THE UNIVERSITY OF ALBERTA

LIVING WITH SLEEP APNEA AT WORK, HOME AND LEISURE: A PHENOMENOLOGICAL STUDY

BY

© MARY O. COLLINSON

A THESIS

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PROSPERO: *We are such stuff*
As dreams are made on; and our little life
Is rounded with a sleep.

The Tempest 4.1.156
William Shakespeare

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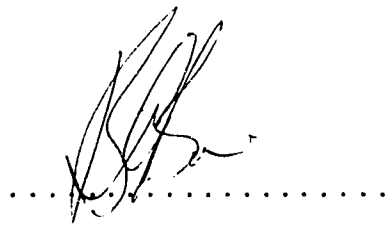
The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled "Living with Sleep Apnea at Work, Home and Leisure: A Phenomenological Study," submitted by Mary O. Collinson in partial fulfillment of the requirements for the degree of **MASTER OF EDUCATION**.



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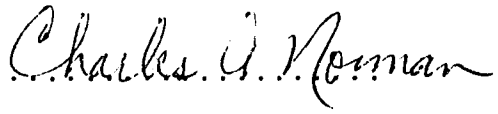

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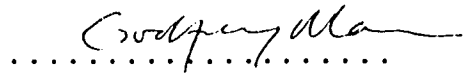

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Date: November 15, 1994.

This book is dedicated

to my husband,

DONALD M. COLLINSON

For your unfailing patience,

understanding, encouragement, support,

love and friendship.

I am constantly amazed by your sensitivity, gentleness,

understanding and insights.

You are truly a wonderful person, and you have brought

great happiness to my life. I am very proud to be

your wife, and I love you dearly.

Abstract

This study, using phenomenological methodology, investigated the experiences of living with sleep apnea, from the patient's point of view, as related to work, home and leisure activities. Unstructured interviews were conducted with a selective sample of eight individuals with sleep apnea. The sample was heterogenous and covered representation from the known apnea population, including young, old, middle-aged, well and less educated, slim, obese, male, female, professional, employed, retired, rich, poor, treated and untreated individuals. The sample covered the full range of types, onsets and severity of apnea and treatments, including central, obstructive and mixed types, childhood, adult and later-adult onset, surgery and CPAP treatment, not yet treated, and resistance to treatment. A range of symptom severity was demonstrated by the participants from very slight to higher levels of cognitive impairment, and from mildly fatigued to excessively sleepy.

Analysis of the interview protocols revealed several themes, the most significant of which were many forms of fear, helplessness, grief, mourning, embarrassment, frustration, and need for understanding. Several common coping strategies and periodicity were shown, as well as potential for job stress, marital stress and social isolation. Information from two participants also indicated a stage process to acceptance of sleep apnea. The stages include shock, realization, denial, mourning, and adaptation, and are similar to descriptions by Gregg, Robertus and Stone (1989) for other chronic illnesses.

This study suggests that the trauma suffered by individuals with sleep apnea before, during and following diagnosis can be significant, and that acceptance and treatment of the illness is not without considerable difficulty for most.

Further study is suggested to investigate the experience of spouses and family members of sleep apnea sufferers; to explore possible relationships between the level of severity, impairment, family concerns and patient emotional comfort and adjustment; and a possible connection between the actual measurable cognitive impairment with dream deficits.

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Chapter I

Introduction

General Overview

Guilleminault (1987) has researched sleep disorders for a considerable number of years, and might be described as the modern discoverer of sleep apnea[1] as a medical condition. His discovery came in the early 1970s while treating Pickwickian[2] patients, so called after Charles Dickens' famous character, the very rotund *Mr. Pickwick of Pickwick Papers*. With the discovery that breathing cessations caused the blood oxygen levels to drop considerably below normal levels, the significance of the "breathlessness" in causing daytime symptoms started to become apparent.

Sleep apnea syndrome (SAS) is a medical (physiological), chronic disorder which results in the cessation of breathing during sleep for durations of fifteen to ninety seconds, or more. These breathing pauses may occur between approximately ten and a hundred times an hour, and result in nocturnal blood oxygen desaturation, and oxygen depletion in the tissues of the body and brain. The breathing pauses result in hypoxia[3] which tends to arouse or partially arouse the person from sleep, further complicating the situation by altering the normal sleep architecture[4], and causing cumulative sleep deprivation. Many physical, neuropsychological, and psychopathological symptoms and dysfunctions result. These include dizziness, sleepiness, extreme fatigue, lethargy, headache, loud snoring, obesity, diminished cognitive functioning, personality changes and emotional instability including depression. Sufferers have been subjected to ridicule and embarrassment because of their symptoms, so the individual's sleep apnea experiences may be intertwined or compounded with secondary and tertiary problems making it very difficult to separate primary influences from others.

In addition to the discomforts of the illness itself, many patients experience frustration and difficulty in obtaining a diagnosis, or are not taken seriously by their

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[1] Apnea, is from a Greek word meaning"breathless." It is defined as "cessation of airflow at the nose and mouth lasting at least 10 seconds," (Lopata, undated).

[2] Pickwickian disease is an illness of the excessively obese. The breathing passageways are so badly obstructed with fatty tissue that breathing, day or night, is impaired.

[3] Hypoxia is deficiency of oxygen reaching the tissues of the body.

[4] Sleep architecture refers to the rhythm, proportion, and cycle of the stages of sleep: the four non-rapid eye movement (Non-REM) stages, and the rapid eye movement (REM) sleep during which the majority of dreams occur. See section on "Sleep patterns" on page 6.

family physician because the physician's knowledge is limited. There is a lack of information on how these circumstances affect the acceptance and adjustment to an illness, or endangers compliance to treatment.

There are no definitive answers: no understood cause; no known cure; no definite treatments that work for everyone; and no way of preventing future escalation of the illness, hence the sleep apnea sufferer lives with uncertainty. If the helping professions are to be effective, understanding must be advanced in the area of the sufferer's feelings, doubts, concerns and fears. Some patients, maybe all, share similar fears and possibly misconceptions without openly identifying them. Only when fears and emotions are expressed and identified do they become possible to cope with. Often sleep apnea victims suffer their illness and symptoms silently and unknowingly for years in the same way as child with poor sight or hearing. The coping mechanisms are likewise silent, subconscious and automatic, sometimes dysfunctional and make understanding all the more clouded.

In addition to symptoms directly caused by SAS, apnea exerts stress on major body organs which can predispose to, or aggravate, stroke and cardiovascular disorders. It has been stated in material published by the Alberta Lung Association that, "of several sleep disorders, sleep apnea is the most consequential in terms of medical severity, economic cost and incidence in the general population." (Lerohl, p. 14). Many researchers have estimated the prevalence of this disorder: Bedard, Montplaisir, Richer, Rouleau and Malo (1991) suggest that between one and ten percent of the population have sleep apnea, Young et al. (1993) estimate the "prevalence of sleep-disordered breathing, defined as an apnea-hypopnea[5] score of 5 or higher, was 9 percent for women and 24 percent for men" (p. 1230), and Guilleminault (1987) suggests that "its prevalence increases with aging and may reach more than fifty percent of the male population above sixty years of age" (p. 618). Applying Bedard et al.'s estimates to the populations of Canada and metropolitan Edmonton gives an indication of the magnitude of the disease. Metropolitan Edmonton has between 8,399 and 83,992 apneics. The Canadian totals would be between 272,968 and 2,729,685[6]. Based on information from sleep laboratories and treatment centres in Alberta, it appears that the majority of those afflicted are unaware, undiagnosed, and untreated.

Purpose of the Study

It would seem appropriate that serious attention should be paid to better understanding and mitigation of the inherent damages to the lives of those affected by such a consequential disorder of such high prevalence. Guilleminault's (1989)

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[5] Hypopnea (or hypopnia) is a reduction in the nasal air flow of one third or more, but not complete cessation.

[6] Statistics Canada 1991 Census report the Canadian population at 27,296,859, and the metropolitan Edmonton population at 839,924.

prevalence estimates above would also indicate that special attention should be given to higher age, higher risk populations. The purpose of this study, therefore, is to examine the experience of living with sleep apnea, from the point of view of the person with the syndrome, as it relates to work, home and leisure activities. Reference to apneics as "patients" will be avoided because, as Conrad (1990) points out, the view intended here of the lives of these participants has little relation to their status as patients (p. 1260), but to their lives as functioning human beings.

From a positivist's model, it may be logical to believe that by understanding physiological limitations we can understand the impact of specific disabilities on the lives of others. Unfortunately, that approach merely scratches the surface of understanding. For a true understanding, it is necessary to experience the life and feelings of the individual directly involved. One method which simulates this experience is to ask 'first-hand experts' to describe the phenomenon: to ask individual's with sleep apnea how they perceive their lives, and to listen to their descriptions and the expressions of their experiences with sleep apnea every day, and every night.

Literature Review

Overview of sleep disorders

Moorcroft (1989) expresses the classification of sleep disorders in a very succinct manner: "Disorders of Excessive Sleepiness (DOES), Disorders of Initiating and Maintaining Sleep (DIMS), circadian rhythm disorders, and other disorders called parasomnias that occur during essentially normal sleep. (The last two I jokingly call D'others)," (p. 256).

DOES includes narcolepsy, sleep apnea syndrome, and periodic limb movements in sleep (previously called nocturnal myoclonus), all of which have organic origins. Narcolepsy is characterised by irresistible sleep attacks and cataplexy (paralysis-like immobility). It is not uncommon for a narcoleptic to fall asleep in a standing position, or in mid-sentence. Sleep apnea accompanies snoring, and is characterized by long snoring and breathing pauses during sleep. The most common limbs involved in periodic limb movements are the legs. The activity has been described as a night long kick-boxing match. There are some forms of treatment for these disorders at the moment, but the conditions are generally chronic and incurable.

DIMS includes insomnia which has a multitude of forms and causes. Some DIMS conditions may be transient or 'curable,' and some may be chronic.

Parasomnias (or D'others), include somnambulance, night terrors, nightmares (Manfredi, Vgontzas & Kales, 1989), and disorders of the sleep-wake schedule. Somnambulance is sleepwalking, and night terrors are dramatic and intense fear created from a dream-like image which leaves no specific memory, and

characterized by screams (Manfredi, Vgontzas & Kales). Disorders of the sleep-wake schedule can result from travel, shift work, or by an absence or unusual circadian sleep/wake rhythm, (Moorcroft, 1989, p. 256).

Even the least offensive sleep disorder is serious because it alters the sleep architecture and deprives the individual of the feeling of starting the next day refreshed. More serious and severe sleep disorders cause other physiological and psychological problems in addition to altering sleep architecture.

Overview of sleep apnea

Sleep apnea must have afflicted people for thousands of years, but because there was limited understanding of sleep behavior, its significance went unnoticed. The cessation of breathing common to sleep apnea was noted long ago, but assumed to be a side effect of severe illness. The periodic cessation of breathing was not seen as a problem until technology advanced sufficiently to measure the details of sleep and breathing and until medical knowledge understood the implication of insufficient oxygen. Medical science was unaware of either the problem in its own right or its potential threat to life and health until about twenty years ago. Since that time, very sophisticated sleep laboratories have been established all over the world in order to study normal and abnormal sleep, and to diagnose the many and varied sleep disorders now known to exist.

Because of the recency of sleep apnea's recognition, there is still much to learn. Most substantial research published to date is less than five years old, and has been conducted by natural scientific methods. In addition, because apnea affects, and is sometimes caused by, the central nervous system which is possibly our most complex system, advances in treatment are extremely slow and relatively primitive.

The common symptoms associated with sleep apnea are snoring, restless sleep, active movements, excessive daytime sleepiness, depression, irritability, compromised performance and altered cognitive functions. Lopata (undated) suggests that sleep apnea "patients can present with chronic cardiopulmonary disease. . . . Nocturnal arrhythmias are well-recognized and these can be life-threatening. A significant number of patients, up to 40%, have systemic hypertension as well." (p. X-3)

There are three types of apnea: central, obstructive and mixed.

Central sleep apnea

With central sleep apnea, "breathing ceases momentarily during sleep because of a transient withdrawal of central nervous system drive to the muscles of respiration" (Bradley & Phillipson, 1992, p. 493).

The exact etiology is unknown, but central apnea is possibly the result of a dysfunction within the brainstem since that is the area believed to contain 'sleep centres,' (Sleep Research Society, 1993, pp. 33-44). It is possible to speculate that central apnea occurs as a result of brain injury during illness such as poliomyelitis (Plum & Swanson, 1958) and other disease processes which "can damage the medullary area, leading to breathing dysrhythmias during sleep", (White, 1989, p. 520). Central apnea, by itself or as a primary apnea, is relatively rare, and the sufferer is usually slim and without other physical characteristics of the person with obstructive sleep apnea. Children with central sleep apnea are often described as failing to thrive.

Obstructive sleep apnea

The majority of sleep apnea cases are of the obstructive type. Physical characteristics of those people suffering this type of apnea include obesity, a short, thick neck, or a receding chin.

The etiology of obstructive sleep apnea may be of several physiologic or pathologic origins. The effect during sleep is some degree of closure or blockage of the air pathway. The "diaphragm continues to contract rhythmically with a progressively greater effort against the closed airway until finally a partial or complete awakening occurs and normal breathing is resumed" (Mosley, 1990, p. 480). Contributing factors can include polyps or other growths, an excess of fatty tissue, a lack of muscle tone, an anatomic abnormality, or a combination of problems. Guilleminault (1987) provides full physiological details.

Mixed sleep apnea

Mixed sleep apnea is a combination of both central and obstructive sleep apnea, often beginning as a central event, and changing to an airway obstruction (see Appendix C)[7]. This type may therefore be more complicating and serious in its effects.

Diagnosis of SAS is often difficult and a cause of frustration to the patient. Presenting symptoms can be inconclusive or misleading to a physician. Also a patient's memory may be faulty. Usually a bed partner can provide more accurate information on symptoms that will lead more directly to the suspicion of sleep apnea. The verification, substantiation or elaboration of a patient's signs and symptoms by others, such as a bed partner, can assist a physician who suspects SAS, but to achieve an accurate diagnosis, a full night's observation in a sleep laboratory is necessary. Observations include polysomnography which usually

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[7] Appendix C shows a polysomnograph recording of a single mixed apnea event, beginning as a central apnea, and finishing as obstructive.

consists of electroencephalography[8], electrooculography[9], electromyography[10], electrocardiography[11], nasal airflow, thoracic and abdominal respiratory effort, and oxyhemoglobin[12] level: all essential for an accurate diagnosis.

A number of researchers (Bedard, Montplaisir, Richer, Rouleau & Malo, 1991; Cheshire, Engleman, Deary, Shapiro & Douglas, 1992; Findley et al., 1986; and Greenberg, Watson & Deptula, 1987) have identified the neuropsychological dysfunctions of sleep apnea, and have attempted to correlate the various dysfunctions with the level of blood oxygen, the level of sleepiness, or the duration of the apneas. Findley et al. and Greenberg, Watson and Deptula found that persons suffering from SAS have impaired attention, concentration, problem solving skills, perceptual organizational ability, motor speed, verbal ability and memory. They also found that the severity of the apnea increases some impairments, but impairments do not correlate highly with levels of hypoxia[13] or hypoxemia[14]. Bonnet (1993) partially explained this lack of correlation by linking both sleepiness and cognitive impairment to sleep disruption. This was achieved by fragmenting the sleep of young normal adults to simulate the effects of sleep apnea.

Sleep patterns

A knowledge of normal sleep patterns, or sleep architecture, is necessary to understand sleep apnea. The normal pattern of sleep is governed by sleep stages, which fall into two major categories: rapid eye movement (REM) sleep and non-rapid eye movement (NREM) sleep. The two unique features of REM sleep are bursts of rapid eye movement along with markedly decreased levels of muscle tonus. NREM sleep can be sub-divided further into stages I, II, III, and IV

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[8] Electroencephalography measures brain waves, which are used to determine stage of sleep.

[9] Electrooculography measures eye movement, which indicate rapid eye movement (REM) sleep.

[10] Electromyography measures electric currents of body movement. Usually the legs are measured for motion, providing indications of periodic leg movements (PLM).

[11] Electrocardiography provides a tracing of the electric currents generated by the heart's function.

[12] Oxyhemoglobin is the non-invasive measurement of blood oxygen, usually by a clamp on an ear lobe or finger, and attached to an oximeter.

[13] Hypoxia is deficiency of oxygen reaching the tissues of the body.

[14] Hypoxemia is deficient oxygenation of the blood.

(Rechtschaffen & A. Kales, 1968). The Sleep Research Society (1993) describes the characteristics of NREM sleep as follows:

> Stage I EEG activity is mostly low voltage and mixed frequency, usually at 3-7 Hz (theta waves). Slow, rolling eye movements are common.
>
> Stage II With a continuing background of low voltage, mixed frequency activity, the EEG contains bursts of distinctive 12-14 Hz waves called "sleep spindles." Eye movements are rare, and the EMG is low to moderate.
>
> Stage III High amplitude, slow waves called "delta waves" appear in the EEG, and the EMG continues as in Stage II.
>
> Stage IV There is a quantitative increase in delta waves to the point of dominating the EEG tracing.

During a typical night, a normal sleeper will cycle through the NREM stages of sleep several times, and return to stages III and II prior to the first period of REM sleep. The first REM sleep usually occurs after about ninety minutes of sleep. Although different for each age group, this cycle, continues during the sleep periods, with the REM portion lengthening and the stage IV portion shortening with each successive cycle. Young adults, for instance, experience REM sleep for about twenty to twenty-five percent of the night's sleep, whereas stage II makes up fifty to sixty percent of the sleep period (Manfredi, Vgontzas & Kales, 1989).

Sleep disorders result in the normal sleep pattern or cycle being completely disrupted by frequent awakenings, or there are different proportions of each stage of sleep. Bedard et al. (1991) found that the percentage of REM sleep was 15.2 percent for control subjects and only 10.1 percent for a group with severe sleep apnea with a similar mean age. Manfredi et al. (1989) found:

> For those suffering sleep apnea, for instance, . . . during each repetitive respiratory pause, hypoxia causes arousal and resumption of breathing, but the patient generally does not fully awaken. This partial but severe sleep deprivation contributes to the most frequent complaint among these patients - excessive daytime sleepiness. (p. 264).

Meyer, Ishikawa, Hata, and Karacan (1987) conducted detailed tests of cerebral blood patterns during sleep and dreaming. They found that, although the different hemispheres and locations of the brain have different flow patterns, generally the normal flow values decrease from the awake stage, further reduce through each of the sleep stages I to IV, and dramatically increase during REM sleep to more than forty percent above the awake state (p. 272). They also found the cerebral blood flow pattern in people with sleep apnea is reduced from normal subjects in the awake state, and further progressively decreased through sleep stages I to III. The most marked decrease noted was in the occipital cortex and brainstem-cerebellar regions. Here there was a 1.5 times greater decrease in sleep apneics at the time of intermittent respiratory arrest, than in normal subjects.

Working brain activity

Luria (1976) reminds us that:

> human mental processes are complex functional systems, and that they are not 'localized' in narrow, circumscribed areas of the brain, but take place through the participation of groups of concertedly working brain structures, each of which makes its own contribution to the organization of this functional system (p. 43).

As part of a system, each brain component then has its contribution to the functioning whole, and like Hunter and Lashley's experimental rodents (quoted in Luria), who were "unable to reproduce the movements learned through training," were able to achieve the "required results" by some other movement (p. 29). Hence, when:

> a pathological focus arising as the result of a wound, or haemorrhage, or of a tumour disturbs the normal working of a given brain area, abolishes the conditions necessary for the normal working of the particular functional system, and thus leads to reorganization of the working of the intact parts of the brain, so that the disturbed function can be performed in new ways (p. 103-4).

Additionally, as Luria points out, it is rare that a focus in the brain destroys "all the nerve elements within that zone," or effects a "precisely demarcated" area (p. 104). It is probably for this reason that many people with sleep apnea function well, and even excel in many ways throughout life. Also, the superb additional flexibility of a young brain is pointed out by Restak (1984) as he explains that a stroke of the magnitude to deprive an adult of speech, when encountered "in a young child of six or seven . . . often has no effect on subsequent language development" (p. 239). The theory Restak suggests to explain this is that the "two hemispheres provide backup systems for each other in the event of damage to only one. . . ." However, because the "brain's hemispheres become so specialized that, beyond childhood, complete recovery from a stroke in one hemisphere is extremely rare" (p. 240).

It is probable that some central sleep apnea is caused by a malfunction or a lesion in the reticular formation. This is the systemic part that Luria explains is "a powerful mechanism for maintaining cortical tone and regulating the functional state of the brain, and that is a factor determining the level of wakefulness," (p. 49) it seems likely that such a malfunction could cause difficulties to many functions.

Blood oxygen saturation levels

Bedard, Montplaisir, Richer, Rouleau and Malo (1991) found that the waking blood oxygen parameters (PaO_2 and $PaCO_2$) for normal sleepers is about 76.7, and 39.1 mmHg (millimetres of mercury), respectively. For the person with sleep apnea there was no statistically significant difference in this index. However, during sleep,

the minimal nocturnal blood oxygen saturation (SaO_2) value for the severe sleep apnea group was only 57.8 percent compared to the controls of 87.8 percent. In addition, the percentage of sleep below 80 and 90 percent oxygen saturation levels for the sleep apnea group was 22.5 and 55.5 percent respectively, compared with only 1 percent below 90% for the controls.

Hence there is a multiple jeopardy situation for the sleep apnea sufferer: sleep deprivation; reduced REM sleep; reduced cerebral blood flow during REM sleep; and reduced oxygen in the blood flow.

Altitude

In studying the negative and long-lasting effects of climbing or simulated climbing to extremely high altitudes (4000 to more than 8000 meters) researchers (Hornbein, Townes, Schoene, Sutton & Houston, 1989; Jason, Pajurkova & Lee, 1989; and Kennedy, Dunlap, Banderet, Smith & Houston, 1989) found subjects exhibited confusion and decreased verbal abilities, (reading, writing, expressive language, spelling and pronunciation). Motor speed and performance, long and short-term memory, and concentration were also affected. There were differences between the symptoms suffered by mountain climbers and those on simulated climbs, as well as differences in susceptibility to the effects of hypoxia between individuals, possibly as a result of individual responses to breathing at high altitude, and the different peaks and valleys of hypoxia encountered. Also, some problems seemed to remain longer after climbers returned to a normal altitude.

Nelson, Dunlosky, White, Steinberg, Townes and Anderson (1990) included metacognition changes, and Shukitt-Hale, Banderet, and Lieberman (1990) considered mood changes and acute mountain sickness in their studies of effects of extreme altitudes. Nelson et al. found that altitude appears to cause climbers to underestimate their abilities to perform tasks and to learn and remember. Shukitt-Hale et al. found altered moods and states associated with altitude sickness, such as loss of appetite, dizziness, fatigue, insomnia, irritability, depression and difficulty with thinking.

Sleep deprivation

We all sleep. We all recognize that we have to sleep. But it is not known exactly why we need to sleep (Sleep Research Society, p. 5). Some of the effects of no sleep over a prolonged period of time, less sleep than needed, or interrupted sleep are understood, and Jacques, Lynch, and Samkoff (1990) and Krueger (1989) found that sleep loss results in reduced reaction time, perceptual and cognitive distortions, irritability and other mood changes.

Questions have been raised regarding the functions of the different stages of sleep, and if deprivation of REM sleep is more detrimental than deprivation of other stages of sleep. It seems to be acknowledged that the more a sleeper is

deprived of REM sleep, the more the sleeper will 'rebound' into REM sleep at the next sleep onset (Dement & Greenberg, 1966; reviewed by Ellman, Spielman, Luck, Steiner & Halperin, 1978), hence it is difficult to reduce REM sleep without radically reducing total sleep. Continuing on this line, Glovinsky, Spielman, Carroll, Weinstein, and Ellman (1990) examined the effects of awakenings from REM or Stage II sleep in healthy young adults, and found that "restriction of total sleep time may be enough to account for the increased sleepiness observed" (p. 556). This might suggest that sleep deprivation directly causes an inability to maintain sustained vigilance (sleepiness) which, in turn, causes cognitive performance deficits in areas such as decision-making, visual discrimination, logical reasoning and performance accuracy. Mitler (1993) agrees and explains that the sleepiness in apnea, or rather the ability to stay awake is an important variable when measuring cognitive functioning.

Adding age to the variables of this complex situation, Mertens & Collins (1986) found that the negative effects of sleep deprivation and altitude on performance increase with age.

Psychological aspects of chronic illness

Chronic illnesses come in a variety of types and severities: some very serious, degenerative, deforming, debilitating and life-threatening, others little more than an inconvenience. Often the same illness is experienced with varying degrees of severity. "Chronic illness [is] always regarded as a personal tragedy," (Kinsman, Jones, Matus and Schum, 1976, p. 159) and more tragic to some than to others. All chronic illnesses have the potential to impact upon the future psychological wellbeing of the individual, and the type of illness, severity, and any disability are only some of the factors which dictate how much distress will be encountered, and what coping resources will be needed. However mild the illness, distress is very likely to occur since there is the clear message to the patient that life will never again be 'normal.' In more serious illnesses, distress is seen in the form of depression, anger and anxiety. Such distress is frequently reported and is common in many types of chronic illness.

With many serious chronic illnesses, "the prognosis is uncertain. No one can say precisely which impairments will disappear completely for an individual or when they will disappear. More important, the future is uncertain" (Kaufman, 1988, p. 342). Although Kaufman was discussing the results of a stroke, other chronic illnesses are characterised by uncertainty: uncertain futures, uncertain impairments, uncertain limitations. Uncertainty of this nature brings anxiety, and is hard to live with especially at the early stages of an illness.

In addition to the distress mentioned, Kaufman (1988) found failure, vulnerability, anger, humiliation, loss, distortion, fear, and entrapment in those who had suffered disability through strokes; and, Brown, Armstrong & Eckman (1993) noted neurocognitive deficits, low self-esteem, poor social competence, and disturbances of body image frequent characteristics of children with sickle cell

disease. Thompson, Hodges, and Hamlett (1990) found anxiety disorder to be common in children with cystic fibrosis, and Deshields, Jenkins & Tait (1989) found high levels of anger in diabetic and hypertensive patients. Gregg, Robertus & Stone (1989) found depression to be common in the early stages for many patients, and fear to be a common element for those having diabetes, arthritis, cancer, or multiple sclerosis, and for those who had suffered a stroke. Garrison & McQuiston (1989) discussed anger and frustration associated with the reduction in optimism, and prolonged periods of crying and sadness in response to the failure of leukemia to go into remission following treatment. They also discussed the direct relationship between levels of pain and psychological coping in that the higher the levels of pain, the harder it is to successfully cope, and also as the length of an illness grew, and the more the deformity and severity, the more despair and anger intensify. Finally, Baker and Pinder (1989) discuss discriminatory practices and feelings of rejection and segregation affecting individuals with disabilities arising from the onset of chronic illness.

Treatment of sleep apnea

Because apnea has so many causes and forms, it is not considered curable, only treatable. The treatments, depending upon the probable cause, can be behavioral, mechanical, and surgical. Behavioral programs are effective only for reducing severity, or eliminating mild obstructive apnea. They include weight loss, sleeping body position training, sleep hygiene training, and drug abstention. Mechanical treatments are usually combined with behavioral programs, and include the use of masks or other breathing support devices attached to small air pressure pumps which 'splint' the airway during sleep. Commonly used breathing equipment includes the nasal continuous positive airway pressure (CPAP) machine, and the bi-level positive airway pressure (BiPAP) machine. Unfortunately, many patients cannot tolerate such treatment, and thus compliance is less than perfect. Milder cases are often managed with a variety of oral or dental appliances which advance the lower mandible or tongue and increase the airway. Surgical treatment includes tonsillectomy and adenoidectomy, tracheostomy[15], uvulo-palato-pharyngoplasty (UPP)[16] by conventional and laser surgery, maxillary and mandibular advancement osteotomy (MMO)[17], and MMO combined with UPP. The long term success of the surgical treatments is sometimes poor, and symptoms may return when scar tissue softens. Medications such as protriptyline, buspirone, and medroxyprogesterone

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[15] The tracheostomy procedure creates a surgical opening directly into the windpipe at the base of the neck.

[16] Uvulo-palato-pharyngoplasty (UPP) is a surgical procedure used to reduce the size of the uvula, and to trim and tighten the tissues of the soft palate. Scar tissue is created during the procedure in order to tighten the tissues.

[17] Maxillary and mandibular advancement osteotomy (MMO) is an oral surgical technique used to advance the jaw and lower face.

acetate have been used, but to date have had short-term success only. These medications reduce the amount of REM sleep, thereby reducing the type of sleep during which apneas occurs. However, sleep apnea patients generally suffer REM sleep deprivation, so the additional deprivation does not lead to long-term success.

Improvements of symptoms with treatment

Because of the wide range of treatments for apnea, most of the published research evaluating treatment results concentrates on CPAP or UPP surgery, and only uses subjects with obstructive sleep apnea. Klonoff, Fleetham, Taylor and Clark (1987); Millman, Fogel, McNamara, and Carlisle (1989); Montplaisir, Bedard, Richer and Rouleau (1992); and Ramos-Platon and Sierra (1992) found a consistent improvement in the cognitive and emotional conditions of those who had been receiving CPAP treatment for one year or more, but did not provide details of the severity or longevity of the subjects' illness.

Most cognitive measures, such as attention and verbal memory are found to improve with treatment. However, some functions remain impaired after treatment, such as manual dexterity, planning and regulating abilities, and verbal fluency. Very long term treatment may correct some of these executive functioning impairments, but it is probable that some individuals incur permanent damage.

These findings agreed with the high altitude studies which found that some physical and cognitive functions return to normal immediately upon return to sea level, and others are still impaired one year later.

Summary

To summarize, there is considerable knowledge about the physiological results of sleep apnea syndrome (SAS), the symptoms, the stresses on the body and secondary medical problems. Also a great deal is understood regarding difficulties involving sleep interferences, comparative mountain climbing sickness symptoms, and some of the psychological effects of chronic illness. It is known that all population segments are affected, but precise percentages of involvement are unknown. Many of the neuropsychological dysfunctions have been identified, but why the dysfunctions are caused is only suspected. A great deal of work is needed to study the disease and its causes, and there is an equal need to find effective treatments and a cure where none currently exists. Treatments used now are far from ideal. All have limitations or potential side effects, as they merely mechanically manipulate the body into bypassing presently dangerous health conditions. To a very limited extent how the treatments work is understood, but why it work on some patients is not.

Limitations of Work to Date

In spite of a few case studies included with the literature, and one study to measure, through questionnaires, the quality of life in mild obstructive sleep apnea (Gall, Isaac & Kryger, 1993), very little is understood about what life is like for the person with sleep apnea. A wealth of qualitative and quantitative research has been done on chronic illnesses generally, and indeed, the work of Gregg, Robertus & Stone (1989) provides wonderful insights into the lives of those suffering diabetes, arthritis, stroke, cancer and multiple sclerosis. Kaufman (1988) adds further understanding and expounds the virtue of the phenomenological method in her article of experiences in the case of stroke. However, qualitative research into the impact on the lives of people who suffer sleep apnea does not exist, and therefore we understand little of the fears and anxieties suffered, and the humiliations experienced. We know very little about the general life, work, and home and leisure activities of both the sufferers and family members, and we can only suspect that the effects of having a disease that is not commonly known or understood could be profound.

All of the research on sleep apnea to date has used natural scientific methods, and has concentrated on obstructive sleep apnea. The major difficulties seem to be that many studies used small sample sizes and patients of differing severity. Often studies have drawn subjects from the aged population who may have other health difficulties such as Alzheimer's disease which confound a clear understanding of sleep apnea. To add to this difficulty, the classification of 'severe' and 'moderate' can be composed differently, depending on whether the duration of the apnea, frequency of the apneas, or blood gas measurements are used. For instance, a patient who ceases breathing one-hundred and twenty times per hour may have a smaller percentage drop in blood oxygen than one who ceases breathing forty times, but for longer durations. This has possibly lead to agreements on findings involving major symptoms and some dysfunctions, and disagreement about many matters such as effectiveness of treatments, and which impairments are reversed with treatment, and which remain.

From the mountaineering and sleep deprivation studies, it is not difficult to understand that a condition that starves the body of oxygen and interferes with sleep would produce some profound effects. But we need to know more. We need an understanding of the human aspects of sleep apnea: how the individual is affected, how daily life is altered, and what emotional stresses are suffered. This can be achieved by a phenomenological study - a human science study. Such a study has not been done before, and certainly not involving patients of sleep apnea. This study is proposed to draw out information of a qualitative nature from patients that is not possible with natural science approaches.

Chapter II

Foundations of Methodology

Rationale for a Phenomenological Approach

The correct choice and application of the research methodology is essential in relation to the kinds of questions being asked, the evidence being sought, and the conclusions to be drawn. Additionally, one must select a focus within the two major approaches to research: the natural science or quantitative techniques and human science or qualitative techniques. If we define *science* as "specific and systematic ways of discovering and understanding how social realities arise, operate, and impact on individuals and organizations of individuals" (Berg, 1989, p. 8), then both methods are valid approaches to scientific investigation. The natural science approach has been the backbone of medical research over the recent past, and is based on positivism, objectivity, and the assumptions that the phenomenon under study must be observable, measurable (or quantifiable) and predictable. Natural science methods use deduction, and concentrate on explanations and causal relationships. On the other hand, human science approaches are inductive, and emphasize understanding and description without theoretical assumptions influencing the outcome. They "examine how people learn about and make sense of themselves and others" (Berg, 1989, p. 6) and "provide a means of accessing unquantifiable facts about the actual people researchers observe and talk to" (Berg, p. 6).

Most of us can reach into our primordial understanding and imagine what it would be like to experience a 'dramatic' illness, such as cancer, or, even more in vogue, AIDS without having experienced the actual condition. We have sufficient information about the effects of these illnesses that we do not need to experience them personally to be able to understand the negative consequences. Sleep apnea is not a 'dramatic' disease, but that does not mean it has any less impact on a victim. Relatively few people know what sleep apnea is, and even less understand the subtle devastation this insidious illness can cause to the sufferer. If more people understood the plight of the apneic, the load would be a little lighter for the sufferer in the same way that the present level of public understanding of epilepsy removes some of the previous fear for epileptics of having a seizure in public.

Psychology and medicine are beginning to understand that there is more to human wellness than biomedical aspects. As Polkinghorne (1989) and others explain, "the error of the traditional approach is the result of separating mind and body into two independent spheres (p. 42) but "the holistic approach posits that the patient's psychological, behavioral, and sociocultural characteristics (as well as physiological and biochemical characteristics) influence the course of illness and recovery and are therefore directly relevant to medical care" (Kaufman, 1988, p. 339). "Experience is a reality that results from the openness of human awareness to the world, and it cannot be reduced to either the sphere of the mental or the

sphere of the physical" (Polkinghorne, p. 42), hence we might gain new insights and ways to help if we look beyond the illness itself by visiting the experiences of the sufferer, and investigate the effects of the illness on the individual's whole being.

An individual's experiential world is personal and cannot be directly experienced by others. This private world is also not observable to others (Valle and King, 1978) and therefore, cannot be quantified or measured by natural scientific methods. The suffering of those with sleep apnea, therefore, cannot be quantified, observed or measured by conventional techniques, hence a human science approach for the study of the effects on the individual's living activities, would provide another vision.

There is a part of the individual that can be helped by empathy and understanding; a value recognized for people with chronic illnesses which has resulted in the establishment of patient support groups for all sorts of conditions. Human science research, used in this way, is somewhat of an extension of a support group, both during and after the research process. Systematically collecting, recording, discovering, interpreting and validating experiences which are often deeply buried in the subconscious is part of the process of phenomenological research. While participants of a study might benefit by the catharsis involved in the interview process, other individuals later may benefit from the analyzed results.

The philosopher Edmund Husserl, introduced the concept of the "life world" (*Lebenswelt*), which is central to the understanding of a lived experience, and includes:

> emotions, motivations, symbols and their meanings, empathy, and other subjective aspects associated with naturally evolving lives of individuals and groups. These elements may also represent their behavioral routines, experiences, and various conditions affecting these usual routines or natural settings (Berg, 1989, p. 9).

The perception that a person has of their *lebenswelt* is their own private reality, whether or not that reality co-incides with the perception of others. From the Kantian philosophy of idealism, we construct our own realities within the two worlds: the **noumenal**, non-material or spiritual world; and the **phenomenal**, the material world of our experience. The ideas of existential phenomenology take this a little further by explaining that we are of the world and that we exist in context: as we interact on our world, our world changes and we are shaped by the same interaction. The experience of any chronic illness is a "lived experience," and Kaufman (1988) explains that social scientists using phenomenological methods have described how the experience of an illness can alter an individual's awareness of self and surroundings.

The phenomenological approach makes it possible to reveal an understanding of the altered "life world" of a person with sleep apnea. It allows the freedom to a person with sleep apnea to draw a picture of his or her life, and to understand **how** life is experienced, rather than **why** it is this way. This method, with its

emphasis on description, allows discovery of details and information not necessarily understood by the researcher prior to the study. I will, during this study, to some extent be entering the life worlds of the participants. This experience will involve co-constitutionality[18] as the interviews will change my views as I gain understanding, and my questions and the interview process will ultimately influence the participants' perceptions. In short, this study cannot be replicated because of the changes that will occur in the researcher and participants during the research process. This does not mean that the findings will be any less valid, less reliable or less worthwhile.

Selection of Participants

The subjects in a phenomenological study are sometimes referred to as co-researchers, and others as participants. These terms indicate the co-operative and interactive nature of the study method, and contrasts the objective, sterile observation of "subjects" in quantitative studies. The way in which interview participants are selected, as for any study, is important and should allow any conclusions drawn to be generalizable to some degree to a total population. In this case, the population involved is all those who suffer from sleep apnea syndrome, but the generalizability is not statistical. The question of generalizability relates to whether the subjective qualities possessed by the participants of the study can be expected to be found in the total population to some greater or lesser extent. Random sampling for qualitative studies is not appropriate, but participants are selected for the richness of their experience of the phenomena in question, and their willingness and ability to elucidate and provide examples and descriptions of their experiences.

The sample of participants for this study is therefore a selective sampling. The major criteria for participant selection was that each had experienced sleep apnea syndrome first hand. They all had to be experts, capable of fully expressing their experiences, and thus illuminating the phenomenon of living with sleep apnea.

In order to not contaminate or skew results with the sleep apnea experiences of a single demographic group, a heterogenous group was selected to cover the total representation of the known apnea population, including young, old, middle-aged, well and less educated, slim, obese, male, female, professional, employed, retired, rich, poor, treated and untreated individuals.

Additionally, in order to "choose an array of individuals who provide a variety of specific experiences of the topic being explored" (Polkinghorne, 1989, p. 48) it was considered ideal to cover the full range of types, onsets and severity of apnea and treatments. These included central, obstructive and mixed sleep apnea,

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[18] The notion of co-constitutionality recognizes that we do not live in the world alone, and that our experiences are built around others: as we affect our world and others, the world and others affect us.

childhood, adult and later-adult onset, surgery and CPAP treatment, not yet treated, and resistance to treatment. (The participants, once selected, did demonstrate a range of symptom severity from very slight to a fair level of cognitive impairment, and from mildly fatigued to severely sleepy. These symptoms do not necessarily parallel the severity of the illness.)

Interview Format

The format used was a series of three or more interviews. Each participant was interviewed three times separately, followed by telephone contacts. The first interviews were recorded on audio-tape and fully transcribed. No audio-tape recording was used at subsequent interviews nor during telephone conversations, but notes were taken.

The first interviews were semi-structured, and began with an open-ended request to tell of experiences and situations caused or influenced by sleep apnea symptoms. A general list of questions was used if information was not forthcoming from a participant's descriptions (see Appendix B). Open-ended, non-leading probes were also used to gain elaboration and expansions where necessary. The result was that each participant explained past and present circumstances and sequelae leading to and following a diagnosis. Explanations included perceptions, beliefs and experiences as well as coping skills and mechanisms employed. Participants told about dreams, levels of sleepiness, memory effects and other cognitive changes as well as social, family and working relations and implications. Pre and post treatment experiences were among the many situations presented.

This style of interview was chosen because it provides freedom to the participant to tell of his or her experiences in the way that is individually perceived to be important. The freedom to pursue unique experiences and emotions was particularly important given the diversity of the group of participants. Since each of the participants was unique in terms of symptoms, severity of illness and treatment, a standard list of questions would not have been appropriate.

Second interviews took place after the transcription and analysis of the first interview. These meetings were very informal, and participants were encouraged to argue or dispute the analysis, and elaborate on experiences and meanings of experiences.

Subsequent meetings and telephone conversations took place to discuss common findings among the participants, and to check or confirm understanding of various comments or questions. Each participant was provided with a written package containing the analysis of their interviews, the synthesis of their experience, and a listing of the common themes among all participants.

Reliability and Validity

Reliability in natural science "refers to the consistency of measurement, the extent to which the results are similar over different forms of the same instrument or occasions of data collecting" (McMillan & Schumacher, 1989, p. 243). Reliability therefore relates to measurement and the error of such measurement, but when measurement is not part of the research method, reliability cannot be viewed in the same way. In qualitative research, Wertz (1986) explains that reliability is supplied by being able to:

> "look again and again and see the same thing, that I can touch and see the same thing; it is the way in which the meaning of 'sameness' and 'thing' is established. This multiplicity is the intrinsic hitherside of unity on the condition that these perspectives are not merely repeatable but also *related to each other* in a single understanding of the thing" (p. 191.)

Hence, if we see the same structures again and again with each of the participants, creating a constant and stable reality, then reliability is established. If another researcher, independently, can also see the same themes and structures from the evidence, then reliability is reinforced. Thus the similarity of experiences of the participants is key to establishing reliability, and as such, reliability means that the research is repeatable to some degree, but with a new researcher and new participants. The exact interview, of course, cannot be repeated or replicated because the participant and researcher undergo transformation during the interview as a result of information shared and knowledge gained.

The validity of each interpretation depends upon accuracy as seen by the participant in question. Research cannot be reliable if it is not valid, and hence the reliability rests on it own merits after the establishment of its face validity. If the participants recognize the essence of their experiences as they described, and there is a 'goodness of fit,' then the interpretation is valid. If individual participants agree with the interpretation of their experience, shared experiences confirmed between participants, and independent researchers agree with interpretations, then there is a good measure of reliability and validity. If the participants are homogeneous as far as experiencing the phenomenon in question, and heterogeneous in other ways, then the validity is strengthened by finding shared structures.

Chapter III

Method

Introduction

The objective of this chapter is to outline the procedures followed in phenomenological research, and the specific procedures followed in this study. This type of research involves the study of conscious experience or contents of conscious experience, usually beginning with the question to be investigated, continuing with unstructured interviews of willing, knowledgeable participants, and ending with descriptions and new understandings of how others view their lived world.

The phenomenological researcher's focus is on a latent or deep structure of meaning rather than obvious or surface meaning. Generally in phenomenological research, thematic analysis is used to uncover the deep structures of the phenomenon being investigated, and to understand the meaning of these structures. When thematic analysis is complete, a process of aggregation into higher order clusters takes place, and the researcher strives to accurately and illuminatively describe the essential structures of the experience. In the case of this study, the essential structures should reflect the experience of a person living with sleep apnea at work, home and leisure.

When the essence of a lived experience is understood, the researcher may then systematically create a composite picture or description of that experience. The exact steps in the process from the beginning of the inquiry to the end description will be detailed later in this chapter. Before that, I will provide my rationale for choosing to study the lives of individuals with sleep apnea. Following that will be a brief introduction to the concept of bracketing[19], and an introduction to the eight participants or subjects of this study.

Rationale for This Study

My first encounter with sleep apnea was when my mother was unconscious and in the last few days of her life. A palliative care nurse pointed out her interrupted breathing pattern, and gave it a name. A few years later I met, and married my present husband. When we were getting to know each other, he explained that he suffered from sleep apnea, and that he stopped breathing at night periodically, but he always resumed again. This information did not have any impact upon me until we were bed partners. I would lie sleepily beside his quiet

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[19] Bracketing is a self-reflective process used in phenomenological research whereby the researcher identifies, examines and attempts to suspend personal preconceptions, presuppositions and biases.

body, using all my mental powers available to will him to start breathing again.

During those early years, my husband, Don had a very primitive CPAP (continuous positive airway pressure) machine and mask. The machine seemed to consist of something that sounded like a two-stroke electrical generator motor, and the mask was clear plastic which needed periodic re-inflation with a hypodermic syringe. Needless to say, Don used this equipment infrequently because the noise was almost as disturbing to him and everyone else in the house as his interrupted snoring.

Sometime during the first year of our marriage, I discovered that part of me resembles a female canine when I suffer long-term sleep fragmentation or deprivation. Don, on the other hand, takes all in his stride as his nature is to endure with eternal patience. He seemed totally unaffected physically and emotionally by his illness, his fragmented sleep, and the noisy machine. The difference between us lead me to wonder if I had been single too long to be a spouse, and that we were totally incompatible. It was at about that time, when I was sleeping in another room, that we agreed it would be better for both of us to endure, and maybe accommodate to, the steady noise of his breathing machine all night and every night than for both of us to suffer sleep deprivation and sleeping apart. Very shortly after that decision, Don purchased a new machine with a sound level closer to a refrigerator motor than a freight train, and we settled into comfortable, sleep-filled nights and a tranquil marriage.

A few years ago, with encouragement from a sleep specialist, Don and I, together with another patient, were involved in establishing a Sleep Apnea Society of Alberta regional patient support group, with a view to arranging meetings every few months. At the group meetings we met sleep apnea sufferers who were obviously more profoundly affected by their illness than Don, and people who had more exterior symptoms of their illness.

At the beginning of the Master's degree program, I began to look into aspects of cognitive impairment caused by sleep apnea and sleep deprivation, and was quite astonished at the potential consequences. From there, at each opportunity, I examined a different side of the effects of sleep apnea, until I finally realized that the impact of the illness on the whole person had not been explored by any current research. If there were people so profoundly affected by the illness cognitively and physically, then what must the complications be on their whole lives! The subject for my study was thus born, and the most appropriate way to complete such a study was by a qualitative method.

Preconceptions and Presuppositions

Listing and examining one's preconceptions, presuppositions and biases is a process called 'bracketing.' This process involves self-reflection, and is an important component in phenomenological research. Edmond Husserl, an early developer of phenomenology, considered it not only necessary for the researcher to

list presuppositions, but to continue reduction of predispositions and prejudices to the point of suspension, so that the phenomenon reveals itself through disciplined naivety and objectivity. Martin Heidegger, possibly the second most revered person in the field of phenomenology, and who developed existential phenomenology, disagreed. Heidegger felt that as human beings, it is impossible to completely suspend biases and predispositions. Heidegger therefore considered it appropriate for the researcher to state his or her position clearly, and then to make the argument with the understanding that it is impossible to be truly objective. In tune with Heidegger's philosophy, I will state my preconceptions and predispositions, fully recognizing that my view and interpretation of the participants interviewed are biased in many ways, and indeed that my analysis will be similarly biased. However, I trust that sufficient evidence is presented here, along with the arguments, to allow the reader to reach parallel conclusions to those stated.

In an attempt to organize my presuppositions, I have separated them into a group of categories, and will deal with each category separately, although some may overlap.

(1) Bodily Sensations and Psychological Trauma.

From discussions with my husband, Don, as to how he felt, I originally concluded that tiredness and a kind of lightheadedness might be the only bodily sensations associated with untreated sleep apnea. Since I did not consider varying degrees of severity, and I thought Don to be a typical person with the condition, I assumed that all people suffering from apnea would experience similar bodily sensations. Later, at meetings of the patient support group I met many other people with sleep apnea, and from observations and discussions, I found that my understanding was misguided. However, very little was expressed by the patients during the meetings as to the variety of symptoms felt, other than sleepiness. I also considered that the apnea condition might cause some functional difficulties which, when treated, would disappear. Initially I had no conception that deep psychological trauma could be caused by what seemed a relatively mild illness. Again, using Don as my major source of information, I did not recognize that his incredibly stable personality and upbringing of stoicism provided me with an inaccurate impression.

(2) Recognition of the Illness by the Individual.

Because Don quite readily discussed some of the problems probably caused by the illness, I assumed that a person with sleep apnea, once treated, automatically had a clear retroactive view of the signs and symptoms relating to the condition. Some sufferers, like Don, have lived their entire lives with the condition, and therefore see an almost instant change in some of the symptoms upon treatment, such as the disappearance of the lightheadedness. Others may have suffered only a few years, and it could be assumed that their recollection of how they felt prior to the onset was clear enough to directly associate changes with the illness. I now have a clearer insight and recognition concerning conscious and unconscious accommodation to the affects and changes resulting from afflictions

having slow and incipient onsets and durations. The slow transitional change in functioning over a long period of time, blends onsets and terminations such that there are no direct comparisons for the sufferer to remember or to delineate before and after states. Hence many dysfunctions caused by an illness are not readily associated as symptoms. Therefore, when explaining or responding to questions, it is difficult for a patient to accurately portray changes brought about during accommodation to the condition and treatment.

(3) Family Stresses.

It was not until becoming involved with the patient support group that I realized that the stresses initially placed on our marriage were a result of Don's sleep apnea and our management of the problem. It simply had not occurred to me that the illness could possibly impact as heavily as it did. With this information in mind, I was surprised that the participants of my study had not experienced more marital stress and upset from the effects of the apnea. It may be that the need to adjust to a new relationship as well as dealing with the effects of the apnea compounded our difficulties.

(4) Treatment and Diagnosis.

My involvement with Don came after the discovery of his apnea, and after the start of his treatment. I therefore had had no knowledge of how difficult it had been for him to accept his CPAP treatment or to accommodate to its use. This lack of information led me to believe that treatment, and accommodation to treatment, was automatic and uneventful. Later contacts at the patient support groups dispelled this idea, but still did not provide an inkling of the actual grief and trauma resulting from intolerances to CPAP therapy. Additionally, some experienced the fear and anxiety of being dependent on the machine for the rest of their lives.

The diagnosis of Don's apnea was apparently simple. His own physician was exceptionally astute, and although sleep apnea was almost unheard of at the time, she suspected the problem from the information Don was able to provide. It was then a matter of proceeding quickly through the steps of diagnosis, prescription, purchase of a machine, and accommodation. At that time existing air pumping machines were adapted to CPAP use and the titration[20] or individual pressure adjustments were less sophisticated in the accuracy and predictability of use. His machine had a dial with which he could adjust the air pressure to whatever level was comfortable. Follow-up studies were completed at the Sleep Laboratory to measure after treatment statuses.

Many people with sleep apnea have had experiences similar to Don's, with exceptionally astute physicians recognizing the signs and symptoms of a relatively

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[20] Titration refers to the assessment made during two overnight sessions to ascertain the level of positive air pressure necessary to maintain the breathing passages.

uncommon and newly categorized illness. However, many others experience distress, frustration, helplessness, and depression because their symptoms are not recognized, and apnea is not initially identified. The length of time taken to run the gamut of physician roulette in the hopes that one will make the necessary connection is, in some cases, nothing short of tragic. One could speculate for instance, that Liz, one of this study participants, might not have suffered the stroke and had her later health seriously compromised if a diagnosis had been made earlier when she was young enough for interceptive treatment. She might also have been saved the long experience of night terrors and other physical and mental stresses.

(5) Associated Parasomnias.

The literature is very clear on other sleep disorders and parasomnias that often accompany sleep apnea, such as periodic leg or limb movements (PLM). However, little information exists regarding the awareness of breathlessness or the feeling of suffocation that two of the participants of this study experience. Don is not aware of snoring, snorting, breathing pauses, or any other of his nocturnal activities. Again, automatically I considered all patients to be similar to Don, and the literature supported this. Awareness, on a minor or mild panic level, apparently only exists if initiated by me as a response, if the CPAP machine operation becomes compromised or there are co-existing problems such as nasal-sinus obstructive conditions. The latter are related to colds, allergies and the accumulations of mucous secretions.

The literature also provides little information about the disruptive nature of PLM and other parasomnias on marital relations.

(6) Fears, worries and concerns.

Fear, of course, is something that no person wants to admit unless in an extreme or non-threatening situation. The fears experienced by sleep apnea patients are thus almost never suggested, and few patients wish to admit affliction with any fears, worries, or concerns. Also, the majority of patients are male, and society still expects men to be fearless, which further hides the fear from view. Don, in his pragmatic way, never discussed his fears. However, once told of the kinds of fears experienced by the participants of the study, Don was very capable of empathising and explaining many hidden fears associated with the illness. Again, the medical literature, because of its very clinical nature, has completely ignored this very important aspect of side effects of the illness.

Bracketing Conclusion

Understanding now what I didn't understand before engaging in this study, it is easy to simply state that I have learned a great deal from the participants, and from their openness and readiness to discuss innermost feelings. I have therefore changed. Perceptions and understandings have changed. From comments by participants, they too have changed, not just in understanding the ailment, but in

understanding their own coping strategies and emotions connected with sleep apnea.

My biases, I hope are clear. Some old biases have been broken down by new information gained from living with a sleep apnea sufferer for seven years. Others have been broken down by this study process, and it may be that some personal biases regarding apnea I have yet to recognize. My view of the data, then is not totally objective, but influenced by informed and possibly uninformed biases.

Introduction to the Participants

The subjects in phenomenological research are referred to as participants or co-researchers, to emphasize the co-operative and voluntary nature of the research (Osborne, 1990). Because phenomenological research involves inquiry into the experiences and perceptions of the participants, there is a special need for them to be co-operative and voluntarily open. The researcher attempts to enter their worlds through their words, and to illuminate the phenomena under investigation. It is therefore paramount that the participants possess the experiences involved with the phenomena, and that they be willing and able to express details of their experiences and feelings.

The participants for this study were chosen for their experiences of sleep apnea, and their willingness to express their story, and emotions, and also because of their heterogeneity in representing the wide population of those who suffer from sleep apnea.

Children are occasionally afflicted with sleep apnea. However those children seriously afflicted with apnea are rarely able to express themselves well. Finding a child or very young person with sleep apnea and with the ability to express feelings and experiences clearly proved impossible. The participants who were chosen included two women and six men. The women were aged 58 and 86, and the men 35, 37, 59, 60, 61 and 63. Two participants were retired, one male and one female, and the work of the others was varied: a dairy farmer, a police officer, an engineer, an office worker, a businessman, and a lawyer. The severity of the apnea ranged generally from moderate to severe. All except one had at least one symptom that was severe. Refer to Table 1 for a brief tabulation of the participants.

Table 1

Summary of the Participants and Sleep Apnea Syndrome Symptoms.

David (Farmer) Age: 35 CPAP Severe Central	Liz (Retired) 86 Untreated Severe Obstructive	Ann (Lost job) 58 CPAP Mod/Severe Obstructive	Ray (Engineer) 59 CPAP Severe Mixed	Dean (Policeman) 37 Untreated Severe Obstructive	Charles (Lawyer) 61 CPAP Mod/Severe Obstructive	Paul (Businessman) 60 Surgery Mild/Moderate Mixed	Brad (Retired) 63 Untreated Mild/Moderate Obstructive
Inert sleeper	'Thrashes,' somnambulance, & night terrors.	'Thrashes' when CPAP not used.		Periodic leg movement.	'Deep sleeper.'	'Flails' arms and may sit up when asleep.	Excessive movement, kicking & violent nightmares.
Difficult to wake	Sleepy in early a.m.	Needs to sleep till 8.	Cannot sleep beyond 7 a.m.	Never feels refreshed.	Fatigued at 2 p.m.	Not refreshed in morning.	Wakes exhausted
Sleepiness still a problem.	Sleepiness big problem.	Sleepiness controlled.	Sleepiness almost under control.	Sleepiness a problem.	Slight fatigue only.	Enjoys a nap after supper.	Some fatigue & napping
Has never dreamed	Is aware of 'pre sleep dreams.'	Seldom dreams since apnea.	Seldom dreams since apnea.	Never finishes a dream now.	No change since apnea.	No change since apnea.	Dreams more violent and traumatic.
Poor memory	No noticeable memory loss	Poor memory	Significant memory loss and impaired problem-solving.	Very slight memory loss	Slight memory loss and less creativity mid-afternoon.	No noticeable memory loss	No noticeable memory loss
		Aphasia without CPAP	Aphasia				

All details provided by self-report or deduced from other information given by participants.

Those chosen were either selected at the Sleep Disorders Laboratory, or from the membership of the Sleep Apnea Society of Alberta Edmonton Regional Patient Support Group. Initial participant contact was by telephone or in person at which time the nature of the study was explained. A written description of the project was then provided at the first in-person meeting (see Appendix A). It was emphasised to prospective candidates that they could withdraw at any time they wished, and they were encouraged to identify any concerns whatsoever arising from the research process. All prospective candidates became participants, and none withdrew from the study.

The initial interviews lasted between thirty and sixty minutes. Some meetings were held in the University of Alberta Sleep Disorders Laboratory, some in an interview room at the Faculty of Education, University of Alberta, and others were held at the participants' homes or work places, in quiet rooms away from interruptions.

Although the taped interviews were unstructured, there was a core of questions that were asked if the answers did not flow from the conversation (see Appendix B). Very few of these question were actually asked because the participants provided their answers in the descriptions of their experiences, and the researcher simply requested clarification or elaboration. The direction of the interview was entirely dependent on the participant, usually starting from the first awareness of an illness. There was a striking similarity in the manner each of the participants used humour during the first interview. They all interjected humour into their experiences, and seemed very willing to laugh and share a joke at the shortcomings brought by apnea. Since these interviews, I have also noticed the same kind of bravado used by others with sleep apnea at meetings, almost to the point that it seems to be an unwritten club rule that a poor memory is worn with honour. This area deserves more consideration and analysis, and will be dealt with in later chapters.

The second meetings and the discussions of the analyses were remarkably uneventful. Minor amendments were requested by two participants, and the meetings usually involved only additional information and clarification. One participant expressed a certain discomfort at the accuracy of the analysis and synthesis: he said it was like looking into a mirror.

Naturally, during the process of the interviewing, analysis, and amending the analysis, the researcher and participants developed a perceived certain warm attachment. This was increased by the mutual sharing of experiences and information that was aside from the study purpose. I am deeply indebted to all of the participants for their candour, frankness and openness with which they answered questions and provided information.

In order to protect identities and assure anonymity, each participant was assigned a fictitious name, and any potentially identifiable life details or experiences were changed slightly in content, but not in a way significant to the study.

Data Analysis

Data analysis in phenomenological research is aimed at uncovering the essential structures of the phenomenon under investigation. The nature of sleep apnea and what it means to those afflicted is a complex phenomenon containing identical, similar and different individual elements. Therefore identifying the essential structures of the phenomenon in question, with all their associated sub-elements, and separating them from other unrelated elements in the life experiences adds to the complexity. The analysis must take into account all the associated elements and synthesize them into a total experience. As mentioned earlier, to do this, phenomenology uses a process of thematic analysis. This is a process where phenomenological themes, which emerge during the explanation of the experience, are extracted and examined.

For this study, data analysis began with a complete transcription of the first interview with each participant. The result, or protocol, was then read many times and examined for key words, phrases and meaningful statements. At times, the original audio tapes and field notes were reviewed to assist in interpreting tonal qualities, body posture and hand gestures not available from the written protocols. Each apparently meaningful phrase was then extracted and listed in a tabular form. Keeping the original statement in context, an interpretive description in the form of a paraphrase was added to each meaningful statement. Sometimes this process was simple because the meaning was very obvious, but at others, insight and creativity were called upon to provide the interpretation. The purpose of these interpretations is to reflect the deep or underlying meaning the participant has for the subject in the discussion, and thus represent a hidden facet of the phenomenon under investigation.

When interpretive meanings were supplied, a thematic descriptor was then assigned to the statement and interpretation. The thematic descriptor acts to condense each theme behind the statements, and builds a generalized picture of the themes belonging to the main structure of the phenomenon under investigation. Each participant's meaningful or significant statements, paraphrases and thematic descriptors, are presented in tabular form, (see Tables 3, 5, 7, 9, 11, 13, 15 & 17), and they represent what is known as the "First Order Thematic Abstraction" for each participant. An example of this tabular format is presented below to aid the understanding of the procedures followed.

Example 1:

30. My dad got sick, the hired man quit, . . . and it just wasn't worth the hassle. . .. So I quit school. I had a semester left to go. . . [I] started farming and that's where I've been ever since.	I sacrificed my schooling in my last year to provide support, but it didn't change my parent's view of me.	Resentment.

In this example, the original meaningful statement identified by the researcher is in column one, the interpretative paraphrase in column two, and the thematic descriptor in column three.

The interpretative leap made in this passage takes the reader directly from a relatively innocent statement, through the underlying context that his parents have always considered him lazy because of his fatigue and sleepiness. He expected his sacrifice for the family business to improve his parent's view of him, which did nct occur. The result was resentment. The correctness of this interpretation is assessed by the participant in his evaluation of the analysis. Whether or not resentment is an essential structure involved with the response to sleep apnea is unknown by this one statement analysis. However, examination of all of the interview analyses may uncover the truth about the status of resentment, and any other structures.

Each interview is analyzed, tabulated and presented in this manner. The next step in the process is a condensation of each participant's interview analysis into a collection of the major themes within the interview analysis.

The themes generated within each analysis are grouped together into clusters, and again, presented in tabular form. The condensation of the themes, along with a generalized description of the occurrences, are known as the "Second Order Thematic Abstractions," and form the basis of the synthesis of the participants experience with sleep apnea. An example of this process follows:

Example 2:

1. **Fear** excerpts from Table 9: 1, 5, 8, 9, 10, 13, 17 & 18.	Dean is aware that sleepiness could cause a serious or fatal traffic accident, and has witnessed the devastation of such accidents. He also has a fear of being dependent on a machine, and is concerned for changes that his apnea may cause in his marital relationship and career plans.

In this example, Dean's clustered second order theme of 'fear' is identified in the first column. The numbers underneath the thematic cluster refer to the original significant statements in Table 11 which relate to the particular theme from which the cluster is formed. The text in the right-hand column is a generalized description of a Dean's experience of 'fear' associated with sleep apnea.

Each participant's second order thematic abstractions are clustered and described in this manner, and are presented in Tables 4, 6, 8, 10, 12, 14, 16 & 18.

The next procedure used in this study is a tabular listing of the significant second order clustered themes across all participants (Table 19) which is useful to observe the frequency of the various themes of each of the participants, and comparing each of the experiences of the participants with those of the others. The essential structures may then be judged from the frequency of occurrence of the themes.

The next step in analysis is the process of further refinement and condensation, which involves defining each of the themes from those identified

across all participants from the second order thematic abstractions (see list of Definitions and Descriptions of Significant Second Order Themes Across All Participants). These definitions act as a guide for the reader as to the general interpretation of the themes found in the protocols, and which may be essential structures of the phenomenon.

The final step in the phenomenological data analysis involves a further condensation of all abstractions into "Third Order Abstraction of Common Clustered Themes," (see Table 20). In this process, the themes that are commonly found are clustered in groups which are linked by some cause or process in the response to sleep apnea.

In summary, the process of phenomenological data analysis can be considered as a hierarchial procedure to systematically examine the evidence and identify the essential structure of a person's experience living with sleep apnea. By this process, the researcher becomes able to identify the similarities and differences of the participants' experiences, and distinguish the essential structures of the central experience from the surface structure of each individual's experience. The familiarity also enables the researcher to provide an analysis of the differences and similarities of the participants, and relate that to the differences in structures of the experiences.

Chapter IV

Results

Introduction

In this chapter the results of the phenomenological analyses of the participants' experiences of the phenomenon of living with sleep apnea will be presented. After an overview of the data analysis tables (Table 1) which is designed to guide the reader through the hierarchial procedures of the phenomenological data analysis, each of the eight participants' experiences are presented separately, constituting a within person analysis. The data presented in this section provide a view of the unique experiences, and begin with a brief description of the individuals including their particular symptoms of sleep apnea and personal background. Next the First and Second Order Thematic Abstractions (Tables 3, 5, 7, 9, 11, 13, 15 & 17, and Tables 4, 6, 8, 10, 12, 14, 16 & 18 respectively) are presented as explained in Chapter III. These are then followed by a synthesis of the entire sleep apnea experience of each individual.

Following chapters will present a between person analysis beginning with a section entitled "Definitions and Descriptions of the Significant Second Order Themes Across all Participants," and will be outlined later.

Table 2

Overview of Data Analysis

	Within Persons Analysis		Between Persons Analysis	
Participant	First Order Themes	Second Order Clustered Themes	Second Order Themes for all Participants	Third Order Clustered Themes
David	Table 3	Table 4		
Liz	Table 5	Table 6		
Ann	Table 7	Table 8		
Ray	Table 9	Table 10		
Dean	Table 11	Table 12	Table 19	Table 20
Charles	Table 13	Table 14		
Paul	Table 15	Table 16		
Brad	Table 17	Table 18		

David (Tables 3 and 4)

David may have had central sleep apnea for most of his life, which has now become mixed, and severe. Although he uses CPAP, sleepiness is still a problem and his major symptom. Because he cannot recall a time when he didn't have to fight sleepiness, he has difficulty identifying related experiences. He has, in other words, lived most of his life with the condition, but had no idea that he was abnormal, or that his struggle to stay awake was greater than that of anyone else. The post-treatment revealing of pre-treatment experiences are therefore reflections of retroactive understanding, and may be distorted by a less than perfect memory and personal perception.

At the time of our first interview, David was 35. He was married, and had three young children. His wife provides a very supportive atmosphere for David. He works on the family farm, often from 8:00 a.m. to 10:30 p.m. or later, and is responsible for the dairy herd. This constitutes a very demanding life for anyone without the complication of a disability.

David appears to be a very easy-going, happy person, who has learned to live with his disability without apparent bitterness. He is of medium height and build, with an extremely fair complexion. He is clean shaven, and looks more like a businessman than a farmer, and certainly is without the characteristic weathered look.

Table 3

Thematic Abstractions of David's Experiences with Sleep Apnea

	Excerpts from Transcript	Paraphrases	Themes
1.	It got so that I was falling asleep standing up, if you can believe that! I saw the doctor, and went on Ritilin to keep me awake. I didn't like the side effects, and I didn't like the fact that I had to keep taking more to get the same effects, and I decided to stop doing that and to look for further treatment - to other doctors or specialists, something else - just keep looking for another kind of treatment.	I didn't believe that Ritilin was right for me. The side-effects and the increasing doses scared me. I had to find a better solution.	Need for understanding; Frustration; Helplessness; and Desperation.
2.	I just knew I had to do something about it, because if I didn't do something, I was very possibly going to have an accident . . . It was getting so bad that I just had to do something.	Only hope of survival is to find alternative medicine/cure.	Fear; Frustration and Desperation.
3.	I didn't know what was wrong. I didn't realize until I had been tested. Realized how bad it was, and realized what could happen, from talking with doctors about other people going through the same things . . .falling asleep driving.	Once I knew the severity of the condition, my attention changed from finding a cure to fear of what might have happened.	Intensified fear.
4.	Things I did to stay awake would be to eat a lot, to eat while I was working, and drink a lot of coffee, and pop.	I would constantly eat to stay awake: often eating unhealthy food.	Coping.
5.	Suppertime seemed to be a real bad time . . . [but] once I got up and going after supper again, [the sleepiness] would be o.k. for a while, and then it would gradually get worse and worse as the evening wore on.	The sleepiness is harder to resist at some times of the day than at others.	Coping; and Periodicity.
6.	You just have to find ways to stay awake, and as far as running machinery - our tractors all have cabs on them - you had to have air conditioning, or you had to have something, radio, going pretty loud to keep you awake.	Experimentation to find methods to stay awake.	Coping.
7.	Going back even further, I always had a problem with getting up in the morning. I wouldn't hear the alarm clock.	Conventional means of waking up don't work.	Helplessness.
8.	My parents thought I was lazy, and they probably still do think I'm lazy. They know I have sleep apnea, but they don't quite understand it I don't think as much as they should.	My parents know my tiredness is caused by an illness, but they still consider me lazy.	Resentment; Need for Understanding; Grief; & Helplessness.

9. It kind of hurts me that [people] don't believe that I have a problem, or that it's not as serious as I tell them it is.	People's lack of understanding hurts me.	Need for understanding; and Grief.
10. I know it is frustrating for my wife when she tries to get me up on time, and it doesn't always work. And she gets totally frustrated.	I understand my wife's frustration when she can't wake me.	Need for understanding: & Marital stress.
11. It is very frustrating when you can't get to work on time, and it's not very good for relationships with my parents.	I wish I could wake up and get to work on time like anyone else.	Need for understanding; and Frustration.
12. I just put [my parent's opinion] in the back of my mind, and, you know, what can I do! . . . If they don't want to believe it.	I block my parents' from my mind. They don't want to change their opinion.	Helplessness; and Grief.
13. We have a daughter who is wanting to stay in bed later than she should . . . and I feel kind of badly getting on her case because it is possible she has the same thing that I do.	I feel uncomfortable reprimanding my daughter for staying in bed - she may have apnea.	Projection.
14. In my younger years . . . I was not the life of the party. . . because I could fall asleep anywhere . . . They just figured I couldn't handle my liquor, and I was poor company, . . . but they all understand that was the way I was, and they more or less put up with it. Either that or didn't bother with me.	I lost friends because I fell asleep, but others accepted me, and thought I couldn't hold my liquor.	Poor self image; Rationalization; Social isolation; and Embarrassment.
15. Then I developed a [nasal] drip problem . . . I thought maybe that it was allergies, but none have shown up. I can be working and all of a sudden my nose will start to run . . . but it seems I am more or less stuck with that.	After all this, I get a nasal drip to make life more difficult.	Helplessness; & Victimization.
16. I don't really think [I would have chosen other work if I hadn't had sleep apnea]. I have always enjoyed farming, and that is what I have done all my life . . .. Working on the farm has been very enjoyable for me - it has provided me very well. Very long hours.	I may have chosen other work had I thought of more choices. I convinced myself I enjoy farming, & it is profitable for me in spite of long hours.	Rationalization; and Reaction formation.
17. I have an aunt who happened to pick me up from the hospital last time I was being tested. She was having a hard time believing that I had such a problem, and I made a strong believer out of her because she had to keep me awake while I was driving. It opened her eyes immensely, and changed her total attitude on the problem.	I scored a small victory of having my aunt change her attitude towards sleep apnea and laziness.	Need for understanding.
18. When we go to the city or anywhere else, my wife or someone else has to be with me to keep me awake. It is very <u>frustrating</u> 'cause I can't go any place by myself . . .. I am very caged, and I don't have freedom, and I am very thank-	I understand the need for a 'supervisor' when driving, but it is very frustrating that I cannot have the freedom of others.	Helplessness; Frustration; Fear; Grief and Marital stress.

ful for my family that they do care enough. . . my wife just won't let me drive alone, and that is quite understandable.		
19. [Driving limits my work.] Work has become a real . . . I would say that because of the way my work has changed . . . in the last 5 or 6 years, I have done less work with machinery because I stay more or less with the dairy end of the operation.	Need for safety limits my duties, so I have been shifted almost entirely to the dairy operation, away from heavy equipment.	Resentment; Helplessness; Grief and Fear.
20. I enjoy the dairy. I don't resent the move to the dairy 'cause I enjoy milking the cows, and I like the fact that it is just a quarter of a mile - I can walk there, it is good exercise - I get lots of good exercise milking cows anyway. I enjoy the walk, even in winter time. It is nice being out on the equipment doing the field work, but it has gotten to the point where I know it isn't safe for me to be out there, and it worked out best for all concerned, 'cause I am in a place where I am close to home, someone can come check on me if they can't get me on the 'phone. It has worked out better for me that way. I like my job - the hours are long, and strange.	I enjoy dairy work, but I resent being forced to change. I have to find nice things to say about my position to prevent myself from getting angry.	Rationalization; Helplessness; Fear; and Reaction formation.
21. I was not dreaming. [Dreams] didn't show up [on the polysomnogram] 'cause I was being interrupted too often - I just didn't get into that deep a sleep. Now when I [was tested] last time, . . . it showed up that I was dreaming, but I did not remember that I had dreams. I can't remember dreams, period.	I didn't used to dream. Now I apparently do, but I don't remember them.	Dream deprivation.
22. As far as having a dream, . . . well that would be very strange to me, and I don't know how I would react.	I don't know what a dream would feel like.	Dream deprivation.
23. I was rather shocked when my little boy came to our bed, . . . he was all upset - he'd had a nightmare. This really threw me. I said, "now, do you want to explain this to me? Can you tell me about your nightmare?"	My son's nightmare shocked me, and I didn't know how to deal with him.	Dream deprivation.
24. My daughters will talk in their sleep. My oldest daughter told me she couldn't talk to me at the time - she happened to be sleeping . . . she told me she was too busy to talk to me, she had a load of grain to haul. Obviously there is some brain activity there! So maybe I shouldn't worry about her either - I don't know.	I may have passed apnea to my children. The girls sleep talk, so they couldn't have sleep apnea.	Rationalization.
25. They [daughters] are quite fascinating when they are asleep and they start talking, and maybe I'm the same way and don't know it	I sleep talk too, so that doesn't rule out apnea. I am always	Poor self-image; and Other directedness.

because they say I mumble when they are trying to get me up - but I'm just worried that I might say something that is not very nice.	trying to be the person others want me to be.	
26. I just felt that [after treatment] it helped as far as my driving, and I wasn't as crabby. I seem to be able to handle my kids probably a little better as far as being not as 'touchy' with them, aggravated as easy.	Treatment helped with my driving and I am a nicer person.	Poor self-image.
27. I am not sure if [the crabbiness] is me, or if it is the apnea, or because I'm just not rested properly. But it bothers me when it is pointed out to me that I have been a real turkey, and when I have time to look back on the event that set me off or aggravated me, that it's very trivial, and should not have affected me that way. I am very irritable. It does bother me. It is one of the things I have to work on.	I really don't like being crabby, and it bothers me to know that I have been aggravated by something insignificant. I wish I could be nice all the time, like my wife.	Poor self-image; and Other directedness.
28. At first I didn't now how [sleeping with a mask was going to affect me. Like I say, I tried it in the hospital for one night, and I thought, well, people have to make adjustments - this is a minor adjustment as far as I am concerned, compared to what other people have to do.	Sleeping with a mask over my face is a minor inconvenience compared to adjustments others less fortunate have to make.	Coping; Helplessness; and Acceptance.
29. [My mother] got so tired of trying to get me up, that she would throw cold water in my face, and I have heard that that is not the thing to do .. . . It woke me up! [chuckle] It was irritating, but there wasn't a heck of a lot that I could do about it, and at that time I was young enough, and if I wanted my job, and I wanted to stay [at home], I pretty much had to put up with it.	Mother would throw cold water in my face to wake me. I think she didn't have a choice. It was extremely irritating, but my home and job depended on putting up with it.	Helplessness; Victimization; and Anger.
30. My dad got sick, the hired man quit, . . . and it just wasn't worth the hassle. . .. So I quit school. I had a semester left to go . . . [I] started farming and that's where I've been ever since.	I sacrificed my schooling in my last year to provide support, but it didn't change my parent's view of me.	Resentment.
31. Yes, [if I hadn't had apnea] I think the relationship [with my parents] would have been better, and that they wouldn't feel that they need to check up on me as much . . . and I wouldn't have to bargain for time off - the bargaining would be easier. Maybe I would be able to get my work done faster without the problem, and put in a more consistent day.	Much of the difficulties with my parents is a direct result of the sleepiness.	Victimization; Grief; Frustration; & Helplessness.

Table 4

Second Order Thematic Abstractions of David's Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 1: 2, 3, 18, 19 & 20.	David realizes that his sleepiness is potentially very dangerous. This fear was initially self-induced, and intensified by others' stories and concerns following diagnosis.
2. **Helplessness:** 1, 7, 8, 12, 15, 17, 18, 19, 20, 19 & 31.	David has no control over his apnea, diagnosis, treatment, energy levels, falling asleep, and others' images of him. He saw no escape from his mother's treatment as he currently sees no escape from the long work hours and difficulties with his parents. His duties are restricted, and he has no freedom to drive alone.
3. **Grief:** 8, 9, 12, 18, 19 & 31.	David grieves for the close relationship with his parents that he never had, and because others do not understand his problem. He also grieves for his lost freedom to drive alone.
4. **Embarrassment:** 14.	David experienced embarrassment at not being able to stay awake when socializing when he was younger.
5. **Frustration:** 1, 2, 11, 18 & 31.	David experienced great frustration at not getting effective medical help and a diagnosis. The inability to get to work on time and to disprove his laziness has also caused him frustration.
6. **Desperation:** 1 & 2.	David experienced desperation to find another solution and diagnosis when he found the drug treatment was not helping and may be harmful.
7. **Need for understanding; and Other directedness:** 1, 8, 9, 10, 11, 17, 25 & 27.	He craves his parents' understanding, approval and acceptance in the same way his wife and children accept and support him. He tries to be the person he thinks he should be for others, and it is painful for him to think that others believe he is using the apnea as an excuse or to gain sympathy.
8. **Coping:** 4, 5 & 6.	The coping skills are a series of experiments to find ways to help him stay awake.
9. **Periodicity:** 5.	Sleepiness is much harder to fight at certain times of the day, or during some activities.

10. **Job stress:**	Because of the difficult relationship with his parents and the difficulty staying awake, David experiences increased job stress.
11. **Resentment:** 8, 19 & 30.	He consciously puts his parent's opinion out of his mind. Anger may be the emotion when he thinks of his feelings caused by his mother's cold water treatment. There is resentment at his loss of freedom, especially with driving.
12. **Poor self-image:** 11, 14, 25, 26 & 27.	The accusations of laziness, and the inability to drink heavily when he was younger have contributed to a poor self-image. Irritability from sleep fragmentation confirms that image, and causes uncertainty about his personality. There is a large discrepancy between David's desired and perceived personalities. David strives to be the perfect person others seem to want him to be.
13. **Social isolation:** 14.	David lost friends if they didn't accept his falling asleep at social functions.
14. **Marital stress:** 10 & 18.	David's marriage is stressed during the times when his wife has difficulty getting him to wake in time for work, and when she has to accompany him on a trip into town or elsewhere.
15. **Victimization:** 15, 29 & 31.	Concomitant with the diminution of life experiences because of the restrictions on him, David may be slipping into the role of the victim or the sick-person.
16. **Projection:** 13.	David projects on to his daughter his own enjoyment of staying in bed.
17. **Rationalization:** 14, 16, 20 & 24.	David uses rationalization to help him soften the embarrassment of many situations in which he now finds himself, and also he protects himself against the thought that his daughter may have sleep apnea by noting her dreams.
18. **Acceptance:** 28.	The acceptance of CPAP came easily since it appeared to be a minor adjustment.

Synthesis of David's Experience

David's work, home and leisure activities are seriously affected by the sleepiness caused by his sleep apnea. In addition, David is possibly emotionally scarred by events that were precipitated by the symptoms of his sleep apnea, especially the misunderstandings and poor relationship with his parents. Possibly all of David's emotions could be boiled down to the feeling of frustration, a real need for understanding, and helplessness. David is aware of the frustration connected with not being able to change his parents opinion, and with how hard it is for him to get up in the morning. He also recognizes that frustration and a feeling of imprisonment result from the restriction on his driving. He is less aware of the deeper level of frustration connected with having a chronic illness that is not understood and for which there is no cure.

David's relationship with his parents contrasts with the relationship with his wife and children. The latter relationship seems to him almost too good to be true. There is an unspoken fear that his wife's patience will run out and that she will then share the same view as his parents.

The understanding he needs is not only of him personally, but for his family, friends, and those he works with to understand what it means to have the life sentence of sleep apnea, and to endure the anguish of fighting it all day and every day. All the helplessness, loss of control, resentment, poor self-image, fear, and rationalization flow from the frustration and need for understanding, and the treatment that he has received from those who do not understand.

Liz (Tables 5 and 6)

Liz's apnea is severe obstructive apnea, and she believes she may have had it for many years. She also suffers night terrors, has violent nocturnal physical activity, and is frequently aware of night time breathing obstruction. She is 86 years old, retired, widowed, lives alone in a senior citizen's apartment complex, and no longer drives a motor vehicle. She is less than 5 ft. tall, and considerably overweight. She has grown children and several grandchildren.

Liz's outlook is fatalistic towards her health problems: her respiratory functioning is impaired, she has hypertension, her heart is fragile, and her knees are unreliable for support. Between our first and second interviews, she suffered two strokes. She now believes her travel days are over, but before her strokes she joined many seniors' group tours. In spite of her condition, Liz is very active socially. She still has a number of card-playing friends, mostly living within the same building. She also was an avid needleworker before her strokes, but now finds needlework confusing and difficult.

Also between the first and second interviews, Liz visited a surgeon regarding the removal of a growth that had been detected, and was suspected of being the cause of the breathing obstruction. She was told, however, that surgery, given her age and general condition, presented too high a risk. She tried CPAP, but found it intolerable, and hence she continues untreated.

In the meantime, Liz has experimented with sleeping positions, and has found that if she sleeps propped up on two pillows, her apnea seems better.

Table 5

Thematic Abstractions of Liz' Experiences with Sleep Apnea

Excerpts from Transcript	Paraphrases	Themes
1. Well [the sleepiness] is a nuisance at the moment because I'm working away at this [needlework], and all of a sudden my work's on the floor, and I'm [asleep]. Several times I've found myself wanting to get up because I . . . want to go and lie down, and the next thing I know is I find myself [asleep].	I have little control over falling asleep.	Frustration; Helplessness.
2. A couple of times I've nearly fallen right on my head because I haven't really made that effort to get up. I just can't seem to get going.	I have found myself close to a fall.	Fear.
3. The only reason I would be angry at myself is because I am trying to get this work finished up, and the sleep interrupts it. That's all.	The sleepiness prevents me completing my needle-work.	Frustration.
4. My husband told me that I scared the life out of him, he says 'you stop breathing at night' . . . It was my daughter - she went on a trip with me, . . . and she counted up to 50 I think she said, before I started to breathe again. It scared her. She insisted that I get referred. I have been to doctors and told them about it, and they just pass it off.	Family members pointed out my lack of breathing at night, but doctors passed it off as unimportant.	Frustration; Fear; and Other directedness.
5. You begin to wonder whether you are in your right mind or not, or whether you are a hypochondriac, or what!	Maybe I am crazy or a hypochondriac.	Frustration; Concern for sanity.
6. Definitely you could say that [there was a feeling of relief knowing that it wasn't my imagination].	Finally I knew it wasn't my imagination, so I was relieved.	Concern for sanity; and Acceptance.
7. When I first noticed the sleepiness was when . . . we played cards at night. It was my turn and I would deal, and the cards had been all the way around the table and it was my turn to deal again - I had been asleep. Someone would poke me and say 'it's your turn,' and I would wake right up.	It is embarrassing to find I have fallen asleep during card games.	Embarrassment.
8. They thought [my falling asleep] was funny. I thought it was funny too! I mean you laugh with them - well, I mean what can you do?	They laugh at me because of sleeping during social occasions.	Helplessness; & Embarrassment.

9. When I can't catch my breath at night. . . . You begin to think you are going to pass right out. . . . I know last night two or three times it happened to me. You wonder, you know, if you are going to get it stopped - if you are going to catch your breath again or not, or whether you are going to keep on lying there.	I am scared and panic when I don't breathe at night. I wonder if I am going to die.	Fear & Desperation.
10. One night I found myself standing up beside the bed. It bothered me that it caught me so.	Nocturnal activity is bothersome.	Fear.
11. It feels like you are suffocating.	I feel I am suffocating.	Fear & Desperation.
12. You are just afraid, and you are afraid you are going to die. That you are not going to be there in the morning.	I am afraid of dying suddenly at night.	Fear & Desperation.
13. I've been away on holiday to Jasper, and the night before last I could hear myself talking and screaming . . .. I was dreaming something, and I couldn't catch my breath. The other lady came in to see what was the matter, but I had been asleep. . ..	My screaming bothers other people, and is embarrassing.	Embarrassment; and Fear.
14. Well it is terrifying - you wonder if you will catch your breath. And sometimes it seems like it takes quite a while before you can get it back. I was really scared that night I found myself standing up beside the bed.	I am sometimes really frightened, especially when I can't catch my breath at night.	Fear; Helplessness; & Desperation.
15. I don't know, but [the sleepiness] seems most of the time when I'm playing cards, or when I am trying to concentrate, or when I am working [on needlework] . . . or if I am reading lots of time. And that's frustrating.	The sleepiness interrupts most when it's least wanted.	Frustration; & Periodicity.
16. I can get up and get my breakfast and I could go right back to bed again, or sit down here and drop right off to sleep. But if I haven't had too bad a night, well it doesn't bother me till later on.	Sleepiness is usually worst in the early morning, and later in the day.	Periodicity.
17. It's a good job I don't [still drive] because I would fall asleep at the wheel.	I would be even more scared if I drove a car.	Fear.
18. Well, I wash my face with a cold, wet washcloth, and try that, and do that, and do it and do it and do it, and finally I have to go and lie down. It works for a bit, but only works sometimes.	I use a cold, wet washcloth on my face, but it only works sometimes.	Frustration & Coping
19. I go to my daughter's on Sunday. She has a great big, soft chair that lies back, and I'll sit there and we will talk, and I'll say "I've got to go and lie down". . . . But I don't really	Sitting in a soft chair brings uncontrolled sleep, but sleep is not refreshing.	Helplessness.

feel refreshed when I wake up.		
20. Oh, that's a joke [when I fall asleep playing cards]. "Now what does the sleeper get?" . . . It's always passed off that way. And I don't mind. I just go along with it.	I get called names for falling asleep.	Embarrassment.
21. [If I were younger], I think it might be different. I think I might resent it.	Because of my age, sleep is more socially acceptable.	Resentment.
22. I visited my granddaughter in Kelowna, B.C., my daughter put me on the bus in Calgary, and I slept from Calgary to wherever the bus stopped. Every time the bus stopped, I woke up. I slept all the way from Calgary to Kelowna. The bus driver said to my granddaughter, "You won't have to put Grandma to sleep tonight!" (laughter)	I fell asleep on a bus trip, and the driver joked about it.	Embarrassment.
23. [Feeling of falling in dreams is] frightening. It frightens you at the time.	My dreams are frightening.	Fear.
24. It interrupts my work and my card games, and it bothers you to wonder whether maybe one of these days you won't come back. They say it's not really dangerous that way, but... One article I read said that not many people die from it, but....	The sleepiness is a bother and the breathlessness is a worry. Knowing that it is unusual to die during apnea doesn't change the fear.	Frustration; and Fear.

Table 6

Second Order Thematic Abstractions of Liz' Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 3: 2, 4, 9, 10, 11, 12, 13, 14, 17, 23 & 24.	Liz experiences fear of nocturnal suffocation which is caused by an awareness of breathing cessation, and fear of falling when sleeping overtakes her. Liz recognizes that she would have more fear if she were still driving an automobile.
2. **Helplessness:** 1, 8, 14 & 19.	Liz is helpless to control when or where sleep will overtake her, and cannot change others' opinions that her sleeping is amusing. She also experiences a feeling of helplessness in the night when she cannot breathe.
3. **Embarrassment:** 7, 8, 13, 20 & 22.	Sleeping and probably snoring at social events has caused ridicule and embarrassment. Night screaming is also embarrassing and causes concern from others.
4. **Frustration:** 1, 3, 4, 5, 15, 18 & 24.	Frustration is caused by inability to work on schedule, and by difficulty achieving serious consideration from medical professionals.
5. **Desperation:** 9, 11, 12 & 14.	Liz's fear of nocturnal suffocation contains elements of desperation since the panic she experiences is somehow more than fear alone.
6. **Coping:** 18.	Attempts at coping with the sleepiness are rarely successful.
7. **Periodicity:** 15.	The sleepiness is harder to fight at certain times or during certain activities.
8. **Resentment:** 21.	Liz recognizes that if she were younger, she might resent having sleep apnea, and resent the ridicule directed at her for sleeping.
9. **Acceptance:** 5 & 6.	Because of her difficulty in achieving a diagnosis, she readily accepted the diagnosis when made. Age, too, may have helped her accept the condition.
10. **Other directedness:** 4.	The worry that her late husband and daughter expressed regarding her breathing pauses concerned her. She sought medical help at the insistence of her daughter.

Synthesis of Liz' Experience

The largest inconvenience caused by Liz' apnea is that it prevents her from doing her needlework and other activities normally considered leisure. This might be considered unimportant to some, but to an elderly, retired person with few other pleasures, it is ultimately important. On the positive side, her age allows her to deal with the results of her sleepiness with less embarrassment than younger people since it seems to be more acceptable, even expected, for an older person to fall asleep in public. Because Liz is not in the work force, and no longer drives a motor vehicle, the fear of an accident is less for her than for many other apnea victims. However, the fear of dying directly from apnea induced suffocation is very real and possibly her most serious concern.

Liz experienced great frustration in having her condition considered seriously by the medical profession, and consequently the ultimate diagnosis, when made was a relief rather than a shock. Quite possibly her age, life experiences, fatali attitude, and involvements with other medical problems has helped her accept t diagnosis without apparent trauma.

The complication arising from the two strokes suffered following our initial interview, possibly as a secondary result of the apnea, is distressing. Liz now finds that her motion is slower, her needlework is much more difficult, her speech is slurred, and travel is no longer enjoyable or possible. The quality of her life has been reduced significantly, and she still has to cope with additional problems.

Liz' lack of tolerance for CPAP therapy is not surprising. Now that surgery is not an option, she is faced with living with apnea and related health difficulties until they claim her life. She believes that her new sleeping position has solved her problems, and at 86, her perception and physical comfort are important. With her current high blood pressure, history of strokes, and compromised heart, Liz seems to be a candidate for a fatal incident at any time.

Ann (Tables 7 and 8)

Ann is an attractive, dark-haired woman in her late 50's who has moderately severe obstructive sleep apnea which developed between 1978 and 1982. She is moderately overweight, and attributes the apnea to her short neck and wide face.

Ann's heritage is Ukrainian. Her mother did not encourage education, and would punish her for doing homework. However, she persisted, and has done her best to educate herself by taking a variety of courses and seminars, and by reading avidly.

Ann has used CPAP for seven years, and her symptoms have been significantly reversed by the treatment to the point that she is quite safe to drive a car by herself, and now only experiences some memory loss and occasional fatigue.

Ann's marriage failed just prior to the onset of the apnea, and she was forced to join the workforce for the first time. Although she and her husband live together, it is a relationship of convenience only, and the support she receives from him is minimal. She is strongly independent and stoic, and puts on a grand facade of not needing emotional support.

At the time of the second interview, Ann had just lost her job. She was finding it hard to reassess her self-image as that of 'unemployed,' and realized how important her job had been for her identity. Her hope was of gaining work that would allow her to start a little later in the morning to accommodate the schedule her body seems to need since the onset of the apnea.

Table 7

Thematic Abstractions of Ann's Experiences with Sleep Apnea

	Excerpts from Transcript	Paraphrases	Themes
1.	There was just this real draggyness, this tiredness, and what really alarmed me, [driving back into town] . . . I just could not stay awake. I tried everything - I drank coffee, bought some Coke and drank that . . . and I found myself driving through the ditch.	Uncontrollable tiredness resulted in driving off the road.	Helplessness; Coping; Fear.
2.	I told my husband about [the near accident] and he was really alarmed, you know. And since, he just won't let me drive alone.	My husband, out of concern, restricted my driving.	Helplessness; and Other directedness.
3.	[The near accident] was pretty scary. I thought I was very lucky not to have had an accident.	Close call very frightening	Fear.
4.	I thought it could happen again, but that was before treatment.	I was always afraid of falling asleep at wheel.	Fear.
5.	[I would fall asleep] at the opera, at concerts, at the theatre. . . This is very embarrassing. I remember going to the opera, and there was just no way I could stay awake. . . I was falling asleep and there was nothing I could do.	Inability to stay awake at social events caused me and my companions extreme embarrassment.	Embarrassment; & Helplessness.
6.	[It was] very embarrassing for one thing! But kind of lacking control in a way.	I was embarrassed. It shows lack of control.	Embarrassment; Helplessness.
7.	I don't know if I was or if I wasn't snoring, which made it even more embarrassing.	I was probably snoring, which made it worse.	Embarrassment.
8.	[Snoring intensity] varies, but I find that as time goes on that I am almost totally dependent on the CPAP. I just cannot sleep without it now.	I am dependent on a machine for my sleep.	Dependence on machine.
9.	I remember [being invited] to *the Fringe* one year, . . and we were sitting in the front row. Again, I just could not stay awake, and it must have been very embarrassing for [my friend] because she knew a lot of the actors personally, and the director, and so on. . . . and even probably unsettling for the actors if they could see me falling asleep.	Falling asleep at the theatre caused embarrassment, and regret for the embarrassment and discomfort I caused my friend and others.	Embarrassment; and Other directedness.
10.	[The reaction of friends to falling asleep at theatre] was that they never asked me again!	I assume I lost friends as a result of sleeping.	Social isolation.
11.	It's very rare - very rare that I remember a	I don't dream as	Dream

dream. Since the sleep apnea started, I really don't have a lot of dreams - I don't remember dreams very often.	much any more	deprivation.
12. Somehow there is an emotional element to this. . . . My husband . . made some very bad investments, and we were fighting a lot - a lot. There was a lot of crying on my part, and a lot of screaming, which probably didn't do my throat muscles any good! And it was about that time that I started getting symptoms of the sleep apnea.	I think the emotional upset and fighting triggered the apnea. I may not have developed apnea if it were not for that trouble.	Victimization; & Marital stress.
13. I was in an office job at [the time the apnea started], and I remember driving to work absolutely fighting to stay awake. I am sure I wasn't as sharp, as bright as I should have been during the daytime because I was so tired. My job was quite demanding too. . . . But then when I came home I was just so wiped out. And of course I haven't had a social life since before that whole trauma started in 1978 - I haven't had a social life at all.	I am not always as sharp as I should be, and the effort of employment left no energy for social activities.	Mourning; Social isolation; Role-strain; Job stress; & Grief.
14. The problem became that with working, I was so tired, that there was no way that on Saturday I could clean my house, cook a meal and entertain somebody, because I would fall asleep. I was falling asleep. It became just too difficult to fight that so I gave up entertaining. I found I just couldn't handle it.	Wage-earning, caring for house and family, an active social life and sleep apnea cause role strain. Something had to be reduced.	Role-strain; and Social isolation.
15. And even going out to concerts and things like that that I enjoyed, I started doing less and less of that, and now I almost don't go at all.	I didn't have the time or energy to pursue a social life.	Social isolation; and Grief.
16. I have adapted to [social isolation]. I have become a sort of a recluse, you know. I try not to think about it because I know it would bother me. I am very good at blocking. So I just try not to dwell on it, and focus on other things in my life.	I adjusted by becoming a recluse, and by not thinking about it.	Avoidance; Sublimation; and Grief.
17. Well I don't know if [poor memory] has caused me problems. The little sticky notes are a great substitute for memory! I have them all over!	My memory is poor, but I manage by using 'Post-it' notes.	Coping.
18. I liken it to a computer, you know. By the time you get to 60 there are quite a few files in there, and it just takes it longer to find the right one. You have to sort through a lot more stuff. I think I am like anyone else - I put things away where I think I will remember - a safe place - and of course I forget where that safe place was . . . . My friends tell me they have the same problem.	My memory is probably poor due to my age, not necessarily to sleep apnea.	Rationalization.

19. I put on weight, but as the sleep apnea progressed, I became less and less energetic, and I was always eating to give myself a sort of a fix of energy.	My weight increased as the apnea became worse.	Coping; and Frustration.
20. I could very easily cat-nap. . . . I'll fall asleep, and I can sleep like that for an hour, just sitting straight up. Don't they call that power nap?	I nap to ease the sleepiness.	Coping.
21. I still have problems with sleepiness, but not as much [since using CPAP]. It varies, depending upon how I am emotionally and physically.	CPAP helped, but my physical and emotional state affect my level of sleepiness.	Dependence on machine.
22. [The sleepiness] was bad in the early morning, and it was bad at night.	The sleepiness is worse at certain times of the day.	Periodicity.
23. I always said I needed a job that I could start at 9 a.m. I was never a morning person, so I trained my body to kind of jump out of bed, but mentally I'm not there!	I feel I needs to sleep a little later to be really rested, but my job doesn't allow that.	Job stress.
24. [When the apnea started], I never had dreams any more, I never had kind of that deep sleep.	I don't dream or have deep sleep any more.	Dream deprivation.
25. Maybe if this whole emotional problem hadn't come up, and I had a more placid lifestyle I had prior to that, maybe I would never have had sleep apnea. I somehow feel that all that gnashing of teeth that we went through had something to do with it.	I may not have developed apnea if I had not had all the turmoil and trouble.	Rationalization; Victimization.
26. Last year I was able to lose about 15 lbs [in the fall], and that really helped me. This year I neglected my body, so I am paying the price for that. [The price involves apnea and image too.] I don't think it is acceptable to be overweight in our society. I think you get treated as a lesser person. . . . It is like people see that there is part of your life that is un-disciplined - out of control.. . . I think being obese is in the same category as smoking and alcoholism. I think it is an addiction.	Reduced weight improves my health and self image. Obesity lowers self image and is a sign of lack of discipline and control. It is very undesirable.	Poor self-image; Helplessness; Self punishment; & Frustration.
27. I don't think I would drive a long distance, but I feel o.k. in the city.	I feel safe driving short distances, but not long.	Fear.
28. I do feel I'm restricted. I often think about, you know, going on tours, like older people go on tours, you know. I would have to have a single room, I couldn't share my room, it would cost me more, I would have to drag this little machine around, and so on. You know, I think it does restrict me.	Apnea restricts my activities and plans.	Helplessness; Dependence on machine; and Frustration.

29. [Thinking of the restriction], I suppose it would depress me a little. I am more depressed about other things than I am about that. I try not to dwell on my apnea. . . . It's here, I've got to cope with it, I've got to use my machine, and that's that!	I don't think about things that would depress me. I just do what I have to.	Coping; Depression;& Acceptance.
30. [My husband and I] have our own rooms. But that didn't come about - the snoring, that was just starting, so that was part of it, but we really kind of separated at that time because of our fighting. You know, it was my husband who moved out. I found that really difficult at first. Probably of all the things, that is the thing that kind of bothers me.	I attribute my marriage break-down to fighting, but consider apnea symptoms part of the cause. My husband rejected me.	Marital stress; Loss of self worth; Grief; & Rejection.
31. Well, I think [the apnea] had something to do with [the marriage break-down] . . . because, you know, I was starting to snore. . . . I can't blame it entirely on the apnea.	Snoring could have been partially responsible for marriage break-down.	Marital stress.
32. [Using CPAP] would turn anybody off (laughter). I have thought about that - I've thought, "gee, what if I was left alone - and just even for companionship . . ." and I ruled that out right away, and I'd think "no, there is nobody who would put up with that!"	No bed partner would tolerate CPAP.	Negative body image.
33. There was really no-one that I needed to be pretty for, you know. It didn't matter . . . . so I just let myself go to pot!	I lost reason to stay in shape and attractive.	Depression; Self punishment.
34 I would hear myself saying this garbled stuff, and wonder 'where did that come from.' It was as if someone else was saying it, and I knew it wasn't making sense. People reacted strangely to it for a second.	I experienced aphasia prior to CPAP treatment, and found it very unsettling.	Embarrassment; Mourning; and Helplessness.

Table 8

Second Order Thematic Abstractions of Ann's Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Tabl [illegible]	Much of Ann's fear was related to the fear of an accident prior to her treatment.
[illegible] **ess:** 1, [illegible] 5, 6, 26, 28 & 34.	Helplessness relates to loss of control Ann once felt over her sleepiness and the restrictions placed on her driving. She now experiences some helplessness from the restrictions placed on her by CPAP treatment.
3. **Grief:** 13, 15, 16 & 30.	Ann grieves for the loss of her marriage, and the loss of quality and quantity in her social life.
4. **Mourning:** 13 & 34.	Ann noticed functioning losses prior to treatment, both in general cognitive ability and specifically in a type of aphasia that caused her to speak gibberish occasionally. Treatment seems to have solved most of the cognitive problems, except memory.
5. **Embarrassment:** 5, 6, 7, 9 & 34.	Ann has experienced the extreme embarrassment of sleeping at public social occasions. The embarrassment was intensified by the probability that snoring accompanied her sleep, and grief that she embarrassed companions. The sleeping is perceived to have impacted her social life.
6. **Frustration:** 19, 26 & 28.	Although not given to frustration, Ann admits that the restrictions on travel caused by CPAP are frustrating, as is the difficulty in controlling her weight. Also she finds it embarrassing and frustrating when she has guests and feels compelled to make explanations of the couple's sleeping arrangements.
7. **Coping:** 1, 17, 19, 20 & 29.	Although she doesn't attribute her poor memory to apnea, she compensates by using 'Post-it' notes. Ann has noticed the burst of energy snack foods provide, but has also noticed that her sleepiness is better when her health is good and her weight down.

8. **Periodicity:** 22.	Sleepiness is much harder to control at some times of the day and under certain conditions.
9. **Job stress:** 13 & 23.	During the second interview, Ann explained that she had lost her job two weeks earlier, and realized how much stress the job had been for her because of the sleepiness, and also because she felt that she needed to sleep until 8 a.m. to be well rested.
9. **Dependence on machine:** 8, 21 & 28.	Ann is very dependent on CPAP to provide quality sleep and keep her cognitive skills at the present level. She regrets the restrictions on her life that CPAP causes and feels that it would be impossible, for body image reasons, to use it in a normal marital relationship.
10. **Poor self-image:** 26.	Ann's poor self-image is related to a negative body image because of her extra weight.
11. **Social isolation:** 10, 13, 14 & 15.	Ann attributes her social isolation directly to symptoms of apnea: sleeping at social events, and to insufficient energy to entertain at home.
12. **Marital stress, and Role-strain:** 12, 13, 30 & 31.	The sleepiness and fatigue of apnea caused strain between the roles of homemaker, social entertainer, and wage-earner. The marriage was not stressed by apnea, but the apnea symptoms possibly prevented resolution.
13. **Victimization:** 12 & 25.	Ann does not generally play 'victim,' but does believe that the apnea was triggered by emotional stresses that were present in the marriage prior to onset of the apnea.
14. **Rationalization:** 18 & 25.	Ann rationalizes her poor memory as being a function of her age, and rationalizes that she may not have ever developed apnea were it not for the emotional trauma in her marriage.
15. **Other directedness:** 2 & 9.	The perceived embarrassment caused to her companions when she slept at functions has possibly caused Ann not to pursue previous social attachments. Ann also recognized the concern for her life shown by her husband when having a near traffic accident.
16. **Acceptance:** 29.	Ann did not recall any difficulty accepting the diagnosis since she did not think it was very

serious. Also she accepted CPAP quite readily, especially since it provides her with quality rest.

17. **Rejection:** 30.

Ann tries hard to cover the pain of her husbands' rejection. She explained during our second meeting that he told her she was unattractive because of her weight.

Synthesis of Ann's Experience

Ann has experienced great upheavals in her life since she developed sleep apnea, but rather than blaming the apnea for causing her problems, she believes that the apnea was caused or triggered by the stresses that she encountered within her personal life at that time.

Ann now finds herself in a lonely marriage which went sour at the time of the onset of her apnea. She gained weight as a result of age and the apnea, and therefore became 'unattractive' in her own eyes and that of her husband. Ann's social life and companionship with female friends diminished greatly when her uncontrolled apnea caused her to fall asleep during social occasions. Also the couples, who were the basis of the social activities of the marriage, drifted away because her marriage did not support such socializing. She had to join the workforce late in her life, and found little in common with those with whom she worked. At the time of the second interview, Ann had just lost her job and was actively searching for employment in a very competitive market. Since the majority of social contacts are usually made in the work-place, Ann finds little opportunity for making new friends who share similar interests. Now that her sleepiness is under control and she would like some social life, she finds that it is almost too late to create the potential.

She does not believe that using CPAP would be possible during a normal marital relationship because she doubts that a partner could tolerate the breathing equipment in the marriage bed, without feeling the patient to be less attractive.

Ray (Tables 9 and 10)

Ray is 59 years old, has severe obstructive sleep apnea, and is fairly overweight but certainly not obese. He believes that his apnea started about 10 years ago. He is a very pleasant fellow, with light blue sparkling eyes, a good mind, a quick smile, a quick wit, and an enjoyment of humour. He appears to be very outgoing and friendly, and is capable of off-the-cuff performances and speeches, but he admits a poor self-concept. He is an electrical engineer with a large corporation, and is married with children who are in their 20's. He has an excellent relationship with his wife, who is self-employed, enjoys working at home in the evenings, and is concerned for Ray's well-being and health. They have a very loving, solid relationship, and she provides much needed support for Ray, including attending apnea patient support meetings with him.

Ray has been using CPAP for four years, which has reduced his sleepiness, but has not reversed his cognitive functioning problems such as poor memory, lessened problem-solving abilities, aphasia, and speech slurring. However, he agrees that he has accepted the apnea and CPAP, and simply goes on as best he can to enjoy life in spite of his problems.

Table 9

Thematic Abstractions of Ray's Experiences with Sleep Apnea

	Excerpts from Transcript	Paraphrases	Themes
1.	My wife noticed that I snore quite heavily, then she noticed there were periods during the night where I stopped snoring. That scared her.	My wife was concerned by my night breathing cessation.	Other directedness.
2.	I would go to a meeting where they had a slide presentation, or - I can remember . . . we stopped at the Interpretive Centre on the Crow's Nest Pass. They have an interesting presentation . . . . I would fall asleep watching that kind of thing. It didn't matter how interesting it was or anything else, I would fall asleep. The lights would go low, or we would go visit somebody in somebody's home, I would fall asleep, or I would fall asleep at the wheel of the car!	I couldn't control sleep at times in spite of interest. The sleep would come during public gatherings, at meetings, friends houses, and even when driving.	Helplessness; and Fear.
3.	Oh, well, my wife caught me [falling asleep at the wheel of the car], and never let me forget it!	My wife was very worried because of lack of safety.	Fear.
4.	Well, its embarrassing. During work, you are attending a meeting, and fall asleep. Then your colleagues have a tendency to laugh, and say, 'hey Ray's sleeping again!'	Falling asleep during meetings causes colleagues to be amused and brings embarrassment.	Embarrassment; & Helplessness.
5.	The busier I kept, the better off I seemed to be. I needed that in order to get through the day.	I need stimulation and activity to stay awake.	Coping.
6.	I remember one time we had a stress management course, and they said "everyone will sit here, and you will relax and close your eyes," - and that was the wrong thing for me. Before I knew, I was snoring away heavily, and everyone was laughing. So it was really embarrassing.	I fell asleep and snored, during a course. My colleagues laughed.	Helplessness; & Embarrassment.
7.	My wife won't let me drive the car by myself [on long trips] because I fall asleep at the wheel.	I am not allowed to drive far by myself.	Helplessness.
8.	I had to take a trip to Kelowna, so I went on the Greyhound bus. I must have fallen asleep. I was very uncomfortable because I know I snore. . . . I must have fallen asleep, and when I woke up it seemed like everybody had moved to the back of the bus.	On a bus trip, I fell asleep and was mortified to find that all other passengers had moved to the back, presumably to avoid the noise of my snoring.	Helplessness; & Embarrassment.

9. I swore that I would never ride again on public transportation.	I have restricted my methods of travel.	Helplessness; and Grief.
10. CPAP . . .has compensated for that. I don't fall asleep at meetings anymore during the day, and I can drive my car without falling asleep.	CPAP treatment has solved some problems, but not all.	Dependence on machine.
11. For the first hour or so I have a tendency to want to [fall asleep], but if I can survive that long, then I'm good for the rest of the day.	Sleepiness is worse at the beginning of the day.	Periodicity.
12. I couldn't live without [CPAP].	CPAP is essential to me.	Dependence on machine.
13. I have a job where I have to read technical manuals, etc. and I read it and think 'this is very interesting, this is really worthwhile knowing.' A week down the road I can't tell you anything about it!	Any technical information I learn by reading I forget fast.	Mourning; Frustration; and Job stress.
14. I have to keep notes - constantly. A journal during the day of who called me and what they called me about. Frankly, I'm lost without it.	I constantly have to compensate for my poor memory.	Coping.
15. I wonder if I attribute all my problems to sleep apnea when they are not a sleep apnea problem. . . . I blame it all on it, and I don't know that I should.	I wonder if I don't blame apnea for more than I should.	Questioning personal response.
16. There are situations [trouble-shooting at work] where I have a problem because I know I have dealt with this before in the past, and I have a solution, but I don't know what it is. Very frustrating.	Even when I know a problem has been solved, I can't remember how.	Frustration; Mourning; and Job stress.
17. The new problems that I find a solution to - well they are gone in a much shorter period of time.	I can't even remember solutions that I create.	Mourning.
18. I used to sit back with an approach to a problem and cut through the chaff and find out what the basic structure of how I am going to organize this thing. And now, I am confused at the outset. I don't even break it down into any kind of logical step - I'm confused immediately.	My problem-solving and abstract thinking skills are not good anymore. I feel useless sometimes.	Mourning; and Job stress.
19. With the situation that we have got right now in this country, I feel that I am at a real dis-advantage. I could possibly be replaced with someone younger, with a better memory.	My poor memory and problem-solving skills could cost me my job.	Fear; and Job stress.
20. No, [no-one has said that my work is not as good]. I wish it was if it were true. Once in a while maybe, if they would say, "well you are doing pretty good," or "you are not as quick as	I can't assume that my work is satisfactory just because I am not told that it is bad. I would	Uncertainty; Need for confirmation of self worth.

you used to be." I could deal with that.	like some feedback.	
21. When you are having coffee together, you talk about [apnea] because you want to help somebody in case they've got it too.	I would like to be able to help others who have apnea and don't know it.	Need for understanding.
22. So they are aware that I've got it, but whether or not they believe what I've been saying, because frankly I didn't know or believe originally.	Others may not believe or understand me.	Need for understanding.
23. I feel uncomfortable speaking after a period of time - my mouth feels like it is full of marbles and cotton batten - I don't know, it is a very strange kind of feeling.	My mouth doesn't always work well, and it feels as if I am not in control.	Helplessness; & Poor self-image.
24. [I find myself using] the kind of wording that I didn't want, or knowing what I am going to say, and finding out that all of a sudden, having a fairly good vocabulary, I can't think of a word that fits in here any more.	Sometimes what I say is not what I want to say, and I can't find words that are very familiar.	Poor self-image; and Mourning.
25. I used to condemn my mother because she used to call me by my brother's name - and I find that I do that! - and I am only 58 years old! I can't believe it - that I would do that sort of thing. . . . I have to stay away from names. Absolutely, I have a real problem trying to remember names.	My inability to recall names correctly causes me self-contempt.	Poor self-image; and Mourning.
26. I worked in the TV industry, and I have done commercials on TV, so I am not afraid of getting up and speaking, or I had the vocabulary to get by on. And it's all gone. I don't like to get up in front of people, I slur some of my words, or I'm looking for words that I can't find, and I find that really annoying.	I feel that my speaking abilities are bad, so I avoid public speaking now.	Reduced confidence; and Mourning.
27. [My wife] doesn't like [CPAP] very much. It's a fairly noisy one.	My CPAP is noisy and it disturbs my wife.	Marital stress.
28. I think I have to compensate in a lot of additional ways. I assume the role of the silent intellectual who never says too much (laughs) . . . [and] I carry a piece of paper or a pad around in my pocket, because I might think of something that I should do tomorrow . . .so I write it down. If I don't, it's gone - I would never remember again. I have to live that way.	I am constantly trying to compensate for my reduced abilities.	Coping.
29. I have to organize myself - I have to come to work earlier, and have a journal, write down everything that I'm going to do or try to do that day, jot down in my notes that I made from the night before on my little pad, and then before I leave, organize things on my desk for	I try to compensate by spending more time on organizing my time and writing notes.	Coping.

the next day.

30. I probably have very low self-esteem. I don't feel happy about myself. I have gained a lot of weight and I seem to be continually putting it on. I haven't the willpower to stop it - eating is probably the only enjoyment I have.	My extra weight causes me low self-esteem, but not enough to do anything about it.	Poor self-image.
31. I am not comfortable with myself, and I am uncomfortable in my clothes.	I don't like being over weight.	Poor self-image.
32. I think stress on the job [caused the lack of social life]. When I got home, I would just like to settle down in the comfort and seclusion of your own home, and shut out the outside world.	I chose to reduce my social life because of job stress.	Job stress; Social isolation.
33. I miss [dreams]. I used to dream all the time. I used to have terrible dreams. Yes, bad ones! I miss them! (laughs).	Once I had quite frightening dreams, and I now miss that excitement.	Dream deprivation.
34. I hardly dream at all any more. . . . I think that dreaming is part of your imagination. If you have a good imagination, devising plots and schemes, dreaming is a good thing. I really miss it.	Lively dreams show imagination. I don't have much imagination any more.	Dream deprivation.
35. I get up at 6 o'clock every morning, and when the weekend comes, it would be nice to sleep in a little. But, if I sleep in more than an hour, if I sleep more than eight hours, I am in real trouble.	I would like to be able to get up late and luxuriate in a lazy week-end, but I can't.	Grief.
36. You feel that mother nature is playing a lot of tricks on you. You've been pretty healthy all your life, and now . . . you have to wear this stupid machine at night to go to sleep. . . . There are all these little things that individually don't account to much, but collectively it is a bit of a nuisance, to put it mildly.	Sleep apnea, by itself is not really a big problem, but added to all other little items of ill-health of middle age, it amounts to a trial.	Mourning; and Helplessness.
37. Maybe I am using this as a crutch.	Maybe I use sleep apnea as a crutch.	Questions personal response.

Table 10

Second Order Thematic Abstractions of Ray's Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 8: 1, 2 & 3.	Ray recognized that his sleepiness before treatment could lead to a traffic accident, which caused him fear. His current fear is that he could lose his employment because of his diminished cognitive skills.
2. **Helplessness:** 2, 6, 7, 8, 9, 23, 35 & 36.	For Ray, helplessness was most related to the control he had lost to the sleepiness, and to the restrictions placed on his life for purposes of safety and avoiding embarrassment. CPAP treatment has solved much, but not all of this helplessness. The restrictions caused by CPAP treatment also cause Ray feelings of helplessness.
3. **Grief:** 9.	Ray is still afraid that he may fall asleep when travelling by bus, hence will not use public transportation. He grieves for the freedom he has lost.
4. **Mourning:** 3, 16, 17, 18 & 36.	Before the apnea, Ray had a good memory, speaking skills, vocabulary, and superior problem-solving skills, which are a vital part of his professional stock-in-trade. With the impairment of these skills, Ray has had to reassess his identity, and he seems to be mourning those skills that are no longer good.
5. **Embarrassment:** 4, 6 & 8.	Ray has been the butt of colleagues' jokes when sleep overtook him, and has been embarrassed to the point of humiliation by passengers' reactions to his sleeping on buses.
6. **Frustration:** 13 & 16.	Because of the highly technical nature of his job, Ray finds his diminished memory and cognitive skills very frustrating.
7. **Need for understanding:** 21 & 22.	When talking about his apnea to his colleagues, he seeks their understanding.
8. **Coping:** 5, 14, 28 & 29.	The majority of Ray's coping is given to methods to compensate for his lost cognitive skills. He also finds that to control sleepiness he depends on the

	stimulation from high work activity.
9. **Periodicity:** 11.	For Ray, the sleepiness is much more profound at the beginning of the day.
10. **Job stress and fear of loss of employment:** 13, 16, 18, 19 & 32.	Ray perceives himself as an engineer with reduced memory, speech and problem-solving skills who has a stressful job. Although he works extremely hard to compensate for his reduced skills, the concern that he may be replaced by a younger, brighter person is always with him. The fear of losing employment certainly adds stress to an already stressful position.
11. **Dependence on machine:** 10 & 12.	Ray is very dependent upon the CPAP unit to provide him with quality sleep and thus keep his sleepiness under control.
12. **Poor self-image:** 23, 24, 25, 30 & 31.	Much of Ray's poor self-image seems to stem from the loss of cognitive skills, and a negative body image that his extra weight has caused.
13. **Social isolation:** 32.	Ray attributes his social isolation to stress of his work, possibly starting at the time his children were small. However, he now finds that he prefers a very quiet social life.
14. **Marital stress:** 27.	In addition to CPAP being unpleasant for both partners, Ray explained that it stifles bedtime opportunities to heal marital disputes.
15. **Acceptance:**	During the second interview, Ray explained that he had accepted the diagnosis of sleep apnea with little difficulty, and accepted CPAP as necessary and positive.
16. **Other directedness:** 1.	His wife's concern for his health was partially responsible for his seeking medical help.
17. **Questioning personal response:** 37.	Ray questions whether he uses his apnea as a 'crutch' and blames it for too much.

Synthesis of Ray's Experience

Ray finds that his apnea is just another little trial that seems to go along with increasing years and decreasing health. Although his marriage has not really suffered from the apnea induced stresses, there has been some degree of effect.

Ray has experienced the fear of falling asleep at the wheel of an automobile, and the extreme embarrassment of colleagues and members of the public laughing at his snoring. However, the biggest area of perceived threat the apnea causes is to his future employment. Although he has not been given any direct indications that his work is unsatisfactory, he feels he could, at some time before his retirement, be replaced by a younger person with the kind of capabilities he once had before the apnea impaired his skills. He is aware that the diminution of his verbal and problem-solving skills, has worked to reduce his self-confidence, self-esteem, and self-worth as an engineer.

Ray's social life is quiet by his choice. He attributes this to the time commitment needed when his children were young, to stress at work, and to personal preference. Although he seems to prefer quiet evenings to an active social life, it is a moot point as to whether his life would have been more active had he not developed apnea and had thus had more energy to spend pursuing social or leisure activities.

Dean (Tables 11 and 12)

At the time of our first interview, Dean was 37, and a detective on one of Alberta's major city police forces. His severe obstructive sleep apnea was diagnosed about a month prior to the first interview. Our first interview took place after the first night of Dean's CPAP titration[21], and on the evening of his second night with the machine. At the time of the second interview, he was planning to undergo surgery to remove pathology and correct a physical abnormality which was expected to solve 50 percent of his breathing obstruction. In addition to sleep apnea, Dean has severe periodic leg movements which subjects his wife to considerable disturbance at night. Dean is tall, slightly overweight, and appears to be very intelligent and well educated. Dean has not experienced severe apnea symptoms, but finds a general fatigue to be a constant problem, and occasionally he finds sleepiness close to overtaking him.

Several years ago, Dean endured a blow on the head which caused trauma to his temporamandibular joint (jaw), and considerable face, head and neck pain. He had consulted a dentist who not only diagnosed and treated his jaw trauma, but suggested that he be checked for a sleep disorder.

The relationship Dean has with his wife is a good, supportive and understanding one, but not one without difficulties. The couple have been married only for a few years, and Dean recognizes that some of their marital stress emanates from his difficulty adjusting to married life. Dean may receive more understanding and support because his wife understands, first hand, what it is to suffer a relatively debilitating chronic disease.

The light of Dean's eye is their 2 year old son, and he is quick to take pictures of him from his wallet and share them with anyone who shows the slightest interest. This child was born with some life-threatening abnormalities that required multiple surgeries and very careful monitoring.

The baby's illness, his wife's chronic illness, his profession, shift work and the impact of Dean's apnea are all accumulative in compounding the stress in the marriage.

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[21] Titration refers to the assessment made during two overnight sessions to ascertain the level of positive air pressure necessary to maintain the breathing passages.

Table 11

Thematic Abstractions of Dean's Experiences with Sleep Apnea

Excerpts from Transcript	Paraphrases	Themes
1. I found [CPAP] very constricting, and when I woke this morning, I was almost panicky to get the mask off, just because it was there. But I am concerned about the dependency on a machine just for lifestyle on the whole. It actually really concerns me.	Wearing a mask to sleep is restricting and creates a feeling of panic. I hate the thought of having to be dependent on a machine every night.	Helplessness; Fear; and Desperation.
2. I convinced myself that the degrading of the jaw joint was what was causing most of the problems and symptoms.	I avoided thinking of another cause for my fatigue.	Denial; and Rationalization.
3. I was aware of two things: one that my wife complains about the snoring - excessively; and also I have quite violent leg movements during the night. So I was assuming that I was uneasy or something, and that would cause the leg movements.	I decided to explain violent nocturnal leg movements as being caused by job stress.	Denial; Rationalization; and Other directedness.
4. When I went back to see the Doctor, and he said "you have sleep apnea, and you stop breathing 17 times an hour and the most is up to about 58 seconds" or something, - it was like someone hit me with a sledge-hammer. I was almost panicked.	I did not believe I had a sleep disorder, so the diagnosis was devastating.	Shock.
5. I didn't know how the Department would react to it because I work shift-work, I work nights, and I drive a vehicle all the time - that's part of my job.	I was afraid that my employer would react unfavourably to the apnea.	Fear.
6. So I didn't really prepare myself - I had told myself it wasn't existing, that it was [the jaw] problem that was causing [the sleepiness and other symptoms].	I was not prepared for the diagnosis of a sleep disorder.	Shock.
7. When I read the literature now about moodiness, sleepiness, tiredness, lack of energy - I see all those things in myself, and I know my wife has mentioned my moodiness, and sometimes it is mentioned by people at work.	Now I can see some of the other symptoms, such as moodiness.	Enlightenment & explanations.
8. I have scared myself a few times driving - especially . . . at night. . .. If you are out on the road - and I am always by myself - it is very easy to get lulled and tired.	I see how other people have fallen asleep at the wheel.	Fear; and Periodicity.

9. It's not a lot of warning [that sleep is coming], and that's what actually surprises me. I have always heard of people, and seen the results of people falling asleep at the wheel and being killed, or whatever, and thought there must be some warning.	As a police officer, I have seen the results of people falling asleep at the wheel, and now understand how it happens.	Fear.
10. I try to stay away from places like the highway or open stretches of road where there is that line that can serve to mesmerize you.	I try to avoid conditions that will enhance my sleepiness.	Fear.
11. [The Department], I think fortunately or unfortunately for me, are pretty ignorant to what [apnea] is and the risks. I haven't kept it from them and I have told Personnel . . . I don't think they are aware - or I am over-feeling the seriousness of it.	My employer was not concerned, so that makes me wonder if I am over-reacting.	Questioning personal response.
12. Part of me says that I am over-reacting to this - that it's not a big deal. But in the back of my head I am feeling it is a very big deal.	It feels devastating, but it seems that it shouldn't.	Questioning personal response.
13. I guess what would concern me is that [the Department] could feel that they have to pull me off the street. And that would be a concern to me. I wouldn't want to leave the street. . . . But if they do, they do!	Work duties and career could be limited in future.	Fear.
14. Of course the leg movements, for example, don't bother me at all, but they wake Carla up, and that's hard on her. . . . So it's minor, but not minor. So that causes strains, and even with the CPAP machine, you know, you get the information and realize the costs and that involved, and that causes family strains.	Nocturnal leg movements and the cost of CPAP add to the strains of a new family situation.	Marital stress; Financial stress; and Other directedness.
15. It's hard to tell yourself that you are going to spend $1,500 or whatever it's going to cost, and not know, in fact, whether you can even live with that.	I don't think I could use CPAP. The cost is an important factor.	Financial stress;
16. I am feeling very out of place here [at the sleep lab] when I come in. First of all, it's mostly men that I've seen here, . . they could all be my father. And that's very hard to accept.	Why me. I am young, and apnea is an old man's illness.	Disbelief; Denial; and Resentment.
17. One of my best friends from childhood, . . . had a heart attack this summer. And the two of us have talked about that this summer, and you know, he's got a pacemaker, you know, 36 years' old and with a pacemaker! I though a lot about that, and got this news after that, and I'm 37 and I'm looking at being hooked up to a machine for the rest of my life. That's really hard to accept at my age.	I am like my young friend who has had a heart attack and must depend on a machine to live.	Fear; and Grief.

18. [The cause is unknown, and] these unknowns are very scary.	I wish I knew why.	Fear.
19. [The extra weight is caused by] poor eating. I can blame part of it on shift work - but where I start to notice it is the availability on nights, to stop and grab a pop or chocolate bar. [Dean explained later that he found a chocolate bar gave him a "burst of energy" which temporarily counteracted the sleepiness.]	Junk food is easy to use as a stimulant on night shift.	Coping.
20. I'm not sure that I know what it is to feel well rested any more. . . . People tell you they wake up and just feel like a million dollars in the morning, and I don't remember that. I feel tired. I am sluggish right now. . . . At no time during the day did I really feel full of energy.	I am always sleepy, with little or no energy. I miss that feeling of energy.	Mourning.
21. Different things at work stimulate me, and I don't notice the sleepiness at all. And other things -- I am taking a supervision training course, and if the guy isn't particularly flamboyant at one of the lectures, it can certainly quickly nod me off. I noticed that I had trouble even back in university before I was on the job, I remember I found lectures and things -- fighting to keep awake in them, and now I wonder if it went back that far.	Some situations on the job are stimulating and tiredness is not a problem, but some situations lull me to sleep fast.	Helplessness.
22. I find when something is happening, whether it is a little bit of adrenaline or whatever that kicks in and keeps me going. If I have something to go to, I can spring out of [the sleepiness] almost any second. And even if I have been driving and I have pulled over because I am really feeling tired, if an accident or an injury accident or something where we have to go high speed, it comes in where you are 100% functioning all of a sudden.	An emergency call overrides any sleepiness.	Coping.
23. [The social life is] pretty non-existent right now. Because of the job, and because my wife is working part-time, and we really didn't want our son in any kind of out of home care. . . . So I don't think that's a lot to do with the sleepiness at all.	Lack of social life is due to jobs and scheduling to allow personal child care.	Social isolation.
24. Sometimes [I dream] quite a bit. I haven't for a little while. Sometimes I have some quite vivid dreams. After certain incidents on the job I have had a series of dreams, and that's pretty normal . . . you know some of the things aren't very nice that we deal with, and they come back and haunt you.	Sometimes I have vivid dreams stemming from work incidents. I think that is quite normal.	Stress relief.
25. I have concerns about [the use of CPAP as a	I couldn't use CPAP	Resistance;

treatment], for example, it's not real easy to get the mask off in a hurry. I can see it scaring my son. When you look at the people around here with them on, we laugh, and it's a joke you know, but when you have little ones it's not so funny for them.	because the mask scares me.	Projection.
26. Often for couples, when you go to bed you are lying in bed and you're talking, and you sort of discuss things and you fall asleep. Well that's going to be non-existent [with CPAP] because you can't talk with that th ng on. All you get is a burst of air. It limits the positions you can sleep in - you know it has ome fairly major effects. I guess the idea c being hooked to a machine all the time - for - I am really fighting that in my own r right now. . . . In my own mind I have made my own mind that I am not prepared to live wi.h that. But, I can't say that until I find out what the surgeon thinks.	I think CPAP would interfere with a normal night's sleep and with normal marital life. I would prefer surgery with a lesser chance of success, and greater risks for that reason.	Grief; and Resistance.
27. I guess, for me if [CPAP] was a thing you had to do for a couple of months, that's not a big deal, but I am looking at the rest of my life with it.	The idea of long-term dependence on the machine is frightening.	Fear; and Grief.
28. It's really a gut-wrenching emotion for me. Again, I am fighting it. One of the things on my job and my lifestyle is that we don't express our emotions very much . . . . I have really fought this. It is really a tight emotion for me - I haven't felt this uneasy about anything, ever.	The idea of CPAP is very painful.	Pain; and Shock.
29. I hear, and it may be incorrect, that [surgery] may be 50/50 or even worse, that it will help. What happens if I just leave it - I suppose that's an option too. I don't think that's a good one, but it's an option.	I see surgery as having a questionable success rate, but better than no treatment.	Resistance.
30. I can see people starting on something like the CPAP machine, and after a while just saying 'it's not worth it' and not using it one night, and then that seemed o.k., - getting yourself to a healthy level, and then letting yourself slide back down.	I don't think I would use CPAP enough to keep my health.	Projection.
31. If it had to happen, I kind of wish it could have been 20 years later.	I am too young to have this.	Anger.
32. I think a big part of it is not knowing why I have it. Our [child was born with problems]. No-one can tell us why . . .. Was it something that happened to him in the womb, was it hereditary - they can't tell us. . . . They are unknowns. This is just another - we have got over all those, they are behind us. And then this other unknown came in, and it's just like 'give us a break!'	If I knew why I developed apnea it would help me to adjust. Life seems to be a succession of struggles to overcome unknowns.	Victimization; and Anger.

33. I really thought that the surgery on the jaw was going to solve my problems, and then to find out that - it just hasn't set easy with me. I was totally unprepared for this.	I had not considered a problem beyond the jaw, so I was unprepared to learn of the apnea.	Denial; Shock.

Table 12

Second Order Thematic Abstractions of Dean's Experience

Thematic Clusters	Generalized Description
1. Fear excerpts from Table 9: 1, 5, 8, 9, 10, 13, 17 & 18.	Dean is aware that sleepiness could cause a serious or fatal traffic accident, and has witnessed the devastation of such accidents. He also has a fear of being dependent on a machine, and is concerned for changes that his apnea may cause in his marital relationship and his career plans.
2. Helplessness: 1 & 21.	Dean has experienced the loss of control of his body to a physical condition, and is beginning to notice loss of control over other areas of his life. The feeling of helplessness that the lost control brings is not comfortable, neither is the loss of freedom he is anticipating for his future if he has to use CPAP.
3. Grief: 17, 26 & 27.	Along with the fear of dependence on a machine, Dean grieves for restrictions that a machine will place on his recreation, and he grieves for the loss of bedtime companionship with his wife that the machine may cause.
4. Mourning: 20.	Because apnea has caused chronic fatigue, Dean mourns the loss of feeling of being refreshed by a good night's sleep.
5. Desperation: 1.	Dean experienced desperation and a "panicky" feeling from a breathing obstruction or perceived obstruction by the CPAP mask.
6. Coping: 19, 22 & 30.	He has found the consumption of a candy bar provides a burst of energy and wards off sleepiness. Dean has also noticed that when a high level of activity is demanded by his work, his sleepiness is overridden.
7. Periodicity: 8.	Long quiet times in the middle of the night bring the worst sleepiness for Dean.
8. Dependence on machine:	Dean has very negative feelings about the need for CPAP therapy and about having to be dependent on a machine.

9. **Resentment:** 16.	Dean resents having sleep apnea, and also resents the fact that he has what he considers an illness of overweight, elderly men.
10. **Social isolation:** 23.	Social isolation is something that is self-imposed, and is not seen as a problem. Other matters, such as the upbringing of children, have higher priority.
11. **Marital stress:** 14 & 15.	Dean has not been married long, and seems to have had more than his share of difficulties. The apnea is viewed as a potential cause of more stress to the relationship directly, and to the finances of the couple.
12. **Projection:** 25 & 30.	Dean projected his own fear of the mask on his son, and his resistance to CPAP on others.
13. **Shock, disbelief, denial rationalization, pain, resistance & anger:** 2, 3, 4, 6, 16, 25, 26, 28, 29, 31, 32 & 33.	At the time of the first interview, confirmation of apnea was recent. Added to that, Dean had avoided preparing himself for the diagnosis by rationalizing that his symptoms were related to a jaw injury. It would seem that Dean is passing through the stages of adjustment to chronic illness (Gregg, Robertus & Stone, 1989, pp. 5-6.)
14. **Other directedness:** 3 & 14.	Dean is aware and concerned that his sleep disorder disturbs his wife, and concerned also that the possible use of CPAP may further disturb her. These factors may influence his future decisions about treatment.
15. **Questioning personal response:** 11 & 12.	In his work, Dean has dealt with many people experiencing severe trauma. Now he faces personal trauma, he is surprised at his emotions, and wonders if he is not over-reacting.

Synthesis of Dean's Experience

At the time of the first interview, Dean was feeling highly traumatized and experiencing considerable mental pain and anguish as a consequence of the news that he had sleep apnea. He appeared to be going through early stages of adjustment, and because of his youth, the acceptance was difficult.

Although concerned that the apnea might cause a change in his work duties or interfere with the future of his career, his attention was focused on shock, disbelief, denial, questioning, and anger. This is in keeping with the adjustment process some other chronic illness patients experience when learning of their illness.

Dean felt much of his difficulty related to lack of answers to his questions of "why me: apnea is an older man's disease." Because he rationalized that a previous jaw injury accounted for his symptoms, and because he was not suspicious or accepting that he could be so afflicted, the shock and trauma were magnified by the reality of the diagnosis. He felt that this was one more piece of bad news in a long succession of medical problems within his family. The combination of all these factors made acceptance difficult for him.

In addition to concern for his marriage and career, Dean was devastated by the possibility of having to use CPAP as a life support system. Not only did wearing the mask create some panic and fear, but CPAP therapy meant he would have to give up his wilderness recreational activities. This was more than he was prepared to face.

At the time of the second interview, Dean had consulted a surgeon, and had learned that some pathological problems could be removed surgically at the same time as correcting structural abnormalities which may solve a major portion of his apnea. He was feeling considerably less traumatized, not only because of effect of the time, but also because the surgeon had provided hope of a partial cure that would not necessitate the use of CPAP.

Dean's wife's first-hand experience with chronic illness, coping with the illness and surgery of their son, adjusting to shift work, and now Dean's apnea seem to be very unwelcome complications to a new marriage. However, the couple seem to have weathered most of their problems successfully, and Dean's surgery gives him hope that he will not have to use CPAP for many years.

It could be that Dean was initially experiencing the same feelings of devastation that the other participants may have felt long ago when they were first diagnosed with apnea, but that time has obliterated their memory of that trauma, and they now deal with it relatively pragmatically and efficiently. Maybe Dean will adjust to the apnea without hopelessness, and live with it in the same pragmatic way as so many other patients. Only time will tell.

Charles (Tables 13 and 14)

Charles, who is in his very early 60's has moderately severe obstructive sleep apnea, and like Ann, attributes it to the obstructive architecture of his anatomy. He is the senior partner of a law firm, and also is very active in other businesses. He has had a colourful background of extra-curricular activities which he has now given up in favour of a quiet and relaxed home life in his non-working hours.

Charles and his wife have been married for over 35 years, are best friends as well as husband and wife, and from the impression given by Charles, they are totally devoted to each other. Charles has children who may develop sleep apnea, but he makes no apologies for the way he is built and for any possible genetic transfer of the illness to them. He is a very large man, and gives the impression of being physically powerful although he admits he could lose some weight. He is very independent and confident giving the impression of using his time and energy efficiently and economically.

Charles' apnea is moderately severe, and he believes he has had it about five years, but he seems to have escaped severe daytime sleepiness. He does, however, notice some afternoon fatigue accompanied by a slight loss of creative thinking. He has used CPAP for three years, but has not noticed a significant reduction of his apnea symptoms.

Table 13

Thematic Abstractions of Charles' Experiences with Sleep Apnea

	Excerpts from Transcript	Paraphrases	Themes
1.	My wife is a very light sleeper, and I am a very deep sleeper. As a result of that, she would tell me that when I slept, I would hold my breath, and she would lie awake and say "is he going to start up again?" . . . I also had a snoring problem which was very disturbing to her.	My wife was worried by the cessation of my breathing, and disturbed by my snoring.	Other directedness.
2.	As a result of reading [some articles on the invention of the CPAP machine], and from my wife's observations of what I was doing in sleep, it appeared to me to be fairly obvious that I had a problem.	My wife and I were able to recognize that I had sleep apnea from the reading we had done.	Self-diagnosis.
3.	I would be waking up all the time and going back to sleep, and I would be very tired during the day. Although, because I am a high energy person, I could carry myself through, but my feeling of well-being was sliding.	I used to experience sleep fragmentation and fatigue. Although I could still manage, I missed feeling refreshed and well.	Sleep fragmentation; and Mourning.
4.	I decided in a simplistic way that [CPAP] was what I needed.	I must get onto CPAP to save my life.	Acceptance.
5.	As a result of the machine, my rest was significantly increased, and my energy level was still high, but during mid-afternoon, around 2 o'clock, I would be very tired, but I have a tendency to drive myself, and I guess I compensated for it. But the CPAP machine was really a life-saver for me.	CPAP improved my energy, but I still have a low period in the afternoon, for which I compensate by hard work. I am grateful for CPAP.	Periodicity; Coping; and Dependence on machine.
6.	It was a very simple decision for me: either I use the CPAP machine or I had a serious problem. So I simply adapted to it.	I simply decided to adapt to CPAP to avoid a serious problem.	Acceptance.
7.	I don't like the fact of going to sleep with a a mask on my head. I don't like the fact that my wife has to sleep elsewhere most of the time because the machine will keep her awake.	I regret the need for CPAP because it disturbs my wife's sleep so we have to sleep separately.	Grief; and Marital stress.
8.	The sexual part isn't the important part, it's the companionship that you have, and I think in a husband/wife relationship it is important that you are together.	I miss the feeling of companionship in our marriage.	Grief; and Marital stress.

9. So bedtime was the time when we did a little reading before we went to bed or when we went to bed we had time to talk. I'd be lying there thinking about things, you know. So from the point of view of the great relationship you have between spouses - it affects that.	Bedtime has changed in content, and I really miss the way it used to be.	Grief; and Marital stress.
10. I wish it could be done in some different way, for example, I've read a bit about the laser technology which is coming up, and once it's perfected . . . I would get that rather than have the CPAP machine.	I wish surgery was a viable alternative to CPAP, so that normal bedtime could be restored.	Grief.
11. I like the outdoors, and I do fly-in fishing, I go hunting, and I find it quite a bother sometimes on fishing trips there is no power. So you can't use [CPAP].	CPAP restricts my fly-in fishing and other recreation.	Grief.
12. I am sufficiently concerned that I don't like not being with the machine. In other words I feel that I have got to have that machine every night, period.	I am concerned enough for my health that I always use the machine.	Dependence on machine.
13. So I am married to the machine - it's almost like my lifeline - that's the way I look at it in my mind. But it does create problems, and the most significant one is the bedtime problem to me.	I depend on CPAP for a continued feeling of well-being, but it is not a perfect solution.	Dependence on machine; and Grief.
14. In the afternoon, - mind you I am 61, and maybe that's an excuse, - I think that in the afternoon I have developed a pattern of not taking anything that requires a lot of creativity and innovative thinking on my part as a lawyer. I would leave that to the morning, because I think in the afternoon there is a certain amount of - I don't want to say 'impairment' - maybe that's what I am thinking, maybe I should say 'impairment.'	I rearrange my work schedule to accommodate the times that my impairment is the worst.	Periodicity; Coping; and Mourning.
15. I don't think I am as strong mentally in the afternoon as I am in the morning, and whether that is related to the apnea or not, I can't be sure, but I feel it is.	I think the reduction in my thinking skills is related to sleep apnea.	Periodicity; Mourning, and Questioning response.
16. I don't think my memory is as strong as it was, but yet test it against the facts on a file with the secretaries - it hasn't suffered a great deal!	My memory is not as good as it used to be, but it is still pretty good.	Rationalization.
17. I don't sleep at the wheel! Nothing like that.	I'm safe to drive.	No problem
18. I do not need any support or sympathy from anybody. I'll look after my own problems, and . . . even if it was something else,	I am independent and don't need support or sympathy from anyone.	Independence and self-reliance.

some other major problem I had, I would keep it to myself. I may talk about it to my wife, but probably no-one else. I do not need to share my burdens with others.		
19. [I am] not at all [fearful that my apnea becomes common knowledge]. I don't particularly care who knows what. . . . But I am not about to tell anybody about it.	I don't care who knows I have apnea, but I am not going to tell them.	Independence and self-reliance.
20. Not only do I have an active law practice, Mary, I am active in business as such. As a result of that and as a result of my own make-up, I am not much of a social person in the sense that I am not someone who is interested in going to parties and things like that.	I have a very busy law practice and am active in business, so I choose to have a limited social life, especially at my age.	Social isolation.
21. My relationship with my wife - which is very good - but it's a question of how you are together. We have been married 40 years, and we are good friends and husband and wife as well, so I find that [interference of CPAP] troubles me [illegible] anything else. If there is one single [illegible] would say that's my pal and me is the [illegible]ing.	It really hurts me that CPAP interferes so much with the quality of my marital relationship.	Grief; and Marital stress.
22. I should be losing weight, but I suppose I have got a human frailty in the sense that that's tough for me.	All right, I could lose some weight, but that would take effort.	Difficult to lose weight.
23. I remember my feeling [when the diagnosis was confirmed.] My feeling was 'I've got to get on that machine or I'm a dead duck!' . . . I wasn't angry or disappointed or terribly shocked. I was very pragmatic in saying 'this is my lifeline, I'd better get on it.'	I pragmatically accepted the diagnosis, and quickly arranged [illegible] get a CPAP machine.	Dependence on machine.
24. I was surprised by the detail in the sense of how many times I stopped breathing, how long I held my breath . . . [that] <u>really</u> surprised me.	I knew I had a problem, but was surprised to know of the severity.	Fear.
25. Basically, I suppose the most sobering thing is the idea that your brain isn't getting the oxygen.	I really didn't like the idea that my brain was being starved of oxygen.	Fear.
26. Emotionally I was kind of happy that the diagnosis was confirmed because I was convinced of it [but] I didn't realize the severity.	The diagnosis was easy to accept, but I was surprised at the severity.	Fear.
27. I think, by virtue of the fact that I may have to get the pressure increased, yes, [I am concerned that the symptoms my escalate]. I have that concern in my mind. I think it is more of a practical concern,	I believe that my apnea will escalate, and the impairment of my mental processes may increase.	Fear.

yes, I think that it is going to escalate. That's what I think. Whether it is true or not, I have no idea. But I have that feeling.		
28. My background is from a mother and father who were strong people. I had an excellent childhood. We were self-reliant. We had good educations. A lot of self-confidence. Also training for 'don't worry about things you can't do anything about - you adjust - you overcome, and you do what you have to do.'	My upbringing provided me with a strong base of self-confidence and strength.	Confidence.
29. [When] I was getting tested for the level of pressure for the machine, there were two other guys there, and one fellow couldn't get used to the mask. He said "I just absolutely couldn't stand the mask." And I have difficulty understanding that because it seemed to me so obvious. . ..I just said 'well I'm going to get used to it because that's the way it has to be.'	I listened to others who were not persistent in adjusting to CPAP, and decided I had no choice.	Acceptance.
30. When I was extremely tired, I have woken up after what I suspect is my REM sleep, and I have removed my mask, almost like in a bit of a daze. Then I sort of come to, and wonder 'what did I do that for'! I have done that three times, and I don't know why, because I am a person who wouldn't be without it.	Although CPAP is needed, I hate it, and will get rid of it whenever I can.	Fear.

Table 14

Second Order Thematic Abstractions of Charles' Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 11: 24, 25, 26, 27 & 30.	Charles has not experienced falling asleep at the wheel, but has considered that the illness may escalate and cause him some further disabilities. He may also have some deep-seated fear of dependence on CPAP.
2. **Other directedness:** 1.	Charles noticed his wife's concern for his absence of breathing, and together, he and his wife determined the problem.
3. **Grief:** 7, 8, 9, 10, 11, 13 & 21.	The greatest difficulty Charles has with apnea is the loss of bedtime marital companionship caused by CPAP disturbing Judy's sleep.
4. **Mourning:** 3, 14 & 15.	Cognitive impairment is small but noticed. As a lawyer who needs an excellent memory and creativity, Charles mourns for his mid-afternoon cognitive abilities that are now weaker than they used to be.
5. **Coping:** 5 & 14.	Charles schedules his work to avoid his times of lower energy.
6. **Periodicity:** 5, 14 & 15.	Charles has noticed that his fatigue is worse at some times of the day than others.
7. **Dependence on machine:** 5, 12, 13, 23 & 30.	Charles recognizes that he is dependent on the CPAP machine for his continued health, and while he appreciates the value of the machine, he regrets that it is necessary for its negative effects.
8. **Social isolation:** 20.	Charles has experienced a very full social life in the past, and his current social isolation is self-imposed and quite preferred.
9. **Marital stress:** 7, 8, 9 & 21.	Although Charles' marriage is not suffering, there is stress placed on the relationship by the loss of quality bedtime companionship.

10. **Rationalization:** 16.	Charles rationalizes that his memory has not suffered greatly, but he measures it, not against his former capacity, but against the present memories of the secretaries.
11. **Acceptance:** 4, 6 & 29.	Although not welcoming apnea, Charles has accepted it with pragmatism, as he has also accepted the CPAP treatment.
12. **Questioning personal response:** 15.	Charles is not entirely certain that he can blame his apnea for the reduced mental abilities in the afternoon.

Synthesis of Charles' Experience

The symptoms of Charles' apnea are relatively mild, and hence there has been minimal impact on his life. Although the apnea itself is quite severe, early diagnosis, early treatment, and his natural high energy levels seem to be responsible for the low level of symptoms. However, even with mild symptoms, Charles grieves for the lost qualities in his relationship with his wife that the apnea treatment has caused, and gently mourns the mild impairment of his cognitive skills which are so important for a lawyer. He feels that once laser surgery is developed to the point of being risk-free and highly successful, he will pursue an operation. He may not be a good candidate for any surgery, no matter how tried and successful the technique, and hence this hope for the future may be completely futile. However, it seems to be the kind of hope that he needs to hold on to, whether realistic or not.

For the future, Charles has a concern that escalation of the severity of the apnea will occur, and with it there may be some further cognitive impairment. However, he is a very confident, pragmatic, strong-willed and self-reliant man who is not given to thinking about what might happen. If any such misfortune should strike, (and it shouldn't if treatment is continued) he will deal with it pragmatically when that time comes. Until then, he will not waste time and emotion on unnecessary worry.

Paul (Tables 15 and 16)

Paul's first interview was the only interview at which a third person was present. Paul had requested that his wife attend, and since Paul provided little direct information on his condition or experiences, Grace's information and comments were very helpful. Although having his wife attend the interview may have inhibited Paul's comments, and deviated from the plan of the research, Grace's input provided an alternate approach to living with apnea. In subsequent interviews with Paul, Grace was not present, but Paul's attitude did not change.

Paul is in his early 60's, and has mild to moderate mixed sleep apnea which was treated by uvulo-palato-pharyngoplasty (UPP)[22] surgery five years ago. Although the surgery was interpreted as successful, Paul's wife now notices an increase in his apneas and in his periodic leg and body movement. Paul, like his wife, is a warm, playful, and charming, person. He and his wife seem to genuinely care a great deal for one another. Paul, in his very relaxed, laissez-faire way, does not seem concerned or convinced that he is in any way affected by any illness, and indeed doesn't see his level of sleep apnea as anything significant, and certainly not worth concern. However, his wife sees it differently, and they are both frequent attendees of the patient support group meetings.

Paul is not overweight for his height and age, although he believes he could reduce his weight about 10 lbs.

Paul's original symptoms, noticed by his wife, were snoring, absences of breathing, pronounced nocturnal upper and lower limb activity, and trunk activity, severe enough to cause him to sit up in bed at the end of an apnea. The symptoms that his wife now notices are his breathing becoming gradually shallower until it ceases very quietly, and then resumes with a gasp. She also notices a continuing increase in nocturnal body activity post-surgically. Paul is not aware of any of the apnea symptoms, but attributes his tiredness to restless and fragmented sleep, suggesting that it is to be expected with an increase in age. Because Paul has not personally felt or witnessed symptoms such as daytime sleepiness, memory loss, or other cognitive or physical impairment, he does not take the problem seriously, and it remains somewhat of a joke for him.

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[22] UPP is a surgical procedure used to reduce the size of the uvula, and to trim and tighten the tissues of the soft palate. Scar tissue is created during the procedure in order to tighten the tissues.

Table 15

Thematic Abstractions of Paul's Experiences with Sleep Apnea

	Excerpts from Transcript	Paraphrases	Themes
1.	I was bothered by restless sleep, and finally I got kicked out of the bedroom.	Grace was disturbed by my snoring and night activity.	Other directedness.
2.	Well, they sort of gave me the run around. I went to my own medical doctor, who said, well you have to go and see so-and-so who is a throat specialist, and from there I went to see another specialist, and somewhere along the line I ran into [a sleep specialist]. The whole process took about 2 years.	I experienced delay and difficulty getting a diagnosis.	Frustration.
3.	Well I didn't think I had any symptoms, and I still don't think I have any.	I don't think I have any symptoms.	Denial.
4.	I enjoy a little nap after supper. But apart from that, I am still able to work as well as I ever could.	My apnea doesn't bother me, and I still work hard.	Denial.
5.	The only thing is, that some mornings, I am tired when I get up.	I am sometimes tired in the morning.	Periodicity.
6.	[Regarding sleeping separately], I do have visiting privileges. I didn't have a problem with that. Why shouldn't both of us have a good night!	For practical reasons, sleeping separately works out advantageously.	Acceptance; and Marital stress.
6.	Well the thought has occurred to me that [the symptoms] may get worse, and there is nothing they can do.	The apnea could escalate and become very serious.	Fear.
7.	I cannot sleep on my back. . . If I sleep on my stomach, then it is going to be very difficult to keep a mask on. . . Maybe that is something that I am going to have to change if the mask will do me some good.	I don't like the idea of using CPAP - it will mean so many changes.	Grief.
8.	I sleep very restlessly at the best of times, so for me to keep [a mask] on, it probably won't work. But I will look at it, and if I think there is some value to be had, I will give it a try.	With my restless sleep, CPAP will be very difficult.	Fear; and Acceptance.
9.	I don't think that it is worse than any other illness. If I shouldn't wake up one morning, then that's too bad!	Apnea is not really serious but I guess it could kill me.	Fear.

10. I think if [CPAP] is necessary, then it is necessary.. . I hope it never comes that I have to go on a trip and drag that thing along.	I will try CPAP if absolutely necessary, but I don't want to take it on a trip.	Fear.

Table 16

Second Order Thematic Abstractions of Paul's Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 13: 6, 8, 9 & 10.	The severity of Paul's symptoms has increased in the last few years, and he now fears escalation of symptoms, death, disability, and restrictions that may accompany use of CPAP.
2. **Frustration:** 2.	Paul experienced some difficulty and delay in achieving a diagnosis.
3. **Grief:** 7.	Paul grieves for the anticipated change in his sleeping position in order to use CPAP.
4. **Periodicity:** 5.	Paul finds he is fatigued after supper, and sometimes in the morning after a bad night.
5. **Marital stress:** 6.	Paul and Grace can no longer sleep together because of Paul's restlessness.
6. **Acceptance:** 6 & 8.	Paul has accepted sleeping separately fr and he is in the process of accepting t need CPAP treatment.
7. **Denial:** 3 & 4.	As long as the symptoms of his apparent to him, Paul can, and has a problem.
8. **Other directedness** 1.	Paul recognized that his wife wa body activity and his breathing i thus sought medical help.

Synthesis of Paul's Experience

Paul, in his very relaxed, laissez-faire way, shows no apparent concern about his apnea, and says he is not convinced that he is in any way affected by any illness. He doesn't see his level of sleep apnea as anything significant, and not worthy of worry. This attitude may be entirely appropriate, or it may be avoidance to cover a fear that the escalation of his apnea has started and that nothing is possible to halt that escalation. Paul does not acknowledge many symptoms of apnea, and attributes his tiredness to restless and fragmented sleeping, rationalizing that it is to be expected with the increase in age. Paul's wife witnesses and acknowledges symptoms and effects and tries to initiate action. On the other hand, Paul does not overtly acknowledge the reality of his condition. Whether or not he deals with the return of his symptoms through denial and humour, or attempts to reduce family concern and stresses in this way is unknown. A simplistic answer may be that Paul truly does not, or cannot, identify or accept an identity with apnea and deals with it accordingly.

At the time of our second interview, Paul had completed a follow-up study at the Sleep Disorders Laboratory, but was reluctant to disclose the outcome, giving the impression that there were no significant findings. He did, however, disclose that he was given a prescription for CPAP. He had also been provided with a prescription from his family doctor for a nasal lubricant cortisone spray, but he again rationalized, stating that the breathing obstruction was caused by Alberta's dry air and that the spray just alleviated such dryness. Since his wife, Grace, was not present to hear what was said, Paul's explanations cannot be verified. However, there exists a good possibility that Paul is deluding himself because the truth is too terrible for him to face.

Brad (Tables 17 and 18)

Brad is a small man, with a large nose, a small, narrow chin and a dental overbite modifying his facial profile. He has glaucoma which may be the reason his eyes appear very round, and his pupils very small. The impression created by his nose and chin is accentuated by the effect of the small pupils with very light eye colour, which overall, gives him the appearance of a very kindly eagle. Brad is 63 years old, and in spite of his asthma, is very active. He says he has always enjoyed athletics: he currently curls and golfs, and has boxed and done a good deal of running.

What may not be apparent from the excerpts of the interview is that he reports spending long periods of time awake at night, and when he does sleep he experiences a succession of very disturbing, violent and active dreams that seem to involve themes of competition and fighting for self preservation and breath.

He explained that about five or six years ago, while treating his asthma, his doctor suspected a sleep disorder because of his tiredness, and so arranged a sleep study with fully polysomnograph testing. Following that study, Brad spent a night in a hospital attempting to use CPAP equipment. Unfortunately he has been claustrophobic since childhood, and the breathing equipment caused him a great deal of anxiety and distress. It would appear that his distress was mainly a phobic reaction which is not uncommon, even among people without phobias. The distress was accentuated by the flow of air leaking from the mask into his eyes brought about because of his large nose and small chin, which, in turn, irritated the glaucoma.

Brad does not seem terribly knowledgeable about sleep apnea, the testing or treatment options. The complication of phobias, asthma and glaucoma decrease his tolerance for treatment. He also, like many patients, expects the medical profession to have positive solutions to all problems and to take a guardian-like approach to make sure that each problem is solved. He seems very sincere, but his lack of understanding could be causing much of his difficulty, and his phobias could be contraindications for general treatment regimes, limiting or negating solutions.

He seems to be a very genuine but naive man with a serious health problem for which there will be no simple answer.

Table 17

Thematic Abstractions of Brad's Experiences with Sleep Apnea

Excerpts from Transcript	Paraphrases	Themes
1. I have struggled with this for maybe five years. I have gone to meetings, hoping I could see something that I figure will help me. I haven't been able to do that yet.	I have tried to find help for some years.	Frustration; & Desperation.
2. I fought [CPAP mask] all night. I couldn't synchronize with the machine. I would be breathing out and it would be forcing air in, and vice versa. But I struggled with it until 3 o'clock, and finally gave up.	Trying to sleep with a CPAP mask was a terrible experience.	Frustration; & Desperation.
3. My experiences at night, that have been going on these last five years, are mostly dreams and holding my breath. It gets so bad that my wife can't sleep with me.	My sleep has been night-mares and fighting for breath for the last five years.	Fear; Other directedness. and Grief.
4. I think holding my breath is also when I dream, and it gets to be quite violent, because the more I get out of breath, the more violent the dream is.	The more I have to fight for breath at night, the more violent my dreams.	Grief.
5. [In a dream] I'm having a race, and I can't quite get to the line. I wake up, and I am just gasping for air and my heart is really pounding.	I dream of competition, violence, struggling, and fighting for survival.	Fear; Grief; & Desperation.
6. [When I wake up like that] I am tired right out, and panicky. I am really panicky.	My nightmares cause panic and physical fatigue.	Fear.
7. [The reaction to wearing the mask] - It's fear. It's just like you are being strangled. Like I am running out of air. Like I am going to choke. It's panic. It's suffocating - total panic.	Wearing the mask was much like my violent nightmares.	Fear; and Desperation.
8. By 3 o'clock I was ringing wet, and just about exhausted. That's the way my nights are, sort of, when I start holding my breath. I get into this panic situation.	Trying to use the mask created physical and emotional exhaustion.	Fear; and Desperation.
9. Yes, [I had claustrophobia before doing the CPAP tests]. I couldn't crawl under buildings, and I don't like the darkness.	Claustrophobia is not new to me.	Fear.
10. [If my wife] touches me to get me to breathe at about the point that I am in one of these violent dreams, I could strike out at her. . . . If I am having a boxing match, and I just want to throw that last punch, and if she touches me, then I do.	I am concerned that I could injure my wife when I have violent nightmares.	Marital stress; and Other directedness.

11. I had a dream two nights ago that I had got to catch plane. . . I am starting to run, and I get out of breath, and there is a guy behind me. He wants to get ahead of me, but I can't let him because only one of us is going to get on the plane. My wife said I was moving as though I was running in the bed. So she put her foot on mine gently to stop them, and I gave her a terrible kick.	Themes from my life experiences are twisted into my nightmares, and sensations of touch are incorporated into the fabric of my dreams.	Fear; Other directedness; and Marital stress.
12. [I get sleepy] at 4 o'clock every day.	4 o'clock is a bad time.	Periodicity.
13. [Recently,] I run out of patience in a hurry. If things don't go right, I may get wound up. I get stressed out - if [when curling] my rock hits a straw and goes into the boards, I get very upset. I can't put it aside - I want to challenge it like I do with my dreams.	I am no longer able to pass off minor disappointments. My days are becoming like my nights.	Mourning.
14. I always was a fiery kind of a fellow. Lots of energy, but things wouldn't bug me like they do now. I could deal with the issue and go on to something else, but now they really bug me. I think it is because I am tired.	The tiredness causes things to bother me much more than they used to.	Mourning.
15. [When my son and daughter in law were killed] I started to take sleeping pills, and that didn't work for me - they made me hold my breath even more. So I just had to tough it out.	The detrimental effect of sedatives meant that I had to suffer my grief without medication to help.	Helplessness.
16. I can't drink any alcohol before I go to bed, or take any sleeping pills because then I hold my breath longer.	Alcohol or sleeping pills aggravate the apnea. I'd like a drink now and then.	Grief; and Helplessness.
17. Really, the only time [the marriage suffers] is when I am tired out and don't have the energy to go out somewhere. . . . No, in spite of all these problems, we don't really have a marriage problem. She is very understanding.	Sometimes I am too tired to go out with my wife for events. This effects the marriage.	Marital stress.
18. The only time I felt a little resentful is I can't really get anyone to understand my situation. The claustrophobia, the mask, whether it is my chin blocking things off - I'm not fat, so what is it? They never follow it up. No-one has ever followed this situation up.	I am resentful that no-one seems to understand my problems, and that no-one seems to care.	Need for understanding; Frustration; & Resentment.
19. I have talked to doctors, and they just pass me off.	Doctors don't seem to take me seriously.	Frustration; & Need for understanding.
20. That's the only time I felt resentful about things - when nobody wanted to listen. Then you called me - you said "it sounds unique, sounds different." Now I felt really good because, hey, somebody is listening to what I	The lack of interest from other people makes me resentful, but someone showing interest makes me feel good.	Resentment; & Need for understanding.

am trying to say.		
21. The mask didn't work, and [testing and treatment plans were] just dropped.	No-one followed up after the CPAP failure.	Frustration.
22. I had a quick visit to Dr. J., who . . . . said "I'll set it up, but it's going to be 10 months from now." And then I'm gone again, so I felt rejected again.	The long wait for testing caused a feeling of being lost and forgotten in the system.	Frustration; Rejection.

Table 18

Second Order Thematic Abstractions of Brad's Experience

Thematic Clusters	Generalized Description
1. **Fear** excerpts from Table 16: 3, 5, 6, 7, 8, 9 & 11	The themes of violence and struggling for self preservation that pervade Brad's dreams not only create fear and panic, but are probably created by his fear of death by suffocation. His claustrophobia creates additional fear.
2. **Helplessness:** 15 & 16.	The apnea is worsened by sleeping pills and alcohol, and so he had to endure the grief of the loss of his son and daughter-in-law without medication help.
3. **Frustration:** 1, 2, 18, 19, 21 & 22.	The experience of trying to use CPAP was very frustrating to Brad. He also is very frustrated by the lack of understanding others have for his situation, and the inability to get any positive help.
4. **Desperation:** 1, 2, 5, 7 & 8.	The inability to get a solution to his problems and the feeling of breathing obstruction, with or without the CPAP mask, provide Brad with feelings of desperation.
4. **Need for understanding:** 18, 19 & 20.	Lack of sleep, and sleep invaded by violent dreams does not have an easy solution, and is not completely understood by those to whom he talks. He not only seeks understanding, he seeks a miracle cure that will avoid aggravating any of his other medical problems.
5. **Grief:** 3, 4, 5 & 16.	Brad experiences grief for the loss of quality sleep and the good effects that it has, and the ability to take a little drink before going to bed.
6. **Mourning:** 13 & 14.	Brad notices that his personality has changed, and now little things bother him more than they once did. He mourns the loss of his more stable personality.
8. **Periodicity:** 12.	Quite regularly at about 4 p.m. every day Brad finds that he is especially tired.

9. **Marital stress:** 10, 11 & 17.	Although Brad's says his wife is understanding, his violent reactions to her during a dream, and his lack of energy occasionally could impact on their relationship. His wife's sleep is also fragmented by his affliction.
10. **Resentment:** 18 & 20.	Brad resents having a problem that is not widely understood. He is also resentful that medical professionals appear disinterested.
11. **Other directedness** 3, 10 & 11.	Concern that he may injure his wife when he strikes out during a dream, and the lack of sleep that he is causing his wife are both partly responsible for his searching for help.

Synthesis of Brad's Experience

Brad's sleep apnea was suspected many years ago by a very astute physician while treating Brad for asthma. The discovery was quite a surprise for Brad at the time because he had not noticed any symptoms that would indicate a problem. Unfortunately, over the years, Brad's symptoms, which might indicate more of a problem with periodic leg (or limb) movement than with sleep apnea, and which are not classic for obstructive sleep apnea, have escalated to the degree that he never has a comfortable and restful night. What little sleep he gets is plagued by violent, competitive nightmares filled with themes of fighting for survival and breath.

Brad's asthma, glaucoma and claustrophobia have prevented a successful treatment program, and have complicated his situation considerably. He is also deathly afraid of conventional surgery because he understands that it will cause swelling in his throat following the operation, which gives him more visions of choking to death. This leaves the choices of treatment in question, and leaves Brad with his problem, totally unresolved and increasing in intensity

Brad's relative ill-health has not yet impeded his athletic endeavours, and as long as he can participate in his sports, he may not feel that the health problems are insufferable. It is probably his athletic interests that have prevented obesity and have helped stave off the escalation of apnea symptoms. However, his energy levels are beginning to suffer, he feels, from the lack of sleep and possibly oxygen desaturation.

Like many of us, Brad believes he knows his body quite well, and until he consulted a surgeon after our initial interview, he was convinced that the problem originated with the size, shape, and functioning of his jaw and tongue. He had been assured his anatomy is not unusual enough to cause the problems, and he has drawn hope from the new information he is receiving about surgical possibilities. In the meantime his nightmares, and search for relief continue.

Chapter V

Between Person Analysis

In this chapter, the phenomenological analyses of the participants' experiences will be presented, and a between person analysis will begin. This section will start with the Definitions and Descriptions of Significant Second Order Themes Across All Participants which explains the terms used in the first and second order thematic abstractions, and describes the general themes as they relate to the experience of sleep apnea found in this study. The order of listing of the second order themes is consistent throughout, and reflects the author's perception of the importance of each of the themes, listing most important first. Following this is a listing of the "Significant Second Order Themes Across All Participants" (Table 19) which provides a reference to begin the comparison of between participant experiences. Finally, a table (Table 20) showing the "Third Order Abstraction of Common Clustered Themes is presented. This shows higher abstractions of the "Second Order Themes for all Participants," or a condensation of the lower order themes into higher order groups.

A composite picture of a sleep apneic's experience will be described in Chapter VI using the thematic descriptions and highest order abstractions of common themes to provide a structure.

Definitions and Descriptions of Significant Second Order Themes Across All Participants

The definitions given here are decontextualized dictionary definitions for the words or terms used, but represent the investigator's interpretations of the participants expressions of emotional states. Examples for each are provided from the participant protocols. Some experiences result in several emotions, and the resultant overlapping definitions complicate the descriptions of the themes described, and the lives of those afflicted.

1. **Fear:** Fear might consist of:

    a. fear of a fatal or near fatal traffic accident;
    b. fear of sudden death at night;
    c. fear of disability;
    d. fear of loss of career or employment;
    e. fear of being dependent on a machine, which includes fear of forgetting to take equipment when travelling, or fear of not having resources to cope with a breakdown;
    f. fear of being abandoned by one's family, and
    g. fear of escalation of the illness and symptoms.

'Fear' includes emotional reactions such as apprehension, the unknown, potential harm, anxiety, panic, and terror. It would appear that the untreated apneic has good cause for a great deal of fear, usually arising from direct symptoms. Treatment, if successful, should reduce symptoms and the basis of much of the fear, but treatment is not always simple or successful. Fear and concern for progression and the appearance of new symptoms are likely, and insidiously incapacitate performance whether or not they are used by the individual as an excuse for actions or inaction. Fear of the unknown may also play a part, and may lead to a search for desperate remedies or solutions. A better informed apneic is likely to have lower levels of fear in all areas. Fear and desperation (see point 7. **Desperation**) are closely linked.

Example from Liz, Table 5, point 12:

> You are just afraid, and you are afraid you are going to die. That you are going to be there in the morning.

2. **Helplessness:** Helplessness is felt as a response to the loss of control apneics feel over staying awake during the day, and from the restrictions placed on living activities for the sake of safety, such as driving a car alone, or using power equipment or potentially dangerous machinery for which concentration is critical. Although a great deal of control is regained after successful treatment, the use of CPAP itself can create a feeling of helplessness because of the loss of freedom and imposed dependence.

Example from Ann, Table 7, point 5:

> [I would fall asleep] at the opera, at concerts, at the theatre. . . This is very embarrassing. I remember going to the opera, and there was just no way I could stay awake. . . I was falling asleep and there was nothing I could do.

3. **Grief:** Restrictions on normal life activities, including recreation, because of sleepiness, fatigue, or treatment (CPAP), can cause grief. The degree of grief seems to depend upon the level of importance of the lost activity. For instance, carrying and using a 7 kilogram electrical breathing unit while hiking and backpacking is an incredible handicap, even if power sources are readily available. But for someone who does little travelling the inconveniences can be minimal.

Example from Charles, Table 13, point 7:

> I don't like the fact of going to sleep with a mask on my head. I don't like the fact that my wife has to sleep elsewhere most of the time because the machine will keep her awake.

4. **Mourning:** As with the grief over a lost quality of life, 'mourning' here refers to the sadness the individual has over a part of the person that is no longer present. This loss relates to the loss of memory, creativity, problem-solving skills, speaking abilities, and other cognitive or physical abilities that become

decreased significantly. Mourning and grief can be closely interrelated and indistinguishable in resulting behavior patterns.

Example from Ray, Table 9, point 18:

> I used to sit back with an approach to a problem and cut through the chaff and find out what the basic structure of how I am going to organize this thing. And now, I am confused at the outset. I don't even break it down into any kind of logical step - I'm confused immediately.

5. **Embarrassment:** Many victims of sleep apnea have been deeply embarrassed, even humiliated, by falling asleep in public and during social events. For most the embarrassment is intensified by the knowledge that loud snoring accompanies sleep. Many have been ridiculed for their sleep and possible snoring. A poor self-image may be enhanced or initiated.

Example from Ray, Table 9, point 4:

> Well, its embarrassing. During work, you are attending a meeting, and fall asleep. Then your colleagues have a tendency to laugh, and say, 'hey Ray's sleeping again!'

6. **Frustration:** The frustration experienced by apneics is generally related to the inability to stay awake and pursue activities as desired. However, some have experienced frustration at their inability to think and function to potential, of being understood, or to achieving a timely diagnosis.

Example from David, Table 3, point 18:

> When we go to the city or anywhere else, my wife or someone else has to be with me to keep me awake. It is very <u>frustrating</u> 'cause I can't go any place by myself. . . . I am very caged, and I don't have freedom, and I am very thankful for my family that they do care enough . . . my wife just won't let me drive alone, and that is quite understandable.

7. **Desperation:** Desperation can be a reaction to a real, perceived, or expected breathing restriction, either from direct awareness of an apnea, from CPAP mask or machine failure, or claustrophobic or suffocation feelings associated with the mask. It is a desperation to restore normal breathing. Also the inability to achieve a diagnosis and/or successful and comfortable treatment can cause desperation. From discussions with patients at the patient support groups this becomes evident from the inventions, problem solutions, and ready grasping and interest at any new or revolutionary type of treatment or device that is discussed or displayed. Desperation is closely linked with fear (see point 1) which in turn results from conscious and unconscious threats or stresses emanating from known and unknown potential and real consequences of the disease.

Example from Brad, Table 17, point 5:

> [In a dream] I'm having a race, and I can't quite get to the line. I wake up, and I am just gasping for air and my heart is really pounding.

8. **Need for understanding:** Apnea is not commonly understood, which can cause a desperate need for individual understanding, especially is a long history of being accused of laziness is the case.

Example from David, Table 3, point 8:

> My parents thought I was lazy, and they probably still do think I'm lazy. They know I have sleep apnea, but they don't quite understand it I don't think as much as they should.

9. **Coping:** Most people with sleep apnea have experimented with a variety of methods to stay awake. Most have used the consumption of snack foods and coffee, which may provide a boost of energy, but further complicates the apnea. For those who have demanding or particularly active work, sleepiness is overridden in times when high activity is required.

Example from David, Table 3, point 4:

> Things I did to stay awake would be to eat a lot, to eat while I was working, and drink a lot of coffee, and pop.

10. **Periodicity:** All the participants in this study experienced times during the day when the sleepiness was at its worse. The worse time of day seems to differ for each individual.

Example from Ann, Table 7, point 22:

> [The sleepiness] was bad in the early morning, and it was bad at night.

11. **Job stress:** In the current times of economic difficulty, job stress is generally high. For those with a disability or perceived disability, stress is increased as the individual strives to compensate for the disability. It is likely, therefore, that apnea increases job stress for even the most competent in the workforce.

Example from Ray, Table 9, point 19:

> With the situation that we have got right now in this country, I feel that I am at a real disadvantage. I could possibly be replaced with someone younger, with a better memory.

12. **Dependence on machine:** Some apneics have a positive attitude and seem to accommodate well to using CPAP therapy because of the benefits to health and well-being. Although there may be regret for the restrictions it

causes, a positive attitude (see point 20. **Acceptance**) seems to correlate with CPAP accommodation. Others, however see such a dependence as negative, abhorrent, and a cause for fear.

Example from Charles, Table 13, point 12:

> I am sufficiently concerned that I don't like not being with the machine. In other words I fee that I have got to have that machine every night, period.

13. **Resentment:** Some individuals may feel a great deal of resentment and anger which may be directed at family members, especially if there is a perceived lack of understanding of the difficulties faced by the sleep apnea victim. Resentment may occur as a result of perceptions that typical sleep apnea sufferers are grossly obese and elderly. Young apneics object to being given the same classification. Much resentment may be alleviated when there is a strong family support network in place, especially involving a supportive spouse.

Example from Dean, Table 11, point 16:

> I am feeling very out of place here [at the sleep lab] when I come in. First of all, it's mostly men that I've seen here, . . . they could all be my father. And that's very hard to accept.

14. **Poor self-image:** It is extremely hard to draw conclusions about why a person has a poor self-image since it will have a great deal to do with personality, upbringing, and experiences with success and failure. However, when skills and abilities deteriorate because of cognitive deterioration, a poor self-image can result or be magnified. If body image is also involved, obesity may enhance a poor self-image. Some apneics see CPAP as being 'unattractive' to a bed partner, which produces a negative body image.

Example from Ray, Table 9, point 31:

> I am not comfortable with myself, and I am uncomfortable in my clothes.

15. **Social isolation:** Not all people need a busy social life, and many of the participants of this study experienced a reduced social life by choice. One, however, has experienced unwanted social isolation imposed by the effects of apnea, and now that the apnea is treated, is finding difficulty developing a satisfactory social life.

Example from Ann, Table 7, point 15:

> And even going out to concerts and things like that that I enjoyed, I started doing less and less of that, and now I almost don't go at all.

16. **Marital stress:** All male participants judged their marriages as either good or exceptionally happy. For this study, 'marital stress' was defined as anything

that had the potential to damage the relationship, whether or not damage was caused. The sleep fragmentation of both partners caused by symptoms of sleep apnea can severely stress any relationship, and the use of CPAP can interfere with companionship and bedtime processes for healing marital disputes.

Example from Brad, Table 17, point 10:

> [If my wife] touches me to get me to breathe at about the point that I am in one of these violent dreams, I could strike out at her.

17. **Victimization:** There may be a tendency for individuals with sleep apnea to feel they are 'victims,' and to slip into the role of the 'sick-person.' This may stem from the constant feeling of fatigue or sleepiness which often persists, to some extent, after treatment.

Example from Ann, Table 7, point 25:

> Maybe if this whole emotional problem hadn't come up, and I had a more placid lifestyle I had prior to that, maybe I would never have had sleep apnea.

18. **Projection:** The defence mechanism of attributing one's own traits, faults, or attitudes to others seems to be a way of protecting the apneic from unpleasant realities until he or she is prepared to deal with them.

Example from Dean, Table 11, point 30:

> I can see people starting on something like the CPAP machine, and after a while just saying 'it's not worth it.'

19. **Rationalization:** It seems common for apneics over 50 years old to explain the loss of cognitive skills, especially memory, on age. It is probable that the use of this defence mechanism helps to avoid the fear that escalation of the symptoms could further impact cognitive skills.

Example from Charles, Table 13, point 16:

> I don't think my memory is as strong as it was, but yet test it against the facts on a file with the secretaries - it hasn't suffered a great deal!

20. **Acceptance:** Sleep apneics who have adjusted to CPAP treatment well, have reached acceptance of the condition. It may be that some have passed through the stages of shock; realization; denial; mourning; to adaptation (Gregg, Robertus & Stone, 1989, pp. 5/6). The level of the severity of symptoms, age of the individual, and personality could all be variables that influence the ease of acceptance.

Example from Charles, Table 13, point 6:

> It was a very simple decision for me: either I use the CPAP machine or I had a serious problem. So I simply adapted to it.

21. **Denial:** The use of this defence mechanism seems to be a part of the process of adjusting to and accepting a chronic illness. Denial is much like the disbelief that one feels when faced with devastating news: the belief is present at a superficial level, but it is too horrifying to face.

Example from Paul, Table 15, point 3:

> Well I didn't think I had any symptoms, and I still don't think I have any.

22. **Other directedness:** All of the participants in this study have been aware of concern from a family member, usually a spouse. This concern has alerted them to a possible medical condition, and has spurred them into seeking medical help.

Example from Ray, Table 9, point 1:

> My wife noticed that I snore quite heavily, then she noticed there were periods during the night where I stopped snoring. That scared her.

23. **Questioning personal response:** Some participants are not sure which of their troubles are related to sleep apnea, which to age or other conditions, and what reaction is appropriate. It is not surprising that those who blame apnea for loss of abilities wonder if they are blaming it too much, too little, or using apnea as a crutch.

Example from Ray, Table 9, point 15:

> I wonder if I attribute all my problems to sleep apnea when they are not a sleep apnea problem. . . . I blame it all on it, and I don't know that I should.

Table 19

Significant Second Order Themes Across all Participants

Note: x indicates the presence of a given theme as an essential structure of that participants experience.

Second Order Themes	David	Liz	Ann	Ray	Dean	Charles	Paul	Brad
1. Fear	x	x	x	x	x	x	x	x
2. Helplessness	x	x	x	x	x			x
3. Grief			x	x	x	x	x	x
4. Mourning			x	x	x	x		x
5. Embarrassment	x	x	x	x				
6. Frustration	x	x	x	x				x
7. Desperation	x	x			x			x
8. Need for understanding	x			x				x
9. Coping	x	x	x	x	x	x		
10. Periodicity	x	x	x	x	x	x	x	x
11. Job stress	x		x	x				
12. Dependence on machine			x	x	x	x	x	
13. Resentment	x	x			x			x
14. Poor self-image	x		x	x				
15. Social isolation	x		x	x	x	x		
16. Marital stress	x		x	x	x	x	x	x
17. Victimization	x		x					
18. Projection	x				x			
19. Rationalization	x		x			x		
20. Acceptance	x	x	x	x		x	x	
21. Denial					x		x	
22. Other directedness	x	x	x	x	x	x	x	x
23. Questioning personal response				x	x			

In the following table, Table 20, seven third order themes have been identified and listed from the lower order themes. To the right of each third order theme is listed the second order themes involved. These themes will be used to guide the creation of a composite picture of a sleep apneic's experience and discussion (Chapter VI).

Table 20

Third Order Abstraction of Common Clustered Themes

Third Order Themes	Common Clustered Themes (Second Order Themes for All Participants)
1. Reactions to Restrictions Caused by Sleepiness.	1. Fear (of fatal or near fatal traffic accident) 2. Helplessness 3 Embarrassment 4. Frustration 5. Need for understanding
2. Reactions to Restrictions Caused by CPAP Treatment	1. Fear of dependence on machine 2. Dependence on machine 3. Grief
3. Response to Diminished Cognitive Skills	1. Fear (of loss of career or employment) 2. Fear (of disability) 3. Embarrassment 4. Mourning 5. Poor self-image
4. Response to Other Sleep Apnea Symptoms	1. Fear (of sudden death) 2. Desperation
5. Response to Sleep Apnea Generally	1. Fear 2. Resentment 3. Denial 4. Victimization 5. Rationalization
6. Response to Difficulty Obtaining Diagnosis.	1. Frustration 2. Helplessness
7. Results of Sleep Apnea and its Symptoms	1. Marital stress 2. Job stress 3. Social isolation 4. Coping strategies

Chapter VI

A Composite Picture of a Sleep Apneic's Experience

Introduction

When the thematic analysis of each participant's protocol is complete and a synthesis presented, the overall picture for the individual is shown. The purpose of this chapter is to provide an overall view of all individuals in a composite picture of the phenomenon of living with sleep apnea at work, home and leisure. This composite is created from the data drawn from all the participants, and presented in the order of the seven third order themes identified on Table 20. These third order themes are:

Reactions to Restrictions Caused by Sleepiness;

Reactions to Restrictions Caused by CPAP Treatment;

Response to Diminished Cognitive Skills;

Response to Other Sleep Apnea Symptoms;

Response to Sleep Apnea Generally;

Response to Difficulty Obtaining Diagnosis; and

Results of Sleep Apnea and its Symptoms.

The Definitions and Descriptions of Significant Second Order Themes Across All Participants as listed on pages 92/98 will be used, and also references to specific experiences of individuals. It is intended that the similarities and differences in the essential structures of the participants' experiences will thus be exposed.

Reactions to Restrictions Caused by Sleepiness

The themes involved in this discussion of a person's experience of living with sleep apnea are "Fear," "Helplessness," "Embarrassment," "Frustration," and "Need for understanding."

All of the participants recognized the fear, helplessness, and frustration that accompanies excessive daytime sleepiness and the restrictions which follow, such as driving, and power equipment use. David, Ann and Ray have experienced restrictions in their driving, and of course, understood the fear and frustration of this situation. In addition to driving, David has experienced restricted work duties which deprived him of several elements he used to enjoy.

Possibly more significant to the individual than the sleepiness itself is the fear of accidents that may be caused as a result of sleeping at the wheel. This fear

ranges in intensity from mild concern for someone who has never fallen asleep at the wheel, to outright terror for one who has. This type of fear is understandable to most people who drive in situations where they may encounter monotonous, long, straight highway stretches. It therefore might be assumed that someone suffering from a sleep disorder might have an intense fear of traffic accidents. This fear is intensified yet again by concern from family members.

Another restriction to a victim of apnea occurs through embarrassment from falling asleep in public. Ray was so humiliated by reactions to his sleeping and possible snoring that he swore he would never travel on public transportation again. Liz, Ann and David had experienced similar ridicule at social occasions. Long distance travel is an unresolvable dilemma or "Catch 22" if an apneic, with driving restrictions, does not wish to risk or repeat embarrassments on planes and buses. For people who need to travel for employment, or who like to travel for leisure, this type of restriction is a very serious impediment.

The restrictions imposed on some sleep apnea victims by others, or by themselves are in response to a feeling of helplessness, which in turn cause an escalation of helplessness. For instance, a person who is helpless to prevent sleep at a theatre, concert or meeting, will, out of that feeling of helplessness, avoid such events. The immediate problem is solved, but in so doing another is created - that of social isolation and sometimes loneliness, which is another feeling very much like helplessness. Many of the participants have experienced this vicious circle.

David may be a special case, or he may be typical of those special few who grow up with central sleep apnea. The sad disbelief and lack of understanding his parents had for him were a constant source of distress, stress, and anguish. He wanted, as would any son, to have respect, love, and understanding from his parents, but reality was a constant state of conflict. Apnea may or may not have caused the state of David's relationship with his parents. However, it would seem probable that his symptoms caused his mother frustration to the point where any possibility of a normal parent and child relationship was destroyed.

The final type of restrictions caused by sleepiness on an individual's life is a need to restructure activities to avoid the periodicity of the worst times of day. First, obviously, the individual has to learn when the best and the worst times are, and reschedule all possible activities to accommodate. It was interesting that each of the participants noted different times when sleepiness was worst, and presumably this is as individual as are our personal circadian rhythms.

Many people in the work force do not have the luxury of being able to reschedule work activities. For instance a police officer cannot reschedule work to co-incide with energy levels. The requirement is to respond to whatever crisis is indicated, and complete desk work whenever time and opportunity permits.

As sleep apnea escalates and affects more functions, there is a lessening possibility of scheduling normal working days to avoid bad times, and there are increasing frustrations and difficulties coping with the restrictions, especially for an untreated apneic.

Reactions to Restrictions Caused by CPAP Treatment

The themes identified as relevant to the discussion of this element of living with sleep apnea are "Dependence on machine," "Fear of dependence on machine," and "Grief."

There seems to be little doubt that those who have persisted and accepted CPAP treatment and use it every night, not only recognize its benefits, but depend on it very solidly. They depend on it for a good night's sleep, symptom reduction, and for protection of their future health of mind and body. In order to be able to use a machine such as CPAP, it is necessary to have a positive dependence.

For some who have not used CPAP and for those who cannot tolerate it, the idea of being dependent on a machine may be quite abhorrent. A great deal of the negative feelings about the machine stem from several areas: negative body image when wearing the mask; fear of loss of companionship with spouse; fear of loss of mobility and travel; physical discomfort and restricted sleeping position. There may also be some primary emotion which causes distaste for machine support, and remind us of the dehumanizing "human/machine," such as *Star Trek's* "the Borg," and the mutilated humans rebuilt as part machine, as in the movie *Robocop*. It could be that the science fiction nature of dependence on a machine or the fact that one is incomplete without machine support is sufficient to cause negative feelings or inadequacy in many people.

Even those who are able to use CPAP regularly, have a love/hate relationship with it for the good and the bad that it brings. The use increases health and energy, which is offset by serious physical (and possibly financial) constraints, especially for travel[23], marital relationships, and even body image. Those who have not used it but who are faced with the possibility of using it, recognize the negative effects, and must weigh the positives carefully against the negatives. In such situations, it would be more difficult to accept CPAP when the apnea is mild, and symptoms are slight.

Response to Diminished Cognitive Skills

The responses to diminished cognitive skills include "Fear of loss of career or employment," "Fear of disability," "Embarrassment," "Mourning," and "Poor self-image."

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[23] CPAP units come with standard, padded carrying cases. Since the machine is fairly delicate, the units must be included as carry-on luggage. Security personnel at most North American airports now recognize this equipment. However, in some areas it is necessary to explain and demonstrate the equipment when passing through airport security. To date all equipment needs main power for operation, and no battery-operated units are yet available.

Whether brilliant or of low intelligence, no one would like to see even a minor destruction of abilities. It is easy, therefore, to understand the fear of the apneic who has discovered that cognitive skills are slipping away. Both Ray and Ann suffered the embarrassment of impaired speech. Ray constantly feared losing his job, as well as being frustrated and mourning the loss of his problem-solving skills and memory for technical details. Charles, who, like Ray, relied on creativity and problem-solving in his profession, experienced the sadness and mourning for a loss of that part of himself. Maybe the old adage *the bigger they are the harder they fall* is appropriate here, for while David, Ann, Charles and Ray had all noticed a diminution of their cognitive functions, Charles and Ray suffered the most because they relied so heavily on higher cognitive functions in their professional work.

It is fairly well understood that sleep apnea increases in severity with age. It is understandable, therefore, that apneics will have concerns and even fears that their illness will escalate and leave them with a profound disability. Those participants in this study who admitted this concern included Ann, Ray, Dean, Charles and Paul. Dean, because of his profession, was not only concerned about impairments that may jeopardize his career, but also that his employer might consider sleep apnea a source of danger for him and others, and thereby take actions which could adversely affect career and future.

Memory is often the first noticeable loss in cognitive powers with apnea, but when the loss is severe it is not easy to discount or explain by age. All of the participants in this study had noticed memory loss except Liz, Paul and Brad (see Table 1).

Memory loss, as noted earlier, is often the subject of comment at Sleep Apnea Society patient support meetings, and is commonly the subject of humour. Humour too, about other difficulties associated with sleep apnea, seems to be a common way of handling embarrassment and pain. Liz joked about being called "the sleeper," and saw humour in the bus driver's comment to her granddaughter at Kelowna. Although Ray was obviously very embarrassed when other passengers moved away from him on the bus, he was able tc joke about the incident, but barely. He also used humour to explain his methods of compensation, saying that "I assume the role of the silent intellectual who never says too much" which was delivered with perfect timing and facial expressions designed to amuse. Dean was the only participant who did not engage in humour, and in fact found nothing amusing at all about sleep apnea or its effects. Both humour and seriousness reflect variations in coping methods.

The question of whether a poor self-image is a direct response to the loss of cognitive skills is very questionable. However, it is logical that a person who sees himself diminished cognitively, could see himself as a lesser person. It may then be quite appropriate to suggest that while a loss of cognitive skills does not cause a poor self-image, it can enhance it and prevent the growth of a positive self-image.

Response to Other Sleep Apnea Symptoms

The response to other sleep apnea symptoms include "Fear of sudden death," and "Desperation."

Liz suffered the most of any of the participants with the fear of sudden death. She understood that night death from apnea is rare, but that did nothing to reduce her fear. The awareness or semi-awareness of breathing obstruction during the night was the cause of her severe distress, shared partly by Brad who had a semi-awareness of choking. However, Brad's greater distress was from nocturnal activities and nightmares that provided very frightening images, with loss of breath being the central theme. Dean and Brad also experienced "panicky" feelings and desperation from interference in breathing when wearing the CPAP mask.

The awareness of impaired breathing among people with sleep apnea may be much more common than the current literature suggests. These problems, like sleep apnea itself, are not commonly understood, and medical science is at a loss to know how to treat them if they cannot be managed by medication, traditional CPAP or surgical methods. The question is whether the disease, a symptom or a side effect is being treated, and sometimes whether or not one is related to the other.

The possible consequences of apnea, such as hypertension, cardiac arrhythmias and stroke are all life threatening. Many people who have sleep apnea understand these risks, and are concerned, but many others either do not understand or do not want to believe these risks apply to them. Paul and Dean understood the secondary risks quite plainly, and yet Dean considered that he may forgo CPAP treatment, and Paul deluded himself that he had no symptoms.

Response to Sleep Apnea Generally

The responses to sleep apnea generally include: "Fear," "Resentment," "Denial," "Victimization," and "Rationalization." The major fears, including fear of a fatal accident, sudden death, disability, loss of career or employment, escalation of symptoms, and dependence on a machine, have been discussed. However, there are other common fears, such as fear of being abandoned by one's family, fear of passing the illness to one's children, and fear of the unknown.

David and Ann suggested a hint of fear of being abandoned by their families. David was very grateful for the love and patience his wife showed, which contrasted with the relationship with his parents. In expressing this gratefulness, it is possible to read David's wonderment at the fact that his wife has stayed with him through all his problems. Ann, on the other hand, was staying with her husband for convenience and mutual dependence. She recognized that her husband might wish to sever the relationship at any time. At her age, and just having lost her job, the stability of Ann's position seemed precarious.

The question of passing the illness on to children arose twice during the first interviews. Charles and David both recognized that their children could have or might develop apnea[24]. Charles explained, that he was not responsible for his own or his children's build any more than he could change them, and hence he was not going to blame himself. He had, however, encouraged his children to received testing at the Sleep Disorders Laboratory. David, on the other hand, rationalized that they were apnea free, and only thought about getting tests made.

Since apnea is a relatively "new" illness, there are unknowns, and for the person who wants answers to everything, like Dean, these unknowns play a large part in avoiding acceptance of the illness and dealing with it in an effective manner. As with any illness, accident, or major life hazard, there is frequently an element of questioning almost everything, especially 'why.'

Resentment by the participants to having the illness seems to be surprisingly slight, but resentment against others for how they deal with those afflicted, and resentment for the restrictions seem to be more common. Dean resented developing the illness so young; Liz recognized that if she were younger she might resent being laughed at as well as having the illness; Brad was resentful that no-one seemed to understand his problem; and David clearly resented the restrictions on his driving and freedom.

Denial is closely related to resentment. Dean and Paul used denial to some extent. Because of his youth and the surprise and shock of his diagnosis, Dean was, at the time of our first interview, in a state of denial. Unlike Dean, Paul had known of his apnea for some years, and had undergone surgery for the condition. Paul's denial may have been related to expectations in that he saw himself as cured even though the apnea symptoms were escalating. Denial may have been the result of surprise and shock that he, once again, faced CPAP treatment.

Victimization does not seem to be common among the participants of this study. Only David and Ann felt victimized to some extent. David's feeling of victimization emanated from his relationship with his parents, and Ann's because of the break-up of her marriage.

<u>Response to Difficulty Obtaining Diagnosis</u>

The elements involved in the "Response to Difficulty Obtaining a Diagnosis" are "Frustration," and "Helplessness."

Many people in crisis or tense situations have felt that 'the waiting' is worse than the problem itself. Part of the reason for this is that the individual has no control over the situation, and thus feels helpless. Victims of apnea who do not

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[24] Sleep apnea is not heredity. However, certain physical characteristics that may cause apnea may be inherited, such as a long soft palate.

obtain a definitive diagnosis within a reasonable time suffer from this feeling of helplessness.

The very nature of sleep apnea is such that the sufferer is generally unaware and must completely rely on others to describe symptoms and suspicions of a potential problem. Because the major symptom of cessation of breathing happens only when the individual is sleeping, it is obvious only to others. Often bed partners notice this symptom, but do not realize that it is abnormal, which makes it unlikely to be reported to a physician. Helplessness is increased too when an individual experiences excessive daytime sleepiness or some other major symptom, but the physician fails to make an intuitive jump to suspect a sleep disorder. The result of a physician being unable to detect the problem, or treating the individual for other conditions heightens the helplessness, and often gives the apnea time to become serious.

Physicians face a particular challenge in suspecting sleep apnea because of the newness of the illness, and the sketchy details that may be obtained from the patient. In addition, the apnea victim's memory may be faulty, and thus the doctor's questions may be answered incompletely or incorrectly, and mislead the diagnosis. As a possible result of these complications, three of the eight participants in this study encountered extreme frustration and difficulty in having their problem diagnosed. The feeling of helplessness is compounded by the fact that the individual feels out of control and that life and health are in the hands of others who may not understand. Liz's complaint was summarily dismissed by several doctors; David was treated with heavy doses of drugs for another disorder; and Brad, with his particularly complicated case, kept getting lost in the system without any follow-up.

The desperation outlined in this study has been duplicated at patient support group meetings where there have been examples of patients inventing and making devices to hold their nasal passages open while they sleep, and a multitude of other self-help devices and tricks to help reduce suffering where medical knowledge has failed. The exceptionally high interest shown for any device or 'cure' that is discussed shows the desperation to find a way of dealing with the apnea or an associated problem. Unfortunately, many devices marketed are useless for most, but the desperation creates an over-eager clientele.

Results of Sleep Apnea and its Symptoms

The results of sleep apnea and its symptoms shown in this study are "Marital stress," "Job stress," "Social isolation," and "Coping strategies" for the sleepiness that lead to poorer health, and a host of adjustment strategies that can disrupt normal active life at home, work and leisure.

All the male participants of this study, with the possible exception of Dean, had very stable and secure marriages that had endured the test of time. Dean had been married only a few years, Liz was widowed some years ago, and Ann was emotionally separated from her husband.

Apnea induced marital stress factors were identified by all participants, with the exception of Liz. The familial effects of such stress cannot be disregarded. Whether perceived or real, apnea stresses and related coping mechanisms superimposed upon a relationship have the potential for varying degrees of damage. David recognized that his apparent 'laziness,' caused frustration and aggravation for his wife and children. The inconvenience to his wife and family of having to accompany him when driving also caused stress. Brad found that his marriage suffered a little on the occasions when he lacked energy to go out with his wife and Ann found, before her treatment, that she did not have the energy to carry the load of worker, homemaker and social entertainer. Dean, Paul and Brad had violent body movements during sleep which disturbed the spouses. Paul and Charles no longer slept with their respective wives because of the disturbances, and Brad was worried that he would strike out and injure his wife during sleep. Dean was a loud snorer, and Ray and Charles found that the CPAP equipment caused a potential rift between spouses, and a loss of bedtime companionship. Ray explained that CPAP "stifles bedtime opportunities to heal marital disputes," and therefore could be very damaging for a relationship.

When economic times are harsh, the threat of job loss increase stress for all people. When a person is constantly fatigued, has a poor memory, other cognitive skill diminution, and never feels at peak performance level, the pressure to compensate and compete with younger and healthier individuals places additional stress on employees. David, Ann and Ray were severely affected by this type of stress. All these participants during their initial interview expressed concern for their employment, and prior to the second interview with Ann, she had been laid off. Charles, a senior partner in a law practice, did not feel this type of threat. He did, however, recognize that his creativity was somewhat diminished. Re-scheduling his working day was necessary in order to compensate. Charles, then, felt job stress of a different nature.

David and Dean had little time for social life, but did not feel deprived. Ray and Charles valued their quiet home life and chose not pursue social activity. Liz, before her strokes, had a surprisingly active social life of bus tours and playing cards with friends. Paul felt that he had as much social life as he wanted, and Brad was often too tired to go out. Ann desperately missed the social life she had had prior to her apnea. Her story of role conflict superimposed on lack of energy left her with little opportunity for entertaining at home. Ann's friends' embarrassment at her sleeping during social functions seemed to drive them away.

When an individual constantly feels tired or fatigued, any social activity may be too much. Also, what is enough social activity for one individual is too much for another since individual needs and desires differ. It would be an overstatement and judgement to say that all of the participants of this study had impoverished [illegible]. However, Ann certainly recognized that she wanted, and possibly [illegible]e social activity.

[illegible] coping strategies used by the participants to overcome sleepiness before the[illegible] noses largely involved consumption of snack food or caffeine that led to

increased weight, more disturbed sleep, and consequently poorer health, and increased apnea.

Conclusion

The composite picture of an individual, presented here, is a conglomerate of the experiences of all participants living with sleep apnea at home, work and leisure. The picture is extremely complex and differs a great deal depending upon age, sex, and individual life circumstances. The severity of the apnea and the symptoms manifested partly influence the resultant distress, for instance severe daytime sleepiness and severe cognitive skill losses will affect the individual more than mild fatigue and slight memory loss.

Personality, up-bringing, family support mechanisms, life experiences and their timing also influence the psychological impact on the individual. Financial status, gender, marital status and age, also influence how the affliction will be interpreted and accepted and what the degree of response or reaction will be to the phenomenon and events encountered.

All aspects of the disease, other associated disorders, and general state of health provide additional variables to further complicate the picture. Obviously, an individual with apnea as well as asthma or some other chronic illness will be more likely to have difficulty with treatment, and therefore more difficulty with the affliction. Also, one who has apnea and the added complication of night terrors will experience more fragmentation of sleep and suffer the anguish of sleep deprivation in addition to deprivation of oxygen.

In spite of the complexities and individual differences, this study has shown that there are severe limitations on the work, home and leisure lives of those afflicted with apnea, and there is potential psychological trauma and distress from feelings of fears, helplessness, grief, mourning, embarrassment, frustration, desperation, and other negative emotions. Fortunately many of those with apnea have the capacity to cope with or rise above their problems, to manage their affliction, adjust their activities, and live productive and relatively full lives. Others, however, in the same position, do not have the personal resources or support mechanisms, are unable to adjust, and are condemned to a life of difficulties and frustration. Their life functions are irreparably compromised, and the consequences spread to those around them.

Chapter VII

Final Discussion

Introduction

This study has examined, phenomenologically, the home, work and leisure lives of eight people with sleep apnea. From reading the data it is apparent that there is a potential for many people with sleep apnea to incur serious physical and emotional damage. Indeed, there are individuals for whom life has been destroyed and their families fractured because of the stresses of this illness. It is useful to note that all the participants experienced fear, whether or not the fear was for the same situation. By identifying the fears and difficulties, and educating patients, families, medical personnel and general public, some problems may be averted, lessened, or managed so a patient can pursue a relatively normal and active life.

Few of us can understand the distress of knowing what it is to have an illness that comes with a life sentence from onset to the grave. The idea of chronicity of illness itself, excluding the symptoms, can have a devastating, psychological impact. The awareness or certainty of never being cured and the reality of an altered life is difficult to accept, giving rise to varying degrees of hopelessness and compromise. While it is unusual for sleep apnea to render a patient totally physically or emotionally incapacitated, the impact varies between individuals. The kind of family support the patient has also makes an impact on the acceptance and management of illness. This study identifies that sleep apnea causes its victims some strains, distresses, and traumas that are shared by other sleep disorder and chronic illness sufferers, and also shows that it causes some stresses which are unique and distinct. In spite of how well the participants deal with sleep apnea, they carry considerable, parallel burdens and must adapt their lives accordingly.

Conclusions of this study will be related to work on other chronic illnesses and the similarities and differences will be detailed in the following sections.

Differences, Similarities and the Literature on Chronic Illness

This study clearly identifies a number of factors which influence how a person reacts to, accepts and adjusts to sleep apnea, and indeed to treatment. Some influencing factors again are:

i) personality type

ii) state of self concept

iii) upbringing

iv) station in life

v) age at onset

vi) length of time to diagnose, and time since diagnosis

vii) state of general health

viii) associated disorders

ix) family support systems

x) existing and imposed stress

xi) level of intelligence

xii) knowledge of the illness

xiii) survival or coping abilities and adaptability.

A change in health state directs change for an organism to accommodate and adopt functions related to survival. Survival implications for chronic conditions also impose long term considerations. Apnea is chronic and plays no favourites in this regard.

Gregg, Robertus and Stone (1989), while discussing aspects of chronic illness generally, explain that:

> Individuals who are afflicted with a chronic medical condition such as arthritis or diabetes must ultimately modify their view of themselves so that it more accurately represents the reality of their changed situation. In cases of acute illness these changes in self concept are most often temporary and of little consequence for the individual. . . . In the case of chronic illness, however, the notion of 'sickness' and the changes associated with this altered status must become an on-going aspect of one's concept of self, (p. 9)

About body image, they also explain,

> This factor includes one's conception of physical appearance, stamina, functional capacity, and endurance, as well as a perception of how physically attractive one is to others. . . . Chronically ill persons, especially if they have experienced any deformity or loss of physical capacity, may need to reconsider and perhaps modify their body image so that it will coincide with their present perceptions about themselves, (p. 7).

Personality, experiences and upbringing play a large part, not only in the development of intellectual, emotional and bodily self-images but also in the ability to reassess these images following a change in circumstance. Superimposed chronic conditions can become the motivation for adaptation or the justification to excuse non-adaptive behavior. Some in this study admitted poor self images, and some additionally admitted negative self body image because of excess weight. Only the female participant with poor self-image was concerned with body image while wearing the CPAP mask. The mask to the male participants was an inconvenience but not considered to reduce body image in the eyes of their bed partners. It could be that women who have a low self image are more likely to reject the use of CPAP for body image reasons.

The participant with a very positive self-image was able to accept his apnea, adjust his work life to fit his physical and mental needs, and unquestioningly pursue and comply with CPAP treatment. He also accepted the loss of part of his marital relationship that he prized so dearly, and although he admits overweight, is quite content with his body image.

Certainly the obesity that often comes with sleep apnea helps to destroy positive body image, and the diminution of body function and skills works to destroy self-image. However, the more positive that self-image is to start with, the better the chance of adaptation.

Time, too, following diagnosis, plays an important part in the patient's progress through the necessary steps to adjustment. Kubler-Ross (1969) identifies five stages involved in dying: Denial, Anger, Bargaining, Depression, and Acceptance. These stages seem to be very similar to the "stages of adjustment of chronic illness" described by Gregg, Robertus and Stone (1989) of Shock, Realization, Denial, Mourning, and Adaptation, (p. 6). Kimball uses a similar set of steps discussing the adaptation of a patient saying:

> Acceptance of a chronic illness such as rheumatoid arthritis is not a simple matter; it may be months or even years before an effective adjustment is achieved, if at all. Arthritis patients may go through some of the same stages (in a less dramatic fashion) that are faced by those who experience a severe traumatic injury: shock, denial, anger, bargaining, depression, and acceptance, (p. 142).

Only one participant had recently learned of his illness, and he was the only one apparently proceeding through the adjustment stages. At the time of the first interview, he was experiencing shock, denial and anger, and was not at all comfortable with his situation. Another participant, experiencing a return of apnea following surgery, also seemed to be in a state of denial: denial that his illness had returned and was escalating, not apparently "cured" by the surgery. Possibly those patients who would be most likely to opt for surgery are those who have a negative view of CPAP therapy.

The differences between the two young male participants, one probably having had apnea all his life, and the other just having learned of his illness, is interesting. Where the first has accepted and adjusted to his apnea, the second is experiencing pain and denial. Onset during the 'prime of life' can obviously be a distinct blow to aspirations, and re-evaluation becomes necessary. The negative implications and restrictions of CPAP might be better faced initially rather than after surgery and a recurrence of symptoms. It seems apparent that surgery can provide an escape from the reality of the chronicity but may be only a temporary comfort.

Gregg, Robertus and Stone (1989) mention various fears experienced by chronic illness sufferers: "Fear of Death, Fear of Incapacitation, Fear of Pain, Fear of Abandonment, and Fear of Spreading the Disease to Others." (pp. 5/6.) There seems to be little doubt that all participants of this study either experienced and were influenced by these fears or at least fully recognized them as concerns.

Cognitive skill and other functioning loss caused by severe sleep apnea can also result in an individual experiencing a kind of "phenomenological death" as described by Kastenbaum (1991):

> There are two types of phenomenological death. First, part of the person may die in the mind of the surviving self. Partial death can range in personal significance from trivial to profound. . . . The essence of phenomenological death in this first sense, then is that there is a surviving self that recognizes the loss of one or more components of the total self. The person is alive enough to know that part of him or her has died. But there is an element of mourning - for a part of your own self.
>
> Second, the total self may take on a deadened tone. The person does not experience life as freshly or intensely as in the past. Pleasures do not really please. Even pains may have become heavy, tedious burdens rather than sharp pangs, (p. 47).

The mourning experienced by the participants refers to that of the first type of phenomenological death, but it is possible that those who are constantly sleepy may experience the second type.

Many sleep apnea sufferers, usually prior to treatment, mention their irritability. It would be easy to conclude that the irritability has a connection with lowered nocturnal blood oxygen or REM deprivation. On the other hand, it could be related to the worry and concern caused by having an illness that is not understood.

All of the participants, with the exception of one, used humour to create a facade over the pain of their declining memories and other cognitive losses. As mentioned earlier, bravado and jesting about shortcomings are common at the patient support groups, and seem to be used as defence mechanisms to protect the individual from the reality of the severity of the situation. A benefit of patient support groups generally is that they provide an atmosphere of empathy and understanding without threat, and, indeed, an opportunity to laugh (and cry) with others in similar circumstances.

One participant noted that her sleep apnea onset followed a time of particular emotional stress, and also noticed that when she was stressed, her apnea bothered her more than when she was not. Gregg, Robertus and Stone (1989), agreeing with this observation explain:

> that stress is often associated with disease onset. That is, persons with a propensity for certain illnesses are often initially diagnosed following a prolonged stressful event such as divorce or the death of a loved one. . . . In addition, stress frequently plays a significant role in the course of the disease, often worsening both the symptomatology and the functional outcomes for the patient, (p. 8).

Kimball (1971) explains that stress can be expressed as "the repeated bombardment of the individual with crises that batters down his defensive reactions

and diminishes his ability for readjustment, adaption, and homeostasis, (p. 46)." Another participant commented on his health in latter years, and the part his apnea plays:

> You've been pretty healthy all your life, now you've got fallen arches so you can't walk, you have to wear this stupid machine at night to go to sleep, . . . all these little things that individually don't account to much, but collectively it is a bit of a nuisance, to put it mildly.

This view was reflected again by another participant who referred to the bombardment of problems in life that have to be overcome.

Station in life is possibly another factor that can influence the ease of adjustment. Obviously a well-established person who is self-employed or with substantial power and influence does not suffer any financial strains involved with apnea. Appropriate treatment equipment can be bought without concern for the family budget. There also is security and protection, to a large extent, from the likelihood of being forcibly transferred from work or being fired. The unemployed or those with limited financial resources, on the other hand, cannot easily afford treatment equipment, and are more likely to have serious concerns about future career or employment.

The level of knowledge of sleep apnea seemed to vary considerably between the participants of this study. Some had gathered considerable information from their reading, and others had learned from attending Sleep Apnea Society patient support group meetings. Lack of knowledge to the point of naivety of others may have resulted in non-compliance or a lack of motivation to use CPAP therapy. The comfort level of those with superior knowledge seemed to be higher, but this conclusion is somewhat speculative.

In order to obtain a more global picture of the lives of sleep apnea sufferers, the next section deals with the work, home and leisure life of the participants of this study.

Reflections on Work Life

Of the eight participants, two were retired, two were self-employed, one employed on the family farm, two employed in large organizations, and one unemployed.

There is no question from this study that sleep apnea interferes with the working lives of most sufferers, and also affects those who are searching for employment. Those with symptoms of daytime sleepiness, fatigue, memory loss or other cognitive deterioration not only find that their work is affected, but the fear of losing their employment, or having their career plans changed or restricted because of the illness or inefficiency is very stressful and debilitating. Stress is also created in a perceived need to compensate for inefficiencies, either from sleepiness or cognitive impairments.

Use of power equipment or potentially dangerous machinery, whether or not necessary for employment, can present serious complications. Power equipment or heavy equipment operators throughout the spectrum of locomotive engineers to dentists and surgeons could face serious legal and moral implications of liability.

Reflections on Home Life

Much of the comfort, security, harmony and pleasure people derive from their home lives comes from living with people who are loving, affectionate, and helpful to one another. When sleep is disturbed for either or both partners night after night, tiredness, fatigue, and irritability result. Home life then is possibly the first area that sleep apnea affects when tempers of sufferers and family members become stretched from the effects of cumulative sleep deficit.

The next area of family life to suffer because of the symptoms of apnea are likely to stem from unfulfilled home obligations. It becomes increasingly difficult for a seriously fatigued person to spend diminished energy on household chores, and since employment is often given a higher priority than home, there is little energy left over for commitments to the home and family. Another obligation to family may be to entertainment, be it activities with children, family gatherings, visiting friends, or outings. These pleasures become duties, and then chores when a person suffers the fatigue of apnea and fights sleepiness each day and all day. The result of unfulfilled obligations can become the object of disharmony if the wishes of the family run contrary to the needs of the sufferer.

Obesity and fear can also play a large part in destroying family harmony, especially when coupled with a poor self-image. A person who no longer resembles the slim and youthful individual at the time of the marriage, may feel unattractive and undesirable to the spouse. The spouse too, may find little attractive about the apneic as she or he has changed: is less bright, lethargic, and obese. To add to this, the fatigue is likely to diminish interest in sexual activities, which can create feelings of undesirability for both spouses. Although the participants of this study were not immediately concerned that they would be abandoned, this fear is indicated strongly in the literature as commonly felt by persons with chronic illnesses, and this study indicates that sleep apnea sufferers share this concern. When a person becomes fearful that the spouse is dissatisfied with the relationship, a rift over some minor disagreement or misunderstanding can cause difficulties, especially since the fear can impede two-way communication as each party hears only what they expect. If the CPAP treatment prevents or impedes bedtime processes for healing marital disputes, then there is danger that minor disagreements may linger, accumulate and cause more profound lasting difficulties.

Reflections on Leisure Life

Leisure and leisure activities can often be part of family living, and some were referenced earlier. However, there is often much more to leisure than that which surrounds the family.

Travel, as noted, is one type of leisure activity severely restricted by CPAP treatment. People who highly value wilderness living and camping must re-evaluate needs for leisure activities against needs for CPAP treatment. This, of course, has serious implications for young people who cannot afford the luxury of a more expensive vacation.

Travelling when sleepy, whether treated by CPAP or not, presents difficulty, for work, family or leisure. Some patients are restricted from driving an automobile alone for safety reasons, which leaves public transportation if they do not have a companion. Bus, train and air travel can have humiliating results. For many, there are simply no ways to travel unless a friend or family member is willing to drive or can ride as a 'watchdog alarm.'

Social life and leisure life are closely linked, whether attending an evening at the opera, a movie, or a play. However, for many people with apnea, these activities are impossible without incurring enormous embarrassment because of the tendency to fall asleep and snore. The lingering memory of previous adverse experiences and embarrassments tend to foster asocial behavior patterns.

Young people, whether children, teenagers, or single adults, face significant difficulties if they have sleep apnea. It is not difficult to imagine the ridicule and rejection likely to greet a young woman or man when faced, for the first time, with a bed partner. The partner will either discover a snoring ability capable of waking the immediate neighbours, or that sleeping with a person impersonally clad with a distorting face mask is rather unromantic. Even a little cruelty or joking at such a time could be very damaging for a delicate self-image. If especially sensitive about body image, the result could be escape or rejection.

Tabulation of Conclusions

This phenomenological study of individuals living with sleep apnea exposed the uniqueness of each as well as disease-related commonalities. The perceived views others have of affected individuals also affects actions and reactions of those with the condition. The range of individual and collective experiences support a number of conclusions, all of which help to give insight into related human behavior patterns and help identify the current status of sleep apnea, its implications for patients and its effects on our society. The following statements reflect individual and collective conclusions supported by the phenomenon recorded and the data tabulated.

1. Sleep apnea is not widely known or understood, being a relatively newly recognized chronic medical condition. Although variously successful therapies and interceptive procedures are available, no cure has been developed. These factors profoundly influence those seeking information, a diagnosis or treatment, and life quality and duration can be seriously compromised.

2. Whether directly causative or not, sleep apnea is generally identified as a negative factor in the promotion or retention of family and marital relationships.

3. Sleep apnea has wide ranging effects. Those effected include patients, their families, friends, and employers. There is a significant cost to society in productivity and health care expenses.

4. Self concepts and self images of those afflicted with apnea often suffer, leading to additional emotional distress.

5. Cognitive skills and abilities diminish, especially when apnea is not treated early. Such effects are not easily treated nor is treatment always effective.

6. Many of the fears experienced by those with other chronic illnesses are shared by those with sleep apnea. Those fears are of death, incapacitation, pain, abandonment, and of spreading the disease to others (Gregg, Robertus and Stone, 1989, pp. 5/6).

7. Apnea sufferers have additional fears, such as of injuring others, of loss of career or employment, of being dependent on a machine, and of escalation of the illness symptoms.

8. There is always an emotional impact of sleep apnea on its victims, but the severity is related to age at onset, personality, station in life, severity of symptoms, and other factors mentioned earlier in this chapter.

9. There are restrictions and limitations on the lives of sleep apnea sufferers, sometimes severe, and always frustrating. These limitations, either resulting from safety precautions or treatment, foster feelings of loss of control and helplessness.

10. Social isolation and loneliness are often consequences of sleep apnea and its symptoms either because of diminished energy or a wish to avoid embarrassment.

11. The more knowledge a chronically ill patient has about that illness, the better equipped he or she is to accept and cope with it with reduced trauma. Fear of the unknown is very discomforting.

12. Medical professionals, especially general practitioners with a high level of awareness and knowledge of sleep apnea, can prevent or alleviate a great deal of suffering, anxiety and frustration for sleep apnea patients by making an early referral of sleepy patients for a sleep study.

13. The common elements of the phenomena of living with sleep apnea disclosed by this study. Fear, marital stress, other directedness and periodicity seem to be shared universally. Developing coping mechanisms,

feelings of helplessness, and embarrassment are common for those who have relatively severe symptoms. Grief, mourning, frustration and social isolation are other components.

Because the nature of this study involved the participant's perceptions, no precise medical data was requested or used as to severity of the illness. It is therefore impossible to conclude from this study that severity of illness and severity of symptoms are correlated, or that severity of illness has any impact whatsoever on the individual's abilities to adjust. However, the patient's perception of the severity of the symptoms may be correlated with the ease or difficulty of accepting and adjustment comfortably.

Chapter VIII

Implications for Future Research

This study was specifically intended to investigate the perceptions of people living with sleep apnea. The perceptions, fears, concerns and problems faced by the spouses and family members of these people were not directly investigated. It is probable that the fears of the spouse and family members are very similar to the fears and concerns experienced by persons with sleep apnea, possibly focussing on obvious problems such as potential sudden death at night. It would seem likely that the level of severity or functional impairment of the patient would have a great deal to do with the level of concern of the spouse. In medicine, it seems infrequent that spouses and family members are considered in a patient's overall treatment plan, whereas they can be a vital support system that can make the difference between success and failure of the overall adjustment to a medical condition. For this reason, an investigation of the fears of patient spouses could provide very useful information for aiding patient adjustment and treatment.

None of the participants of this study fell solidly under the heading of acting the role of a "sick-person" with possibly one exception. However, none of the participants were severely functionally impaired by sleep apnea, again, with the possible exception of that same individual. It might be useful to understand the role of severity of disease, level of family concerns, and level of impairment in the maladjustment of a patient who takes on the role of a "sick-person." Also understanding the possible part that over-protection of family members plays, and ownership of responsibility for treatment in this scene may also be enlightening.

The understanding of cognitive changes and their relationship to severity of hypoxia, percentage of desaturation, length of apnea, length of time at low oxygen saturations, and the relationship of other variables have been investigated. However, the role of dreaming in sleep apnea has not been investigated, and may yield useful information as an additional correlate. The levels of severity of apnea with the different levels of recalled dream activity may be profitable to study. There may also be some connection between measurable cognitive impairment and dream deficits. This study suggests that there may be indications that a lack of dreaming, or a change in the amount of dreaming may be caused by the deterioration of cognitive skills (or the lack of development of cognitive skills), or may involve some change to a specific part of the brain as a result of oxygen desaturation. Since it is now recognized that some dreams occur in Non-REM sleep, (Sleep Research Society, 1993, p. 57) the lack of REM sleep should not be the reason for an absence of dream recall.

Also the possible relationship between nocturnal physical activity and dreaming may be interesting to investigate. Periodic leg movement is also often associated with sleep apnea although it can occur without apnea. Some PLM is described in the literature to be a hypoxic response, so explaining why the same or a similar problem occurs without oxygen desaturation could lead to relief for many

sufferers. It seems possible that PLM may be a slight version of REM Behavior Disorder, known to cause dreamers to physically play out their dreams, and happens when the muscle atonia that normally limits movements during REM sleep is not present, and the physical and dream worlds are not disconnected during dreams, (Sleep Research Society, 1993, p. 79).

Another item worthy of study would be the cyclical effects of fear associated with sleep apnea. If the patient (whether a sleep apnea sufferer or a sufferer of any other chronic illness) experiences high levels of fear, it would be beneficial to know if that fear interferes with good health and with the illness itself.

Other items which may be useful to investigate are whether the majority of medical doctors are aware of sleep apnea and are familiar with the signs and symptoms of the illness. The fact that three of the eight participants experienced considerable difficulty obtaining a referral to a sleep laboratory and achieving a diagnosis may or may not be significant. This seems to be in line with many complaints, such as a telephone caller wishing to join the patient support group explained how his doctor prescribed a high fibre diet and more exercise after the patient had explained to the doctor that his wife had timed his nocturnal breathing pauses at close to three minutes in length, with very little regular breathing between. Certainly in more recent times, publicity in popular publications and television programs have increased awareness of the affliction, and has enhanced self-diagnosis as well as referrals, but the actual level of awareness and knowledge is unknown.

The level of knowledge among the general public, other sub-populations, and patients may also prove interesting to measure, but only if a follow-up study could measure improved knowledge at a future time. Special interest groups such as the Sleep Apnea Society of Alberta have worked very hard to increase awareness. Any increase in awareness of the public and special interest groups is important, not only for the comfort of those who recognize they have sleep apnea, but to improve the treatment and assistance for those afflicted so that they may continue to contribute as active members of society to their best potential.

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APPENDIX A

STUDY DESCRIPTION

Title of Research Project:

Living with Sleep Apnea at Work, Home and Leisure.

Description:

My name is Mary Collinson, and I am a graduate student in the Department of Educational Psychology at the University of Alberta. I am researching the effects of sleep apnea on the individual's life-world. My advisors are listed at the end of this document.

This research project is in partial fulfilment of the degree of Master of Education, and it is intended to provide information on what it means to have and to live with sleep apnea, and how it relates to home, leisure and work activities, from a patient's point of view. The findings of this study may provide valuable information which could assist health care professionals and families to deal more effectively with those having sleep apnea. The short-range benefits to you may come as a result of a better understanding of the condition, and may give some insights into better coping mechanisms.

This study will involve three or four meetings. The first will be an interview in which you will be asked to talk about your experiences of sleep apnea and your feelings and perceptions about those experiences. You are the expert, and there are no "right" or "wrong" responses. This interview, should you agree, will be audio-taped to aid accurate transcription.

The second meeting will provide an opportunity for you to examine my analysis and understanding of your experiences. At this time you may agree or disagree with all or part of my work, and you may point out my misunderstandings, elaborate for better clarity, or make whatever comments you wish.

At the third meeting, I will share with you a comparison of the analyses of all the participant interviews. You, of course, will not know the identify of the other participants, as they will not know yours.

The final meeting will be held if possible and feasible. It will be a group meeting of all the participants. However, if you are concerned about the disclosure of your identify to the other participants, then you may wish to opt out of this part of the study.

As has already been pointed out, your participation in this study is very much appreciated and of course completely voluntary. You can change your mind at any time and withdraw from the study if you feel it necessary for personal reasons. Your information will be confidential in that only you and I will know your identify. For the purposes of the study, you may choose or will be given another name, and any identifying details will be disguised to ensure anonymity. Should you decide to withdraw your participation at any time during the study, all records obtained from you will be destroyed, if it is your wish.

Because this study involves discussion of emotions and feelings, and possibly issues which may be sensitive to you, there is a risk of psychological discomfort. Should you experience any difficulty or discomfort during or after the interviews, please advise me or one of the other investigators as soon as possible.

If you have any questions or concerns, now or in the future, please do not hesitate to contact me.

<u>Investigators</u>

Dr. Bruce Bain, Department of Educational Psychology, Office Tel: 492-3693
Mary O. Collinson, Department of Educational Psychology, Home Tel: 465-7080
Dr. Godfrey Man, Department of Pulmonary Medicine, Office Tel: 492-6215
Dr. Charles Norman, Department of Educational Psychology, Office Tel: 492-3802

VOLUNTEER CONSENT FORM

Title of Research Project:

Living with Sleep Apnea at Work, Home and Leisure.

Consent:

I, _____ acknowledge that the research procedures described on the Study Description Sheet, and of which I have a copy, have been explained to me, and that any questions I have asked have been answered to my satisfaction. I agree to participate in this study, and understand that I may contact one of the investigators at the telephone numbers listed on this form to ask additional questions, or indicate concerns. I also understand that I may opt out of the study, without penalty, at any time, should I feel a personal need to do so. I am assured that my anonymity will be protected at all times, and that personal records and tape-recordings relating to this study will be kept confidential. I reserve the right to decline participation in the final group meeting if I feel that my identity disclosure at such a meeting may be undesirable.

Signed _____ date _____

Investigator _____ _____

Witness _____

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APPENDIX B

Core Questions:

1. When were you first aware of any of the symptoms of sleep apnea?

2. Have any symptoms caused you particular problems?

3. Did you find times before treatment that sleepiness caused you difficulties at work?

4. Can you recall some times when sleepiness made some activity particularly difficult?

5. Do you feel there are times that you are treated differently because of the apnea?

6. Do you have a busy social life?

7. Do you dream? If so, what are your dreams like?

8. Was your apnea easy to diagnose?

9. Do you think that sleep apnea, or the way people have treated you because of the apnea, have changed the direction of your career, or life?

10. Were there times that you feel you had to be more self-disciplined than others to achieve the same?

11. What tricks did(do) you use to make yourself stay awake to achieve what you wanted(want)?

12. Does your sleepiness remain at the same level all day long?

13. Do you think your marriage or family life has suffered because of the apnea?

APPENDIX C

Following is a segment of 30 seconds from a full polysomnograph record showing a classic mixed apnea event. The event starts as a central apnea, and changes to an obstructive apnea approximately half-way through. Note how the chest and abdomen are motionless at the beginning of the episode. At the change to obstructive, nasal flow is unsuccessfully attempted as the chest and abdomen begin to attempt to restort inspiration. Also note the chin and leg activity especially at end of the apnea event.

An Mixed Apnea Event of 30 Seconds taken from a Polysomnograph Recording