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A Multi-Methods Observatonal Study Of Persistent Vocalizations In Nursing Home Residents With Advanced Dementia

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Abstract

Persistent vocalizations (PVs), otherwise known as disruptive vocalizations or problematic vocalizations, are commonly exhibited by nursing home residents (NH) with advanced dementia. Older adults exhibiting this behavioral symptom of dementia can have detrimental outcomes such as physical exhaustion. PVs also cause distress to others in the same environment including other residents, NH staff, and visitors. The purpose of this body of work was to describe PVs in persons with advanced dementia in relation to observational and physiological variables prior to, during and after an episode of PVs. The Need-driven Dementia-compromised Behavior model informed this work. A systematic review was completed to learn the state of the science on the phenomenon of NH residents with dementia and PVs. Field observations of nine NH residents with advanced dementia and PVs were conducted. This was followed by combining physiological measures (heart rate and respiration rate) and directed observations from video recordings and sound meter readings on three of the participants. The state of the science reveals that there is limited available knowledge on this phenomenon, particularly around non-pharmacological interventions that are effective at minimizing PVs. A conventional content analysis was completed on field notes from the directed observations and three themes emerged: Routine of Staying in Room was identified for participants considered “disruptive” to others; Caregivers Interactions as Triggers to PVs (providing care without communicating and personal care); and Depends on the Day. Analysis of video recordings and physiological data revealed that the three participants had high heart rates prior to, during and after a PV episode compared to baseline heart rates. This body of work represents the only known research to look at the combination of PV characteristics and physiological characteristics of the NH residents with dementia exhibiting PVs.

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Justine S. Sefcik

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A MULTI-METHODS OBSERVATONAL STUDY OF PERSISTENT VOCALIZATIONS IN NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA

DEDICATION

To all the people who believed in me, including those who have given me a chance.

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ABSTRACT

A MULTI-METHODS OBSERVATONAL STUDY OF PERSISTENT VOCALIZATIONS IN NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA

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Persistent vocalizations (PVs), otherwise known as disruptive vocalizations or problematic vocalizations, are commonly exhibited by nursing home residents (NH) with advanced dementia. Older adults exhibiting this behavioral symptom of dementia can have detrimental outcomes such as physical exhaustion. PVs also cause distress to others in the same environment including other residents, NH staff, and visitors. The purpose of this body of work was to describe PVs in persons with advanced dementia in relation to observational and physiological variables prior to, during and after an episode of PVs. The Need-driven Dementia-compromised Behavior model informed this work. A systematic review was completed to learn the state of the science on the phenomenon of NH residents with dementia and PVs. Field observations of nine NH residents with advanced dementia and PVs were conducted. This was followed by combining physiological measures (heart rate and respiration rate) and directed observations from video recordings and sound meter readings on three of the participants. The state of the science reveals that there is limited available knowledge on this phenomenon, particularly around non-pharmacological interventions that are effective at minimizing PVs. A conventional content analysis was completed on field notes from the directed observations and three themes emerged: *Routine of Staying in Room* was identified for

participants considered “disruptive” to others; *Caregivers Interactions as Triggers to PVs* (providing care without communicating and personal care); and *Depends on the Day*. Analysis of video recordings and physiological data revealed that the three participants had high heart rates prior to, during and after a PV episode compared to baseline heart rates. This body of work represents the only known research to look at the combination of PV characteristics and physiological characteristics of the NH residents with dementia exhibiting PVs.

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CHAPTER 1: INTRODUCTION

Introduction to the Problem

Persistent vocalizations (PVs), otherwise known as disruptive or problematic vocalizations, have prevalence rates as high as 81% among nursing home (NH) residents with dementia, making PVs one of the most common behavioral symptoms of dementia (Kunik et al., 2010). While not all aberrant vocal noises are bothersome, many different types of PVs can be disturbing and stressful to others within proximity of the sounds (Cohen-Mansfield & Werner, 1997b; Sloane, Davidson, Knight, Tangen, & Mitchell, 1999). This dissertation defined PVs as any vocal sounds, repetitive verbalizations or inappropriate use of words that are upsetting either to persons exhibiting them or to others in the environment, including family members, other residents and care providers. The term PVs is a nonjudgmental label to describe this behavioral symptom of dementia. PVs are considered a need based behavior, as such, PVs are a way that a person with advanced dementia communicates a need.

For NH residents with PVs there can be negative effects such as physical exhaustion, or consequences from actions of others such as being placed in isolation to facilitate a more peaceful environment (Barton, Findlay, & Blake, 2005). In addition, PVs from one resident can cause reactive vocalizations in other residents (Dwyer & Byrne, 2000). When one or more residents are exhibiting PVs in a NH, it makes for a noisy, stressful environment for everyone. This includes employees, other residents, families, and other visitors to the nursing home. Working with residents with PVs is challenging because this need driven behavior is difficult to treat (Draper et al., 2000). Pharmacological interventions are often prescribed to manage PVs, although the efficacy

is generally modest at best and there are negative consequences such as over-sedation, worsening of cognitive function and risks of adverse effects, including stroke and death (Harding & Peel, 2013; Maher et al., 2011; Preuss, Wong, & Koller, 2016; Seitz et al., 2013). Additionally, the pharmacological interventions prescribed in the United States are all "off-label" as there have been no compounds approved by the Food and Drug Administration (FDA) for behavioral symptoms associated with dementia (Preuss et al., 2016).

Due to these concerns, experts recommend non-pharmacological interventions as the first line of treatment for all behavioral symptoms of dementia including PVs (American Geriatrics Society and American Association for Geriatric Psychiatry, 2003). However, there is currently little data on effective non-pharmacological interventions that NH staff can use to manage PVs (Randall & Clissett, 2016). Furthermore, research has shown that staff members are not always equipped with the knowledge to deal appropriately with dementia related symptoms and may feel insecure when implementing non-pharmacological interventions (Kolanowski, Fick, Frazer, & Penrod, 2010). Proper management of behavioral symptoms is important because it could improve the NH residents' quality of life (Buhr & White, 2006) and reduce caregiver stress as well as stress to all others in the same environment (Edberg, Sandgren, & Hallberg, 1995).

Background and Significance

Globally, over 46 million people live with dementia and this number is projected to increase to 131.5 million by 2050 (Prince et al., 2015). In the US approximately 876,600 people with dementia reside within NHs (Alzheimer's Association, 2016; Harris-Kojetin et al., 2016). Nearly all diagnosed with dementia exhibit behavioral symptoms of

dementia at some time during their disease process (Selbæk, Engedal, Benth, & Bergh, 2014; Wetzels, Zuidema, de Jonghe, Verhey, & Koopmans, 2010). Prevalence rates of PVs are reported as high as 81% (Kunik et al., 2010), indicating that approximately 710,000 NH residents are exhibiting PVs at some point.

Often in the literature when behavioral symptoms of dementia are described they are referred to as behavioral and psychological symptoms of dementia (BPSD) or neuropsychiatric symptoms (Kales, Gitlin, & Lyketsos, 2015; Selbæk et al., 2014; van der Linde, Dening, Matthews, & Brayne, 2014; Wetzels, Zuidema, Jansen, Verhey, & Koopmans, 2010). These are overarching terms for the various behavioral symptoms exhibited by persons with dementia over the course of their disease (e.g. agitation, psychosis, affective symptoms, and apathy). PVs fit under the broad categories of agitation or aggression in this literature. The literature typically refers to PV as verbal aggression or verbal agitation, although similar terms are used interchangeably such as verbal non-aggression for verbal agitation (Beck et al., 1998; Cohen-Mansfield, 1997, 2000; Cohen-Mansfield, Marx, & Rosenthal, 1989; Cohen-Mansfield & Billig, 1986). Table 1.1, adapted from Sefcik and Cacchione (2015), displays how verbal aggression and verbal agitation are defined in the literature, provides prevalence rates and displays typical behaviors associated with each type of PVs (Kunik et al., 2010; Majić et al., 2012; Zuidema, Derksen, Verhey, & Koopmans, 2007).

Table 1.1

Verbal Aggression and Agitation

	Verbal Aggression (Vocally Aggressive)	**Verbal Agitation (Verbal Non-Aggression/Vocally Agitated)**
General Definition	Verbally striking out at others.	Vocalizations that are inappropriate for the social setting.
Prevalence	Estimates range from 10 to 81% (Kunik et al., 2010; Zuidema et al., 2007)	Estimates range from 10 to 76.3% (Majić et al., 2012; Zuidema et al., 2007)
Examples of PV Type	• Screaming • Cursing • Temper outbursts • Making strange noises • Verbal sexual advances • Making threats	• Negativism • Does not like anything • Constant requests for attention • Verbal bossiness • Complaining or whining • Relevant interruptions • Irrelevant interruptions • Repetitive sentences/words

Other vocal behaviors (also PVs) observed in older adults with dementia include singing, laughing and talking to self. Although, these are not characterized as verbal aggression or verbal agitation behaviors, they can also be disturbing to others in the same environment. Additionally, there is literature suggesting that some PVs may serve as a self-stimulation function and are not a sign of aggression or agitation (Beck et al., 2002; Cohen-Mansfield & Werner, 1997b; Cohen-Mansfield, Werner, & Marx, 1989).

PVs are widely believed to be need-driven behaviors and serve as a communication method for older adults with advancing dementia who have limitations with expressing their needs (Algase et al., 1996; Draper et al., 2000; Matteau, Landreville, Laplante, & Laplante, 2003). There are times when a staff member can identify a resident's need and intervene to minimize or resolve the PVs (Cohen-Mansfield

& Werner, 1997b). The needs that underlie PVs vary widely and can include physical needs (e.g., pain, needing to use the bathroom), psychological needs (e.g., wanting attention, attempts to self-stimulate), or environmental discomforts (e.g., uncomfortable temperatures, overstimulation from noise or crowds) (Algase et al., 1996; Cohen-Mansfield & Werner, 1997b). NH staff must be vigilant to determine the meaning behind the PVs they observe (Clavel, 1999). Specific strategies can be developed to prevent or reduce PVs when the unmet need that causes PVs is determined (Algase et al., 1996; Clavel, 1999; Cohen-Mansfield & Werner, 1997b).

As dementia progresses and cognition deteriorates, it becomes increasingly difficult to identify a specific unmet need (Cohen-Mansfield, Dakheel-Ali, Marx, Thein, & Regier, 2015; Cohen-Mansfield & Werner, 1997b). A major concern is that NH staff often perceive that pharmacological interventions are effective, reliable, and promote a calm environment for everyone (Kolanowski et al., 2010). Nursing staff have been observed using inappropriate interventions with residents who exhibit PVs, including administering chemical restraints, giving verbal reprimands, avoiding residents, and placing residents in seclusion (Cariaga, Burgio, Flynn, & Martin, 1991; Dwyer & Byrne, 2000). Additional concerns include staff desensitization to the PVs when working with them routinely (Werner, Cohen-Mansfield, & Newman, 1999), resulting in a failure to explore their meaning and to intervene. Proper management of PVs improves residents' quality of life (Buhr & White, 2006), reduces caregiver burden and promotes a pleasant, therapeutic environment (Edberg et al., 1995).

However, there is currently a dearth of evidence related to proper prevention and management of PVs. Having a greater understanding of PVs and the mechanisms

underlying PVs will lead to interventions that target the underlying cause. Physiological measures such as heart rate, respiration rate and body movement are indicators of stress and pain. High heart rates have been found to be indicators of stress and worry (Brosschot, Van Dijk, & Thayer, 2007b; Lewis & Phillips, 2012a). Likewise, changes in respiration rates and body movements are signs of acute stress and pain (AGS Panel on Persistent Pain in Older Persons, 2002; Warden, Hurley, & Volicer, 2003). Although pain is understood to be a potential underlying cause of PVs (Hadjistavropoulos et al., 2014), there are no known studies exploring what is occurring physiologically to a person prior to, during or after PVs episodes. The ability to describe specific physiological changes (heart rate and respiration rate) that occur prior to or during PVs would allow NH staff to identify precursors to PVs and design and implement effective, appropriate interventions to prevent or minimize PVs. The assimilation of observational and physiological data in this study will help build the evidence for managing the PVs.

A descriptive observational multi-methods study was designed to gain a deeper understanding of PVs exhibited by NH residents with advanced dementia. Through the combination of field observations and physiological measures and directed observations, a deeper understanding of this complex phenomenon will contribute to the current limited understanding of this phenomenon.

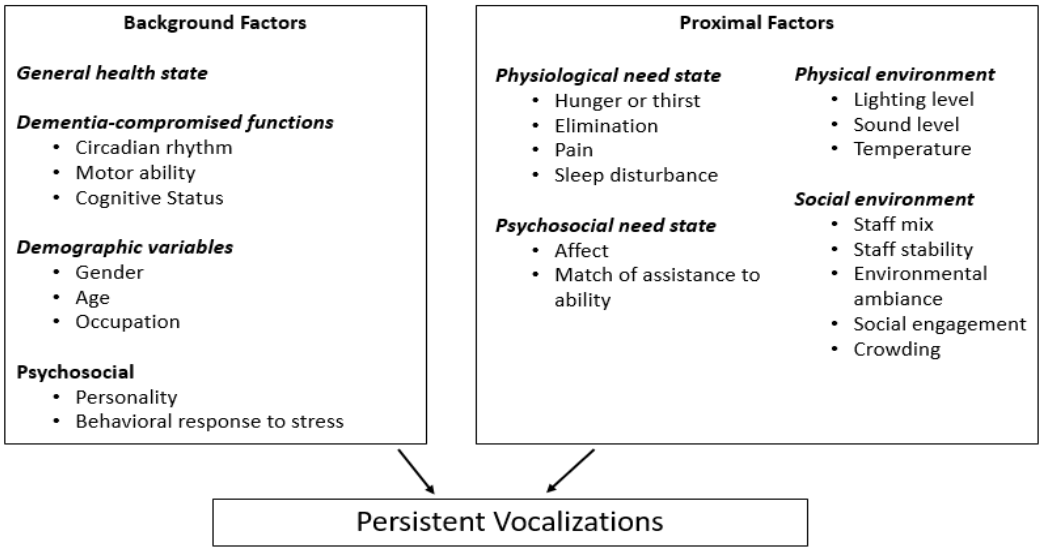
Theoretical Approach

This study was informed by the Needs-driven Dementia-compromised Behavior model (NDB) (Algase et al., 1996). This model posits that behaviors considered disruptive to caregivers (specifically wandering, vocalizations, and aggression) are actual

signals that a cognitively impaired person has an unmet need. Behaviors are the best way a person with dementia can communicate through this lens.

There are three major concepts in this conceptual framework. These are background factors, proximal factors, and need-driven behaviors. The concept of background factors includes neurological cognitive, general health, and psychological factors are thought to function in producing need-driven behaviors. The proximal factors are defined as the fluctuating aspects of the person with dementia's immediate physical and social environment. The subconcepts are personal, physical environment, and social environment. The concept of need-driven behaviors includes the subconcepts of wandering, vocalizing, and physical aggression. The combination background factors and fluctuating proximal factors and the inability to express a need leads to the PVs as a need-driven behavior. The proximal factors in the NDB model have been adapted by Beck and Vogelpohl (1999) to exchange the subconcept of personal factors with physiological need state and psychosocial need state. See Figure 1.1.

Figure 1.1: Modified Need-driven Dementia-compromised Behavior Model



Gaps in the Literature

Currently there is little research on PVs exhibited by NH residents with dementia. Studies on behavioral symptoms of dementia have lumped PV into agitated or aggressive categories and the PVs are not often distinguished from other behaviors (Nagaratnam, Patel, & Whelan, 2003; van der Linde et al., 2014). In other words, few studies have differentiated between PVs and other disruptive behaviors (Beck et al., 2011). This makes extrapolating information regarding PVs from descriptive and intervention study data on behavioral symptoms of dementia difficult. Only one study has been found in the literature that audio recorded vocal behaviors of NH residents with dementia to examine the acoustic properties with attempts to link them to resident and verbalization characteristics; however the study results were inconclusive (Cohen-Mansfield, Werner, Hammerschmidt, & Newman, 2003). This dissertation incorporated multiple techniques of gathering data for NH residents with dementia and PVs. This is the first known study to describe observational and physiological variables in relation to PVs in persons with advanced dementia. Novel research strategies include direct observations, video recording and capturing physiologic data (heart rate and respiration rate).

Purpose and Specific Aims

The purpose of this dissertation was to describe PVs in persons with advanced dementia in relation to observational and physiological variables prior to, during and after an episode of PVs. By conducting field observations and combining physiological measures and directed observations from video recordings and sound meter readings, this study provides a deeper understanding of the complex phenomenon of PVs.

The first aim was to gain a greater understanding of the phenomenon of PVs and specifically describe the physical and social environmental contexts surrounding PVs in NH residents with advanced dementia. First, a systematic review determined the state of the science on the phenomenon of NH residents with dementia and PVs. This paper reveals that there is currently little evidence on this phenomenon. There is a need for future research in this area, particularly involving non-pharmacological interventions focused specially on PVs. Second, a qualitative descriptive study of participant observations included nine residents from four NHs supported by information provided by their NH caregivers. To our knowledge, this is one of the first naturalistic studies to explore this phenomenon.

The second aim was to describe characteristics (type, frequency, intensity and non-verbal behaviors) of PVs using video recordings, directed observations, and decibel readings of PV episodes. The third aim was to describe physiological characteristics (heart rate and respiration rate) prior, during and after PV episodes. These aims were achieved through in-depth analysis of three participants (See Table 1.2). This work represents the only research to look at the combination of PV characteristics and physiological characteristics of NH residents with dementia exhibiting PVs.

Table 1.2

Specific Aims with Corresponding Chapters

Specific Aim	Chapter
Aim 1: To describe the physical and social environmental contexts surrounding PVs in NH residents with advanced dementia.	II, III
Aim 2: To describe characteristics (type, frequency, intensity and non-verbal behaviors) of PVs using video recordings, directed observations, and decibel readings of PV episodes.	IV
Aim 3: To describe physiological characteristics (heart rate and respiration rate) prior, during and after PV episodes.	IV

Summary

This dissertation explores the complex and under-researched topic of PVs among NH residents with advanced dementia. This descriptive, multi-methods dissertation provides a deeper understanding of the complicated phenomenon of PVs by conducting field observations and combining physiological measures and directed observations including video recordings of participants. Having a greater understanding of PVs and the mechanisms underlying them will lead to targeted interventions to address the underlying cause. Proper management of PVs is important to improve the NH residents' quality of life, reduce caregiver burden, and decrease the stress of others in the environment. The results of this innovative study will lay the foundation for future research to develop and test interventions to prevent and manage PVs.

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CHAPTER 2: STATE OF THE SCIENCE: PERISTENT VOCALIZATIONS AMONG NURSING HOME RESIDENTS WITH DEMENTIA

Abstract

This systematic review examines the current state of the science on the phenomenon of persistent vocalizations (PVs) among NH residents with dementia. PVs have otherwise been known in the literature as disruptive or problematic vocalizations. Having a better understanding of PVs and the research completed to date on this phenomenon is important to guide further research on the use and development of effective non-pharmacological interventions. Our literature search revealed eight research articles that met the inclusion criteria. These studies were published in 2011 or earlier and involved small sample sizes. The majority of studies were descriptive or correlational. Only one non-pharmacological intervention study for PVs exhibited by NH residents with dementia was identified. Give the paucity of research on this phenomenon; recommendations for additional research are given.

Introduction

Over 46 million people globally are living with dementia (Prince et al., 2015). This number is projected to increase to 131.5 million by 2050. Nearly all those diagnosed with dementia will exhibit behavioral symptoms of dementia (Selbæk et al., 2014; Wetzels, Zuidema, de Jonghe, et al., 2010). A common behavioral symptom of dementia is persistent vocalizations (PVs), otherwise known as disruptive or problematic vocalizations. For the purpose of this systematic review, PVs are defined as vocal sounds, repetitive verbalizations or inappropriate use of words that are upsetting either to persons exhibiting them or to others in the environment, including family members, other residents and care providers. Prevalence rates of PVs have been reported as high as 81% among nursing home (NH) residents with dementia (Kunik et al., 2010). With approximately 876,600 U.S. NH residents with dementia (Alzheimer's Association, 2016; Harris-Kojetin et al., 2016), these rates indicate that approximately 710,000 NH residents exhibit PVs at some point.

While not all aberrant vocal noises are bothersome, many PVs can be disturbing and stressful to others within proximity of the sounds (Cohen-Mansfield & Werner, 1997b; Sloane et al., 1999). For NH residents with PVs there can be negative effects such as physical exhaustion and placement in isolation to facilitate a more peaceful environment (Barton et al., 2005). In addition, PVs from one resident can cause reactive vocalizations in other residents (Dwyer & Byrne, 2000). When one or multiple residents are exhibiting PVs, it makes for a noisy, stressful NH environment for everyone, including employees, other residents, families, and other visitors (Bourbonnais & Ducharme, 2010).

Many experts believe that PVs serve a communicative purpose and are an indication of an unmet need (Algase et al., 1996; Draper et al., 2000; Matteau et al., 2003). The meaning behind PVs varies widely and can range from physical needs such as experiencing pain or needing to use the bathroom; psychological needs for attention or attempts to self-stimulate/soothe; or environmental discomforts due to uncomfortable temperatures, or overstimulation from noise or crowds (Algase et al., 1996; Beck et al., 2011; Cohen-Mansfield & Werner, 1997b).

NH staff must be vigilant to determine the meaning behind observed PVs (Clavel, 1999). Once the meaning is determined, strategies can be developed to prevent or reduce PVs (Algase et al., 1996; Clavel, 1999; Cohen-Mansfield & Werner, 1997b). However, NH staff have reported a lack of education related to the assessment and management of behavioral symptoms of dementia and knowledge about the effectiveness of non-pharmacological interventions (Kolanowski et al., 2010). Kolanowski and colleagues (2010) reported that NH staff members who feel unequipped to work with residents exhibiting behaviors expressed insecurity about implementing non-pharmacological interventions and expressed that pharmacological interventions are efficient and reliable to promote a calm NH environment for others.

Pharmacological interventions are often prescribed to manage PVs, although this is discouraged because there are negative consequences such as over-sedation, worsening of cognitive function, risks of adverse effects, including stroke and death, and efficacy is modest at best (Harding & Peel, 2013; Maher et al., 2011; Preuss et al., 2016; Seitz et al., 2013). Due to these concerns, experts recommend non-pharmacological interventions as the first line of treatment for all behavioral symptoms of dementia including PVs

(American Geriatrics Society and American Association for Geriatric Psychiatry, 2003). However, there is insufficient evidence on non-pharmacological interventions for behavioral symptoms of dementia (Cabrera et al., 2015).

In current research, PVs are often grouped together with other behavioral and psychological symptoms of dementia (BPSD) (such as physical aggression and wandering) and are categorized as aggressive or agitated behavior (Kales et al., 2015; van der Linde et al., 2014). Additionally, some studies include participants from settings other than NHs such as community-dwelling older adults with dementia. This makes it difficult to have a thorough understanding of the characteristics and correlates of PVs exhibited by NH residents with dementia or to develop effective interventions for this specific group of people. Having a better understanding of PVs and the research completed to date on this phenomenon is essential to support next steps of developing effective non-pharmacological interventions. Proper prevention and management of behavioral symptoms such as PVs is important to improve residents' quality of life (Buhr & White, 2006) and reduce caregiver stress and stress to others in the same environment (Edberg et al., 1995). Therefore, the purpose of this State of the Science paper is to examine and report on the available published research focused specifically on NH residents with dementia who exhibit PVs.

Methods

Search strategy. A search was conducted on June 30, 2016 in the PubMed, Scopus, Ovid Medline and CINAHL databases for articles published in English. Search terms included "dementia" combined with "vocal behaviors", "vocally disruptive behaviors", "disruptive vocalizations", "problematic vocalizations", "persistent

vocalizations", "verbal aggression", "verbal agitation", "vocally aggressive", "verbal non-aggression", or "vocally agitated". Articles were included if the focus was specifically on research involving vocal behaviors of older adults with dementia residing in NHs. Articles were excluded if they were: (a) reviews of the literature including systematic reviews, (b) case reports, (c) had three or less participants (due to being similar to a case report), (d) focused on medication use, (e) were in a setting other than a NH, (f) looked at a combination of behavioral and psychological symptoms of dementia, and (g) included any participants who did not have a diagnosis of dementia. There were no limits placed around the dates of publication.

Findings

Study selection and characteristics. The search yielded 360 non-duplicate articles. The first author screened articles based on titles, abstracts and full texts. Many articles (n=353) were not included because of the exclusion criteria. The end result was eight articles that satisfied the inclusion criteria. There was one intervention study identified, with the remainder being descriptive studies (n=7). Of the descriptive studies, one was qualitative in nature and took a critical ethnography approach to understand screams of NH residents with dementia (Bourbonnais & Ducharme, 2010). There were no mixed-methods studies identified. Sample sizes ranged from 7 to 138 in studies published between 1999 and 2011. Six studies were conducted in North America (4 in the U.S. and 2 in Canada) and two in Europe. See Table 1 for details on the eight studies.

Table 2.1 Table of Evidence

Author, Year, Type of Study and Country	Label for PVs	Aims	Sample Size	Tools Used to measure PVs	Additional Tools Used	Results
Beck & Vogelpohl 1999 Descriptive Study US	Problematic Vocalizations	To examine the ways in which factors from the NDB model related to PVs	97	45 item disruptive behavior scale	• Demographic data • MMSE • Katz ADL • MOSES	Screaming and yelling were most frequent, and was correlated positively with aggressive physical behaviors such as scratching, hitting, and pinching; being a man and having disordered sleep patterns and a negative affect related significantly to aggressive vocal behaviors
Beck et al. 2011 Correlational Study US	Problematic Vocalizations	To examine the relative contributions to PV variables derived from the NDB model.	138	Videotaped participants for seven 20-min periods on two nonconsecutive days – the recorded rates of PVs per minute as defined by the VBS and the CMAI History of PVs from MDS 2.0 and reports from staff or family	• Actigraph on wrist • Background data from interviews and chart reviews • MMSE • Cumulative Illness Rating Scale for Geriatrics • MDS 2.0 - motor ability • Neuroticism Extroversion Openness Five Factor Inventory • Behavioral Response to Stress Scale • The Physiological Need State Assessment (investigator developed instrument) - looked at hunger, thirst, pain and the need for elimination • Indoor humidity gauge thermometer • The Observable Displays of Affect Scale	Agreeableness, conscientiousness, positive affect, and discomfort were associated with nonaggressive vocalizations. General health state, age and negative and positive affect were associated with aggressive vocalizations. Background factors of gender agreeableness, GHS, age, affect and discomfort were predictors of verbally nonaggressive behaviors.
Bédard et al. 2011 Intervention Study Canada	Verbal agitation (VA)	Main objectives: 1) identify the proportion of persons with dementia who demonstrate significant behavioral improvements with a need-based intervention to reduce VA and 2) to further evaluate the effectiveness of this type of intervention	26	Recorded occurrence of VA for 30 min by RA with handheld computer (VA behaviors from the CMAI – swearing and verbal aggression, constant demands for attention, repetition of phrases or questions, making strange noises, screaming, moaning, negativity and verbal sexual advances) Typology of vocalizations to characterize VA by RA	• Sociodemographic data • Dysphoria scale of the Neuropsychiatric Inventory – Nursing Home Version • Functional Autonomy Measurement System • Dementia Rating Scale-2 • Intervention checklist and tracking of participant's level of engagement	Compared to the baseline, VA frequency was reduced by 14% whereas duration was reduced by 40% during the intervention phase. Slightly more than half of participants 54% showed significant behavioral improvement in the duration of VA during the intervention. People with higher cognitive functioning demonstrated a better response to the intervention. VA returned to a levels similar to the baseline phases immediately after the intervention.

Author, Year, Type of Study and Country	Label for PVs	Aims	Sample Size	Tools Used to measure PVs	Additional Tools Used	Results
Bourbonnais & Ducharme 2010 Descriptive Study Canada	Screams	To explore the meaning of screams in older persons living with dementia and their influencing factors	7	An observational tool was developed based on the authors literature review Semi-structured interview with family and formal caregivers	• Sociodemographic and descriptive data via questionnaires	Major themes and subthemes: Meaning of Screams: a) Living Between Two Worlds: Vulnerability, Suffering and Loss of Meaning; b) Modulations in the Meanings of Screams: When the End Explains the Means; c) Singularity of the Meanings of Screams Factors Influencing the Meaning of Screams: a) Stability and Flexibility in the Nursing Care Organization: Conditions influencing the Meanings of Screams; b) The Home Environment of An Older Person is Also the Home of Other Older Persons, as well as a Work Environment: Reciprocal Effects on the Meanings of Screams; c) Learning the Unique Language of Each Older Person and Its Influence on the Interpretation of the Meanings of Screams; d) "Being With" Older Persons by Respecting Their Personality, Wishes and Needs: Repercussions on the Meaning of Screams; e) Shifts in Power Relations within the Triad (To Relinquish, to Impose, or to Be Imposed Upon) and its Outcomes for the Meanings of Screams; f) Feelings of Powerlessness and Guilt: A Shared Experience for Family and Formal Caregivers Derived from the Meanings of Screams
Cohen-Mansfield et al. 2003 Correlational Study US	Vocally Disruptive Behaviors	The aims of the study were to: 1) characterize the sounds emitted during VDB by NH residents and 2) to investigate whether the properties of VDB correlate with a) characteristics of the older person emitting the sound and b) characteristics of the sounds emitted by the person as perceived by research assistants.	26	Sonographic evaluation and acoustic analysis of recordings of PVs Direct observations of participants for 2 weeks by RAs Typology of Vocalization rating quality of sound and disruptiveness by RA Screaming Behavioral Mapping Instrument by RA	• Demographic and background information • Medical information from chart review • Physical Self-Maintenance Scale of Lawton and Brody • Brief Cognitive Rating Scale	Results were generally inconclusive

Author, Year, Type of Study and Country	Label for PVs	Aims	Sample Size	Tools Used to measure PVs	Additional Tools Used	Results
Matteau et al. 2003 Correlational Study Canada	Disruptive Vocalizations	To explore the relationship between language deterioration and manifestations of PVs in persons suffering from dementia who are living in NHs.	66	CMAI vocalization subset items	•Functional Linguistic Communication Inventory •Functional Assessment Staging •Functional Autonomy Measurement System •Depression – from medical record •Sleep disorders and pain – from medical record	Altered Language Skills (ALS) group produced PVs at a significantly great frequency than the Preserved Language Skills (PLS) group. ALS group emitted a significantly greater number of distinct DV forms than the PLS group.
Palese et al. 2009 Descriptive Study Italy	Disruptive Vocalizations	To evaluate the effectiveness of the daily interventions used by the nurses.	22 (nurses)	Nurses kept a structured diary recording the strategies that they used for managing the observed PV and the duration of each episode.	N/A	Residents with the greatest cognitive impairment (defined as a MMSE score of equal to or less than 2) exhibited the most frequent PVs with moaning and making noises noted as the most common type, and occurred the most when residents were in their room. The nurses' structured observations revealed that they thought PVs were most commonly related to loneliness (30.6%) and discomfort (such as incorrect posture or constipation) (23.8%). In some cases they were unable to hypothesize a cause (9.4%) and these PV episodes lasted longer in duration
van der Geer et al. 2009 Descriptive Study The Netherlands	Verbal and vocal agitation	1. What is the current supply of music, both non-specific and tailored, to patients with dementia and verbal and vocal agitation living in Dutch nursing homes during various care activities? 2. Are the musical preferences of the residents known and are these preferences taken into account when determining the kind of music to be played?	37 (NH physicians and care providers) 51 residents were discussed	In person interviews with a semi-structured survey with NH physician and staff members.	N/A	Related to PVs: PVs varied from occasionally (n=8, 16%) to more than once a day (n=33, 65%) and almost the entire day (n=10, 19%). For 12 residents (24%), the amount of time this behavior was displayed varied significantly from one incident to the next. Top 3 PV manifestations: Screaming and shrieking 16 (315), continuous and excessive demands for attention 14 (28%), shouting 11 (22%)

Terms Used to Label the Phenomenon of PVs

The literature contains numerous terms to express the phenomenon of PVs. These include disruptive vocalizations (Matteau et al., 2003; Palese, Menegazzo, Baulino, Pistrino, & Papparotto, 2009), problematic vocalizations (Beck et al., 2011), verbal agitation (Bédard, Landreville, Voyer, Verreault, & Vézina, 2011), verbal and vocal agitation (van der Geer, Vink, Schols, & Slaets, 2009) and vocally disruptive (Cohen-Mansfield et al., 2003). Bourbonnais and Ducharme (2010) choose to refer to the PVs they were investigating as "screams" to avoid preconceived meaning to the behavior. Each of these terms convey a negative connotation within the literature.

Tools Used to Measure PVs

Measurement tools used to gather data on residents with PVs varied by study. The most frequently used tool to capture PVs were the verbal categories within the Cohen-Mansfield Agitation Inventory (CMAI) (Beck et al., 2011; Bédard et al., 2011; Matteau et al., 2003). Out of 29 behaviors there are eight categories that represent vocal behaviors: cursing, constant unwarranted request for attention or help, repetitive sentences/questions, making strange noises (including inappropriate laughter, unwarranted crying or weeping), screaming, complaining, negativism, and making verbal sexual advances. Depending upon the study, the CMAI was completed retrospectively by a nursing assistant or research assistant or in real time by a research assistant. There were studies where the CMAI was completed in addition to other tools to measure PVs. One study, Beck and colleagues' (2011), included video recording participants for seven 20-minute periods on two nonconsecutive days. Researchers logged the rates of PVs per minute from the video recordings. PVs were defined by the verbally agitated items in the

CMAI as well as items from the Verbal Behavior Scale (VBS) (Beck et al., 1998; Beck et al., 2011).

Beck and Vogelpohl (1999) tested the Need-driven Dementia-compromised Behavior model with data collected from NH residents with PVs. The measures included the 45-item Disruptive Behavior Scale from which they focused on the aggressive vocal behaviors (screams/yells, uses hostile/accusatory language toward others, makes threats implying physical harm to others, makes threats imply physical harm to self) and the agitated vocal behaviors (repeats phrase(s)/word(s), talks constantly, makes repetitious noises) from the scale (Beck et al., 1997). They found that the background factor of being a male and the proximal factors of disordered sleep patterns and a negative affect were significantly related to aggressive vocal behaviors. Additionally, the background factor of being cognitively impaired and the proximal factor of having disordered sleep patterns were associated significantly with agitated vocal behaviors.

Other studies used unique methods to measure PVs. Cohen-Mansfield and colleagues (2003) audio recorded PVs and completed sonographic evaluation of the tapes and evaluated the acoustic structures of the sound files. Palese and colleagues (2009) requested that nurses' keep structured diary recordings for the strategies they implemented for managing PVs and the duration of each PV episode. The study by van der Geer and colleagues used individual semi-structured interviews with NH staff to learn about the nature and intensity of PVs observed. Bourbonnais and Ducharme (2010) developed their own observational tool which was based on their review of the literature to observe screaming. This tool focused on characteristics of the screams (intensity, type, and duration), elements of the social and physical environment, and general observations

of the nursing home's functioning. Additionally they developed an individual semi-structured interview guide that was conducted with family and formal caregivers which included questions about screams. Field notes were also taken during the data collection process. There was not one consistent method for gathering information regarding PVs.

Characteristics of Individuals Exhibiting PVs

All of the studies that met the inclusion criteria had a different focus and reported on different characteristics of the persons with dementia exhibiting PVs. Matteau and colleagues (2003) found that participants with altered language skills exhibited PVs at a greater frequency than those with dementia who tested as having preserved language skills. In Palese and colleagues study (2009), those with the greatest cognitive impairment (defined as a Mini Mental State Examination score of equal to or less than 2) exhibited the most frequent PVs with moaning and making noises noted as the most common type, and occurred the most when residents were in their room. Beck and Vogelpohl (1999) found that screaming and yelling were the most frequently exhibited PVs by those in their sample. Similarly, van der Geer and colleagues (2009), found that screaming and shrieking, continuous and excessive demands for attention, and shouting were the top three categories of PVs exhibited. They also reported that 10 participants (19%) in the study exhibited PVs for almost an entire day.

Beck and colleagues (Beck et al., 2011) used the Need-driven Dementia-compromised Behavior (NDB) model to identify the characteristics of persons with dementia who are likely to exhibit PVs. They used measurements that corresponded to the background and proximal factors of the NDB model to identify factors associated with nonaggressive and aggressive PVs. Nonaggressive PVs were associated with

background factors such as agreeableness and conscientiousness of the persons exhibiting PVs and the proximal factors of positive affect and discomfort. A positive history of agreeableness and conscientiousness predicted a decrease in PVs, while having a positive affect and discomfort was predictive of increased PVs. Aggressive PVs on the other hand, were associated with background factors such as, general health state and age, and the proximal factors of negative and positive affect. Poorer general health predicted an increased likelihood of aggressive PVs, while an increase in age tended to decrease PV incidences. Being more emotive with increases in both positive and negative affect corresponded to an increase in PVs. Looking at the combined PV subcategories the odds of PVs for women were nearly twice that for men.

Meanings Attributed to PVs

In Palese and colleagues' (2009) observational descriptive study, the researchers described training 22 nurses working with 346 NH residents with dementia and PVs to keep a week-long diary of the PVs observed and strategies they used for managing PVs. Nurses' structured observations revealed that they thought PVs were most commonly related to loneliness (30.6%) and discomfort (such as incorrect posture or constipation) (23.8%). In some cases they were unable to hypothesize a cause (9.4%) and these PV episodes lasted longer in duration than when the nurses were able to identify a cause (Palese et al., 2009). In contrast, Bourbonnais and Ducharme (2010), from their critical ethnography described seven categories where screams were used by people with dementia to communicate: dissatisfaction, satisfaction, pain, emotions, physical needs, desire to modify environment, and enigmatic.

Techniques Used by Nurses to Manage PVs

Analysis of the content of nurses' diaries in Palese and colleagues' study and discussions with the nurses revealed four categories of strategies. Nurses revealed the following: 1) single strategy such as an emotional intervention (speaking or touching the patient) or a physical intervention (managing a specific need), 2) multiple strategies which included emotional and physical interventions one or more times, 3) pharmacological strategies, and 4) no intervention (due to no time/excessive workload or exhausted all other possible strategies). Nurses felt more satisfied when they used multiple strategies to intervene when residents with dementia were exhibiting PVs. Data collected demonstrated that nurses were involved with managing residents with PVs for approximately 100 minutes per shift.

Intervention Study

One intervention study was identified that focused specifically on NH residents with verbal agitation (Bédard et al., 2011). Trained research assistants administered a 30-minute one-on-one intervention that included the components of comfort, attention and stimulation. Just over half of the participants (54%) had behavioral improvement during the intervention (at least a 50% reduction of PVs). Unfortunately, immediately following the intervention, PVs returned to baseline levels.

Discussion

This systematic review set out to learn the state of the science for the phenomenon of PVs among NH residents with dementia. The identification of only eight studies demonstrates that this is an understudied area of research. Additionally, the studies were dated from 2011 or earlier, providing evidence that there is a lack of attention to this specific behavioral symptom known to have negative effects to those exhibiting the

behavior and those in the immediate environment exposed to the PVs. Challenges of conducting NH research, particularly intervention research, have been documented (Buckwalter et al., 2009; Garcia, Kelley, & Dyck, 2013; Hall, Longhurst, & Higginson, 2009; Maas, Kelley, Park, & Specht, 2002; Mentes & Tripp-Reimer, 2002; Sefcik & Abbott, 2017; Sefcik & Kim, 2016; Tilden, Drach, Tolle, Rosenfeld, & Hickman, 2002). These challenges including gaining entrée into NHs, staff turnover and support, and gaining consent from legally authoarized representatives, which may be among contributing factors to the paucity of published research on our phenomemon of interest.

Within the identified literature, there was a lack of consistency with labeling aberrant vocal behaviors exhibited by NH residents with dementia. Due to the inconsistency of labeling PVs and the lack of a standard definition, researchers developed their own specific focus, such as verbal agitation or screams. This lack of definition and variation in labeling PVs makes it difficult to compare study findings and advance the science. Additionally, the descriptive studies were cross-sectional and exploratory, many with small sample sizes resulting in preliminary findings, which are by nature inconclusive and difficult to generalize to larger populations.

Only one intervention study was identified that focused specifically on PVs among NH residents with dementia. Bédard and colleague's (2011) non-pharmacological intervention study was able to decrease PVs by 50%, however, after the intervention period ended, PVs returned to baseline levels. The lack of available evidence for effective, lasting non-pharmacological interventions for PVs reinforces the critical need for more research. Larger sample sizes in studies are needed to provide stronger evidence regarding interventions effective in reducing PVs. Based on findings from Bédard and

colleagues', future research should aim to provide longer durations of interventions or shorter periods of time with more frequent dosage (Bédard et al., 2011).

Overall, little is known about the ways that NH staff selects and implements non-pharmacological interventions for residents exhibiting behavioral and psychological symptoms of dementia, particularly PVs (Kolanowski, 2009). This review identified only one study that specifically examined nurses' interventions for residents exhibiting PVs. Larger sample sizes are needed to confirm the generalizability of this information and study participants should be expanded to other staff working in NHs who provide interventions such as Certified Nursing Assistants, Recreational Staff, and Social Workers.

Most of the studies reviewed were not driven by theory. In two of the studies the Need-driven Dementia-compromised Behavior (NDB) model guided the research. The NDB model is a widely recognized framework that posits that behaviors such as PVs which are considered disruptive by caregivers, are actually the best way that a person with dementia can communicate their unmet needs (Algase et al., 1996; Beck et al., 2011). More research investigating the proximal, background and environmental factors described in the model that contribute to PVs is essential.

Several additional recommendations for future research have been identified after reviewing the current literature on PVs among NH residents. Very little is known about the phenomenon of PVs. Negative attitudes based on old terminology may have contributed to the lack of research. We suggest the nonjudgmental term of persistent vocalizations. Research is needed to further describe the observable characteristics of PVs in an attempt to come to a consensus definition and label. Until this research is

completed we recommend the use of the following definition based on this systematic review of the literature: PVs are vocal sounds, repetitive verbalizations or inappropriate use of words that are upsetting either to persons exhibiting them or to others in the environment, including other residents, care providers and family members.

Larger observational studies could aid in identifying modifiable triggers. In addition, research investigating the physiological response to PVs could illuminate a greater need to intervene for persons with dementia who exhibit PVs. These studies are needed before multi-site studies can be conducted with large numbers of heterogeneous participants to gain a better understanding of prevalence rates of PVs. Longitudinal studies that map the progression of PVs over time are recommended (Lai, 1999). Additionally, research needs to be completed to determine underlying causes of PVs, particularly in cases where cognition has severely deteriorated and staff members have difficulty determining unmet needs.

This review may have limitations inherent in investigating phenomenon without a consensus term or definition to search. It is possible that relevant research was not identified due to studies using other terms to describe PVs, which were not in our search terms. However, we tried to reduce this possibility by utilizing terms previously identified from the literature when updating evidence-based practice guidelines related to non-pharmacologic management of behaviors in persons with dementia (Sefcik & Cacchione, 2015).

Conclusion

PVs exhibited by NH residents with dementia are a significant problem for the residents exhibiting PVs and all others in the immediate environment. This systematic

review reveals that there is currently little research on NH residents with dementia and PVs. Inconsistent terms and definitions are used in the research. There is also little data on effective non-pharmacological interventions for this unique population. This is an underdeveloped area of nursing research and future research in this area will have a positive impact on the quality of care delivered to all residents in NHs. Due to the effect of PVs, research in this area can make residents exhibiting PVs more comfortable, reduce caregiver stress and ease NH visitors' feelings of distress.

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CHAPTER 3: PERSISTENT VOCALIZATIONS IN PERSONS WITH ADVANCED DEMENTIA: ENVIRONMENTAL AND SOCIAL CONTEXT

Abstract

Purpose: To describe the physical and social environmental contexts surrounding persistent vocalizations (PVs) in nursing home (NH) residents with advanced dementia.

Design and Methods: This qualitative descriptive study involved participant observations of nine residents from four NHs supported by information provided by caregivers. Field notes were analyzed using conventional content analysis.

Results: Three themes emerged. *Routine of Staying in Room* was identified for participants considered "disruptive" to others; *Caregivers Interactions as Triggers to PVs* (providing care without communicating and personal care); and *Depends on the Day*.

Implications: Two themes demonstrated the importance of the social environment proximal factor within the Need-driven Dementia-compromised Behavior Model. Participants spending most or all of their time in their room to manage their PVs may actually exacerbate their PVs. Instead, continued attempts to engage individuals in activities could address an unmet need for socialization, thereby minimizing PVs. Ongoing, mandatory, evidence-based training on dementia care for all NH staff across the US could have a significant impact on the delivery of holistic quality care for persons with dementia and PVs.

Introduction

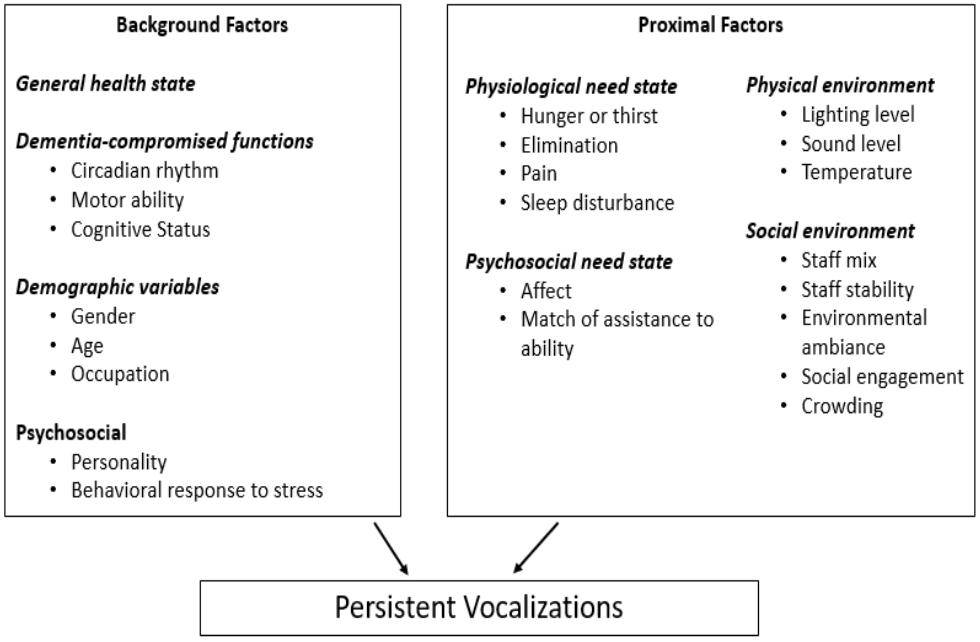
Among older adults residing in U.S. nursing homes (NHs), 64% have been diagnosed with Alzheimer's disease or other dementias (Alzheimer's Association, 2016). Dementia-related behaviors such as persistent vocalizations (PVs) are one of the most challenging aspects of caring for someone with dementia. PVs are vocal sounds, repetitive verbalizations or inappropriate use of words that are upsetting either to persons exhibiting them or to others in the environment, including family members, other residents and care providers. They are often referred to in the literature as disruptive or problematic vocalizations (Beck et al., 2011; Randall & Clissett, 2016). PVs are common, occurring in as many as 81% of residents with dementia and are associated with physical exhaustion, risk for social isolation, and use of psychotropic medications to those exhibiting PVs and emotional distress to those in the same environment (Barton et al., 2005; Draper et al., 2000). Identifying the factors that are associated with PVs is crucial to designing evidence-based interventions to prevent and manage these behaviors.

Most research examines PVs as one type of behavioral and psychological symptom of dementia (BPSD). In these studies, PVs are grouped with other behavioral symptoms and given a label such as agitation (van der Linde et al., 2014). While more than one behavior can occur at a time (Choi, Budhathoki, & Gitlin, 2016), the clustering of behaviors hinders a deeper understanding of PVs (van der Linde et al., 2014) including the ability to identify specific precipitants and outcomes of PVs. This, in turn prevents the development of targeted interventions for PVs (Beck et al., 2011; Nagaratnam et al., 2003).

Proper recognition and management of PVs is important to improve NH residents' quality of life (QOL), reduce caregiver burden, and decrease the stress on others in the environment (Beck et al., 2011). However, there is an identified lack of high-quality research on non-pharmacological interventions for PVs (Randall & Clissett, 2016). An important step for developing effective person-centered non-pharmacological interventions for NH residents with advanced dementia and PVs is a naturalistic inquiry to observe this behavior where the person with dementia resides, to identify patterns and potential triggers or precipitants to this need-driven dementia-compromised behavior.

The purpose of this study was to describe the physical and social environmental contexts surrounding persistent vocalizations (PVs) in nursing home (NH) residents with advanced dementia. To our knowledge, this is one of the first naturalistic studies to explore this phenomenon. The Need-Driven Dementia-Compromised (NDB) model informed this investigation. The NDB model posits that persons with dementia exhibit behaviors such as PVs to communicate an unmet need (Algase et al., 1996; Beck & Vogelpohl, 1999). This model proposes that background factors (neurological factors, cognitive factors, health status, psychosocial factors) and proximal factors (fluctuation in the person's physical or social environment, or a changing need within themselves) (See Figure 2.1) precipitate need-driven behaviors (i.e., PVs) as a way of expression. This model facilitates the first step of identification of situational precipitants for developing targeted strategies to modify PVs.

Figure 2.1: Modified Need-driven Dementia-compromised Behavior Model



Methods

This naturalistic inquiry used a qualitative descriptive study design which included participant observations supported by brief, informal conversations with NH staff (Kim, Sefcik, & Bradway, 2016; Lincoln & Guba, 1985; Sandelowski, 2000). The observational design was selected for the ability to explore participants' routines, PVs that occurred, and the context of the PVs within the participants' natural environment (Green & Thorogood, 2013; Lincoln & Guba, 1985). The information provided by staff added depth to the observations and facilitated a greater understanding of what was observed (Green & Thorogood, 2013).

Setting and Sample

We conducted this study in four NHs in two states in the Northeastern US. Two NHs had a locked dementia unit where five of the participants lived. The other four

participants lived on units where there were a mix of cognitively intact and cognitively impaired residents. Eight participants lived in semi-private rooms. The other participant had a private room and a paid companion 4-5 days a week for 6 hours a day.

Participants were included if they had a medical diagnosis of dementia, a history of PVs per nursing staff report, moderate to severe dementia as determined by a Mini Mental Status Examination (MMSE) Score of ≤ 20, understood and spoke English, 65 years of age or older, and needed extensive assistance by staff to ambulate or were non-ambulatory. We excluded residents who had a documented serious mental illness other than dementia, dissented from participation, were physically restrained, or took frequent trips out of the facility.

Procedures

Approval to conduct this study was received from the University of Pennsylvania IRB. We obtained permission from each facility's NH administration to conduct the study and then contacted a key NH contact (i.e., Nurse Manager or Social Worker) who identified potential participants for the study. The key contact from each nursing home made initial contact with the legally authorized representatives of the potential participants to obtain permission for the primary investigator (JS) to call regarding further study details. Legally authorized representatives provided written informed consent. The PI notified key NH contacts of the observation days. NH contacts introduced the investigator to each of the participants and to the staff working on the unit. During introductions to participants, the PI assessed for and received assent from the participants, which was established by observing positive behavior (i.e. acting agreeable, being cooperative, positive emotion such as smiling). Indicators of dissent included verbal or

non-verbal signs (e.g., being non-cooperative or emotional expressions of unhappiness) that suggested an unwillingness to participate (Black, Rabins, Sugarman, & Karlawish, 2010).

Data Collection

The PI who completed all participant observations had extensive experience as a NH nurse and a researcher conducting observations of persons with dementia residing in NHs. She collected data from April to November, 2016. Observations of each participant occurred on the day and evening shifts on weekdays and weekends. The study included a total of 87 hours of observations with an average of 580 minutes per participant. Slight variation in hours observed was due to participant wake time in the morning and bedtime in the evening. The PI did not observe the participants during personal care, but instead waited outside the room or nearby in the hallway until care was complete.

The PI handwrote field notes into a notebook in real time as the situation allowed. For instance, the PI wrote field notes in real time if a participant was lying in bed. In situations where participants were in common areas with numerous people around or moving from one area to another, key words and short hand notes supported field notes expanded upon later. The NDB model guided the field notes for this study. The PI-focused observations and notes on the proximal factors indicated in the model to make note taking of observations manageable. The proximal factors included physiological need state, psychological need state, physical environment, and social environment (See Table 3.1) (Algase et al., 1996; Beck & Vogelpohl, 1999). In addition, the PI specifically observed for and noted the participants' routine, vocalization timing, and other

observations about the participant or environment deemed important to capture (for example, participant interactions with staff and other residents).

Table 3.1

Proximal Factors from NDB Model

Proximal Factors

- Physiological Need State
  - Hunger or thirst
  - Elimination
  - Pain
  - Discomfort
  - Sleep disturbance
- Psychosocial Need State
  - Affect
  - Match of assistance to ability
- Physical Environment
  - Light level
  - Sound level
  - Temperature
- Social Environment
  - Staff mix
  - Staff ability
  - Ward ambiance
  - Presence of others

Data Analysis

The PI typed all field notes into a Word document and then uploaded all notes into Atlas.ti V7, a qualitative software used to store, manage and analyze the field notes. No a priori codes were used for analysis even though the NDB model guided the field notes. Instead, conventional content analysis (Hsieh & Shannon, 2005) was performed. This technique involved deriving in vivo codes from word-by-word review of the data, then sorting and organizing the codes into clusters based on their relationship. The PI then developed categories and themes from these clusters (Elo & Kyngas, 2008; Graneheim & Lundman, 2004; Hsieh & Shannon, 2005). This allowed for identification of categories and themes beyond analysis based on the NDB model.

The PI and a research assistant (RA) independently completed a first level coding of a subset of field note documents and developed a draft codebook of identified categories and definitions. This codebook was refined with frequent team meetings (with PI, RAs, and mentors) and during second level coding. The PI and two RAs completed second level coding independently and met regularly to reconcile all coding for consensus. The team discussed and finalized the findings for this study.

Trustworthiness

This naturalistic inquiry was guided by Lincoln and Guba (1985) to ensure trustworthiness. Field journals, peer debriefing, using two people for coding and maintaining an audit trail ensured trustworthiness. Field journals served two purposes. First, the journals were a daily log of the field observations. Second, they served as a personal log to write entries of reflexive and introspective thoughts on what was happening in the field, a record of thoughts on additional ideas that came to mind, a listing of possible analysis strategies, and a way to vent challenges experienced when within the field. Debriefing occurred with peers and faculty, not involved with the study, through an Advanced Qualitative Collective at the University of Pennsylvania (Abboud et al., 2016). The group challenged the investigator's potential biases and were an audience to test analytical ideas during sessions that involved review of the data and the investigator's coding schema. Additionally, the investigator and two RAs coded data independently and met to reconcile all coding to increase the rigor of the study. Finally, trustworthiness was supported by an extensive codebook which provided an audit trail with definitions for each category and reflected each analytical decision made.

Findings

Participant characteristics. Almost all of the participants were female (88.9%), white (88.9%), and were all over 85 years of age (range 88-94). For the sample, the mean number of diagnoses was 12.1, mean number of medications was 7, and the mean number of psychotropic medications was 1.9. Five of the participants were taking routine pain medication and none of the participants had received prn medications the week before the observations. There were no documented medication changes at the time of observations. Provided in Table 3.2 is the demographic information.

Table 3.2

Demographics

Demographics of Participants (N= 9)	
Variable	**n (%)**
Age (years)	
≥85	9 (100)
Mean, range	90.9, 88 - 94
Gender	
Female	8 (88.9)
Male	1 (11.1)
Race	
White	8 (88.9)
Black or African American	1 (11.1)
No. of current diagnoses	
<5	1 (11.1)
5 to 10	4 (44.4)
11 to 15	1 (11.1)
>15	3 (33.3)
Mean	12.1
No. of routine medications	
<5	1 (11.1)
5 to 10	6 (66.7)
11 to 15	2 (22.2)
Mean	7
No. of routine psychotropic medications	
1 – 4	9 (100)
Mean	1.9
No. of participants given PRN medications within a week of the observation day	0
No. of participants taking routine pain medications	5 (55.6)

Three themes emerged from the participant observations: *Routine of Staying in Room*; *Caregiver Interactions as Triggers to PVs* and *Depends on the Day*. Below we provide exemplars of PVs observed during field observations (See Table 3.3). All participants' names throughout the paper are pseudonyms.

Table 3.3

Exemplars of PVs Heard from the Participants by Shift

Exemplars of PVs observed		
Participant	**Day Shift**	**Evening Shift**
P1 - Anna	Occasionally mumbling	Yells out various short phrases followed by some periods of quiet: • "I don't care" followed by noises that are nonsensical • "I'll kill you, I'll kill you there" • "Just take care of her bell, blah, blah, blah, blah" • "Your stupid" • "What's your name, what's your name"
P2 - Beatrice	Chanting phrases for long periods of time: • "Daddy, daddy, daddy", "backa, backa, backa", "No, no, no", "have to put her in the pile, back, back, back", "Shame on you grandma", "That's a terrible daddy, you can't do that"	Calling out a few words followed by periods of quiet: • "Let's go"
P3 - Clara	Repeating: "Bah, bah, bah"	• Unintelligible vocalizations and nonsensical words. • A few clear words heard: "I can't get out" • Chanting: "go, go ,go, go, go, go, go, bye-bye, bye-bye"
P4 - Doris	Yelling out intensely loud noises.	Intensely yelling out loud noises. Yelling out only some words that could be understood: "Come on!", "Come here!"
P6 – Fannie	No PVs observed	• Yelling "ahh, ada ad ado" for long periods of time. • Occasionally heard saying: "oh my god"
P7 – Glenn	Occasionally yelling out "oh yay, oh yay", "hurry up, hurry up"	Occasionally yelling out "away, away, away", "take it to the baby"

P8 - Harriet	No PVs observed	No PVs observed. Asking investigator multiple repetitive questions during a conversation.
P9 - Irene	No PVs observed	No PVs observed. Observed yelling back at another resident who yelled at her for kicking the back of her chair.

*P5 Was not observed exhibiting PVs. ** *Pseudonyms used in table.*

Routine of staying in bedroom

Through conversations with NH staff and field observations, the PI discovered that five participants spent all or the majority of their day in their room. These participants were seen by staff as being "disruptive," or were observed to upset other residents with their PVs. The PI observed that these participants tended to exhibit more PVs per field notes than the other study participants who spent more time outside of their rooms. The participants below exhibited PVs that were intense, inappropriate or threatening precipitating the isolation in the participants' rooms.

Doris exhibited the loudest and most intense PVs. Staff explained that Doris' routine was to stay in her room all day including mealtime. While sitting in her room with the television on, Doris exhibited intense agitated unintelligible yelling heard throughout the NH unit. At one point, she yelled directly at the investigator "Come here! Come here!" However, she could not express what she needed when the investigator responded to her. The Certified Nursing Assistant (CNA) explained this was how Doris usually behaved.

NH staff explained that Glenn stayed in bed all day because, as they stated, "he is really disruptive" and sometimes verbally sexually inappropriate when in common areas.

They added that activities staff provided 1-on-1 visits with Glenn, although the investigator was not able to observe these visits. From time to time Glenn was heard mumbling words and making kissing noises and other times yelling out things like “oh yay, oh yay, oh yay” and “five thousand dollars.”

A CNA described Anna’s routine after lunch as receiving incontinence care, followed by a period in which Anna stayed in her room for the afternoon because of previous complaints about her yelling in the main living room area. Anna’s CNA stated she would move Anna to the main living room area at 4:30pm “unless she’s really loud” and then she would stay in her room until dinner was served. Anna was observed out in the main living room until dinner was served when she was observed to yell “you’re stupid” and mumble loudly at the dining room table. Another female resident sitting at the table yelled out at Anna “Be quiet, be quiet” “shut your stupid mouth, shut up and go home.” At the end of dinner Anna’s PVs increased and she was yelling out “I’ll kill you, I’ll kill you there” and the CNA brought Anna to her room and assisted her into bed.

In contrast to the five participants who spent most of their time in their rooms, there were participants who did not exhibit any PVs during their observations and spent their day outside of their rooms. Eleanor and Irene both spent their day in common areas from the time they got up until they were back in bed in the evening. Similarly, Harriet did not exhibit any PVs and spent most of her day around other residents. She did have an afternoon nap because she “likes to sleep”, but this was unrelated to her history of PVs. Staff described times when they had to “evict” Harriet from the dining room because of racial comments she made during meals or when she made fun of her tablemate. The PI did not observe this behavior. In addition to being around other residents in the common

areas, these participants were also consistently around NH staff as they went about their work providing additional stimulation and interaction.

Caregiver Interactions as Triggers to PVs

Providing care without communicating. There were many instances where the PI observed the NH staff doing something to a participant without providing communication, such as moving their wheelchair from one location to another. These caregivers' actions without communication resulted in the participants being startled resulting in the participant exhibiting PVs. Beatrice was sitting in her room quietly when a staff member entered without talking to Beatrice and proceeded to apply lotion to her face. Beatrice responded by hitting out and yelling nonsensically at the caregiver. Later, Beatrice was sitting in the dining room prior to lunch mumbling some words when a CNA attempted to wipe her hands with a wet wipe without speaking. Again, Beatrice reacted with anger on her face, tensed hands and an increased volume of the mumbling.

Clara was seen being wheeled out of her room after morning care by a CNA and placed in the hallway outside of her room. The CNA first put a blanket on her without talking to her resulting in Clara vocalizing with an angry look on her face. Her vocalizations quieted when the CNA walked away. The CNA came back and put a rolled up blanket on the side of Clara's right arm, which again resulted in the same vocalizations. The third time the CNA approached Clara she brought a pocketbook out of Clara's room and put it in her lap only saying "here Clara" which again resulted in loud vocalizations with an angry facial expression as a response.

Personal care. Although direct observations did not occur during bathing or incontinence care (to maintain participants' privacy and dignity), the investigator learned

from standing in the hall or through conversations with CNAs that six participants exhibited PV episodes during personal care. The PI heard Anna, Clara, Doris, and Fannie exhibiting PVs through a closed door during personal care. The PI also heard Glenn yelling during personal care. Despite verbal cues from the CNA during morning care, Glenn was heard yelling profanity and sexually inappropriate comments at the CNA. Glenn was quiet after receiving care and clean linens.

The full time evening CNA for Irene described her routine and PVs patterns. The CNA reported that Irene called out with care and says "ow" with any movement of her joints. Later that evening, behind the closed door, the PI did not hear vocal noises from inside the room. Although the investigator could not hear Irene making any vocal noises, her routine evening shift CNA reported that she had called out during care as "she always does."

Depends on the day

The NH staff familiar with each participant had identified these participants for this study as someone who exhibited frequent PVs. NH staff who routinely worked with the participants spoke about typical PVs exhibited by the individuals and in some cases even mimicked the participant's PVs (i.e. repetitive words or noises). For four of the participants (Anna, Doris, Fannie, and Harriet) at least one staff member recognized a pattern of the typical time of day an individual exhibited PVs (See Table 3.4). One Registered Nurse (RN), however, said that "unless she's [Anna] really bad" she doesn't notice her vocalizations. For two participants, staff explained situations when PVs occurred: Eleanor would talk gibberish when irritated and Irene had PVs when angry. For the remaining three participants (Beatrice, Clara, and Glenn) staff members stated that

they did not think there was a pattern to the individual's PVs. For instance, a CNA said that Glenn yelled out "whenever he wants".

Table 3.4

Theme 3 – Depends on the Day

Participant	Patterns of PVs	Depends on the Day	Unusually quiet
P1 - Anna	Day RN – *Yells out during care* Day RN Supervisor – *Usually vocal around lunch time* (12pm) Day CNA – *Vocalizations typically around 1pm* Evening CNA – *Usually making noise on the evening shift, even at the end of shift when in bed; hasn't noticed any triggers to PVs*	Day RN – *Some days she's loud* Day CNA – *Vocalizations depends on the day*	Day RN – *You're making her quiet* (She's sleeping) Evening CNA – *unusually quiet* 3 Evening Shift CNAs – joke they want to recruit PI for their shift
P2 - Beatrice	Day CNA – *Doesn't think there's a pattern*	Day CNA – *sometimes PVs all day, sometimes PVs in bed, sometimes quiet*	Evening CNA – *unusual that she's so quiet tonight*
P3 - Clara	Day CNA – PVs vary in terms of time of day, doesn't recognize any triggers		Day RN – *quiet today; your fault, come more often*
P4 - Doris	Day CNA – *sometimes yells out in the morning before morning care* Evening CNA – *usually vocal around 3:30pm* Evening RN – *at 9pm or 10pm she might have vocalizations*	Day RN – *not vocal every morning* Day CNA – *Yells out a lot, but varies, doesn't yell out every day* Evening RN – *vocalizations are not every day*	Evening CNA – *That's not like her* (sleeping) Evening RN – *must be because you are here, you should come every day* (quiet)
P5 - Eleanor	Recreation Aide – *will have a normal conversation unless she's irritated and then she will talk gibberish*	Recreation Aide – *some days she is quiet, some days she talks all the time*	Recreation Aide – *quiet and not talking today; she's out of it* (sleeping)

			Day CNA – *out of it today*
P6 - Fannie	Day CNA – *gets like this in the afternoon* (exhibiting PVs) Evening CNA – *all day, every day* (she had PVs)		
P7 - Glenn	Evening CNA – *he yells out whenever he wants* (normal routine)		
P8 - Harriet	Day CNA – *used to vocalize at lunch, but not anymore; starts to call out later in the day* Evening RN – *getting her to dinner is when vocalizations start*	Activities Leader – *She got her days that she can be feisty*; *if you're around long enough you'll see it* Evening RN – *she has her days*	
P9 - Irene	Day RN – quiet unless she is angry about something	Day CNA – has her days; quiet today, sometimes has vocal outbursts Activities Leader - she gets those days; she has those days she talks; if you're around long enough you'll see it	Evening CNA – not talkative today, sometimes she's talkative, but she might be tired tonight

In addition to the typical patterns or lack of identified patterns, staff reported that most participants had daily fluctuations in their PVs. For six participants (Anna, Beatrice, Doris, Eleanor, Fannie, Harriet, and Irene) staff members made comments such as "she has her days", "some days she's loud" and it "depends on the day" (See Table 3.4). Furthermore, for six of the nine participants, at least one staff member expressed that a participant was "unusually quiet" during the day or evening shift the participant was being observed (See Table 3.4). The participants being "unusually quiet" when the investigator was present was even a joke among staff in two of the NHs. When Doris was

observed to be quiet on the evening shift the RN joked "must be because you are here, you should come every day."

Relationship of Findings to NDB Model

Physiological need states (hunger or thirst, elimination, pain, discomfort and sleep disturbance) and psychosocial need state (affect, match of assistance to ability) from the NDB model were not easily identified through observations and were not significantly reflected in the findings section. Although, one CNA reported that joint movement precipitated PVs during personal care and another participant's PVs became louder and more agitated related a bowel movement. Additionally, many field notes were taken about the physical environment (light level, sound level, and temperature) per the NDB model, however these factors were found to be less important in relation to observed PV episodes after completing a conventional content analysis. The social environment domain from the NDB model appeared to be the most important factors identified as unmet needs and triggers for PV episodes in this study.

Discussion

This observational study set out to describe the social and environmental factors surrounding PVs in NH residents with advanced dementia. For the first theme, *routine of staying in room*, participants considered "disruptive" because of their PVs were observed to spend the majority or all of their time in their rooms alone. This type of intervention is typically used to promote a quieter environment for other residents and staff (Barton et al., 2005). However, past research had identified that PVs such as screaming were associated with greater time alone and a need for sensory stimulation (Algase et al., 1996; Cohen-Mansfield, Werner, & Marx, 1990). It is unclear from this naturalistic

observational study whether being alone for our participant may have contributed to the exacerbation of participants' PVs. We recommend more research looking specifically at the social environment proximal factors from the NDB model as a contributor to PVs.

Recent studies reported on the most common unmet needs of NH residents with dementia: loneliness/need for social contact, boredom/sensory deprivation, and a need for meaningful activity (Cohen-Mansfield et al., 2015), stimulating daytime activities, and company (Hancock, Woods, Challis, & Orrell, 2006). Conversely, NH residents who could participant in interviews reported that social contacts, variety of stimuli and activities, and meaningful/enjoyable activity were among the list of things relevant to their QOL (Schenk, Meyer, Behr, Kuhlmey, & Holzhausen, 2013). Contact with nursing staff is valued when there was a personal commitment, engagement, empathy, and dedication, rather than just someone performing their job in a professional manner (Schenk et al., 2013).

A nurturing social environment within a NH was just as important for older adults as having their physical needs met (Shippee, Henning-Smith, Kane, & Lewis, 2013). Participants in our study who spent more time outside of their rooms had the benefit of being around other residents and NH staff. When residents spent the majority of their time in their rooms, they had limited opportunities to engage in social interactions with others. A study on social integration and interactions among NH residents with dementia (Abbott, Sefcik, & Van Haitsma, 2015) found that participants spent only a small portion of their day (10-16%) interacting with other people. When they did have an interaction (social, care related, and re-direction), this was observed to occur the most in common areas with a large television screen (30%), followed by activity rooms (23%), and

residents' rooms (7%) and less used areas such as the chapel (2%). This demonstrated that 93% of all social, care related or redirection interactions occurred outside the residents' rooms. Based on these findings and our study findings, we recommend that NH staff trial encouraging and assisting residents with advanced dementia and PVs out of their room and into commons areas to increase social interaction opportunities throughout the day and evaluate if its effective for reducing PVs.

Our study suggests that some participants may have benefited from additional attention paid to their social environment. As the NDB model postulates, when there is an unmet need in one of the proximal factors categories (i.e. social environment), then the unmet need is likely to precipitate a need-driven behavior (Algase et al., 1996). What may be happening with some of the study participants is a recurrent negative reinforcing pattern. Participants were moved to their room without staff recognizing the unmet need precipitating their PVS, which may have caused an exacerbation of the PVs due to loneliness or the original unmet need. Participants may have been limited to their rooms because they were still exhibiting PVs or perceived that they might exhibit PVs. Staff were observed or even explained to the investigator that they to respond to others' discomfort caused by a participant's PVs by keeping or moving the participant to their room. It was not clear if the staff considered the notion that the participant's PVs were how they communicated their personal unmet needs.

Exposure to more socialization and activities could prove beneficial with reducing PV episodes. Even when persons with dementia are no longer able to initiate socialization or activities, they may engage when someone else takes the lead and provides prompts (Cook, Fay, & Rockwood, 2008). NH administration may consider adding additional

activities staff hours when developing budgets and hiring staff. A greater number of recreational therapists/activities staff members have been associated with better QOL for NH residents (Shippee et al., 2013).

We also found in this study, that PVs may be provoked or worsened when staff provide care that isn't aligned with principles of dementia care (Sefcik & Cacchione, 2015). This finding suggests that inadequate staff training may contribute to PVs, as postulated in the NDB Model (Beck & Vogelpohl, 1999). Bourgeois and colleagues (2004) found ineffective communication skills among nursing aides working with NH residents with dementia until a training program was implemented. In addition, these interactions were missed opportunities to engage, communicate and socialize with participants.

Further education and training is recommended for all NH staff on how to holistically care for and recognize the needs of residents with dementia and PVs. Specific training on how to implement appropriate interventions is recommended to address unmet needs of persons with dementia (Orrell, 2008). Currently, less than half of the states in the US require some dementia training for NH staff (Burke & Orlowski, 2015). At the time of this study, only one of the states in which the study was completed had recently implemented a regulation that facilities with dementia special care units must provide initial and ongoing mandatory training and support to staff members who care for residents with dementia. Policy implications include a movement to ensure that all US NH staff facility-wide have mandatory annual standardized dementia training. This training would have to be broad in nature and not just focus on appropriately meeting the physical needs of residents with dementia, but also the social needs. Training offered to

NH staff would broaden staff members' perceptions of residents' needs. For this training to be effective however, it needs to be evidence-based and evaluated on whether it makes a difference to the residents' lives (Bird, Anderson, MacPherson, & Blair, 2015; Fossey et al., 2014).

For the third theme, *depends on the day*, we found considerable variation in the incidence of PVs among and within participants. This variation had no discernible explanation, either through observation or staff reports. In persons with dementia and PVs behavioral logs, a systematic assessment completed each shift for a few days, may provide valuable information regarding patterns and potential triggers to PVs.

Although this was a rigorously executed qualitative study, some limitations existed. A limitation of this study was that personal care was not directly observed and therefore, the PI was unable to have a full picture of possible precipitants of PVs during personal care. Although the PI spent an average of 580 minutes observing each participant, it may be useful for the investigator to be present in the NH prior to enrollment to assist with identifying candidates for the study. Additionally, structured interviews at a time when the CNAs were not working on the NH unit may have been more beneficial in eliciting information regarding their residents' routines and potential patterns of PVs. To facilitate gathering comprehensive information from CNAs in future studies we recommend including the CNAs in formal interviews and providing incentives for CNAs to participate. Additionally, the PI's presence may have caused the staff to act differently; however, previous research found no reactivity trends during investigator observations (Schnelle, Ouslander, & Simmons, 2006).

The illumination of how some participants who exhibit PVs spend their days is a strength of this study. Two themes (routine of staying in room and caregivers interactions as triggers to PVs) contribute to the exploration of the importance the social environment proximal factor within the NDB model, particularly staff mix and social engagement, and provided further empirical support for this domain. Nursing and activities staff could use the knowledge generated from this study to improve the QOL of NH residents with advanced dementia and PVs. Effective communication prior to and while interacting with the residents and continued attempts to involve individuals in social and activity programs could meet unmet needs for personal interaction and socialization. Careful attention to patterns of PVs could lead to effective interventions to minimize isolation and PVs. NH administration and educators could use the knowledge generated about the proximal factor staff mix to require more staff education related to all aspects of dementia care. Annual mandatory, evidence-based dementia care training for all NH staff members could have a significant impact on the delivery of holistic quality care for persons with dementia and PVs.

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CHAPTER 4: MULTI-METHODS OBSERVATIONS OF NURSING HOME RESIDENTS WITH ADVANCED DEMENTIA AND PERSISTENT VOCALIZATIONS

Abstract

Background: Persistent vocalizations (PVs) are associated with negative effects on the person exhibiting them and to those in the same environment. Few studies have investigated PVs in-depth and there are no known studies exploring what is occurring physiologically when a person is exhibiting PVs.

Methods: This observational multi-methods study involved simultaneous collection and analysis of both quantitative (sound level readings, heart rates, and respiration rates) and qualitative behavioral analysis of video recordings.

Results: The three participants demonstrated different types of vocalizations and body movements during PV episodes. Physiologically the participants' exhibited higher heart rates compared to baseline heart rates.

Conclusion: Clinical implications of this study include providing interventions that may soothe the person and reduce their PVs, discomfort and stress levels.

Introduction

Persistent vocalizations (PVs), otherwise known as disruptive or problematic vocalizations, have prevalence rates as high as 81% among nursing home (NH) residents with dementia (Kunik et al., 2010). While not all aberrant vocal noises are bothersome, many PVs can be disturbing and stressful to others within proximity of the sounds (Cohen-Mansfield & Werner, 1997b; Sloane et al., 1999). For NH residents with PVs there can be negative effects such as physical exhaustion and placement in isolation to facilitate a more peaceful environment (Barton et al., 2005). When one or more residents are exhibiting PVs in a NH, it makes for a noisy, stressful environment for everyone, including employees, other residents, families, and other visitors.

PVs are any vocal sounds, repetitive verbalizations or inappropriate use of words that are upsetting to others in the same environment. PVs are widely believed to be need-driven behaviors and serve a communicative purpose for older adults with dementia who have limitations with expressing their needs (Algase et al., 1996; Draper et al., 2000; Matteau et al., 2003). According to the Needs-driven Dementia-compromised Behavior (NDB) model (Algase et al., 1996), proximal factors, consisting of aspects of a person's physical and social environment, are likely to precipitate need driven behaviors such as PVs. Proximal factors that may precipitate PVs include physiological (e.g., pain, hunger) and psychosocial (e.g., match of assistance to ability) need states, as well as physical (e.g., lighting levels) and social environments (e.g., presence of others).

PVs are typically characterized negatively as verbal aggression and agitation (Beck et al., 2011; Cohen-Mansfield, 2000; Sefcik & Cacchione, 2015) and are perceived by NH staff as difficult and challenging to manage (Algase et al., 1996). Currently, there

is limited evidence of effective non-pharmacological interventions to manage PVs (Randall & Clissett, 2016). Moreover, pharmacological interventions have generally modest efficacy with many adverse effects, including sedation, worsening of cognitive function and increased risk of stroke and death (Harding & Peel, 2013; Maher et al., 2011; Seitz et al., 2013).

Few studies have explored PVs in-depth and there are no known studies exploring what is occurring physiologically when a person is exhibiting PVs. Having a greater understanding of PVs and the physiological response will lead to interventions to address the physiological response and if discerned, target interventions to address underlying cause(s). To gain a deeper understanding of the complex phenomenon of PVs this descriptive multi-methods study combined physiological measures and directed observations including video recordings of participants.

Physiological measures such as heart rate, respiration rate and body movement are known indicators of stress and pain. High heart rates are indicators of stress and worry (Brosschot, Van Dijk, & Thayer, 2007a; Lewis & Phillips, 2012b). Likewise, changes in respiration rates and body movements are signs of acute stress and pain (American Geriatrics Society, 2002; Warden, Hurley, & Volicer, 2003b). Having the ability to distinguish whether PVs result in physiological changes in heart rate, respiration rate, and body acceleration can facilitate development of interventions to decrease PVs.

The purpose of this study was to describe PVs in persons with advanced dementia in relation to observational and physiological variables prior to, during and after an episode of PVs. The aims were to:

1) Describe characteristics (frequency, type, intensity and non-verbal behaviors) of PVs

using video recordings, directed observations, and decibel readings of PV episodes.

2) Describe physiological characteristics (heart rate and respiration rate) 5 minutes prior, 5 minutes during and 5 minutes after PV episodes.

By describing the characteristics of the PVs and physiological characteristics prior to, during, and after PV episodes, we can provide insight into how to recognize distressful PVs and potentially prevent or decrease PVs in persons with dementia.

Methods

Design

This observational study involved simultaneous collection and analysis of both quantitative and qualitative data. Quantitative data included sound level readings to display intensity of vocalizations, heart rates, and respiration rates. Qualitative data included behavioral coding completed on video recordings.

Participants

This study involved three NH residents who lived in two facilities in the Northeast. Table 4.1 provides the inclusion/exclusion criteria. All participants were Caucasian women with advanced dementia who required total assistance with all activities of daily living. They all had a history of exhibiting PVs as reported by NH staff. Age ranged from 89-93, all took routine psychotropic medications, none had taken prn psychotropic medications at the time of observation and two took routine pain medication. One participant was hard of hearing. Baseline heart rates extracted from the medical record ranged from 69-80. Data were collected for these participants during June and July 2016.

Table 4.1

Inclusion/Exclusion Criteria

Inclusion criteria	***Exclusion criteria***
• A medical diagnosis of dementia • Moderate to severe dementia as determined by a MMSE score ≤20 • Understands and speaks English • Ability to obtain consent from the resident and/or the resident's responsible party • Consent or assent from the resident • A history of persistent vocalizations per nursing staff report • Resident requires extensive assistance by staff to ambulate or is non-ambulatory (to allow for consistent videotaping) • 65 years old or greater • Long-term care resident in the nursing home	• A documented serious mental illness other than dementia • A MMSE score >20 • Speaks a language other than English • Inability to obtain consent from the resident and/or the resident's responsible party • Dissent from the resident • Has a heart pacemaker (BioHarness cannot be used) • A history of frequently removing clothing as reported by NH staff (participant may remove BioHarness during use) • Ambulates independently and wanders • Less than 65 years of age • Has a documented need for frequent trips outside of the facility (such as hemodialysis or chemotherapy) • Sub-acute or post-acute patient • A marked deformity of the back or torso (such as kyphosis or multiple sclerosis) or a wound that would interfere with wearing the BioHarness properly • Bariatric residents (maximum length of garment belts is 52") • Physical restraints are being used

Ethical Considerations

Each NH administration and the University of Pennsylvania Institutional Review Board approved this study. Written informed consent was provided by the person with

dementia's legally authorized representative. Acting agreeable and cooperative with the application of the garment belt was evidence of assent from participants. Indicators of dissent included verbal or non-verbal signs (i.e., attempting to remove the garment belt) that suggested an unwillingness to participate (Black et al., 2010). The primary investigator (PI) was a Registered Nurse with extensive background of working in NHs with older adults with advanced dementia. This paper used pseudonyms for the participants.

Procedures

The PI spent a mean of 10 hours on average observing each participant prior to data collection for this study to gain an understanding of participants' routine and PVs patterns. We used this information to schedule a time to conduct video observations and collect physiological data. The PI notified NH staff of the observation schedule. On the day of recording, assent was received from the participant and a nursing assistant assisted with placing the Zephyr BioHarness 3.0 garment belt around the participants' torso. The PI observed participants during a time that would not interfere with their normal routine. Mealtime and personal care times were avoided. The PI observed two participants in their bedroom, as this is where they routinely sat. The PI observed the third participant sitting in an enclosed sun patio. The PI operated a high-definition video recorder connected to a tripod. In rare cases when NH staff entered the frame, the lens was covered because the staff were not consented for video recording. The protocol was to video record participants, collect sound meter readings, and physiological data for approximately two-hours on each participant. The PI extracted the participant's demographic data from the participants' medical record.

Measures and Data Collection

Video recordings and behavioral coding. To attain three 5-minutes segments of the pre-vocalization period, PV episode, and post-vocalization period, the PI obtained continuous video recordings of participants. In cases where the participants were not silent for five-full minutes during the pre-vocalization or post-vocalization period, a 2-minute video segment of the participant being silent was selected. The selected time intervals are guided by a study that used 4-minute and 2-minute time segment looking at heart rate reactivity in infants and included video coding (Holsti, Grunau, Oberlander, & Whitfield, 2005). The PI and a research assistant (RA) together used the following criteria to select video footage for analysis:

- Pre-vocalization period: In each case, participants exhibited PVs prior to the application of the garment belt and at the beginning of data recording. Therefore, the pre-vocalization period was identified from a video segment of at least two minutes and no more than five minutes following one complete minute where the participant did not exhibit PVs.
- Vocalization period: Following the selection of the Pre-vocalization video segment the video tape was reviewed by the PI and RA to identify a full 5 minutes of consistent PVs with only brief quiet periods and without NH staff interruptions.
- Post-vocalization period: Following the vocalization period a video segment was selected following one complete minute of the participant without any PVs closest to the end of the two hour video recording (Cohen-Mansfield & Werner, 1997a).

To address the first aim of the study a codebook was developed by the PI and RA to capture facial expressions, verbal expressions, and behavioral expressions for coding to

describe the characteristics (frequency, type, intensity and non-verbal behaviors) of the PVs. The codebook was then revised after feedback from the full team. The codebook also used the items from the Verbal Behavior Scale (VBS) (Beck et al., 2011), Pain Assessment in Advanced Dementia Scale (PAINAD) (Horgas & Miller, 2008), and relevant literature (Sefcik & Cacchione, 2015). All items from the VBS and PAINAD were included in the codebook used for video coding. When the videos were previewed new codes for any additional observed behaviors were added. During the coding process, when any analytical decisions were made the codebook was updated. The PI and RA coded all video segments together frame by frame in the Noldus software Observer XT and reached complete agreement with all codes.

Intensity of vocalizations. A 3M SoundPro sound level meter was used to record continuous sound levels. It allowed for quantification of sound level at one second increments and had the ability to record sounds ranging from a soft whisper (30dB) to a gun blast (130dB) (Joosse, 2011; Knight & Baguley, 2007).

Biophysiological data. The Zephyr BioHarness System was used to collect continuous heart rate, breathing rate and body acceleration data. This lightweight portable system was worn by participants around their torso, directly on their skin underneath clothing. The device was made out of conductive fabric with electrocardiogram (ECG) and respiration sensors inside the fabric. The use of the device was pilot tested with older adults with advanced dementia and found to be well tolerated and did not create restlessness or agitation (Sefcik, Libonati, & Cacchione, 2014).

Verbal Behavior Scale (VBS) – This eight item tool captures verbal behaviors and is a subscale of the Disruptive Behavior Scale (DBS) (Beck et al., 2011). The eight items fall

under one of two categories – aggressive or agitated. Under the aggressive category are: screams/yells, uses hostile/accusatory language toward others, uses obscene or profane language, makes threats implying physical harm to others, makes threats implying physical harm to self. Under the agitated category are the following variables: repeats phrase(s)/word(s), talks constantly, and makes repetitious noises. Interrater reliability tests of the full 45 item DBS yielded an interclass correlation coefficient of .80 ($P < .001$) (Beck et al., 1998). The PI and RA completed VBS for each of the pre-vocalization, vocalizing and post-vocalizing from the video segments for each participant.

Pain Assessment in Advanced Dementia Scale (PAINAD) – This is a 5-item behavioral observation tool focusing on breathing, vocalizations, facial expressions, body language, and consolability as indicators of pain. The items are rated from 0 (normal) to 2 (worst symptoms) with descriptions given of indicators of pain to guide the rating. The PAINAD has acceptable validity and reliability (Herr, Bursch, Ersek, Miller, & Swafford, 2010; Horgas & Miller, 2008; Warden et al., 2003b). The PI and RA completed the PAINAD for each of the pre-vocalization, vocalizing and post vocalizing from the video segments for each participant.

Results

All participants were exhibiting PVs prior to the start of data collection; therefore, a quiet time was selected as the pre-vocalization period after one minute of observed silence at the beginning of the video recording. The PI selected a 2-minute post-vocalization period for Beatrice because she did not have a post-vocalization 5-minute period of analysis toward the end of the video recording. Clara had 5-min intervals for all three-time periods. In Doris' case pre-vocalization periods consisted of less than 5

minutes of silence before the next PV episode started, so a 2-minute period was selected for analysis.

Aim 1

PV Frequency and Type. During the 5-minute vocalization observation period the three participants exhibited different types and frequencies of PVs. Beatrice exhibited a mixture of noises and words for two long periods of time that consisted of 99% of the observation (1% of the time was a brief quiet period). Clara exhibited 12 repetitious noise episodes that consisted of 63% of the time (37% brief quiet periods). Doris exhibited 5 periods of screaming that consisted of 89% of the time (11% brief quiet periods). The PI counted brief quiet periods that lasted more than 5 seconds. No other types of vocalizations were observed.

Intensity. Decibel (dB) readings revealed a range of 46 to 59 dB for all the participants during the pre-vocalization period and 47 to 59 dB post-vocalization period. These decibel readings represent the level of ambient noise in the environment. Beatrice sat in an enclosed glass patio with the air conditioner running throughout the observation. Clara had ambient background noise heard during 16% of the pre-vocalization period, 65% of the vocalization time point, and 87% of the post-vocalization period, which consisted primarily of staff members talking near the entrance of Clara's room. An alarm was ringing in the hallway for 4% of the pre-vocalization observation. Doris had a television playing in her private room for all three time frames.

During the vocalization periods (See Table 4.2), dB readings reached as high as 89dB. Clara's dB readings were the least of the three participants with the mean dB for

the vocalization period being 54 dB with a peak of 64 dB. Doris had the most intense vocalizations with a mean dB reading in her room of 78 dB and a peak of 89 dB.

Table 4.2

Decibel Readings from Three Time Periods

Participant	**Mean (Min-Max)**		
	Beatrice	Clara	Doris
Pre-Vocalization dB	59 (59-62)	46 (46-50)	57 (54-61)
Vocalization dB	64 (60-68)	54 (46-64)	78 (56-89)
Post-Vocalization dB	59 (59-60)	47 (47-51)	58 (53-63)

Non-verbal behaviors. Behavioral coding observations (See Table 4.3) of Beatrice during the PV interval showed that she spent the majority of time fidgeting (97%) (PAINAD Score = 5; VBS score = 2). This was evident by her moving her hand around for 97% of the time. For smaller percentages of time she was moving her hand and arm way from her body (5%), picking her clothing (4%), moving her legs (2%), rocking (2%), shaking head (2%), and touching her face (2%). During the pre-vocalization period, she was fidgeting 95% of the time with less fidgeting during the post-vocalization period (38%). During the vocalization period, Beatrice showed anger on her face per the PAINAD definition in the codebook, which was different from the frown she displayed in the pre-vocalization period and a flat effect in the post-vocalization period. Her eyes were completely open during the vocalization period, which was different from the pre-

vocalization period where they were open 53% of the time, and the post-vocalization period where they were open 11% of the time.

The PI observed Clara's fists clenched during the vocalization period 63% of the time (PAINAD score = 4;VBS score = 12), where she looked relaxed during the pre- and post-vocalization periods (PAINAD score = 0 both time periods). Behavioral coding for Clara showed that the majority of her body movements occurred during the vocalization period. Her hands were primarily moving (77%), as well as her legs moving (34%), hand and arm moving away from her body (32%), and her mouth moving without vocalizations being heard (25%). The PI observed far less movements in the pre-vocalization period (leg movement 7%; mouth moving without vocalizations 7%) and in the post-vocalization period (leg movement 9%; moving hand 1%). Clara had her eyes closed 96% of the time during the vocalization period compared to 97% in the pre-vocalization period and 100% during the post-vocalization period. Clara's facial expressions were flat for all three-time periods.

The PI observed Doris tense during the entire vocalization period (VBS score = 5) and during the post-vocalization period (PAINAD Score during PV episode = 6; post-vocalization = 6), which was different from the pre-vocalization period where the PI only observed a clenched fist (PAINAD score = 3). Doris was moving her legs the entire 5-minute period of the vocalization period whereas there was no leg movement in the pre-vocalization period and leg movement only 5% of the post-vocalization period. All three time intervals she had a consistent hand tremor. She also had her eyes open and a frown observed throughout all three-time intervals. Additional observations included a nurse entering the room to assess Doris who was yelling loudly during the last 1% of the time

interval. Prior to the post-vocalization period the PI began holding Doris' hand because of the intense, agitated yelling. The PI coded as consoling through touch during the post-vocalization period.

Table 4.3

Behavioral Coding

Behaviors	Modifiers	Percentage (interval duration)								
		Beatrice			Clara			Doris		
		Pre-	Vocal	Post-	Pre-	Vocal	Post-	Pre-	Vocal	Post-
Relaxed		5		62	100	37	100			
Not relaxed	Fidgeting	95	97	38		63				
	Fists clenched							100		
	Rigid		3							
	Tense								100	100
No body movement		6	3	33	86	4	90			
Body movement	Hand tremor							100	100	100
	Hand/arm motion away from the body	1	5	1		32				
	Leg movement	12	2		7	34	9		100	5
	Moving hand	94	97	67		77	1			
	Moving mouth repeatedly				7	25				
	Picking at clothing	2	4							
	Rocking	13	2							
	Shaking head	2	2							
	Touching eyes	1								
	Touching face	24	2	17						
Flat affect				100	100	100	100			
Facial Expressions	Angry		100							
	Frown	100						100	100	100
Eyes open		53	100	11	3	4		100	100	100
Eyes closed		47		89	97	96	100			
No consoling		100	100	100	100	100	100	100	100	
Yes consoling	Investigator									100
PAINAD		2	5	3	0	4	0	3	6	6
VBS		0	2	0	0	12	0	0	5	0

Aim 2

Heart rate and respiration rate. Each participant's heart rates and respiration rates for each vocalization period are presented in Table 4.4. Because each participant was vocalizing prior to the BioHarness system being placed, a baseline heart rate for each participant was extracted from their medical record. There was very little variation in heart and respiration rates during observation. Baseline respiratory rates were not recently recorded in the medical record. Beatrice's baseline heart rate was 80. Her mean heart rate during all three vocalization periods was 94 demonstrating a mean increase in her heart rate of 14 beats per minute. Clara's baseline heart rate was also 80, her mean heart rate during the three-vocalization periods ranged from 92 to 97 bpm. Demonstrating a mean increase of 15 bpm. Doris' baseline heart rate was the lowest at 69 bpm, her mean heart rate during the three-vocalization periods ranged from 96 to 103 bpm. Demonstrating a mean increase of 30 bpm. Respiration rates on the other hand for all three participants were low during the three-vocalization periods (See Table 4.4).

Table 4.4

Heart Rates and Respiration Rates

Physiological Interval Mean (Min-Max)									
Physiological Data	**Beatrice**			**Clara**			**Doris**		
	Pre-	**Vocal**	**Post-**	**Pre-**	**Vocal**	**Post-**	**Pre-**	**Vocal**	**Post-**
Heart Rate (bpm)	94 (90-101)	94 (89-98)	89 (86-94)	98 (92-103)	97 (93-101)	92 (89-96)	103 (97-107)	100 (95-107)	96 (92-102)
Baseline HR	80			80			69		
Respiration Rate (breaths/min)	11 (6-16)	10 (6-16)	10 (8-12)	11 (4-19)	11 (3-17)	11 (4-15)	12 (8-16)	8 (2-14)	12 (7-17)

Despite a small sample size, a General Linear Model Repeated Measures ANOVA was completed in SPSS. We used baseline heart rates and mean heart rates for each condition: pre-vocalization, vocalizing and post-vocalization. Due to the small sample size, only trends toward significance were seen (Table 4.5) when contrasting baseline heart rates with each condition. Analyzing the within subjects across the three conditions demonstrated small, but statistically significant differences between vocalizing and post vocalization and pre-vocalization and vocalizing. See Table 4.5.

Table 4.5

Repeated Measures ANOVA

Heart Rates - Overall Mean (SD)			
Baseline	Pre-vocalizations	Vocalization	Post-vocalization
76 (6.4)+	98 (4.5)*	97 (3)^+	92 (3.5)*^
Pre-Vocalization to Vocalization * p = 0.009 Vocalization to Post-vocalization ^ p = 0.005 Baseline to Vocalization + p = 0.059			

Discussion

The purpose of this study was to describe PVs in persons with advanced dementia in relation to observational and physiological variables prior to, during and after an

episode of PVs. We observed different types and intensity of vocalizations and body movements during PV episodes for each participant. One participant vocalized for 99% of a 5-minute time period. While one participant exhibited PVs, the sound meter captured the highest reading of 89 dB which is equivalent to a hair dryer blowing (Centers for Disease Control and Prevention, 2017). Participants exhibited increased heart rates from their baseline during all three-time periods, suggestive of physiologic stress. Replication of this study with larger sample sizes are needed to confirm statistical findings.

On the days of data collection all three participants were vocalizing prior to the application of the garment belt and since two participants were so vocal, we were unable to obtain a full 5-minutes of silence during a pre-vocalization period for one person and 5-minutes of silence during a post-vocalization period for another. We recommend for future studies to select smaller time periods (e.g. 2 or 3 minutes) to analyze so that the 3 time points are consistent in the length of time. We found that our participants each exhibited their own type of vocalizations during the vocalization period for the majority of the time frame (63-99% of 5 minutes) with only short periods of silence. The literature supports that PVs can be episodic in nature and last minutes, or they can be constant and last over an entire shift (Barton et al., 2005; Palese et al., 2009).

With the combination of ambient background noise already occurring and the addition of vocalizations, mean decibel readings ranged from 54 to 78 dB. Sound level readings of 30 dB correspond with whispering, 60 dB with normal conversation, 80 dB with a ringing telephone, and 90 dB with a hair dryer (Centers for Disease Control and Prevention, 2017). The high mean decibel reading of 78 corresponded to Doris' intense yelling and with the yelling being almost as loud as a continuously ringing phone, the PI

offered Doris' consoling by holding her hand. Doris' yelling slowed and then stopped during the handholding.

The intense volume of PVs contribute negatively to the NH environment and contribute to stress on the staff and other residents (Bourbonnais & Ducharme, 2010). However, persons with dementia and PVs should be the first concern as they may be expressing an unmet need (Algase et al., 1996). This is the first known study to look at what is happening physiologically when a person with dementia is exhibiting PVs. Physiologically, our three participants' had relatively high heart rates during the three time periods compared to baseline heart rates. This could be evidence of a state of stress during PV episodes, including the pre-vocalization and post-vocalization time period. Each of the participants were vocalizing before the BioHarness garment belt was applied, likely not allowing for a resting baseline heart rate to be obtained during the pre-vocalization period.

Participants had more observable body movements during PV episodes, compared to the pre-vocalization and post-vocalization period. Our study findings also show that all three participants were observed moving hands and legs, and not their torsos during the video recordings sections we analyzed. We specifically enrolled individuals who were non-mobile for this study to allow for consistent video recording. We suggest replicating this study in participants with PVs who are more mobile to describe what their body acceleration is prior to, during and after a PV episode. However, it might be difficult to video record and consistently code video recordings if participants' backs are to the camera.

We acknowledge that we only had three participants in this study. However, clinical implications related to these participants include providing interventions that can potentially soothe the person and reduce their PVs, discomfort and stress levels. It is widely believed that PVs are a way that persons with dementia communicate unmet needs (Algase et al., 1996). The Need-drive Dementia-compromised Behavior (NDB) model provides guidance for assessment of unmet needs which include physiological and psychosocial need states and physical and social environments factors (Algase et al., 1996). Nurses working to identify unmet needs should simultaneous assess psychological and physical discomfort and pain (Lemay & Landreville, 2010). Psychological discomfort states of people with PVs could be related to depression, anxiety, or sleep disturbances (Lemay & Landreville, 2010). Physical pain may also be the culprit as verbal and physical aggression has been associated with NH residents with dementia whom were unable to self-report pain (Ahn, Garvan, & Lyon, 2015; Chow et al., 2016). NH staff could develop a checklist based off the proximal factors in the NDB model to guide the identification of unmet needs and various practical individualized interventions to implement to help minimize PVs. Knowing the resident and being proactive to anticipate their needs is the best approach (Algase et al., 1996). For example, making sure the resident is hydrated, seated comfortably, and has social interactions planned throughout the day, may reduce PV episodes. Nursing staff assessing for psychological and physical discomfort and pain should also be a priority.

When non-pharmacological comfort treatments are not effective in reducing PVs, then non-opioid analgesics are recommended to treat discomfort or pain that the older adults with dementia may not be able to communicate (Kovach et al., 2006; Lemay &

Landreville, 2010). The next recommended step is a consultation by a practitioner for potential pharmacological treatment of depression or anxiety as warranted with the consideration of other psychotropic medication after all alternatives have been ineffective (Kovach et al., 2006; Lemay & Landreville, 2010). In our study two participants were receiving routine pain medication, although one of these participant did have a PAINAD score from the video observations of 6 (10 being most severe) during the vocalization and post-vocalization intervals. Pain assessments on all older adults with dementia and PVs should be completed routinely to assess for adjustments needed in their medication dosages. There are limitations to current objective pain scales and the use of biomarkers such as cardiac measures of NH residents with dementia warrants further investigation (Chow et al., 2016).

We acknowledge limitations of this study. The homogeneity of the participants and small sample size limited the generalizability. The complexity of the multi-methods data collection and analysis necessitated the small sample size. This multi-methods study will inform future research with larger samples. Additionally, all participants were vocalizing prior to the application of the garment belt, and therefore we do not have a complete picture of the person when resting and not vocalizing. Future research recommendations include observing the participant on a day when they are not exhibiting PVs and comparing these observations to a day when they do exhibit PVs.

In summary, this is the first known study exploring what is occurring physiologically when a person is exhibiting PVs. We simultaneously analyzed quantitative (sound level readings, heart rates, and respiratory rates) data and qualitative behavioral coding of participant recordings. We identified that our participants exhibited

different types of vocalizations and body movements during PVs episodes. Physiologically, our three participants' exhibited high heart rates compared to baseline heart rates. We suggest that clinical implications of this study include providing interventions that may soothe the person and reduce their PVs, discomfort and stress levels.

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CHAPTER 5: CONCLUSION

Introduction

Major gaps exist in the literature related to the phenomenon of PVs among NH residents with advanced dementia. PVs have a negative impact on the residents exhibiting them, as well as other NH residents, staff and visitors (Barton et al., 2005; Cohen-Mansfield & Werner, 1997b; Sloane et al., 1999). We designed a descriptive observational multi-methods study to gain a deeper understanding of PVs exhibited by NH residents with advanced dementia. Through the combination of field observations and physiological measures and directed observations, a deeper understanding of this complex phenomenon contributed to the current limited understanding of this phenomenon. The Need-driven Dementia-compromised Behavior (NDB) model informed this investigation (Algase et al., 1996).

The specific aims of this dissertation were to: 1) describe the physical and social environmental contexts surrounding PVs in NH residents with advanced dementia; 2) describe characteristics (type, frequency, intensity and non-verbal behaviors) of PVs using video recordings, directed observations, and decibel readings of PV episode; and 3) describe physiological characteristics (heart rate and respiration rate) prior, during and after PV episodes. This final chapter summarizes the results and discusses the challenges associated with conducting this research, implications for clinical practice and future research.

Summary of Findings

The first aim was to describe the physical and social environmental contexts surrounding PVs in NH residents with advanced dementia. This aim was addressed

through completing a systematic review to determine the state of the science on the phenomenon of PVs and completing participant field observations of older adults living in a NH with dementia and PVs. The second and third aims were: (2) To describe characteristics (type, frequency, intensity and non-verbal behaviors) of PVs using video recordings, directed observations, and decibel readings of PV episodes, and (3) To describe physiological characteristics (heart rate and respiration rate) prior, during and after PV episodes. We achieved these aims through video recording participants with advanced dementia and PVs while collecting continuous sound meter readings and physiological data (heart rate and respiratory rate). We used the software Observer XT to analyze these data points in addition to completing behavioral coding in the software. Table 5.1 presents the principle findings of each aim.

Table 5.1

Principle Findings of Specific Aims

Aim	**Chapter**	**Principle Findings**
Aim 1: To describe the physical and social environmental contexts surrounding PVs in NH residents with advanced dementia.	II	Our literature search revealed 8 research articles that met inclusion criteria. These studies were published in 2011 or earlier and involved small sample sizes. Only one non-pharmacological intervention study for PVs exhibited by NH residents with dementia was identified.
	III	Three themes emerged from the participant observations: 1) *Routine of Staying in Room*; 2) *Caregivers Interactions as Triggers to PVs* and 3) *Depends on the Day*.
Aim 2: To describe characteristics (type, frequency, intensity and non-verbal behaviors) of PVs using video	IV	Observed were different types and intensity of vocalizations and body movements during PV episodes for each participant. One participant vocalized for 99% of a 5-minute time period. Another participant's PVs measured as high as 89

recordings, directed observations, and decibel readings of PV episodes.		dB on the sound meter. More body movements were observed during PV episodes.
Aim 3: To describe physiological characteristics (heart rate and respiration rate) prior, during and after PV episodes.	IV	Participants' exhibited increased heart rates from their baseline during all three-time periods, evidence of physiologic stress. Respiration rates were low in general during the three time periods.

Overall, the findings of this dissertation adds to the currently limited knowledge of PVs among NH residents with advanced dementia. With this dissertation, we have continued the work to refocus the view of PVs as being disruptive or problematic from the perspective of the person observing the behavior to a less judgmental, more objective label that focuses on the needs of the residents with dementia. We have suggested future research use the non-judgmental term of persistent vocalizations (PVs). We also suggest the following definition to be used in future studies: PVs are vocal sounds, repetitive verbalizations or inappropriate used of words that are upsetting either to the persons exhibiting them or to others in the environment, including other residents, care providers, and family members. In addition, with this body of work we added to the science regarding potential precipitants and physiological responses of PVs.

Challenges

There were several challenges associated with this study. The most significant challenge was gaining entrée into NHs to start data collection (Sefcik & Kim, 2016). Despite having letters of support from NH corporate offices or individual NH

adminstration support prior to starting data collection, it was difficult to make initial contact with NH administrators and/or Directors of Nursing when everything was in place to start the study. Or, there were times initial contact was possible, but it was difficult to maintain contact to get everything in place to start the study. In one situation there was a Director of Nursing who was ready to move forward with allowing the study to commence but then shortly after left her position. Following this I was unable to connect with the new DON despite multiple attempts. In contrast, there was a situation where a NH was interested in allowing the study to take place, however did not have anyone who met the study criteria during the time of recruitment.

Another challenge was obtaining consent from the legally authorized representatives (LAR). Per the NH administrations' wishes, a key NH staff member was to reach out to LARs on my behalf to obtain permission for me to contact them with additional study material. In some situations contact was delayed because of the NH staff members' workload. In addition, we had less than a 50% enrollment rate. There were four cases where LARs told NH staff that they didn't want to learn more about the study, two cases where I mailed information about the study but was unable to make contact with the LAR to discuss the study further, and five cases where the LAR did not want to consent to have their loved one in the study.

An additional challenge occurred during data collection for the second phase of the study to gather video recordings, sound meter readings and BioHarness data (for heart rates and respiration rates). I found through my field observations and conversations with nursing staff on the units that some of the participants PVs were more episodic than the key NH contacts had initially indicated to me. With other participants who were observed

to exhibit more frequent PVs, there were days I would go into the NH for data collection with all the equipment and participants would be sleepy and not exhibiting PVs. This relates to the theme *Depends on the Day* from the field observations. In some cases the staff were unable to share with me any consistent patterns to the participants' PVs that could help me schedule a time when I could most likely record PV episodes. The staff could however easily cite to me previous days that week that the participants had long PV episodes. Additionally, the data analyzed with the video recordings for this dissertation were on days when the participants had been observed to exhibit PVs prior to setting up the equipment. I had hoped that the participants would have longer periods of silence during the observation to show a true quiet period, however this was not the case. What we saw instead were only brief periods of quiet before vocalizing again.

Barriers to conducting research in NHs has been previously documented (Buckwalter et al., 2009; Garcia et al., 2013; Hall et al., 2009; Maas et al., 2002; Mentes & Tripp-Reimer, 2002; Sefcik & Abbott, 2017; Sefcik & Kim, 2016; Tilden et al., 2002). Challenges of gaining entrée into NHs, staff turnover and support, gaining consent from LARs, and the emotional challenge of investigating PVs may be among some of the reasons that our state of the science on NH residents with advanced dementia and PVs demonstrated little attention has been given to this phenomemon.

Regardless of the challenges faced by researchers to conduct NH research, continued research involving NH residents with dementia and PVs is needed to improve quality of life for all NH residents. Below we discuss implications for clinical practice based on our study findings and recommend areas for future research.

Implications for Clinical Practice

This body of work has some important clinical implications. From analysis of field notes from directed observations we found that residents who were considered the most disruptive because of their PVs spent the majority of their time in their rooms (Theme *Routine of Staying in Room*). Not only may this contribute to further episodes of PVs related to loneliness or decreased stimulation (Algase et al., 1996; Cohen-Mansfield et al., 1990), this reduces staff members opportunity to observe the PV episodes, recognize potential triggers, and provide effective interventions to reduce PVs.

When we analyzed the physiological data of three participants prior to, during, and after PV episodes, we found heart rates higher than the participants' baseline. In one participant the difference between her baseline heart rate and mean heart rate during the three vocalization time periods (prior to, during and after a PV episode) was 30 bpm. This participant also had higher pain scores from the Pain Assessment in Advanced Dementia (PAINAD) scale completed during the video coding. We believe that all this information together suggest that if NH staff complete assessments and provide soothing interventions for the older adults with PVs, a reduction with their PVs, discomfort, and stress levels may occur.

Based on our findings we also recommend further education and training for all NH staff on how to holistically care for and recognize the needs of residents with dementia and PVs. We found that *Caregivers Interactions as Triggers to PVs* (providing care without communicating and personal care) provoked PVs. Ongoing, mandatory education that aligns with priniciples of dementia care (Sefcik & Cacchione, 2015) that could be effective at reducing PV epidsodes. We recommend that this training have a

specific focus on the residents' social environment since this domain from the NDB model appeared to be the most important factor identified as unmet needs and triggers for PV episodes in this study.

Implications for Future Research

Additional studies focused on NH residents with advanced dementia are essential. Our state of the science systematic review demonstrated the paucity of focused research on this phenomemon. When all behavioral symptoms of dementia are studied and reported together, it is difficult to extrapulate the characteristics of PVs and what interventions are most effective for preventing, treating or reducing PVs.

Based on our study findings, we believe that future research is critical in the area of intervention research that particularly addresses physical and psychological pain and social isolation. The NDB model could drive the development of these interventions. We only identified one intervention study focused solely on NH residents with dementia and PVs. Future directions for intervention research include monitoring NH residents with dementia and PVs physiological responses to delivered interventions aimed at reducing the behavior. Using video recordings, Pain Assessment in People With Dementia (PAINAD), Verbal Behavior Scale (VBS) as well as the BioHarness garment belt to combine behavioral and physiological data and comparing the days without vocalizations with days with vocalizations is recommended as a new direction building on this research. However, there were some challenges with having staff assist with placing the BioHarness on participants due to busy schedules, as well as times when participants wore the BioHarness and did not exhibit PVs. We recommend utilizing devices such as actigraphs that are easier to apply to older adults with dementia (on their wrists) and can

record continous data for longer periods of time. To address any of these proposed directions for research, larger sample sizes are required. This will entail significant support for research from NHs with persons with dementia and PVs, engagement with their LARS, and funding from extramural sources.

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