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Understanding Sleep And Sleep Disturbances In Nursing-Home Eligible Community Dwelling Older Adults: A Mixed Methods Study

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Abstract
ABSTRACT

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Miranda S. Varrasse

Barbara J. Riegel

It is estimated that one-half to two-thirds of older adults have at least one sleep related complaint and older adults with chronic conditions and functional limitations are even more likely to suffer from sleep disturbances. Sleep disturbances can lead to poor overall health, a decrease in physical and cognitive function, and an increase in health care service utilization and cost. Yet, sleep complaints are often underreported and underdiagnosed. Nursing-home eligible older adults who remain living in the community are at an increased risk of nursing home placement, due to their high level of care needs, comorbidities and functional status. Sleep disturbances may increase the risk of decline but relatively little is known about sleep disturbances in this high risk group. The overall purpose of this concurrent nested mixed methods study [QUAL+quan] was to describe sleep characteristics in 40 nursing-home eligible, community dwelling older adults. Qualitative data were weighted more heavily and obtained via semi-structured interviews. Quantitative data consisted of three self-report sleep surveys and one week of actigraphy and sleep diary. Data were collected concurrently and analyzed sequentially.

Our final sample of 40 older adults was comprised of Black (100%), primarily female (85%) older adults with a mean age of 72.37 ± 9.54. The two major findings were: 1) the majority of the sample had objectively poor sleep quality and napped frequently during the day, regardless of self-perceptions of sleep quality, and 2) these older adults had adjusted their health expectations and adapted to their sleep disturbances. We also identified modifiable targets for intervention development and testing. To our knowledge this is the first mixed methods study of sleep in nursing-home eligible, community dwelling, at-risk older adults. These results begin to equip us to intervene on modifiable factors that have the potential to improve health outcomes in this vulnerable population.

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DEDICATION

To my fiancé, Tommy, for your unconditional love and support during this adventure. Thank you for encouraging me to pursue my dreams and celebrating each milestone with me along the way.

To my parents, for your inspiration throughout my life. Thank you for always believing in me and providing me with countless opportunities to grow and learn.

To my family and friends, for your constant reminder to enjoy life. Thank you for the motivation to persevere through the most challenging times.

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ABSTRACT

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Our final sample of 40 older adults was comprised of Black (100%), primarily female (85%) older adults with a mean age of 72.37 ± 9.54. The two major findings were: 1) the

majority of the sample had objectively poor sleep quality and napped frequently during the day, regardless of self-perceptions of sleep quality, and 2) these older adults had adjusted their health expectations and adapted to their sleep disturbances. We also identified modifiable targets for intervention development and testing. To our knowledge this is the first mixed methods study of sleep in nursing-home eligible, community dwelling, at-risk older adults. These results begin to equip us to intervene on modifiable factors that have the potential to improve health outcomes in this vulnerable population.

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CHAPTER 1: INTRODUCTION

Human beings spend about one third of each day sleeping. To put this into perspective, a 60-year-old has spent about 20 years of his/her life asleep. Despite the fact that sleep is an integral part of human lives, the scientific knowledge about this phenomenon has only developed over the past five decades. Sleep is defined as "a reversible state of perceptual disengagement and unresponsiveness from the environment"[1] and is characterized by certain key features such as its natural recurrence, decreased or absent consciousness, muscle relaxation, immobility, and stereotypical body posturing.[2]

It is estimated that 50 to 70 million Americans suffer from some type of sleep disorder, impacting daily function as well as adversely affecting health and longevity.[3] As the previous statistic requires assessment and diagnosis of a sleep disorder, it can be inferred that sleep disturbances are even more numerous. Sleep disturbances and sleep disorders represent a major unmet public health burden.[3] Sleep disturbances are highly prevalent in older adults, yet are often undetected. Sleep disturbance is a broad term that is useful for capturing global sleep complaints and is used throughout this dissertation to refer to any sleep disruption that includes *dysregulation of sleep homeostasis, sleep deficiency, sleep fragmentation, insufficient sleep or impairment of sleep quality or quantity*.[4] Sleep disturbances include, but are not limited to, nonrestorative sleep, insufficient sleep, poor sleep quality, sleep continuity disturbances, and long or short sleep duration. Sleep disturbances extend beyond the boundaries of traditional sleep disorders,[5] but sleep disorders such as insomnia, sleep apnea, restless leg syndrome, periodic limb movement disorders, parasomnias, hypersomnias, and circadian disorders

all include some type of sleep disturbance in their diagnostic nosologies. Insomnia symptoms are the most common sleep disturbances and insomnia disorder is the most common sleep disorder affecting older adults.[6] These terms are described further in Chapter 2.

The importance of assessing and treating sleep disturbances is evolving. Sleep has been the focus of two Institute of Medicine (IOM) Reports[3,7] and is included in the Healthy People 2020 goals.[8] Two major research agendas also focused on sleep, one published by the National Center on Sleep Disorders Research within the National Institutes of Health[4] and another by a joint task force of the Sleep Research Society and the American Academy of Sleep Medicine.[9] Older adults are particularly susceptible to sleep disturbances due to physiological age-related changes, but these disturbances are not considered a normal part of aging. Sleep disturbances can have a wide range of detrimental physical, psychological, social, and economical consequences if left untreated. As such, it is critical to address sleep in older adults.

The older adult population is expanding, and aging is associated with chronic conditions and functional limitations that accentuate sleep disturbances. According to the U.S. Census Bureau, the number of individuals over the age of 65 is expected to increase to 72.1 million by 2030, accounting for 19% of the U.S. population.[10] Approximately three quarters of Americans aged 65 and older have two or more chronic medical conditions[11] and more than one third of people 65 years and older are disabled or experience some limits in daily function.[12] Research suggests that mobility impairment and physical inactivity are risk factors for sleep disturbances.[13,14] As the majority of older adults want to remain living in their homes, despite functional limitations, we need to

have a better understanding of sleep and sleep disturbances in this at-risk group. Failure to recognize sleep disturbances in at-risk older adults precludes optimizing sleep health, diagnosing and treating sleep disorders, and preventing adverse effects on health and quality of life.

Specific Aims

Healthy sleep is critical for maintaining functional independence, optimizing quality of life, and potentially delaying institutionalization.[15,16] It is estimated that one-half to two-thirds of older adults have at least one sleep related complaint and older adults with chronic conditions and functional limitations are even more likely to suffer from sleep disturbances.[16,17] While a significant body of literature describes sleep in older adults, little is known about sleep disturbances in *nursing-home eligible* older adults who remain living in the community. Nursing-home eligible older adults have demonstrated an inability to provide some kind of health-related care need themselves or need assistance with activities of daily living; thus warranting licensed professional care.[18] Our goal was to better understand sleep disturbances in this at-risk group.

Despite the high prevalence of sleep disturbances in older adults, they are unlikely to mention sleep problems at a health care visit. One population based study of 2000 adults (25% of sample ≥ age 60) reported that only 13% of respondents had consulted a healthcare provider for sleep problems and older age was associated with lower odds of consulting a provider for a sleep problem.[19] Older adults may have adjusted their health expectations, have different perceptions of acceptable sleep,[20] or expect to have poor sleep simply as a consequence of aging.[21] Older adults may perceive sleep disturbances to be a lower priority than other health issues, attribute their sleep disturbance to a side

effect of a necessary medication, fear being labeled as drug seeking, or believe there are no acceptable treatment options.[22] Health care providers also play a role: A 2008 National Survey found that six in ten primary care providers reported that they did not routinely discuss sleep during regular office visits.[23] Therefore, sleep disturbances are under reported, under explored, and under diagnosed in older adults.

Programs for All-Inclusive Care for Elders (PACE) present a unique research opportunity to explore sleep and sleep disturbances in at-risk older adults. To qualify for PACE, one must be age 55 or older and certified by the state to need nursing home level care. The typical PACE member is similar to the average nursing home resident in terms of functional limitations (need assistance with an average of three activities of daily living) and comorbid conditions (average eight conditions).[24] PACE members remain living in the community, yet are at a high risk for nursing home placement. Sleep disturbances may speed time to nursing home placement, but current evidence is conflicting and limited.[25,26] Our hope is that the greater depth of understanding gained from this study will lead to the development and testing of future interventions designed to improve sleep in this at-risk population.

The purpose of this mixed methods study was to describe sleep characteristics in 40 nursing-home eligible, community dwelling older adults enrolled in a PACE program. We conducted a concurrent nested mixed methods study [QUAL+quan] with the collection of both qualitative and quantitative data. Qualitative data was prioritized because so little is known about this population and obtained through in-depth interviews. Actigraphy and standardized sleep surveys were used to collect quantitative data about sleep and sleep disturbances and to augment the qualitative data. Data were integrated in

the analysis phase. Innovative aspects of this protocol included targeting an at-risk group of older adults where little research has been done and triangulating qualitative, objective and self-report measures of sleep.

The Specific Aims were to:

1) Explore perceived sleep quality, beliefs about sleep, and facilitators of and barriers to sleep via in-depth qualitative interviews.
2) Describe objective and self-reported sleep characteristics and sleep disturbances via actigraphy and standardized sleep surveys (Pittsburgh Sleep Quality Index, Insomnia Severity Index, Epworth Sleepiness Scale, sleep diary).
3) Describe older adults' recognition and interpretation of sleep disturbances by triangulating qualitative, objective and self-reported sleep characteristics.

Older adults who fail to recognize the importance of sleep disturbances are at increased risk for poor outcomes such as cognitive impairment, falls, and subsequent nursing home placement.[23] It is critical to understand this population's perceptions of sleep quality, beliefs about sleep, and facilitators of and barriers to sleep before interventions can be developed and tested. This research closely aligns with National Institute of Nursing Research's (NINR) mission of successful symptom management. This study investigates sleep disturbances in order to build the evidence for successful symptom management of this multifaceted aging issue.

CHAPTER 2: BACKGROUND

In this chapter, we first provide conceptual clarity by clearly defining the terminology used throughout this dissertation. Next, we provide a review of the literature related to sleep in older adults. Finally, we highlight key gaps from the literature review and discuss the conceptual model guiding this work.

Key Definitions

Sleep disturbance. Sleep disturbance is a broad term that refers to any disruption in sleep that includes dysregulation of sleep homeostasis, sleep deficiency, sleep fragmentation, insufficient sleep or impairment of sleep quality or quantity.[4]

Sleep quality. Sleep quality is a complex phenomenon, which makes it challenging to define and measure.[27] For this dissertation, sleep quality refers to the subjective report of ability to fall or stay asleep, refreshing sleep, and daytime sequelae of sleep quality.[27]

Daytime sleepiness. Sleepiness is a subjective sensation of the desire or need to sleep. Excessive daytime sleepiness is difficulty in maintaining a desired level of wakefulness[28] or the feeling of being drowsy with a tendency to actually fall asleep or nap.[29]

Insomnia. Insomnia is often used inconsistently and in different contexts to refer to a symptom or a clinical disorder. For example, more broadly, insomnia may be used to indicate self-reported general poor sleep and more narrowly, can refer to individuals with sleep-state misperception, a specific type of insomnia disorder.[30] Insomnia symptoms include difficulty initiating or maintaining sleep or awakening too early.[6] Insomnia disorder is defined as a chronic or acute sleep disorder characterized by a complaint of

difficulty initiating and/or maintaining sleep and/or a subjective complaint of poor sleep quality that results in daytime impairment and a subjective report of impairment.[4] According to the DSM-5 criteria, the sleep difficulty must occur at least three nights per week, be present for at least three months and occur despite adequate opportunity to sleep.[31]

It is estimated that nearly 30% of the general population suffer from symptoms of insomnia and 10-20% have insomnia disorder, with the prevalence increasing with age and varying depending on the diagnostic criteria utilized.[23] One study estimated that 35% of older adults have insomnia disorder.[6] For the purposes of this dissertation, the term "insomnia symptoms" is used to represent any nighttime sleep problems or daytime sleep complaints that may not warrant a clinical diagnosis of insomnia or in cases where studies did not specify diagnostic criteria or how insomnia was operationalized. The term "insomnia" is used to refer to insomnia disorder based on specific diagnostic criteria.

Sleep characteristics. Sleep characteristics refer to common sleep-related variables that are often of interest to researchers and clinicians. Specifically, sleep latency (SL) refers to how many minutes it takes to fall asleep, starting from the first intention to fall asleep. Wake after sleep onset (WASO) is the total amount of time awake during the night, starting from the time the person falls asleep. Sleep efficiency (SE) is the percent of time spent in bed asleep. Sleep efficiency is calculated by dividing total sleep time by the time in bed and multiplying by 100. Total sleep time (TST) is the actual time asleep during the sleep period. Twenty-four hour TST refers to the time asleep during a 24-hour period. Nap refers to any time a person is asleep during the non-sleep period.

Age-Related Sleep Changes

Although sleep disturbances are common across the lifespan, older adults are more vulnerable to sleep disturbances due to age-related physiological changes. The sleep-wake cycle is regulated by a two process model, Process S and Process C.[32] Process S is the homeostatic need for sleep while process C is the circadian process that operates on roughly a 24-hour period. Sleep homeostasis and the circadian arousing processes that control sleep change with age.[23] There is a decreased homeostatic sleep drive in addition to reduced circadian signaling strength due to degeneration of the suprachiasmatic nucleus (SCN), a group of cells in the hypothalamus that regulate circadian rhythm.[33] Older adults' sleep patterns are therefore more vulnerable to fragmented sleep, characterized by an increase in the number of sleep stage shifts, arousals and awakenings.[34] Sleep architecture changes that accompany aging include decreased total sleep time, decreased sleep efficiency, decreased slow wave and rapid eye movement (REM) sleep, and increased stage one and two non-REM sleep.[23] Older adults also go to bed earlier and wake up earlier in relation to their endogenous melatonin secretion (sleep promoting hormone), suggesting that aging is associated with decreased melatonin output and phase advances of sleep and circadian rhythms.[34] In addition, normal external cues that help entrain the circadian rhythms of the sleep-wake cycle may be weaker in older adults. In sum, older adults are highly susceptible to nighttime sleep fragmentation, circadian phase shifts, and spend more time in lighter sleep stages.

Nursing-Home Eligible Older Adults

The older American adult population continues to expand. In 2015, 55.8 million older adults were enrolled in Medicare and the projected growth by 2040 is now at 82

million.[35] The vast majority of older adults have two or more chronic medical conditions;[36] 35-40% have limitations in daily function.[12] An analysis of Medicare and Medicaid claims data for over 30 million older adults revealed that 67% of Medicare beneficiaries had two or more chronic conditions and 36% had four or more chronic conditions, with the prevalence increasing with age.[36] Findings from another study revealed that the average health expenses of people with four or more conditions were almost double those of people with two or three conditions and seven times higher than those with one or no chronic condition.[37] Despite age-related difficulties that challenge successful aging in place, almost all (90%) older adults prefer to live independently in their homes for as long as possible.[38,39] Policy makers and health providers also support older adults remaining in their homes to avoid the costs associated with institutionalization.[40] One study revealed per person expenditures were five times as high and national expenditures were three times as high for nursing home residents compared to community dwelling older adults.[41] Sleep disturbances may be caused or exacerbated by chronic conditions, and sleep disturbances may add to the complexity of aging in place as well as the cost of managing chronic conditions.[23]

Nursing-home eligible older adults have demonstrated an inability to provide some kinds of health-related care need themselves or need assistance with activities of daily living; thus warranting licensed professional care.[18] Nursing-home eligible older adults who live in the community are a unique population, given the fact that they have similar levels of functional decline and comorbidities as older adults that reside in nursing homes or assisted living facilities, yet have chosen to remain living in their homes. This is particularly interesting in the context of sleep, given that we know that

sleep environment has an impact on sleep and sleep disturbances. For example, decreased stimuli, increased time in bed, limited light exposure and noise in nursing home settings is known to affect circadian rhythms and sleep patterns of the residents.[42,43] Nursing-home eligible older adults who live in the community are an understudied population, as most of the existing sleep research has been conducted in healthy community dwelling older adults or in nursing home residents.

The limited literature to date suggests that sleep disturbances speed time to nursing home placement. In one study, self-reported insomnia symptoms were a significant predictor of shortened time to nursing home placement for men, but not women.[25] In another study using objective sleep measures, greater time awake after sleep onset and worse sleep efficiency were associated with greater odds of subsequent placement in long-term care among white older women.[26] A more recent, prospective study of primarily white (88%) middle-aged and older adults revealed that participants with two symptoms of insomnia had greater odds of hospitalization, home health service use, or nursing home use compared to those reporting no symptoms of insomnia.[44] One explanation of these findings is that insomnia symptoms may exacerbate existing medical conditions, thus resulting in increased health service use. The previous study suggested that if the association between insomnia symptoms and health care services is indeed causal, treating the insomnia symptoms would result in a 6-14% decrease in health service utilization.[44] By recognizing and treating sleep disturbances, we may be able to decrease symptom burden and decrease health care service costs, but more research with this unique population is needed before we can make such a conclusion.

Sleep in Adult Day Health Care Programs

Only two studies were found that described sleep disturbances in a community dwelling population with comparable chronic conditions and functional status to those enrolled in a PACE setting. One study of 50 (94% male) older veterans enrolled in a Veterans Affairs (VA) Adult Day Health Care (ADHC) Program found that objectively measured nighttime sleep disturbances were significantly associated with poorer physical function, even after controlling for covariates such as posttraumatic stress disorder, demographics, and sleep medications.[45] Almost the entire sample (96%) needed assistance with activities of daily living, had physical limitations and had significant levels of multimorbidity.[45] Another study of older veterans enrolled in a VA ADHC Program found that more than 67% (n=68) of participants reported one or more characteristics of poor sleep and 38% met the International Classification of Sleep Disorders (ICSD)-2 diagnostic criteria for insomnia.[46] The investigators found multiple discrepancies between markers of poor sleep, the endorsement of sleep problems and positively rated sleep quality. Only about half of the participants who met insomnia criteria (10/19) had spoken to their provider about their sleep problems.[46] More research is needed to understand sleep disturbances in nursing-home eligible older adults with comparable functional limitations as these two studies included only veterans, a predominantly male population.

Consequences of Sleep Disturbances

Negative consequences of untreated sleep disturbances are well documented in the literature. There is a bidirectional relationship between sleep disorders and serious medical problems.[23] Hypertension and cardiovascular disease,[47-49] cerebrovascular

disease,[50] and depression[51-56] are examples of diseases that are more likely to develop in individuals with a sleep disorder. Likewise, having any of these diseases places a patient at a higher risk of developing a sleep disturbance or disorder.[23] For example, sleepiness is a symptom of depression and people with depressive symptoms may be less likely to participate in activities or to spend more time in bed. Being sedentary and spending too much time in bed can negatively impact the amount of consolidated and refreshing sleep that one is able to get.[53]

Insomnia is a risk factor for new onset and recurrent medical and psychiatric illness and increases older adults' susceptibility to illnesses that occur with advancing age.[23,57,58] The risk of developing heart disease in those with insomnia symptoms ranged from 1.47 to 3.90 in one meta-analysis, after controlling for age and cardiovascular risk factors.[48] Evidence supports an increased risk of mood disturbances and depression in older adults with insomnia symptoms.[51-56] Data from one study revealed that having insomnia symptoms was associated with almost a 25% increased risk of developing depressive symptoms.[52] Somatic complaints accompanying insomnia symptoms and other sleep disturbances include headaches, muscle aches and joint pain.[57]

Sleep disturbances, overall, are strongly linked to poorer well-being and quality of life.[59] Sleep disturbances can lead to poor overall health, a decrease in physical function and premature death.[34] Specifically, there is an association between sleep disturbances and falls in older adults. A literature review on this topic revealed that the risk of falls was higher among those with insomnia,[60] reduced sleep efficiency,[61] nighttime sleep problems,[62] and daytime sleepiness.[63]

Daytime consequences of untreated sleep disturbances can include excessive daytime sleepiness and poor performance. In epidemiological studies, estimates of daytime sleepiness in community dwelling older adults range from 10-30%[64-66] and reach upwards of 70% in nursing home residents.[67] Additionally research suggests sleep deprivation leads to more impairments in performance (reduced vigilance, working memory and executive function) during the day.[68,69]

Social consequences of sleep disturbances involve increased healthcare utilization, increased absenteeism, decreased productivity at work and increased risk of accidents. Hundreds of billions of dollars are spent each year on direct medical costs related to sleep disturbances including doctor visits, hospital stays, and medications.[3] Insomnia in particular, is associated with high levels of overall healthcare utilization and increased direct and indirect healthcare costs.[57,58] Over a 6 month period, direct costs related to untreated insomnia in U.S. older adults were estimated to be $1,143 per person greater for patients with insomnia compared to matched controls.[70]

Assessment Considerations

Although more than half of older adults have at least one sleep complaint,[16,17] older adults may not mention sleep problems during a health care visit. Primary care providers do not routinely ask about sleep during a patient visit.[71] Reasons for omitting a sleep assessment during patient visits include lack of time, lack of knowledge on the importance of assessing for sleep disturbances, few known nonpharmacological treatment options, and especially with the older adult, higher priority health issues. Thus, a major problem arises: sleep disturbances in the older adult population are highly prevalent, yet vastly undetected.

Normal physiological changes of aging impact sleep architecture, but sleep disturbances are not an expected change of aging. Previous investigators assumed that a complaint of sleep disturbance from an older adult was due solely to normal age-related changes in sleep and that older adults should simply be educated that they are experiencing ontogenetically normal variations in sleep.[72] While extant research clearly links age and prevalence of sleep disturbances, recent studies suggest that age-related physiological changes alone may not completely explain poor sleep in older adults. In one cross-sectional study, advancing age alone was not associated with an increase in self-reported sleep disturbance, tiredness, or lack of energy.[73] Similarly, findings from a three-year longitudinal study suggest that sleep disturbances reported by older adults are more dependent on physical, environmental and health factors than on age-dependent sleep changes.[74] These results suggest that sleep disturbances may be mediated by factors other than physiologic age-related sleep changes.

The presence of multiple chronic conditions further complicates the assessment of sleep in older adults. Clinicians have time constraints and may not prioritize sleep as a high priority issue. They may attribute sleep disturbances to medications taken to treat various conditions. There are few clinicians trained in sleep medicine, and primary care clinicians may not have enough knowledge to assess sleep disturbances or may not know what they can do if they identify a sleep disturbance. Empirical evidence suggests there are a large number of older adults with both sleep disturbances and other chronic conditions. Thus, there is a need to increase clinicians' awareness and understanding of sleep disturbances in older adults so that they are better at assessing and treating sleep problems.[75]

As previously discussed, older adults may not complain of sleep problems for a variety of reasons. They may expect to have poor sleep simply because they are aging.[21] This issue may be complicated by an age-related adjustment of health expectations, where older adults have a different perception of acceptable sleep in comparison to their younger counterparts.[20] Older adults may also prioritize other health problems and not perceive their sleep disturbances to be of high priority compared with competing health issues.[76] Older adults may attribute their sleep disturbance to side effects of a necessary medication, fear being labeled as drug seeking, fear the stigma that is commonly associated with psychological illnesses (i.e., insomnia), or feel that nothing can be done.[5] Other possible explanations are that, over time, older adults adapt to poor sleep or that fewer daytime demands or lifestyle changes may influence their perception of sleep problems.[77]

Gap in the Literature and Purpose for the Study

Geriatric sleep research to date has focused on healthy community dwelling older adults or older adults living in nursing homes or assisted living facilities. There is a gap in the literature related to sleep in nursing-home eligible older adults who remain living in the community. The purpose of this dissertation was to examine sleep characteristics and sleep disturbances both objectively and from the perspective of community dwelling nursing-home eligible older adults. This study was the first to triangulate qualitative interviews, objective actigraphy data and self-report sleep surveys to fully describe sleep and sleep disturbances in this at-risk population. The mixed methods approach was anticipated to yield rich data that will provide a broad perspective on an important and unexplored phenomenon in this population. Integrating the data in the analysis phase was

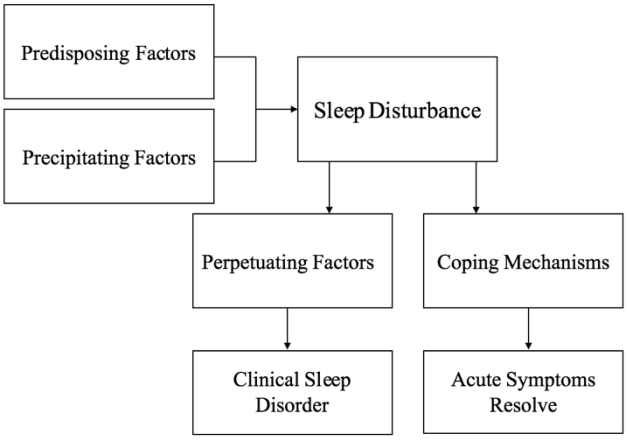
key to gaining a better understanding of this at-risk group's recognition and interpretation of sleep disturbances that may or may not be objectively present. This detailed level of data is needed to inform tailored interventions to be tested in subsequent studies. To our knowledge, this was the first such study to describe sleep in nursing-home eligible, community dwelling older adults in this manner.

In sum, sleep disturbances can lead to poor overall health, a decrease in physical function, and an increase in health care utilization and cost. By gaining a better understanding of sleep and sleep disturbances in nursing-home eligible older adults, an at-risk population, we are more equipped to intervene on modifiable factors that have the potential to decrease symptom burden and decrease health care utilization and cost.

Conceptual Model

A modified version of the diathesis-stress model, also referred to as the "3-P" model, guided this dissertation.[72] The 3-P model was originally focused on the specific sleep disturbance of insomnia but we took a more global view of the phenomenon of disturbed sleep. Spielman postulated that there are predisposing, precipitating and perpetuating factors that play a role in the development and maintenance of insomnia. Conceptually, predisposing, precipitating and perpetuating factors can be viewed as classes of causes of disturbed sleep. Predisposing factors such as, sociodemographic

Figure 2-1: Modified Version of the Diathesis-Stress Model



factors, genetics, epigenetics, pre-existing psychiatric or medical conditions and a lifetime allostatic buildup of stressors increase one's susceptibility to sleep disturbances. Precipitating factors such as loss of physical function, grief, a new diagnosis of a disease, and retirement are events that may push one over a hypothetical threshold, whereby disturbances can transition into a clinical sleep disorder (i.e., insomnia). Perpetuating factors are maladaptive strategies such as, increased time spent in bed, excessive worry about sleep, napping, negative attitudes toward sleep and unusual sleep times, which maintain the clinical sleep disorder. Dysfunctional beliefs are presumed to play a role in perpetuating sleep disturbances, specifically, insomnia.[72] Positive coping mechanisms are relaxation techniques, improvement in sleep hygiene, resolution of the precipitating event, and positive attitudes toward the sleep environment. The qualitative component of this research will yield a better understanding of both maladaptive strategies and positive coping mechanisms used by this population, as these are modifiable factors that are amenable to future interventions.

CHAPTER 3: METHODS

The aims of this study warranted the use of mixed methods to fully understand sleep in this at-risk population. Sleep is a complex construct that requires subjective, behavioral, and physiological perspectives to fully appreciate its multidimensionality.[30] Understanding sleep characteristics and sleep disturbances in this population required exploration of perceived sleep quality, beliefs about sleep, facilitators of and barriers to sleep, and self-reported and objective sleep characteristics. Integration of these results enabled achievement of our third aim: to describe older adults' recognition and interpretation of sleep disturbances. Therefore, given the purpose and specific aims of this study, mixed methods was an appropriate research design to expand our current knowledge of sleep in at-risk older adults and to inform future intervention research.

Preliminary Data

Before embarking on the dissertation study, we conducted a pilot study to test the feasibility of the measures planned for use in the current study. The specific aims of our Institutional Review Board (IRB)-approved preliminary study were to test the feasibility of using objective (wrist actigraphy) and self-report surveys (sleep diary, Pittsburgh Sleep Quality Index [PSQI], Insomnia Severity Index [ISI], Epworth Sleepiness Scale [ESS]) in ten older adults at one Program for All-Inclusive Care (PACE) site.

Measuring and assessing sleep requires meticulous thought and consideration. Various objective and subjective measurement tools exist in the literature. Polysomnography (PSG), commonly referred to as a sleep study, is the gold-standard objective measure of sleep. Due to the unique challenges and limitations associated with PSG, we used actigraphy as the objective measure of sleep for this preliminary study.

Actigraphy can supplement self-reported sleep characteristics and serve as an objective measure of sleep-wake patterns in situations in which PSG is not warranted or feasible. Actigraphy is a movement-based approach for estimating sleep that provides a home-based, longitudinal, objective sleep measurement at a relatively low cost and minimal intrusiveness to the participant. Participants wear a wrist-watch device containing the accelerometer in order to measure activity. The device stores information and then a computer software program is used to determine the variables of interest. Actigraphy is discussed in further detail below in the measurement section.

Challenges also exist when using subjective sleep measures. The most well-known and validated subjective sleep surveys were developed in young adult populations, yet have been validated and are often used to measure sleep in older adults. Additionally, there are numerous sleep surveys in the literature and participant burden must be considered.

The participants in our pilot study were primarily female (9 of 10), Black (10 of 10), older adults (mean age 69.6 ± 9.36), with multiple chronic conditions (mean 13.8 ± 4.66). Almost all (9 of 10) participants wore the Actiwatch for the full seven days and sleep diaries were 79% complete. Objective results indicated that only three participants got the recommended sleep duration of 420-480 minutes (group mean 337.25 ±100.84 minutes); two participants had long sleep latencies (>30 minutes), but nine had more than 30 minutes of wakefulness after sleep onset and seven had poor sleep efficiency (<85% of time in bed asleep). Seven participants reported poor sleep quality (PSQI >5; mean 9.60 ± 4.40) and seven participants reported insomnia symptoms (ISI ≥ 8; mean 9.8 ± 6.6); yet only three had excessive daytime sleepiness (ESS ≥11). Despite high rates of

objective nocturnal sleep disruption, there was minimal daytime sleepiness reported, highlighting the importance of qualitative interviews in gaining an in-depth understanding of older adults' recognition and interpretation of their sleep disturbances.

We were encouraged to learn that the proposed study was feasible, demonstrated by the fact that despite their high level of comorbidity, participants were not bothered by wearing Actiwatch and many reported "I didn't even realize I had it on." Additionally, participants reported that the sleep surveys were not too burdensome. We also learned optimal timing for recruitment and enrollment for the proposed project and that we needed to refine and eliminate unnecessary questions on the sleep diary to reduce burden and increase completion rates.

Study Design

This mixed methods study used a concurrent nested design (QUAL+quan).[78] The primary strength of this design is that results from the dominant method (QUAL) are enhanced by the other method (quan) to yield a broader perspective than either method alone.[78] Both qualitative and quantitative data are necessary to explore sleep and sleep disturbances in this population because sleep is a complex, multidimensional construct. Qualitative data were obtained through in-depth, semi-structured interviews using open-ended questions to glean information on how older adults perceive sleep and sleep disturbances. Qualitative description allows us to understand complex experiences or events embedded within the human context.[79,80] The qualitative data were weighted most highly because ultimately, we wanted to understand nursing-home eligible older adults' perceived sleep quality, beliefs about sleep, and facilitators of and barriers to sleep from their point of view. The thick description of perpetuating maladaptive factors and positive

strategies used to improve sleep allowed us to identify modifiable factors to target in subsequent intervention research. Objective sleep measures and standardized sleep surveys augmented the qualitative data and further described sleep and sleep disturbances in a manner that is comparable to results from other populations. Qualitative and quantitative data were integrated in the analysis phase to elucidate older adults' recognition and interpretation of their sleep disturbances.

Participants and Sample Selection

A purposive sample of 40 older adults (aged ≥55) with and without perceived poor sleep was recruited for this mixed methods study. Purposive sampling facilitates generalizability of study findings because it allows for information-rich cases and the development of thick description of the phenomenon of interest.[80] Specifically, maximum variation sampling (a purposive sampling technique),[81] was used to explore sleep and sleep disturbances and allowed us to capture central themes that cut across the most diverse group of individuals. The strength of this approach is that the emergent themes from a heterogeneous sample should reflect core experiences and shared aspects of the phenomenon of sleep.[78] In maximum variation sampling, participants are selected because of a specific characteristic. In this study, participants were selected based on age, sex and perceptions of good or poor sleep. It is known from the literature that self-reported and objective measures of sleep and sleep characteristics vary by age and sex.[76,77,82-84] We targeted adults aged 55-65 years, 66-75, and 76 and older, female and male adults with both good and poor sleep. We asked one question during screening to determine if the older adult perceived s/he was a good or poor sleeper: "Do you feel you sleep well or poorly?" The participant's response was used to designate him/her as a good

or poor sleeper for sampling purposes. Sampling variation was monitored by the PI to ensure adequate representation of ages and male and female participants with both good and poor sleep.

Participants were recruited from the Mercy Living Independently for Elders (LIFE) - West Philadelphia center. The LIFE program is a Program of All-inclusive Care for the Elders (PACE) model that promotes independence, autonomy, and dignity by keeping Medicare and Medicaid dual-eligible qualified for nursing home older adults living in their homes. The LIFE day center is licensed and regulated by the Pennsylvania Department of Aging and has been successfully providing all-inclusive care to residents of West Philadelphia since 1998. The membership currently consists of 444 older adults with an average age of 80.2 years. Members are primarily Black (86.5%), female (70%), and Medicare and Medicaid dual-eligible (95.7%). LIFE vans transport members from their homes to the LIFE center. During our pilot study, we gained access to LIFE and established relationships with LIFE staff, thus increasing the feasibility of this study. After obtaining IRB approval, a total of 40 participants were recruited and compensated for their time and effort with a $25 VISA gift card.

Inclusion and Exclusion Criteria. Participants had to meet the following inclusion criteria: age ≥55 years; cognitively intact or mild cognitive impairment (Montreal Cognitive Assessment [MoCA] ≥20)[85]; residing in the community; and able to speak and write in English. Exclusion criteria included moderate and severe cognitive impairment.

Procedures

After seeking and obtaining expedited IRB approval, the following procedures

were used for screening, enrollment and data collection (these are expanded from those used for the pilot study, which demonstrated feasibility).

Screening Procedure. The Mini-Mental Status Exam (MMSE) is administered at enrollment and every six months at LIFE, so the Director of Nursing Research at LIFE generated a list of all members with an MMSE score >26, as preliminary evidence of intact cognition.[86] Employees of LIFE initiated contact with LIFE members, and asked permission for a researcher to contact them, as required by Health Insurance Portability and Accountability Act (HIPAA) regulations. The PI then approached members at the LIFE center who agreed to screening. The PI used a brief screening script that included a general overview of the study. If the member was interested, the sleep screening question ("Do you feel you sleep well or poorly?") was asked, and age and gender were recorded.

Next, the MoCA was administered in person, in a private setting, to assess current cognitive function. We began using a cut-point of MoCA ≥23 but later lowered this to ≥20 as discussed below. The consent form (including HIPAA Authorization) was reviewed in detail, with ample time provided for the participant to ask and have questions answered. Participants also had the opportunity to take the consent form home and review it with a loved one or a health care provider. Those who wished to participate and completed the consent form were enrolled. Demographic and clinical data were obtained from the electronic medical record (EMR), while sleep surveys and interview data were collected in person at LIFE. The participant had the option to begin data collection immediately after consent or at a separate, subsequent visit.

The first data collection session consisted of sleep surveys, a qualitative interview, and instructions for wearing the Actiwatch and completing the sleep diary for

one week. During the week of wearing the Actiwatch and completing the sleep diary, the participant received two phone calls from the PI to make sure that the Actiwatch was on and that there were no problems completing the sleep diary. In a second session 7-10 days later, the participant returned the Actiwatch and sleep diary and received compensation for study participation.

Data Collection and Measurement

Qualitative and quantitative data were collected in a single session to obtain an accurate comparison between the data. If sleep surveys (quantitative) and interviews (qualitative) were collected on different days, we might get different answers due to recall bias, which would have confounded the analysis. First, the sleep surveys were administered, followed by the in-depth interview. This sequence was chosen to prevent biased answers on the sleep surveys that could potentially occur after the interview.[87] Also, during the course of an in-depth interview, a participant-researcher relationship may develop, which potentially risks a subsequent socially-desirable response on the sleep surveys. Sequencing the quantitative assessment followed by the qualitative interview also allowed the participant-researcher relationship to evolve so that rich, descriptive information could be elicited while guarding against biases.[88] Both sleep surveys and interviews needed to be completed prior to placement of the Actiwatch and completion of the sleep diary, as completing a sleep diary may heighten awareness of a sleep pattern that may not otherwise have been recognized.

Screening. The Montreal Cognitive Assessment (MoCA) assesses different cognitive domains: attention and concentration, executive functions, memory, language, visuoconstructional skills, conceptual thinking, calculations, and orientation. The total

possible score is 30 points. In a population of community-dwelling older adults, using a cut-point of 26, the MoCA detected 97% of those with cognitive impairment but specificity was poor (35%).[85] Using a lower cut-point score of 23, the MoCA exhibited excellent sensitivity (96%) and specificity (95%).[85] We began the study with a MoCA cut point of 23. After screening 35 members with MMSE scores 28 or greater (preliminary evidence of intact cognition), more than half scored less than 23 on the MoCA. Therefore, due to low enrollment and expert opinion (psychiatrist and nurse practitioner who work with this population daily), the MoCA cut-point was lowered to 20. The MoCA detects mild cognitive impairment and is much more challenging then the MMSE. We used the MoCA for descriptive purposes and not as a main outcome or variable in our study. We wanted the participants to be able to complete the sleep diary for one week and wear the Actiwatch. Therefore, in this unique population with multiple chronic conditions, our team chose MoCA ≥20 as a reasonable cut-point for study inclusion.

Qualitative Data Collection. Perceived sleep quality, beliefs about sleep, and facilitators of and barriers to sleep were explored qualitatively in a single one-on-one, face-to-face, audiotaped interview lasting approximately 30 minutes to one hour. The interview was conducted in a private setting using a semi-structured interview guide with theoretically derived questions and probes based on the 3-P conceptual model (predisposing, precipitating and perpetuating factors), existing literature, and the research team's clinical experiences working with older adults with sleep disturbances. Open-ended questions were used in order to provide moderate structure while allowing the participants to freely communicate their own perceptions.[80] Probing questions helped

focus the conversation, encourage elaboration, and elicit additional description. The open-ended interview questions used to explore perceived sleep quality began broadly and were followed by additional questions and probes that elicit in-depth descriptions (i.e., Tell me about a typical night's sleep; tell me about the quality of your sleep). Questions that targeted beliefs about sleep (i.e., How important is it for you to sleep well?) and facilitators of and barriers to sleep (i.e., Describe what helps you sleep well/ Describe what makes you sleep poorly) were used to ensure a rich description of the phenomenon (See Appendix for full Interview Guide). Field notes were recorded during and immediately after each interview to capture the PI's observations and thoughts about the interview and to augment the recorded interview.[89]

Quantitative Data Collection. Demographic information and clinical data were collected from the electronic medical record for every participant including age, gender, race/ethnicity, medications and chronic conditions. Wrist actigraphy was used as the objective measure of sleep, in conjunction with a sleep diary for one week. Actigraphy[90,91] measures movements through the use of an accelerometer.

Periods of activity and inactivity are analyzed in order to estimate sleep/wake status.

Table 3.1. Objective Quantitative Outcomes

Variable	**Definition**
Sleep latency	Time it takes a person to fall asleep, starting from first intention to sleep
Wake after sleep onset	Time awake during the night, starting from the time the person falls asleep
Total sleep time	Actual time a person is asleep
24 hour total sleep time	The amount of time a person is asleep during a 24 hour period
Sleep efficiency	Percent of time spent in bed that a person is asleep
Nap	Any time outside the nighttime sleep interval that the person is asleep

Computer programs are used to derive levels of activity/inactivity, rhythm parameters (such as amplitude or acrophase), nighttime sleep/wake parameters (such as total sleep time, sleep efficiency, sleep latency, wake after sleep onset) and daytime naps.[92] Wrist actigraphy monitoring has been shown to be a reliable way to objectively monitor sleep-wake cycles in normal ambulatory individuals[90] and correlates with PSG in older adults.[93] In patients with insomnia and hypersomnia, there is evidence to support the use of actigraphy in the characterization of circadian rhythms and sleep patterns.[94]

Actigraphy was measured using the Actiwatch-2 device (Koninklijke Philips, N.V.). This device is a piezoelectric accelerometer worn on the wrist. Movement data were sampled at a rate of 32 Hz, and activity counts were recorded in 60-second epochs. Additionally, the Actiwatch-2 has Silicon photodiode light sensors, and a button that enables participants to signal when they first try to fall asleep and when they get out of bed in the morning. The button can also be used to signal naps.

Sleep diaries allow for prospective sleep self-monitoring. A sleep diary measures night-to-night sleep patterns, habits, and daytime activities that may influence sleep.[95] The sleep diary has two components to be completed at bedtime and wake time. Bedtime components relate to the events of the day preceding the sleep/wake time components to the sleep period just completed. Various forms of sleep diaries have been used extensively in studies of adults.[96] Using a sleep diary in conjunction with actigraphy provides a more reliable representation of sleep habits; both actigraphy and sleep diary are validated for seven-day use in older adults.[91,92] We kept sleep diary questions to a minimum to reduce burden and increase completion rates (See Appendix). Each participant was instructed on how to wear the Actiwatch and complete the sleep diary for

seven days. In addition, each participant received two phone calls during that week, to make sure s/he was wearing the Actiwatch and that s/he was not having any problems completing the diary. Variables derived from actigraphy can be found in Table 3.1.

The Pittsburgh Sleep Quality Index (PSQI)[27] was the self-report measure of the perception of habitual sleep quality. The PSQI measures seven domains for the prior month: 1) sleep quality; 2) latency; 3) duration; 4) habitual sleep efficiency; 5) use of sleep medications; 6) disturbance; and 7) daytime dysfunction. A global score (0-21 points) is obtained by summing the scale domain scores. Higher scores indicate poorer global sleep quality. Internal consistency reliability of the PSQI is in the range of 0.77 to 0.83 and test-retest reliability is good.[27] When global PSQI scores were dichotomized to good sleep (≤5) and poor sleep (>5), the diagnostic sensitivity was 89.6% and specificity was 86.5% for its ability to distinguish "good" versus "poor" sleepers.[27] Scores on the PSQI have been validated by comparison with PSG results.[97] PSQI has also been validated in older adults and the global PSQI score was internally consistent in both women and men (α = 0.78 and 0.69, respectively).[98,99]

The Insomnia Severity Index (ISI)[100] was used to assess self-reported insomnia symptoms. The index includes seven items that evaluate: (a) the severity of sleep-onset (initial), (b) sleep maintenance (middle), (c) early morning awakening (terminal) problems, (d) satisfaction with current sleep pattern, (e) interference with daily functioning, (f) noticeability of impairment attributed to the sleep problem, and (g) level of distress caused by the sleep problem. The items are rated on a 5-point Likert scale, where 0 indicates no problem and 4 indicates a very severe problem. The scores are summed with a total severity score ranging from 0 to 28. The ISI can be interpreted as

follows: absence of insomnia (0–7); sub-threshold insomnia (8–14); moderate insomnia (15–21); and severe insomnia (22–28).[101] A cut-point of ≥15 is used to indicate clinical insomnia. Principal component analysis found that one factor explained 68.99% of total variance, with internal consistency reliability equal of 0.91.[102] One study showed that the ISI was valid in primary care, with excellent internal consistency (Cronbach $\alpha = 0.92$).[103] Convergent validity was supported by significant correlations between total ISI score and measures of fatigue, quality of life, anxiety, and depression.[101]

The Epworth Sleepiness Scale (ESS)[104] was the subjective measure of daytime sleepiness used. Respondents rate the likelihood of falling asleep in eight soporific situations using a 4-point Likert scale ranging from never dozing (0) to high chance of dozing (3). Scores are summed, with higher scores indicating higher sleepiness, or categorized as not sleepy (<11) or sleepy (≥11). Test-retest reliability (correlation coefficient = 0.82) and internal consistency (correlation coefficient = 0.88) have been established in addition to its single factor structure.[105] ESS has a sensitivity of 93.5% and a specificity of 100% for distinguishing pathological from normal sleepiness.[106] The ESS was internally consistent in older women and men (α =0.76 and 0.70, respectively).[99,107]

The Cumulative Illness Rating Scale (CIRS) was used to measure comorbidity and clinical burden. The CIRS was initially developed in 1968[108] and was modified to measure medical burden in older adults with complex medical problems.[109,110] The CIRS evaluates 14 biological systems on a 0 (selected system corresponds to no disease) to 4 (acute organ dysfunction requiring emergency treatment). Scores are summed and totals can range from 0 to 56, with higher scores indicating a higher level of comorbidity. The CIRS has good intra-rater reliability (intra-class correlation [ICC] 0.86) and inter-rater

reliability based off both patient interview and chart review (ICC's 0.81 and 0.78, respectively).[111] The CIRS is a valid measure of health status in older adults as evidenced by its ability to predict 18 month mortality and rehospitalization.[110] The CIRS has significant associations with mortality, acute hospitalization, medication usage, laboratory test results, and functional disability.[112] For this study, electronic medical records were reviewed for evidence of preexisting diseases, medications and demographic information.

Data Management

Audio-recordings, transcribed interviews and field notes were de-identified and stored on a password-protected server at the University of Pennsylvania School of Nursing. The REDCap (Research Electronic Data Capture) system was used for quantitative data processing and management. REDCap is a password protected, HIPAA compliant, web-based application that is designed to support quantitative data collection for research studies.[113] We used standard operating procedures to guide all data management activities, such as the naming and identification of variables, data cleaning and handling of missing data. To reduce data collection time, increase accuracy, and prevent data loss, sleep surveys were completed directly in REDCap with the help of the PI. Additionally, the PI entered all data obtained from the EMR into REDCap. Data entry screens were designed to incorporate range checks and concurrent checks to minimize errors. Missing fields were not allowed.

Data Analysis

All audio-recorded interviews were transcribed verbatim, with accuracy confirmed, and coded using *ATLAS.ti* version 7.5.16, a software package and powerful

analytical tool for the qualitative analysis of large bodies of textual data. All actigraphy data was configured, retrieved, managed, scored and exported using Philips Actiware 6.0.8, a computer software package commonly used to analyze actigraphy. Stata version 14.1 was used for all subsequent quantitative analysis. Data analysis occurred sequentially. Qualitative data analysis began immediately once the taped interviews were transcribed. Quantitative analysis began after the completion of the preliminary qualitative analysis. Integration of the qualitative and quantitative followed, as described in detail below.

Qualitative Analysis: Aim 1. The analysis of the qualitative interview data was done using thematic content analysis, an inductive analytic method.[114] Data management and analysis entailed the following major activities: 1) processing qualitative data, including careful review of interviews and transcriptions, 2) analyzing data to identify perceived sleep quality, beliefs about sleep, and facilitators of and barriers to sleep, and 3) analyzing data to identify themes and patterns related to the factors of interest. The emergence of themes was analyzed within-cases then across cases to identify commonalities among subsets of individuals.[115] Preliminary analysis of the qualitative data included a line-by-line review that yielded clusters of data. These clusters were then labeled into brief headings, based on an *a priori* code list generated from the conceptual model. Additional codes derived from this data were linked to interview questions to yield coding categories. Summarization of coding categories was performed within-cases, then across cases, and subsequently cross-classified to yield a descriptive analysis. Finally, emerging themes both within and across coding categories were identified; and

review of fit with data verified. In this manner, we generated a rich description of perceptions regarding sleep and sleep quality developed directly from the participants.

Quantitative Analysis: Aim 2. Descriptive statistics were used to characterize the sample, with measures of central tendency and variation for continuous measures, and frequencies and percentages for dichotomous and categorical variables. Standardized sleep surveys and actigraphy were scored by the PI. Relationships among self-report and objective measures of sleep disturbances were also analyzed. Due to the small sample size, the correlational analyses were done using non-parametric Spearman rho tests to protect against skewed data, with an *a priori* significance level set at $p < 0.05$.

Actigraphy data for each 60 second epoch were automatically scored (0 = wake, 1 = sleep) using a validated scoring algorithm in the Philips Actiware 6.0.8 software prior to export. Each epoch was scored as wake if the algorithm resulted in a score at or above the low threshold (20); epochs below the threshold were designated as sleep. We chose the low threshold (indicating high sensitivity) setting because our sample was comprised of older adults with low activity. The low threshold setting is more likely to score movement epochs as wake, which has been found to be most accurate and consistent with PSG in studies of older adults.[93,116,117]

Investigators that manually scored actigraphy in conjunction with sleep diary data produced sleep-related variables that were more aligned than PSG–derived variables from an automated scoring process.[118] Others have reported using a standard scoring algorithm to set rest intervals, which is appropriate and highly reproducible.[119] Therefore, we used sleep diary, ambient light and activity levels to hand score rest intervals and correct the automated actigraphy scoring algorithm when necessary to ensure that actigraphy data

was valid and reliable.

Integrated Data (Mixed) Analysis: Aim 3. The first step of data integration was to compare the quantitative, objective actigraphy data and sleep survey data with the qualitative data in order to strengthen the results in this new area of study. Then, using a matrix, the qualitative data were analyzed given actigraphically-derived total sleep time and scores on the Pittsburgh Sleep Quality Index, Insomnia Severity Index, and Epworth Sleepiness Scale. In this manner, the results from the dominant method (QUAL) were enhanced with the findings from the other method (quan) to yield a broader perspective of sleep disturbances in this population. We examined congruence between the data sets (i.e., we qualitatively discerned if a person had good or poor sleep and then determined if the quantitative objective and sleep survey data supported this conclusion). For example, if a participant discussed a specific sleep disturbance (e.g. short sleep quantity), we confirmed the sleep disruption using actigraphy and responses on standardized sleep surveys. The quantitative data was used to augment the qualitative data by enhancing the picture of how participants perceived, recognized, and interpreted sleep disturbances.

Ensuring Quality

Methodological rigor[120,121] in the qualitative and mixed methods portion of this study was ensured through the following steps: 1) enhancing credibility via member checking, the process by which findings are validated as representative of the experience of the participants,[120] 2) establishing confirmability via audit trails to preserve integrity and regular meetings with the mentorship team where findings were discussed to determine validity of inferences,[121] 3) establishing reliability of coding by using a second person to code a subset (n=2) of interviews, 4) engaging in peer debriefing and 5)

triangulation during the data integration phase to increase the credibility and dependability of the findings.[78] A colleague well trained in qualitative data analysis independently coded two interviews chosen at random. The coding was then reviewed line by line to determine the level of concordance. Discrepancies were discussed and >95% agreement was achieved.

Protection of Human Subjects

Risks and Adequacy of Protection against Risk. The participants were made aware that this research study was voluntary and there would be no penalty or loss of benefits to which they are entitled regardless of their decision to participate. This allowed us to address any role conflict or coercion, so the participant did not feel s/he had to participate in the study in order to remain in the LIFE program. Participants also had the opportunity to think about whether or not they would like to participate in the study. In order to ensure that the participant truly understood what the research study entailed and that his/her participation was voluntary, each participant was asked to reiterate the purpose of the study and options if s/he chose not to be in the study.

We offered the participant the opportunity to break the first session into two visits (screening and consent [Visit 1]; quantitative sleep surveys and qualitative interview [Visit 2]). It was possible that a participant could become anxious or stressed during data collection because of the questions asked, the burden of data collection, or for other personal reasons. Although this did not occur, if a participant would have become stressed, data collection would have been delayed to tend to the participant's emotional needs.

Loss of confidentiality was considered very low likelihood given the protections we had in place and our experience in systems of protecting private information. All data were coded with a study specific identifying number and all data (quantitative and qualitative) was de-identified.

Potential Benefits of the Proposed Research to Human Subjects and Others. It is possible that these study results may benefit older adults in the future, but participants were not expected to directly benefit. They could gain a heightened awareness of their sleep habits and patterns after completing the sleep diary, but they were not expected to realize an immediate or direct benefit from participating.

Importance of the Knowledge to be Gained. The overall purpose of this mixed methods study was to describe sleep characteristics and sleep disturbances in nursing-home eligible, community dwelling older adults. We gained a greater understanding of sleep disturbances and contributed to the knowledge of this understudied phenomenon in high-risk older adults. Results from this study will provide foundational knowledge for intervention research in older adults with a high level of care needs, in order to develop interventions for this population.

Data and Safety Monitoring Plan. The data quality control process associated with primary data processing consisted of the following stages: potential participant prescreening and screening for eligibility, data validation, and data auditing in order to ensure that all stages of the data handling process were subjected to data quality control. Prior to conducting any study activities, all research staff and the PI completed the required training and met the NIH criteria for continued training in responsible conduct of research.

All project records reflect only the unique study identification number of each participant. Information linking the study ID to the participant is stored on a separate password-protected and encrypted secure file on the School of Nursing server. Data on and access to the servers are electronically protected by multiple firewalls/ passwords/encryption layers including a Secure Socket Layer.

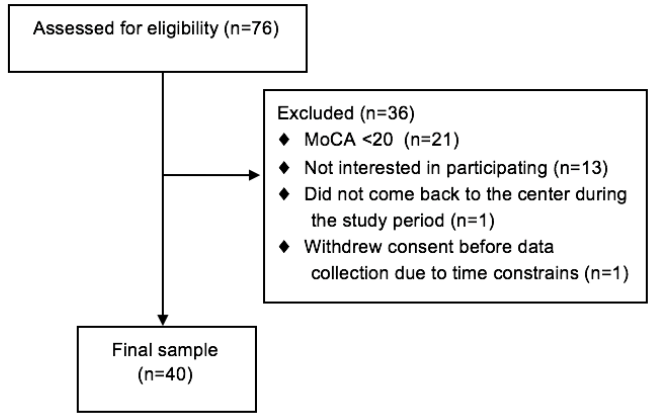
CHAPTER 4: RESULTS

The results of this concurrent nested mixed methods study are presented in this chapter. The purpose of this study was to describe sleep characteristics in 40 nursing-home eligible, community dwelling older adults. Specifically, we sought to explore perceived sleep quality, beliefs about sleep, and facilitators of and barriers to sleep; describe objective and self-reported sleep characteristics and sleep disturbances; and describe older adults' recognition and interpretation of sleep disturbances by triangulating qualitative, objective and self-reported sleep characteristics. The first section describes screening, demographic and clinical characteristics of the sample. Additionally, we provide a short summary of the self-reported sleep characteristics to put the qualitative data in context. Next, to address the study aims, we present the qualitative, quantitative, and integrated results in that order.

Screening, Demographic and Clinical Characteristics

Seventy-six participants were screened for enrollment in this study. Mini Mental Status Exam scores ranged from 28-30 (mean 29.1). Participants were not enrolled if Montreal Cognitive Assessment (MoCA) scores were less than 20 (n=21); they were not interested after going over the consent (n=13); they expressed interest but did not come back to the center during the study period (n=1); they withdrew consent before data collection because of family time constraints (n=1). See Figure 4.1.

Figure 4-1: Screening and Enrollment



A final sample of 40 participants was recruited from the Mercy LIFE - West Philadelphia center. The sample was Black (100%) and primarily female (85%), which is consistent with the population demographics. The age of participants ranged from 59 to 92 years (mean 72.37 ± 9.54). Fourteen (35%) participants were aged 55-65; 18 (45%) were aged 66-75; and 10 (25%) participants were aged 76 or greater. None of the participants had a bed partner and 30 (75%) lived alone. All had multiple chronic conditions, with Cumulative Illness Rating (CIRS) scores ranging from 2 to 30 (mean 15.55 ± 5.91). Participants had some mild cognitive impairment, with MoCA scores ranging from 20 to 29 (mean 24.05 ± 2.44). On average, they were taking 10.58 ± 3.63 medications. Table 4.1 provides demographic and clinical characteristics of the sample.

Table 4.1: Baseline Demographic and Clinical Characteristics of the Sample of 40 Older Adults

Demographic Variables	**Overall Sample**
Age (Years)	72.38 ± 9.54
Gender	
Female	34 (85%)
Male	6 (15%)
Race/Ethnicity	
Black	40 (100%)
Non-Hispanic	40 (100%)

Living arrangement	
Alone	30 (75%)
Roommate(s)	10 (25%)
Clinical variables	
Montreal Cognitive Assessment	24.05 ± 2.44
Cumulative Illness Rating Scale	15.55 ± 5.91
Total Number of Medications	10.58 ± 3.63
Medical Comorbidities	8.75 ± 3.03
Allergic rhinitis	19 (47.5%)
Anemia	9 (22.5%)
Angina	6 (15%)
Asthma	12 (30%)
Atrial fibrillation	3 (7.5%)
Cardiovascular disease	17 (42.5%)
Chronic hepatitis C	3 (7.5%)
Chronic obstructive pulmonary disorder	10 (25%)
Constipation/Diarrhea	25 (62.5%)
Diabetes	23 (57.5%)
Eye disease	7 (17.5%)
Gastroesophageal Reflux Disorder	22 (55%)
Gout	5 (12.5%)
Heart failure	10 (25%)
Hyperlipidemia	22 (55%)
Hypertension	35 (87.5%)
Hypothyroidism	2 (5%)
Insomnia	6 (15%)
Kidney disease	2 (5%)
Pain	29 (72.5%)
Obstructive sleep apnea	2 (5%)
Osteoporosis/osteoarthritis	16 (40%)
Stroke	5 (12.5%)
Mental Illness	17 (42.5%)
Depression	13 (32.5%)
Anxiety	9 (22.5%)
Schizophrenia	3 (7.5%)
Bipolar	2 (5%)

Sleep survey data summary. On the initial sleep screening question (Do you feel you sleep well or poorly?), participants self-identified as good sleepers (40%), poor sleepers (50%), or were undecided whether they were a good or poor sleeper (10%). This was purposeful in order to get a representative sample of both good and poor sleepers. Interestingly, four individuals were reluctant to describe their sleep as good or poor;

rather said their sleep was sometimes good and sometimes bad. We herein refer to this group as undecided sleepers. On self-report sleep surveys, the majority of participants had poor sleep quality and more than half reported insomnia symptoms; yet most participants did not report sleepiness during the day. See Table 4.4, Table 4.5, and the quantitative results section for more detail.

Qualitative Results

In this section the results from the qualitative analysis are presented. The themes are presented in broad categories: 1) perceived sleep quality, 2) beliefs about sleep, and 3) facilitators and barriers.

Sleep quality (Theme 1). Sleep quality was described in terms of quantity, latency, continuity, and consequences.

Participants described sleep quality as getting or not getting enough hours of sleep, ability to fall or stay asleep, and the next day effects. They decided if they had had a good night sleep based on their feelings in the morning. One woman in her 60s said, "Because of my body in the morning. My body feels good if I slept good, but if I didn't sleep good, my body is tired." Participants often reflected on their past experiences; a good sleeper was always a good sleeper, a bad sleeper never slept well, or a bad sleeper used to sleep well.

> "The sleep pattern hasn't changed…all night long you're flippin' from the top of the bed to the bottom of the bed... I have to laugh…it's so funny. I said, what are you gonna do? Some nights I get angry…I'm really tired…I wanna sleep. But it just don't happen… I've had sleep problems from a child. I've always had sleep problems. So I don't know."

Sleep quantity. Participants described their sleep quantity as adequate (40%), inadequate (45%), or they were ambivalent (15%). Not surprisingly, most of those who self-identified as poor sleepers described inadequate sleep duration and those who

identified as good sleepers were comfortable, happy, and content with their sleep duration. Table 4.2 below uses illustrative quotes to describe the breakdown of qualitative accounts of sleep quantity by self-identified sleep quality on the initial sleep screening question.

Table 4.2: Assessment of Sleep Quantity
Based on the Response to "How do you feel about the amount of sleep you get?" (n=40)

	Adequate quantity	Inadequate quantity	Ambivalent about quantity
Good sleeper (n=16)	14 (87.5%)	2 (12.5%)	
	"I feel good about that…I get more sleep than I'm not getting."	"I could get a couple, maybe two more hours."	
Poor sleeper (n=20)	1 (5%)	14 (70%)	5 (25%)
	"I get enough sleep, I can sleep on til 11:00-12:00 during the day."	"I feel bad…I'm not sleeping. You know, I'm not sleeping."	"Oh well, I don't even pay no attention to it…I got used to it. Now I just sleep for a couple hours and wake up."
Undecided sleeper (n=4)	1 (25%)	2 (50%)	1 (25%)
	"I do get a lot of sleep…I do get a lot of rest…that's what I enjoy."	"Not good. I wanna sleep a whole lot more."	"Sometimes it's good, sometimes it's not."
	16/40 (40%)	18/40 (45%)	6/40 (15%)

Sleep quantity was often described in the context of how participants felt the next day. Those who believed they got enough sleep felt well rested, had a pleasant demeanor and were ready to tackle the day. One woman in her late 80s described, "I feel that sleep has always been a friend to me…it takes me places. I dream... I feel good after I sleep…

it seems to revive me, renew me…renew for the next day." Those who were unhappy with their sleep duration often mentioned the consequences of inadequate sleep such as feeling drowsy, dragging, not being a nice person, or not having enough energy. For example, one woman in her mid 80s said, "I don't feel good about it…it makes you sluggish…you don't have no get-up-and-go like I would when I get my five or six hours of sleep."

Interestingly, the sleep duration that participants reported or wished they got ranged from 4 to 10 hours. There were various comments related to perceptions of how much sleep quantity was necessary, specifically regarding age and what they have heard from others. For example, one woman in her 70s explained, "Just everybody talk about…the older you get, the less sleep. Some old people scared to sleep…they think they gonna die in their sleep. I said you don't have no control over that." Some participants believed that more sleep was required with aging; while others believed that less sleep was necessary with aging. For example, one woman in her 80s said, "I think when you're older, you need more rest" while another woman in her 90s said, "I don't think older adults require all the sleep that you would require. Because we're not as active."

Sleeping well. Participants described sleeping well as an overall positive feeling, feeling good in the morning and being refreshed with enough energy to engage in daytime activities. A best night's sleep was described primarily in terms of uninterrupted sleep of a self-identified adequate duration. Four self-identified good sleepers believed their sleep was so good every night such that they could not differentiate a best night's sleep from a normal night while two self-identified poor sleepers could not think of any

good or best night's sleep. One woman in her 80s said, "My best night's sleep is every night I think." Another woman in her 60s said, "I can't remember. I really can't remember my best night's sleep."

Sleeping poorly. Sleeping poorly was characterized as having a negative effect on mood and making next day activities challenging. Participants talked about "tossing and turning" and not getting "any sleep". When asked about a "worst night's sleep", participants described difficulty falling asleep, interruptions in sleep or inadequate sleep duration. For example, one woman in her 60s who described herself as always having poor sleep said, "I can't sleep at all. I lie there tossing and turning, tossing and turning…the sleep would never come." A man in his late 60s said, "I can't sleep. I wanna go to sleep and I can't." Fourteen participants described their worst night's sleep in terms of what they believed caused the poor sleep. Among the perceived causes were worrying about loved ones or finances, bad dreams, environmental factors such as noise and light, death of a loved one, pain, constipation and nocturia.

Regular sleep problems. The self-identified good sleepers did not report any daily sleep problems. The self-identified poor and undecided sleepers who had regular sleep disturbances described difficulty falling sleep, difficulty maintaining sleep, early morning awakening and next day consequences.

Precipitating factors. Participants who described regular sleep disturbances often attributed the sleep disturbance onset to illness. They identified stroke, cardiac problems, diabetes, hallucinations, gout, pain, chicken pox during childhood, and trauma as factors precipitating sleep disturbances. They discussed consequences of their illnesses: minimal daytime activity, functional impairments, and new medications. Additionally, a few

participants mentioned night shift, death of a loved one, new living environment and simply getting older as precipitating factors to their sleep disturbances.

Attitudes and Beliefs (Theme 2). Beliefs about sleep centered on sleep importance as well as personal and external factors that affect sleep.

Sleep importance. Most (90%) participants had positive feelings towards sleep, such that sleep was believed to be extremely important in their lives. Sleep importance was expressed in terms of the daytime effect. Participants talked about the consequences of poor sleep on mood, daily function, and health. An undecided sleeper in her 60s said, "It's very important for me to sleep well…I know if I don't get my sleep, I'm gonna be very angry. I'll be upset. I'll be nasty to people for no apparent reason because I'm tired and I'm grouchy." Another woman in her 60s said, "If I don't sleep well, my knees will let you know, that it's been a bad night…I can hardly walk."

Additionally, participants talked about the positive effects of good sleep, such as improved mood, daily function, health, and quality of life. A self-identified poor sleeper in her 80s said, "It's important because you feel better…you're ready to meet the day. You got a smile on your face because you had a nice good night's rest."

Four self-identified poor sleepers did not express the importance of sleep; two believed sleep was not important and two were ambivalent towards sleep importance. The participants who believed sleep was not important described needing less sleep with age and a lack of consequences from poor sleep indicating it must not be important. The participants who were ambivalent said, "I don't even know what that means anymore" and "It's not helping (me) not to sleep". Additionally, four participants mentioned even

though sleep was important, they do not sleep and therefore they would not let it bring them down. They had adapted. One woman in her 70s said:

> "It's always been important to me but it just don't happen… I don't worry too much about it now. I really don't… you know you get used to doin' something every day until it just don't bother me. I automatically know when I go in there I'm not gonna sleep. So I might doze off, but I'm not gonna have a good quality of sleep because I never have."

Regardless of whether a participant identified as a good or poor sleeper, less than a quarter of the sample had concerns about their sleep. One self-identified good sleeper in her late 80s said, "I don't have too many worries because, after I say my prayers…I go to sleep, I know the angels are looking after me." The self-identified poor and undecided sleepers who did not worry about sleep had adjusted to the sleep disturbances. One poor sleeper said, "I stopped worrying about it so much…I don't worry about it so much like I used to. Either I sleep or I don't sleep…that's it." Another poor sleeper said, "I don't feel worried or concerned about it, really…I don't go to work or anything, so I don't have to worry about it." One undecided sleeper said, "I'm not really worried…I'm doing okay… it's been a long time since I had any illness or anything like that."

The eight participants who did have concerns about their sleep were all self-identified poor sleepers. They were primarily worried about preventing untoward consequences such as illness, bad mood, or negative effects on daily activities. Half of these participants were also concerned with falling asleep and getting enough sleep.

> "It concerns me that it may cause heart problems. It may not, but it's my concern. That it may cause… heart problems… I already don't eat—I mean I don't have a good appetite…I think that not sleepin' is not helpin' it any either… sometimes it depresses you…you just feel depressed."

Personal factors. Narratives described positive, negative, and ambivalent beliefs around personal factors that affected sleep. Some participants identified strategies they

could do to improve sleep; while others believed there was nothing that could improve their sleep or they were not aware of anything. Personal strategies included improvements in sleep hygiene (do not nap or doze during the day, regular and routine bedtime, do not eat late at night, lights and television off, limit fluids near bedtime); increase daily activity (primarily physical activity but also mention of increasing social interaction to decrease loneliness); and avoid stress (have a clear mind, let things go, pray, decrease worries).

Participants who believed nothing could be done to improve their sleep expressed negative or ambivalent views. They described trying everything to improve their sleep without any success. They also mentioned that they wished they knew what could be done to improve their sleep. Others believed their sleep was good and that there was no room for improvement. Additionally, three participants mentioned that if their sleep was to get any better, they would be dead. Table 4.3 below uses illustrative quotes to describe personal strategies participants identified to improve sleep, by self-identified sleep quality. Please note, each participant could provide more than one response.

Table 4.3: Personal Strategies used to Improve Sleep
As identified in responses to "What can you do to improve your sleep?" (N=40)

	Sleep hygiene	Increase physical activity	Avoid stress/ clear mind	Death	Do not know/nothing
Good sleeper (n=16)	"Stay off the computer."	"I think I could be more active."	"If I got problem just let it go so I can get some rest."	"What more would I want? Short of death..."	"I don't really know how I can improve it. I don't have a problem with it now."
Number of responses per group	3	2	3	3	8

Poor sleeper (n=20)	"Watch what I eat and not doze so much during the day."	"Be a little more active than just sitting around."	"Stop thinking so much about what I have to do the next day."		"I really don't know. I tried everything." "I honestly truly wish I knew."
Number of responses per group	7	7	2	0	7
Undecided sleeper (n=4)	"…do what I have to do early and go to bed"	"I probably need to exercise more."	"Trying not to get myself confused about my problems."		"I just go with the flow."
Number of responses per group	2	2	2	0	1
Total	12/40	11/40	7/40	3/40	16/40

Seventy-five percent of good sleepers, 55% of poor sleepers and all of the undecided sleepers believed daily activities affected sleep. In total, 67.5% of all participants believed daily activities affect sleep while 32.5% believed they did not. One self-identified poor sleeper in her 60s said, "Usually, I am so worn out within the course of the day until it makes me sleep even better. I prefer to be worn out." Additionally, 25% of self-identified poor sleepers believed even though they should be tired with increased daily activities, they still do not sleep well.

> "I can…have an active day… doin' things…get home…feel like I'm rested…tired…wanna go to sleep…then sit there in the recliner chair… lay across the bed…still don't go to sleep…I mean I think my sleep is all messed up…that's my opinion. I'm not for sure."

External factors. Narratives revealed positive, negative and ambivalent beliefs around external factors that affected sleep. Participants primarily believed the only role

for their primary care provider (PCP) was to provide sleep medication. One poor sleeper in her 60s said, "The only thing they gonna do, they gonna give me like Ambien and stuff…I don't want it." Twenty participants had negative or ambivalent beliefs about sleep medication; these reflected in comments about adding another medication to an already long list, medication does not improve sleep, wanting to fall asleep naturally, fear of death, fear of addiction, and feeling groggy the next day. One good sleeper in her 70s said, "…every pill is not for everybody… they give you pills, you go to sleep, you don't wake up…I know some people take pills and don't go to sleep." Positive beliefs were expressed by four participants who used a sleep medication and felt the sleep medication was effective. "It's very important. I take it every night, as I say, clockwork…if I don't, I know what I'm headed for." All participants who had positive beliefs about sleep medication self-identified as poor or undecided sleepers.

Other roles for the PCP included the provider as an outlet for talking through problems that may impede sleep. One poor sleeper said, "If it wasn't for her (nurse practitioner), I wouldn't be sleeping at night like I do…or getting through the day or anything like I do without going crazy." The PCP also gave suggestions for ways to improve sleep hygiene. One good sleeper in her 60s explained, "They told me…to stop drinking water in the middle of the night." Some mentioned there was nothing the PCP could do because their sleep does not need any improvements. Two participants had negative beliefs about the provider such that the PCP does not do anything for them. Primarily, beliefs were positive towards the providers.

Narratives also reflected overwhelmingly positive descriptions of the sleeping environment. The participants felt calm, comfortable, relaxed, and safe in their bedrooms.

They were often excited to describe their room and proud of the way that it was set up and decorated. One woman in her 70s said, “I know it’s just another room, but that’s my bedroom. To me, that’s my relaxing room.” Negative attitudes were expressed by five good sleepers, four poor sleepers and one undecided sleeper. These were related to room size, clutter or cleanliness, dissatisfaction with sleep surface (i.e., mattress or sofa), dissatisfaction with the living arrangement, and loneliness. One man in his 60s said, “I feel like everybody forgot about me…when I’m in my room…they just feelings that go away, after… a while.”

Facilitators and Barriers (Theme 3). Facilitators of and barriers to sleep can be categorized into behavioral, physiological, psychological, and environmental factors.

Facilitators. Behavioral facilitators of sleep included eating or drinking close to bedtime, watching television, listening to music, praying, or increased activity (social interaction, physical activity, cognitive exercises) during the day. Physiological facilitators included the use of sleep medication or continuous positive airway pressure (CPAP). Psychological facilitators included positive emotions, pleasant mood, having peace of mind, minimal stress or worry. Environmental facilitators included bedroom characteristics such as noise, light, and temperature. Of note, about one third of the participants mentioned that nothing helps them sleep well or that they could not think of anything.

Interestingly, most (80%) of the sample reported that they went to sleep with their television (TV) on. Participants described falling asleep while watching TV and some would even laugh, “the TV is watching me”. Some would turn the TV off if they woke up during the night; others left their TV on no matter what. One man said, “I leave the TV

on because I'm the kinda person that needs to hear somebody talking…I'm not dead… that's the only reason I keep the TV on…I need to make sure that I'm still alive." One undecided sleeper in her 60's said, "My TV is…my boyfriend…it's on all night…I just turn the volume down a little…I have to have it talking to me and I go right to sleep."

***Barriers*.** Behavioral barriers were primarily modifiable sleep hygiene factors. For example, eating (including type of food) or drinking too close to bedtime affected sleep (primarily in the direction of eating or drinking contributing to poor sleep; but a few participants mentioned that if they went to bed on an empty stomach that they would not have good sleep or that food decreased the effectiveness of their medication). Four participants viewed the TV as a barrier to sleep due to the noise or attracting the participant's attention to watch a particular program. Minimal activity during the day was a barrier; yet, too much activity causing pain and increasing restlessness was also a barrier. Napping during the day was considered a barrier to some participants; but also viewed as a way to make up lost sleep to others. Physiological barriers included pain, medications and illness. Interestingly, despite the fact that the most of the older adults were getting up to the go the bathroom during the night; they did not necessarily view this as a barrier to sleep. For instance, when asked specifically about barriers, few participants mentioned nocturia.

Participants generally described nocturia in terms of a normal part of the night. If they were ever upset or disturbed by getting up to go to the bathroom, it typically no longer bothered them. One good sleeper in her 70s said, "I wouldn't consider it a sleep problem. Just going to the bathroom all the time." A few self-identified poor sleepers were still annoyed by getting up to use the bathroom during the night. One woman in her

80s said, “There’s times where I’m tryin’ to sleep… then I have to go to the bathroom…I don’t feel like gettin’ up and goin’ to the bathroom. I think that keeps me from gettin’ the proper rest.” Participants generally attributed nocturia to aging, a weak bladder or their medication (i.e., water pill).

> “I don't really know how many hours I sleep because it seems like I don't sleep no time, the way I be up all night long, tossing and turning and going back and forth to the bathroom….I'm up all night long…going to the bathroom….Maybe four or five time because I take these pills…to take the water out of me…I'm going all night long.”

Medications were a barrier to sleep in that they were on too many medications, side effects of medications, or the lack of a sleeping pill. One female poor sleeper in her 80s said, “I do think some of that medication causes me not to sleep…I still believe it’s some of this medication…I take about 12 or 13.” Certain illnesses were viewed as barriers to sleep including posttraumatic stress disorder, insomnia, anxiety, constipation, and cold or flu. Psychological barriers were primarily related to stress, anxiety and worrying. Participants described difficulty falling asleep as they were thinking about family problems, financial concerns and health issues. Additionally, participants described thinking about things that they could no longer do for themselves and the reliance on others due to functional limitations. Grief associated with the death of a loved one was also a barrier.

Environmental factors that served as barriers included noise and living arrangements. Noise both inside and outside of the home was considered a barrier. Environment noises included roommates coming into the house late at night, phone ringing, TV or radio on a night, thunderstorms, high traffic area, accidents, trains, trolleys and loud people outside. The living environment affected sleep when s/he was unhappy

with the living arrangement, did not feel safe, or when a new home did not include previous facilitators.

> "So I know if they (neighbors) are in there, that door (front door to building) is open…I don't feel safe with that door open at night…not only that, when you go out in the morning, you don't know who is in the hallway…. I don't feel safe. And if I do fall asleep, I'm not a sound sleeper."

Similar to the facilitators, about 25% of participants believed there was nothing that interfered with their sleep, or they could not recognize it. One male good sleeper said, "I don't sleep poorly…Nothin' interferes with my rest. I be good, restin' real good." One woman poor sleeper in her 60s said, "I don't know what makes me sleep or what makes me not sleep. I just know I cannot sleep."

Quantitative Results

Self-report sleep surveys. On the initial sleep screening question, participants self-identified as good (40%), poor (50%), or were undecided (10%) sleepers. The majority (70%) of the participants had poor sleep quality (Pittsburgh Sleep Quality Index scores 9.25 ± 5.07); yet most (75%) did not report daytime sleepiness (Epworth Sleepiness Scale scores 7.65 ± 5.36). More than half of the participants reported insomnia symptoms and 25% of the sample met Insomnia Severity Index (ISI) criteria for clinical insomnia (ISI scores 9.23 ± 7.17). See Table 4.4 below for more detail.

Table 4.4: Self-reported Sleep Characteristics of Older Adults (N=40)

	Overall Sample N (%); Mean ± SD	**Score Interpretation**
Screening Question		
Good sleeper	16 (40%)	Qualitative response to
Poor sleeper	20 (50%)	"Do you feel you sleep
Undecided sleeper	4 (10%)	well or poorly?"
Global Pittsburgh Sleep Quality Index	9.25 ± 5.07	
Good Sleep Quality	12 (30)	Good sleep (score ≤5)
Poor Sleep Quality	28 (70)	Poor sleep (score >5)
PSQI Subscales		PSQI Subscales
Subjective sleep quality	1.28 ± 0.81	Minimum Score = 0
Sleep latency	1.55 ± 1.15	(better)
Sleep duration	1.53 ± 1.32	Maximum Score= 3
Habitual sleep efficiency	1.50 ± 1.38	(worse)
Sleep disturbances	1.48 ± 0.68	
Use of sleep medications	1.03 ± 1.42	
Daytime dysfunction	1.45 ± 1.34	
PSQI Raw Scores		
Sleep duration	344.25 ± 125.27	Normal: 420-480 minutes
Sleep latency	48.75 ± 69.69	Normal: <30 minutes
Insomnia Severity	9.23 ± 7.17	
No insomnia symptoms	18 (45%)	No insomnia (0-7)
Insomnia symptoms	12 (30%)	Insomnia symptoms (8-14)
Clinical insomnia	10 (25%)	Clinical insomnia (15-28)
Epworth Sleepiness Scale Total Score	7.65 ± 5.36	
Not sleepy	30 (75%)	Not sleepy (<11)
Sleepy	10 (25%)	Sleepy (≥11)

PSQI- Pittsburgh Sleep Quality Index

Actigraphy variables. All actigraphy variables were averaged over a one-week period. Only five (12.5%) participants got the recommended (420-480 min or 7-8 hours) sleep at night (393.59 ± 78.33 min); 75% did not get enough sleep (less than 420 min) and 5% got more than the required amount (more than 480 min). About 25% had long sleep latency (23.22 ± 18.45 min); almost all had long periods of wakefulness after sleep onset (107.93 ± 50.1 min) and 87.5% had poor sleep efficiency (72.98% ± 9.30%). With

napping, 24 hour total sleep time tended to be long for most participants (77.5%); 12.5% got the recommended sleep amount but 10% still did not get enough sleep. The average duration of total napping per day was 162.80 ± 83.22 minutes with a mean nap frequency per day of 33.95 ± 15.05 naps. That is, on average participants were nodding off almost 34 times each day. The average duration of intentional napping (defined as >10 minutes) per day was 33.15 ± 11.51 minutes with an intentional nap frequency per day of 2.5 ± 1.47 naps. See Table 4.5 below.

Table 4.5: Actigraphically Derived Sleep Characteristics of Older Adults (n=40)

Variable	Overall Sample	Interpretation
Total sleep time	393.59 ± 78.33	Normal: 420-480 mins
Short sleeper	30(75%)	<420 mins
Long sleeper	5(12.5%)	>480 mins
24 hour total sleep time	556.39 ± 114.23	TST + naps
Total nap time	162.80 ± 83.22	
Frequency/day	33.95 ± 15.05	
Intentional nap length (mins)	33.15 ± 11.51	Nap ≥ 10 mins
Frequency/day	2.50 ± 1.47	
Sleep latency	23.22 ± 18.45	Normal: < 30 mins
Long sleep latency	11(27.5%)	Long: ≥ 30 mins
Wake after sleep onset	107.93 ± 50.11	Normal: < 30 mins
Long WASO	39(97.5%)	Long: ≥ 30 mins
Sleep efficiency	72.98 ± 9.30	Normal: >85%
Poor sleep efficiency	35(87.5%)	Poor <85%

mins- minutes; TST- total sleep time; WASO- wake after sleep onset

Correlations between demographic variables, clinical variables and sleep surveys. The correlations between demographic variables, clinical variables, and sleep surveys can be found in Table 4.6. Age was significantly negatively correlated with the screening sleep question (p=0.02) and the Pittsburgh Sleep Quality Index (p=0.03) such that those with older age reported better sleep quality. Gender was significantly

correlated with Montreal Cognitive Assessment; men had worse cognition scores (p=0.03). As expected, the sleep screening question was highly correlated with the Pittsburgh Sleep Quality Index (r=0.71; p<0.001) and the Insomnia Severity Index (r=0.75; p<0.001), but not the Epworth Sleepiness Scale. Living alone was significantly negatively correlated with Epworth Sleepiness Scale (r=-0.32; p=0.04) and age (r=-0.32; p=0.04); those who lived alone had higher scores on Epworth Sleepiness Scale (increased sleepiness) and were older. The following correlations were statistically significant (p<0.05) when looking specifically at individual diseases and sleep surveys: hepatitis C and insomnia with Pittsburgh Sleep Quality Index scores (r=0.35, 0.36, respectively); asthma, headache, and bipolar disease with Epworth Sleepiness Scale scores (r=0.36, 0.33, -0.32, respectively); hypertension and smoking with Insomnia Severity Index scores (r=0.34, 0.33, respectively). No other correlations were statistically significant.

Table 4.6: Correlations between Demographic, Clinical and Sleep Survey Variables in older adults (n=40)

	Gender	MOCA	CIRS	Living situation	Screening question	PSQI	ESS	ISI
Age	0.16	-0.07	-0.27	-0.32**	-0.38**	-0.34**	0.04	-0.27*
Gender		0.35*	-0.13	0.16	-0.18	-0.07	-0.14	0.00
MoCA		1.00	-0.19	-0.14	-0.22	-0.04	-0.00	-0.03
CIRS				0.07	0.19	0.08	0.22	0.21
Living Situation					-0.07	0.03	-0.32**	-0.14
Screening question						0.71**	0.12	0.75**
PSQI							0.12	0.79**
ESS								0.29*

MoCA- Montreal Cognitive Assessment; CIRS- Cumulative Illness Rating Scale; PSQI- Pittsburgh Sleep Quality Index; ESS- Epworth Sleepiness Scale, ISI- Insomnia Severity Index

Spearman's correlation coefficient; Two-tail significance

*significant at p<0.10; **significant at p<0.05

Correlations between demographic and clinical variables and Actigraphy.

There were no statistically significant correlations between demographic/clinical variables and actigraphy variables (Table 4.7). When looking at individual medical conditions, the following correlations were statistically significant ($p<0.05$): total sleep time and asthma ($r=-0.36$), 24 hour total sleep time and constipation ($r=0.33$); sleep latency and electrolyte imbalance ($r=-0.37$); wakefulness after sleep onset and headache ($r=0.34$); sleep efficiency and headache ($r=0.36$); sleep efficiency and constipation (0.38); nap duration and gastroesophageal reflux disorder ($r=0.34$).

Table 4.7: Correlations between Demographic, Clinical and Actigraphy Variables in Older Adults (n=40)

	TST	24hr TST	SL	WASO	SE
Age	-0.04	0.11	0.44	0.02	-0.10
Gender	0.17	0.16	0.00	-0.09	0.12
MoCA	0.11	-0.01	-0.30	0.05	0.12
CIRS	0.17	0.17	-0.20	-0.25	0.22
Living situation	-0.01	0.11	0.02	-0.08	0.06

MoCA- Montreal Cognitive Assessment; CIRS- Cumulative Illness Rating Scale; TST- total sleep time; 24hr TST- 24 hour total sleep time; SL- sleep latency; WASO- wake after sleep onset; SE- sleep efficiency

Spearman's correlation coefficient; Two-tail significance

*significant at p<0.10; **significant at p<0.05

Correlations between Subjective Sleep Surveys and Actigraphy Variables.

There were no statistically significant correlations between any of the sleep surveys (Pittsburgh Sleep Quality Index, Insomnia Severity Scale, Epworth Sleepiness Scale) and actigraphy variables (total sleep time, 24 hour total sleep time, sleep latency, wakefulness after sleep onset, sleep efficiency, napping total).

Integrated Results

Integration of the data required that the results be anchored on a key variable, perceived sleep quality obtained during qualitative interview. We examined the qualitative interviews and categorized each person as perceiving his or her sleep to be good, poor or undecided. Next, we compared our categorization to their response on the initial sleep screening question (Do you feel you sleep well or poorly?). Thereafter, themes that emerged from the qualitative data, responses to self-report sleep surveys, and objective total sleep time derived from actigraphy were integrated to further describe sleep in this population. We used our qualitative categorization (perceived sleep quality based on the interview) and compared this with scores on the various sleep surveys and total sleep time derived from actigraphy. The following criteria were used to indicate sleep disturbances: Pittsburgh Sleep Quality Index greater than 5 indicated poor sleep quality; Insomnia Severity Index greater than or equal to 8 indicated insomnia symptoms; Epworth Sleepiness Scale greater than or equal to 11 indicated daytime sleepiness, total sleep time less than 420 minutes (7 hours) or greater than 480 minutes (8 hours) indicated poor total sleep time.

Recognition and Interpretation. Integrating the data allowed us to identify concordance and discordance in recognition and interpretation of sleep disturbances and to use that conclusion to describe how older adults recognize and interpret sleep disturbances. There was a lack of concordance in the qualitative interviews of three participants (two men, one woman) who self-identified on the sleep screening question as having poor sleep quality. Although they identified as poor sleepers on the initial sleep screening question, they reported good sleep quality during the interviews. These participants talked about sleeping well most of the time and had positive feelings in the morning. Lack of concordance can be illustrated by one man in his 70s who initially said he was a poor sleeper on screening. But in the interview he said, "I sleep pretty good…I feel good in the mornings when I wake up…sleep problems, I just don't have any."

The other 37 participants' responses on the initial sleep screening question aligned with the data from their qualitative interviews. Those who self-identified initially as having good sleep described good sleep during the interviews; those who self-identified initially as having poor sleep described poor sleep during the interviews; those who were undecided initially described sleep that was variable and were designated undecided sleepers from the interviews.

As stated above, we chose to anchor based on ratings of sleep in the qualitative interviews rather than the initial sleep screening question. Therefore, there were 19 good sleepers, 17 poor sleepers and 4 undecided sleepers.

Good sleepers. When comparing qualitative interviews and actigraphy, 16/19 good sleepers had insufficient (87.5%) or long (12.5%) total sleep time on actigraphy.

There was discordance such that qualitative interviews indicated the participants perceived their sleep quantity to be good, yet 16 had objective total sleep time outside the recommended range of 7 to 8 hours.

We explored this result further by comparing self-identified sleep duration on interview and Pittsburgh Sleep Quality Index with objective total sleep time from actigraphy. Seven participants overestimated sleep duration, seven participants underestimated sleep duration and five participants accurately identified sleep duration (within 30 minutes). Of the three good sleepers who got the recommended amount of objectively measured sleep, only one accurately described perceived sleep duration while the other two participants overestimated their sleep length.

We noticed a pattern in the qualitative data in those who perceived that their sleep was good although objectively they had poor sleep (primarily insufficient sleep duration) on actigraphy. These participants mentioned that their sleep was so good that it could not get any better. They tended to have negative beliefs about sleep medications, believed their sleep was so good that there was no room for improvement, or they had the option to nap during the day. That is, the participants who perceived their sleep was good but had objective poor sleep were the same people who had negative beliefs about sleep medications or had the option to nap during the day.

When comparing the qualitative interviews with self-reported sleep surveys, there was discordance on the Pittsburgh Sleep Quality Index in 42% of the good sleepers. That is, 42% of the sample reported that they were good sleepers on interview but their sleep quality scores were poor. Scores on the Insomnia Severity Index and the Epworth Sleepiness Scale were primarily concordant among this group (89.5% and 79%,

respectively). Table 4.8 below describes comparisons between the good sleepers' qualitative and quantitative data. Means and standard deviations are presented for the quantitative data and illustrative quotes are presented for the qualitative data.

Table 4.8: Concordance and Discordance between Qualitative and Quantitative Data in Older Adults Rated as Good Sleepers, with Illustrative Quotes (n=19)

Construct (instrument)	Concordant Group	Discordant Group	Overall Mean (SD)/Normal Values
Total sleep time (Actigraphy)	3/19 (12.5%)	16/19 (87.5%)	386.12 ± 87.89 minutes
Mean ± SD	465.01 ± 9.65 minutes	377.57 ± 90.84 minutes	Normal TST is 420-480 minutes
Qualitative exemplar	"I sleep well…regular amount of sleep."	"My night's sleep are great."	
Sleep quality (PSQI)	11/19 (57.9%)	8/19 (42.1%)	5.26 ± 2.40
Mean ± SD	3.64 ± 1.21	7.50 ± 1.46	Normal score is <5
Qualitative exemplar	"On a regular basis…I sleep well."	"I sleep pretty good."	
Insomnia (ISI)	17/19 (89.5%)	2/19 (10.5%)	3.37 ± 3.20
Mean ± SD	2.65 ± 2.45	9.5 ± 2.12	Normal ISI <8
Qualitative exemplar	"I'll just fall right asleep."	"Sometimes I get to sleep too fast."	
Daytime sleepiness (ESS)	16/19 (87.5%)	3/19 (12.5%)	6.68 ± 4.07
Mean ± SD	5.82 ± 3.26	13.00 ± 2.65	Normal ESS scores <11
Qualitative exemplar	"I'm not tired at all."	"I feel rested."	

PSQI- Pittsburgh Sleep Quality Index; ISI- Insomnia Severity Scale; ESS- Epworth Sleepiness Scale; SD- standard deviation

Concordant refers to interviews that aligned with the quantitative data, such that good sleepers had good sleep metrics on the quantitative measures; Discordant refers to interviews that did not align with quantitative data, such that good sleepers had poor sleep metrics on the quantitative measures

The good sleepers who had daytime sleepiness and insomnia symptoms on the sleep surveys all talked about having the option to nap during the day. One man in his 60s, a woman in her 80s and a woman in her 90s mentioned feeling sleepy during the day sometimes, but would simply take a nap. For example, "I'm a little exhausted…I lay down for a couple hours…wake back up."

Poor sleepers. The majority (82.4%) of poor sleepers discussed having poor sleep and had poor sleep (objective total sleep time outside the recommendation duration) on actigraphy, thus recognizing their sleep disturbance. The three (all women) self-identified poor sleepers that actually got adequate sleep did have long periods of wakefulness after sleep onset and poor sleep efficiency, which indicate nighttime disturbances.

We explored this result further by comparing self-identified sleep duration on interview and Pittsburgh Sleep Quality Index with objective total sleep time on actigraphy. Twelve participants (10 women) underestimated their sleep duration, four women accurately identified sleep duration, while one woman overestimated sleep duration. Of the three poor sleepers who got the recommended amount of sleep when measured objectively, only one (a 90-year-old with depression) accurately described perceived sleep duration while the other two participants underestimated their sleep. The two participants who subjectively underestimated their sleep duration, were both women in their 60s who grossly underestimated sleep duration and had maladaptive beliefs that likely perpetuated their sleep disturbances. "I get so mad with myself sometime cuz I can't sleep. I hate to see the night coming…I can't sleep …I watch the clock." The older woman that self-identified as a poor sleeper recognized that she got enough rest: "I get

enough rest cuz I can sleep on…", but believed she naps too much during the day, "My sleepin' is horrible. I'm sleepin' off and on every time I sit down."

When comparing the qualitative data with self-reported survey data, all of the poor sleepers reported poor sleep quality and 94% had insomnia symptoms or clinical insomnia. Interestingly, ten (59.8%) did not report daytime sleepiness on the Epworth Sleepiness Scale. Of the ten poor sleepers who did not report daytime sleepiness, half mentioned being sleepy during the interview with an inability to sleep. They also had maladaptive beliefs towards sleep: "The only worries or concerns that I have about my sleep is that I get enough sleep…and when it's time for me to go to sleep that I can go to sleep." The other half of the self-identified poor sleepers who did not score as sleepy on the Epworth Sleepiness Scale did not mention being sleepy during the day and had a sense of adaptation, "I don't have any worries about it (sleep). It's just one of those things that happen to some people."

Table 4.9 below compares qualitative and quantitative data in poor sleepers. Means and standard deviations are presented for the quantitative data and illustrative quotes are presented for the qualitative data.

Table 4.9: Concordance and Discordance between Qualitative and Quantitative Data in Older Adults Rated as Poor Sleepers, with Illustrative Quotes (n=17)

Construct (Instrument)	Concordant Group	Discordant Group	Overall Mean ± SD
Total sleep time (Actigraphy)	14/17 (82.4%)	3/17 (17.6%)	412.18 ± 67.91 minutes
Mean ± SD	401.88 ± 70.88 minutes	460.24 ± 5.60 minutes	Normal TST is 420-480 minutes
Qualitative exemplar	"Terrible…I don't think I get enough sleep."	"I toss and turn all night…seems like I don't sleep no time."	

Sleep quality (PSQI) Mean ± SD Qualitative exemplar	17/17 (100%) 13.53 ± 3.86 "It's (sleep quality) terrible."	0/17 (0%)	13.53 ± 3.86 Normal score is <5
Insomnia symptoms (ISI) Mean ± SD Qualitative exemplar	16/17 (94.1%) 15.65 ± 5.16 "…wakin' up about 3:30, 4:00 in the morning."	1/17 (5.9%) 7 "I don't sleep straight through."	15.65 ± 5.16 Normal ISI <8
Daytime sleepiness (ESS) Mean ± SD Qualitative exemplar	7/17 (41.2%) 15.86 ± 4.18 "My body be tired."	10/17 (59.8%) 4.70 ± 2.63 "I'm tired…a lot too."	9.29 ± 6.52 Normal ESS scores <11
PSQI- Pittsburgh Sleep Quality Index; ISI- Insomnia Severity Scale; ESS- Epworth Sleepiness Scale SD- standard deviation Concordant refers to interviews that aligned with the quantitative data, such that poor sleepers had poor sleep metrics on the quantitative measures; Discordant refers to interviews that did not align with quantitative data, such that poor sleepers had good sleep metrics on the quantitative measures			

Undecided sleepers: When we asked the initial sleep screening question, four participants (3 women; 1 man) were reluctant to identify themselves as good or poor sleepers. After analyzing their qualitative interviews, we agreed that these participants perceived their sleep to be in between. Given that these participants were back and forth about their sleep, such that sometimes it was good and sometimes it was bad, we were not able to determine concordance. Rather, descriptive statistics for this group indicate that all had poor sleep on actigraphy (actigraphy total sleep time 350.08 ± 61.10), three reported poor sleep quality (Pittsburgh Sleep Quality Index scores 10 ± 3.83) and insomnia symptoms (Insomnia Severity Scores scores 9.75 ± 3.78), while none of the

participants reported daytime sleepiness (Epworth Sleepiness Scale scores 5.25 ± 4.27). Additionally, one undecided sleeper overestimated sleep duration, two underestimated sleep duration and the one man accurately identified sleep duration.

Other sleep variables. The majority of participants had long wakefulness after sleep onset and poor sleep efficiency. We examined the qualitative data to further describe those with normal wakefulness after sleep onset and good sleep efficiency. The one participant with normal wakefulness after sleep onset and good sleep efficiency was in her late 70s. This participant had a routinized day because her functional impairments warranted a caretaker. Additionally, this participant said, "On a regular basis…I sleep well…It's (sleep) important…" She mentions that she was always a good sleeper, felt sleep was extremely important and had positive beliefs about sleep. An additional four participants (three good sleepers [female] and one poor sleeper [male]) had good sleep efficiency, despite having long wake after sleep onset. On interview, all of these participants had very positive beliefs about sleep and most (three of the four) perceived their sleep to be good.

Based on the objective actigraphy data, the participants napped more than 2.5 hours per day, broken into almost 34 nap periods. We defined an intentional nap to be more than 10 minutes in duration; anything less than that was considered an unintentional nap (i.e., dozing or nodding off). Intentional napping accounted for roughly 20% of total napping. We reviewed the qualitative interviews to determine whether or not participants discussed napping. We found that of the 35 participants who mentioned naps, 26 napped daily or occasionally and nine (2 good; 5 poor; 2 undecided sleepers) mentioned that they do not take naps. One woman who self-identified as a poor sleeper and had an Epworth

Sleepiness Scale score of 11 (indicating sleepiness) said, “I’ve noticed that I can get tired…get extremely tired to the point that I will sit at a table…my head goes down...I have no control over once I get so tired…I just black out…I doze off cuz I’m extremely tired…mentally and physically tired…exhausted.” There was no difference between the mean number of napping minutes per day for those who said they napped or did not nap. A woman in her 80s, classified as a poor sleeper but without subjective reports of daytime sleepiness, with a mean nap duration of 83 minutes and a mean total sleep time of 523 minutes said, “Don’t understand it…by me not sleeping well at night, you would think I would wanna nap during the day, but not me. I’m still just as wide awake.”

Beliefs about napping varied such that some believed a nap was beneficial while others believed napping would negatively affect their nighttime sleep. One woman in her 80s who self-identified as a poor sleeper reported napping daily, “I love to take a nap…everybody takes a nap in the afternoon…about an hour…it makes you feel good.” One woman in her 60s who self-identified as a good sleeper said, “If I get tired or somethin’ I’ll do something…if I take a nap I know I’m gonna be up all night”, while another poor sleeper in her 60s said, “Because I sleep during the day, that may affect me sleeping at night. I don’t know.”

Summary

The majority (87.5%) of participants had objectively short sleep duration (mean total sleep time 6.6 hours); yet only 16 of the 40 older adults self-identified as poor sleepers at enrollment. The majority of the participants had objectively poor sleep quality and napped frequently during the day. Sleep quality and insomnia symptoms were prevalent based on the self-report instruments, yet few reported daytime sleepiness.

CHAPTER 5: DISCUSSION

The purpose of this concurrent nested mixed methods study was to describe sleep and sleep characteristics in 40 nursing-home eligible, community dwelling older adults. We found the majority of the sample had poor sleep quality, regardless of self-perceptions of sleep quality. Few reported daytime sleepiness, despite objective nocturnal sleep disruptions and frequent napping during the day. There was evidence that these older adults had adjusted their health expectations and adapted to sleep disturbances. We also identified modifiable targets for intervention development and testing.

Few participants got the recommended quantity of sleep during the one-week period in which they were monitored. Many had long periods of wakefulness after sleep onset. Sleep efficiency was poor and a majority reported poor sleep quality. Our sample had worse sleep than a nationally representative sample of community dwelling older adults who reported a mean total sleep time of 7.25 hours, wake after sleep onset of 39 minutes and sleep efficiency of 82%. Our sample also had worse sleep than a sample of community dwelling older veterans enrolled in a Veterans Affairs (VA) Adult Day Health Care (ADHC) Program; their primarily white males slept a mean of 7.7 hours in total with sleep efficiency of 83.7% and mean Pittsburgh Sleep Quality Index (PSQI) score of 6.[45] Sleep characteristics in our sample of nursing-home eligible, community dwelling, Program of All-Inclusive Care for the Elderly (PACE) enrollees, was most aligned with those living in assisted living facilities. Despite purposefully enrolling self-identified good and poor sleepers, our descriptive results aligned best with those of Fung et al. who studied older adults in assisted living facilities. They also found insufficient total sleep time (6.3 hours), poor sleep efficiency (77%), and subjectively reported poor

sleep quality (total PSQI 8).[122]

Our sample napped over 30 times a day with a combined daytime nap total of over two and a half hours. Intentional napping (> 10 minutes) accounted for only 20% of total nap time. Therefore, these nap episodes were fragmented such that the participants were dozing on and off for short periods of time frequently throughout the day. About a quarter of the sample said they did not nap on interview and the vast majority reported no daytime sleepiness. These results are similar to those of a study of older adults referred to a sleep center; almost 40% failed to perceive that they were napping when undergoing a multiple sleep latency test, an objective measure of daytime sleepiness.[123] These authors also reported that those with low sleepiness scores and high scores on the Insomnia Severity Index (ISI) were less likely to perceive napping. Other studies have found that, although older adults nap more as they age, they may underreport their naps.[124-126]

Daytime napping in older adults is still controversial. Research suggests that consolidated napping may compensate for short nighttime sleep duration and prevent or reduce daytime sleepiness.[127,128] Two studies reported that short (<30 min) frequent (4 or more times a week) napping was associated with an 84% increase in Alzheimer's disease[129] and longer, more frequent naps were associated with poorer cognitive function.[130] In contrast, Li and colleagues recently reported significant cross-sectional and longitudinal associations between afternoon napping of moderate duration (30-90 minutes) and improved cognition in Chinese older adults.[131,132] Further research is necessary to explore appropriate timing, frequency and duration of naps, intention to nap, and effects of napping over time.

Another possible explanation for older adults not reporting sleepiness may be due to an inability to sense sleepiness. Interoception is a complex concept, but simply put it refers to the perception of stimuli that originate within the body[133] or the internal sense of the condition of the body.[134] Research suggests that there are age-related declines in interoception. For example, studies have shown that the ability to feel resting heart beat,[135] accurately identify prevailing heart rhythms in atrial fibrillation,[136] feel pain,[137] and sense dyspnea[138] all decline with age. There is also evidence to suggest the pathophysiology of heart failure may neutralize perceptions of daytime sleepiness,[139-141] even when there is evidence of objective sleepiness.[141] Therefore, these older adults with multiple chronic conditions may not be able to sense that they feel sleepy due to declines in interoception or the complex pathophysiology of their medical conditions. This could be extremely dangerous, especially for those who still operate a vehicle.

Another possible explanation for low reports of daytime sleepiness could be that the Epworth Sleepiness Scale may not adequately capture sleepiness in this population. One criticism of the instrument is that it includes two questions related to driving and being a passenger in a vehicle. The total score on this instrument is an aggregate sum, so if an older adult does not drive and therefore skips these questions, their scores will inherently be lower (higher scores indicate more sleepiness). In our study, we asked the participants each question to prevent omitted responses and prompted our participants to answer the driving question as if they were a passenger in a vehicle; we know they spend time as passengers because they are transported to the LIFE center in vans. That said, half of our poor sleepers who were not considered sleepy based on score on the Epworth Sleepiness Scale did mention being sleepy or tired during the qualitative interview.

Perhaps in our case, it is not omitted questions driving the low sleepiness rates, but the cut point for discriminating sleepy versus not sleepy may not be accurate for this population.[142] Other investigators have lowered the cut point for various disease states, such as heart failure.[141,143]

There were no statistically significant correlations between self-reported sleep survey data and the objective actigraphy data. This discordance has been noted in other studies and highlights the importance of using multiple methods when measuring sleep. Our results are consistent with other studies of older adults that found those labeled poor sleepers and those with a diagnosis of insomnia tend to subjectively underestimate objectively measured total sleep time,[144,145] while healthy older adults and those considered good sleepers tend to overestimate total sleep time.[145-147]

There was also discordance between the actigraphy data and qualitative accounts of sleep, primarily in the good sleeping group. Despite objective sleep disturbances, their qualitative accounts of sleep were good. These participants may not have recognized their objective sleep disturbances. Explanations for the tendency of self-identified good sleepers to overestimate their sleep is that they may have become accustomed to age-related sleep changes and do not perceive it as a disturbance.[76,77,84] This could hold true for the good sleepers who underestimated their sleep as well, such that they may have adjusted their perceptions of acceptable sleep quantity. Additionally, it could be that if a participant did not feel an immediate consequence (i.e., morning headache), they may not recognize their short sleep duration as a problem and therefore may have self-identified as a good sleeper. Interestingly, this group believed their sleep was so good that it could not get any better. They mentioned negative beliefs about sleep medications or they had

the option to nap during the day. These factors may also explain the interpretation of sleep disturbances in this group.

The majority of poor sleepers had concordant data; their qualitative accounts and actigraphy both reflected poor sleep. Some participants subjectively underestimated their total sleep time. This discordance could be related to sleep state misperception; however, given that objective total sleep time was poor, we did not explore this further. Plausible explanations for misperceptions have been published elsewhere by Harvey and colleagues.[148] The poor sleepers with adequate total sleep time also had poor wake after sleep onset and poor sleep efficiency, indicating nocturnal sleep disturbances. These results are consistent with one meta-analysis that concluded wakefulness after sleep onset and sleep efficiency worsen with age, but sleep latency remains relatively stable across the lifespan.[149]

We found that roughly one third of the participants did not know what could be done to improve their sleep and could not think of anything that made their sleep better or worse. This finding could indicate a knowledge deficit or adaptation. Additionally, most participants believed that their primary care provider would give them sleeping medication if they complained about their sleep. Most participants had negative beliefs about sleep medications and did not want another medication. The belief that there are no suitable treatment options or disapproval of existing treatment options may in part explain their underestimation of their sleep disturbances.

Those who endorsed their sleep disturbances but did not worry or express concerns about them may also have simply adjusted to the sleep disturbance. Although some poor sleepers truly wanted to improve their sleep, among the group as a whole,

there was a sense of having adapted at this point in life. This is consistent with other research in healthy older adults that found older adults tend to adapt their perception of what is "acceptable" sleep and therefore do not necessarily complain even in the face of compromised sleep quality.[76,150] Additionally, older adults may not worry about a sleep disturbance because they have fewer daytime demands.[77] This conclusion is supported by our qualitative results where the participants described being able to choose what they do or do not do the next day.

Participants believed sleep was important and that sleep greatly affected their next day. They believed that good sleep improved mood, daily function, health and overall quality of life. Interestingly, beliefs about how much sleep is needed by older adults varied among the participants. Although the National Sleep Foundation recommends 7-8 hours of sleep for older adults,[151] participants believed they should get between four and ten hours of sleep. Variations could be due to previous experience, knowledge deficit, perceived consequences, or adjusted health expectations.

Insomnia symptoms were reported regularly by these participants; they had trouble falling asleep, trouble staying asleep, or awakened too early. This result is consistent with the literature; insomnia symptoms are the most prevalent sleep disturbances in older adults.[6] The participants who did have concerns regarding their sleep were primarily focused on the deleterious effects of poor sleep on health. It was difficult to discern in these situations if the person's worry or concern was maladaptive, such that it might be perpetuating the sleep disturbance. There is a fine line here; we want the older adult to recognize the sleep disturbance in order to proactively seek methods to

mitigate it; yet we do not want them to be so worried that they are perpetuating the disturbance.

Consistent with the 3P model underlying this study, precipitating factors of sleep disturbances were illness, consequences of illness, and grief.[72] Perpetuating maladaptive factors heard during the interviews included spending too much time in the bedroom, leaving the television on since s/he could not fall asleep, worrying or thinking about falling sleep, and negative attitudes toward the sleeping environment. We know that maladaptive beliefs can be instrumental in perpetuating sleep disturbances and can be modifiable targets for intervention.[152]

These older adults discussed behavioral, physiological, psychological and environmental facilitators of and barriers to sleep quality. Behavioral factors aligned with sleep hygiene practices, which are strategies by which one can create an environment and routine that is most conducive to sleep. Current sleep hygiene recommendations can be put into the following categories: creating a stable sleep pattern, having a nondisruptive sleep environment, reducing presleep tension, and dietary and lifestyle modifications.[153] Literature suggests that improving sleep hygiene alone may not be effective in improving sleep in older adults.[154] The majority of the older adults had their television on at night and did not believe it affected their sleep in any way. Participants perceived the television to be comforting when they lived alone. Therefore, targeting the nondisruptive sleep environment (i.e., encouraging older adults to turn off the television) may not have the desired effect on sleep.

Activity (physical, social or cognitive) is a major modifiable target for interventions to improve sleep quality in this population. The older adults recognized that

minimal activity during that day was a barrier to sleep and that increased daily activity tended to facilitate better sleep. A recent review of exercise interventions and sleep in older adults highlighted the positive effects of exercise on subjective sleep quality,[155] with specific studies reporting improvements in sleep quality with aerobic exercise,[156] yoga,[157] and a bidirectional relationship between exercise and sleep quality in older adults.[158] One study with a nationally representative sample of older adults found that those with more social participation had better sleep quality.[159] Another study found that cognitive training in older adults improved sleep quality.[160] Taken together, we believe that targeting activity in this population may improve sleep quality.

Limitations

Our sample was primarily female and Black, so results cannot be generalized to all older adults. However, these results may be generalizable to other PACE settings with comparable population demographics. We looked globally at sleep disturbances as we wanted to capture any sleep problems. Therefore, we cannot make conclusions regarding specific sleep disorders (i.e., obstructive sleep apnea). Also, although actigraphy is the most commonly accepted instrument for objectively measuring sleep longitudinally and prospectively, we recognize its limitations. The accelerometer measures movements (activity and inactivity) and only serves as a proxy for the sleep/wake cycle. Actigraphy does not have diagnostic capabilities, cannot provide information about sleep architecture, or differentiate if a person is sleeping or resting quietly. Additionally, we looked only at average objective sleep variables, and there may have been night to night variability. Lastly, we note that the quantitative analysis is limited due to the small sample size. However, this sample size was warranted given the emphasis on the

qualitative component of the study.

Implications

This study is the first to describe sleep characteristics and sleep disturbances in nursing-home eligible, community dwelling older adults. The major findings are that these older adults had objectively poor sleep quality, napped frequently throughout the day, and often failed to perceive their sleep disturbances and the consequences of poor sleep. Additionally, these older adults appeared to have adjusted their health expectations regarding sleep and adapted to disturbances, rather than actively seeking solutions. The rich data obtained in this study suggested several modifiable targets for the treatment of sleep disturbances in this population.

One clinical implication of this study is that primary care providers need to assess both nocturnal sleep and daytime napping. Sleep in nursing-home eligible older adults who remain living in the community was more comparable to sleep in individuals who live in assisted living facilities than community dwelling older adults. The older adults in our study had objectively measured sleep disturbances, whether or not they recognized the disturbance. Given that this population is at a high risk for nursing-home placement, sleep disturbances are associated with detrimental health consequences and poor quality of life, and the individuals might not complain of sleep problems, providers must proactively assess sleep. We need to increase primary care providers' awareness and understanding of sleep and sleep disturbances in older adults in general, but specifically in this at-risk population. If primary care providers routinely assess and treat sleep disturbances, we may be able to decrease symptom burden and decrease health care service costs and utilization in this population.

Further research in this population is greatly needed. First, replication studies in this specific population would make the conclusions more generalizable. A larger sample size would allow further investigation into relationships between sleep disturbances and other factors such as specific comorbid conditions. Longitudinal studies would clarify associations between sleep disturbances and multiple chronic conditions and the direction of causality. Additional research can also focus on specific sleep disorders.

Future research is necessary to develop, test and validate sleep measures that are more suitable for use in at-risk older adults. The most widely accepted instruments used in sleep research were developed in younger adults. We found discordance between subjective interviews and subjective sleep surveys. Thus, we believe instruments designed specifically from older adult populations may be more valid and reliable.

We identified modifiable targets for treatment in this population. Tailored interventions that target activity, maladaptive beliefs, and poor sleep hygiene should be developed and tested in nursing-home eligible, community dwelling older adults. No interventions were found in studies of this at-risk population. Improving sleep in this population is critical.

APPENDIX

Interview Guide		
Topic/Rationale	**Question**	**Follow Up/ Probe**
General	What does sleeping well mean to you? What does sleeping poorly mean to you?	
Daytime Characteristics	Tell me about a typical day.	Describe your activity during the day. Describe food, caffeine, alcohol consumption during a typical day.
Nighttime Characteristics	Tell me about a typical night sleep.	Tell me what you do before you go to bed. Describe your sleeping environment (probe related to temperature, noise, light, presence of bed partner, sleep space).
Sleep Quality	Tell me about the quality of your sleep.	Describe how well you feel you sleep on a regular basis. Describe how you decide if you had a good or bad night sleep.

Beliefs	How important is it for you to sleep well? Tell me about how you feel regarding your sleep environment. Tell me how you feel about how much sleep that you get. Describe any worry or concerns that you have regarding your sleep. Describe the best night sleep. Describe the worst night sleep. Describe what you believe causes poor sleep. Describe what you believe happens if you have a poor night sleep. Tell me how your daily activities affect your next night sleep. Tell me what you believe can be done to improve your sleep.	Describe what makes it important. Describe what makes you feel <own words>. Describe what makes you feel <own words>. What makes it the best? What makes it the worst? Tell me what you do after a bad night sleep. Describe how you feel during the day. Describe your role in improving your sleep. Describe your primary care provider's role in improving your sleep.
Facilitators	Describe what helps you sleep well.	How important is it for you to <factors that help them sleep well>?
Barriers	Describe what makes you sleep poorly.	Describe what you do to eliminate or manage <factors that make you sleep poorly>.

Sleep Disturbances	Tell me about *one* time you did not sleep well. Describe any sleep problems that you experience *regularly*.	Describe what happened during the night. Describe how you felt the next day. What do you think contributed to <own words>? Can you describe when you started to notice it? Describe what you have done to eliminate <own words>, if anything. Describe what makes <own words> better. Describe what makes <own words> worse. Describe how you feel during the day.

*Note: This is a semi-structured interview guide. The interviewer will use these topics as a guideline, but can follow topical trajectories that may stray from the exact ordering of these questions.

Sleep Diary

SLEEP DIARY INSTRUCTIONS

1. Each evening, please fill in the EVENING DIARY page (1 page)
2. Each morning, please fill in the MORNING DIARY pages (2 pages)
3. Please fill in your responses with a PEN
4. When writing a time of day, please indicate A.M. or P.M. with each time written in the diary
5. Return the sleep diary to researchers with your actiwatch device

EVENING	Date and Day of the Week	Time you are completing the evening diary (hh:mm)	Did you remove Actiwatch today? (Yes/No)	If yes, what time and for how long? (hh:mm)	When and how long did you nap or doze today? (hh:mm)
Example	Friday, April 1st	9:30 pm	Yes	10:00 am 20 minutes	12:30 pm 20 minutes
Day 1					
Day 2					
Day 3					
Day 4					
Day 5					
Day 6					
Day 7					

MORNING DIARY	Date and Day of the Week	Time you are completing the morning diary (hh:mm)	Name/Dose/ Time of any sleep medication you took last night?	What time did you physically get into bed last night? (hh:mm)	When did you start trying to go to sleep/ turn off the light? (hh:mm)	How long did it take you to fall asleep? (minutes)
Day 1						
Day 2						
Day 3						
Day 4						
Day 5						
Day 6						
Day 7						

MORNING DIARY Page two	How many times did you awake then go back to sleep?	In total, how long did these awakenings last? (minutes)	When did you wake up and not fall back to sleep? (hh:mm)	What time did you get out of bed for the day? (hh:mm)	Time alarm was set or time you intended to awaken. (hh:mm)	How many hours of actual sleep did you get last night?
Day 1						
Day 2						
Day 3						
Day 4						
Day 5						
Day 6						
Day 7						

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