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Nighttime Postural Care Sleep-Based Outcome Measures and Education: Preparing Care Providers of Children with Cerebral Palsy

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Nighttime Postural Care Sleep-based Outcome Measures and Education: Preparing Care Providers of Children with Cerebral Palsy

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List of Abbreviations

CP: Cerebral Palsy

CSQ: Chailey Sleep Questionnaire

GMFCS: Gross Motor Function Classification System

HaPI: Health and Psychosocial Instruments

ICC: Intra-class Correlation

ICF: International Classification of Functioning, Disability and Health

NTPC: Nighttime Postural Care

PI: Primary Investigator

PSQ: Paediatric Sleep Questionnaire

SD: Sleep Diary

SDSC: Sleep Disturbance Scale for Children

SDSC-R: Sleep Disturbance Scale for Children-Revised

Chapter 1

Background and Need for Research

Nighttime postural care (NTPC), an intervention that employs sleep care positioning systems to position the body symmetrically during rest and sleep, is particularly suited for children with severe Cerebral Palsy (CP) (Wynn & Wickham, 2009; Gericke, 2006). This intervention, common in the United Kingdom but new to the United States, holds promise in reducing health risks by addressing sleep, pain and body shape distortions. However, understanding NTPC's impact is difficult given limitations regarding study protocols and challenges in research design. Future research requires both outcome measures capable of capturing changes and evidence-based training protocols. This thesis has two overarching aims: 1) examine sleep-based measures used in NTPC intervention research and 2) investigate an online training program's feasibility for use in educating caregivers.

Cerebral Palsy

Cerebral palsy, the most common motor disability, is present in 1 / 323 children and permanently affects body movement and coordination (Centers for Disease Control and Prevention, 2019b; Centers for Disease Control and Prevention, 2019c). CP is caused by either abnormal brain development or the brain being damaged during development (damage occurring before, during or after birth resulting from injury, infection or blood flow loss) and affects a child's ability to control their muscles (Centers for Disease Control and Prevention, 2019a). Although this health condition is not a progressive disorder, those with

CP may die prematurely due to its preventable secondary conditions including pneumonia, inflammatory respiratory and other conditions (World Health Organization, 2019; Holmes et al., 2012; Maudsley, Hutton, & Pharoah, 1999). Because the severity of disability is associated with cause of death (Maudsley et al., 1999), it is important to understand what distinguishes CP as being “severe”.

Care providers (including health professionals and non-professionals) can understand both the severity of the child’s health condition (e.g. CP) and the factors determining disability using the Gross Motor Function Classification System (GMFCS) and the International Classification of Functioning, Disability and Health (ICF), respectively. The GMFCS includes a five level scale (Table I) for describing the person’s motor skill function and is useful when determining future assistive technology or equipment-related needs (e.g. like mobility aids, positioning equipment, etc.) (CP Alliance Research Foundation, 2018). The ICF provides a framework for understanding determinants of health and disability (Figure 1), making it possible to focus intervention and potentially prevent secondary conditions (World Health Organization, 2019). In the paragraphs that follow, I will first provide explanation of the GMFCS and ICF, then use these constructs to describe the health condition of CP, and last outline how NTPC aims to facilitate health or limit disability.

Table I

Gross Motor Function Classification System Extended & Revised Levels I to V

Levels	Functional Ability
GMFCS I	Walks, gross motor limitations of speed, balance, or coordination
GMFCS II	Walks, handheld device assistance, minimum gross motor skill
GMFCS III	Walks, device indoors, wheeled mobility outdoors, assisted sit & stand
GMFCS IV	Moves, physical assistance or powered mobility, may roll, creep or crawl
GMFCS V	Transported or moves, adapted powered mobility, cannot be fully aligned

Note. GMFCS abbreviated descriptors for 6-12 year old age band, found in "Content validity of the expanded and revised Gross Motor Function Classification System", by R. Palisano et. al., (2008), *Developmental Medicine & Child Neurology*, 50, 744-750.

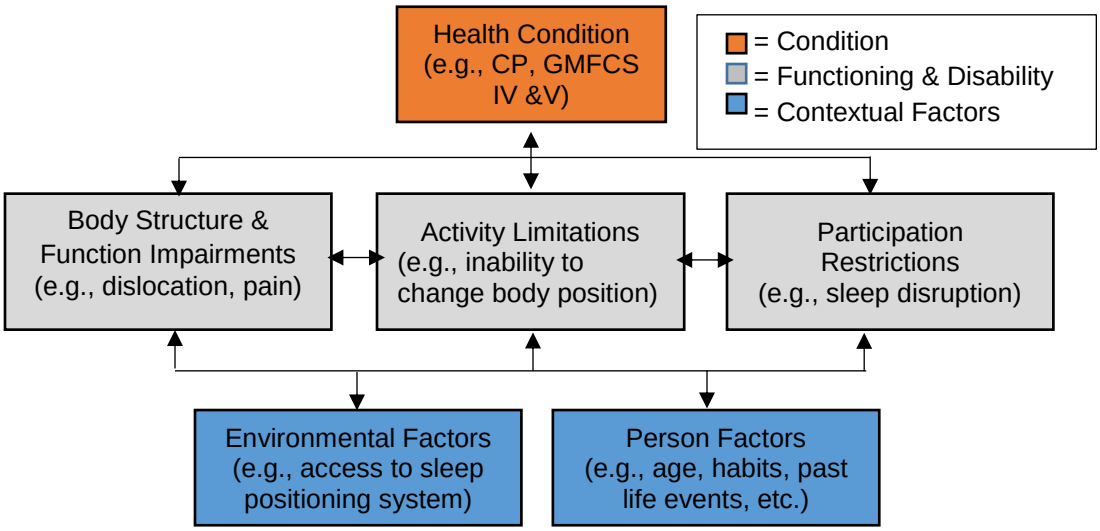

Figure 1. Visual representation of ICF Framework showing relationship of factors affecting health for person with CP. Modified from "*What is the ICF Framework,"* by McMaster University.

Gross motor function classification system

Gross Motor Function Classification System descriptions are helpful for revealing the severity of CP and are typically applied to functional tasks like sitting or walking (Table I) (Palisano et al., 1997). Those classified at level I have the least limitations, while those at level V have severe functional limitations (Palisano et al., 1997). Therefore, children rated IV and V have the greatest degree of disability. While care providers use GMFCS to understand current function, the ICF shapes their thinking around healthcare approaches (Figure 1).

International Classification of Functioning

According to the ICF framework, function is made up of three components and is viewed as having a complex interaction between the person's diagnosed health condition (e.g. CP, GMFCS IV and V) and context (environmental and personal factors) (World Health Organization, 2001). Function (or disability) is described by the person's physiology (body structures and functions) combined with actions they are able to take (activity) and what they are able to do in life (participation) (World Health Organization, 2001). Context is described by the person's background such as age, habits, past life events, etc. (person factors) and their surrounding environment (environmental factors) (World Health Organization, 2001). Health professionals gain insight into a particular health condition as well as the potential impact of intervention by examining the relationships between such factors.

NTPC providers, applying the ICF framework, can better understand the health condition of CP by identifying relevant examples of each ICF domain and examining their interconnectivity. For example, NTPC providers might consider how the severity of the person's movement problems (aspect of health condition) affects functional aspects like hip dysplasia or dislocation (human body structures or functions), inability to change body position (functional activity) and poor sleep (functional participation). Simultaneously, providers might consider how the child's age and lack of access to daily living products like sleep positioning systems (contextual factors) affect those same aspects of functioning as well as the corresponding impact that functioning would have on the person's movement problems. In this example above, NTPC providers might reasonably expect the lack of access to postural support, combined with the limitations across all three functional domains to result in a more severe case of CP. However, research would need to be conducted to confirm association between specific factors; the ICF merely proposes that interaction exists.

Interaction between functional domains The ICF framework not only assumes interconnectivity between the person's health condition, function and context, but also depicts that relationships exist across the functional domains of body structure and function and activity and participation (WHO, 2001). These assumptions about functional domain interconnectivity are supported by past research. For example, investigators have found that the child's inability to change position is linked to orthopedic conditions and orthopedic conditions like scoliosis, pelvic obliquity, hip subluxation and dislocation are considered

contributors to pain (Sato, Iwasaki, Yokoyama, & Inoue, 2014; Agustsson, Sveinsson, Pope, & Rodby-Bousquet, 2019; McKearnan, Kieckhefer, Engel, Jensen, & Labyak, 2004). Conversely, pain (known to be a chronic and persistent experience for those with CP) is thought to have a bidirectional relationship with sleep participation, such that poor sleep is exacerbated by pain and vice versa (McKearnan, et al., 2004; Dutt, Roduta-Roberts, & Brown, 2015; Castle, Imms & Howie, 2007). To stop the progression of such factors and mediate their effect on sleep disruption, which is known to occur at very young ages for those with severe CP (Mol, Monbaliu, Ven, Vergote & Prinzie, 2012; Newman, O'Regan, & Hensey, 2006; & Romeo et al., 2014), interventions incorporating sleep positioning systems have been considered.

Sleep systems as environmental factors. According to the ICF, sleep systems are examples of environmental factors, falling under the category of products for personal use in daily living (WHO, 2001). These systems are used during periods of rest and sleep to prevent or neutralize disability (Polack, Clift & Clift, 2009).They (Figure 2) differ from other supportive sleep products in both the aim of the equipment and design. In contrast to other supportive sleep products, sleep systems aim to position the entire body towards symmetry and are designed with a base layer that holds component parts in a stable position (Polack, Clift & Clift, 2009). Before these systems were developed, a child's night positioning typically involved use of pillows or wedges that readily shifted out of position or wearing of orthotics that applied isolated force. Unlike miscellaneous use of pillows and isolated application of orthotic devices, sleep systems allow

persons with CP to receive whole-body positioning, intended to afford comfortable alignment and facilitate sleep. Sleep systems are the equipment used as a part of NTPC implementation.

*Figure 2***.** Images of person and sleep system. Left image of person in sleep system. Unlike what is shown in this image, the pillow between the legs would be placed under the top fitted sheet. Right image shows example arrangement of component parts, which would be sandwiched between a base sheet and top fitted sheet.

Nighttime postural care as environmental factor. Nighttime Postural Care, also considered an environmental factor within the ICF framework, is a health service that employs sleep systems. NTPC involves a planned approach to postural support and is inclusive of many stages such as referral, assessment, prescription, funding and ordering, product preparation, fitting, user training, maintenance, repairs and follow-up. Problems at any service delivery stage can affect NTPC intervention success. Consensus report from postural care experts, state that children, GMFCS IV and V, should receive this intervention as soon as possible after birth and that all directly involved in their care should receive intervention training (Gericke, 2006). However, little evidence & no consensus exists about either instruments that are suitable for tracking intervention changes or training programs thought to be capable of producing competent NTPC implementers. Without suitable outcome measures we cannot understand the

extent to which NTPC affects health and without education known to be effective we cannot understand if those carrying out NTPC are appropriately qualified to deliver high fidelity intervention.

Need for Research

Future NTPC intervention and research protocols should include outcome measures suitable for detecting changes in children with CP, GMFCS IV and V, and evidence-based training known to produce competent care providers. To address previous research gaps, this author embarked on dissertation work including a systematic review of sleep-based measures used in NTPC impact studies and a randomized control trial examining a newly developed online NTPC training program.

Aims of the dissertation work. This dissertation includes two overarching aims, to: 1) examine sleep-based measures used in previous NTPC intervention research and 2) investigate an online NTPC training program's feasibility for educating care providers. Chapters' one and five provide overview and concluding information reflective of both aims. Figure 3 shows how the remaining dissertation chapters relate to these two aims.

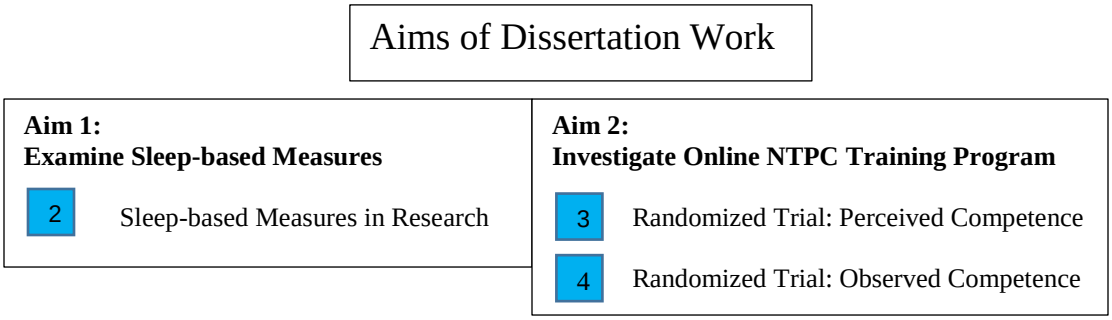

Figure 3. Schematic of thesis chapters two through four and their relevance to the primary dissertation aims.

Project Significance

This project has potential to advance health care services, filling a gap in knowledge about the suitability of NTPC implementation tools (sleep-based assessments and caregiver training program) for persons with severe CP. Study results provide information meant to guide NTPC service delivery and inform research protocols. NTPC providers might use study results to establish standardized practices for capturing NTPC sleep-related changes and ensure those implementing NTPC are qualified to do so, ultimately affecting the health of children with CP, GMFCS IV & V.

Chapter 2

Sleep-Based Measures for Intervention Research

Chapter Overview

This chapter includes results from the NTPC sleep-based instruments systematic literature review. This review paper entitled “Sleep Assessments for Children with Cerebral Palsy Receiving Nighttime Postural Care Interventions: A Systematic Review” is under final preparations for journal submission.

Synopsis

AIM This systematic review of sleep-based assessments used in nighttime postural care (NTPC) intervention research, examines the measures’ ability to capture meaningful change in children with Cerebral Palsy (CP) Gross Motor Function Classification System (GMFCS) IV and V. NTPC is a rehabilitation intervention that employs sleep-positioning systems for persons with severe CP. Research on NTPC’s impact yields mixed conclusions. This variation may in part be due to the types of assessments used to measure change. *METHOD* Two investigators searched English-Language peer-reviewed publications from electronic databases via two library systems, identifying original NTPC intervention studies, published between 2000 and 2018, with sleep as a primary or secondary outcome. Authors used guiding questions proposed by Coster (2013) to analyze the sleep-based measures suitability as outcome measures. *RESULTS* Investigators found six out of eight English language peer-reviewed NTPC intervention studies that measured sleep using 10 sleep-based instruments. None of the instruments completely met criteria for suitability as

outcome measures. *INTERPRETATION* To capture meaningful change and understand the impact of NTPC on sleep, combined use of the Sleep Disturbance Scale for Children-R and triaxial actigraph may be the most useful approach. Given lack of research on both measures' suitability with children GMFCS IV and V, simultaneous examination of their sensitivity and specificity is warranted.

Nighttime postural care and sleep-based measures

Nighttime postural care (NTPC) is an intervention that incorporates sleep care positioning systems (sleep systems) to position the body in symmetry during rest and sleep. NTPC experts from multiple disciplines, based on their clinical findings along with existing evidence, recommend its implementation as soon as possible after birth for children with Cerebral Palsy (CP), Gross Motor Function Classification System (GMFCS) IV and V (Gericke, 2006). However, original research on this intervention has yielded mixed outcomes (Dawson et al., 2013; Goldsmith, 2000; Hankinson & Morton, 2002; Hill, Parker, Allen, Paul & Padoa, 2009; Mol et al., 2012; Pountney, Mandy, Green, & Gard, 2002; Pountney, Mandy, Green & Gard, P. 2009; Underhill, Bryant, & Pountney, 2012). These mixed outcomes may partly be due to the sleep-based measures used in NTPC impact studies. The impact of NTPC on sleep is better understood when the most appropriate outcome assessments are used to measure intervention effects. This systematic review examines the sleep-based measures used in NTPC intervention research and their suitability as outcome measures for children, GMFCS IV and V, receiving NTPC.

Nighttime Postural Care Effect on Sleep Disruption

Before examining these sleep-based measures, it is important to both understand which sleep disruptions are most common for children with CP, and how NTPC acts to remediate such disruptions. The most common sleep disruptions for children with CP include problems of sleep initiation and maintenance, sleep–wake transition, and breathing (Marriner, Pestell, Bayliss, McCann, & Bucks, 2017; Newman et al., 2006). Additionally, for children with active seizure disorders, daytime sleepiness and total sleep time are also common problems (Newman, et al., 2006). Pain and discomfort, need for turning to redistribute pressure, and repositioning for gastrointestinal relief are reported reasons for some of these disruptions (Petersen, Harvey, Reddihough, & Newall, 2015). NTPC acts primarily by positioning the child in a symmetrically aligned position making it possible to reduce the body shape distortions associated with pain (Hill and Goldsmith, 2010; Waugh & Hill, 2009). One might suspect other aspects of sleep disruption could also be addressed, if full body positioning affords comfort. For example, offloading of boney prominences might result in less need for repositioning. Additionally, improvements in posture and reduction of stress might lead to better breathing and fewer seizures. Since NTPC aims to address factors associated with sleep disruption, researchers have examined the interventions' impact on sleep.

The reported impact of NTPC differs between studies; some studies show improved sleep and others find no change. For example, one questionnaire-

based study, found children (24 out of 27) slept about the same, better or much better after one year's use of the sleep system (Goldsmith, 2000). Another questionnaire study found a significant difference in the child's ability to "settle easily into sleep" (n=7, 0.05 mean change; Mann-Whitney, $\alpha = 0.01$), but no significant difference in sleep hours or awakenings (Hankinson & Morton, 2002). Other investigators, using polysomnography, found no significant difference in sleep for 10 children, when comparing one night with and one night without sleep system (Hill, et al., 2009). Additionally, Underhill et al. (2012), employed actigraphy with 11 children, finding no significant difference in sleep-wake patterns when comparing sleep conditions (4 nights in sleep system, 4 nights out of sleep system). Although studies' sample numbers were low, mixed results across studies could also be due to the type and caliber of the sleep-based instruments being used.

Choosing Criteria for Analyzing Outcome Measures

Choosing reliable and valid outcome measures is one way to ensure studies capture meaningful results (Kielhofner, 2006). However, factors beyond the assessment's psychometrics, like the measure's relevance for a particular population and intervention, need consideration (Coster, 2013). While past reviews have examined sleep-based measures on their psychometric properties of reliability and validity (Bautista et al., 2018), none have examined their match to the specified population of children, GMFCS IV and V, receiving NTPC intervention. The COSMIN Risk of Bias Checklist is one comprehensive tool investigators use to rank measurement instruments. However, this checklist is

limited to patient report measures and most useful for examining psychometric criteria (Mokkink et al., 2019). To thoughtfully examine both caregiver report and biometric devices on their ability to capture changes for a specified population and intervention, this review's primary investigator has chosen Coster's (2013) questions to guide analysis. While many of Coster's questions are listed in the section that follows, the complete list of 15 questions can be found in the paper entitled "Making the Best Match: Selecting Outcome Measures for Clinical Trials and Outcome Studies"(Coster, 2013).

Coster's Guiding Questions

Coster's (2013) guideline for determining a tool's usefulness as an outcome measure, involves asking a series of "who", "when" and "how" questions. Examples of some "who" questions include: If someone other than a professional will be the respondent is it probable that the respondent will be able to complete the assessment; and will the identified respondents be available throughout the study period (Coster, 2013). Examples of "when" questions include: Does the length of time between assessments match the time over which the instrument is likely to show effects; and can the measure be administered as often as required by the study design (Coster, 2013). Examples of some "how" questions include: Does the instrument address the relevant domains of greatest importance; does the measurement dimension reflect the type of change expected from the intervention; is the measure sensitive to the degree of change expected for this population; and are item and scale wording appropriate (e.g., meaningful, understandable) for this population (Coster, 2013).

By examining the sleep-based assessments using Coster's (2013) questions, the authors of this paper hope to both understand which NTPC sleep-based instruments are suitable for capturing intervention changes and create a dialogue among rehabilitation professionals regarding future choice of measures for children with CP, GMFCS IV and V.

Systematic Review

To our knowledge there are no previously published systematic reviews examining the sleep-based assessments used in NTPC intervention research. Additionally, while previous authors have conducted systematic reviews of validated sleep measures used for children with CP (Bautista, Whittingham, Edwards, & Boyd, 2018), none examine the sleep-measures' application specifically to children with CP, GMFCS IV and V.

For the purposes of this study, the term "systematic review" is defined as a search, appraisal and comprehensive overview of evidence on a particular topic (Pericic & Tanveer, 2019). The authors of this review aim to 1). Identify the sleep-based measures used in NTPC intervention research 2). Analyze via Coster's (2013) guiding questions, if the instruments are suitable for use as NTPC outcome measures for children with CP GMFCS IV and V; and, 3). Make outcome measure recommendations for both clinicians and researchers.

Eligibility and data collection process. Eligible articles included English-language full-length peer-reviewed original research articles that examined sleep as a primary or secondary outcome of NTPC intervention.

Knowing the number of NTPC intervention studies was limited, investigators considered articles published between 2000 and 2018. Investigators excluded systematic reviews, as well as studies measuring the outcome of sleep apnea (rather than NTPC intervention change); however, investigators did use reviews to confirm an exhaustive search

Search methods. Two investigators independently completed a thorough and exhaustive search of the literature between January and May of 2018, screening titles and abstracts based on inclusion/exclusion criteria. To ensure up to date data, one of the investigators conducted an additional search via two University's libraries, in October of 2019. Investigators searched the following databases: OVID Medline, CINAHL, OT Search, Cochrane Database of Systematic Reviews and Health and Psychosocial Instruments (HaPI). The primary search terms included: Cerebral palsy AND nighttime postural care, cerebral palsy AND nighttime postural care equipment, cerebral palsy AND nighttime positioning equipment, cerebral palsy AND postural management, cerebral palsy AND postural management equipment, sleep AND postural management equipment, sleep measures AND postural care, sleep measures AND postural care NOT obstructive sleep apnea, cerebral palsy AND sleep systems, cerebral palsy AND sleep systems NOT obstructive sleep apnea, cerebral palsy AND sleep orthosis. To determine existence of additional studies investigators conducted author and citation searches of known NTPC researchers and scoping or systematic review reference lists.

Method of analysis. The primary investigator of this systematic review methodically applied Coster's (2013) questions, determining each sleep-based instrument's suitability as a NTPC outcome measure for use with children having CP, GMFCS IV and V. Examination entailed an iterative process of reviewing Coster's (2013) questions, published literature about each measure (e.g. psychometric studies), published literature about sleep for the identified population, and NTPC intervention research. Additionally, the primary investigator contacted prior study authors to gain additional data when published research on sleep-based measures contained insufficient information that limited ability to proceed with analysis. It was not this investigators intent to analyze how past research studies' used the sleep-based measures, but rather to understand whether the instruments are suitable for the purpose of outcome measurement.

Results. Using filters for peer-reviewed journal and English language articles, initial search results of "sleep assessments AND postural care" revealed over 4839 abstracts; however most of these were not studies examining the impact of NTPC intervention. Use of terms "cerebral palsy AND nighttime postural care" revealed 42 abstracts, many of which included conference proceedings or research on sleep apnea. Investigators narrowed the search to include only NTPC original research studies resulting in 10 articles, two of which were not full-length publications. No discrepancies existed among investigators about the inclusion of these 8 publications. Of the eight full-length NTPC impact studies, six examined sleep as a primary or secondary outcome (Table II).

Therefore, the primary investigator included six peer-reviewed published studies for full review.

Table II.

Outcomes and Sleep-based Measures from Original Research Studies

First author, year	Study outcomes	Sleep-based measures used
Dawson, 2013	Sleep-related ventilatory function	Sleep diary
Goldsmith, 2000	Sleep, pain, muscle tone, position	Home-made questionnaire with interview
Hankinson, 2002	Sleep, hip migration, position	sleep diary, home-made questionnaire
Hill, 2009	Sleep, respiratory function	Paediatric Sleep Questionnaire, polysomnography
Mol, 2012	Sleep disturbance, parental burden	Sleep Disturbance Scale for Children
Pountney, 2009	Hip subluxation, medical procedures	No sleep measure reported
Pountney, 2002	Hip migration	No sleep measure reported
Underhill, 2012	Sleep, pain	Actigraphy, Chailey Sleep Questionnaire, Sleep diary, interview

Note. Eight original research articles investigating impact of nighttime postural care intervention. The two studies by Pountney et al. (2002; 2009) did not include sleep as an outcome; thus, are not included in further analysis.

Collectively the six studies used 10 different sleep-based instruments. Some studies used only one measure, while others used three. Several studies incorporated sleep diaries, so in total there were eight distinct measures. Because two of the eight were investigator-made instruments with insufficient

description and no psychometric analysis (Goldsmith, 2000; Hankinson & Morton, 2002), they could not be critically examined. Therefore, analysis ultimately comprised of six sleep-based measures (four caregiver report questionnaires and two biometric monitoring devices): Actigraphy, Chailey Sleep Questionnaire (CSQ), Paediatric Sleep Questionnaire (PSQ), Polysomnography, Sleep diary (SD), and Sleep Disturbance Scale for Children (SDSC) (Table III).

Table III.

Description of Six Sleep Measures used in Nighttime Postural Care Impact Studies

Name	Type	Description
Actigraphy	BD	Wearable accelerometer, tracks rest and activity cycles via gross motor movement (Underhill et al., 2012)
Chailey Sleep Questionnaire	CR	Thirty-six item clinical & 35 item sleep profile, guides intervention for children, GMFCS III-V (Chailey Heritage Clinical Services, 2009)
Paediatric Sleep Questionnaire	CR	Twenty-two items, identifies sleep related breathing disorder, daytime sleepiness and other behaviors in children (Chervin, Hedger, Dillon, & Pituch, 2000; Hill et al., 2009)
Polysomnography	BD	Clinic-based testing for diagnosing sleep disorder. Records brain waves, blood oxygen, heart rate, breathing, eye/leg movements (Hill et al., 2009)
Sleep Diary	CR	Several weeks' nightly record of sleep activity, e.g. time to bed, time to sleep, night waking, overall sleep time (Dawson et al., 2013; Underhill et al., 2012)
Sleep Disturbance Scale for Children	CR	Twenty-six items for evaluating sleep disturbances of past six months including sleep initiation/maintenance, breathing, arousal, transitions, daytime sleepiness, and sweating in children (Bruni et al., 1996)

Note. Four caregiver report (CR) and two biometric devices (BD).

Critical analysis. Prior to examining the sleep-based instruments on criteria of “who” and “when”, and “how”, Coster (2013) suggests investigators first consider both their expectations of intervention and the intricacies of the construct being measured (e.g. sleep disruption). Regarding intervention expectations, due to the complexity of sleep and the processes surrounding NTPC, one could reasonably expect changes to occur over a period of months. For some intervention recipients, immediate sleep-related changes may occur (e.g. those with pronounced reduction in pain); however, many children likely require longer periods before the sleep system is routinely used or produces effect on body systems. Regarding the construct of sleep, past research tells us the aspects of sleep most relevant to those with CP, GMFCS IV and V, include difficulty with sleep initiation and maintenance, alteration in sleep–wake transition, occurrence of sleep breathing disorders, increases in daytime sleepiness and decreases in total sleep time (Marriner et al., 2017; Newman, et al., 2006). Therefore, instruments considered suitable as outcome measures for this intervention and population must be sensitive to change over a period of time (e.g. I propose more than a few months) and include items or methods for assessing the aforementioned sleep-related issues.

Analysis overview. Upon examining the six NTPC sleep-related instruments, Actigraphy, CSQ, PSQ, polysomnography, SD, and SDSC, no one measure meets Coster’s (2013) collective criteria of “who”, “when” and “how”. While some instruments are capable of capturing sleep-related changes based

on “who” and “when” criteria, none of the instruments meet criteria on account of “how” the measure is used.

To ensure clear communication of each measure’s suitability as an outcome measure, this paper’s author incorporates green, yellow and red light rankings. Color-based rankings reportedly make it easier for readers to comprehend and act upon information (Novak & Honan, 2019). Definitions of the color rankings used in the following paragraphs (which are modified from those used in other studies) include: Green, which represents “good enough”, “having minor problems in comparison to other instruments”; yellow which represents “mostly adequate” or “need for further development or testing”; and red which represents “inadequate or inappropriate”. These color rankings are meant to help readers of this dissertation understand the usefulness of the sleep-based measures for children, GMFCS IV & V receiving NTPC.

Who criteria. When choosing an instrument based on the “who” criteria of Coster (2013), the primary question is whether those administering the assessment have the necessary qualifications. On this criterion, the investigator rated each of the instruments, the caregiver report assessments and monitoring devices, with a green light (for English-language users).

Caregiver report instruments received a green-light ranking based on their ease of use. For example, PSQ developers reported making revisions after pilot testing, creating simple and concise items (Chervin et al., 2000). Additionally, Sleep Disturbance Scale for Children developers stated they removed items not understood by mothers after pilot testing (Bruni et al., 1996). Also, Chailey Sleep

Questionnaire designers reported having incorporated simple language as well as a glossary into their instrument (Chailey Heritage Clinical Services, 2009). Additionally, the sleep diaries required recording of information typically understood by caregivers, such as time to sleep, time awake, sleep duration, etc. Since developers either changed items in response to caregiver testing or included familiar language in their assessments, they received a green light on Coster's "who" criteria.

Monitoring devices received green-light rankings on "who" criteria; because either administration requires credentials, or skills for device use were considered minimal. For example, polysomnography administrators are deemed clinically equipped to assess sleep disorders if they hold Registered Polysomnographic Technologist credentials; and, actigraphy users generally need to only follow basic instructions about device wear or removal ((Board of Registered Polysomnographic Technologists, 2019; Martin & Hakim, 2011). Although studies using these devices (Hill et al., 2009; Underhill et al., 2012) did not discuss information about administrators' capacity one could reasonably expect that administrators met requirements, or researchers had opportunity to adapt instructions to meet users' needs. Collectively the instruments, both caregiver reports and monitoring devices, appear to be a "good enough" match to the skills of their users.

When criteria. In choosing a measure on the criterion of "when", Coster's questions (2013) primarily relate to whether the instrument can be administered when NTPC intervention changes are expected to occur and at times that make

sense for the intended population (e.g. children with CP, GMFCS IV and V). On this criterion, the SDSC, SD, and actigraphy receive a green light, the PSQ a yellow, and Polysomnography and CSQ a red light.

The SDSC, SD, and actigraphy can all be administered at times that account for both NTPC intervention changes and the night-to-night sleep variations typical of the population. The SDSC measures sleep disruption over six-month periods, timing that potentially allows for NTPC intervention sleep-related changes to take effect. Sleep diary administration is flexible and affords recording of data at select intervals throughout intervention. Similarly, actigraphy allows flexible scheduling, having the added potential of recording continuous data throughout intervention, without presenting undue burden on the user. Given their intended use, these instruments are a "good enough" match for children with CP, GMFCS IV and V, based on criteria of "when" NTPC outcome assessment takes place. While these instruments receive a green light, the PSQ was given a yellow light.

The PSQ receives a yellow-light ranking because the measure is only partially adequate with respect to timing of administration and further testing is needed to understand its ability to capture change over time. The measure assesses symptoms over a one month period, timing that might allow NTPC changes to take effect. However, if the PSQ was administered every month, over a period of months to years, this would likely present undue burden for caregivers. Additionally, studies thus far have measured its use as a diagnostic tool or predictor of post-surgical (Adenotonsillectomy) improvement, not for

measuring changes over time (Chervin et al., 2000; Hill et al., 2009; Rosen et al., 2015). Although PSQ does not fare as well as SDSC and actigraphy on aspects of timing, it does better than Polysomnography and CSQ.

Both Polysomnography and CSQ receive a red light ranking when considering the aspect of time, because they are inappropriate or not intended for use to track changes. Polysomnography, while valuable for initially diagnosing sleep disruption, only accounts for sleep at a moment in time; thus, cannot capture night-to-night variations or be representative of a child's typical sleep. Additionally, cost of polysomnography prohibits its use if researchers/clinicians strive to collect data at multiple intervals throughout NTPC intervention periods. Like Polysomnography, the CSQ is most useful for initial identification of sleep problems. The instrument's developers designed the assessment to pinpoint sleep problems and guide clinical intervention, not to capture intervention changes (Sussex Community NHS Foundation Trust, 2019; Underhill et al., 2012). Since giving Polysomnography and CSQ red light ratings, questions addressing the criteria of "how" will only be applied to the four remaining instruments (PSQ, SD, actigraphy and SDSC).

How criteria. When examining an instrument on the criterion of how it is used, Coster's (2013) primary questions (applied to NTPC sleep-related outcomes and the identified population) relate to whether the instrument's 1) sleep domains include those considered to be of greatest importance, 2) items relate to children GMFCS IV and V, and 3) sensitivity and specificity are appropriate. In this context, sensitivity refers to the instrument's ability to detect

sleep disruption or disorder, and specificity the instruments ability to detect absence of sleep disruption or disorder. Based on these criteria, PSQ and SD receive red light rankings; while, actigraphy and SDSC receive yellow-light rankings.

This review's primary investigator gives red light rankings to instruments if they address no more than two of the five most pertinent sleep domains (sleep initiation and maintenance, sleep–wake transition, sleep breathing, daytime sleepiness and total sleep time) or include items not relevant to children with CP, GMFCS IV and V. The PSQ, for instance, addresses the domains of sleep apnea and daytime sleepiness but not sleep quality (initiation, maintenance, and quantity) or nocturnal epilepsy. Additionally, 8 of the 22 items are not relevant to the population (e.g. items like fidgets, on the go, interrupts, and one on obesity). Like the PSQ, sleep diaries also fail to address important domains. Sleep diaries include sleep quality, but cannot measure nocturnal epilepsy and obstructive sleep apnea (Ulate-Campos, Tsuboyama, & Loddenkemper, 2018). For these reasons, PSQ and sleep diary were given red light rankings.

The investigator gives a yellow-light ranking to actigraphy and SDSC; while they fare better than other sleep measures, both fall short in fully covering all five domains or having wholly relevant items. For example, actigraphy measures sleep-quality and nocturnal epilepsy, missing only the domain of obstructive sleep apnea; and, the SDSC measures sleep quality and sleep-related breathing issues, yet is unable to measure nocturnal epilepsy (Ulate-Campos, 2018). Additionally, all but three of the 26 SDSC items (excessive

sweating upon falling asleep, excessive sweating during sleep, and sleepwalking) are applicable to children with CP, GMFCS IV and V (Marriner et al., 2017). None of the measures alone meets domain related criteria. However, SDSC and actigraphy are the most comprehensive; and if used together, could measure all the identified sleep-related domains of greatest importance. Therefore, this review's investigator further examines each instrument on criteria of sensitivity and specificity.

Both measures receive a yellow-light ranking on the criteria of sensitivity and specificity because there is need for further examination. Developers of these instruments did conduct some statistical analysis; however, children GMFCS IV and V were either not included during testing or researchers did not specifically examine the construct of sleep (O. Bruni, personal communication, November 19, 2017; Oftedal, Bell, Davies, Ware, & Boyd, 2014). For example, Bruni et al. (1996) reported good specificity (0.74) and sensitivity (0.89) of the SDSC when comparing clinical and healthy populations; however, children with CP were not part of the study sample. Additionally, investigators found only one peer-reviewed publication that reports actigraphy's specificity and sensitivity. While their study populations specifically included children with CP, GMFCS IV and V, they did not examine the construct of sleep (Oftedal et al., 2014). The study found that triaxial actigraphy (not uniaxial) could discriminate sedentary versus active states, but sleep itself was not tested (Oftedal et al., 2014). Although these instruments show potential for use with children GMFCS IV and V, further studies are needed.

Of the sleep-related instruments used in NTPC impact studies, actigraphy and SDSC are the only given yellow-light versus red-light rankings. Each could be used as a NTPC outcome measure; however, additional information would be needed to ensure these measures fully capture the most relevant changes for those with CP, GMFCS IV and V. If used jointly, they cover all sleep-related domains identified as important to the intervention and population.

Interpretation. As stand-alone measures, none of the reviewed instruments (Chailey Sleep Questionnaire, polysomnography, PSQ, sleep diary, SDSC and actigraphy) can fully capture the anticipated NTPC sleep-related changes relevant to children with CP, GMFCS IV and V. Those conducting research or measuring sleep-related NTPC intervention changes might consider collective use of SDSC and triaxial actigraphy; however, not without examining sensitivity and specificity for children GMFCS IV and V.

Limitations. One might consider it a limitation that some of Coster's (2013) questions were not discussed in this paper. While the investigator conducting this review's analysis did carefully consider all 15 questions outlined by Coster (2013), prioritization was given to those considered most relevant or important to communicate with readers interested in using sleep-based measures among children having CP, GMFCS IV and V. Readers of this paper might review Coster's (2013) work to verify the appropriateness of the approach.

One might also consider it a limitation that detailed information about each measure's psychometrics was not communicated. However, psychometrics was not the focus of this review, given that past studies have examined the reliability

and validity of sleep-based measures. While some psychometric information will be included in this paper's discussion section, readers interested in such information should review prior publications.

Discussion. Understanding changes in sleep, resulting from NTPC intervention is difficult, given the type and variety of sleep instruments used in past studies. This review's primary investigator found most sleep-related instruments used in NTPC research are not intended or appropriate for use to capture intervention changes of children with CP, GMFCS IV and V. Of the instruments investigated SDSC and triaxial actigraphy, if used together, proved most promising. However, NTPC researchers would need to collect sensitivity and specificity data, further analyzing these measures' ability to capture meaningful changes in sleep for children with CP, GMFCS IV and V.

Researchers typically examine a range of outcomes to understand NTPC's impact; thus, capturing sleep-related changes with one instrument would be optimal, especially given the potential burden caregivers might experience in gathering so much data. For example, commonly examined NTPC outcomes, other than sleep, include musculoskeletal, sensory, and breathing-related functions, number of medical procedures, ease of daytime cares, and caregiver burden (Dawson et al., 2013; Goldsmith, 2000; Hankinson & Morton, 2002; Hill et al., 2009; Mol et al., 2012; Pountney et al., 2002; Pountney et al., 2009; Underhill et al., 2012). Depending on the measures being used to track these changes, caregivers are likely responsible for either directly tracking data or at the very least scheduling times at various points throughout the study during which

investigators can collect information. Given such expectations around data gathering, it's best to keep the number of outcome measurement tools to a minimum.

This systematic review's finding of the need to use more than one sleep-related measure to understand NTPC's effect on sleep, although not ideal, is consistent with past research. For example, supplementation of caregiver report with objective measures is common due to the inherent bias of subjective measures (Meltzer, Walsh, Traylor, & Westin, 2012). Additionally, authors supporting actigraphy typically recommend combined use of sleep diaries, since caregiver's information gives context to actigraph recordings and is useful for explaining data artifacts (Acebo et al., 2005). Until other options for understanding sleep-related changes become available, it seems NTPC investigators will need to use multiple sleep-related instruments.

This paper's author has found no study that investigates actigraphy's validity as a sleep measure with children, GMFCS IV and V. Because actigraphy tracks body movement using accelerometers it is questionable whether the tool has potential for differentiating sleep and wakefulness; given such children rest in sustained positions (Sato et al., 2014). The only study investigating use with children at GMFCS IV & V compared uniaxial (tracks movement in one axes) to triaxial actigraph (tracks movement in three axes), aiming to establish sensitivity and specificity cut off points for periods of activity and inactivity (Oftedal et al., 2014). They did not examine children at times of sleep. Their investigators found during waking hours, only triaxial actigraph (not uniaxial) was valid for those with

GMFCS IV and V. They also concluded persons at GMFCS I-III should have different specificity and sensitivity cut off points from those at GMFCS IV-V. Oftedal et al.'s (2014) results, suggest future investigators must examine sensitivity and specificity of triaxial actigraph if used to assess sleep for children at GMFCS IV-V.

Although sleep diary is not appropriate for use as an outcome measure on its own, past investigators have identified its value as a supplement to actigraphy. For example, previous investigators found sleep diaries helpful for explaining sleep movements or disruptions caused by parent handling or filling data gaps at times when actigraph is turned off or not working (Tsai & Thomas, 2010; Acebo et al., 2005). Because actigraphy cannot account for these contextual factors, researchers/clinicians using triaxial actigraph will likely incorporate sleep diary into their study protocols. It is beyond the scope of this paper to suggest data collection schedules for actigraphy and sleep diary. However, investigators of future studies will need to weigh the benefits of having supplementary data with the potential caregiver burden such data gathering presents, especially when considering that sleep is only one of many outcomes tracked during NTPC intervention.

While previous authors credit the SDSC for its psychometric properties, inconsistency exists in the literature regarding the validity of the English-language version and its applicability to children with CP. In a previous systematic review Bautista et al. (2018) reported the SDSC had strong psychometric properties but was problematic, having not yet been validated in

English or tested in children with CP. It is true that the original version was validated in Italian, not English, and that children with CP were not included in the study sample (O. Bruni, personal communication, November 30, 2019). However, Marriner et al. (2017) did conduct factor analysis on the English-language version with children having CP (n=54/417; 10 with tetraplegia or spastic quadriplegia), which resulted in the instrument's revision (SDSC – R) and removal of three items (2 hyperhidrosis and one sleep maintenance item) (R. Bucks, personal communication, December 17, 2019). The authors did not specify the GMFCS levels of the children in their study sample; however, their results strengthen support for using the SDSC-R version over the original for clinical populations that include children with CP (Marriner et al., 2017).

Conclusion

None of the sleep-based measures used in past NTPC intervention studies meet criteria as stand-alone outcome measures for use with children GMFCS IV and V. Using the Sleep Disturbance Scale for Children-R combined with triaxial actigraph may be the most useful approach for future studies; however, those examining NTPC changes should simultaneously investigate both measures' sensitivity and specificity. Thus far, little research exists on use of these measures with children in GMFCS IV and V. Future investigators and clinicians examining effects of NTPC interventions must carefully consider the measures' ability to capture the anticipated changes most relevant to the intervention; they also must carefully select instruments that best match the client population and context.

Chapter 3

Randomized Trial: Perceived Competence

Chapter overview

This chapter includes results of a randomized experimental design study, comparing perceived caregiver competence (knowledge, ability and confidence) pre and post educational intervention (Lesson A), to a control (Lesson B). The primary research question addressed in this chapter is as follows: Is there a difference in perceived competence to implement aspects of NTPC for caregivers completing the online “sleep care positioning training program” (Lesson A), compared to those completing Lesson B. The paper is under final preparations for journal submission.

Prior to conducting the study discussed in this chapter, the author of this dissertation, Jennifer Hutson, along with postural care student scholars from St. Catherine University, developed the “sleep care positioning training program”, an evidence-based two hour online video-based program. Additionally we conducted a pilot study, results of which shaped the study’s protocols, including its outcome measures. This training program and randomized study are the ones discussed in this chapter.

Synopsis

AIM To understand the effect of online training on perceived caregiver competence for implementing nighttime postural care (NTPC). *METHOD* In this mixed methods, parallel group double-blind randomized trial, investigators assigned 38 adult caregivers of children with cerebral palsy (34 females, 4 males) into groups (Lesson A or Lesson B) to complete differently formatted 2-

hour online training (interactive video-based or self-guided web-links). Each participant positioned a simulated “client” in a sleep system. Investigators collected baseline, post-training, and post-simulation questionnaire data. *RESULTS*. Both groups had significant increases in total average self-perceived competence scores post-training: Lesson A group, average change 1.53 points [SE 0.12], $p < 0.0001$; Lesson B group, 1.06 points [SE 0.12], $p < 0.0001$. Comparing groups, Lesson A group showed greater change (0.46 points [SE 0.17], $p = 0.0078$). Subjective themes included describing Lesson A as *a better lesson matching my learning style* and Lesson B as *overwhelming, not knowing what I was supposed to learn. INTERPRETATION* Sleep care positioning education caused increased perceived competence for health professionals and non-professionals. Gain was significantly greater for those completing the interactive video-based lesson versus a web-link lesson, suggesting the “sleep care positioning training program” (Lesson A), better prepares NTPC caregivers.

Background

Nighttime postural care employs sleep positioning systems (Figure 2), supporting persons with CP in alignment and addressing secondary health conditions like body shape distortion, pain, and impaired sleep (Dawson et al., 2013; Goldsmith, 2000; Hankinson & Morton, 2002; Hill et al., 2009; Mol et al., 2012; Pountney et al., 2002; Pountney et al., 2009; Underhill et al., 2012). Practitioners might recommend NTPC to prevent the need for invasive interventions like joint surgery or botulinum toxin injections (Pountney et al., 2009). Despite potential health benefits, NTPC outcomes are mixed, possibly due to lack of training (Goldsmith, 2000; Hankinson & Morton, 2002; Hill et al., 2009; Humphreys et al. 2019; Bacon & Lind, 2013; Castle, Stubbs, & Soundy, 2014; Innocente, 2014)

More than 10 years have passed since the Mac Keith Multidisciplinary Meeting consensus statement (Gericke, 2006) highlighted a need to create postural care training for direct care providers of persons with CP, yet a lack of education persists today. After conducting a literature review, Wynn and Wickham (2009), suggested best practice includes knowledgeable professionals skilled in NTPC service delivery and non-professionals (e.g., parents, family, NTPC recipients, etc.) trained in sleep system use. Despite calls for such standards, caregivers do not have the required training. For example, in the United Kingdom, which has over 20 years of implementation, investigators (Castle et al., 2014), found only 5.4% (3 out of 57) of surveyed professionals serving NTPC recipients had any postural care education. Additionally, in countries like the United States where this intervention is new, many caregivers have no knowledge of NTPC. Thus, training programs are essential.

Online education could expedite training and potentially advance NTPC competence. Digital technologies allow training of many people in a short period and McCutcheon, Lohan, Traynor & Martin (2015), found digital formats no less effective than face-to-face training for developing clinical nursing skills. While online education is potentially effective for clinical skill development, there is no published research regarding effects of online training for NTPC interventionists. Experimental research is necessary for understanding online training's ability to prepare persons for NTPC implementation.

Previous authors have suggested the content and outcomes necessary in caregiver education. Some recommend that NTPC education for professionals

include postural care purpose, sleep system types and uses, and assessment methods (Goldsmith, 2000; Hankinson & Morton, 2002; Hill et al., 2009; Humphreys et al. 2019; Innocente, 2014; Wynn and Wickham, 2009; McCutcheon et al., 2015; & Waugh & Hill, 2009). Others recommend non-professionals, especially those providing night to night care, be trained with an aim of advancing their perceived NTPC competence, based on study results showing parents with lower perceived competence felt more burdened (e.g. parental stress, tiredness, and time required for positioning the child) (Mol et al., 2012). The need for NTPC training, combined with these recommendations, led scholars to the development the online "sleep care positioning training program".

Jennifer Hutson and postural care scholars from St. Catherine University, developed online training that included six modules addressing NTPC topics identified in the literature. Then, this study's investigators designed a randomized trial testing the online training. This paper presents results, addressing the primary question: Is there a difference in perceived competence to implement aspects of NTPC for caregivers completing the online "sleep care positioning training program" (Lesson A), compared to those completing Lesson B.

The current study's aim is to understand caregivers' perceived NTPC competence (knowledge, ability and confidence) after completing the sleep care positioning training program. We hypothesized perceived competence would increase at post-training for caregivers assigned to both Lesson A and B, with Lesson A group showing greater change. We also hypothesized no difference

between professionals and non-professionals in perceived NTPC confidence at post-training.

Methods

Investigators used a mixed methods double-blind parallel group (Lesson A and Lesson B) design, randomly assigning a consecutive sample of adult caregivers of persons with CP to an educational intervention (Lesson A or Lesson B). St. Catherine University's IRB monitored this study, which took place between May and September 2018 in the Midwestern United States.

Participants. Investigators emailed flyers, recruiting participants from clinics serving persons with CP and Universities educating healthcare providers. We included adult professional or non-professional caregivers of persons with movement disorders, primarily CP. We excluded participants without knowledge of the sleep habits or routines of persons with such diagnoses. Professionals included practitioners holding professional health degrees. Non-professionals included caregivers, such as family members of children with CP and healthcare students attending University.

Participant activities. Participants completed their assigned activities on one scheduled date. Study completion involved consent process, baseline (before training) questionnaire (Appendix A), online education, post-training questionnaire (Appendix B), positioning of a simulated “client”, post-simulation questionnaire (Appendix C), and exit interview. Investigators gave $50 gift cards to participants completing all aspects of the study.

Randomization and allocation. Investigators followed randomization and balanced allocation protocols. The Principal Investigator (PI) enrolled participants, no more than five on any given day, assigning subject numbers and professional vs. non-professional labels. The research assistant completed randomization, drawing concealed numbers from an envelope, and an information technologist registered participants, by giving them access to their assigned online lesson. The research assistant used a threshold difference of three, applying Zelen's model of co-variate adaptive randomization (Chow & Chang, 2006), to balance professionals and non-professionals by group. Investigators applied protocols for blinding participants, such that the PI, participants, and clinician's observing participants during simulation (positioning a person in a sleep system) did not know to which lesson the participant was assigned.

Participants had the option of completing the non-assigned lesson in addition to their assigned lesson; 11 of the 38 participants opted to do so. Investigators verified that participants' completed all research activities (with the exception of the exit interview) in advance of the optional non-assigned lesson.

Lesson A and Lesson B intervention commonalities. Both groups completed online education covering six topic areas, approximately two hours long, delivered in a University classroom. Topics included evidence for NTPC, risk factor monitoring, sleep system types and set up, positioning methods, and outcome measures. Participants completed training individually using computers, via D2L Brightspace, a cloud-based learning management system, accompanied

by a research assistant who used a script to log in the participant and introduce the course. Investigators designated a classroom for each group, allowing no more than five participants per classroom at any one time. Research assistants did not inform participants of group assignment and gave instructions to keep training details confidential. These processes enabled blinding.

Lesson A and Lesson B intervention differences. Each group's lesson differed by format. Lesson A consisted of six specifically designed video tutorials with interactive learning checkpoints (using Camtasia® video creation software). Lesson B consisted of six summary pages with prompts to click on embedded web-links holding freely available web-based information. Address inquires about the study protocol and sleep care positioning training program to Jennifer Hutson at jahutson@stkate.edu

Simulation. After their assigned lesson and post-training questionnaire, participants positioned a "client" in a commercial sleep system (henceforth simulation). The "client" was one of the investigators. The PI gave simulation instructions to participants, asking each to set up the bed and position the "client" as best they could, selecting from the available sleep system components, which investigators placed in a consistent manner on a table adjacent to the bed. The "client's" start position consisted of head turned left with lower extremities flexed and right windswept. The "client" wore straps that held their lower extremities in a knee flexed position, simulating typical posture of someone with CP.

Data collection measures. Investigators collected quantitative and qualitative data using questionnaires at baseline, post-training and post-

simulation for participants' ratings of perceived competence and lesson feedback and open-ended questions at exit interview for participant perceptions. During all participant activities, investigators recorded statements and observations onto fieldnotes.

Questionnaires. The PI designed questionnaires (Appendix A-C) after reviewing the literature on competence, conducting a pilot study (not published) and consulting an academic measurement expert. Questionnaires included a) 20 four-point self-ratings (very low, low, high & very high) of knowledge, ability and confidence, b) Two questions on preparedness for NTPC implementation, and 3) three semi-structured questions soliciting lesson feedback. The 20 self-ratings addressed questions on NTPC research, health risks, sleep system types and set up, positioning methods, and outcome measures, and were divided into categories, with six questions about knowledge, seven on ability, and seven on confidence. For example, questions about NTPC research included “How would you rate your *knowledge* of NTPC research; How would rate your *ability* to tell others about NTPC research; and How *confident* are you that you can tell others about NTPC research”. An example of a semi-structured question is “if you were given the task of revising, adjusting, or redesigning the sleep care positioning program, what would you change?”

Fieldnotes and exit interviews. The fieldnotes were collected by research staff while participants completed their assigned lesson primarily to verify participant’s active engagement and by the PI during exit interview to obtain lesson feedback. The fieldnotes included two columns, one for recording

direct observations and statements and another for investigator's impressions. For those completing only their assigned lesson the investigator recorded responses to the question: "Any information you provide will help us know more about the usefulness of the lesson. What other input do you have about the lesson (design, format, etc.)?" For those opting to complete the non-assigned lesson, the investigator recorded responses to: "Now you have seen both lessons, describe any input you have about the usefulness of one lesson compared to another".

Statistical power. Before data collection began, investigators chose a significance level (0.05) and planned to enroll at least 30 participants. With 15 participants per group, we had 80% power to detect a difference between groups of 1.06 standard deviations, where "standard deviation" describes variation within groups (e.g., Cohen's d = 1.06). This is the first study examining perceived confidence of caregivers after online NTPC education, so no prior data was available to supply a value for a "standard deviation". Post-hoc, the standard errors and confidence intervals associated with each comparison (e.g., of groups according to the change from baseline to post-training) show the study's actual statistical power.

Data analysis quantitative. Each participant provided a total average perceived competence score (total average from knowledge, ability and confidence sub-scores) at three times: baseline, post-training, and post-simulation. Investigators analyzed scores using a mixed linear model; the random effect was participant, and fixed effects were group (Lesson A or Lesson

B), participants' status (professional vs. non-professional), time (baseline, post-training, and post-simulation), and all two-way and three-way interactions. Investigators tested change over time within each group using a contrast in the group-by-time interaction (which combines professionals and non-professionals). Investigators compared groups at each time point, also using contrasts in the group-by-time interaction. Statistical analyses used JMP (v. 14. 0.0 Pro, SAS Institute, Cary NC).

Data analysis qualitative. For qualitative data, investigators used a modified grounded theory approach of open, axial and selective coding similar to that described by Bhattacherjee (2012). Investigators read recorded responses from questionnaire and interview, line-by-line, coding them into categories and themes.

Results

Thirty-eight participants (34 females, 4 males) enrolled. Random assignment resulted in 19 Lesson A and 19 Lesson B group participants and balanced allocation of professionals (8 Lesson A, 7 Lesson B) and non-professionals (11 Lesson A, 12 Lesson B). Of the 38 enrolled, 37 completed the entire study. One Lesson B-group participant did not complete the simulation or the post-simulation questionnaire due to time constraints. On average, participants had five years' caregiving experience with limited NTPC-related knowledge, only one having direct NTPC sleep system knowledge (Table IV).

Table IV. *Participant characteristics*

A. Participant status, title, and years in caregiver role

Status	Caregiver Title and Years
Pro (n=15)	Occupational & Physical Therapists, Assistive technologist
Non-pro (n=23)	Non-Professional unspecified, healthcare students, mothers, other
Years	Ranged from 0 to 35, average 5 years as caregiver

Note. Pro, health professional; Non-pro, non-professional care provider; Years, number of years as caregiver; Non-professional other, includes a group home direct care provider and one inclusion specialist.

B. Participant prior experience with postural care

Type	*n*=37
None or little	15
Night positioning but not sleep system	10
General positioning	4
Day positioning	4
General sleep interventions	2
Sleep assessment	1
Nighttime postural care and sleep systems	1

Total average perceived NTPC competence increased significantly within both groups from baseline to post-training and from baseline to post-simulation (Table V). The change in perceived competence post-training was significantly greater for Lesson A group (difference in average changes 0.46 [SE 0.17], p = 0.008). Lesson A group also had a greater increase from baseline to post-simulation but this did not reach significance (difference in average changes 0.28 points [SE 0.17], p = 0.11).

Table V.

Total average perceived competence change from educational training

Variable	Group	Average Point Change	*SE*	*p*
Pre to Post Training				
	Lesson A	1.53	0.12	< 0.0001
	Lesson B	1.06	0.12	< 0.0001
Pre to Post Simulation				
	Lesson A	1.30	0.12	< 0.0001
	Lesson B	1.02	0.12	< 0.0001

Note. Average refers to the total average point change from the 4 point questionnaire of perceived competence. Comparing total average change score using a contrast in group-by-time interaction.

Investigators compared groups on NTPC readiness, using participants' ratings from the statement "because of the training I can readily use the intervention with my child or client". Lesson A group felt significantly more ready to use the intervention (compared to Lesson B) post-training (t=3. 33, [SE 0.72], *p*=0.001). At post-training Lesson A and B groups averaged 3. 32 [SE 0.48] and 2.63 [SE 0.76] respectively.

Examining total average questionnaire ratings at post-simulation based on status (professional or non-professional), investigators found ratings closely matched within Lesson B group (professional average 2.78, [SE 0.19]; nonprofessional average 2.83, [SE 0.15]); while Lesson A group scores showed more differentiation (professional average 3. 23, [SE 0.17], non-professional average 2.85, [SE 0.15]), with professionals appearing to have greater competence gains (Figure 4). However, when accounting for group, status as

professional to non-profession did not differ significantly from baseline to post-simulation ($F(2,67) = 0.08$, $p = 0.92$).

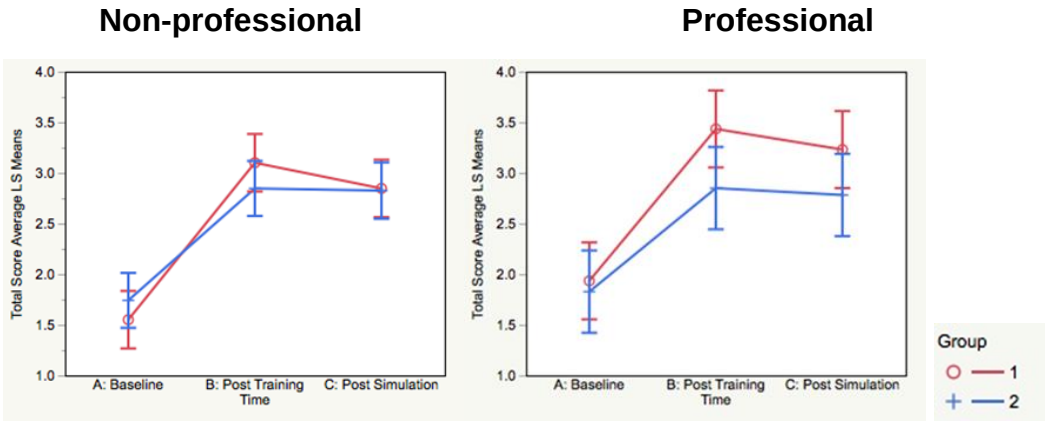

Figure 4. Total score average ratings for non-professional caregivers (left) and professional caregivers (right), comparing across Lesson A (group 1) and Lesson B (group 2) groups from baseline to post-training to post-simulation.

The eleven participants who opted to see both lessons described the differences between Lesson A and Lesson B. Qualitative data revealed two key themes differentiating the lessons: Theme 1). Lesson A is a *better lesson matching my visual learning style*; and, Theme 2) Lesson B is *overwhelming*, *difficult to know what I was supposed to learn*. One participant stated, "*I'm so glad I got mine [Lesson A]. I saw on the one [Lesson B] that there was reading and you have to click on the links. I think it would be more confusing what I was supposed to learn versus being told what to know*". Another said, "*I think it is a way better format [Lesson A]…I'm a visual learner. I didn't really feel like I know what I was doing [Lesson B]. I didn't feel like I got the most out of my time until doing that [Lesson A] lesson*". Table VI gives additional participant statements.

Participant responses showed caregivers felt the online interactive video-based lesson (Lesson A) afforded an increased opportunity to learn.

Table VI

Participant Comparisons of Lesson Formats

Status	Theme	Participant Quotes
Lesson A	a better lesson matching my learning style	• I'm more visual and kinesthetic. • I feel like the video is a better lesson. It felt more streamlined. • The video module one would be a lot more effective (with) pictures, videos. It checked in regularly to make sure you understood. • I definitely think the one is more useful. I'm definitely walking away thinking I learned something and I wouldn't if I had the other and that's because of the way I learn…. the video is better. • I think I would have had a better idea (during simulation) after the videos. It might be my learning style. • With my learning style, I would learn more with the one with the videos.
Lesson B	overwhelming difficult to know what I was supposed to learn	• My version (Lesson B) was too heavy on the readings. So I think I forgot a lot. • The (Lesson B) one was more technical reading, more clicking back and forth. • The (Lesson B) one felt heavy. I feel overwhelmed when I see all the places I have to go. • Wasn't sure what (I) was supposed to learn because it was broad spectrum. • Some are better than others about doing self-guided. I wondered if I was supposed to be going to this link. I think you want to make it as fool proof as possible. • The second one (was) overwhelming.

Note. Each bullet point within the lesson category, either Lesson A or B, shows a different participants' statement. A participant may have a statement within each of the respective lesson categories.

Discussion

The online interactive video-based lesson, as compared to the self-guided web-link lesson, resulted in greater total perceived competence of caregivers

post-training on topics of NTPC implementation including research evidence, risk factor monitoring, types and set up of sleep systems, methods of positioning the person and outcome measures. The sleep care positioning training program (Lesson A), based on change in perceived competence, is effective for training professional and non-professional caregivers in NTPC.

The sleep care positioning training program (Lesson A), has potential to advance NTPC practice, given its inclusion of topics such as research evidence, types of sleep systems, ways to position the person and tools to assess change. Wynn and Wickham's review (2009), suggests for best practice, non-professionals be trained in using positioning equipment and health professionals be knowledgeable about postural management, equipment and assessment; yet, past studies show even clinicians serving NTPC recipients lacked such training (Humphreys et al., 2019). The online training program examined in the current study may advance NTPC best practice by addressing this knowledge gap and educating non-professional and professional NTPC caregivers.

The online training may also potentially reduce caregiver's perceived burden. Mol et al. (2012), found that parents implementing NTPC with their children experienced less care burden when they felt more competent. Non-professionals in the current study perceived higher competence after completing the online sleep care positioning training program. Thus, based on Mol et al. (2012), they could experience less caregiver burden when providing NTPC, after receiving the training. Given Mol et al.'s (2012) additional claim that high burden negatively affects parents' rest and functioning, the non-professionals' improved

feeling of competence after completing the sleep care positioning online training may also translate into health benefits for those caregivers.

Most online education research compares its effects to in-person training; this study adds to the literature by comparing two online formats (interactive video-based versus self-guided web-links). In their systematic review, McCutcheon et al. (2015), concluded that online could be as effective as traditional face-to-face training for developing clinical skills. The current study shows online training using interactive videos with embedded quizzes bolsters caregivers' feelings of competence more so than training that includes summaries with links to web-based information. While these effects might relate to the limited NTPC web content currently available, rather than training format, study participants' reports indicate a preference for video-based education even when the content itself is equivalent. Future studies could continue examining the differing effects of online education formats as more web-based information on NTPC becomes available.

Creating online education with interactive videos and embedded quizzes is both time and cost intensive and may be impractical for health educators to employ regularly. In the current study, the video-based lesson required purchase of video editing software and months of development while the web-link lesson demanded less than a month's time. Since participants completing the web-link formatted education reported significant increases in perceived competence, educators and practitioners may feel reassured that such training has some

effect. Educators must consider available resources and outcomes when making decisions about NTPC training format.

Despite McCutcheon et al.'s (2015), finding that online can result in greater learning of clinical skills than face-to-face education, this outcome likely depends on the type of skill required. For example, online training might suffice for educating caregivers on NTPC research or choosing outcome measures but the complex skill of positioning a person likely requires in-person practice. Participants in this study articulated this sentiment, communicating a need to have additional hands-on training to prepare for sleep system positioning with their child or client. Ultimately, educators need to match training methods to the skills necessary for NTPC implementation.

Limitations

The participant sample included in this study may not be representative of the larger caregiver population, given that investigators did not obtain a random sample. Readers must generalize cautiously to the larger population of caregivers. Additionally, one cannot expect participants' positioning ability to translate to all children with CP. Investigators hoped to recruit more family members of children with CP but a majority of the non-professional participants identified as either unspecified non-professionals or healthcare students. This study's sample also tended to be highly educated, with most participants holding a bachelor's degree and many pursuing graduate education. Additionally, in this study the "client" being positioned in the sleep system was most similar to persons with CP having limited knee extension, but sufficient flexibility at the

head/neck, torso and pelvis to achieve a symmetrical posture. Therefore, positioning scores may not translate to children with limited or less flexible orthopedic conditions. Thus, readers should not conclude that the sleep care positioning training program is effective for all family members of all persons with CP. A future study might include a sample of caregivers with less education or "clients" with more flexibility limitations.

Investigators of this study designed their own questionnaires, which one might also consider to be a limitation. However, investigators took steps prior to conducting the study to ensure the questionnaire was appropriately designed, and during/after conducting the study, by examining internal consistency reliability. Based on a literature review, investigators determined no existing outcome measure could capture change specific to the NTPC educational content, thus warranting a new measure. A measurement consultant and pilot study conducted by the investigators informed the questionnaires' design, leading to a rating scale change from 5-point to 4-point and modification of the questionnaire's confidence subcategory language, respectively. Additionally, investigators examined the internal consistency reliability of the questionnaire's knowledge, ability and confidence subsections, finding significant correlation across all sections ($p < 0001$) with r (which ranged from 0.66 to 0.95), being highest when comparing the ability and knowledge sub-scores. This examination, combined with the identified design changes aimed to address potential measurement related limitations.

Conclusion

Online interactive video-based training, compared to a self-guided web-link version, resulted in greater perceived competence to implement NTPC. The sleep care positioning training program is effective for educating professional and non-professional caregivers in aspects of NTPC intervention.

Chapter 4

Randomized Trial: Observed Competence

Chapter overview

This chapter includes results from the same randomized experimental design study (discussed in chapter 3), but with content covering the outcome of caregivers' observed competence for positioning the person in a sleep system. The primary research question addressed in this chapter is as follows: Is there a difference in observed competence to position a person in a sleep system for caregivers completing the online "sleep care positioning training program" (Lesson A), compared to those completing Lesson B. The paper is under final preparations for journal submission.

Synopsis

AIM Examine caregivers' ability to position a person in a sleep system after completing online nighttime postural care training. *METHOD* For this mixed-methods parallel-group double-blind study, investigators randomly assigned 38 caregivers of children with cerebral palsy (34 females, 4 males, 15 professionals, 23 non-professionals) to groups to complete differently formatted 2-hour online training (Lesson A: interactive video-based or Lesson B: self-guided web-links). Raters assessed 37 participants during their positioning of a "client". Investigators examined participants' ability to self-assess by testing correlation between participants' self-ratings of competence and observed competence ratings during positioning of "client". *RESULTS* Lesson A and B groups correctly completed 11.85 [SE 0.83] and 12.60 [SE 0.84] of 16 positioning tasks, not differing significantly (average difference 0.75 items [SE 0.54], $p = 0.17$). Lesson A groups post-simulation self-ratings were significantly associated with positioning ability ($r = 0.53$, $p = 0.019$). Professional caregivers performed significantly better than non-professionals ($F(1,92.34) = 16.62$, $p < 0.0001$).

Commonly missed tasks include “placing head/neck in neutral” and “snugging up parts”, with more error variation amongst Lesson B group participants. Themes of “struggled with (bracket) covers” and “brackets not oriented properly” revealed caregivers’ difficulties with sleep system parts. *INTERPRETATION* This online interactive video-based lesson is effective; both professional and non-professional caregivers accurately completed most sleep system positioning tasks after online training.

Background

Nighttime postural care (NTPC) for people with severe cerebral palsy requires caregivers be trained in positioning skills; however, studies of training effectiveness are essentially nonexistent. NTPC uses sleep systems to support persons in symmetry, preferably in supine, to optimize health and prevent secondary conditions associated with premature death (Waugh & Hill, 2009). Since postural alignment is fundamental to NTPC (Innocente, 2014), caregivers must be competent in positioning strategies, which are complex. Investigators have yet to identify whether available education leads to skilled caregivers.

Different investigators emphasize different training components and agree that education should include distinctions between various sleep systems and instruction on positioning (Innocente, 2014; Wynn and Wickham, 2009; Humphreys et al., 2019; Polack et al., 2009; & Gericke, 2006). Wynn and Wickham (2009), report professional caregivers need training in both different sleep system types and postural management, while non-professionals require education in proper sleep system use. Other investigators emphasize therapists may need training from specialists, families should be trained in hands-on sleep

system practice, not just demonstration and learn to address comfort through postural management (Humphreys et al., 2019; Polack et al., 2009). Innocente's (2014), results suggest therapists be trained to select a sleep system best matching the client's need while considering environment, to reduce product abandonment. Despite agreement that professional *and* non-professional caregivers need appropriate education, there is little evidence about training format.

Online education seems reasonable and necessary whether in countries where NTPC intervention is standard practice or little known. In countries where the intervention is new, large numbers require training and reliance on in-person methods would slow dissemination. Even in areas like the UK where NTPC is standard practice, caregivers lack training and some, 40.4% in one survey of professionals, prefer online formats (Castle et al., 2014). While these factors lend support for NTPC online education, it is crucial to understand whether online training gives caregivers competence to position a person in a sleep system.

To date, no peer-reviewed publications report the effect of NTPC education on caregivers' actual positioning ability. The current paper presents results of a mixed methods double-blind parallel-group randomized trial examining the effect of "the sleep care positioning (online) training program". This is the primary research question addressed in this paper: Is there a difference in observed competence to position a person in a sleep system for caregivers completing the online "sleep care positioning training program" (Lesson A), compared to those completing Lesson B. Two sub-questions include: 1. How

many of the 16 positioning tasks, deemed representative of competence, do caregivers complete? And 2. Is there a difference between caregivers in their self-assessed ability to position a person, based on the lesson they completed (e.g. Lesson A or Lesson B)?

We hypothesized that both professional and non-professional caregivers would a) correctly perform *most* of the 16 positioning tasks, b) their self-ratings of perceived ability would be associated with actual ability and c) there would be no difference in positioning ability based on assigned lesson.

Regarding hypothesis a, because this study is a first of its kind to examine positioning competence, investigators did not determine in advance how many correctly completed positioning tasks, of the 16, equated to *competence*. Investigators hypothesized that most of the positioning tasks would need to be completed, but did not anticipate caregivers would correctly complete all 16 tasks.

Methods

The investigators recruited a consecutive sample of adults from the Midwestern U. S. using emailed flyers. We included adult professional or non-professional caregivers of persons with movement disorders, primarily CP. We excluded participants without knowledge of the sleep habits or routines of persons with such diagnoses. Participants agreed to participate in the research study and to publication through process of informed consent. Using Zelen's (Chow & Chang, 2006), covariate adaptive randomization approach, participants

were assigned to group (Lesson A or Lesson B) and balanced (using a threshold of three) based on their status as professional (holding a health-based professional degree) or non-professional (University students, family members or caregivers of persons with CP without healthcare degrees). Protocols allowed blinding to group assignment of the primary investigator (PI), sleep system positioning observation raters, and participants. The Principal Investigator (PI) enrolled participants. Then the research assistant completed randomization, drawing concealed numbers from an envelope, and the information technologist registered participants, giving them access to their assigned online lesson. The study took place from May to September 2018 and was approved and monitored by St. Catherine University Institutional Review Board.

Determining Participant Sample Size. Because no published studies examining NTPC positioning competence exist, investigators could not use past literature to inform the power calculation. Investigators chose a significance level (0.05) and planned enrollment of 30 participants, at minimum, to allow for analysis. With 15 participants per group, we had 80% power to detect a difference between groups of 1.06 standard deviations, where "standard deviation" describes variation within groups (e.g., Cohen's d = 1.06). Post-study, using the rule-of-thumb that a two-sample t-test has 80% power to detect a difference between groups of square root (17/N) standard deviations (e.g., Cohen's d = square-root(17/N), we determined sample size adequacy. The standard errors and confidence intervals associated with each comparison (e.g.,

of groups according to the change from baseline to post-training) show the study's actual statistical power

Participant activities. Participants completed all activities on one scheduled date: Baseline questionnaire (immediately preceding training), assigned online training, post-training questionnaire, positioning of a "client" in a commercial sleep system (henceforth "simulation"), and post-simulation questionnaire. Investigators employed consistent procedures, introducing participants to each activity.

Intervention similarities and differences. Both online lessons (Lesson A and Lesson B), took place in a University classroom using a cloud-based learning management system (D2L Brightspace) and contained modules on evidence for NTPC, risk factor monitoring, sleep system types and set up, positioning methods, and outcome measures. The positioning modules of both lessons included video-based instruction. Investigators designated a classroom for each group, allowing no more than five participants per classroom at any one time. Research assistants did not inform participants of group assignment and gave instructions to keep training details confidential. These processes enabled blinding. The lesson formats differed by source and design (e.g. Lesson A positioning modules, created by a University's postural-care scholars, consisted of interactive videos embedded with learning checkpoints. Lesson B's positioning modules included summary statements and links to freely available information from sleep system manufacturers).

Simulation description and protocols. Simulation involved positioning a "client" in a hospital bed using a designated commercial sleep system. The investigators followed consistent protocols, including: 1) *Participant instructions* ("position the client to the best of your ability, do not use notes or ask observers for help"), 2) *"Client" positioning* (a specified asymmetrical-lying start position common to persons with CP), and 3) *Room set up* (bed centered against north wall, clinician raters sitting at tables in predetermined locations, sleep system parts arranged on tables in fixed positions)**.**

Simulation raters. Health practitioners trained in study protocols, observational strategies, and use of the simulation observation instrument, rated participants' positioning skills during the simulation. The primary clinician raters included an assistive technology professional and an occupational therapist; they rated 30 and 29 participants, respectively. Two secondary raters (both occupational therapists, one the PI) completed the remaining observations. The PI rated simulations whenever the primary raters were unavailable. Investigators established the protocol of using at least two raters during simulation to further advance the methodological rigor of the study.

Outcome measures. Investigators developed and used a questionnaire and a simulation observation instrument, respectively, to examine perceived and observed positioning competence (given the absence of outcome measures capable of measuring NTPC competence). The PI developed these measures with assistance from a consultant with measurement expertise.

The questionnaire included 23 self-ratings of competence on a 4-point scale (very low, low, high & very high). Three questions specifically addressed positioning the person and are relevant to the analysis contained in this chapter: "How would you rate your: knowledge of how to position a person in a sleep system?"; "… ability to position a person in a sleep system?", and "How confident are you that you can position a person in a sleep system?" The remaining questions, which are pertinent to information contained in chapter 3 of this paper, addressed other aspects of NTPC (e.g. NTPC evidence, risk factors and how to monitor, sleep system types and set up, and outcome measures).

The *simulation observation instrument* included several pages and contained both a ratings-based list of 16 positioning tasks and space for detailed description of performance observations (Appendix D). The 16 positioning items (listed on the instrument's first page) covered three primary skill areas including ability to align the "client's" body (4 items), place sleep system components relative to other sleep system parts (5 items), and place sleep system components relative to the "client's" body (7 items). The instrument's remaining pages included instructions for recording observations of the positioning performance, in its entirety. This layout afforded quantitative and qualitative data analysis.

Data analysis quantitative. Investigators computed participants' average correct positioning/simulation score (number of "yeses" out of 16) and then compared groups using a mixed linear model to examine differences in observed positioning ability based on group (Lesson A or B) and status (professional or

non-professional). Investigators calculated averages from participants' self-ratings of positioning competence at three times: baseline, post-training, and post-simulation. These were analyzed using a mixed linear model; the random effect was participant, while fixed effects were group (Lesson A or Lesson B), participants' professional vs. non-professional status, time, and all two-way and three-way interactions. We compared groups on changes between time points (baseline, post-training, and post-simulation) using contrasts in the group-by-time interaction. Lastly, investigators examined relationships between participants' average self-ratings of positioning competence and average correct positioning/simulation scores to understand groups' ability to self-assess, using Pearson's correlation (r). Analyses used JMP (v. 14. 0.0 Pro, SAS Institute, Cary NC).

Additionally, investigators examined interrater reliability using intra-class correlation (ICC); we did this separately for all simulation observation raters and for the two primary clinician raters along with the PI.

Data analysis qualitative. Investigators identified, tabulated and coded themes from comments made by clinician raters corresponding to tasks completed incorrectly. First, we listed each participant's incorrectly completed tasks, organized them into a table and then identified the tasks most frequently missed or performed incorrectly. The PI then reviewed line-by-line any descriptive data corresponding to those frequently missed tasks, coding them into categories and themes (using an approach to open, axial and selective coding modified from that described by Bhattacherjee, 2012).

Results Quantitative Overview

Thirty-seven of 38 participants (34 females, 4 males; 15 professionals, 23 non-professionals) completed the questionnaires and the simulation activity. All participants completed their assigned training (19 Lesson A, 19 Lesson B). One participant left before the simulation due to a time conflict/other obligation. Most participants had little to no previous experience with NTPC (Table IV). Only one had both experience in NTPC and sleep system knowledge.

Group comparisons. When comparing groups based on their total average observed positioning/simulation scores (Table VII), there was no difference between groups; however there was difference based on participant's status as professional or non-professional. While Lesson B group averaged 0.75 more tasks [SE 0.54] than Lesson A group, the groups did not test significantly different ($F1, 92.32 = 1.91$, $p = 0.17$). However, professionals did differ significantly from non-professionals ($F1, 92.34 = 16.62$, $p < 0.0001$), a difference that did not depend on group assignment ($F1, 93.59 = 0.11$, $p = 0.75$).

Table VII

Total average simulation scores by status and group

Status/Group	Total Average	SE
Status		
Professional	13.33	0.86
Non-professional	11.12	0.82
Group		
Lesson A	11.85	0.83
Lesson B	12.60	0.84

Note. Total average indicates number of correctly completed positioning tasks out of 16.

Comparing self-ratings of ability to position the person, post-training, Lesson A group showed significantly higher self-ratings compared to Lesson B group: average difference 0.64 points [SE 0.25], $p = 0.014$ (average change within Lesson A group 1.53 [SE 0.18]; average change within Lesson B group 0.90 [SE 0.18]). Post-simulation, after positioning the "client", self-ratings did not differ significantly between groups: average difference 0.21 points [SE 0.26], $p = 0.423$ (average change within Lesson A group 1.10 [SE 0.18]; average change within Lesson B group 0.90 [SE 0.18]).

Examining correlations between participant self-ratings and clinician observed ratings, neither group's total average self-ratings of positioning competence taken immediately post-training were significantly associated with actual positioning ability (Lesson A, r = 0.14, n=19, $p = 0.56$; Lesson B, r = 0.03, n=18, $p = 0.90$). However Lesson A group's self-ratings taken immediately after the simulation were significantly associated with their actual positioning

ability (r = 0.53, n=19, *p* = 0.019), while Lesson B group's post-simulations scores were not significantly associated (r = 0.15, n=18, *p* = 0.55). Nonetheless, comparing the groups according to this association showed no significant difference (slope difference 1.56, [SE 1.39], *p* = 0.27)

Interrater reliability. Investigators found good agreement between the trained raters responsible for recording simulation observations (scoring of correctly completed positioning tasks out of 16): ICC was 0.80 including all raters and 0.78 including the two primary raters and the PI. McHugh (2012), suggests that while Cohen might consider this level of agreement substantial, healthcare related studies should deem 0.61 to 0.79 as moderate and 0.80 to 0.90 as strong agreement.

Descriptive and Qualitative Data

Based on the descriptive data, the investigators found 35 participants positioned the “client” in supine and two in side-lying, taking on average 13.7 minutes (range 6 to 31) to complete sleep system positioning. The most challenging positioning tasks appeared to be "placing head and neck in neutral without excessive chin tuck or extension" (23/37 participants given “no” rating) and "snugs up all [positioning] parts" (20/37 rated “no”). Overall, caregivers in both groups (Lesson A or Lesson B) missed tasks belonging to the body alignment category, more than items involving placement of sleep system components in relation to other parts and placement of sleep system parts in relation to the "client’s” body.

While groups performed similarly in some respects, caregivers receiving Lesson B showed greater variation. For example, we calculated items missed by nine or more of each group's participants and found caregivers receiving Lesson A only made errors on two tasks at this frequently, "snugs up all parts "(11) and "head neutral" (9). By contrast, caregivers completing Lesson B made errors on five different tasks with that frequency, including "head neutral" (14), "chest symmetrical" (10), "chest bracket snug" (9), "pillow under thighs" (9), and "snugs all parts" (9). Based on these observational data, caregivers receiving Lesson A were somewhat more consistent in their positioning task errors.

Overall, themes from raters' written statements showed participants appeared to have little difficulty interacting with sleep system positioning components, with the exception of the positioning brackets (Table VIII). Raters reported participants "struggled with (bracket) covers" (19/37 participants; 10 Lesson A, 9 Lesson B) and "brackets not oriented properly" (5/37 participants; all from Lesson A group). In some cases, clinician raters interpreted these difficulties as a factor in some caregivers ultimately not using that sleep system part.

Table VIII

Rater descriptions of problems with positioning during simulation

Theme	Recorded observations by raters
Struggles with covers	• covers not secure, large • not secured not correct elastic not used • Velcro part covered • inaccurate placement • struggles with large covers • cover not secured over end that attached to Velcro sheet • seemed confused with large covers • attempted large covers but did not use • covers not secured correctly • did not use elastic strap • covers not figured out, large covers • covers backwards, struggled with covers (for) large brackets • unsuccessful large covers
Errors orienting brackets	• laterals oriented backwards • brackets backwards • brackets upside down • struggled covers and large brackets • bracket backwards

Note. Each bullet point reflects a recorded observation made by a primary clinician rater. Each bullet point within a particular theme represents a different participant.

Discussion

The 2-hour online sleep care positioning training program (Lesson A), effectively trains caregivers (professional and non-professional) to complete most of the tasks for positioning a person in a commercial sleep system, yet current results indicate that some tasks require additional training or support for competence. Investigators recognize that some of the 16 positioning tasks may not be necessary for competence (e.g. pillow under head, covers on lateral brackets); and that tasks pertaining to pressure relief and alignment are likely

most important. After either online training, caregivers in this study completed an average of 12 of 16 positioning tasks correctly and actions involving body alignment and snugging up all parts of the sleep system proved most challenging. Since alignment is a key aim of NTPC and pressure relieving outcomes likely relate to offloading boney areas with snugly fitting parts (Waugh & Hill, 2009; Innocente, 2014), online sleep care positioning trainees may benefit from hands-on practice or supplemental materials to reinforce such positioning criteria. This study's investigators recommend future research be conducted to establish minimum positioning competence cut off points or standards and effective hands-on training programs meant to supplement knowledge that can be obtained from the online sleep care positioning training program.

Future NTPC educators using Lesson A (video-based format with embedded quizzes) rather than Lesson B (web-links to freely available content) may be better able to determine the type of supplementary training required of learners to achievement competence in all 16 positioning tasks. For example, based on observational clinician ratings, caregivers completing Lesson A required additional training in snugly placing the sleep system parts and positioning the "client's" head and neck in neutral. Determining the type of supplementary materials required by Lesson B learners is more complicated, given the variety of errors observed in their performance. We suspect the variation of errors in Lesson B group resulted from the self-guided nature of that lesson's format which is consistent with participant reports. Study participants described Lesson B as *overwhelming* and said it was *difficult to know what I was*

supposed to learn, given their uncertainty about whether they had accessed the correct links or spent enough time on one link versus another. Although the analyses showed Lesson A and B groups did not differ on average number of positioning tasks completed correctly, the descriptive data suggests future educators use Lesson A over B, because consistency in caregiver performance errors would make it easier for educators to follow up with supplemental training.

NTPC caregiver competence might improve by permitting access to resources at the time of positioning. This study's investigators wanted to understand how online training alone prepared caregivers, so participants could not use notes/resources while positioning the simulated client, which likely limited their observed competence. Future educators using the online program could offer caregivers a menu of resources for use during positioning, such as manufacturers' product pamphlets, sleep care positioning training program videos, or quality measures like the Posture and Postural Ability Scale (a scale that includes posture quality ratings) (Rodby-Bousquet, Persson-Bunke, & Czuba, 2016). These tools afford caregivers visual prompting and ability to assess their work. Future investigators might also examine positioning competence comparing those using supplemental materials versus not using such resources.

Investigators were not surprised about the lack of significant difference between groups (Lesson A & B) on the outcome of average number of positioning tasks completed correctly post-education, given that both Lesson's positioning modules used video formatting. Statements made by participants in

the current study combined with previous studies reveal that NTPC education recipients prefer visual training and report benefits from video-based modalities (Bacon & Lind, 2013). Similarities between lessons, specific to the positioning-based training content may have made Lesson A appear to have less effect that it actually did.

Not surprisingly, health professionals performed better compared to non-professional caregivers at positioning the person in the sleep system. Health professions receive formal education addressing body alignment and use of assistive devices, so they have a point of reference from which to apply NTPC information. We caution readers from concluding that non-professionals have less capacity for learning; rather, we expect that caregivers have the same capacity for NTPC competence but need further training to acquire equivalent knowledge.

Limitations

The participant sample included in this study may not be representative of the larger caregiver population, given that investigators did not obtain a random sample. Readers must generalize cautiously to the larger population of caregivers. This study's participants resided in a large city in the mid-west United States, non-professionals were mostly college educated, and professionals were generally from rehabilitation therapy disciplines. Many of the participants had Bachelor's degrees, or were students enrolled in occupational or physical therapy University programs or were practicing therapists. Future studies might include

more family members of persons with cerebral palsy, or persons from other disciplines (e.g. nurses, physicians or insurers) or persons with less education.

One might also consider another limitation to be the fact that more than one person played the role of “client”. Because scheduling conflicts made it impractical to have one person as “client”, the PI created “client” protocols and provided training so “clients” presented and behaved consistently. For example, each “client” assumed a specified asymmetrical start position on the bed wearing straps to hold their lower extremities in a consistent position and did not speak except to say “yes” or “okay”. Such protocols aimed to reduce "noise" variation in study outcomes. While investigators took steps to control for differences that might arise, future studies could enhance internal validity by having one consistent “client”.

Conclusion

After a 2-hour online sleep care positioning training program, caregivers correctly completed most tasks required for positioning a person in a commercial sleep system. Certain tasks require additional training or support for competence. Educators using the interactive video-based training package (Lesson A) versus the self-guided lesson incorporating freely available web-links might have greater understanding of caregiver’s supplementary training needs.

Chapter 5
Conclusion and Next Steps

Dissertation Work Overview

The research studies of this dissertation may be useful in supporting the fidelity of NTPC research and practice. The studies fill a gap in the literature about sleep-based instruments suitable for use to measure intervention changes for children with severe CP and an online training program's capacity to educate care providers. The systematic review study addressed the sleep-based instruments used in NTPC impact studies. The randomized trial addressed the outcome of caregiver competence for persons completing the "sleep care positioning training program". The studies' information about outcome measures and educational tools can be used by future interventionists and researchers to shape their pathways of care and study protocols.

In chapter 2, this author discussed systematic review results, analyzing existing sleep-based instruments for their suitability as outcome measures. Study investigators found that none of the sleep-based instruments used in past NTPC intervention research met criteria as stand-alone outcome measures for use with children GMFCS IV and V. Investigators concluded that combined use of the SDSC-R and triaxial actigraphy (along with concurrent examination of their sensitivity and specificity), may be the most promising approach moving forward for interventionists and researchers measuring NTPC sleep-related changes.

In chapters 3 and 4, this author discussed results of the randomized trial that investigated both perceived and observed competence of caregivers to

implement NTPC after receiving the online “sleep care positioning training program”. Study investigators found the sleep care positioning education resulted in increased perceived competence for both health professionals and non-professionals on topics of NTPC evidence, risk factor monitoring, sleep system types and set up, positioning methods, and outcome measures. Investigators also found that after education caregivers completed on average between 11 and 13 of the 16 positioning tasks identified as competence indicators, with no difference when comparing those receiving the video-based formatted lesson versus the self-guided web-link lesson. Investigators concluded that a video-based formatted lesson versus a lesson incorporating freely available web-links made caregivers feel better prepared for NTPC intervention. Investigators also concluded that either online lesson could, in part, prepare caregivers for positioning persons in a sleep system, but that educators providing the video-based interactive “sleep care positioning training program” would have a clearer understanding about any additional training needs caregivers might have, making it easier for educators to design future educational programs.

Activities Post Dissertation Research

Based on results of this dissertation work and input from person’s attending an international conference, where the “sleep care positioning training program” was presented, this author and a research assistant updated the online lessons. We made changes such as adding callouts (arrows and highlights) on head/neck alignment images to emphasize optimal positioning, new images showing optimal pelvic joint positioning, etc. We also created three new

abbreviated versions of the online training called “sleep care positioning training program, the basics”. Each of these 30 minute videos contain matching content about NTPC evidence, risk factor monitoring, and outcome measures; but include information on a different commercial sleep system (with tutorials on set up and positioning). The “basics” videos are intended for caregivers who want introductory information about NTPC and already know which sleep system they will be using; while, the original (but edited) version is best suited for those wanting NTPC introductory information and have not yet chosen their sleep system. The intention is to make both versions publicly available.

The “sleep care positioning training program” has since been used to educate an interdisciplinary team of health professionals providing NTPC. We have included the program in a care pathway as a baseline competency for occupational therapists and assistive technology professionals working at a hospital that specializes in treating children with complex conditions. We also added the program to their online training management system (HealthStream). Once we make final edits and set release parameters, occupational therapists will be required to take that training and other members of the healthcare team can access the program as an optional learning opportunity.

Not only is the sleep care positioning training program embedded into a NTPC pathway for one healthcare organization, but so too is the SDSC sleep-based measure. Currently occupational therapists administer the SDSC as a part of the NTPC evaluation and we have begun discussions around updating the care pathway to include SDSC-R and triaxial actigraphy for purposes of

measuring outcomes. Despite contributions made to this hospital's care pathway, we need to do much more in advancing knowledge related to NTPC.

Future Directions

I am intending to use the study results from this dissertation work to inform protocols of a future longitudinal study investigating the health outcomes of children with CP, GMFCS IV and V, receiving NTPC. We will use the sleep care positioning training program as a baseline competency (combined with hands-on positioning training) for all caregivers. Additionally, we will use SDSC-R and triaxial actigraphy (supplemented with sleep diary) as sleep-based outcome measures while simultaneously examining their sensitivity and specificity. Although this dissertation work will inform my own research, the intent is that other investigators consider its application and relevance to their study protocols.

When designing future NTPC impact studies, investigators must incorporate evidence-based protocols that include standardized training procedures for all care providers and outcome measures that are both suitable to the identified population and capable of capturing intervention changes. Procedures such as these will lead to better understanding of NTPC's impact.

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Appendix A: Baseline Sleep Care Positioning Questionnaire

Participant Code: _____Last 4 digits phone # _____

Today's Date: □□/□□/□□□□

Circle the number best representing your knowledge, skills, & confidence of nighttime postural care.

RATING SCALE: 1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH				
How would you rate your knowledge of				
Nighttime postural care (NTPC) research	1	2	3	4
Health risks to check	1	2	3	4
Sleep systems available in the U. S.	1	2	3	4
How to position a person in a sleep system	1	2	3	4
Ways to know if NTPC is working (assessment, outcome measure)	1	2	3	4
How would you rate your ability to				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4
RATING SCALE: 1 = NOT AT ALL CONFIDENT 2 = LITTLE CONFIDENCE 3=SOMEWHAT CONFIDENT 4= VERY CONFIDENT				
How confident are you that you can				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4

What else can you tell us about your knowledge and ability or previous training related to the nighttime postural care intervention or sleep care positioning systems?

_____

_____

_____

Current care providing role **Number of years as care provider** _____

Please place an X in the box that best describes current primary position. Also record number of years as care provider.

- ☐ Assistive technology practitioner (ATP)
- ☐ Occupational therapist
- ☐ Physical therapist
- ☐ Nurse
- ☐ Non health professional (family member, friend, personal care assistant etc.)
- ☐ Other (please specify: _____

I have used a sleep care positioning system with my child or client □ Yes □ No

If yes, describe (e.g. for how long, what brand/s, etc.) _____

_____

Appendix B: Post-Training Questionnaire

Participant Code: _____Last 4 digits phone # _____

Today's Date: □□/□□/□□□□

Time it took you to complete the training program: □:□□(hours and minutes)
Please answer the following questions to help us determine the usefulness of the nighttime postural care intervention, sleep care positioning program
Circle the number best representing your knowledge, skills, & confidence of nighttime postural care.

RATING SCALE: 1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH

1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH				
How would you rate your knowledge of				
Nighttime postural care (NTPC) research	1	2	3	4
Health risks to check	1	2	3	4
Sleep systems available in the U. S.	1	2	3	4
How to position a person in a sleep system	1	2	3	4
Ways to know if NTPC is working (assessment, outcome measure)	1	2	3	4
1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH				
How would you rate your ability to				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4
1 = NOT AT ALL CONFIDENT 2 = LITTLE CONFIDENCE 3=SOMEWHAT CONFIDENT 4= VERY CONFIDENT				
How confident are you that you can				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4

2. Please rate the following statements about the nighttime postural care intervention using the following scale:

1 = Strongly Disagree 2 = Disagree 3 = Agree 4 = Strongly Agree

1	2	3	4	Because of the training I know more about the sleep care positioning
1	2	3	4	The training prepared me to use this intervention with my child or client
1	2	3	4	Because of the training I can readily use the intervention with my child or client

3. Describe any perceived barriers you see to using the intervention with your child or client:

4. What additional assistance, if any, might you need in order to feel competent to use this intervention with your child or client?

5. If you were given the task of revising, adjusting, or redesigning the sleep care positioning program, what would you change?

6. Other comments:

Please place an X in the box that best describes current primary position. Also record number of years as care provider

Current care providing role

- ☐ Assistive technology practitioner (ATP)
- ☐ Occupational therapist
- ☐ Physical therapist
- ☐ Nurse
- ☐ Non health professional (family member, friend, personal care assistant etc.)
- ☐ Other (please specify: _____

Number of years as care provider ___

Appendix C: Post-Simulation Questionnaire

Participant Code: _____Last 4 digits phone # _____

Today's Date: □□/□□/□□□□

Time it took you to complete the training program: □:□□ (hours and minutes)**Please answer the following questions to help us determine the usefulness of the nighttime postural care intervention, sleep care positioning program**

Circle the number best representing your knowledge, skills, & confidence of nighttime postural care.

RATING SCALE: 1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH

1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH				
How would you rate your knowledge of				
Nighttime postural care (NTPC) research	1	2	3	4
Health risks to check	1	2	3	4
Sleep systems available in the U. S.	1	2	3	4
How to position a person in a sleep system	1	2	3	4
Ways to know if NTPC is working (assessment, outcome measure)	1	2	3	4
1 = VERY LOW 2 = LOW 3= HIGH 4= VERY HIGH				
How would you rate your ability to				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4
1 = NOT AT ALL CONFIDENT 2 = LITTLE CONFIDENCE 3=SOMEWHAT CONFIDENT 4= VERY CONFIDENT				
How confident are you that you can				
Tell others about NTPC research	1	2	3	4
Make a plan to monitor health risks	1	2	3	4
Tell others about sleep systems available in the U. S.	1	2	3	4
Set up sleep system in the bed	1	2	3	4
Position a person in a sleep system	1	2	3	4
Choose tools to track changes (e.g. assessments, measures)	1	2	3	4
Tell others about assessments used to measure NTPC changes	1	2	3	4

2. Please rate the following statements about the nighttime postural care intervention using the following scale:

1 = Strongly Disagree 2 = Disagree 3 = Agree 4 = Strongly Agree

1	2	3	4	Because of the training I know more about the sleep care positioning
1	2	3	4	The training prepared me to use this intervention with my child or client
1	2	3	4	Because of the training I can readily use the intervention with my child or client

3. Describe any perceived barriers you see to using the intervention with your child or client:

4. What additional assistance, if any, might you need in order to feel competent to use this intervention with your child or client?

5. If you were given the task of revising, adjusting, or redesigning the sleep care positioning program, what would you change?

6. Other comments:

Please place an X in the box that best describes current primary position. Also record number of years as care provider

Current care providing role

- ☐ Assistive technology practitioner (ATP)
- ☐ Occupational therapist
- ☐ Physical therapist
- ☐ Nurse
- ☐ Non health professional (family member, friend, personal care assistant etc.)
- ☐ Other (please specify: _____

Number of years as care provider ___

Appendix D: Simulation Observation Instrument

Instructions for use of table: *Put an X in either the Y (yes) or N (no) column for all tasks indicating if task was completed. In the cue column use the codes for cuing to determine the appropriate letters to record for each task. Avoid cuing. If participant asks a question or requests help say "Just do the best you can and let me know when you are finished positioning the person in the sleep system". Record any detail of interest in the notes column (i.e. starts and stops, observable behaviors, timing considerations, contextual factors, actions/statements made by research observer, actions/statements made by participant, list of errors, etc.).*

Codes for Cueing: PP=Physical prompt, VC=Verbal cue, DB="do your best"

Instructions for field note sheet (page/s with divider line): *Record any other observations and impressions from the simulation.*

On left-hand side of paper, write down only what you **see** and **hear** from investigator, mock client / and participant. Note some of the following:

- Describe the set up and environment of the space
- What participants said and asked in response to the instructions (were there questions?)
- What participant and investigator(s) said and asked during simulation?
- What specific aspects of demonstration / simulation elicited questions?
- How time was used
- How questions were answered
- Number and time of breaks taken

On right-hand side of paper write down **impressions** and **questions** you have about what you are seeing and hearing.

Did the participant

- adequately perform the specified tasks?
- adequately communicate or interact with mock client?
- seem frustrated during any point of the simulation?
- clearly understand what they were to do during the session?
- respond readily / have difficulty responding to problems that arose?
- seem to improve or gain new learning in some way during simulation?

Did the mock client

- appear comfortable in the sleep system
- accidently cue the participant in any way
- act in a way to interfere with simulation process

TABLE ON FOLLOWING PAGE.

Simulation Start Time: □:□□ Simulation End Time: □:□□

Your (researcher) Name: _____Name of Mock Client: _____

Directions: ***Put X in either the Y or N column for every item in the table***

Codes for Cueing: PP=Physical prompt, VC=Verbal cue, DB="do your best"

The Participant Places or Positions	**Y**	**N**	**Cue**	**Notes**
Velcro receptor sheet snug to mattress				
Covers over lateral positioning brackets				
Lateral positioning brackets onto receptor sheet				
Air mantle over receptor sheet & under fitted sheet				
Coolover fitted sheet on top of air mantle				
Pillow under head				
Lateral positioning bracket snug at the trunk bilaterally				
Lateral positioning bracket snug at hip/thigh bilaterally				
Pillow under thighs to raise legs				
Pillow between thighs separates the knees				
Pillow under calves to raise heels				
Snugs up all parts once all in position				
Head/neck is neutral and not with excessive chin tuck or extension				
Chest symmetrical and level				
Pelvis symmetrical and level				
Legs slightly wider than hip width apart				

Use this box to describe or draw the order of tasks / steps as completed:
(use arrows as needed)

Data-based Observations	Interpretations/Questions/Comments