Preventing Neural Tube Defects and Promoting Health among Individuals with Neural Tube Defects and their Families

By

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Dedication

This literary work is a footprint of the relentless effort of my small supportive global village that has been my anchor despite the polarity of time zones.

To my family whose heart is bigger than they are many: To Dad and Mum, for the love and encouragement. You remain the gentle yet stern echo that kept me focused on the goal.

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Abstract

Neural tube defects (NTDs) are common and serious birth defects of the brain and spine. Low- and middle -income countries have higher prevalence of NTDs than high-income countries. Neural tube defects significantly impact the quality of life of affected individuals and their families, especially in low- and -middle income countries, such as Uganda. Adequate folic acid intake lowers women's risk of having children with NTDs by 70%. However, less than half of women of childbearing age worldwide take folic acid supplements. Several gaps in literature exist regarding prevention of NTDs and health promotion among individuals with NTDs and their families.

The application of theories or conceptual models to research on topics such as health promotion among individuals with NTDs and their families can be useful. I could not identify studies where scholars had applied theories or conceptual models to guide their scholarship about individuals with NTDs and their families. Regarding interventions designed to improve women's intake of folic acid, there is a paucity of an in-depth understanding of characteristics and components of interventions to guide and improve research to support women in taking folic acid. Nurses in Uganda and other countries are in key positions to implement folic acid guidelines. We do not know about the influences on nurses' implementation of folic acid guidelines or about valid and reliable measures of these influences.

In this dissertation, I addressed related gaps in literature in three, related papers. In the first paper, I proposed that the PRECEDE-PROCEED (PPM) could be useful to scholarship about individuals with NTDs and their families. I reviewed prior literature about individuals with NTDs and their families and identified examples reflecting each of the factors of the PPM. I concluded that the PPM can be helpful to guide scholarship about individuals with NTDs and their families. The PPM a) includes a breadth of factors relevant to individuals with NTDs and their families, b) is logically consistent, and c) is explicit in providing relationships among the concepts, and (d) is comprehensive in providing general guides for practice, education, and policy.

In the second paper, I conducted a systematic review to evaluate interventions promoting intake of folic acid supplements among women of childbearing age worldwide. All studies that met the inclusion criteria were conducted in high-income countries. I noted variation in intervention characteristics and components across studies as well as methodological weaknesses. From these papers, I summarized women's barriers to taking folic acid supplements.

The third paper reports on my study to develop and evaluate a questionnaire of influences on nurses' implementation of folic acid guidelines, guided by the PPM. Initially, I had 106 items. With these items, I proposed 5 scales and 2 subscales, with 13 single items. Through an iterative process with other nurses and researchers, the items were reduced to 53. Based on expert ratings, content validity indices of items (I-CVIs) ranged from 0.57 to 1. I observed high 1-CVIs >0.80 on clarity of wording, relevance to PPM factors, cultural appropriateness for the Ugandan health care context, and for comprehensiveness of proposed sets of items. Content validity indices of scales and subscales were high and ranged from 0.86 to 0.91. I revised 18 items based on expert feedback. I omitted 4 items because they had low I-CVIs ≤ 0.80 on relevance and cultural appropriateness for the Ugandan health care context. I retained 49 items. Of the 49 items: (a) 36 items made up proposed scales and subscales and (b) 13 items were single items.

To assess construct validity, I performed confirmatory factor analyses on the proposed scales and subscales, comprising of 36 items. Based on a congeneric model, I observed that 10 items had low factor loadings and small conceptual contribution to scales and subscales, so I deleted these 10 items. I conducted another congeneric model with 26 items. Based on goodness of fit measures, factor loadings of >.30, with all factor loadings significant at $p < 0.05$, I concluded that this statistical model was a good fit for the data.

To assess internal consistency reliability, I computed McDonald's omegas. Based on McDonald's omega, all 5 scales had acceptable to high reliabilities, varying from 0.70 to 0.86. Two subscales reflecting nurses' beliefs (about need for folic acid and side-effects of folic acid) had lower internal consistency reliabilities of 0.54 and 0.58 respectively.

To evaluate whether the proposed scales would measure the same latent constructs across different subsamples of nurses, I divided my sample into two, based on level of education. Using an approach called factorial invariance, I examined values for model fit indices. These indices indicated the configural and weak models fit the data well, with similar standardized loadings across two subsamples of nurses. The final questionnaire resulted in 39 items (26 items for proposed scales and subscales, and 13 single items).

New knowledge generated through this scholarship could inform nursing practice and education, health care policies, and research aimed at preventing neural tube defects and promoting the health of individuals with NTDs and their families.

Chapter 1: Introduction

My early interest in neural tube defects began during my clinical practice as a baccalaureate nurse, in a limited resource country, Uganda. I became specifically committed to prevention of neural tube defects (NTDs) among women of childbearing age, as well as promoting the health of individuals with NTDs and their families. While in Uganda, I worked at a specialized neurosurgical hospital that provides care to children with NTDs and their families. At that time, this was the only specialized neurosurgical hospital in East and Central Africa. We took care of children with NTDs such as spina bifida, anencephaly, encephalocele, and tethered cord. Through my observations and interactions with the children and families, I learned about their physical, social, psychological, financial, environmental, and challenges, and how such challenges affected their quality of life.

Meanwhile, I had learned about the role of folic acid in prevention of NTDs. Women can reduce their chances of having babies with NTDs by 70% when they take adequate folic acid (i.e. 0.4mg daily; MRC Vitamin Research Group, 1991; Meethal, Mayanil, Hogan & Iskandar, 2013). Also, when women with previous NTD-affected pregnancies take 4mg of folic acid daily, then their chances of having other babies with NTDs reduces by 72% (MRC Vitamin Research Group, 1991).

However, in Uganda, many women of childbearing with whom I interacted shared that they did not take folic at all or took it only during mid to late pregnancy. Yet, the ideal timing for taking folic acid to prevent NTDs is prior the first month of pregnancy, before the neural tube is formed (Centers for Disease Control and Prevention [CDC], 2018). Many women did not know about NTDs and the role of folic acid in prevention of NTDs. Also, in Uganda, many health care providers especially nurses with whom I interacted had limited knowledge regarding folic acid guidelines for prevention of neural tube defects. Thus, they did not implement the guidelines of the World Health Organization.

When I got the opportunity to pursue a PhD in Nursing at the University of Wisconsin-School of Nursing, I decided to focus my research on prevention of NTDs through folic acid intake among women of childbearing age in limited resource settings and health promotion among individuals with NTDs and

their families. With my minor area of study in prevention and intervention science, I applied a relevant conceptual model, the PRECEDE-PROCEED Model (PPM) to my scholarship on folic acid and NTDs. My dissertation aims were to (a) demonstrate the relevance of the PPM to scholarship about individuals with NTDs and their families, (b) evaluate interventions designed to promote intake of folic acid supplements among women of childbearing age worldwide, and (c) develop and evaluate a questionnaire regarding nurses' influences on implementation of folic acid guidelines, guided by the PPM.

Background

Neural Tube Defects

The commonest types of NTDs are spina bifida and anencephaly (Tomita & Ogiwara, 2017; Allen, Vessey, & Schapiro, 2010). The three major types of spina bifida are spina bifida occulta, closed neural tube defects, and spina bifida cystica. Spina bifida occulta is the mildest type, in which individuals are usually asymptomatic and the spinal cord and roots are normal but one or more of the vertebrae fail to form (CDC, 2018). Closed NTDs consist of a group of defects in which development of the spinal cord is affected by malformations of fat, bone, or meninges (National Institute of Neurological Disorders and Stroke [NINDS, 2013]).

Spina bifida cystica is more severe than closed neural tube defects. Spina bifida cystica includes meningoceles and myelomeningoceles and either the meninges or the meninges and spinal cord protrude through a defect in the vertebral arch. This causes a cystic swelling under the skin (Elsevier, 2012). Unlike myelomeningoceles, most meningoceles are covered with skin (NINDS, 2013). The extent of nerve tissue and spinal cord involvement depends on the level at which the spinal defect occurs (Allen, Vessey, & Schapiro, 2010).

Anencephaly is a severe open neural tube defect, characterized by an exposed cranial neural tube. It is incompatible with life (Tomita & Ogiwara, 2017). Infants alive at birth die within hours, but occasionally survive for a few days with permanent unconsciousness (Tomita & Ogiwara, 2017).

Newborns with anencephaly have a malformed cerebellum, brainstem, optic nerves, spinal cord, and no hypothalamus (Tomita & Ogiwara, 2017).

Folic Acid

Folate, or vitamin $B_{9,}$ is one of 13 essential vitamins (Greenberg, Bell, Guan, & Yu, 2011). Because folate cannot be synthesized de novo by the body, it must be obtained either from diet or supplementation (Greenberg, Bell, Guan, & Yu, 2011). Dietary folate is a naturally occurring nutrient found in foods such as green leafy vegetables, legumes, liver, and citrus fruit. Folic acid is a synthetic form of folate that is more stable than folate (Blom et al., 2006; Pitkin, 2007). Folic acid is a synthetic, dietary supplement available in enriched foods and pharmaceutical vitamins (Greenberg, Bell, Guan, & Yu, 2011). Demands for folate increase during pregnancy because it is required for growth and development of the fetus (Greenberg, Bell, Guan, Yu, 2011).

Significance of the Problem on a Global Perspective

Neural tube defects have significant life-long impacts on the physical, psychological, social, and financial wellbeing of individuals and families. Developmentally and physically, individuals with NTDs have diverse issues including: hydrocephalus, muscular-skeletal deformities, learning disabilities, and bowel and bladder dysfunction (Avagliano et al., 2018; Allen, Vessey, & Schapiro, 2010; Verpoorten & Buyse, 2008). Socially, the majority of individuals with NTDs and their families are isolated (Bannink, Idro, & Van Hove, 2016; Devine, Holmbeck, Gayes, & Purnell, 2011) because of the physical disabilities associated with NTDs, limited societal awareness about the social needs of individuals with NTDs, and limited accommodation in the community.

Psychologically, individuals with NTDs have high risk for depression and anxiety (Holmbeck & Devine, 2010). Stress (Holmbeck, et al., 2002; Holmbeck & Devine, 2010) and depression (Nahal, Wigert, Imam, and Axelsson, 2017) are common among parents of individuals with NTDs because of the financial costs, time, and physical energy that parents dedicate to care for their children. The financial burden of caring for individuals with spina bifida is substantial. Financially, individuals with spina bifida

incur 13 times more medical costs than those without (Ouyang, Grosse, Armour, & Waitzman, 2007). Among parents of individuals with spina bifida, loss of employment can be an issue because one parent often stays at home to support their child (Nahal, et al., 2017).

Gaps in literature

The application of conceptual models or theories can be useful to research on topics such as prevention of neural tube defects and health promotion among individuals with NTDs and their families. I reviewed literature to identify what conceptual models or theories scholars had used regarding NTDs. However, I did not identify studies where scholars had applied conceptual models or theories to guide their scholarly work about individuals with NTDs and their families.

To guide scholarship about individuals with NTDs and their families, scholars could apply comprehensive, logically consistent, and explicit models (Fawcett, 2005; Bartholomew & Mullen, 2011), such as the PRECEDE-PROCEED Model (PPM; Green & Kreuter, 2005). If scholars applied the PPM to guide their scholarship, then they could be comprehensive and systematic in identifying challenges among individuals with NTDs and their families and successful in planning, implementing, and evaluating interventions to manage NTDs. As a result, scholars could promote the health of individuals and families dealing with NTDs (Chapter 2).

Some researchers have reviewed interventions that aim to promote intake of folic acid supplements among women of childbearing age (Chivu, Soares-Weiser, & Braunstein, 2008). Prior researchers had focused on whether or not interventions had increased women's awareness, knowledge, and intake of folic acid. In the literature, there was no in-depth description of: (a) the characteristics and components of interventions that aimed to improve women's intake of folic acid supplements, (b) researchers' challenges in implementing such interventions, or (c) barriers that women face in taking folic acid supplements. To promote intake of folic acid supplements among women of childbearing age, a greater or in-depth understanding of the components of previous folic acid interventions is essential (Chapter 3).

Regarding implementation of folic acid guidelines for prevention of NTDs, nurses are in key

positions to implement folic acid guidelines. Two gaps in literature are that: (a) there are no documented influences on nurses' implementation of folic acid guidelines and (b) there are no valid and reliable measures to reflect such influences. Williams et al. (2006) designed a survey to study health care workers' practices about folic acid and recruited only health care providers in the USA. Williams et al. (2006) evaluated health care workers' knowledge about folic acid and practices of recommending folic acid.

The William's et al. (2006) study had some limitations. First, researchers did not address other concepts, such as workers' beliefs, professional norms, or external barriers. Second, researchers did not apply a theory or conceptual model that could have made the breadth of their variables more comprehensive. Third, the reliability and validity of the Williams et al. (2006) survey had not been assessed at all. If we had valid and reliable measures of influences on nurses' implementation of folic acid guidelines, then we could use these measures in future research to describe important influences and design interventions accordingly (Chapter 4).

Conceptual Framework

I applied the PRECEDE-PROCEED Model (PPM) to guide my research. The PPM provides an organized structure for planning, implementing and evaluating health promotion and disease prevention interventions. I applied the PPM to my research because it is comprehensive and logically adequate (Fawcett, 2005) in addressing not only individual factors but also interpersonal and environmental influences to behavior. Specifically, I applied the PPM to scholarly work about individuals with NTDs and their families. Also, I applied the PPM to guide the development and assessment of a new questionnaire about influences on nurses' implementation of folic acid guidelines. Scholars have documented how the PPM has been useful in guiding similar studies about disease prevention and health promotion (Azar, Solhi, Nejhaddadgar, & Amani, 2017; Mbonu, Borne, & Vries, 2010; Tramm, McCarthy, & Yates, 2011; Tremblay, et al., 2001) and in guiding instrument development (Nahidi, Tavafian, Heidarzadeh, Hajizadeh, & Montazeri, 2014).

The PPM (Green & Kreuter, 2005) has two major components: PRECEDE and PROCEED. The term PRECEDE stands for Predisposing, Reinforcing, and Enabling Constructs in

Educational/Environmental Diagnosis and Evaluation. PRECEDE represents assessment processes of issues regarding the phenomena and the educational and policy strategies that could support implementation of future interventions. The term PROCEED stands for Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development (Greene and Kreuter, 2005). The PROCEED represents an implementation and evaluation processes of an intervention. I have provided more detail about the PPM in Chapter 2.

Introduction to the Three Papers

The following three papers represent a cohesive program of research with a focus on developing new knowledge that could inform prevention of NTDs among women of childbearing age through folic acid intake and promote health among individuals with NTDs and their families. I applied the PPM to guide my first paper regarding scholarship about individuals with NTDs and their families. I applied Phases 2 (epidemiological assessment) and 3 (educational and ecological assessment) of the PPM to guide research designed to develop and evaluate measures to use in future research. The three papers are in the form of manuscripts for submission for publication and each is prepared to meet the requirements of targeted journals.

The first paper of my dissertation is located in Chapter 2, titled *Application of the PRECEDE-PROCEDE Model to Scholarship about Individuals with NTDs and their Families.* In this paper, I proposed that the PPM could be useful in guiding scholarly work about individuals with NTDs and their families. The specific aims were to: (1) provide a brief overview of the PPM and (2) apply PPM factors to previous scholarship about individuals with NTDs and their families. To assess whether the PPM factors in published studies would be relevant to individuals with NTDs and their families, I looked for examples from prior research that reflected each of PPM factors. I organized the examples of variables in prior research according to the PPM factors.

Important conclusions of this paper were that the PPM could be helpful to guide scholarship about individuals with NTDs and their families. I found it relatively easy to summarize research about FA

intake according to the factors in the PPM. The PPM includes a breadth of factors relevant to individuals (e.g., beliefs and behaviors) with NTDs and their families (e.g., genetics and environment).

Also, by systematically applying phases 1 (social assessment), 2 (epidemiological assessment), and 3 (educational and ecological assessment) of the PPM, scholars may be able to identify gaps in literature regarding the care of individuals with NTDs and their families. Then, research scholars can apply phases 4 (administrative and policy assessment and intervention alignment) to design educational and systems interventions that could prevent NTDs or improve care of individuals with NTDs and their families. Then, research scholars can apply phases 5 (implementation), and 6 to 8 (evaluations) of the PPM to implement and evaluate educational and systems interventions that could be designed to prevent NTDs or to improve care of individuals with NTDs and their families. Guided by phases 4 to 8 of the PPM scholars, clinicians, and policy makers could collaborate to revise policies that could address issues identified in phases 1, 2, and 3 regarding individuals with NTDs and their families. By applying the PPM to future research & scholarship about individuals with NTDs and their families, we could advance our understanding of the breadth of challenges for individuals and families and how to address them accordingly.

The second paper is located in Chapter 3, titled *Interventions Promoting Women's Intake of Folic Acid Supplements: A Systematic Review.* The purpose of the systematic review was to evaluate interventions, which were designed to promote intake of folic acid supplements among women of childbearing age worldwide. Specific aims of this study were to: (a) evaluate characteristics and components of interventions that were designed to promote intake of FA supplements among women of childbearing age, (b) describe methodological challenges that researchers faced in implementing these interventions, and (c) describe barriers to taking FA among women of childbearing age

I searched PubMed, PsycINFO, Medline, CINAHL, SciELO and Cochrane databases for relevant interventions aimed at promoting intake of folic acid supplements among women (15 to 49 years). I searched for articles published in English from 1992 and 2017. I presented our results following the

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff, Altman, & Prisma Group, 2009).

Important findings from this review follow. All studies that met inclusion criteria were conducted in high-income countries. Intervention characteristics and components varied across studies such as delivery modes, involving and training health care providers as interveners, evaluating intervention fidelity, documenting study measures, utilizing conceptual models (in only one study), and providing women with free folic acid supplements. Also researchers had documented women's barriers to taking folic acid supplements such as, forgetting to take supplements and uncertainty about folic acid benefits.

Also, we found some methodological issues in prior research regarding FA. This included difficulty in retaining participants, especially women of low socio-economic status, and interveners' lack of fidelity to study protocols. This review provided a better understanding of characteristics and components to consider in designing future interventions to promote intake of folic acid supplements among women of childbearing age to decrease risks of having children with NTDs. Findings from this paper provided suggestions for researchers to improve study designs to address methodological issues and women's barriers to taking folic acid. Another suggestion is that researchers could apply conceptual models with breadth, such as the PRECEED-PROCEED Model, to guide designing, implementing, and evaluating of interventions. We need models that can guide scholars to address both (a) individual and systems factors that influence women's folic acid intake and (b) individual and systems factors that could influence clinicians' education and counseling of women about folic acid. A third suggestion is that researchers can conduct studies in low- and middle -income countries where folic acid interventions are rare.

The third paper is located in chapter 4, titled *Influences on Nurses' Implementation of Folic Acid Guidelines: Development and Evaluation of a Questionnaire.* The purpose of this study was to develop and evaluate a questionnaire of influences on nurses' implementation of folic acid guidelines. I conducted this study in two phases. Specific aims for phase 1 were to: (1) develop items to reflect constructs from each factor from the PPM: *predisposing, reinforcing, enabling,* and *environmental factors* proposed to

influence nurses' implementation of folic acid guidelines and (2) assess the content validity of proposed items, scales and subscales. Specific aims for phase 2 were to: (1) assess the construct validity of proposed scales and subscales revised questionnaire (2) assess the internal consistency reliability scales and subscales.

For phase 1, using a descriptive design, a team of seven nurses from USA and Uganda developed new items. We developed items to reflect *factors* from the PPM: *predisposing, reinforcing, enabling, and environmental factors* proposed to influence nurses' implementation of folic acid guidelines. To assess the content validity of proposed items, scales and subscales (questionnaire version 1.0), a sample of seven content experts from Uganda and USA provided feedback about the new items. I followed Polit and Beck's (2012) methods for computing content validity indices (CVIs) for items (I-CVIs) and for scale (S-CVIs). I revised the items based on expert descriptive feedback.

For phase 2, using a cross-sectional, quantitative descriptive design, I assessed the construct validity and internal consistency reliability of proposed scales and subscales (questionnaire version 1.1). I recruited a sample of 302 clinical nursing students and licensed nurses in Uganda to respond to an online questionnaire. To assess construct validity of proposed scales and subscales (questionnaire version 1.1), I conducted confirmatory factor analysis using *Mplus version 8.3*. To assess the internal consistency reliability of proposed scales and subscales, I computed McDonald's alpha omegas and Cronbach alphas using *NCSS.* To evaluate whether the proposed scales measured latent constructs in a similar pattern across two different subsamples of nurses, I conducted factorial invariance. A summary of findings and my interpretations are found in chapter 4 of this dissertation.

In chapter 5, I discuss the contributions of my scholarship across my three papers. I share implications for nursing practice, education, health policy, and health-related research. Also, I present conclusions and future directions for research regarding NTDs.

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Chapter 2: Application of the PRECEDE-PROCEED Model to Scholarship about Individuals with NTDs and their Families

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Abstract

Background. We reviewed health-related literature to identify what theories and conceptual models scholars had used regarding individuals with neural tube defects (NTDs) and their families. Although theories and conceptual models could be useful to guide scholarship about individuals with NTDs and their families, we could not identify studies where scholars had applied theories or conceptual models to this topic. We proposed the PRECEDE- PROCEED Model (PPM) as one model that could guide scholarship about individuals with NTDs and their families because it is comprehensive in providing guidance for practice for nursing practice, health-related research, nursing education and health policy. The PPM is also logically consistent. Compared to other health behavior theories, the PPM is more comprehensive in addressing both individual and external factors that can influence behavior and is broad enough to encompass disease prevention and management. Compared to the socio-ecological model, the PPM is more explicit about the relationships among concepts.

Purpose. To demonstrate the relevance of the PPM to health-related scholarship about individuals with NTDs and their families.

Methods. I searched major scientific databases: PubMed, PsychINFO, Cochrane Library, and CINAHL for selected health-related literature about individuals with NTDs and their families published in English. We included studies published from 2000 to 2019 because we were interested in recent studies. After reviewing the health-related literature about individuals with NTDs and their families, we sought to identify variables in this literature that exemplified each of the PPM factors. We synthesized our findings by phases of the PPM.

Conclusions. We have synthesized health-related literature about individuals with NTDs and their families guided by the PPM. Because we easily identified variables that reflected PPM factors and organized our findings by the PPM phases, we have demonstrated that the PPM is relevant to scholarship about individuals with NTDs and their families. The PPM can be helpful to guide related scholarship because (a) it includes a breadth of factors relevant to disease prevention and health promotion regarding

NTDs, (b) it is logically consistent, and (c) it is explicit in providing propositions between the constructs and across the phases. Applying the PPM phases and factors to such scholarship could enable scholars to describe, explain, and predict the challenges of individuals and families in a comprehensive manner.. By applying the PPM to future scholarship about individuals with NTDs and their families, we could advance our understanding of the breadth of challenges for such individuals and families and how to address them accordingly.

Background

Neural tube defects (NTDs) are serious birth defects of the brain and spine (CDC, 2017). The commonest types of NTDs are spina bifida and anencephaly; the latter is incompatible with life (Tomita & Ogiwara, 2017). Globally, 300,000 babies are born with NTDs per year (CDC, 2017). Individuals living with NTDs experience significant physical, psychosocial, and financial challenges throughout their lifetime (Rofail, Maguire, Kissner, Colligs, & Abetz-Webb, 2013 Liptak and El Samra, 2010; Ouyang et al., 2007). Also caring for individuals with NTDs has physical, psychological, social, and financial implications for families (Rofail et al., 2013; Bannink, Idro, Van Hove, 2016).

Scholars (e.g., researchers and clinicians) from different countries have documented the complex physical, psychosocial, and financial challenges among individuals with NTDs (Nahal et al., 2017; Civil et al., 2014; Copp et al., 2015; Mazur, Lacy, & Wilsford, 2011). The application of theories or conceptual models to research on topics such as living with NTDs can be a useful guide in describing and explaining issues about the phenomena, and in planning, implementing and evaluating interventions. We reviewed scientific literature to identify what theories or conceptual models other scholars had used regarding individuals with NTDs and their families. However, we did not identify health-related literature where scholars had applied theories or conceptual models to guide their scholarly work about individuals with NTDs and their families.

We reviewed existing conceptual models and theories that were comprehensive, logically consistent, and explicit (Fawcett, 2005; Bartholomew & Mullen, 2011) to address a breadth of challenges among individuals with NTDs and families. These challenges include physical, psychosocial, financial and environmental challenges. Also, we reviewed conceptual models and theories that were credible to scholars (Fawcett, 2005) or had been applied among populations to identify population challenges, design possible interventions, develop, implement and evaluate interventions.

Conceptual models such as the socio-ecological model (Bronfenbrenner, 1979) have been helpful to describe multiple levels of influence on behavior (e.g., individual, interpersonal, organizational,

community, and public policy) and how behaviors shape and are shaped by the multiple levels. However, the socio-ecological model is not explicit because it lacks propositions. Yet, propositions are important in predicting and explaining health behavior.

Health behavior theories, such as the health belief model (HBM) was originally developed in the 1950s to explain preventive behaviors (Hauchbaum, 1958; Rosenstock, 1974). Later, researchers extend the HBM to guide the study illness behaviors (Kirscht, 1974). The HBM includes the concepts of: perceived susceptibility, perceived seriousness of a disease, perceived benefits, perceived barriers, cues to action, and self-efficacy (Champion & Skinner, 2008). Each concept individually or in combination, could be applied to explain health behavior (Hayden, 2009).

Researchers have applied the HBM to guide their studies on prevention topics. For example, researchers have applied the HBM to examine breast cancer screening behaviors among women (Skinner, Champion, Menon, & Sheshadri, 2002). Researchers have applied the HBM to guide interventions to promote breast cancer screening behaviors among women (Lauver, Settersten, Kane, & Henriques, 2003). Others have applied the HBM to examine risky sexual behaviors among adolescents and young adults (Hounton, Carabin & Henderson, 2005). However, findings regarding relationships between the HBM constructs have yielded inconsistent results across studies (Champion & Skinner, 2008).

The HBM has some limitations. Although the HBM identifies constructs that can influence behavior, relationships between and among the constructs are not explicit (Janz, Champion, & Stretcher, 2002). As such, the validity of the HBM has not been established due to variation in application of the Model (Champion & Skinner, 2008). Also, the HBM does not integrate important external factors that could influence behavior. Such external factors include the environment (e.g., geographic accessibility, financial affordability) and policy regulation.

Another individual level health behavior theory is the theory of planned behavior (TPB; Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975). The TPB is an extension of the Theory of Reasoned Action

(Fishbein, 1967). The major constructs of the TPB include: attitude, subjective norms, perceived behavior control, which moderate the intention to perform a behavior.

Researchers have applied the TPB to guide studies on prevention topics. For example, Pawlak, Brown, Meyer, & Connell (2008) applied the TPB to examine women's behavior of multivitamin intake. Consistent with the TPB, intention to use multivitamins was the most important direct predictor to multivitamin. Other studies that have provided support for the TPB include studies on breast care screening behaviors on (Montano, Thompson, Taylor & Mahloch, 1997). The studies have supported perceived control as a direct predictor of both intentions and behaviors.

The TPB has some limitations. Although the TPB incorporated a concept of perceived control (Ajzen & Fishbein, 1980; Fishbein & Ajzen, 1975) which could reflect indirectly environmental factors such as geographic accessibility or financial affordability. However, this theory does not incorporate the external or environmental factors that are independent of individuals and are influenced by health and social policies. Therefore if scholars applied either the HBM or the TPB to scholarship about individuals with NTDs and their families, then they would be likely to omit important external factors that could influence behavior, health and quality of life.

We proposed the PRECEDE-PROCEED Model (PPM; Green & Kreuter, 2005) as one model that could be applied to scholarship about individuals with NTDs and their families. Compared to the socio-ecological model, the PPM has propositions (a) between the constructs within the phases (b) between and across phases. Compared to the health belief model and the theory of planned behavior, the PPM is more adequate by including both individual and external factors that could influence health behavior, health outcomes and quality of life among individuals and populations including. Also, the PPM is more adequate because it includes Phases and constructs that are needed to address both disease prevention and disease management, for example, by including Phase 4 about educational, systems, and policy influences and interventions.

Scholars have applied the PPM in studies about health promotion among individuals with chronic illnesses such as diabetes, cancer and HIV/AIDs. In these studies, scholars have documented how the

PPM has been relevant to their scholarship (Azar, Solhi, Nejhaddadgar, & Amani, 2017; Mbonu, Borne, & Vries, 2010; Tramm, McCarthy, & Yates, 2011;Tremblay, et al., 2001). Also, conditions such as diabetes, cancer, and HIV/AIDs are relevant to NTDS because they are all chronic conditions. Thus, we propose the PPM would be helpful in scholarship about individuals with NTDs and their families.

The purpose of this paper is to demonstrate the relevance of the PPM to scholarship about individuals with NTDs and their families. Our specific aims were to: (1) provide a brief overview of the PPM and (2) apply the PPM phases and factors to scholarship about individuals with NTDs and their families. If scholars applied the PPM to guide their scholarship about NTDs, then they could be comprehensive in (a) identifying challenges among individuals with NTDs and their families, (b) successfully planning, implementing and evaluating interventions to manage NTDs and promote the health of individuals and families.

Overview of the PPM

The PPM provides an organized structure for planning, implementing, and evaluating interventions to promote health among populations. According to the PPM, the initial focus is on the distal outcome, i.e., quality of life (QoL) of the population of interest. When scholars apply the PPM in their work on individuals with NTDs and their families, they can: (a) assess the QoL of individuals and families, in Phase 1, (b) identify challenges that hinder individuals and their families from achieving their needs in Phases 2, (c) focus on those factors that can be changed and have the greatest impact on health and QoL in Phase 3, and (c) apply the PPM to design, implement and evaluate interventions in Phases 4 to 8.

The PPM (Green & Kreuter, 2005) has two major components: PRECEDE and PROCEED. The term PRECEDE stands for Predisposing, Reinforcing, and Enabling Constructs in Educational/Environmental Diagnosis and Evaluation. PRECEDE represents the assessment process. The term PROCEED stands for Policy, Regulatory, and Organizational Constructs in Educational and Environmental Development (Greene and Kreuter, 2005). The PROCEED represents the implementation and evaluation processes.

The PRECEDE component has four phases (1-4) focusing on the assessment processes of issues regarding the phenomena and the resources, educational and policy strategies that could support implementation of future interventions. Phase 1 refers to social assessment and includes a factor of quality of life. Phase 2 refers to epidemiological assessment and includes factors of genetics, health, and environment. Phase 3 refers to educational and ecological assessment and includes predisposing, reinforcing, and enabling factors. Phase 4 refers to administrative and policy assessment and intervention alignment and includes factors of educational strategies and policy regulation and organization. The PROCEED component has phases 5–8 and are focused on implementation and evaluation of interventions. Phase 5 refers to implementation. Phases 6 to 8 refer to the evaluation phases (Green & Kreuter, 2005). Figure I shows the PPM.

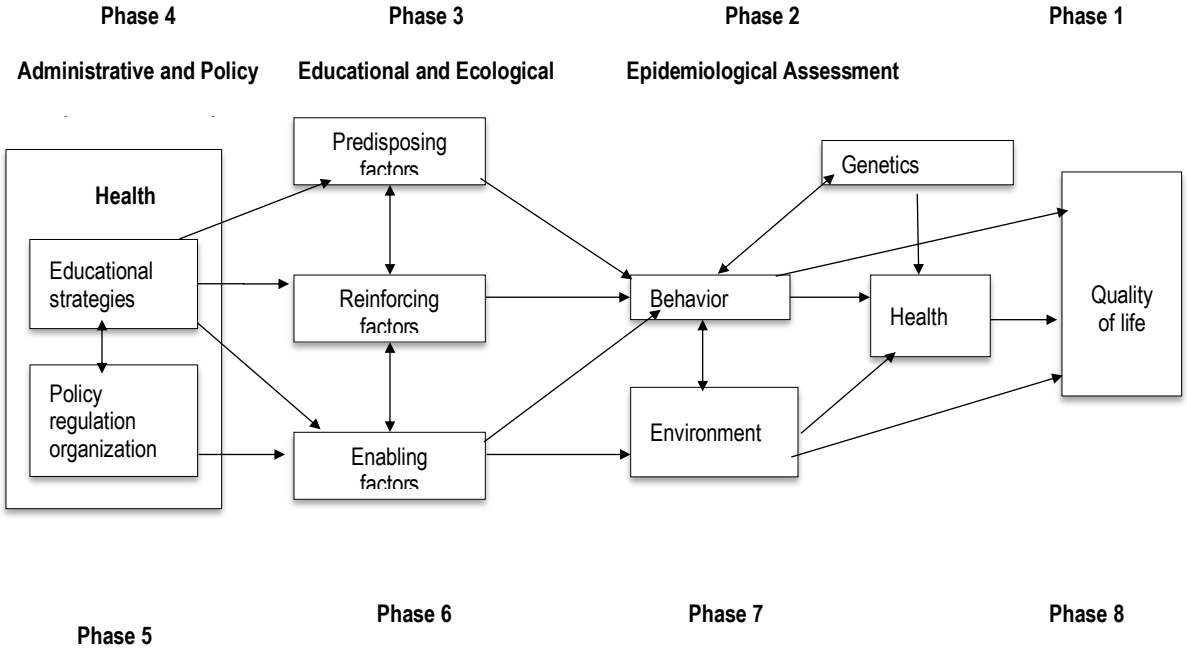

Figure 1. PRECEDE-PROCEED Model. Source: Green & Kreuter (2005). Adapted and with permission from Green & Keuter (2017).

We searched major scientific databases: PubMed, PsychINFO, Cochrane Library, and CINAHL for articles written in English about (a) quality of life among individuals with NTDs and their families (b) issues among individuals with NTDs and their families, (c) family functioning among individuals with NTDs or spina bifida, (d) psychological issues in caregivers of individuals spina bifida, and (e) self-care and independence in individuals with NTDs or spina bifida. We used the following key words: spina bifida, neural tube defects, caregiver, family, self-management, self-care, quality of life, impact, psychosocial. We included evidence from *Guidelines for the Care of People with Spina bifida*. We included evidence from major websites such as the Centers for Disease Control, Spina Bifida Association, World Health Organization and the International Federation of Spina Bifida and Hydrocephalus. Because we were interested in recent health- related information about individuals with spina bifida and their families, we included articles published from 2000 to 2019.

In Table 1, we provide the phases of the PPM, aligned with factors of the PPM and definitions of the factors. Then, we share examples of the PPM factors drawn from literature about individuals with NTDs and their families. In sharing these examples, we propose that the PPM factors are relevant to guide scholarship about individuals with NTDs and their families.

Table 1

Phases of the PRECEDE-PROCEED Model (PPM) and Application of PPM Factors to Published Studies about Individuals with NTDs and their Families

Phases of the PPM	Factors	Definition	Examples of Application of PPM Factors to Studies about Individuals with NTDs	Examples of Application of PPM Factors to Studies about Families of Individuals with NTDs
1-Social assessment	Quality of life	Individual or group perceptions regarding their wellbeing and whether their needs are being met	Low self-image, social isolation, school drop-out (Rofail et al., 2014), underemployment (Copp et al., 2015)	Loss of employment, social isolation, chronic sorrow (Nahal et al., 2017), parental stress (Holmbeck & Devine, 2010)
2-Epidemiological assessment	Genetics	Population genetics explores genetic composition of groups of people	Individuals with NTDs have high genetic predisposition of having children with NTDs (Copp et al., 2015)	Parents of children with NTDs and close biological relatives have high genetic predisposition of having children with NTDs (Copp et al., 2015)

	Health	Per the PPM, health focuses on population health problems due to individual, social and environmental influences	Depression, anxiety, urinary and bowel incontinence (Ouyang et al., 2015), obesity (Dosa et al., 2019), hydrocephalus (Stepanczuk et al., 2014), learning disabilities (Allen & Vessey, 2010)	Parental depression, anxiety (Civil et al., 2014; Malm-Buatsi et al., 2015)
	Environment	Components of social, economic, and physical environment that contribute to behavior, health outcomes, or QoL	Institutional availability of supportive equipment (e.g., limited supportive devices; Banninka et al., 2016) Geographic accessibility to care (e.g., limited specialty neurosurgical hospital near one's home; IFSBH, 2018) Financial affordability of services (e.g., limited finances for neurosurgical costs; Grosse et al., 2016)	Institutional availability of social support (e.g., limited parent support groups within communities; IFSBH, 2018) Geographic accessibility to transport (e.g., limited access to appropriate transport for children with spina bifida; IFSBH, 2018) Financial affordability of health care services (e.g., limited finances for health care services for children; IFSBH; 2018)
	Behavior	Actions of individuals or populations for a specific purpose	Self-care behaviors (e.g., poor diet, inability to perform clean intermittent catheterization and bowel management; SBA, 2018)	Family support to children (e.g., providing limited support to children during self-care activities such as catheterization. Delay in seeking care for children with spina bifida; IFSBH, 2018)
3-Educational and Ecological Assessment	Predisposing factors	Antecedents to performance of a behavior	Limited knowledge about: diet, physical activity (Soe et al., 2012), shunt-failure, urinary tract infections (Sawin et al., 2009). Lack of self-efficacy in performing bowel management (Verhoef et al., 2005)	Lack of knowledge among family members about what to expect in children with NTDs Lack of self-efficacy among family members in supporting children to perform self-care activities Family beliefs about causes of NTDs (e.g., belief that NTDs are a due to curses; Banninka et al., 2015)
	Reinforcing factors	Factors that provide feedback or reward for a behavior	Social norms about individuals with NTDs, negative attitudes of family, peers, society, and health care providers	Negative attitudes of community members towards children with spina bifida and their families (Nahal et al., 2017)

			about individuals with NTDs (SBA, 2018)	
	Enabling factors	Antecedents that facilitate performance of a behavior	Lack of educational resources about self-care (e.g., diet, exercise) Lack of skills (e.g., in bowel management (SBA; 2018) Lack of skills in spina bifida care among health- care providers or school personnel (IFSBH, 2018)	Lack of care coordination for families of individuals with spina bifida (SBA, 2018) Lack of information about providers and resources for supporting parents in caring for their child with spina bifida (IFSBH, 2018)
4- Administrative and Policy Assessment and Intervention Alignment	Educational strategies	Proposing educational strategies e.g., guidelines for implementing the planned interventions or programs	Guidelines about self-care for individuals with spina bifida (SBA, 2018)	Guidelines for supporting families on topics e.g., mental health among family members (SBA, 2018)
	Policy regulation and organization	Proposing policy changes and resources	Policies about: social inclusion, affordable health care, inclusive transportation, & employment opportunities for individuals with NTDs (IFSBH, 2018; SBA, 2018)	Policies about: Prevention practices for NTDs, affordable health care services, inclusive transportation and access to multidisciplinary care (IFSBH, 2018)
5- Implementation	Implementation of Educational strategies	Conversion of educational strategies into actions	Provision of educational resources about self-care to individuals with spina Providing in-service training to personnel caring for individuals with NTDs (e.g., healthcare providers, school and community personnel) (SBA, 2018; IFSBH, 2018)	Provision of information about providers and resources to families through websites, workshops Training families in skills (e.g., bowel management) Provision of community-based rehabilitation services (SBA, 2018)
	Implementation of Policies and organization changes	Revisions in policies, regulations and/or organizations	Revisions in policies about: social inclusion, affordable health care, inclusive transportation, & employment opportunities (IFSBH, 2018; SBA, 2018)	Revisions in policies about: prevention practices, affordable health care services, inclusive transportation (IFSBH, 2018)

6 to 8 - Evaluation	Process Evaluation	Evaluation of type, quantity and quality of services, personnel, policies, and resources of an intervention	Evaluate if: (a) personnel involved in caring for individuals with NTDs have received relevant training, (b) educational materials about self care are appropriate for individuals with NTDs (IFSBH, 2018)	Evaluate if educational resources for families are appropriate e.g., are educational materials tailored to their needs (SBA, 2018; IFSBH, 2018)
	Impact evaluation	Evaluation of intermediate outcomes of an educational intervention or other policy/regulation change on program objectives	Evaluate: individual knowledge about self-care and ability to perform self-care in individual with spina bifida (SBA, 2018)	Evaluate: family knowledge about resources and ability of family members (e.g., parents) to support their children in gaining independence (SBA, 2018)
	Outcome evaluation	Evaluation of long-term impacts of an educational intervention or other policy/regulation change on program objectives	Evaluate improved (a) physical and mental health status for individuals with spina bifida, (b) availability of, access to and affordability of health care services for individuals with spina bifida (SBA, 2018)	Evaluate (a) achievement of optimal mental health among family members, (b) improved availability of, access to and affordability of health care services (SBA, 2018)

Note. Examples of application of PPM to the study of individuals with NTDs are common in children, youth and adults. Examples of application of PPM to study of families of individuals with NTDs are common in adults. SBA= Spina Bifida Association; IFSBH= International Federation of Spina Bifida and Hydrocephalus.

Application of PPM to Scholarship about Individuals with NTDs and their Families

Phase 1-Social Assessment

Quality of Life

Quality of life refers to individual or group perceptions regarding their wellbeing and whether their needs are being met. *Quality of life* is relevant to scholarship about individuals with NTDs. For example, QoL among individuals with NTDs has been measured by, and can be reflected in, low self-image, negative parent/sibling relationships, low school performance, feeling socially isolated, limited independence (Rofail et al., 2014), early school drop-drop out, low finances, and underemployment among individuals with NTDs (Copp et al., 2015; Zukerman et al., 2011).

Quality of life among family members (e.g., parents and siblings) living with individuals with NTDs can be reflected in some variables identified by earlier researchers. *Quality of life* outcomes could be reflected by: loss of employment opportunities, because one of the parents often stays at home to support their child (Arkansas Center for Birth Defects Research & Prevention, 2017; Nahal, Wigert, Imam, and Axelsson, 2017). Also, other antecedents to quality of life may be; social isolation of families (Nahal, et al., 2017), guilt and chronic sorrow in parents due to self-blame for child's condition (Nahal, Wigert, Imam, &Axelsson, 2017), and parental stress (Holmbeck, et al., 2002; Holmbeck & Devine, 2010).

Phase 2- Epidemiological Assessment: Health, Behavioral and Environmental Assessments

Health

Researchers have applied the concept of health to studies about individuals with NTDs and their families. For example, *health* has been measured by and reflected in the degree of health related problems that individuals with NTDs and their families encounter. Common health problems for individuals with NTDs include: depression, anxiety, stress, urinary and bowel incontinence, skin related issues, renal failure (Liptak, & El Samra, 2010), hydrocephalus (Mazur, Lacy, & Wilsford, 2011; Stepanczuk, Dicianno, & Webb, 2014), obesity (Dosa et al., 2019), and pain (Roehring & Like, 2008). Learning disabilities are common in individuals with spina bifida including challenges in perceptual-motor skills, comprehension, organization, attention, sequencing and reasoning (Allen et al., 2010). Among family members examples reflecting *health* include depression and anxiety (Civilibal, Suman, Elevli, & Duru, 2014; Malm-Buatsi et al., 2015) related to uncertainty about their child's future and health (Nahal, Wigert, Imam, and Axelsson, 2017).

Behavioral Assessment

In the literature, we identified examples reflecting *behavior* among individuals with NTDs. For example, scholars have documented some actions of individuals with NTDs that have direct influence on their health issues. *Behavior* among individuals with NTDs is reflected by the degree of self-care behaviors (Spina Bifida Association, 2018). Among individuals with NTDs, poor self-care behaviors

identified in the literature include (a) poor diet, (b) poor compliance to bladder and bowel management protocols, and (c) poor physical activity (Spina Bifida Association, 2018). Among family members, *behavior* has been reflected by delay in seeking care for children with spina bifida, providing limited support for children in performing self-care activates (e.g., clean intermittent catheterization and bowel management), and not taking adequate folic acid supplements to prevent giving birth to babies with NTDs (International Federation of Spina Bifida and Hydrocephalus [IFSBH, 2018]).

Environmental Assessment

In the literature, we identified examples reflecting *environmental factors* among individuals with NTDs and their families. For example, scholars have documented components of the social, economic, and physical environment that could influence *behavior, health, or QoL*. Based on literature about individuals with NTDs, we identified availability, access, and affordability issues that are reflective of *environmental factors*. To clarify, in this paper we defined availability, accessibility, and affordability based on available literature. Institutional availability refers to presence of resources or services in sufficient quantity within institutions (McLaughlin, & Wyszewianski, 2002). Accessibility refers to ease of getting to resources or services (e.g., distance of service user to service provider; Evans, Hsu, & Boerma, 2013; McLaughlin, & Wyszewianski, 2002; Woldemichael, Takian, Sari, & Olyaeemanesh, 2019). Financial affordability refers to ability to pay for services without financial hardship (Evans, Hsu, & Boerma, 2013).

One example of an *environmental factor* for people with NTDs is the geographic accessibility to multidisciplinary care, routine and preventive health care services for individuals with spina bifida (IFSBH, 2018). A second example of *environmental factor* is institutional availability of: services and supportive equipment such as (a) accommodations within mainstream schools for urinary and bowel management, (b) accommodation for wheel chair use (Banninka, Idro, & Van Hove, 2016) and (c) employment opportunities for youth and adults with spina bifida (Copp et al., 2015; Zukerman et al., 2011). A third example of *environmental factor* is affordability of services including: (a) medical care services for individuals with spina bifida because of the high medical and surgical costs (Grosse, Berry,

Tilford, Kucik, & Waitzman, 2016; Sandler, 2010; Mahmood et al., 2011) and (b) lack of affordable transportation to hospitals and clinics (IFSBH, 2018).

Among families dealing with NTDs, we identified examples reflecting *environmental factors*. For example, among families, there is limited availability of parental supports within the community (IFSBH, 2018). Regarding accessibility, families have limited access to multidisciplinary care services for their children (Spina Bifida association, 2018; IFSBH, 2018). Regarding affordability of services, families lack finances to pay for neurosurgical and routine care for their children with spina bifida (Spina Bifida association, 2018; IFSBH, 2018).

Genetics

Genetics is a factor in the PPM and is relevant to individuals with NTDs and their families. Genetics plays a vital role in the development of NTDs (Crider, Young, Berry et al., 2012; George & Brent, 2008). In the literature, we identified examples reflecting *genetics.* For example, scholars have documented that both individuals with NTDs and their biological relatives have high genetic predisposition of having children with NTDs (Copp et al., 2015; Rampersaud, Melvin, & Speer, 2006).

Phase 3-Educational and Ecological Assessment

Predisposing Factors

Predisposing factors are antecedents to performance of behaviors by individuals (Green and Kreuter, 2005). Such influences are often individual level factors. In the literature, we identified examples reflecting *predisposing factors* among individuals with NTDs. One example was the lack of knowledge about appropriate diet and physical activity, which was negatively associated with engaging in healthy diet and exercise among individuals with NTDs (Soe, Swanson, Bolen, Thibadeau, & Johnson, 2012). Sawin, Bellin, Roux, Buran, & Rei (2009) and Davis et al. (2005) noted that lack of knowledge about signs of skin breakdown, shunt-failure, and urinary tract influenced not engaging in self-care among individuals with NTDs. Another example reflecting *predisposing factors* is lack of self-efficacy to perform self-care activities (e.g., bowel management and self-catheterization) (Krogh, Lie, Bilenberg, & Laurberg, 2003; Verhoef et al., 2005).

In the literature, among family members of individuals with NTDs, we identified examples that reflect *predisposing factors* to seeking care and providing support to children during self-care. Examples include: lack of knowledge about (a) what to expect with children with NTDs and (b) how to care for children with NTDs. Also lack of self-efficacy about supporting children with spina bifida in performing self-care activities is a *predisposing factor* to providing actual support to children with NTDs. Beliefs about causes of spina bifida are an example reflecting *predisposing* factors. Because some parents believe that spina bifida is due to a curse, they would not seek medical care for their children (Banninka, Stroekena, Idrob and Hovea, 2015).

Reinforcing Factors

To apply reinforcing factors to studies about NTDs, we identified examples of variables that function as feedback or reward for behaviors related to NTDs. From prior research, one example of *reinforcing factors* that can influence self-care behavior among individuals with NTDs includes the degree of family support in helping children with spina bifida to be more independent (Holmbeck & Devine, 2010; Stepansky, et al., 2010). Regarding family members, an example reflecting *reinforcing factors* includes: attitudes of community members towards family members of children with spina bifida. More negative community attitudes are positively associated with poor health care seeking behavior among parents for their children (Nahal, et al., 2017; Banninka et al., 2015). This is because they would want to keep them at home away from the public (Banninka et al., 2015).

Enabling Factors

To apply *enabling factors* to studies about individuals with NTDs and their families, we identified examples reflective of antecedents to healthy behaviors such as self-care and health care seeking behaviors. Among individuals with spina bifida, educational resources on how to perform self-care activities reflect *enabling factors* (SBA, 2018; IFSBH, 2018). Educational resources include: information about self-catheterization, bowel management, assessing signs of shunt malfunction, healthy diet, where and how to access care (SBA, 2018). However, among individuals with NTDs, educational

are limited (SBA, 2018; IFSBH, 2018). When individuals with NTDs lack such educational resources, then they are not likely to engage in healthy behaviors (SBA, 2018).

A second example reflective of enabling factors is the training and experience of health care providers and school personnel about caring for individuals with NTDs (IFSBH, 2018). However, literature suggests that many health care providers and school personnel lack of skills in spina bifida care (IFSBH, 2018). When health care providers lack the necessary training, then they may not be in position to educate and counsel patients with spina bifida about self-care (IFSBH, 2018).

A third example from literature reflecting *enabling factors* is the skills among individuals with spina bifida to perform self-care (IFSBH, 2018). However, many individuals lack skills in self-care (IFSBH, 2018). If individuals with spina bifida have written information on how to perform self-catheterization, but have not received demonstration of or practice for how to perform catheterization, individuals may not be able to perform catheterization well. Regarding family members, examples reflecting *enabling factors* include: skills to support children in performing self-care activities and care coordination to link for families to resources and services (Spina Bifida Association, 2018). If scholars applied *enabling factors* to scholarship about individuals with NTDs and their families, then they could identify antecedents that facilitate performance of healthy behaviors such as self-care and health care-seeking behaviors.

Phase 4 - Administrative and Policy Assessment and Intervention Alignment

Based on literature, we identified policy strategies reflecting policy regulation and organization that could support implementation of interventions for individuals with NTDs and their families. These proposed policies include: (a) to set up, monitor, and evaluate spina bifida registries, to ensure that individuals with spina bifida receive the best possible health care, (b) to raise awareness on rights of people with spina bifida to reduce stigma globally, (c) to improve universal health coverage, social protection, and access to multidisciplinary care, (IFSBH, 2018), (d) to improve care coordination for individuals with spina bifida and their families to avoid duplication of services and unnecessary costs, (e) to improve social inclusion for individuals with spina bifida (e.g., in schools; Spina Bifida Association,

2018; 2014), and (f) to prevent NTDs by recommending and supporting intake of adequate folic acid and food fortified with folic acid among women of childbearing age (CDC, 2016).

From the literature, some examples reflecting *educational strategies* are training and educational resources. For example, individuals with spina bifida can be trained to perform self-care activities (e.g., bowel management and urinary catheterization; IFSBH, 2018). One example of an *educational strategy* regarding family members is involving the family in skills training (e.g., urinary catheterization and bowel management) so that they are able to support their children (IFSBH, 2018). A second example of *educational strategy* is providing the family with information about providers and resources to build their caring for children with spina bifida (Spina Bifida Association, 2018). Examples regarding personnel who provide care for children and families include: (a) training of health care providers in communicating with spina bifida patients and their families, (b) training providers to provide individualized care that meets the needs and values tailored to each family (Bhogal, & Brunger, 2010; Parens & Asch 2003), (c) training school personnel about appropriate care and accommodations for students with spina bifida (Spina Bifida Association, 2014).

In the literature we reviewed, common resources needed to implement educational and policy interventions for individuals with NTDs and their families were identified. They include time, financial resources, as well as trained personnel (IFSBH, 2018; Spina Bifida Association, 2018).

Phase 5- Implementation

The goal of phase 5 of the PPM is to implement: (a) educational strategies and (b) changes in policies, regulations and/or organizations. We identified examples of policy changes, organization and education strategies that have been implemented.

Several programs exist to address issues related to individuals with NTDs and their families. For example, the International Federation of Spina Bifida and Hydrocephalus (IFSBH) is the worldwide umbrella organization for Spina bifida and Hydrocephalus. The IFSBH disseminates information about spina bifida globally to families, individuals, professionals, and community volunteers. Also, IFSBH organizes capacity building workshops for personnel who provide services to people with spina bifida. In

the US, the National Spina Bifida Program aims to improve spina bifida patient registry, identify centers of excellence in spina bifida, and organize public health awareness about NTDs (Spina Bifida Association, 2013). Through global partnerships, the March of Dimes promotes policies, programs and best practices that address the issues related to birth defects (March of Dimes, 2018).

To provide educational resources, websites such as Center for Parent Information and Resources provides information about spina bifida to individuals and their families (Center for Parent Information and Resources, 2015). The updated Guidelines for the Care of People with Spina Bifida are available through the Spina bifida Association website. The Guidelines provide the most up-to-date information to in caring for people with spina bifida (Spina Bifida Association, 2018). The IFSBH implemented the Spina Bifida and Interdisciplinary Program that offers a coordinated, multidisciplinary approach towards individualized care in limited resource settings (IFSBH, 2018). IFSBH and the March of Dimes provide informational brochures about NTDs (e.g., risk factors, treatment prevention) in plain language to individuals with spina bifida, their families, and community members (IFSBH, 2017; CDC, 2016). Folic acid guidelines with recommendations on prevention of NTDs among women of childbearing age through folic acid intake are available through health organization websites such as the World Health Organization (WHO), Centers for Disease Control (CDC), and March of Dimes (WHO, 2017; CDC, 2017; March of Dimes, 2016).

To prevent NTDs, some researchers have conducted interventions that aim to educate and counsel women of childbearing age about folic acid intake (Lawrence, Watkins, Ershoff, & Petitti, 2003; de Smit, Weinreich, & Cornel, 2015). These interventions reflect educational strategies or counseling strategies designed to increase folic acid intake among women of childbearing age. Some interventions have involved providing folic acid information and counseling through online videos (Schwarz et al., 2008) and pamphlets (de Smit et al., 2015; Flores, Prue, & Daniel, 2007). Other interventions have involved training interveners (e.g., health care providers and community educators) about folic acid (Chacko, et al., 2003; Robbins, et al., 2005) so that interveners would be able to educate and counsel women about taking folic acid.

Phases 6 to 8-Evaluations

In the literature, we identified examples reflecting process evaluation. One example is evaluating appropriateness of information provided to individuals with NTDs (e.g., based on family culture, age and developmental stage of individuals with NTDs; SBA, 2018). A second example is evaluating whether clinicians in different specialties integrate interventions to address QoL issues into clinical practice (SBA, 2018). A third example is evaluating whether there is improved communication between families of individuals with NTDs and members of the care team (Miller et al., 2009).

Examples reflecting impact-evaluation include: (a) evaluating individual knowledge about self-care and ability to perform self-care in individual with spina bifida (SBA, 2018). Among family members, impact evaluation includes (a) evaluating family knowledge about resources and (b) evaluating ability of family members (e.g., parents) to support their children in gaining independence (SBA, 2018). Examples reflecting outcome evaluation include: (a) evaluating physical and mental wellbeing of individuals with spina bifida and families and (b) evaluating access to coordinated multidisciplinary acre for individuals with spina bifida and their families (Spina Bifida Association, 2018).

Discussion

We had proposed that the PPM is comprehensive, logically consistent and explicit for guiding scholarship about individuals with NTDs and their families. After providing a brief overview of the PPM, we have applied the factors of the PPM to health related literature about individuals living with NTDs and their families. Through our examples from published research, we have demonstrated how identified variables align with the PPM factors. However, we are not aware of scholars who have applied the PPM prospectively to their work regarding individuals with NTDs and their families.

To demonstrate how the PPM is relevant to scholarship about individuals living with NTDs and their families, we have explained and exemplified how scholars can apply the PPM to organize their scholarship related to individuals with NTDs and their families. When scholars organize their scholarship according to the PPM, then they are likely to be comprehensive in identifying the breadth of relevant

challenges (Azar, Solhi, Nejhaddadgar, & Amani, 2017; Mbonu, Borne, & Vries, 2010; Tramm, McCarthy, & Yates, 2011).

We have exemplified the application of PPM *factors* to planning, implementing and evaluating studies about individuals with NTDs and their families. Scholars can systematically apply phases 1, 2, and 3 of the PPM to identify the physical, psychosocial, financial, and environmental challenges among individuals with NTDs and their families. Second, scholars could apply phase 4 of the PPM to design possible educational, systems and policy interventions that could address the identified challenges. By doing so, scholars are likely to develop coherent plans that address such a breadth of challenges. Third, scholars can apply phase 5 of the PPM to implement the educational, systems and policy interventions. Fourth, scholars can phases 6 to 8 to evaluate the short-term, intermediate and long-term impacts of educational, systems, and policy interventions. With such application, the PPM can help scholars think about why, how and what to do to achieve the goal of the intervention.

To guide future research about individuals with NTDs and their families, researchers can apply the PPM to plan, implement and evaluate interventions to address the physical, psychosocial, financial, and environmental challenges among individuals with NTDs and their families. Also, clinicians (e.g., nurse practitioners, physicians) engaged in quality improvement can apply the PPM to identify areas of improvement in caring for individuals with NTDs and their families.

Conclusions. We have applied the PPM to health-related literature about individuals with NTDs and their families. In organizing examples from the literature by the PPM factors, we have explained how the PPM factors are relevant to scholarship about individuals with NTDs and their families. The application of the PPM to individuals with NTDs and their families aligns with the nursing discipline, which focuses on the physical and psychosocial health of individuals and their environment, similar to the PPM. As demonstrated in this paper, the PPM can be helpful to guide scholarship about individuals with NTDs and their families, because (a) it includes a breadth of factors relevant to individuals with NTDs and their families, (b) it is logically consistent, and (c) it is explicit in providing propositions between the constructs and between and across phases. it is explicit in providing relationships among the concepts.

Applying the PPM factors to such scholarship could enable scholars to describe, predict and explain the challenges of individuals and families in a comprehensive manner than other health behavior theories and conceptual models such as the theory of planned behavior, the health belief model, and the socio-ecological model. Also, by systematically applying phases 1, 2, and 3 of the PPM to their scholarship, research scholars can identify gaps in literature regarding the care of individuals with NTDs and their families. Then research scholars can apply phases 4 to 8 of the PPM to plan, implement and evaluate educational and systems interventions that could address the issues in the care of individuals with NTDs and their families. Guided by phases 4 to 8 of the PPM, research scholars, clinicians and policy makers could collaborate to revise policies that could address issues identified in phases 2 and 3, regarding individuals with NTDs and their families. By applying the PPM to future research & scholarship about individuals with NTDs and their families, we could advance our understanding of the breadth of challenges for individuals and families and how to address them accordingly.

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Chapter 3: Interventions Promoting Women's Intake of Folic Acid Supplements: A Systematic Review

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Abstract

Background. Adequate folic acid (FA) lowers women's risk of having children with neural tube defects (NTDs). Less than half of women of childbearing age worldwide take FA supplements. In low- and middle-income countries, NTD prevalence is higher than in high-income countries. Researchers have conducted interventions to support women in taking FA. We do not have in-depth understanding of characteristics and components of such interventions to guide and improve future research to support women in taking FA, regardless of country and socio-economic status.

Objective. We conducted this systematic review to evaluate characteristics and components of interventions that were designed to promote intake of FA supplements among women of childbearing age worldwide.

Method. We searched PubMed, PsycINFO, Medline, CINAHL, SciELO and Cochrane databases for relevant interventions aimed at promoting intake of FA supplements among women (15 to 49 years) published in English from 1992 and 2017.

Results. All eight studies that met inclusion criteria were conducted in high-income countries. Intervention characteristics and components varied across studies including: delivery modes, involving and training health care providers as types of interveners, evaluating intervention fidelity, documenting study measures, utilizing conceptual models, and providing women with free FA supplements. Methodological challenges included: difficulty in retaining participants, especially women of low socio-economic status, and interveners' lack of fidelity to protocols. Women's common barriers to taking FA supplements included forgetting to take supplements and uncertainty about FA benefits.

Conclusions. This review provides better understanding of characteristics and components to consider in designing interventions to promote intake of FA supplements among women of childbearing age. Researchers could improve study designs to avoid past methodological issues and address women's barriers to taking FA. Researchers could apply conceptual models such as the PRECEDE-PROCEED Model to address individual and external influences on: (a) women's intake of FA supplements and (b) clinicians' practice of educating and counseling women about FA. Additional studies are needed in low-

and middle -income countries where FA interventions are rare. With improved FA interventions, researchers, clinicians, and policy makers could support women's intake of FA supplements to decrease risks of having children with NTDs.

Key words: Folic acid interventions, Women of childbearing age, Systematic review

Introduction

Adequate levels of folic acid (FA) lower women's risk of having children with neural tube defects (NTDs) by 50%-70% [1]. Neural tube defects (NTDs), including spina bifida and anencephaly are common serious birth defects that occur during the first four weeks of conception; they occur because of incomplete closure of the brain or spinal cord [2]. Globally, more than 300,000 pregnancies are affected by NTDs each year [3] resulting in pregnancy termination, miscarriage, neonatal death or lifelong disability in offspring [4].

NTDs have significant impacts on the quality of life of affected children, families, and communities. Physical abnormalities associated with NTDs include hydrocephalus, muscular-skeletal deformities, and bowel and bladder dysfunction [5-7]. Developmental abnormalities include learning disabilities [5].

The majority of individuals with NTDs are socially isolated [8-10] for several reasons. They typically have physical disabilities associated with NTDs. Community organizations often lack adequate accommodations for people with such disabilities. The social networks around individuals with NTDs often fail to appreciate the social needs of individuals with NTDs. Social isolation of affected children and their families is worse for individuals in low- and middle- income countries [11] due to limited resources to provide the special accommodations. Psychologically, individuals with NTDs have high risk for depression and anxiety [10].

Financially, children with spina bifida incur 13 times more medical costs than those without [12]. Within the US, children with spina bifida incur an estimated total lifetime direct cost of $791,900 in health care services [13]. Such life-long economic burdens are amplified when families are poor and live in low- and middle-income countries where there are limited social and community health resources to address their needs [14].

For a brief clarification of how countries are categorized by income level, we share the following. Several world organizations, including the World Bank, World Health Organization (WHO) and United Nations Development Programme use different methods to classify countries. The World Bank uses the

Atlas method to classify countries based on Gross National Income Per Capita [15]. The current classification of countries according to the World Bank is in four groups: (a) low, (b) lower-middle, (c) upper-middle, and (d) high-income countries. In this paper, we use the World Bank classification because the Gross National Income is associated with quality of life measures such as infant mortality rates and life expectancy at birth [15].

There are several health organizations that have made recommendations about FA. These organizations are: the World Health Organization (WHO), Centers for Disease Control, March of Dimes, and International Federation for Spina Bifida and Hydrocephalus (IFSH). The organizations recommend that all women of childbearing age take 0.4mg of FA supplements daily as a preventive strategy for NTDs [1, 16-18]. On average, the adherence to FA supplements among women of childbearing age worldwide is still below 50% [19]. And globally 44% of pregnancies are unplanned [20]. Thus, assuring adequate intake of FA supplements among women of childbearing age remains a global challenge.

The WHO supports mandatory fortification of foods with FA because mandatory food fortification improves folate status at population level and provides a safety net against NTDs where women of childbearing age have not been taking FA [18]. However, worldwide, 60% of countries either do not have mandatory food fortification policies or only voluntarily fortify selected foods with FA [18]. Unfortunately, even with FA fortification, not all women of childbearing age get the recommended daily amount of FA. Reasons could be because of individual factors such as women's age and pregnancy status. External factors could include health care providers' not recommending FA to women [21, 22] and limited availability and access to folic acid supplements.

When countries provide selective, voluntary fortification of foods with FA, they may not reach groups of women at greatest risk for FA deficiency such as those with low socio-economic status (SES) or those living in rural areas [23, 24]. Low SES women are more likely to consume (a) cheaper grains that may not be fortified with FA or (b) grains from small-scale mills that do not have the capacity to fortify foods with FA [25]. Therefore, worldwide, women of childbearing age are recommended to take 0.4mg of FA on a daily basis to ensure that they receive the recommended dose, regardless of whether some

accessible foods have been fortified [1]. This recommendation is especially important in low and middle-income countries where: (a) fertility rates are higher [26], pregnancies are more likely to be unplanned [27], and (c) the prevalence of NTDs is higher than that of high-income countries [28].

Some researchers have evaluated interventions to promote intake of FA supplements among women of childbearing age [29]. The researchers focused mainly on whether or not interventions had increased women's awareness, knowledge, and intake of folic acid. In the literature, there is no in-depth description of: (a) the characteristics and components of interventions that aim to improve women's intake of FA supplements, (b) researchers' challenges in implementing such interventions, and (c) barriers that women face in taking FA supplements. To promote intake of FA supplements among women of childbearing age for prevention of NTDs, a greater or in-depth understanding of the components of existing FA interventions is essential.

The aims of this current systematic review were to: (a) evaluate characteristics and components of interventions that were designed to promote intake of FA supplements among women of childbearing age, (b) describe methodological challenges that researchers faced in implementing these interventions, and (c) describe barriers to taking FA among women of childbearing age. If we synthesized findings from prior FA interventions, then we could (a) provide recommendations on what components to include for improved outcomes in future FA interventions, (b) strive to overcome prior researchers' methodological challenges, and (c) design studies and policies to overcome barriers to taking FA supplements among women of childbearing age.

Method

We conducted a systematic review of interventions designed to promote intake of FA supplements among women of childbearing age. The results are presented according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [30]. We developed protocols for bibliographic searches, study inclusion and exclusion criteria and data extraction before beginning the search.

Eligibility Criteria

We included studies that met these criteria: (1) provision of FA supplements or vitamin supplements containing FA to female participants, (2) evaluation of female participants' intake of FA supplements before and after the intervention, and (3) utilization of designs that were randomized controlled trials (RCTs) or quasi-experimental. We excluded the following: (1) reviews or summaries of other studies, (2) studies that involved use of vitamin supplements that did not contain FA, and (3) studies that did not evaluate participants' intake of FA supplements before and after the intervention. We did not include studies that involved assessment of blood folate concentrations as the only outcome measure because we were interested in women of childbearing age and their behavior of taking FA supplements.

Search strategy and Study Selection

A health sciences librarian assisted with identification of relevant databases to conduct the search. We searched six databases: PubMed, PsycINFO, Medline, CINAHL, SciELO and Cochrane for relevant studies. Search terms included: "periconceptional folic acid" [MeSH] OR "folic acid" [MeSH] AND "intake" AND "education" OR "counseling" AND "women of childbearing age" AND "neural tube defects prevention". We limited our search to intervention studies involving women aged 15 to 49 years, written in English, published from 1992 to 2017. We chose the year 1992 as the start date because this is when the CDC recommended that women of childbearing age consume 0.4mg of FA daily to reduce NTDs [1]. Also, we hand-searched reference lists of studies we proposed to include and review. Two individuals independently screened titles and abstracts of retrieved publications using a priori eligibility criteria. We removed duplicates and discussed which publications to include.

Data Extraction and Quality Appraisal

We extracted information from the studies meeting inclusion criteria. Extracted data included: citation, study design, study setting, sample, intervention characteristics and components, methodological challenges, and the primary results. To guide the appraisal of the methodological quality of the selected intervention studies, we utilized QualSysts; an appraisal checklist comprised of fourteen items, for qualitative and quantitative studies [31].

Results

From our initial database search, we retrieved a total of 361 publications. After removal of duplicates, 353 studies remained. Then we excluded most publications (n = 333) because they did not meet inclusion criteria. We conducted a full text assessment of 12 articles. Eight publications met our inclusion criteria. See Figure 1. The methodological quality of studies that met our inclusion criteria varied from 70% to 89% with a possible total score of 100%. Table 1 summarizes data from studies that met included criteria.

Study Designs

Among the eight studies reviewed, most (n=5) were quasi-experimental studies [32-36]. Three studies were randomized controlled trials [37-39]. In only one study, researchers reported utilizing a conceptual model to guide the design, implementation and evaluation of the intervention [37]. Researchers utilized the trans-theoretical model (TTM) to guide their examination of the effectiveness of web-based education about FA. The treatment group received five educational modules on FA, each corresponding to the five stages of TTM, whereas as control group received an educational brochure on FA without TTM guidance.

Study Settings

All eight interventions were conducted in high-income countries. Most of the studies (n=6) were conducted in the United States. One study was conducted in Norway and another from Netherlands. In most (n =5) studies, researchers recruited and delivered FA interventions in clinical settings including urgent care, well- baby clinics, medical centers, hospitals, community and routine gynaecological care clinics [32, 35, 36, 38, 39]. Also, researchers recruited and delivered interventions in local community settings [33, 34] and university settings [37].

Characteristics of Participants

The eight studies included a total of 9,171 female participants, with ages ranging from 18 years to 30 years. Marital status was reported in only four studies; in these studies, many participants were single ranging from 42% to 76%. In five studies, researchers reported ethnicity or race of the participants; in two

studies, most participants were black ranging from 52% to 72% [35, 39], most participants were white ranging from 53% to 95% [35, 36]. In one study, all were Hispanic [33]. In seven studies, all participants were English-speaking [32, 34-39]. In one study [33], participants were all Spanish speakers in the US. Income level was reported for one study; most participants (58%) had low-income levels below $30,000 per year [38]. Education level of participants was reported in four studies [34, 36, 37, 39]. In three studies, most had a college degree [34, 36, 39]. In one study, all participants (100%) were completing a college degree [37].

Characteristics and Components of Interventions

Interveners and Training of Interveners

In most interventions, researchers involved health care providers as interveners [32, 34-36, 39] including physicians [32, 39], nurses [35, 36], and pharmacists [36]. In one study, researchers had health educators as interveners [34]. In one study, researchers involved community health advisors and staff from health organizations (e.g., such as public health organizations, child health advocacy groups, CDC, March of Dimes) [33]. In two studies, the interveners received face-to-face training about FA supplements and the intervention processes [35, 39]. Interveners received training during either clinic meetings [36] or workshops [39].

Modes of Intervention Delivery

Researchers utilized different modes of intervention delivery. In most studies (n=5), researchers utilized face-to-face tailored FA counseling [32, 33, 35, 36, 37]. Some face-to-face counseling was delivered on (a) a one-on-one basis [32, 33, 35, 36, 39] or (b) both one-on-one and small groups [33]. In one study, researchers used phone calls to deliver reminder messages to participants [39].

In two studies, researchers utilized technology to counsel participants about FA supplements on one-on-one basis [38, 39]. Whereas some participants watched an online video about FA [38], others read online information about FA supplements [37]. In five studies, researchers utilized printed information about FA, such as pamphlets with participants [32-34, 36, 39]. To tailor FA information to expected

participants, one team involved the target population in designing illustrations and FA information brochures [36].

Provision of Free FA Supplements

In four studies, researchers provided free FA or multivitamin supplements containing FA to participants. The delivery of supplements was made either at clinic visits or through mail [35, 36, 38, 39]. Participants received a six-month supply of FA tablets [38], three-month supply of vitamins containing FA [35, 36], or a one-month supply FA tablets [39].

Intervention Dose

In most interventions (n=5), researchers did not report the length of time for counseling and educating participants about FA [32-35, 38]. In three studies [36, 37, 39], the time for counseling and educating participants ranged from 60 seconds [39], 10 minutes [37], and 15 minutes [36]. The duration of interventions varied from 6 weeks [37] to 30 months [36]. In most studies (n=5), researchers documented the frequency of intervention sessions. In these five studies, most contacts were one-time sessions [32, 35, 36, 38]. In other studies, counseling and educating participants occurred in two [39] to four sessions weekly sessions [37].

Measurement

None of the researchers for the eight interventions reported both the validity and reliability of the measures. Only one research team described the reliability of the measures used [37]. In only three studies, researchers provided a consistent definition of "regular" or "adequate" FA intake, which was defined as "daily use of FA" as an outcome measure for FA intake [33, 34, 39]. Across most studies (n=5), the definition for measurement of "regular" or "adequate" FA intake was inconsistent (e.g., recent use of FA [38], use or intended to use FA [32], use of FA four times a week [36] or use of FA supplements one to four times a week [35], or taking a multivitamin with FA [37]).

Intervention Fidelity

In most studies (n=5), researchers did not report whether interveners used standardized protocols for consistency during implementation [33-35, 37, 38]. In three studies, interveners used standardized

scripts during counseling sessions about FA use with participants [32, 36, 39] to evaluate fidelity of intervention delivery. Researchers in one study provided (a) interveners with checklists to indicate whether or not they had counseled participants about FA and (b) written information about FA to participants [39]. In two studies, researchers documented that interveners often forgot to counsel participants about the benefits of taking FA [35, 36]. To remind interveners to counsel participants about FA, researchers included questions about FA to routine patient history forms used in clinics [36].

Collection of Outcome Data

In three studies, researchers reported loss of some participants to follow-up, regardless of whether the follow-up data were obtained in person or by phone [36, 38, 39]. In one study researchers reported a 40% loss of participants to follow up; those less likely to complete follow-up were: (a) enrolled at a county clinic, (b) of low SES, (c) self-identified as black, and (d) less likely to report recent intake of FA supplements [38].

In two studies, researchers reported contamination of control groups with some information that the treatment groups were to receive [32, 39]. One research team [39] allowed physicians to choose whether or not to include FA advice to participants in the control group. Thus 85% of participants in this control group reported receiving counseling about FA. In another study, the treatment and control groups were recruited from the same clinic. So, the control group could have received FA information similar to the treatment group [32].

Participants Barriers to Taking Folic Acid

In five studies, researchers reported participants' barriers to taking FA supplements [32, 34, 35, 38, 39]. In four studies, participants reported forgetting to take FA supplements [34, 35, 38, 39]. In three studies, participants reported uncertainty about the benefits of FA supplements [35, 38, 39]. In three studies, 54% to 94% of participants reported that they were not planning to become pregnant so there was no need to take FA [32, 34, 39]. In one study, 16% participants believed that they were getting enough FA from food so they did not need FA supplements [39]. In one study, participants (22%) reported difficulty taking FA pills because of an "after taste" [39].

Discussion

To our knowledge, this systematic review is the first to: (a) evaluate characteristics and components of interventions that were designed to promote intake of FA supplements among women of childbearing age, (b) describe methodological challenges that researchers faced in implementing the interventions, and (c) describe barriers to taking FA among women of childbearing age. We found only eight published interventions about FA, despite the fact that NTDs are a global problem and NTDs are preventable with a low-cost intervention. Only three of these interventions involved randomized controlled designs. Among the studies reviewed, we found only one study [37] in which researchers described how they utilized a conceptual model to guide their intervention development, implementation, and evaluation.

All eight studies reviewed were from high- income countries, although we did not limit our search to countries of particular income status. We found no published intervention studies in low- and middle- income countries. However, low- and middle- income countries have higher prevalence of NTDs than high-income countries [28].

In designing future FA intervention studies, researchers need to consider the characteristics of the target population of women (e.g., age, race, language, and education level). If they knew, then they could…..customize interventions according to population characteristics and needs. In the studies reviewed, interventions were tailored to particular populations of women, such as: (a) college-aged female students of childbearing age [37], (b) women who had given birth recently and were expecting to become pregnant in the near future [32], and (c) special populations such as young women from minority racial or ethnic groups [33, 35].

Recruiting women in low and middle- income countries with low SES can be challenging because most women live in rural areas and have limited access to health care [18]. Yet, these very populations have a higher risk of giving birth to children with NTDs [18] because they typically have low intake of FA [25]. Future researchers can use more creative, effective and community-based, participatory research strategies [40] to recruit women of low SES. For example, in the U.S., researchers utilized different

strategies within the community intervention to recruit Spanish speaking women through (a) tailored FA media messages on television and radio and (b) involvement of Spanish- speaking community health educators to recruit women [33].

Involving the target population in designing FA interventions [36] could improve women's acceptability of FA interventions and therefore promote their intake of FA supplements [32, 33]. Within community settings, women's acceptability of FA information could be improved by involving local community workers. One way could be through involving the community health advisors to provide culturally appropriate, locally based, and holistic health advice to women about FA benefits [33]. Other researchers have documented that the provision of free FA supplements to women could improve their intake of FA supplements [35-37, 39].

Although health care providers play a major role in implementation of FA interventions, other professionals could also be instrumental during delivery of interventions. Such professionals include health educators [35], professionals working with health care organizations, and community health advisors [33]. In designing future interventions, researchers could consider involving other professionals who interact with women other than health care providers (e.g., community health advisors or educators).

Findings indicate that to increase fidelity to intervention protocols, a combination of strategies could be of value. For example, if interveners were adequately trained about their role in implementing interventions with reminders to educate and counsel women about FA, then their fidelity to intervention protocols could increase. Reminder strategies for interveners could be to include FA questions as part of patient history forms [36]. Monitoring of intervention fidelity is useful in identifying protocol violations. If interveners delivered interventions as intended, then researchers could replicate interventions in future studies [41, 42].

Findings suggest that researchers could utilize different modes of delivery to educate and counsel women about FA including (a) face-to-face education and counseling, (b) computerized counseling, (c) printed information about FA, and (d) social media. A face-to-face mode of delivery could work well in clinic settings where health care professionals are more available to provide health services to women.

Computerized technology could be successful in clinic, school settings and rural settings. Also in designing FA interventions, researchers could combine two modes of delivery such as: (a) face to-face counseling and printed information about FA or (b) computerized counseling and printed information about FA.

Across studies, we found that researchers did not document their intervention doses consistently. Researchers mostly reported the frequency of contacts of education and counseling sessions but reported the length of time of education and counseling sessions less. If researchers were consistent in documenting the dose, then scholars could examine dose-response relationships.

Three of eight studies reviewed indicated that researchers faced a challenge of loss to follow up, especially of women with low SES and those who had not completed a college education [36, 37, 39]. Increasing retention of women of low SES in interventions designed to promote FA is critical. This population is (a) at greatest risk of FA deficiency, and (b) at higher risk of having children with NTDs. If researchers increased participant retention, then this could facilitate evaluation of the long-term effectiveness of FA interventions, including among women of low SES.

Women's barriers to taking FA supplements were mainly due to individual factors rather than external factors. They included: (a) forgetting to take FA supplements, (b) uncertainty about FA benefits and beliefs about need for FA supplements, and (c) losing or misplacing the FA supplements. Women who were uncertain about FA benefits were those who were not planning to get pregnant and therefore, they irregularly took FA supplements. In line with the CDC [1], to address uncertainty about FA benefits, it may be important for health providers to help women of childbearing age recognize that because 44% of pregnancies are unplanned, women should take FA on a daily basis. However, this strategy alone may not be effective in addressing the challenge of irregular FA intake.

Limitations

Our systematic review had some limitations. We focused this review on only intervention studies for increasing FA supplementation among women of childrearing age. We included papers written in English only, therefore it is possible that we missed studies published in other languages. Although we

searched for studies in low and middle-income countries, the articles we found were only from high-income countries. Thus our finding may not be generalizable to low- and middle- income countries.

Research, Practice and Policy Implications

In designing interventions to support women's intake of FA supplements, researchers could consider important intervention characteristics and components including: (a) utilizing a single mode or a combination of delivery modes (e.g., face-to-face, computerized technology, and printed information), (b) choosing and training interveners who provide care to women of childbearing age, (c) providing free FA supplements or ensuring that FA supplements are accessible to women of childbearing age and (d) clearly documenting measures, intervention dose and intervention fidelity.

Researchers could design intervention studies to address methodological issues. If researchers designed studies with strategies to improve participant recruitment and retention especially women of low SES, then we could have better data with which to evaluate the effectiveness of FA interventions in these population. If researchers utilized standardized protocols in training interveners, then interveners could have higher rates of fidelity of delivery. If researchers monitored and documented fidelity of interventions, then we could have information on whether or not interventions were delivered as intended. The limited number of intervention studies designed to improve FA intake and guided by conceptual models and theories suggest directions for further research. Researchers could utilize conceptual models such as the PRECEDE-PROCEED Model (PPM) to explore individual and systems factors influencing intake of FA supplements in women of childbearing age in high-income and low- and middle- income countries.

Guided by conceptual models such as the PPM, researchers could develop educational interventions to address women's barriers (e.g., individual factors) to taking FA. Such interventions could include education and counseling about supplemental FA intake among women. Health policy makers could develop interventions to address systems barriers to women taking FA such as improving availability, affordability, and accessibility of FA, especially women of low SES. Health care

professionals, scholars, and policy makers could evaluate the outcomes of educational and policy interventions.

Conclusions. This review provides a better understanding of some characteristics and components to consider in designing interventions to promote intake of FA supplements among women of childbearing age. In low- and middle -income countries, there has been a paucity of interventions designed to promote intake of FA supplements among women of childbearing age. Yet, such countries have higher prevalence of NTDs than high-income countries. In designing future studies, researchers need to improve their methods to address researchers' methodological issues identified. To allow for replication of interventions that are methodologically sound and relevant, researchers could document explicitly their methods better than in the past. Researchers could apply conceptual models such as the PRECEDE-PROCEED Model to address individual and external influences on: (a) women's intake of FA supplements and (b) clinicians' practice of educating and counseling women about FA. With improved interventions designed to improve FA intake among women, multidisciplinary researchers, clinicians, and policy makers could improve women's intake of FA supplements to decrease risks of having children with NTDs.

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Availability of Data and Materials

All data reviewed and synthesized in this study are included in this manuscript.

Ethics Approval and consent to participate

Not applicable, because this is a systematic review of previously published data that does not require ethics approval.

Author's contribution

CO. Development of study specific aims, study protocol, literature review, search strategy, literature search, data extraction, synthesis and interpretation of results, and drafting manuscript. SZ. Development of study specific aims, study protocol, search strategy, review of literature search, data extraction, and manuscript revisions. DL. Development of study specific aims, synthesis of results, interpretation of results, and manuscript revisions.

All authors reviewed manuscript and made intellectual contribution to manuscript content and approved final version.

Competing Interests

None of the authors have any competing interests

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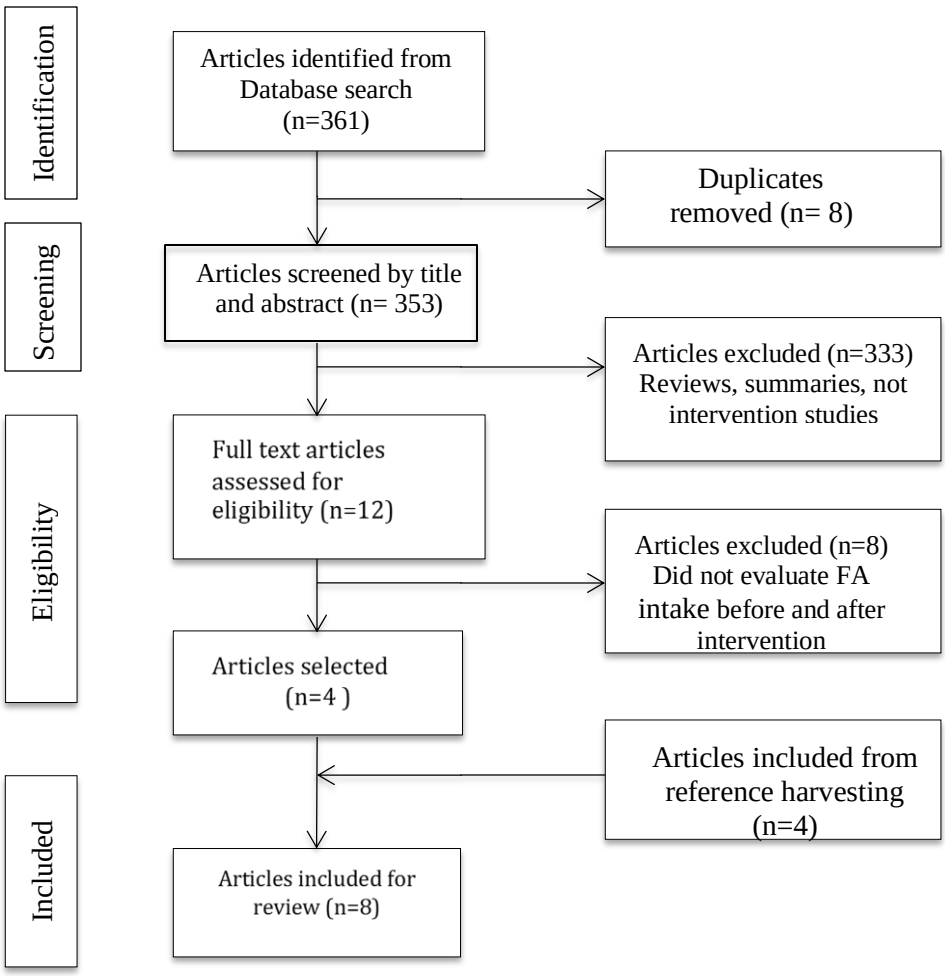

Figure 1. Flow diagram of literature review using the PRISMA guidelines (Moher et al., 2009).

Table 1: Summary of Interventions Designed to Increase Intake of Folic Acid Supplements Among Women of Childbearing Age

Citation	Design	Study Setting	Sample Characteristics	Intervention Characteristics and Components	Methodological Issues for Researchers	Primary Results Interventions
Schwarz E et al. (2008)	RCT	Urgent care clinics USA	N=446 I: 227 C: 219 Women 18-45 yrs English speaking	I: Participants received a one time, 15 minute computerized counseling on FA with provision of 200 free FA tablets Follow up at 6 & 7 months by phone C: Computerized counseling on emergency contraception. Follow up at 6 months & 7 by phone	Researchers did not document: (a) validity and reliability of measures used and (b) whether interveners used standardized protocols during implementation 40% of participants lost to follow up	Participants in intervention group, 32% group were significantly more likely to report taking supplements with FA than participants in control group, 21%
Robbins JM et al. (2005)	RCT	4 clinics: 2 affiliated with a medical school, and 2 private practices USA	N=322, I: 162 C: 160 Women 18 to 45) years English speaking	Involved health care providers as interveners. Intervener training on FA and intervention processes during workshops I: 60 seconds face- to- face tailored FA counseling of participants, printed information on FA, provision of 30 free FA tablets. Researchers used phone calls to deliver reminder messages to participants after 1 to 2 weeks. Use of standardized scripts during participant counseling Follow up at 2 months C: Participant counseling on preventive health behavior, pamphlet on health behavior Follow up at 2 months	Researchers did not documentation on validity and reliability of measures used Contamination of control group with information the intervention group received 12% of participants lost to follow up	Participants in Intervention group, 68% reported increased weekly intake of FA supplements relative to baseline compared with an increase of 20% relative to baseline for participants in control group
Lawrence JM et al. (2003)	Quasi-experimental interrupted time series	Medical Centers and Medical Offices served by Kaiser Foundation Health Plan (KFH) USA	N=3438 1: 2306 C: 1132 Women 18-39 yrs English & Spanish speaking	Involved nurses and pharmacists as interveners Intervener training on FA and intervention processes during workshops. Involved target population in designing FA materials. 1:Two interventions groups, (1) Provider intervention and (2) Direct mail/Pharmacy Information Intervention. Provider Intervention: A one time 15-minute face- to- face counseling tailored counseling of participants on a one- on- one basis. Use of standardized scripts during participant counseling. Use of printed information about	No documentation on validity and reliability of measures used 50% of interveners reported forgetting to counsel participants about FA Loss of some participants to follow up	Participants in Direct mail/Pharmacy Information Intervention group, there was a small but significant increase in participants who reported regular intake of multivitamins containing FA. Increase was higher at In provider

	FA with participants Pharmacy Information Intervention Mailing 100 multivitamins containing FA from pharmacy to participants. C: Kaiser Permanente Health phone script on multivitamin use. Brochures about multivitamins in English & Spanish	intervention group and control group, there was no change in multivitamin intake among participants

Table 1 Continued

Authors & Year	Design	Study Setting	Sample Characteristics	Intervention Characteristics and Components	Methodological Issues for Researchers	Key Results of Interventions
Milan JE, White AA. (2009)	RCT	University setting USA	N=808 I: 204 C: 204 Female degree seeking college students 18-29 Years	Mode of Intervention delivery: Technology to deliver FA education and counseling to participants on one-on-one basis. I: Intervention tailored by stage of Trans-theoretical Model (TTM) Intervention dose: 4 online education, counseling sessions C: One online education session without tailoring by stage per TTM Duration: 6 weeks	No documentation on validity and reliability of measures used	At post-test, in intervention group, 32.6% reported taking multivitamin In control group 19.9%
Chacko MR et al. (2003)	Quasi Experimental	Reproductive health clinics in 3 urban settings USA	N=387 Mean age:18 years English speaking Low-income adolescent & young adult women	Interveners: Nurses and health educators. Mode of Intervention delivery: face-to-face education and counseling with provision of 90 multivitamins	Researchers did not document: (a) validity and reliability of measures used (b) whether interveners used standardized protocols	At pretest, only 9% reported taking multivitamins with FA daily in a month. Post-test, intervention, 46% reported taking a multivitamin at least 11 to 20 times in a month Pre-test and Post test, participants, 9% who took a multivitamin daily in a month was the same

Table 1 Continued

Authors & Year	Design	Study Setting	Sample	Intervention Characteristics and Components	Methodological Issues for Researchers	Key Results of Interventions
Daltveit AK et al. (2004)	Quasi-Experimental	Norway	N=2364 C: 1,146 I: 1, 218 Women 18 to 45 years English speaking	Interveners: health care providers I: Mode of intervention delivery: printed information about FA C: No intervention	Researchers did not document: (a) whether interveners used standardized protocols and (b) intervention dose parameters	Post-test, among participants in intervention group, use of FA supplements increased by 8.9%. Among participants in control group, use of FA increased by 2.4%
de Smit, DJ et al. (2015)	Quasi Experimental	4 Well Baby Clinics Netherlands	N=413 I: 198 C: 215 Mothers who attended 6 month & 11 month post baby delivery visit English speaking	Interveners: physicians I: participants who attended 6 month post baby delivery visit Mode of Intervention delivery was face- to-face education and counseling with participants Use of printed information about FA with participants C: Were participants whose 6-month visit had taken place prior implementation of intervention. Outcome was measured at 11 month visit postpartum	Researchers did not document: (a) whether interveners used standardized protocols during implementation and (b) dose parameters Contamination of control group with some information the treatment group received	In intervention group, among participants who expected to be pregnant within a year, 65% reported intention to use FA. In control group, among participants who expected to be pregnant within a year, 42% reported intention to use FA.

Table 1 Continued

Authors & Year	Design	Study Setting	Sample	Intervention Characteristics and Components	Methodological Issues for Researchers	Key Results of Interventions
Flores, AL et al. (2007)	Quasi-Experimental	Clinics and communities within 8 states in USA	N= 1,027 I: 515 C: 512 Spanish speaking Hispanic women 18 to 35 years	Involved staff from health organizations and community health advisors as interveners I: 4 months paid campaign in Spanish-language in 2 states within the US Modes of Intervention delivery: (1) face-to-face FA education and counseling. Some face-to-face counseling was delivered (a) on one-on-one and (b) small group counseling. (2) Printed information about FA, e.g., pamphlets Comparison group: 6 month voluntary and unpaid public service campaigns in 6 comparison markets within 6 USA states Mode of delivery: printed information about FA, e.g., pamphlets Main message was: NTDs form when women do not know they are pregnant so, need to take FA before pregnancy	Researchers did not document: (a) intervention dose parameters, (b) validity and reliability of measures used, and (c) whether interveners used standardized protocols during implementation	Intervention group, 21.2% were more likely to report increased intake of supplements containing FA daily Comparison group: 15.6% likely to report increased intake of supplements containing FA daily

I; Intervention Group, C; Control Group, FA; Folic acid, TTM; Trans Theoretical Model

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Chapter 4: Influences on Nurses' Implementation of Folic Acid Guidelines: Development and Evaluation of a Questionnaire

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Abstract

Background. Neural tube defects reduce quality of life of affected individuals and families. Low- and middle- income countries such as Uganda have higher prevalence of neural tube defects than high-income countries. Nurses in Uganda and other countries are in key positions to implement folic acid guidelines. There are no known influences on nurses' implementation of folic acid guidelines or valid and reliable measures of influences for use in research.

Aim. To develop and evaluate a questionnaire of proposed influences on nurses' implementation of folic acid guidelines, based on the PRECEDE- PROCEED Model. I assessed the content validity of the items, scales and subscales. I assessed the construct validity and internal consistency reliability of the proposed scales and subscales.

Methods. For phase 1, using a descriptive design, a team of seven nurses from USA and Uganda developed questionnaire items proposed to measure influences on nurses' implementation of folic acid guidelines, based on literature and the PRECEDE- PROCEED Model (PPM). Based on the PPM, items reflected *predisposing, reinforcing, enabling and environmental factors* proposed to influence nurses' implementation of folic acid guidelines. Five proposed scales, two subscales, and 13 single items were created. Seven content experts from Uganda and USA rated all items for content validity. I computed content validity indices for items and scales. I revised or omitted some items based on expert ratings and descriptive feedback. For phase 2, using a cross-sectional, descriptive design, a convenience sample of 302 licensed nurses or clinical nursing students in Uganda responded to a revised questionnaire. To assess construct validity of the proposed scales and subscales, I conducted confirmatory factor analysis. To assess internal consistency reliability of the proposed scales and subscales, I computed McDonald's alpha omegas and Cronbach's alphas. To evaluate whether the proposed scales would measure the same latent constructs across different subsamples of nurses, I divided my sample into two, based on level of education. Using an approach called factorial invariance, I examined values for model fit indices.

Results. In phase 1, through an iterative process and peer review items became more concise and reduced in number from 106 to 53 items. Content validity indices of items varied from 0.57 to 1.00. Content validity indices of scales and subscales varied from 0.86 to 0.91. Based on expert descriptive feedback and ratings, 49 items were retained. For phase 2, for confirmatory factor analysis, the congeneric model was a good fit for the data, based on goodness of fit measures, 26 of factor loadings > .30, and all factor loadings significant, $p < 0.05$. Based on McDonald's omega, 5 scales had internal consistency reliabilities from 0.70 to 0.86. Two subscales about nurses' beliefs (re: need for folic acid and side- effects of folic acid) had internal consistency reliabilities of 0.54 and 0.58 respectively. In analyses to assess factorial invariance, I observed similar standardized loadings of items on seven factors across two different subsamples; model fit indices indicated the configural and weak models fit the data well. The final questionnaire had 39 items.

Conclusions. Based on literature and the PRECEDE- PROCEED Model, I developed and evaluated a questionnaire of proposed influences on nurses' implementation of folic acid guidelines in Uganda. Results provide support for (a) content validity of most items, scales and subscales, (b) construct validity for all scales and subscales, and (c) internal consistency reliability of 5 scales. Results provide additional support for validity of the scales and subscales because findings were stable across two different subsamples. With some revisions, researchers could improve the internal consistency reliability on two subscales.

Implications for Nursing and Health Policy. Nurse researchers could administer the new questionnaire among nurses in low- and middle -income countries such as Uganda to describe relationships between influences on, and nurses' reported practices of educating and counseling women of childbearing age. Based on the PPM phases 2 and 3, researchers could examine relationships between (a) predisposing factors (nurses' knowledge and nurses' beliefs regarding FA), (b) reinforcing factor (nurses' normative practices), (c) enabling factors (continuing education about folic acid), (d) environmental factors (availability of folic acid resources, access to folic acid guidelines) with nurses behavior (nurses' educating AND counseling women about folic acid). Based on the findings, researchers could apply

phases 4 to 8 of the PPM to: (a) design, implement and evaluate educational interventions to improve nurses' implementation of folic acid guidelines and (b) design, implement and evaluate policy and systems interventions in health organizational settings to improve nurses' implementation of folic acid guidelines in Uganda.

Key Words. Construct Validity, Content Validity, Internal Consistency Reliability, Folic Acid Guidelines, Measures

Background

Low- and middle -income countries have significantly higher prevalence of neural tube defects (NTDs), such as spina bifida than high-income countries (World Health Organization [WHO], 2015). In Uganda specifically, the estimated number of children born with spina bifida per year is 1,400 (Warf, Wright & Kulkarni, 2011). Neural tube defects have significant impacts on the physical, psychosocial, and financial wellbeing of affected children, families, and communities (Avagliano et al., 2018; Holmbeck & Devine; 2010). The life-long consequences of NTDs are more profound in low- and -middle income countries (Sims-Williams, Kabachelor, & Warf, 2017; Onrat, Seyman, & Honuk, 2009) such as Uganda, due to limited resources to take care of individuals with NTDs, including poor health infrastructure, and few specialists to care for individuals with NTDs.

Health organizations such as the WHO, CDC, and March of Dimes recommend that all women of childbearing take 0.4mg of supplemental folic acid daily as a preventive strategy for NTDs (CDC, 2015; WHO, 2014; March of Dimes, 2016). When women take 0.4mg of folic acid daily, their risks of having children with NTDs are reduced by 50% to 70% (CDC, 2015; MRC Vitamin Research Group, 1991). In Uganda, the Ministry of Health recommends that women take appropriate amounts folic acid through supplements and diet prior to conception (MOH, 2010), consistent with WHO recommendations.
In Uganda and other low- and -middle income countries, assuring adequate intake of folic acid among women of childbearing age remains a challenge. Yet, 50% of pregnancies are unplanned (Ministry of Health [MOH], 2010). Also, in Uganda, the high reproductive rate of 6 births per woman and early age of pregnancies (Uganda Demographic & Health Survey, 2016) could increase the number of children born with NTDs. As such, there is urgent need to understand how health care providers such as nurses could promote folic acid intake among women of childbearing age in Uganda.

In most countries, nurses make up the majority of health care workers; they play major roles in nutrition education and counseling for women. Nurses in Uganda are in key positions to implement folic acid guidelines. However, we do not have an in-depth understanding about the factors that influence

nurses' implementation of folic acid guidelines. In Uganda, one research article on folic acid intake suggested that few nurses understood the importance of women of childbearing age taking folic acid prior to pregnancy or provided information to women of childbearing age about the benefits of taking folic acid prior to pregnancy (Bannink, 2015).

When health care providers such as nurses educate and counsel women of childbearing age about folic acid benefits, then women's intake of folic acid can increase (Schwarz, Sobota, Gonzales et al., 2008; Robbins, Cleves, Hobbs & Collins, 2005). However, these data were generated in only high-income countries. In low- and middle -income countries such as Uganda, there is limited research on nurses' and other health care providers' practices regarding recommendations for folic acid with women of childbearing age.

There is no known published research on influences regarding nurses' implementation of folic acid guidelines in any country of the world. If researchers knew the important influences on nurses' practice regarding folic acid with women of childbearing age, then they could develop interventions to support or address these influences. By doing so, nurses could improve implementation of folic acid guidelines.

There are no known measures about influences on nursing practice regarding folic acid. This is true in Uganda and elsewhere in the world. Williams et al. (2006) designed a survey to study health care workers' practices about folic acid in the USA. Williams et al. (2006) evaluated health care workers' knowledge about folic acid and practices of recommending folic acid. One limitation to this study is that the researchers did not address other concepts, such as workers' beliefs or professional norms or external barriers to implementation of folic acid guidelines. Williams et al. (2006) did not apply a theory or conceptual model that could have made development of questionnaire items more comprehensive. Another limitation is that the researchers did not evaluate the validity and reliability of their survey.

Yet, researchers need valid and reliable measures to study nursing practice about folic acid well (Heale & Twycross, 2015; Morrison-Beedy & Melnyk, 2012). If researchers had valid and reliable measures of influences on nurses' practice about folic acid, then such measures could be used in research

regarding nurses' implementation of folic acid guidelines. For example, researchers could use measures for pre-and post-evaluation purposes with interventions designed to promote nurses' implementation of folic acid guidelines.

Conceptual Framework. To understand the breadth of influences on nursing practice regarding folic acid in Uganda, we applied a model that has been useful in similar public health situations: the PRECEDE-PROCEED Model (PPM; Green & Kreuter, 2005). The PPM is a comprehensive model for planning, implementing and evaluating the effectiveness of health promotion and disease prevention interventions. Because the PPM emphasizes contextual factors beyond that of the individual client or health care worker (Green & Kreuter, 2005), it is broader and more adequate than most behavioral models. The PPM has been helpful in guiding scholarly work on health promotion and disease prevention (Ondoma, 2019; Azar, Solhi, Nejhaddadgar, & Amani, 2017; Mbonu, Borne, & Vries, 2010; Tramm, McCarthy, & Yates, 2011; Tremblay, et al., 2001).

According to the PPM, *predisposing, reinforcing, enabling and environmental factors* directly influence behavior and are modifiable (Green & Kreuter, 2005). Because I was interested in factors that directly influence behavior and are modifiable, I applied *predisposing, reinforcing, enabling and environmental factors* to nursing practice regarding folic acid. For each factor, I considered relevant and important concepts based on the PPM. Then, for each specific concept, I developed items based on the PPM, relevant literature (WHO, 2010; CDC; 2016; Westat, 2000; Abu-Hammad, Dreiher, Vardy & Cohen, 2008), and practice experience in Uganda.

For example, based on the PPM, for *predisposing factors*, knowledge and beliefs concepts were important and changeable. For *reinforcing factors*, the concept of normative practices was important. For *enabling factors*, the concept of continuing education was important. For *environmental factors*, the concepts of availability and accessibility were important. I proposed that these concepts would reflect the PPM *factors.* I proposed the concepts would reflect the PPM *factors.* Figure 1 shows the PPM (Green & Kreuter, 2005).

Study Purpose. The purpose of this study was to develop and evaluate a questionnaire of proposed influences on nurses' implementation of folic acid guidelines. I conducted this study in two phases. Specific aims for phase 1 were to: (1) develop items to reflect constructs from each factor from the PPM: *predisposing, reinforcing, enabling,* and *environmental factors* proposed to influence nurses' implementation of folic acid guidelines and (2) assess the content validity of new items, scales and subscales. Specific aims for phase 2, were to: (1) assess the construct validity of scales and subscales revised questionnaire (2) assess the internal consistency reliability of scales and subscales.

Methods for Phase 1

The University of Wisconsin–Madison, Institutional Review Board deemed phase 1 of the study exempt. Figure 2 provides a summary of the steps in phase 1.

Aim 1, Development of Items

Design. Using a descriptive design, I developed new items to reflect constructs within *predisposing, reinforcing, enabling and environmental factors* that I proposed to influence nurses' implementation of folic acid guidelines. I followed the deductive process of developing items (Hinkin, 1998; Schwab, 1980) that involved review of relevant literature and the PPM (Green & Kreuter, 2005). Scholars suggest following the deductive approach where theories or models exist (Hinkin, 1998; Viega, 1991).

Sample and Setting. A team of seven nurses was involved in developing new questionnaire items. One was a PhD- prepared nurse faculty at a Midwestern University in the USA with expertise in theory and instrument development. Four were PhD nursing students in USA, with experience in instrument development. Two were nurse consultants in Uganda with master's in nursing.

Item Generation. The team followed a deductive approach of developing questionnaire items (Hinkin, 1998; Schwab, 1980). The team generated new items based on the constructs within PPM factors, existing relevant literature (e.g., folic acid guidelines, beliefs and practices about folic acid; CDC,

2016; WHO, 2010; Westat, 2000; Abu-Hammad et al, 2008; Williams et al., 2006), and nursing practice experiences in Uganda..

I proposed items to reflect constructs from each *factor* of the PPM and sought feedback from a team of nurses. For items reflecting *predisposing factors,* I developed items about (a) nurses' knowledge about folic acid guidelines, (b) nurses' beliefs regarding educating and counseling women about folic acid, and (c) nurses' beliefs regarding folic acid. Items about nurses' beliefs regarding educating and counseling women about folic acid were proposed to comprise one scale. Items about nurses' beliefs regarding folic acid were proposed to comprise two subscales (re: need for folic acid and side- effects of folic acid).

For items reflecting *reinforcing factors*, I developed items about nurses' normative practices regarding educating and counseling women about folic acid in Uganda, based on the PPM. The items were proposed to comprise a scale. Table 1.0 shows initial items. For items reflecting *enabling factors,* I developed items about continuing education about folic acid. For items reflecting *environmental factors*, I developed items about: (a) availability of folic acid resources and (b) accessibility to folic acid guidelines, based on the PPM. I proposed the items would comprise scales. To clarify, availability refers to presence of resources (McLaughlin, & Wyszewianski, 2002). Accessibility refers to ease of getting to resources (Evans, Hsu, & Boerma, 2013; McLaughlin, & Wyszewianski, 2002; Woldemichael, Takian, Sari, & Olyaeemanesh, 2019). Table 1.0 shows the initial items.

Data Analysis. Through an iterative process, I compiled and synthesized feedback about the initial items from the team of nurses in Uganda and USA. In consultation with the team of nurses in USA and Uganda, I excluded items that were deemed to be inapplicable. To improve readability and comprehension of the items for the population of interest, I reviewed items for approximate 8th grade reading level by assessing approximate number of syllables per word and the sentence length (Paz, Liu, Fongwa, Morales, & Hays, 2009). In consultation with the team of nurses, I revised words that had more than three syllables and reduced the length of long sentences.

Aim 2, Assessment of Content Validity

Design, Sample, and Setting. Using a cross-sectional descriptive design, a sample of seven content experts assessed the content validity of the proposed items, scales and subscales (questionnaire version 1.0). Content validity is the extent to which items on a measure adequately represent the content of the concept being measured (Polit & Beck, 2012). To assess the content validity, experts recommend a sample size from 5 to 12 content experts (Polit & Beck, 2012; Lynn, 1986). Experts were professionals in health related fields, knowledgeable about NTDs, folic acid, and the population of interest (i.e. nurses in Uganda). Three were physicians with experience in neurosurgery, including NTDs and folic acid, or published research on folic acid and NTDs. One was a biochemist and nutritionist with published research on vitamins including folic acid. Three experts were nurses with bachelor's or master's in nursing, professional training in midwifery, or clinical experience with folic acid and NTDs in the Ugandan health care system.

Data Collection. A research team member other than the principle investigator invited content experts to participate electronically in our study via email. This was done to blind the principle investigator to experts' identity. Experts participated via *Qualtrics* website. Completion of the questionnaire signaled experts' consent. I asked experts to rate each item for (a) clarity of wording, (b) relevance to each factor from the PPM (Polit & Beck, 2012; Rubio et al, 2003; Lyn, 1986) and (c) cultural appropriateness (Rubio et al, 2003; Lyn, 1986; Kreuter, Lukwago, Bucholtz, Clark, & Sanders-Thompson, 2003) within the context of Ugandan health care. I asked experts to rate each set of items on comprehensiveness (Polit & Beck, 2012; Rubio et al, 2003; Lyn, 1986).

For clarity of wording, I asked experts to rate items with options from 1 '*not at all clear'*, 2 '*somewhat clear*, 3 '*clear'*, to 4 '*very clear'*. For relevance to PPM factors, I asked experts to rate items from 1 '*not at all relevant'*, 2 '*somewhat relevant'*, 3 '*relevant*', to 4 '*very relevant'*. For cultural appropriateness within the Ugandan health care context from 1 '*not at all culturally appropriate'*, 2 '*somewhat culturally appropriate,* 3 '*very culturally appropriate*' to 4 '*very culturally appropriate'*. For comprehensiveness of each set of items, I asked experts to rate each set from 1 '*not at all comprehensive*, 2 '*somewhat comprehensive*', 3 '*comprehensive*' to 4 '*very comprehensive*'. If experts rated an item or a

set of items less than 3, then I asked for comments for item revision or suggestions to improve. To clarify, a set of items reflected a PPM factor.

Data Analysis. I used Microsoft Excel for analyses. I examined the data for missing values and patterns of missing data (Fox-Wasylsyshyn & El-Masri, 2005). I did not have missing data from the expert sample.

I followed Polit and Beck's (2012) method for computing content validity indices (CVIs). I computed CVIs by item (I-CVIs). Also, I computed CVIs by scale (S-CVIs).To compute the I-CVIs, I combined expert ratings of '3' or '4' into one category to reflect agreement and ratings of '1' or '2' into one category to reflect disagreement. Then, I summed experts' ratings on 'agreement' and 'disagreement' and divided them by the number of experts (n=7). I calculated the S-CVIs by averaging the I-CVIs of items in each scale (Polit & Beck, 2012; Lynn, 1986; Beck & Gabel, 2001). I used ≥ 0.80 to determine the acceptability of I-CVIs and S-CV1s; the maximum score was 1.00 (Polit & Beck, 2012; Lynn, 1986; Beck & Gabel, 2001). If an I-CVI or S-CVI were less than 0.80, then I either revised or omitted the items. I considered content expert comments in revising the items.

Results of Phase 1

For aim 1, through an iterative process and peer review (i.e., from the team of nurses in USA and Uganda), we made items more concise and fewer in number (from 106 to 53 items)(Questionnaire version 1.0). For aim 2, content experts provided their ratings and feedback on the 53 items. Based on expert ratings, I-CVIs were 0.57 to 1.00. Most items had high I-CVIs > 0.80; 77% of items on clarity, 88% of items on relevance, and 77% of items on cultural appropriateness. For the 5 scales and 2 subscales, S-CVIs varied were 0.86 to 0.91. Table 1.1 shows the 1-CVIs and S-CVIs. I revised 18 items based on expert feedback. I omitted a total of 4 items because they had low I-CVIs < 0.80 on relevance and cultural appropriateness for the Ugandan health care context. One omitted item was about nurses' beliefs about educating and counseling women about folic acid and 3 items were about nurses' normative practices

about folic acid. I retained 49 items. I called the resulting questionnaire version 1.1. See Table 1.3 and appendices 2 to 8 for items.

Methods for Phase 2

All necessary local, national and international Institutional Review Boards (IRBs) in USA and Uganda approved the study. Specifically, I obtained approval from the (a) University of Wisconsin Health Sciences Institutional Review Board, (b) local IRB in Uganda (i.e., Mbarara University of Science and Technology Research Ethics Committee, and (c) national IRB in Uganda (i.e., Uganda National Council for Science and Technology).

Design. I used a cross-sectional, descriptive design to: (1) assess the construct validity of the scales and subscales (version 1.1) and (2) assess the internal consistency reliability of the scales and subscales revised questionnaire (version 1.1).

Sample and Setting. Using convenience sampling, trained personnel recruited a sample of 302 participants who were either clinical nursing students or licensed nurses in Uganda representative of the target population. A sample size of 200 and above is desirable to conduct factor analysis (Meyers, Gamst, & Guarino, 2006; MacCallum, 1996; Comrey and Lee, 1992). To enhance representativeness of the different levels of nursing education in Uganda, we recruited licensed nurses and clinical nursing students with different levels of nursing education (e.g., enrolled, certificate, bachelor's degree in nursing science and master's degree in nursing science). And, trained personnel recruited in two different districts and two different sites in each district in Uganda

Inclusion and Exclusion Criteria. Nursing students or licensed nurses were included if they: (a) lived and worked in Uganda, (b) were at least 18 years of age, and (c) were comfortable reading, writing and speaking about health care in English. Trained personnel assessed students' and nurses' degree of comfort with English by self-report. Clinical nursing students who had not yet started clinical experiences were excluded.

Questionnaire version 1.1. I invited clinical nursing students and licensed nurses to respond to items. The questionnaire included items reflecting (a) *predisposing factors* (i.e., nurses' knowledge about folic acid guidelines, nurses' beliefs regarding educating and counseling women about folic acid, nurses' beliefs about folic acid (re: need for folic acid and side effects of folic acid), (b) *reinforcing factors* (i.e., nurses' normative practices regarding educating and counseling women about folic acid), (c) *enabling factors* (i.e., continuing education about folic acid), (d) *environmental factors* (i.e., availability of folic acid resources and access to folic acid guidelines). For items on nurses' knowledge about folic acid guidelines, participants responded to multiple-choice options. For beliefs and normative practices items, participants responded to response options of 1 to 5: 1=*Disagree*, 2=*Strongly Disagree*, 3= *Neither Agree Nor Disagree*, 4= *Agree*, 5=*Strongly Agree*. For items about continuing education about folic acid, the options were '*Yes*', or '*No*' or '*I don't know*'. For items about availability of folic acid resources and access to folic acid guidelines, nurses responded to '*Yes*' or '*No*'.

To maximize the potential of obtaining sufficient numbers of trustworthy responses, I set up items in *Qualtrics* in particular ways. I designed items in *Qualtrics* such that once a participant picked a response and proceeded to the next item, they were not given an option to go back to the previous item to review or change their responses. To minimize missing data, I set up item progression such that participants had to respond to one item at a time, before proceeding to the next one.

Data Collection Procedures.

I identified three personnel in Uganda with master's or bachelor's degrees in Uganda. The personnel had experience in conducting research in Uganda. In consultation with a UW-Madison IRB staff, I provided the personnel with online training on research ethics, how to recruit potential participants, and to collect data from human participants.

The trained personnel invited participants to complete the questionnaire electronically using android tablets, via a *Qualtrics* offline app. The questionnaire was anonymous. Participants' completion of the questionnaire implied consent. Participants responded to items by clicking on response options.

Trained personnel in Uganda uploaded participants' data onto a secure encrypted server for the researcher in the US to use in real time.

The trained personnel gave each participant a gift to feel appreciated, yet not pressured to participate. Nursing students received water bottle worth 10,800 Ugandan shillings (3 US dollars). Licensed nurses received 15,000 Ugandan shillings, equivalent to 4 US dollars. 15,000 Ugandan shillings was worth their transport to and from home.

Data Analysis. I used Stata version 15 (Juul & Frydenberg, 2014), Mplus version 8.3 (Muthen & Muthen, 2019), and NCSS statistical software (2019) to analyze the data. For initial analyses, I used Stata to examine data for missing values and patterns of missing data (Fox-Wasylyshyn & El-Masri, 2005). To examine patterns in responses, I reviewed the raw data. To describe sample characteristics, I computed descriptive statistics including frequencies. To describe the relationship between ordered categorical items, I computed polychoric correlation matrices (Holgado–Tello, Chacón–Moscoso, Barbero–García, & Vila–Abad, 2010). Using polychoric correlations provides a more accurate estimate of relationships between ordered categorical items than Pearson correlation (Holgado–Tello et al., 2010). To describe the relationship between dichotomous categorical items, I used tetrachoric correlations to obtain a more accurate estimate of relationships than Pearson correlation (Bonett & Price, 2005).

I assessed the construct validity and internal consistency reliability of proposed 5 scales and 2 subscales (version 1.1) based on the classical test theory approach (Traub, 1997). The assumption of the classical test theory is that each person has a true score that would be obtained if there were no errors in measurement. Based on this assumption, the observed score on a measure is a combination of an underlying true score on the concept of interest and a random error (Traub, 1997).

Aim1, Assessment of Construct Validity

To assess the construct validity of the 5 scales and 2 subscales, I conducted factor analysis following Kroonenberg and Lewis' (I982) procedures. Confirmatory factor analysis (CFA) enables researchers to test a hypothesized factor structure or conceptual model (Bryne, 2012). Because we had

developed our items based on the PPM, we hypothesized that items reflecting a particular construct within the PPM factors would load together. Also, by directly comparing alternative measurement models, CFA allows one to assess which model best fits one's data through factor loadings (Polit and Beck, 2012; Swisher, Beckstead, & Bebeau, 2004; Strauss & Smith, 2009).

I constructed a CFA model on the data from a sample of 302 nurses using weighted list square mean and variance adjusted (WLSMV) estimation. Because the data were categorical and not normally distributed, WLSMV was an appropriate approach to estimate the measurement model parameters (Byrne, 2012). I conducted an oblique model because I assumed the proposed seven measures would be correlated with each other (Byrne, 2012).

I chose to limit the measurement model to seven factors (i.e., a seven-factor oblique congeneric model). Factor 1 was proposed to reflect the construct of beliefs (i.e., nurses' beliefs about educating and counseling women about folic acid. Factors 2a and 2b were proposed to reflect the construct of beliefs (re: nurses' beliefs about folic acid and need for folic acid) respectively. Factor 3 was proposed to reflect the construct of normative practices (i.e., nurses' normative practices regarding educating and counseling women about folic acid). Factor 4 was proposed to reflect the construct of continuing education (i.e., continuing education about folic acid). Factors 5 and 6 were proposed to reflect the constructs of availability of resources (i.e., availability of folic acid resources) and accessibility to resources (i.e., access to folic acid guidelines) respectively.

First, the least restrictive measurement model was tested with a congeneric model. The assumption in using a congeneric model is that proposed items of scales measure the same latent variable, with possibly different scales, different amounts of error, and different degrees of precision (Raykov, 1997). To evaluate which congeneric model best fit the data, I used five fit indices commonly recommended. The fit indices were: (a) normed Chi-Square (x^2/df) with acceptable ratios ≤ 2 to ≤ 5 (Schermelleh-Engel & Moosburger, 2003; Tabachnick & Fidell, 2007, Ullman, 2001; Wheaton et al., 1977; Schumacker & Lomax, 2004), (b) root mean square of approximation (RMSEA) with acceptable

values of ≤0.07 (Hu & Bentler, 1999; Steiger, 2007), (c) comparative fit index (CF1) ranging from 0.0 to 1.0, with acceptable values ≥ 0.95 (Hu & Bentler, 1998), (d) Tucker Lewis index (TLI) with acceptable values of ≥ 0.95, (e) standardized root mean square residual (SRMR) ranging from 0 to 1, with acceptable values of <0.05 to ≤ 0.08 (Hu & Bentler, 1999; Bryne, 1998; Diamantopoulos & Sigauaw, 2000).

In addition, I compared three more restrictive measurement models to test which of the alternative measurement models might fit the data best (Polit and Beck, 2012; Swisher, Beckstead, & Bebeau, 2004; Strauss & Smith, 2009). Using more restrictive measurement models would be useful in determining which measure of reliability was the most appropriate (Graham, 2006). The more restrictive models were: (a) the tau-equivalent model, (b) the partial tau –equivalent model, and (c) the parallel model (Graham, 2006). Appendix 1 provides description of these more restrictive models.

In addition to using the five fit indices, I also referred to a test, the Chi-square difference test (Difftest ; Hu & Bentler, 1999). The Difftest enables a researcher to evaluate a good fitting model for the data. Because the more restrictive measurement models were nested, the Difftest provided the difference between the chi-square statistics of the models with constrained and non-constrained parameters (Hu & Bentler, 1999). A non-significant Difftest supports a good fitting model (Hu & Bentler, 1999).

Aim 2, Assessment of Internal Consistency Reliability

Both Cronbach's alpha and McDonald's omega were used to examine internal consistency reliability. Both were used because the Cronbach's alpha is based on the assumptions of the tau-equivalent models; if the assumptions are not met, then Cronbach's alpha underestimates the true reliability of measures (Graham, 2006). If the assumptions of the tau equivalent models are met, then values for Cronbach's alpha and McDonald's omega and are similar (Graham, 2006). Desirable values for Cronbach's alpha and McDonald's omega are 0.80 or higher. Values from 0.70 are acceptable for new

measures (Viladrich, Angulo-Brunet, & Doval, 2017; Polit & Beck, 2012; McMillan & Schumacher, 2001).

Assessment of Factorial Invariance

Factorial invariance is a statistical approach that evaluates whether or not the same latent variable(s) can be measured across different subsamples (Timmons, 2010; Bialosiewicz, Murphy & Berry, 2013). In other words, examining factorial invariance refers to examining whether or not findings are stable across subsamples. To apply this approach, I divided my sample into two subsamples based on level of education. One subsample was participants with higher levels of nursing preparation (i.e., nurses with bachelor's degree in nursing and registered nurses, and clinical nursing students in the bachelor's degree or registered nursing programs). Another subsample was participants with lower levels of nursing education in Uganda (i.e., certificate and enrolled nurses, and clinical nursing students in the certificate or enrolled nursing programs).

There are four levels to examining factorial invariance, each level building upon the previous one (Bialosiewicz, Murphy & Berry, 2013). By introducing additional equality constraints to the next level of factorial invariance, the levels become stronger compared to the former (Bialosiewicz, Murphy & Berry, 2013). The levels of factorial invariance include (a) configural invariance, (b) weak invariance, (c) strong invariance, and (d) very strong invariance (Timmons, 2010).

Configural invariance is a statistical approach used to test whether or not the same items or scales measure the same latent variables across different subsamples (Timmons, 2010; Bialosiewicz, Murphy & Berry, 2013). If the values of the model fit indices are within acceptable range, then the configural invariance model is a good fit for the data. Weak invariance builds upon the configural invariance to test: (a) whether the same items measure the same latent variable across subsamples and (b) whether factor loadings of items are similar across subsamples (Hong, Malik, & Lee, 2003; Bialosiewicz, Murphy & Berry, 2013). In addition to the weak invariance specifications, strong invariance requires that item intercepts are constrained to be equivalent across subsamples (Bialosiewicz, Murphy & Berry, 2013). In addition to strong invariance specifications, very strong factorial invariance requires that indicator

residuals are constrained to be equivalent across subsamples groups (Bialosiewicz, Murphy & Berry, 2013; Timmons, 2010). To consider use of measures across subsamples, at least the configural and weak invariance models should be fit data for the data (Hong & Malik, 2003).

To use the "typical" subsample assessments with factorial invariance, the number of response options for items across all subsamples should be equal (Rutkowski, Svetina, & Liaw, 2019; Agresti, 2013). In this study, the number of response options for items across the two subsamples of nurses was not equal; item response options varied from five, three, and two. I considered collapsing some item responses to make the responses similar across subsamples (Brown, 1991). However, one of five response options was a neutral response option (i.e., neither agree or disagree); collapsing the response options into two categories would have affected accuracy of results. As an alternative, I constructed two separate models to assess configural invariance across the two subsamples of nurses. For weak invariance, I assessed and compared whether or not the standardized factor loadings across subsamples were similar.

Results of Phase 2

Sample Description

I had no missing data of the sample. Table 1.2 shows a summary of the sample characteristics. For highest level of nursing preparation among licensed nurses, the majority (40%) were registered nurses. Among licensed nurses, the majority (81%) had 2 to 4 years of work experience. Among clinical nursing students, the majority (35%) were in their 2nd year of their 3 to 5 year study. The majority of participants (31%) had worked in the antenatal clinic for the past 6 months. The majority of participants (42%) had worked with women of childbearing age for up to one year or less.

Item level analysis

Predisposing Factors. For the 13 items regarding nurses' knowledge about folic acid guidelines, I computed frequencies for items with correct and incorrect responses. Ten of the 13 items had frequencies above 50% with incorrect responses. Some items with high scores of incorrect responses included: (a) some natural sources of folic acid, (b) degree to which folic acid can reduce the chances of women giving

birth to babies with NTDs, and (c) the amount of folic acid that women of childbearing age need. See table 1.3 for the frequencies of item responses.

I examined 12 items about nurses' beliefs regarding educating and counseling women about folic acid. Nine items had high mean scores above "4", reflecting agreement. One item had a low mean score below "3" reflecting disagreement: (a) women prefer to discuss folic acid with peers rather than with health care professionals. See Appendix 2 for item scores.

For seven items about nurses' beliefs regarding folic acid, in one of the two subscale, 3 of the 4 items about nurses' beliefs regarding need for folic acid, had high mean scores about "4" reflecting agreement. The following items about nurses' beliefs regarding need for folic acid had high mean scores about 4 reflecting agreement: (a) 'taking folic acid is not needed until pregnancy is confirmed" and (b)" women who take birth control pills do not need folic acid.' See Appendix 3 for item scores. In another subscale, 2 of the 3 items about nurses' beliefs regarding side effects of folic acid, had low mean scores below "3" reflecting disagreement. See Appendix 4 for item scores.

Reinforcing Factor. I examined 7 items about nurses' beliefs regarding nurses' normative practices about educating and counseling women about folic acid. Four items had high mean scores above "4", reflecting agreement. See Appendix 5 for item scores.

Enabling Factor. For 4 items about continuous education about folic acid, I computed frequencies of items with "Yes" and "No" responses. All items had high frequencies on "Yes", reflecting majority of nurses received continuing education about folic acid. See Appendix 6 for frequency of responses.

Environmental Factors. For 4 items about availability of folic acid resources, I computed frequencies on "Yes" and "No" responses. Three items had moderate to low frequencies of 50% and below on "Yes", reflecting majority of nurses did not have available folic acid resources. See Appendix 7 for frequencies.

For 2 items about access to folic acid resources, I computed frequencies on "Yes" and "No" responses. The 2 items had low frequencies on "Yes" response, below 50%, reflecting majority of nurses

did not have access to folic acid guidelines. See table Appendix 8 for frequencies of responses to access to folic acid guidelines.

Appendices 9, 10, 11, and 12 show associations between ordered categorical items using polychoric correlations. Appendices 13 and 14 show associations between categorical items that are dichotomous using tetrachoric correlation.

Aim 1, Assessment of Construct Validity

In assessing the least restrictive seven-factor congeneric model, I considered dropping a total of 10 items; 5 items had low loadings <0.30 (Swisher et al., 2004), 5 items had high modification indices above 30 and indicated some cross loadings (Fabriga et al., 1999; Tabachnick & Fidell, 2001). Before deleting the 10 items, I considered the conceptual contribution of each item to the content of the scale (Pett, Lackey, & Sullivan, 2003). Because the conceptual contribution of each item to the scale content was small or negligible, I deleted the 10 items. The congeneric model had a total of 26 items.

Table 1.4 (Model 1) shows the least restrictive seven- factor congeneric measurement model. I accepted the model because of the small x^2/df ratio, CFI >0.95 at 0.956, TLI of almost $\geq$ 0.95 at 0.949, RMSEA <0.70, and SRMR <0.80. The values indicated the model fit the data well. Table 1.5 shows the standardized loadings for the seven- factor congeneric model. All loadings were > 0.30 and significant at $p < 0.05$ level. Figure 3 shows the congeneric model.

Table 2.5 shows the results of the more restrictive measurement models. Results indicated although model 2 had some support for fit from the small $x^{2/}$df, RMSEA, and SRMR. Overall, model 2 did not fit the data well, with significant Difftest, CFI < 0.95, and TLI < 0.95. Comparing model 2 to model 1, I observed Model 2 had decreases in CFI and TLI, increases in x^2/df, RMSEA, SRMR, and a significant Difftest. Therefore, I rejected model 2.

Results of the partial-tau equivalent model (model 3) indicated that freeing 15 loadings in the seven- factor tau equivalent model resulted in a model that fit the data well. Comparing model 3 to model 2, I observed an increased CFI and TLI, RMSEA, SRMR, and a non-significant Difftest indicating

improvement in the fit. Therefore I accepted the partial-tau equivalent model as having a good fit for the data.

The most restrictive measurement model (Model 4), indicated a poorer fit for the data. This is because compared to model 3, model 4 had decreases in CFI and TLI, increases in x^2/df, RMSEA, SRMR, and a significant Difftest. Therefore, I rejected model 4.

Aim 2, Assessment of Internal Consistency Reliability

In this study, because the tau-equivalent assumptions were not met, Cronbach's alpha underestimated the internal consistency reliability of the proposed scales and subscales in comparison to McDonald's omega coefficient. See Table 1.6 for Cronbach's alpha and omega coefficient values for the proposed scales and subscales. Also, Table 1.6 shows the estimated decrease in Cronbach's alpha compared to McDonald's omega. Therefore I accepted McDonald's omega as a more realistic measure for internal consistency reliability than Cronbach's alpha.

All the 5 scales had acceptable to relatively high values of omega coefficient, ranging from 0.70 to 0.86. The 2 subscales about nurses' beliefs about need for folic acid and nurses' beliefs about side-effects of folic acid had low omega coefficient values of 0.54 and 0.58 respectively. Appendix 16 shows the final questionnaire (version 1.2).

Assessment of Factorial Invariance

Using the configural invariance approach, values of fit indices indicated the model fit the data well across the two subsamples of nurses. The factor loadings of items on seven factors were similar among nurses with different education. See 1.7 for the configural model results for the two subsamples of nurses. Using the weak invariance approach, similar standardized loadings of items on seven factors across the two subsamples indicated support for acceptance of the weak invariance model. Figure 4 shows the standardized loadings across the two subsamples of nurses.

Discussion

Addressing some gaps in the literature about NTDs, I have proposed that *predisposing, reinforcing, enabling, and environmental factors* of the PPM could be applied to describe potential influences on nurses' implementation of folic acid guidelines. I have developed new scales, subscales, and items about nurses' implementation of folic acid guidelines to reflect constructs within the *predisposing, reinforcing, enabling, and environmental factors* of the PPM. I have assessed the content validity of the items, scales, and subscales and evaluated the construct validity and internal consistency reliability of the scales and subscales. By doing so, I have contributed to knowledge that could be useful to guide future research in providing an in-depth understanding of *predisposing, reinforcing, enabling,* and *environmental* influences on nurses' implementation of folic acid guidelines in Uganda.

Building on limited, previous research (e.g., Williams et al., 2006), I have applied the PPM to generate new measures about nursing practice and FA. Williams et al. (2006) developed measures to evaluate health care worker's knowledge about folic acid in the USA, yet they did not: (a) assess reliability and validity of the measures, (b) apply a theory or conceptual model to guide item development or (c) address a breadth of related concepts (e.g., professional norms or external barriers to practice of recommending folic acid). Because I developed items based on a comprehensive model (PPM ;Green & Kreuter), I addressed additional relevant and concepts that Williams et al. (2006) did not .

Regarding phase 1, aim 1 and 2, findings provided support for the content validity of most items, scales, and subscales. Most items were rated as cultural appropriateness within the Ugandan health care context. One item with an important finding that scored low on cultural appropriateness.

Regarding phase 2, aim 1, findings provided support for construct validity of 5 scales and 2 subscales, based on the final seven-factor congeneric model and partial-tau, equivalent model. From these findings, one can conclude that the proposed scales and subscales were good measures of the constructs from the PPM, as proposed.

Regarding phase 2, aim 2, we observed acceptable to high internal consistency reliabilities for 5 scales, based on McDonald's omega coefficient. However, two subscales about nurses' beliefs (regarding

need for folic acid and side- effects of folic acid) had low internal consistency reliabilities. One possible reason for the low internal consistency reliabilities could be that these subscales had few items (Hinkin (1998).

Additional findings, with factorial invariance approaches, revealed that the proposed measures yielded stable findings across two subsamples of nurses based on education level. Because findings were stable across the two subsamples, one can conclude that the proposed measures do reflect the constructs from the PPM; *predisposing, reinforcing, enabling,* and *environmental factors* proposed to influence nurses' implementation of folic acid guidelines.

Findings from descriptive data on licensed nurses and clinical nursing students responses are informative. To clarify, in Uganda, both licensed nurses and clinical nursing students provide nursing care to patients or clients in health organization settings. Most licensed nurses and clinical nursing students did not have correct knowledge about folic acid guidelines. The majority , 64% of licensed nurses and clinical nursing students did not know some of the natural sources of folic acid. The majority, 55% of licensed nurses and clinical nursing students did not know that folic acid can reduce the chances of women giving birth to babies with NTDs by 50% to 70%. The majority, 63% of licensed nurses and clinical nursing students did not know the amount of folic acid women of childbearing age need daily.

Of note, results from the descriptive data suggested that there was limited availability of folic acid resources (e.g., decision tree for folic acid supplementation) within the licensed nurses and clinical nursing students' work place. Also results suggested that licensed nurses and clinical nursing students had limited access to folic acid guidelines within their work place. Such results highlight the importance of evaluating external factors (e.g., the environment; Green & Kreuter, 2005) as possible influences on behaviors.

Strengths

This study had some strengths. Regarding the sample, I minimized bias by recruiting licensed nurses and clinical nursing students with different levels of nursing education and from two different

districts in Uganda. By doing so, I enhanced representation of nurses in Uganda. The sample size of 302 participants was large enough for assessing the construct validity (Meyers, Gamst, & Guarino, 2006; MacCallum, 1996; Comrey and Lee, 1992) and internal consistency reliabilities of the questionnaire.

I designed the questionnaire to be culturally appropriate for the Ugandan health care context. For example, I asked experts to provide their ratings and descriptive comments about the suitability of item content to the Ugandan health care. Based on expert descriptive feedback, I revised some items to improve on cultural appropriateness. By doing so, I enhanced obtaining useful contextual information from the licensed nurses and clinical nursing students.

By design, I maximized obtaining sufficient numbers of trustworthy responses. I set up items through the *Qualtrics* app such that once a participant chose a response and proceeded to the next item, they did have an option to go back to the previous item to review or change their responses. I did not have missing data because I set up items such that a participant had to respond to an item before proceeding to the next one.

Limitations

I acknowledge some limitations to this study. Scholars suggest that a scale or subscale could at least have 3 items (Marsh, Hau, Balla, & Grayson, 1998). However, one subscale about nurses' beliefs about side effects of folic has two items. Another scale about access to folic guidelines has two items. However, found support for construct validity.

Because the sample was a convenience sample, it is possible that some degree of sample bias was introduced. However, I had approximate numbers of licensed nurses in each category of nursing within the recruitment sites. Also, in each recruitment site, I had approximate numbers of clinical nursing students and their levels of education. Based on this information, I calculated the number of participants we would need to recruit from each category.

Because the responses were dependent on participant self-report, it is possible that to some degree, some responses may not have been accurately answered. For example, participants could have

responded to items about availability of folic acid resources by recall. However, in the instructions, I had requested participants to be as truthful as possible.

Implications

The revised questionnaire (version 1.2) is helpful to future researchers. Nurse researchers could administer the new questionnaire among nurses in additional settings in Uganda to describe relationships between influences on nursing practices and nurses' reported practices of educating and counseling women of childbearing age, based on PPM factors. Specifically, researchers could apply phases 2 and 3 of the PPM to examine relationships between: (a) predisposing factors (nurses' knowledge about folic acid guidelines, nurses' beliefs about educating and counseling women about folic acid, and nurses' beliefs about folic acid), (b) reinforcing factor (nurses' normative practices), (c) enabling factors (continuing education about folic acid), and (d) environmental factors (availability of folic acid resources, access to folic acid guidelines), and nurses' behavior (nurses' reported practices educating & counseling women about folic acid).

Based on findings from proposed subsequent studies above, researchers could apply phases 4 to 8 of the PPM to design, implement and evaluate educational interventions to improve nurses' implementation of folic acid guidelines. For example researchers could collaborate with nurse educators to improve nursing curriculum regarding nurses' knowledge about folic acid. Also, based on descriptive findings from this current study, researchers could collaborate with nurse leaders to design, implement and evaluate educational interventions to address nurses' knowledge about folic acid guidelines.

Based on findings from subsequent studies, researchers could apply phases 4 to 8 of the PPM to design, implement and evaluate systems interventions to improve nurses' implementation of folic acid guidelines in Uganda. For example, researchers could design interventions to address environmental factors influencing behavior within the health organizational settings. Also, based on the descriptive findings from this current study, researchers could collaborate with nurse leaders and other clinicians

within the settings to design systems interventions that could improve availability and access of folic acid resources and guidelines within the health organization settings.

Based on findings from subsequent studies, researchers could apply phases 4 to 8 of the PPM to revise organizational policies to improve nurses' implementation of folic acid guidelines. For example researchers could collaborate with nurse leaders and policy makers to decide what policy changes would be most feasible and helpful to improve implementation of folic acid guidelines within health organizational settings in Uganda.

This study provides one example of instrument development. Researchers could follow the methods described in this study to develop measures. Researchers could conduct more research to improve on the internal consistency reliabilities of the subscales regarding nurses' beliefs about need for folic acid and side effects of folic acid. For example researchers could develop more items to add to the two subscales and then evaluate the internal consistency reliability.

Conclusions

To my knowledge, this is the first study to develop a questionnaire of proposed influences on nurses' implementation of folic acid guidelines in Uganda (a) that is guided by the PPM, (b) that is culturally appropriate, and (c) whose content validity, construct validity and internal consistency reliability have been assessed. Applying the PPM to guide item development and evaluation was innovative. With content expert ratings, I have documented acceptable to high content validity of the questionnaire. The questionnaire has good construct validity. The five proposed subscales had acceptable to high internal consistency reliability. With some revisions, researchers can improve on the internal consistency reliability of the two proposed subscales about nurses' beliefs (re: need for folic acid and side effects of folic acid).

We now have a questionnaire that could be useful to researchers in providing an in-depth understanding of *predisposing, reinforcing, enabling,* and *environmental* influences on nurses' implementation of folic acid guidelines in Uganda. Researchers could apply phases 4 to 8 of the PPM in

future studies to design, implement and evaluate educational and systems interventions and improve policies to address influences on nurses' implementation of folic acid guidelines in Uganda. If researchers, clinicians, and policy makers collaborate to address or support such influences, then they could support nurses' implementation of folic acid guidelines in Uganda. If nurses can support women in taking folic acid, then women's risks of having babies with NTDs could decrease.

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Appendix 1

Description of Alternative Restrictive Models

Model	Description
Tau-equivalent Model	Is more restrictive compared to the congeneric and partial- tau equivalent models. By constraining each item to one factor, the model assumes that each item measures the same latent variable, on the same scale, with the same degree of precision, but with possibly different amounts of error (Raykov, 1997
Partial tau –equivalent Model	Allows for some loadings to be freely estimated after removing equality constraints on some items that have high modification indices (Byrne, Shavelson, & Muthen, 1989).
Parallel Model	Is the most restrictive measurement model assumes that each individual item measures the same latent variable, on the same scale with the same degree of precision, and same amount of error (Arbuckle, 2003; Raykov, 1997).

Table 1.0.
Measures Reflecting Predisposing, Reinforcing, Enabling, and Environmental Factors Proposed to Influence Nurses' Implementation of Folic Acid Guidelines

PPM Factors	Definition of Factors	Measures	Item Response Options	Number of Items (n)[a]
Predisposing Factors	Antecedents to behavior	Nurses' knowledge about folic acid	Multiple choice	13
		Nurses' beliefs regarding educating & counseling women about folic acid*	Response options 1 to 5 1-Strongly disagree 2-Disagree 3-Neither Agree nor Disagree 4-Agree 5-Strongly Agree	13
		Nurses' beliefs about folic acid* (1) Need for folic acid[+] (2) Side effects of folic acid[+]	Response options 1 to 5 1-Strongly disagree 2-Disagree 3-Neither Agree nor Disagree 4-Agree 5-Strongly Agree	 4 3
Reinforcing Factors	Factors that provide feedback or reward for a behavior	Nurses' normative practices regarding educating and counseling women about folic acid*	Response options 1 to 5 1-Strongly disagree 2-Disagree 3-Neither Agree nor Disagree 4-Agree 5- Strongly Agree	10
Enabling Factors	Antecedents that facilitate performance of a behavior	Continuing education about folic acid*	Response options Yes No I don't Know	4
Environmental Factors	Components of social, economic, and physical environment that contribute to behavior	Availability of folic acid resources* Access to folic acid resources*	Responses options Yes No	4 2

Note. *Scales; [+]Subscales; [a]Questionnaire version 1.0

Table 1.1

Content Validity Indices for Items and Scales Reflecting Predisposing, Reinforcing, Enabling, and Environmental Factors Proposed to Influence Nurses' Implementation of Folic Acid Guidelines

	I-CVIs	I-CVIs	I-CVIs	I-CVIs	S-CVIs
Items (n)	C	R	Cu	Co	
Nurses' knowledge about folic acid guidelines (n=13)	0.71-1.00	0.86-1.00	0.71-1.00	1.00	+
Nurses' beliefs about counseling and educating women about folic acid* (n=13)	0.71-1.00	0.57-1.00	0.57-1.00	1.00	0.91
Beliefs about folic acid*					
Nurses' beliefs about need for folic acid+ **(**n=4)	0.71-1.00	0.86-1.00	0.71-1.00	1.00	0.90
Nurses' beliefs about side effects of folic acid+ (n=3)	1.00-1.00	0.86-1.00	0.86-1.00	1.00	0.95
Nurses normative practices*(n=7)	0.71-1.00	0.57-1.00	0.57-1.00	1.00	0.90
Items about continuing education about folic acid* (n=4)	0.86-1.00	0.86-1.00	0.86-1.00	1.00	0.93
Items about Availability of folic acid resources* (n=4)	0.71-1.00	0.71-1.00	0.71-1.00	1.00	0.89
Items about access to folic acid resources* (n=2)	0.71-.86	0.86-0.86	0.86-0.86	1.00	0.86

Note. n= number of items; I-CVIs= Content validity indices by item; S-CVIs= Content Validity Indices by scale;
C= Clarity; R= Relevance; Cu= Cultural Appropriateness; Co= Comprehensiveness
*Scales; [a]Subscales; [b]Questionnaire version 1.0; +Fo**r** Items that did not constitute a scale, we did not compute S-CVIs

Table 1.2
Sample Characteristics

Characteristic	Frequency	Percent
Level of Highest Nursing Preparation		
Registered BSN	31	14.49
Registered Nurse[a]	86	40.19
Enrolled Nurse[b]	42	19.63
Certificate Nurse[c]	36	16.82
Other	19	8.88
Total	214	100.00
Years Working as Licensed Nurse		
30 Years or More	5	2.34
20-29 Years	17	7.94
10-19 Years	38	17.76
5-9 Years	33	15.42
2-4 Years	81	37.85
1 Year or Less	38	17.76
Unknown	2	0.93
Total	214	100.00
Year of Study among Clinical Nursing Students		
Year 5 (Internship)	9	5.23
Year 4	23	13.37
Year 3	47	27.33
Year 2	61	35.47
Year 1	31	18.02
Unknown	1	0.58
Total	172	100.00
Type of Clinic Worked in for Past 6 months		
Antenatal	93	30.79
Obstetric and Gynaecology	56	18.54
Pediatrics	12	3.97
Medical & Surgical	68	22.52
Intensive Care	5	1.66
Outpatient	48	15.89
Psychiatry	9	2.98

Other	11	3.64
Total	302	100.00
Years Working with Women of Childbearing Age		
30 Years or More	4	1.32
20-29 Years	5	1.66
10-19 Years	30	9.93
5-9 Years	33	10.93
2-4 Years	102	33.77
1 Year or Less	128	42.38
Total	302	100.00

BSN= Bachelor of Science in Nursing
[a]Similar to Registered Nurse without college Degree in US
[b]Similar to Licensed Practical Nurse in US
[c]Similar to Certified Nursing Assistant in US

Table 1.3

Frequencies of Item Responses about Nurses' Knowledge Regarding Folic Acid Guidelines

Item	Items with Correct Responses (%)	Items with Incorrect Responses (%)*
1. FA benefits	18.87	81.13
2. Recommended FA dose for WCA	37.42	62.58
3. When is FA helpful during pregnancy	51.99	48.01
4. FA in food	46.36	53.64
5. Conditions that FA can prevent	14.24	85.76
6. Natural sources of FA	36.09	63.91
7. Conditions that increase risk for NTDs	35.76	64.24
8. FA dose in high risk women	37.09	62.91
9. Best time for women to take FA	58.61	41.39
10. FA and reduction of NTD risk	28.81	71.19
11. Amount of FA absorbed in food	44.70	55.30
12. Sources of man-made FA	56.62	43.38
13. FA and sexually active women	78.15	21.8
Total	41.90	58.10

* Includes Items with "No" and "I don't know" response option

FA=Folic acid; NTDs= Neural tube defects; WCA= Women of childbearing Age

Appendix 2

Distribution of Item Responses about Nurses' Beliefs Regarding Educating and Counseling Women about Folic Acid

	Items	Mean	SD	1 SoD	2 D	3 NAD	4 A	5 SoA
	Nurses' beliefs regarding educating and counseling women about folic acid							
14	Discussing with women about folic acid is best done in groups rather than one on one	3.77	1.35	10.26	13.36	2.65	36.09	37.42
15	One role of midwives is to discuss folic acid with women	4.44	0.98	4.64	2.32	0.33	30.13	62.58
16	Women prefer to discuss folic acid with peers rather than with health care professionals	2.23	1.23	33.44	37.08	8.28	15.23	5.96
17	In antenatal clinics, nurses' roles include discussing folic acid with women and their partners	4.39	0.90	2.98	2.32	3.31	35.43	55.96
18	One role of doctors is to discuss folic acid with women patients during clinic visits	3.43	1.20	4.97	11.92	6.29	44.37	32.45
19	In family planning clinics, nurses have a role to discuss folic acid with women	3.82	1.31	8.61	14.24	1.99	36.42	38.74
20	Discussing folic acid with women of childbearing age is good nursing care	4.45	0.88	2.32	3.31	2.65	30.70	60.93
21	Written information about folic acid is one good way to educate women about folic acid	3.75	1.25	6.95	15.89	3.97	41.06	32.12
22	Nurses in high school settings have a role to discuss folic acid with students	3.76	1.21	6.29	15.23	4.64	43.74	30.13
23	One good way for women to learn about folic acid is through social media such as Facebook and WhatsApp	2.95	1.36	18.87	25.50	10.60	31.79	13.25
24	Sharing facts verbally about folic acid is one good way to educate women about folic acid	4.46	0.73	0.66	2.98	0.99	40.40	54.97
25	Including women's spouses in discussions about folic acid is important in helping women to take folic acid	4.61	0.65	0.33	1.32	2.98	28.15	67.22

Note. SD= Standard Deviation; SoD = Strongly Disagree; D = Disagree; NAD = Neither Agree nor Disagree; A = Agree; SoA = Strongly Agree

Appendix 3

Distribution of Item Responses about Nurses' Beliefs Regarding Need for Folic Acid

	Items	Mean	SD	1 SoD	2 D	3 NAD	4 A	5 SoA
	Nurses' beliefs regarding need for folic acid							
26	Women who have a balanced diet don't need to take folic acid supplements	3.99	1.05	3.64	10.26	2.65	49.67	33.77
27	Taking folic acid is not needed until pregnancy is confirmed	3.84	1.29	8.28	13.58	1.99	30.08	38.08
28	The amount of folic acid that women need is the same for all women of childbearing age	2.85	1.33	14.57	39.74	5.30	27.15	13.25
29	Women who use birth control pills do not need folic acid supplements	3.72	1.26	7.95	13.58	8.28	38.74	31.46

Note. SD= Standard Deviation; SoD = Strongly Disagree; D = Disagree; NAD = Neither Agree nor Disagree; A = Agree; SoA = Strongly Agree

Appendix 4

Distribution of Item Responses about Nurses' Beliefs Regarding Side Effects of Folic Acid

	Items	Mean	SD	1 SoD	2 D	3 NAD	4 A	5 SoA
	Nurses' beliefs regarding side effects of folic acid							
30	Folic acid can lead to increased weight gain in women	2.40	1.29	31.13	32.12	8.28	22.85	5.63
31	The folic acid that is available in natural foods is safer for women's bodies than man-made folic acid	3.41	1.29	9.27	21.52	9.27	39.07	20.86
32.	During pregnancy, folic acid can have serious side effects to the unborn baby	1.62	0.95	59.27	29.14	3.97	5.30	2.32

Note. SD= Standard Deviation; SoD = Strongly Disagree; D = Disagree; NAD = Neither Agree nor Disagree; A = Agree; SoA = Strongly Agree

Appendix 5

Distribution of Item Responses about Nurses' Normative Practices Regarding Educating and Counseling Women about Folic Acid

	Items	Mean	SD	1 SoD	2 D	3 NAD	4 A	5 SoA
	Nurses' normative practices regarding educating and counseling women about folic acid							
33.	In my clinic, nurses usually talk to pregnant women about folic acid	3.64	1.18	3.64	7.62	49.34	0.00	39.40
34.	In my clinic, nurses usually talk to women with anemia about folic acid	4.08	1.05	3.97	8.28	2.98	45.03	39.74
35.	In my clinic, nurses only talk to women about folic acid if the doctor orders them to do so	2.18	1.23	32.78	44.04	2.98	12.58	7.62
36.	In my clinic, nurses usually talk to women about eating foods rich in folic acid	4.26	0.81	0.99	4.64	2.98	50.00	41.39
37.	My supervisor expects nurses to talk to pregnant women about folic acid supplements	3.89	1.17	2.98	4.64	43.05	0.00	49.43
38.	My supervisor does not expect nurses to talk to all women of childbearing age about folic acid supplements	4.17	1.06	3.31	8.94	2.65	38.41	46.69
39.	My supervisor expects nurses to discuss with women about foods rich in folate	4.29	0.71	0.99	1.66	3.97	53.97	39.40

Note. SD= Standard Deviation; SoD = Strongly Disagree; D = Disagree; NAD = Neither Agree nor Disagree; A = Agree; SoA = Strongly Agree

Appendix 6

Frequencies of Item Responses Regarding Continuing Education about Folic Acid

		Frequency of Responses (%)	
	Items	**0 No**	**1 Yes**
	Continuous education about folic acid		
40.	In the past year, I have received education on the dose of folic acid recommended for most women of childbearing age	47.68	52.32
41.	In the past year, I have received education on the benefits of taking folic acid to women	15.23	84.77
42.	In the past year, I have received education on the age when women should take folic acid	32.78	67.22
43.	In the past year, I have received education on how to educate and counsel women about folic acid	27.15	72.85

Appendix 7

Distribution of Item Responses about Availability of Folic Acid Resources

		Frequency of Responses (%)	
	Items	**0 No**	**1 Yes**
	Availability of folic acid resources		
44.	In my work place, a copy of the folic acid guidelines is available	50.33	49.67
45.	In my work place, a copy of a decision tree for folic acid supplementation for patients is available	66.56	33.44
46.	In my work place, posters about folic acid and neural tube defects are available	47.35	52.65
47.	In my work place, teaching aids about folic	49.67	50.33

	acid and neural tube defects are available

Appendix 8

Distribution of Item Responses about Access to Folic Acid Guidelines

		Frequency of Responses (%)	
	Items	**0 No**	**1 Yes**
	Access to folic acid guidelines		
48.	In my work place, a copy of folic acid guidelines for prevention of neural tube defects is easy to locate	55.96	44.04
49.	In my work place, a copy of the decision tree for folic acid supplementation for patients is easy to locate patients is available	66.56	33.44

Appendix 9

Polychoric Correlation Matrix for Proposed Items about Nurses' Beliefs Regarding Educating and Counseling Women about Folic Acid

Item	14	15	16	17	18	19	20	21	22	23	24	25
14	1											
15	0.149	1										
16	0.046	0.024	1									
17	0.084	0.340	0.019	1								
18	0.129	0.350	0.037	0.344	1							
19	0.089	0.209	-0.002	0.197	0.322	1						
20	0.170	0.349	-0.028	0.395	0.330	0.163	1					
21	-0.029	0.106	0.056	0.043	0.196	0.102	0.105	1				
22	0.161	0.112	0.021	0.171	0.305	0.339	0.269	0.147	1			
23	0.049	0.078	0.087	0.024	0.257	0.132	0.167	0.245	0.109	1		
24	0.099	0.187	-0.139	0.171	0.086	0.133	0.193	-0.072	0.082	0.042	1	
25	0.041	0.325	-0.138	0.359	0.240	0.095	0.339	0.038	0.252	0.266	0.417	1

Appendix 10

Polychoric Correlation Matrix for Proposed Items about Nurses' Beliefs Regarding Need for Folic Acid

Item	26	27	28	29
26	1			
27	0.351	1		
28	-0.106	-0.124	1	
29	0.193	0.303	-0.003	1

Appendix 11

Polychoric Correlation Matrix for Proposed Items about Nurses' Beliefs Regarding Side Effects of Folic Acid

Item	30	31	32
30	1		
31	0.400	1	
32	-0.106	0.375	1

Appendix 12

Polychoric Correlation Matrix for Proposed Items about Nurses' Normative Practices Regarding Educating and Counseling Women about Folic Acid

Item	33	34	35	36	37	38	39
33	1						
34	0.530	1					
35	-0.383	-0.140	1				
36	0.482	0.373	-0.236	1			
37	0.359	0.340	-0.145	0.435	1		
38	0.221	0.252	-0.331	0.232	0.297	1	
39	0.129	0.209	-0.158	0.290	0.270	0.286	1

Appendix 13

Tetrachoric Correlation Matrix for Proposed Items about Continuing Education on Folic Acid

Item	40	41	42	43
40	1			
41	0.793	1		
42	0.398	0.659	1	
43	0.577	0.763	0.568	1

Appendix 14

Tetrachoric Correlation Matrix for Items about Folic Acid Resources

Item	44	45	46	47
44	1			
45	0.727	1		
46	0.462	0.465	1	
47	0.576	0.447	0.712	1

Table 1.4

Goodness of Fit Values for Four Measurement Models of 7 Scales Regarding Proposed Influences on Nurses' Implementation of Folic Acid Guidelines

Model	Phase	x^2 (df)	p-value	x^2/df	RMSEA	SRMR	CFI	TLI	x^2 diff (df)	p-value	Decision
Model 1: 7 Factor Congeneric Model	1	366.602 (278)	0.0003	1.32	0.032	0.064	0.956	0.949	—	—	Accept
Model 2: 7 Factor tau-equivalent Model	2	400.159 (290)	0.0000	1.38	0.035	0.069	0.946	0.939	34.042 (12)	0.0007	Reject
Model 3: 7 Factor Partial tau-equivalent Model (freed F1, F3, F4 items)	3	370.529 (281)	0.0003	1.32	0.032	0.065	0.956	0.949	4.619 (3)	0.2019	Accept
Model 4: 7 Factor Parallel Model based on Partial tau-equivalent	4	380.747 (284)	0.0001	1.34	0.034	0.067	0.952	0.945	9.843 (3)	0.0200	Reject

x^2= Chi-Square; df= degrees of freedom; x^2/df= Normed Chi-Square; RMSEA= Root mean square of approximation; CFI=Comparative fit index; TLI= Tucker Lewis index; Standardized Root Mean Square Residual

Table 1.5

Standardized Loadings for the 7 Factor Congeneric Model of the Scales and Subscales of Proposed Influences on Nurses' Implementation of Folic Acid Guidelines

Item	Factor 1	Factor 2a	Factor 2b	Factor 3	Factor 4	Factor 5	Factor 6
15	0.516						
17	0.558						
18	0.616						
19	0.437						
20	0.587						
22	0.482						
24	0.325						
26		0.483					
27		0.657					
29		0.483					
30			0.707				
31			0.566				
33				0.782			
34				0.591			
36				0.695			
37				0.538			
40					0.661		
41					0.893		
42					0.679		
43					0.941		
44						0.789	
45						0.796	
46						0.717	
47						0.802	
48							0.859
49							0.865

F1= Nurses' beliefs regarding educating and counseling women about folic acid
F2a=Nurses beliefs regarding need for folic acid
F2b=Nurses' beliefs regarding side effects of folic acid
F3=Nurses' normative practices regarding educating and counseling women about folic acid
F4= Continuing education about folic acid
F5= Availability of folic acid resources
F6=Availability of folic acid guidelines

Table 1.6
Internal Consistency Reliabilities of Scales (N=26)

	F1	F2a	F 2b	F3	F4	F5	F6
Cronbach's alpha	0.578	0.465	0.513	0.648	0.707	0.708	0.681
Omega coefficient	0.698	0.544	0.581	0.734	0.862	0.863	0.850
Percent attenuation	-17.2%	-14.5%	-11.7%	-11.7%	-17.9%	-17.9%	-19.8%
Number of items	7	3	2	4	4	4	2

F1= Nurses' beliefs regarding educating and counseling women about folic acid
F2a=Nurses beliefs regarding need for folic acid
F2b=Nurses' beliefs regarding side effects of folic acid
F3=Nurses' normative practices regarding educating and counseling women about folic acid
F4= Continuing education about folic acid
F5= Availability of folic acid resources
F6=Availability of folic acid guidelines

Table 1.7

Goodness of Fit Values for Configural Model of the 7 Scales Regarding Influences on Nurses' Implementation of Folic Acid Guidelines

Model	Phase	x^2 (df)	p-value	x^2/df	RMSEA	SRMR	CFI	TLI	x^2 diff (df)	p-value	Decision
Model for Group 0: 7 Factor Configural Invariance	1	305.422 (279)	0.1328	1.09	0.030	0.096	0.945	0.936	__	___	Accept
Model for Group 1: 7 Factor Configural Invariance	1	353.105 (278)	0.0015	1.27	0.046	0.101	0.915	0.901	__	___	Accept

Group 1= Nurses with lower level of nursing education; Group 2= Nurses with higher level of nursing education
x^2= Chi-Square; df= degrees of freedom; x^2/df= Normed Chi-Square; RMSEA= Root mean square of approximation; CFI=Comparative fit index; TLI= Tucker Lewis index; Standardized Root Mean Square Residual

Appendix 15. *Final Questionnaire Version 1.2*

Predisposing Factors

The following questions are about what you understand about folic acid. Please select the answer that matches what you think is most true. We value your honest answers*

1. For women, the health benefits of taking folic acid include:
    a. Folic acid reduces the chance of having anemia
    b. Folic acid promotes healthy skin and nails
    c. Folic acid promotes healthy hair
    d. All the above

2. Women in their reproductive years need
    a. 120 mg of folic acid daily
    b. 400 mg of folic acid daily
    c. 0.4 mg of folic acid daily
    d. I don't know

3. Folic acid plays a key role in the growth of the baby's brain and spine
    a. During the 1st month of pregnancy
    b. During the 3rd month of pregnancy
    c. During the 6th month of pregnancy
    d. I don't know

4. Women can easily get enough folic acid from the food they eat daily
    a. True
    b. False
    c. I don't know

5. Taking the right amount of folic acid at the right time can reduce women's chance of having babies with
    a. Anencephaly
    b. Spina bifida
    c. Low birth weight
    d. All the above

e. A and B

6. Which of the following are natural sources of folic acid?
   a. Citrus fruits such as oranges
   b. Legumes such as beans
   c. A + B
   d. I don't know

7. Conditions that increase women's chances of having babies with brain or spine abnormalities include
   a. Diabetes
   b. Obesity
   c. History of neural tube defects
   d. All the above
   e. I don't know

8. Women who are at higher risk of having babies with neural tube defects need
   a. 120mg of folic acid daily
   b. 0.4mg of folic acid daily
   c. 4 mg of folic acid daily
   d. I don't know

9. The best time for women to get good amounts of folic acid to prevent having babies with abnormalities of the brain, spine or spinal cord would be:
   a. When women learn that they are pregnant
   b. After women attend their first antenatal visit
   c. Before and during the first few months of pregnancy
   d. I don't know

10. Folic acid can reduce women's chance of having babies with spine or brain abnormalities by
   a. 10%-29%
   b. 30%-49%
   c. 50%-70%
   d. 80%-99%
   e. I don't know

11. How much of the folic acid in our foods can be absorbed?
    a. 100%
    b. 50%
    c. 75%
    d. I don't know

12. Man-made folic acid can be found in
    a. An Iron-folic tablet
    b. A single folic acid tablet
    c. A multivitamin tablet
    d. All the above A + B + C

13. Which statement about sexually active women is true?
    a. Women of childbearing age who can get pregnant need folic acid
    b. Women who use contraceptives do not need folic acid
    c. Women who do not plan to get pregnant do not need folic acid
    d. I don't know

***Correct answers are in bold**

The following statements refer to your opinions about educating and counseling women about folic acid. We use the term "discuss" in items below to mean "educating and counseling" and to be concise.
Mark how much you agree or disagree with each statement using the words below. We value your honest answers.

14. One role of midwives is to discuss folic acid with women

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

15. In antenatal clinics, nurses' roles include discussing folic acid with women and their partners

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

16. One role of doctors is to discuss folic acid with women patients during clinic visits

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

17. In family planning clinics, nurses have a role to discuss folic acid with women

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

18. Discussing folic acid with women of childbearing age is good nursing care

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

19. Nurses in high school settings have a role to discuss folic acid with students

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

20. Sharing facts verbally about folic acid is one good way to educate women about folic acid

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

The following statements are about your opinions about folic acid. Please mark how much you agree or disagree with each statement using the words given.

21. Women who have a balanced diet don't need to take folic acid supplements

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

22. Taking folic acid is not needed until pregnancy is confirmed

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

23. Women who use birth control pills do not need folic acid supplements

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

24. Folic acid can lead to increased weight gain in women

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

25. The folic acid that is available in natural foods is safer for women's bodies than man-made folic acid

Strongly Disagree	Disagree	Neither Agree or Disagree	Agree	Strongly Agree

Reinforcing Factor

The following statements address the usual practices in your work setting.
Mark how much you agree or disagree with each statement using the words given. Please respond honestly about your current practice

26. In my clinic, nurses usually talk to pregnant women about folic acid

Strongly Disagree	Disagree	Neither Agree nor	Agree	Strongly Agree

		Disagree		

27. In my clinic, nurses usually talk to women with anemia about folic acid

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

28. In my clinic, nurses usually talk to women about eating foods rich in folic acid

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

29. My supervisor expects nurses to talk to pregnant women about folic acid supplements

Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

Enabling Factor

The following statements are about continuous education. Think back over the past year about any classes, education, or training you have received. Then indicate whether '*Yes*' or '*No*' you have received information or training on the following.

30. In the past year, I have received education on the dose of folic acid recommended for most women of childbearing age

Yes	No

31. In the past year, I have received education on the benefits of taking folic acid to women

Yes	No

32. In the past year, I have received education on the age when women should take folic acid

Yes	No

33. In the past year, I have received education on how to educate and counsel women about folic acid

Yes	No

Environmental Factors

The following items are about whether or not folic acid resources for maternal-child health are available in your work place.
For each item, mark 'Yes' if these resources are available;
or 'No' if they are not available,
or 'I don't Know'

34. In my work place, a copy of the folic acid guidelines is available

Yes, available	No, not available	I don't know

35. In my work place, a copy of a decision tree for folic acid supplementation for patients is available

Yes, available	No, not available	I don't know

36. In my work place, posters about folic acid and neural tube defects are available

Yes, available	No, not available	I don't know

37. In my work place, teaching aids about folic acid and neural tube defects are available

Yes, available	No, not available	I don't know

The following items are about how easy or difficult it is to locate folic acid resources in your work place. Think about your work place and indicate 'Yes', if easy to locate folic acid resources or 'No', if not easy to locate folic acid resources or 'I don't Know'

38. In my work place, a copy of folic acid guidelines for prevention of neural tube defects is easy to locate

Yes	No	I don't know

39. In my work place, a copy of the decision tree for folic acid supplementation for patients is easy to locate

Yes	No	I don't know

Note. Deleted Items in are not included

Figure 1

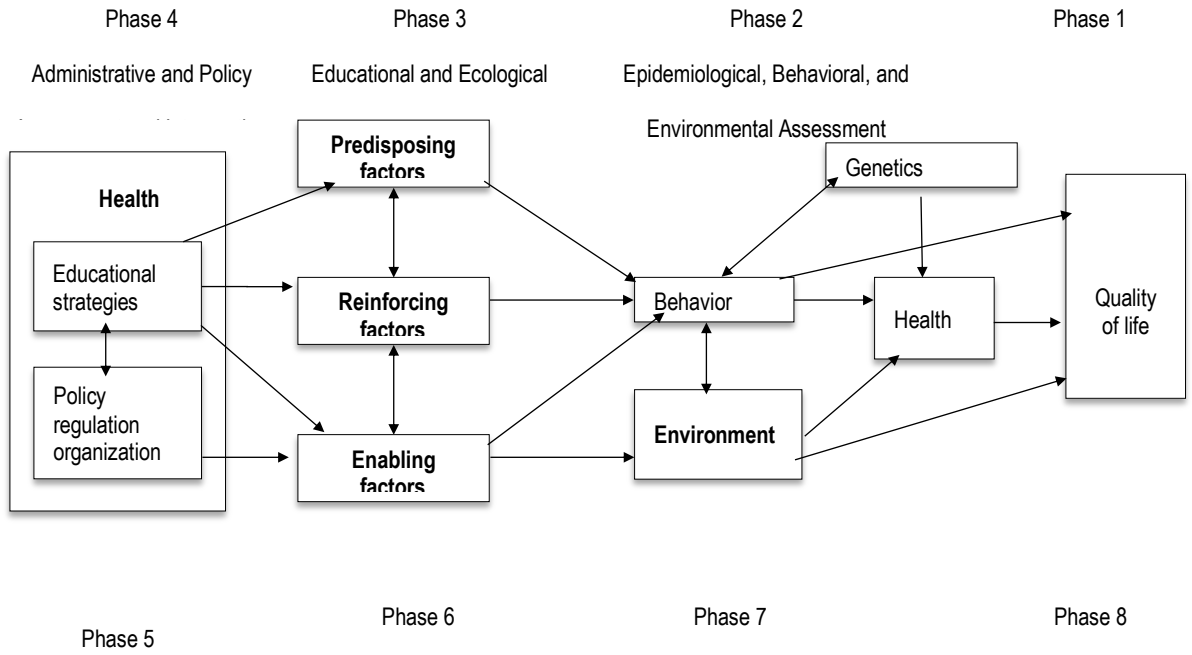


Figure 1. PRECEDE-PROCEED Model. Factors addressed in this study are in bold.

Source: Green & Kreuter (2005). Adapted and with permission from Green & Keuter (2017).

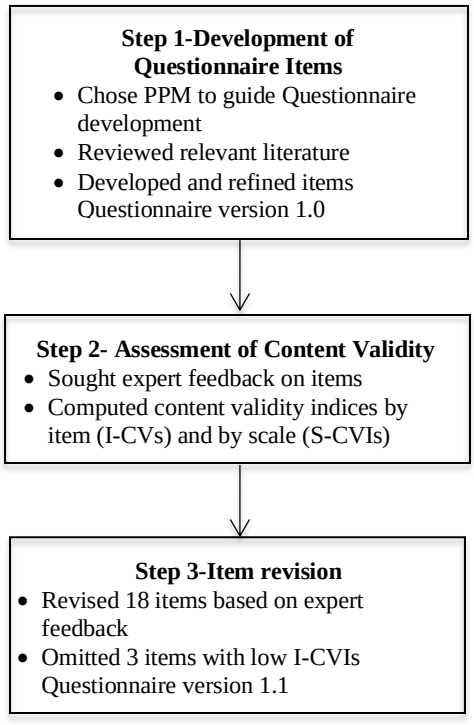


Figure 2. Phase 1-Study steps

Figure 3. Congeneric Model

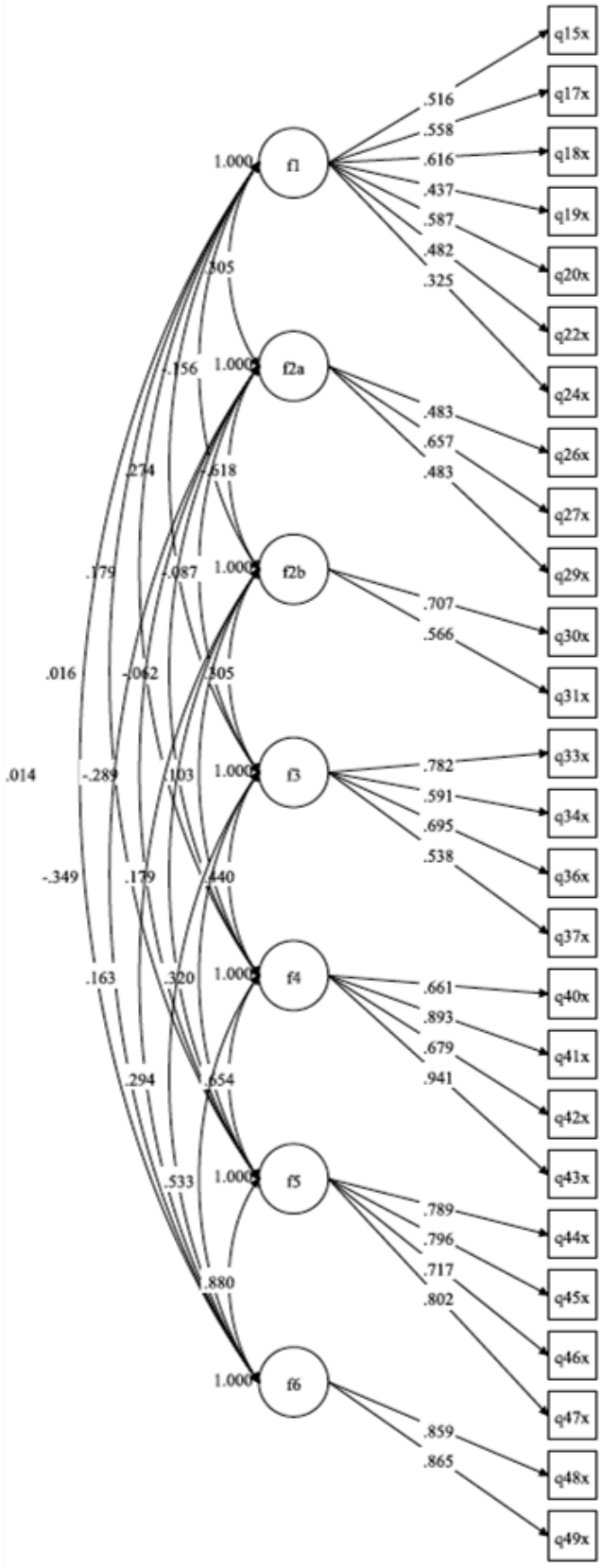
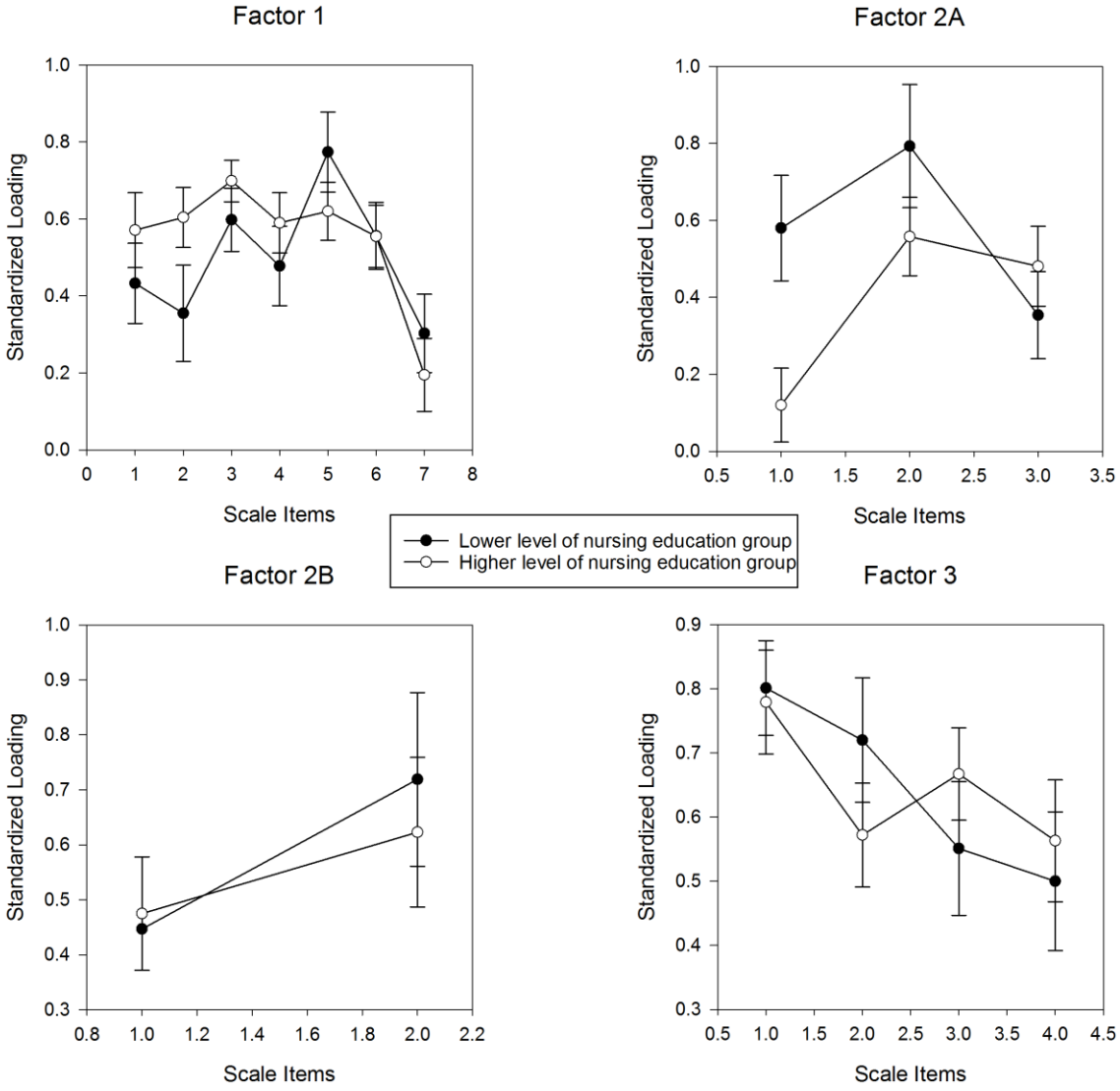
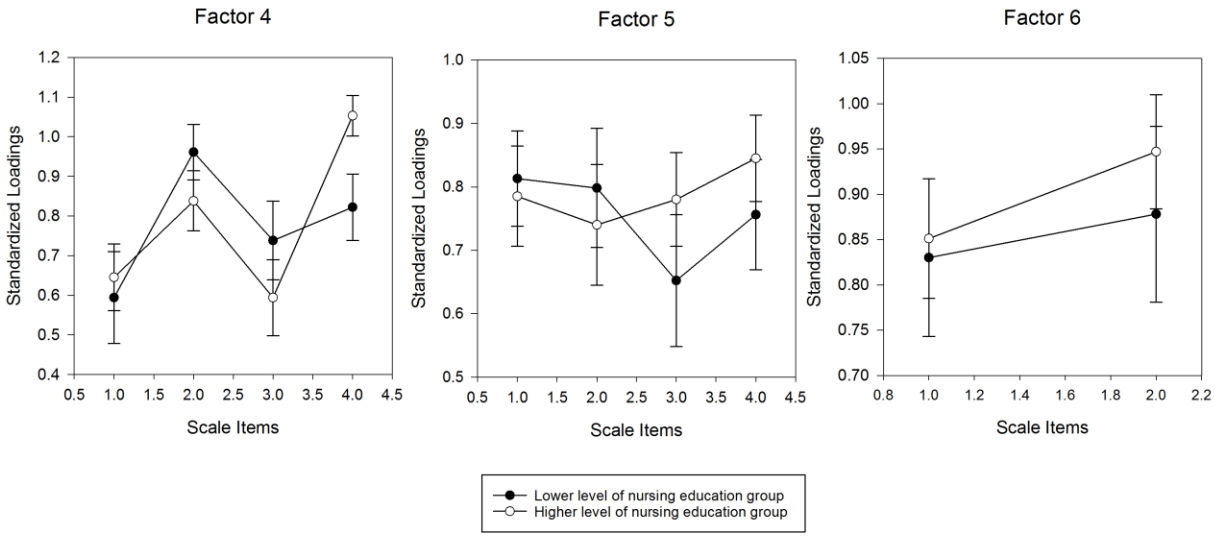


Figure 4. Comparison of Standardized Loadings for Nurses with Higher Levels of Nursing Education and Nurses with Lower Levels of Nursing Education



Factor 1= Nurses' beliefs regarding educating and counseling women about folic acid
Factor 2A=Nurses beliefs regarding need for folic acid
Factor 2B=Nurses' beliefs regarding side effects of folic acid
Factor 3=Nurses' normative practices regarding educating and counseling women about folic acid



Factor 4= Continuous education about folic acid
Factor 5= Availability of folic acid resources
Factor 6=Availability of folic acid guidelines

Chapter 5: Discussion

In this chapter, I summarize key findings of this dissertation. In chapter 2, I demonstrated the relevance of the PRECEDE-PROCEED Model (PPM) to scholarly work about individuals with neural tube defects (NTDs) and their families. In chapter 3, I report on a systematic review to describe and evaluate interventions designed to promote intake of folic acid supplements among women of childbearing age worldwide. In chapter 4, I report on how I developed and evaluated a questionnaire about proposed influences on nurses' implementation of folic acid guidelines. In this chapter, I discuss implications for nursing practice, nursing education, health policy and nursing research regarding (a) promoting health of individuals with NTDs and their families, (b) promoting intake of folic acid among women of childbearing age, and (c) promoting nurses' implementation of folic acid guidelines.

Summary

In chapter 2, I had proposed that the PPM (Green & Kreuter, 2005) is logically consistent, comprehensive and explicit for guiding scholarly work about individuals with NTDs and their families. After providing a brief overview of the PPM, I innovatively applied the PPM to organize the literature about individuals living with NTDs and their families. Through examples, I demonstrated how researchers and clinicians in practice have identified variables in their work that aligned well with the PPM factors and constructs within these factors. Prior to this paper, no known scholar had applied the PPM to scholarship regarding individuals with NTDs and their families.

In chapter 3, I build on the work in chapter 2, by focusing on interventions promoting folic acid intake among women of childbearing age. Therefore in chapter 3, I conducted a systematic review to: (a) evaluate characteristics and components of interventions that were designed to promote intake of folic acid supplements among women of childbearing age, (b) describe methodological challenges that researchers faced in implementing these interventions, and (c) describe barriers to taking folic acid among women of childbearing age. Prior to conducting this systematic review, Chivu, Tulchinsky, Soares-

Weiser, Braunstein & Brezis (2008) had conducted a systematic review of interventions that aimed at promoting intake of folic supplements among women of childbearing age. The authors did not document whether they considered interventions conducted worldwide. The researchers focused mainly on whether or not interventions had increased women's awareness, knowledge, and intake of folic acid. I built on this team's review by providing an in-depth understanding of the characteristics and components of interventions that aim to improve women's intake of folic acid supplements worldwide. I also described researchers' challenges in implementing such interventions. Furthermore, I described barriers that women face in taking folic acid supplements.

Findings from the systematic review I conducted revealed that all eight studies that met inclusion criteria were conducted in high-income countries. Five were quasi-experimental studies. Three studies were randomized controlled trials. Intervention characteristics and components varied across studies. For example, for modes of delivery, in most studies (n=5) researchers utilized face-to-face tailored counseling. In two studies, researchers utilized technology to counsel participants about folic acid supplements. In four studies, researchers provided free folic acid or multivitamin supplements containing folic acid to participants. In most interventions (n=4), researchers involved health care providers as interveners. Overall, in few studies (n=3), interveners documented how they evaluated fidelity of intervention delivery. In only one study, researchers applied a conceptual model to guide their study.

Findings indicated that researchers faced some methodological challenges. Three studies indicated that researchers faced difficulty in retaining participants, especially women of low socio-economic status and those who had not completed a college education. Overall, among the studies, few researchers documented the extent of interveners' fidelity to study protocols. In five studies, researchers reported women's common barriers to taking folic acid supplements; these included forgetting to take supplements and uncertainty about folic acid benefits.

Chapter 4 builds on my work in chapter 3, by focusing on nurses and nursing students in one low OR middle- income countries where there is need for research to promote women's intake of folic acid. I developed and assessed a questionnaire of proposed influences on nurses' implementation of folic acid

guidelines. For phase 1 of the study, I developed scales and items to reflect constructs of or *predisposing, reinforcing, enabling* and *environmental factors* proposed to influence nurses' implementation of folic acid guidelines based on the PPM and (2) assessed the content validity of the items, scales and subscales. For phase 2, I (1) assessed the construct validity of the scales and subscales and (2) internal consistency reliability of the scales and subscales.

For phase 1, a team of seven nurses from Uganda and USA generated 106 items. Through an iterative process and peer review, I compiled and synthesized feedback about the initial items from the team of nurses in Uganda and USA. In consultation with the team of nurses in USA and Uganda, I excluded items that were deemed to be inapplicable. To improve readability and comprehension of the items for the population of interest, I reviewed items for approximate 8th grade reading level by assessing approximate number of syllables per word and the sentence length (Paz, Liu, Fongwa, Morales, & Hays, 2009). In consultation with the team of nurses, I revised words that had more than three syllables and reduced the length of long sentences. This process resulted in 53 items; 5 proposed scales, 2 proposed subscales and 13 single items.

To assess content validity of items, scales, and subscales, I sought feedback from a team of seven content experts from USA and Uganda. I followed the methods recommended by Polit & Beck (2012) to compute content validity indices for items and scales. Based on the ratings of the content expert, content validity indices of the 53 items varied from 0.57 to 1.00. Most items had high I-CVIs > 0.80; 77% of items on clarity, 88% of items on relevance, and 77% of items on cultural appropriateness. Content validity indices of scales varied from acceptable to high (i.e., from 0.86 to 0.91). Based on the validity indices and descriptive feedback from experts, I revised 18 items and omitted 4 items. This process resulted in 49 items (36 items making up proposed scales and subscales and 13 single items), which I called (Questionnaire version 1.1).

For phase 2, I assessed for construct validity of the proposed scales and subscales, using confirmatory factor analysis. Confirmatory factor analysis enables researchers to test a hypothesized factor structure or conceptual model (Bryne, 2012). Because I had developed items based on the PPM, I

hypothesized that items reflecting constructs or factors of the PPM would load together. Also, by directly comparing alternative measurement models, confirmatory factor analysis tests the model that best fits the data through factor loadings (Polit and Beck, 2012; Swisher, Beckstead, & Bebeau, 2004; Strauss & Smith, 2009).

I chose to limit the analyses to seven-factors (i.e., a seven-factor oblique congeneric model) because I had proposed seven new measures proposed to be scales and subscales (a total of 36 items). Factor 1 was proposed to reflect the construct of beliefs (i.e., nurses' beliefs about educating and counseling women about folic acid. Factors 2a and 2b were proposed to reflect the construct of beliefs (re: nurses' beliefs about folic acid and need for folic acid) respectively. Factor 3 was proposed to reflect the construct of normative practices (i.e., nurses' normative practices regarding educating and counseling women about folic acid). Factor 4 was proposed to reflect the construct of continuing education (i.e., continuing education about folic acid). Factors 5 and 6 were proposed to reflect the constructs of availability of resources (i.e., availability of folic acid resources) and accessibility to resources (i.e., access to folic acid guidelines) respectively. Therefore, I had a total of 5 scales and 2 subscales for confirmatory analysis. My conclusion was based on having acceptable values of the model fit indices, factor loadings > 0.30, and factor loadings that were statistically significant at $p < 0.05$.

In assessing the least restrictive seven-factor congeneric model, I considered dropping a total of 10 items; 5 items had low loadings <0.30 (Swisher et al., 2004), 5 items had high modification indices above 30 and indicated some cross loadings (Fabriga et al., 1999; Tabachnick & Fidell, 2001). Before deleting the 10 items, I considered the conceptual contribution of each item to the content of the scale (Pett, Lackey, & Sullivan, 2003). Because the conceptual contribution of each item to the scale content was small or negligible, I deleted the 10 items. The congeneric model had a total of 26 items.

Then, I assessed the internal consistency reliability of the proposed scales and subscales (26 items) using McDonald's omega and Cronbach's alpha. Desirable values for Cronbach's alpha and McDonald's coefficient omega are 0.80 or higher and values from 0.70 are acceptable for new measures

(Polit & Beck, 2012; McMillan and Schumacher, 2001). For my learning purposes, I chose to compare the findings for both these approaches to reliability. Indeed, I observed in my data that the Cronbach's alpha statistics underestimated the internal reliability of all scales and subscales in comparison to McDonald's omega coefficient (Graham, 2006). I accepted McDonald's omega as a more realistic measure for internal consistency reliability than Cronbach's alpha.

Five scales had acceptable internal consistency reliabilities varying from 0.70 to 0.86. Because these were new measures, values from 0.70 were acceptable (Polit & Beck, 2012; McMillan and Schumacher, 2001). Two subscales regarding nurses' beliefs (re: need for folic acid and side- effects of folic acid, had low internal consistency reliabilities of 0.54 and 0.58 respectively. The process resulted in a final questionnaire of 39 items (26 items making up scales and subscales and 13 single items). I called the final Questionnaire version 1.2.

I innovatively applied the PPM to develop and evaluate a questionnaire of proposed influences on nurses' implementation of folic acid guidelines. To my knowledge, no researchers had conducted a study in which they had developed a questionnaire that reflected both individual and external factors and BB type of constructs or factors or had applied the PPM to prevention of NTDs. Based on the acceptable content validity indices the questionnaire is culturally appropriate for the Ugandan health care context. The construct validity and internal consistency reliability of the questionnaire have been assessed for use among nurses within the Ugandan health care setting.

Research

Research about Individuals with NTDs and their Families

Because the PPM (Green & Kreuter, 2005) includes a breadth of factors that I have demonstrated to be relevant to individuals with NTDs and their families (Chapter 2), the Model could be helpful to guide researchers' work in this area. Some examples follow. Researchers could apply phase 1 (*Social assessment*) of the PPM to conduct descriptive studies about impact of NTDs on the quality of life among individuals with NTDs and their families. In doing so, scholars can advance our understanding of the breadth of challenges for individuals with NTDs and families regarding quality of life.

Researchers could apply the PPM phases 2 (epidemiological assessment) and 3 (educational and ecological assessment) to examine individual and external challenges of individuals with NTDs and their families. Researchers could apply phases 4 (administrative policy and intervention alignment) and 5 (implementation) to design and implement educational and educational, systems and policy interventions that could address the identified challenges. Then researchers can apply phases and 6-8 (evaluations) to evaluate the short-term, intermediate and long-term impacts of their interventions By systematically applying the PPM, researchers could build on knowledge regarding the care of individuals with NTDs and their families.

Research on Promoting Folic Acid Intake among Women of Childbearing Age

Because few researchers have applied theories or conceptual models to guide either descriptive and intervention research about folic acid supplements among women of childbearing age, future researchers can do so. They could apply the Phases 2 and 3 of the PPM to describe individual and external factors influencing intake of folic acid supplements in women of childbearing age; they could compare such findings from high-income and low- and middle- income countries. In low- and middle -income countries where there is high prevalence of NTDs and paucity of interventions to promote folic acid intake among women of childbearing age, researchers could design descriptive studies to identify local women's needs and barriers to taking folic acid supplements. Based on their findings and prior research, researchers could apply what they learn from such studies to design and test interventions to promote women's folic acid supplement use.

Researchers can consider important intervention characteristics and components identified in the systematic review (Chapter 3). For example, researchers could utilize a single mode of delivery or a combination of delivery modes (e.g., face-to-face, computerized technology, and printed information). A face-to-face mode of delivery would be preferable in clinic settings where health care professionals are more available to provide health services to women. Computerized technology could be successful in clinic, school and rural settings.

Guided by the Phase 5 (implementation) researchers could provide free folic acid supplements or ensure that folic acid supplements are accessible to women of childbearing age. Provision of free folic acid supplements would be a cheaper option compared to the cost of taking care of children with NTDs. Also in limited resources settings such as in countries in sub-Saharan Africa (e.g., Uganda), the cost of a bottle of folic acid with 90 to 120 tablets is about 2 dollars and lasts for 3 months. Yet 1 kilogram of flour fortified with folic acid costs 3 times the bottle of folic acid and lasts for one to 2 days depending on family size.

If researchers designed studies with strategies to improve participant recruitment and retention especially women of low socio- economic status, then we could have data to accurately evaluate the effectiveness of folic acid interventions in these population. Increasing retention of women of low socio-economic status in interventions designed to promote folic acid is critical. This is because this population is (a) at greatest risk of folic acid deficiency, and (b) at higher risk of having children with NTDs.

To improve fidelity to study protocols, researchers need to utilize standardized protocols in training interveners. By doing so, interventionists could have an improved likelihood of equal level of skill. Also, if researchers were consistent in documenting all dose parameters, then scholars could use dosing data to examine dose-response relationships for designing future folic acid interventions. If researchers monitored and documented fidelity in delivery of interventions, then (a) interveners could have increased adherence to intervention protocols and (b) researchers could have information on whether on not interventions were delivered as intended and identify areas of improvement, and (c) other researchers could replicate interventions in future studies (Broners et al., 2017; French et al, 2015).

Research on Promoting Nurses' Implementation of Folic Acid Guidelines.

The newly developed and evaluated questionnaire (version 1.2) reported in Chapter 4 would be helpful to provide an in-depth understanding about the influences on nurses' implementation of folic acid guidelines not only in Uganda but also in additional settings similar to Uganda. With new data, researchers could apply phases 2 and 3 of the PPM to examine relationships between: (a) predisposing

factors (nurses' knowledge about folic acid guidelines, nurses' beliefs about educating and counseling women about folic acid, and nurses' beliefs about folic acid), (b) reinforcing factor (nurses' normative practices), (c) enabling factors (continuing education about folic acid), and (d) environmental factors (availability of folic acid resources, access to folic acid guidelines), and nurses' behavior (nurses' reported practices educating & counseling women about folic acid). Then, researchers could apply phases 4 to 8 of the PPM to design, implement and evaluate educational and systems interventions to improve nursing practice regarding folic acid guidelines.

To further improve on the newly developed questionnaire (version 1.2) researchers could conduct further measurement studies. One, they could strive to generate more items in hopes that they could improve on the internal consistency reliabilities of the subscales regarding nurses' beliefs (re: need for folic acid and side effects of folic acid).

Education and Practice

Individuals with NTDs and their Families.

Clinicians (e.g., nurse practitioners and physicians) can apply the PPM in their practice and scholarship to identify areas of improvement in caring for individuals with NTDs and their families. For example, when clinicians apply phases 2 (epidemiological assessment) and 3 (educational and ecological assessment) of the PPM, then they could assess and then identify potential influences on the behaviors of individuals with NTDs and their families in caring for those with NTDs.

If leaders in practice, such as clinic administrators, were to apply the PPM factors to the behaviors of all their clinic staff, then they could identify what the clinic staff may need or lack to provide quality care to individuals with NTDs and their families. For example, clinic staff may lack knowledge about the issues that these people face and they may lack skills in caring for individuals and families. Then guided by phases 4 to 8 of the PPM (i.e., phases 4; administrative and policy assessment and intervention alignment, 5; implementation; 6 to 8; evaluations) clinicians could design, implement and evaluate educational strategies to improve provider skills. This suggestion supports the mission of the International Federation of Spina Bifida and Hydrocephalus to improve the quality of life of people with

spina bifida and their families (International Federation of Spina Bifida and Hydrocephalus; IFSBH, 2018).

Promoting Folic Acid Intake among Women

In line with the World Health Organization recommendation (WHO, 2017), health care professionals (e.g., nurse practitioners, nurse midwives, and obstetricians) working with women could make a deliberate effort to include folic education and counseling as part of their routine practice. In addition, health care professionals could include assessment, and evaluation of supplemental folic acid intake in women of childbearing age as part of their routine practice.

Also, if health care providers were better informed about the barriers that women face in taking FA supplements, then they would be more aware of this as a clinical issue. If they were more aware of this, then they could incorporate strategies to support women in overcoming barriers to taking folic acid. For example, to help women in remembering to take folic acid, health care providers could suggest to women to put the folic acid supplements in a place where they will easily see the supplements each day. Another suggestion could be for women to set a timer on their phones as a reminder to take folic acid supplements. For women who find difficulty in taking folic acid supplements due to the unpleasant taste of folic acid, health care providers could suggest other alternatives such as folic acid gummies.

Promoting Nurses' Implementation of Folic Acid Guidelines

In chapter 4, based on findings from the descriptive data, I believe that education of nursing students and licensed nurses regarding folic acid knowledge need to be improved in Uganda. My findings indicated that licensed nurses and clinical nursing students had low scores on several items about folic acid knowledge. Overall, nurses had incorrect responses on 58% of items. Because clinical nursing students and licensed nurses are in key positions to educate and counsel women about folic acid, they need to have the correct facts about folic acid. Items that nurses had high scores of incorrect responses above 50% included: (a) amount of folic acid for women in reproductive years and for women at high risk of getting babies with NTDs, (b) health benefits of taking folic acid, (c) examples of conditions that folic

acid prevents, (d) by what percentage folic acid reduces NTD risk, and (e) conditions that increase women's risk of having babies with NTDs.

In chapter 4, results from the descriptive data about nurses' beliefs regarding folic acid suggest that majority of licensed nurses (mean score of approximately 4) and clinical nursing students agreed on items that: (a) taking folic acid is not needed until pregnancy is confirmed and (b) women who take birth control pills do not need folic acid. Yet, according to the folic acid guidelines, women of childbearing age need to take folic acid daily regardless of pregnancy status and whether or not they are taking pills for birth control (U.S. Preventive Services Task Force, 2017).

In designing nursing curriculum for students and continuing education for nurses in practice, nurse educators could apply phases 4 to 8 to design, implement and evaluate an educational intervention for nursing. Educators can provide correct facts about the topics identified in my knowledge items and especially those that nurses responded to incorrectly. Also nurse educators could address nurses' beliefs about need for folic to provide the right information. Findings from my descriptive data indicate that the majority of the licensed and clinical nursing students, 84% preferred to learn more about folic acid through continuing nursing education. The finding is based on one additional item I had as part of my questionnaire "What are some ways for you to learn more about folic acid" to provide information for a future intervention.

Health Policy

Individuals with NTDs and their Families

Health policy makers and scholars can apply the PPM to identify, implement and evaluate policies that could support the implementation of interventions regarding individuals with NTDs and their families. Policy makers could apply phase 5 (implementation) to implement policies that I identified in prior literature (Chapter 2). The identified policies reflect *policy regulation and organization* of the PPM.

For example, to support interventions that aim to improve health care for individuals with spina bifida, policy makers could (a) set up, monitor, and evaluate spina bifida registries, to improve health care for individuals with NTDs, (b) improve universal health coverage and access to multidisciplinary care for

individuals with spina bifida (IFSBH, 2018), and (c) to improve care coordination for individuals with spina bifida and their families to avoid duplication of services and unnecessary costs.

Promoting Folic Acid Intake among Women

Guided by phases 4 to 8 of the PPM, health policy makers could plan, implement and evaluate policies to improve the availability, affordability and accessibility of folic acid supplements to women of childbearing age especially women of low socio-economic status. Availability refers to presence of resources or services in sufficient quantity (McLaughlin, & Wyszewianski, 2002) such as presence folic acid within clinic and hospital settings. Access refers to ease of getting to resources or services (e.g., Evans, Hsu, & Boerma, 2013; McLaughlin, & Wyszewianski, 2002; Woldemichael, Takian, Sari, & Olyaeemanesh, 2019) such as distance women have to travel to clinic or pharmacy to get folic acid. Affordability refers to ability to pay for services without financial hardship (Evans, Hsu, & Boerma, 2013) such as ability to pay for folic acid.

Promoting Nurses' Implementation of Folic Acid Guidelines.

Findings from descriptive data on licensed nurses and clinical nursing students responses are informative (Chapter 4) and could be helpful in planning future interventions. Findings revealed from that there was limited availability of folic acid resources (e.g., decision tree for folic acid supplementation) within the licensed nurses and clinical nursing students' work place. Also results suggested that licensed nurses and clinical nursing students had limited access to folic acid guidelines within their work place. Guided by phases 4 to 8 of the PPM, researchers could collaborate with policymakers to develop, implement and evaluate policies to improve nurses' implementation of folic acid guidelines.

Findings provide guidance for designing educational interventions for licensed nurses and clinical nursing students. Regarding knowledge about folic acid guidelines, the majority, 64% of licensed nurses and clinical nursing students did not know some of the natural sources of folic acid. The majority, 55% of licensed nurses and clinical nursing students did not know that folic acid can reduce the chances of women giving birth to babies with NTDs by 50% to 70%. The majority, 63% of licensed nurses and clinical nursing students did not know the amount of folic acid women of childbearing age need daily.

Based on these findings, researchers could apply phases 4 to 8 of the PPM collaborate with nurse leaders to design, implement and evaluate educational interventions to address nurses' knowledge about folic acid guidelines.

Future directions

For my program of research, I will continue to focus on prevention of NTDs through folic acid intake among women of childbearing age and health promotion among individuals with NTDs and their families. I plan to continue focusing my work in limited resource setting, such as Uganda, and then expand to countries within sub-Saharan Africa. I plan to administer the revised questionnaire to nurses in additional settings in Uganda to identify the possible influences on nurses' implementation of folic acid guidelines. One study purpose is to describe relationships between influences on nursing practices & nurses' reported practices of educating & counseling women about folic acid, guided by phases 2 and 3 of the PPM. Based on future findings, I plan to collaborate with nurse scholars, clinicians and policy makers to design, implement and evaluate interventions that would address the major issues that could support nurses' implementation of FA guidelines , guided by phases 4 to 8 of the PPM. If such influences are addressed, then we could improve nurses' implementation of folic acid guidelines in Uganda. If nurses can support women in taking folic acid, then women's risks of having babies with NTDs would decrease.

Health promotion among Individuals with NTDs and their Families

I plan to continue applying the PPM to my research. In consultation with my mentors at the UW-Madison School of Nursing, I plan to build a program of research to design, implement, and evaluate relevant interventions for individuals with NTDs and their families in Uganda. As a first, step I have begun collaborating with an interdisciplinary team of nurses, social workers, physicians, nutritionists, and physiotherapists in Western Uganda. The team works with spina bifida individuals and their families. Guided by the PPM, we plan to collaborate with individuals with NTDs and their families to: (a) identify their main challenges and (b) address their needs through intervention research. By doing so, we could contribute to improving their quality of life, based on phase 1 of the PPM is to improve the quality of life of individuals and populations (Green & Kreuter, 2005).

Nursing Education

Also, I plan to support nursing education in Uganda. I plan to collaborate with two Universities of Nursing in Uganda to be an adjunct professor. I would share concepts related disease prevention and health promotion among children with special health care needs and their families, and how to apply theories and models to guide scholarly work.

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