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Breaking through Limbo: Experiences of Adults Living with Obstructive Sleep Apnea

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Abstract

Obstructive sleep apnea (OSA) is a potentially devastating condition that diminishes quality of life and leads to serious consequences without treatment. Diagnosis often is delayed and, once diagnosed, adherence to prescribed therapy tends to be a major barrier to management. This grounded theory study was focused on the experiences of a diverse group of 82 adults who were at various points in the process of obtaining a diagnosis and living with OSA. Participants described being in “limbo” and needing to break through that limbo to be successful at managing their OSA. Results provide new insights into the experience of living with OSA that can be beneficial in promoting treatment and shaping effective management of the condition.

Obstructive sleep apnea (OSA) is a potentially devastating condition that affects an estimated 18–20 million persons in the U.S. As many as 4 million of those individuals are thought to have a severe form of OSA with apneic or hypopneic events occurring more than 30 times per hour during sleep. A frequently cited estimate is that among the middle aged population, 4% of men and 2% of women are thought to have this condition (Stradling & Davies, 2004; Young, Palta, Dempsey, Skatrud, Weber, & Badr, 1993; Young, Peppard, & Gottlieb, 2002), although other reports indicate that OSA is underestimated and underdiagnosed with likely incidence as high as 20% of the population. Based on the Sleep in America Poll conducted by the National Sleep Foundation, the recommendation emerged that as many as 1 in 4 American adults should be evaluated for sleep apnea (Hiestand, Britz, Goldman, & Phillips, 2006).

OSA is associated with a variety of serious consequences including hypertension, cardiovascular disease, stroke, and metabolic syndrome. The high level of daytime sleepiness that results from lack of restorative sleep in untreated OSA has been associated with diminished quality of life; depression; social isolation; increased accident rates; and decreased performance at work, school, and other activities (Mulgrew, Nasvadi, Butt, Cheema, Fox, Fleetham, Ryan, Cooper, & Ayas, 2008; Harris, Glozier, Ratnavadivel, & Grunstein, 2009; Somers, White, Amin, Abraham, Costa, Culebras, Daniels, Floras, Hunt, Olson, Pickering, Russell, Woo, & Young, 2008; Botros, Concato, Mohsenin, Selim, Doctor, & Yaggi, 2009; Drager, Bortolotto, Figuelredo, Krieger, & Lorenzi-Filho, 2007; Haentjens, Van Meerhaeghe, Moscariello, De Weerd, Poppe, Dupont, & Velkeniers, 2007; Tasali & Ip, 2008). The magnitude and severity of consequences, as well as the increasing incidence of OSA, are sufficient to consider it an important public health problem.

There are effective therapies for treatment of OSA with the primary therapy being the use of Positive Airway Pressure (PAP) devices during sleep. Although PAP therapy is considered highly effective for OSA, adherence to prescribed therapy tends to be poor. Numerous studies indicate that less than 50% of people for whom PAP therapy has been prescribed

adhere to the treatment on a long term basis (Bollig, 2010; Weaver & Sawyer, 2010). Less than 50% adherence is a troubling statistic even without further explanation, yet this is even more disturbing when taking into consideration how adherence (usually called compliance in the sleep literature) typically is evaluated. Generally an individual is considered compliant if he or she uses the PAP device a minimum of 4–5 hours /night for 5 nights/week even though that measure falls short of the 7–9 hours of sleep generally recommended for the average adult (National Sleep Foundation, 2011). In spite of that minimal requirement, adherence is widely considered to be the most challenging problem in the treatment of OSA once diagnosed (Arfoosh & Rowley, 2008; Galetke, Puzzo, Priegnitz, Anduleit, & Randerath, 2011; Haniffa, Lasserson, & Smith, 2005; Shapiro & Shapiro, 2010; Wang, Gao, Sun, & Chen, 2012).

The problem with adherence, however, only exists for people who have been diagnosed and for whom therapy has been prescribed. It is not uncommon for people with OSA to go without an accurate diagnosis for extended periods of time due to misdiagnosis or delays on the part of the affected individuals in seeking diagnosis and treatment (Rahaghi & Basner, 1999). In many cases, the occurrence of an accident, such as when an individual falls asleep while driving a vehicle, is the stimulus for testing and diagnosis. In spite of the availability of reliable diagnostic tests along with generally effective therapy, and in spite of devastating health and quality of life consequences of untreated OSA, diagnosis, treatment, and subsequent adherence to therapy continue to be major problems in the management of this condition. In addition, while much research has been focused on the low adherence rate with PAP therapy, little is known about the general experience in the diagnosis and management of OSA. Understanding the experience is essential to provide a basis for improving diagnosis rates and successful therapy and to avoid the extensive negative sequelae associated with this important health problem.

Study Aims

The purpose of this study was to answer the question “What are the experiences of individuals living with Obstructive Sleep Apnea?” The study was conducted in association with an NIH funded P20 Self Management Science Center. Specific aims included identifying barriers to diagnosis, treatment effectiveness, and adherence to prescribed therapy; identifying strategies for self-management reported by persons with OSA; and to develop a grounded theory of the experience of living with and managing OSA. The results provide a basis for intervention and planning to promote improved diagnosis and treatment for this population. In addition, the results were expected to provide beneficial descriptive information that would promote further development of emerging theoretical approaches to self management (Ryan & Sawin, 2009).

Methods

A Grounded Theory design (Charmaz, 2006; Glaser, 1978; Glaser & Strauss, 1967) was used in this study of a sample of diverse adults who were at various stages of living with OSA. Grounded Theory was the method of choice for this study because of its focus on the experiences of participants as they perceived them, without imposition of a particular theoretical perspective or restriction in the focus to a particular aspect of OSA. Living with OSA involves more than just management of the technology and the treatment after diagnosis, and the grounded theory approach is ideal for this broader focus on the experience as defined by the participant. The resulting product, being a substantive theory grounded in those experiences (Charmaz, 2006), can add to existing theoretical understanding of chronic illness. Although there is a large theoretical base available addressing chronic illness in general, and specific disease entities or conditions in particular, there is a lack of literature

that provides theoretical perspectives on adults living with OSA. Prior studies of OSA using qualitative methods generally have been focused on the post treatment phase such as extensive studies of ways to increase adherence (Dickerson & Kennedy, 2006; Moreira, 2008), studies of quality of life and relationships with PAP treatment (Reishtein et al., 2006), and studies aimed at instrument development (Flemons & Reimer, 2002). None of these approaches addresses the broader experience of living with OSA that begins with first awareness of the condition and progresses through an often lengthy diagnostic period (Almeida et al., 2012; Bröstrom et al., 2010; Firestone & Gander, 2010; Sawyer, Deatrick, Kuna, & Weaver, 2010; Van de Mortel, Laird, & Jarrett, 2000).

Following approval by the Institutional Review Board of the investigator's university, subjects were recruited through an active internet discussion forum, by word of mouth referral, and by referral from a local sleep diagnosis and treatment center. After obtaining informed consent, data were collected from each participant using telephone or email means as the participant preferred, or face-to-face for those who were geographically accessible and willing to engage in such interaction. Telephone and face-to-face interviews were audio-recorded and transcribed verbatim by a skilled transcriptionist experienced in maintaining confidentiality. Follow up contact occurred when needed to gain additional clarity or, on occasion, updates about an individual's ongoing experiences. Email interviews involved multiple interactions between the participant and the researcher or research assistant to ensure depth and clarity in the conversation.

Email interviews have been used in numerous studies and have been found to be a useful and viable means of data collection for qualitative research. Although email interviews lack the observational data, such as nonverbal responses, that can be noted with face-to-face interviews, they have the advantage of providing access to geographically diverse participants and, as McCoyd and Kerson (2006) noted, provide "particularly detailed and thoughtful responses" (p. 403), likely related to greater time for reflection and to compose responses (Egan, Chenoweth, & McAuliffe, 2006; McCoyd & Kerson, 2006). Email interviews in this study were consistent with those observations. All three interview formats were effective in generating rich, detailed transcripts about the experiences of the participants.

NVivo 8.0 (QSR International, 2008) software was used for data management and analysis proceeded from initial open, substantive coding through category construction. Using the constant comparative analysis approach described by Glaser & Strauss (1967), Glaser (1978), and Charmaz (2006), the process of analysis began with open, substantive coding in which the responses of the participants were examined and captured in assigned code words or short phrases that reflected the substance of each idea. Numerous codes were assigned to each passage or idea in order to capture as many interpretations as possible rather than force the responses prematurely into specific labels. Codes typically were verbatim words that participants used to describe their experiences, with the codes selected to provide maximum clarity and consistency in depicting the experiences of the participant group. In the second phase, initial categories were formed based on similar and dissimilar ideas reflected in the codes. In a process referred to as constant comparative analysis, codes and ideas were constantly compared to identify commonalities within and across categories. Categories then were examined to identify patterns in the data. In the final analytic stage the researcher continued to look across and within the patterns to identify an overarching construct, the "core variable," that illustrated the Basic Sociopsychological Process reflected in the experiences of the participants. Throughout the analytic process the researcher constantly returned to the raw data and explored multiple questions in the data to ensure that the results were grounded in the data and not forced by the researcher (Glaser, 1992).

Results

The sample for this study was comprised of 82 participants who had a wide range of experiences with OSA. Approximately two thirds of the sample were male (N =53, 65%; Female N = 29, 35%), and the majority (N=78) self-identified as “white.” Two identified as Hispanic, one Asian, and one Middle Eastern. Ages ranged from 21 to 82 (M= 52). Although ethnic diversity was limited in the sample, there was a varied representation of other characteristics including socioeconomic status, insurance status, education, employment, marital status, and geographic locations. The majority identified the location in which they received health care as the US, with numerous additional descriptors including small town, medium sized city, and larger city. Six participants were non US citizens residing outside the US (Australia = 1, Canada = 2, India = 2, Taiwan = 1). Data from these participants initially were analyzed separately due to differences in health care systems and sociocultural contexts that might have affected their experiences. Overwhelming similarities were discovered, however, which led to these data being included along with those of the other participants.

The history of experience with OSA for these participants ranged from no symptoms to more than 30 years of awareness of some type of problem. Participants were designated as 0 years time living with OSA if they had not yet been diagnosed and had no personal awareness of having OSA other than someone else pointing out the possibility to them. One young man, as an example of participants in this category, had been told by a bed partner that he had episodes where he “stopped breathing” when he slept and the partner encouraged him to seek medical attention. He was not aware of any difficulties or symptoms other than his partner’s report. Five others also were pre-diagnosis but were aware that they might have OSA; at the time of the interview, however, they had not received a formal diagnosis for a variety of reasons. For the sample overall, the range for time since diagnosis was pre-diagnosis to 21 years post diagnosis.

Basic Sociopsychological Process: Breaking Through Limbo

Grounded theory designs lead to a primary product that is a theoretical framework that reflects the experiences of the sample involved in the study (Charmaz, 2006; Glaser, 1978; Glaser & Strauss, 1967). For the participants in this study, living with Obstructive Sleep Apnea was characterized as “Living in Limbo,” with the term “limbo” a term specifically used by 4 participants to describe their experience of struggling to live with their condition. The participants in this study described their near unanimous experience of struggling with numerous unknowns in their effort to arrive at a positive outcome in living with their OSA. The core variable, Breaking Through Limbo, reflects the reports of the participants as they struggled with unknowns related to *Delayed diagnosis, Lack of knowledge before and after diagnosis, and Lack of support/follow up after diagnosis*. Once a correct diagnosis was obtained, participants found themselves engaged in a *Battle to adhere* to their therapy as they dealt with not only a period of initial adjustment to therapy but an array of side effects and challenges associated with the treatment and, in many cases, lack of knowledge and resources to be successful in their struggle. Each of these categories of experience, and how they contributed to the Basic Sociopsychological Process of *Breaking Through Limbo*, is addressed in the following sections (Figure 1).

The Limbo of Diagnosis

For the majority of the individuals in this study, the experience of living with OSA started long before they had a formal diagnosis. Nearly all of these participants struggled with symptoms and sequelae of OSA for many years before being diagnosed. This struggle, and

delay in diagnosis, is made vivid by the statement of a 63 year old female who described spending 17 years of her life battling fatigue and seeking treatment for what she knew was a sleep problem before finally receiving an appropriate diagnosis:

When I was a teenager I had days when I would wake up feeling as if I had been running all night and I asked the doctor about that. It was definitely not normal for me. Not that I was a hyper personality, but I was very athletic and this bothered me. The answer I got was: "It is because you are going to an all girl school." Well, that made that teenager furious! I did not understand what was wrong with my sleep, but I knew it was something about the quality of my sleep.

During those many years of dealing with fatigue and what she was convinced was a sleep-related problem, she reported that she received a multitude of reactions from health care providers ranging from the dismissal evident in the quote to being prescribed sleeping pills or antidepressants and referred for psychotherapy. Meanwhile, she was given prescriptions for the growing number of medical problems she faced during this time (difficulty sleeping, hypertension, depression, anxiety). Her sleep complaints always were presumed to be a part of those other problems rather than the primary cause. She reported that all of those other medical problems were resolved when she finally received treatment for the sleep disorder she knew she had lived with since her teenage years.

For all of the participants in this study, the journey through limbo started with the effort to obtain an accurate diagnosis and obtaining that diagnosis rarely was a straightforward procedure. Other participants described similar experiences of complaints being ignored, with misdiagnosis being reported by more than half of the participants (N=42, 52%). In other cases, however, the reason for the delay in receiving an accurate diagnosis rested with the participant. Some of the participants in this study never reported complaints of fatigue or excessive sleepiness to their physicians as they lacked knowledge that what they were experiencing could be related to a medical condition or that there might be an effective treatment for their perpetual sleepiness (N=35, 44%). For many, there was a lack of willingness to seek treatment (N=64, 78%) for a variety of reasons, including lack of realization that what they were experiencing could be a serious condition. As one participant stated, "I had other health problems that took priority"; he was unaware that those priorities (depression and cardiovascular disease) likely were related to his untreated OSA. A small group of participants (N=4) who did realize that they might have OSA expressed concern about having to admit they had a medical condition, as one middle-aged and self-described "healthy" male commented, "I didn't want to admit there might be something wrong with me."

The first step in the process, then, for these participants living with Obstructive Sleep Apnea, concerned the challenge of getting a correct diagnosis, most commonly through negotiation of the medical system to gain an accurate diagnosis but, on occasion, through self-awareness and increased knowledge as motivators to seek a diagnosis. The lack of appropriate diagnosis constituted the first phase of limbo for nearly all of these individuals. Financial resources were a factor for 7 participants who, in spite of awareness that they might be suffering from a treatable condition, were unable to afford the sleep study necessary for diagnosis and initiation of treatment.

It is worth noting that there was skepticism among three individuals in this study about OSA as a legitimate diagnosis. One participant commented that, in spite of increased media attention to OSA, he "didn't think there was such a thing" and the attention to OSA was "just another way for the medical establishment to make money." He described the recent development of sleep diagnostic centers in shopping centers in his area and a "quick CPAP"

storefront as examples that led him to question the legitimacy of OSA as a medical condition that warranted treatment.

As evident in these descriptions of the early phase of the experience, lack of knowledge often contributed to delays in obtaining an accurate diagnosis. Lack of awareness that daytime sleepiness could be indicative of a medical condition, that other problems such as depression or cardiovascular disease might have sleep as a primary cause, or that there was anything that could be done about extreme sleepiness caused some individuals to delay seeking treatment. Lack of knowledge was widespread among the participants in this study both before and after diagnosis. As one male participant commented in a statement that reflected the status of many in this study, “My knowledge of OSA at the time [prior to diagnosis] was no knowledge”; another commented, “I didn’t know there were any options” [re: treatment]. Many participants also were not aware of the potential consequences of untreated OSA. As one 67 year old woman exclaimed in regard to having learned of the potential consequences of the condition, “I had no idea it could kill me!”

Lack of knowledge persisted for many of the participants well after diagnosis and initiation of therapy. The participants in this study who were recruited through an internet discussion forum had turned to the internet seeking information and answers when they were unable to get help with problems that arose or believed they had no one to turn to in order to understand their condition and deal with the challenges they faced during treatment. Lack of knowledge was evident also in that 20% of the participants in this study who did have a PAP machine did not know the manufacturer of their machine, the particular model, or the pressure settings that had been prescribed for their therapy.

After diagnosis, nearly all of the participants who had been diagnosed and had therapy prescribed reported their perception that care was not individualized. With few exceptions ($N = 11$), participants described the feeling of having been “turned over” to the equipment provider (DME, durable medical equipment provider), most often a Respiratory Therapist working with a home care agency. A standard description was that the therapist delivered the machine, provided only minimal essential instruction on how to use it, occasionally with some information about cleaning and mask care, and then, as two participants specifically stated, “left as if to say ‘Bye, and have a good life.’ ” Faced with life-altering fatigue, 100% of those who had therapy prescribed reported at the time of data collection that they had “tried” to use the prescribed therapy. That same number, 100%, also reported that they found it challenging to adjust to the use of the PAP therapy and needed assistance with the challenges they faced, sometimes in the form of basic information related to problem solving. Challenges included discomfort with the interface, or the mask through which PAP was provided to the individual; condensation in the delivery hose as a result of humidification of the pressurized air; leaks and soreness associated with mask use; problems getting used to wearing the PAP interface; mouthbreathing; removing the mask while asleep, and numerous other problems and challenges confronted by the users. Only 11 participants reported that they were able to get the help and support they needed with those challenges from either their health care provider or the equipment provider. With only those 11 as the exceptions, participants reported a lack of follow up with the physician who prescribed the therapy, lack of communication between the sleep specialists and the primary care physician, and lack of follow-up (or at least helpful follow-up) from the equipment provider. Seven individuals reported persistent sleepiness in spite of what they described as good adherence to the prescribed therapy. These seven reported that they had tried to use the equipment provided and followed directions yet, in spite of their best efforts, did not feel better after initiation of PAP therapy.

Participants who turned to the internet for information and support reported that they found a supportive community online and it was helpful to be able to interact with others who understood their situations and who could provide, from their own experience, what the participants described as useful suggestions for dealing with the challenges of therapy. They also found, however, suggestions for managing their own therapy, such as changing pressure settings, which sometimes were helpful to them and sometimes made their situations worse. Participants reported that they learned on the internet discussion forum about different types of machines, the ability of some machines to provide data about the individual's sleep, and the possibilities for monitoring, if not managing, their own care. The majority of participants expressed frustration that they were not given a choice of equipment but were "stuck" with whatever the DME provided, and many (N=37, 45%) expressed a desire to have been more involved in decision making regarding their therapy. Participants (N=22, 27%) who had sought information on the internet prior to diagnosis and were aware of types of machines available as well as different delivery interfaces indicated that they discussed equipment with the DME and were assertive in getting the specific types of equipment they desired, some paying out of pocket when the desired equipment cost more than their insurance would allow. They also reported that it was a struggle to get the equipment they preferred as equipment providers tended to offer only a limited selection and rarely those with more sophisticated technology such as the ability for the individuals with OSA to monitor their conditions.

In contrast to the reported lack of support from health care providers, a part of the experience that contributed to the feeling of limbo that was widely expressed by participants, everyone in the sample who had a bed partner or significant others or family who knew about the OSA reported that they received considerable support from those individuals as they pursued treatment for their condition. Concerns about bed partner reaction had been an important aspect of the experience for many prior to diagnosis and a reason cited by some for delays in seeking a diagnosis. Although nearly one half of the participant group expressed these concerns, these same individuals reported that their bed partners were very supportive and concerns about intimacy and possible rejection had not been realized. Participants with consistent bed partners, in fact, indicated that those relationships had improved. Partners no longer were compelled to sleep in separate rooms because of the disruption caused by the apnea, either through snoring, limb movement, or the repeated distress of witnessing apnea events. A few participants created humorous stories regarding their condition and equipment, such as one male who created stories about being a "fighter pilot" due to the similarity between the PAP interface and the breathing equipment worn by pilots. Although there was near universal support for the individual regarding the therapy, this did not dispel the feelings of awkwardness and stigma some continued to experience. One married male, with a wife of nearly 30 years, reported "you don't feel like much of a catch" in regard to how he felt about wearing his PAP equipment, even though he described his wife as "very supportive." Others, who were not in long-term relationships, expressed concern about dating and how to "break the news" to someone they were dating if the relationship progressed to a higher level of intimacy. All of those who were either dating or anticipating future relationships expressed concern about future partners reactions to the PAP equipment and how to share information about that part of their lives with others.

The willingness to share information with others beyond the bed partner and, for a few, the immediate family was mixed. A small number of participants (N=5) became devoted to educating others about OSA and its dangers as well as how beneficial treatment could be. Rather than keep their condition hidden, as numerous participants described, they took advantage of informal opportunities to educate others about a condition they saw as life altering and dangerous. Those who had friends with OSA shared their own experiences with

that friend and described less delay in seeking a diagnosis and treatment. Sometimes awareness that a friend or coworker had OSA was not present until the participant was diagnosed and disclosed his or her diagnosis. Others, however, described considerable reluctance to discuss their condition, often to the point of making extra effort to keep the diagnosis hidden. One male who worked in an occupation that required him to share sleeping quarters with coworkers would not sleep in one of the available beds, choosing instead to sleep sitting up in a recliner. He would not use his PAP therapy while at work, and slept upright in order to allay the apnea events that would occur if he were to lie down to sleep.

In regard to support and follow up, it was interesting to note that three participants specifically mentioned the absence of nurses in their experiences related to OSA and described how they thought nurses could be an important part of treatment, particularly in regard to the need for individualization and coordination of care. As one stated, “We [people with OSA] cannot be pigeonholed. Each of us has to be looked at as an individual.” Another also emphasized the need for better coordinated care. In regard to what is lacking, he said: “It’s a matter of integrating the care... one of the question marks in my mind is why aren’t any nurses involved in this?” Although the participants knew that the interviewer was a nurse, these comments came without any prompting by the interviewer and without any prior mention of nurses during the interview.

Living in Limbo

The feeling of living in limbo while dealing with the diagnosis and treatment of OSA was pointed out with great clarity by this 47 year old female in describing her experiences:

So I feel I was in kind of a limbo. And if I should have taken any more responsibility for visiting a sleep doctor or revisiting my doctor, I didn't know that and my doctors weren't telling me that - unlike any other aspects of healthcare. Like when I saw [other specialists] my PCP made sure I knew who they were, that they were good, that I went ... she'd get follow up reports...None of that happened with sleep apnea.

While everyone in the sample stated that they had “tried” to adhere to the prescribed therapy once diagnosed, lack of involvement in care, lack of follow up, and poor communication among providers, as described previously, created substantial barriers to adherence and success with therapy. Family members, bed partners and, for some, friends and others living with OSA themselves were important sources of support. Nonetheless, struggles and challenges with equipment and treatment problems made the process difficult. Nine (11%) of the participants faced the challenge that even though they reported good adherence to their therapy, they were not experiencing any subjective improvement in their condition. Those who did experience relief from their extreme sleepiness were more likely to report a positive reaction to their diagnosis and therapy and better adherence.

Consequences of Limbo

Without effective therapy, obstructive sleep apnea poses a serious challenge to the health, functioning, and emotional well being of the affected individual. One 43 year old male described his situation after being without adequate diagnosis and treatment for much of his life:

Sleep apnea has pretty much ruined my life, I could have been anything and had all the opportunities one could have, but being exhausted constantly took its toll on me emotionally, physically. I failed out of college, lost girlfriends, and developed a

drug problem. Looking back, it seems clear to me what the root of all these problems were.

He continued to describe why he was interested in participating in this study, stating “I would really like to be part of something that might prevent other people from going through what I have and am dealing with.”

Summary and Discussion

The participants in this study described a near universal struggle with obtaining an accurate diagnosis, confronting the implications of the diagnosis for personal identity and lifestyle, getting proper treatment and support, and learning to live with their condition and the required therapy. For some, the delayed diagnosis was a result of personal reluctance or lack of knowledge to seek medical care; for others, misdiagnosis was a common occurrence. Throughout their descriptions, there was a common experience was that of being “stuck” or “in limbo” with little knowledge or guidance as to how to seek treatment as well as to live with and manage the condition. The substantive theory constructed through this study, organized around the core variable of Breaking Through Limbo, captures not only the limbo experienced by the majority of participants in this study but also provides insight into those who had moved beyond that sense of limbo. Many people living with OSA who lack knowledge, resources, follow up, and professional support continue to struggle to live with their condition and the prescribed therapy, or abandon the treatment as evidenced by high rates of noncompliance. In this study, participants who reported having adequate personal and professional support and access to resources to help with challenges described more integration of the condition into their personal lives with better adherence to therapy. Implications for future research are evident in the need to test various ways of meeting the needs of individuals diagnosed with OSA in an effort to promote movement to a level of effective engagement and management.

The results of this study confirm existing reports about delayed diagnosis of obstructive sleep apnea as demonstrated by studies of people being treated for OSA as well as evidence supporting the prevalence of undiagnosed OSA (Finkel, Searleman, Tymkew, Tanaka, Saager, Safer-Zadeh, Bottros, Selvidge, Jacobsohn, Pulley, Duntley, Becker, & Avidan, 2009; Menon, Rudraraju, Daniel, Pansuriya, & Basit, 2010; Rahaghi & Basner, 1999). Adherence, as noted previously, is also reported to be one of the biggest challenges with treatment of OSA, and challenges with therapy were extensive among the participants in the present study. All of the participants, however, reported that they had tried to use the PAP therapy but encountered significant challenges with managing the treatment that kept them from being successful. Some of the problems reported included challenges for which there are simple solutions, such as condensation in the hose as a result of a heated humidifier or mask leaks. Participants in the present study also expressed some desire to be more involved in their care, including the desire of some to be able to monitor their own sleep with the use of data capable machines. Other chronic conditions may provide effective models for people with OSA in regard to the emphasis on self management. In the case of diabetes involving an insulin pump, there is a corollary with OSA in that it involves effective use of mechanical devices for management. Other conditions have been addressed in recent years through an emphasis on self-management showing the value of patient involvement in management of the condition (Lorig & Holman, 2003). Self management theory (Grey, Knafl, & McCorkle, 2006; Ryan & Sawin, 2009) may provide a useful foundation for future research to evaluate the effect of providing therapy that is congruent with the goals and desires of the individuals to promote involvement and self management with OSA.

The experiences of the majority of the participants present a clear contrast to the management of other chronic conditions where there not only is greater public awareness

but extensive education and follow up regimens instituted after diagnosis, such as the standard practice for individuals with heart disease or diabetes. For the majority of participants in this study, follow up was lacking and there was evidence of persistent challenges to integrate the condition as part of personal identity and to incorporate elements of the condition into daily existence. More than half of the participants did not know the manufacturer or the type of machine they were prescribed or their prescribed pressure settings. These experiences are in contrast to common approaches to other chronic conditions where there is extensive education about the condition and a need for technical competence in managing equipment, such is the case with diabetes involving insulin pump technology.

The experiences of the individuals in this study reveal a pressing need for eliminating barriers to diagnosis on the part of both health providers and the affected individuals. Many of the individuals in this study had considered themselves healthy and were without any significant medical history, thus the diagnosis of OSA presented their first encounter with a chronic condition that, although it could be managed very effectively, most likely would not go away. This first occurrence of an illness and the threat to self that the diagnosis presents is one factor that accounted for the resistance to obtaining an accurate diagnosis. Numerous participants, however, described extensive experience with various symptoms being treated without the underlying cause of OSA being addressed. Increased public awareness of the presentation of OSA and the seriousness of untreated apnea may aid in reducing the time to obtain a proper diagnosis. Public awareness programs also may help to diminish the sense of stigmatization experienced by some individuals with OSA, this stigma prompting them to delay seeking therapy or interfere with proper treatment, such as evidenced by the individual who refused to use his PAP equipment in the presence of coworkers. Once the diagnostic process is initiated, however, there can be significant delays in obtaining the required sleep study, with delays ranging up to a year or more in the US (Flemons, Douglas, Rodenstein, & Wheatley, 2004). Investigations are needed to determine if more prompt diagnosis and improved access are associated with better outcomes for people with OSA.

Many of the participants in this study also described a desire to be involved in their care, at minimum during the initial phases for selection of a PAP machine and delivery interface. This finding is consistent with self-management theory (Lorig & Holman, 2003; Ryan & Sawin, 2009) as well as other studies of experiences with the management of chronic illness. Hayes, Frearson, Keller, Cartmale, & Lewis-Hayes (2010) studied adults with Type I diabetes who discontinued the use of their insulin pumps and found what seems an ironic development in that the pumps were abandoned because of a desire for more control by the affected individuals. Participants who reported a desire for more control indicated they wanted to do more “than pushing a few buttons” (p. 14), preferring to test and inject insulin themselves rather than rely on the machine. Hayes et al. also reported problems with a mismatch between the outcomes of therapy and the expectations of that therapy, a phenomenon that may be relevant to the treatment of OSA as well. A similar study by Todres, Keen, and Kerr (2010), also focused on the experiences of people with Type I diabetes and their “living with a machine,” showed a desire for control over care on the part of the individuals with diabetes as well as a need for ongoing support and feedback. In both of these studies, findings regarding control and congruence of expectations are consistent with self-management theory. The current study of people’s experiences living with OSA indicates congruence with these findings and points to the need for further exploration of self-management with this population to promote improved outcomes.

Similarly, additional research is needed to test modalities for provision of ongoing professional support and information, particularly to deal with the many challenges encountered at the initiation of therapy. As noted previously in regard to public awareness,

increasing knowledge and awareness of professionals may be appropriate as well. The frequency of missed diagnosis as well as lack of followup indicate that professional education could be beneficial in improving diagnosis and followup care for people with OSA. Roecklein, Schumacher, Gabriele, Baran, & Richert (2010), for example, developed a study to test an intervention to provide personalized information to people newly diagnosed with OSA and the effect on adherence. Results did not reach statistical significance, most likely due to the short time frame of the study, but did show promise in promoting improved adherence. The results of the present study, as well as those of Roecklein et al. (2010) and other studies of adherence, show potential for finding benefits with greater involvement in care. Research on patient activation demonstrates the importance of this concept with other conditions and is an area of potential benefit in the treatment of OSA.

It is important to note that the majority of the participants became involved in this study as a result of their participation in an online OSA discussion forum. Those individuals may be more self-directed or have greater information seeking desires than others who do not seek resources to learn more about their condition and thus might show a higher desire for engagement in their care. They may also represent those with OSA who have not received the information and follow-up they needed from professional care providers and, thus, had to turn to other resources. Additional effort to recruit community dwelling individuals who are receiving care and support from a variety of resources would be beneficial to gain more insight into the array of experiences of people living with OSA.

Increased involvement of people of varying ethnicities is needed to enhance understanding of OSA as well. According to the National Heart, Lung, and Blood Institute (2012), race and ethnicity may be factors in the development of OSA. Data regarding the specific incidence of OSA in non-white populations is lacking, however, and relatively few studies have been focused on people of varying ethnicities. Many of the projections have been based on genetic and other risk factors such as incidence of obesity and craniofacial structure (American Lung Association, 2010). Research is needed to determine the actual occurrence of OSA in different population groups and to understand the experiences of people who are not well represented in apnea research.

In spite of limitations in the sample, the experiences of those recruited via the internet forum were remarkably consistent with those recruited through other means. It is evident that there are a substantial number of people who are not obtaining prompt and accurate diagnosis nor are they receiving the ongoing care and support needed to be successful in managing this potentially devastating condition. Since adherence is widely regarded as the biggest challenge in treatment of OSA, the results of this study emphasize the potential significance of matching management approach and resources with the expectations and desires for involvement by affected individuals. This study reveals some areas for focus in future research to develop innovative interventions to alleviate the challenges to diagnosis and effective treatment in this growing population.

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Figure 1.
Breaking through limbo: the experience of living with OSA