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# Editor's Perspective

## The Role of Knowledge Development in Evidence Based Practice

As health care professionals, we all hear the word "evidence-based practice." The call for evidence-based practice has resonated throughout all areas of healthcare, including nursing practice. This directive for evidence-based health care emphasizes the need for all clinicians to provide high quality patient care that is effective, safe, and cost-effective. More than ever, nurses are being called upon to embrace evidence-based practice, holding our profession accountable to implementing high quality patient care that is also cost-effective.  As the body of knowledge and scientific literature around best practice continues to evolve, nurses need take into consideration the combination of research findings, clinical expertise, and patient preference and values when planning patient care—the foundation of evidence-based practice.  However, there may be clinical situations in which there are insufficient data and/or varying degrees of evidence within the literature to guide evidence-based decision-making in practice. A gap in current knowledge exists in these instances, providing nurse researchers and nurse clinicians with an opportunity to contribute to the knowledge base in efforts to inform evidence-based practice.

Randomized controlled trials (RCT) are considered the gold standard for testing the effectiveness of interventions, however, RCTs represent only one type of study providing evidence (Cowell, 2015). Numerous other methodologies are useful in closing the knowledge gap and contribute to the understanding of best nursing practice that is evidence-based. Recent evidence-based practice initiatives have increased the need for and the production of all types of reviews of the literature including integrative reviews, systematic reviews, meta-analyses, and qualitative reviews (Whittemore & Knafl, 2005). Scientific integrative, systematic, and meta-analytic literature reviews are recognized as valuable studies because these reviews synthesize multiple studies that address a clinical problem (Cowell, 2015).  Review methods that summarizes past empirical or theoretical literature to provide a more comprehensive understanding of a phenomenon or healthcare problem are significant in developing this knowledge (Broome, 1993).  For example, integrative reviews have the potential to build nursing science, informing research, practice, and policy initiatives and are a critical tool in providing the foundation for evidence-based nursing interventions and evidence-based clinical practice guidelines (Whittemore & Knafl, 2005).  The integrative review method is the only approach that allows for the combination of diverse methodologies and has the potential to play a greater role in evidence-based practice for nursing. Furthermore, these methods provide varied perspectives while combining diverse methodologies to create a more well-rounded evidence review. These reviews present the state of the science, contribute to theory development, and have direct applicability to practice and policy (Whittemore & Knafl, 2005).

Research and evidence-based practice both rely on a clear understanding of what is being studied—the phenomenon of interest. Antecedent to providing evidence-base practice, one needs to fully understand the phenomenon at hand. Therefore, concept analyses are also important to discerning evidence-base practice.  Concept analysis can be defined as the dissection of a concept into simpler elements to promote clarity while providing mutual understanding within nursing (Foley & Davis, 2017). They create new perspectives and help generate new knowledge, providing a foundational understanding of phenomenon to inform evidence-based practice in nursing.  Sandelowski (1996) also suggests using case studies in research so that the holistic nature of nursing care can be addressed. Therefore, nurses should take into consideration the findings from varying methodologies along the research continuum (from qualitative to quantitative methodologies) in combination with clinical expertise, and patient preference and values when planning evidence-based care to patients.

Furthermore, outcomes of evidence-based care also consider the cost effectiveness of care, effectiveness of nursing interventions, credibility of the nursing profession, and accountability for nursing practice. In this issue of the Journal of Nursing Practice Applications and Reviews of Research, knowledge developed through the abovementioned methodologies and the outcomes of evidence-based practice are disseminated to help narrow the knowledge gap and contribute to the knowledge base around evidence-based practice in nursing.  Nurses have mobilized in response to the call of evidence-based practice by promoting research initiatives, such as those within this journal issue, that highlight the valuable contributions that nurses have made, and will continue to make, to support knowledge development that serves as the foundation of evidence-based practice in nursing.

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**Cynthia Ayres, PhD, RN, FNAP**
Editor-in-Chief

# President's Message
## Make a Difference: Advocate

The Philippine Nurses Association of America (PNAA) is turning 40 years old this year, 2019!

On this 4th decade of its existence, the focus is on advocacy. After all, PNAA was organized in 1979 to advocate for Filipino nurses who immigrated to this country and found difficulties in getting licensed as registered nurses and were subjected to working conditions that were substandard compared to others working in similar capacities. Oral historians have relayed situations of Filipino nurses' living quarters that were not at par with those offered to other migrant nurses coming from Europe; evenings and nights work shift assignments were relegated to Filipino nurses, while American nurses would be assigned the day shift. Recruitment irregularities were rampant as recruitment agencies took advantage of nurses who were brought to the USA on working visas (Choy, 2003).

Racial tension was thick in the 1970's. There was an influx of immigrants and Asians were eyed with suspicion. The 1976 Narciso-Perez case in Michigan (two Filipino nurses were charged with killing ICU patients but were later exonerated) galvanized the Filipino community to band together and form a support group for the nurses (Choy, 2003). Five Filipino nursing organizations (PNA New Jersey, PNA Illinois, PNA Southern California, PNA New York and PNA Michigan) came together and formed what we now called PNAA.

At its early beginnings, PNAA set out with five-pronged goals that included "the formulation of strategies for acting on issues concerning implementation of human rights and public policies that directly or indirectly affect Philippine nurses in their personal and professional endeavors." Pioneering PNAA leaders/advocates worked to remove barriers in the work environment for Filipino nurses such as the development of procedural guidelines and policies to safeguard human rights and advocate for the nurses. Tutorial classes were held to assist in passing the nursing board examination; classes in cultural assimilation and understanding were held; and leadership scholarships were offered. The PNAA collaborated with Filipino community groups, state nursing associations, the American Nurses Association (ANA), and Philippine embassies located in few major cities in the US. In the ensuing years, advocacy for Filipino nurses in the US was among the major activities of PNAA in particular, in dealing with illegal recruitment practices, inequitable salaries, and unfair treatment in the workplace.

The PNAA has grown, now counting 51chapters with over 5000 members across the USA. In the past two decades, PNAA leaders advocated for the removal of Commission of Graduates of Foreign Nursing Schools (CGFNS) examination requirement for licensure in some states and it has successfully lobbied for making Manila as an International testing site for the National Council Licensure Examination.

Filipino nurses have become significant part of the health care landscape in America. Filipino nurses have distinguished themselves as excellent clinicians, administrators, researchers, educators, entrepreneurs, and leaders in nursing: rising to the top of their chosen fields of nursing, earning top honors from healthcare and government institutions, and contributing greatly to the Philippine Gross Domestic Product through dollar remittances. Through the organized efforts of PNAA and the support and partnership of its chapters, numerous educational, humanitarian, medical and community outreach projects have been conducted in a feat to give back not only to the communities they live and work in the USA but more importantly to the motherland, the Philippines and other countries that have suffered from calamities.

On this 40th year of PNAA as a professional ethnic organization, we look back with gratitude to the PNAA forerunners for boldly paving the way in consistently advocating for our Filipino nurses and Filipino-American communities in America. As leaders and members of this organization, we must continue to forge on, mindful that the issues of the distant past are not completely eradicated. The PNAA Human Rights Committee continues to deal with referrals from its chapters regarding irregularities in recruitment (changing contract signed in the Philippines to a different contract when they reach the American soil, reports of discrimination and unlawful work termination of Filipino nurses). The PNAA Legislative Committee has been proactive in addressing issues affecting nurses' migration such as the Yoder Bill.

The 2018-2020 Executive Board and its committees aim to continue harnessing on advocacy. The PNAA is in congruence with the American Nurses Association (ANA) belief that "advocacy is a pillar of nursing. Nurses instinctively advocate for their patients, in their workplaces, and in their communities; but legislative and political advocacy is no less important

to advancing the profession and patient care" (ANA, n.d.). At their strategic planning meeting, current PNAA Executive Board members outlined their aspirations for advocacy in local, national, and global arenas, focusing on human rights and becoming a visible force in the legislative process. We will continue to send PNAA fellows to Washington DC to learn more of the legislative process and become more involved in supporting legislation affecting nursing and health care. PNAA recently became an Organizational Affiliate to the ANA, as such, the PNAA will align itself with the ANA's plan of establishing legislative and regulatory priorities, recommending strategies for the execution of the advancement of a policy issue, and educating members about the political realities as well as advancing PNAA's agenda.

PNAA will forge ahead with the mantra "Make a difference: Advocate!"

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**JOURNAL OF NURSING PRACTICE APPLICATIONS & REVIEWS OF RESEARCH**

# Sexual and Reproductive Health in Women with Cystic Fibrosis: A Dimensional Concept Analysis

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**Abstract**

**Background:** Cystic fibrosis (CF) is no longer a childhood disease. People with CF are living well into adulthood as a result of advancements in research and clinical care. Women with CF desire to become pregnant and accomplish the same life goals as women without CF.

**Objective:** The purpose of this concept analysis paper is to identify gaps in nursing knowledge and explore potential barriers to the provision of appropriate sexual and reproductive health (SRH) education to women with CF.

**Methods:** A review of literature of SRH in women with CF was analyzed using dimensional analysis of 20 sources found across multiple databases.

**Results:** This analysis revealed four dimensions from three perspectives related to the topic of SRH in women with CF. The dimensions are prioritization of care, knowledge of topic, comfort with topic, and previous experiences. The perspectives are those of the patient, partner or parent and provider.

**Conclusion:** This dimensional analysis revealed gaps in nursing knowledge and potential barriers to the provision of appropriate SRH education to women with CF.

*Keywords: cystic fibrosis, sexual, reproductive, dimensional analysis, concept analysis*

## Background

Cystic fibrosis (CF) is a genetically acquired, progressive disease affecting the lungs, pancreas, and other organs due to an alteration in a protein that leads to production of excessively tenacious secretions (Cystic Fibrosis Foundation [CFF], 2018). As with most chronic conditions, individuals with CF have periodic exacerbations that affect quality of life. More than half of the approximately 70,000 individuals living with CF worldwide are now older than 18 years, with the median predicted survival age of 47.7 years (CFF, 2018). Women with CF are now achieving life goals of motherhood, establishing careers, or attending college due to advances in medical care (CFF, 2018). In fact, women with CF now meet developmental milestones at a time close to that of women not affected with CF (Frayman & Sawyer, 2015). The rising survival rate, paired with near normal fertility, provide opportunities for women with CF to make decisions about sexual and reproductive health (SRH) much the same as women not affected with CF (Tonelli & Aiken, 2007). Contrary to common misconceptions, pregnancy does not shorten life expectancy for women with CF (Goss, Rubenfield, Otto, & Aiken, 2003). Current research presents evidence of pregnancies carried to term with resultant healthy babies among women with CF (Ladores, Kazmerski, & Rowe, 2017). Due to advances in science, CF is no longer a disease of childhood; therefore, CF-specific sexual and reproductive health (SRH) education is an important component of comprehensive CF clinical care.

A review of the literature reveals that women with CF do not receive enough education regarding SRH (Gage, 2012). Women with CF report that they are not satisfied with the limited SRH education and counseling they receive from their CF healthcare team (Kazmerski, Slocum, Gmelin, Borrero, & Miller, 2016). Despite advancements in life expectancy and reproductive health, research demonstrates significant gaps in SRH education for women with CF (Frayman & Sawyer, 2015). For the woman with poor lung health, omission of SRH education may impact decision-making and result in detriment to the woman's overall health, while appropriate and timely provision of education may help to more fully understand and prepare for the risks associated with pregnancy (e.g., decreased lung function) (Gage, 2012). Of pregnancies among women with CF, 26% are reported as unplanned (Gatiss, Mansour, Doe, & Bourke, 2009).

Despite evidence that women with CF want CF-specific SRH education to be provided by the CF healthcare team (Kazmerski, Tuchman

et al., 2016), there is also evidence that it is not included in routine delivery of care (Gage, 2012). The purpose of this concept analysis paper is to identify gaps in nursing knowledge and explore potential barriers to the provision of appropriate SRH education to women with CF.

## Methods

Dimensional analysis (Caron & Bowers, 2000) was chosen to evaluate the concept of SRH in women with CF. Dimensional analysis is useful to understand the social construction of a concept and how socially constructed concepts can differ among perspectives (Rodgers & Knafl, 2000). Dimensional analysis has been shown to be useful in the development of nursing theories and knowledge (Rodgers, 2000). Dimensional analysis will: (a) determine if social inconsistencies exist, (b) facilitate an exploration of each dimension from the perspectives identified, (c) explore potential relationships between the perspectives, and (d) aid in identifying and examining assumptions (Rodgers, 2000). A database search was conducted using CINAHL, PubMed, Scopus, and PsycINFO. Truncated key terms used in various combinations included: sexual, reproductive, cystic fibrosis, fertility, education, and women. Figure 1 depicts the steps in the literature search, and Table 1 summarizes the
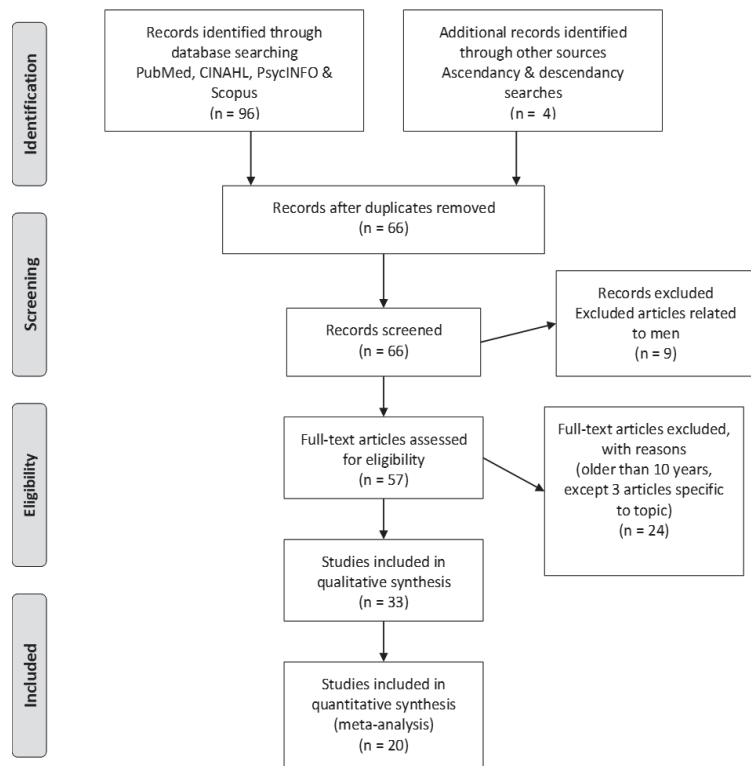


**Figure 1.** Steps in the review of literature. Adapted from "Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement" by D. Moher, A. Liberati, J. Tetzlaff, D. G. Altman, The PRISMA Group, 2009, Public Library of Science Medicine, 6(7), e1000097. doi:10.1371/journal.pmed1000097

**Table 1. Databases Searched in the Review of Literature**

| Database Searched | Terms Searched |
|---|---|
| PubMed | • Sexual AND reproductive AND women AND cystic fibrosis<br>• Fertility AND cystic fibrosis<br>• Sexuality AND reproductive AND education AND cystic fibrosis |
| CINAHL | • Sexual AND reproductive AND women AND cystic fibrosis<br>• Fertility AND cystic fibrosis<br>• Sexuality AND reproductive AND education AND cystic fibrosis |
| PsycINFO | • Sexual AND reproductive AND women AND cystic fibrosis |
| Scopus | • Sexual AND reproductive AND women AND cystic fibrosis |
| Ascendancy | • Searched bibliographies of selected articles |
| Descendancy | • Searched bibliographies of selected articles |

search terms used for each database. English articles published in the last 10 years were included for preliminary review, and articles focusing on men with CF were excluded. Initially, a filter was utilized to limit articles to those published within the past 10 years (2008-2018); however, this filter was subsequently removed due to the limited number of articles that emerged from the initial search. After removal of duplicates and non-relevance, the initial yield of 96 articles was narrowed down to 20 that were included in the final analysis.

## Results

This analysis revealed four dimensions related to the topic of SRH in women with CF: prioritization of care, knowledge of topic, comfort with topic, and previous experiences. These dimensions will be explored from the perspectives of the patient, partner/parent, and the healthcare provider. Prioritization of care relates to the provider who feels SRH care is important but is not a priority of care for the patient (Kazmerski, Borrero et al., 2016). Knowledge of topic relates to knowledge that is or is not possessed by the patient or provider and impacts the decision-making of the woman with CF (Tsang, Moriarty, & Towns, 2010). Comfort with topic concerns the discomfort or embarrassment that may be experienced by the patient, partner/parent, or provider in discussing the topic of SRH (Gage, 2012). Previous experiences of the patient or provider relates to the importance women with CF place on the experiences of others, as well as their previous experiences related to SRH care (Simcox, Hewison, Duff, Morton, & Conway, 2009) and previous experiences of the provider in the provision of SRH which may impact their decision to initiate or fail to initiate conversations about SRH (Kazmerski et al., 2018).

A review of the 20 articles suggests that there is a significant gap in the provision of SRH care to women with CF. Table 2 represents a synthesis of findings from the literature reviewed and incorporates fit with dimensions and perspective.

**Prioritization of care.** The dimension of prioritization of care is evident in the literature in studies that have shown that women with CF desire SRH care to be provided by their CF healthcare team (Gage, 2012). CF providers value SRH care education for their patients and identify it as a critical element of CF care (Kazmerski, Borrero et al., 2016). Parents described that they feel SRH education should be provided to patients at about age 13-14, demonstrating parents' prioritization of SRH. Mothers of girls with CF have indicated that they would like more information regarding SRH, showing that they value SRH education for their daughters with CF (Nixon, Glazner, Martin, & Sawyer, 2003). The dimension of prioritization of care is well documented in the literature, and SRH care for women with CF is prioritized by the patient, partner/parent, and the provider. Related to the dimension of prioritization of care, the patient may place a high value on SRH, while the provider may prioritize lung health above SRH. That is, providers may place a "low priority" (Kazmerski, Borrero et al., 2016) on SRH, and instead, focus on current pulmonary symptoms or other physical issues. Sensitivity from the CF provider, while meeting the needs of each patient, is needed (Simcox et al., 2009) to provide patient-centered, comprehensive CF care. In fact, if the provider does not initiate conversations about SRH, patients may feel that their provider does not support their decisions related to SRH (Simcox et al., 2009).

**Knowledge of topic.** The dimension of knowledge of topic is described in the literature as a deficit of knowledge by the patient (Gage, 2012), and educational deficits on the part of the provider (Kazmerski, Borrero et al., 2017). Women with CF often feel that they do not have enough information to make informed choices about sexual and reproductive aspects of their lives (Sawyer, Phelan, & Bowes, 1995). Providers indicated that they need additional training regarding CF-specific, SRH topics (Kazmerski, Borrero et al., 2016). Despite limited research in SRH for women with CF, it is apparent that deficits exist in the knowledge of the SRH topic.

**Comfort with topic.** The dimension of comfort with topic is noted in the literature for both the patient (Havermans, Abbott, Colpaert, & DeBoeck, 2012) and the provider (Kazmerski, Borrero et al., 2017) and is represented as a potential barrier to the provision of SRH care for the woman

**Table 2. Synthesis of Review of Literature**

| Author (Date) | Major Finding | Dimension | Perspective |
|---|---|---|---|
| Askew (2017) | More information regarding SRH is wanted. | ▪ Knowledge of topic | Patient Parent |
| Frayman (2015) | Gaps exist in SRH education for adult women with CF. | ▪ Knowledge of topic | Patient Parent |
| Gage (2012) | Women with CF want SRH information. | ▪ Knowledge of topic<br>▪ Comfort with topic | Patient Provider |
| Gatiss (2018) | Women with CF have high rates of unplanned pregnancy and do not receive optimal SRH care.<br>CF teams lack training in SRH care. | ▪ Knowledge of topic<br>▪ Prioritization of care | Patient Provider |
| Goss (2003) | Women with CF who become pregnant do not have shortened lifespans.<br>Healthcare providers should not impose their view onto patients. | ▪ Prioritization of care | Patient Provider |
| Havermans (2011) | Mothers of children with CF want more SRH information.<br>CF healthcare team should initiate SRH care. | ▪ Comfort with topic<br>▪ Knowledge of topic | Patient Parent |
| Hull (2000) | Unplanned pregnancies among women with CF may be related to lack of knowledge regarding fertility. | ▪ Knowledge of topic<br>▪ Prioritization of care | Patient Provider |
| Jacobs (2015) | Adolescents with CF want SRH information. | ▪ Knowledge of topic | Patient Provider |
| Kazmerski et al. (2018) | 80% of women in study desire to have children.<br>SRH care is unaddressed during routine CF care. | ▪ Knowledge of topic<br>▪ Comfort with topic<br>▪ Previous experiences | Patient Provider Parent |
| Kazmerski, Borrerro et al., 2017 | Barriers exist in the provision of SRH care. | ▪ Comfort with topic | Patient Provider |
| Kazmerski et al. (2016) | CF providers face barriers to provision of SRH care (embarrassment [comfort] with topic], lack of knowledge. | ▪ Comfort with topic<br>▪ Prioritization of care<br>▪ Knowledge of topic | Patient Provider Partner |
| Kazmerski, Miller, Abebe, Matisko, Schachner, & Spahr (2015) | Association exists between knowledge of condition and adherence to therapy. | ▪ Knowledge of topic | Patient Provider |
| Ladores (2017) | Women have carried pregnancies to term and delivered healthy babies while taking ivacaftor. | ▪ Knowledge of topic | Patient |
| Sawyer (2001) | Training is needed for providers regarding SRH. | ▪ Knowledge of topic | Provider |
| Sawyer, Phelan, & Bowes (1995) | Lack of knowledge about SRH has a major impact on lives of women with CF. | ▪ Knowledge of topic | Patient |
| Tsang, Moriarty, & Towns (2010) | CF healthcare providers lack SRH expertise.<br>Adolescent girls with CF and their mothers want SRH information. | ▪ Knowledge of topic<br>▪ Comfort with topic | Patient Provider Partner |
| Simcox, Hewison, Duff, Morton, & Conway (2009) | Those with CF are as likely as healthy peers to consider starting a family. | ▪ Knowledge of topic<br>▪ Prioritization of care | Patient Partner |
| Withers (2012) | Adolescents with CF have unmet SRH care needs. | ▪ Knowledge of topic<br>▪ Comfort with topic | Patient Provider Parent |

with CF. CF program directors reported "embarrassment" or "discomfort" with the topic of SRH as a reason that they do not introduce the topic (Kazmerski et al., 2016). Other providers linked discomfort with the topic to concerns about communicating a sensitive topic (Tsang et al., 2010).

**Previous experiences.** Previous experiences of the patient and provider are noted in the literature (Kazmerski, Gmelin, Slocum, Borrero, & Miller, 2017). Whether the experience was positive or negative may impact whether the patient or provider addresses the topic of SRH. A patient's previous negative experience may make her reluctant to ask questions or introduce the topic of SRH, although this may be necessary to begin the conversation (Tsang et al., 2010).

**Relevant perspectives.** The dimensions of prioritization of care, knowledge of topic, comfort with topic, and previous experiences may vary, depending on whether they are viewed from the perspective of the patient, parent/partner, or the provider. Less research is available on the perspective of the partner/parent of the woman with CF. Importantly, these differing perspectives may impact the delivery of comprehensive care to women with CF.

The perspective of the patient regarding the dimension of knowledge of topic is well established in literature as a priority. Women with CF report that they want more knowledge about CF-specific SRH (Kazmerski et al., 2018). It is also well documented that providers indicate knowledge of this topic is important, yet the very omission of SRH education may convey the opposite message to the patient. This perceived contradiction is supported in the literature in which the provider's perspective of knowledge of SRH is purportedly the same as the patient's perspective (Gage, 2012).

The patient perspective related to the dimension of comfort with topic may vary from patient to patient and may also vary from provider to provider, resulting in a complicated combination of perspectives. If a provider feels the patient is uncomfortable with the topic, they may defer initiating a conversation about SRH, to the parent or primary healthcare provider, even if they are comfortable with the topic. Conversely, the provider who is uncomfortable may defer a needed conversation with their patient to their primary health care provider or parent.

The perspectives of the patient, partner/parent, and provider related to the dimension of previous experiences on SRH may impact the delivery of care by the healthcare provider, affect the reception of SRH care by the patient, or influence whether the significant other is included in the conversation or education regarding SRH. Previous experiences with providers may be a factor in the reluctance of the patient to introduce the topic of SRH (Kazmerski et al., 2018) and result in educational deficits with a potential to impact the health of the patient. Previous experiences of the provider may affect the willingness or reluctance to introduce the topic of SRH.

Figure 2 is a conceptual model derived from the synthesis of the literature and represents the dimensions of prioritization of care, knowledge of topic, comfort with topic, and previous experiences and the relationship of these dimensions from the perspectives of the patient, partner/parent, and provider. The identified dimensions of prioritization of care, knowledge, comfort and previous experiences are central in the figure. The perspectives of patient, partner/parent, and provider (CF healthcare team), are interrelated and represented by the double arrows between each perspective. The broken circles around the dimensions represent the flow of the dimensions in relationship to the perspectives. The relationship between the perspectives and the dimensions impacts the continuum of SRH healthcare delivery and is represented by the forward-moving arrow of SRH and the total concept of SRH impacting this continuum.

A limitation of this concept analysis is the sparse available literature on the topic. Comfort with the topic, which has been identified as a dimension, may be a barrier to research in this area. Researchers may have the same reluctance to initiate this work as the reluctance documented in literature regarding the omission of SRH care by the CF healthcare team.
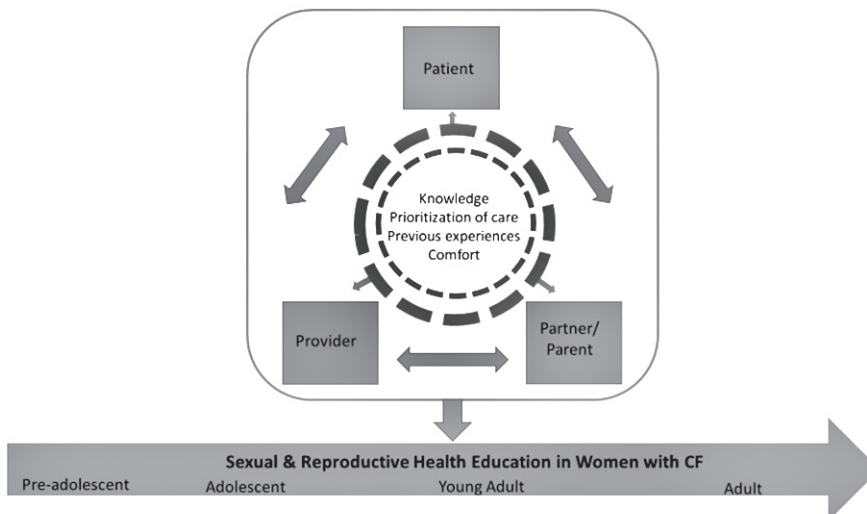


**Figure 2.** Conceptual model of relationship between dimensions of SRH and perspectives.

## Implications for Practice

Women with CF have the same SRH care needs as women without CF. With an average life expectancy of 47.7 years (CFF, 2018), they are living long enough to experience sexual and reproductive choices and require routine SRH care. Comprehensive health care for women includes SRH care, and the comprehensive health care for women with CF should not omit this aspect of care. With the heavy burden of care experienced by women with CF, it is important to research ways to incorporate SRH care into the routine provision of care for women with CF.

This dimensional analysis revealed gaps in nursing knowledge and potential barriers to the provision of appropriate SRH education to women with CF. Despite evidence that women with CF want CF-specific SRH education to be provided by the CF healthcare team (Kazmerski, Borrero et al., 2016), there is also evidence that it is not included in routine delivery of care (Gage, 2012).

This paper used a dimensional analysis approach to analyze the concept of SRH education in women with CF and introduced the dimensions of prioritization of care, knowledge of topic, comfort with topic, and previous experiences from the perspectives of the patient, their partner or parent, and the provider of CF healthcare. Analysis of this concept established the importance of this topic, and the relevance to comprehensive care of women with CF. SRH education should be provided at age-appropriate intervals, addressing developmentally sensitive topics at each interval to provide patient-centered, comprehensive CF care. Educational resources are needed to assist members of the CF healthcare team in delivery of this care in an effective and efficient manner. Upon completion of this literature review-based concept analysis of SRH care for women with CF, three key implications for practice are noted: (a) individuals with CF require specialized SRH care; (b) SRH must be a component of comprehensive CF care; and (c) further work is needed to develop effective ways to provide SRH care to women with CF. Additionally, several research questions emerged from the analysis, including: (a) How can the barriers to provision of SRH care for women with CF be addressed and overcome?, (b) How can SRH care be effectively incorporated into the routine care of women with CF?, (c) What are the best approaches to educate and train CF healthcare providers in SRH care delivery?, and (d) What are the unique SRH needs of women with CF and how can we best meet them?

## Conclusions

Using a dimensional analysis approach, the dimensions of prioritization of care, knowledge of topic, comfort with topic, and previous experiences were identified from a review of the literature, as well as three distinct perspectives related to these dimensions. Viewed from the varied perspectives of the patient, parent/partner, and provider, multilayered differences exist in the dimensions.

This study contributes to the sparse literature on the SRH needs of women with CF, as well as implications for clinical care and future research. Given that women with CF are living longer, carrying pregnancies to term, and delivering healthy babies, now is the time to underscore the importance of SRH as part of comprehensive clinical care.

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**JOURNAL OF NURSING PRACTICE APPLICATIONS & REVIEWS OF RESEARCH**

# Young Adult with End-Stage Cystic Fibrosis: A Missed Opportunity for Implementing Timely Palliative Care

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## Abstract

**Background:** Cystic fibrosis is a chronic, progressive, life-limiting genetic disease that affects approximately 70,000 individuals worldwide. While advances in clinical care have improved overall patient outcomes, a cure is still not available. For those with advanced disease, palliative care may offer strategies to improve quality of life.

**Clinical goals and clinical problem(s):** This case report describes a young adult female, KS (pseudonym), living with severe lung disease secondary to cystic fibrosis.

**Assessment:** KS was not eligible for lung transplantation due to various psychosocial, physical, and mental factors. Despite being offered palliative care on several occasions, she declined.

**Implementation:** Palliative care is part of the interdisciplinary approach to caring for patients with an incurable illness, and especially for KS who will likely never receive a lung transplant. It is clear that KS did not understand the purpose and benefits of palliative care.

**Evaluation and Discussion:** This is an unfortunate example of a missed opportunity for palliative care involvement before a medical crisis arises. Implications for improving education of patients, families and providers, and changing clinical practice to integrate specialized palliative care services early before a medical crisis arises are presented.

*Keywords: cystic fibrosis, palliative care, transplantation*

## Background

Cystic fibrosis (CF) is the most common genetic disorder among Caucasians, with one of every 31 Americans carrying a genetic variant of the disease (Cystic Fibrosis Foundation, n.d.). The genetic mutation that causes CF is responsible for multi-system organ complications including: lung infections, pancreatic insufficiency, kidney failure, poor growth velocity, and infertility (Cystic Fibrosis Foundation, n.d.). This autosomal recessive genetic disease affects 30,000 people in the United States, with half of this population aged 18 or older (Cystic Fibrosis Foundation, n.d.). CF was first described in the 1930's as a disease of childhood. At that time, approximately 80% of patients diagnosed with CF died within their first year of life (Child Life, 2018). With significant advances in research, genetic testing, pharmacotherapeutics, and clinical care, people with CF are now living well into adulthood with the median predicted survival age increasing from 31 years in 2002 to 47 years in 2016 (Cystic Fibrosis Foundation, 2017). The leading cause of death in CF patients is end-stage lung disease with lung transplantation as the only curative therapy to extend survival (Yusen et al., 2014).

Currently, CF-related end-stage lung disease is the third most common indication for lung transplantation in the United States (Yusen et al., 2014). In 2017, there were approximately 269 lung transplantation procedures due to end-stage CF (Cystic Fibrosis Foundation, 2017). Guidelines for lung transplantation are stringent as providers seek to allocate a scarce number of resources to patients with the best chance of survival (Orens et al., 2006). Lung transplantation care requires long-term medication adherence and is associated with significant morbidity and mortality risk (Orens et al., 2006). Thus, criteria for lung transplantation criteria include factors that would be contraindications, such as medication non-adherence, incurable extrapulmonary infection, inability to follow-up with office visits, untreatable psychiatric conditions, inconsistent or absent social support networks, or recent (within six months) substance addiction (Orens et al., 2006).

Palliative care (PC) is specialized medical care that is focused on providing seriously ill patients with relief from symptoms, pain, and stress, with the goal of improving quality of life for the patient and family (Center to Advance Palliative Care, 2018). For patients with serious illnesses, such as CF, PC can improve treatment adherence, increase understanding of expected symptoms, improve symptom management, and increase support surrounding difficult decisions (Bakitas, Bishop, Caron, & Stephens, 2010; Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013; Robinson, 2009). However, the stigma that PC is inconsistent with curative treatment contributes to patients receiving little or no PC until death is imminent (Robinson, 2009). Of 35 patients who did not receive a lung transplant, 46%

participated in long-term palliative care, 17% received no palliative care, and 37% received palliative care only within 48 hours of dying (Bourke et al., 2009). In this case report, the shift to palliative care usually occurred around the time the patient was deemed ineligible for lung transplantation.

Linneman et al. (2018) found that out of 38 adolescents and adults with CF, only 5% discussed their care preferences with their CF team, and only11% completed advanced directives. However, most CF patients (84%) had worries about living with advanced disease. In this case report, the missed opportunity for PC in a young adult living with CF-related end-stage lung disease without the possibility for lung transplantation is explored.

## Case Presentation

### History

KS was a 20-year-old female with end-stage CF (F508del homozygous mutation), CF-related diabetes, pancreatic insufficiency, severe depression, anxiety, and chronic malnutrition who was transitioning from pediatric to adult care. She was diagnosed with CF at 10 months of age and had a long and difficult CF journey leading to irreversible declines in her health. Her chronic illness has been complicated by psychosocial, physical, and mental factors.

### Psychosocial Concerns

KS grew up in poverty with unstable housing. Her family had difficulty obtaining sufficient food to meet her caloric needs and difficulty purchasing prescribed medications and supplements. Through the years, social workers helped her complete forms for food stamps and other resources, but neither she nor her family ever submitted the paperwork to the county.

KS struggled in school and withdrew from high school at age 16. Since then, she enrolled in multiple General Education Development (GED) programs but did not complete any program. At age 18, KS eloped and moved to a military base for a year where she did not take her prescribed medications and subsequently experienced a severe CF exacerbation. Shortly after, she filed for divorce and moved back to her home state. Her level of functioning in society as an adult was limited, and she seemed uninterested in functioning independently of her grandmother, who still accompanied her for clinic visits. Her grandmother, the primary caregiver, was also limited in her ability to care for KS due to her own health issues.

KS was unemployed, her only income Social Security payments of $650 per month, which made it difficult for her to afford adequate housing, nutrition, transportation, and medication. KS had a known history of drug abuse. People smoked inside the home, exacerbating her respiratory symptoms. KS's father was frequently incarcerated for

drug-related charges. KS had a longstanding record of "no-shows" for her clinic visits and inpatient admissions, in part due to transportation difficulties. Numerous complex social determinants of health have led to declines in KS's physical and mental health that made it difficult for the CF team to provide her with optimal care.

## Physical Concerns

As an adolescent, KS had at least two admissions where she was prematurely discharged due to unwillingness to cooperate with the plan of care (e.g., leaving the hospital without approval for hours at a time and not receiving antibiotic therapy or airway clearance). She frequently refused to participate in physical therapy, despite knowing its importance in lung health and overall well-being. Generally, KS did little to maintain her health. She reported not checking her blood glucose or taking her insulin. Her DEXA scan showed a Z-score of -2.8, demonstrating bone loss but she seldom took her supplements or performed weight bearing exercise. Her Vitamin D level was chronically suboptimal yet she did not take her prescribed vitamins. She was prescribed dronabinol (Marinol) and cyproheptadine (Periactin) for appetite stimulation but, similar to her other medication regimens, she took them inconsistently. During a typical admission, KS gained 3-4 kg., but lost it shortly after discharge. Her weight was consistently low with a body mass index of 16.

Most worrisome was her lack of engagement in regular airway clearance therapies. Her pulmonary function steadily declined with her forced expiratory volume in one second decreasing from the mid-80s to the low 40s in a period of four years. The CF care team discussed with KS that because of her deteriorating lung function, she would need a lung transplant. However, due to her history of poor adherence, lack of adequate and stable caregivers and support network, and illicit drug use (with no reported plans to stop), she would not qualify for a transplant. Given her history of overall poor adherence to her medical regimen, her health continued to decline.

## Psychological Concerns

KS was first diagnosed with depression and anxiety in her pre-adolescent years. She took prescribed antidepressants inconsistently. KS had two admissions for suicidal ideation with a stated plan of overdosing on insulin. Given her multiple co-morbidities, chaotic personal life, and history of drug abuse, it was not surprising that she struggled with mental health. She had access to a specialist CF psychologist through a regional pediatric health center; however, she did not consistently attend her scheduled CF tele-psychology appointments.

## Palliative Care

KS was first introduced to PC two years ago at age 18 as a way to help her plan for the future and create care goals. KS and her grandmother were adamantly opposed to accepting PC services. As her physical and mental health continued to decline, PC was offered multiple times. She declined and responded with giggles and said that palliative care was "only for old people" and not people "like her." It was difficult to fully identify the reasons for her resistance which may have been due to any of the following: lack of understanding, fear and uncertainty about her inevitable poor prognosis, or discomfort with any serious topic due to her lack of maturity and stunted developmental growth. When the CF care team attempted to discuss her declining lung function and her need for improved compliance, she did not engage or communicate with the team.

Palliative care is part of the interdisciplinary approach to caring for patients with an incurable illness, especially for KS who will likely never receive a lung transplant. It is clear that KS did not understand the purpose of PC and the benefits she could experience by receiving specialized PC. This is an unfortunate example of a missed opportunity for PC involvement before a medical crisis arises. Patients such as KS, who are living with an incurable illness and high risk of critical exacerbations, are at risk for suffering from prolonged intensive and painful care at the end of life that may not be aligned with their preferences.

## Discussion

It can be difficult to elucidate care goals in a complex patient like KS, and also difficult to ensure the care received is congruent with the patient and family's preferences when the patient has such a complex social history. Nearly half of American children live in or near poverty; childhood poverty increases the risk of difficulty with self-regulation, executive function, and poorer prognosis for those with chronic illnesses (like CF), among other negative associations (American Academy of Pediatrics, 2016). The culture of poverty was identified as an issue in KS's care, and one that was addressed through the years by social workers; however, for complex reasons, the patient was unable or unwilling to take advantage of some services available to her. There were missed opportunities where PC involvement could have facilitated discussion surrounding preferences for care and documentation of preferences for patients living with advanced disease, and (a) improved the continuity of care during multiple admissions over many years; (b) improved the quality of transitions of care from pediatric to adult care; (c) contributed expert communication skills during difficult conversations regarding goals of care and advanced directives; (d) enhanced symptom management using innovative and alternative medications to address pain patient with complex substance abuse issue; (e) enhanced family support using a family-centered approach to care where family members often serve as proxy decision-makers and caregivers; (f) improved connections to resources such as social work, child-life, psychiatric care, and nutri-

tional support while transitioning between in-patient and out-patient settings.

Palliative care in CF is in its infancy and there are no clinical guidelines that outline the different aspects of PC delivery that fully meets the unique needs of this patient population. The CF Foundation recently established a PC initiative to investigate how PC can be best integrated into comprehensive CF care, and to identify the how, when, who, where and why of PC in CF. Friedman et al. (2018) recently piloted a primary palliative care model for the structured assessment of symptoms, distress, and coping (CF-CARES). Over four visits, the researchers enrolled CF patients and gathered demographic information, performed a baseline assessment, provided a menu of supportive services, and interval follow-up surveys three and six months later to evaluate symptoms and quality of life. Findings showed that one-third of the participants older than 12 years diagnosed with CF reported anxiety symptoms, one-half reported depression symptoms, as well as other numerous distressing symptoms.

Despite the benefits of palliative care for patients with CF (Hoblet et al., 2018; Linnemann et al., 2018), there are barriers to implementing timely PC in CF care. KS's resistance to initiating PC because it was "for old people" is a common barrier in providing PC to seriously ill patients even though there is much suffering associated with serious illness like CF prior to the end of life period. The stigma and misconception that PC is exclusively associated with death and dying is common in CF patients, family members, and providers (Dellon et al., 2018). Other non-cancer pediatric populations associated PC with "giving up" on aggressive care; however, in retrospect, they would recommend PC to other parents with seriously ill children (Currie et al., 2016). Missed opportunities for early discussion of care preferences for patients living with advanced CF disease may prevent patients and families from using services such as hospice. Keim-Malpass et al. (2018) found that privately insured adolescents and young adults have short length of stays in hospice care (ages 16-19 years staying for a mean 3.56 days; ages 20-24 years staying for a mean 2.26 days). Additionally, adolescents with a usual source of primary care in the last year of life were more likely to enroll in hospice (Keim-Malpass & Lindley, 2017). KS did not have a usual source of care outside of her acute hospitalizations and this could have influenced her ability to discuss preference for living with advanced CF and eventually preference for end-of-life care. The home hospice model requires a stable and safe home to receive end-of-life care and an in-home caregiver. In addition to systemic differences and disparities in hospice use, the home environment and availability of viable caregiver would have been an issue for KS even if she preferred home hospice care.

Based on this case report, there are several areas that prompt

a change in practice. An accurate and thorough explanation of specialized PC services and how these services may benefit the patient and family should be provided earlier rather than later (Boldt, Yusuf, & Himelstein, 2006). According to Dellon et al. (2018), after hearing a description of PC, patients with CF and their families felt that PC could be helpful in providing additional support that is very much needed during the exacerbations of chronic illness and limited treatment options for the incurable disease (Dellon et al., 2018). Nurses caring for patients with chronic illnesses like CF often develop long-term relationships and good rapport with patients over the course of weeks, months, and years. Given that they spend more time with the patient than other members of the healthcare team, training for nurses about how to initiate conversations about and encourage utilization of PC resources may lead to greater acceptance of PC services by patients with chronic illness. Additionally, criteria should be developed for nurses to use to advocate for the initiation of PC services for chronically ill patients when the physician team has not started these discussions.

Other barriers to earlier and more comprehensive PC involvement in CF care are the limited number of PC specialists and disparities in access to specialized PC. Results from a national survey (adults with CF (n=77), caregivers (n=104), and CF clinicians (n=352) demonstrated unmet PC needs of adults with CF and significant discrepancies regarding clinician PC skills (Kavalieratos & Dellon, 2018). Clinicians rated their PC skills (e.g., pain and depression assessment, discussion of prognostic uncertainty) as "excellent" to "very good" whereas patients and caregivers evaluated the clinicians' skill set in these same areas as "poor" to "good." Clinicians reported that only 19% had specific PC training and all three groups identified that the lack of specific PC training in clinicians is a significant barrier in accessing PC.

At KS's current institution, there is one pediatric PC team, which is the only specialized PC team located in her state. While PC is growing as a specialty, and the number of PC programs located in children's and adult hospitals steadily increasing, the ratio of seriously ill patients outweighs the number of available specialized PC providers (CAPC, 2015; Feudtner et al., 2013). Primary PC is provided by the clinicians already caring for these patients and families and involves basic PC skills; however, many CF clinicians are not trained or do not understand how to integrate this care into an existing multi-disciplinary approach (Hobler et al., 2018). The lack of clinical guidelines to integrate primary PC in CF care and, when available, specialized PC, presents challenges for clinicians and researchers on developing and evaluating standards of practice for PC involvement in CF care (Hobler et al., 2018). Specifically, the timing, level of involvement in generally long illness trajectories, triggers for including specialized PC teams, and development of quality metrics for palliative and end-of-life care in CF

care require further investigation.

## Conclusions

Early patient-provider conversations about early integration of PC into the CF care team are needed to improve goal concordant CF care (Zimmerman et al., 2016). Cystic fibrosis is a lifelong illness that is generally diagnosed at birth or early childhood and presents unique challenges to PC. In this case report, an opportunity was missed to integrate PC into the treatment plan for this patient with end-stage CF. Common misconceptions on the purpose and benefits of PC involvement often delay PC until death is imminent, often times, after long periods of suffering. A total rebranding of PC as "supportive care" has been suggested to decrease the stigma surrounding PC integration. Future studies are needed to examine the role of early PC integration in improving symptom management and quality of life. Evidence-based guidelines must be established in order to integrate PC in interdisciplinary CF care across the lifespan and clinical settings to fully meet the needs of this vulnerable population.

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**JOURNAL OF NURSING PRACTICE APPLICATIONS & REVIEWS OF RESEARCH**

# Gender Differences in Health-Related Quality of Life in Adults with Cystic Fibrosis: An Integrative Literature Review

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**Conflict of Interest**
The authors declare that there is
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## Abstract

**Background:** Life expectancy for individuals with cystic fibrosis (CF) has doubled in the last 20 years. There is currently no cure for the disease, thus, it is imperative that quality of life is optimized. Females with CF consistently report a poorer health-related quality of life than males, however, the causes of this disparity remain unknown.

**Objective:** The purpose of this integrative literature review was to examine the state of the science related to factors that influenced gender differences in health-related quality of life (HRQoL) in those with CF.

**Methods:** Databases used in the literature review included Scopus, PubMed, PsycINFO, and Google Scholar. Sources were included if they: 1) were available in the English language; 2) included adolescents and/or adults (> 12 years) with CF; 3) included gender differences in HRQoL in CF; and 4) were published between the years 2003 and 2018.

**Results:** A total of 29 articles were included in the review. The following gender differences in CF-specific HRQoL emerged from the literature review: 1) females were more likely to challenge their prescribed treatment regimen, needed more support to complete treatments, and were also less compliant with their prescribed treatment regimen when compared to males; 2) females reported more CF-related strain compared to males; 3) in those diagnosed during childhood, (birth to 10 years) lung function declined faster in females over age 40 when compared to males; 4) females were more susceptible to poorer HRQoL despite a similar lung function to males 5) females noted a better HRQoL in the area of body image despite a lower BMI; 6) activity level declined with puberty in females with CF, which was not present in males; 7) in a social setting, females were more embarrassed of treatment regimen and found it harder to maintain a job or college course compared to males; and 8) females reported higher levels of anxiety, depression, and emotional strains related to CF and lower self-esteem when compared to males.

**Conclusion:** This literature review showed several gender differences in the HRQoL between males and females with CF, including physical and psychosocial aspects. While the physical aspects of HRQoL in CF may be stable over time, the psychosocial aspects varied over time, thus indicating a need to understand the determinants or factors for the differences in the trajectory of physical versus psychosocial quality of life in order to design theory-driven interventions that can improve patient outcomes.

*Keywords: cystic fibrosis, health-related quality of life, gender, adults*

## Background

Cystic fibrosis (CF) is a chronic, progressive, life-limiting disease with no cure. It is the most common recessive, genetic disease among Caucasians (Bodnar et al., 2014). The mutation on chromosome 7 leads to an abnormality in the CF transmembrane conductance regulator protein and results in abnormal transport of chloride across cell membranes (Schindler, Michel, & Wilson, 2015). The resulting thickened secretions obstruct the airways, gastrointestinal and reproductive tracts, and contribute to the heavy treatment burden of CF that includes chest physiotherapy, pancreatic enzymes, oral and intravenous antibiotics, and high-fat diet requirements, which add up to approximately two to four hours per day for routine health maintenance (Abbott, Morton, Hurley, & Conway, 2015; Forte et al., 2015). Acute CF exacerbations occur frequently and result in additional treatment requirements that include long hospitalizations several times per year.

### Health-Related Quality of Life

Due to advances in research and comprehensive clinical care, CF is no longer a disease of childhood. Currently, greater than 50% of the CF population has reached adulthood, with an average life expectancy of 47 years (CFF, 2017; Dill, Dawson, Sellers, Robinson, & Sawicki, 2013; Forte et al., 2015). As quantity of life increases, it has become imperative to also improve quality of life in this population (Forte et al., 2015). Health-related quality of life (HRQoL) encompasses the impact of CF on all aspects of daily living and includes both physical and psychosocial aspects. The disease-specific, gold standard instrument used to measure HRQoL in this population is the Cystic Fibrosis Questionnaire-Revised (CFQ-R), which consists of 12 domains and 50 items. The Cystic Fibrosis Quality of Life (CFQoL) questionnaire, which consists of 9 domains and 52 items, is less commonly used, but in order to integrate findings from the literature review, the domains of both instruments were defined and compared (See Table 1). Both instruments report a score for each domain with zero being the worst possible HRQoL and 100 being the best possible quality of life (Dill et al., 2013; Gee, Abbott, Conway, Etherington, & Webb, 2003).

Literature reviews on HRQoL in CF do exist, such as those by Calella, Valerio, Brodlie, Donini, and Siervo (2018) and Habib et al. (2015), which focus on fac-

tors influencing health outcomes and HRQoL; however, the purpose of this integrative review of the literature was to present evidence regarding gender differences in HRQoL of those with CF, making it unique from those currently published.

### Gender Differences in CF

HRQoL varied between males and females with CF. Females were over 50% more likely to die of CF before age 20 compared to males (Berge, Patterson, Goetz, & Milla, 2007). In addition, females were subject to more frequent pulmonary exacerbations and infections and had shorter life expectancies (Arrington-Sanders et al., 2006). The gap in survival between the two genders has been reported across international patient populations (e.g., India, Spain, Germany, and the United States) with a lower survival rate consistently reported in females with CF (Dill et al., 2013; Groeneveld et al., 2012; Schmidt, Wenninger, Niemann, Wahn, & Staab, 2009). There is currently no definitive causative explanation for the poorer outcomes seen in females with CF (Habib et al., 2015).

The gender differences in HRQoL varied by developmental

**Table 1. Domains of Health-Related Quality of Life by Measurement Tool**

| Domain Instrument(s) | Definition | |
|---|---|---|
| Physical Functioning | Limitations in physical activity related to CF. | CFQ-R; CFQoL |
| Body Image | How people with CF feel that the disease has made them look and feel different from peers. | CFQ-R; CFQoL |
| Social Functioning | How CF and associated treatments have affected socialization. | CFQ-R; CFQoL |
| Health Perceptions | How people with CF feel about health status in terms of whether they feel healthy. | CFQ-R |
| Respiratory Symptoms/Chest Symptoms | How often respiratory symptoms such as coughing are present. | CFQ-R; CFQoL |
| Treatment Burden/Treatment Issues | To what extent the prescribed treatment regimen makes life more difficult. | CFQ-R; CFQoL |
| Emotional Functioning | To what extent the participant felt worried or upset about CF. | CFQ-R; CFQoL |
| Role Functioning | How CF interferes with school, work, etc. | CFQ-R |
| Vitality/Energy | How energetic people are able to be despite having CF. | CFQ-R |
| Eating Difficulties | How difficult CF makes it for them to be able to eat. | CFQ-R |
| Digestive Symptoms | Presence of abdominal pain associated with CF. | CFQ-R |
| Weight | Issues gaining weight. | CFQ-R |
| Career Concerns | How CF interferes with career. | CFQoL |
| Interpersonal Relationships | How CF affects relationships with others. | CFQoL |
| Future Concerns | Concerns for the future because of CF. | CFQoL |

stage because of two primary etiologies: 1) the chronic progressive nature of CF; and 2) the developmental changes that occur naturally, such as puberty. When children were compared to adolescents and adults, children reported a better HRQoL in all domains, and then as age increased, HRQoL inversely decreased (Bodnar et al., 2014; Hegarty, Macdonald, Watter, & Wilson, 2009). When a cohort of individuals with CF was followed over a 10-year period, an increased rate of respiratory-related hospitalizations was found to occur in adolescent girls compared to boys (Stephenson et al., 2011). For the females with CF, the decline in lung function occurred earlier (12-14 years of age versus 19-20 in males) and at a steadier rate and was associated with more frequent hospitalizations (Groeneveld et al., 2012; Patterson, Wall, Berge, & Milla, 2008; Stephenson et al., 2011). The purpose of this literature review was to examine the state of the science related to gender differences in HRQoL in those with CF.

## Methods

A literature search was conducted in Scopus, PubMed, PsycINFO, and Google Scholar databases using the terms "Gender AND health-related quality of life in cystic fibrosis" in January of 2019. The range of publication dates was limited to the period of 2003-2018 because: 1) publication of articles in this field began to peak in 2003; and 2) gender differences were not discussed in many HRQoL articles in CF, so the longer timeframe was needed to fully capture the evidence regarding the gender differences. The initial search yielded a total of 6,182 articles. After removing duplicates, 4,980 sources remained. After reviewing the abstracts according to the inclusion and exclusion criteria, a total of 48 articles were selected for full review. Sources were included if they: 1) were available in the English language; 2) included adolescents and/or adults (> 12 years) with CF; 3) reported gender differences in HRQoL in CF; and 4) were published between 2003 and 2018. Sources were excluded if: 1) they were duplicates or secondary sources (e.g., review articles); 2) they involved diseases other than CF, such as asthma or COPD; 3) HRQoL by gender was not examined or measured; 4) study participants were post-transplant; 5) articles were not available in English; or 6) they only included children < 12 years. The age range was chosen because the gender differences in HRQoL in the CF population do not emerge until adolescence. Additionally, articles that focused on post-transplant participants were excluded because of the drastic differences in HRQoL pre-versus post-transplant. Using these criteria, 29 articles were included in the review. See Figure 1 for PRISMA diagram of search strategy.
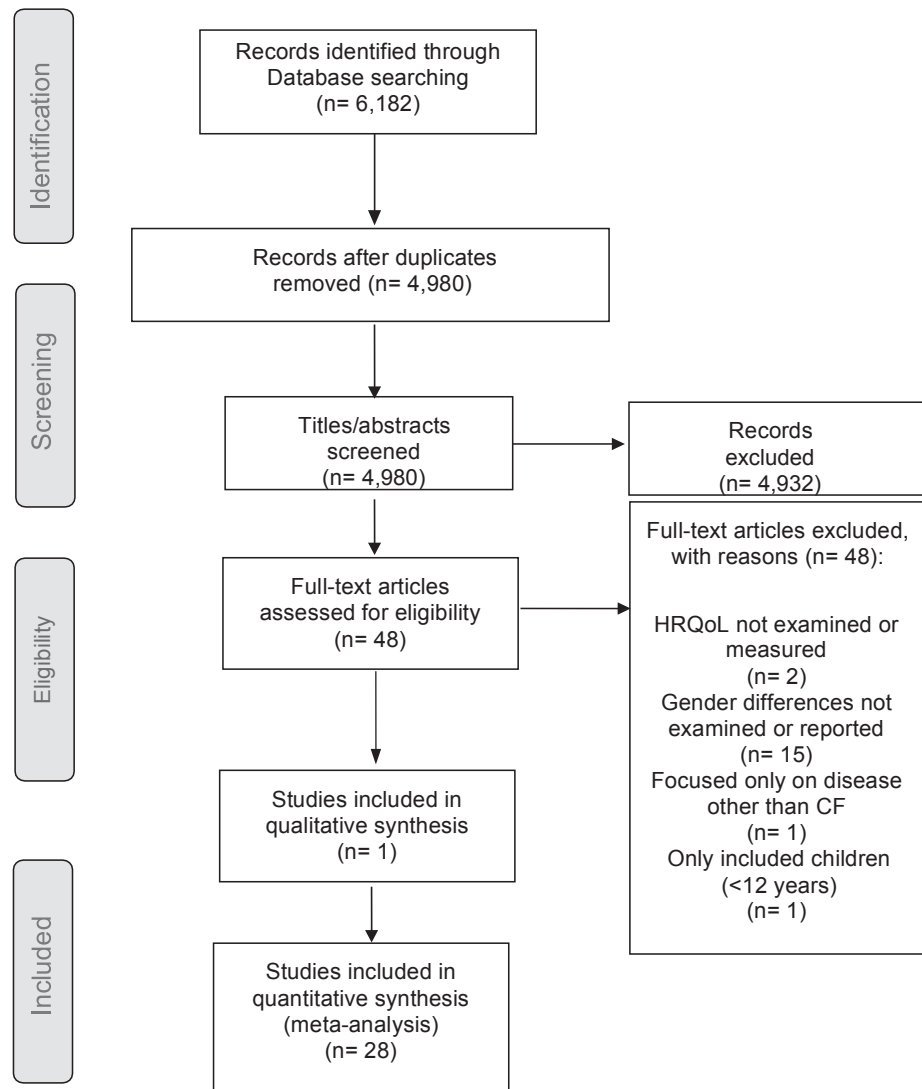


**Figure 1.** PRISMA Diagram

## Results

### Gender Differences in HRQoL

Gender differences in various areas of HRQoL emerged from the literature review including: 1) treatment compliance/regimen; 2) personal outlook; 3) age; 4) lung health; 5) nutritional status and resulting body image; 6) physical functioning; 7) social functioning; and 8) mental health (See Table 2 for a synthesis of all reviewed articles).

### Treatment Compliance/Regimen

Treatment compliance or treatment regimen involved how the prescribed CF-related treatment regimen effected HRQoL and corresponding treatment compliance. Females with CF needed encouragement and support from someone else in order to be compliant with their treatment regimen (Berge et al., 2007). However, they also indicated that being compliant made them feel different from peers and they,

**Table 2. Matrix of Gender Differences in Health-Related Quality of Life in Cystic Fibrosis**

| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Abbott et al. (2007) | Not Available (N/A)  United Kingdom | 221 people with CF  148 controls  Age: mean age 24 years | □ BMI, lung function, etc. □ Eating attitudes: dieting, preoccupation with food, pressure from others □ Rosenberg's self-esteem scale □ CFQoL: to measure HRQoL | □ Females had lower BMI, weight, and height. □ Females reported more dieting behavior, more preoccupation with food, and more pressure from peers to eat. □ Females reported lower self-esteem. □ Females were more likely to challenge prescribed treatment regimen. |
| Abbott et al. (2015) | 1998-2010  United Kingdom | 234 people with CF  Age: 14-48 years | □ Clinical assessments occurred every 2 years at a clinic follow-up □ The Cystic Fibrosis Quality of Life (CFQoL) Questionnaire | □ Females report a significantly better body image than males *(P < 0.001)* over time. □ A decrease in 1 unit of BMI resulted in same decrease in body image for men and females. □ Being female was a predictor of poorer HRQoL in the area of concerns for the future *(P= 0.05)*. |
| Arrington-Sanders et al. (2006) | 1997-2001  United States | 98 people with CF  Age: 10-18 years | □ Child Health Questionnaire: domains- global health, physical functioning, general pain, behavior, mental health, self-esteem, general health perceptions, role behavior | □ No significant differences between males and females in FEV1 □ Females: poorer HRQoL in global health, physical functioning, mental health, and general health perceptions (p < 0.05) □ After controlling for FEV1 and age, females reported poorer global health, mental health, and general health perceptions (p < 0.05). |
| Berge et al. (2007) | N/A  United States | 17 people with CF  Age: 16-21 years | □ Open-ended questions were used during focus groups □ Each theme had to be identified by half for the gender to be considered a representative theme | □ Three main themes: □ Treatment regimen/compliance: females needed someone to hold them accountable for their treatment regimen and felt different from their peers while males were more independent and felt accepted by peers □ Health-related problems: females reported concerned about diabetes □ Outlook: females need support to deal with CF while males were optimistic and saw CF as part of their identity |

| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Borawska-Kowalczyk et al. (2015) | N/A<br><br>Poland | 140 people with CF<br><br>Age 6-18 | ☐ HRQoL: measured by the Cystic Fibrosis Questionnaire-Revised (CFQ-R) | ☐ Physical functioning: males reported significantly higher HRQoL than females (p < 0.05)<br>☐ BMI significantly affected body image (p = 0.001), weight (p = 0.01).<br>☐ Both males and females were not satisfied with their weight. |
| Casier et al. (2011) | 13-month recruitment period<br><br>Belgium | 40 people with CF<br><br>Age: 14-22 years | ☐ HRQoL: measured by the CFQ-R | ☐ Using t-tests, gender was related to both social and emotional functioning with females reporting a poorer HRQoL on both. |
| Chevreul et al. (2014) | 2012-2013<br><br>France | 240 adults with children with CF<br><br>Age: Mean age for children: 8.5 years<br><br>Mean age for adults: 28.6 years | ☐ HRQoL: measured by EQ-5D questionnaire<br>☐ The EQ-5D measures dimensions of mobility, self-care, everyday activities, pain, and anxiety/depression | ☐ No significant gender difference in HRQoL for patients |
| Dill et al. (2013) | 2003-2007<br><br>United States | 333 adults with CF from 10 CF centers<br><br>Ages: 19-64 years | ☐ HRQoL: measured by CFQ-R | ☐ Being female, lower lung function, and more pulmonary exacerbations were associated with lower physical functioning on CFQ-R.<br>☐ Females scored significantly lower in areas of physical functioning (p < 0.001), vitality p < 0.05), and respiratory symptoms and higher in body image. |
| Forte et al. (2015) | N/A<br><br>Brazil | 51 people with CF<br><br>Age: Mean age 25 years | ☐ HRQoL: measured by CFQoL questionnaire | ☐ Gender was a significant predictor of CFQoL scores for weight and body image. |
| Gancz et al. (2018) | 2009-2012<br><br>Brazil | 31 people with CF<br><br>Age: 14-21 years | ☐ BMI, lung function<br>☐ HRQoL: measured by CFQ-R | ☐ No gender differences in the domains of the CFQ-R<br>☐ Stated that result may be due to small sample size |

| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Gee et al. (2003) | N/A<br><br>United Kingdom | 223 people with CF<br><br>Age: Mean age ~25 years | ☐ BMI, lung function<br>☐ HRQoL: Measured by CFQoL | ☐ Significant gender differences found in the areas of body image, chest symptoms, career concerns, emotional responses, and concerns for the future<br>☐ Males reported a poorer body image most notably in those with moderate lung disease denoted by lung function of 41-69%.<br>☐ Significant relationship in both males and females between BMI and body image.<br>☐ Strongest relationship for females was in between emotional functioning and lung function while for males it was between physical functioning and lung function.<br>☐ Females reported a poorer HRQoL in areas of chest symptoms, emotional functioning, concerns for the future, and career issues.<br>☐ Females appeared to be more susceptible to poorer HRQoL despite similar clinical characteristics (BMI, lung function). |
| Gee et al. (2005) | N/A<br><br>United Kingdom | 223 adults with CF<br><br>Age: 20-29 years | ☐ BMI, lung function (FEV$_1$), presence of diabetes, presence of intravenous device<br>☐ HRQoL: measured by CFQoL | ☐ Females had a lower BMI and lung function compared to males.<br>☐ Females had higher scores in domain of body image and lower scores for chest symptoms and emotional functioning.<br>☐ Females and those with higher BMI reported a better body image. |
| Groeneveld et al. (2012) | N/A<br><br>Spain | 28 people with CF<br><br>Age: 6-17 years | HRQoL: measured by CFQ-R | ☐ Females reported worse HRQoL in areas of emotional functioning, treatment burden, and respiratory symptoms when compared to males.<br>☐ Higher age was associated with less favorable body image, when adjusting for gender. |
| Hebestreit et al. (2014) | 1999-2001<br><br>Germany and Switzerland | 76 people with CF<br><br>Age: Mean = 20 years | ☐ HRQoL: measured by CFQ-R | ☐ Females reported poorer HRQoL in the area of role functioning.<br>☐ There were no other significant differences between genders in HRQoL domains. |
| Hegarty et al. (2008) | N/A<br><br>Australia | 33 people with CF<br><br>Age: 6-18 | ☐ HRQoL: measured by CFQ-R | ☐ Females reported a better HRQoL (mean = 74.69) when compared to males (mean = 54.82) in the area of treatment burden.<br>☐ No other statistically significant effects of gender on HRQoL were found. |
| Kundsen et al. (2016) | 2013-2014<br><br>Denmark | 67 people with CF<br><br>Age: 18-30 years | ☐ Morisky Medication Adherence Scale<br>☐ Major Despression Inventory<br>☐ HRQoL: measured by CFQ-R | ☐ Females reported more symptoms of depression than males. |

| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Nick et al. (2010) | Retrospective analysis of data collected from 1992-2008  United States | 156 people with CF  Age: 40-86 years | ☐ CF Foundation Patient Registry ☐ Colorado CF Database ☐ Multiple Cause of Death Index | ☐ Annual age-related decline in lung function was not different between genders. ☐ In those diagnosed during childhood (birth to 10 years), lung function declines faster in females over 40 years of age compared to males. ☐ In those who are diagnosed with CF as adults, lung function decline was equal for males and females. |
| Olveria et al. (2016) | 2011-2012  Spain | 336 people with CF  Age: Mean age = 28.1 years | ☐ Hospital anxiety and depression scale ☐ HRQoL: measured by CFQ-R | ☐ No significant differences between males and females in scores indicating depression. ☐ Scores indicating anxiety were significantly higher in females. ☐ Higher anxiety levels were associated with being female and having more exacerbations in the past 6 months. |
| Patterson et al. (2008) | 2002  United States | 103 people with CF  Age: 10-21 years | ☐ Living with CF Questionnaire: to measure different family, peer, and personal factors shown to be associated with CF | ☐ Females experienced more strains and sought more support than males. ☐ Females reported being more embarrassed to cough, skipping high fat foods, and skipping medications and pills more than males. ☐ Emotional and physical strains of CF occurred more frequently in females. ☐ Self-esteem was significantly higher for males and was associated with better adherence. |
| Platten et al. (2013) | N/A  United Kingdom | 105 people with CF  Age: Mean = 27.8 | ☐ HRQoL: measured by CFQ-R ☐ Clinical Outcomes Routine Evaluation Outcome Measure 34 (CORE-OM) – to assess mental health ☐ Rosenburg Self-esteem Scale | ☐ Gender explained 8.2% of variance in mental health symptoms. ☐ Females reported a significantly poorer HRQoL in the domains of emotional functioning and social functioning. ☐ Females reported lower self-esteem and higher levels of psychological distress. |
| Sawicki et al. (2009) | 2006  United States | 204 people with CF  Age: Mean = 35.4 years | ☐ HRQoL: measured by the CFQ-R ☐ Treatment activities measured via survey | ☐ Time spent doing CF-related treatments and total number of medications did not differ significantly by gender. ☐ Females reported a higher treatment burden than males. |
| Sawicki et al. (2011) | 2003-2005  82 study sites in North America | 337 children, 398 adolescents, and 631 adults with CF | ☐ HRQoL: measured by the CFQ-R | ☐ In teens, female gender was associated with lower physical functioning domain of CFQ-R. |

| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Selvaduari et al. (2004) | N/A<br><br>Australia | 148 people with CF<br><br>Age: 9-17 years | ☐ Habitual activity: activity diary | ☐ In pre-pubescent children, there was no difference in activity levels between males and females with same level of disease severity.<br>☐ Pubescent females had a significantly lower activity levels when compared to males with similar disease severity.<br>☐ Significantly lower levels of activity and quality of life in pubertal females who are pancreatic insufficient compared to those who were pancreatic sufficient. This difference not present in males. |
| Shoff, et al., (2013) | 1985-1998<br><br>United States | 95 people with CF<br><br>Age:9-19 years | ☐ HRQoL: measured by the CFQ | ☐ No significant gender differences in mean CFQ scores or in nutritional status indicators.<br>☐ Differences between girls and boys were most prominent in those who had short stature, more specifically physical functioning in females and body image in males.<br>☐ Three areas of the CF-Q showed gender-specific associations with nutritional status which were eating. disturbances, physical functioning, and body image. |
| Simon et al. (2011) | N/A<br><br>United States | 54 families including a member with CF | ☐ HRQoL: measured by CFQ-R<br>☐ 24 hour diet recall<br>☐ Medical chart review | ☐ Percent of the recommended dietary reference intake was an average of 30 points lower for females when compared to males.<br>☐ 44.8% of females were inconsistent with treatments compared to 8% of males.<br>☐ Females were significantly more likely to |
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| Author/Date | Time Frame/ Location | Sample | Measurement/ Instrument | Relevant Findings |
|---|---|---|---|---|
| Stofa et al. (2016) | 2013 Greece | 77 people with CF Age: 18 years and older | ☐ HRQoL: measured by CFQoL | ☐ No statistically significant differences in HRQoL reported between males and females. |
| Thomas et al. (2006) | 2000-2002 Australia | 279 people with CF Age: 2-19 years | ☐ HRQoL: measured by CFQoL | ☐ Females reported significantly lower HRQoL based on the emotional domain in all ages (p = 0.001). ☐ Female teens had lower scores for physical functioning, vitality, body image, and emotional functioning and higher score for weight compared to male teens although not statistically significant. |
| Tomaszek et al. (2018) | 2016-2017 Poland | 95 people with CF Age: 14-25 years | ☐ HRQoL: measured by CFQoL | ☐ Females perceived their ability to maintain a job or college course as worse than males. ☐ Gender was a significant predictor of HRQoL ☐ Females reported significantly poorer HRQoL when compared to males in concerns for the future and career issues. |
| Uchmanowicz, et al. (2015) | 2012 Poland | 30 people with CF Age: Mean = 25 years | ☐ HRQoL: measured by CFQoL | ☐ In all subscales of the CFQoL other than interpersonal relationships, females reported their quality of life lower than males. ☐ Females scored highest in interpersonal relationships while males scored highest on physical functioning. ☐ Females aged > 25 evaluate their HRQoL as worse in all domains than females < or = to 25. |

therefore, intentionally missed treatments to spend time with friends and appear "normal" (Berge et al., 2007). Abbott and colleagues (2007) also found that females were more likely than males to challenge the treatment regimen that they were prescribed. In terms of compliance, Simon and colleagues (2011) found that 45% of females were inconsistent with their treatments compared to 8% of males. Patterson and colleagues (2008) also stated that females tended skip medications more often than males. In contrast, males with CF chose to be compliant after learning from their mistakes and took greater control of their treatments independently (Berge et al., 2007). In addition, males did not feel different from peers and instead often took the approach of explaining their treatments to peers whom they found to be accepting of their disease and its limitations (Berge et al., 2007). Findings have been inconsistent in the HRQoL domain of treatment burden. Females self-reported a poorer HRQoL in the area of treatment burden in some studies (Groeneveld et al., 2012; Sawicki, Sellers, & Robinson, 2009) while reporting a better HRQoL in others (Hegarty et al., 2008). When time spent performing CF-related treatments and number of medications were examined, neither varied significantly by

gender (Sawicki et al., 2009). These findings shed further light on why females may have a poorer HRQoL in the area of treatment burden despite similar disease severity when compared to males.

**Personal Outlook on CF**
Personal outlook includes how those with CF perceive their outlook on life related to CF. In terms of general outlook on their disease, females reported acceptance of CF and males reported optimism and a positive attitude, indicating overall positive perspectives from both genders (Berge et al., 2007). Females needed support in order to deal with the depressive symptoms that they experienced related to CF (Berge et al., 2007). This included support from not only friends and family, but also mental health providers (Berge et al., 2007). Concurrently, females have noted more CF-related strains and sought more support than males (Patterson et al., 2008). Conversely, males more easily incorporated CF into their identity as a part of them for which they took full responsibility (Berge et al., 2007).

**Age**

Females with CF over age 25 years scored lower in all domains of HRQoL compared to females aged 25 or younger (Uchmanowicz, Jankowska-Polańska, Rosińczuk, & Wleklik, 2015). In addition, annual age-related decline in lung function did not vary by gender (Nick et al., 2010). However, when looking at age at diagnosis of CF in those diagnosed during childhood, birth to 10 years, lung function declined faster in females when compared to males over age 40 (Nick et al., 2010). Conversely, in those with CF who were diagnosed with CF after age 10, lung function decline was equal in males and females (Nick et al., 2010).

## Lung Health
Lung function, measured by forced expiratory volume in one second (FEV1), was shown to be a predictor of HRQoL scores (Tomazek et al., 2018). There were no significant differences in lung function, measured by FEV1, between males and females (Arrington-Sanders et al., 2006). After controlling for FEV1, females still had a poorer HRQoL in the areas of mental health and overall health perceptions when compared to males (Arrington-Sanders et al., 2006). Females reported a significantly lower HRQoL in the area of respiratory functioning on the CFQ-R and the chest symptoms domain of the CFQoL when compared to males (Dill et al., 2013; Gee et al., 2003; Gee, Abbott, Conway, Etherington, & Webb, 2005). For females, the strongest relationship was between lung function and emotional functioning, while for males it was between physical functioning and lung function (Gee et al., 2003). Females were shown to be more susceptible to poorer HRQoL despite a similar lung function when compared to males (Gee et al., 2003).

## Nutritional Status and Resulting Body Image
Nutritional status was measured by height, weight, and body mass index (BMI) across published studies. Suboptimal nutritional status, as measured by a lower BMI, was associated with more frequent hospitalizations, increased likelihood of being infected with P. aeruginosa, decreased lung function, and lower scores on the HRQoL domains of treatment burden, body image, and weight (Bodnar et al., 2014; Borawska-Kowalczyk & Sands et al., 2015; Dill et al., 2013; Forte et al., 2015; Shoff, Tluczek, Laxova, Farrell, & Lai, 2013). Gender has also been shown to be a significant predictor of HRQoL scores for both weight and body image (Forte et al., 2013). In addition, females reported a better HRQoL in the area of body image when compared to males (Abbott et al., 2015; Dill et al., 2013; Gee et al., 2003; Gee et al., 2005). This is despite females having a lower BMI, weight, and height when compared to males (Abbott et al., 2007). In terms of BMI, a decrease in 1 unit of BMI resulted in equal decreases in body image for males and females (Abbott et al., 2015). Females noted more dieting behavior and preoccupation with food when compared to males (Abbott et al., 2007). Females were also more likely to skip the needed high fat food than males (Patterson et al., 2008). Percent of the recommended dietary reference intake was an average

of 30 points lower for females compared to males (Simon et al., 2011). This evidence shows that women perceive their body image and weight as more positive despite a lower BMI and weight and also tend to illustrate more dieting behavior when compared to males.

## Physical Functioning
Physical functioning refers to the amount of limitation in physical activity related to CF. The physical functioning domain of HRQoL was most strongly correlated with lung function. Across the literature, HRQoL scores trended with FEV1, wherein as lung function declined physical function scores also declined (Abbott et al., 2013; Bodnar et al., 2014; Borawska-Kowalczyk & Sands, 2015; Dill et al., 2013). The physical functioning domain has been noted as a predictor of greater mortality (Dill et al., 2013; Forte et al., 2015). In addition, females self-reported a poorer HRQoL in the domain of physical functioning (Arrington-Sanders et al., 2006; Borawska-Kowalczyk & Sands, 2015; Dill et al., 2013; Sawicki et al., 2011; Uchomanowicz et al., 2015). In terms of activity level, there were no differences between males and females prior to puberty; however, females who had experienced puberty had a significantly lower activity level when compared to males who had a similar level of disease severity (Selvadurai. Blimkie, Cooper, Mellis, & Van Asperen, 2004). In addition, females who had experienced puberty and were pancreatic insufficient had lower levels of activity and poorer HRQoL, which is a difference not found in males (Selvadurai et al., 2004).

## Social Functioning
Social functioning refers to how CF and associated treatments have affected socialization. Females consistently had a poorer HRQoL in the social functioning domain of the CFQ-R compared to males (Casier et al., 2011; Dill et al., 2013; Groeneveld et al., 2012; Platten, Newman, & Quayle, 2013). Females noted being more embarrassed to cough in public and skip medications and pills as a result when compared to males (Patterson et al., 2008) Using the CFQoL Questionnaire, females perceived both their personal ability to maintain a job or college course as poorer than males and also experienced more career issues (Tomaszek et al., 2018). Uchmanowicz and colleagues (2015) also found that while females had a poorer HRQoL in all domains other than one, they did report a better HRQoL in the area of interpersonal relationships.

## Mental Health
Emotional functioning is the mental health component measured by HRQoL instruments. Females consistently had a poorer HRQoL in the area of emotional functioning (Casier et al., 2011; Gee et al., 2003; Gee et al., 2005; Groeneveld et al., 2012; Platten et al., 2013; Thomas et al., 2006; Uchmanowicz et al., 2015). Higher emotional strains and psychological distress were also present in females compared to

males (Patterson et al., 2008; Platten et al., 2013). Females with CF consistently noted a lower self-esteem when compared to males (Abbott et al., 2007; Patterson et al., 2008; Platten et al., 2013).

Anxiety and depression. Individuals with CF who screened positive for anxiety and depression, and had an FEV1 < 50% had a poorer HRQoL (Olveira et al., 2016). In fact, those with elevated symptoms of depression and anxiety noted a poorer HRQoL across all 12 CFQ-R domains (Olveira et al., 2016).When looking at gender differences in anxiety and depression among those with CF, females reported higher levels of both anxiety and depression (Berge et al., 2007; Knudsen et al., 2016; Olveira et al., 2016).

## Discussion

This integrative literature review illustrates the state of the science regarding gender differences in HRQoL of those with CF. Significant gender differences present in the literature include: 1) females were more likely to challenge their prescribed treatment regimen, needed more support to complete treatments, and were also less compliant with their prescribed treatment regimen when compared to males (Abbott et al., 2007; Berge et al., 2007; Simon et al., 2011); 2) females noted more CF-related strain compared to males (Patterson et al., 2008); 3) in those diagnosed during childhood (birth to 10 years) lung function declined faster in females over age 40 when compared to males (Nick et al., 2010); 4) females were more susceptible to poorer HRQoL despite a similar lung function to males (Gee et al., 2003); 5) gender was a significant predictor of HRQoL scores in the areas of weight and body image (Forte et al., 2015); 6) females tended to report a better HRQoL in the area of body image despite a lower BMI (Abbott et al., 2007; Abbott et al., 2015); 7) activity level declined with puberty in females with CF, which was not present in males (Selvadurai et al., 2004); 8) in a social setting, females were more embarrassed of their treatment regimen and found it harder to maintain a job or college course compared to males (Patterson et al., 2008; Tomaszek et al., 2018); and 9) females self-reported higher levels of anxiety, depression, and emotional strains related to CF and lower self-esteem when compared to males (Abbott et al., 2007; Knudsen et al., 2016; Olveira et al., 2016).

While factors influencing HRQoL have been previously reviewed, this literature review is the first to illustrate the state of the science regarding gender differences in HRQoL of those with CF. This review also has implications for research and practice as discussed below.

## Implications for Research

Some of the factors gleaned from this literature review that warrant further investigation of gender differences in CF HRQoL include why/how: 1) females were more likely to

challenge their prescribed treatment regimen, needed more support to complete treatments, and were also less compliant with their prescribed treatment regimen when compared to males; 2) females experienced more CF-related strain compared to males; 3) females tended to report a better HRQoL in the area of body image despite a lower BMI; 4) activity level declined with puberty in females with CF, which is not present in males (Selvadurai et al., 2004); 5) females found it harder to maintain a job or college course compared to males; and 6) females had higher levels of anxiety, depression, and emotional strains related to CF and lower self-esteem when compared to males. Future research needs to be conducted to provide a holistic explanation of the gender differences in HRQoL and inform intervention development to address the gender gap. Quantitatively examining individuals' with CF gender differences and then qualitatively exploring their insights about gender-specific facilitators and barriers to HRQoL might glean useful information to inform future interventions to improve HRQoL in the CF population.

## Implications for Practice

The link between HRQoL and clinical health outcomes (e.g., FEV1, BMI, weight, etc.) illustrates the usefulness of CFQ-R in routine clinical practice to guide healthcare provider decision-making (Dill et al., 2013). By using the CFQ-R during routine clinic appointments, healthcare providers would be able to: 1) identify problems in specific HRQoL domains; and 2) identify a change in HRQoL over time, which would allow prompt investigation of causes and implementation of strategies. Lastly, this review illustrates the importance of discussing gender-related issues with those with CF at clinic visits to promote awareness as well as early detection of gender-specific needs of this population.

## Limitations

The articles included in this review did not all use the same measurement tool for HRQoL (See Table 2 for instruments used in each study). The slight variations in the domains of the instruments (See Table 1 for descriptions) and results concerning gender differences by domain make it difficult to characterize and generalize HRQoL and the subsequent gender differences.

## Conclusions

In conclusion, this integrative review of the literature revealed that there are stark gender differences in multiple domains of HRQoL among individuals with CF. Additional research is necessary to fully understand the factors and determinants of the gender gap in HRQOL outcomes in order to develop theoretically-based interventions that can narrow the gender gap and improve quality of life in this population.

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**JOURNAL OF NURSING PRACTICE APPLICATIONS & REVIEWS OF RESEARCH**

# An Integrative Review Examining the Manifestation and Trajectory of Depression from Pregnancy to Postpartum in Childbearing Women

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**Abstract**

**Background:** Depression is a significant concern impacting the health of our maternal populations and directly contributing to maternal mortality. While postpartum depression (PPD) is documented to have significant impacts on maternal child health and maternal mortality, no known study to date has examined the manifestation and trajectory of PPD in women of childbearing age.

**Objective:** The purpose of this study was to conduct an integrative literature review to examine the trajectory of PPD. In order to best prevent, treat, and manage PPD, it is important to understand the manifestation of this illness.

**Methods:** An integrative literature review was conducted utilizing CINAHL, PubMed, and ProQuest Nursing and Allied Health. After the inclusion and exclusion criteria were applied, 14 articles were included in this literature review.

**Results:** Of the 14 original research articles included in this integrative review, 10 (71%) determined that women who developed PPD also experienced depression either antepartum or before pregnancy. Through this literature review, the trajectory of PPD was described as being the manifestation of earlier depression, rather than a new onset of a depression episode.

**Conclusion:** There are several opportunities for addressing the trajectory of PPD. It is essential for the allied health care force to better recognize PPD, its prevention, and its treatment as early as possible in the perinatal period. With the knowledge of this trajectory of PPD in mind, further studies need to explore these health care implications.

*Keywords: postpartum depression, perinatal depression, antenatal depression, trajectory, maternal mortality*

## Background

Postpartum depression affects 17% of women globally. While the rates of postpartum depression vary by region, they are nearly twice as high during this period as compared to other points in a women's life (Shorey et al., 2018). The rates of depression also vary by income and are highest among low-income women living in high-income countries. This number is believed to be much higher (between 23% and 52%) among low-income women (Pooler, Perry, & Ghandour, 2013; Thompson & Fox, 2010). Untreated depression is a significant health concern during the perinatal period, from pregnancy until up to 12 months postpartum, given the physiological and psychosocial implications for both women and their infants. Women who have PPD may experience symptoms such as crying more often than usual, feeling anger, withdrawing from loved ones, feeling numb or disconnected from their babies, worrying about hurting their babies, and not feeling able to care for their babies or be good mothers (Brummelte & Galea, 2016).

While PPD is known to be a major risk factor for maternal complications, there are still questions regarding when and how this type of depression begins (Yonkers et al., 2001). Because of the numerous physiological, psychological, and psychosocial variables influencing the presentation of PPD, understanding the manifestation and trajectory, or path, of this illness remains highly complex. It is uncertain if postpartum depression is a new manifestation of depression or a continuation of a previous episode of depression in childbearing women. Therefore, the purpose of this integrative literature review is to examine existing studies on depression during pregnancy and the postpartum periods to describe the trajectory of PPD.

## Methods

### Design

An integrative literature review design was utilized to search for existing studies on depression during pregnancy and postpartum to describe the trajectory of PPD. This type of review was chosen over a systematic review for its function as a discussion of findings in comparison to a systematic review's critical analytical approach to data (Russell, 2005). In addition, integrative literature reviews include not only randomized clinical trials like their systematic literature review counterparts, but also studies that are cross-sectional, cohort, and longitudinal designs, among other types (Russell, 2005). Incorporating multiple study designs into this integrative review formulated a robust understanding of the trajectory of PPD.

### Literature Search Strategies

CINAHL, PubMed, and ProQuest Nursing and Allied Health databases were utilized for this review. Keywords included in the search: *"postpartum depression," "post-partum depression," "postnatal depression," "perinatal depression," "antenatal depression," "prenatal depression," "trajectory," "longitudinal study," "predictive study"* in combination. Using these specific keywords and combined search terms, a search was conducted within the aforementioned databases.

### Inclusion/Exclusion Criteria and Evaluation Strategies

Articles included in this integrative review were published in the most recent decade, from 2008 to 2018, to represent contemporary perspectives on the manifestation and trajectory of PPD. These included original research studies and clinical trials with human subjects published in the English language in a peer-reviewed journal. The initial search turned up a total of 13,298 articles. Among these articles, the titles were screened for relevancy and the inclusion criteria, for a total of 488 articles. The articles were further examined against the exclusion criteria as follows: (1) studies that did not collect data on the condition of the mother before the birth, as well as postpartum, as this literature review makes a comparison; (2) studies that investigated more than prior experience of depression as being a risk factor for developing postpartum depression, since this review focuses solely on prior exposure to depression; (3) studies that did not investigate if having depression before giving birth and/or before becoming pregnant is related to developing postpartum depression. After rejecting the articles that met the exclusion criteria, 14 articles remained and were included in this literature review. These articles exclusively explored the trajectory of PPD, spanning the time frame from antepartum to postpartum.

### Data Synthesis & Analysis

The data from the articles remaining from the literature search were analyzed as well as synthesized, according to steps defined by Whittmore and Knafl (2005). This involves data from primary sources—the 14 publications that make up this review—to be ordered, coded, categorized, and summarized into a cohesive product. The first step is data reduction. In this phase of the analysis process, the articles are separated into subgroups based on a system that is individualized and tailored to the data. For this review, the data extracted were the type of trajectory found for postpartum depression and the points in time at which data was collected (pre-pregnancy, pregnancy, post-pregnancy, and/or after considerable time had passed). These two categories pertained to this literature review and are essential to answering the research questions. The extracted and coded data was then assembled into a display matrix table in the second step of Whittemore and Knafl (2005) method. The table includes source, data collection points, type of trajectory, and conclusion. This allows for data comparison, the third step of the analysis process. This phase involves pattern recognition and theme and relationship identification in order to answer the research questions.

## Results

A search of literature provided the 14 articles that met the inclusion criteria of this paper (Table 1). All studies were descriptive and contained quantitative data. Studies were conducted in the United States and internationally in Korea (Choi, Park, Park, Ko, & Shin, 2014; Park, Karmaus, & Zhang, 2015); France (Waerden et al., 2015); Norway (Fredriksen, von Soest, Smith, & Moe, 2017); Australia (Eastwood et al., 2017; Patton et al., 2015); Patton, Romaniuk, Spry, Coffey, Olsson, & Doyle, 2015); Iran (Abdollahi, Zarghami, Azhar, Sazlina, & Lye, 2014); and Canada. The women in the studies comprise both first-time mothers and those who gave birth to a second child. All of the studies surveyed the mothers before and after giving birth, but

### Table 1. Studies Included in the Integrative Literature Review

| Source | Title | Sample | Depression Screening Tool | Data Collection Points | Description of Symptom Trajectory | Conclusion |
|---|---|---|---|---|---|---|
| Abdollahi, F., Zarghami, M., Azhar, M. Z., Sazlina, S., & Lye, M. (2014) | Predictors and incidence of post-partum depression: A longitudinal cohort study | n = 2,279 Country: Iran | EPDS | 32-42 weeks into gestation, 2 weeks postpartum, 2 months postpartum, 3 months postpartum | Depression during the second and third trimesters was a strong predictor of PPD | PPD is the manifestation of earlier depression |
| Ahmed, A., Feng, C., Bowen, A., & Muhajarine, N. (2018) | Latent trajectory groups of perinatal depressive and anxiety symptoms from pregnancy to early postpartum and their antenatal risk factors | n = 615 Country: Canada | EPDS | Twice during pregnancy: early (at 17.4 +/− 4.9 weeks of gestation), and late (at 30.6 +/− 2.7 weeks of gestation); and at early postpartum (at 4.2 +/−2.1 weeks postpartum) | Four trajectories were found: low-stable (48%), moderate-stable (43%), postpartum (4%), and antepartum (5%) | PPD is the manifestation of earlier depression |
| Denckla, C. A. et al. (2017) | Distinguishing postpartum and antepartum depressive trajectories in a large population-based cohort: The impact of exposure to adversity and offspring gender | n = 12,121 Country: England | EPDS | 18 weeks gestation, 32 weeks gestation, 8 weeks postpartum, 8 months postpartum, 2 years postpartum, 3 years postpartum, 5 years postpartum | Four-class trajectory model: *resilient* (77.6%), *improving* (7.7%), *chronic* (10.7%), and *emergent* (4%) | Inconclusive/ mixed results |
| Eastwood, J., Ogbo, F. A., Hendry, A., Noble, J., Page, A. (2017) | The impact of antenatal depression on perinatal outcomes in Australian women | n = 17,564 Country: Australia | EPDS | First prenatal visit and 6 weeks postpartum | Maternal depression during pregnancy was significantly associated with postnatal depressive symptoms | PPD is the manifestation of earlier depression |
| Fredriksen, E., Soest, T., Smith, L., & Moe, V. (2016) | Patterns of pregnancy and postpartum depressive symptoms: Latent class trajectories and predictors | n = 1,036 Country: Norway | EPDS | 21 weeks into gestation, 28 weeks into gestation, 32 weeks into gestation, 36 weeks into gestation, 6 weeks postpartum, 6 months postpartum, 1 year postpartum | Four trajectories were found: pregnancy only (4.4%); postpartum only (2.2%); moderate-persistent (10.5%); and minimum symptoms (82.9%) | PPD is the manifestation of earlier depression |
| Guyon-Harris, K., Huth-Bocks, A., Lauterbach, D., & Janisse, H. (2016) | Trajectories of maternal depressive symptoms across the birth of a child: Associations with toddler emotional development | n = 120 Country: United States | EPDS | Third trimester, 3 months postpartum, 1 year postpartum, 2 years postpartum | Low-decreasing (47.5 %), stable-low (22.5 %), stable-moderate (21.7 %), and increasing (8.3 %) | PPD is the manifestation of earlier depression |
| Luoma, I., Korhonen, M., Salmelin, R. K., Helminen, M., Tamminen, T. (2015) | Long-term trajectories of maternal depressive symptoms and their antenatal predictors | n = 329 Country: United States | EPDS | Third trimester, 2 months postpartum, 6 months postpartum, 4-5 years postpartum, 8-9 years postpartum, and 16-17 years postpartum | A model including four symptom trajectories (very low-8%, low-stable-53%, high-stable-27%, and intermittent-3%) was selected to describe the symptom patterns over time. All of the women who had PPD had some level of depression before birth | PPD is the manifestation of earlier depression |
| McCall-Hosenfeld, J. S., Phiri, K., Shaefer, E., Zhu, J., & Kjerulf, K. (2016) | Trajectories of depressive symptoms throughout the peri- and postpartum period: Results from the first baby study | n = 2802 Country: United States | EPDS | Third trimester, 1 month, 6 months, 12 months | Six distinct depressive trajectories: most were low-constant, one was high-constant, and one encompassing 1.7% of mothers was increasing | Inconclusive/mixed results |
| Mora, P. A., Bennet, I. M., Elo, I. T., Mathew, L., Coyne, J. C., & Culhane, J. F. (2008) | Distinct trajectories of perinatal depressive symptomatology: Evidence from growth mixture modeling | n = 1,735 Country: United States | CES-D Scale | First[t] prenatal care visit, 3 months postpartum, 11 months postpartum, 25 months postpartum | Four trajectories were found: *chronic* depression (7%); *prenatal* only (6%); *postpartum*, which resolves after the first year postpartum (9%); *late*, present at 25 months postpartum (7%) | PPD is not affected by earlier depression |

| | | | | | |
|---|---|---|---|---|---|
| Park, J., Karmaus, W., Zhang, H. (2015) | Prevalence of and risk factors for depressive symptoms in Korean women throughout pregnancy and in postpartum period | n = 153 Country: Korea | EPDS | First, second, and third trimesters, and 4 weeks postpartum | PPD was significantly associated with depression in the second and third trimesters | PPD is the manifestation of earlier depression |
| Patton, G.C. et al. (2015) | Prediction of perinatal depression from adolescence and before conception (VIHCS): 20-year prospective cohort study | n = 1,000 Country: Australia | EPDS; GHQ-12; CITI | Before pregnancy, 32 weeks into gestation, 8 weeks postpartum, and 1 year postpartum | 34% of women who developed PPD had mental health problems before getting pregnant, compared to 8% of those who did not have mental health problems | PPD is the manifestation of earlier depression |
| Choi, S.K., Park, Y.G., Park, I.Y., Ko, H.S., & Shin, J.C. (2014) | Impact of antenatal depression on perinatal outcomes and postpartum depression in Korean women | n = 467 Country: Korea | EPDS | Prenatal (unspecified time) and 2 months postpartum | 60% of women with PPD had prenatal depression, compared to the women with PPD who did not have prenatal depression | PPD is the manifestation of earlier depression |
| Waerden, J., Galéra, C., Saurel-Cubizolles, M., Sutter-Dallay, & A.-L., Melchior, M. (2015) | Predictors of persistent maternal depression trajectories in early childhood: Results from the EDEN mother–child cohort study in France | n = 1,807 Country: France | CES-D Scale | 24-28 weeks into gestation, right after birth, 4 months, 8 months, 1 year, 2 years, 3 years, 4 years, and 5 years | Five trajectories were identified: no symptoms (60.2%); persistent intermediate-level depressive symptoms (25.2%); persistent high depressive symptoms (5.0%); high symptoms in pregnancy only (4.7%); high symptoms in the child's preschool period only (4.9%) | PPD is the manifestation of earlier depression |
| Woolhouse, H., Gartland, D., Mensah, F., Giallo, R., & Brown, S. (2016) | Maternal depression from pregnancy to 4 years postpartum and emotional/behavioral difficulties in children: Results from a prospective pregnancy cohort study | n = 1,507 Country: Australia | EPDS | Early pregnancy (mean of 15 weeks gestation), 3 months postpartum, 6 months postpartum, 1 year postpartum, 4 years postpartum | 7% reported symptoms during both pregnancy and at 4 years, 28% reported symptoms only in postpartum | Depression was episodic and not chronic |

there were variations in the timing and frequency of data collection. In sum, the data collection periods represented in these studies ranged from the pre-conception period of a woman's life to four years postpartum.

*A Prominent Trajectory*

Of the 14 articles included in this integrative review, 10 determined that women who developed PPD also had experienced previous depression, either while antepartum or before pregnancy. The study conducted by Eastwood et al. (2017) followed a large sample of 17,564 mothers of infants born in Australia. The study found that "maternal depressive symptoms during pregnancy was strongly associated with postnatal depressive symptoms" (p. 7). This conclusion was also seen in another Australian study by Patton et al. (2015), which found a strong association between maternal depressive symptoms during pregnancy and subsequent postnatal depressive symptoms. Two of the articles described relationships between postpartum depression and individual trimesters. Park et al. (2015) found that postpartum depression was significantly correlated to the second and third trimesters. It was discovered in the Choi et al. (2014) research study that women who were depressed in their third trimester were more likely to develop PPD.

Waerden et al. (2015) found five distinct trajectories of symptomology; the dominant one, however, was prenatal depression followed by postpartum depression. Similarly,

another study found four distinct trajectories to describe the symptomology of PPD (Fredriksen et al., 2017). The trajectory that the majority of the sample followed was "persistent," meaning the women had depressive symptoms in the prenatal period as well as the postpartum period, rather than only the prenatal period or only the postpartum period. A study conducted in the United States also found a four-class model for symptom trajectory and described "stable" depressive symptoms among the majority of participants, defined as depressive symptoms experienced during both the prenatal period and the postpartum period (Guyon-Harris, Huth-Bocks, Lauterbach, & Janisse, 2016). This trend of four trajectory patterns continued with a 2015 Finnish study in which the "stable" category fit the majority of the women with PPD (Luoma, Korhonen, Salmelin, Helminen, & Tamminen, 2015). This trend was further seen in a recent study (Ahmed, Feng, Bowen, & Muhajarine, 2018), in which four perinatal symptom trajectory groups were found in Canadian mothers, with "moderate-stable" representing more of the sample than either "postpartum" or "antepartum" alone.

*Outliers*

Two studies we reviewed did not find a strong trajectory of depression during pregnancy extending to the postpartum period (Mora et al., 2008; Woolhouse, Gartland, Mensah, Giallo, & Brown, 2016). In the Woolhouse et al.'s (2016) study, 1,507 women were surveyed from early pregnancy to four years postpartum. Among the women reporting de-

pressive symptoms at four years postpartum, 7% reported symptoms only during pregnancy and 28% reported symptoms only postpartum. This suggests PPD is just as likely, if not more likely, to occur in mothers who did not have depression before pregnancy or in the prenatal period. The other study that came to similar conclusions was a study conducted by Mora et. al (2008) that followed more than 1,700 women from their first prenatal visit to two years postpartum. This study found that 7% of the women had had depression earlier in life as well as developing PPD, 6% had depression antepartum with PPD development, 9% had only PPD, and 7% developed depression two years postpartum (with the remaining percentage not having any depressive symptoms). Therefore, in this study there was not a particular conclusion about the trajectory of PPD, which suggests that pre-pregnancy and antepartum depression have no effect on the development of PPD.

A U. S. study conducted in Pennsylvania established six trajectories among the participants (McCall-Hosenfeld, Phiri, Schaefer, Zhu, & Kjerulff, 2016). The first was the prominent trajectory mentioned in earlier studies, in which depressive symptoms in the prenatal period are followed by postpartum depression symptoms. However, there was another significant trajectory found in the data that started as no depression in pregnancy and showed an increase in depressive symptoms until at least one year postpartum, which is when the study ended. This symptomology needs further exploration. Another recent study by Denckla et al. (2018) showed similar results. It found a four-class model of PPD symptomology starting in the prenatal period. These classes include chronic (10.7%), which begins and ends with high depressive symptoms; emergent (4%), with increasing symptomology; and improving (7.7%), with decreasing symptomology. This suggests that more mothers who developed PPD had prenatal depressive symptoms; however, a significant number of mothers follow other trajectories, according to this study.

## Discussion

This integrative literature review is the first known comprehensive examination describing postpartum depression as the manifestation of earlier depression, during either the antenatal period or preconception. The findings from this review present implications for nursing practice, as healthcare workers and providers work to both prevent and treat PPD in our childbearing population. To improve nursing practice, the use of integrated health care approaches such as Collaborative Care could enhance health care providers' ability to identify and track women with perinatal depression during pregnancy. Collaborative Care employs a population based approach to provide team-based care in the postpartum period and track treatments to target (McGregor, Lin, & Katon, 2011). This approach is shown to be effective with perinatal women (Huang et al., 2017) and

reduces overall health care costs (Katon et al., 2012). Despite the proven effectiveness, nursing practice has yet to fully utilize Collaborative Care models to address pressing health needs. Past research studies demonstrate that Collaborative Care models are appropriate for women of all racial and ethnic backgrounds (Huang et al., 2012; Huang et al., 2017). Studies such as MomCare (Grote et al., 2014), a trial to improve perinatal mental health of low-income women, address additional factors, such as trauma that might complicate pregnancy and contribute to maternal mortality. In addition, Collaborative Care models are suited for communication across clinics, such as the neonatal intensive care unit and primary care. Families who experience complications and/or multiple births might be at increased risk for perinatal depression (Huang et al., 2017; Lefkowitz, Baxt, & Evans, 2010) and Collaborative Care models would provide additional support.

Understanding that postpartum depression is not episodic in nature but rather an arc between pre-existing depression and resurfacing of depressive symptoms has systemic implications for both nursing education and practice. For nurses, proper prevention begins with completing a full assessment of patients, with particular consideration to current lifestyle and environmental stressors, as well as family and individual history of depression and anxiety. Through knowing our patient's background, nurses are better prepared to offer anticipatory guidance through pregnancy and the postpartum period. The results of this integrative literature review encourage health care providers to re-envision PPD as an arc of perinatal depression, rather than the primary manifestation of new-onset depression following the birth of an infant. Future studies of both quantitative and qualitative design are needed to determine the objective onset and perceived experience of depression as related to the timing within the perinatal period.

Utilizing the perinatal depression trajectory framework should encourage nurses in outpatient ob-gyn and pediatric practices to utilize every patient visit to assess women's mental health for signs and symptoms of PPD. As nurses, we are uniquely positioned to refer patients for formal psychiatric care and to public health nursing for follow-up in the home setting. In addition to these formal referrals, we can use a systematic approach to verbally assess for PPD during outpatient visits. The visits are opportunities to build trust and rapport and to communicate our support for our patients. They encourage open dialogue and may reduce the stigma attached to challenging issues, including PPD. Segre, O'hara, Arndt, and Beck's (2010) study examined nurses' views as to whether nurses should screen for PPD and also treat new mothers with mild PPD (N = 520). Their results showed that the majority of study participants agreed that having nurses screen for depression in the outpatient setting would be a good idea. A great majority of

participants—93.7%—also agreed with the concept of nurse-delivered counseling in the home setting for women with mild PPD.

## Implications

The nursing implications of the trajectory of PPD discussed in this paper involve both recognition and prevention of PPD, as well as treatment. Nurses are the main point of contact between the patient and the hospital or outpatient center, which gives them the most opportunity to facilitate the patient's care plan and course of treatment. In the postpartum unit, the nurse can pay attention to women at high risk for PPD based on their previous depression and supply them with literature and the appropriate resources early on, enabling early detection of PPD and referral to treatment at or before the standard 6-week follow-up visit. Universal screening for depression and depressive symptoms is one way to detect women in need of referral and follow up for perinatal depression. Screening tools such as the Edinburgh Postnatal Depression Scale are free to use and widely available in numerous languages. Recent practice guidelines, such as the National Institute for Health and Care Excellence guidelines in the United Kingdom or the United States Preventive Task Force recommendations, suggest screening for depression during pregnancy and postpartum, but the precise timing of these screenings remains unclear (Pawlby et al., 2008; Siu et al., 2016). The earlier follow-up will allow for better detection of perinatal depression when patients need treatment most. The effects of PPD occur less often and last longer than those of the "baby blues," which often occur during the first two weeks after having a baby. Accordingly, future studies are needed to investigate the trajectory of perinatal depression distinct from the period of baby blues in postpartum women.

## Limitations

This integrative review is not without some limitations in both study design and data. The study design of this review was limited to journal indices available to study authors; therefore, sources included are based upon those that were retrievable, and results are not intended to be exhaustive. The study design also included data limitations with regard to the screening tools utilized to measure PPD. Different screening tools were used to identify previous depression and postpartum depression. Many of the studies in this integrative review utilized the Edinburgh Postnatal Depression Scale (EPDS) as a form of measurement, but there were inconsistencies in the measurement of PPD from study to study. Patton et al. (2015) used the 12-item General Health Questionnaire (GHQ-12), and the Composite International Diagnostic Interview (CIDI) in addition to the EPDS. In contrast, Mora et al. (2008) used the Center for Epidemiology Studies Depression (CES-D) Scale, a 20-item survey with scores ranging from 0 to 60. Also, there were discrepancies noted in what constitutes a positive response to the EPDS screening tool, ranging from 10 to 12, which may impact the overall study result. It is noteworthy to mention that while the EPDS is known for its usefulness in the United States, its validity in non-Western cultures is debated due to its etic considerations (Laungani, 2000).

## Conclusions

In conclusion, this review found that the literature to date supports the notion that postpartum depression is not the manifestation of a new depressive disorder, but rather the resurfacing of previous depression first experienced preconception and/or during the antenatal period. With the knowledge of this trajectory in mind, the health care implications to better improve prevention and treatment of PPD are numerous. Early detection and initiation of treatment can help mothers and families enhance both the physiological and psychosocial health of their families, as well as help to reduce maternal mortality.

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**JOURNAL OF NURSING PRACTICE APPLICATIONS & REVIEWS OF RESEARCH**

# Human Trafficking: Knowledge and Awareness in Nursing Practice

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## Abstract

**Background:** Human trafficking (HT) is a global, national, and local public health issue with many quantifying concerns, including the identification and care of these individuals. Perpetrators of trafficked individuals target vulnerable populations through force, violence and victimization. Nurses in the clinical setting are in a crucial position to recognize, assess, and refer victims of HT. However, nurses may not be aware of the presence of HT in their communities or of the signs and symptoms that may alert nurses of potential HT victims.

**Objective:** The purpose of this study was to gain a better understanding of nurses' familiarity of HT, their perception of HT as a problem in their community, and their ability to recognize, assess, and refer potential HT victims for assistance.

**Methods**: A literature review and descriptive cross-sectional study using survey methodology was used to help gain a better understanding of nurse's familiarity and perception of human trafficking.

**Results:** Findings of this study have the potential to inform the development of educational interventions to increase identification, assessment, and referral of HT victims who present to the clinical setting for care.

**Conclusion:** Identification and proper reporting of potential HT victims can be challenging to the healthcare professional because of the perplexing and covert nature of HT. Healthcare professionals are at the front lines in both facilitating the identification of potential victims and treating and referring them to the right resources. Several comments made by the respondents clearly identified the need for HT education related to insufficient education and understanding of this public health issue.

*Keywords:* human trafficking, nurse, educational resources, nursing survey results

## Background

Human trafficking (HT) is a global, national, and local public health issue with many quantifying concerns that include accurately identifying the victims and providing proper healthcare needs for these individuals. It is a crime of modern-day slavery in which this crime has been underestimated and underreported (Coppola & Cantwell, 2016; Hachey & Phillippi, 2017). The "traffickers target vulnerable populations which frequently include persons living in poverty, refugees from areas of conflict, runaways, and homeless youth, victims of domestic violence or sexual assault and ethnic minorities" (Long & Dowdell, 2018, p. 376). The perpetrators often seek out these persons using force, violence or intimidation to control their victims (Scannell, MacDonald, Berger, & Boyer, 2018).

According to the U.S. Department of State (2013), human trafficking is the recruitment, harboring, transportation, provision, or obtaining of a person for labor or services through the use of force, fraud, or coercion for the purpose of subjection to involuntary servitude, peonage, debt bondage, or slavery. Victims of trafficking may be performing jobs or activities which they were coerced or deceived into and which they cannot leave (International Labor Organization [ILO], 2012). Furthermore, individuals are considered to be trafficking victims "regardless of whether they once consented or even participated in a crime as a direct result of being trafficked" (Office to Monitor and Combat Human Trafficking, 2014, p.1).

There are several risk factors associated with human trafficking. These include social determinants of health such as poverty, lack of formal education, limited English proficiency and limited support systems (Hachey & Phillippi, 2017). A history of violence, trauma and abuse are also highly related to risk for trafficking, and globalization issues of migration, refugee displacement, and victims located in conflict zones and civil wars also increase the risk of an individual being trafficked (Hachey & Phillippi, 2017). Individual HT victims suffer from numerous physical and psychological problems (Coppola & Cantwell, 2016; Hachey & Phillippi, 2017). For victims held in captivity, healthcare professionals are often the only people who may encounter and interact with them. More often than not, healthcare professionals who care for the victims may not recognize that the individual is being trafficked (Hachey & Phillippi, 2017; Long & Dowdell, 2018). Subtle cries for help may go unnoticed if the healthcare provider is not aware of the signs and symptoms of HT.

A recent study (Long & Dowdell, 2017) revealed that 87.8% of human trafficking survivors had been in contact with a healthcare provider in some capacity during their victimization. Furthermore, it concluded that 68.3% had received an evaluation in the emergency department. This short window of time in the health care setting may offer opportunities for early identification and timely treatment of trafficked victims (Baldwin, Eisenman, Sayles, Ryan, & Chuang, 2011).

## Significance

Human Trafficking is a global problem with national roots. The United Nations Office on Drugs and Crime (UNODC) recognized HT as an issue in 2004 and brought forth The United Nations Convention against Transnational Organized Crime document that helped bring about international policies and offered legal advice to governments on preventing this world health issue (UNODC, 2004). Globally, the estimated number of victims is difficult to identify as there are numerous barriers due to inconsistencies with both national and international laws, secrecy related to the nature of the crime and its impact on society, lack of awareness that trafficking is occurring in a particular geographical area, fearing personal safety if one were to be become involved in helping a victim, and failure of victims to freely identify that they are being victimized (Lutz, 2018; Konstantopoulos et al., 2013). The UNODC's Global Report on Trafficking in Persons (2004) recognizes that "legislation does not always comply with the Protocol, nor does it cover all forms of trafficking and their victims, leaving far too many children, women and men vulnerable. "Even where legislation is enacted, implementation often falls short because of either lack of early identification or lack of follow through after identification" (UNODC, 2004, p. 1).

Trafficking for forced labor is prominently detected in North, Central and South America and "accounts for more than half of all the detected HT victims; in South America alone, the share is above 40 percent. It is very likely that trafficking for forced labor is underreported to an unknown extent in some South American countries" (UNODC, 2004, pg. 72). In the United States (U.S.), the government estimated that approximately 600,000 to 800,000 people were trafficked across global borders each year, and if trafficking within all countries were to be included in the total world figures, approximately 2 million to 4 million people were trafficked annually (United States Government Accountability Office, 2006). Of those trafficked victims, 80% are women, with 50% of these females considered to be minors (Doyydaitis, 2010; Miller, Decker, Silverman, & Raj, 2007; U.S. Department of State, 2007). An estimated 50,000 women and children are annually trafficked into the U.S. (Barrows & Finger, 2008; Doyydaitis, 2010; Miller et al., 2007). It is important to note that the exact number of U.S. victims of HT is difficult to determine due to the underground nature of trafficking networks and practice (Miller et al., 2007).

Published data do not represent the full scope of human trafficking. These statistics are "considered reliable estimates

based on information gathered from governmental and non-governmental organizations around the world. Even though different sources report different information, it is reasonable to say that whatever the estimated numbers, they are all too high and there are far too many victims" (Peters, 2012, p. 281). Significant underreporting can be related to several factors, including lack of general awareness and lack of identifiable resources to assist victims (UNODC, 2014; Polaris, 2017).

In a multi-city study conducted at the University of Pennsylvania, Wolfe, Greeson, Wasch and Treglia (2018) found that one in five of the youth were victims of sex trafficking and that two out of three homeless females reported being solicited for paid sex. Cities represented by this study were Phoenix, Washington DC, and Philadelphia. For all genders, 22% of those homeless youth who were approached for paid sex had this happen on the first night of being homeless. Transgender youth were particularly vulnerable, with 90% of transgender youth reporting being offered money for sex. Ninety-five percent had a history of child abuse. Among those who were maltreated, the highest percentage of youth reported being sexually abused (49%), followed by physical abuse (33%). In addition, 67% percent of those trafficked did not graduate from high school (Wolf et al., 2018).

Not only is it challenging to identify the number of victims both on a global and national level, but it is also perplexing that healthcare professionals may not recognize the signs or know how to manage these individuals once they are identified. Lutz' (2017) study on integrating human trafficking education into a standard nursing curriculum recognized there were gaps in knowledge among healthcare providers regarding definitions of HT, laws related to the public health issue, global and national prevalence, identification and treatment of victims, as well as community resources available to help identified victims. In a study conducted by Egyud, Stephens, Swansan-Bierman, DiCuccio, and Whiteman (2017) on educating emergency room nurses found that formal education and screening is necessary to identify true victims of HT because they can resemble victims of other crimes, including prostitution, domestic violence, abuse, addiction and assault.

Coppola and Cantwell (2016) recognized how nurses working at the frontlines in clinical settings or emergency departments intersect with this hidden and underestimated public health issue. Nurses are the first healthcare professionals that victims encounter when seeking care. "Trafficked victims typically receive healthcare only when their condition becomes serious" and nurses caring for these individuals may not clearly recognize that there is more to their initial call for help (Sabella, 2011, p. 32).

Several organizations and associations have presented position statements based on the nature and importance of this issue and reinforce the position that healthcare providers have an obligation to recognize and help identified victims. American Academy of Pediatrics Policy Statement (2017) recommend that all individual healthcare professionals can prevent trafficking, recognize victims and intervene appropriately. The statement further indicates that there should be global efforts to address the social determinants of health, which are intimately connected to push and pull factors for human trafficking; and advocate for training of health care professionals (Greenbaum et al., 2017).

The Emergency Nurses Association and International Forensic Nurses Dual Position Statement on Human Trafficking Awareness posits that nurses "play a vital role in recognizing and responding to the needs of victims…. (and that) capturing these lifesaving opportunities requires proactive measures aimed at education awareness and training" (Emergency Nurses Association and International Forensic Nurses, 2018, p 2).

The Association of Women's Health, Obstetrics and Neonatal Nursing Organization (AWHONN), an organization supporting nurses caring for both female and infant populations, put forth a position statement recognizing HT as a health issue recommending several initiatives, including developing a validated, brief screening tool to better identify victims of human trafficking in the clinical setting; advancing research on the long term health implications for victims; and enhancing multisector collaboration and coordination in order to support information sharing (AWHONN, 2016).

## Literature Review

Studies have found that the percentage of victims in the U.S. who encounter health care professionals while under the control of the trafficker ranges from 28 percent (Lederer & Wetzel, 2014) to 87.8 percent (Family Violence Prevention Fund, 2005). Traffickers may bring or allow the victims to obtain medical care either when their illnesses or injuries are interfering with their ability to work or for routine care including obtaining contraceptives or testing for sexually transmitted infection (STI) (Tracy & Konstantopoulos, 2012).

Several studies (Beck et al., 2015; Grace et al., 2014; Chisolm-Straker, Richardson & Cossio, 2012; Ross et al., 2015) have shown that training can have a significant impact on clinicians' knowledge of trafficking and their ability to recognize and care for these victims. Beck et al. (2015) conducted a survey to evaluate knowledge gaps and training needs of medical providers in order to demonstrate the importance of provider training to meet the pediatric HT victim's specific needs, and to highlight barriers to the identification of and response to victims. Findings in a sample

of 168 participants, indicated 48% correctly classified a minor as a HT victim, and 42% correctly distinguished an HT victim from a child abuse victim. In all, 63% of respondents said that they had never received training on how to identify HT victims. Those with training were more likely to report HT as a major problem locally ($p \leq .001$), to have encountered a victim in their practice ($p \leq .001$), and to have greater confidence in their ability to identify victims ($p \leq .001$). The greatest barriers to identification of victims reported were a lack of training (34%) and awareness (22%) of HT.

Grace et al. (2014) conducted a study aimed to determine whether an educational presentation increased emergency department (ED) providers' recognition of HT victims and knowledge of resources to manage cases of HT. Knowledge increased by an average of 1.42 points in the intervention group versus 0.15 points in the comparison group (1.57 [1.02–2.12], $p < 0.001$); the proportion of participants who rated themselves as knowledgeable/ very knowledgeable increased from 7.2% to 59.0% in the intervention group and was unchanged (15.0%) in the comparison group. Knowledge of who to call if they encountered a potential victim increased more in the intervention group (from 24% to 100%) than the delayed intervention comparison group (from 20% to 35%): (61.4% [28.5%–94.4%], $p = 0.005$). Additionally, the proportion of participants in the intervention group who suspected that a patient was a victim of HT doubled (from 17% to 38%), whereas the comparison group remained at 10% (20.9% [8.6%–33.1%], $p = 0.003$)

Chisolm-Straker et al. (2012) developed and piloted an educational intervention for emergency providers on HT and how to identify and treat these patients. Findings indicate that prior to the intervention, 4.8% felt some degree of confidence in their ability to identify and 7.7% to treat a trafficked patient. After the 20-minute intervention, 53.8% felt some degree of confidence in their ability to identify and 56.7% care for this patient population.

Ross et al. (2015) conducted a cross-sectional survey to estimate the proportion of National Health Service (NHS) professionals who have come into contact with trafficked people and to assess NHS professionals' knowledge and confidence to respond to human trafficking. Thirteen percent of the participants reported previous contact with a patient they knew or suspected of having been trafficked; among maternity services professionals this was 20.4%. However, 86.8% (n = 679) reported lacking knowledge of what questions to ask to identify potential victims and 78.3% (n = 613) reported that they had insufficient training to assist trafficked people. Seventy-one percent (n = 556), 67.5% (n = 528) and 53.4% (n = 418) of respondents lacked confidence in making appropriate referrals for men, women and children, respectively, who had been trafficked.

## Purpose of the Study

Nurses in the clinical setting are in a crucial position to recognize, assess, and report victims of HT. However, nurses may not be aware of the HT in their communities or of the signs to alert them of potential HT victims. Therefore, the purpose of this study is to gain a better understanding of nurses' familiarity of HT, their perception of HT as a problem in their community, and their ability to recognize, assess, and refer potential HT victims when encountered in the clinical setting. Findings of this study have the potential to inform the development of educational interventions to increase identification, assessment, and referral of HT victims in the clinical setting.

## Methods

This descriptive, cross-sectional study using survey methodology helped to gain a better understanding of nurses' familiarity of HT, their perception of HT as a problem in their community, and their ability to recognize and assess potential HT victims in the clinical setting. All registered nurses licensed in the state of New Jersey were to be included. No registered nurses were excluded. After obtaining University Institutional Review Board approval, an online survey was sent to approximately 120,000 Registered Nurses either working or retired in New Jersey, through a listserv obtained from the State Nurses Association. The listserv included all NJ registered nurses to the date the researchers obtained the list. Of the emails sent, 2400 emails were returned as undeliverable. A total of 117,600 emails were successfully delivered. The final sample was 734 individual RNs, having a response rate of 0.6%. This response rate was quite low and therefore generalizability to all New Jersey nurses is very limited.

Qualtrics, an online, secure survey program, was used to collect the survey data. The survey was pre-tested with faculty colleagues and minor revisions were made to the questions prior to utilization. Demographic questions were asked, such as gender, age, education, clinical practice, and educational sessions or programs related to HT attended.

To assess familiarity of HT, nurses were asked "How familiar are you with the term "Human Trafficking"? Response options ranged from extremely familiar to not familiar at all. Knowledge was assessed through questions related to those individuals they considered victims of HT and the characteristics they presented with; demeanor, eye contact, and escorts.

To assess for nursing awareness based on these characteristics, they were asked, "In your opinion, do you believe Human Trafficking is a problem in your community?" Response options ranged from strongly agree to disagree.

To assess nurses' ability to identify victims of HT and provide resources to assist them, nurses were asked, "When

you suspect a patient is a victim of human trafficking, do you address your suspicion with the patient?" Response options ranged from always to never.

Additionally, nurses were asked "If the patient validated your suspicion, were you able to refer the patient to any help?" Response options were dichotomized, yes/no. Open-ended questions were also asked to obtain additional information around resources available to both HT victims and nurses. Finally, an open comments section was included at the end of the survey to collect any other information that the nurse wished to share.

After results were collected, unfinished responses and duplicates were removed from the data set, which was then analyzed for significant trends and indicators. All analyses were performed using SAS 9.4 (TS1M2) for windows operating system.

Some of the questions included "skip logic," an option that did not appear to those for whom it did not apply (as determined by how the respondent answered a previous question), and as a result, percentages included in this article indicate the percentage of respondents who answered that particular question.

Chi-Square tests were used to establish the dependency among the variables. Only the significant results with p-value less than 0.05 are reported here. A limitation worth noting is that even though p-value is affected by sample size and the sample size for this survey for some questions were not high enough, some of the dependency was not significant at the 5% level. A multiple linear regression model was also built to understand the simultaneous impact of above-mentioned variables on the frequency of addressing the issue.

### Results

**Demographics**

The respondents' ages ranged from 18-84 years of age (M = 45.54). There were 39 (5.42%) males and 681 (94.58%) female respondents. Most respondents indicated that the most primary language spoken was English (99.38%) and Spanish (41.34%). Other languages included Russian, Vietnamese, Hindi, and other bilingual.

Of the respondents, 43.21% responded having a Bachelor's degree and 27.93% had Master's degree education. Approximately 43.47% of the respondents' primary place

of employment was in the hospital setting. The remaining respondents worked in office, clinic, academic and other settings including but not limited to college health facilities, correctional facilities, telehealth, long term care and acute care facilities, home care, drug and alcohol rehabilitation facilities, and insurance companies. Close to 43% of the respondents indicated that they had worked in healthcare five year or less and approximately 20% had worked more than 16 years. About 76% of the respondents were employed full-time while 17.66% were employed part-time. Job titles of the respondents included staff nurses, unit managers, directors, nurse practitioners, research nurses, nurse educators. Additionally, 17.39% of the respondents worked in pediatrics and 82.6% worked in adult care. See Table 1 for sample demographics.

**Knowledge and Familiarity with HT**

Most respondents (n = 550, 86.62%) were familiar with the concept of HT while about 85 respondents (13.38%) were slightly or not familiar at all. The respondents considered that victims of HT were associated with underage girls forced into prostitution; associated with a person who is traded for goods or services; associated HT with a factory worker working in unsafe conditions; associated HT with a domestic helper who is forced to work more than 12 hours a day; associated HT with a foreign worker who is smuggled into the country. Nineteen (0.69%) respondents indicated

**Table 1. Sample Demographic Variables**

| Characteristic | *n* | % |
|---|---|---|
| Nursing Practice Specialty | | |
| Neonates | | 2.66% |
| Pediatrics | | 11.91% |
| Adolescents | | 2.82% |
| Adults | | 63.95% |
| Older Adults | | 18.65% |
| Age | | |
| 18-24 | 15 | 2.08% |
| 25-34 | 83 | 11.53% |
| 35-44 | 114 | 15.83% |
| 45-54 | 171 | 23.75% |
| 55-64 | 257 | 35.69% |
| 65-74 | 78 | 10.83% |
| 75-84 | 2 | 0.28% |
| 85 or older | 0 | 0.00% |
| Years in Practice | | |
| 0-5 years | 273 | 42.86% |
| 6-10 years | 103 | 16.17% |
| 11-15 years | 88 | 13.81% |
| More than 16 years | 173 | 27.16% |
| Degree Earned | | |
| Diploma | 30 | 4.68% |
| Associates | 88 | 13.73% |
| Bachelors | 277 | 43.21% |
| Masters | 179 | 27.93% |
| Doctorate | 23 | 3.59% |
| Currently in program | 44 | 6.86% |

other scenarios, including "adult men and women forced into prostitution," "male/female not underage," and "any that could have been taken or kidnapped" while only three (0.11%) responded they did not know.

**Awareness of HT as a Problem**
When asked if they believed HT is a problem in their community, almost half of the respondents (46.07%) neither agreed nor disagreed, and more than half agreed it was (53.93%).

**Ability to Identify HT Victims**
One hundred and forty-six respondents (22.99%) indicated that they possibly had provided care to an HT victim, while 49 respondents (7.72%) indicated they definitely cared for a HT victim. Of that number, 38 respondents (15.77%) recognized the signs during the physical examination, 136 respondents (56.43%) during the health history intake, and 67 respondents (27.80%) suspected they were an HT victim at some other point during their encounter. Examples of these include during a treatment, noting lack of eye contact during encounter, and discussion during subsequent encounters. The suspicions stemmed from noticing a "weird relationship between parent and guardian" if a child was suspected of being a victim; observing strange characteristics while the victims were "waiting in the waiting room"; while others found that "the client volunteered the information."

One hundred and seventy-five respondents (27.56%) offered they definitely never cared for a patient who they either suspected or was a victim of HT; and 265 respondents (41.73%) did not know whether or not they cared for a victim of human trafficking. Of the nurses who indicated suspicion, 152 respondents (45.11%) verbally validated their suspicion with the patient, 110 respondents (32.64%) sometimes did; while 75 respondents (22.26%) never did.

The patient's overall demeanor, presence of an escort, lack of eye contact, unexplained bruises or discomforts, were all factors that led the nurses to suspect HT. All characteristics were part of the survey choices that allowed for free text by the respondents. Most responded that the patient's overall demeanor was noted to be withdrawn, quiet, fearful, guarded, and anxious. The types of eye contact the nurse noted were poor, avoided, minimal, or lacked eye contact. The suspected HT victim's responses to questions were vague, short worded, evasive, minimal, and poor. Responses also included that the nurses' suspicion was heightened when an escort was present and refused to leave the patient alone with the nurse. Responses noted that the presence of bruising and/or contusions were sometimes or always noted on multiple areas of the patient's body. Respondents noted that patient visits to the facility were sometimes to frequent.

The nurses were also asked if they addressed their suspi-

cions with the patients and if so, how did the patient react. Approximately 135 respondents (76.07%) indicated that victims who were addressed about the possibility of their being HT victims, did not react positively, while 41 respondents (23.30%) responded extremely, very or moderately well. Only 44 respondents (24.18 %) indicated that the patient verbally validated their suspicions, while 138 respondents (75.82%) did not provide verbal validation.

**Ability to Provide Resources**
Sixty-four respondents (45.71%) offered help to HT victims while 76 respondents (54.29%) did not offer help. When help was offered to the victims, 32 of the victims (32.32%) accepted help, 38 respondents (38.38%) were unsure if they accepted it, while 29 of the victims (29.29%) did not accept it. Not all respondents offered a response to the above question on whether the victim accepted help from the provider. Respondents offered that a majority of cases were referred to the social worker (75%), while police and authorities (42.31%) and human trafficking hotline or resource center (16.35%) were also suggested. Other examples of referrals offered included battered woman's shelter, advocacy groups, safe house, and Sexual Assault Nurse Examiner (SANE) nurse (19.23%).

**Available HT Nursing Education**
Three hundred and ninety-one respondents (63.06%) indicated that they have not attended nor participated in any program or session dedicated to HT education. Two hundred twenty-nine respondents (36.93%) stated (36.93%) stated that they had attended HT education as follows: forty-nine (7.90%) respondents attended a training workshop, 42 (6.77%) attended a conference or symposium, 86 (13.87%) attended a webinar or web-based presentation, and 52 (8.39%) attended other symposiums. There were no follow up questions on the survey to identify who offered the training or in what capacity it was presented.

More than half of the respondents (58.77%) identified how HT education was not provided by the nurses' places of employment, while only 196 respondents (33.39%) did not know if any HT education was available where they worked. Only 46 respondents (7.84%) stated that there definitely was HT education at their place of employment. When asked if their place of employment offered social services or outreach programs for identified victims of HT, 348 respondents (59.39%) did not know..

When asked about barriers in their place of employment that prevented outreach or social services to victims of HT, 40 respondents (22.99%) indicated there were barriers, although 56 respondents (32.18%) were not aware of any barriers. Respondents who stated there were barriers indicated lack of federal agency support, lack of funding, lack of HT knowledge, and lack of training.

The survey also asked nurses about whether there was interest in attending a HT program that would include HT materials and information about mechanisms for assisting victims. Greater than three quarters of respondents (86.42%) offered they would attend educational sessions, while the remaining indicated they were either not interested or indifferent.

## Correlations

Chi-Square test shows that health care professionals with stronger beliefs or perceptions that Human Trafficking is a problem in the community are more likely to address the problem with a patient when they suspect the patient is a HT victim (p = 0.0064). About 54% of the people who "Strongly Agree/Agree" that Human Trafficking is a problem in the community almost always address the issue with their victims, while only about 42% always address the problem and 37% sometimes address the problem in the other groups who do not strongly beleive that HT is a problem in the community.

While checking the impact of attendance at a HT program on addressing the issue, Chi-Square test demonstrates a strong relationship. Among health care professionals who attended at least one HT program or conference, about 56% addressed the issue almost all the time whereas only 35% did so among the people who did not attend any (p = 0.0049).

Awareness about the characteristics of the victims also influences RNs to address the problem more frequently than those who are not aware. About 59% of the RNs who indicated they were aware of at least one characteristic addressed HT with their patients, while only 29% of the rest took the similar action (p < 0.0001).

Services or training at the work place motivate people significantly to address the issue. Though there are few places where such training and services are available, it shows that about 68% of those who address it almost all the time worked in an environment that offered training and services to victims, while only 41% among others do so (p = 0.0345). Further tests also show people with services/trainings can help the victims effectively than others. About 67% of those who have had HT training helped the victims while only 42% of the others could the same (p = 0.0396).

## Multiple Regression

To understand the simultaneous effect of all the variables on the frequency of addressing the issue of HT in the clinical setting, a multiple linear regression model was used. The dependent variable in the model was the frequency of addressing the issue and the independent variables are, (1) "How strongly they believe that HT was a problem in their community " (p = 0.0097), (2) "Aware of the Characteristics of the victims (yes/no)" (p < 0.0001), (3) "Number of programs/sessions attended about Human Trafficking" (p < 0.0001) and "Whether place of employment provides services or training" (yes/no) (p < 0.0015). All the variables are standardized to compare the individual effects in terms of percentages. Model checking and outlier detection were performed. In terms of percentages, "Awareness of the Characteristics" has the highest impact (52.6%) which is followed by "Attending Programs" (23.3%), "Training program at work place" (12.3%) and the least impact on all variables was "Belief that Human Trafficking is a problem in their community" (11.2%).

## Discussion

Identification and proper reporting of HT can be challenging to the healthcare professional because of its perplexing and covert nature. In any healthcare setting, the healthcare professionals are the first in helping to facilitate treatment/ referral after identifying them as victims. Several comments made by the respondents clearly identified the need for HT education for New Jersey RNs, as several respondents noted a lack of proper training and understanding of this serious public health issue. However, since this was a limitation of the study it is difficult to generalize on a national level, but the impact of this public health issue is greatly recognized.

One respondent offered "It appears that the victim is treated as a commodity by the handlers and the arrival in a healthcare environment may occur frequently as a result of this relationship. There may be other human conditions, such as abusive relationships, which can mimic the symptoms of Human Trafficking so the education offerings could consider these other human conditions and assessments, interventions, and evaluations for these as well." One respondent offered they feel that "(t)here currently is no information available. (When they) worked for immigration detention, "we heard these stories all day long, but outside in the real world" we hear nothing.

Nurses also need to keep in mind that some victims may not trust the sources of referral. Language or social barriers can lead to feelings of isolation and victims may not either speak or understand English, and may therefore depend on the trafficker for interpretation. "Any information that victims receive is totally controlled, which keeps them unaware of any resources or services designed to help" (Peters, 2013, p. 283).

The survey results overwhelmingly indicate that RN respondents lack HT information and want to learn. As discussed above, several organizations and associations have presented position statements based on the nature and importance of this issue and reinforce the position that healthcare providers have an obligation to recognize and help

identified victims. However, it is not clear how frequently or consistently education and training are offered, or in what capacity it is offered.

There are at least 36.93% of the respondents who have attended HT training in one form or another. However, based on the survey response, it is not standard onboarding process to include HT as part of orientation. Currently, there is no HT education available specifically directed toward the RN population. For example, in the state of New Jersey, "all healthcare workers and volunteers in New Jersey who have contact with patients – regardless if the contact is clinical or non-clinical – must complete training in recognizing and intervening in cases of human trafficking" (New Jersey Hospital Association, 2018). These materials are geared toward all healthcare workers, including RNs, and volunteers. The material is general and does not include information on how to identify and assess potential victims. Furthermore, this mandatory material is accessed as online training modules that must be completed to maintain certification and licensure and part of annual compliance training.

RNs have specific skills in patient assessment which is not addressed in the online training materials. Registered nurses would benefit more from face to face training sessions specifically on assessing, identifying and providing follow up for HT victims. Several hospitals have instituted algorithm protocols and practices for their Emergency Department staff, but lack the formalization of a national program (Egyud et al., 2017; Grace et al., 2014; Greenbaum, 2016).

## Limitations

Generalizability of the study findings may be limited. Study participants were recruited from a population of New Jersey nurses. Therefore, findings may not be fully applicable in other parts of the country where the demographics of both nurses and potential HT victims may vary. In addition, the use of self-report questionnaires certainly raises concern about the validity of study conclusions. Study participants may have provided responses to present themselves in the best possible light, despite their actual behaviors. Furthermore, voluntary response bias may have occurred due to self-selected volunteers willing to be participants in this study.

An additional limitation is the use of a listserv, which may not have had updated information to reach potential participants. Thousands of emails were not able to be delivered and were returned to sender. Since the survey was sent by email, there was also the concern that several of the emails were sent to the junk inbox, or recipients may have considered the emails spam and did not open the link. Due to the above-mentioned limitations, study findings should be taken with caution.

## Conclusions

Registered Nurses in the clinical setting are in a crucial position to recognize, assess, and refer victims of HT. However, nurses may not be aware of the HT in their communities or of the signs which could alert them that their patient may be a victim of HT. If victims can be identified, then they may be referred to the appropriate support services. This survey indicated that RNs may lack information related to identifying, assessing and referring HT victims. Face to face education for RNs, which includes demonstration and return demonstration of assessment techniques, may improve patient outcomes for the population of HT victims. The results of this survey only help to open to door to more research on human trafficking and implementation of more training for healthcare professionals.

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# Utilization and Cost among Home Health Care Patients with Cognitive Impairment: Data Analysis of Service Use by Cognitive Status and Primary Source of Payment

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**Conflict of Interest**
The authors declare that there is no conflict of interest.

## Abstract

**Background:** People with disorders of dementia experience cognitive, behavioral and psychiatric syndromes, require increasing support, and their care needs are complex and multidimensional. Nearly one-third of home health care patients in the U.S. have moderate to severe cognitive impairment, yet unique patterns of service use and cost have not been well examined.

**Objective:** This study makes novel comparisons of home health care service use and cost between patients with moderate-to-severe cognitive impairment and those with little-to-no cognitive impairment.

The goal is to determine whether an association exists between cognitive impairment status and home health care service volume, type, readmission, duration, and cost, both in the general home health care population and within each of four categories of primary source of service payment, including Medicare, Medicaid, private insurance, and self-pay.

**Methods:** This study uses nationally-representative home health care data from the most recent and final (2007) National Home and Hospice Care Survey, consisting of 3,309 home health care patients nested within 595 agencies.

This study compares service use and cost between patients with moderate-to-severe cognitive impairment and those with little-to-no cognitive impairment, as well as variations in the relationships between cognitive status and service utilization and cost by primary source of payment.

**Results:** On average, those with moderate-to-severe cognitive impairment receive services for 111 more days, including about three more medical and two more non-medical service visits, and are 8% more likely to be readmitted to home health care. Additional costs of service that are associated with significantly greater durations and intensities of service are more likely to be incurred on multiple occasions because of readmission. The most influential factor in determining service costs is the insurance program used to pay for services.

**Conclusion:** These findings suggest that patients with moderate-to-severe cognitive impairment may require services which are estimated to cost between 45% and 179% more than the services provided to those who have little-to-no cognitive impairment, on average, depending on primary source of payment. The rapid aging of the population, coupled with the considerable complications associated with dementia care, lends particular urgency to the need for intervention, program development, and policy change in this arena.

*Keywords: dementia, neurocognitive disorder, cognitive impairment, homecare, home health services, utilization, costs*

## Background

Over 78 million Baby Boomers were born in the U.S. between 1946 and 1964 (U.S. Census Bureau, 2014), and the oldest members of this cohort turned 65 in 2011. One in five Americans will be over age 65 by 2030 (U.S. Census Bureau, 2014). Within the first four decades of the 21st century, the global population across all age groups is predicted to increase by 33%, whereas the number of people age 65 and older will increase by 160%, and those age 80 and above will increase by 233% (Kinsella & He, 2009). The rapid aging of the population corresponds with increases in the incidence of age-associated illnesses of dementia, and this trend will continue as the proportion of older adults rises dramatically in the coming decades (Alzheimer's Association [AA], 2017). By 2050, the projected rate of diagnoses of Alzheimer's disease, the leading age-associated cause of dementia by far, will reach about 1,000,000 new cases per year, which translates to one new Alzheimer's diagnosis every 33 seconds (AA, 2017). In the U.S., 13% of people age 65 and older have dementia and nearly two-thirds are women (AA, 2017). Dementia is the leading chronic disease contributor to disability among older adults (Wimo, Jönsson, Bond, Prince & Winblad, 2013). The annual global cost of dementia is already estimated at $604 billion, or the equivalent of about 1% of the world's Gross Domestic Product (Wimo et al., 2013), and health systems in every country will be significantly impacted by the extreme escalation in the number of older people living with dementia.

Formal care services for older adults and those living with disabilities are provided by a continuum of programs in both community and institutional settings that provide health, mental health, and aging services (Alkema, Wilber, & Enguidanos, 2007). Many families facing dementia rely upon formal, paid care services due to the family's limited availability or the excessive burdens of care.

As depicted in Figure 1, the use of formal care, intensity of family involvement, and functional dependence of patients increase as dementia symptomatology worsens. The period of shared care, when the efforts of informal caregivers are supplemented by services from community-based care providers, presents an opportunity to address health and quality of life through supportive and effective home-based assistance. This supplemental care is arranged by family caregivers in order to off-load some of the more basic care tasks, thereby alleviating their feelings of worry and strain (Hansen, Hauge & Bergland, 2017; Mondor et al., 2017; Pot, Zarit, Twisk & Townsend, 2005). The effectiveness, efficiency, and adequacy of such services in meeting the unique needs of people with dementia remains unclear, however.

## Purpose of the Study

Previous studies of home health care utilization have examined determinants of care services, timing of nursing home placement, and correlates of help-seeking behavior among caregivers (Beeber, Thorpe & Clipp, 2008; Clarkson et al., 2018; Sussman & Regehr, 2009; Wattmo, Wallin, Londos & Minthon, 2010; Weber, Pirraglia & Kunik, 2011). Home health care, the community resource most often used among community-dwelling individuals with dementia, is used by fewer than half of dementia patients overall (Weber et al., 2011). To date, there have been few studies in the United States describing the population of home health care patients with cognitive impairment as compared to those who do not have cognitive deficiencies. It is likely that differences exist in the frequency, periodicity, and type of services provided, and the overall costs of care. For example, Medicare currently pays more than half of all health care costs for people with dementia. Furthermore, the cost associated with this particular group of patients is nearly three times as much as non-demented peers enrolled in Medicare (Bentkover et al., 2012). In addition, Medicare beneficiaries with dementia account for one-third of Medicare
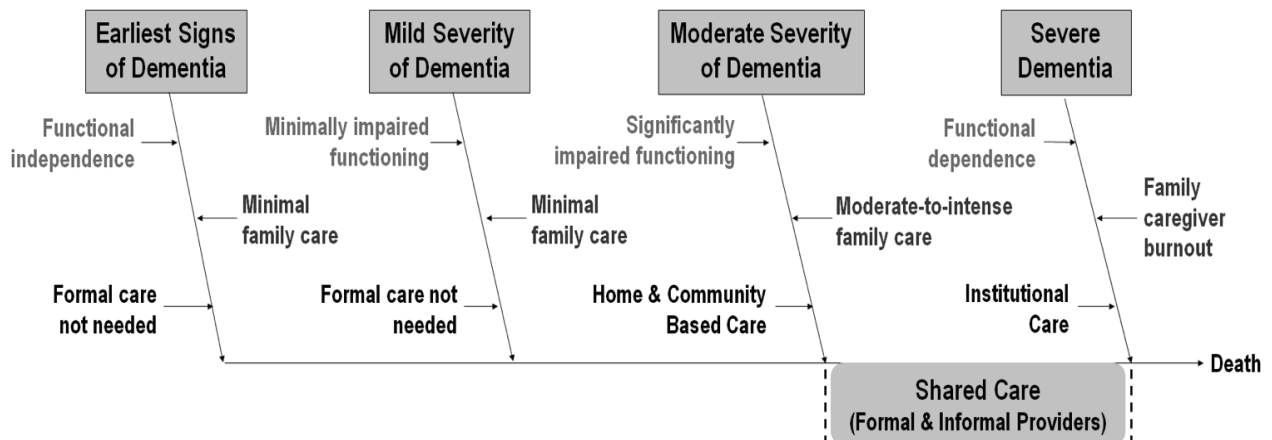


**Figure 1.** Depiction of progression of symptoms and care provision in dementia

spending but comprise only 13% of all Medicare recipients (Boustani, Schubert & Sennour, 2007).

Growth in the home health care sector has outpaced growth in every other setting of health care (Clarkson et al., 2017; Hansen et al., 2017; Mondor et al., 2017; Kelly, Morgan & Jason, 2012). In addition, policymakers have prioritized efforts to increase reliance on community-based care in recent decades (Doty, 2010) because informal and formal providers share in the provision of care when people with moderate-to-severe dementia remain at home. This study determines whether an association exists between cognitive impairment and home health care service volume, type, readmission, duration, and cost, both in the general home health care population and within each of four categories of primary source of service payment (Medicare, Medicaid, private insurance, and self-pay). This is an initial step toward identifying determinants of home health services required by people living with dementia or cognitive deficits. Policymakers and advocates for appropriate and accessible health care are working to determine the right balance between quality and costs of care as the health care delivery system continues to evolve. Outcomes of this research will be helpful when examining policies that govern service reimbursements as well as innovative home-based dementia care practices.

## Methods

**Study Design**

This study uses a descriptive and exploratory design to compare service use and cost between patients with moderate-to-severe cognitive impairment and those with little-to-no cognitive impairment, as well as variations in the relationships between cognitive status and service utilization and cost by primary source of payment.

Data used in this study were extracted from the 2007 National Home and Hospice Care Survey (NHHCS), a nationally representative sample survey conducted by the National Center for Health Statistics (Centers for Disease Control and Prevention [CDC], 2015). The 2007 NHHCS was the final and most recent survey in a series of seven cross-sectional sample surveys of U.S. home health and hospice agencies which began in 1992. NHHCS data describe home health and hospice agencies, services, staff members, and patients. Participating agencies were either certified by Medicare and/or Medicaid or were licensed by a state, and all provided home health and/or hospice services. This study did not include hospice-related data since the focus was exclusively on home health care patients.

More recent data from U.S. home health care providers may be obtained through the National Study of Long-Term Care Providers (NSLTCP) which was initiated in 2012. Its goal is to monitor "trends in the supply, provision, and use of the major sectors of paid, regulated long-term care services" and to focus on primary data collection on the residential care community and adult day services sectors, as well as existing administrative data from home health, nursing home, and hospice providers (CDC, 2018). The NSLTCP datasets include home health data which are mostly administrative in nature and only cover a subset of people age 85 and older who receive home health services in either residential care communities or adult day service centers. Instead, use of the 2007 NHHCS data is preferred in this study because of its primary data collection from home health agencies serving a diversity of clients of all ages who receive care services in their own home dwellings. The NHHCS sampling frame is described on the website of the National Center for Health Statistics and summarized by Kaplan (2017). This current study examines a subsample from the 2007 wave of NHHCS consisting of 3,309 home health care patients nested within 595 agencies, all of whom received at least one home health care service visit and for whom data from the patient's cognitive functioning assessment were available.

## Measures

**Independent Variables**

In this study, basic demographic characteristics of patients (Table 1), such as age, gender, marital status, and race/ethnicity, serve as factors that likely predispose patients to using home health services and are deemed to be self-explanatory in terms of operational definitions. Patient characteristics which relate to their level of illness and need for home health service include incontinence of bladder and bowels, difficulty managing medications, need for help with activities of daily living, recent emergency medical care, number of diagnoses, and use of assistive or medical devices.

Dichotomous "Yes" or "No" responses were recorded for the use of assistive devices, use of medical devices, bladder incontinence, bowels incontinence, the need for help with taking medications, use of any emergency care services during the current service period, inpatient care prior to the current home health admission, and whether the patient received any surgical, diagnostic or therapeutic procedures prior to the current admission. Cognitive impairment status is the illness-level factor of primary importance for this study and the management of this variable is described in detail below.

Patient characteristics which enable or challenge their use of home health services include whether or not they have an informal caregiver and their relationship to that person, whether or not they live alone, and the primary source of payment for services. The options for primary source of payment for services include Medicare, Medicaid, private insurance, and self-pay by the patient or family. Each program limits the type and extent of healthcare coverage in different ways, and distinct profiles of service use and associated costs of care have been documented across payors

**Table 1. Variables Representing Determinants of Home Health Care Service Utilization**

| Categories | Constructs | Operational Definitions | Variable Type |
|---|---|---|---|
| Predisposing Factors | Age | Age of patient at time of survey | Ratio |
| | Gender | Gender of patient | Nominal |
| | Marital Status | Current marital status of patient | Nominal |
| | Race/Ethnicity | Race/ethnicity of patient | Nominal |
| Enabling Factors | Habitation Status | Who patient currently lives with | Nominal |
| | Informal Caregiver Relation | Relationship of informal caregiver to patient | Nominal |
| | Service Primary Payment Source | Primary source of payment for services | Nominal |
| Illness-Level Factors | Cognitive Status | Degree of assistance needed due to cognitive impairment | Nominal |
| | Incontinence Status | Bladder and/or bowel incontinence | Nominal |
| | Medication Problems | Patient needs help taking medications | Nominal |
| | Need for ADL Assistance | Number of ADLs patient needs help with | Ratio |
| | Need for Emergency Care | Patient used emergency care | Nominal |
| | Number of diagnoses | Total number of diagnoses | Ratio |
| | Use of Assistive Devices | Use of one or more assistive devices | Nominal |
| | Use of Medical Devices | Use of one or more medical devices | Nominal |

**Table 2. Outcome Variables**

| Categories | Constructs | Operational Definitions | Variable Type |
|---|---|---|---|
| Service Cost | Average Daily Charges | Amount billed in last complete billing cycle divided by number of days that in billing cycle | Ratio |
| Service Utilization | Total Service Volume | Number of visits for all services | Ratio |
| | Medical Service Volume | Number of visits for medical services | Ratio |
| | Non-Medical Service Volume | Number of visits for non-medical services | Ratio |
| | Days of Service | Number of days receiving care in the current service period | Ratio |
| | Readmission Status | Current enrollment is or is not a readmission | Nominal |

in prior studies (Bentkover et al., 2012). It is possible that home care patients have one or more insurance programs paying for some or all of their home care service, or they may be paying out of pocket. The NHHCS dataset offers sufficient cases of patients from each payor category to evaluate potentially meaningful differences in study outcomes between these groups of patients. Identifying the primary source of payment in the analyses is essential, as service profiles are directly shaped by insurance program coverage goals, such as Medicare's short-term, medically-focused home care benefit.

Cognitive impairment status is the patient characteristic evaluated as the key predictor variable to determine if the sampled patients who have cognitive impairment differ significantly from those who do not have cognitive impairment in terms of service utilization outcomes. The NHHCS uses case records as documented sources of information for describing patients' current health status, including levels of cognitive functioning. This is reported using the following scale: 1) No cognitive impairment; 2) Requires only occa-

sional reminders (in new situations); 3) Requires some assistance/direction in certain situations (is easily distracted); 4) Requires a great deal of assistance/ direction in routine situations; and 5) Severe cognitive impairment (constantly disoriented, comatose, delirium). In this study, patients are considered moderately-to-severely cognitively impaired if they were reported to belong within any of the three moderate-to-severe impairment categories (a score of 3, 4, or 5 on the 5-point scale). This approach for defining cognitive impairment is consistent with conceptual frameworks used to describe cognitive decline associated with dementia (American Psychiatric Association, 2013; Tullai-McGuinness, Madigan & Fortinsky, 2009; Weiner & Lipton, 2009; Zarit & Zarit, 2007). Using this operational definition, 32% of the home health care sample in the 2007 NHHCS dataset is found to have moderate-to-severe cognitive impairment, a proportion that is consistent with the expected range for a home health care sample of this age and health status. Cognitive impairment status is not highly correlated with any other patient characteristics. The strongest relationships are found between cognitive impairment status and both blad-

der and bowels incontinence ($r = 0.31$ and $r = 0.35$ respectively), and these variables are not highly correlated and their use in the multivariate analyses of this study are not a major concern. Correlations between cognitive impairment and the dependent variables are minimal ($r = 0.02$-$0.17$). Thus, there were no further explorations of mediation effects and interaction terms were not included in multivariate regression tests.

**Dependent Variables**

One dependent variable in this study is the average daily charge for services, a patient-specific variable derived by dividing the total amount billed by the agency in the last complete billing cycle by the number of days covered by those charges.  This variable represents the cost of services for each patient relative to the quantity of services and is used to demonstrate meaningful associations between cognitive impairment and costliness of home health care. Service volume variables also serve individually as outcomes (dependent variables) in the analyses, and include: the total number of service visits during the 60 days prior to the date of the interview as well as the number of medi-

cal and non-medical service visits during this time frame; the overall length of the current episode of care from date of admission to date of interview; and whether or not the current enrollment is a readmission. These dependent variables demonstrate both the overall duration and intensity of service provision and the distinct array of medical and non-medical service visits.  Medical visits include the provision of skilled nursing, occupational therapy, and physical therapy.  Non-medical visits cover care rendered by home health aides and social workers. See Table 2.

**Data Analysis Procedures**

Using univariate and bivariate descriptive analyses, including measures of dispersion, correlational analyses, chi-square and independent sample t-tests, this research shows the statistical relationships between cognitive impairment and other patient characteristics.  Since insurance programs vary in terms of payment coverage for home health care services in terms of types and extent of services, each of the four main primary payer categories (Medicare, Medicaid, Private Insurance, and Self-Pay) are compared using bivariate descriptive statistics.  An additional analysis as-

**Table 3a. Influence of Relevant Patient Characteristics on Service Utilization**

| | Days of Service | | Total Visits | | Medical Visits | | Non-Medical Visits | |
|---|---|---|---|---|---|---|---|---|
| | (n = 2,387 Patients in 569 Agencies) | | (n = 2,388 Patients in 570 Agencies) | | (n = 2,388 Patients in 570 Agencies) | | (n = 2,388 Patients in 570 Agencies) | |
| Intercept | 290.24 | *** | 23.00 | *** | 13.06 | *** | 5.53 | *** |
| Cognitive Impairment Score | 17.70 | *** | 0.08 | | -0.16 | ** | -0.30 | *** |
| Age | 1.39 | *** | 0.05 | *** | -0.0005 | | 0.02 | *** |
| Male | -4.19 | | -1.10 | *** | -0.13 | | -1.30 | *** |
| a    Hispanic | 72.80 | *** | 5.61 | *** | 0.53 | ** | -1.37 | *** |
| a    African American | 61.09 | *** | -0.94 | *** | -0.23 | | -1.21 | *** |
| a    Other Race/Ethnicity | 21.50 | | 0.52 | | -0.58 | | -3.29 | *** |
| Has a Spouse or Partner | -34.75 | *** | 1.68 | *** | 0.40 | * | 0.19 | |
| b    Lives with Family | -32.60 | *** | -4.45 | *** | -0.84 | *** | -0.85 | *** |
| b    Lives with Others | -53.44 | *** | -7.19 | *** | -3.01 | *** | -2.13 | *** |
| Has an Informal Caregiver | -21.83 | *** | -4.35 | *** | -3.39 | *** | -0.20 | |
| c    Primary Payor is Medicare | -123.67 | *** | 8.28 | *** | 8.26 | *** | -0.91 | ** |
| c    Primary Payor is Medicaid | 25.29 | * | 10.73 | *** | 4.15 | *** | 1.79 | *** |
| c    Primary Payor is Private Insurance | -75.41 | *** | 12.32 | *** | 9.24 | *** | -1.36 | *** |
| Incontinence of Bladder | 59.10 | *** | -1.08 | *** | 0.10 | | 0.36 | *** |
| Incontinence of Bowels | -21.33 | *** | -0.03 | | 0.14 | | -0.07 | |
| Needs Help with Medications | 60.51 | *** | 5.21 | *** | 2.78 | *** | 1.46 | *** |
| Uses Assistive Devices | 33.07 | *** | 6.10 | *** | 3.02 | *** | 2.29 | *** |
| Uses Medical Devices | 24.80 | *** | 0.58 | ** | 1.35 | *** | -0.66 | *** |
| Number of ADLs for which help is needed | -11.69 | *** | 2.50 | *** | 0.89 | *** | 1.36 | *** |
| Any Recent Episodes of Emergency Care | -35.30 | *** | 1.80 | *** | 1.32 | *** | -0.20 | |
| Total Number of Diagnoses | 0.94 | | 0.36 | *** | -0.0001 | | 0.30 | *** |

All measures Group Mean Centered

a    Compared to: White
b    Compared to: Lives Alone
c    Compared to: Primary Payor is Self Pay

\*      $p < .05$
\*\*     $p < .01$
\*\*\*    $p < .001$

sesses the relationship between patient cognitive impairment status and service volume and cost while accounting for relevant patient characteristics. Analytical models include patient characteristics in order to identify variations in the association of cognitive impairment status on service volume and cost.

### Results
Cognitive status and psychosocial and clinical characteristics were previously examined and the significance of relationships between cognitive impairment and findings of greater medical daily care needs, medical emergencies, and incontinence were previously reported in another publication (Kaplan, 2017).

### Influence of Patient Characteristics on Service Cost and Utilization
Tables 3a and 3b provide the results of analyses of the influence of patient characteristics on service cost and utilization. Each relevant patient characteristic is shown to significantly influence one or more service cost or utilization outcomes. This includes primary source of payment for

services, suggesting that each variable must be accounted for in assessing differences in service costs and utilization between patient groups paying for services with distinct types of insurance or resources.

### Number of Continuous Days of Home Health Care Service
The number of continuous days of home health care service is significantly impacted by the cognitive impairment status of patients ($p \leq .001$). On average, a one-point increase in cognitive impairment score (more impairment) is associated with a 17.7 day increase in the duration of service above the average 290.24 days, a 6% increase in the duration of service. Nearly all the patient characteristics, with the exception of gender, "other" ethnicity, and total number of diagnoses, have significant relationships with days of service. Of these, meaningful and significant increases in days of service are associated with both Hispanic and African American ethnicity (as compared to Caucasian), payment through Medicaid, urinary incontinence, need for assistance with medications, and the use of assistive and medical devices. Conversely, meaningful and significant decreases in

**Table 3b. Influence of Relevant of Patient Characteristics on Service Cost and Readmission**

| | | Average Daily Charges | | Readmission | |
|---|---|---|---|---|---|
| | | (n = 2,255 Patients in 541 Agencies) | | (n = 2,344 Patients in 563 Agencies) | |
| | Intercept | 67.96 | *** | 0.27 | *** |
| | Cognitive Impairment Score | 3.33 | *** | -0.01 | * |
| | Age | 0.01 | | 0.001 | *** |
| | Male | -0.11 | | 0.03 | *** |
| a | Hispanic | 0.42 | | -0.09 | *** |
| a | African American | -14.87 | *** | -0.02 | ** |
| a | Other Race/Ethnicity | 1.97 | | 0.02 | |
| | Has a Spouse or Partner | 4.05 | *** | -0.01 | |
| b | Lives with Family | 2.45 | *** | -0.03 | *** |
| b | Lives with Others | 3.36 | ** | -0.05 | *** |
| | Has an Informal Caregiver | 0.32 | | 0.02 | *** |
| c | Primary Payor is Medicare | 23.00 | *** | 0.07 | *** |
| c | Primary Payor is Medicaid | 7.82 | *** | 0.12 | *** |
| c | Primary Payor is Private Insurance | 14.20 | *** | -0.09 | *** |
| | Incontinence of Bladder | -3.63 | *** | 0.01 | |
| | Incontinence of Bowels | -5.57 | *** | 0.04 | *** |
| | Needs Help with Medications | 16.62 | *** | 0.02 | *** |
| | Uses Assistive Devices | 7.20 | *** | 0.04 | *** |
| | Uses Medical Devices | -1.90 | *** | 0.05 | *** |
| | Number of ADLs for which help is needed | 7.39 | *** | -0.01 | *** |
| | Any Recent Episodes of Emergency Care | 3.76 | *** | 0.09 | *** |
| | Total Number of Diagnoses | 2.75 | *** | -0.002 | |

All measures Group Mean Centered
a   Compared to: White
b   Compared to: Lives Alone
c   Compared to: Primary Payor is Self Pay

\*     $p < .05$
\*\*    $p < .01$
\*\*\*   $p < .001$

days of service are associated with having a spouse/partner or informal caregiver, living with family or others, incontinence of bowels, and recent emergency care. Importantly, the largest reduction in days of service are associated with payment for home care services through Medicare (123.67 fewer days than the average 290.24 days- a 43% decrease in duration of service) or private insurance (75.41 fewer days- a 26% decrease) as compared to paying out of pocket.

### Total Number of Service Visits

The total number of service visits for home health care does not have a significant relationship with the cognitive impairment status of patients, although many patient characteristics do. Of note, service payment by all three insurance categories has a significant ($p \leq .001$) and meaningful increase in total number of service visits as compared to the average 23 visits among those paying out of pocket, including Medicare (8.28 additional visits), Medicaid (10.73 additional visits), and private insurance (12.32 additional visits).

### Number of Medical Service Visits

The number of medical service visits represents a subset of total visits during which patients received services that were medical in nature. This includes visits for the provision of skilled nursing, occupational therapy, and physical therapy. The cognitive impairment status of patients has a significant ($p \leq .01$) relationship with the number of medical service visits. On average, a one-point increase in cognitive impairment score is associated with a 0.16 visit decrease below the average 13.06 medical visits. While statistically significant, this magnitude of impact is not clinically meaningful. More meaningful decreases in the number of medical visits are associated with having an informal caregiver and living with others. Significant and sizeable increases in the number of medical visits are associated with needing help with medications and using assistive devices. Of note, service payment by all three insurance categories has a significant ($p \leq .001$) and meaningful increase as compared to the average 13 medical service visits among those paying out of pocket, including Medicare (8.26 additional visits), Medicaid (4.15 additional visits), and private insurance (9.24 additional visits).

### Number of Non-Medical Service Visits

The number of non-medical service visits represents a subset of visits during which patients received services that were non-medical. Non-medical visits include those made by home health aides and social workers. The number of non-medical service visits is significantly impacted by the cognitive impairment status of patients ($p \leq .001$). On average, a one-point increase in cognitive impairment score (more impairment) is associated with a 0.3 visit decrease in the number of non-medical service visits above the average 5.53 non-medical visits. While significant, this magnitude of impact is not clinically meaningful. Significant and meaningful decreases in the number of non-medical service visits are associated with male gender, all non-Caucasian ethnicities, and living with others. Significant and meaningful increases in number of non-medical service visits are associated with the need for help with medications, use of assistive devices, and additional numbers of activities of daily living for which help is needed. As for the influence of insurance, significant decreases in the number of non-medical service visits are associated with service payment through Medicare (0.91 fewer visits) and private insurance (1.36 few visits), while increases in non-medical visits are associated with Medicaid (1.79 additional visits), as compared to the average 5.53 non-medical visits among those paying out of pocket.

### Average Daily Charges

Cognitive impairment status has a modest, yet significant ($p \leq .001$) impact on average daily charges. On average, a one-point increase in cognitive impairment score (more impairment) is associated with a $3.33 increase in average daily charges above the average value of about $68. African American ethnicity has a large and very significant influence, with an average $14.87 lower average daily charge than Caucasian ethnicity ($p \leq .001$). Sizeable and highly significant increases in daily charges are also associated with the need for help with medications, the number of activities of daily living for which help is required, and the use of assistive devices. As suspected, the influence of primary sources of payment for home care services is both significant and sizeable. Self-pay is the omitted referent primary payor category, thus comparing patients enrolled in each insurance program to those who pay out of pocket. All three insurance categories have highly significant impacts on average daily charges ($p \leq .001$), with $23 higher daily charges among patients paying for care with Medicare, $14.20 higher charges in Private Insurance, and $7.82 higher charges in Medicaid as compared to those paying out of pocket.

### Readmission Status

Ordinary least squares (OLS) regression analyses were used to examine readmission status. In this case, a positive finding for "readmission status" means the home health care patient was readmitted for service at the same agency through which services were provided at least once before. Cognitive impairment status has a minimal yet significant ($p \leq .05$) relationship with readmission status. On average, a one-point increase in cognitive impairment score is associated with a 1% greater probability of a service enrollment being a readmission above average probability of 27%. More sizeable and significant ($p \leq .001$) impacts on readmission are seen among Hispanic ethnicity (9% lower probability, as compared to Caucasian ethnicity) and the presence of a recent emergency hospitalization (9% higher

probability). The significant ($p \leq .001$) influence of payor category is noteworthy as well, with 7% higher probability of readmission among Medicare patients, 12% higher readmission likelihood among Medicaid patients, and 9% lower probability of readmission among patients with private insurance (as compared to those paying out of pocket).

## Cognitive Status Among Patients by Primary Payor

Nearly 1/3 of home health care patients were assessed as having cognitive status indicative of moderate-to-severe impairment. Table 4 depicts variation in cognitive status within the sample as organized by primary source of payment for home health services. Notably, moderate-to-severe cognitive impairment is found in a greater proportion of Medicaid patients (42%) and a lesser proportion of patient paying for services through private insurance (20%).

## Services Cost and Utilization

The six dependent variables in this study represent home health care service cost and utilization constructs. Tables 5a and 5b provide results of statistical analyses to describe the sample of home health care patients in terms of average daily charges for service ($64.41, S.D. $71.70), number of days in service period (267.12, S.D. 343.78), total number service visits (20.18, S.D. 21.78), number of visits for medical services only (11.65, S.D. 12.05) and number of visits for non-medical services only (5.22, S.D. 8.83). Additionally, 29% of sampled patients were readmissions.

In all six service utilization measures, which serve as the dependent variables in subsequent multivariate analyses, patients with moderate-to-severe cognitive impairment

have higher mean values and proportions, on average, than their peers (Tables 5a and 5b). Despite a noteworthy difference in the average daily cost of care ($72.09, as compared to $60.84), patients with moderate-to-severe cognitive impairment do not have statistically significant differences in costs of care from their less impaired peers. The volume of service, however, is statistically different between these two groups. Patients with moderate-to-severe cognitive impairment average more than 111 additional days of service than their peers (340.51, as compared to 229.30). A similarly high number of additional service visits are seen among patients with moderate-to-severe cognitive impairment, with 24.36 visits, on average, as compared to 17.97 visits among their less impaired peers. Statistically significant differences are seen in medical service visits (13.29, as compared to 10.80 among those with little-to-no cognitive impairment) as well as non-medical service visits (6.44, as compared to 4.57 among those with little-to-no cognitive impairment). The rate of readmission among patients also varies, and those with moderate-to-severe cognitive impairment have a significantly higher readmission rate than their less impaired peers (35%, as compared to 27%).

## Services Cost and Readmission

The results of the analyses of services cost and readmission by primary payor category are presented in Table 5b. There were no statistically significant differences in the average daily cost of care between cognitively impaired patients and their peers in any of the four primary payor categories, although meaningful differences are present with greater daily costs among cognitively impaired patients in each payor category. The readmission rate only differs significantly by cognitive impairment status among the Medicare

**Table 4. Cognitive Status by Primary Payor**

| Cognitive Status | All Patients (n=3255) | | Medicare (n=1907) | | Medicaid (n=850) | | Private Insurance (n=291) | | Self Pay (n=102) | |
|---|---|---|---|---|---|---|---|---|---|---|
| | *Freq.* | *%* | *Freq.* | *%* | *Freq.* | *%* | *Freq.* | *%* | *Freq.* | *%* |
| **Little-to-No Cognitive Impairment** | | | | | | | | | | |
| No cognitive impairment | 1573 | 45% | 878 | 44% | 385 | 37% | 213 | 72% | 39 | 51% |
| Requires occasional reminders | 760 | 23% | 494 | 26% | 188 | 21% | 28 | 8% | 31 | 15% |
| **Sum** | **2333** | **68%** | **1372** | **70%** | **573** | **58%** | **241** | **80%** | **70** | **66%** |
| **Moderate-to-Severe Cognitive Impairment** | | | | | | | | | | |
| Requires some direction | 514 | 17% | 327 | 18% | 131 | 19% | 18 | 5% | 18 | 24% |
| Requires a great deal of direction | 328 | 12% | 178 | 11% | 106 | 18% | 25 | 12% | § | |
| Severe cognitive impairment | 80 | 3% | 30 | 2% | 40 | 6% | 7 | 3% | § | |
| **Sum** | **922** | **32%** | **535** | **30%** | **277** | **42%** | **50** | **20%** | **32** | **34%** |

All values represent weighted estimates within patient categories (table columns)

§= suppressed for confidentiality reasons

subpopulation, with readmissions for 43% of patients with moderate-to-severe cognitive impairment as compared to 29% of patients with little-to-no cognitive impairment.

### Service Utilization

Analyses of service utilization by primary payor category demonstrate that the overall length of service periods for patients with moderate-to-severe cognitive impairment differs significantly from those with little-to-no cognitive impairment in both the private insurance subpopulation (347.07 days, as compared to 136.78 days) and the sub-population of people paying out of pocket (740.34 days, as compared to 307.22 days). Significant differences by cognitive impairment status in the total number of service visits and subset of non-medical visits are found only in the Medicare subpopulation. The average number of visits for Medicare patients with moderate-to-severe cognitive impairment is greater than the number of visits for their less impaired peers (22.16 visits, as compared to 16.25 visits), as is the number of non-medical visits (6.07 visits, as compared to 3.39 visits). The number of medical visits only differs significantly in the Medicaid subpopulation, with 13.25

visits for Medicaid patients with cognitive impairment as compared to 7.52 visits for their less impaired peers.

### Discussion

The analyses in this study demonstrate varying proportions of patients with moderate-to-severe cognitive impairment across primary payor subpopulations. With 85% of home health care patients receiving services covered primarily by Medicare or Medicaid, it is clear that the vast majority of people who are enrolled in home health care programs are either over the age of 65, living with a disability, or living in poverty. Among those patients who pay for services with one of these entitlements-based insurance plans, more than twice as many have their services paid for by Medicare than by Medicaid (59%, as compared to 26% of the full sample). For those patients who have moderate-to-severe cognitive impairment, as compared to their less impaired peers, statistically significant differences are found in some primary payor categories, with a disproportionately smaller group of cognitively impaired patients paying with private insurance (5%, as compared to 10% of those with little-to-no cognitive impairment) and a moderately larger group paying with

### Table 5a. Home Health Care Services Utilization by Primary Payor

| Cognitive Impairment Status | n | Days of Service | | Total Service Visits | | Non-Medical Service Visits | | Medical Service Visits | |
|---|---|---|---|---|---|---|---|---|---|
| | | Mean | (S.D.) | Mean | (S.D.) | Mean | (S.D.) | Mean | (S.D.) |
| **All Patients** | 3255 | 267.12 | (343.78) | 20.18 | (21.78) | 5.22 | (8.83) | 11.65 | (12.05) |
| Little-to-None | 2333 | 229.30 | (325.47) | 17.97 | (19.88) | 4.57 | (8.48) | 10.80 | (10.73) |
| Moderate-to-Severe | 922 | 340.51* | (358.22) | 24.36* | (23.60) | 6.44* | (9.12) | 13.29* | (13.70) |
| **Medicare** | 1907 | 183.30 | (259.67) | 18.09 | (17.92) | 4.27 | (7.37) | 12.46 | (10.25) |
| Little-to-None | 1372 | 170.35 | (256.78) | 16.25 | (15.82) | 3.39 | (6.60) | 11.98 | (9.74) |
| Moderate-to-Severe | 535 | 209.60 | (264.54) | 22.16* | (21.16) | 6.07* | (8.32) | 13.57 | (11.23) |
| **Medicaid** | 850 | 515.75 | (425.55) | 27.23 | (29.14) | 8.46 | (11.49) | 10.20 | (15.63) |
| Little-to-None | 573 | 479.28 | (456.76) | 24.29 | (29.64) | 8.83 | (12.32) | 7.52 | (12.73) |
| Moderate-to-Severe | 277 | 555.55 | (371.08) | 29.97 | (26.23) | 7.92 | (10.13) | 13.25* | (16.27) |
| **Private Insurance** | 291 | 178.18 | (270.10) | 18.44 | (20.68) | 3.65 | (7.86) | 11.66 | (11.86) |
| Little-to-None | 241 | 136.78 | (209.59) | 17.57 | (20.16) | 3.66 | (8.11) | 10.95 | (10.85) |
| Moderate-to-Severe | 50 | 347.07* | (370.52) | 22.06 | (21.22) | 3.58 | (6.55) | 14.59 | (14.07) |
| **Self Pay (Patient/Family)** | 102 | 443.93 | (559.50) | 18.65 | (29.07) | 10.08 | (13.56) | 4.51 | (11.13) |
| Little-to-None | 70 | 307.22 | (453.84) | 20.23 | (29.51) | 12.05 | (13.33) | 3.31 | (9.86) |
| Moderate-to-Severe | 32 | 740.34* | (532.50) | 13.43 | (20.45) | 5.69* | (12.52) | 5.60 | (6.56) |

All values represent weighted estimates within patient categories (table rows)

\* = Statistically significant difference (p < 0.05) by cognitive impairment

**Table 5b. Home Health Care Services Cost and Readmission by Primary Payor**

| Cognitive Impairment Status | Sample Size | Average Daily Charges ($US) | | Readmission | |
|---|---|---|---|---|---|
| | n | Mean | (S.D.) | Frequency | % |
| **All Patients** | 3255 | 64.41 | (71.70) | 1011 | 29% |
| Little-to-None | 2333 | 60.84 | (70.26) | 683 | 27% |
| Moderate-to-Severe | 922 | 72.09 | (73.36) | 312 | 35%* |
| **Medicare** | 1907 | 71.31 | (73.40) | 670 | 33% |
| Little-to-None | 1372 | 67.80 | (71.90) | 449 | 29% |
| Moderate-to-Severe | 535 | 79.77 | (76.88) | 211 | 43%* |
| **Medicaid** | 850 | 51.98 | (65.08) | 239 | 26% |
| Little-to-None | 573 | 44.77 | (60.16) | 165 | 29% |
| Moderate-to-Severe | 277 | 62.48 | (65.64) | 70 | 22% |
| **Private Insurance** | 291 | 59.86 | (64.88) | 49 | 18% |
| Little-to-None | 241 | 58.93 | (63.59) | 37 | 18% |
| Moderate-to-Severe | 50 | 64.81 | (67.15) | 12 | 21% |
| **Self Pay (Patient/Family)** | 102 | 33.43 | (87.82) | 27 | 14% |
| Little-to-None | 70 | 30.91 | (85.31) | 16 | 9% |
| Moderate-to-Severe | 32 | 31.04 | (68.91) | 9 | 17% |

All values represent weighted estimates within patient categories (table rows)

* = Statistically significant difference ($p < 0.05$) by cognitive impairment

Medicaid (30%, as compared to 25% of those with little-to-no cognitive impairment).

The dramatic and significant differences in service volume between home health care patients with moderate-to-severe cognitive impairment and their less impaired peers comprise a key finding of this study. Despite non-significant, moderately higher average charges per day of service, patients with meaningful levels of cognitive impairment receive services for an average 111 additional days as compared to those with little or no impairment. The association of many more days of service with moderate-to-severe cognitive impairment represents a profile of service use for this group of patients that is more consistent with chronic disability than with short-term, post-acute medical care. This finding suggests a need to look at service reimbursement criteria for moderate-to-severely cognitively-impaired individuals receiving home health care. The increased number of days of service for this group underscores the severity of need for home health services. Policy change would ideally allow for sufficient coverage of the expected higher number of visits as well as targeted interventions that will address the complex needs of dementia patients. Intermittent home health services with short service periods may be effective when few visits and brief services are appropriate and specific to the needs of the individual patient. Yet,

these findings indicate that such models of service delivery are inadequate for people with moderate-to-severe cognitive impairment. As such, innovative and patient-centric care management models should be culled from research literature to examine what works best for these patients.

The insurance program used to pay for services is a highly significant correlate of service cost and volume. As compared to self-paying patients, those using Medicare, Medicaid and Private Insurance all generally experience varying degrees of higher average daily charges and additional service visits. Yet the Medicaid group tends to receive services for many more days than the self-pay group, while both the Medicare and private insurance groups receive services for many less days than the self-pay group. Medicare and private insurance programs are typically paying for costly, more skilled, short-term home health care interventions, while Medicaid is paying for slightly less costly interventions, which can be skilled care or a combination of both skilled and custodial care, provided over longer periods of time. This finding also fits with expectations based on the structured scope of each of these insurance programs.

Comparing costs of care across patient groups can illustrate the relationships between daily costs, duration of service, and cognitive impairment status. Calculating total costs

based on sample averages of daily charges and length of service episodes generates profiles of the total costs of home health care for patients with and without moderate-to-severe cognitive impairment. On average, patients who have little-to-no cognitive impairment receive services with an average total cost of $13,951 (229.30 days x $60.84/day) and those with moderate-to-severe cognitive impairment receive services with an average total cost of $24,547 (340.51 days x $72.09/day). The difference between these two estimated profiles is $10,596 in average additional total costs for patients with moderate-to-severe cognitive impairment. In addition, significantly higher numbers of visits are received by patients with moderate-to-severe cognitive impairment, on average, as compared to their less impaired peers, and this significant difference is found for both medical and non-medical visits. Coupled with the fact that these cognitively impaired patients are significantly more likely than their peers to be readmitted to home health care, these findings suggest that such excess costs are more likely to be expended multiple times.

Within the four primary payor groups there are several additional noteworthy profiles of service use and cost among patients with cognitive impairment. The Medicare group is the only insurance group which demonstrates significant differences in the number of visits and the proportion of readmissions for patients with moderate-to-severe cognitive impairment. As compared to Medicare patients with little-to-no cognitive impairment, these more impaired peers accrue about $11 of additional charges per day, on average, with service episodes lasting over a period of 39 additional days of service. The average total costs for these two groups of Medicare patients, based on average charges and days of service, is $11,550 for those with little-to-no cognitive impairment and $16,720 for those with moderate-to-severe cognitive impairment—a difference of $5,170 that represents an estimated 45% greater average total cost of service. Because Medicare patients are only eligible for short service periods and are therefore discharged quickly from home health care, those with the complex care needs associated with cognitive impairment are likely to be readmitted at a higher rate than those with little-to-no cognitive impairment. This underscores the importance of program planning and policy change to provide for effective, dementia-specific interventions for home health care patients with moderate to severe cognitive impairment to help stabilize, educate, and empower these patients and their families to better address issues of safety and care quality in the hope of avoiding a revolving door phenomenon that appears to be common among these types of patents.

The Medicare home health benefit is designed to cover services that respond to acute medical needs over short time-frames. The other primary payor categories should therefore demonstrate longer service periods, lower proportions of readmission, and lower daily charges. Self-pay patients with moderate-to-severe cognitive impairment actually have similar daily costs but a much longer service period (740 days) than those with little-to-no cognitive impairment (307 days), and this results in a $13,484 difference in estimated cost that represents a 142% greater average total cost of service. Patients paying for service with Medicaid benefits are enrolled in home care for longer periods of time (516 days), on average, than their Medicare counterparts (183 days). Among Medicaid patients, those with moderate-to-severe cognitive impairment have a higher average daily cost and longer service period ($62.48 and 565 days) than their less impaired peers ($44.77 and 479 days), which results in an estimated $13,253 difference in cost that represents a 62% greater average total cost of service. In the Private Insurance group, patients receive care for relatively short periods, as seen with the Medicare group (178 days for Private Insurance, as compared to 183 days for Medicare). However, the differences between cognitively impaired patients and their less impaired peers are more dramatic. Private Insurance patients with moderate-to-severe cognitive impairment have a higher average daily cost and longer service period ($64.81 and 347 days) than those with little-to-no cognitive impairment ($58.93 and 137 days), and this results in a $14,433 difference in estimated cost that represents a 179% greater average total cost of service. This represents the largest cost differential between cognitively impaired patients and their peers within any of the four primary payor categories. Thus, patients with moderate-to-severe cognitive impairment receive services that cost approximately $5,170-$14,433 more, on average, than the services received by their less cognitively impaired peers. This represents a range of 45% to 179% greater costs for patients with moderate-to-severe cognitive impairment, on average, as compared to those with little-to-no cognitive impairment, depending on primary source of service payment.

It is evident from the above analysis that payor source for home health services also affects utilization and cost for individuals with cognitive impairment. Patients with moderate-to-severe cognitive impairment receive longer and more costly services than those with little-to-none cognitive impairment. Furthermore, Medicare as a payor source for home health is short-term and intermittent, requires individuals to be homebound, and the care they require must be medically reasonable and necessary. This being the case, it is expected that the number of days that an individual receives home health service is limited. Even with Medicare as the payor source, there is a difference between the utilization and cost of care between those with and without moderate-to-severe cognitive deficits. The other payor sources also show variances in utilization and cost between those with and without demonstrable cognitive impairment. Allowances for utilization and cost should be put in place for those suffering from moderate-to-severe levels of cogni-

tive impairment. For example, policy should be developed to cover innovative evidence-based care management models as well as quality improvement initiatives to enhance and track the quality and propriety of home health services provided to patients with dementia or cognitive impairment. Any recommendations borne out of the significant complexity of care of home health patients with moderate-to-severe cognitive impairment should include interventions to address the emotional and physical burnout that family and caregivers experience while caring for the patient. Furthermore, the continuum of care should also be utilized more with policy enhancements to increase access and coverage. Respite care is meant to provide a short break to families and caregivers of people with dementia. However, this is underutilized and underfinanced by insurance. It may be ideal for healthcare organizations to offer respite care as an integrated feature of services delivered in the community and for payor sources to reimburse such care. People living at home with moderate-to-severe cognitive impairment comprise a significantly growing sector of our population. As a society, we need to proactively examine our policies and practices in health care delivery in the community to offer recommendations for assuring appropriate levels of effective interventions to support families facing the unique and multidimensional challenges of dementia.

## Limitations

This study is a cross sectional analysis of existing survey data and making causal inference in such studies is difficult at best. Establishing causality is therefore not an aim of this research. The numerous variables and analyses of this study suggest a small likelihood of finding significant relationships based on chance alone. However, the variables included in this study are theoretically relevant, and, while some type-1 errors may be expected, this study offers findings that can be used to guide theory testing and replication in future studies. The underdeveloped state of knowledge in the areas addressed by this study supports the preliminary investigation of meaningful relationships between selected variables, and this study specifically tests the significance of associations among factors initially considered to be most relevant.

The use of data from a single survey year does not allow for the investigation of changes in outcomes as characteristics of home health care agencies change over time. However, such a study is not possible with the National Home and Hospice Care Survey data. Despite multiple survey periods spanning two decades, each data collection effort utilized a distinctly random sample of eligible agencies. The NHHCS data offer a unique analytical opportunity to underscore that the home health care industry is a rapidly evolving environment in which regulations and reimbursements change frequently.

The 5-point scale used in the NHHCS questionnaire to cat-

egorize cognitive impairment is identical to the cognitive functioning measure used in the Outcome and Assessment Information Set (OASIS), the uniform data collection instrument used by certified home health care providers at the time of service initiation, change, and discharge for all benefits-funded skilled-care patients. Dementia, as a clinical condition or research construct, cannot be operationally defined without high quality diagnostic information. Unfortunately, this type of information is not available in NHHCS. However, this OASIS scale used here as a proxy measure for cognitive impairment is significantly correlated with a "gold standard" measure of cognitive impairment called the Short Portable Mental Status Questionnaire ($r =$ .62, significant at $p =$ .01) (Tullai-McGuiness et al., 2009). Importantly, this proxy measure should not be considered an indicator of dementia status. It cannot be used to draw distinctions between acute conditions such as delirium and long-term conditions such as coma.

## Conclusions

The research described in this report identifies a large number of compelling factors that significantly influence the relationship between cognitive impairment and service volume and cost. The most influential factor in determining service costs, by far, is the insurance program used to pay for services. With regard to service cost and utilization, this research demonstrates that home health care patients with moderate-to-severe cognitive impairment receive services for many more days, including more medical and nonmedical service visits, and are more likely to be readmitted to home health care as compared to their less impaired peers. Excess costs of service associated with significantly higher durations and intensities of service are more likely to be expended on multiple occasions because of readmission. These findings suggest that patients with moderate-to-severe cognitive impairment require services which cost between 45% and 179% more than the services provided to those patients who have little-to-no cognitive impairment, on average. In 2007 there were an estimated 1,460,000 people receiving home health care service each day (Caffrey, Sengupta, Moss, Harris-Kojetin, & Valverde, 2011). With 32% of these patients living with moderate-to-severe cognitive impairment, the excess costs described above warrant serious attention from health care practitioners and policymakers. As the number of older adults with neurocognitive disease are expected to triple by the year 2050 (Prince et al., 2013), it is critical to identify models of home health care service delivery that both effectively respond to the unique needs of these impaired patients and control, or even reduce, the excess costs associated with their care.

Future studies should examine causality among the constructs and relationships described in this study so that policymakers can better gauge the potential impact of regulations that govern these industries and insurance pro-

grams.  Further research involving similar and more recent data might better identify home health care patients who are more likely representative of older adults living with dementia.  In addition, more detailed home health care billing and service data can be used to better understand the complex relationships among insurance programs, patient cognitive impairment status, and service cost and volume.  Most importantly, researchers studying home health care for patients with cognitive impairment should endeavor to incorporate measures of service quality and health and mental health outcomes in order to assess the effectiveness of services in general and in response to the implementation of innovative models of practice.  The rapid aging of the population, coupled with the considerable complications associated with dementia care, lends particular urgency to the need for intervention, program development, and policy change in this arena.

## Approvals

Required Statement: The research in this paper was conducted while the first author was a Special Sworn Status researcher of the U.S. Census Bureau at the Center for Economic Studies.  Research results and conclusions expressed are those of the authors and do not necessarily reflect the views of the Census Bureau, Centers for Disease Control and Prevention, or National Center for Health Statistics.

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