The Experience of Claustrophobia in Continuous Positive Airway Pressure Therapy

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Obstructive Sleep Apnea (OSA) is recognized as a public health problem affecting millions of people and becoming more prevalent with increasing population obesity. Untreated OSA results in poor sleep quality causing fatigue and excessive sleepiness the next day and a multitude of other long-term physiological and psychosocial problems which impair quality of life and increase healthcare costs from cardiovascular disease, motor vehicle accidents and operative risk/complications. Obstructive sleep apnea (OSA) is a disease that changes the person’s world making sleep more difficult with multiple awakenings to go to the bathroom or because of being awakened by snoring, an apnea, or a bed partner concerned about the breathing pattern. Continuous positive airway pressure (CPAP), the mainstay therapy of OSA, is difficult for many people to use, but especially for those with claustrophobia. We do not know what causes claustrophobia, the fear of confined spaces, but we do know that the experience is different for individuals and may represent a fear of restricted space or a fear of suffocation. In claustrophobic people, the mind irrationally associates a small space such as a MRI machine, closet, elevator or CPAP mask, to imminent danger of harm or death, even though none is present. The underlying problem seems to be an overwhelming anxiety that can turn to panic which is often accompanied by breathlessness or a sensation of impending suffocation, feeling loss of control, and a need to flee the space. CPAP healthcare providers opine that claustrophobia is a significant cause of CPAP usage problems.

We have a critical gap in knowledge about claustrophobia and CPAP therapy. We cannot predict who will be successful in using CPAP and who will abandon CPAP therapy. In this study, I hope to better understand the experience of claustrophobia and CPAP using two qualitative interviews and a drawing to obtain narrative stories about the practical or lived experience of OSA, CPAP and claustrophobia. Improved understanding of claustrophobia and CPAP will enable health care providers to intervene more effectively which can result in reduced complications and premature death. Providers and caregivers may be better able to assist patients to become successful CPAP users or to choose alternate therapies more suited to the patient, reducing frustration and not delaying effective treatment of OSA. The end result will be improved patient outcomes.

The purpose of this interpretive phenomenological study beginning summer 2018 is to explore the lived experience of claustrophobic in adult patients with OSA who have been prescribed CPAP. The sample of up to 30 participants will be recruited primarily from a university-based sleep disorders center in a large urban area in the Midwest. I propose to answer the following questions: What is the meaning of claustrophobia in patients with OSA? What are the bodily sensations of claustrophobia in patients with CPAP? How have lifetime experiences impacted claustrophobia in patients with CPAP? How do claustrophobic patients cope with the challenges of using CPAP? I want to discover how participants came to know they had claustrophobia and how the claustrophobia affects personal and family life as well as their ability to use CPAP. What challenges do claustrophobic patients face and what resources do they use when using CPAP? How do they manage to use CPAP, and what interferes with the development of their skillful use? I will use two semi-structured qualitative interviews each lasting 1-2 hours and a drawing about the experience of claustrophobia to obtain narrative stories about the practical/lived experience of patients with OSA and claustrophobia. I will examine the lived understanding related to claustrophobia and their skills and struggles in using CPAP. I will also examine how claustrophobia is embodied. Because claustrophobia is an anxiety disorder, I will measure levels of anxiety and depression in participants using both a visual analog scale and validated instruments. I will examine adverse child experiences as a contributing factor in the development of claustrophobia. I will also ask participants to complete a validated general claustrophobia questionnaire that has additional CPAP specific items added to determine potential claustrophobia-inducing situations. Data from the baseline questionnaires will be used to describe the sample, reporting percentages or means/standard deviations as appropriate. It is unknown if demographic/baseline patterns will be identified from the baseline data and analysis of
qualitative interviews, but the size of the sample will not allow statistical inference. Qualitative data analysis involves reviewing textual and pictorial data from the interviews and field notes for identification, examination and interpretation of patterns and themes to answer the research questions. Interviews and field notes will be examined for convergent or divergent general or specific themes, paradigm cases and exemplars; participants will be recruited until theme and meaning saturation is achieved. Codes related to childhood and adult experiences of claustrophobia may emerge along with how claustrophobia presents itself to the body and what coping skills aid the participant in daily life to meet the challenges of claustrophobia. Descriptions of the drawings may also illuminate codes related to use of color or positioning on the paper as well as objects participants chose to draw about what claustrophobia is like for them. Participants will validate interpretive summaries. There will be triangulation of data with interviews and questionnaires.

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References:  
Baron, R. J. (1985). An introduction to medical phenomenology: I can't hear you while I'm listening. *Annals of Internal Medicine, 103*(4), 606-611.


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Abstract Summary:
This dissertation explores what claustrophobia, fear of enclosed spaces, is like for people who use a machine called continuous positive airway pressure (CPAP) at night when sleeping to keep the throat open. What causes claustrophobia is different for individuals and their ability to use CPAP varies.

Content Outline:
The experience of claustrophobia in continuous positive airway pressure therapy

I. Background
1. Obstructive Sleep Apnea (OSA)
2. Continuous Positive Airway Pressure (CPAP) therapy
3. Claustrophobia
4. Theory

II. Purpose of the study-questions posited
1. What is the meaning of claustrophobia in patients with OSA?
2. What are the bodily sensations of claustrophobia in patients with CPAP?
3. How have lifetime experiences impacted claustrophobia in patients with CPAP?
4. How do claustrophobic patients cope with the challenges of using CPAP?

III. Study design-interpretive phenomenology
1. Description of sample
   1. Age, gender, height, weight, race, income category, medical conditions, medications, and alcohol use
   2. Apnea hypopnea index and CPAP compliance
3. Specific questionnaire responses: Adverse Childhood Experiences, Beck Anxiety Inventory, Claustrophobia Questionnaire, Epworth Sleepiness Scale, Patient Health Questionnaire-9
2. Two semi-structured interviews covering OSA, CPAP and claustrophobia
3. Drawing activity --what is claustrophobia like for you?

IV. Study preliminary results

1. Description of sample
2. Themes including embodiment or technology
3. Exemplars or paradigm cases

V. Implications for Nursing

1. Scant literature on topic currently available-fills a critical gap in knowledge about claustrophobia and CPAP and will lead to additional studies examining the intersection of claustrophobia and CPAP in practice.
2. Disease versus illness-first study to explore the lived experience of patients with OSA and claustrophobia who are prescribed CPAP and how they embody a relationship (or habit) that allows some patients, but not others, to spontaneously respond to CPAP without prior reasoning.
3. Long term goal is to assist providers to help patients to become successful CPAP users or to choose alternate therapies more suited to the patient reducing frustration and not delaying effective treatment of OSA. The end result will be improved patient outcomes.

First Primary Presenting Author

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Professional Experience: Employed by Saint Louis University since 1979. Work at the Sleep Disorders Center since 2007 as a Nurse Practitioner (ANCC certified since 1997) and the Director of the CPAP Adherence Clinic. I see all types of sleep patients. 2018 PhDc in Dissertation phase for my PhD in Nursing. 2016 Associate Professor of Medicine. Mentor Pulmonary/Critical Care fellows in sleep related research projects and publications. 2015 Awarded Excellence in Nursing Award, Medical Surgical Nursing, St. Louis Magazine and Goldfarb School of Nursing. 2013 Doctor of Nursing Practice degree at SLU. Capstone: Impact of confidence and motivation on CPAP adherence. 1992 Finalist Missouri Tribute to Nurses Research.

Author Summary: Dr. Dettenmeier is experienced in the care of patients with obstructive sleep apnea (OSA) who use continuous positive airway pressure (CPAP) therapy. She is currently interested in researching the effects of claustrophobia in patients with sleep apnea. Dr. Dettenmeier’s goal is to help providers and caregivers to better assist patients with becoming competent CPAP users or to choose more appropriate therapies resulting in the effective treatment of OSA.