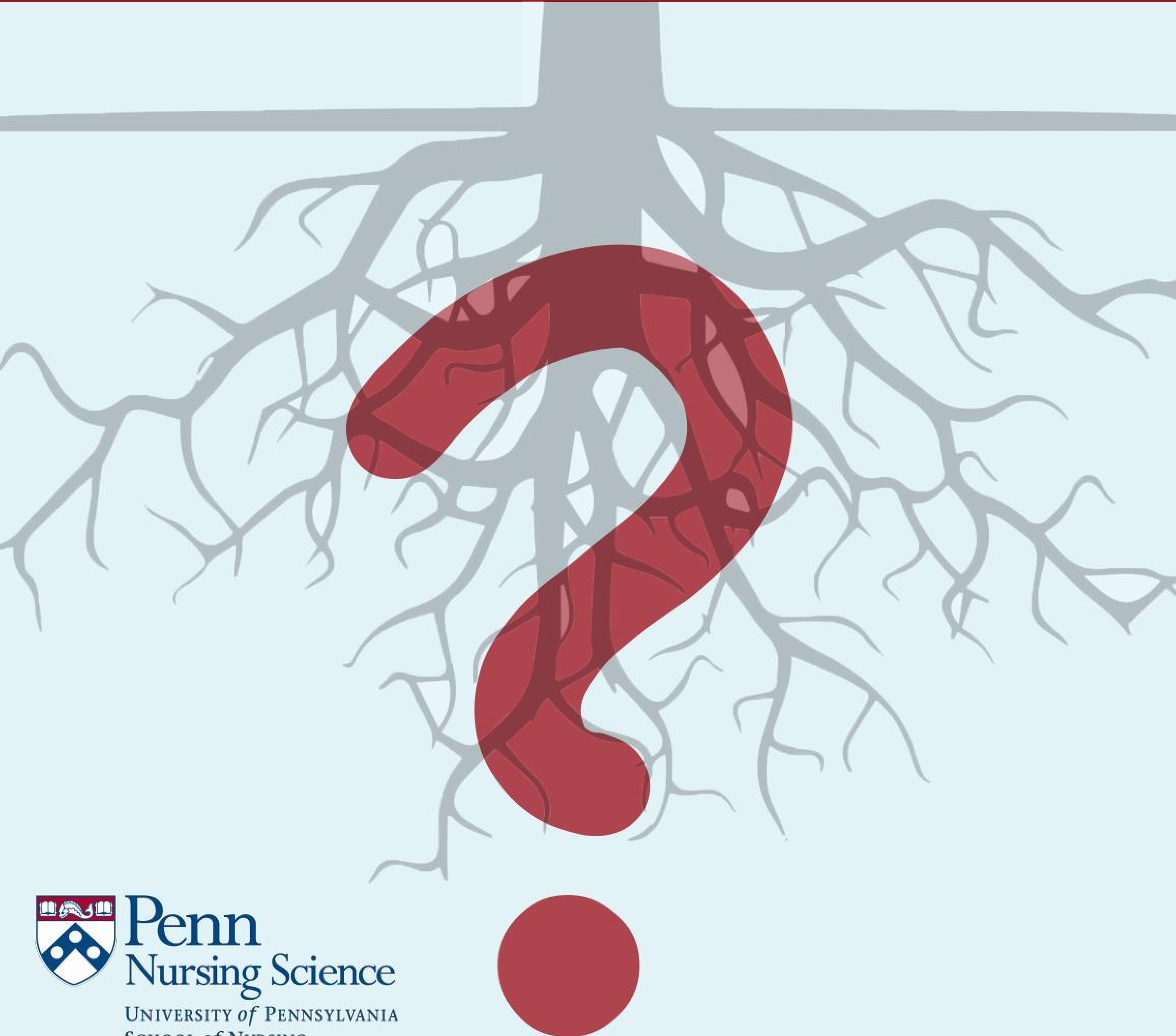
JNDSS

JOURNAL OF NURSING DOCTORAL STUDENTS SCHOLARSHIP

Volume 5 • 2017



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Mission

The Journal of Nursing Doctoral Students Scholarship is a scholarly publication dedicated to the development of doctoral student scholarship and the advancement of nursing science. This journal is peer reviewed by doctoral students, edited by doctoral students, and targeted towards health practitioners, educators, scientists, and students. This journal has both a professional and an educational mission. To serve the profession, each issue features articles that represent diverse ideas, spark intellectual curiosity, and challenge existing paradigms. Doctoral students will have an opportunity to explore and analyze issues and ideas that shape health care, the nursing profession, and research around the world. To fulfill its educational mission, doctoral students will be trained in the editorial and administrative tasks associated with the journal's publication and assisted in preparing original manuscripts for professional publication. This journal will be evidence of the scholarly development of nurse scientists.

Thank You

We extend our sincere thanks to the following individuals (faculty, post-docs, and doctoral students) for their time and effort invested into the current edition (listed in alphabetical order):
Rinad S. Beidas, PhD
Pamela Cacchione, PhD, CRNP, BC, FAAN
Darina Petrovsky, PhD, RN
Justine S. Sefcik, MS, RN
Timothy J. Sowicz, PhD, RN
Maxim Topaz, PhD, RN

We would like to thank the following doctoral student peer-reviewers for their rigorous reviews and thoughtful suggestions to the authors (listed in alphabetical order):
Iman Al Hashmi, University of California, Los Angeles
Katherine Bernier, University of Connecticut
Lisa Blair, The Ohio State University
Lila De Tantillo, University of Miami
Nicholas Giordano, University of Pennsylvania
Sarah Givens, Case Western Reserve University
Letitia Graves, University of Pittsburgh
Kayla Herbell, Case Western Reserve University

We would also like to thank Anne Pugh for the graphic design and production of the current edition, as well as Claudia Lewis, Syracuse University, for the cover illustration concept.

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Darina Petrovsky, PhD, RN first received her Bachelors of Musical Arts from the University of Michigan, and then pursued her Masters in Nursing (MN) from the Frances Payne Bolton School of Nursing (FPB) at Case Western Reserve University (CWRU). At graduation Darina was awarded the Dean's Legacy Award for her academic excellence, service to the larger community and the capacity for leadership and innovation in health care. Darina combined her passions for music and care for older adults to continue her doctoral studies at the University of Pennsylvania working with Pamela Cacchione, PhD, CRNP, BC, FAAN and Roy Hamilton, MD, MS, where she was the first nursing student to enroll and complete a Certificate for Social, Cognitive and Affective Neuroscience. In her dissertation, Darina explored the cognitive abilities associated with music in older adults with mild cognitive impairment (MCI). Darina is a member of the Gerontological Society of America (GSA); the American Academy of Neurology and Sigma Theta Tau International Society. She was a Ruth L. Kirschstein NRSA Pre-Doctoral Fellow (NIH/NIA; F31AG055148) and her past accomplishments include being selected as a 2014-2016 National Hartford Centers of Gerontological Nursing Excellence Patricia G. Archbold Scholar and 2014-2016 Jonas Nurse Leader Scholar.

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Editorial

The Evolution of Implementation Science

It has been widely cited (Balas & Boren, 2000) that it takes, on average, seventeen years to translate just fourteen percent of research into clinical practice. This delay in translation of evidence to practice is recognized by both researchers and clinicians as unacceptable and over the past decade, a new science has emerged aimed at narrowing this gap. Termed "implementation science (IS)," the main goal of this type of research, as related to the healthcare field, is to improve the quality and outcomes of health services. The National Cancer Institute (NCI) defines implementation research as "the use of strategies to adopt and integrate evidence-based health interventions, and change practice patterns within specific settings." In order for our readers to gain further insights into this important and evolving science, we interviewed Dr. Rinad Beidas, an Assistant Professor and Director of Implementation Research in the Center for Mental Health Policy and Services Research/ Department of Psychiatry in the School of Medicine at Penn.

How has implementation research evolved?

Researchers have long been interested in matters related to improving the quality of healthcare, but there is a growing need to understand the science of how evidence gets into the hands of those who deliver services. Positioned under the umbrella of health services research, early efforts in IS were aimed at studying implementation barriers and facilitators, with an emphasis on qualitative methods. The current iteration of IS research focuses on strategies to improve the uptake of evidence into practice utilizing comparative effectiveness and mixed methods approaches. Furthermore, testing of rigorous IS methodologies to improve generalizable knowledge, and inform evidence-based policy are included in the scope of IS.

Hoping to build a critical mass of high quality implementation research, the *Implementation Science* journal was launched in 2006, publishing papers describing barriers and facilitators to implementation, theory, methods, and testing of implementation strategies. The National Institutes of Health (NIH) also held its first IS conference in 2007 in order to disseminate information and many of its institutes now offer funding for IS research across all disciplines.

What is the difference between quality improvement (QI), QI research, from IS?

I am answering this question with the caveat that I am an IS researcher, and perhaps a QI expert would answer this question differently. A few years ago at a conference, Dr. David Chambers, the Deputy Director of NCI, presented a Venn diagram displaying these three areas under the health services research tent. Dovetailing from that view, my opinion is that QI examines a localized specific problem at a particular site, with the typical goal of improving patient outcomes. The goal is to change practice but not to generate generalizable knowledge, and less frequently focuses on the primary outcomes of provider behavior. QI research overlaps IS research in that there is a focus on methods to glean generalizable evidence to apply and scale to other settings; they are, however, rooted in different histories. QI research borrows from seminal work by Deming and colleagues (Deming & Edwards, 1982), or Six Sigma™ whereas, IS draws from Roger's diffusion of innovation (Rogers, 2010) and is more broadly interdisciplinary in nature, pulling from many types of methodologies and strategies, and often aimed at changing provider behaviors.

What are some of the IS strategies that have been successfully used in healthcare?

This is a difficult question to answer as the IS field is still in the phase of testing IS strategies and many examples of successful implementation work (so less about advancing the science per se) have sprung from natural experiments in which systems have made inroads in changing provider practice. A few disciplines have made the most progress in testing IS strategies namely the National Institute of Mental Health (NIMH), NCI, and more recently the National Heart, Lung, and Blood Institute which has established its own dissemination and implementation research section. Although the verdict is out on the most effective implementation strategies, there are a few promising programs. The Veterans Health Administration has successfully launched REP (replicating effective programs) in concert with facilitation from technical assistance, consultation and support (Kilbourne, Neumann, Pincus, Bauer, & Stall, 2007). Other trials mainly situated in agencies or schools, are testing a feasible, acceptable, and preliminarily effective IS strategy called LOCI which aims to change the implementation climate and leadership influence (Aarons, Ehrhart, Moullin, Torres, & Green, 2017). In collaboration with Penn's Center for Health Incentives & Behavioral Economics, we were just funded to launch an NIMH ALACRITY Center Grant (P50; Beidas, Mandell, Volpp, PIs) to leverage principles of behavioral economics to develop and test implementation strategies that incentivize both patients and providers coupled with participatory design to gain stakeholder involvement.

What are the challenges of utilizing an IS approach?

There are a number of challenges impacting the IS research movement: (1) there remains an imprecise language or terminologies in this field which affects generalizability; this has been documented in the literature (Graham, Tetroe, & Gagnon, 2009) (2) measurement has been an ongoing challenge--there is a relative paucity of validated IS tools which limits the types of journals that will publish IS work, and lessens the visibility of this work; also, it makes it difficult to complete meta-analyses. Russ Glasgow, the Society for Implementation Research Collaborative and others, are addressing this issue and even creating a repository for validated IS measures (3) currently, there are sixty-one IS models and frameworks which tend to include lists of variables rather that specifying the relationship between variables (Tabak, Khoong, Chambers, & Brownson, 2012). This limits causality—one way to "unpack" some of these causal mechanisms is to borrow from other theories, e.g., the Theory of Planned Behavior explains a substantial variation in behavior, so we may be able draw from this theory to explain provider behavior.

Can you speak to the balance between upholding fidelity of an intervention in controlled studies versus the need for adaptation to facilitate effective translation of knowledge to less controlled practice settings?

David Chambers has written a great deal about this with regard to his Dynamics Sustainability Framework (Chambers, Glasgow, & Stange, 2013). It is assumed that there is a voltage drop in the effectiveness and efficacy of interventions themselves when moved from tightly controlled settings into the practice community. Although a researcher does not want to see a "watered-down" version of a validated intervention used in the practice setting, a treatment, as originally developed and tested, may not be the right puzzle piece for every setting--there seems to be a dissolution of an essential effective ingredient upon translation. One solution to this dilemma might be to develop and test the intervention in the setting in which implementation is intended rather than in a more controlled lab setting or in large academic medical centers. One challenge with this approach, however, may be the difficulty in demonstrating a strong effect size as compared to a large efficacy trial. Those that believe in adaptation suggest that is it necessary, and the right "puzzle piece" can be derived from identified core ingredients of an intervention to fit the needs of a certain population/setting--however, most tested interventions do not separately identify the core ingredients. There are certainly sequelae to sacrificing fidelity since adaptation can either make outcomes better or worse, Shannon Wiltsey-Stirman at Stanford is currently creating a coding system demarcating changes made to certain mental health interventions and then testing outcomes accordingly (Stirman, Gutner, Langdon, & Graham, 2016).

In your opinion, what is necessary to move this type of research forward?

In order to address some of the aforementioned challenges, we need (1) more causal theories and frameworks, (2) more mechanisms for IS strategies, (3) better measurement, and (4) more comparative effectiveness studies testing various IS strategies. Within the field, there are areas that need more study including adaptation, sustainability, and a new area getting attention from NIH – de-implementation or divesting of old things not working well which may require very different strategies than those needed for implementation.

What advice do you have for burgeoning scientists for integrating IS into their work?

Firstly, develop an awareness of IS strategies, and design for implementation from the onset as you develop your studies so that your work will ultimately be translated successfully. Secondly, know the experts in this field and access resources that are available to you, e.g., out of Penn's Center for Mental Health Policy and Services Research there is a journal club, there is also a working group that meets quarterly, you can e-mail me (Rinad) to join the listserve at rbeidas@upenn.edu . Additionally, we offer a graduate course (HPR611 Implementation Science) in the spring term and the next Penn IS Institute will be held in June 2018. Thirdly, use your clinical intuition to ameliorate problems and find a place where you can leverage natural experiments so you do not have to be the one studying the effectiveness of the intervention AND the implementation; you might be interested in layering on an IS component to an existing intervention study. Lastly, never underestimate the importance of community partnerships to understand their context, and develop strong relationships before you start to change practices.

Concluding Thoughts

We thank Dr. Beidas for her generosity of time and expertise as she discussed this important field. There are opportunities for new researchers to partner with IS experts to strengthen study designs that will facilitate the translation of evidence to practice in a more expeditious fashion. Sue had the opportunity to attend the IS Institute in 2017, and Guy completed the IS HPR course and we highly recommend the same for any Penn doctoral students. For those of you outside of Penn, please seek out other continuing education experiences that are becoming more proliferative as this science continues to advance! Good Luck!

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Acknowledgements

We would like to again thank Dr. Rinad Beidas for taking the time to thoughtfully discuss the evolution of implementation research with us, hence furthering our understanding of this important and emerging science.

Gender Differences in Health-Related Quality of Life in Cystic Fibrosis: A Concept Analysis

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Abstract

Aim. To conceptually analyze gender differences in health-related quality of life (HRQoL) in the context of people with cystic fibrosis (CF).

Background. Life expectancy has recently doubled for people who have CF placing importance on improving HRQoL. Even though studies indicate that women have an overall poorer HRQoL than men, the areas in which the differences occur vary. A concept analysis is needed to better define gender differences in HRQoL in order to inform interventions that will bridge the gap in HRQoL between men and women diagnosed with CF.

Design. Rodger's evolutionary method of concept analysis was used to analyze the data.

Data sources. CINAHL and PubMed databases were searched for publications between the years 2000-2016. Search terms included HRQoL and CF.

Review methods. A total of 248 articles were identified. Of those, 231 were screened for the measurement of HRQoL and the examination of gender-related differences. Thirteen articles were included in the review based on inclusion criteria.

Results. Essential attributes of gender differences in HRQoL included physical functioning, body image, social functioning, health perceptions, respiratory symptoms, treatment burden, and emotional functioning. Antecedents for the differences were age at diagnosis, specific gene mutation, and variability in the presentation of symptoms. The consequence of the gender differences was survival variability.

Conclusions. Consistently using the definitions that emerged from this concept analysis will help the scientific community to effectively dialogue on how to best serve this population.

Keywords: concept analysis, nursing, Rodgers evolutionary method, health-related quality of life, CF, cystic fibrosis, gender differences

Cystic fibrosis (CF) is a chronic, genetically transmitted disease that affects approximately 80,000 people worldwide (Arrington-Sanders et al., 2006; Cohen-Cymberknoh, Shoseyov & Kerem, 2011). The disease results from an abnormality in the CF transmembrane conductance regulator gene that produces abnormal chloride transport across cell membranes (Schindler, Michel, & Wilson, 2015). This abnormal transport generates thickened secretions that interfere with mucus clearance in the respiratory, gastrointestinal, and reproductive tracts that require extensive treatment regimens, including chest physiotherapy and digestive enzymes multiple times per day (Schindler et al., 2015). CF interferes with physical functioning, the amount of treatment burden, social development, and clinical health (e.g., lung function) (Arrington-Sanders et al., 2006; Uchmanowicz, Jankowska-Polańska, Rosińczuk, & Wleklik, 2015). With recent advances in CF treatment, the life expectancy of the CF population has doubled over the past two decades with great variability in survival (Abbott et al, 2009; Korzeniewska et al., 2009). Thus, it is important to focus on improving the health-related quality of life (HRQoL) of this population. In the context of people with CF, HRQoL encompasses the physical, social, psychological, and functional aspects of daily living and how CF impacts each one (Havermans, Colpaert, Vanharen, & Dupont, 2009). HRQoL has been well studied in people diagnosed with CF. Evidence suggests that there is a large difference between the HRQoL of men versus women (Arrington-Sanders et al., 2006). A clear definition and better understanding of the gender differences could inform more effective therapeutic interventions for this population (Uchmanoqicz et al., 2015). The purpose of this concept analysis is to better define HRQoL in terms of gender differences and identify such similarities in order to come up with a consistent definition to be used in discussions related to practice, policy, and research. This concept analysis is presented through the background of gender differences in HRQoL literature, data sources included in the concept analysis, and results of the analysis. From the rigorous process of concept analysis, a better definition of the gender differences in HRQoL in CF emerges.

Background

In the literature, HRQoL varies between men and women with CF (Arrington-Sanders et al., 2006, Berge, Patterson, Goetz, & Milla, 2007; Abbott, Morton, Hurley, & Conway, 2015). Women are found to have a poorer HRQoL than men (Arrington-Sanders et al., 2006). Women are also prone to more frequent pulmonary exacerbations, infections, and shorter life expectancies (Arrington-Sanders et al., 2006). Furthermore, HRQoL declines as age increases, which amplifies the importance of studying HRQoL in order to develop optimal clinical practice guidelines (Arrington-Sanders et al., 2006; Uchmanowicz et al., 2015). The difference in HRQoL between men and women becomes notable during adolescence. Subsequently, as age increases, gender-specific interventions are needed to address the specific developmental concerns of each gender. The importance of HRQoL was noted by the CF Foundation in their recommendation to incorporate quality of life as a measure of outcomes for people with CF (Arrington-Sanders et al., 2006).

Currently, there is no published concept analysis on HRQoL specific to CF, indicating a need for such analysis. Additionally, the areas in which the gender differences occur in those with CF vary. In a cross-sectional study of 98 participants by Arrington-Sanders and colleagues (2006), women reported having a poorer quality of life than men in mental health, overall health, and health perceptions; however, Uchmanowicz and colleagues (2015) reported that women have a poorer quality of life when compared to men in physical and social functioning, emotional and future concerns, body image, and career concerns. Conversely, the same women reported a higher HRQoL in the area of interpersonal relationships. These studies provide evidence that HRQoL needs to be better defined in terms of gender differences.

Concept Analysis Method

Rodgers' evolutionary method is the most suitable method of concept analysis for HRQoL for several reasons. First, HRQoL is a multi-dimensional concept that factors in the physical symptoms of CF as well as the emotional and psychological aspects of the disease that are known to vary from person to person (Uchmanowicz et al., 2015). Rodgers' evolutionary method has the capability to address dynamic concepts such as HRQoL, that vary depending on contextual factors, making this method applicable to HRQoL (McEwen & Wills, 2014). Second, the evolutionary method views concepts as constantly evolving and requiring continuous effort to further define and depict a clearer conceptual meaning over time (McEwen & Wills, 2014). The concept of HRQoL has been well studied across the CF literature; however, with the recent increase in life-expectancy and advances in available treatments, this concept is constantly changing and being redefined (Korzeniewska et al., 2009). Third, Rodgers' evolutionary method adjusts for the various factors that are interwoven to make up HRQoL, paired with the variability from person to person, by allowing the steps of the analysis to occur concurrently (McEwen & Wills, 2014). In addition, the inductive component of Rodgers' evolutionary method will allow evidence of HRQoL specific to gender differences to be gathered and analyzed inductively to discern a clearer definition of the concept.
The steps encompassed in Rodgers' evolutionary method are: 1) identify the concept and associated terms; 2) select an appropriate setting or sample for data collection; 3) collect data to identify the attributes of the concept as well as the contextual basis of the concept; 4) analyze the data regarding the characteristics of the concept; 5) identify an exemplar of the concept; and 6) identify hypotheses and implications for further development (McEwen & Wills, 2014). Steps one and two have already been described in the introduction and background sections. Step three is covered in the data sources section; steps four and five are covered in the results section. The final step is covered in the discussion section.

Data Sources

In June of 2016, a literature search was conducted in CINAHL and PubMed databases using the term "health-related quality of life in CF" that yielded 248 results. The search was then narrowed to those that were written in English and with access to full-text. There were then 231 total articles screened for: 1) the measurement of HRQoL, and 2) the mention of gender differences. After screening the abstracts, articles were excluded if they did not include both measurement and examination of gender. Once an advanced search was conducted within CINAHL to remove the duplicates that were also in PubMed, six articles remained, and one was selected. The remaining PubMed search resulted in 12 articles being selected for a total of 13 articles (see Figure 1 and Table 1).

Once the chosen articles were read, one additional resource was selected from the reference page of the article by Arrington-Sanders et al. (2006) to explore the evolution of HRQoL specific to gender differences over time. In order for the literature review to be as rigorous as possible, literature published in the fields of nursing, adult medicine, pediatrics, behavioral science, psychology, genetics, and respiratory therapy was included because each of these disciplines plays a role in HRQoL management. Also, so that the findings could be as generalizable as possible, studies from various geographical locations including the United

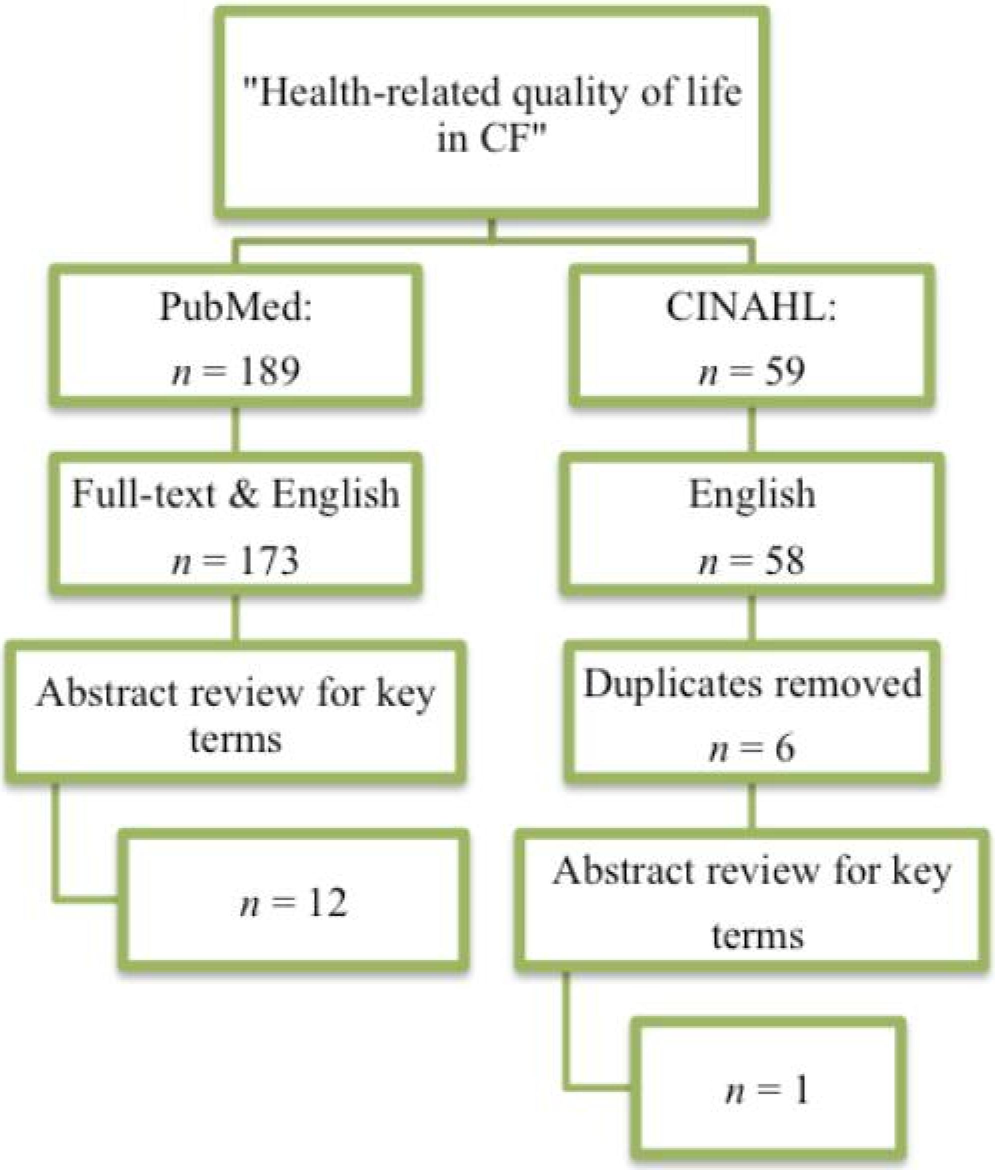

Figure 1. Detailed search process within the PubMed and CINAHL databases.

States, Germany, India, and Spain were incorporated. Literature published between the years of 2000 and 2016 was included to gather a broader understanding of how gender differences in HRQoL in CF have evolved over time and what attributes remained unchanged.

Results

Characteristics of the Concept

The characteristics of the concept will be discussed in terms of antecedents, surrogate terms, attributes, and consequences. Tofthagen & Fagerstrom (2010) define these terms as follows: 1) Antecedents are phenomena that precede and predict or influence the concept; 2) Surrogate terms are words that have the same meaning and are used interchangeably in the literature; 3) Attributes are the concept of interest's defining characteristics; 4) Consequences are things resulting from the concept.

Antecedents

Age at diagnosis, specific gene mutation, and variability in the presentation of CF symptoms are all antecedents that vary from person to person at diagnosis and influence the future HRQoL of the individual (Berge et al., 2007). Age at diagnosis can contribute to whether a person with CF has a negative or positive HRQoL (Cohen-Cymberknoh et al., 2011). Early diagnosis and intervention are essential to treat and slow the progression of lung disease. Children diagnosed in infancy have been shown to have better pulmonary function and nutritional status throughout childhood than those diagnosed later in life (Cohen-Cymberknoh et al., 2011). Earlier diagnosis via newborn screening positively impacts lung

Table 1. **Summary of Articles Reviewed for Gender Differences in HRQoL (2003-2016)**

Study	Participants	Design	Gender Findings
1. Abbott et al. (2015) Longitudinal Impact of Demographic and Clinical Variables on Health-Related Quality of Life in CF	234 CF patients recruited from a large adult CF center in the United Kingdon, ages 14-48	Longitudinal observational study	Model coefficient for body image was 0.58 ($p < 0.001$) showing women had a better body image.
2. Arrington-Sanders et al. (2006) Gender Differences in Health-Related Quality of Life in Adolescents with CF	98 CF patients recruited from two medical centers in two cities from 1997-2001	Cross-sectional study	• Compared to men, women experienced poorer HRQoL in global health, physical functioning, mental health, and general health perceptions ($p < 0.05$). • The domains of global health, mental health, and general health perception showed statistically significant gender differences in multivariate models with an effect size that is moderately clinically significant (0.5-0.8).
3. Berge et al. (2007) Gender Differences in Young Adults with CF During the Transition to Adulthood: A Qualitative Investigation	11 women and 6 men with CF attending a specific CF center in Minnesota, ages of 17-21	This exploratory qualitative study used grounded hermeneutic analysis.	• Three main themes emerged: 1) treatment regimen/compliance, 2) concerns about other health related problems, and 3) personal outlook of CF. • Treatment regimen/compliance- Women needed someone to hold them accountable for their treatment regimen, and felt different from their peers, while men were more independent and felt accepted by peers. • Health-related problems- Women reported more depression and both genders were concerned about diabetes. • Outlook- Women need support to deal with CF while men were optimistic and saw CF as part of their identity.
4. Borawska-Kowalczyk & Sands (2015) Determinants of Health-Related Quality of Life in Polish Patients with CF-Adolescents' and Patents' Perspectives	70 patients treated at the CF center in Institute of Mother and Child in Warsaw, Poland with confirmed diagnosis of CF, ages 6-18 years old	Cross-sectional study	For the domain CFQ-R domain physical functioning, men reported significantly better HRQoL than women ($p < 0.05$).
5. Dill et al. (2013) Longitudinal Trends in Health-Related Quality of Life in Adults with CF	333 adults with CF 18 years or older, receiving care at 1 of 10 centers	Prospective longitudinal panel study	Women experienced significantly poorer physical functioning ($p < 0.001$), less vitality ($p < 0.05$), worse respiratory symptoms, and better body image.
6. Forte et al. (2015) Relationship Between Clinical Variables and Health-Related Quality of Life in Young Adult Subjects with CF	51 participants were 16 and older with confirmed CF diagnosis	Cross-sectional study	Male gender was positively associated with the body image domain.
7. Gee et al. (2003) Quality of Life in CF: The Impact of Gender, General Health Perceptions, and Disease Severity	223 adolescents and adults who have CF	Cross-sectional study	• Men had a higher HRQoL in the area of body image. • Women reported a poorer HRQoL in all other domains.
8. Groeneveld et al. (2012) Health-related Quality of Life of Spanish Children with CF	28 children with CF ages 6-17 who had been treated within two CF centers	Cross-sectional study	Women reported worse HRQoL in areas of social functioning, treatment burden, and respiratory symptoms when compared to men.
9. Habib et al. (2015) A Systematic Review of Factors Associated with Health-Related Quality of Life in Adolescents and Adults with CF	23 articles including adolescents and adults >14 years who have CF	Systematic review	• Women consistently report poorer physical functioning. • Women score higher in the area of body image.
10.Jamison et al. (2014) Children's Experiences of CF: A Systematic Review of Qualitative Studies	43 articles including 729 people who have CF ages 4-21 years	Systematic review	Women who have CF tend to report more emotional symptoms and are hospitalized more frequently than men when controlling for disease severity.

Table 1. ***Summary of Articles Reviewed for Gender Differences in HRQoL (2003-2016)*** *Continued*

Study	Participants	Design	Gender Findings
11. Kir et al. (2015) Health Related Quality of Life in Indian Children with CF	45 children and 14 adolescents ages 6 years and older diagnosed with CF, and could read and write Hindi	Cross-sectional study	• Did not find any difference in self-reported HRQoL in any of the included age groups. • Those infected with pseudomonas reported poorer HRQoL in the respiratory domain (67.2) compared to those who did not have pseudomonas (76.9).
12. Schmidt et al. (2009) Health-Related Quality of Life in Children with CF: Validation of the German CFQ-R	136 children ages 6-13 years with confirmed CF diagnosis	Cross-sectional study	Women reported a significantly poorer emotional state, treatment burden, and digestive symptoms on the CFQ-R.
13. Uchmanowicz et al. (2015) Health-Related Quality of Life and Patients Suffering from CF	30 people hospitalized in two CF institutions between February and April of 2012, between the ages of 16 and 42	Cross-sectional study	• In all subscales of the CFQoL other than interpersonal relationships, women reported their quality of life as poorer than men. • Women scored highest in interpersonal relationships while men scored highest on physical functioning.

Abbreviations: CF = Cystic-Fibrosis, CFQoL = CF quality of life questionnaire, CFQ-R = CF questionnaire revised, HRQoL = health-related quality of life

function and nutritional status, improving survival and positively impacting HRQoL (Cohen-Cymberknoh et al., 2011). Additionally, lung function is usually normal in infants diagnosed by newborn screening, compared with those diagnosed even a short time later at the age of three months who show signs of pulmonary inflammation and structural lung damage, thereby negatively impacting HRQoL (Cohen-Cymberknoh et al., 2011).

Specific gene mutations can impact disease severity and influence HRQoL. A study by McKone, Goss, and Aitken (2006) found that people with CF who have two copies of the F508del mutation have a more severe clinical presentation than those who have one copy of the F508del mutation or those who lack the F508del allele. Therefore, having the F508del mutation is associated with a poorer quality of life. In terms of variability of CF symptoms, the more body systems that are affected in a person with CF, the poorer the HRQoL. For example, some people can present with only respiratory symptoms while others present with only gastrointestinal issues. Those who present with more than one affected system tend to have a poorer quality of life (Berge et al., 2007).

Surrogate terms

In relation to people who have CF, HRQoL incorporates the physical and psychosocial aspects of the disease and has been explored as a predictor of survival (Abbott et al., 2009; Dill, Dawson, Sellers, Robinson, & Sawicki, 2013). An associated term for HRQoL is quality of life, and these terms are used interchangeably in the literature (Uchmanowitz et al., 2015). Also, gender and sex are surrogate terms when defining the differences in HRQoL of boys and girls (Groeneveld et al., 2012).

Attributes

The most common attributes of HRQoL include physical functioning, social functioning, chest or respiratory symptoms, emotional functioning, body image, treatment burden, and health perceptions (see Table 2) (Abbott et al., 2009; Berge et al., 2007; Dill et al., 2013; Kir et al., 2015; Schidmt, Wenninger, Niemann, Wahn, & Staab, 2009; Tluczek et al., 2013; Uchmanowicz et al., 2015).

In further evaluating the findings involving these attributes, women with CF consistently self-report having a poorer quality of life in the areas of physical symptoms and emotional functioning, and men self-report having a poorer HRQoL in the area of body image (Berge et al., 2007; Dill et al., 2013; Groeneveld et al., 2012; Schmidt et al., 2009). Interestingly, despite the inclusion of geographically diverse populations, the gender differences in the domains of HRQoL remained similar across studies involving the CF populations of India, Spain, Germany, and the United States (Dill et al., 2013; Groeneveld et al., 2012, Kir et al., 2015 Schmidt et al., 2009).

The most common instrument used to evaluate HRQoL in the literature is the CF Questionnaire Revised (CFQ-R). It has been validated across different languages and cultures because it includes a separate version for each developmental stage (Abbott et al., 2009; Dill et al., 2013; Groeneveld et al., 2012; Kir et al., 2015; Royce & Carl, 2011; Schmidt et al., 2009; Tluczek et al., 2013). Another common HRQoL questionnaire specific to the population is the CF Quality of Life Questionnaire (CFQoL), which has also been validated in several studies (Abbott et al., 2009; Gee et al., 2003; Uchmanowicz et al., 2015). The attributes that both instruments have in common for HRQoL are physical functioning, body image, social functioning, health perceptions, respiratory symptoms, treatment burden and emotional functioning (see Table 2 for definitions). The surrogate terms used between the two instruments that portray and assess the same aspects of CF are respiratory symptoms vs. chest symptoms, treatment burden vs. treatment issues, and emotional functioning vs. emotional responses (Abbott et al., 2009; Dill et al., 2013).

Table 2. **Attributes of health-related quality of life in CF**

Attribute	Participants	Design
Physical Functioning	Limitations in physical activity related to CF (Arrington-Sanders et al., 2006)	Women consistently report poorer HRQoL than men (e.g., more disruption in exercise, climbing stairs etc.)
Body Image	How people who have CF feel that the disease has made them look and feel different from peers (Quittner et al., 2012)	Men consistently report poorer HRQoL than women (e.g., less muscular and skinnier than they would like).
Social Functioning	How CF and associated treatments have affected socialization (Quittner et al., 2012)	Women consistently report poorer HRQoL than men (e.g., less comfortable in social situations).
Health Perceptions	How people with CF feel about health status in terms of whether they feel healthy (Quittner et al., 2012)	Women consistently report poorer HRQoL than men (e.g., feel less healthy).
Respiratory Symptoms	How often respiratory symptoms such as coughing are present (Quittner et al., 2012)	Women consistently report poorer HRQoL than men (e.g., more frequent coughing or wheezing).
Treatment Burden	To what extent the prescribed treatment regimen makes life more difficult (Quittner et al., 2012)	Women consistently report poorer HRQoL than men (e.g., feel that treatments make life more difficult).
Emotional Functioning	To what extent the participant felt worried or upset about CF (Quittner et al., 2012)	Women consistently report poorer HRQoL than men (e.g., feel more sad, worried, or useless).

Abbreviations: CF = Cystic-Fibrosis, HRQoL = health-related quality of life

Consequences

A consequence of HRQoL is survival. In terms of gender, women with CF have a poorer HRQoL than men and consequently a poorer prognosis (Arrington-Sanders et al., 2006). Furthermore, evidence supports that patients' self-reported quality of life can be used as a prognostic indicator of survival (Abbott et al., 2009). Specifically, the respiratory symptoms and emotional functioning areas of the HRQoL questionnaires have been declared as the most important areas to predict survival in CF patients (Abbott et al., 2009). A study by Gee, Abbott, Conway, Etherington, & Webb (2003) also states that women tend to have more serious respiratory symptoms and a lower survival rate than men. Furthermore, women have more pulmonary exacerbations and less lung function than men. This results in a poorer HRQoL in the area of physical functioning, which indicates more long-term health, as well as in respiratory symptoms which is more indicative of current health status (Dill et al., 2013). These two areas combined are predictive of survival (Dill et al., 2013).

Exemplar of the Concept

The exemplars of HRQoL were based upon a systematic review of 43 qualitative studies that included over 700 people with CF from ages 4 to 21 years of age from various countries, making these exemplars as generalizable as possible to the CF population (Jamieson et al., 2014).

Exemplar of good health-related quality of life

An adolescent included in the study by Jamieson et al. (2014) stated that having CF pushed him into adulthood earlier than peers without CF in a positive way. This maturity allowed the adolescent to become more resilient and worry less about trivial matters (Jamieson et al., 2014). Multiple participants felt that a positive attitude was essential to completing the cumbersome daily treatment regimen associated with CF. One participant stated that signs and symptoms indicating a worsened health status could be used as motivation to pay closer attention to personal health (Jamieson et al., 2014). Feeling that they had control over their own health was associated with a positive HRQoL. The ability to take control of their own health and being more independent along with participating in group physical activities provides a sense of empowerment and feeling that CF has not defined or conquered them (Jamieson et al., 2014). In terms of support, many of the participants felt that it was important to be in contact with others who have CF because they are facing the same day-to-day struggles. Hope for a cure and for a lung transplant made one woman feel that she could be normal and like everyone else.

Exemplar of poor health-related quality of life

In a meta-synthesis of 43 studies, women who had CF associated moving out of their family home and losing the constant support of their parents with the onset of depression (Jamieson et al., 2014). In addition, within the same study, both men and women expressed feeling "out of the loop" and socially isolated because of frequent school absences associated with CF. One women reported that it is hard to keep up with what is happening in school and what her peers are doing when she misses up to three weeks of school at a time. Jamieson and colleagues also reported that children expressed being bullied or isolated due to peers feeling that their disease was contagious. Viewing parental protectiveness and oversight as interference and dominance led to feelings of defiance and an increased rate of risk-behaviors such as drinking alcohol or smoking. Adolescents shared that they chose not to comply with prescribed treatments just to spite their parents' orders.

For personal relationships, one woman stated that she had to be very cautious when telling boyfriends about her disease, because in the past they had all broken up with her when they found out. Reasons given for this social isolation includes others thinking CF is contagious, and the noticeability of coughing and differences in physical appearance due to CF. One woman stated that as the severity of CF increased, it became much harder to participate in sports because she easily became tired, short of breath, and began coughing. Another woman expressed that she loved to run but no longer could because it made her feel as if she could not breathe. For loss of control in health management, one participant stated that health care providers always talk in medical terms which was frustrating because he was concerned with his appearance and they were not addressing the issue in a manner in which he could understand (Jamieson et al., 2014).

Discussion

In terms of the theoretical implications of HRQoL, a quality of life theory developed from Abraham Maslow's Hierarchy of needs, proposed by Sirgy (1986), is a descriptive theory that describes the self-reported gender differences in HRQoL. The perspective of this quality of life theory is that a certain population's needs must be assessed and concrete conclusions must be reached in order for the needs to be met (Sirgy, 1986). By better defining the gender differences, health care interventions can be developed to address gender-specific needs. Maslow held the perspective that health and functionality are best achieved when personal responsibility is taken of ones' own needs (Ventegodt, Merrick, & Andersen, 2003). There are three tiers of needs: physiological, social and environmental, and transcendence. Physiological needs, such as sleep, food, and water, must be met first. Second, we need to understand the world around us that incorporates social and environmental factors, and third, transcendence, defined as becoming an integrated and valuable part of the world, must be actualized (Ventegodt et al., 2003). This theoretical consideration would help better influence the order in which interventions need to be prioritized to achieve optimal health. For example, optimizing lung function would take precedence over social concerns.

The literature suggests women consistently self-report having an overall poorer HRQoL than men even with equal disease severity. Furthermore, women have more emotional symptoms, are hospitalized more frequently, and bear a poorer prognosis than men (Jamieson et al., 2014). The only area of HRQoL in which men tend to report a poorer HRQoL is in the area of body image; in other words, compared to women, men tend to devalue their appearance, especially as it pertains to the concept of strength and masculinity (Habib et al., 2015). Yet, women consistently report a poorer HRQoL in the areas of emotional functioning, physical functioning, respiratory symptoms, and social functioning across studies (Habib et al., 2015).

Gaps in the literature include very few publications specific to the gender differences in HRQoL within the CF population. Additionally, there is a gap in survival between men and women which has been reported internationally indicating a lower survival rate in women. For women, there is an average decrease in life expectancy of approximately four years until 20 years of age when compared to men (Arrington-Sanders et al., 2006). Yet, there is currently no confirmed explanation for the poorer outcomes in women (Habib et al., 2015). A suggested explanation is hormonal differences associated with puberty in women. Estrogen amplifies inflammation of lung tissue (Sweezey & Ratjen, 2014). Higher levels of estrogen seem to correlate with lung infections in women who have CF (Sweezey & Ratjen, 2014).

In order to address gaps in the literature, correlation between physical functioning and survival must be explored. Physical functioning could offer a cause for the worsened outcomes in women. Interventions could be developed to encourage physical activity in women with CF to test its effect on physical functioning (Habib et al., 2015). Studies indicate that additional mental health interventions are needed in order to help address the gender gap in HRQoL regarding emotional aspects of the illness (Berge et al., 2007; Dill et al., 2013). Also, individualized treatment plans for men and women may be needed to address the gender-specific needs (Berge et al., 2007). For example, for women, more exercise and mental health services could be recommended to address the poorer HRQoL in physical functioning (e.g., participate in exercise or sports) and emotional functioning (e.g., social isolation, loneliness, stigma). For men, poorer HRQoL in the area of body image is thought to be related to the masculine build and wish to be heavier, while women prefer to be thin due to cultural norms. Nutritional interventions for men could be offered to optimize weight and nutrition as much as possible to help address the gap in body image (Habib et al., 2015). According to the quality of life theory discussed above, these biological/physiological needs must be met first before social isolation can be addressed.

In order to help address the social isolation due to physical appearance differences, people with CF need proper education on the impact of the illness on sexual and reproductive health before puberty occurs due to the common two-year delay that occurs in people with CF (Fraymen & Sawyer, 2015). Evidence shows that despite this delay, people with CF engage in risky sexual activities just as frequently and at the same age as their peers (Fraymen & Sawyer, 2015). Education is paramount due to the implication that sexually transmitted infections, such as Hepatitis B and C as well as HIV, can pose as a contraindication for lung transplantation (Fraymen & Sawyer, 2015), and in many cases contraception methods must be individualized due to possible drug malabsorption, pulmonary hypertension, and risk for venous thromboembolism. Also, an unplanned pregnancy can jeopardize the health of a woman with CF (Fraymen & Sawyer 2015).

The challenge for the future is to develop HRQoL measurements to be used to develop interventions that improve the well-being of the population in multiple domains (e.g., physical functioning, emotional functioning, etc.) and minimize adverse effects of current treatments (Abbott et al., 2015). Lung function, BMI, gender, and pulmonary status are known to contribute to how HRQoL is self-reported in people with CF (Abbott, Hart, Morton, Gee, & Conway, 2008). Because HRQoL incorporates the psychosocial aspects of the disease, emerging research focuses on using coping to explain HRQoL domains. An afflicted person's perception of her disease state is influenced her coping skills (Abbott et al., 2008). Coping factors are not captured in the HRQoL instruments currently being used, yet coping could be related to variations in HRQoL over time. For example, optimism is associated with positive coping strategies and greater treatment compliance (Abbott et al., 2008). Coping strategies, spiritual transcendence, encouraging resilience, and hardiness counseling and training may have a positive impact in improving HRQoL in those aging with CF as observed in other chronically ill populations (Vance, Burrage, Couch, & Raper, 2008). Unfortunately, this area is understudied as it relates to HRQoL in the CF population.

Conclusion

The etiology of the gender differences in HRQoL is still not clearly defined; however, this concept analysis describes the areas in which HRQoL is consistently different between men and women with CF in geographically diverse populations in order to inform interventions to address the gap in health status. Also, by uniting the concept of HRQoL in geographically diverse studies as well as combining the findings regarding HRQoL from two different measurement tools, a better definition is given to the aspects of gender differences to offer evidence to influence survival outcomes in this population. A conceptual framework that could be used to guide future research is Wilson and Cleary's quality of life model. This model emphasizes the importance of linking the clinical assessment with quality of life measurement (Wilson & Cleary 1995). As such, the main concepts within the conceptual model strongly resemble the domains of HRQoL instruments. The foundational components of HRQoL are incorporated into the model including biological and physiological variables, symptom status, functional status, general health perceptions, and overall quality of life along with how individual characteristics and the environment impact each. With the guidance of the model, HRQoL can influence and guide clinical care and research to be more individualized to each person with CF.

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Survival Rates in Veteran and Civilian Lung Cancer Populations: A Comparative Analysis

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Abstract

Nurse scientists are vital to the field of health services research and as such it is imperative to recognize the intrinsic strengths and shortcomings of commonly used outcome measures, specifically survival rates. This comparative analysis provides a brief overview of survival rates used in the context of two articles, each measuring cancer care quality improvement measures in the Department of Veterans Affairs (VA) compared to civilian health systems. These articles are used to illustrate how one outcome measure used in quality of healthcare evaluation can lead to two opposing conclusions. Collectively, the included studies examine clinical quality improvement efforts made in the VA's cancer treatment efforts from 1995 – 2004 by assessing survival rates in care seeking veterans with lung cancer compared to their civilian peers. This side-by-side comparison is a unique opportunity to examine parallel health services research, across similar populations using the same outcome of interest, and the opposing conclusions reached in this line of work. This comparative analysis is a learning tool for future nurse scientists and an exercise aimed to assist students in understanding the valuable methodological tools available to them in conducting their own line of inquiry in health policy evaluation research with observational data.

Keywords: Health services research; cancer care; veteran health; survival rate

Background

In the modern American healthcare system, patients and their caregivers depend on access to clinicians practicing in health systems with demonstrated commitments to providing high quality healthcare. However, what has remained elusive in the healthcare market is a demonstrable and proven means by which consumers can evaluate provider performance at a health system level. One metric often employed by health service researchers to conduct side-by-side analyses of hospitals and health systems includes survival rates. Survival rates as defined by National Cancer Institute (NCI) refers to, "The percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease" (NCI, 2017). While survival rates can be used to examine survival in a number of diseases, including HIV and myocardial infarction, in the context of this article, survival rates refer to the proportion of individuals surviving after cancer diagnosis based on the health system they seek care or payer of their cancer treatment (e.g. Department of Veterans Affairs and Medicare). In health services research, survival rates are system-level aggregated quality measures used to compare clinical care across healthcare systems. For example, cancer survival rates may be a metric of how well providers and health systems implement recommended screening guidelines, how effective and accurate cancer screenings are in at-risk populations, and the extent to which patients receive recommended evidence-based care after diagnosis. One concern that may arise when comparing healthcare systems' survival rates, is the need to account for the characteristics of the patients a provider or system may serve based on the comorbidities and intrinsic risk factors that may increase the likelihood of death, despite all quality efforts implemented.

The Department of Veterans Affairs (VA) cares for nearly 8 million veterans annually with a healthcare network of 144 hospitals (NCVAS, 2015). Quality improvement has been a VA priority since the 1990's, with the initiation of organizational policies to improve clinical performance (Trivedi et al., 2011). The success of these reforms has been mixed, particularly in cancer clinical research (Kizer & Dudley, 2009). In this paper, two peer reviewed articles examining cancer survival rates between patients receiving care at the VA and those receiving cancer treatment outside of the VA are evaluated to demonstrate the use of survival rates in health services research. Campling et al. (2005) conclude that overall survival rates of VA lung cancer patients are inferior to that of the civilian population, whereas Landrum et al. (2012) determined that the survival rates of VA lung cancer patients were equivalent to, if not better than civilians, providing an opportunity to analyze opposing results on the same outcome. This comparative analysis (Appendix 1) provides a brief overview, both the benefits as well as the shortcomings, of using survival rate as an outcome of interest in health services research. The two studies used for this analysis examine lung cancer survival rates in veteran populations to that of the general public and come to opposing conclusions, despite using the same quality measure. Uniquely these two studies span concurrent time periods, employ similar methodologies, study comparable populations across studies with lung cancer diagnoses, and thereby allows student researchers to appreciate approaches used in calculating survival rate as a quality measure in VA cancer treatment over time.

Measuring Survival Rate

Both Campling et al. (2005) as well as Landrum et al. (2012) compare survival rates of patients with cancer in the VA hospital system with survival rates of patients seen outside the VA system. Campling et al. (2005) solely evaluated outcomes of patients diagnosed with lung carcinoma in Pennsylvania (PA) whereas Landrum et al. (2012) studied nationwide survival rates of older veterans and Medicare enrollees diagnosed with lung, colorectal, or hematological cancers. Campling et al. (2005) calculated both median survival rates in months and 5 year survival probability. Survival was measured from the date of recorded cancer diagnosis to death, as long as the death, by any cause, was reported in PA, from 1995 to 2001. Alternatively, the other researchers evaluated survival rate using national data from 2001 to 2004 (Landrum et al., 2012). To calculate the outcome, both articles utilized the Kaplan-Meier survival curve, a non-parametric statistic used to measure the fraction of patients living for a discrete amount of time after being diagnosed with cancer (Kaplan & Meier, 1958). Both used the Cox proportional hazard model which provides an estimate of the treatment effect on survival after adjustment for other explanatory variables, confounders, allowing researchers to estimate the hazard ratio (HR), also known as the risk, of death for an individual diagnosed with cancer (Cox, 1972). Typically, survival rates increase when healthcare systems improve at preventing death, curing disease, or provide earlier accurate diagnoses.

Determining a Sample

Campling et al. utilized cancer databases from the Pennsylvania Cancer Registry to create a civilian sample and identified veterans using International Classification of Diseases for Oncology (ICD-O-2) codes used at VA Medical Centers in PA (2005). Patients with mesothelioma morphology were excluded from analysis due to the small number of cases seen in VA facilities. Further, this particular analysis focused solely on males. Researchers further divided the two cohorts by race (white, black, and other). Patients' disease stages were coded according to the Surveillance, Epidemiology, and End Results (SEER) criteria as localized, regional, distant. Patients were compared on age, race, disease stage, and histologic subtype of lung carcinoma between the VA and civilian population. A total of 27,936 PA civilian patients with lung cancer were compared to 862 veterans in the PA VA system. This disproportionate sample size and lack of case-control or matching approaches used is of concern for the given analysis employed by the authors.

Alternatively, Landrum et al. (2012) collected VA data using the Veterans Affairs Central Cancer Registry (VACCR). This database receives and stores information on cancer diagnosis and treatment compiled at 132 VA Medical Centers that diagnose and/or treat veterans with cancer. This allowed for a much larger sample to be statistically matched with the general cancer population (U.S. Department of Veterans Affairs, 2003). The researchers merged Medicare claims data with the SEER database to identify a national representative sample of men 66 years of age and older diagnosed with common cancers, including lung cancer, to match the similarly aged cancer diagnosed veteran population. The SEER Program registry includes stage of cancer at the time of diagnosis and patient survival data (NCI, 2015). The sample was compared across cohorts by 6 disease-specific cancers. Individuals diagnosed with cancers not of interest and those without complete disease history data were excluded. This analysis focused on the non-small-cell lung cancer (NSCLC) and small-cell lung cancer findings, so as to draw a succinct comparison between the two articles. Landrum et al.'s final sample of lung cancer patients, both NSCLC and small-cell, included 15,560 veterans and 36,537 civilians, a more robust sample than Campling et al (2005).

Methods for Risk Adjustment & Mediating Factors

Campling et al. (2005) used a two-sample Student t-test for age, and a chi-square test for categorical variables like disease stage, race, and histology. Potential confounders and interactions were stratified and HRs were conducted for the multivariate analysis. Using the Cox proportional hazards regression model to compare cancer patients allows the researchers to adjust for variables that are known to affect survival, like age and disease stage, and in turn improves the estimates that the effect type of treatment associated with a facility, VA and non-VA, has on survival.

Landrum et al. (2012) examined the stage of cancer at diagnosis and tumor size using the American Joint Committee on Cancer (AJCC) staging criteria, which was standardized across the VA and SEER databases in 2004, thereby allowing the researchers to recode archaic cancer staging diagnoses prior to 2004 (e.g. localized, regional, distant, unknown). Additionally, the Landrum and colleagues searched for observable differences in the use of guideline recommended therapies between the VA and Medicare facilities, such as the use of curative surgical interventions for early staged NSCLC. Patient demographics included age, race/ethnicity, marital status, and history of previous cancer. Modified Charlson scores were utilized to characterize the severity of comorbidities. Socioeconomic status was ascertained from census data based on the zip codes of each patient. The Charlson Index is a prognostic taxonomy for comorbid conditions which allows health services researchers to account for and alter the risk of short-term mortality in their analyses for patients enrolled in longitudinal studies with varying degrees of health conditions and comorbidities that may influence the survival rate (Charlson, Pompei, Ales & MacKenzie, 1987)

In an effort to account for the significant clinical and demographic differences in patients seen in the VA compared to the general Medicare population, a concern of Campling et al.'s work, a propensity score (PS) adjustment was used to estimate the effect of receiving care through the VA versus care through Medicare in Landrum et al.'s study. A logistic regression model was used to calculate the propensity of being treated in the VA on the basis of age, race, marital status, Charlson score, previous cancer, census region, quarter-year of diagnosis, and socioeconomic conditions by zip code. Regression coefficients and observed covariates were used to estimate the PS for each man to be treated in the VA. In observational studies, such as this one, the researcher has no control over treatment assignments, and groups may have large differences in observed covariates making it difficult to compare the quality of the facility's care provided. The PS provides a summary measure to control for multiple confounders concurrently rather than matching participants on each individual characteristic. A standardized mortality ratio (SMR) propensity-score weight was applied. SMR is the ratio of cancer related deaths observed in a study population over a defined period of time compared to a standard, or general, population's death rate (Curtin & Klein, 1995). In this scenario, the rate VA patients would experience if they were Medicare patients with similar risk factors. This approach prevents a reduction of the original sample size (Austin, 2011). Final sample cohorts for NSCLC were well balanced for analysis between the VA and Medicare cancer populations (13,434 and 13,356, respectively). PS are often utilized in observational studies, where randomization is not possible, because they enable researchers to ensure a balance across participants on observable characteristics (race, age, sex, etc.). However, a limitation of PS is the inability to account for unobserved variables and confounders therefore; Landrum et al. (2012) performed a sensitivity analysis to address the PS's limitations. In their study, four potential unmeasured confounders, like smoking status, were considered to be associated with both poor care and worse survival rates. Assumptions regarding differences between VA and Medicare patients in the prevalence of these four confounders and the relationship these confounders have with survival rates were estimated from randomized control trials and external national based surveys. HRs were further adjusted by comparing survival rates with these additional confounders.

Results

Campling et al. (2005) found that Non-VA patients had a higher probability of survival, with a median survival of 7.9 months after diagnosis, than VA cancer patients, 6.3 months (p=0.002). Further, they found 5-year overall survival rate to be 12% for VA patients and 15% of total non-VA cancer patients in PA. The authors determined that while the cumulative survival probability among white males, using a log-rank tests, was greater for non-VA patients (p=0.0007) that there was no significant difference in survival among black patients with cancer in PA's veteran or private healthcare systems (p=0.92). Furthermore, the authors demonstrated that even after accounting for a marginal interaction effect between race and hospital system (p=0.11) real differences exist in risks between VA and non-VA whites. The significant HR for white lung cancer patients seen at the VA compared to the non-VA facilities (HR, 1.26' 95% CI, 1.15-1.37) is not seen among black patients in either VA or private healthcare system (p=0.06; p=0.006).

Landrum et al. (2012) demonstrated that veterans seeking care for NSCLC experienced better survival rates, both all-cause and cancer-specific, compared to their peers in the Medicare cohort (All cause HR, 0.91; 95% CI, 0.88-0.95). Cancer specific rates are the probability of surviving cancer in the absence of other causes of death. This translates to an adjusted median survival of 8 months for VA patients compared to only 6 months for Medicare patients. Alternatively, cancer specific survival rates for small-cell lung cancer for VA diagnosed patients about the same to those in Medicare diagnosed patients (HR, 0.99; 95% CI, 0.93-1.05). After adjusting initial HR using SMR PS weights, which highlights the VA impact identifying earlier stages of cancer at diagnosis, a real difference in HR reduction (2%) exists for VA NSCLC patients compared to those in Medicare with similar tumor size and stage at diagnosis (HR, 0.98; 95% CI, 0.94-1.01). As stated before, the SMR weighted effect estimates the survival rate a typical VA patient would have had in Medicare services. Further sensitivity analysis for smoking demonstrates the continued benefits VA NSCLC patients have in HR reduction when accounting for unobserved variables (HR, 0.91 for NSCLC vs HR, 0.98 for small cell).

Discussion of Limitations & Conclusions

The methodological differences between the two articles demonstrate the evolution in data resources and statistical approaches for evaluating health outcomes in the veteran and civilian populations. Campling et al.'s survival results would have been strengthened by better statistical modeling so as to demonstrate if the survival rates are the result of veteran characteristics or system wide treatment, but the data needed to do so was lacking. In response to a national directive in 1998, many VA facilities began local cancer registry operations and a national Veterans Administration Central Cancer Registry (VACCR) was formally recognized in 2003 (US VA, 2003). This data resource may not have been available at the time of data collection for Campling et al. (2005) and highlights the limitations and difficulties health service researchers have when seeking to compare large datasets internally and externally from the VA. An additional limitation of Campling et al., was that patients who did not die as residents of Pennsylvania may have been missed. Campling et al., highlight the significant proportion of localized or earlier stage cancer in their VA population. The researchers point to the elevated proportion of squamous cell carcinoma and small-cell lung cancer, potentially a result of smoking non-filtered cigarettes. The researches note higher smoking rates in the veteran cohort compared to the civilian population. The histological breakdown of cancer types allows for a better comparison between the two studies' cancer populations since about 85% to 90% of lung cancers in the US are NSCLC, including squamous cell carcinoma (NCI, 2015). Racial disparities within the VA's and non-VA cancer patients require further analysis to best understand care related differences in survival across races. When conducting tapered matched comparisons a focal group, is compared to two or more non-overlapping matched comparison groups, often divided across racial or ethnic lines. These groups are constructed from one total population so that the individuals in the comparator groups increasingly resemble those in the focal group with each analysis (Daniel, Armstrong, Silber & Rosenbaum, 2008). Therefore as more baseline characteristics of the comparator groups are excluded, or tapered, the disparity in outcomes can be more extensively observed.

A tapered match to address these internal racial disparities could have strengthened the overall conclusion that VA lung cancer patients, by race, have lower survival rates than the civilian population in Campling and colleagues' work. Tapered matching would have also allowed for a formal comparison of white patients across different matched sets, such as SEER rating, rather than the regression model used comparing all coefficients in the model. The result that veteran cancer care is poorer than civilians' is limited because of the lack of controlling for comorbidities.

Landrum et al.'s sensitivity analysis of a representative national lung cancer patient sample allows for a more holistic and comprehensive comparison in survival rates among veterans and civilians that Campling et al. was unable to do with earlier local data, and in turn illustrates superior veteran cancer care, compared to the general Medicare population, as measured using lung cancer survival rates. Matching on PS helps to remove confounding factors typically attributed to poorer survival rates of veterans. However it is important to recognize Landrum et al.'s use of external data sources to determine smoking status and the use of zip codes to estimate income levels of each pair is not as accurate as knowing true participants statuses. Future research should work to find more comprehensive databases with these confounders included in their databases such as using both administrative and chart-based data. Alternatively, Landrum et al., could have utilized tapered matching to better match civilians to veterans and look at disparities in treatment and clinical presentation not only by system but also by race within each system. Another approach for future research examining cancer survival rates is the use of difference-in-difference studies to assess the quality of care in VA facilities to private facilities before and after policy reform in the 1990's. Employing difference-in-difference study design approach in health services research offers researchers the opportunity to evaluate changes in outcomes, such as lung cancer survival rate, after implementation of major policy or care changes and examining trends before and after in the facilities impacted by changes compared to control facilities. By doing so researchers in the VA assessing quality care initiatives would be able to identify the association between policy implementation and survival rate outcomes estimated by examining all interactions between the pre-post period and exposed-unexposed facilities (e.g. civilian health systems) using a regression model (Dimick & Ryan, 2014).

Nursing Science Implications

This comparative analysis, contextualized in a side-by-side comparison of veteran cancer care research, serves as a brief overview of utilizing survival rates and other analytic approaches as an outcome measure available to nurse scientists conducting health services research. Using the same outcome measure, survival rate, two opposing conclusions are reached on the quality of veteran cancer care, thereby demonstrating the value of additional statistical approaches to strengthen health service research. Nurses are at the intersection of patient care and clinical care policy implementation. As such, it is imperative nurse scientists evaluate meaningful clinical outcomes, such as survival rates, and accurately interpret the methods of analysis used in research to best understand and assess the effectiveness of health policies within the health systems where they conduct research or access data. Doing so optimizes policy, implementation, and prolongs sustainability to patient populations, such as those in the VA (Stetler et al., 2006). The authors provide this comparative analysis as a learning tool for future nurse scientists involved in health services research with the hope that seeing both the shortcomings of various methodologies and their intrinsic strengths, particularly in policy evaluation, will better inform the application of these approaches in their own lines of inquiry.commitment, control, and challenge (hardiness), he or she will employ transformational coping measures, practice positive health behaviors, and make use of social support, which will affect his or her well-being.

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Appendix 1

	Campling et al. (2005)	**Landrum et al. (2012)**
Objective	Examine differences in the characteristics and survival of Pennsylvanians with lung cancer in the VA hospital system compared with civilian patients seeking treatment elsewhere from 1995-2001	Compare the survival rates of older patients with cancer in the VHA and fee-for-service Medicare and examined whether differences in the stage at diagnosis, receipt of guideline-recommended therapies, and unmeasured characteristics explain survival differences from 2001-2004
Outcome of Interest	Survival rate for lung cancer patients	Survival rate for NSCLC and small-cell lung cancer patients
Datasets Used	• Veterans Administration Health Care Network • Pennsylvania Cancer Registry	• VA Central Cancer Registry • Surveillance, Epidemiology, and End Results (SEER)
Sample Size Cohorts for Final Analysis	862 (VA) 27,936 (Non-VA)	13,434 (VA) 13,356 (Medicare)
Highlighted Analytic Methods Utilized	• Kaplan–Meier Curve • Cox proportional hazards model	• Kaplan-Meier Curve • Weighted Cox proportional hazard model • Propensity score matching • Charlson Index • Standardized Mortality Ratio
Relevant Results	Median Survival Rate • 6.3 months in VA • 7.9 months in non-VA	Median Survival Rate • 8 months in VA • 6 months in Medicare
	Adjusted Hazard Ratio for death among VA patients compared with non-VA patients [95% CI] • 1.22 [1.20, 1.23]	Adjusted Hazard Ratio for death among Medicare patients Relative to VA [95% CI] • 0.91 [0.88, 0.95] NSCLC • 0.99 [0.93, 1.05] Small-cell lung cancer
Key Findings	• VA lung cancer patients have inferior survival rates to that of patients in the remainder of the state and this was • Race was a major variable of consideration and illustrates differences in survival by race	• Lung cancer survival rate for senior male veterans seeking care in the VA was better than or equivalent to the survival rate for matched Medicare patients • Risk adjustment on severity and potential confounders illustrates survival advantages in veteran cancer populations

Abbreviations: CF = CF, HRQoL = health-related quality of life

Key Terms	
Survival rate	Percentage of people in a study or treatment group who are still alive for a certain period of time after they were diagnosed with or started treatment for a disease
Kaplan-Meier Curve	A non-parametric approach to measure the proportion of individuals alive from a predetermined point, such as time of cancer diagnosis or exposure to treatment, till the event occurs, often death
Cox Proportional Hazard	An estimate of the treatment effect on survival while adjusting for other covariates and confounders, thereby producing an estimated hazard ratio (HR), or risk death to an individual or population after accounting for predetermined factors; a HR of 1 at any particular time in analysis indicates the rate of event occurring is comparable between groups
Propensity score	A statistical adjustment used in observational studies to measure treatment effect by accounting for covariates that influence the likelihood of participants receiving treatment; allows researchers to balance observed covariates, however unlike random assignment, it does not balance unobserved covariates
Tapered Matching	Tapering is the iterative removal of intrinsic discrepancies between the study sample and the population being compared to; as the general population or control cohort's characteristics are removed throughout analysis the disparity in outcomes can be isolated and measured
Charlson Index	A validated index of comorbidities and risk factors for mortality used to measure disease burden in weighted statistical analyses to account for likelihood of survival
Difference-in-Difference	Given a parallel trend in outcomes, such as annual cancer survival rates, between two cohorts this approach allows for a pre-post event (e.g. intervention or policy intervention) assessment across panel data, provided the event was implemented only in only one cohort

Child Obesity: Analysis of a Population Health Problem

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Abstract

Nearly one out of every three children in the US are either overweight or obese (Ogden et al., 2016) as defined by the Center for Disease Control and Prevention (CDC, 2015b). Overweight and obese children are at increased risk for developing serious chronic illnesses such as type two diabetes, hypertension, and depression.

Efforts to reduce prevalence of child obesity is a challenge. Understanding the contributing factors is critical to effectively approach the problem with viable solutions. The purpose of this article is to present a model that encompasses direct and indirect contributing factors for child obesity. This model could be used by nurses and other clinicians for hypothesis testing, intervention design, and policy reform.

Child obesity is a serious public health issue associated with multiple chronic diseases (World Health Organization, 2015). In children, overweight is defined as a body-mass-index (BMI) between the 85th and 94th percentile for age and sex, and obesity is defined as a BMI greater than the 95th percentile for age and sex (CDC, 2015). Clinicians and public health experts are trying to reduce the prevalence of children who are overweight or obese.

The basic cause of overweight and obesity is an imbalance in which energy consumption is greater than energy expenditure. However, factors leading to energy imbalance are woven in a complex matrix that involves biology, behavior, culture, environment, and economics operating at the individual, family, and community levels (Public Health Agency of Canada, 2015). Identifying key factors to target is a challenging, but essential, component for finding a sustainable solution to reduce the child obesity epidemic. This article will discuss prevalence, disparities, comorbidity, costs, and contributing factors for child obesity.

Prevalence and Disparities of Child Obesity

According to the World Health Organization (2015), in 2013 an estimated 42 million children under the age of five were overweight globally. In the United States, 31.8% of children ages 2 to 19 are overweight or obese (Ogden, Carroll, Kit, & Flegal, 2014). Over the past three decades, prevalence of child obesity has tripled from 5% in the 1970s to 16.9% in 2010 (Fryar, Carroll, & Ogden, 2012).

The results of 2011-2012 National Health and Nutrition Examination Survey (NHANES) indicated improvement in obesity prevalence for preschoolers when compared to 2009-2010 survey results (Ogden, Carroll, Kit, & Flegal, 2012; Ogden et al., 2014). However, the improvement is not consistent across all racial/ethnic groups. In the 2009-2010 NHANES report, non-Hispanic white children ages 2 to 5 had an obesity prevalence of 9.2%. This improved to 3.5% according to 2011-2012 NHANES. In contrast, for Hispanic children ages 2 to 5, there was an increase in prevalence from 16.2% to 16.7%. These statistics demonstrate that child obesity does not affect the population equally.

In fact, per 2011-2012 NHANES, Hispanic children have the highest prevalence of overweight and obesity compared to Asian, African American, and Caucasian children in most age groups (Ogden et al., 2014). African American children rank second in prevalence for overweight and obesity. In both groups, more than a third of children are overweight and more than a fifth are obese.

Just as child obesity is not equally distributed among racial/ethnic groups, it is also not equally spread among income groups. According to the 2011/12 National Survey of Children's Health (NSCH) (2012), 26.6% of children living at 0 to 99% of the federal poverty level (FPL) were obese. As income increases, the prevalence of obesity decreases. Only 9.0% of children living at 400% FPL or higher are obese. A similar trend follows for children who are overweight (The Child and Adolescent Health Measurement Initiative, 2012b).

Comorbidities of Child Obesity

The list of illnesses associated with child obesity is extensive. They included joint problems, asthma, sleep apnea, fatty liver disease, gallstones, and gastro-esophageal reflux (Center for Disease Control and Prevention, 2015a; Must, 1996). Children who are severely obese are also at increased risk for genu valgum, slipped capital femoral epiphysis, and tibia vara (Must, 1996).

However, the greatest health threats for children who are overweight or obese exists in cardiometabolic morbidity. A systematic review identified a number of robust studies that found associations between childhood overweight or obesity and adverse cardiovascular effects later in life (Reilly & Kelly, 2011). One of the studies found that 70% of obese children had at least one cardiovascular risk factor such as high blood pressure or high cholesterol, and 39% of obese children had two or more risk factors (Freedman, Mei, Srinivasan, Berenson, & Dietz, 2007).

The incidence of diabetes has increased parallel to the prevalence of obesity (Crothers, Kehle, Bray, & Theodore, 2009). About 15 years ago only 3% of new onset diabetes in adolescents were type 2 diabetes. (D'Adamo & Caprio, 2011). Now about half of new cases are recognized as type 2 diabetes. At the time of type 2 diabetes diagnosis, over 85% of children are either overweight or obese (Pulgaron & Delamater, 2014).

In addition to the physical issues, obesity is associated with a number of psychological health concerns. Obese children are at increased risk for exclusion and bullying (Crothers et al., 2009). They are more likely to have depression, low self-esteem, and distorted body image (Crothers et al., 2009; Must & Strauss, 1999). In a study of 244 children ages 8 to 17 entering a weight management program, 36.4% were depressed (Morrison, Shin, Tarnopolsky, & Taylor, 2015). According to the 2011/12 NSCH, 39% of children with one or more reported emotional, behavioral or developmental issues were overweight or obese (The Child and Adolescent Health Measurement Initiative, 2012a).

Costs of the Problem to Society

Childhood prevention programs come at a significant cost. For example, the Robert Wood Johnson Foundation pledged $500 million towards prevention efforts in 2007, and the California Endowment pledged $1 billion towards building health-promoting communities across the state (Finkelstein et al., 2014).

To justify the cost of prevention programs, policymakers need an estimated cost of childhood obesity from health and economic perspectives (Finkelstein, Graham, & Malhotra, 2014). A study in Australia found evidence to support that children who are overweight or obese at four to five years of age have higher prescription and medical care costs over the following five years compared to healthy weight peers (Au, 2012). Researchers estimate $12,660 to $19,000 as the incremental lifetime medical cost of an obese child compared to a healthy weight child (Finkelstein et al., 2014). Additionally, obesity in adolescence is associated with adverse social and economic outcomes such as decreased education attainment and lower income (Reilly et al., 2003).

Contributing Factors for Child Obesity

Obesity is a complex issue with many contributing factors. The primary factors are an imbalance of surplus energy intake and insufficient energy consumption. However, the indirect contributing factors that lead to this energy imbalance ferment from a complex mix of culture, behavior, economics and environment. Figure 1 (page 24) is a model of contributing factors for child overweight and obesity. From left to right, the model depicts how three indirect factors (food industry, parenting, and low socioeconomic neighborhoods) feed into the primary direct factors of increased energy intake and insufficient energy consumption. Research supporting the organization of the model is summarized in Table 1, located in the appendix (on page 35).

Data from the NSCH and Pediatric Nutrition Surveillance System (Center for Disease Control and Prevention, 2015c; The Child and Adolescent Health Measurement Initiative, 2012b) support that children from low income families have increased prevalence of obesity compared to families with higher incomes. Lower income, minority neighborhoods are likely to lack an environment supportive of physical activity (Gordon-Larsen, Nelson, Page, & Popkin, 2006; Moore, Diez Roux, Evenson, McGinn, & Brines, 2008). They are less likely to have recreation facilities and parks which leads to decreased physical activity and increased weight. People living in lower socioeconomic neighborhoods report higher perceptions of unpleasantness of neighborhoods, unattended dogs, neighborhood crime, untrustworthy neighbors, and they were less likely to meet the Center for Disease Control's recommendations for physical activity (Wilson, Kirtland, Ainsworth, & Addy, 2004). Low-income communities also tend to have greater availability of fast food restaurants (Newman, Howlett, & Burton, 2014). Furthermore, these neighborhoods are less likely to have access to healthy foods

Figure 1: Contributing Factors for Child Obesity

because they lack grocery stores (Treuhaft & Karpyn, 2010). Conversely, individuals with access to healthy food have a lower risk for obesity (Larson, Story, & Nelson, 2009).

The food industry is another significant, indirect contributor to obesity. Energy-dense, nutritionally poor foods and beverages contribute to childhood overweight and obesity (Sonntag, Schneider, Mdege, Ali, & Schmidt, 2015). Food and beverage manufacturers and chain restaurants offer many products that are high in sugar, fat, and salt to satisfy consumer taste preferences (Cornwell & McAlister, 2011). These outlets have lower-priced food and beverage items that appeal to economically disadvantaged consumers.

The food industry also advertises to children who are exposed to many marketing messages, promotional events/displays, trade characters, and packaging (Cornwell & McAlister, 2011). Snack, convenience, fast foods, and sweets account for 83% of advertised foods (Harrison & Marske, 2005). Food preferences and habits set in childhood influence food choice over the lifespan (Cornwell & McAlister, 2011).

Parents are another predominant player in factors contributing to obesity in children. Parents have great influence in shaping their children's attitudes and behaviors (Rodenburg, Kremers, Oenema, & van de Mheen, 2014). They generally have the most control over the home and family environment. If parents have poor dietary habits, their children often model similar patterns (Hood et al., 2000). Parenting styles and practices have strong impact over children's obesogenic behaviors (Patrick, Hennessy, McSpadden, & Oh, 2013)

Many elements contribute to child obesity in complex relationships. It is important to note that Figure 1 does not incorporate all the contributing factors for child obesity. Some contributors to child obesity not mentioned in the model are sleep, breastfeeding, and genetics (Center for Disease Control and Prevention, 2015a).

Recommendations

Efforts to reduce prevalence of child obesity is a challenge. Understanding the contributing factors is critical to effectively approach the problem with viable solutions. The contributing factors model could serve as a map to assist researchers in identifying relationships between factors and potential gaps in knowledge. It can also be used by public health nurses to develop interventions aimed at reducing prevalence of child obesity. Food industry, parenting, and low socioeconomic neighborhoods are presented in the model because these are three areas that have potential for behavioral intervention, environmental change, and policy reform.

Summary and Conclusion

Childhood overweight and obesity is one of the nation's greatest public health concerns. It effects about one third of children (Ogden et al., 2014). As these children develop comorbidities associated with being overweight or obese, they will endure increased healthcare costs along with other burdens.

While the direct contributing factors for child overweight and obesity are easy to identify, indirect contributing factors originate from more complex interactions of behavior and environment. To stop the domino effect of child obesity, it is essential to untangle and address the many indirect contributing factors.

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Table 1. **Evidence Table for Contributors to Child Obesity**

Citation	**Purpose of Study**	**Research Design** ***Sample*** ***Setting***	**Method of Investigation** ***Variable 1*** ***Variable 2***	**Findings from the Study**
(Cecil, Tavendale, Watt, Hetherington, & Palmer, 2008)	To examine the relationship between fat mass and obesity-associated (FTO) gene variant & body-mass index (BMI). Also, to explore the role of the FTO variant in energy expenditure and eating behavior	Cross-sectional ***Sample*** *97 prepubertal schoolchildren ages 4 to 10* ***Setting*** *Northeastern Scotland*	Participants recruited from Energy Balance Study. The students were evaluated for adiposity, energy expenditure, & eating behavior. ***Variable 1*** *Food energy intake: calculated using manufacturer information, amount of food consumed at test meal assessed by weighing the food items before and after eating* ***Variable 2*** *Metabolism: Resting metabolic rate assessed by indirect calorimetry, with the use of a ventilated hood*	Increased food intake (energy intake) at test meals was associated with children carrying the FTO gene variation.
(Wake, Nicholson, Hardy, & Smith, 2007)	To examine relationship between child's body mass index (BMI) & parenting styles	Cross-sectional ***Sample*** *4983 children ages 4 - 5* ***Setting*** *Australia*	Trained professional completed 1:1 interviews with primary care givers (usually mom), secondary parent completed questionnaire. Separate statistical analysis performed for mothers, fathers, and combined. ***Variable 1*** *Parenting style: Self-reported behavior using 3 continuous scales for warmth, control, irritability and categorized as being authoritative, authoritarian, permissive, or disengaged* ***Variable 2*** *Child's weight status: classification according to the International Obesity Task Force age- and gender-specific criteria for BMI (kg per meter squared).*	No association between mother's parenting dimension and child BMI status (p-value ≥ 0.69) Strong association between paternal parenting dimension and child BMI status (p-value < 0.001) Children with permissive or disengaged fathers, had increase odds of having higher BMI by 59% & 35%, respectively. *To note: This study used different means to gather parental data, had missing data, and compared data sets using same statistical methods.*
(Rodenburg, Kremers, Oenema, & van de Mheen, 2014)	To study parental feeding styles with child snacking behavior and weight	Cross-sectional ***Sample*** *1275 Parent-child dyads* ***Setting*** *Netherlands* *(Most children about 9 years of age)*	Parents completed questionnaire of feeding style and children's snacking intake. Child's BMI measured. The relation between feeding style, snacking behavior, and BMI completed using linear regression. ***Variable 1*** *Parental feeding style: validated Dutch translation of the Parental Feeding Style Questionnaire that assessed 4 style dimensions (Instrumental Feeding, Emotional Feeding, Encouragement, Control)* ***Variable 2*** *Children's snacking behavior: measured by validated questionnaire.* *Child BMI (kg/meter squared) based on age-gender specific values from 1997 National Growth Study in Netherlands*	Pearson's correlation: negative association between child snacking and child BMI & child sugar sweetened beverage (SSB) intake and child BMI. Negative associations of Instrumental Feeding and Emotional Feeding with child fruit intake and positive associations with energy-dense snack intake.
(Cornwell & McAlister, 2011)	2 studies were conducted Study 1: Develop survey measure of taste preference & learn if child's sugar-fat-salt (SFS) palate relates to food choices. Study 2: Examine how knowledge of certain food & drink brands are related to palate.	Cross-sectional ***Sample*** *108 children aged 3 - 5 years* ***Setting*** *middleclass preschool in a large metropolitan city.*	Focus on Study 2: Children sorted picture cards to create a collage reflecting their knowledge on specific brands. The 21-item taste preference survey was conducted. ***Variable 1*** *Study 2: Brand preference measured using same 21-item taste preference survey* ***Variable 2*** *Study 2: Brand knowledge tested using "brand representation task"*	Study 2: Child SFS palate is significantly predicted by child brand knowledge (β = .65, p < .001). Fast-food and soda brand knowledge is linked to the development of a preference for sugar, fat and salt in food
(Kral, Remiker, Strutz, & Moore, 2014)	To compare energy intake at a meal in normal-weight and obese children	Randomized, crossover design ***Sample*** 25 normal-weight and 25 obese children, ages 8-10 years ***Setting*** Location N/A	Children were given the same meal once a week over 3 weeks. Each time, the meal was increased in portion size. ***Variable 1*** Same meal served with sequentially larger portion sizes ***Variable 2*** Children's relative reinforcing value of food was assessed using a behavioral choice task	Environments that offer large portions of palatable foods affect all children's intake irrespective of their weight status or how reinforcing they find food to be.

Table 1. ***Evidence Table for Contributors to Child Obesity (Continued)***

Citation	Purpose of Study	**Research Design** ***Sample*** ***Setting***	**Method of Investigation** ***Variable 1*** ***Variable 2***	Findings from the Study
(Newman, Howlett, & Burton, 2014)	To examine the impact of fast food availability on childhood obesity	Cross-sectional Preschool childhood obesity rates for 2718 U.S. counties	Hierarchical regression analysis examined direct & interactive effects of predictors on preschool obesity rates. ***Variable 1*** *Low-income preschool obesity rate from the Pediatric Nutrition Surveillance System (PedNSS)* ***Variable 2*** *(1) The per capita number of fast food restaurants, (2) The level of urbanization (rural versus urban), and (3) Economic environment (persistent poverty present versus persistent poverty not present) taken from the Food Environment Atlas*	Higher level of fast food restaurant saturation may lead to increased prevalence of childhood obesity in more economically disadvantaged, urban areas (p<0.01)
(Petrunoff, Wilkenfeld, King, & Flood, 2014; 2012)	To examine parental perception of everyday foods and differences between low & high socioeconomic status	Cross-sectional ***Sample*** 88 parents of 3-5-year-old ***Setting*** New South Wales, Australia	13 focus groups with discussion questions organized into 4 topic areas: Types of food & context, influences on food provision, "Everyday & sometimes foods", Strategies- what could make it easier to limit 'extra foods" ***Variable 1*** *Focus group questions with framework analysis* ***Variable 2*** *Mix of pre-schools & day care centers to get different social characteristics*	Common themes: Most parents accept juice as "everyday" food but not soda. Both low & high SES rarely mentioned weight status. "Extra" foods can be frequent as long as balance with healthy foods.
(Rollins, 2004)	Assess the role of television as tool for childhood obesity prevention.	Literature Review ***Sample*** 40 studies ***Setting*** Locations varied	Literature review of relationship between television & childhood obesity	Children who spend the most time with media are more likely to be overweight, marketing in the media may be key mechanism
(Zarnowiecki, Sinn, Petkov, & Dollman, 2012)	To investigate extent to which parents' knowledge & attitudes on nutrition & food predict young children's knowledge of healthy foods	Cross-sectional ***Sample*** 216 families of children aged 5-6 years ***Setting*** Adelaide, Australia	192 parental & children data form the Health Food Knowledge Activity compared using structural equation modelling. ***Variable 1*** *Parent questionnaire that measured lifestyle variables, parents' nutrition knowledge and attitudes to food* ***Variable 2*** *Children's nutrition knowledge was measured using the Healthy Food Knowledge Activity*	Parents' nutrition knowledge directly predicted children's nutrition knowledge (r = 0·30, P < 0·001). Parents with lower SES had lower nutrition knowledge.
(Nelson, Gordon-Larsen, Song, & Popkin, 2006)	To identify meaningful patterns of sociodemographic and built features in neighborhood environments and to describe the cross-sectional associations between these neighborhood patterns and adolescent physical activity (PA) and weight status.	Cross-sectional ***Sample*** 20,745 adolescent participants ***Setting*** United States	Using data from National Longitudinal Study of Adolescent Health, cluster analyses identified homogeneous groups of adolescent sharing neighborhood characteristics. ***Variable 1*** *Neighborhood measures on socioeconomic status, crime, road type, street connectivity, PA recreation facilities* ***Variable 2*** *Physically active (five or more bouts/week of moderate to vigorous PA) and overweight (>95)*	Six neighborhood patterns identified: (1) rural working class; (2) exurban; (3) newer suburban; (4) upper-middle class, older suburban; (5) mixed-race urban; and (6) low-socioeconomic-status (SES) inner-city areas. Those living in rural working class & mixed-race urban more likely to be overweight. Older suburban areas were more likely to be physically active.
(Duncan, Johnson, Molnar, & Azrael, 2009)	Evaluate the relationship between perceived neighborhood safety and overweight status, & evaluate validity of neighborhood safety perception	Cross-sectional ***Sample*** 125 high school students ***Setting*** Boston	Students reported their perceptions on neighborhood safety. BMI was calculated using reported height & weight. Chi-square statistics used to compare perceived neighborhood safety with the several associated dimensions ***Variable 1*** *Neighborhood safety measured via survey questions* ***Variable 2*** *Overweight status measured using BMI*	Regression models to estimate the effect of perceived neighborhood safety on overweight/at-risk for overweight status found that those who rarely or never felt safe in their neighborhoods were 1.21 times more likely to be at-risk for overweight or overweight. (95% CI: 1.05, 1.40)

Table 1. ***Evidence Table for Contributors to Child Obesity (Continued)***

Citation	**Purpose of Study**	**Research Design** ***Sample*** ***Setting***	**Method of Investigation** ***Variable 1*** ***Variable 2***	**Findings from the Study**
(Singh, Kogan, Van Dyck, & Siahpush, 2008)	To examine independent and joint associations between several socioeconomic, demographic, and behavioral characteristics and obesity prevalence	Cross-sectional ***Sample*** 46,707 children aged 10–17 years ***Setting*** United States	Data from 2003 NHANES was used. Logistic regression analysis was used to estimate odds of obesity and adjusted prevalence. ***Variable 1*** *Sociodemographic measures: age, gender, race/ethnicity/ household composition, place of residence, language spoken at home, parental education, poverty status, social capital index, neighborhood safety, school safety* ***Variable 2*** *Behavioral measures: physical activity, recreation computer use, television watching, sports participation*	Factors shown to be independently associated with significantly higher risks of childhood and adolescent obesity include black and Hispanic ethnicity, non-metropolitan residence, lower household education and higher poverty levels, low neighborhood social capital, and increased levels of television viewing and physical inactivity.
(Thomsen, Nayga, Alviola, & Rouse, 2016)	To determine if food deserts are associated with child obesity	Longitudinal ***Sample*** 110,384 school-age students ***Setting*** Arkansas	Used fixed-effects panel data regression models to estimate the effect of residing in a food deserts Food store locations (from Dun and Bradstreet) Child BMI z-scores	Food deserts may be a risk indicator for elevated child BMI
(Galvez et al., 2009)	To determine if the presence of convenience stores and fast-food restaurants near a child's home is associated with increased risk for childhood obesity	Cross-sectional ***Sample*** 323 6- to 8-year-old boys and girls ***Setting*** East Harlem, NY	Calculate odds ratio. Controlled gender, race/ethnicity, and family income. ***Variable 1*** *Food-store data on convenience stores, specialty stores, grocery stores, supermarkets, fast-food restaurants, and restaurants, collected via walking survey of East Harlem zip codes 10029 and 10035 in 2004* ***Variable 2*** *Child BMI*	Children residing near a convenience store had increased odds for elevated BMI.

The Process of End of Life Care Decision Making: A Conceptual Framework

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Abstract

End of life (EOL) care decision making research should focus on not only the kind of decisions made for EOL care, but how individuals process those decisions. The purpose of this paper is to propose a conceptual framework that will elucidate the EOL care decision making process using concepts proposed from behavioral decision research. The new proposed conceptual framework consists of a three-step process: 1) anchoring, 2) framing, and 3) making a decision. Anchoring is the initiation of EOL care discussion which has an impact on decision-making. Framing describes how patients have different perceptions of EOL situations despite experiencing similar conditions. Lastly, making a decision enables patients to process system 1 thinking (i.e. unconscious, fast, and intuitive thinking process) as well as system 2 thinking (i.e. conscious, slow, and analytical thinking process). Based on the proposed conceptual framework, health care providers should consider initiating the first EOL care discussion cautiously with patients, assist patients to frame their EOL situation without biases, and help patients to choose appropriate care options that truly reflect their values and wishes.

Keywords: end-of-life, hospice care, palliative care, decision making, conceptual framework

Medical decision making has traditionally adapted the paternal approach where the physician takes the lead in guiding the patient towards making a decision about a medical treatment. However, recently, health care has become diverse in goals and treatments. Thus, medical decision making has now evolved into collaborative involvement of both patients and physicians to share information, and to reach an agreement (Charles, Gafni, & Whelan, 1997). This shared decision making is more important in end of life (EOL) situations because the patients' wishes and values should guide the choices of health care goal and health care options (Frank, 2009).

End of life is defined as the status in which a patient is not expected to live more than two years or the patient's life will not be prolonged for more than three months despite further medical treatment (National Institute for Health and Clinical Excellence, 2009). In most medical decisions, the goal of the treatment plan is the cure of disease. However, during EOL care decision making, the patients and family members have difficulties accepting that the disease is incurable and many are hesitant to begin discussions about EOL care (Ladin, Buttafarro, Hahn, Koch-Weser, & Weiner, 2017). Consequently, patients and their families often feel frustrated and depressed as they struggle in choosing the next course of medical actions (Block, 2001; Fried, Bullock, Iannone, & O'leary, 2009; Van den Heuvel et al., 2016). Patients making EOL care decisions should understand medical information regarding the status, prognosis, and treatment options for their diseases. Often, health care providers deliver this information. However, beyond sharing medical information, health care providers should help patients decide about their care by ensuring the following: patients should understand their medical status and care options; patients should assess their own values and wishes before making any decisions; and patients consider their values and wishes to guide their care options. For example, if a patient thinks that 'painlessness' is the most important thing to him or her, he or she needs to be guided to choose palliative care.

The plethora of studies on patients' attitude, knowledge, and preferences in various EOL contexts signify the increasing importance of EOL issues especially in an era where life expectancy continues to rise (Cervantes, Jones, Linas, & Fisher, 2017; Evans, Finucane, Vanhegan, Arnold, & Oxenham, 2014; Hughes & Cartwright, 2014; Robinson et al, 2012;). Various studies have been conducted on decisions made at the end of a person's life or about his or her EOL care, such as completion of advance directives (Hickman & Pinto, 2014), place of death (Chen & Miller, 2016), do not resuscitate (DNR) order (Crosby, Cheng, DeJesus, Travis, & Rodriguez, 2016), and treatment choices (Rahman, Bressette, Gassoumis, & Enguidanos, 2016). However, the majority of research studies were mainly conducted on care decision outcomes, such as frequencies of certain decisions and factors affecting those decisions such as age, health status, educational level, religion, and race or ethnicity. These studies did not demonstrate nor elucidate how those factors interplayed with each other during the process of EOL care decision making. In other words, research has mainly focused on 'what patients facing EOL issues think' rather than 'how these patients think'.

To understand how to assist patients in making decisions in important care situations such as EOL care, we need to know not only the kinds of decisions that are made, but also how those decisions are made - the decision making process. Therefore, the purpose of this paper is to describe a conceptual framework that will elucidate the EOL care decision making process using concepts proposed from the Behavioral Decision Research (BDR) that focuses on the process of personal choices to describe EOL care decision making process from individual perspectives.

End of Life Care Decision Making Process

Several attributes of end of life (EOL) care decision making affect the dynamic and context of decision making. Before we can understand the interplay of factors used to make EOL care decisions, we should consider how EOL care decision making differs from typical decision making discussed in behavioral decision research. Four attributes retrieved from EOL care literature that distinguished EOL care decisions are health literacy, emotional effect, difficulty making trade-offs, and variation in the level of engagement.

Health Literacy

Health literacy is the ability to obtain, understand, and interpret health information and service, and the competence to apply several types of information to improve health (U.S. Department of Health and Human Services, 2010). To obtain and use information in EOL care decision making, a patient should understand his or her disease including the prognosis, possible treatment options, and the outcomes of treatments. To understand and interpret these types of information, health literacy is needed. However, it is difficult to have medical knowledge and health literacy in short time unless patients are medical experts. Therefore, when a patient has low health literacy, he or she becomes dependent on health care providers. Consequently, in the process of decision making, many patients tend to rely and mimic health care providers' decisions (Ladin et al., 2016).

Emotional Effect

When people hear that they cannot recover from their current disease, they have intense feelings such as frustration, depression, fear of death, and death anxiety (Brown et al., 2014; Diegelmann, Schilling, & Wahl, 2016). In addition, people need time to accept the fact that they are dying. This acceptance of death affects the readiness of EOL care discussion, which may drive or delay the EOL care discussion and decision making (Kryworuchko, Strachan, Nouvet, Downar, & You, 2016). Sometimes, patients are urged to make decisions before they can fully comprehend the information given to them. In this case, patients could make decisions irrationally and intuitively. Another emotional aspect in EOL care decision making is the overwhelming feeling of uncertainty about their health status (Miller, Morris, Files, Gower, & Young, 2016). Moreover, in EOL care decision making, patients perceive themselves as too emotional to make a decision and often rely on their families to make a rational decision on their behalf (Ko & Berkman, 2010).

Difficulty Making the Trade-offs

EOL decision making is difficult because EOL experiences are not discretely quantifiable and are influenced by a variety of factors. Concrete fact and certain result facilitate decision making. For example, a person choosing a credit card knows the interest rate and the credit limit. A person can easily compare a credit card with 3 % interest rate and $1000 limit to a credit card with 6% interest rate and $2000 limit. If a person prefers lower interest rate, that person will choose the former one. Conversely, if a person prefers higher credit limit to lower interest, that person will choose the latter one. However, in EOL care decisions such as pain treatment options, health care providers, by themselves, cannot accurately quantify current pain level as a discrete level or number nor predict how much medicine would decrease a certain percentage of the pain. Also, if a person chooses life sustaining treatment such as ventilator care, we can assume that it could provoke pain or discomfort. However, we cannot suggest an exact number for how much pain or discomfort it would cause. Therefore, even though trade-offs are a common strategy for making decisions when a person have several options, EOL care decision makers have difficulty making a decision based on the trade-offs (Bélanger et al, 2016).

Variations in the Level of Engagement

In EOL care decision making, patients have various preferences of getting information and willingness of engagement. Sometimes, this level of information provision or level of engagement in decision making is determined by family members (shared decision making). In some cultural contexts, for example in East Asia, family members are considered as the final decision makers. (Kwak & Salmon, 2007). In addition, surrogate decision making is common in EOL care because patients are generally too ill to make a decision. However, research has shown that family members, who are the most frequent surrogates, have different preferences in EOL care from patients (Winter & Parks, 2008). This is because EOL care preferences are not usually communicated in advance among family members (Eunjeong Ko, Roh, & Higgins, 2013) and even if they know the patients' wishes and preferences, the family members' opinion could be different from the patients' (Foo, Lee, & Soh, 2012).

The decision making process and dynamics in EOL care decision making can vary. For example, physicians could conclude that further treatment is futile, while family members still want the patients to live regardless what it takes, whereas the patient values quality of life rather than quantity of remaining years. Even if they all agree that the patient's best interest is foremost, stakeholders (physicians, family members, and patients) could have different opinions on what the best EOL care decision is. And these different points of view make the context of EOL care decision making complex.

Conceptual Framework: End of Life Care Decision Making Process

The conceptual framework (Figure 1) describes the care decision making process that an individual employs when facing EOL issues. The framework employs behavioral research research, which aims to support people in making complex decisions based on the understanding of how people behave (Payne, Bettman, & Johnson, 1992). For this framework, the focus is on the patient as the decision maker.

Anchoring: Initiation of EOL Care Decisions.

When a person is diagnosed with a serious illness or a person's health status is deteriorating, the initial EOL care conversation usually starts. The first EOL care discussion informs patients of their care options. Discussing these options generally influences the patients view on EOL care. The anchoring effect is a cognitive bias in which people put more strength or focus on the first information they had (Tversky & Kahneman, 1975). This information includes health information, care options that are suggested at the beginning (default option), and experience of EOL care discussion. For example, the first EOL care discussions are usually made in a clinical setting where aggressive treatments are set as default. This initial experience largely affects how patients view their situations; it is natural to select treatment for cure over the hospice or palliative treatment in clinical setting. As such, the first information and the first experience of EOL care discussions and decision making including the setting and default options affect the rest of concurrent care decision making (Feudtner, 2007; Halpern et al., 2013).

When the maximum numbers of cycles of chemotherapy is presented as 'standard therapy' to advanced cancer patients, they are more likely to prefer to continue their chemotherapy (Brom, Onwuteaka-Philipsen, Widdershoven, & Pasman, 2016). Physician's attitudes or perspectives on EOL care also have considerable impact on patients' EOL care decision making. When physicians perceive curative treatment as a default or standard treatment and palliative/hospice care as alternatives, they will present those perceptions when they lead the initial EOL care discussion. And these suggested default options affect people's EOL care choices (Halpern et al., 2013).

Framing

After the conversation with their health care providers, patients frame their situation based on their perception of what is happening. Even if identical medical information is given to more than two people, the interpretation of this information will vary from one person to another. Their age, sex, and current health status affect how individuals frame their situation. Social determinants such as ethnicity, religion, education level, and socioeconomic status as well as previous experiences affect the framing of one's situation (Tversky & Kahneman, 1985).

When people have their own frames to interpret the same phenomenon, and these different views have an effect on decision making, it is called the "framing effect". The framing effect can explain how the same factor affects a certain decision differently. For example, spirituality affected both Whites and Blacks in Bullock's study (2011). However, spirituality helped the White people to access palliative care, while spirituality blocked the Black people from palliative care since they thought palliative care as 'hastening of death' (Bullock, 2011). Therefore, even if spirituality affects both groups equally, the decision making could yield opposite outcomes. Another example is the choice between DNR (Do not resuscitate) and full code. People who preferred DNR framed resuscitation as painful, violent, and traumatic procedure, while people who preferred full code framed resuscitation as "restoration of life." In addition, people who preferred DNR framed DNR as comfort care while people who preferred full code considered DNR as suboptimal care or "sit there and die" (Downar et al., 2011). People also frame the same phenomenon differently, based on their previous experience of health care or EOL care, trust between health care providers, and their cultural background (Bullock, 2011; Velez Ortiz, Martinez, & Espino, 2015).

Making a decision

After framing their situation, patients will start to deliberate on possible care options. Care options, like treatment, place of death, or enrollment to hospice may be suggested by health care providers. Following the discussion with providers, patients then consider their own circumstances, and narrow down their options. They also assess their own wishes and values. These wishes and values are then linked to the available options.

When people need to make complex decisions, they tend to process information in a simple way. Daniel Kahneman and Shane Frederick (2002) have proposed the dual process of thinking: system 1 and system 2 thinking. System 1 thinking is unconscious, fast, and intuitive thinking process, while system 2 thinking is conscious, slow, and analytical thinking process. This dual process of thinking concepts was adopted to explain errors in clinical reasoning and diagnosis for physicians making medical decisions (Norman et al, 2017). Intuitive system 1 thinking involves searching possible diagnostic hypotheses; analytical system 2 thinking involves getting additional information from physical exam or lab report and differentiating diagnosis (Norman et al, 2017). Although it seems to make more sense that people adopt system 2 thinking when they make a care decision about their lives, previous research suggested that patients also adopt system 1 thinking when they make EOL care decisions. For example, patients' previous experiences with EOL care have a significant impact on their own EOL care decisions (Amjad, Towle, & Fried, 2014) and their trust toward health care providers affect their care decisions (Bullock, 2011; Heyland et al., 2006) in addition to objective medical information.

Patients are overloaded and overwhelmed by information in EOL care decisions. Patients are told about their current, usually devastating and deteriorating, health status. They also learn new medical knowledge related to their current status. Based on these new medical knowledge, patients need to learn several issues such as what is their disease and the process, whether their situation is different from others and how the difference changes the disease process. In addition, EOL care decision making is a constant cyclical process. After patients make a care decision and then their physical condition changes, they need to make subsequent care decisions to consider the physical changes that just happened. Patients need to make a series of care decisions, called as "cascade" of decisions (Slomka, 1992) and this brings decision fatigue. Therefore, there should be an effort to understand EOL care decisions not only based on rational thinking process but also based on heuristic.

Representativeness is one type of heuristic used in decision making particularly under condition of uncertainty. When people need to process complex information, they tend to simplify that information by choosing one salient characteristic and substituting that characteristic as 'representative' of the information (Kahneman, & Tversky, 1972). In EOL care decision making, this representativeness heuristic cause misunderstandings of EOL options. For example, when it comes to cardio-pulmonary resuscitation (CPR), people tend to substitute CPR for a procedure that revives life rather than considering its components including side effects. Therefore, people estimate the success rate of CPR higher than actual rate (Sharma, Jayathissa, & Weatherall, 2016; Zijlstra, Leenman-Dekker, Oldenhuis, Bosveld, & Berendsen, 2016). Also, people tend to simply think 'do not resuscitate (DNR) order' as opposition to CPR, and interpret DNR order as 'not resuscitating', thus 'giving up life' or 'letting patients die' (Downar et al., 2011). Similarly, people simplify the attributes of hospice care as 'stopping treatments.' So, people believe that if they get hospice service, health care providers will neglect them, speeding up their death (Enguidanos, Yonashiro-Cho, & Cote, 2013).

Discussion and Conclusion

Health care providers can help patients with EOL care decision making in several ways. First, health care providers need to approach cautiously when they initiate the first EOL care discussion with patients. Health care providers often have difficulties in initiating EOL topics, so this could lead to unpleasant and awkward discussions for both patients and health care providers (Brooks, Manias, & Nicholson, 2016; Kryworuchko et al., 2016). The first conversation has more impact than further discussions, and the first discussion affects the rest of discussions. Therefore, the first discussion should be carefully done so that patients are not misled to certain decisions. Furthermore, the first EOL care discussion should be used as an opportunity to build trustful and open atmosphere between health care providers and patients.

Second, health care providers should understand common misunderstandings and bias that patients might have in EOL care decisions and help patients to frame their situation without biases. When people frame their current status, they might have incorrect assumptions about certain care options. These erroneous beliefs could originate from their own experience, their emotional status or cultural beliefs. To guide patients to frame their current status without offending the patients' feelings, health care providers also should understand patients' background including the patients' personal and social context.

Third, when patients deliberate on possible care options, health care providers should help them to assess their own values and wishes, and then help patients to link those to appropriate care options to truly reflect the patients' values and wishes. If a patient values palliative care the most, health care providers should suggest the options that have the most possibility to provide palliative care. Also, patients may not even refer to their own values and wishes in EOL care. To help those patients, health care providers should assess patients' life values as a starting point in EOL care conversation before treatment options are offered.
A conceptual framework for the end of life (EOL) care decision making is proposed. This is a new approach to explain EOL care decisions using concepts developed in the Behavioral Decision Research. To apply this conceptual framework in EOL care decisions, empirical research to apply this framework is needed. In addition, considering the various stakeholders engaged in EOL care decision as shared decision making, this framework needs further modification to be applied in various situations.

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Appendix A

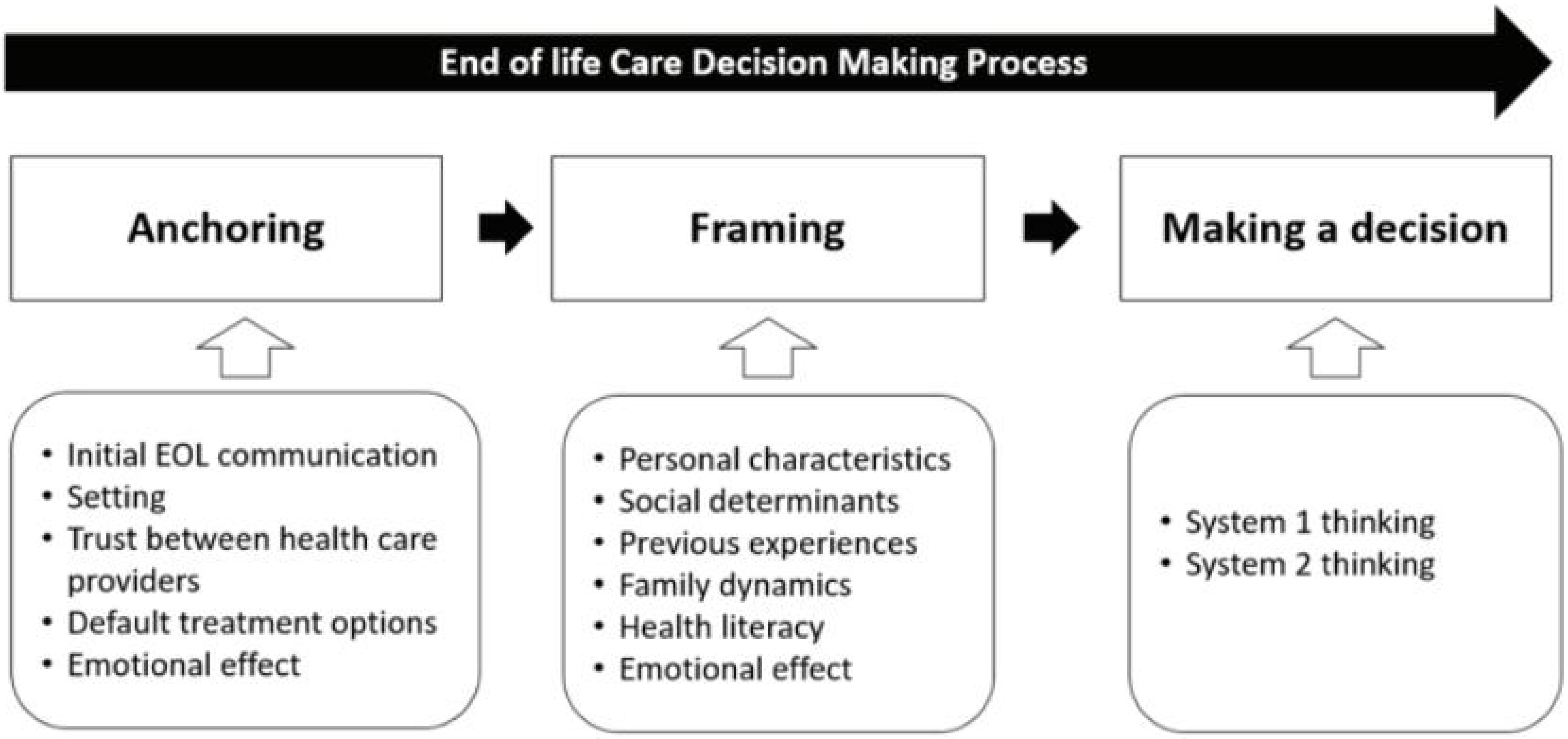

Figure 1. End of Life Care Decision Making Process

Sleep of Intermediate Care Patients with TBI: Role of Nursing Activities during Nighttime Hours

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Abstract

Background: Sleep disturbance is a problem for patients with traumatic brain injury (TBI). For patients housed in the hospital in a non-ICU setting, nighttime nursing care activities can be a main factor in how well a patient may sleep. Aims: This study describes the documented nighttime care provision to intermediate-care patients with TBI and examines the relationship between the average number of documented nighttime nursing care activities and the proportion of nights patients were documented as having slept well.

Methods: Retrospective chart review study. Subjects were identified from the trauma registry as being hospitalized following a moderate-severe TBI between January and March 2013. Data were extracted from the electronic medical record (EMR). The variables of "mean nighttime care activities" and "slept well" were created from nursing notes in the EMR and recorded for patients between 2200 and 0800 HRS for up to 7 days. Demographic and injury variables were also extracted. Data analysis included descriptive statistics, bivariate correlations, and simple regression analyses. P-values ≤ 0.05 were considered statistically significant.

Results: 34 subjects met inclusion criteria. Initial mean GCS was 4.1 and average length of stay was 5.9 days. Sleep/rest was poorly captured in the nursing documentation. The mean number of nighttime care activities per patient was 5.6. Patients were reported to have slept well for only 16% of the nights they were housed on the unit. Pearson's r for correlation between nighttime care activities and sleep quality was weak.

Conclusions: A standard way of capturing sleep/rest within the medical record needs to be developed to allow for better documentation and nursing care planning. Further research is needed in this understudied phase of care to better gauge the factors that influence sleep disturbances.

Keywords: acute care, sleep, brain injury, nursing care

Introduction

According to the most recent epidemiologic reports, 2.8 million adults in the United States suffered a traumatic brain injury (TBI) in 2013. Of these people, 282,000 required hospitalization (Taylor, Bell, Breiding, & Xu, 2017). The frequent monitoring and surveillance that occurs during hospitalization can create a care environment that is not always supportive of recovery. The care environment that will be the focus of this investigation is that of the neuroscience specialty intermediate care unit--the phase of hospitalization that follows the neurological intensive care unit (ICU); the former is often referred to as the neuro-acute-care unit or the neuro- *floor.*

Sleep is known to be an important behavior for recovery from injury and has only recently been explored in hospitalized patients with TBI (Chiu, Chen, Chen, Chuang, & Tsai, 2013; Duclos et al., 2014). Sleep patterns need to be further explored among the target patients housed in the neuroscience specialty intermediate care unit because as the last phase of in-patient hospitalization, it is a critical juncture for evaluating functional outcomes (Schumacher, Walder, Delhumeau, & Müri, 2016). Although, sleep has been shown to be a reliable indicator of functional outcomes in the hospitalized patient with moderate and severe TBI (Sandsmark et al., 2016), to date, and to our knowledge, only two studies have assessed the sleep of this target population in an *intermediate-care setting.* While studies that assessed sleep in an ICU setting are valuable contributions to the body of literature, the care that is administered in the neurological ICU is different from that of the neuroscience specialty intermediate care unit with regard to workflow, workload, and responsibility of nursing staff (Nelson, Valentino, Iacono, Ropollo, Cineas, & Stuart 2015). This difference in patient care delivery suggests the neuroscience specialty intermediate care unit is a novel research environment that requires its own evidence.

While housed in an intermediate-care unit, the patient may not only experience sleep disturbances brought on by their injuries, but also by the care environment itself (McNett, Sarver, & Wilczewski, 2012). Sleep disturbances in this population arise from both intrinsic and extrinsic factors (Watson, Dikmen, Machamer, Doherty, & Temkin, 2007; Yoder, Yuen, Churpek, Arora, & Edelson, 2013) and greatly contribute to functional outcomes. Sleep disturbances are pertinent to hospitalized patients with moderate and severe TBI because; of their inability to maintain restful sleep (intrinsic in origin) (Duclos et al., 2014) and the increased likelihood of being awakened from their sleep owing to patient-care related interruptions (extrinsic in origin) (Yoder et al. , 2013). Both of these conditions highlight the multifactorial nature of sleep disturbances in the hospitalized patient with moderate and severe TBI.

In patients following TBI, intrinsic sleep disturbances are believed to be caused by damage to brain circuitry responsible for regulating sleep and wakefulness (Viola-Saltman & Watson, 2012). Extrinsic factors, conversely, are a direct result of disruptions that are common in the environment, including ambient noise, light exposure, and nighttime nursing care activities. Nighttime nursing care can compound the sleep disturbances that are precipitated by intrinsic sources (Alway, Halm, Shilhanek, & St Pierre, 2013; Yoder et al., 2013) and may be especially problematic for patient recovery following TBI (Massengale, 2015). The purpose of our study is to examine a potential relationship between the nurses' nighttime care-provision to patients with moderate and severe TBI and the nurse's documentation of the patients' sleep quality. Demographics and injury variables of the intermediate-care patient with severe TBI are discussed, nurse-driven nighttime care activities are identified, and implications for practice are noted.

Related Literature

The ideal caregiving environment is one that facilitates useful interaction with the patient and one that facilitates healing (Stichler, 2001). An essential element of professional nursing practice is the maintenance of an environment of care conducive to healing and optimal recovery. In exploring some of the causes for sleep disturbance in hospitalized patients, environmental stimuli have been implicated as a main source (Buxton et al., 2012; Elliot, Rai, & McKinley, 2014; Pilkington, 2013). Nighttime care provision has been identified as a noxious stimulus and a cause for sleep disturbance. For example, the typical patient with TBI in this setting will likely encounters interruptions due to nightly repositioning, vital sign checks, or neuro-checks (Inouye, 2013).

Among the studies that examined sleep among intermediate-care patients with TBI (Chiu et al., 2013; Chiu, Lo, Chiang, & Tsai, 2014), though conditions were not characterized as part of their investigation, the hospital environment was *noted* as a precipitating factor in sleep disturbance. While essential, excessive nighttime provision can impede optimal sleep (Duclos, Beauregard, Bottari, Ouellet, & Gosselin, 2015) and potentially decrease neurological processing and daytime vigilance (Bonnett, 2005; van Enkhuizen, Acheson, Risbrough, Drummond, Geyer, Young, 2014). Unfortunately, to date, there is limited published information on care provision to intermediate-care TBI patients, much less care provision on these patients during the nighttime hours. Also lacking in the literature is an analysis of nursing documentation done during the nighttime hours for these patients. This study aims to address these gaps by providing a better understanding of nighttime care provision for severely injured TBI patients housed in the neuroscience specialty intermediate-care unit and the relation of that care to sleep quality. This study investigates how documented nighttime care provision corresponds with documented sleep reports in this patient sample.

Aims

The specific aims of this study are to: describe the documented nighttime care provision to neuroscience specialty intermediate care patients with TBI, and examine the relationship between average number of documented nighttime care activities and the proportion of nights patients were documented as having slept well.

Methods

This retrospective chart review study is the first step in a program of research examining sleep and care environments of patients with TBI. A list of patients with ICD-9-CM diagnoses of TBI hospitalized at a level 1 trauma center between January and March 2013 was provided to the PI by the trauma registry to allow for screening against eligibility criteria. The interval of January to March was selected so that one full quarter the year was collected. Furthermore, this interval was based on numbers of patients admitted to the hospital with moderate and severe TBI. During this period of data collection, there were no ongoing quality improvement sleep hygiene campaigns. Institutional Review Board (IRB) approval was received from the University of Washington (UW) for this medical record study.

Subjects

Eligibility criteria for subjects: 1) Admitted to between January-March 2013 with ICD9-CM diagnosis of TBI (codes 800.0-801.9, 803.0-804.9, 850.0-854.1, or 959.01); 2) Initial Glasgow Coma Scale score (GCS) on Admission to the Emergency Department (ED) of <8, indicating severe brain injury (Jenett & Teasdale, 1977). Subjects were excluded if they spent less than 24 hours on the neuro intermediate care unit or died during the first seven days on that unit.

Screening

Of the 83 patients initially identified by the trauma registry, 34 met the eligibility requirements and were included in the study.

Demographic Variables

Demographic information was extracted from the electronic medical record (EMR) and included age, gender, race, ethnicity, insurance coverage, length of stay (LOS) on the neuro-unit, and marital/partnered status. Civil unions and common law marriage were recognized as partnered.

Injury Variables

The GCS score from the initial physician's note on admission to the ED came from the EMR, while the Injury Severity Scale (ISS) score came from the trauma registry. The ISS is a measure designed to reflect the extent and overall intensity of an individual's bodily injuries (Baker, O'Neil, Haddon & Long, 1974; Baker & O'Neil, 1976). The ISS ranges from 1 (least severe) to 75 (most severe) with higher scores indicating greater likelihood of mortality (Baker & O'Neil 1976).

Nightly Caregiving

Nursing activities carried out between the hours of 2200 and 0800 were identified as nighttime care activities. The time interval of nighttime care was selected based on the combined clinical experience of the authors. It was agreed that this time interval is when patients were expected to be sleeping, preparing for sleep, or emerging from sleep. These activities included toileting the patient, providing oral care, patient hygiene, turning the patient, and giving medications. Though not exhaustive, these care activities are common among neuroscience specialty intermediate care unit patients with severe TBI who are generally unable to provide self-care (Nelson et al., 2015). Each activity was extracted from the EMR for either the first seven days the patient was housed on the unit, until the patient was discharged from the unit, or until the patient was transferred to a higher level of care (ICU) for unforeseen complications. In any event, the data from the patient were still used. Subsequently, the five nighttime care activities were averaged over each patient's respective days of data collection on the unit. For example, if a patient was on the unit for three days and then was transferred to the ICU owing to complications, their nighttime care activities were averaged over 3 days. This data was then collapsed into a single category that gave an average of all nighttime care activities. This average of all care activities was named "mean nighttime care activities" and reflected the specific LOS for each of the 34 patients.

Sleep Variable

A binary questionnaire ("Yes/No") was used to extract data from the EMR-based, nurses' end-of-shift summary. This questionnaire asked whether or not the patient slept well. "Yes" was recorded if there was explicit documentation in the summary by the nurse that the patient slept well or slept well through the night. "No" was recorded if there was documentation that the patient did not sleep well or slept poorly. Accounts of patient "currently resting" were not included in the analysis because these statements do not explicitly speak to the quality of sleep. If there was no report of whether the patient had or had not slept well, then an "unknown" response was recorded.

Data Analysis

SPSS 19.0 (IBM, Armonk, New York) and [R]Studio (3.3.1) was used to manage and analyze the data. Data analyses include descriptive statistics, bivariate correlations, and simple regression analyses. A p-value ≤ 0.05 was considered statistically significant.

Controlling for Confounding Variables

Given that the authors were interested in nursing care as the independent variable, rather than patient factors, controlling for age was not appropriate in this context. As such there should be no difference in care activities based on age alone. Also, given that the dependent variable—"slept well"-- was the documented account of the night-shift nurses' end-of-shift-summary, there is no evidence to support that the dependent variable would change with the statistical controlling of age. For objective measures of sleep (actigraphy/ polysomnography), controlling for age and other patient factors would be appropriate, however, in this context of patients with TBI, it is not appropriate to consider. Conversely, future studies should control for these patient factors when looking at objective measures of sleep (Arnardóttir, Thorsteinsson, & Karlsson, 2010).

Correlation

To see if there was a relationship between the percent of nights the patient was documented as sleeping well (dependent variable) and the mean nighttime care activities (independent variable), a correlation (zero-order) was calculated. This statistic ranges from +1 to -1 and values closer to either of the numbers indicate a strong relationship between the variables being compared.

Simple Regression

A simple regression analysis was conducted to see if mean nighttime care could predict the percent of nights the patient was reported as sleeping well.

Results

Characteristics and Demographics

Of the study sample (n=34), 88.2% were male (n=30), 79.4% were white (n=27), and the average age was 46 years old. (see Table 1 for details on sample characteristics and demographics). Figure 1 shows a scatter-plot of individual observations for each of the 34 patients. The entire sample was documented as sleeping well for less than half (< 50%) of the nights they were housed on the neuroscience specialty intermediate care unit. Based on descriptive statistics and sample characteristics, patients in this study were similar in their demographics to other published studies of hospitalized TBI patients (Chiu et al., 2013; Susman et al., 2002; Udekwu, Kromhout-Schiro, Vaslef, Baker, & Oller, 2004).

Table 1. ***Demographic Characteristics of Intermediate-care Patients with TBI on Neuroscience Unit (N=34)***

Measure	n	%
Male	30	88.2
White	27	79.4
Marital status: Single	16	47.1
Marital status: Married	14	41.2
Had health insurance	22	64.7
	M	**SD**
Length of stay on unit (days)	5.91	1.78
Glasgow Coma Scale Score (GCS)	4.09	1.96
Injury Severity Score (ISS)	29.18	16.13
Functional Independence		
Measure (mFIM)	7.62	3.06
Patient Age	46.68	18.32

Note: The GCS used for this study was obtained from initial physicians note in the emergency department.

Figure 1.

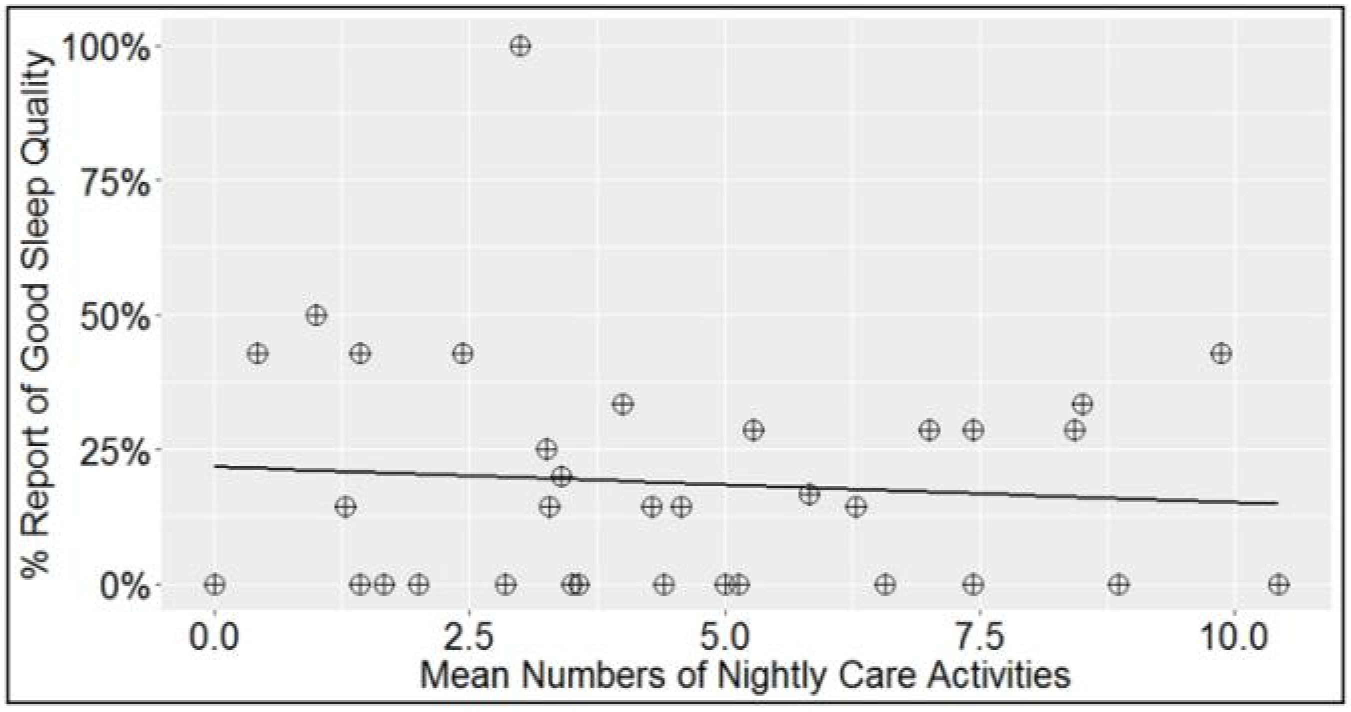

Table 2. ***The Study Samples' Documented Care Activities per Night (N=34)***

Measure	M	SD	Min.	Max.
Toilet	1.7	1.1	0	4.0
Turns	1.5	1.0	0	3.6
Bath	1.2	0.9	0	4.0
Medication	1.0	1.2	0	6.7
Oral	0.2	0.4	0	1.4
Total	5.6	4.6	0	19.7

The mean nighttime care activities range from 0 to 10; this means that some patients received as many as 10 care-activities on a given night. The average number of nighttime nursing care activities (Table 2) administered between the hours of 2200 to 0800 was 5.6.

Correlation & Regression

Table 3 shows the output from the zero-order correlation. The Pearson r between documented sleep quality and mean nighttime care was weak (*r* = 0.05). Conversely, Table 4 shows the Pearson *r* when medications are not included as a care activity.

Table 3. ***Zero-Order Correlations Including Medication as a Nighttime Care Activity (N=34)***

Measure	M	SD	1.	2.
Outcomes				
1. Reports of sleeping well	0.2	(0.2)	--	
Predictors				
2. Mean of nighttime care activities	5.6	(2.4)	.05	--

Note: Report of sleeping well is a proportion, but is treated as a percentage in the body of this article; p-value = 0.8.

Table 4. ***Zero-Order Correlations Excluding Medications as a Nighttime Care Activity (N=34)***

Measure	M	SD	1.	2.
Outcomes				
1. Reports of sleeping well	0.2	(0.2)	--	
Predictors				
2. Mean of nighttime care activities	4.5	(2.8)	-.08	--

Note: Report of sleeping well is a proportion, but is treated as a percentage in the body of this article; p-value = 0.6.

Table 5 shows the regression model which suggests that, given the mean amount of nighttime care activity, patients in this sample were expected to sleep well for about 16% of the nights they were housed on the unit; that is, about 1-2 nights in the first week. Table 6 shows what the regression model would look like without medication included as a care activity. Furthermore, the percent of nights the patients slept well can be expected to increase by 0.05% for each additional care activity.

Table 5. ***Simple Linear Regression for Percentage of Nights Patients Slept Well and Mean Nighttime Care Including Medication Administration (N=34)***

	R^2_{total}	$R^2_{adjusted}$	F(1,32)	p	b	(SE)	t(32)	p
Report of slept well	0.002	-0.03	0.09	.765				
Intercept					0.16	(0.09)	1.70.	09
Mean nighttime care w/ RX					0.004	(0.02)	0.30	.765

Note: Mean nighttime care activity is an average of nursing care activities completed between the hours of 2200-0800. Reports of "slept well" is the percent of nights (here listed in proportion form) a patient was documented as having slept well. Predictors were not standardized for analysis. RX is short hand for medications.

Table 6. ***Simple Linear Regression for Percentage of Nights Patients Slept Well and Mean Nighttime Care Excluding Medication Administration (N=34)***

	R^2_{total}	$R^2_{adjusted}$	F(1,32)	p	b	(SE)	t(32)	p
Report of slept well	0.007	-0.024	0.23	.634				
Intercept					0.22	(0.07)	2.97	.006
Mean nighttime care					-0.007	(0.01)	-0.48	.634

Note: Mean nighttime care activity is an average of nursing care activities completed between the hours of 2200-0800. Reports of "slept well" is the percent of nights (here listed in proportion form) a patient was documented as having slept well. Predictors were not standardized for analysis.

Discussion

Main Findings

The main results of this study suggest that there was not association between mean nighttime care activities and the nurses' documentation of the patients sleep quality. Furthermore, nighttime care activities from the EMR did not seem to be a reliable predictor of the patient's sleep quality (which was also based on the nurses' end-of-shift summary).

No Relationship between Mean Nightly Care activities and Sleep Quality

This finding was likely related to the limited documentation of sleep quality found in the EMR. Our findings of "no relationship" and "no clinical significance between the documented accounts of sleep quality and documented nighttime nursing activities" were consistent with results of a study done by Ugras and colleagues (2015) where the frequency of nocturnal patient care activities and reports of patient's sleep disturbance in a neurosurgical ICU were not statistically significant. The care activities included in our analysis were similar to those used in the Ugras et al. 2015 analysis.

Unlike our study, Ugras et al. (2015) developed their own questionnaire for collecting the patient's sleep quality and collected data in a prospective manner. The studies by Ugras and colleagues (2007, 2015) also focused on ICU patients, thus our study extends available knowledge to intermediate care patients in neuroscience specialty units. A study of (non-TBI) intermediate care patients (n=108) in a tertiary, general-ward hospital also failed to find a statistically significant difference between the patients' report of being sleep deprived and environmental/health personnel related factors (Shafiq et al., 2006). Some of the reasons cited for this result include: investigating the patient's sleep only during the night, the patient's recall bias, and patient's attitudes and expectations of care (Shafiq et al., 2006).

A drawback to the retrospective chart review is that we could not account for the quality of information initially entered in the chart. However, results from a study by Ritmala-Castren, and colleagues, (2014) showed that patient's report of sleep quality and nurse documentation of sleep corresponded only about 57% of the time. In that study, nurses documented the overall quality of the patient's sleep for just 27% of the patients (n = 114)—a result that was similar to our report. Both the study by Ritmala-Castren et al. (2014) and this study reinforced the need for better documentation of sleep quality in the medical record. This could be accomplished with a specific item in the flowsheet and may heighten nurses' awareness of the importance of sleep for hospitalized patients. Interestingly, data from a time and motion study of night-shift nurses (Desjardins, Cardinal, Belzile, & McCusker, 2008) suggest night-shift nurses spend significantly more time on indirect care, including documentation, compared to their evening-shift and day-shift counterparts. Thus, the quality of documentation would be expected to be better on the night-shift. Furthermore, based on the available documentation, we were unable to tell who initiated certain care activities like toileting.

That there was not association between mean nightly care activities and sleep quality may also be due to the way we chose to define and quantify nursing activities. Though we could not identify a standard tool to quantify nursing care in an intermediate hospital setting, a modified use of the ICU-specific nursing activities score (NAS) may have been an alternative approach (Miranda, Nap, de Rijk, Schaufeli, Iapichino, & TISS Working Group, 2003; Reis-Miranda & Jegers, 2012). The types of nursing activities we selected may have also been an issue. Medication administration carries a mild weight per the NAS (Miranda et al., 2003). The heterogeneity in how researchers capture what hospital nurses do generally (Reis-Miranda & Jegers, 2012) and what hospital nurses on night shift do (Nelson et al., 2015) can be a problem for the development of environment of care interventions. Another limitation was that sleep quality was not assessed with a gold standard measure like actigraphy or polysomnography.

This is an area for future research.

Strengths of this study were that its methods and analyses can be implemented and conducted with relative ease. Seamless and parsimonious methodologies are important when initiating research in patients associated with an understudied phase of care like those described here (patients with moderate and severe TBI). Moreover, this study added to the growing body of literature concerning sleep and health outcomes of patients hospitalized with TBI by showing the frequent occurrence of patient-care activities during nighttime hours. Where previous work in this target population has focused on sleep disturbances in the ICU/critical care phase, with this study, we were able initiate a discourse about those housed on a neuroscience specialty intermediate-care unit.

Clinical Implications

Despite overwhelming evidence that patients with TBI have trouble sleeping (Ouellet, Beaulieu-Bonneau, & Morin, 2015), further studies need to be done to uncover the mutable causes among severely injured, hospitalized sub-populations. Even if documentation of patient sleep may not be widely practiced in some hospital organizations (Meissner, Riemer, Santiago, Stein, Goldman, & Williams, 1998; Ritmala-Castren et al., 2014), improved documentation could benefit the intermediate-care patient with TBI (Gearing, Olney, Davis, Lozano, Smith, & Friedman, 2006) given the known influence of quality sleep on cognition and functional outcomes (Sandsmark et al., 2016). Intentional documentation of patient sleep quality may cause the health-care team to pay closer attention to hospital factors that influence the patient's sleep health (Griffith, Thompson, Rathore, Jehi, Tesar, & Katzan, 2015; Hillestad et al., 2005). Closer attention to the environmental factors that may influence the sleep health of patients with TBI may challenge the health-care team's perception that sleep disturbances in these patients are unmodifiable (Alway et al., 2013; Yoder et al., 2013). This may allow for bedside nurses to advocate for sleep-promoting, environment-of-care changes in a more impactful way. Moreover, a standard method of assessing, diagnosing, planning, implementing, evaluating and documenting sleep health should be a part of this initiative (Enomoto et al., 2010; Fanfulla, Ceriana, D'Artavilla- Lupo, Trentin, Frigerio, & Nava, 2011). More empirical research studies need to be conducted on this group so that pertinent guidance about documentation of sleep/rest can be enacted; this guidance can better inform nursing interventions to promote sleep health and improve overall quality of life while in the hospital.

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Historical and Feminist Perspectives on Depression in Mothers of Children with Autism Spectrum Disorders

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Abstract
Mothers of children with Autism Spectrum Disorder (ASD) are at very high risk for depression. The prevalence estimate of depression in this population is 36.5%, compared to 10% in the general adult population. Using Albert Bandura's Social Cognitive Theory as a framework, this analysis discusses the phenomenon of interest from both a historical and a feminist perspective. Examples of research questions and corresponding methods for each perspective are discussed, as well as the advantages and disadvantages of each theoretical approach. Based on the present analysis, future research should include both mothers and fathers, and interventions to improve depression should focus on the parent in the context of the family, not just the child's behavior.

Keywords: Autism spectrum disorders, parents, mothers, depression, historicism, feminism

Autism Spectrum Disorder (ASD) is a neurodevelopmental condition affecting 1 in 68 children and is characterized by deficits in social communication and interaction as well as repetitive behaviors or interests (Centers for Disease Control and Prevention [CDC], 2014; American Psychiatric Association [APA], 2013). As prevalence reports are rising and public awareness is increasing, the issues surrounding ASD, particularly regarding etiology and treatments, have become a topic of debate in both the popular media and within scientific circles. Despite many uncertainties in the science, one finding is consistent and well-established in the literature: raising a child with ASD is a stressful experience. Parents of children with ASD have higher rates of stress, anxiety and depression than parents of typically-developing (TD) children (Fisman, Wolf & Noh, 1989; Ingersoll, Meyer & Becker, 2011; Almansour, Alateeq, Alzahrani, Algeffari & Alhomaidan, 2013; van Steijn, Oerlemans, van Aken, Buitelaar & Rommelse, 2014; Olsson & Hwang, 2001) and parents of children with other disabilities including developmental delay, Down syndrome, fragile X, cerebral palsy, and intellectual disability (Dumas, Wolf, Fisman & Culligan, 1991; Eisenhower, Baker & Blacher, 2005; Montes & Halterman, 2007; Piven & Palmer, 1999; Olsson & Hwang, 2001). In addition to the child's symptoms and behavioral problems, these parents must also face social stigma and frustration navigating special needs services (Benson, 2006; Bromley, Hare, Davison & Emerson, 2004; Ekas & Whitman, 2010; Farrugia, 2009; Firth & Dryer, 2013; Feldman, Hancock, Rielly, Minnes & Cairns, 2000; Phetrasuwan & Shandor Miles, 2009; Schieve, Blumberg, Rice, Visser & Boyle, 2007; Tomanik, Harris & Hawkins, 2004; Zablotsky, Anderson & Law, 2013). Depression is an emotional state involving persistent sadness and loss of interest in activities (APA, 2013). While depression affects 10% of the general adult population, studies report that 28-79% (median 36.5%) of mothers of children with ASD suffer from clinically-significant depressive symptoms (Abbeduto et al., 2004; Carter, Martinez-Pedraza & Gray, 2009; Garber, Ciesla, McCauley, Diamond & Schloredt, 2011; Gatzoyia et al, 2014; Micali, Chakrabarti & Fombonne, 2004; Smith, Seltzer, Tager-Flusberg, Greenberg & Carter, 2008; Taylor & Warren, 2012). The high prevalence of depressive symptoms in mothers of children with ASD has important implications for the mother's quality of life and the well being of her family, as well as the child's development.

Depressive symptoms in a mother can affect all family dynamics and the ability to interact successfully with her child. Moreover, mothers with low self-esteem and frequent feelings of hopelessness may be unable to implement complex treatments in their home. The leading intervention for ASD is applied behavioral analysis (ABA) which uses behavioral assessments and behavioral strategies to increase social skills acquisition and decrease undesirable behaviors in a child with ASD. In order to ensure effectiveness, the behavioral plan for a child requires the mother to implement the intervention independently with fidelity in their own home (Feinberg et al., 2014). However, depressive symptoms in a mother can affect the implementation, which may lead to feelings of inadequacy and a worsening of depressive symptoms (Mahoney, Boyce, Fewell, Spiker & Wheedon, 1998; Osborne, McHugh, Saunders & Reed, 2008). A greater understanding of this phenomenon is critically needed for the Autism community.

Researchers and clinicians are interested in gaining a greater understanding of the relationships among parental characteristics, child characteristics, risk factors and depressive symptoms in this population to inform the development of tailored and effective interventions for mothers of children with ASD. Albert Bandura's Social Cognitive Theory can be used as a framework to illustrate the relationships among risk factors (see Appendix). The theory proposes bidirectional relationships among one's behavior, environment, and personal factors including thoughts, beliefs and emotions (Bandura, 1986). A person experiencing depression holds negative self-perceptions, leading to maladaptive coping behaviors and negative interactions with the environment. These negative interactions reinforce the poor self-perceptions, resulting in a feedback loop of negativity. The concept of self-efficacy, a person's judgment of his or her ability to act in a specific context, is central to the Social Cognitive Theory (Bandura, 1986). One's sense of self-efficacy develops based on past experience, vicarious experience, social interactions, and physiological and emotional state (Bandura, 1986).

The low self-efficacy which is present in depression plays a key role in the negative cycle described above not only as a personal factor, but also as a mediator. There is evidence indicating that self-efficacy mediates the relationship between child behavior and maternal depression (Hastings & Brown, 2002; Rezendes & Scarpa, 2011). The presence of this mediator has crucial implications for interventions. Given the large body of evidence connecting child problem behaviors to maternal depression, studies recommend treating the problem behavior with the end goal of improving maternal depression. However, this recommendation overlooks both the role of self-efficacy and the impact of maternal depression on intervention effectiveness. In order to improve depressive symptoms in this population, research should not only focus on the environmental factor of child behaviors but should emphasize the critical importance of the mother's personal factors.

The purpose of the present paper is to analyze the phenomenon of maternal depression using both a historical and a feminist lens, and to propose areas of research based on the perspectives. Examples of research questions and corresponding methods for each philosophy are discussed, as well as the advantages and disadvantages of each theoretical approach. Based on the present analysis, there are also suggestions for future research directions and changes to clinical practice.

A Historical Approach

Historians declare that truth and knowledge cannot be separated from their particular context of person, place and time (Reed & Crawford Shearer, 2012). The study of history is the search for truth in the past with the purpose of understanding the present and applying that truth to the future (Gaddis, 2002). While other theoretical perspectives are interested in results, history concerns itself with processes (Reed & Crawford Shearer, 2012). This search often becomes the examination of cause, which cannot be known in the absence of context (Gaddis, 2002). Some historians would even argue that there is no single cause for an event, for every cause has an antecedent, and that instead history results from the intersection of multiple causes of varying significance (Gaddis, 2002).

Since the past cannot be replicated, the historian creates a representation of a past reality through a narrative. By choosing what details to include in the narrative, the historian becomes responsible for communicating the truth in a succinct but complete way (Gaddis, 2002). To provide this narrative accurately, the historian must become immersed in the culture of the place and time of interest, while simultaneously taking advantage of the broadened understanding made capable by retrospect (Gaddis, 2002). However, the historian must be careful to remain objective and withhold subconscious moral judgments of past events based on current values and knowledge (Gaddis, 2002). These judgments are bound to the context in which the historian writes the narrative, limiting the generalizability of the analysis. If the historian chooses to include these judgments, the writer's bias should be purposeful and made clear to the reader, for it does not represent the truth of the period of interest.
Since ASD was first described in 1943, scientists have engaged in the search for a definitive cause, resulting in some controversial attributions regarding the etiology of ASD. In 1943, Leo Kanner, a child psychiatrist and the head of the Behavior Clinic for Children at Johns Hopkins University, published a case series describing the symptoms and behaviors of eleven children at the clinic. He borrowed the term 'autism' from a Swiss psychologist who had used the term in 1910 to describe symptoms of childhood schizophrenia (Silverman, 2012). Kanner began using 'autism,' 'schizophrenia' and 'psychosis' interchangeably. In addition to recording the

children's repetitive and obsessive behavior, language delays, and peculiar use of language, he also wrote about the parents of the children as being unloving, mechanical and obsessive. While Kanner himself believed autism to be of an organic origin, he chose to leave the explanation for etiology very open to interpretation in this report, setting the stage for later debates regarding the role of parents in the development of autism (Silverman, 2012). One year later Hans Asperger, a child psychiatrist in Vienna, published his own case study of autistic children. The children described in Asperger's report had more language skills than those in Kanner's, and Asperger believed autism to be an "abnormal personality structure" instead of a disability (Silverman, 2012, p.37). He emphasized the children's talents and believed they could be successful in life despite their social quirks. Asperger supported the idea that autism develops organically and acknowledged the potential role of heritability. Meanwhile in Baltimore, Kanner did not believe that genetics play a role. In emphasizing that "the emotional refrigeration which the children experience from such parents cannot but be a highly pathogenic element in the patients' early personality development, superimposed powerfully on whatever predisposition had come from inheritance," Kanner inadvertently coined the term 'refrigerator mothers' which has haunted mothers since the 1950s (Kanner & Eisenberg, 1956; Silverman, 2012, p.38). Kanner's readers understood his statement to mean that mothers who are emotionally distant from their children cause a lack of infant bonding and a failure to develop socially.

Kanner and colleague Leon Eisenberg published the diagnostic criteria for autism in 1956, describing it as "extremely aloof behavior, repetitive and circumscribed activities, and near-typical intelligence" (Silverman, 2012, p.39). Once the criteria were defined, other scientists started studying autism and publishing their ideas regarding etiology, creating tension between supporters of the psychogenic theories and supporters of the biological theories. The most well-known researcher to implicate the family as the cause of autism is Bruno Bettelheim. He published The Empty Fortress, Infantile Autism and the Birth of the Self in 1967, which was an instant best-seller. Despite his fame, his credentials and methods have since been brought under serious scrutiny (Silverman, 2012).

Despite Kanner and Eisenberg's diagnostic criteria, autism was not an independent diagnosis in the second edition of The Diagnostic and Statistical Manual (DSM) published in 1968. The term was used to describe the criteria for schizophrenia, childhood type as "autistic, atypical or withdrawn behavior, failure to develop identity separate from the mother's and general unevenness, gross immaturity, and inadequacy in development" (Silverman, 2012, p.40). To further the development of the science surrounding autism, Kanner founded the Journal of Autism and Childhood Schizophrenia in 1971. The journal was later renamed The Journal of Autism and Developmental Disorders as it is known today.

Autism began to gain legitimacy as a diagnosis and as a science in the late 1970s and 1980s. In 1975, parents successfully lobbied for autism to be included in the Individuals with Disabilities Education Act to ensure their right to free public education. The DSM-III in 1980 included infantile autism under the category of pervasive developmental disorder. Researchers began using magnetic resonance imaging and computed tomography scans to compare brain imaging between autistic and typically-developing individuals, indicating a shift in scientific thought toward the biological theory (Silverman, 2012). The criteria for an autism diagnosis became more inclusive when it was renamed autistic disorder in the 1987 DSM-III-R. The gold standard diagnostic instruments, the Autism Diagnostic Observation Schedule and the Autism Diagnostic Interview, both of which are still used today, were published in 1989. The 1990s and 2000s offered fast-moving research, new ways of defining autism, and new controversies. Hans Asperger's work was published in English in 1991, offering a different view of autism to the English-speaking world (Silverman, 2012). Asperger's disorder was added to the DSM-IV in 1994. In 1998, the infamous article claiming a link between the MMR vaccine and childhood autism was published. The article has since been redacted and the evidence refuted, but not before it could leave a permanent stain on the public's feeling of safety regarding vaccines. In 2007, the Centers for Disease Control (CDC) released its first estimate of the prevalence of autism as 1 in 150 children (CDC, 2014). In 2012, the DSM-V radically reorganized the criteria for diagnosis of Autism Spectrum Disorder as occurring along a continuum, encompassing what used to be divided into Autism, Asperger's Syndrome and Pervasive Developmental Delay. In the same year, the CDC also released a new estimate of 1 in 88 children (CDC, 2014). In 2014, the CDC released its most recent prevalence estimate of 1 in 68 children (CDC, 2014).

The history of autism sheds light on issues surrounding the disorder to this day. Researchers and parents alike are still searching for the cause and the cure. The consensus among scientists is that the etiology lies in a combination of genetics and environmental interactions. There is no cure per se, but behavioral therapies have been shown to be effective in improving symptoms. These answers are not sufficient for many parents who are desperate to know why their child has autism and how to face the difficulties of raising him or her. Many parents turn to the internet and the media for advice and support, which reveals that some parents still do not trust vaccines. Others are willing to try anything, including the gluten-free casein-free diet which actor Jenny McCarthy claims cured her son's autism, in the absence of any evidence base. This uncertainty, combined with the tradition of blaming 'refrigerator mothers,' can lead mothers to feel guilty for their child's disorder. The sentiments of uncertainty, blame and guilt are echoed in mothers' accounts about their feelings of depression (Dale et al., 2006).

Future research using historical methods would be helpful in understanding more about the perspectives of mothers of children with ASD from the 1940s to the present. Some research questions the historian might ask include (1) how has the presence of depressive symptoms in mothers of children with ASD changed over time, (2) how have mothers' coping strategies changed since the 1940s, and (3) what do mothers from different decades believe to be the cause of ASD? Answers to these questions can promote an appreciation for the historical underpinnings of the ASD diagnosis and give researchers and providers unique insight into mothers' experiences in the present.

The historian would need access to primary sources such as medical records, diaries, letters and interviews. However, the sources may be limited in the information they offer. The number of recorded diagnosed cases of ASD is very low in the early years of the time period of interest. Of those recorded cases, some may be misdiagnosed due to the early stages of the development of diagnostic criteria and methods. The limited availability of data restricts the questions that can be studied and the potential generalizations. For these reasons, the researcher may benefit from the added perspective of the feminist method.

A Feminist Approach

Feminism cannot be defined succinctly for it encompasses several different theoretical perspectives regarding gender, including liberal feminism, radical feminism, and poststructural feminism. Feminism has developed in reaction to mainstream thought applying men's experiences to all humans and placing higher value on it than the women's experiences (Beasley, 1999). Liberal feminism is based on the idea that men and women are equals, and the social remedy lies in simply including women in the spheres typically reserved for men (Beasley, 1999). Radical feminism highlights and celebrates the differences between men and women, and calls for a social revolution in response to sexual oppression (Beasley, 1999).

Poststructural feminism, which developed from the writings of Michel Foucault, disregards the issue of sameness or difference of the sexes and instead focuses on power structures (Beasley, 1999). Poststructural feminists do not seek to create one unifying female identity because women are not a homogenous category and womanhood is not a static concept (Beasley, 1999). In lieu of favoring one gender over another, the transcendence of gender can increase objectivity in discourse (Harding, 1986). The woman's identity and subjectivity are formed instead "within the interstices of powerful discourses, languages, and vocabularies that operate subtly to mold gender, race, class, and sexual identity" (Thompson, 2007, p.134). This theory rejects metanarratives such as oppression, freedom and liberation, and instead proposes that discourse develops in a historical context and is subject to change (Doering, 1992; Thompson, 2007).

Despite the theoretical differences, there are some common threads connecting feminist thought and research methods. The first is that the analysis centers around the woman, womanhood, and the woman's experience, maintaining an awareness of possible differences among women (Beasley, 1999; Campbell & Bunting, 1991). The second is that the goal of a line of inquiry is to understand the perspective of a particular group of women, highlighting subjective information including emotion (Campbell & Bunting, 1991). Lastly, feminist research actively attempts to improve the status of women in society and criticizes any form of sexual hierarchy (Beasley, 1999; Campbell & Bunting, 1991). Further, feminist research methods are based on four assumptions: women's experience can be a legitimate source of knowledge; subjective data are valid; research participants are 'experts' on their own lives; knowledge is relational and contextual (Campbell & Bunting, 1991). Research questions should focus on issues that women want to address, and research should be executed in a nonhierarchical manner wherein researchers and subjects should be considered partners (Campbell & Bunting, 1991). For this reason, research subjects should be referred to as 'participants.'

The literature regarding parents of children with ASD indicates that there are differences in mothers' and fathers' experiences in raising a child with ASD. While both mothers and fathers experience psychological distress, the level and sources of stress differ between mothers and fathers, with mothers consistently reporting higher levels of stress and depression than fathers (Davis & Carter, 2008; Fisman et al., 1989; Hastings et al., 2005b; Foody, James & Leader, 2014; Moes, Koegel, Schreibman & Loos, 1992; Herring et al., 2006; Sharpley & Bitsika, 1997; Olsson & Hwang, 2001). Very high rates of depression occur among women during their child-bearing and child-rearing years (Garber, Ciesla, McCauley, Diamond & Schloredt, 2011). Not only does child behavior have a stronger impact on mothers' stress than fathers' (Hastings et al., 2005b), but different aspects of child behavior are associated with stress in each parent (Davis & Carter, 2008). Mothers and fathers also differ in the way they perceive their environment; specifically, mothers have more positive perceptions than fathers regarding social support from family and friends (Hastings et al., 2005b; Altiere & von Kluge, 2009). For families of children with ASD, the presence of a father in the home is a protective factor against maternal depression (Olsson & Hwang, 2001; Machado, Celestino, Serra, Caron & Pondé, 2014). Meanwhile, mothers who are younger (Barker et al., 2011), face more financial barriers (Gatzoyia et al., 2014; Abbeduto et al., 2004; Taylor & Warren, 2012), have a family history of depression (Eriksson, Westerlund, Anderlid, Gillberg & Fernell, 2012; Piven et al., 1991) or who themselves present with symptoms of ADHD or ASD are more at risk for depression (van Steijn et al., 2014; Ingersoll et al., 2011).

In the case of motherhood and mental illness, responsibility and blame are two key forms of social control. Women, regardless of their employment outside of the home, assume the majority of responsibility in domestic life and child-rearing, subjecting mothers to blame when their children misbehave or experience illness (Jackson & Mannix, 2004; Schiebinger, 1999). Women performing child care often must interact with health professionals, opening their actions to scrutiny and judgment from providers which the fathers can avoid (Jackson & Mannix, 2004). Many mothers feel that their child's health care provider is judging or blaming them for their child's condition; these feelings are not unfounded, for a review of the literature revealed that 72 psychopathologies are blamed on mothers, including arson, fetishism, incest, incontinence, schizophrenia, sibling jealousy, transsexualism, tantrums, and ulcerative colitis (Jackson & Mannix 2004). This blame causes women to question themselves, lowering their perceptions of parenting self-efficacy and leaving them vulnerable to experience depressive symptoms.

Social roles delineate expectations of normal behavior and, just as importantly, make it possible to identify abnormal behavior. Psychiatry and the medicalization of unhappiness have been used to restrict women to their prescribed social role as wife and mother (Wright & Owen, 2001). A woman who does not perform the duties of her role is considered to suffer from some mental pathology. When a person is unhappy, he or she attempts to find and address the source of the unhappiness in his or her life; however, when unhappiness is diagnosed as anxiety or depression, the person stops searching outside of herself for the source of unhappiness. In western culture, depression has tended to be more of a female than a male disorder (Wright & Owen, 2001). Men tend to cope by placing blame outside of themselves, resulting in violence; women tend to internalize and blame themselves, which increases the likelihood of depression (Wright & Owen, 2001).

Self-blame is a particularly salient issue for mothers of children with ASD, as women can only speculate about the cause of their child's condition yet historical precedent blames mothers, as previously discussed. In a mixed-methods study involving interviews with 16 mothers, the mothers attribute their child's ASD to a variety of causes, including genetics, complications during pregnancy and birth, the MMR vaccine, and maternal behaviors (Dale, Jahoda & Knott, 2006). Even when mothers believe the cause to be out of their control, they blame themselves for passing on a gene or for having their children vaccinated. Mothers who believe they have personal control over their child's condition report higher levels of depressive symptoms (Dale et al., 2006). Furthermore, mothers are angry and frustrated about the lack of support and the burden of responsibility.

More research using feminist methods is needed to answer questions such as (1) What is the prevalence of depression among mothers compared to fathers of children with ASD? (2) Do mothers and fathers differ in their perceptions of parenting self-efficacy? and (3) What kind of intervention improves depressive symptoms in mothers of children with ASD? A variety of methods can be used to study these questions, including epidemiological studies, surveys, qualitative interviews, and randomized-controlled trials. It is important to note that, in order to be able to detect any gender differences, data should be analyzed separately based on the gender of the participant.

Implications for Future Research and Practice

In contrast to the historical perspective, the feminist perspective offers the researcher more freedom in terms of research topics and methods, and has greater potential to influence practice. A feminist suggestion for nursing practice emphasizes asking mothers about their experiences with motherhood during women's health assessments, giving them an opportunity to reflect which can be beneficial to mental health (Jackson & Mannix, 2003). However, this perspective is not without its drawbacks. Ignoring gender issues leaves invisible hierarchies in place, but calling attention to stereotypes may reinforce them, a phenomenon known as the difference dilemma (Schiebinger, 1999). The researcher needs to be aware of his or her own assumptions and expectations of behavior (Wright & Owen, 2001). It is important for future ASD research to include both mothers and fathers in order to avoid further perpetuating assumptions of maternal responsibility and blame (Jackson & Mannix 2004; Wright & Owen, 2001). Researchers and providers alike should employ parent-focused, instead of child-focused, interventions to improve parental depression. Fathers should not be excluded from intervention studies for they also experience depression; however, the results should be analyzed separately for mothers and fathers to assess differences in effectiveness. Examples of interventions that have been successful in this population include problem-solving education (Feinberg et al., 2014), Mindfulness-Based Stress Reduction and Positive Adult Development (Dykens, Fisher, Taylor, Lambert & Miodrag, 2014).

Conclusion

While a historical analysis of ASD offers valuable insight into the experience of mothers today, the feminist approach is more useful for those researchers interested in creating interventions. Focusing on the personal factors described in Bandura's Social Cognitive Theory, especially emotion, is a goal that is in harmony with feminist thinking. More research is needed to further explore parents' experiences and thoughts about raising a child with ASD. Provider training needs to be developed to raise awareness of parent depression and teach pediatric providers how to have discussions about parents' mental health. Researchers and providers should be sensitive to mothers' feelings of guilt even in the absence of overt blame, and should understand that these mothers desperately need to be supported.

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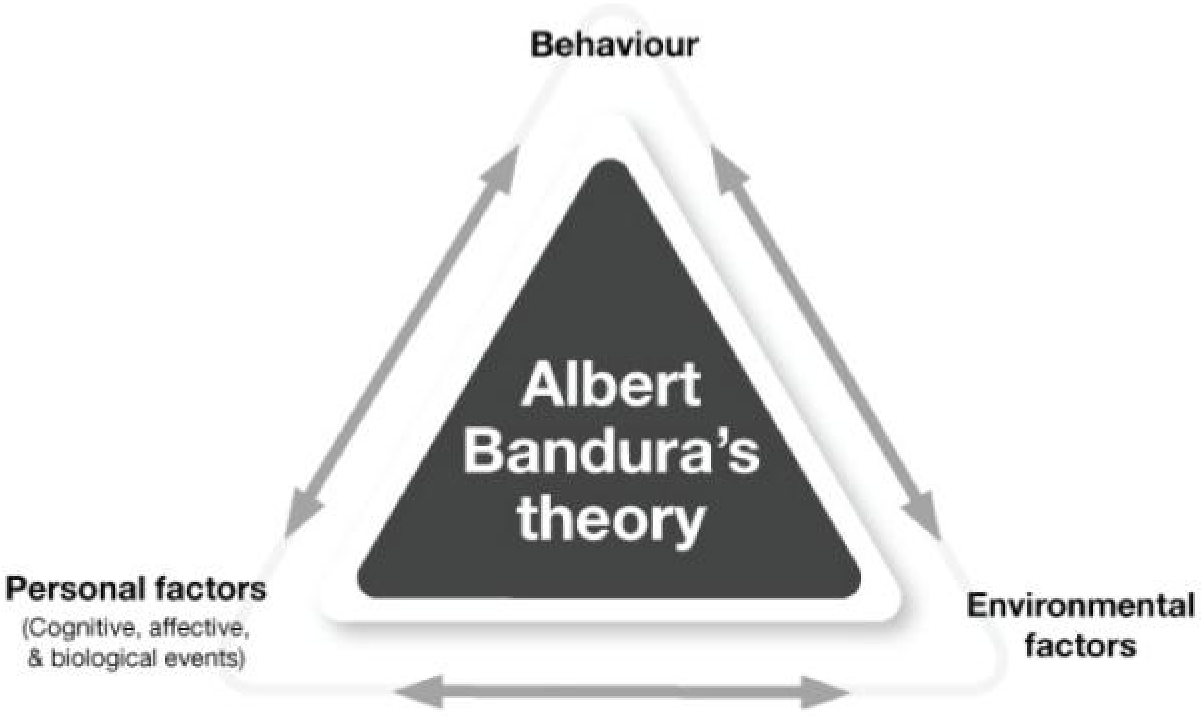
Appendix

Model of Albert Bandura's Social Cognitive Theory



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The Journal of Nursing Doctoral Students Scholarship is a scholarly publication dedicated to the development of doctoral student scholarship and the advancement of nursing science. This journal is peer reviewed by doctoral students, edited by doctoral students, and targeted towards health practitioners, educators, scientists, and students. This journal has both a professional and an educational mission. To serve the profession, each issue features articles that represent diverse ideas, spark intellectual curiosity, and challenge existing paradigms. Doctoral students will have an opportunity to explore and analyze issues and ideas that shape health care, the nursing profession, and research around the world. To fulfill its educational mission, doctoral students will be trained in the editorial and administrative tasks associated with the journal's publication and assisted in preparing original manuscripts for professional publication. This journal will be evidence of the scholarly development of nurse scientists.

Types of acceptable manuscripts for submission:

- Personal Opinion Pieces
- Reflections on Practice, Research or Policy
- Historical Research
- Methodological Articles
- Case Studies
- Commentaries
- Research Briefs
- Concept Analysis
- Theoretical Frameworks
- Systematic or Focused Literature Reviews

Author Guidelines

We prefer manuscripts no longer than 20 pages and no shorter than 3 pages (font: Times New Roman; font Size: 12 points; text Color: black; double spaced; margins -1 inch; text in one column). However, special considerations will be made for submissions that exceed the requested size. We prefer references following the APA 6th edition format but we will accept any other citation style. Please place each figure or table in the body of the manuscript and on a separate page at the end of the manuscript. Please send your submissions in a Word format to the Guy Weissinger, Editor, and Marta Bruce, Editor-Elect at JNDSS@nursing.upenn.edu

Manuscripts will be reviewed by at least 2 reviewers. In the event that reviewers have a request for minor revisions, the authors will have 2 weeks to complete the revisions. The target date for the sixth (6th) publication is Fall 2018. We are also accepting submissions of art work for consideration, including drawings and photographs. These artistic expressions related to nursing or healthcare will be incorporated and presented throughout the upcoming 6th issue of our journal.

Finally, we need your help reviewing the submitted articles. Being a reviewer is a great experience, excellent addition to your CV and a gift you are sharing with your peers. Please send us an email to JNDSS@nursing.upenn.edu to indicate your interest in becoming a reviewer.