

How do you manage the uncertainty of ________________?

How do these uncertainties make you feel?

What uncertainties does living with oxygen bring to your life?
   Probes  Equipment failure
   Running out of O2
   Safety

You stated that ________________ caused you feelings of uncertainty, what do you do to
decrease these feelings of uncertainly?

What changes have occurred if any in the amount of uncertainty that you feel?

If a change is noted ----- What do you feel is the reason of the change?

FAMILY/SUPPORT PERSON RELATIONSHIPS - CAREGIVING

What would you say are the most important things in your life as it is now?
   How important is the oxygen to you?
   How important is your family/support persons to you?

What does living with long term oxygen mean to your family/support persons?

What effect has your being on long term oxygen had on your family?

Family Members –

On average how much time a week (if any) would spend on care giving activities.

Describe the effect has these care giving activities had on you?
   Impact on: social life, work life, family life, personal time,
   your relationship with __________

What effect has these care giving activities had on other family members?
   Probes  Are you a closer knit family?
   Are the duties shared?
   Would you say it has caused distance or hard feelings in relationships?

Have relationships changed since being on long term oxygen.
What assistive/positive forces have helped you manage your care giving responsibilities? (Love, spirituality, finances, credible authorities, previous knowledge...)

What restraining/negative forces affect your ability to manage your care giving responsibilities? (Other responsibilities, family relations, money, lack of resources...)

RELATIONSHIP WITH HEALTH CARE PROVIDERS

What health care practitioner do you feel has been most helpful in the management of your disease, (please don’t mention the name on tape)? Who has been most helpful with your oxygen services.

Family - What health care practitioner do you feel has been most helpful in assisting you with the management of _____________’s disease? Oxygen services.

Do you feel you have enough contact with this health care practitioner?

If your answer is no, how much contact to you feel you should have and how could the amount of contact be improved?

What resources did you/do you use to obtain more information about your disease?

What services, programs or supports have you found to be available in your Community (example Manitoba Lung).

What should Communities be providing for individuals with Chronic Respiratory disease? Individuals on oxygen? Examples Changes to the built environment, information, exercise/rehab programs, disease self-management education.

PROGRAM IMPROVEMENT

What suggestions can you offer that would improve the oxygen program and services you receive?

Probes

More information on disease management/equipment management
Improved oxygen equipment
Health care support
Home care support
Changes in programs

How would these suggestions improve your quality of life?

How would these suggestions make the home oxygen program better for others?
CONCLUSION

What would you say best describes the experience living on long term oxygen?

Is there anything further you would like to say?

*Family - Is there anything further you would like to say?*
## Appendix D
### FIELD NOTE GUIDE

<table>
<thead>
<tr>
<th>Field note date:</th>
<th>Interview date:</th>
<th>Participant code:</th>
</tr>
</thead>
</table>

### Environmental:
- Location of oxygen equipment?
- Presence or absence of mobility oxygen equipment?
- Condition of oxygen tubing (length, presence of coiling, cleanliness)?
- Was the oxygen dependant participant utilizing oxygen? If so length of time.
- Use of safety measures related to oxygen equipment? (ie. no smoking signs)
- Any evidence of the oxygen dependent participant having difficulty moving about the Environment?
- Assistive devices noted? (ie. walkers, reachers, eating utensils ect.)

### Physical appearance/respiratory symptoms:
- Description of physical appearance and evidence of respiratory symptoms (oxygen participant only)
- Evidence of stress, fatigue, anxiety, and/or frustration in the main family/support person?
<table>
<thead>
<tr>
<th>Field note date:</th>
<th>Interview date:</th>
<th>Participant code:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Family Interactions:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respectful, courteous, polite, power struggles?</td>
</tr>
<tr>
<td>Evidence of family support/caregiving?</td>
</tr>
<tr>
<td>Evidence of dependency?</td>
</tr>
<tr>
<td>Nature of family/support dynamics related to the oxygen experience?</td>
</tr>
<tr>
<td>Evidence of assistive forces (ie phone #s of Home Care, Dr., oxygen supplier)</td>
</tr>
</tbody>
</table>

| Other related observations: |
Appendix E

Sample Access Letter

Ms. Mary Smith
Regional Home Care Coordinator/Manager

Dear Ms. Smith:

My name is Dianne Brown and I am a graduate nursing student currently enrolled in a Masters of Nursing Program at the University of Manitoba. I completed my course work requirements and have developed a proposal to conduct research as part of the thesis component of my University program.

My research is qualitative and descriptive in nature. The purpose of my study is to explore and describe the experience of living on long term oxygen from an individual and family/support person viewpoint and to determine what positive and negative aspects of in-home oxygen therapy affect the quality of my life.

Selection criteria of oxygen dependent participants in this study will be:

- individuals who are treated with oxygen utilizing a oxygen concentrator (owed, rented, or provided by home care or third party payer) for a minimum of 4 weeks with the oxygen prescribed for at least 15 hours a day.

- individuals who are able to read and understand English.

- individuals who are 55 years and older.

- individuals who can understand and provide a written informed consent.

- individuals who are not experiencing an acute exacerbation of their illness and therefore not hospitalized at the time of the interview.
Following a thorough verbal explanation of the study and the completion of an informed consent, oxygen dependent participants and their key family and or/support persons who they have personally designated will take part in 1 to 2 interviews lasting approximately one and one half hour each. The interviews will be held at a location and time convenient to the oxygen participant. This will most likely be the individual’s home. The oxygen dependent participant will be also asked to complete a short form to obtain basic demographic information. The names of the participants will be kept strictly anonymous. The individual’s participation in the study will be voluntary and the individual may withdraw from the study at any time. My thesis committee is supervising this research. The chairperson of this thesis committee is Dr. D. Gregory who may be contacted by phone (204) 474-6223 or in writing at the Faculty of Nursing, University of Manitoba, Winnipeg, Manitoba, R3T 2N2.

I am approaching your agency for access given the services you provide to individuals who qualify for and require oxygen concentrator services. If my request for access is approved by your organization I will provide you with telephone script for you to utilize in approaching prospective participants. I recognize there may be direct costs with respect to mailings or phone contact the cost of which I am willing to reimburse your agency. I am willing to acknowledge the support of your organization in future publications in relation to this study and will provide you with a summary of my research findings. Estimated time commitment in contacting potential participants is approximately 15 – 30 minutes.

Confidentiality of the participants will be strictly maintained. Participant and family/support person interviews will be audio-taped with the permission of the participant(s). Data from observations made during interviews will be recorded by way of a field note guide. Each interview will be assigned a code and participant names will not be revealed or recorded. If a name of an individual or name of a oxygen supplier is inadvertently disclosed on tape, the typist will be required to leave a blank space in the transcription. All interviews will be numerically coded according to participant and interview. Interview data in the form of; audiotapes, transcriptions and field notes will be kept by in the researcher in a secure location. Only the researcher and thesis committee members, as appropriate, will have access to the raw data. Any written documentation of findings occurring as a result of this study will be worded in such a manner that individual identities cannot be deciphered.

This study has received ethical approval at the University of Manitoba from the Human Ethics Secretariat/Nursing Education Ethical Review Board. Please find attached, a copy of the ethical approval form. A copy of my thesis proposal can be made available upon request. Thank you for your time and consideration of my request. Should you have any further questions or concerns regarding this request for assistance to access oxygen dependent participants, please feel free to call me at the following phone number . I look forward to your response.

Yours truly,

Dianne Brown, R.N. B.Sc.N.
Appendix F

Approaching Study Participants (Script)

Dianne Brown is a registered nurse who is currently studying in the Master of Nursing Program at the University of Manitoba. She is interested in family care giving and in learning more about the experiences of people and their families who use long term oxygen therapy in the home. If you are interested in participating in this study she would like to talk to you and your family members or support persons who you feel support you the most and provide assistance to you and your oxygen equipment.

I am contacting to you today to see if you would consider discussing your experiences with her? Her meetings with you and your family members would take approximately 1 to 1 ½ hours and she may need to meet with you 1 to 2 times.

Please keep in mind you are under no obligation to be part of the study. Would you be interested in discussing your oxygen experience with her?

If Yes:
Do I have your permission to give her your name and phone number.
With your permission she will contact you within 2 to 3 weeks to provide you with more information about this study. If you agree to speak to her you are still under no obligation to be part of the study and you may withdraw from the study at any time.

Thank you for agreeing to participate, Dianne will be calling you within the next few weeks to arrange an appointment time that suits you and the family/support persons you wish to participate with you.

If No:
Thank you for letting me talk to you today.
Appendix G
Oxygen Dependant Participant Consent Form

I ________________________, volunteer to participate in this study titled Living with Long Term Oxygen Technology: Individual and Family Perspectives. I understand that the purpose of the research project is:

To explore and describe the experience of living on long term oxygen from an individual and family/support person viewpoint and to determine what positive and negative aspects of in-home oxygen therapy affect the quality of my life.

This thesis project is being carried out by Dianne Brown, a registered nurse and a Master’s of Nursing student at the University of Manitoba, Winnipeg, Manitoba. Dianne is interested in family care giving and this study will help health professionals learn more about what it is like for families living with long term oxygen. Dianne is available by telephone at _______________________. She is being supervised by Dr. D. Gregory of the Faculty of Nursing University of Manitoba who may be reached at (204) 474-6223. Dr. P. Hawranik and Dr. J. Bond are also supervising the study. The Education/Nursing Research Ethics Board of the University of Manitoba approved this study. If I have any concerns regarding any aspect of this study I may discuss them with the Human Ethics Secretariat by calling 204-474-7122.

I understand that:
- Dianne Brown will interview me 1 to 2 times for approximately 1 to 1½ hours about my experiences living on long term oxygen in my home.
- Participation in the study is entirely voluntary. I am under no obligation to participate and I have the right to withdraw from the study at any time and/or may refrain from answering any questions I prefer not to discuss, without prejudice or consequence.
- The interview will take place at a time and place convenient to me and will include family and/or support person or persons that provide support to myself and my oxygen equipment and who I have asked to participate.
- With my permission the interviews will be audio-taped using a tape recorder. I can request to have the tape recorder turned off at any time.
I will be asked to fill out a short form requesting information about my family and myself.

Dianne Brown may take notes during and after the interview. These notes will be of observations she has made during the interview (eg. location of the oxygen equipment, type and number of assistive devices (eg. walker, portable oxygen tanks), family communication patterns, signs of shortness of breath).

If I experience fatigue and/or feelings of shortness of breath during the interview, I may request the interview be stopped so that I may rest or I may request the interview be rescheduled for another time.

At any time during the research process I may ask Dianne Brown or her thesis supervisor, Dr. D. Gregory (204) 474-6223, to provide answers to any questions I have regarding the study.

Information I provide on audio tape will be put into print form by a typist. Following the interview, Dianne Brown may contact me by telephone to clarify any questions she has from her review of the interview information. The time involved will be approximately one and one half hours for each interview. I understand that the information I give will be kept confidential. Only Dianne Brown will have access to my name and any identifying information. Numbers will identify the interview tapes and notes and no one will have access to the identifying information but Dianne Brown. My name will not be used in the typewritten notes of the interview, the study report or any publication or presentations related to the study. All notes, tapes, and forms containing information I have provided will be stored at in a locked and secure area. The interview tapes will be transcribed: only the researcher and her thesis committee members will have access to this information. I may receive a summary of the study results if I so desire.

I understand that there may be no benefits to me personally however; this is my opportunity to share my experiences, opinions and ideas about living on long term oxygen. Hopefully the write ups of this information may help health care professionals and oxygen service providers understand how they can better assist individuals living on in-home oxygen therapy.

I understand that participation in this study is voluntary. I recognize that my signature below indicates my consent to participate in this study exploring the experiences of individuals and family’s living with long term oxygen. Information for this study will be obtained through interviews conducted by the researcher.
Any information I provide will be kept strictly confidential and I am entitled to withdraw from questioning and/or the study at any time.

I have received a copy of this consent form for my records. My signature signifies my agreement to participate in this study under the above terms.

Participant: ____________________________
Researcher: ____________________________

Date: ____________________________

Living with Long Term Oxygen Technology: Individual and Family Perspectives

I would like to be sent a summary report of the study’s findings:

Yes _____ No _____

Please mail this summary of the findings to:

Name: ____________________________
Address: ____________________________

______________________________

______________________________
Appendix H
Family/Support Person Consent Form

I ________________________________, volunteer to participate in this study titled Living with Long Term Oxygen Technology: Individual and Family Perspectives. I understand that the purpose of the research project is:

To explore and describe the experience of living on long term oxygen from an individual and family/support person viewpoint and to determine what positive and negative aspects of in-home oxygen therapy affect the quality of my life.

This thesis project is being carried out by Dianne Brown, a registered nurse and a Master’s of Nursing student at the University of Manitoba, Winnipeg, Manitoba. Dianne is interested in family care giving and this study will help health professionals learn more about what it is like for families living with long term oxygen. Dianne is available by telephone at _______________. She is being supervised by Dr. D. Gregory of the Faculty of Nursing University of Manitoba who may be reached at (204) 474-6223. Dr. P. Hawranik and Dr. J. Bond are also supervising the study. The Education/Nursing Research Ethics Board of the University of Manitoba approved this study. If I have any concerns regarding any aspect of this study I may discuss them with the Human Ethics Secretariat by calling 204-474-7122.

I understand that:

- Dianne Brown will interview me together with my oxygen dependent family member on one to two occasions for approximately 1 to 1½ hours about my experiences supporting someone living on long term oxygen in the home.
- Participation in the study is entirely voluntary. I am under no obligation to participate and I have the right to withdraw from the study at any time and/or may refrain from answering any questions I prefer not to discuss, without prejudice or consequence.
- The interview will take place at a time and place convenient to me and will be audio-taped using a tape recorder. I can request to have the tape recorder turned off at any time.
- Dianne Brown may take notes during and after the interview. These notes will be of observations she has made during the interview (e.g., location of the oxygen equipment, type and number of assistive devices (e.g., walker, portable oxygen tanks), family communication patterns, signs of shortness of breath).
- If I experience fatigue during the interview, I may request the interview be stopped so that I may rest or I may request the interview be rescheduled for another time.
- At any time during the research process I may ask Dianne Brown or her thesis supervisor, Dr. D. Gregory (204) 474-6223, to provide answers to any questions I have regarding the study.

Information I provide on audio tape will be put into print form by a typist. Following the interview, Dianne Brown may contact me by telephone to clarify any questions she has from her review of the interview information. The time involved will be approximately one and one half hours for each interview. I understand that the information I give will be kept confidential. Only Dianne Brown will have access to my name and any identifying information. Numbers will identify the interview tapes and notes and no one will have access to the identifying information but Dianne Brown. My name will not be used in the typewritten notes of the interview, the study report or any publication or presentations related to the study. All notes, tapes, and forms containing information I have provided will be stored at in a locked and secure area. The interview tapes will be transcribed: only the researcher and her thesis committee members will have access to this information. I may receive a summary of the study results if I so desire.

I understand that there may be no benefits to me personally however; this is my opportunity to share my experiences, opinions and ideas about the family experience of living on long term oxygen. The information from this study may help health care professionals and oxygen service providers understand how they can better assist individuals living on in-home oxygen therapy.

I understand that participation in this study is voluntary. I recognize that my signature below indicates my consent to participate in this study exploring the experiences of individuals and family’s living with long term oxygen. Information for this study will be obtained through interviews conducted by the researcher. Any information I provide will be kept strictly confidential and I am entitled to withdraw from questioning and/or the study at any time.
I have received a copy of this consent form for my records. My signature signifies my agreement to participate in this study under the above terms.

Participant: ____________________________

Researcher: ____________________________

Date: ____________________________

Living with Long Term Oxygen Technology: Individual and Family Perspectives

I would like to be sent a summary report of the study’s findings:

Yes _____  No _____

Please mail this summary of the findings to:

Name: ____________________________

Address: ____________________________
APPROVAL CERTIFICATE

20 July 2001

TO: Dianne M. Brown
   Principal Investigator

FROM: Lorna Guse, Chair
   Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2001:049
   “Living with Long Term Oxygen Technology: Individual and Family Perspectives”

Please be advised that your above-referenced protocol has received human ethics approval by the Education/Nursing Research Ethics Board, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.