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A Systematic Review of Self-Management Interventions for Inflammatory Bowel Disease

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Abstract

Purpose: To conduct a systematic review of self-management interventions for adults with inflammatory bowel disease (IBD) to (a) describe self-management skills in the interventions and (b) describe the effects of the interventions on the health-related outcomes measured.

Design: Systematic review of self-management interventions for adults with IBD using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Methods: The search was conducted using Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, and Proquest databases. Search terms were inflammatory bowel disease OR Crohn* disease OR ulcerative colitis AND self-management. We also used additional limits (adults ≥18 years of age and published in English). The self-management skills were organized according to Lorig and Holman's five self-management skills.

Findings: Six reports met the inclusion criteria. One intervention contained all five of the self-management skills. Most interventions contained two skills. Four studies demonstrated positive effects of self-management on disease activity. Two interventions revealed positive effects on disease-specific health-related quality of life (HRQOL), and one intervention revealed positive effects on generic HRQOL. One study showed positive effects of symptoms.

Conclusions: The interventions reviewed varied in the approaches, theoretical perspectives, self-management skills, and outcomes measured. Additional research is needed to understand which are the active components of self-management.

Clinical Relevance: Support for self-management skills is an important component of nursing care for people with IBD.

Inflammatory bowel disease (IBD) primarily consists of Crohn's disease and ulcerative colitis and is characterized by intestinal inflammation and follows an unpredictable trajectory between active disease and remission (Cosnes, Gower-Rousseau, Seksik, & Cortot, 2011). In Europe 2.2 million people have IBD, and in the United States 1.4 million people have IBD, and the incidence is rising across the globe (Loftus, 2004; Molodecky et al., 2012). Currently there is no cure for IBD, and people with IBD often face reduced health-related quality of life (HRQOL) compared to the general population (Bernklev et al., 2005). A growing body of literature suggests that effective self-management contributes to improved health outcomes such as pain, disability, and healthcare utilization in a variety of populations (Barlow, Wright, Sheasby, Turner, & Hainsworth, 2002; Grey, Knafl, & McCorkle, 2006), but little is known about the components of self-management or its effect among patients with IBD (Barlow, Cooke, Mulligan, Beck, & Newman, 2010; Kemp, Griffiths, & Lovell, 2012). In addition, a previous review that focused on disease education interventions in IBD concluded that self-management showed more promise than disease education interventions (Barlow et al., 2010).

Self-management is a dynamic, interactive process that captures the complexity of living with chronic illness in the context of daily life (Grey et al., 2006). Self-management includes skills that assist people in successfully managing chronic conditions on a day-to-day basis (Lorig & Holman, 2003). Corbin and Strauss (1988) described self-management as work with three main tasks: (a) illness-related work, (b) everyday life work, and (c) biographical work. Extending that definition, Lorig and Holman (2003) defined five core self-management skills: (a) problem solving, (b) decision making, (c) finding and utilizing resources, (d) forming partnerships with healthcare providers, and (e) taking action. The purpose of this article is to conduct a systematic review of self-management interventions for adults with IBD to (a) describe self-management skills in the interventions and (b) describe the effects of the interventions on the health-related outcomes measured.

Methods

A systematic review of self-management skills and health-related outcomes of self-management for IBD was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

Search Strategy

Medline, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Embase, and Proquest (a dissertation database) databases were used to search the literature. Search terms included inflammatory bowel disease OR Crohn∗ disease OR ulcerative colitis AND self-management. Additional limits included age ≥18 years and published in English. Randomized controlled trials that tested the effects of at least one self-management skill were included. Reports that included only children or adolescents were excluded. Reports published prior to October 2014 were included in the review.

Intervention Selection and Data Extraction

One researcher reviewed all of the titles and abstracts and identified potentially relevant articles. Next, she read all potentially relevant articles in full text and identified the final reports included in the review. Data were extracted and organized into literature tables. The main fields included authors, year of publication, study design, sample, inclusion criteria, location of study, self-management skills, outcomes (type and effect), study instruments, results, and limitations. The self-management skills were organized according to Lorig and Holman's (2003) five self-management skills: (a) problem solving, (b) decision making, (c) finding and utilizing resources, (d) forming partnerships with healthcare providers, and (e) taking action.

Quality Assessment

Quality assessment was conducted using the six domains from the Cochrane risk of bias tool, random sequence generation, allocation concealment, blinding of outcome assessment, incomplete outcome data, selective reporting, and other bias (i.e., power and use of intention to treat analysis; Higgins & Green, 2009). The domain of blinding of participants and personnel was not included because it is not possible to blind participants in self-management interventions (Lorig & Holman, 2003). All domains were evaluated for risk for potential bias (high, low, or unknown risk due to incomplete reporting; Higgins & Green, 2009).

Results

Study Characteristics, Samples, and Settings

Figure 1 contains the details of the selection process. Four hundred fifty reports were identified. Six reports, published between 2001 and 2014, met the study criteria. All were randomized controlled trials, and all of the participants had IBD. The samples had diverse clinical and demographic characteristics, outcomes, and study quality. **Table 1** provides an overview of the interventions. There were a total of 1,815 participants ($n = 28$ to 635 per trial) with IBD, with ages ranging from 16 to 86 years. Three studies included participants with both active and inactive disease (Elkjaer et al., 2010; Hueppe, Langbrandtner, & Raspe, 2014; Kennedy et al., 2004), and three studies only included participants with inactive disease (Keefer, Doerfler, & Artz, 2012; Keefer et al., 2013; Robinson, Thompson, Wilkin, & Roberts, 2001).

The self-management interventions were delivered in a variety of settings, including hospital clinics (Kennedy et al., 2004; Robinson et al., 2001), on the Internet (Elkjaer et al., 2010), via mail (Hueppe et al., 2014), and in academic health centers (Keefer, Doerfler, et al., 2012; Keefer et al., 2013). The studies also took place in a variety of locations including the United States (Keefer, Doerfler, et al., 2012; Keefer et al., 2013), the United Kingdom (Kennedy et al., 2004; Robinson et al., 2001), Denmark and Ireland (Elkjaer et al., 2010), and Germany (Hueppe et al., 2014). All studies had a

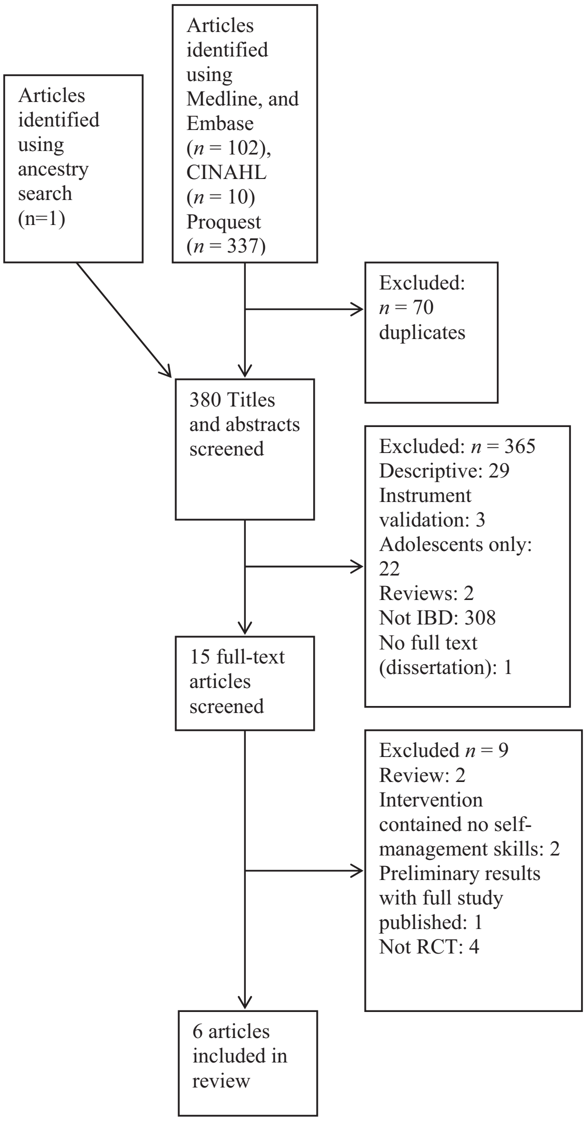

Figure 1. Flow of information through literature search.

12-month follow-up period. All six studies also only reported outcomes at 12-month follow-up.

Self-Management Skills

Table 2 provides an overview of the self-management skills included in the interventions. Three self-management programs included personalized plans for self-management of IBD, when and how to self-start prednisone for active disease, education about when and how to contact the clinic, and the system change of open-access clinics with no regular appointments and same-day appointment scheduling (Elkjaer et al., 2010; Kennedy et al., 2004; Robinson et al., 2001). IBD treatment teams, including physicians, nurses, and administrative staff, implemented the interventions. These three programs included two of the five self-management skills: (a) decision making skills around what to do in a disease flare-up (i.e., education about how to determine if you are in a flare-up and self-starting of prednisone) and (b) forming partnerships with healthcare providers by providing open-access clinics and education about when and how to contact the clinic.

One study was based on a project management framework, cognitive behavioral therapy, and social learning theory (Keefer, Doerfler, et al., 2012). Project management is a problem-solving process that is used in corporate America. Psychologists delivered the intervention. This intervention addressed five self-management skills. This study focused on (a) problem solving regarding allocation of limited resources, including time, money, and emotional resources; (b) making disease management decisions; (c) utilizing a team of people with varying skills to support the self-management plan; (d) consulting with diverse healthcare providers, including physicians, nurse educators, dieticians, and psychologists, to meet self-management goals; and (e) taking action through taking charge of personal health and setting in time-limited goals.

Keefer et al.'s (2013) intervention taught self-management skills through gut-directed self-hypnosis, a type of medical hypnosis. Medical hypnosis focuses on reframing problems, relaxation, letting go of critical thoughts, and changing behaviors. The gut-directed hypnosis included seven fully scripted sessions and a recording to practice self-hypnosis at home that focused on the health and function of the gastrointestinal tract. Psychologists delivered the intervention. This intervention included two self-management skills taught through hypnotic suggestions focusing on self-management, including (a) how to solve problems around stress and (b) how to recognize and take action around disease activity.

Hueppe et al.'s (2014) intervention was based on the idea of patient empowerment and contained tailored advice for IBD-related problems. The interventionists (public health professionals and a physician) sent a survey to the participants to assess for IBD management problems and sent back via mail a list of tailored advice on how to manage specific problems. The advice was diverse, from medical management to relaxation exercises. This intervention contained one self-management skill: making decisions around perceived disease management problems. Despite being labeled as a self-management intervention, this intervention largely contained disease education with little skill training.

Table 1. Inflammatory Bowel Disease (IBD) Self-Management Interventions

Author (year) country	Study population	Intervention	Outcomes	Main findings
Elkjaer et al. (2010) Denmark and Ireland	Mild to moderate ulcerative colitis taking 5-aminosalicylic acids *N* = 333	Web-based treatment program with personalized self-management plans with open access to providers with no routine appointments compared to usual care	Disease self-management Quality of life Adherence Disease course after 1 year	Increased adherence and disease knowledge and disease specific quality of life Shorter duration of relapse No difference in rates of relapses, days lost due to illness or hospitalizations. 88% of participants found the intervention feasible; 81.4% wanted to continue in Denmark, and 88% wanted to continue in Ireland
Hueppe et al. (2014) Germany	IBD patients of second largest health insurance company in Germany with one hospital stay or one case of temporary work disability in 2009 or 2010 N = 462	Patient activation and information program via mail Automated data analysis with tailored written advice on how to cope with IBD-related problems and appropriate health services compared to usual care	Health-related quality of life Social participation Healthcare utilization Number of screened problems Self-management skills	Improved quality of life Increased social participation Decreased disability days Fewer outpatient visits Fewer disease-related problems Improved self-management skills Decrease in loss of vitality No differences in disease activity between groups 47% followed at least one recommendation
Keefer et al. (2013) United States	Quiescent ulcerative colitis *N* = 54	Gut-directed hypnotherapy compared to nondirected discussion on ulcerative colitis and the "mind–body connection"	Prolong clinical remission Proportion of patients at 52 weeks still in remission Number of days to first relapse	Significantly increased prolonged clinical remission No significant differences between groups over time in quality of life, perceived stress, or psychological factors 52% continued to practice hypnotherapy at 1 year

Continued

Table 1. Continued

Author (year) country	Study population	Intervention	Outcomes	Main findings
Keefer, Doerfler, et al. (2012) United States	Quiescent Crohn's disease $N = 28$	"Project management" based on principles of cognitive behavioral therapy and social learning theory compared to treatment as usual	Prolonged remission Quality of life Self-efficacy Perceived stress	Improved global quality of life Improve bowel health and systemic health Increased self-efficacy Decreased perceived stress
Kennedy et al. (2004) United Kingdom	Established ulcerative colitis and Crohn's disease at 19 hospitals $N = 635$	Personalized self-management plans with open access to providers with no routine appointments compared to usual care	Quality of life Healthcare service use Patient satisfaction	No difference in quality of life scores Decreased GI appointments, less nonattendance for appointments, and fewer disease relapses 74% of the participants preferred to continue self-management
Robinson et al. (2001) United Kingdom	Established ulcerative colitis in remission at four hospitals $N = 203$	Personalized guided self-management intervention Personalized self-management plans with open access to providers with no routine appointments compared to usual care	Interval between relapse and treatment Rates of primary and secondary care consultations Quality of life Acceptability	Decreased clinic nonattendance and number of appointments Relapses treated earlier, trend for shorter relapses, less inappropriate self-treatment, and less time spent at the doctor No difference was seen in quality of life scores 95% of participations wanted to continue the intervention

Note. GI = gastrointestinal.

Table 2. Self-Management Skills and Outcomes of Inflammatory Bowel Disease (IBD) Self-Management Interventions

Author (year)	Self-management skills	Quality of life (instrument)	Symptoms measured	Disease activity (instrument)
Elkjaer et al. (2010)	(2) Decision making (4) Partnerships with providers	Improved global QOL ($p = .04$) (IBDQ)	Depression symptoms improved in control group	Shorter duration of relapse (18 days [95% CI 10–21] vs. 77 days [95% CI 46–108]) (Modified Mayo Score)
Hueppe et al. (2014)	(2) Decision making	Improved global QOL (4.4; 95% CI 7.7–1.0, $p = .011$) (EuroQol visual analog scale)	Not measured	No differences in disease activity between groups (German Inflammatory Bowel Disease Activity Index)
Keefer et al. (2013)	(1) Problem solving (5) Taking action	No change in global QOL (IBDQ) No change in generic quality of life (SF-36)	Not reported	Prolonged remission ($F = 4.8$, $p = .03$) (Simple Clinical Colitis Activity Index)
Keefer, Doerfler, et al. (2012)	(1) Problem solving (2) Decision making (3) Finding/utilizing resources (4) Partnerships with providers (5) Taking action	Improved global QOL ($F(1) = 15.2$, $p = .001$) No change social or emotional function (IBDQ)	Improved bowel ($F(1) = 6.5$, $p = .02$) and systemic ($F(1) = 9.3$, $p = .007$) symptoms (IBDQ) in intervention group	Not measured
Kennedy et al. (2004)	(2) Decision making (4) Partnerships with providers	No change in global QOL (IBDQ)	No difference in depression or anxiety scores	Fewer disease relapses (difference -0.36 (95% CI -0.63 to -0.09); $p = 0.013$) (self-report diary)
Robinson et al. (2001)	(2) Decision making (4) Partnerships with providers	No change in global QOL (IBDQ)	Not measured	Nonsignificant trend for shorter relapses (self-report diary)

Note. Self-management skills: (1) problem solving, (2) decision making, (3) finding and utilizing resources, (4) forming partnerships with health care providers, and (5) taking action. CI = confidence interval; IBDQ = Inflammatory Bowel Disease Questionnaire; QOL = quality of life; SF-36 = Short Form (36-item) Health Survey.

Health-Related Outcomes

Table 2 provides an overview of the primary health-related outcomes. Health-related outcomes that were measured in the interventions included HRQOL, disease activity, symptoms (anxiety, depression, bowel symptoms, and systemic symptoms), medication adherence, disability days, perceived stress, self-efficacy, and time to treat relapse. Three health-related outcomes were measured in two or more studies: HRQOL, disease activity, and symptoms.

Health-related quality of life. Five interventions used the Inflammatory Bowel Disease Questionnaire (IBDQ) to measure disease-specific HRQOL. Beyond the global score, the IBDQ has four subscales: bowel symptoms, systemic symptoms, emotional function, and social function (Guyatt et al., 1989). One study reported the subscale scores separately from the global score (Keefer, Doerfler, et al. 2012). One intervention used a generic HRQOL measure, the EuroQol visual analog scale (Hueppe et al., 2014). One study used both a disease-specific and generic measure of HRQOL, the IBDQ and the Short-Form-12, respectively (Keefer et al., 2013).

Three interventions revealed positive effects of self-management on either disease-specific or generic HRQOL. Two studies, one of which provided personalized self-management of IBD and open-access clinics, improved global IBDQ scores (Elkjaer et al., 2010; Keefer, Doerfler, et al., 2012). Three interventions, one consisting of self-hypnosis and two that provided personalized self-management of IBD and open-access clinics, found no difference in global IBDQ scores (Keefer et al., 2013; Kennedy et al., 2004; Robinson et al., 2001). The intervention that included support for decision making delivered by mail revealed a favorable effect on generic HRQOL (Hueppe et al., 2014). In contrast, Keefer et al. (2013) found that, using the project management framework, disease-specific and generic HRQOL did not significantly change.

Disease activity. Disease activity was measured as an outcome in five studies. Two interventions measured disease activity through self-report symptom diary, and three studies used well-validated self-report symptom-based clinical disease activity indices. The disease activity questionnaires have well-validated clinical cut-off scores. Questions in all three indices are similar and include questions about the number of stools per day, the presence of blood in stool, fever, and overall well-being, and were validated against endoscopy (Walmsley, Ayres, Pounder, & Allan, 1998). Disease activity was operationalized in four different ways: (a) cumulative clinical disease activity scores (Hueppe et al., 2014), (b) amount of time spent with active disease (Elkjaer et al., 2010; Robinson et al., 2001), (c) length of time spent in inactive disease (Keefer et al., 2013), and (d) number of episodes with active disease during the study period (Kennedy et al., 2004). Four interventions found favorable effects on disease activity (Elkjaer et al., 2010; Keefer et al., 2013; Kennedy et al., 2004; Robinson et al., 2001), and one study found no difference in disease activity scores (Hueppe et al., 2014).

Symptoms. Three of the interventions evaluated the effects of self-management on symptoms. Keefer, Doerfler, et al. (2012) found that both bowel and systemic symptoms improved in their project management intervention. Kennedy et al. (2004) found no difference in anxiety and depression scores in their intervention of personalized self-management of IBD and open-access clinics. In contrast, Elkjaer et al. (2010), in a web-based intervention of personalized self-management of IBD and open-access clinics, found improvement in depression in the control group of usual care control compared to the intervention group. Generalized conclusions about symptoms cannot be drawn due to the lack of consistency of the symptoms measured.

Quality

An overview of the quality of the studies is presented in **Table 3.** The most frequent limitation was the lack of blinding of the outcome assessment. Only one intervention provided a description of the blinding of the outcome assessment. In this intervention both the gastroenterologists and the participants were blinded to the outcomes of the intervention (Keefer et al., 2013). The second most common quality concern was the lack of statistical power analysis or low levels of power. Only four reports included a power analysis (Hueppe et al., 2014; Keefer, Doerfler, et al., 2012; Keefer et al., 2013; Kennedy et al., 2004), and one of these interventions was underpowered (Hueppe et al., 2014).

Discussion

Only one study contained all five of the self-management skills as defined by Lorig and Holman (2003). Most of the interventions contained two self-management skills, with decision making and partnering with healthcare providers being the most common skills included. A variety of interventions were used to teach participants how to incorporate self-management skills. Most of the interventions focused on self-management of disease management, and there was limited focus

Table 3. Quality Assessment

Author (year)	Random sequence generation	Allocation concealment	Blinding of outcomes assessment	Incomplete outcome data	Selective reporting	Other bias
Elkjaer et al. (2010)	L	L	U	L	L	H
Hueppe et al. (2014)	L	L	U	H	L	H
Keefer et al. (2013)	L	U	L	L	L	L
Keefer, Doerfler, et al. (2012)	L	U	U	L	L	H
Kennedy et al. (2004)	H	U	U	L	L	H
Robinson et al. (2001)	H	L	U	L	L	H

Note. H = high risk of bias; L = low risk of bias; U = unclear risk of bias.

on symptom management, employment, education, or leisure roles. Additional self-management research is needed that includes all five self-management skills so that the interventions can be deconstructed to better understand which self-management skills are vital to positive outcomes so these skills can be included in practice (Lorig & Holman, 2003).

The results showed favorable effects of self-management on disease activity. This further supports the idea that self-management, in conjunction with coordinated medical care, may have the potential to modify disease activity (Keefer et al., 2011). However, half the interventions only included individuals with inactive disease. Therefore, one cannot tell if the effects of self-management interventions differ across the trajectory of disease activity. Future research needs to include a more diverse sample in terms of disease activity. This type of research is needed to better understand if treatment differences depend on patient characteristics (Assmann, Pocock, Enos, & Kasten, 2000).

One study used both generic and disease-specific HRQOL measures, as is recommended to obtain a more complete picture of HRQOL in IBD (McColl, Han, Barton, & Welfare, 2004). The IBDQ has four domains: two domains measure symptoms (bowel and systemic) and two domains measure function (emotional and social), and all domains should be reported rather than just the global score (Guyatt et al., 1989). Researchers should report these HRQOL domains separately, as opposed to a global score, as substantial information is lost without the use of HRQOL subscale scores (Hobart, Williams, Moran, & Thompson, 2002).

Future Research

Additional self-management research is needed that assesses symptom outcomes. Only two of the six studies included any symptom as an outcome (Keefer et al., 2013). However, symptoms are of singular importance in IBD because they are among the most distressing aspects of IBD (Stjernman, Tysk, Almer, Strom, & Hjortswang, 2010), and thus should be addressed as an outcome of self-management, as they are in other immune-mediated diseases (Lorig & Holman, 2003; Plow, Finlayson, & Rezac, 2011). We also noted that the term symptom was used interchangeably with both disease activity and HRQOL, but these three terms are conceptually distinct and should not be confused, because a lack of conceptual clarity leads to chaotic literature (Anderson & Burckhardt, 1999). Future research, such as a concept analysis, is needed in IBD to distinguish these concepts.

All four of the large IBD self-management trials were conducted in Europe. Due to the difference in global healthcare systems, insurance, and cultural beliefs, large self-management trials are needed in other areas of the world to determine the feasibility and effects of self-management in diverse healthcare settings and cultures.

Limitations

A single author screened all the abstracts and articles. The same author also conducted the data abstraction and quality screening. Only English-language articles were reviewed; thus, relevant articles may have been missed. Some grey literature may have been missed since only one database (Proquest) was searched to obtain dissertations and no unpublished articles were included. The descriptions of the interventions were often vague; as a result, there may have been additional skills taught that were not captured due to insufficient detail.

Clinical Relevance

Nurses working on multidisciplinary health-care teams have an important role in teaching self-management skills in IBD (Keefer, Kiebles et al., 2012). In each encounter, nurses should assess for what self-management skills an individual is currently using and teach self-management skills that are lacking. Training in motivational interviewing and cognitive behavioral therapy can assist nurses in assessing for readiness for self-management and in teaching self-management skills (Bos-Touwen et al., 2015). System changes, as were implemented in three of the interventions, may be necessary for successful self-management.

Conclusions

Self-management shows promise as the means to improve the outcomes for the large and growing population of patients with IBD. Additional research is needed to better understand the active components of self-management and how self-management works in diverse populations across the globe.

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Clinical Resources

- Self-Management in IBD from Crohn's and Colitis UK and The Royal Society of Medicine in London: https://videos.rsm.ac.uk/video/self-management-of-ibd
- Stanford Self-Management Programs: http://patienteducation.stanford.edu/programs/
- U.S. Department of Health and Human Services Self-Management Support: http://www.orau.gov/ahrq/sms_home.html

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CLINICAL SCHOLARSHIP

Exploring the Masculine Identity in the Context of HIV Prevention in Chile

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Abstract

Purpose: This study aims to describe human immunodeficiency virus (HIV)-related knowledge and beliefs, as well as understanding attitudes towards masculinity in the context of HIV prevention, held among Chilean men.
Design: This study reports the qualitative findings of a sequential qualitative-quantitative mixed methodology study: Bringing men into HIV Prevention in Chile, NIH R01 TW007674-03.
Methods: Twenty in-depth interviews using a qualitative, descriptive approach to elicit information for the study were conducted among men residing in two communities of low socio-economic status in Santiago, Chile.
Findings: Content analysis of interviews revealed three main themes regarding *machismo* and how it relates to HIV: sexuality and *machismo*, the changing nature of *machismo*, and violence against women.
Conclusions: Addressing HIV and intimate partner violence through developing education programs tailored to meet the needs of Chilean men are needed to include men in HIV prevention efforts.
Clinical Relevance: Specifically, incorporating ideas of what men consider healthy masculinity and working to destigmatize men who have sex with men are important steps in addressing the negative aspects of *machismo*.

The most recent report from the Joint United Nations Program on HIV/AIDS (2011) indicated that over 34 million people worldwide were living with the human immunodeficiency virus (HIV), with 2.7 million new infections, and 1.8 million HIV-related deaths, which reflects an increase in HIV prevalence worldwide. This situation is similar in Latin America, where the total number of people living with HIV (PLWHIV) continues to grow, with a significantly higher number of HIV cases experienced among men in comparison to women (United Nations AIDS [UNAIDS], 2011). This growth in new infections is heavily concentrated among populations of men who have sex with men (MSM), sex workers, and injection drug users (UNAIDS, 2012).

According to UNAIDS (2011), the prevalence of HIV among adults in Chile was approximately 0.4% up to 2011. From 1986 to 1990, the ratio of men to women living with HIV was 7:1, however as of 2011 the ratio had dropped to 3.6:1. Even with increased cases of HIV among women, men still represent the larger portion of total cases (Chilean Ministry of Health, 2007, 2010;

Ministerio de Salud, 2011). The main form of transmission in the Chilean population occurs through sexual contact (87.6%) with the highest rates being among adult men (UNAIDS, 2012). These data are reflected in Santiago, the region where more than half of the Chilean population resides and has been identified as having the third highest prevalence of HIV (Ministerio de Salud, 2011).

The majority of the reported HIV cases in Chile were acquired through sexual contact with an infected partner, a pattern that may be explained by the presence of traditional gender roles and gender inequalities presented in the concepts of *machismo* and *marianismo* (Cianelli, Ferrer, & McElmurry, 2008). *Machismo* is the expression of a masculine identity that frames men as providers, independent, strong, willing to face danger, dominant, heterosexual, virile, knowledgeable, aggressive, and in control of women (Cianelli et al., 2008; Gonzalez, Molina, Montero, Martinez, & Leyton, 2007). *Marianismo* is the expression of a feminine identity considered the complement of *machismo*; it denotes the submission of women to men and an ideal of women as being pure, dependent, vulnerable, abstinent until marriage, innocent, silent, and self-sacrificing (Cianelli et al., 2008; Patz, Mazin, & Zacarias, 1999). *Marianismo* discourages women from confronting their sexual partners about their sexual behavior and supports the submission of women to men (Arciniega, Anderson, Tovar-Blank, & Tracey, 2008; Cianelli et al., 2008).

The concept of *machismo* encourages men to have multiple female sexual partners as a way to express their masculinity. Having multiple sexual partners puts men and their partners at higher risk for contracting HIV because of the increased possibility of having a sexual contact who has HIV. Sexual contact under the influence of drugs and alcohol or having coerced sexual contact can increase HIV risk (Caceres, 2002; Cianelli et al., 2008; Gonzalez et al., 2007). In addition, the threat of being stigmatized for being an MSM, due to homophobia associated with *machismo*, is often considered cause for an MSM to engage in sexual contact with women (Estrada, Rigali-Oiler, Arciniega, & Tracey, 2011; UNAIDS, 2010). MSM have been reported to conceal having male sexual partners and continue sexual relationships with female partners, who believe they are engaged in a monogamous relationship (Cianelli et al., 2008; UNAIDS, 2010).

Intimate partner violence (IPV) and coerced sexual relationships are reported to be related to the negative aspects of machismo, increasing the risk for HIV acquisition (Miner, Ferrer, Cianelli, Bernales, & Cabieses, 2011). IPV is an important issue many Chilean women experience in relationships, and its significance can often be interrelated with cultural norms learned during childhood, such as that women must be good wives and mothers; that women must be respectful of and dependent on men; that men make all the important decisions, including those that have to do with women's aspirations and goals in life; and that women must subordinate their pleasure to the decisions and feelings of men (Arcos et al., 1999; Cianelli, 2003; Cianelli et al., 2008).

However, while domestic violence in Chile is extremely taboo and some people accept the aggressor's actions because of *machismo*, the culture promotes the supremacy of men over women (Cianelli, 2003; Cianelli et al., 2008). The reason why this is taboo relates also to *machismo*, since men can act aggressively and will receive no punishment; most women will stay silent, because it is accepted and sometimes even seen as something they deserve.

Machismo has also been reported to promote protective factors against HIV acquisition, in which a man is expected to treat women with respect, work hard to provide for his loved ones, and be a good husband and father (Arciniega et al., 2008; Cianelli et al., 2012; Neff, 2001). These positive traits are sometimes referred to as caballerismo (Arciniega et al., 2008; Cianelli et al., 2008). The changes in Chilean society—such as women working outside the home, equal access to education for women and men, and the identification of more egalitarian relationships in which men develop activities that are traditionally related to the woman's role in society—may indicate a change in cultural values (Contreras & Plaza, 2010; Salinas, 2007). Chilean women are reported to be less willing to accept behaviors associated with *machismo*, particularly if they work outside of the home (Contreras & Plaza, 2010). Similarly, those women with more education reportedly experience less presence of traditional gender roles and have more access to work outside the home (Contreras & Plaza, 2010). However, other studies conducted in Chile indicated that even when men are open to gender equity, in daily life women are still responsible for household chores and childcare (Salinas, 2007).

Gaining deeper understanding of how Chilean men relate to masculinity, and *machismo* in particular, may help to identify sexual risk factors for HIV acquisition and increase men's ability to discuss health-related issues related to certain risk factors. That understanding can be achieved through men's testimonies and discourses of the meanings they assign to male roles and their connection to HIV, something not previously reported for Chile or foreign countries.

This study aims to qualitatively describe HIV-related knowledge and beliefs, as well as understanding of masculinity and HIV prevention held among Chilean men residing in two socio-economically disadvantaged communities in the Chilean capital, Santiago. Information was obtained through the original study, which used a sequential qualitative–quantitative design to identify contextually specific needs of low-income Chilean men and then to test the effectiveness of a culturally tailored peer group, an HIV/AIDS prevention intervention based on models that have been utilized for low-income Latinas in Chicago (Peragallo et al., 2005) and for adults and adolescents in rural Malawi (Norr et al., 2006).

Methods

To report the qualitative findings of the sequential qualitative–quantitative study, Bringing Men into HIV Prevention in Chile, a qualitative, descriptive approach using in-depth interviews to elicit information was utilized. This method was selected because it provides an in-depth understanding of the phenomenon of interest by obtaining a detailed view from the participant's perspective (Creswell, 2007). Researchers stay closer to the data and to the meaning participants give to the facts (Sandelowski, 2000). The researchers obtained information from in-depth interviews with participants to disclose aspects of the phenomena that were less accessible in other research methods.

Setting and Participants

The study was conducted in Santiago, Chile, specifically in two low-income communities located in the southeast area of Santiago's metropolitan region. This region, together with Arica-Parinacota, Tarapacá, and Valparaíso, has a large concentration of people living with HIV in Chile (Department of Epidemiology, Chilean Ministry of Health, 2013). The southeast area is one of the most affected by HIV infection in the Region Metropolitana (Chilean Ministry of Health, 2009). Considering their similar socioeconomic statuses, their high-risk profiles, and the potential benefits for the community that their participation could offer, these communities were invited to participate in the study.

Twenty men participated in the study. To be eligible, participants met the following inclusion criteria: (a) being Chilean, (b) being at least 18 years old, (c) living in one of the two selected communities, and (d) being willing to participate. All the participants were between 18 and 60 years old, lived in low-income communities in the southeast area of Santiago, and had at least 7 years of formal education. Most of them were working in construction or low-paying jobs.

Saturation was used to determine the sample size of the qualitative data. At the point when no new data were emerging from the interviews, it was determined that the topic was saturated, indicating that the limits of the phenomena had been covered, and the interviews were terminated. To accurately describe the phenomena under study, saturation of data in the study was obtained with 20 participants.

Ethics and Recruitment

The original study was approved by the Institutional Review Board at the Escuela de Enfermería, Pontificia Universidad Católica de Chile.

Participants were recruited from healthcare centers, sports clubs, and other community-based organizations in two low-income communities in Santiago, Chile. In addition, the research team placed fliers at popular sports gatherings in the two communities (e.g., churches, community centers, grocery stores, service agencies, libraries). Men who read the fliers and were interested in the study called a toll free number directed to the study. The study staff members contacted the potential participants to further describe the study and determine eligibility. If a potential participant was interested and met inclusion criteria, an appointment to conduct consent was made. Once the study was explained and written informed consent was obtained, an assessment was completed and the interview was scheduled.

Data Collection

Twenty in-depth interviews were conducted by research staff who were trained and led by the principal investigator and co-investigators. After obtaining consent, the interviewers conducted the in-depth interviews using a semistructured interview. This type of interview is most effective in situations where the interviewer only has one chance to interview someone. In-depth interviews allowed the researchers to gather rich data about *machismo* in the context of HIV prevention (Bernard, 1995). In-depth interviews were conducted using a semistructured interview guide (**Table 1**). The interview guide is often substantially less structured than the type of questionnaire used in survey research or opinion polling (Lofland & Lofland, 1995). A semistructured interview guide was appropriate for the purposes of this research because it allowed the interviewer to follow the guide and cover the same areas with each study participant. The questions chosen to guide the discussion were based on literature review, input from a panel of experts, and opinions of community leaders. Probes were used to stimulate the participant during the interview. The interviews lasted 30 to 60 min, and all the interviews were audio recorded. *Machismo* and HIV are topics that are not typically discussed openly among Chilean men in the community; consequently, a face-to-face interview facilitated the disclosure of perceptions about these topics.

Active listening and sensitivity to the verbal and nonverbal responses of the study participants was an important aspect considered by the interviewers. Interviewers responded neutrally to the participants throughout the interviews, without influencing their answers (Patton, 2002).

Data Analysis

All the audio recordings were transcribed verbatim in Spanish and translated to English for content analysis by a transcription and translation service. We were careful not to include any identifying information in the transcriptions. The research staff meticulously reviewed the transcriptions to verify that there were no discrepancies in either the Spanish or English versions. Research files were stored in a locked area, and digital files were saved in password-protected computers.

The principal investigator and a co-investigators of the study listened and reviewed all the transcriptions for accuracy. Qualitative content analysis was used to identify and define the major themes that emerged from the interviews. Content analysis is a method used to recognize, code, and categorize patterns from text data (Patton, 2002; Sandelowski, 2000). To analyze the transcripts, directed content analysis was used, a type of analysis recommended when there is prior literature related to the phenomenon of interest that can be of benefit from further description (Hsieh & Shannon, 2005).

Based on prior literature reviews of experiences working with different Chilean communities (Cianelli et al., 2011, 2012), broad categories were defined for the purpose of coding. We applied predetermined themes based on previous research findings in this field to guide the analysis of the interviews (see the interview guide, **Table 1**). A codebook and a coding sheet were developed to facilitate the coding process. Four research team members independently coded line by line, without input from others. At the point of completion, the results were compared, and a 90% agreement of transcription was obtained. The coders together determined the final themes and subthemes from the predetermined codes and new findings in the coding process.

Results

Three main categories emerged from the interviews regarding *machismo* and how it relates to HIV: sexuality and *machismo*, the changing nature of *machismo*, and violence against women.

Sexuality and *Machismo*

The participants in these two communities described *machismo* as a constant concession between what it is to be a man on an individual level and what society expects a man to be. This definition was tied into the previously mentioned concepts of *machismo* and *caballerismo*, in that men described both negative and positive aspects of masculinity. The term *machismo* was interwoven throughout most of the interviews as something negative that some men exhibit and other men do not. One man said:

> I have *machismo* attitudes inculcated [from my family] since I was a kid, attitudes also inculcated as a social habit . . . the society is like this [*machista*] in this country and one is raised *machista* . . . I see it [*machismo*] as normal sometimes, but suddenly I realize that this is not normal . . . but you have it recorded in your system and one is like this.

In addition, a *machista* man is described as "apprehensive, jealous, reckless, unaffectionate, a man who treats women very badly" ("aprensivo, celoso, poco cuidadoso, poco cariñoso, el hombre como que trata muy mal a la mujer"). A participant said:

> The man in his relationship is careless . . . I think that, the man does not know how to take care of his partner . . . I mean as we say in the jargon "does not care his land," it does not matter . . . is because of the *machismo* that he has . . . "this is mine, this is my property," as a cabinet or something that he buys, he says "this TV is mine, I have the bill for this and this is mine." It is a rooted term [for example, this man] married a woman or the woman lived with this guy and [the man thinks] "I can make twenty thousand mistakes but this is mine [the woman], I am free to make several mistakes because this is mine [the woman]."

While most participants did associate *machismo* with negative aspects of masculinity, some men also described a different type of *machismo* that could be used as a facilitator of HIV prevention, as someone who is "understanding, loving, serious, and patient" (*comprensivo, amoroso, serio, paciente*). In this description, these men may have been describing the previously defined concept of *caballerismo*, without referencing the specific term. The men also talked about the constant pull they felt in trying to be loving, kind, and faithful while also trying to prove themselves as "*macho*" through sexual contact with women. In the following subthemes, we will discuss the roles of both female and male sexual partners and their relationship to *machismo* and HIV prevention.

The Role of Female Sexual Partners

As mentioned, the negative interpretation of *machismo* was a prevalent narrative throughout the interviews. The way in which men treat their female partners was

Table 1. Interview Guide

Topic/themes	Interview questions
HIV/AIDS	What is the first thing that comes to mind when hearing HIV/AIDS?
	Do you know how HIV/AIDS is transmitted?
	Do you think that HIV/AIDS is affecting men in your community?
Machismo	How do Chilean men behave in relationships?
	Tell me five words that best describe Chilean men in relationships.
	What have you heard about Chilean men have more than one sexual partner?
	What have you heard about Chilean men sometimes having a man as a sexual partner?
	What have you heard about Chilean men who have a man and a woman as sexual partners?
	Do you think that Chilean men's behavior in relationships is related to the possibility that women in your community can acquire HIV/AIDS?
Marianismo	How do Chilean women behave in relationships
	What do you think of the following sentence? "Chilean women and men have the same rights in the relationship." Is this the same in the sexual context?
	What have you heard about Chilean women having more than one sexual partner?
	Tell me five words that best describe Chilean women in relationships.
	Do you think that Chilean women's behavior is related to the possibility that women in your community can acquire HIV/AIDS?
Domestic violence	How would you describe domestic violence in relationships?
	Have you heard of the term "sexual violence"?
	Do you think that Chilean culture somehow accepts domestic violence?
	Do you believe that domestic violence is related to the possibility that the women in your community can acquire HIV/AIDS?
Substance abuse	Tell me what is happening with drug use in your community, including alcohol.
	Do you think drug use is related to the possibility that the women in your community can acquire HIV/AIDS?
HIV/AIDS prevention	Do you think people in this community know how to prevent HIV? What are the forms of prevention?
	What are the factors that promote and/or impede HIV prevention in these men?
	What do you think should be done to prevent HIV/AIDS among men in your community?
	If there was an HIV prevention program for men, what do you think that content should include? Do you think there should be an HIV/AIDS prevention program in this community?

described as a key component of maintaining a macho identity. Interviews also revealed that having multiple female sexual partners, or at least claiming to have them, was an essential part of being macho. The phrase "the more women, the more manly" (*"entre más mujeres, más hombre"*) was frequently heard in the interviews. One participant said:

> I believe . . . for example that infidelity exemplifies the *machismo* because . . . it is normal or parents tend to instill male children that "the more women, the best macho you are." Do you understand me? . . . and therefore is a way of predispose their sons to take that attitude with their partners. . . .

The men talked of having a primary female sexual partner, as well as keeping other female sexual partners on the side. Men emphasized the superiority earned by a man who could maintain their primary partner, usually the mother of his children, and could also have sexual relationships with other women. A man said:

> A man will not let go to the first partner, I mean one will look for an adventure, but after that will go back to the first partner . . . for example . . . a friend, he always says he is bored, he is bored of being always with the same person, then he tries new things, find new people and have fun.

When discussing relationships with women, men described a common double standard in which a man who has more sexual partners is not only accepted, but seen as "more manly" (*"más hombre"*) and a woman who has more than one sexual partner "is not a proper young lady" (*"no es señorita"*). In other words, men are pressured to have more sexual partners to demonstrate more masculine behavior, and women are discouraged from having sexual partners to demonstrate more feminine behavior. One participant said:

> The presence of the macho culture requires do not compromise feelings, the emotional part; [for this reason, men] tend to compromise the behavioral part . . . several times if you have more relationships or more contacts with women, or the more "winner" or gallant you are . . . the culture or the group of men tend to see you better, you have a better value.

The concept of maintaining multiple sexual partners to feel more macho was identified as a widespread trait among men by the interviewees. The participants explained that men are just "this way" and that men have "more open and crazy sexual minds" (*"una mente sexual mas abierta, mas loca"*), using nature to explain and justify this double standard. Finally, participants reported condom use as extremely uncommon and that both cost and lack of knowledge were major obstacles for men in the community. One participant, while demonstrating clear risk perception of unsafe sex, explained that while he understood the importance of condom use, people do not use them:

> Men do not take precautions. Not all men use condoms . . . they may buy it, but they do not use it or they may not know how to use it. I personally go looking for other partners and I do not use a condom, but I should use one.

Another man said:

> [it makes difficult to use condoms] in men the [high] cost . . . a box of condoms is not enough for a week if you have an active sexual life. And you do not go to the clinic to ask for condoms, because I believe, everyone told me that those condoms are bad [quality] that I should not go to get them. . . . [There is also] fear of going to buy condoms from the pharmacy. . . fear of being stigmatized by the society and that sex is bad. Even when you are buying condoms in the pharmacy, the ladies next to you look at you. . . . The Chilean society does not realize that this is to prevent pregnancy and STDs, besides AIDS and syphilis.

Here the participants cite both access challenges and lack of knowledge on condom use as the primary reasons for not using condoms. Similarly, another participant explained that while it is common for both men and women to have multiple sexual partners, many do not use protection because they do not understand the risks involved. This explanation further highlights lack of HIV prevention knowledge and risk as a barrier to condom use.

The Role of Male Sexual Partners

Defining masculinity based on sexuality goes beyond sexual relationships with women. Men also described the weight of sexual relationships with men in the context of *machismo*. Being a *maricón* or *marica*, derogatory terms used to label homosexual men, was a consistent fear expressed by participants. One of the ways to avoid the *maricón* label is rooted in reporting sexual activity with women. Not only did men describe feeling pressure to have multiple female sexual partners, but a need to make their sexual histories public within their social circles. A participant explained the idea that "there's a double standard: one acts macho so that nobody calls him anything else . . . so that nobody calls you a faggot or something." Another participant said:

> In a group of five people, [a group of] five men sit down to talk . . . the one who has fewer women is not so macho as it should . . . that is, if you talk about abstinence or if you say: look guys, for a personal choice I prefer abstinence, [the men will say] no way, this guy is a faggot without any doubt.

In this sense, being a *mariquita* was depicted as the antithesis of a macho identity, though not all men expressed negative views towards homosexual men. Participants acknowledged that men sometimes had experiences with other men when under the influence of alcohol or if they were bored with their female partner. Sexual experimentation with other men during adolescence was also acknowledged as something that occurred in the community. A man said:

> [I have seen] gay men with [heterosexual] drunk men, with men who are drunk, then the drunk man always messes with the gay . . . to experiment, to satisfy their animal instinct . . . he gets involved with a gay, and they have relationships and whatever.

Although participants wanted to exhibit *macho* characteristics in the context of homosexuality, men also distanced themselves from *machismo*, again stressing the dynamic relationship many had with masculinity. Many of the men expressed that they did feel they had *machismo* beliefs. However, they explained that they also saw it among other men in the community.

The Changing Nature of *Machismo*

Many of the men reported that ideas of masculinity are being reorganized and redefined. Men also noted that the definition of *machismo* is changing and that it does not have the connotation it once did. For example, one man stated, "A Chilean man is a coward" ("*Un hombre chileno es un cobarde*") and explained that often Chilean men have children with more than one partner, which stigmatizes the act of having more multiple sexual partners. Another man interviewed stated:

> It [*machismo*] has changed, before the woman had to be totally dependent on the man for everything and if he arrived at 6 a.m. and wanted fried eggs and his friends did too then the woman would have to be there and do what he said. Today this has changed; women do not do this. They are working and the man cannot make these demands because a woman can support herself and does not need to rely on the man for support.

This statement is significant, as it recognizes the changing nature of the masculinity experienced in the sampled communities and explains that in typical *machista* relationships men have explicit power over women, particularly financially. However, with more and more women entering the workforce in Chile, this domination cannot function in the way it once did. Another participant said:

> Well, my opinion . . . now the relationship has changed . . . before was the man who worked, however now . . . women are incorporating in the workplace, they are being more independent . . . the man in this case will not like to admit it, I mean there are still some families that this [a woman working outside home] is not right, the woman has to stay at home to take care of the children.

The participant´s negative reaction to *machismo* demonstrates the diverse way in which men in these communities experience masculinity. Contrary to the belief that all men are hypersexual and that having multiple partners is natural, men rejected this overarching definition of masculinity. Some men stated that they viewed themselves as equals with their female partner and that the sexual relationship was discussed between them in such a way so that both people were satisfied. One participant shared his belief that:

> Men and women are equal in relationship, women are stronger these days, demanding their rights. If my wife does not want to have sex, then I do not force her—we have to enjoy it. Some people are not this way.

Men shared that they communicated with their female partners and actively defined roles and responsibilities within the relationship. In these instances, the power play between men and women was seen as more egalitarian—recognizing women's desires and needs as valid—and that recognizing this is not contradictory to being masculine.

Furthermore, men recognized the changing nature of interpersonal relationships, marriage, and the family unit. One man shared:

> Before, the term macho did not exist . . . it was Don Juan or *mujeriego* in the 1960s. My father had three women with whom he had children—I only met two of them. Me personally, I did a lot [sexually] when I was single, but when I was married there were very few times that I visited those apartments, the ones that there are so many of downtown, but I also matured in the sense of giving them up one at a time.

This statement traces the history and reorganization of masculinity and marriage within the Chilean context. This participant acknowledged that historically, *machismo* was not recognized as it is today. The *machos* or Don

Juans used to have a positive connotation, but today the concept of multiple sexual partners is not as commonly accepted. However, this respondent did say he at one point of his life frequented brothels during marriage and had to slowly quit going. At the same time, this participant made it clear that he did not go to brothels as often as he believed men of previous generations tended to, acknowledging both the present and past conditions of *machismo*.

Violence Against Women

Many of the participants reported having witnessed domestic abuse, whether physical, sexual, or financial, in their communities among other men. However, none of the men disclosed any personal experiences of violence in their own relationships towards their female partners. Though participants recognized that the male identity is changing, they spoke of violence in their communities and explained how this violence tied into the *machismo* identity. One man mentioned that "being *macho* is abusing power through verbal and psychological violence and infidelity." According to this participant's description, *machismo* incorporates violence against women as a way to establish power among men over women, clearly defining roles within intimate relationships and society. Domestic violence against women was regarded by participants as something relatively normal within relationships and that very few individuals intervened when they were witness to acts of violence in the sampled communities. For example, one of the men said, "So each person worries about himself, like if I see another guy hitting his wife it's not my problem." Another participant said:

> It's a little sad, that it doesn't have to be this way, but the people or society are used to it, the same way they're used to keeping quiet for example, when things like crime happen, when people are assaulted, everyone keeps quiet.

According to interview data, there is a general acknowledgement that violence against women exists in communities and there is a culture of silence and fear of getting involved in someone else's business. However, at the same time, the participants also described the changes that were happening in their communities. For example, one participant explained that children these days are capable of calling the police immediately if they experience violence in their homes, something that was not typical in the past:

> Today if the kids are around, I would say my granddaughter, my granddaughter is 11 years old and knows perfectly well that we have their address or if she sees something physical or whatever, she can call the police.

In the statement above, the participant, while acknowledging the prevalence of domestic violence and general complacency and fear of responding, he notes that children today know exactly what to do if they see violence and are capable of calling the police. Other participants said that older women would not call the police or try to stop violence against them. However, many participants noted that women today do not tolerate violence and will call the police or file a police report.

The narratives depict a change in the response to violence, but even so, they confirm that violence against women is still present in the communities. Although positive changes in women and young people's reactions when faced with violence are clear in participant interviews, it is also evident that violence against women in these communities is far from being eradicated. A man said:

> Everyone knows [about domestic violence] but is hidden . . . everything hidden, but ultimately everyone knows that there is violence in every house, in one way or another. Violence occurs at any time, you walk down the street and you can hear a person yelling, or the same violence, for example if one day I argue with my dad, with [xxx], and I do not talk to them and I will not feel bad, I think that's also violence, though not physical.

Discussion

These findings revealed that the men did not feel vulnerable to contracting HIV because of cultural characteristics related to *machismo* and its consequences, such as homophobia and acceptance of male social dominance that promotes risky behavior for HIV. The findings indicated that for Chilean men the main form of acquiring HIV is sexual contact and that the presence of traditional gender roles increases the transmission, which is congruent with the literature (UNAIDS, 2012; Cianelli et al., 2008). The results of this study are essential for HIV prevention because, as evidenced earlier, many aspects of *machismo* can put men and women at risk for HIV/AIDS (Caceres, 2002; Cianelli et al., 2008; Parker, 1996; Miner et al., 2011; Pérez-Jiménez, Seal, & Serrano-García, 2009).

The themes identified in these interviews demonstrate the importance of societal pressure incorporated in the definition of masculinity and *machismo*. In many instances, men talked about the difficulties they faced trying to prove their masculinity in order to avoid being called homosexual, confirming previously conducted research that has demonstrated the complexity of the male identity, particularly among Latinos (Estrada et al., 2011; UNAIDS, 2010). Participants made direct links between the fear of being labeled homosexual and feeling pressured into having multiple sexual partners to avoid it. This is congruent with the literature, which describes that homophobia associated with *machismo* is often considered cause for MSM to engage in sexual contact with women (Estrada et al., 2011; UNAIDS, 2010).

At the same time, the participants acknowledged that men in the community did have sexual contact with other men. The stigma attached to male–male sexual contact creates a dangerous situation because, as reported in the interviews, men may enter into multiple sexual relationships with men and women, without using condoms, increasing their own risk for HIV and that of their partners, particularly those who believe they are in a monogamous relationship (Cianelli et al., 2008; Pérez-Jiménez et al., 2009). The use of drugs and alcohol was linked with this type of behavior, and it should be addressed in future studies because it can increase HIV risk (Caceres, 2002; Cianelli et al., 2008; Gonzalez et al., 2007).

The interviews clearly illustrated the struggle between caballerismo and *machismo* as defined by Cianelli et al. (2008) and Arciniega et al. (2008). The men defended their role as traditional provider and protector of the family, but rejected the negative abusive definition of *machismo*. Men talked about how the meaning of masculinity is changing and that the roles of men and women are not defined as they used to be. Additionally, men explained that the contexts where roles of masculinity develop are also changing, as each generation considers these changes and implements them when raising their children. This claim is important in that it follows previously conducted research on both the positive and negative aspects of male identity—*machismo* and *caballerismo* (Arciniega et al., 2008). However, while positive change towards more equal gender roles was a clear theme in the interviews, the emphasis on multiple sex partners, infidelity, and ambivalence about condom use were reported as remaining solid aspects of *machismo* today. Furthermore, the recognition that these ways of life put both men and their sexual partners at much higher risk for HIV/AIDS was communicated.

This initiative is essential for HIV prevention because, as evidenced earlier, many aspects of *machismo* can put men and women at risk for HIV/AIDS (Caceres, 2002; Cianelli et al., 2008; Miner et al., 2011; Parker, 1996; Pérez-Jiménez et al., 2009). However, there are other aspects of the male identity which could be used as facilitators of HIV prevention (Cianelli et al., 2008; Pérez-Jiménez et al., 2009).

Although the role of women is changing, domestic violence is still prevalent and used as a method of maintaining control over women and expressing masculinity. According to the interviews, women in the sampled communities are still expected to forgive both infidelity and abuse (Cianelli et al., 2008; Miner et al., 2011). This trend coincides with previous research within the Chilean community conducted by Cianelli et al. (2008), who identified that women call this behavior *marianismo*. While progress towards extinguishing the community's acceptance of IPV has been made, it is important to understand how domestic violence, as well as other negative aspects of the macho identity such as multiple female sexual partners, and aggressive and dominant behaviors, increase the risk for HIV. IPV has been labeled as a risk factor for contracting HIV and a barrier to HIV prevention (Miner et al., 2011; Pérez-Jiménez et al., 2009). This is an important aspect of *machismo* that should be targeted when developing HIV prevention education in Chile.

Conclusions

The information extracted from these narratives gives insight to the struggles fought among men to understand their own identity within the community. These results were used to adapt the *Mano a Mano para Hombres* intervention, specifically in how to incorporate the role of the culture in HIV prevention among men. Based on these results, the intervention included different activities to increase awareness about HIV transmission and the consequences of infection and reduced misconceptions about the topic. For example, role playing is an excellent technique that can be included in prevention programs with Chileans to improve communication between partners.

In addition, these results should be considered in public health initiatives targeting men in Chile. Creating a public health response that incorporates and addresses different aspects of *machismo* is essential if men are to be engaged in public health interventions. Education programs addressing HIV prevention and IPV that are tailored to meet the needs of Chilean men are needed to incorporate men in HIV prevention. Specifically, incorporating ideas of what men consider healthy masculinity and working to destigmatize MSM are important steps in addressing the negative aspects of *machismo*.

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Clinical Resources

- Chilean Ministry of Health: http://web.minsal.cl/vihsida-e-its/
- Flacso Chile: http://www.flacsochile.org/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Dying Care Interventions in the Intensive Care Unit

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Abstract

Purpose: Providing high-quality end-of-life care is a challenging area in intensive care practice. The aim of the current study was to assess the practice of registered nurses (RNs) with respect to dying care and spiritual support interventions in intensive care units (ICUs) in the Czech Republic (CR) and find correlations between particular factors or conditions and the frequency of NIC interventions usage.

Design and Methods: A cross-sectional, descriptive study was designed. A questionnaire with Likert scales included the particular activities of dying care and spiritual support interventions and an evaluation of the factors influencing the implementation of the interventions in the ICU. The group of respondents consisted of 277 RNs working in 29 ICUs in four CR regions. The Mann–Whitney *U* test and Pearson correlation coefficient were used for statistical evaluation.

Findings: The most and least frequently reported RN activities were "treat individuals with dignity and respect" and "facilitate discussion of funeral arrangements," respectively. The frequencies of the activities in the biological, social, psychological, and spiritual dimensions were negatively correlated with the frequency of providing care to dying patients. A larger number of activities were related to longer lengths of stay in the ICU, higher staffing, more positive opinions of the RNs regarding the importance of education in a palliative care setting, and attending a palliative care education course.

Conclusions: The psychosocial and spiritual activities in the care of dying patients are used infrequently by RNs in CR ICUs. The factors limiting the implementation of palliative care interventions and strategies improving implementation warrant further study.

Clinical Relevance: Assessment of nursing activities implemented in the care of dying patients in the ICU may help identify issues specific to nursing practice.

Contemporary consumer society with its technological advances is characterized by medicalization and institutionalization of care for patients in the terminal stages of disease (Borowske, 2012). Out of all the deaths in 2012, 17% of patients died in intensive care units (ICUs) in the Czech Republic (CR; Institute of Health Information and Statistics of the Czech Republic, 2013). The ICU mortality rates range from 15% to 24% worldwide, and there is an increase in ICU use during the last 30 days of life (Intensive Care National Audit and Research Centre, 2014; Teno et al., 2013). The role of intensive care nurses shifts in these situations from providing aggressive life-saving care to end-of-life (EOL) care (Espinosa, Young, Symes, Haile, & Walsh, 2010). Intensive care nurses are often confronted with existential questions, such as the meaning of suffering and death (Hov, Hedelin, & Athlin, 2007). The term EOL care has been adopted by regulatory bodies in European countries, at times with the understanding that palliative care is predominantly associated with cancer, whereas EOL care could be applicable to all patients (Radbruch & Payne, 2009). In accordance with this practice, we make use of the term EOL care in this article.

The performance of EOL nursing interventions may be difficult in the field of critical care medicine with highly sophisticated therapeutic and nursing procedures. The factors required for quality EOL care in the ICU include communication on the part of healthcare staff with patients and family, a supportive environment, and professional knowledge and skills on the part of nurses (Attia, Abd-Elaziz, & Kandeel, 2013; Fridh, 2014; Holms, Milligan, & Kydd, 2014; Levin, Moreno, Silvester, & Kissane, 2010). Additional important factors include skilled pain management, mutual acceptance of death, managing care, and promoting comfort (Beckstrand, Callister, & Kirchhoff, 2006; Kongsuwan & Loscin, 2009). Nursing time options also significantly affect the use of palliative interventions. Time is crucial in building trusting relationships with families, and it is important to have time to develop a quality relationship with families by getting to know the patient and family members over time (Liaschenko, O'Conner-Von, & Peden-McAlpine, 2009). The barriers for providing EOL care in the ICU include a lack of nursing experience and education, low staffing levels, and an environment not designed for EOL care (Espinosa et al., 2010).

Selection of nursing interventions for a specific patient is one of the key nurse competencies. The Nursing Interventions Classification (NIC) is a comprehensive, research-based, standardized classification of the interventions that nurses perform. It is useful for clinical documentation and communication of care across all types of healthcare settings (Bulechek, Butcher, & McCloskey Dochterman, 2008). It can be used for a selection of specific nursing activities (Hahn, 2014). Dying care and spiritual support interventions include activities related to the physical, social, psychological, and spiritual human dimensions (Bulechek et al., 2008).

Providing quality EOL care is a challenging area in intensive care practice. There is an increasing awareness of differences in clinical practices in EOL across Europe and worldwide (Ball et al., 2010; Gysels, Pell, Straus, & Pool, 2011; Meñaca et al., 2012). Beckstrand et al. (2006) stated in their previous study that national surveys are needed to help overcome potential regional differences in care of dying patients in ICUs. The objectives of the current study were to consequently assess the use of NIC interventions (dying care and spiritual support) with dying patients in the ICU in the CR and identify correlations between particular factors or conditions and the frequency of NIC interventions usage.

Methods

Design and Sampling

A cross-sectional, descriptive study design was used in order to conduct the present research. A convenience sample of nurses was recruited for this study from 29 ICUs in four regions of the CR (Olomouc, Moravian-Silesian, Zlín, and Prague). The inclusion criteria were as follows: a registered nurse (RN) providing direct patient care in the ICU, active practice in the ICU for at least 1 year, and signed informed consent.

Procedure

The study was approved by the local ethics committee (No. UPOL-4264/1040-2014). The study was approved via phone calls or meetings with the head nurses of the ICUs at all the participating hospitals. The researchers and head nurses had one meeting to discuss the details of the study, survey procedures, questionnaires, potential number of participants from each hospital, and data collection methods. The head nurses were given the questionnaires and a cover letter for the RNs explaining the purpose and importance of the study and their rights as research participants. Questionnaires and cover letters were distributed by the head nurses on their wards. The RNs returned the completed questionnaires in a sealed envelope to the head nurses, who handed them over to the researchers.

Measures

A structured questionnaire was developed by the authors from the recent literature (Bulechek et al., 2008) and was divided into two parts. The first part of the questionnaire consisted of activities of two interventions (dying care and spiritual support) from the NIC system suitable for different communities with various levels of secularization (Bulechek et al., 2008).

The questionnaire included 31 nursing activities (24 dying care interventions and 7 spiritual support interventions) in total. The dying care intervention (5260) is defined as "the promotion of physical comfort and psychological peace in the final phase of life." It contains 24 activities of the somatic and psychosocial dimensions, which focus on the patient as well as on support for the patient's family members. Our questionnaire featured all the 24 activities. The spiritual support intervention (5420) is defined as "assisting the patient feel a balance and connection with a greater power." It contains 29 religious and nonreligious activities related to the human spiritual dimension. Our questionnaire included seven mostly nonreligious activities. A large previous research on spiritual support determined that the remaining 22 activities appeared extremely rarely in Czech nursing practice (Kisvetrová, Klugar, & Kabelka, 2013).

The structured questionnaire included 31 nursing activities divided into four dimensions by the expert panel. It was designed by the authors of this article. We addressed experts from four areas (physician, clinical psychologist, hospital chaplain, and research nurse). There were 11 activities in the biological dimension, 6 in the social dimension, 9 in the psychological dimension, and 5 in the spiritual dimension. Selected activities were assessed using the Likert scale, ranging from 1 (*always*) to 5 (*never*).

The second part of the questionnaire consisted of items related to seven factors or conditions with a potential impact on providing EOL care according to the results of previous studies: (a) frequency of care for dying patients (Fridh, 2014); (b) length of patient's stay in the ICU (Aslakson et al., 2014); (c) staffing conditions (Penoyer, 2010); (d) time options for providing dying care (Liaschenko et al., 2009); (e) RNs' personal attitudes towards death (Braun, Gordon, & Uziely, 2010); (fa & b) communication with patients and the families of patients (Liaschenko et al., 2009; Adams, Mannix, & Harringzon, 2015) and (ga, b, & c) education in palliative care (Espinosa et al., 2010). The items investigated opinions of RNs concerning the factors using Likert scales ranging from 1 (*always/strongly agree/extremely sufficient*) to 5 (*exceptionally/strongly disagree/not at all sufficient*).

Data Analysis

The sample size calculation was based on the methodology described by Tichacek (ŽIaková, 2009), that is, 2.5% of the defined population sample (approximately 10,500 RNs working in CR ICUs). The calculations suggested that a minimum of 450 questionnaires were needed for distribution, assuming that 60% of the distributed questionnaires would be completed (Kisvetrová et al., 2013). The face validity of the questionnaire was performed by a panel of experts. The reliability was tested using internal consistency, which was measured using Cronbach's α coefficient for the entire questionnaire and for each dimension separately. A value of greater than 0.70 was considered acceptable (DeVon et al., 2007). The Shapiro–Wilk test was used for testing the correspondence of the calculated parameters to a normal distribution. Data with a normal distribution were reported as the mean ± standard deviation (*SD*). All parameters not fitting the normal distribution were presented as the mean, median, and SD. The Mann–Whitney U test and Pearson correlation coefficient were used for the statistics. Statistical significance was defined as $p < .05$. All data were analyzed using IBM SPSS Statistics (version 22.0; SPSS, Inc., Chicago, IL, USA).

Table 1. Demographic Data of Responders

Number of subjects; *N* (%)	277 (100)
Age (mean years ± *SD*)	34.71 ± 8.06
Length of practice	
Median years; mean years ± *SD*	8; 9.17 ± 6.84
Gender	
Female; *n* (%)	261 (94.2)
Male; *n* (%)	16 (5.8)

Results

Sample Characteristics

A total of 450 questionnaires were distributed in 29 ICUs in the four regions of the CR over the course of 14 months (March 2013–April 2014). Of those 450 distributed questionnaires, 277 were completed, collected, and statistically analyzed. The majority (94.2%) of the respondents were female. The age range of the respondents was 23 to 59 years. The length of work experience in the ICU ranged from 1 to 38 years. Complete demographic data of the respondents are shown in **Table 1**. The internal consistency of the structured questionnaire was considered acceptable because Cronbach's α coefficient was 0.92 for the entire questionnaire, 0.89 for the biological dimension, 0.85 for the social dimension, 0.87 for the psychological dimension, and 0.76 for the spiritual dimension.

The frequencies of activities are listed in **Table 2**. The most frequently used activities were "treat individuals with dignity and respect" (mean 1.28 ± 0.77 points), "monitor pain" (mean 1.30 ± 0.80 points), and "assist with basic care, as needed" (mean 1.32 ± 0.84). In contrast, less frequently used activities were "communicate willingness to discuss death" (mean 3.01 ± 1.21), "offer culturally appropriate foods" (mean 2.80 ± 1.36), and "facilitate discussion of funeral arrangements" (mean 2.75 ± 1.30).

The greater frequency in providing care to dying patients was related to providing more biological, social, psychological, and spiritual activities. No significant correlations existed between the frequencies of providing activities in particular dimensions and the feelings of

Table 2. Frequency of Activities Used

Dimension/activity	Mean (*SD*)	Median
Biological dimension	1.84 (1.12)	1
Monitor pain	1.30 (0.80)	1
Assist with basic care, as needed	1.32 (0.84)	1
Provide frequent rest periods	1.54 (0.90)	1
Monitor deterioration of physical and/or mental capabilities	1.63 (0.97)	1
Minimize discomfort, when possible	1.67 (0.92)	1
Medicate by alternate route when swallowing problems develop	1.76 (1.04)	1
Identify the patient´s care priorities	1.85 (0.94)	1
Offer fluids and soft foods frequently	1.96 (1.12)	1
Postpone feeding when patient is fatigued	2.31 (1.17)	2
Modify the environment, based on patient´s needs and desires	2.42 (1.06)	2
Offer culturally appropriate foods	2.80 (1.36)	3
Social dimension	2.22 (1.14)	2
Respect the need for privacy	1.67 (0.91)	1
Support the family's efforts to remain at the bedside	1.88 (0.97)	1
Stay physically close to frightened patient	2.10 (1.09)	2
Respect the patient's and family's specific care request	2.36 (0.94)	2
Include the family in care decisions and activities, as desired	2.67 (1.14)	2
Facilitate discussion of funeral arrangements	2.75 (1.30)	2
Psychological dimension	2.11 (1.12)	2
Monitor patient for anxiety	1.95 (1.05)	1
Be available to listen to individual´s feelings	1.96 (1.09)	1
Monitor mood changes	2.02 (1.21)	1
Assure individual that nurse will be available to support individual in times of suffering	2.03 (1.10)	1
Be open to individual's expressions of concern	2.03 (1.10)	1
Express empathy with individual's feeling	2.15 (1.06)	2
Reduce demand for cognitive functioning when patient is ill or fatigued	2.41 (1.13)	3
Support patient and family through stages of grief	2.44 (1.20)	2
Encourage patient and family to share feelings about death	2.67 (1.17)	3
Spiritual dimension	2.13 (1.22)	2
Treat individual with dignity and respect	1.28 (0.77)	1
Provide privacy and quiet times for spiritual activities	2.04 (1.13)	1
Arrange visit by individual's spiritual advisors	2.21 (1.18)	1
Facilitate obtaining spiritual support for patient and family	2.22 (1.09)	1
Communicate willingness to discuss death	3.01 (1.21)	3

RNs about death, time options of RNs, and difficulties in communicating with dying patients and their relatives (**Table 3**).

Discussion

The study results indicated the use of dying care and spiritual support interventions among dying patients in the ICU in the CR. "Treat individuals with dignity and respect" was the most often provided activity. Baillie (2009) also confirmed that the nursing staff has a major effect on a patient's dignity. Staff who are attentive to patients, connected, friendly, helpful, unobtrusive, and respectful enhance a patient's dignity. Dignity means being able to be who I am, giving respect, and receiving it back (Jacelon & Henneman, 2014; Silva, Campos, & Pereira, 2011).

The results of a recent study support the importance of this activity in the Czech population. A professional marketing agency STEM/MARK survey revealed that Czech people primarily worried about losing their dignity in the terminal stage of life. This is often associated with fear of self-insufficiency, dependence and a need for assistance (STEM/MARK, 2011). This fear may be associated with the degree of institutionalization of the dying in the CR (Loučka, Payne, Brearley, & EURO IMPACT, 2014a; Loučka, Payne, Brearley, Slama, & Spinkova, 2014) and with negative experience with institutional care for dying patients from earlier years, when only care concerning biological needs was provided in EOL care. Although approximately 80% of the Czech population does not wish to die in a medical institution, three fourths of the population currently die in hospitals, long-term care facilities,

Table 3. Correlation Between Studying Factors and Biological, Social, Psychological, and Spiritual Dimensions Activities

Factor	Pearson correlation coefficient (*r*), *p* value			
	Biological dimension	Social dimension	Psychological dimension	Spiritual dimension
Responder´s attitude to death	−0.01	0.11	−0.04	0.11
Frequency of patient care at the end of life	−0.22**	−0.22	−0.21**	−0.21**
The average length of stay of dying patient in the ICU	0.22**	0.33**	0.22**	0.30**
Personnel conditions for palliative nursing care in the ICU workplace	0.22**	0.31**	0.16**	0.30**
Time options for nurses providing palliative care	−0.04	−0.09	−0.07	−0.06
Communication with the dying patient without difficulties	0.11	0.01	0.11	0.02
Communication with dying patient´s relatives without difficulties	0.07	0.04	0.02	0.12
Offer educational activities about palliative care rate	0.13*	0.13*	0.15*	0.07
Educational activities in palliative care that ICU nurses consider important	0.33**	0.32**	0.30**	0.32**
Participation in the educational activities in the field of palliative care	0.21**	0.27**	0.27**	0.21**

Note. ICU = intensive care unit. **p* < .05; ***p* < .01.

hospices, or social facilities. One can therefore assume that RNs in healthcare facilities perceive support for the dignity of patients as a priority in EOL care at present.

Activities focused on the biological needs of the patient and "respect the need for privacy" and "support the family's efforts to remain at the bedside" from the social dimension were the most often provided activities in the dying care intervention. As reported by Fridh (2014), dying patients and their close relatives need proximity and privacy in the ICU.

In contrast, "offer culturally appropriate foods" was the least frequent activity provided for dying patients in the ICU. This might be affected by the minimal migration from non-Western countries in the CR in contrast to many other European countries (Høye & Severinsson, 2010). Furthermore, the CR is not a diverse and multicultural country, such as Australia (Bloomer & Al-Mutair, 2013) or the United States (Ezenkwele & Roodsari, 2013). Another reason may be the fact that some of the activities are less applicable to caring for patients in an ICU. It is not always possible, for example, to "offer culturally appropriate foods," because most if not all ICU patients are intubated or otherwise unable to eat. In addition, many people at EOL are unable to eat over their last days.

Activities related to dialogue about death and funeral arrangements were also less frequently used in the presented study. The low frequency of the activity "facilitate discussion of funeral arrangements" may be related to a recently spreading practice in CR, that is, a cremation without any public funeral ceremony. This is quite specific in the European as well as the global context (Nešporová, 2011). More than half of the respondents reported that it was difficult to communicate with the dying patient or the relatives of the patients. Lind, Lorem, Nortvedt, and Hevroy (2012) also stated that discussions about death with the patient or the relatives of the patient are difficult for ICU nurses. Palliative interventions form only a small part of the competencies of nurses, and the nurses may not have enough experience or the communication skills required (Dawson, 2008). No correlation was found, however, between providing activities in particular dimensions and the views of RNs on the communication difficulties in our study.

Nursing intervention in EOL care is not only supposed to relieve pain and alleviate related signs and symptoms connected with an individual's biological dimension, maintain the dignity of patients, and provide support for family members, but also to reduce spiritual and religious suffering (Beckstrand et al., 2006; Mularski et al., 2006). Nevertheless, the study results revealed the infrequent use of spiritual support interventions, which might be related to the widespread secularization of Czech society. Only 20% of the population in the CR identified themselves as believers in 2011 (Czech Statistical Office, 2011). Czech nurses claimed that activities involving spiritual support were the duties of clinical psychologists and chaplains and the activities of religious nuns and hospice nurses (Kisvetrová et al., 2013).

Half of the respondents viewed staffing conditions as suitable for palliative nursing interventions in the ICU. Furthermore, the quality of the staffing conditions positively correlated with the frequency of all the activities in all dimensions. A recent study revealed that a poor design in emergency departments does not allow privacy for dying patients or grieving family members (Attia et al., 2013). Another study performed by Lombardo et al. (2013) demonstrated that an insufficient number of ICUs are designed to preserve patient privacy and create a restful atmosphere.

The results of the present study also demonstrated a negative correlation between the frequency of providing activities in all dimensions and the frequency of providing care to dying patients in the ICU. The relationship between the experience of RNs in EOL care and the attitude toward dying patient care has also been confirmed by another study (Lange, Thom, & Klime, 2008). The study results demonstrated a positive correlation between the importance of RN education concerning palliative interventions, participation in educational activities concerning palliative care, and the choice of providing activities related to all four dimensions. The results of the present study are in agreement with previous studies, which revealed that improved education about EOL care, staff support, and better communication would improve care for dying patients and their families (Espinosa et al., 2010).

The study limitations should also be mentioned. Firstly, we were unable to find a standardized survey that would address the study goals. The items were formulated, however, based on the international classification of the NIC. Secondly, the number of respondents was limited. Thirdly, the positive relation between education and the higher frequency of each of the activities in our study may be affected by counterintuitive assessments on the part of RNs. Our results did not differ all that significantly from those in other studies (Beckstrand, Smith, Heaston & Bond, 2008; Choi, Lee, Kim, Kim, & Kim, 2012).

Conclusion

Defining the nursing activities that ICU nurses can implement into EOL patient care may help identify issues that are specific for the current nursing practice in intensive care medicine. The study results revealed that Czech nurses perceive "treat individuals with dignity and respect" as a key activity for EOL patients in the ICU. RNs primarily focused their activities on the biological needs of patients. Subsequent research should focus on obtaining information concerning particular changes in the range and frequency of interventions provided by nurses in the ICU before and after taking the course on palliative interventions. Support for palliative care education could increase the frequency of the use of activities in psychosocial and spiritual dimensions in the ICU and improve the competence of RNs for communicating with the patient and family about issues related to death and dying.

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Clinical Resources

- American Association of Critical-Care Nurses: http://www.aacn.org/
- European Association for Palliative Care: http://www.eapcnet.eu/
- Intensive Care National Audit and Research Centre: https://www.icnarc.org/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Knowledge, Beliefs, Behaviors, and Social Norms Related to Use of Alternative Tobacco Products Among Undergraduate and Graduate Nursing Students in an Urban U.S. University Setting

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Key words
Alternative tobacco products, nursing students, smoking cessation counseling

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Abstract

Purpose: The purpose of the study was to assess nursing students' knowledge, beliefs, behaviors, and social norms regarding use of alternative tobacco products (ATPs).

Design and Methods: This anonymous online survey was conducted with all students enrolled in a college of nursing. The survey utilized measures from several national tobacco studies to assess knowledge and beliefs about ATPs (hookahs, cigars or cigarillos, bidis, kreteks, smokeless tobacco, electronic cigarettes) compared to cigarettes, health effects of ATPs, personal use of ATPs, and social norms. Data were analyzed in SPSS 22.0 (SPSS Inc., Chicago, IL, USA). Descriptive statistics and frequencies were performed for basic sociodemographic data. Paired samples *t* tests were performed to determine differences for scaled measures.

Findings: Nursing students demonstrated very low levels of knowledge about ATPs and their health consequences, despite high rates of ATP personal use. About 76% of participants reported use of one or more ATPs once or more in their lifetimes. A greater proportion of students had used hookahs or waterpipes (39.6%) compared to cigarettes (32.7%).

Conclusions: Nurses' lack of knowledge about the emerging use and health threats associated with ATPs may undermine their ability to provide appropriate tobacco cessation counseling. Research is needed to identify gaps in nurses' education regarding tobacco cessation counseling and to develop new counseling approaches specific to use of ATPs.

Clinical Relevance: Nurses play critical roles in counseling their patients for tobacco cessation. Further research and education about the risks presented by ATPs are critical to reducing excess tobacco-related mortality.

Nurses and other healthcare providers play key roles in screening and smoking cessation for their patients. However, studies have shown that providers who themselves smoke are less likely to assess and counsel their patients about smoking cessation (Braun et al. 2004; Sarna, Brown, Lillington, Wewers, & Brecht, 2000; Ulbricht et al., 2008). A report analyzing data from the U.S. National Tobacco Use Supplement comparing smoking rates in healthcare professionals from 2003 to 2010–2011 demonstrated continued declines among physicians to 1% and registered nurses to 7% (Sarna, Bialous, Nandy, Antonio, & Yang, 2014). These rates are significantly lower than the general population rate of 18.1%. Healthcare providers as a group have among the lowest rates of smoking in the United States. An international review of tobacco smoking among nurses revealed an overall pattern of smoking reduction since the 1970s, with higher rates in some developing countries. However, there were considerable inconsistencies in developed countries, with some reporting rates significantly higher than those in the United States. Asian countries generally had lower rates for female nurses, who are culturally less inclined to smoke (Smith & Leggat, 2007).

Though rates of cigarette smoking in the United States have declined dramatically over the past several decades, the Centers for Disease Control and Prevention (CDC) recently warned that the rise in use of alternative tobacco products (ATPs) may undercut the success of efforts to decrease cigarette consumption (CDC, 2012a). For example, recent studies of U.S. college and university students have shown that 40% to 54% have used ATPs during their lifetimes (Cobb, Ward, Maziak, Shihadeh, & Eissenberg, 2010; Primack et al., 2008; Rahman, Chang, Hadgu, Salinas-Miranda, & Corvin, 2014). Little is known about use of these products by healthcare providers. Reports of ATP use among international medical students have found rates of up to 20% (Nawaz, et al. 2007; Senkubuge, Ayo-Yusuf, Louwagie, & Okuyemi, 2012). A recent study conducted with medical students in an urban U.S. medical center found that about 4% reported current cigarette use, 4.8% currently used ATPs, and 51.7% reported lifetime use of ATPs. Students in the study consistently estimated cigarettes to be more harmful that ATPs despite the absence of research evidence comparing the two (Zhou et al., 2015). No studies of nurses' use of ATPs have been published to date.

The most common ATPs used today are hookahs, electronic cigarettes (e-cigarettes), cigars, and cigarillos. Hookah, also known as waterpipe and narghile, is an alternative nicotine delivery system to cigarettes in which shisha (tobacco or nontobacco combustible materials) is smoked. The shisha is heated in a bowl of charcoal that is ignited to create smoke. Smoke from the bowl is drawn through a tube that passes through a water jar that cools and humidifies the smoke (American Lung Association, 2007). In contrast, e-cigarettes, which resemble tobacco cigarettes, do not contain any tobacco but do deliver nicotine that has been vaporized electronically to simulate tobacco smoke (Caponnetto, Campagna, Papale, Rosso, & Polosa, 2012). Smokeless tobacco, also called chewing and spit tobacco, is a less commonly used ATP. Bidis and kreteks are small rolled cigarettes containing tobacco, cloves, and sometimes flavors. While the prevalence of bidi and kretek use in the United States is low compared to other ATPs, they contain more nicotine, tar, and carbon monoxide than conventional cigarettes and are therefore more injurious to the health of smokers (Watson, Polzin, Calafat, & Ashley, 2003).

The health effects of all ATPs are understudied. A systematic review of 24 studies conducted by Akl and colleagues (2010) concluded that hookah smoking was associated with increased risks for lung cancer, respiratory disease, and low birth weight. These studies, however, had some methodological limitations, and more rigorous studies are needed. A small study employing direct laboratory comparison of hookah use to cigarette use in the same individuals found far greater carbon monoxide levels and exposure to smoke in hookah use, but similar nicotine levels in cigarettes and hookahs (Eissenberg & Shihadeh, 2009). While e-cigarettes have been promoted as a harm reduction strategy for tobacco smokers, the health effects of this product have not been thoroughly studied.

Over the past 30 years nurses have made significant contributions to screening and smoking cessation for their patients (Rice & Stead, 2008). As the use of ATPs increases in the general population, nurses will need to adapt their smoking cessation counseling skills to address those changes. Studies are needed to assess nurses' current knowledge, beliefs, social norms, and personal use related to ATPs.

This study examines current use of cigarettes, marijuana, and ATPs, as well as knowledge, beliefs, social norms, and behaviors regarding use of ATPs among undergraduate and graduate nursing students in a large, urban university.

Methods

This anonymous, cross-sectional survey was conducted online over a 7-week period from mid-February to April 2014 with all students enrolled in a college of nursing. The study was deemed exempt by the institutional review board because it was anonymous.

Sample and Recruitment

Prior to the study, the investigators met with leaders of the undergraduate and graduate student organizations at the College of Nursing to discuss the study and seek support from the association leadership. Support for the study was also sought and provided by college administrators and faculty. The organizational leaders provided valuable feedback on recruitment approaches and incentives to encourage participation. The research team met with the leaders of each organization and described the study and encouraged participation by all students. Organization leaders then described the study to their constituencies and encouraged participation. An email describing the study purpose was sent several weeks later to all matriculated students within the College of Nursing, encouraging their participation and offering an incentive of an i-Pad mini. This incentive would be awarded by raffle for all participants who completed the study. A link was provided at the end of the survey for participants to register for the raffle. There was no email link between the survey and the raffle. Five email reminders were sent over the next 8 weeks to the entire student body to encouraging participation. In addition, faculty in required courses encouraged students to participate.

Data Collection and Measures

We collected data by an anonymous, online survey using Survey Monkey software (Palo Alto, CA, USA). In total there were 33 items. The survey was pilot tested with 15 health sciences students, residents, and junior faculty in a masters of science class. Based on their feedback, wording and order of some questions was changed. Pretesting estimated the time to completion at 10 min to reduce respondent burden. In addition to demographic variables, we used several valid and reliable measures from national and international tobacco research studies, including the National Youth Tobacco Survey (NYTS; CDC, 2012b). The NYTS is conducted annually by the CDC and designed to provide national data on indicators key to the design, implementation, and evaluation of comprehensive tobacco prevention and control programs. We adopted several questions from the World Health Organization-CDC Global Health Professional Survey (GHPS; CDC Foundation, World Health Organization, & World Lung Foundation, 2015), a school-based survey of third-year health sciences students conducted globally every year. Both surveys are widely used in tobacco research and are considered the standard for the field. The measures from both the NYTS and the GHPS were derived from the CDC (2012c) Youth Risk Behavior Survey (YRBS). Reliability studies were conducted on the YRBS with 1,679 students; the YRBS demonstrated high reliability across two testing periods 2 weeks apart. Kappa statistics were calculated for each of the 53 items, and group prevalence rates were estimated for the two testing periods. Kappas ranged from 14.5% to 91.1%, with 71.7% of items rated as high reliability. There were no significant differences in prevalence rates for the two testing periods (Brener, Collins, Kann, Warren, & Williams, 1995). Measures used in a survey of medical students on ATPs were also included in this survey (Vanderhoek et al., 2013). Detailed questions in each domain are described below.

Demographics. We assessed sociodemographic variables including age, gender, race or ethnicity, undergraduate or graduate student status, and completion of at least one clinical rotation.

Knowledge and beliefs. We assessed knowledge and beliefs about various ATPs (hookahs, cigars or cigarillos, bidis, kreteks, smokeless tobacco, e-cigarettes) by asking "How much tobacco does one cigar contain compared to conventional cigarettes" and "What do e-cigarettes contain?" To assess knowledge about the health effects of ATPs compared to cigarettes, we asked participants to "Please rate the degree (on a scale of 1–5) to which [ATPs or cigarettes] are responsible for each of the following diseases" (gastrointestinal [GI] tract cancer, chronic obstructive pulmonary disease [COPD], coronary artery disease [CAD], gallstones, etc.) and posed the question "How does the potential for addiction to each of the products compare to cigarettes?"

Personal use. In addition, we asked questions about personal use of ATPs from the GHPS (e.g., "Please indicate your use of the following tobacco products [once or more in my life, past year, past 30 days, never]").

Social norms. Consistent with the literature on social norms theory (Lapinski & Rimal, 2005), we defined social norms as the prevalence of tobacco or ATP use among friends and family, and we asked questions from the NYTS (e.g., "To the best of your knowledge, which of the following behaviors, if any, do your friends [family] engage in?" [Choose all that apply.])

Data Analysis

We used SPSS 22.0 (SPSS Inc., Chicago, IL, USA) to conduct our analysis. We performed descriptive statistics and frequencies for sociodemographic data. We performed frequency analyses to determine students' knowledge and beliefs about tobacco and ATPs, social norms for cigarette and ATP use, and patterns of personal tobacco and ATP use. Knowledge of the respective contributions of ATPs versus cigarettes for specific diseases was measured on a scale ranging from 1 (*"not at all responsible"*) to 5 (*"largely responsible"*). Mean scores were calculated for each disease according to ATP or cigarette category. Paired samples *t* tests were performed to detect differences in these mean scores. Pearson's chi-square tests detected differences in social norms of tobacco use by family and friends according to respondents' education level (undergraduate vs. graduate).

Results

Recruitment emails were sent to 1,883 students in the College of Nursing. Among the 961 nursing students who accessed the survey, 828 responded to all 33 questions, for a response rate of 44%. The remaining 133 did not complete the entire set of knowledge questions and were eliminated from this analysis.

Participant Characteristics

The majority of participants self-identified as female (88.4%), White (57.1%), and undergraduate, both traditional and accelerated (students with a prior undergraduate degree; 55.8%). The mean ages were 24.7 years for undergraduate participants and 32.4 years for graduate students, with an overall range of 18–58 years. Most (73.7%) had completed at least one clinical course rotation.

Table 1. Knowledge and Beliefs About Tobacco and Alternative Tobacco Products Among Nursing Students ($N = 821$)

Question	Frequency of correct responses *n* (%)
What percentage of U.S. high school students have used any tobacco product in the past 30 days? Answer = 16–20%	209 (25.5)
How much tobacco does one cigar contain compared to conventional cigarettes? Answer = >1 pack (20 cigarettes)	16 (1.9)
What are bidis? Answer = small, thick hand-rolled cigarettes	126 (15.3)
What are kreteks? Answer = a mixture of tobacco and cloves	53 (6.5)
Which of the following are found in electronic cigarettes? Answer = all options (except "I don't know")	72 (8.8)
Compared to cigarettes, what is the potential for addiction for: Answer = "currently the answer is not known"	
Hookahs	22 (2.7)
Cigars	137 (16.7)
Cigarillos	18 (2.2)
Bidis	39 (4.8)
Kreteks	50 (6.1)
Smokeless tobacco	9 (1.1)
E-cigarettes	54 (6.6)

Table 2. Students' Knowledge and Beliefs About the Contribution of Cigarettes Compared to Alternative Tobacco Products (ATPs) to Various Diseases ($N = 828$)

	ATPs Mean (*SD*)	Cigarettes Mean (*SD*)	p^a
Bladder cancer	3.40 (1.10)	3.76 (1.12)	<.001
GI cancer	4.12 (0.93)	4.59 (0.70)	<.001
Liver cancer	3.40 (1.05)	3.71 (1.07)	<.001
Lung cancer	4.12 (0.93)	4.88 (0.46)	<.001
CAD	3.92 (0.92)	4.55 (0.68)	<.001
COPD	4.05 (0.95)	4.82 (0.54)	<.001
Gallstones	3.26 (1.06)	3.52 (1.10)	<.001

Note. Knowledge scored from 1 to 5, where 1 = *not at all responsible*; 2 = *slightly responsible*; 3 = *somewhat responsible*; 4 = *moderately responsible*; and 5 = *largely responsible*. CAD = coronary artery disease; COPD = chronic obstructive pulmonary disease; GI = gastrointestinal.

[a] Paired samples *t* test.

Knowledge and Beliefs About Health Effects of Tobacco and ATP Use

Approximately 25% of participants correctly identified the percentage of U.S. high school students who had used any tobacco product within the past 30 days (16%–20%; **Table 1**). However, participants were markedly less knowledgeable about ATPs. With the exception of bidis, fewer than 10% of nursing students correctly identified the amount of tobacco in a cigar versus a conventional cigarette (1.9%), the toxicants contained in e-cigarettes (8.8%), and the contents of kreteks (6.5%).

Knowledge and Beliefs About Tobacco's and ATPs' Contributions to Various Diseases

When comparing the contributions of tobacco products on disease prevalence (where 1 = *not at all responsible* and 5 = *largely responsible*; **Table 2**), mean scores were significantly higher ($p < .001$) for cigarettes versus ATPs across all diseases (bladder, GI, liver, and lung cancers; CAD; COPD; and gallstones).

Personal Use of Cigarettes, Marijuana, and ATPs

A greater proportion of students had used hookahs or waterpipes (39.6%) "once or more in my life" compared to cigarettes (32.7%), and marijuana (35.3%; **Table 3**). Use patterns within the past 30 days, however, were higher for cigarettes (7.9%) and marijuana (6.0%) compared to hookahs (2.9%). Overall, 75.8% of participants reported use of one or more ATPs (cigars or cigarillos, hookahs, bidis or kreteks, smokeless tobacco, e-cigarettes) once or more in their lifetime.

Table 3. Patterns of Tobacco and Alternative Tobacco Product (ATP) Use Among Nursing Students ($N = 819$)

	Frequency of tobacco or ATP use *n* (%)			
Product	Once or more in my life	In the past year	In the past 30 days	Never
Cigarettes	268 (32.7)	48 (5.9)	65 (7.9)	438 (53.5)
Cigars/cigarillos	173 (21.1)	22 (2.7)	3 (0.4)	621 (75.8)
Hookahs	324 (39.6)	81 (9.9)	24 (2.9)	390 (47.6)
Bidis/kreteks	23 (2.8)	2 (0.2)	1 (0.1)	793 (82.5)
Smokeless tobacco	43 (5.3)	2 (0.2)	2 (0.2)	772 (94.3)
Marijuana	289 (35.3)	70 (8.5)	49 (6.0)	411 (50.2)
E-cigarettes	57 (7.0)	35 (4.3)	19 (2.3)	708 (86.4)

Table 4. Prevalence of Tobacco and Alternative Tobacco Product (ATP) Use Among Nursing Students' Friends and Immediate Family Members ($N = 821$)

Social category and type of tobacco product	Overall ($N = 821$) *n* (%)	UG ($N = 455$) *n* (%)	Grad ($N = 366$) *n* (%)	p^a
Friends' use of tobacco and ATPs				
Cigarettes	551 (67.1)	326 (39.7)	225 (27.4)	.002
E-cigarettes	280 (34.1)	175 (21.3)	105 (12.8)	.002
Chewing tobacco	130 (15.8)	86 (10.5)	44 (5.4)	.004
Cigars, cigarillos, little cigars	218 (26.6)	132 (16.1)	86 (10.5)	.046
Hookahs/waterpipes	354 (43.1)	232 (28.3)	122 (14.9)	.000
Bidis/kreteks	16 (1.9)	12 (1.5)	4 (0.5)	.067
None of my friends use any form of tobacco	211 (25.7)	98 (11.9)	113 (13.8)	.002
Immediate family members' use of tobacco and ATPs				
Cigarettes	280 (34.1)	154 (18.8)	126 (15.3)	.882
E-cigarettes	77 (9.4)	37 (4.5)	40 (4.9)	.226
Chewing tobacco	34 (4.1)	21 (2.6)	13 (1.6)	.376
Cigars, cigarillos, little cigars	94 (11.4)	60 (7.3)	34 (4.1)	.076
Hookahs/waterpipes	64 (7.8)	38 (4.6)	26 (3.2)	.510
Bidis/kreteks	11 (1.3)	7 (0.9)	4 (0.5)	.525
None of my immediate family members use any form of tobacco	468 (57.0)	259 (31.5)	209 (25.5)	1.00

Note. Grad = graduate students; UG = undergraduate students.

[a] Pearson chi-square test.

Social Norms for Tobacco and ATP Use

Social norms surrounding tobacco and ATP use were defined by use patterns among friends and immediate family members. Cigarettes were the most frequently reported tobacco product used by both friends (67.1%) and family (34.1%; **Table 4**). Immediate family members of more than half of all students (57%) compared to only 25.7% of friends reported never using any forms of tobacco. When comparing cigarettes and ATP use among friends, undergraduates consistently reported significantly higher use for both compared to graduate students. Undergraduates reported 39.7% of friends currently smoked cigarettes compared to 27.4% of graduate students ($p > .0001$), and 28.3% of undergraduates reported friends smoked hookah compared to 14.9% of graduate students ($p >. 0001$). However, there were no significant differences between undergraduate and graduate students' family members' use of any tobacco products.

Discussion

To the authors' knowledge, this is the first study of undergraduate and graduate nursing students in a large urban university to assess knowledge, beliefs, social norms, and behavior regarding ATPs, an emerging health threat. Student participants overall demonstrated very low levels of knowledge and inaccurate beliefs about these products and their health consequences. They consistently rated cigarettes versus other tobacco products as resulting in higher health risks for diseases like cancers, heart disease, and respiratory disease, despite the lack of studies comparing them. These responses persisted despite the option to choose the response "answer currently unknown." Fewer than 2% correctly estimated the amount of tobacco in one cigar compared to a conventional cigarette (one pack of cigarettes equals one cigar), and only 8% were aware of the harmful products contained in an e-cigarette.

The rate of cigarette smoking for nursing students was significantly lower (7.9%) than the U.S. adult cigarette smoking rate of 18% in the past 30 days and consistent with national studies of healthcare professionals, in which nurses current smoking rates were found to be 7.1% (Sarna, et al., 2014). Almost 40% of participants reported lifetime hookah smoking, about 10% in the past year, and about 3% in the past 30 days. These rates are similar to those reported in the study of medical students in an urban U.S. medical school, where 43% reported ever using a hookah, 16% in the past year, and 1% in the past 30 days (Zhou et al., 2015). Overall, 75.8% of student nurses reported lifetime use of an ATP and 5.9% current use. Smoking by health professionals is a well-known obstacle to screening and tobacco cessation counseling with their patients. Reducing the use of ATPs among health professionals is an important priority (Fiore, 2008).

Higher rates of tobacco use were reported among participants' friends than among their family members for both undergraduate and graduate students. However, undergraduates were significantly more likely than graduate students to report that their friends smoked cigarettes and used ATPs, hookahs in particular ($p < .000$). Almost one third of undergraduates reported their friends smoked hookahs. More studies are needed to better understand the role of environmental factors and social norms that influence use of ATPs in settings such as hookah bars, in advertisements that portray ATPs as exotic and glamorous, and in student education about personal health.

The health consequences of tobacco use are well established and reflected by high mortality among smokers due to cardiovascular disease, respiratory diseases, and numerous cancers (U.S. Department of Health and Human Services, 2014). Further, a recent study reported excess mortality due to smoking tobacco in diseases not previously associated with smoking, such as renal failure, intestinal ischemia, and infections (Carter et al., 2015). New forms of products that include tobacco and nicotine delivery present new threats to the reduction in tobacco use achieved over the past several decades. Research and education of health professionals about the risks presented by these products is critical to reducing excess tobacco-related mortality.

This study has some notable limitations. It was conducted in a single urban university setting with a highly diverse student body. More studies of health professions students are needed to assess the best approaches to developing educational programs about associated health risks and personal use. Although the survey was anonymous, it was conducted in an academic setting, and participants may have given more socially desirable responses, therefore underestimating the extent of tobacco product use. In addition, a number of participants who accessed the survey did not complete the entire survey. Reasons for this may include lack of knowledge or concerns about privacy, resulting in an underestimated knowledge gap or extent of tobacco use.

This study revealed a low level of awareness among nursing students about ATPs and their potential dangers to personal and consumer health. Nurses' lack of knowledge about the emerging use and health threats associated with ATPs may undermine their ability to provide appropriate tobacco cessation counseling.

Clinical Resource

- Centers for Disease Control and Prevention guidelines for smoking cessation: http://www.cdc.gov/tobacco/campaign/tips/quit-smoking/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Culturally Embedded Risk Factors for Cambodian Husband–Wife HIV Transmission: From Women's Point of View

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Abstract

Purpose: The purpose of this study was to use interview data to examine the validity of a recently published theoretical model of HIV transmission between husband and virginal wives in rural Cambodia.

Design: This study used a qualitative description method with a sample of women diagnosed with HIV/AIDS in Phnom Penh, Cambodia.

Methods: Data were collected through in-depth interviews conducted with 15 women who self-identified as having contracted HIV from their HIV-positive husbands. Interviews were conducted in Khmer, translated and back-translated for accuracy, and then coded using deductive content analysis. Trustworthiness of study results was protected through peer debriefing, coding to consensus, and maintaining an audit trail.

Findings: Each conceptual domain of the prior published theoretical model of HIV transmission was validated and further elaborated by current study data: wives' acceptance of their husbands' involvement with commercial sex workers, the common practice of unprotected sex between HIV-infected spouses and uninfected wives, and wives' beliefs about the value of the ideal Khmer woman. In addition, the current study findings identified a new domain that substantially distinguished between the beliefs and attitudes held about marriage and sex by wives and spouses.

Conclusions: Women were not passive recipients of HIV transmission; they reciprocated with behaviors that were consistent with being a good Khmer woman in rural Cambodia, all of which increased their vulnerability to HIV transmission from their HIV-infected spouses. Future interventions or programs should consider all these factors and not overly rely on simplistic educational messages about wearing barriers for HIV transmission during sex.

Clinical Relevance: The refined theoretical model of HIV transmission from this qualitative research can be used to formulate culturally sensitive and embedded programs for curbing intramarital HIV transmission in Cambodia among the rural poor.

Since the first cases of HIV were detected more than 30 years ago, the number of women diagnosed has been increasing steadily worldwide and now accounts for 50% of people living with HIV/AIDS (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2012). Women are more vulnerable to HIV infection than men because of greater biological susceptibility (the vagina, as opposed to the anus) during sexual intercourse and men's sexual power and privilege (Higgins, Hoffman, & Dworkin, 2010). Gender inequalities and harmful gender social norms hinder women from protecting themselves from HIV (UNAIDS, 2013). Globally, HIV-positive women experience more societal stigma and blame than men because of their gender (Sandelowski, Lambe, & Barroso, 2004; Yang, 2012).

Of the Southeast Asian countries, Cambodia has the worst HIV/AIDS epidemic (Mills, Singh, Orbinski, & Burrows, 2005). In recent years, spousal HIV transmission has become one of the main sources of new HIV cases in Cambodia, accounting for 48% of all new infections (National AIDS Authority, 2015). The rate of new infections occurring among women has dramatically increased from 13% in 1992, to 30% in 2007, to over 50% in 2008 (UNAIDS, 2009). Worldwide, simply being married presents a risk factor for HIV in women reporting sexual intercourse with one partner in their lifetime (Glynn et al., 2001; Smith, 2007). As a result, women who have sex regularly with men who engage in high-risk sexual behaviors are at high risk for HIV transmission (UNAIDS/World Health Organization, 2009). The most recent report published by the Ministry of Women's Affairs (2008) reports that only 1% of Cambodian men use condoms when having sexual intercourse with their wives. Forty-one percent of Cambodian women reported worries about being infected with HIV by their husbands (Sopheab, Fylkesnes, Vun, & O'Farrell, 2006).

Although new infections occur among women in stable marital relationships, very little research has been conducted to understand the social processes and culturally embedded mechanisms that influence HIV transmission from husbands to wives in order to develop a model or theory to inform interventions. A meta-analysis of HIV prevention interventions targeting heterosexual women concluded that those interventions often neglected the social and contextual factors that affect risky sexual behaviors (Logan, Cole, & Leukefeld, 2002). It is critical to develop a model of HIV transmission in marital relationships to guide couple-based prevention programs. A previous theory or model explaining HIV transmission within marriage can be deductively derived and validated through qualitative investigations (Elo & Kyngäs, 2008). Therefore, the purpose of this study is to use qualitative interview data to examine the validity of a recently published theoretical model of HIV transmission between husbands and virginal wives in rural Cambodia. Yang, Lewis, and Kraushaar (2013) developed a model (hereinafter referred to as the original model in this article) through a systematic review of peer-reviewed literature, professional papers, policy reports, and reference books on HIV transmission in marriage in Cambodia. The original model of HIV transmission from spouses to wives included three plausible categories and related factors influencing spousal transmission of HIV (**Table 1**).

Methodology

Design, Setting, and Participants

The qualitative description method guided the study (Sandelowski, 2000). Study participants were recruited from an HIV/AIDS hospital in Phnom Penh, Cambodia, a major treatment and referral center for fiscally challenged and disadvantaged people living with HIV/AIDS in Cambodia. A woman was eligible for the study if she (a) was a married Cambodian woman, (b) self-identified as having contracted HIV through sexual intercourse from her HIV-positive husband, (c) affirmed she had no sexual partners other than her husband, and (d) was able to provide written informed consent. With the hospital's permission and support, study participants were recruited by a site intermediary while patients were waiting to see the healthcare providers. A total of 15 potential participants met study criteria and were invited to participate. Thirteen women came back for the second interview but two did not return. Prior published qualitative HIV/AIDS-related studies produced data in samples as small as 7 couples or 12 participants (Crankshaw, Mindry, Munthree, Letsoalo, & Maharaj, 2014; Mavhandu-Mudzusi & Sandy, 2015). We stopped doing interviews when no new conceptual information was emerging during them. At that time, data were analyzed and findings published as representative.

Data Collection and Management

Semistructured, open-ended questions were administered to elicit detailed descriptions of the women's social expectations, their thoughts about their husbands' extramarital sexual lives, and their experiences in contracting HIV from their husbands. Four broad interview questions were chosen for the current study. Each of these questions had the potential to disprove or elaborate on the three categories from the original model (Yang et al., 2013) and were as follows: "What qualities are particularly important to be a good wife to your husband?"; "What are your and your husband's beliefs about the use of condoms?"; "What do you know about a behavior of a man to have sex with a woman outside the home?"; and "What did you expect from being married and having a husband when you originally wed?" In order to advance the model, the interviews concluded with an open-ended question: "Is there anything else you would like to add or talk about to help us better understand the experience of HIV transmission from husband to wife?"

The questions were pilot tested with two women. The senior author's fluency in the local language (Khmer) is at an intermediate level, requiring the help of an interpreter in the Khmer language. Interviews were

Table 1. Categories and Factors in the Original Model

Categories	Factors
Husbands' involvement with sex workers	Accepted male promiscuity and polygamy The rise of sex work and availability of cheap sex Excessive alcohol consumption Peer pressure and being masculine Sexual adventure Constrained access to wife for sex Higher socioeconomic status HIV transmission through contact with sex workers
Unprotected sex between an HIV-infected husband and his uninfected wife	Spousal trust Spousal communication over sexuality Inability to negotiate Lack of knowledge and perception of HIV/AIDS Limited options for self-protection against HIV infection
Cultural values concerning the ideal Khmer woman	Adhering to the image of a perfect woman Inferior social status Fear of violence from husband

From Yang, Y., Lewis, F. M., & Kraushaar, D. L. (2013). HIV transmission from husbands to wives in Cambodia: A systematic review of the literature. *Culture, Health & Sexuality*, *15*, 3. doi:10.1080/13691058.2013.793403. Adapted with permission of Taylor & Francis Group.

conducted in the Khmer language with assistance from a specially trained bilingual female interpreter. The confidential interviews occurred in a soundproofed office setting within the hospital with only the participant, senior author, and female interpreter present during the sessions.

All interviews were digitally audio-recorded, transcribed verbatim in Khmer, translated into English by professional translators, and 100% verified for accuracy. To ensure the accuracy of the conceptual and semantic equivalence of meaning between the original and translated data, 7 out of 28 transcripts (25%) were back-translated by a second translator. Questionable phrases, words, and even whole ideas were discussed among the research team. Both the Khmer and English versions were closely and carefully reviewed to evaluate and standardize the procedure. Demographic questions included household characteristics, husband's characteristics, and such HIV-specific characteristics as years since diagnosis.

Prior to initiating the study, ethics approvals were obtained from the study center's Institutional Human Subjects Review Committee and the National Ethics Committee for Health Research of the Cambodia Ministry of Health.

Data Analysis

Deductive content analysis was conducted to identify the properties and dimensions of the data (Elo & Kyngäs, 2008). Three members of the research team coded the data. Data analysis proceeded through four phases: (a) labeling interview data to deductively group the codes into conceptually congruent categories; (b) developing matrices to compare ideas within and across cases by validating, integrating, and contrasting with the categories and factors in the original model; (c) identifying new categories needed for those data that did not fit the categories in the original model; and (d) developing a codebook that included the definitions of the factors that were identified in processes (b) and (c) preceding.

The trustworthiness of study results was established by peer debriefing, coding to consensus, and maintaining an audit (Lincoln & Guba, 1985). The research team met weekly to discuss the final factors and the entire structure of the findings to confirm the accuracy of the data interpretation. Atlas.ti 6.0 (ATLAS.ti Scientific Software Development GmbH, Berlin, Germany) was used to manage text data.

Results

The average age of the 15 participants was 33 years (range 28–42), and they had been married an average of 15 years (range 7–26). The average length of time for participants to be HIV positive was 8 years (range 2–14). They believed their husbands had been infected by female sex workers in brothels ($n = 8$), other nonbrothel sex workers (karaoke, beer promotion; $n = 4$), or casual sex partners outside marriage (girlfriend, $n = 1$). Three stated they did not know how their husbands were infected with HIV before the virus was transmitted to the wife.

This data analysis process refined the original model of spouse–wife HIV transmission as shown in **Figure 1**. A wife's acceptance of her husband's promiscuity, delayed partner notification from husband of HIV status, and sexual obedience to husband and endurance of husband's

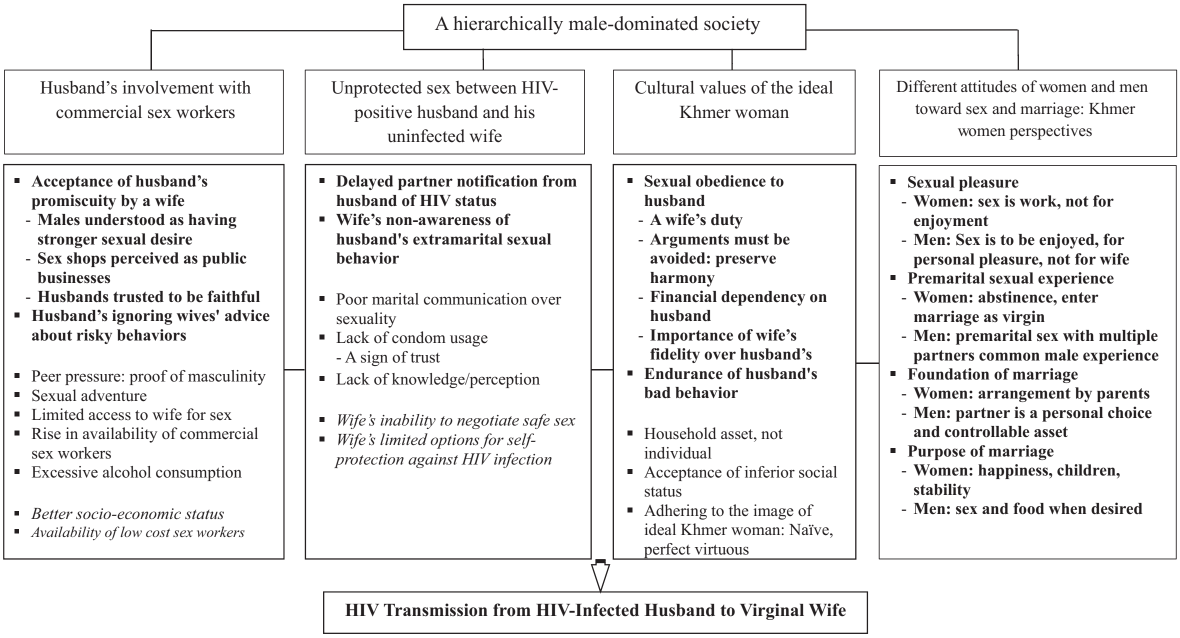

Figure 1. Model of HIV transmission between husbands and wives. Concepts in bold are results not previously known; concepts in regular font are results that validated prior findings in the published literature; concepts written in italics are those not demonstrated in the current study but identified in prior studies.

bad behavior are main factors explored for each category of the original model. The new category of different attitudes of women and men toward sex and marriage covers the four factors of sexual pleasure, premarital sexual experience, marital foundation, and purpose of marriage.

Husband's Involvement With Commercial Sex Workers

Participants in the study viewed male infidelity with commercial sex workers as socially acceptable behavior. They also regarded their husbands' desires for frequent sex as normal behavior and trusted in their fidelity. Husbands ignored their wives' advice about their risky behaviors.

Acceptance of husband's promiscuity by wife. The participants believed that a man cannot be sexually satisfied by only one woman, referring to a popular Cambodian proverb, "No one eats sour soup every day." Women accepted that their husbands may have slept with other women when they were away from home for a long time and felt pity for their husbands for enduring sexual frustration. From the women's perspectives, a man's sexual desire never ends, and he cannot live without sex.

Some study participants believed that their husbands' brothel visits were similar to any other business service because the sex workers were paid openly. The majority of women did not worry that their husbands would fall in love with other women.

> I believe my husband's mind. He does not love any other woman [besides me]. It is just that when he sleeps with other women, he spends money on sex. Like when going to the brothels because they are open for business.

Six participants respected their husbands and trusted their behavior outside the home, confident in their husbands' judgment. The women felt that a pursuit of casual sex outside of the marriage just for fun was acceptable for men but not for women. However, they also firmly believed that a husband should not take another woman as a girlfriend or mistress. According to one woman, "The girls [sex workers] are not his mistresses; he has sex with them just for fun."

Ignoring wives' advice about risky behaviors. Nine women mentioned that their husbands dismissed their opinions, advice, or warnings about their risky behaviors, such as not using condoms with other women. This is illustrated in one woman's statement: "When I said ten words to him, he did not listen to even half of them." Although study participants said they worked hard to satisfy their husbands' needs and wants, their husbands often blamed them for anything that went wrong in their lives.

Unprotected Sex Between an HIV-Positive Husband and His Uninfected Wife

Delayed partner notification from husband of HIV status. Seven couples had been married for some time before the wife was told about the husband's HIV-positive diagnosis. Due to the delayed notification, the women were unaware of the importance of having protected sex with their infected husbands. One participant's husband kept the news to himself for 4 or 5 months in order to spare her the sadness. At first, another woman's husband lied about his HIV status and told his wife he had liver cancer. After 3 days, he told her the truth. Instead of sharing the news with his wife, another woman's husband requested separate household utensils for each member of the family. When she insisted on knowing why, he told her he had contracted HIV.

Unawareness about husband's extramarital sexual behavior. Most participants shared that they had not known about their husbands' sexual behavior outside the home. Investigating a husband's behavior was considered inappropriate for a wife. One woman explained, "I didn't know what he did outside. I just stayed at home. But I heard from my friends that he had other girls and spent money on them."

Cultural Values of the Ideal Khmer Woman

Following the cultural values that define the concept of the ideal Khmer woman rendered the participants powerless when making decisions about sexual relations with their husbands.

Sexual obedience to husband. Being a good Khmer wife involves obeying one's husband's attitudes towards marital sexual relations. Many participants used phrases like "we are women" and "we are wives" to stress the fact that participating in unwanted sex was a woman's fate. If her husband was happy with the couple's sex life, it was considered sufficient. When the husbands of study participants initiated intimate behavior for sexual intercourse, the wives fulfilled their needs obediently, regardless of their personal feelings.

Women shared that they followed their husbands' wishes to avoid arguments over sex matters and preserve harmony in the family. Study participants considered arguments shameful and incongruent with the role of a good wife. Women commented that one important reason to avoid marital arguments was to prevent other household members and neighbors from overhearing them. One woman concluded, "I am his wife so I shouldn't argue with him because it leads to more conflict. As women we should be patient, no answering back. We have to endure our feelings in silence."

Participants acquiesced to their husbands' demands for sex because they felt it was the best way to continue to receive the financial support for the household, including the children. "Typically, he never gave me any money unless he completed his [sexual] desire on my body."

According to the women's narratives, their husbands suspected that their wives were saving energy and passion for boyfriends if the women were not interested in sex. One participant's husband cursed at and beat her when she refused sex, even though he had no evidence that she was having sex with someone else. She recalled, "He said things like this, 'If you won't allow me to sleep with you, it means you have a sahay [boyfriend],' another man."

Endurance of husband's bad behavior. The Khmer culture requires a good wife to endure any undesired behavior of her husband, as depicted in the women's statements during interview sessions. As their marriages continued, wives had to lower their expectations of their husbands acting as the head of a household. From wives' reports, husbands earned money but spent it on drinking and seeing women outside. Wives reported that their husbands did not think about food for children and money their wives needed to meet the basic needs of the family. Some husbands maintained second homes and children with their mistresses. According to the wives' reports, instead of their husbands being faithful and working hard for the family's future, they used any extra money to keep mistresses. One study participant was very bitter about it.

When my husband had another woman, I felt miserable, angry, and upset. People told me that your husband is dating another woman. I confronted my husband and said, "Please stop seeing her because I am your wife," but he didn't listen to me.

Different Attitudes of Women and Men Toward Sex and Marriage: Khmer Women Perspectives

Data from this study resulted in a new category of culturally informed causes of HIV transmission: Different attitudes of women and men toward sex and marriage: Khmer women perspectives. Khmer women in this study reported extensively on their views of marriage and sex and distinguished these views from their husbands' stances in four areas: sexual pleasure, premarital sex, the foundation of marriage, and the purpose of marriage.

Sexual pleasure. Sex was not a core value or a joyful experience for study participants. In the interviews, women regarded sex as work, demanding effort and bringing pain. As described by a participant, "I asked him to finish it [sex] quickly. I did not have a desire to be with him." Most study participants admitted that they passively responded to their husbands' sexual advances and simply lay still during sexual encounters. Women in this study consistently indicated that taking care of the household and children was more important to them as mothers and wives than sexual pleasure, and all of the women said they have never personally enjoyed sex. One woman said, "I have never enjoyed sex and nowadays I just care about living conditions and family." However, in the eyes of the wives, the husbands were interested in sex and in learning and practicing sexual skills as part of enjoying sex. According to the women, many of the men watched pornographic movies and subsequently requested oral sex, playing with the penis, or using different sexual positions, all of which were resented by the women in this study. A woman admitted, "My husband played the sex disc. He then wanted me to do the same as in the sex movie."

Premarital sexual experience. None of the participants had ever experienced sex before marriage and were often fearful of sex on their wedding nights. For example, one participant went through extreme measures to avoid sex when she first married at 15 years of age. She recalled:

> On the first night of marriage, I wore three pairs of trousers. I didn't know anything [about sex] at that time. After a week, he forced me to have sex. I didn't dare to scream or say a word. I was embarrassed with my parents and relatives living together under the same roof.

However, according to study participants, their husbands often had had premarital sex with multiple partners. Those husbands disclosed these practices to their wives only after they were found to be HIV positive. The husbands of two participants were diagnosed with HIV within 3 to 4 months of their weddings. The women believed their husbands were ignorant of their HIV status at the time of the marriages, feeling that the men would not have gone through with the marriages if they had known. One of these women reported that her husband used to have group sex with seven to eight friends as many as four to ten times every month when he was only 14 years old. Other participants also reported their spouses as having multiple sexual partners and participating in group sex before marriage. The women were not happy to learn about their husbands' premarital and postmarital sexual endeavors outside the marriage but accepted them as something they were expected to endure as good Khmer wives.

Foundation of marriage. In most cases, parents of the participants arranged their daughters' weddings, and the women obeyed their wishes. Even though many of the women interviewed often had never met their fiancés before the wedding ceremony, they agreed to marry as their parents expected. Love did not matter in marriage. Of the 15 participants, three were still in school when they were affianced by their parents. "I just followed my parents' arrangement. I got married when I was 16 years old. We didn't love each other but knew that we had to get married [laugh]. I stopped studying as requested by my mom."

Meanwhile, the women participants reported that their husbands had chosen them as their wives. For example, one participant's husband saw his wife during the Khmer New Year celebration and observed her for 5 months before proposing to her parents. It was the husband's responsibility to save and prepare a dowry to get the wife he wanted. She recalled:

> First, during the Khmer New Year, I played Chhougn, Angkun [traditional Khmer New Year game] and he observed me for 5 months, and my parents betrothed me to him, but I did not love him. Anyway, I followed my parents' wishes. He earned money to pay dowry to marry me.

Purpose of marriage. Most of the women said they wanted marriage to bring them a happy family, children, and stable finances. They also hoped that their husbands would be faithful. They were accustomed to seeing many men having extramarital sex and wanted better lives for themselves. One participant described a dream about marriage similar to that of others in the group: "If I had family, I wanted my husband not to know how to drink [to be abstinent] and not to know how to go to have sex with other girls."

On the other hand, some participants felt that their husbands understood marriage as a sexual union. In the women's beliefs, a man wanted a wife so he could be served in bed and at the meal table without having to pay. One woman summed it up: "My husband said that he got a wife just for the purposes, to be served in bed and serve him by cooking."

Discussion

All three categories of factors presented in the original model were substantiated by data obtained in the current study and were further elaborated with current study results. In addition, a new category was identified from the current study, adding a new aspect to the original model: Different attitudes of women and men toward sex and marriage: Khmer women perspectives.

Participants viewed their husbands' infidelity as normal behavior, rationalizing it with old proverbs and understanding males as having stronger sexual desires, and perceived sex shops as public businesses. The culture of pardoning a man's infidelity may have greatly contributed to HIV transmission from husbands to wives.

Gender roles and power dynamics within relationships added more to the concept of women's obedience in sexual relations with their husbands. Striving to be ideal Khmer women, the participants swallowed their own feelings in order to avoid arguments and agreed whenever their husbands wanted to have sex. Additionally, participants reported accommodating their husbands' sexual needs in order to get enough money. In Africa, those men whose wives have jobs and a higher level of education than most women in their socioeconomic status are less likely to have risky extramarital sexual relations (Stephenson, 2010). Educating women and providing them with jobs could help reduce the financial inequality between the genders, thereby giving the women more power and authority over their lives, including the power to negotiate safer sex (LaCroix, Pellowski, Lennon, & Johnson, 2013; Mbonu, Van den Borne, & De Vries, 2010).

This study also identified that women were put at risk because of their spouses' delayed notification of HIV serostatus. This implies that HIV partner notification that provides adequate counseling and testing to partners of persons who have recently learned their status should be scaled up nationwide in Cambodia (Brown et al., 2012). The women participants reported that it was not socially acceptable for a wife to ask about her husband's whereabouts. Poor spousal communication around such topics as risky behavior and condom use can be considered a major risk factor for unprotected sexual relations. A study among 779 HIV-negative women in the north of Thailand showed that open communication with their husbands increased HIV testing in the women (Manopaiboon et al., 2007). Thus, these findings suggest an intervention building communication skills between the women and their spouses could be a strategy for HIV prevention and services.

Women in the current study consistently reported that Khmer men have different attitudes toward extramarital sex and marriage than women, which, at least in part, is an important component of HIV transmission from husbands to wives among married couples in Cambodia. However, because this information was obtained only from the women's perspectives, research with Khmer men is needed to validate these perspectives in order to design effective, culturally appropriate prevention programs. We found that gender-based attitudes and behaviors towards sex as described by study participants influenced the risk for HIV transmission. Preserving a woman's virginity until marriage is highly valued within Cambodian culture (Nakagawa, 2006). A recent national survey reported that, in general, Cambodian women have only one sexual partner over their lifetime, while men have an average of four sexual partners in their lifetime. Men who have never been married have more lifetime sexual partners than married men (National Institute of Statistics, and Directorate General for Health and ICF Macro, 2015). Collectively, these reports support the importance of reaching young adolescents with gender-focused programming. Young men outside the education system are less likely to use condoms and thus should be included in community-based programs (Douthwaite & Sareoun, 2006).

The difference in foundational beliefs about marriage between genders may affect the spousal and sexual relationship as well. Most of the women interviewed had married at a young age, due to parental arrangement. In the Cambodian culture, a man's feelings and opinions are valued, and his parents do not demand his obedience when choosing a wife. The average age at marriage for this study's participants was 20 years, with a range of 14 to 26 years. Women becoming sexually active at an early age have been found to be at higher risk for HIV (Pettifor, van der Straten, Dunbar, Shiboski, & Padian, 2004). Young women were found to have six times higher risk for HIV infection between the ages of 15 and 19 than men at the same age (Glynn et al., 2001). Therefore, encouraging marriage at a later age should be considered in HIV prevention strategies.

The findings from this study may be applied to other married Khmer women with HIV, because the participants' experiences and perspectives appeared to be similar irrespective of individual marriage background, age, education, or income. The refined model needs to further reflect males' experiences and perspectives by engaging male partners in a future study. The refined model's feasibility, as well as prevention programs based on the models and scales to measure each concept, are to be studied in the future.

Conclusions

The complexity of gender roles and the sociocultural status of women in Cambodia acted as behavioral determinants of a husband's involvement with extramarital sex and in a woman's combined acquiescence to the husband's extramarital sexual practices and his marital sexual preferences. These women's behaviors did not involve preventive measures that protected them from HIV transmission; their commitment to being a "good" Khmer woman acted against their active engagement in self-protective or health-enhancing behavior. Instead, their focus was on the stability and harmony of the household family, including the provision of funds from their HIV-infected husband, to whom they were bound by the extended family to obey and please. The validated and expanded model has the potential to inform the development and testing of culturally sensitive programs and services to curb HIV transmission from husbands to wives in Cambodia.

Clinical Resources

- Cambodia Health Strategic Plan 2008–2015: http://www.wpro.who.int/health_services/cambodia_nationalhealthplan.pdf
- Ministry of Women's Affairs. A fair share for women: Cambodia gender assessment: http://www.adb.org/documents/fair-share-women-cambodia-gender-assessment
- National Center for HIV/AIDS, Dermatology, and STD. Annual report 2013: http://www.nchads.org/Report/annual_report_2013_eng.pdf
- UNAIDS Asia and Pacific Region, Cambodia: http://www.unaids.org/en/regionscountries/countries/cambodia/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

The Air Quality Health Index and Emergency Department Visits for Otitis Media

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Abstract

Purpose: The purpose of this study was to explore novel multipollutant exposure assessments using the Air Quality Health Index in relation to emergency department visits for otitis media (OM).
Design: This study was a retrospective analysis using information from emergency department visits for OM, air pollution, and weather databases.
Methods: For children 3 years of age or younger, there were 4,815 emergency department visits for OM over a 6-year period across hospitals in Windsor, Ontario, Canada. Both time-stratified case-crossover and nonlinear time series distributed lag analyses were applied to investigate the association between the Air Quality Health Index and visits for OM.
Findings: Using case-crossover analysis, there was an increase in emergency department visits with OM diagnoses 6 to 7 days postexposure to increased ozone and 3 to 4 days after exposure to increased particulate matter. For every 1 unit increase in the Air Quality Health Index, discharge diagnosis of OM increased 5% to 6% three days postexposure. Effects were stronger using the nonlinear time series analysis. The overall risk for OM, in the first 15 days after an increase in the Air Quality Health Index, was 1.22 times the risk of OM on days following no increase in exposures.
Conclusions: These findings confirm that there is an association between the multipollutant Air Quality Health Index and emergency department visits for OM. The findings can be used to inform risk communication, patient education, and policy.
Clinical Relevance: Clinicians can use the Air Quality Health Index as an education and advocacy tool to promote and protect the health of those at high risk for OM to reduce exposures.

Otitis media (OM) is one of the most common diseases of young children, associated with substantial healthcare utilization and potential long-term consequences. OM is characterized by inflammation of the middle ear linked to anatomic, genetic, infectious, and environmental factors (Coticchia, Chen, Sachdeva, & Mutchnick, 2013; Lack, Caulfield, & Penagos, 2011). Environmental and behavioral factors that increase the risk for OM include exposure to tobacco smoke, bottle-feeding (as opposed to breast-feeding), daycare attendance, and specific outdoor pollutants (Ladomenou, Kafatos, Tselentis, & Galanakis, 2010; Zemek, Szyszkowicz, & Rowe, 2010). There is mixed evidence that allergies are linked to OM (Lack et al., 2011). There is a paucity of both evidence and statistical modeling methods on the relationship of ambient multipollutant exposure and childhood OM.

Otitis Media and Outdoor Air Pollution

Broadly, OM includes a continuum of conditions of inflammation of the middle ear from acute OM (AOM) to OM with effusion (OME) and chronic suppurative OM (CSOM). Globally, there are an estimated 709 million cases of AOM each year, with a high incidence rate for toddlers and preschool children (ages 1–4 years) of 61 per 100, and infants (less than 1 year) of 45 per 100 (Monasta et al., 2012). Up to 80% of children experience at least one episode of OME (Qureishi, Lee, Belfield, Birchall, & Daniel, 2014). Of the estimated 31 million cases of CSOM, over one fourth occur in children less than 5 years old. A common reason for a healthcare visit, OM accounts for at least one annual ambulatory care visit for every four children in the United States, with the greatest proportion of these visits composed of infants and toddlers (National Institute on Deafness and Other Communication Disorders, 2012). One of the most common complications from OM, particularly CSOM, is hearing loss.

Because of anatomically smaller, shorter, and more horizontally aligned Eustachian tubes, small children are more at risk for OM (Coticchia et al., 2013). The Eustachian tube connects the middle ear to the nasal passage and is lined with cells that provide a mucociliary transport system to eliminate potential infectious and inflammatory agents from the middle ear. The Eustachian tube is essential for drainage of middle ear fluid, prevention of backward flow from the nasopharynx to the middle ear, and allowing air exchange and pressure balance. When infectious (particularly viral), allergic, or other irritants trigger inflammation in the nasal mucosa, the opening of the Eustachian tube may become narrowed or blocked, leading to fluid stasis in the middle ear. This fluid stasis leads to inflammation, and an environment for the proliferation of bacterial pathogens such as Haemophilus influenzae, Streptococcus pneumoniae, and Moraxella catarrhalis commonly seen in AOM. AOM, OME, and CSOM are linked to Eustachian tube dysfunction. Generally, AOM demonstrates a consistent temporal relationship with viral upper respiratory infections, peaking 3 to 4 days after the onset of nasal and upper respiratory infection symptoms. CSOM and OME are closely linked to AOM. Theorized to be associated with chronic bacterial biofilm colonies in the middle ear, the chronic inflammatory middle ear conditions frequently follow or precede AOM, but may be tied to inflammation from allergic causes (Qureishi et al., 2014).

Poor indoor and outdoor air quality is associated with an increased risk for OM. Exposure to second-hand smoke increases the amount of pathogens present in the nasopharynx (Brook, 2010; Fuentes-Leonarte et al., 2015). Exposing human middle ear epithelial cells to diesel exhaust particles and acrolein induces an inflammatory response and decreases the cell's viability, indicating a direct cellular link between air pollution and OM (Song, Lee, Lee, Chae, & Park, 2012, 2013). In human studies of outdoor air pollution, an increased risk for OM has been linked to combinations of persistent organic pollutants, increased levels of carbon monoxide, fine particulate matter (PM2.5), nitrogen oxides, and woodsmoke (Karmaus, Kuehr, & Kruse, 2001; MacIntyre et al., 2011; Zemek et al., 2010). Given that infection, irritation, and allergy of the entire respiratory system, eye, ear, nose, and throat are often linked, additional evidence includes observed associations between air pollution and hospital visits for respiratory (Kousha & Rowe, 2014; Szyszkowicz & Kousha, 2014) and nonrespiratory (Kousha & Castner, 2014; Szyszkowicz, Shutt, Kousha, & Rowe, 2014) diseases. Thus, it is plausible to hypothesize that increased exposure to air pollution will lead to inflammation, thereby increasing the risk for OM. An ED visit for OM serves as a population-based proxy for the amount and severity of disease present.

Coal-fired power plants and automobile traffic are major sources of ambient air pollution. The U.S. Environmental Protection Agency (EPA) has identified that cross-border air pollution from power plants is particularly problematic for states in the midwestern and northeastern portion of the country (U.S. EPA, 2014a). The city of Windsor, Ontario, Canada, is situated just across the United States–Canadian border from Detroit, Michigan. With prevailing winds directly from Detroit and one of the busiest international crossings for automobiles, Windsor has been dubbed one of the most polluted cities in North America (Ministry of the Environment and Climate Change, 2015; Wilhelm, 2008). Windsor provides a unique opportunity to investigate the potential impact of international cross-border air pollution on OM.

The Air Quality Health Index (AQHI) was developed to communicate health risks associated with air pollution levels to the public (Stieb et al., 2008). The index was developed using Canadian mortality data to estimate risk coefficients. Calculated in real time each hour based on 3-hr average values, the AQHI is publicly updated every hour to report ambient air quality and advise risk reduction behaviors and outdoor activities. Because the AQHI was developed using mortality data, associations to morbidity are not as well known. The potential to use the AQHI to communicate risks of population morbidity, such as early childhood OM, requires additional research. The AQHI is unique in its origins in mortality calculations. However, many countries have similar measures of air multipollutant air quality, including the Air Quality Index used in the United States, Europe, and China.

Purpose

The purpose of this study was to explore novel multipollutant exposure assessments using the AQHI in relation to ED visits for OM for children ages 3 years and younger in Windsor, Ontario, Canada. The significance of this ecological study includes assessing if the temporal relationship between increased exposure to air pollution and OM at the population level is consistent with the commonly known chronological sequence of viral or bacterial pathogenesis pathways between nasal mucosal inflammation and OM at the individual level. In addition, this study is a foundational step to evaluate the usefulness of the AQHI as a public health education and risk communication tool, along with other air quality alerts, for OM in children less than 3 years of age.

Methods

This study utilized a time-stratified ecological case-crossover design with the ED visit as the unit of analysis. In this design, the case event day, or ED visit day, is compared to control days that are the same day of the week within the same month. For example, a case day might be the second Tuesday of the month, in which case the control days are the first, third, and fourth Tuesdays of the month.

Data on ED visits for OM by children birth to 3 years of age in Windsor, Ontario, Canada were retrieved from the National Ambulatory Care Reporting System. Because the peak incidence of AOM is in children 6 to 24 months of age, this analysis was limited to children 3 years of age and under (McWilliams & Goldman, 2011). Visits by location (Windsor) were identified using the first three alphanumeric characters of each patient's postal codes in the city of Windsor (21 postal codes in total). The International Classification of Diseases, tenth revision (ICD-10), codes were used to identify the cases classified as OM. ICD codes are used in 117 countries and provide a standard numeric code based on the clinical diagnosis (World Health Organization, 2015). ED visits with ICD-10 codes H65 (nonsuppurative otitis media) and H66 (suppurative and unspecified otitis media) were used to measure visits for conditions related to middle ear inflammation (both acute and chronic).

Data on ambient air pollution were supplied by Environment Canada (http://www.etc-cte.ec.gc.ca/NapsData). The AQHI formula incorporates three ambient air pollutants: ground-level O_3, NO_2, and $PM_{2.5}$. AQHI is based on 3-hr average values and is calculated as:

$$\begin{aligned}\text{AQHI} = {} & 10/10.4\,(\exp(0.000871 * NO2) \\ & + \exp(0.000537 * \text{O3}) + \exp(0.000487 * PM2.5) \\ & - 3) * 100.\end{aligned}$$

AQHI is represented on a scale of 1 to 10 to create a stratified risk score (Stieb et al., 2008). Individual pollutants (O_3, NO_2, and $PM_{2.5}$) that comprise the AQHI, as well as carbon monoxide (CO) and sulfur dioxide (SO_2) values, were collected as separate variables. Daily averages of NO_2, $PM_{2.5}$, CO, and SO_2 were calculated, while O_3 represented an 8-hr daily maximum.

Statistical Analysis

The case-crossover design used in this study is an adaptation of the case–control methodology widely accepted and used in ecological studies of air pollution and health outcomes. The case-crossover method is effective in situations in which exposures, disease processes, and induction periods all have short time intervals. By definition, in the case-crossover technique the cases act as their own controls on a set of predefined control days proximate to the time they became cases. A time-stratified approach to determine controls was adopted as it has been shown to produce unbiased conditional logistic regression estimates (Janes, Sheppard, & Lumley, 2005). In the design, controls are matched to case periods by day of week for the case period (day). The control periods are determined as other days in the same month and year. This strategy was employed in this study; three or four controls are present for each case. Data were adjusted for humidity and temperature.

Time series methodology and distributed lag nonlinear models (DLNMs) were also used to investigate delayed dependencies. In order to better show these pollutant effects, DLNM was also applied to implement constrain lags technique for lags 0 to 15 to estimate relative risk. DLNM gives us a modeling framework that can represent nonlinear exposure, response dependencies, and delayed effects at the same time. R statistical package (Open Source Software Project-R Core Team, Vienna, Austria), DLNM, was used, which allows description of the nonlinear and delayed effects between predictors and an outcome in time-series data at the same time (Gasparrini, 2011). The results from the case-crossover models are reported as odds ratios (ORs). Results from the time series methodology and DLNMs are reported as relative risk.

Results

Descriptive Results

There were 4,815 ED visits for OM for the time period examined in children 3 years of age or younger. **Table 1** depicts the descriptive statistics for the AQHI and individual pollutants. **Table 2** depicts the descriptive statistics affiliated with each individual visit, with the majority for male children under 2 years of age. The values are expressed in relation to the total number of diagnosed visits considered in the study.

Table 1. Descriptive Statistics for Air Quality (2,462 Days)

Air quality measure	Mean	*SD*	Interquartile range
Air Quality Health Index	3.2	0.8	1.0
Ozone (O_3) ppb	25.3	11.6	16.5
NO_2 ppb	15.9	6.6	8.5
$PM_{2.5}$ $\mu g/m^3$	4.7	3.8	8.2
CO ppm	0.3	0.1	0.1
SO_2 ppb	10.8	7.1	5.0

Note. ppb = parts per billion; ppm = parts per million.

Table 2. Descriptive Statistics for Emergency Department Visits for Otitis (2004–2010)

Characteristic	*n*	%^{a}
Age (years)		
<2	2,832	58.8
2	1,112	23.1
3	871	18.1
Sex		
Male	2,861	59.4
Female	1,954	40.6
Visits by year		
2004^{b}	589	12.2
2005	775	16.1
2006	728	15.1
2007	703	14.6
2008	717	14.9
2009	661	13.7
2010	642	13.3

^{a}Total percentages may not add up to 100 due to rounding. ^{b}April–December for 2004 only.

Table 3. Odds Ratios for the Association Between a 1-IQR Increase in Pollutant Concentrations and Otitis Emergency Department Visits

Pollutant	Lag	OR	95% CI
Ozone (8 hr)	0	1.03	.88, 1.17
	1	1.05	.91, 1.19
	2	1.03	.89, 1.18
	3	.99	.84, 1.13
	4	.98	.83, 1.12
	5	1.12	.98,.1.27
	6	**1.16***	**1.02, 1.31**
	7	**1.20***	**1.05, 1.34**
NO_2	0	.97	.90, 1.03
	1	.99	.93, 1.06
	2	1.01	.94, 1.07
	3	1.05	.98, 1.11
	4	1.02	.96, 1.09
	5	1.03	.96, 1.10
	6	1.00	.93, 1.06
	7	1.00	.97, 1.07
$PM_{2.5}$	0	.98	.92, 1.05
	1	1.00	.94, 1.06
	2	1.03	.97, 1.10
	3	**1.07***	**1.01,1.13**
	4	**1.07***	**1.01, 1.13**
	5	1.03	.97, 1.09
	6	1.01	.95, 1.03
	7	.98	.92, 1.05
CO	0	.97	.92, 1.05
	1	.98	.94, 1.03
	2	.99	.95, 1.03
	3	1.02	.98, 1.06
	4	1.00	.95, 1.04
	5	1.02	.98, 1.06
	6	1.01	.96, 1.05
	7	1.01	.97, 1.06
SO_2	0	1.02	.97, 1.07
	1	1.02	.97, 1.07
	2	1.02	.97, 1.07
	3	1.05	1.00, 1.11
	4	1.01	.96, 1.06
	5	.99	.94, 1.04
	6	1.02	.97, 1.07
	7	1.00	.95, 1.06

Note. IQR = Interquartile range. Bold font indicates *$p < .05$.

Case-Crossover Analysis Results

The following results are reported for a 1-unit increase in the multipollutant AQHI. AQHI was associated with OM (OR = 1.05, 95% confidence interval [CI] = 1.00, 1.10) applying the case-crossover method for lag 3 with the linear model for weather variables. Results were similar (OR = 1.06, 95% CI = 1.00, 1.14) with a natural spline model and four degrees of freedom for weather variables. Therefore, for every 1-unit increase in the AQHI, discharge diagnosis of OM increased 5% 3 days postexposure, and 6% when weather conditions are included. This relationship bordered on significance, with the lower level of the CI beginning at 1.00.

Table 3 shows the ORs for three individual component pollutants (O_3, NO_2, and $PM_{2.5}$). In addition, ORs were also calculated for two additional air pollutants: carbon monoxide (CO) and sulfur dioxide (SO2). These results are reported for a 1-unit increase (one IQR value), with statistically significant increases in ED visits for OM 6 and 7 days after an increase in ozone exposure and for $PM_{2.5}$ 3 and 4 days after exposure. Thus, there was a 16% increase in ED visits with OM diagnoses 6 days postexposure and 20% increase 7 days postexposure to increased ozone. Three and four days after exposure to increased $PM_{2.5}$, there was a 7% rise in diagnoses.

Distributed Lag Nonlinear Model Results

Since the adverse health effects of air pollution can persist for several days after exposure (Zanobetti, Wand, Schwartz, & Ryan, 2000), in order to better show these

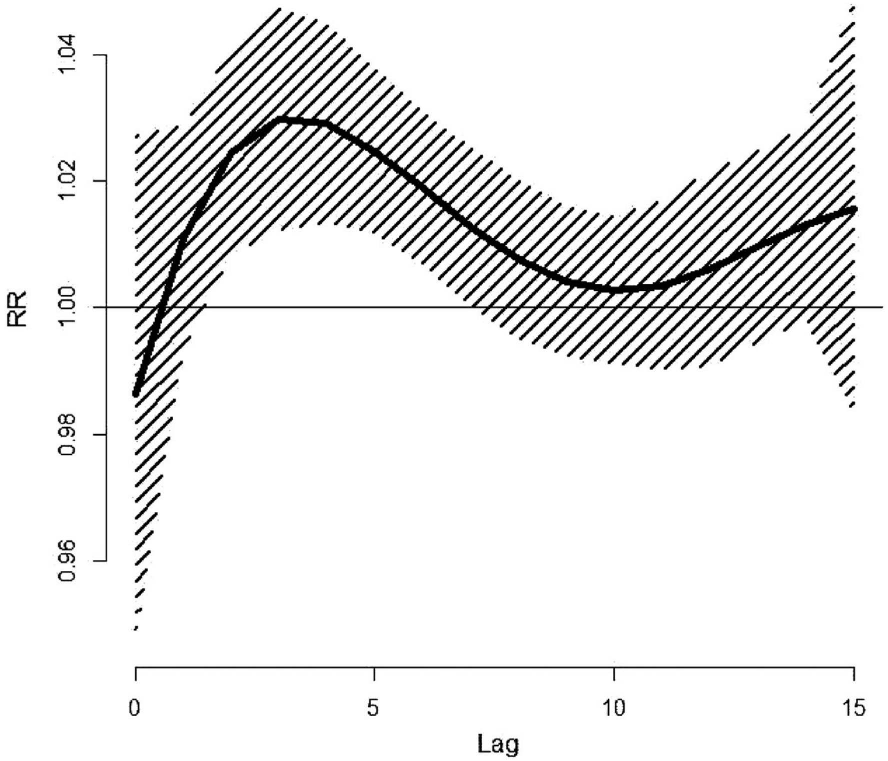

Figure 1. Lag-specific effects of 1-unit increase in daily mean Air Quality Health Index. *Note*. AQHI = Air Quality Health Index, RR = relative risk, Lag represents the days from exposure to increase and emergency department visit for otitis media.

pollutant effects, DLNM was applied to implement the constrain lags technique for lags 0 to 15 to estimate relative risk. Statistically significant results were obtained for lag-specific effects 2 to 7 days postexposure. The overall relative risk for lags 0 to 15 was also increased (1.22, 95% CI = 1.11, 1.33). **Figure 1** shows the effects of a 1-unit increase in daily mean of AQHI along lags (days between increased exposure and outcome). This figure represents the temporal structure of dependency on lags and shows statistically significant results for lags 2 to 7. To clarify, the overall risk for OM, in the first 15 days after an increase in the AQHI, was 1.22 times the risk of OM on days following no increase in exposures. The effect of lag 3 on ED visits for OM is evident and supported by both statistical modeling approaches.

Discussion

Relationships were observed between ED visits for OM and both individual and composite air quality values as measured by the AQHI. This study adds to the scientific evidence of air pollution and OM in two important ways: (a) a temporal relationship was observed, with strongest associations at 3 days, between increased multipollutant exposure and OM that is consistent with other (e.g., viral) pathogenesis pathways between nasal mucosal inflammation and OM, and (b) the utility of the AQHI to model and communicate multipollutant exposure and OM risk was demonstrated.

In the present study, increased PM2.5 alone demonstrated a relationship with an increase in early childhood ED visits for OM at 3 and 4 days after exposure. Since both nitrogen and sulfur oxides contribute to the formation of $PM_{2.5}$, it is noteworthy that both NO_2 and SO_2 demonstrated increased (though nonsignificant) relationships with OM emergency visits 3 days after exposure as well (see **Table 2**). Increased O3 was also associated with increased OM ED visits 6 to 7 days after exposure. Using a multipollutant formula with $PM_{2.5}$, NO_2, and O_3, the AQHI demonstrated an association of increased exposure and increased OM ED visits 3 days after exposure, bordering on statistical significance. Using a second, separate, statistical modeling approach, a relationship was also observed between increases in the AQHI and OM ED visits 2 to 7 days after exposure.

Eustachian tube dysfunction provides an explanation of the potential pathogenesis between increased ambient air pollution and OM (Coticchia et al., 2013). Exposure to cigarette smoke increases a child's risk for developing OM and other diseases involving inflammation or infection of the nasopharyngeal and respiratory mucosa (Csákányi, Czinner, Spangler, Rogers, & Katona, 2012). In laboratory studies, Song, Lee, Lee, Chae, and Park (2012, 2013) demonstrated a direct relationship between middle ear cell dysfunction and inflammation and exposure to common air pollution particles. It is plausible that ambient air pollution directly irritates and inflames the nasal and middle ear mucosa, disrupting the Eustachian tube's mucociliary transport and ability to regulate middle ear air, fluid, and pressure balance. The pooled fluid from this stasis not only causes irritation and inflammation directly worsening chronic inflammation, but enables the proliferation of bacteria commonly seen in acute OM. The 3-day delay between exposure and increased OM emergency visits in the present study is consistent with the typical timeframe between the onset of upper respiratory infection symptoms and AOM (Coticchia et al., 2013). It is unclear if this pollution-related relationship is independent of or synergistic with other allergic or viral triggers of mucosal inflammation.

There has not been a consistent link between individual pollutants and the development of childhood OM in human observational studies, though the types of OM measured have varied by study. Zemek et al. (2010) retrospectively studied AOM emergency visits in Edmonton, Alberta, Canada. While they found associations between OM and carbon monoxide and NO_2, especially in warm weather months, they found no association for $PM_{2.5}$. MacIntyre and colleagues (2011) prospectively studied a birth cohort of children in British Columbia, Canada, and found associations between NO_2, $PM_{2.5}$, and woodsmoke to OM (using both AOM and OME, like the present study). Brauer and colleagues (2006) studied two birth cohorts in Germany and the Netherlands. Relying on parental recall of OM diagnosis, this study demonstrated a significant relationship of NO_2 and OM in the Netherlands, with near significant relationships for $PM_{2.5}$ and elemental carbon. However, these relationships were not significant in a related smaller cohort in Germany. As previously noted, some individual pollutants contribute to the development of other pollutants, which may explain some inconsistency as one pollutant may represent a proxy effect or precursor for other pollutants. Differences in the definitions and measures of the subtypes of OM across the middle ear inflammation continuum may also have contributed to this inconsistency. Measuring air pollution at centrally located community monitoring stations may also underestimate personal exposure and is evidenced by the small magnitude of the relationship between ambient air pollution exposures and health outcomes in these types of observational human studies (Dominici, Zeger, & Samet, 2000). In addition, no previous studies used a multi-pollutant index as this study used with the AQHI.

This present study contributes important evidence to both research and healthcare practice with the use of the multipollutant index, the AQHI. While the AQHI was developed based on mortality, the results obtained for the AQHI indicate that such an index is also useful in morbidity. The study has important policy implications that the reduction of ambient air pollutant levels, particularly in this highly polluted international border setting, has the potential to reduce OM among children younger than 3 years. As AQHI values are widely accessible to the general Canadian public, the results presented in this study also have important nursing and healthcare practice implications to reduce the numbers of ED visits for OM among young patients. Three previous publications support the use of AQHI as a health risk communication and protection tool (Abelsohn & Stieb, 2011; Chen et al., 2013; To et al., 2013). The AQHI was used to estimate the impact of air quality on asthma morbidity, adjusting for potential confounders in Ontario, Canada (To et al., 2013). Research in China using the AQHI demonstrated that the AQHI was an effective tool for communicating the ambient air pollution–related health risks to the public (Chen et al., 2013). Health practitioners can counsel communities and patients to reduce exposure, focusing on tailoring the message to those in high-risk settings or with high-risk comorbidities (Abelsohn & Stieb, 2011; Castner, Gittere, & Seo, 2015).

There are several interventions that healthcare providers can implement to promote and protect general health in areas with poor air quality (Castner et al., 2015; U.S. EPA, 2014b). These interventions range from contributing to public policy efforts to improve air quality to individual patient education. Examples of individual patient education include staying indoors when air quality is poor and reviewing home ventilation and cleaning practices. Other health promotion information specific to OM that should be especially emphasized in communities with poor air quality includes encouraging breastfeeding during the first year of life, adequate immunizations, adequate fluid intake during respiratory infection, hand hygiene, smoking cessation for caretakers, and eliminating or reducing second- and third-hand smoke (Lieberthal et al., 2013).

Future research is needed to further elucidate the relationship between ambient air pollution and OM. Experimental and prospective observational studies in humans are needed to confirm the relationships in this study, as well as replication of these retrospective observational methods in other populations. In particular, investigations on the differences between children who suffer from infection in the absence of poor air quality and those who develop infections prospectively with personal air quality well characterized are warranted.

One promising area for further research is to investigate the potential gene–environment susceptibility to ambient air pollution's relationship with OM in small children (Charlesworth et al., 2010). Current evidence suggests genomic markers are associated with inflammation and cell dysfunction after exposure to diesel exhaust (Kwon, Park, Seo, & Song, 2014). Genetic susceptibility for OM has been mapped to 10q26.3 (OMIM 166760) on the human genome. The ADAM12 gene, which may be linked to inflammatory and epidermal growth factor stimulation, demonstrates increased activity in epithelial cells from the human middle ear after cigarette smoke exposure (Cho et al., 2009; Rye et al., 2014). Additional studies are needed to elucidate the relationships between these genomic markers, behavior, environmental exposures, and the incidence and severity of OM.

The results of the present study should be interpreted alongside several plausible alternative explanations for the association between air quality and increased ED visits for OM. The social and behavioral changes potentially associated with a noticeably poorer air quality day were not measured. More time may be spent indoors with greater exposure to second-hand smoke, changes in handwashing behaviors, or increased social interactions with those with upper respiratory disease. Future studies are warranted to account for social and behavioral variability. In addition, unmeasured personal and community characteristics in the current study require further elucidation in future work, such as immunizations, breast or bottle feeding, exposure to second-hand smoke, specific type of OM, and socioeconomic factors.

There are some limitations in the interpretation of the results of the present study that are typical in ecological research. Multiple statistical comparisons were performed; however, using two different statistical methods strengthens the analysis (Strasak, Zaman, Marinell, Pfeiffer, & Ulmer, 2007). Centrally located air monitors may misclassify pollution exposures. Using only ED visits, many OM cases may not present in the healthcare setting or be seen in other ambulatory settings. Socioeconomic, tobacco smoke, or other individual factors were not adjusted for, as the time-stratified case-crossover adjusts for individual covariates by design.

Conclusions

The results of this study suggest that exposure to a mixture of ambient air pollutants is associated with an increase in ED visits for OM for children less than 3 years of age. The relationship is strongest 3 days after the increased exposure to air pollution. This study contributes to a growing body of evidence that there is a link between poor outdoor air quality and the risk for OM. The findings may be used to support public health and clinician interventions such as public policy support for better air quality, additional cues to support smoking cessation and breastfeeding, and behavior modification to reduce outdoor activity during times of poor air quality.

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Clinical Resources

- Alliance of Nurses for Healthy Environments: http://envirn.org/pg/pages/view/70/user-guide
- Health Canada's Air Quality Health Index: https://ec.gc.ca/cas-aqhi/
- Healthcare without Harm for environmentally responsible healthcare practices: https://noharm.org/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Nursing Students' Willingness to Care for Older Adults in Taiwan

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Key words
Aged care, nursing students, older adults, willingness

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Abstract

Background: The possibilities that nurses will take care of persons 65 years of age or older in hospitals and communities are increasing due to a growing aged population. Nursing students should be prepared to face the challenges of their future practice. Therefore, factors associated with nursing students' willingness to care for older adults need to be identified.

Aim: This study aimed to explore Taiwanese nursing students' willingness to work with older persons and factors associated with this.

Methods: A cross-sectional research design was used. Stratified sampling was applied to recruit participants from seven nursing schools in northern, central, southern, and eastern areas of Taiwan. There were 612 nursing students who successful completed the questionnaire including demographic data, the Attitudes Toward the Elderly Scale, and the Willingness Toward the Elderly Care Scale. Data were collected between November 2012 and January 2013. A stepwise regression analysis was conducted to identify predictors of nursing students' willingness to care for older adults.

Findings: The mean score of nursing students' attitudes toward older people was 73.86 ($SD = 8.9$), with a range of 44–106. The mean score on the willingness to care for older adults was 55.01 ($SD = 6.4$), with a range of 36–75. The length of time with older adults per week ($r = 0.12$, $p = .003$) and grandparents having served as caregivers during the students' childhood ($t = -2.147$, $\beta = .032$) were both positively associated with the willingness to care for older adults. The best predictors of nursing students' willingness to care for older adults were students' attitudes toward older adults ($\beta = 0.38$, $p < .001$), paying attention to issues related to older adults ($\beta = 0.24$, $p < .001$), and having the experience of being a volunteer who served older people ($\beta = 0.10$, $p = .005$), which explained 26.8% of the total variance.

Conclusions: Taiwanese undergraduate nursing students had neutral to slightly favorable attitudes toward working with older adults. Nursing students' positive attitudes about older adults, paying attention to issues related to older adults, and having been a volunteer that served older people were predictors of their willingness to care for older persons. Appropriate and practical strategies should be developed for students in order to increase their preference for caring for older people.

Clinical Relevance: The findings of this study can provide information for faculty members and clinical preceptors for designing curricula and related activities or arranging practicum in the future.

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Nowadays, the possibility that nurses will have to care for persons 65 years of age or older in hospitals and communities is increasing due to growing aged populations. In 2012, 34.9% of hospitalized patients were older adults who had the longest average hospital stays compared to persons of other ages in the United States (Weiss & Elixhauser, 2014). During the same year, 85.1% of nursing home residents, 82.4% of home health patients, and 63.5% of persons in adult day service centers were older people (Harris-Kojetin, Sengupta, Park-Lee, & Valverde, 2013). Similarly, statistics showed that 18.73% of hospitalized patients in Taiwan were older adults in 2003, which had increased to 23.52% in 2013 (Ministry of Health and Welfare, 2014), and 54.2% to 83.3% of residents were 65 years of age or older in long-term care institutions (Department of Nursing and Health Care, 2014; Tseng, Xie, Chen, Zhao, & Kuo, 2011). It was also estimated that 79.33% of the Taiwanese disabled population will be elderly in 2030 and 92.31% in 2060 (Department of Nursing and Health Care, 2014).

Nurses are the largest healthcare professional group in the healthcare work force and provide direct and close care for older patients and residents in hospitals, long-term care settings, and even in homes. Nursing schools have the responsibility to prepare nursing students to face trends of increasing numbers of older adults and the demands for aged care and to motivate students to work with older people after graduation. However, a large body of empirical studies in Western countries has identified that nursing students have less intention to work with older adults or work in long-term care facilities compared to taking care of younger populations or working in acute care settings (Happell, 2002; Haron, Levy, Albagli, Rotstein, & Riba, 2013; McCann, Clark, & Lu, 2010; Moyle, 2003; Stevens, 2011).

In Norway, Kloster, Høie, and Skår (2007) found that undergraduate nursing students' preference for working in the aged care area was the lowest before and even after a nursing education program. Eighty American undergraduate nursing students' preference for working with older adults in nursing homes remained the last of 10 choices even after a 2-year nursing program (King, Roberts, & Bowers, 2013). One longitudinal study indicated that undergraduate nursing students' willingness to work with older adults decreased from 8% to 2% after a 3-year nursing program (Stevens, 2011). Nurses and nursing students' career choices have not changed over time in the past decade, and there was little improvement on attitudes toward working with older adults among healthcare professionals between 1999 and 2009 (Kydd, Wild, & Nelson, 2013). These previous studies indicated that current nursing programs might face challenges and difficulties in increasing students' intentions to choose their future practice in the aged care area.

In Eastern countries, the values and beliefs of filial piety are embedded in a lot of people's minds. Taking care of, respecting, and obeying parents or older family members are, as it should be, duties among the children. Furthermore, it is common in Eastern countries for grandparents to care for their grandchildren during their childhood. The cultural beliefs of and experiences with older adults might influence nursing students' future clinical practice area choices. One Hong Kong study found that 269 undergraduate nursing students had neutral to positive preferences about working with older adults (Lee, Wong, & Loh, 2006). One recent study conducted by Cheng, Cheng, Tian, and Fan (2015) also revealed that 916 undergraduate senior nursing students from seven universities in one province of China had moderate expectancy and values toward gerontological nursing. In addition, Xiao, Shen, and Paterson (2013) reported that Chinese nursing students had a higher percentage of preference for caring for older adults than did Australian nursing students. These studies have indicated that Eastern nursing students were more inclined to work with older adults. However, Shen and Xiao (2012) had different findings and reported that 622 Chinese undergraduate nursing students in one university had less intention to take care of older people than to work in other specialty areas.

The literature has identified that there are positive relationships between nursing students' attitudes toward elders and their intentions to work with older people (Cheng et al., 2015; Haron et al., 2013; Hweidi & Al-Obeisat, 2006; Koren et al., 2008; McKinlay & Cowan, 2003; Pan, Edwards, & Chang, 2009). Cheng et al. (2015) also reported that students who had lived with older families in the same house, had close relationships with older relatives, or had experiences of caring for older persons had higher expectancy and values toward gerontological nursing. Additionally, students who did not have aging prejudice, were under 20 years of age (Shen & Xiao, 2012), had work experiences with older adults (Xiao et al., 2013), had a higher knowledge level (Lee et al., 2006), had previous training experience in aged care, had studied at the diploma-level course or college rather than having studied at a university (Haron et al., 2013), had less anxiety level about aging, and had higher satisfaction with the clinical practice environment (Cheng et al., 2015) were predictors of students' preference to work with older adults. However, age (Carlson & Idvall, 2015; Haron et al., 2013), gender, previous working experience (Carlson & Idvall, 2015), and grades (Shen & Xiao, 2012) were not significantly associated with the willingness to work with the elderly.

Samples in the majority of previous studies were only from one university or college, so they had limitations for generalizing the results to the population in the county where the study was conducted. Furthermore, Taiwanese studies mainly focused on hospital nurses' willingness to care for older adults. It might be a little late to know nurses' interests, because their career choice had been made earlier during their learning at nursing school. Therefore, the current study aimed to do a large survey to explore Taiwanese nursing students' willingness to work with older persons and the associated factors.

Methods

Research Design

This study was part of a cross-sectional research project using self-administered questionnaires to collect data.

Research Setting and Sample

Stratified sampling was used. There were 14 nursing schools in the higher educational system in Taiwan in 2012. Seven universities were selected by random stratification and included three schools in northern Taiwan, one school in central Taiwan, two schools in southern Taiwan, and one school in eastern Taiwan. The inclusion criteria were students who (a) were 20 years of age and older, (b) were enrolled in the school of nursing or department of nursing, and (c) could read Chinese. There were no exclusion criteria. A self-administered questionnaire was distributed to 875 students in the seven schools by the research assistants, and 726 questionnaires were returned by students via placing the questionnaire in a sealed box. Only 612 questionnaires were successfully completed, giving a response rate of 69.9%.

Instruments

Questionnaires had three parts, including sociodemographic data, Attitudes Toward the Elderly Scale, and Willingness Toward the Elderly Care Scale. Sociodemographic data included age, gender, school location, grades, religion, length of being with older adults, nursing home practicum experiences, related gerontological courses, grandparents living with students' families, grandparents having been the main caregivers during childhood, having volunteered to serve older people, and having paid attention to issues related to older adults.

The Attitudes Toward the Elderly Scale, developed by Hsieh and Yang (2009), has 22 items and was used to measure attitudes of nursing students toward older adults. The content validity and construct validity of the tool have been validated. A 5-point Likert scale rating from 1 (*totally disagree*) to 5 (*totally agree*) was used. Items 1 through 10 were negatively worded and were reversely recoded prior to data analysis. Total scores ranged from 22 to 110. Higher scores indicate a more positive attitude toward older adults. Cronbach's α was 0.83 in this study.

The 15-item Willingness Toward the Elderly Care Scale, developed by Liu (2001), was used to understand students' willingness to take care of older adults. This tool was validated by conducting an exploratory factor analysis (Liu, 2001). A 5-point Likert scale rating from 1 (*totally disagree*) to 5 (*totally agree*) was used. Items 3, 6, 7, 9, 10, 12, and 14 were negatively worded and were reversely recoded prior to data analysis. Total scores ranged from 15 to 75. Higher scores indicate a higher level of willingness to care for older adults. Cronbach's α in this study was 0.84.

Data Collection

Ethical approval from the institutional review board (IRB) at the university and approval from the school of nursing or department of nursing in the seven universities were obtained before data collection. Trained research assistants contacted the leader of each class in the selected schools and arranged a time and place to collect data. Prior to distributing the questionnaire, the research assistants explained the study and answered any questions the students had. After completing the questionnaires, students themselves dropped the questionnaires into a sealed box at the front of the classroom. Data were collected between November 2012 and January 2013.

Data Analysis

Data were analyzed using SPSS version 18.0 (SPSS Inc., Chicago, IL, USA). The level of significance was set to .05. A descriptive analysis was performed on the demographic and characteristic data, attitude score, and willingness score by computing the mean (M), standard deviation (SD), and percentage. *t* Tests, one-way analysis of variance (ANOVA), and Pearson product-moment correlation were used to measure associations between variables. A stepwise regression analysis was conducted to identify predictors of nursing students' willingness to care for older adults.

Ethical Considerations

Participants' rights were protected by the authors' abiding by the requirements of the IRB. All students were verbally advised about the purpose, procedures, and rights of the study. The return of a questionnaire in the sealed box was considered agreement to participate in the study without signing a consent form.

Results

Sociodemographic Characteristics of Participants

The sample consisted of 612 nursing students with an age range of 20 to 24 (M = 20.7, SD = 0.9) years. Of these, a majority of students were female (83.7%) and had joined school clubs (75.5%). There were 171 (27.9%) students in the sophomore year, 219 (35.8%) in the junior year, and 222 (36.3%) in the senior year. In this sample, 276 (45.1%) students were studying in universities of northern Taiwan, 105 (17.2%) in central Taiwan, 142 (23.2%) in southern Taiwan, and 89 (14.5%) in eastern Taiwan. Almost half of the students (52.2%) had been mainly cared for by their grandparents during their childhood, and 468 (76.5%) students' grandparents lived with students' families. Four hundred thirty-two (70.6%) students had religious beliefs, and 236 (38.6%) students had experiences of being a volunteer serving older people. Over one third (38.7%) of the students had practicum experiences in nursing homes, and 178 (29.1%) students had taken related gerontological courses. Half of the students (50.8%) paid attention to issues related to older adults, while half of students did not. The average hours of being with older adults per week was 5.1 (SD = 10.1; range 0–70).

Students' Attitudes Toward Older Adults and the Willingness Level to Care for Older Adults

The mean score of nursing students' attitudes toward older people was 73.86 (SD = 8.9), with a range of 44 to 106. After dividing by 5 (5-point scale), the average attitude score was 3.36 (SD = 0.4, range = 2–4.82) for each item. The mean score of the willingness to care for older adults was 55.01 (SD = 6.4), with a range of 36 to 75. After dividing by 5 (5-point scale), the average willingness score was 3.67 (SD = 0.43, range = 2.4–5) for each item.

Relationships of Student's Willingness to Care for Older Adults With Demographic Variables and Attitudes

There were positive relationships between attitudes and willingness to care for older adults ($r = 0.449$, $p < .000$), and between the length of time being with older adults per week and the willingness to care for older adults ($r = 0.12$, $p = .003$). However, student's willingness was not associated with age ($r = 0.042$, $p = .303$).

Students' willingness to care for older adults significantly differed if the grandparents had been the main caregivers during the student's childhood ($t = –2.147$, $p = .032$), if they had experiences of being a volunteer serving older people ($t = –4.162$, $p < .001$), and if they paid attention to issues related to older adults ($t = –9.027$, $p < .001$), but students' willingness did not significantly differ by school location, grades, grandparents living with students' families, religion, the experiences of nursing home practicum, taking related gerontological courses, or joining school clubs (**Table 1**).

Predictors of Student's Willingness to Care for Older Adults

The effects of significant predictor variables were analyzed by a stepwise regression. Dummy coding was used for categorical variables. The best predictors of nursing students' willingness to care for older adults were students' attitudes toward older adults ($\beta = 0.38$, $p < .001$), paying attention to issues related to older adults ($\beta = 0.24$, $p < .001$), and experiences of being a volunteer serving older people ($\beta = 0.10$, $p = .005$), which explained 26.8% of the total variance (**Table 2**).

Discussion

In the current study, students' willingness to care for older adults was neutral to slightly favorable. This finding was similar to those in a British study (McKinlay & Cowan, 2003) and some Asian studies (Cheng et al., 2015; Lee et al., 2006). However, it was contrary to findings in the majority of Western research (Happell, 2002; Haron et al., 2013; King et al., 2013; Kloster et al., 2007; Kydd et al., 2013; Moyle, 2003; Shen & Xiao, 2012; Stevens, 2011). One literature review summarized that societal values about aging would impact students' views about aged care (Neville, Dickie, & Goetz, 2014). Xiao et al. (2013) also argued that collectivist values in Eastern countries encourage individuals to sacrifice themselves to meet societal goals. Confucianism and cultural beliefs of filial piety are societal values in Taiwan and have been inculcated in students' minds since birth. This may be the reason why students had a natural to a little favorable interest to work with older adults.

Nursing students who were mainly cared for by their grandparents during their childhood had significantly higher interest in working with older people compared to those who were not in this study. Furthermore, the length of time being with older adults per week was also positively related to students' willingness. In addition, volunteer experience of serving older adults was a predictor of students' willingness to work with older

Table 1. Comparison of Nursing Students' Demographic Variables and Willingness to Care for Older Adults ($N = 612$)

	Willingness to care for older adults		
Variable	Mean (*SD*)	*t*/F	*P*
Gender		0.561	.575
Male	55.07 (6.7)		
Female	54.68 (6.2)		
Location of the school		1.491	.216
Northern area	54.49 (6.4)		
Central area	55.89 (6.0)		
Southern area	54.96 (6.9)		
Eastern area	55.54 (6.0)		
Year		0.106	.899
Sophomore	55.11 (6.9)		
Junior	54.85 (6.1)		
Senior	55.09 (6.4)		
Living with grandparents		–0.869	.385
Yes	55.42 (6.5)		
No	54.88 (6.4)		
Grandparents were major caregivers during childhood		–2.147	.032*
Yes	55.54 (6.8)		
No	54.43 (5.9)		
Religious beliefs		–0.535	.593
Yes	55.10 (6.5)		
No	54.79 (6.3)		
Had volunteered with older adults		–4.162	<.001**
Yes	56.35 (6.2)		
No	54.16 (6.4)		
Had had a practicum in a nursing home		–1.042	.298
Yes	55.35 (6.2)		
No	54.79 (6.5)		
Had taken gerontology-related courses		–1.683	.093
Yes	55.69 (6.6)		
No	54.73 (6.3)		
Had joined a school club		0.271	.787
Yes	54.97 (6.4)		
No	55.13 (6.5)		
Paid attention to issues regarding older adults		–9.027	<.001**
Yes	57.23 (6.4)		
No	52.84 (5.7)		

Note. Independent *t* test/one-way analysis of variance. $^{*}p < .05$; $^{**}p < .001$.

adults. Based on these findings, the experience of being with older adults in the community (not limited to hospitals or long-term care facilities) might impact students' future career choices. Similarly, Cheng et al. (2015) also reported that students had higher expectancy and values toward gerontological nursing if they had lived with older families in the same house, had close relationships with older relatives, or had experiences of caring for older persons. Therefore, having extensive experiences of being with older adults might influence students' preferences for working with them.

Regardless of whether students had a practicum in a nursing home, there was no difference in students' preference for working with older adults. Liu's (2001) study had a similar finding. Many older people who stay in nursing homes have physical or mental disabilities, so students perceived the working environment to be depressing (Kydd et al., 2013). In addition, the work being perceived as unchallenging, boring, with low pay, and with less qualified staff (Abbey et al., 2006; Carlson, 2015; Kydd et al., 2013) might also affect students' willingness to work with older adults. Haron et al.'s (2013) study also revealed that if nurses' roles and powers in gerontological nursing could be expanded, nursing students would have a greater willingness to work in the geriatric area. Linking the image of the nursing home working environment and less recognized nursing roles with the care of older adults would be a barrier for students to choose aged care as their future career. To overcome this challenge, faculty members might consider arranging students to work with healthy or independent older adults in the community or provide volunteer services to older people before students have their practicum in a nursing home. In addition, previous studies also indicated that an enriched clinical learning environment is very important for students (Abbey et al., 2006; Brown, Nolan, Davies, Nolan, & Keady, 2008; Chenoweth, Jeon, Merlyn, & Brodaty, 2010; Robinson et al., 2008). Therefore, faculty members should carefully screen practicum sites with qualified staff, adequate and appropriate medical supplies and equipment, supportive comprehensive orientation programs for students and staff, and knowledgeable and caring preceptors. An enriched and qualified practice environment might provide positive learning experiences about aged care for students during their practicum, and it would be expected that students might have more positive views about working with older adults.

Nursing students who care about issues related to older people had greater willingness to care for older adults. No similar research was found in the literature. The reason that students paid attention to these issues was they wanted to know more about the elderly, think and reflect about what had happened, and try to make sense of older people's worlds. Nursing faculty members could provide related news, reports, stories, issues, or films—not only negative ones but also positive ones—to nursing students. This would assist nursing students in understanding older persons from different approaches and to have more objective views about the elderly.

The current study also revealed that nursing students held neutral to slightly favorable attitudes toward older

Table 2. Results of a Stepwise Regression Model of Nursing Student's Willingness to Care for Older Adults ($N = 612$)

	Willingness to care for older adults			
Predictor	B	β	95% Confidence Interval	p
Attitudes toward older adults	0.28	0.38	0.22–0.33	<.001
Paid attention to issues related to older adults (ref. no)				
Yes	3.05	0.24	2.14–3.96	<.001
Had volunteer experiences of serving older adults (ref. no)				
Yes	1.31	0.10	0.40–2.22	.005

Note. $R^2 = 0.268$; other variables entered into the regression model included age, gender, living with grandparents, grandparents were major caregivers during childhood, religion, experiences of a practicum in a nursing home, taking related gerontological courses, joining a school club, time being with older adults per week, and school location.

people. The more positive attitudes that nursing students had toward older people, the more willing they were to care for older adults. This finding echoed several studies in the literature (Cheng et al., 2015; Haron et al., 2013; Hweidi & Al-Obeisat, 2006; Koren et al., 2008; McKinlay & Cowan, 2003; Pan et al., 2009). Cultivation of positive attitudes toward older people among nursing students is an important task for contemporary faculty members.

However, age, gender, location of the school, grades, religion, joining school clubs, taking gerontological courses, and having a practicum in a nursing home did not significantly affect students' willingness to work with older adults in the current study.

Study Limitations

One of the inclusion criteria in the study was that students were 20 years of age or older. According to Taiwanese law, persons who are under 20 years of age are minors, so a parent's or guardian's signature is required before such students can participate in the study. It was not practical or convenient for undergraduate students to obtain their parents' or guardians' signatures before filling in the questionnaire. Therefore, the current study did not investigate freshmen's willingness to care for older adults based on the IRB's suggestion. Further studies might consider including freshman nursing students.

Conclusions

It is a critical responsibility for nursing faculty members to cultivate students' positive attitudes toward working with older adults, because the possibilities of taking care of patients or residents who are 65 years of age or older are increasing globally. We suggest designing and arranging activities to give students opportunities to spend more time with older adults, not only those who need assistance, but also those who are still independent. In addition, some positive news, reports, stories, issues, or films should be provided to students in order to assist them in having more objective views about older adults. The findings of this study can provide information to faculty members and clinical preceptors for designing curricula and related activities or arranging practica. Appropriate and practical strategies should be developed to motivate students' intentions to work with older adults in their future professional practice.

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Clinical Resources

- American Association of College of Nursing: http://www.aacn.nche.edu/geriatric-nursing
- Gerontological Nursing Education Consortium Podcasts: http://consultgerirn.org/resources/gnec_podcasts/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Five-Year Bibliometric Review of Genomic Nursing Science Research

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Abstract

Purpose: This bibliometric review profiles the focus, dissemination, and impact of genomic nursing science articles from 2010 to 2014.
Design: Data-based genomic nursing articles by nursing authors and articles by non-nurse principal investigators funded by the National Institute of Nursing Research were categorized into the Genomic Nursing Science Blueprint nursing areas.
Methods: Bibliometric content analysis was used.
Findings: A total of 197 articles met the inclusion criteria. Of these, 60.3% were on biologic plausibility, 12.1% on client self-management, 11.1% on decision making or decision support, 8.1% on family, and 4.0% on communication, with the remaining 4.0% of articles focused on other topics. Few (11.6%) addressed healthcare disparities in the study purpose. Thirty-four references (17.2%) were cited 10 or more times.
Conclusions: Research-based genomic nursing science articles are in the discovery phase of inquiry. All topics were investigated in more than one country. Healthcare disparities were addressed in few studies. Research findings from interdisciplinary teams were disseminated beyond nursing audiences, with findings addressing biologic discovery, decision making or support, and family being cited most frequently. Gaps in the reviewed articles included cross-cutting themes, ethics, and clinical utility. Interdisciplinary research is needed to document clinical and system outcomes of genomic nursing science implementation in health care.
Clinical Relevance: Although the review identifies areas that are encountered in clinical practice, relevance to practice will depend on evaluation of findings and subsequent development of clinical guidelines.

Genomic nurse scientists are at the intersection of human genomics research and the science of health. As the potential health benefits of precision medicine are considered, it is timely to reflect on nursing science's contributions to advancing the understanding of genomic aspects of health. During the decade of the 1990s, genetics was recognized as an essential component of nursing science (Lashley, 1997; Pesut, 1999), but was not yet a prominent focus of nursing research. Over the past two decades, the National Institute of Nursing Research (NINR) has identified the importance of the basic, behavioral, and social science aspects that influence health across populations, communities, and healthcare settings (NINR, 2011; Sigmon, Grady, & Amende, 1997). Also, during this period, the NINR has maintained an emphasis on the integration of behavior and biology (Grady, 2006). The current NINR Strategic Plan (NINR, 2011) continues this emphasis with its focus on investigation of multiple determinants of health, including genomics.

During this same time period, a trajectory of genomics research was mapped (Green, Guyer, & National Human Genome Research Institute, 2011) in which the progression of genomic science moved from understanding the structure of the genome, through understanding the biology of genomes and disease, to advancing the science of medicine and improving the effectiveness of healthcare. Phases of clinical translation of genomic discovery to improve health include genome-based discovery, evidence-based recommendations, incorporation into the healthcare system, and evaluation of impact on health of populations (Khoury, Gwinn, Bowen, & Dotson, 2012). This trajectory of genomic science research also includes discovery of biology of diseases and symptoms, as well as examination of nursing interventions tailored for clients based on genomic variations (Munro, 2015). The dissemination and implementation phase addresses how to enable application of best evidence to improve healthcare outcomes (Eccles & Mittman, 2006). An awareness of genomic aspects of emerging areas of science was identified by the Council for the Advancement of Nursing Science (CANS) Idea Festival Committee (Henly et al., 2015) as a priority in its report on implications for PhD education. New healthcare policies will be needed to enable translation of genomic discoveries into health care (Institute of Medicine, 2014, 2015). Elements of the Precision Medicine Initiative (www.whitehouse.gov/precisionmedicine) are consistent with a nursing science agenda, as described in the NINR Strategic Plan (NINR, 2011), that includes a focus on innovation, as well as health promotion, disease prevention, and advancing quality of life. Further, the future of symptom science is envisioned as including knowledge development regarding genomic and context factors influencing symptom development and expression (Corwin et al., 2014).

An invitational workshop at the National Institutes of Health (NIH) produced the Genomic Nursing Science Blueprint (hereafter referred to as the Blueprint), which identified crucial genomics problems relevant to health (https://www.ninr.nih.gov/sites/www.ninr.nih.gov/files/jnu_12007_Rev_EV.pdf; Calzone et al., 2013). The systematic evidence review, key stakeholder testimony, and main meeting generated the listing of research topics that were then mapped into the NINR Strategic Plan, which contains themes of symptom science, wellness, self-management, and end-of-life and palliative care. The Blueprint contains four components: health promotion and disease prevention, advancing quality of life, innovation, and training, plus a fifth category of cross-cutting themes (e.g., health disparity and policy). In August 2013, a genomic nursing science workshop was convened by the NINR and the Office of Rare Diseases Research, National Center for Advancing Translational Sciences, to consider research topics that address behavioral and social sciences, as well as the biological aspects of genomic nursing science (Tully & Grady, 2015). Components of this review addressing behavioral science were presented at that workshop. The purpose of this project is to conduct a more comprehensive bibliometric review of genomic nursing science published over the prior 5 years in order to examine this production of data-based research in the context of the Blueprint.

Methods

Citation Retrieval

A bibliometric review of data-based genomic nursing science articles published from 2010 to 2014 was conducted by the first author (J.K.W.). A bibliometric analysis is a quantitative analysis of the features of a body of literature (Hawkins, 2001), with the purpose to map literary production in a field and determine the structure of study of that field (Blažun, Kokol, & Vosner, 2015). Bibliometric methods may also use citation analysis as one method to determine the impact of scholarly work within the scientific community (Shuaib, Khan, Shahid, Valdes, & Alweis, 2015). Article inclusion criteria were (a) basic or applied research design, clinical genomic topic that addressed genomic variable(s), or health of a population with a condition with a major genomic component; and (b) research conducted by a nurse (as principal investigator or member of the research team) or a non-nurse funded by the NINR. Articles on other components of the Blueprint addressing training in genomics education or research and articles that reported elements of research methods or designs relevant to genome nursing science were excluded. Validation of 10% of the categorization of articles was conducted by the first three authors (J.K.W., T.T-R., and S.D-H.).

The literature search process for this project had two phases. The first phase began with the goal of capturing nursing-specific publications on topics related to genomic nursing science. The fourth author (J.D.), an experienced health sciences librarian, constructed a sensitive search in collaboration with the first and third authors (J.K.W. and S.D-H.), who have expertise in genomic nursing science, using subject and key word search methods, yielding 593 results. The initial search in PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) used the following key words: registered nurse, nursing, nurses, nursing research. The exact search strategies described above are available upon request.

The second phase of the search progressed through several steps. First, NIH RePORTER was queried by the name of the principal investigator from NINR-funded studies during 2009 to 2014 using the search terms genetics or genomics; the search excluded training grants. Next, to identify articles resulting from NINR funding, Scopus was used to run author searches for the 121 names identified by NIH RePORTER. After gathering citations by authors, the librarian excluded results that were not original research, which produced a total yield of 1,405. Finally, the first author (J.K.W.) further excluded articles that addressed registries, research reviews, theory development, descriptions of healthcare provider genomics education, reports of meetings, and articles that did not report original research.

Mapping citations to the Blueprint. Combining results of both search methods described, the total yield was 1,998. After duplicates were eliminated, abstracts of 1,983 articles were reviewed, and 197 met the inclusion criteria (available upon request). Articles that met the inclusion criteria ($N = 197$) were sorted based on the Blueprint (Calzone et al., 2013). The Blueprint is organized into three levels. NINR Strategic Plan research areas are mapped to level 1. Specific nursing research categories within the research areas are organized in level 2. Level 3 consists of advisory panel genomic nursing research topics in each nursing research category. Articles were coded according to content in the abstract's purpose statement. The initial sorting attempted to place articles into the three major NINR Strategic Plan areas and to identify cross-cutting themes for these articles. Because only one article was found in the area of innovation, this area was not included in the analysis. The paucity of articles on innovation may be due to its recent identification in the 2011 NINR Strategic Plan, with relatively few database articles published within the 2010–2014 timespan for this review. Other papers initially identified in the search that pertained to measurement or healthcare providers were not included in this report. Twenty-two articles addressed instrument development or testing for biologic or other variables, or research designs. An additional 22 papers were located in the search that focused on healthcare providers. These described health attitudes, knowledge, practice, or educational program reports.

Three authors (J.K.W., T.T-R., and S.D-H.) independently sorted 20 total articles (10%). Initial coding using the Blueprint taxonomy resulted in discordant assignment for six (30%) of the mutually coded articles. Consensus for the Blueprint taxonomy was reached on one. Early in the interrater process it became apparent that discordant placement of the articles within the Blueprint was due to the use of the terms communication, decision, personal utility, informed consent, and biologic plausibility in more than one Blueprint level. The three authors agreed that studies whose purpose focused on any of these terms should be sorted using the term rather than attempting to fit the article into the Blueprint structure. Furthermore, the term biologic plausibility was especially challenging when the reviewers discussed the various ways to define biologic plausibility within the Blueprint level 2 categories of risk assessment or symptom management. One interpretation of risk assessment could be for the purpose of primary prevention in a healthy population, and another is that risk assessment encompasses the scope of secondary and tertiary prevention in a symptomatic clinical population. Further dilemmas were that biologic plausibility could mean understanding genomic mechanisms associated with management of symptoms and symptom clusters, or understanding causation of disease in clinically diagnosed populations. Thus, all papers with a biologic plausibility purpose were placed together. Use of the terms without specific application resolved the coding discrepancies.

In addition to Blueprint topics, bibliometric indicators were identified for the review. These included author disciplines, country in which research was conducted, acknowledgment of funding, focus of the journal in which the report was published, and number of citations by other articles. Journals were labeled as clinical when a clinical topic appeared in the title; these journals may also include research-focused articles on clinical topics. Journals with discipline and clinical terms were placed in the clinical category. Journals were labeled as research when the term research, and no clinical topic, appeared in the title. Those that had a discipline term only were placed in the discipline category. Journals with a genomic term were placed in the genomic category. Those with discipline and genomics terms were placed in the genomics category.

Impact assessment. The impact of articles was determined by citation counts and journal impact factors. In nursing academics, the rough rule of thumb is that a paper cited 10 or more times is a "good" paper (Hack, Crooks, Plohman, & Kepron, 2010). Citation counts were obtained using Scopus, and journal impact factors for citations with counts equal to or higher than 10 were located using the Journal Citation Reports database.

Results

One hundred and ninety-seven articles met the inclusion criteria. Of these, 119 were placed in the biologic plausibility category, 24 in client self-management, 22 in decision making or support, 16 in family, and 8 in

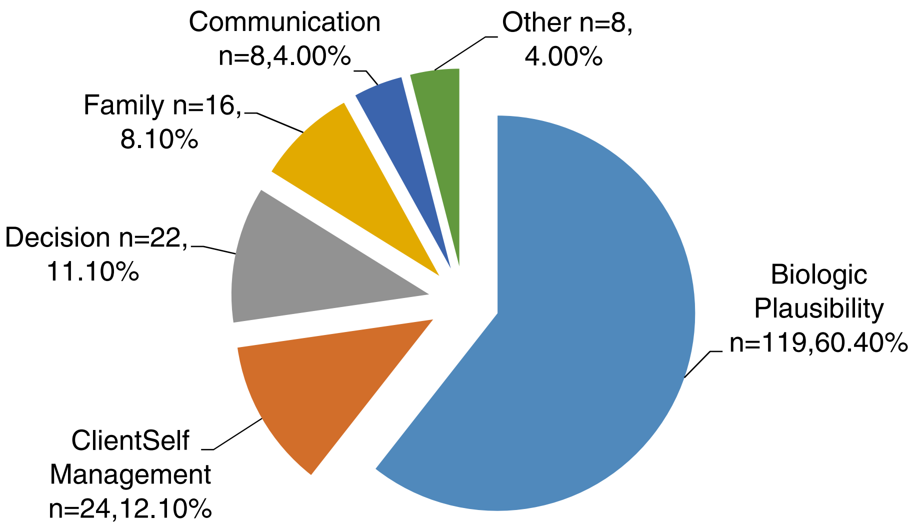

Figure 1. Blueprint topics of nursing science data-based publications, 2010–2014.

Table 1. Authorship, Country, Focus, and Funding of Nursing Science Data-Based Publications, 2010–2014

	Authors			Country		Funded	
Blueprint topics	Nurse and others	Nurse	Others	USA	Not USA[a]	Yes	None acknowledged
$N = 197$	$n = 141$	$n = 24$	$n = 32$	$n = 167$	$n = 30$	$n = 182$	$n = 15$
	71.5%	12.1%	16.2%	84.7%	15.2%	92.3%	7.6%

[a] Australia, Brazil, Canada, Denmark, England, Germany, Iceland, Ireland, Israel, Japan, Jordan, Kenya, Korea, Mali, Nigeria, Norway, Philippines, Scotland, Sweden, Taiwan, and Turkey

communication. The remaining eight articles addressed screening, personal utility of symptom management, disease states, or pharmacogenomics (**Figure 1**). The characteristics of the articles are summarized in **Table 1**. The majority (84.7%) of the studies were conducted in the United States. Most (71.4%) were coauthored by nurses, with others from related disciplines, determined by credentials or departmental affiliation, including biostatistics, communications, engineering, epidemiology, genetic counseling, medicine, molecular genetics, pharmacy, physiology, psychology, public health, and sociology. Twelve percent were authored only by nurses, and 16.2% were authored by investigators solely from other disciplines. Most (92.3%) acknowledged funding from sources that included government, foundations, or institutions. Of the NINR Strategic Plan area of cross-cutting themes, only the health disparities category yielded more than one paper that indicated the cross-cutting theme in the purpose statement.

Biological Plausibility

The topic with the highest number of articles ($n = 119$) was biologic plausibility. This category included examination of relationships between genomic or variants or biologic markers in an inherited disease; diseases with a major genomic component or common chronic condition; and phenotype, symptoms, management of clinical symptoms, or medical diagnosis. Fifty-two studies reported associations among specific genomic variants and symptoms (e.g., sleep difficulties or fatigue); three studies focused on associations among specific alleles and efficacy of drugs or other treatments. Fifty studies reported variants associated with specific medical diagnoses such as cardiac disease, asthma, or orofacial clefting, nine reported biomarkers in genetic or common chronic conditions, and five reported variants associated with ethnicity. Regardless of the phenotype under investigation, research used standard genomic analyses of genotype, gene expression, and exome sequences, or biomarker measures. In addition to DNA, investigators studied mitochondria, telomeres, and proteins in their genomic research. Medical diagnoses or clinical symptoms were identified through self-report or clinical measures. Articles included teams on which nurses were the sole investigators ($n = 4$), interdisciplinary teams ($n = 89$), or teams that did not include nurse authors ($n = 26$). Studies were conducted in Africa, Brazil, Denmark, Norway, Scotland, and the United States.

Client Self-Management

Twenty-four articles addressed client self-management (Blueprint level 2). Studies included those at risk for, or who are diagnosed with, single gene disorders ($n = 16$), such as cystic fibrosis or thalassemia, or multifactorial conditions ($n = 8$), such as congenital anomalies. Articles primarily used interviews ($n = 17$), with some using author-developed measures ($n = 2$) or standardized measures ($n = 3$). Two studies used both standardized measures and interviews. Findings documented emotional and daily life consequences for the person receiving genomic risk or diagnosis information, unmet needs regarding information or coping support, and self-management transition by youth into adulthood. Authors were nurses only ($n = 5$), interdisciplinary teams ($n = 18$), or teams that did not include nurse authors ($n = 1$). Research was conducted with subjects living in Australia, Canada, Ireland, the Philippines, Sweden, Turkey, the United Kingdom, and the United States.

Decision Making or Support

Twenty-two articles addressed decision topics appearing in several nursing research Blueprint categories (level 2). All articles on decision topics were grouped together. Topics included attitudes regarding genomic testing ($n = 4$), decision processes ($n = 10$), and risk perception ($n = 8$). Research participants included those with single gene conditions, such as hereditary breast or ovarian cancer; common chronic conditions, such as hypertension; risk for inherited conditions, detected in prenatal testing; and ethnic communities' attitudes towards genomic testing and research. Designs were descriptive, using qualitative and quantitative methods. Most ($n = 12$) used interviews or focus groups, with others using author-designed measures ($n = 7$), standardized measures ($n = 4$), or media discourse analysis ($n = 1$). Articles included teams where nurses were the sole investigators ($n = 7$), or on interdisciplinary teams ($n = 15$). Research was conducted with subjects living in Canada, Iceland, Israel, the Philippines, Mali, Norway, the United Kingdom, and the United States.

Family

Sixteen articles addressed family topics (Blueprint level 2). Seven used standardized measures, and three of these studies included other sources of data (e.g., medical records or interviews). Seven used qualitative methods only, and two used investigator-designed measures. Participants included healthy adults and children and those with single gene conditions (e.g., Huntington disease, breast cancer, metabolic conditions). Findings reported on daily living ($n = 9$) and responses by family members to an individual with a diagnosis of a genomic condition ($n = 7$). Articles included teams where nurses were the sole investigators ($n = 5$) or on interdisciplinary teams ($n = 11$). Research was conducted with subjects living in Korea, Taiwan, the United Kingdom, and the United States.

Communication

Communication topics appeared in several Blueprint nursing research categories (level 2). All articles on communication topics were grouped together. Eight articles addressed the process of communication of risk information by healthcare providers or information obtained through the Internet. Participants included members of the public, prenatal mothers or couples, parents of children receiving newborn screening, and people with single gene disorders. Four used qualitative designs, and the remainder used either standardized ($n = 2$) or author-designed ($n = 2$) measures. These studies investigated the impact of genomic risk communication, use of online information and support groups, and information needs and preferences. Articles included teams where nurses were the sole investigators ($n = 1$) or on interdisciplinary teams ($n = 7$). Research was conducted with subjects living in Australia, Spain, the United Kingdom, and the United States.

Cross-Cutting Theme: Health Disparities

Twenty-three articles addressed disparities in the purpose statements. These addressed biomarkers associated with clinical problems such as blood pressure or coronary heart disease, as well as values and preferences influencing decisions for genomic testing or biobank participation, symptom management and monitoring, life decisions, and family experiences of parents of children and individuals with single gene conditions, most commonly sickle cell disease. Articles included teams where nurses were the sole investigators ($n = 4$), interdisciplinary teams ($n = 16$), or teams that did not include nurse authors ($n = 3$). Research was conducted with subjects living in Africa or the United States.

Impact

One indicator of the impact of work in a scientific field is the frequency and location where scientific work is

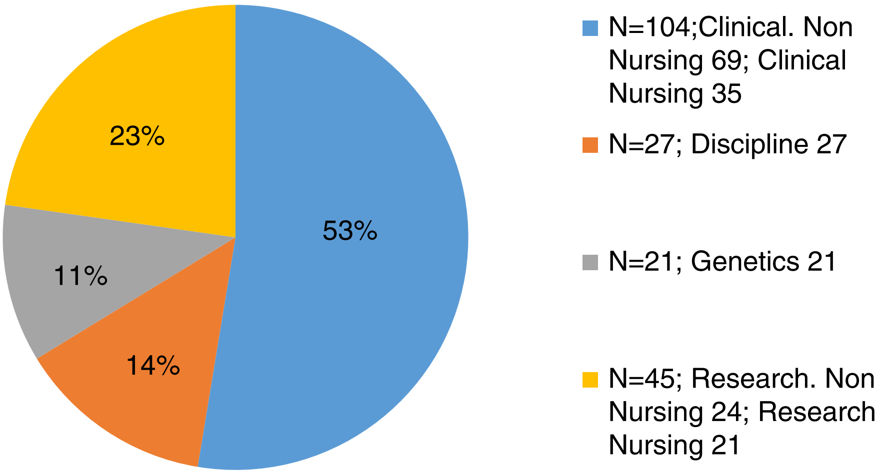

Figure 2. Journal focus on nursing science data-based publications, 2010–2014.

cited. This review included articles published within the past 5 years, with some not having been in the literature long enough to be cited in subsequent studies. Despite that limitation, a Scopus search, which tends to focus on PubMed indexed sources, identified 34 references, cited 10 or more times. These were in journals with impact factors ranging from 0.5 to 42.3, and were primarily clinical journals. Three articles addressed decision making or support, three addressed family, and the remainder ($n = 28$) addressed biologic plausibility findings. Citations were in nursing as well as over 100 clinical journals, suggesting impact within and beyond the discipline of nursing (**Figure 2**).

Discussion

Nursing science contributions to genomic health over the past 5 years mirrored the descriptive nature of knowledge development across disciplines in genomics and health. The review primarily contained papers examining biologic questions that advanced the understanding of genomic aspects of diseases and clinical symptoms; with fewer studies in the areas of communication of risk, quality of life topics, outcomes of treatments, or use by recipients of personal genomic information. No evidence was found in the literature in this review that addressed descriptive or comparative studies of how biologic and behavioral discoveries are implemented into clinical practice, an opportunity that includes examination of personalized nursing interventions (Munro, 2015). None addressed cross-cutting themes of cost, policy, and public education. Very few included the theme of health disparities.

If the Blueprint is the direction agreed upon by genomic nursing scientists and the public, then the state of knowledge is at the discovery phase, with most emphasis on biologic plausibility discovery. Strategies such as sharing of data, using common data elements, and agreed upon standards may accelerate progress (Manolio et al., 2015). All topics were addressed in multiple countries, suggesting that discovery of problems and potential solutions to these problems span national boundaries. However, it is not clear if researchers are working collaboratively within and across countries to move the discovery phase forward towards clinical implementation.

Furthermore, it was not apparent that research teams for individual studies were composed of both biologic and behavioral scientists. Without partnerships across research disciplines, advancement of discoveries to the point of implementation to improve health may be slowed. It is important to note that the work of the Blueprint working group is active and ongoing. Notes and the meeting report are available online at genome.gov. Activities focusing on common data elements, and data sharing of biologic plausibility studies, may accelerate the building of a body of knowledge across individual research programs.

Although advancements in measurement and research designs are essential to analytic and clinical validity as well as personal and clinical utility, these were not specifically reflected in the Blueprint. Attention to valid and appropriate measures in genomic nursing science may also contribute to moving knowledge forward towards implementation. And, although the Blueprint's intent to identify gaps was realized in this review, the structure of the Blueprint made it difficult to be precise on the gaps due to the duplicative use of terms across the taxonomy structure. It is also difficult to judge into which NINR Strategic Plan area a study fit.

Training was not reviewed specifically in this report. However, there were implications for training identified in the Blueprint (Calzone et al., 2013), including training in genomics, biorepositories, bioethics, translation, and interdisciplinary research team skills. The CANS Idea Festival Committee also identified researcher training priorities (Henly et al., 2015). Findings of this bibliometric review support the research skills needed by researchers, supporting the proposed directions for genomic nursing scientist training.

Limitations

This bibliometric review has several limitations. The review was not designed to examine the quality and extent of evidence in any of the topic areas. The review did not seek all research-based publications on the Blueprint topic areas that are conducted by other researchers. It was also beyond the scope of this review to determine gaps in evidence of meaningful patient or family outcomes from application of health-related genomic science across populations, including underserved populations. An examination of personal utility derived from results from genomic nursing science studies may be a starting place for further examination of this issue. The search was confined to citations as catalogued in PubMed or CINAHL. Thus, genomic nursing research articles in journals not indexed in these sources were potentially missed in the review. Finally, the assignment of articles into Blueprint categories may be interpreted differently by other scholars.

Conclusions

Genomic nursing science reported over the past 5 years primarily focuses on describing biologic aspects of diseases or symptoms, client management of symptoms, and individual and family responses to genomic risk information. All topics were examined in several countries. Research conducted by interdisciplinary teams was disseminated beyond nursing audiences. Few articles identified health disparities in their purpose. Interdisciplinary research is needed to document clinical and system outcomes of genomic nursing science implementation in healthcare. This body of genomic nursing science discovery provides a starting point for research leading to application of biologic and behavioral aspects of genomic discoveries into health care that achieves meaningful patient outcomes across populations, healthcare provider disciplines, and healthcare systems.

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Clinical Resources

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- G3C Global Genetics and Genetics Community: http://g-3-c.org/en
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[Correction made after online publication February 2, 2016: References have been updated.]

JOURNAL OF NURSING SCHOLARSHIP

WORLD HEALTH

Nurses as Leaders in Disaster Preparedness and Response—A Call to Action

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Key words
Competencies, curriculum, disaster, education, nursing, policy, practice, preparedness, public health emergency, research, scope of practice

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Abstract

Purpose: To develop a vision for the future of disaster nursing, identify barriers and facilitators to achieving the vision, and develop recommendations for nursing practice, education, policy, and research.

Design and Methods: A series of semistructured conference calls were conducted with 14 national subject matter experts to generate relevant concepts regarding national nursing workforce preparedness. An invitational daylong workshop hosted by the Veterans Emergency Management Evaluation Center, U.S. Department of Veterans Affairs, was held in December 2014 to expand and refine these concepts. Workshop participants included 70 nurses, emergency managers, and a broad range of public health professionals. Conference call notes and audiotapes of the workshop were transcribed and thematic analysis conducted to outline a vision for the future of nursing in disaster preparedness and response, and to articulate an agenda for nursing practice, education, policy, and research to achieve that vision.

Findings: The group developed a vision for the future of disaster nursing, and identified current barriers and opportunities to advance professional disaster nursing. A broad array of recommendations for nursing practice, education, policy, and research, as well as implementation challenges, are summarized in this article.

Conclusions: This project represents an important step toward enhancing nurses' roles as leaders, educators, responders, policymakers, and researchers in disaster preparedness and response. Nurses and the health and human service organizations that employ them are encouraged to engage in an expansive national dialogue regarding how to best incorporate the vision and recommendations into their individual lives and the organizations for which they work.

Clinical Relevance: Nurses comprise the largest healthcare workforce, and opportunities exist to strengthen disaster readiness, enhance national surge capacity, and build community resiliency to disasters.

The past decade has shown a dramatic increase in the frequency and intensity of natural weather-related, technological, infectious disease, and human-caused disaster events (Hay & Mimura, 2010; U.S. Agency for International Development, 2015). With approximately 2.8 million registered nurses in the United States (Health Resources and Services Administration [HRSA], 2013), nurses represent the largest segment of the U.S. healthcare workforce, and, accordingly, "the effectiveness of the healthcare system's response to a public health emergency or disaster is largely dependent on the surge capacity of the nurse workforce" (National Advisory Council on Nurse Education and Practice [NACNEP], 2009, p. 2). Nurses must be prepared to respond to any disaster or public health emergency (NACNEP, 2009; Veenema, 2006, 2013). Employed across diverse settings, nurses collaborate on a daily basis with a broad range of public health or healthcare professionals and are well positioned to partner with health system leaders, individuals, and families to significantly improve population health outcomes and build community resiliency to disasters across the nation. Nurses are consistently ranked by the public as trusted sources of health information (American Nurses Association [ANA], 2014) and therefore have far-reaching influence.

Yet despite significant federal funding for hospital and public health preparedness since the attacks of September 11, 2001, efforts to prepare and mobilize nurses for disaster preparedness and response have been episodic and difficult to sustain. Assessments of professional readiness indicate that the nation's nurses are inadequately prepared to respond to the complex demands of disasters (Baack & Alfred, 2013; Gebbie & Qureshi, 2006; NACNEP, 2009). While some disaster preparedness programs have been developed across various government agencies, schools, and professional organizations, formal systems are not in place to provide pre- and postlicensure nurses with consistent, comprehensive, and updated education and training in emergency preparedness and disaster response. Although the American Association of Colleges of Nursing (AACN) requires disaster education (risk communication, emergency preparedness, and disaster response including self-protection) as part of their essentials of baccalaureate education (AACN, 2008), resources and guidance for implementing this content is inadequate. As a result, educational programs vary greatly and many are not evidence based (Gebbie, Hutton, & Plummer, 2012). Training programs are more often developed in "knee-jerk" response to specific disasters, as for the use of personal protective equipment (PPE) for nurses and other healthcare providers in U.S. hospitals during the Ebola scare (U.S. Department of Health and Human Services, 2014).

In addition, a host of practice, policy, and research challenges limit nurses' effectiveness in response and recovery. For example, healthcare organizations have not systematically adopted crisis standards of care or communicated those to staff. Major policy issues include inadequate integration of nursing into national disaster policy frameworks, the need to strengthen and improve coordination of existing volunteer health systems (Institute of Medicine [IOM], 2014b), inconsistencies in state-based licensure reciprocity for volunteer health professionals, liability concerns, and compensation for volunteers harmed while responding to disasters or public health emergencies (IOM, 2012). In the research arena, additional work is needed to identify nursing practices that are most effective in improving population outcomes across the disaster life cycle, and to increase the overall number of doctorally prepared nurse scientists and specifically those trained in disaster nursing.

Worldwide, it is commonly acknowledged that nurses play an integral role in disaster response (Fritsch & Zang, 2009; Fung, Loke, & Lai, 2008; Usher & Mayner, 2011; Yamamoto 2013; Yan, Turale, Stone, & Petrini, 2015). Globally, disaster nurse readiness is a pressing concern (Chapman & Arbon, 2008) and nurse leaders from many countries have identified disaster nursing education and training as a vital need (Chan et al., 2010; Kako, Mitani, & Arbon, 2012; Usher & Mayner, 2011; Yamamoto, 2013; Yan et al., 2015). Many are facing the challenge of identifying appropriate disaster nursing competencies and implementing effective education and training programs to prepare their nursing workforce (Bahrami, Aliakbari, & Aein, 2014; Chan et al., 2010; Yamamoto, 2013; Yan et al., 2015).

Currently, no country stands apart from the rest as having satisfied the need that exists. However, activities that followed the devastating 1995 Great Hanshin-Awaji Earthquake in Japan serve as a good example of how nursing professionals can collectively organize themselves to respond to need and generate enough momentum to engage key stakeholders in order to establish processes for response and ultimately influence their national response framework. Those efforts were evident when mechanisms were in place to immediately dispatch nurses to care for victims of the Niigata Cheutsu Earthquake in 2004 (Yamamoto, 2013), and their momentum continues today.

The Veterans Emergency Management Evaluation Center (VEMEC), Office of Public Health, Veterans Health Administration (VHA), U.S. Department of Veterans Affairs (VA), with the support of the VA Office of Nursing Services and VHA Office of Emergency Management, initiated this call to action to identify challenges and determine the first action steps in systematically identifying relevant themes to improve the practice of disaster nursing. The aims of the project were to develop a vision for the future of disaster nursing, identify barriers and facilitators to achieving the vision, and develop recommendations for nursing practice, education, policy, and research. The project is targeted to a broad audience that includes nurses, employers, voluntary organizations, educators, policy makers, and researchers. As the largest employer of nurses in the United States (U.S. Department of Veterans Affairs, 2015) and with a mandate to support states and localities in times of a federally declared disaster (Public Law 97–174), the VA is well positioned to initiate this effort.

Methods

A list of subject matter experts in disaster nursing was generated based on a review of the literature. Additional experts were identified using a snowball technique. Eighteen experts were invited to serve as steering committee members charged with informing the aims of the project, based on their subject matter expertise with respect to leadership, contributions, and publications in disaster nursing education, practice, policy, and research. A series of semistructured conference calls were held from September 2014 through December 2014 with the 14 experts who agreed to participate. Discussions included the following:

- What would an ideal vision for the future of disaster nursing look like?
- What factors related to practice, education, policy, and research currently impact disaster nursing?
- What opportunities exist to advance national nurse readiness?
- What actionable recommendations would support advancing national nurse readiness?

Through facilitated discussions, the members identified factors relevant to the practice of disaster nursing, explored their individual and collective vision for the future of disaster nursing, and identified potential next steps in implementing that vision. They served as their own planning committee for a national workshop on disaster nursing in order to further refine their ideas by receiving feedback from nurses working in a wide variety of settings.

The invitational workshop, "Call to Action: Nurses as Leaders in Disaster Preparedness and Response," was convened on December 9, 2014, in Los Angeles by VEMEC. Audience invitations were sent to representatives at 117 relevant federal, state, and local agencies, foundations, hospitals, schools of nursing, and nonprofit organizations in California and across the nation. A total of 70 individuals attended, with representation predominantly from nursing; other participants were emergency management and a broad range of public health professionals.

The workshop was organized into four sessions (**Table 1**). The first session included a series of presentations to orient the audience and provide the necessary background and history of disaster nursing. The second session focused on developing a vision for the future of disaster nursing using the "focus prompt" developed by the planning committee in order to provide a launching point for participants to respond (Jackson & Trochim, 2002). There was also an interactive visioning exercise in which all participants in small groups wrote and shared their vision and then discussed with the audience. The third session included four panel discussions focused on disaster nursing practice, education, policy, and research. Each panel had three to four experts speak, followed by audience discussion. The fourth session served as a recap of the discussions that took place during the day and an overview of the identified barriers and facilitators and the broad range of potential recommendations in the four areas needed to achieve the overall vision for the future of disaster nursing. All sessions were facilitated by a qualified moderator, who was selected for her experience moderating large group discussions and broad expertise in nursing research, education, policy, and practice.

Sessions were audio-recorded and transcribed. Transcripts and written feedback from the participants (vision statements, written questions for panelists) were thematically coded by two of the authors who came to collective agreement, and then the themes were analyzed by the

Table 1. Speakers or Panelists and Topics

Speaker or panelist	Presentation or panel title
Donna Gage, PhD, RN, NE-BC Chief Nursing Officer, Office of Nursing Services, Veterans Health Administration, U.S. Department of Veterans Affairs	Welcome and opening remarks
Tener Goodwin Veenema, PhD, MPH, MS, RN, FAAN Associate Professor, Department of Community and Public Health, Johns Hopkins School of Nursing Center for Refugee and Disaster Response Johns Hopkins Bloomberg School of Public Health	Keynote address and Painting the future landscape
Anne Griffin, MPH, BSN, RN, CNOR Clinical Investigator and Senior Program Manager Veterans Emergency Management Evaluation Center, Office of Public Health U.S. Department of Veterans Affairs	Historical timeline of disaster nursing
Cheryl Peterson, MSN, RN Senior Director, Nursing Programs, American Nurses Association	Practice panel
Linda MacIntyre, PhD, RN Chief Nurse, American Red Cross	
Carole Snyder, MS, RN California State Council President, Emergency Nurses Association	
CDR Derrick Gooch U.S. Public Health Service	
Tener Goodwin Veenema, PhD, MPH, MS, RN, FAAN Associate Professor, Department of Community and Public Health, Johns Hopkins School of Nursing Center for Refugee and Disaster Response Johns Hopkins Bloomberg School of Public Health	Education panel
Joan Stanley, PhD, CRNP, FAAN, FAANP Senior Director of Education Policy, American Association of Colleges of Nursing	
Beverly Malone, PhD, RN, FAAN CEO, National League for Nursing	
RADM Nadine Simons, MS, RN (Ret.) Assistant Surgeon General and Regional Health Administrator, Region IX Office of the Assistant Secretary for Health, U.S. Department of Health and Human Services	Policy panel
John J. Walsh, Jr., MS Co-Director, Vanderbilt Program in Disaster Research and Training Vanderbilt University School of Medicine	
Roberta Proffitt Lavin, PhD, APRN-BC Associate Dean for Academic Programs University of Missouri-St. Louis College of Nursing	
Mary Pat Couig, PhD, MPH, RN, FAAN Program Manager/Emergency Preparedness, Office of Nursing Services, Veterans Health Administration, U.S. Department of Veterans Affairs	Research panel
John J. Walsh, Jr., MS Co-Director, Vanderbilt Program in Disaster Research and Training Vanderbilt University School of Medicine	
Roberta Proffitt Lavin, PhD, APRN-BC Associate Dean for Academic Programs University of Missouri-St. Louis College of Nursing	
Elaine Larson, PhD, RN, FAAN, CIC Associate Dean for Research and Anna C. Maxwell Professor of Nursing Research, Columbia University School of Nursing and Professor of Epidemiology, Columbia University of Mailman School of Public Health	Moderator for panels

larger author group to identify gaps and additional ideas for consideration.

Results

Vision

> To create a national nursing workforce with the knowledge, skills, and abilities to respond to disasters and public health emergencies in a timely and effective manner.

Ideally, nurses would:

- Possess the minimum knowledge base, skills, and abilities regarding disaster response and public health emergency preparedness;
- respond directly or provide indirect support (e.g., shift coverage for those deploying or critical data collection) during a disaster event or public health emergency;
- promote preparedness amongst individuals in their care, families, and communities and within the organizations they represent; and
- demonstrate a commitment to professional preparedness by participating in disaster planning, drills, and exercises within and beyond their specialty environment.

This vision is predicated upon the belief that nurses who possess at least a minimum knowledge base and skill set are better able to keep themselves and their patients and families safe or at least to minimize the harm that may occur. It provides recognition of the broad range of leadership and other skills that nurses bring to disasters. Such a workforce would include all licensed nurses who provide care to individuals, families, and communities, and their efforts would be grounded in a culture of preparedness that would enhance national disaster preparedness and response as well as community resiliency.

Barriers and Facilitators to Achieving the Vision

Panelists and participants highlighted a number of individual, organizational, and environmental barriers and facilitators to achieving this vision (**Table 2**). The identification of these factors helped inform the vision statement and recommended strategies for advancing disaster nursing. While many factors were identified during this process, the recommendations in this article target a select group as being important for the initial steps toward achieving the stated vision.

Table 2. Barriers and Facilitators to Achieving the Vision

Level	Factors
Individual factors for nurses	1. Level of personal disaster preparedness 2. Levels of knowledge, skills, and abilities regarding disasters and public health emergencies 3. Willingness to respond 4. Capacity to educate individuals, families, and/or communities on disaster preparedness and response
Organizational factors	1. Level of institutional commitment to preparedness (e.g., planning, training, PPE, adoption of crisis standards of care, logistics, and effective communications) 2. Presence and influence of nurses in leadership positions in disaster and public health emergency management 3. Empowerment of nurses to lead and report issues/problems 4. Adoption of an interprofessional team approach to disasters
Environmental or systemic factors	1. Authority and degree of coordination, communication, and collaboration among federal-state-local partners 2. Ability to produce and distribute adequate PPE, pharmaceutical supplies, and logistical support 3. Impact of regulations or guidelines requiring disaster preparedness (e.g., Centers for Medicare & Medicaid Services, accrediting bodies) 4. Influence of reimbursement and financial incentives for preparedness and response 5. Need for a national nursing workforce plan for preparedness and disaster response 6. Capacity and constraints of educational systems, employers, and volunteer agencies to prepare nurses for disasters 7. Lack of metrics for evaluation 8. State-based licensure constraints on the ability of nurses to respond to disasters across state lines or outside their practice area (RNs, APRNs) 9. Degree of coordination of multiple volunteer emergency response teams (e.g., ESAR-VHP, MRC, NDMS, American Red Cross) 10. Comprehensiveness of liability protection for nurses and other responders to disasters 11. Prioritization and funding of disaster nursing research 12. Suitability of current research approaches and infrastructure to assess need and inform nursing practice during the disaster cycle 13. Degree of community engagement in disaster planning, ethical considerations, and response

Note. APRN = advanced practice registered nurse; ESAR-VHP = Emergency System for Advance Registration of Volunteer Health Professionals; MRC = Medical Research Council; NDMS = National Disaster Medical System; PPE = personal protective equipment; RN = registered nurse.

Recommendations

1. Practice

Recommendation 1.1. Health care and related organizations support clinical nursing practice during disasters to reflect crisis standards of care and address common barriers to willingness of nurses to respond to a disaster.

Disasters and public health emergencies may require nurses to shift slowly or abruptly from care as usual where the focus is on individual outcomes to a crisis standard of care where the focus is on population outcomes. This shift represents a stark contrast in the way nursing is practiced daily. Training for unique disaster nursing skills such as reverse triage and allocation of scarce resources as well as guidance on triggers for when transitions happen is required in order to provide the best possible care for as long as possible.

Organizations should adopt their own crisis standards of care using a framework such as described in the 2012 IOM Report, *Crisis Standards of Care: A Systems Framework for Catastrophic Disaster Response*. Dissemination efforts should provide clarity to nurses on specific triggers and the impact on disaster nursing scope of practice. As part of the process for adopting crisis standards of care, nursing representation should be evident on all emergency preparedness and disaster-related planning committees and nurses should be provided with regular, ongoing interprofessional disaster education, training, and drills.

Organizations should also recognize factors within their control that influence willingness to respond. In theory, the implementation of crisis standards of care that provide a framework for disaster response may ultimately impact willingness to respond. A systematic literature review identified work environment and climate as one of the major factors either facilitating or hindering the willingness of healthcare personnel to respond to an event (Connor, 2014). Organizations can consider strategies supported by research that could increase response, such as promoting pre-event plans for dependents at home; ensuring the supply of PPE, vaccines, and antiviral drugs for all employees; ensuring nursing representation on all disaster preparedness planning committees; assigning specific roles to nurses; and providing regular ongoing interprofessional disaster education, training, and drills (Balicer et al., 2010; Balicer, Omer, Barnett, & Everly, 2006; Connor, 2014; Goodhue et al., 2012; Irvin, Cindrich, Patterson, & Southall, 2008).

Recommendation 1.2. Establish a collective effort among nurse leaders to advance the practice of disaster nursing and public health emergency preparedness and response.

A collective effort such as a society or association with sufficient policy and operational expertise would be dedicated to advancing the practice of disaster nursing and public health preparedness. This focused initiative might include, for example, a national advisory board of disaster nursing and subject matter experts and legal experts who could author a model scope of practice specific to the specialty of disaster nursing that could be adopted by organizations. They could work with national nursing organizations to promote nurses as leaders in disaster preparedness by issuing position statements and participating in a range of initiatives to advance the practice of disaster nursing. Such collective efforts could lead to a nationwide campaign to engage nurses from all specialty areas.

2. Education

Recommendation 2.1. Develop a national set of disaster nursing competencies to be integrated into the AACN Essentials of Nursing and National League for Nursing (NLN) Guidelines for Nursing Education.

The best way to increase and maintain response capacities and to ensure the sustainability of this capacity is through workforce development. Competency-based disaster nursing programs, standardized disaster curricula, training guidelines, and performance measures are needed across all levels of nursing personnel. The panel proposed that the first step in developing a framework for expanding educational opportunities for nurses would be to identify a minimum set of competencies with respect to disaster preparedness and response. These competencies would ensure that every nurse had the foundational ability to respond at a basic level and could keep him- or herself and patients safe. The panel recognized the broad scope and spectrum of nursing care rendered during disaster events and that not all nurses need to be prepared for all roles. For example, nurses participate as valued members of the disaster response team as first responders, hospital-based first receivers, and those who bring realistic calm to families and communities impacted by catastrophic events. The AACN essentials of baccalaureate education (AACN, 2008) include several statements regarding emergency preparedness, and these competencies could be expanded and made more explicit.

Existing published competencies for nursing or healthcare workforce development have been identified based on retrospective evaluation of disaster response lessons learned or proposed via a systematic consensus-building approach (Daily, Padjen, & Birnbaum, 2010; Hsu et. al., 2006; International Council of Nurses, 2009; Loke & Fung, 2014; Schultz, Koenig, Whiteside, & Murray, 2012;

Walsh et al., 2012). To date, there is no single set of disaster practice competencies accepted for curriculum guidance, either in nursing or in other health professions. Nor are published data available to validate any of the published disaster-related healthcare competencies (Daily et al., 2010). Only scant data support or identify specific knowledge, skills, and abilities that relate to improved outcomes associated with a disaster (Stanley & Bennecoff Wolanski, 2015; Williams, Nocera, & Casteel, 2008).

A national workgroup could review existing published competencies in disaster nursing to develop a limited set of competencies needed by all nurses and worthy of inclusion in national nursing curricular guidelines. Ideally, this work would be in collaboration with the AACN, NLN, National Association for Associate Degree Nursing, and National Council of State Boards of Nursing.

Recommendation 2.2. Establish coalitions of schools of nursing to develop evidence-based and competency-driven didactic and clinical learning opportunities using multiple delivery platforms that can be integrated into the undergraduate and/or graduate nursing curricula.

Different approaches to integrating disaster content into the nursing curriculum exist. Disaster nursing could be presented as a core course with didactic and clinical components, or the content could be woven through existing course work as appropriate. Many important competencies not specific to disasters (e.g., infection control, epidemiology, and risk assessment) could be presented in a disaster context. In addition to establishing minimum knowledge and competencies for all U.S. nurses, it is important to have consistent metrics for evaluation. Members of the education panel questioned whether the current number or types of questions on the National Council Licensure Examination (NCLEX) provided sufficient incentive to drive the inclusion of increased content into the nursing curricula or for evaluating the competence of newly graduated registered nurses. Some options to explore include revising the NCLEX to include a larger number of questions pertaining to disaster nursing, or adding a state-based examination or addendum to the NCLEX. Discussions should be pursued with the National Council of State Boards of Nursing to determine the best way to include this material in standardized testing.

Recommendation 2.3. Broaden life-long, continuing educational opportunities in disaster nursing and public health emergency preparedness and response for nurses through healthcare and related organizations across all healthcare settings.

The panel voiced strong consensus for the nursing education community at large to expand educational opportunities in disaster response and emergency preparedness to accommodate nurses at all levels in their career from prelicensure students to staff and advanced practice registered nurses currently in the workforce. A possible approach would be to establish employer requirements for training and testing (e.g., in conjunction with the Center for Medicare & Medicaid Services regulations or accreditation standards).

The unique learning needs of nurse executives and nursing faculty would need to be addressed as well. The panel proposed that a national framework for the expansion of education and training opportunities be established. This could be accomplished through a national workgroup composed of key stakeholders in disaster nursing education working in collaboration with State Boards of Nursing.

Recommendation 2.4. Establish a national clearinghouse of information to provide guidance and resources on disaster nursing.

The panel endorsed use of a centralized clearinghouse to provide access to timely and updated resources related to disaster nursing. While the primary focus would be to provide resources for nurses and nursing faculty, other audiences might include policymakers, health care organizations, researchers, funders, or emergency managers. Resources might include case studies, research studies, policy issues, interprofessional training tools, exemplars of didactic and clinical learning experiences, an outline of how and where the competencies might be integrated into current nursing curricula, and a directory of media and online resources. The panel also recognized the critical need to develop competencies and resources specific to nurse administrators or executives and others in leadership positions to prepare them for crisis conditions resulting from disasters and emergencies and facilitate decision making in highly ambiguous situations (e.g., regarding allocation of scarce resources, evacuation, and patient transfers).

These resources for disaster nursing could be incorporated as part of an existing clearinghouse (e.g., the Technical Resources Assistance Center and Information Exchange, developed by the U.S. Department of Health and Human Service's Assistant Secretary for Preparedness and Response) or in a new repository, as appropriate. The panel members acknowledged that the success of clearinghouses, however, is dependent on the availability of resources to assure that they are regularly updated and managed to maintain their accuracy. Hence, if such resources are established, they must include management plans to assure feasibility and sustainability.

3. Policy

Recommendation 3.1. Conduct a thorough review of national policies and planning documents addressing disasters and public health emergencies to ensure that they elevate, prioritize, and address the practice of disaster nursing in federal, state, and local emergency management operations.

Despite substantial progress in the development of a coordinated national strategy regarding disasters and public health emergencies, panelists agreed that these policies may not fully capitalize on the untapped potential of the nursing workforce. As a result, panelists strongly supported a broad-based evaluation of national disaster policy and planning documents to identify gaps and ensure that potential roles for nurses and their contributions are fully realized in federal, state, and local disaster operations.

As a starting point, they recommended that the role of nurses be reexamined within the context of the National Response Framework (U.S. Department of Homeland Security [DHS], 2013), the guide to how the United States responds to all types of disasters and emergencies. The panel strongly endorsed the placement of nursing professionals in leadership roles in management of disaster functions related to command and control, coordination of medical services, and decision making regarding patient care and population healthcare needs. For example, embed nurse leaders into response operation leadership roles as a distinct part of the decision-making and management processes within the National Response Framework itself, especially in Emergency Support Function 8—public health and medical services. Most often, emergency situations and disaster events are managed by nonhealth or medical personnel and agencies. As highlighted in the Medical Surge Capacity and Capability Management System (Barbera & Macintyre, 2007), placing trained nurses within the operational response framework can provide distinct advantages, including:

- Timely input by public health and medical managers at decision-making levels regarding life and safety issues for nonhealth responders;
- ability to define medical response priorities across all aspects of an incident and incorporate them into a single cohesive strategy;
- promotion of a proactive rather than a reactive response by healthcare organizations, helping to ensure the continuity of medical operations during an incident; and
- hands-on instruction for public health and medical managers by jurisdictional managers who have extensive incident management experience.

Examples of other priority national policy documents which could benefit from enhanced nursing roles include the Target Capabilities List (DHS, 2007) and the related Universal Task List (DHS, 2005), which collectively outline the capabilities and a framework for planning, priority setting, and program implementation across all government levels in prevention, protection, response, and recovery in events of national significance. Given the complexity of these policies and the numerous stakeholders involved in the public and private sectors, panelists advocated for a review of these policy issues by the National Academy of Medicine or similar body.

Recommendation 3.2. Encourage a culture of volunteerism through national nursing professional organizations by engaging their members to align with volunteer agencies and participate in disaster response.

Volunteer health professionals are essential in meeting surge capacity needs during times of disaster and emergencies (NACNEP, 2009). Given that nurses are the largest component of the U.S. healthcare workforce and play a critical role in surge capacity, panelists strongly recommended that national nursing organizations encourage their membership to volunteer with response teams organized by the government (e.g., the Medical Reserve Corps, Emergency Systems for the Advance Registration of Volunteer Health Professionals) or private organizations such as the American Red Cross. Advance registration through established systems can help ensure that nurses and other professionals are fully prepared to respond during disasters. In contrast, "spontaneous" or unaffiliated volunteers who arrive on a disaster scene may actually impede response efforts (Hodge, Gable, & Cálves, 2005).

The panel also recognized the importance of having policies in place to strengthen and coordinate existing volunteer systems. One of the major challenges is coordination and duplication of volunteers across numerous state and private-based systems (NACNEP, 2009). To that end, the panel endorsed exploration of a national registry or database that could link to the multiple existing systems to improve coordination. The panel acknowledged, however, that the utility of such a registry would be dependent on commitment and resources to maintain updated and accurate information over time.

Faculty and students of schools of nursing are an important untapped source of potential volunteers (Cusack, Arbon, & Ranse, 2010) and have played important roles in response to disasters in other countries such as China (Yang, Xiao, Cheng, Zhu, & Arbon, 2010), Japan (Okumura et al., 1998), and Hong Kong (Fung et al., 2008). While the idea of involving prelicensed nurses in disaster response prompts prudent concern, there have been successful collaborations in the United States between schools of nursing and community stakeholders that have yielded positive outcomes for students in need of real-life learning experiences as well as the communities in need of service following a disaster (Pattillo & O'Day, 2009; Richards, Novak, & Davis, 2009). A next step could build on these successful experiences, and potentially a network of schools could be established pre-event through a coordinated national registry. Participating schools would be prepared to respond by meeting nationally established standards for disaster preparedness prior to an event. The panel proposed further exploration regarding the responsibilities and opportunities for schools of nursing in responding to disasters.

Recommendation 3.3. Facilitate timely and efficient deployment of nurses and other healthcare workers to disaster areas by expanding liability protections for volunteers and providing coverage for volunteers harmed while responding.

A variety of legal, regulatory, and policy issues can impede the ability of nurses and other healthcare workers to respond to and meet surge capacity needs during times of disaster or public health emergencies. Recurrent challenges for volunteer health professionals include timely and efficient reciprocity of state-based licenses, as well as gaps in liability coverage and compensation for harm incurred during response (Hodge, 2006; Hodge et al., 2005; Hodge, Gable, & Vernick, 2008; IOM, 2012, 2014b). The panel also recognized the need to protect volunteers from loss of employment while responding to disasters. While progress has been made to address these challenges through the development of model legislation, expansion of volunteer protection acts (e.g., the Emergency Management Assistance Compact, Model State Emergency Health Powers Act [Gostin et al., 2002], Uniform Emergency Volunteer Health Practitioners Act [2007]), and employment rights legislation (e.g., Uniformed Services Employment and Reemployment Rights Act), important gaps still remain (IOM, 2012). The panel advocated for increased efforts by lawmakers, policymakers, emergency managers, public health officials, and the private sector to address these issues in advance, before disasters and emergencies occur.

4. Research

Recommendation 4.1. Establish a research agenda based on a thorough needs assessment to document gaps in literature, nursing knowledge and skills, and available resources.

To understand what information is needed to fulfill the vision for a national disaster nursing workforce, the panelists endorsed the development of a focused research agenda. As with any research program, this would necessitate a methodical and systematic approach to disaster nursing research that would include:

- Conducting a thorough needs assessment to document gaps in literature, gaps in nursing knowledge and skills, and the available resources;
- partnering with nurses and other healthcare professionals working in the field, nurse scientists, and community members to establish research priorities and a collective commitment to carry the research agenda forward; and
- finalizing a comprehensive research agenda to engage policy makers and funders.

Over the previous several decades, research in public health emergency preparedness has advanced the field in several ways, including the development of standard terminology, healthcare and public health systems assessments, and enhanced healthcare worker willingness, ability, and intention to respond. A recent IOM report (2014a) also highlighted strategies to enable rapid and sustainable research during disasters. Nevertheless, the focus in disaster research remains broadly based, and gaps in the literature have not been systematically addressed. After a thorough review of the disaster nursing literature, specific attention should be given to identifying pertinent gaps and essential areas of emphasis for disaster nursing research.

It is particularly important to assure that nursing research in disaster preparedness and response complements and supplements what is already available and in particular contributes new information for nursing practice and policy. This requires a close relationship with other agencies and disciplines also conducting research. As such, a crosswalk with other national public health emergency preparedness research agendas (e.g., National Academy of Medicine, U.S. Department of Health and Human Services, Centers for Disease Control and Prevention) should be developed. Additionally, in order to have an informed research agenda that will have a sustainable impact on practice, it is essential to interface with nurses in practice, including engagement through professional organizations such as the Emergency Nurses Association, ANA, and Association of Public Health Nurses.

Since all disasters are local, partnerships through community-based participatory research should be developed to help define research priorities and address regulatory (e.g., institutional review board) and other issues in advance (Minkler, 2005). Preplanning will help ensure that when a disaster strikes the necessary mechanisms will be in place to expedite the research.

Recommendation 4.2. Expand research methods to include interventional studies and use both quantitative and qualitative designs.

Currently the research related to disaster nursing is primarily descriptive. A move toward interventional research is needed to identify what works based on current and potentially new frameworks, and how those affected by disasters and the healthcare professionals who respond can achieve improvements in outcomes and safety. Analytic approaches such as data mining with social media and electronic text and idea mapping to visualize scenarios, ideas, and concepts may uncover new approaches and areas for research consideration (Chen, 1988; Weiner, 2011; Weiner & Bartoo, 2014). Interventional research could help in determining methods to create a culture of preparedness; identifying skills and approaches across four phases of disasters—mitigation, preparedness, response, and recovery—each requiring different strategies and approaches; and the effective roles of nurses in preparedness, response, and recovery.

Recommendation 4.3. Increase the number of doctorally prepared nurse scientists serving as principal investigators on disaster research projects.

To our knowledge, there are no formal training programs for nurse scientists interested in research related to disaster preparedness and response, but a number of resources are available for planning and enhancing such training programs. The major challenge, however, may be to develop a cadre of nurse scientists with a sustained interest in the field. The response following natural and human-made disasters has been immediate public concern, which often quickly wanes. Creating a culture of awareness and preparedness among nurse scholars will involve collaboration with educators, practitioners, and policy makers or funders. One effective means to build a body of research is through priorities set by funding agencies. The National Institute of Nursing Research (NINR) is the primary federal funder of training programs for nurse scientists, and although their strategic plan does not currently include disaster preparedness and response as one of their priorities, the panel identified their active involvement and support of such training as being vital. As the NINR and influential professional nursing organizations articulate disaster nursing as a priority, the need for and interest among nurse scholars to focus on disaster nursing research will grow. Other agencies within the National Institutes of Health, HRSA, and private funders such as the Robert Wood Johnson Foundation could also support programs that advance disaster nursing science.

Discussion

In this project, we have proposed a vision for the future of disaster nursing and recommendations for nursing practice, education, policy, and research to achieve of that vision. Unfortunately, previous calls to educate the national nursing workforce for emergency and disaster preparedness (e.g., International Nursing Coalition for Mass Casualty Education Educational Competencies for Registered Nurses Responding to Mass Casualty Incidents, 2003; NACNEP, 2009) were not sustained. Unlike prior efforts, this call to action highlights the need for a more coordinated, interdisciplinary, and structured approach to assuring that the nursing workforce is well prepared for disaster response, and makes specific recommendations for how this might be accomplished. Ongoing assessments of progress toward these ends, with a focus on adapting implementation strategies to address areas where progress is limited, will be essential to the success of this effort.

Multiple reports highlight the nursing profession's breadth and untapped potential during disasters. In 2011, the IOM published *The Future of Nursing: Leading Change, Advancing Health*, which proposed recommendations designed to advance health in the U.S. population by transforming the role of the nurse in the delivery of care. *The Future of American Red Cross Nursing: A Blueprint for Action* (American Red Cross National Nursing Committee, 2012) outlined recommendations for how nurses can and should be actively engaged as full contributors in achieving such priorities during disaster preparedness and mobilization. The Association of Public Health Nurses' (APHN) *The Role of the Public Health Nurses in Disaster Preparedness, Response, and Recovery* (APHN, 2013) recognized that public health nurses possess a broad range of population-based knowledge, skills, and nursing expertise when it comes to disaster preparedness, response, and recovery. Other organizations that have issued reports, briefs, or white papers on the role of nursing in disasters include the Association for Community Health Nursing Educators, ANA, ICN, and World Health Organization (Stanley & Bennecoff Wolanski, 2015). Most recently, the ICN has called for increased support of and safer working environments for nurses as frontline healthcare workers following large numbers of nurses who died during the 2014 Ebola outbreak (ICN, 2015). Taken collectively, these documents provide a foundation for nurses to engage in an expansive national dialogue regarding the future for disaster nursing in the US, with implications for global nursing as well.

Globally, disaster nurse readiness is a pressing concern (Chapman & Arbon, 2008). China, Japan, Taiwan, Iran, and many other countries have identified similar issues related to the identification of appropriate disaster nursing competencies and the challenges with implementation of effective education and training programs to prepare their nursing workforce (Bahrami et al., 2014; Chan et al., 2010; Yamamoto, 2013; Yan et al, 2015). Capacity for crisis nursing leadership during U.S. and international disaster events (Danna, Bernard, Schaubhut, & Matthews, 2010; Johnson, 2002; Samuel, Griffin, White, & Fitzpatrick, 2015) and evidence-based disaster management (Usher et al., 2015) warrants further exploration.

The recommendations presented in this article constitute a point of departure for addressing the barriers and facilitators (see **Table 1**) to preparing a national nursing workforce with the knowledge, skills, and abilities to respond to disasters and public health emergencies in a timely and effective manner. We recognize that these recommendations range in complexity and some may be more challenging to implement than others. For example, successful implementation of the practice and policy recommendations will require the nursing profession to establish or expand partnerships with other healthcare professionals, emergency managers, policymakers, and healthcare organizations. Despite such challenges, we believe these recommendations are critical to enhancing national nurse preparedness, which can ultimately increase the resiliency of healthcare organizations and communities more broadly.

Conclusions

At a time when disasters and public health emergencies are occurring with increasing frequency, it is essential that the breadth and untapped potential of the nursing profession be fully understood and deployed. Despite considerable funding for hospital and public health preparedness since the attacks of September 11, 2001, efforts to prepare and mobilize nurses for disaster preparedness and response have been episodic and difficult to sustain. This article presents a vision for the future of disaster nursing, identifies barriers and facilitators to achieving that vision, and offers recommendations in nursing practice, education, policy, and research. This project represents an important step toward enhancing nurses' roles as leaders, educators, responders, policymakers, and researchers in disaster preparedness and response. Further exploration of these ideas and a commitment to expand the national dialogue within the nursing profession and beyond is needed to truly achieve national nurse readiness.

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Clinical Resources

- American Red Cross Disaster Nursing: http://www.redcross.org/support/volunteer/nurses/students
- ANA Nursing World Resources for Disaster Preparedness & Response: http://www.nursingworld.org/MainMenuCategories/WorkplaceSafety/DPR
- Emergency Nurses Association Emergency Preparedness Resources: https://www.ena.org/practice-research/Practice/Safety/EmergencyPrepared/Pages/Default.aspx
- Technical Resources Assistance Center and Information Exchange (TRACIE): https://asprtracie.hhs.gov/

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WORLD HEALTH

Framework for Evaluating the Impact of Advanced Practice Nursing Roles

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Key words
Advanced practice nursing, evaluation, evaluation framework, human resources, role development, models of care

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Abstract

Purpose: To address the gap in evidence-based information required to support the development of advanced practice nursing (APN) roles in Switzerland, stakeholders identified the need for guidance to generate strategic evaluation data. This article describes an evaluation framework developed to inform decisions about the effective utilization of APN roles across the country.
Approach: A participatory approach was used by an international group of stakeholders. Published literature and an evidenced-based framework for introducing APN roles were analyzed and applied to define the purpose, target audiences, and essential elements of the evaluation framework. Through subsequent meetings and review by an expert panel, the framework was developed and refined.
Findings: A framework to evaluate different types of APN roles as they evolve to meet dynamic population health, practice setting, and health system needs was created. It includes a matrix of key concepts to guide evaluations across three stages of APN role development: introduction, implementation, and long-term sustainability. For each stage, evaluation objectives and questions examining APN role structures, processes, and outcomes from different perspectives (e.g., patients, providers, managers, policy-makers) were identified.

Conclusions: A practical, robust framework based on well-established evaluation concepts and current understanding of APN roles can be used to conduct systematic evaluations.

Clinical Relevance: The evaluation framework is sufficiently generic to allow application in developed countries globally, both for evaluation as well as research purposes.

Internationally, there is a high demand for advanced practice nursing (APN) roles to address unmet population health needs and improve the quality, efficiency, and sustainability of healthcare services (Bryant-Lukosius, 2014). The International Council of Nurses (ICN) defines an advanced practice nurse as a ″registered nurse who has acquired the expert knowledge base, complex decision-making skills and clinical competencies for expanded practice, the characteristics of which are shaped by the context or country in which [she or he] is credentialed to practice″ (ICN, 2008, p. 7). The clinical nurse specialist (CNS) and nurse practitioner (NP) are the most common types of APN roles (Delamaire & Lafortune, 2010; Schober, 2013). In some countries such as Canada, these roles are well established, while in other countries like Switzerland, APN roles are emerging and poised for expansion.

Few countries have proactively or systematically evaluated APN roles, resulting in a dearth of context-relevant evidence to support decision making about the effective use of these roles (DiCenso et al., 2010). As with any healthcare innovation, the failure to evaluate is risky and may limit the impact and long-term sustainability of APN roles. The purpose of this article is to describe an evaluation framework developed for APN roles in Switzerland. While APN roles in Switzerland were the impetus, the assumptions and concepts underpinning the evaluation framework are purposively broad to be generalizable to APN roles in other countries.

Background

Switzerland is at an early stage of APN role development but is positioned for expansion with the establishment of education programs, introduction of pioneer roles, and national efforts of the nursing profession to create a regulatory framework (Morin, Ramelet, & Shaha, 2013). There is no legal definition or recognition of APN in Switzerland, but the ICN (2008) definition and APN competencies defined by Hamric (2014) are accepted within the nursing profession. Education is offered at the master's level, but APN curricula are not standardized across programs (Swiss Association for Nursing Science, 2012). Advanced practice nurses work in roles resembling the CNS. Increasingly, specialist roles are being developed in response to patient needs for chronic disease management (Bundesamt für Gesundheit, 2012), but the types of APN roles required or the priorities for their introduction have not been determined.

Establishing a framework for evaluation at this early stage of APN role development has advantages to promote effective role integration into the Swiss healthcare system. Systematic approaches to evaluation are necessary to make decisions about the optimal design and use of APN roles in new models of care to improve outcomes. A systematic framework would help to anticipate, prioritize, and guide the need for different types and foci of evaluation. For example, initial evaluations could assess the types and number of APN roles (e.g., CNS, NP) needed and the education required to achieve expected outcomes.

Multiple systematic reviews have demonstrated the effectiveness of APN roles for improving patient health and quality of care and reducing healthcare utilization and costs (Bryant-Lukosius et al., 2015; Donald et al., 2015; Newhouse et al., 2011). These studies also indicated a need for conceptually stronger evaluation designs to improve the quality of research and to address knowledge gaps about cost effectiveness and how APN roles contribute to improved patient, provider, and health system outcomes (Donald et al., 2014; Marshall et al., 2015). There is also a need for research to evaluate the impact of nonclinical APN role activities (e.g., leadership, research; Bryant-Lukosius, DiCenso, Israr, & Charbonneau-Smith, 2013).

Role clarity is essential for successful APN implementation (DiCenso et al., 2010). Lack of theory-based evaluations contribute to poorly defined roles with unclear connections between activities and outcomes, and may account for studies reporting no differences in APN outcomes when compared to usual care (Bryant-Lukosius et al., 2015). Lack of a theoretical framework also results in evaluations that fail to capture data about why APN outcomes are not achieved, and thus missed opportunities to refine roles and address barriers to achieve better outcomes.

Methods

The need for an evaluation framework arose in 2012 at a Swiss APN conference. To pursue this issue, the Institute of Nursing Science at the University of Basel convened a group of 15 stakeholders including researchers, advanced practice nurses, APN educators, and healthcare administrators from Germany, Switzerland, Canada, and the United States. From January 2013 to May 2015, this group participated in teleconferences, workshops, and meetings to (a) review and promote shared learning about healthcare and APN evaluation models and evidence about APN evaluations; (b) examine issues about APN role development and evaluation in Switzerland from various perspectives; (c) define the purpose, scope, and target audiences for an evaluation framework; and (d) come to consensus on the framework elements and tools for application. Once the group was satisfied with the framework, an expert panel was assembled to provide feedback. The panel completed an evaluation form and met with the group to discuss the feedback and decide the next steps for strengthening and disseminating the framework.

PEPPA, a Participatory Evidence-Informed Patient-Centred Process for APN Role Development, guided construction of the evaluation framework (Bryant-Lukosius & DiCenso, 2004). PEPPA outlines steps for introducing and evaluating APN roles. With use in over 16 countries, including Switzerland (Boyko, Carter, & Bryant-Lukosius, in press; Serena et al., 2015), and translation in several languages, direction provided by PEPPA promotes applicability of the evaluation framework to diverse jurisdictions. Conceptually, PEPPA encourages the design of patient-centered models of care. It incorporates principles for effective health human resource planning and has been used successfully to introduce APN and other health provider roles (Bryant-Lukosius et al., 2013). PEPPA fosters role clarity by addressing the complexity of APN roles and engaging stakeholders (e.g., patients, providers, administrators), who influence and are influenced by the role design, implementation, and evaluation process. PEPPA offers broad recommendations for evaluation. The enhanced framework outlined in this article was named PEPPA-Plus because it builds on this previous work to provide more detailed guidance for APN role evaluations.

Results

Evaluation Framework Goal and Objectives

The ultimate goal of the evaluation framework is to promote optimal health outcomes for patients and families and to deliver high-quality, patient-centered, and cost-effective care in Switzerland through evidence-informed decision making about the development and use of APN roles in varied practice settings and models of care delivery. This goal will be achieved through these objectives to:

- Provide guidance about sequential steps and systematic approaches for APN role evaluation that are necessary to produce timely, high quality data.
- Identify important information and decision-making needs relevant to three stages of APN role development: introduction, implementation, and long-term sustainability.
- Conduct evaluations that identify and are appropriate for different types of current, emerging, and future APN roles.
- Integrate the perspectives of relevant stakeholders in the planning, implementation, reporting, and uptake of APN role evaluations.

Target Audience

The main target audience is government policymakers, healthcare funders and administrators, and leaders of nursing associations who may sponsor or direct evaluations. They are also influential knowledge users who require evaluation data to make evidence-informed decisions about APN roles. Other framework users may include researchers, healthcare planners, advanced practice nurses, and APN educators.

Framework Assumptions and Concepts

Figure 1 illustrates a matrix of the major framework concepts arising from group discussions and examination of the APN and healthcare evaluation literature. Three assumptions informed the scope of the framework. The first assumption was that the framework should be broad and flexible so that evaluations can accommodate the evolving nature of APN roles in Switzerland and to ensure the relevance of evaluations over time as the roles develop. Opportunities exist to define current roles and to introduce other APN roles for a broad range of patient populations in diverse models of care and practice settings. Different APN roles such as CNSs or NPs have distinct competencies, scopes of practice, job descriptions, and expected outcomes (Schober, 2013). It is important for the framework to not only inform these aspects of APN role development, but also accommodate new roles as they emerge. In the framework matrix, the concept of "type of APN role" is identified to highlight the framework's applicability to varied APN roles and the

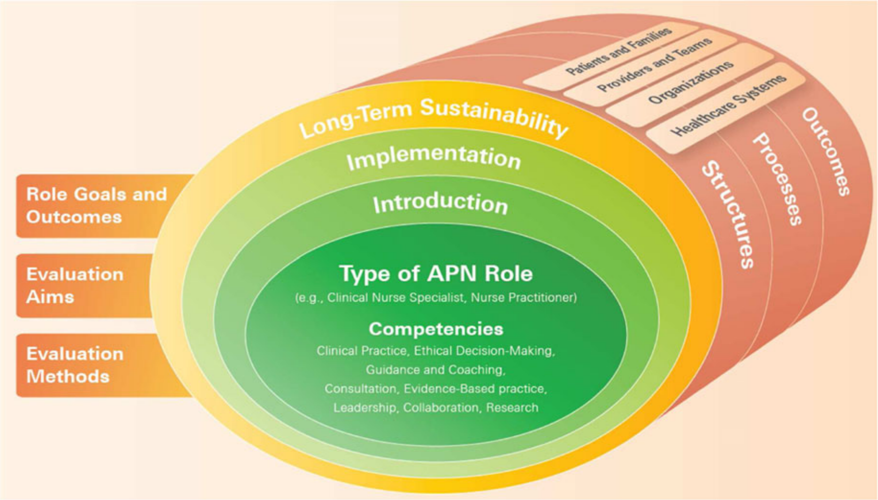

Figure 1. Evaluation framework matrix—key concepts for evaluating advanced practice nursing roles.

importance of examining unique APN role characteristics in evaluations.

A second assumption was that evaluating the outcomes of APN roles, to assess their benefits for the Swiss healthcare system, was of primary importance. However, the evaluation of outcomes must also consider factors related to APN role development. Swiss APN roles are in various stages of development within and across organizations and regions. Expectations for evaluating outcomes must reflect these differences in role maturity. Since many roles are new or under construction, barriers to optimal implementation may exist that negatively impact on outcomes. In addition, little is known about the financial, legal, or administrative structures needed in Switzerland to support effective APN roles. The framework concept of "stage of APN role development" stresses the importance of addressing developmental issues in evaluations.

PEPPA provided conceptual clarity by distinguishing three stages of role development—introduction, implementation, and long-term sustainability—as shown in the matrix (see **Figure 1**), each with important considerations for evaluation (Bryant-Lukosius & DiCenso, 2004). The introduction stage involves identifying the patient population(s) to be the focus of the APN role and engaging stakeholders to establish the need, determine priority role goals and outcomes, define the role, and develop an implementation and evaluation plan. The matrix concept of ″role goals and outcomes″ is foundational to establishing the evaluation plan and creating a clearly defined APN role with activities linked to achieve specific outcomes. The implementation stage involves putting resources in place to support APN role development (e.g., education, policies), recruiting and hiring, and evaluating role implementation and progress in achieving outcomes. The long-term sustainability stage focuses on monitoring and evaluating to assess role impact and health system integration, and to identify new or continuing needs for the role.

The third assumption was that the framework must support APN evaluations examining a broad range of aims, issues, and stakeholder perspectives. Three matrix concepts (see **Figure 1**) are linked to this assumption. ″Role goals and outcomes″ for different types of roles and roles at different stages of development will influence information needs and thus evaluation aims, objectives, questions, and methods. ″Evaluation aims″ may be to explore, describe, understand, assess, explain, or predict aspects of APN roles. Depending on the aim, a number of research (e.g., qualitative, quantitative, mixed methods) or evaluation (e.g., program evaluation, quality improvement) methods may be relevant (Bowling, 2009). The concept "evaluation methods" is highlighted in the matrix to emphasize the importance of diverse evaluation approaches.

Medical Research Council guidelines recommend the use of systematic approaches and diverse evaluation methods to design and examine complex healthcare innovations such as APN roles (Craig et al., 2008). APN role complexity is characterized by interacting competencies (e.g., clinical, research, leadership); focus on challenging healthcare issues requiring actions targeted to multiple groups (e.g., patients, communities, providers, organizations); and the high degree of flexibility and responsiveness required to meet dynamic patient and health system needs (Bryant-Lukosius et al., 2013). Thus, the aims and methods of APN evaluations should reflect the complexity of these roles and the healthcare environments in which they work.

Published APN evaluation models were compared related to their areas of focus, major concepts, applicability, strengths, and limitations. We could not come to a consensus on adopting or adapting one of these models for the framework. Each model had strengths, but in relation to the framework's objectives were limited by their focus on a specific role (Kilpatrick, Lavoie-Tremblay, Lamothe, Ritchie, & Doran, 2012; Sidani & Irvine, 1999), aspect of care (Mitchell, Ferketich, Jennings, & American Academy of Nursing Expert Panel on Quality Health Care, 1998), or quality improvement (National Council for Nursing and Midwifery, 2008); and the lack of complexity (Byers & Brunell, 1998).

A consistent feature of the APN models and PEPPA was the integration of Donabedian's (2005) model. The Donabedian model is relevant for evaluating the quality of healthcare and also for APN evaluations (Gardner, Gardner, & O'Connell, 2013; Nagendran, Maruthappu, & Raleigh, 2011). Given its applicability, Donabedian's (2005) model provided core matrix concepts related to "structures," "processes," and "outcomes" (see **Figure 1**). Structures are the practical, human, physical, and environmental factors (organizational, cultural, political, economic) that influence how APN roles are implemented (Bryant-Lukosius & DiCenso, 2004).

Processes refer to APN role implementation or the types of services and interventions provided and how they are delivered. A core matrix concept is "competencies." To promote the optimal use of nursing expertise and scope of practice, examination of role processes should consider activities relevant to APN competencies (Bryant-Lukosius & DiCenso, 2004). The competencies defined by Hamric (2014) were included in the matrix because of their use in Swiss APN education programs and familiarity among advanced practice nurses. They comprise clinical practice, ethical decision making, guidance and coaching, consultation, evidence-based practice, leadership, and collaboration. Competency related to research (Sastre-Fullana, De Pedro-Gomez, Bennasar-Veny, Serrano-Gallardo, & Morales-Asencio, 2014) was also identified as important. Another essential process factor is the APN role dose. The dose can be affected by the frequency and intensity of advanced practice nurse and patient interactions, education and experience, and target population responsiveness to interventions (Brooten, Youngblut, Deosires, Singhala, & Guido-Sanz, 2012). Monitoring the dose and factors influencing the dose can determine if adjustments in APN role processes or structures are required to optimize outcomes.

Outcomes are the results of APN role structures and processes. Our review of APN models found that outcomes can be evaluated from the varied perspectives of patients (including populations and communities); family members; healthcare providers and teams; and decision makers (e.g., managers, policymakers) in organizations and the broader healthcare system (e.g., governments; Bryant-Lukosius & DiCenso, 2004; Byers & Brunell, 1998; Kilpatrick et al., 2012; Sidani & Irvine, 1999). These perspectives are included as core matrix concepts related to "patients and families," "providers and teams," "organizations," and "healthcare systems."

To determine outcomes to include in the framework, we identified APN-sensitive outcomes from systematic reviews (Bryant-Lukosius et al., 2015; Donald et al., 2015; Kilpatrick et al., 2014; Martin-Misener et al., 2015; Newhouse et al., 2011) and compared these with outcomes defined in APN (Doran, Sidani, & DePietro, 2010; Ingersoll, McIntosh, & Williams, 2000; Kleinpell, 2009) and healthcare (Institute of Health Improvement, 2012; Institute of Medicine [IOM], 2001) models. Through discussion and consensus, a detailed list of outcomes was distilled and categorized into these groups: patient and family, healthcare provider and stakeholder, quality of care, organization, and healthcare use and costs. These outcomes align with those identified by the IOM (2001) and with Swiss Federal Office of Public Health (2013) priorities to promote quality of life, empower patients, and improve healthcare quality.

Role Development and Evaluation Objectives

Based on PEPPA and group consensus, the following evaluation objectives were defined for each stage of APN role development.

Introduction Stage

- Determine patient, family, healthcare provider/team, organization, and health system needs in Switzerland that can be met by APN roles in varied practice settings and models of care.
- Promote APN role clarity among Swiss stakeholders by ensuring a good match between identified needs and the type of APN role, role competencies, and scope of practice.

Implementation Stage

- Ensure that appropriate professional, educational, organizational, and healthcare system policies, funding, and resources are in place to support the introduction of varied APN roles in different practice settings and models of care delivery in Switzerland.
- Improve understanding about how APN roles impact patient, family, healthcare provider/team, organization, and health system outcomes in Switzerland.

- Promote optimal utilization and implementation of APN roles and achievement of expected outcomes in Switzerland by monitoring trends in practice patterns, including deployment, retention, role activities, and barriers and facilitators to role implementation.

Long-Term Sustainability Stage

- Demonstrate the long-term benefits and impact of APN roles for healthcare consumers, providers, organizations, and the overall healthcare systems in Switzerland.
- Ensure APN roles meet the long-term needs of the Swiss healthcare system by identifying ongoing developments, trends, and needs for role revision and support.

Framework Tools

APN evaluations may not occur due to uncertainty about where and how to begin what is perceived to be a daunting task (Bryant-Lukosius, 2009). To overcome this barrier and to facilitate framework application, serial tools were developed (see Appendices with online version of this article). The first tool maps evaluation objectives with examples of structures, processes, and outcomes for each stage of APN role development to generate ideas about information needs and evaluation priorities. Next, an expanded version of this tool offers a template of evaluation questions examining APN role structures, processes, and outcomes. A third tool helps formulate an evaluation plan including the methods. Lastly, a fictional case study integrates matrix concepts to demonstrate framework application for each stage of APN role development. In the introduction stage of the case study, a hospital administrator is confronted by an unexplained rise in emergency department (ED) visits by adults with type II diabetes. This prompts an evaluation plan to identify contributing factors and solutions for reducing unnecessary ED visits. Results of this evaluation are used in the implementation stage to define an APN role and new model of care and create a plan to evaluate the implementation and impact of the APN role and new care delivery processes. In the long-term sustainability stage, the APN role is deemed fully functional and an economic analysis is planned to inform decisions about maintaining the APN role and model of care.

Expert Panel Feedback

Expert panel feedback on the framework and tools was positive, with mean review form scores ranging from 4.0 to 4.6 (scale: 1 = *poor*, 5 = *excellent*) for format, clarity, content, and application. Perceived framework strengths were that it was patient centered, comprehensive, demonstrated the complexity of APN roles and contexts, and sufficiently broad to permit diverse use. Other strengths related to the conceptual and evidence-based foundations of the framework. A suggested area for improvement was to provide more instruction on how to operationalize the framework, which was addressed by adding a section on “how to use the framework.” Other comments related to generic healthcare evaluation issues like assessing readiness for change, managing political environments, and measurement.

Discussion

While factors such as economics, politics, and policy priorities are also influential, the lack of meaningful and policy-relevant evaluation data to make decisions about the optimal design, implementation, and use of APN roles is a significant barrier to effective role planning, role clarity, and integration within healthcare systems (Bryant-Lukosius, 2014; DiCenso et al., 2010). As a result, the full potential of APN to improve patient health, increase access to care, contain costs, and strengthen care quality has not been realized, even in countries with established roles. Ireland has demonstrated the feasibility of systematically evaluating the introduction of APN roles to understand their impact on national goals for healthcare redesign (Begley et al., 2010). While similar evaluations may be more difficult to conduct in larger countries and those with the less centralized healthcare systems like Switzerland, a common national framework may improve understanding of APN role impact by enabling comparative evaluations across jurisdictions. In countries with established APN roles, the framework may inform evaluation needs by determining if evaluation objectives at each role development stage have been met. The framework provides a novel and staged approach to encourage and improve APN evaluations. As the case study illustrates, the introduction stage emphasizes healthcare redesign to examine a number of solutions, including an APN role. This strategy helps to ensure the APN role is a good fit and is clearly defined (e.g., an APN role for community-living adults with type II diabetes) to meet identified needs (factors resulting in rising ED visits) and to generate baseline data for ongoing evaluation. By starting with needs for healthcare redesign, patient, provider, organization, and system perspectives can be incorporated in the evaluation.

The framework promotes systematic and appropriately timed evaluations by defining evaluation objectives for each stage of role development. The objectives facilitate focused and feasible evaluations and avoid premature outcome assessments of underdeveloped roles. This strategy is exemplified in the case study where outcomes such as cost effectiveness are evaluated in the long-term sustainability stage. The framework fosters comprehensive evaluations to inform implementation strategies and improve understanding about role impact by examining structures, processes, and outcomes relevant to APN competencies (Gardner et al., 2013). This aspect is evident in the implementation stage, where structures (patient characteristics) are examined related to APN role processes (interactions) and their combined effects on outcomes from patient (self-care), provider (satisfaction), organization (care quality), and health system (healthcare use) perspectives. By advocating for decision maker involvement in evaluation planning and embracing the use of diverse methods to evaluate roles from varied perspectives, the framework will promote a deeper understanding of the benefits of APN roles and the production of policy-relevant data for decision making (Finegood & MacLeod, 2015).

Different stakeholder groups can apply the framework to address their information needs. Government policymakers can use the framework to evaluate the deployment of APN roles to achieve improvement priorities (e.g., access to care) for specific patient populations (e.g., frail elderly). Educators may want to know how effective university programs are in preparing nurses for advanced roles. Understanding the effect of implementation strategies (e.g., mentorship) on APN role retention may be vital to administrators. Advanced practice nurses can use the framework to assess their progress in meeting expected outcomes. To inform decisions about long-term sustainability, researchers could examine factors to predict the patient populations and models of care where APN roles are most cost effective.

However, since not all stakeholders may recognize their important role in APN role evaluations, engaging them in framework application or participation in evaluations may be challenging (Bryant-Lukosius, 2009). Concerted efforts will be necessary to make target users aware of the framework, understand its potential for generating meaningful data for healthcare decision making, and know how to apply it (Wensing, Bosch, & Grol, 2009). We plan to collaborate with Swiss government policymakers and nursing associations to translate the framework into German and French, disseminate and facilitate framework understanding, and develop a toolkit to support its application. Based on expert panel advice, the toolkit will include generic evaluation resources pertinent to matrix concepts such as developing an evaluation plan, selecting evaluation methods, and measuring structures, processes, and outcomes. Pilot projects in Switzerland and Canada will be conducted to evaluate and refine the framework and toolkit.

Conclusions

New approaches are required to improve evaluations of APN roles as complex healthcare interventions and to better address the information needs of healthcare decision makers. Through international collaboration, a robust, evidence-based, and practical framework was developed to evaluate APN roles across three stages of role development. The broad scope of the framework permits its application to a range of APN roles in Switzerland and other developed countries.

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Clinical Resources

- Advanced Practice Nursing Data Collection Toolkit: http://apntoolkit.mcmaster.ca/
- Canadian Centre for Advanced Practice Nursing Research: http://fhs.mcmaster.ca/ccapnr/

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web site:

Table S1. Framework Assumptions to Address Contextual Issues from Varied
Table S2. Examples of APN Role Structures
Table S3. APN Role Outcomes
Appendix A. Evaluation Objectives and Example Concepts by Stage of Role Development
Appendix B. Evaluation Plan Template
Appendix C. Case Scenario Demonstrating Vertical and Horizontal Integration and Application of Evaluation Framework Concepts
Appendix D. Glossary of Terms

JOURNAL OF NURSING SCHOLARSHIP

PROFESSION AND SOCIETY

Experiences and Lessons Learned in Using Community-Based Participatory Research to Recruit Asian American Immigrant Research Participants

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Key words
Asian American, community-based participatory research, immigrants, recruitment

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Abstract

Purpose: By 2050, the number of international migrants is expected to double from 214 million people. Of these, Asian immigrants are projected to comprise the largest foreign-born population in the United States by the year 2065. Asian American immigrants experience numerous health disparities, but remain under-represented in health research. The purpose of this article is to examine the experiences and lessons learned in applying community-based participatory research (CBPR) principles to access and recruit a sample of Asian American research participants.

Approach: This article reviews unique barriers to research participation among Asian Americans, describes the principles of CBPR, and provides examples of how these principles were employed to bridge recruitment challenges within a qualitative study.

Findings and Conclusions: CBPR facilitated greater research participation among a group of immigrant Asian Americans. Researchers must be additionally mindful of the importance of building trusting relationships with their community partners, understanding the significance of shared experiences, considering fears around immigration status, and considering ongoing challenges in identifying and reaching hidden populations.

Clinical Relevance: Clinicians and researchers can employ CBPR principles to guide their work with Asian immigrant communities and other under-represented groups to facilitate access to the population, improve participant recruitment, and foster engagement and collaboration.

Community based participatory research (CBPR) is a collaborative, action-oriented research approach that seeks to address health disparities through aligning community members' insider knowledge of their communities with academic researchers' methodological expertise (Minkler, 2005; Wallerstein & Duran, 2010). CBPR draws on critical and social theory to promote equal partnership and decision making. This collaboration minimizes the hierarchy traditionally found in research (Minkler & Wallerstein, 2003). The CBPR approach is applicable to many health conditions in a variety of contexts, and has been primarily employed with low-income groups and communities of color (Israel et al., 2010). Core values of this approach include partnership and collaboration between communities and researchers, equitable power distribution, trust and mutual commitment, and an openness to knowledge acquired from participants' experiences (Israel, Schulz, Parker, & Becker, 1998).

These values are the basis for collaborative research partnerships focused on alleviating complex health problems.

Health Disparities Among Immigrant Groups

In many countries, ethnic minority immigrants are a growing segment of the population who are likely to experience health disparities (Miramontes et al., 2015; Pottie et al., 2011). Over the past 20 years, increasing numbers of migrants from middle-income countries in Asia, Latin America, and Eastern Europe have settled in high-income countries such as the United States, Australia, Great Britain, and Canada (Connor, Cohn, & Gonzalez-Barrera, 2013). As an example, by 2050, the population in the United States—which is the world's top immigration destination—is expected to grow from 320 million to 458 million people (Colby & Ortman, 2015), of which 136 million will be immigrants (Ortman & Guarneri, 2009). Similarly, Germany, which ranks second in terms of migrant-receiving countries (Organisation for Economic Cooperation and Development, 2015), is presently experiencing a large and sudden migration wave as a result of the Syrian refugee crisis. A recent analysis of global migration trends notes that African migrants from sub-Saharan Africa move primarily within Africa; the biggest migration flows from West Africa are to Western Europe; Latin Americans move predominantly to North America and Europe; while South Asians and South-East Asians migrate to Western Asia, North America, and less frequently to Europe (Abel & Sander, 2014). These migration trends highlight the fluid changes occurring in host countries. Furthermore, they underscore the salience of broadly understanding CBPR and how it may be employed to better understand the health needs of ethnic minorities to better develop "migrant-sensitive health systems" (World Health Organization, 2010, p. 4).

Immigrants are a subset of the ethnic minority population with myriad health risks and health needs that are poorly understood. For example, Asians represent the fastest growing proportion of newcomers to the United States (Hoeffel, Rstogi, Kim, & Shahid, 2012). Composed of more than 14 subgroups, they are tremendously diverse in geographic origin, language, religious affiliation, immigration status, and cultural beliefs and practices (Tseng, 2009). Historically, Asian Americans have been under-represented in health research, and many studies that do include Asian Americans present aggregated data, masking critical health differences between ethnic subgroups. Disaggregated data demonstrate health disparities among subgroups on a number of chronic conditions, including cancer, heart disease, and mental health problems (Nadimpalli & Hutchinson, 2012). Factors contributing to deleterious health outcomes include limited health literacy, cultural and linguistic factors, and perceived discrimination (Clough, Lee, & Chae, 2013; Harris, 2012; Kandula, Kersey, & Lurie, 2004). Failure to address these factors presents tremendous costs on an already strained healthcare system. Greater research participation among Asian American immigrants is critical in order to better understand their health needs and disparities to develop effective tailored interventions.

Difficulties Recruiting Ethnic Minority Research Participants

Researchers have historically encountered challenges to accessing and recruiting those from under-represented groups. Individual participant-, investigator-, and system-level barriers may contribute to a lack of research participation among ethnic minorities. Participant-level individual factors include lack of time, transportation, linguistic mismatching, fear and mistrust of research, and lack of awareness of participating in research (Han, Kang, Kim, Ryu, & Kim, 2007; Hsu, O'Connor, & Lee, 2013). Investigator-level barriers include poor communication about health research across various phases of the research (George, Duran, & Norris, 2014); the erroneous application to ethnic minorities of recruitment strategies that have been successful with White research participants (Banda, Germain, McCaskill-Stevens, Ford, & Swain, 2012; Hussain-Gambles, Atkin, & Leese, 2004; UyBico, Pavel, & Gross, 2007); and a poor understanding of cultural differences among ethnic minority groups (Sheikh et al., 2009). Finally, system-level barriers include institutionalized racism and discrimination (George et al., 2014); a lack of ethnically diverse researchers (Byrd et al., 2011); and research study design and implementation that is incongruent with community values (Robinson & Trochim, 2007).

Difficulties Recruiting Asian Immigrant Research Participants

A brief literature review highlights specific difficulties in recruiting and retaining immigrants into research studies. Decreased access to and knowledge about research is a recognized barrier to research participation among immigrants (Chen, Kramer, Chen, & Chung, 2005; Harrigan et al., 2014). Linguistic mismatches may alienate English-speaking researchers from research participants with limited English proficiency (Chang et al., 2015; Chen et al., 2005; Shedlin, Decena, Mangadu, & Martinez, 2011). Similarly, competing responsibilities with work and child or elder care take precedence over research study participation, which poses additional constraints on time, lost wages, and transportation difficulties (Chen et al., 2005; Ganann, 2013; Han et al., 2007; Loue & Sajatovic, 2008).

An unfamiliarity and distrust of the research process may limit Asian immigrants' research participation. In addition, skepticism with the trustworthiness of institutions such as universities and hospitals may create distrust. Specifically, undocumented immigrants are a hidden population who may have greater difficulties trusting outsiders since their migration journeys have been difficult and expensive and they fear deportation (Shedlin et al., 2011). For these individuals, research participation and the informed consent document in particular are viewed as a threat to immigration status (Chen et al., 2005; Han et al., 2007; Loue & Sajatovic, 2008; Shedlin et al., 2011). Monetary incentives for research participation may be negatively interpreted due to incongruence with cultural values. Chen et al. (2005) found that among the Chinese, accepting money for research participation was perceived as a degrading act, and others regarded monetary compensation as a scam, which led potential research participants to discredit the research altogether. Researchers must be mindful of the multiple views through which research is perceived. To that end, community member involvement throughout the various phases of research design and implementation are a critical component of ensuring successful participant recruitment from under-represented groups.

Study Example

To contextualize this discussion on employing CBPR principles to access and recruit hard-to-reach populations such as Asian immigrants, this article will use as an example a recent study published by Katigbak et al. (2015). This qualitative study was conducted to explore the roles of community health workers (CHWs) in facilitating the adoption of healthy behaviors among Filipino Americans with hypertension. A subsample of interview participants ($n = 13$) was recruited from among the participants enrolled in a larger intervention study, Project AsPIRE (Asian American Partnerships in Research and Empowerment; Ursua et al., 2014). The purpose of this article is to describe the experiences and lessons learned in applying CBPR principles to recruit immigrant Filipinos into this qualitative study.

Principles of CBPR

Successful CBPR partnerships are underscored by nine guiding principles: (a) recognizing community identity; (b) building on community strengths and resources; (c) developing systems in an iterative and cyclical process; (d) developing equitable involvement of all parties in all phases of the research; (e) engaging in colearning and capacity building; (f) establishing mutually beneficial integration and balance of research and action; (g) addressing public health issues of local importance; (h) sharing participation in the dissemination of research findings; and (i) committing to a long-term process of sustainability (Israel et al., 1998). These CBPR principles are described along with examples of how these principles guided the recruitment of immigrant Asians into a qualitative study.

Recognizing Community Identity

The first CBPR principle refers to identifying the communities with whom researchers work, and understanding the shared values and norms that are bounded by group membership, such as geography or social networks (e.g., family or friends). With this knowledge, researchers aim to strengthen a sense of community through collective engagement among community members (Israel et al., 1998). As an example, 3 years prior to initiating the study the principal investigator (PI) began working with the AsPIRE research team as a volunteer data collector. She attended community forums, health fairs, research meetings, and trainings. At each of these events, a community member who was aware of the PI's desire to work with the community facilitated introductions to leaders and gatekeepers. Participating in these activities are consistent with Israel et al.'s (1998) principle of learning about the communities with whom they plan to partner, and making efforts to understand the various values and beliefs that will influence the collaboration.

Building on Community Strengths and Resources

A CBPR approach identifies and builds upon community strengths, resources, and relationships. By establishing collaborative networks within the community, individuals and organizations can leverage their skills and resources to improve overall health and well-being (Israel et al., 1998). In alignment with this principle, partnering with a local community-based organization (CBO) that was highly visible and respected in the community helped the PI to establish community credibility and facilitated entrée to a number of other organizations. In addition to recruiting study participants, these networks allowed her to recruit community members who participated in the research process as advisory board members, data collectors, transcribers, and interpreters.

Developing Systems in an Iterative and Cyclical Process

This includes developing and maintaining partnerships, community assessment, defining problems, developing research methods, data collection, analysis, and interpretation, disseminating research findings, taking action, and finally, developing plans for sustainability (Israel et al., 1998).

Developing Equitable Involvement of All Parties in All Phases of the Research Process

Collaborative partnerships among community members and researchers involves efforts to identify the research problem, collect and interpret data, and apply the results in a manner that reflects shared decision-making power (Israel et al., 1998).

Engaging in Colearning and Capacity Building

As a dynamic learning process, CBPR facilitates opportunities for reciprocal teaching and learning for all partners. For instance, as researchers learn about community values, strengths, and health needs, community members learn new information or skills that may directly benefit the community (Israel et al., 1998).

To illustrate these three preceding points, the PI actively involved community partners in the research process, and this partnership facilitated reciprocal learning and fostered community members' research skills. Collaborating with a trusted and prominent CHW provided the PI with insider insight into the community. Researchers sought community members' input from the study's inception. Their suggestions drove many methodological decisions. For instance, poor enrollment rates early in the study prompted the research team to modify the recruitment strategy. Feedback from the CHW and community advisors led to the conclusion that CBPR-aligned recruitment methods involving in-person recruitment were more appropriate than mailed recruitment letters. Through this process, the CHW learned about hidden populations (a group of undocumented domestic workers) within the community that she would not have otherwise gained access.

Community members made critical contributions to research discussions and prompted improvements that ultimately strengthened the study, from strategizing about which community events would result in recruitment opportunities, devising culturally appropriate interview questions, to brainstorming effective ways to present research findings. Community members not only gained exposure to the research design and implementation process, but developed their skill set in understanding and applying research principles by participating as data collectors, transcribing interviews, and preparing posters presentations.

Establishing Mutually Beneficial Integration and Balance of Research and Action

The CBPR approach aims to translate research knowledge towards enacting social change (Israel et al., 1998). Thus, researchers benefit from achieving their study goals while community members see the study findings practically applied in a way that improves the community (Israel et al., 1998). Soliciting community members' perspectives on the roles of CHWs helped to reinforce their ownership over the program and highlighted its ongoing contributions to the community. Through capacity building and advocacy, the CHWs empowered community members to organize themselves towards establishing a drop-in community center that became a resource for all residents. Thus, researchers met their study objectives, and the results ultimately validate CHWs as a suitable approach to improve health outcomes for underrepresented immigrants.

Addressing Public Health Issues of Local Importance

CBPR addresses health issues of relevance to the community while considering the social determinants of health from a systems and ecological perspective (Israel et al., 1998). In a foundational community assessment of Filipinos in New York City, concerns emerged regarding the lack of access to affordable and culturally competent healthcare services (Abesamis-Mendoza et al., 2007). The AsPIRE CHW program was developed to respond to this need (Ursua et al., 2014). In seeking to better understand the roles of CHWs in promoting healthy behavior change, researchers further explored these community concerns. They learned that CHWs successfully bridge the divide between the community and the medical establishment, working with individuals, community service agencies, and local government to improve immigrant integration (Katigbak et al., 2015).

Sharing Participation in the Dissemination of Research Findings

This principle acknowledges that information produced from the research is shared, and encourages all partners to participate as coauthors on publications and presentations (Israel et al., 1998). The PI sought feedback from study participants on her interpretations of their words prior to preparing a poster for a national presentation. In addition, the CHW who collaborated with the PI was included as an author on this poster.

Committing to a Long-Term Process and Sustainability

Partners demonstrate their mutual trust, support, and investment towards a common goal (Israel et al., 1998). Academic and community partnerships established through the qualitative study are ongoing, and the study findings were used to inform the activities of current CHW interventions. In summary, these CBPR principles speak to a collectivist orientation to research that aims to build equitable, long-lasting relationships that enhance community health and well-being.

Lessons Learned

The following lessons learned summarize four key themes for researchers to consider when undertaking CBPR work with difficult-to-reach groups, such as Asian immigrants.

Building Relationships and Trust With Communities

Building trusting relationships with community organizations facilitated recruitment and the process of community buy-in. As an outsider seeking to gain access, the PI built a relationship with both the CBO and the academic research team conducting AsPIRE over a 3-year period. The early stages of these relationships were characterized by frequent points of contact, continuous dialogue, and demonstrating that the PI's intentions and long-range plans were aligned with both the CBO's and academic research partner's goals. Establishing these partnerships early on was critical to the PI gaining visibility as someone committed to and invested in being a part of the community. Explicitly stating what gains could be achieved through partnering enabled all parties to recognize areas of synergy moving forward.

Active outreach to participate in community activities and meeting in person conveyed an interest beyond the research project. These approaches in particular were conducive with Filipino cultural values stressing the importance of interpersonal relationships. This "upfront work" described by Shedlin et al. (2011) enabled the PI to connect with community members long before initiating the research study, and minimized potential issues of a power hierarchy between the PI and the community.

The advisory board and multiple community champions were instrumental in identifying best ways to approach the community, convey the importance of the study, and change community members' perceptions of the researcher as "other." Building relationships with researchers allowed community members to engage as equal members of a research team from shaping the study design to disseminating study findings. Researchers benefited from these relationships by learning about their community partners, establishing their credibility, visibility, and gaining added legitimacy to their proposed community work (Islam et al., 2014; Shedlin et al., 2011; Ursua et al., 2014). Strong partnerships with community champions helped to promote trust between community members and researchers. Prior to starting recruitment activities, researchers must be mindful to invest adequate time and resources in building partnerships. These relationships serve as an important informational base for culturally relevant recruitment strategies (e.g., tailored messaging, recruitment sites, and relational dynamics among community organizations and members). Similarly, this information can be further extended to identify and develop strategies for addressing potential barriers to recruitment.

Shared Ethnicity Is Not Synonymous With Shared Experience

Working with the community highlighted the variation and heterogeneity of immigrant experiences. In planning the study, the PI believed that her shared ethnicity with participants would lead them to accept and welcome her as part of the local community. While a shared ethnicity was an asset to understanding some cultural nuances in communication and values, the challenges faced by first-generation immigrants (with which all participants self-identified) were very different from the experiences of the PI, who is a second-generation immigrant. Issues of perceived discrimination, acculturation stress, and financial burdens were more salient for study participants than for the PI herself.

Although linguistic and ethnocultural matching between research participants and study investigators may be perceived as an ideal condition (Chang et al., 2015; Chen et al., 2005), our experience highlights that these similarities alone do not lead to trusting research relationships. Researchers' decisions are greatly shaped and influenced by their social standing (Muhammad et al., 2015). Thus, similar life experiences may be more relevant in bridging differences in social class, income, and education than shared ethnicity or language. Partnering with local community members (such as CHWs) who share these common experiences may be a way to bridge this social distance during the recruitment and data collection periods.

Immigration Status Is a Barrier to Study Participation

The research team gained valuable insight into the daily context of participants' lives that complicate their ability to engage in research activities. Women in a domestic worker's support group shared that many of them were undocumented immigrants. They were fearful of the consequences that participating in research or seeking medical care would have on their immigration status and livelihood. These women had migrated to the United States on their own, often leaving spouses and children behind. They remitted large portions of their wages to dependent family members in their home country. Fears relating to the consequences of revealing their undocumented status weighed heavily on their minds. One participant shared, "I am supporting many [family members] back home [in the Philippines]. What will happen to them if I cannot work here?" (49-year-old woman, mother of 2 college-aged kids). Another participant (a single 49-year-old woman) shared that she had to be very vigilant about only allowing those who "could be trusted" to be aware of her immigration status. In particular, establishing a documentation or paper trail over which one had no control was especially distressing to a number of participants.

Most participants had no previous experiences with research. During the informed consent process, concerns emerged regarding how the informed consent document and interview data could be used beyond the scope of the described research study. Similarly, questions arose about whether the data would be used to discredit CHWs. One participant, a 52-year-old married woman, questioned the PI, stating, "You're not going to use this to fire her or something—she is a good person." These statements were surprising to the PI, since the written recruitment and informed consent materials did not allude to reporting data to individuals or organizations not directly related to the research team. These participant concerns highlighted the need for explicit reassurances about the confidentiality of the research data and clear statements that research participation would not influence one's immigration status. Nonetheless, researchers should anticipate similar concerns to arise. Future work with immigrant groups should assess for unique community issues such as these so they can be addressed with additional explanations in addition to the detailed informed consent.

Reaching Hidden Populations Remains a Challenge

Many participants, especially those employed as live-in caregivers, shared that their free time to participate was severely limited since their work conditions were not consistent with a 9-to-5 workday. It became apparent that flexible alternatives for recruitment and data collection were necessary for this group. Community champions suggested holding interviews on weekends, or outside of normal business hours close to the participants' homes, workplaces, or places of worship, as possible strategies to increase research participation.

Participants noted that although AsPIRE was a well-received project within the community, greater work must be done to reach those who are socially isolated and less inclined to engage with community groups or organizations. These individuals who lack the social supports and resources available through group membership remain a hidden subset of the population and may have higher health risks. One participant mentioned, "There are many [who did not participate in AsPIRE] who could benefit from the program . . . but they don't come out [to community events], so they don't know" (61-year-old married woman). This comment echoed the sentiment shared by other participants concerning the hardships of immigration. Migration brings growth opportunities for many, but for others it drives a profound sense of loss and displacement. These people in particular may be less integrated with the host country and could be experiencing acculturation stress. They might have little interest in health promotion activities and may be engaging in risky health behaviors that further perpetuate health disparities in this group. Thus, innovative methods for effectively reaching hidden subgroups of the population who may have increased health risks are sorely needed.

CBPR approaches may be used to effectively partner with immigrant communities in conducting research. However, recruitment facilitated through community champions and various organizations does not always ensure that vulnerable subsets of the community are reached. Similar to Shedlin and colleagues' (2011) experience in conducting research with undocumented Latino immigrants, we learned from our own participants that future studies seeking to reach hidden populations, namely those who are socially isolated, or undocumented may require more creative recruitment methods. These groups lack a sampling frame; thus, participant-driven recruitment—a form of respondent-driven sampling (Heckathorn, 2002) that is conducted within a CBPR framework—may be a suitable approach to recruiting those from under-represented groups (Tiffany, 2006). Several studies focusing on hidden groups within immigrant populations that include the undocumented, men who have sex with men, and those who are injection drug users (Brouwer et al., 2009; Montealegre, Risser, Selwyn, McCurdy, & Sabin, 2012; Rhodes & McCoy,

2015) have successfully used this sampling strategy to recruit research participants. Limitations to using a CBPR approach from a research standpoint may include the substantial time investment in establishing community partnerships as the process of relationship building may delay project start dates or meeting grant deadlines, and challenges may arise in managing large and diverse groups with multiple interests. Finally, the goals and expectations of collaborators involved in research projects may be misaligned; thus, open and transparent conversations to reach a compromise should be considered. Reaching under-represented groups will be an ongoing challenge in addressing health inequities; however, building strong partnerships that demystify and facilitate the research process towards achieving a common goal are small steps towards improving health outcomes.

Conclusions

The recent explosion of global migration fueled by political unrest, unstable economies, and environmental disasters are accompanied by a concomitant surge in health needs. Thus, targeted methods to access and recruit research participants from under-represented communities is sorely needed. CBPR approaches are a helpful strategy towards this end. Our experience in accessing and recruiting research study participants from immigrant communities may provide guidance to others embarking on similar work. CBPR leverages community members' knowledge and expertise to facilitate the research process. Additional hurdles, however, exist in identifying and gaining the trust of hidden subsets of the target population; cultural brokers or insiders such as CHWs may be critical allies in recruitment. Along with investing greater time and resources in conducting formative work to establish community–researcher partnerships, novel methodologies to reach hidden groups should be explored, such as peer-driven or respondent-driven sampling. Engaging community members as study recruiters who share common experiences—not just a common culture and language—is an important component that should be considered. Through these efforts to partner with immigrant communities, greater strides may be made in addressing their health needs to promote overall health and wellness.

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Clinical Resources

- Centers for Disease Control, Immigrant and Refugee Health: http://www.cdc.gov/immigrantrefugeehealth/
- Evidence-based Clinical Guidelines for Immigrants and Refugees (Canadian Medical Association Journal): http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3168666/pdf/183e824.pdf
- U.S. Committee for Refugees and Immigrants: http://www.refugees.org/resources/for-service-providers/working-with-refugees.html

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