# JOURNAL OF

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#### **EDITORIAL**

# **Enjoying the Benefits**

Starting in January of 2017, the *Journal of Nursing Scholarship (JNS)* will be available only online. No more paper copies will be coming to members of Sigma Theta Tau International (STTI) in the mail. If truth be told, lots of you have already opted out of receiving a paper copy and are accessing the journal online. So the switch won't be novel for some. However, we want all members of STTI to enjoy the member benefit of free access to the journal.

For those of you who currently receive the journal in print format, read on to discover how to make the switch, almost effortlessly, to becoming an online reader. Those of you who are already reading *JNS* online will find new information about our updated technology features. If you are reading this and are not a member of STTI, your access to the journal has not changed. The journal will continue to be available electronically in libraries and you will continue to be able to pay for individual articles on our Wiley site.

So why should any of you care about being able to access *JNS* effortlessly and often? Would it negatively impact your professional life if you never read another article from *JNS*? We hope the answer is an emphatic "yes." We work hard to ensure that the journal is high quality, helpful to your nursing practice, and—most importantly—achieving its mission to "advance knowledge to improve the health of the world's people." By the objective measures we have available to evaluate our success, we are meeting our goals.

JNS has an Impact Factor of 2.128 and is one of only seven nursing journals with an Impact Factor over 2.0. JNS is currently ranked sixth out of the 114 ranked nursing journals in social science and seventh out of the 116 ranked nursing journals in nursing science. We realize that Impact Factor is an imperfect measure of quality, as it is based on citation frequency and not on how useful the content is in practice. We strive to insure that JNS is useful to practicing nurses as well as authors. However, given the steadily increasing number of full text articles that are downloaded from the journal (173,500 in 2015 up from 123,377 in 2011), we do feel that we are providing information that is useful to nurses around the globe.

We don't want our change to an online-only format to cause problems with your continuing to access, read, and use information in the journal. So why make the switch? Online access is the way of the future in publishing as it is convenient, environmentally friendly, and economical.

For society journals, like *JNS*, cost savings are particularly important. Online publishing ensures that there are more resources to strengthen other membership benefits without negatively impacting the benefit of your free journal subscriptions.

So how have we ensured that it is convenient (and effortless, once set up) to access *JNS* online? STTI, in the new web design, has worked to ensure that it is easy to read the current issue of the journal from Sigma's website. If you click on publications (under the title "Learn and Grow" at the bottom of the home page), you will arrive at the publications page, where you can then click on "Journal of Nursing Scholarship" and come to the *JNS* landing page. On this page you will see the table of contents for the current issue. You can click on any article and it will immediately be available to you as long as you are signed in as a member of Sigma Theta Tau.

Of course, if you are anything like me, it is not always easy to manage knowing your membership information. Originally, you had to have your membership number to sign in but now for easier access you can hit the "Forgot password" icon and set a new password if your membership number is not conveniently available. Your e-mail address and password, through a single-sign-on process, allow you to immediately access the Wiley Online Library and all articles from JNS. You can, also through the single-sign-on process, click the "Sign in to JNS" button on the JNS landing page to be rerouted to the Wiley Online JNS page, in which you can read any article from any issue of JNS without having to log in again. Single sign in is a definite advantage and is now easier than ever.

We realize that you might not always want to read your issue of *JNS* from your computer. You lead a busy life and might want to read on your tablet, phone, or other mobile devices. So there is now an easy way to read journal articles without having to carry around your computer. Just as easy (or easier, in my opinion) than grabbing a copy of the paper journal is grabbing your cell phone or tablet and accessing the journal through the mobile app. There is a very thorough explanation of how to download the mobile app on the Sigma website at http://www.nursingsociety.org/learn-grow/publications/journal-ios-apps.

I helped lots of people download the app at the International Nursing Research Congress in July and can confidently say that it is simple to download the app on Enjoying the Benefits Editorial

most phones. If you have problems, please contact us at jns@stti.org and we will problem solve with you (but I think you will be pleasantly surprised at how easy it is to access content on your mobile devices). The articles have been formatted for easy reading on mobile screens. If you are concerned about being out and about without Internet access you can download articles and store them for your reading pleasure at any time, whether or not you have Internet access. When you have Internet access, all of JNS (and Worldviews on Evidence-Based Nursing, too) is at your fingertips.

Now that you can see it is quite convenient to access JNS from your computer and from your mobile devices, you might wonder what is going to help you remember that it is time to read new articles. We want you to read articles from JNS often as well as effortlessly. To that end, a monthly newsletter notifies you as soon as a new issue is available (for JNS as well as Worldviews on Evidence-Based Nursing). The "STTIConnect" monthly newsletter will also remind you at the end of each month. If you are signed in, a click-through feature in both of those newsletters will take you to the full text articles. You can also sign up to get notifications on your mobile device of new issues or new content.

How do you get these journal alerts? You can set up your alert profile on the Wiley Online Library *JNS* page. You can access this directly or from Sigma's website. Once you are logged on as a member, sign into *JNS* and this will take you to the Wiley Online page where you will be already logged in. At the top left of the *JNS* Wiley Online page is a feature called "Journal Tools." Sign up here for alerts at your desired frequency. Once you are signed up you will receive easy reminders that new content is available to view. Once you get an e-mail alert that the new issue is available you can access it immediately either through your mobile app or on your computer.

We want you to enjoy the benefit of being a member of STTI with easy access to journals from wherever you are in the world. You no longer have to wait for the mail or for a whole issue to be assembled before you can access new information. In 2017 we will be advancing knowledge to improve the health of the world's people in a user-friendly, timely, easy-to-read format. Please let us know your thoughts at jns@stti.org and please keep reading, writing for, and using content from *JNS*.

Susan Gennaro Editor



#### CLINICAL SCHOLARSHIP

# Preserving Self: Medication-Taking Practices and Preferences of Older Adults With Multiple Chronic Medical Conditions

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#### Key words

Hermeneutics, medication safety, medications, patient-centered outcomes

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#### **Abstract**

**Purpose:** To examine the experiences of older adults with multiple chronic medical conditions when a new medication was added to their existing multiple medication regimen.

**Design:** A multimethod qualitative design was used. Thirty adults 60 years of age with (a) at least three chronic medical diagnoses, (b) at least five medications at baseline, and (c) a new medication prescription were enrolled in a prospective study of 30 days duration, participating from their homes.

**Methods:** In-depth hermeneutic interviews (2 per 15 participants) and self-assessment diaries recorded on electronic tablets (daily per 30 participants) were completed. Transcribed interviews and self-recorded survey data were analyzed using hermeneutical analysis and ecological momentary assessment and content analysis, respectively.

**Findings:** Common reasons participants did not take medications as prescribed included tolerability, transportation, access to medications, and forgetting. The overarching pattern, "preserving self," was supported by two patterns that subsumed several themes: (a) engaging the powerful hold of my illness, and (b) engaging providers in visioning health.

**Conclusions:** A deeper understanding of the impact of receiving a new prescription and of managing medication reveals the challenges patients experience in preserving a sense of self. Healthcare providers of all disciplines should understand the meaning of medication prescribing and medication taking to ameliorate medication-taking difficulties.

**Clinical Relevance:** The provider–patient relationship is often cited as an area that needs to be addressed in healthcare practice. Our study emphasized the patients' voices and their profound needs around medication management. The emphasis on preservation of self is an important finding that focalizes the concern.

Medication mismanagement and improper medication taking (adherence, or taking medication as prescribed) can be a serious threat to life and health for older persons with multiple chronic medical conditions (MCMCs). Medication nonadherence in older patients with MCMCs ranges from 20% to 80% and can lead to premature hospitalization or extended care facility placement (Chen, Wu, Yen, & Chen, 2007; Chisholm-Burns & Spivey, 2008). Nonadherence has been described as a "serious deficit at the core of medical practice, with consequent massive personal, societal and economic costs" (Marinker & Shaw, 2003, p. 348). Poor medication adherence results in approximately \$100 billion in excess healthcare costs annually (Chisholm-Burns & Spivey, 2008). Patients stop using roughly 50% of medicines prescribed to treat chronic conditions within a matter of months (Hugtenburg, Blom, & Kisoensingh, 2005). While medication nonadherence has been studied for over 50 years, no single strategy has been identified to enhance medication adherence (Peterson, Takya, & Finley, 2003). Furthermore, multifaceted strategies are only modestly effective, and many essential issues concerning adherence to long-term therapies remain unexplored (Schroeder, Fahey, Ebrahim, & Peters, 2004). With a growing aging population, the number of persons with chronic conditions continues to escalate, and challenges related to chronic care quality, effectiveness, and cost remain unresolved (Boyd et al., 2007, 2009; Sidorov, 2008). Medication taking is a cornerstone of chronic condition management; as the number of chronic conditions increases, the number of prescribed medicines also increases (Williams & Manias, 2008). Conversely, as the number of prescribed medicines increases, adherence decreases (Williams Manias, 2008). In this article, the term medication refers to the processes of prescribing, obtaining, or taking medicine; medicine refers to a pharmaceutical therapeutic agent.

Medication taking is controlled by patients and clearly impacts health outcomes. Medication-taking priorities of patients often differ from those of their prescribers, which can lead to nonadherence. In turn, nonadherence exposes the complexities and ambiguities involved in medication use of those with chronic conditions (Townsend, Hunt, & Wyke, 2003). The medication-taking perspectives of older adults with chronic conditions—including their views of their medication regimens, the nature of the medication-related discussions with their health professionals, and how their perceptions and experiences influence their medication-taking behaviors—is poorly understood. Consequently, the effectiveness of medication use may be compromised, thus reducing opportunities to optimize quality of care and improve health outcomes. Results of studies examining the perceptions

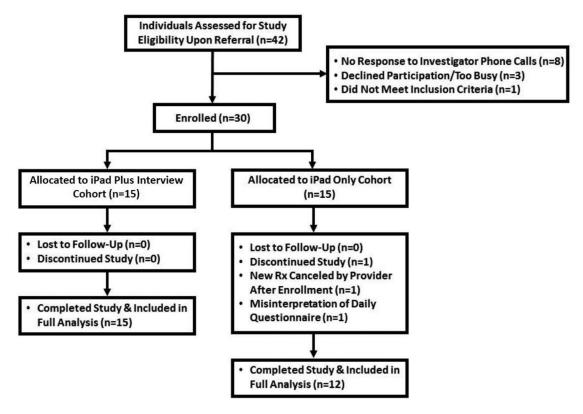
of patients (Corbett et al., in press) indicate that patients commonly believe that healthcare professionals do not listen to them when medicines are prescribed; however, when nurses broker differences in patients' and prescribing healthcare professionals' perceptions of medication regimens and use, emergency department visits and hospital admissions can be averted (Corbett et al., 2013; Naylor et al., 1999, 2004). It is apparent that deeper understandings of patients' perceptions and practices are needed to advise prescribers and healthcare providers who coordinate care and direct treatment. For this reason, the current study was conducted, providing a path toward a more refined practice of patient-centered medication prescribing, monitoring, and management strategies.

This study was a systematic analysis of the patient-centered experience of adding a new medication to an already "full" medication regimen. The incorporation of new prescriber directives, specifically prescriptions, can expose challenges that older adults face in managing chronic illness. The event of receiving a new prescription, and the subsequent experience of using this new medication in combination with an extant regimen, are what make this study unique.

The specific aims of the study were to (a) identify perceptions and behaviors surrounding the medicationtaking process of older adults with MCMCs; and (b) generate an interpretation of the meaning of medication taking among older adults with MCMCs. Thirty patients, 60 years of age or older, diagnosed with at least three chronic medical conditions and taking five or more medicines were recruited through our partner clinics upon receipt of a prescription for a new medicine. Participants completed activity surveys and recorded their thoughts over the course of 30 days via use of electronic diaries. Fifteen of these patients, a number typically suitable for providing descriptive experiences likely to answer the research questions (Creswell, 2013), also participated in in-depth recorded interviews upon enrollment and again upon study completion. Self-recorded data and transcribed interviews were analyzed using content analysis and hermeneutic phenomenological approaches, respectively. The results are a step toward refining prescribing practices and patient-centered education on medication management processes.

#### Methods

A multimethod qualitative design, grounded in postpositivist and phenomenological approaches, was used. Qualitative descriptive (Sandelowski, 2000) and hermeneutic (Diekelmann & Ironside, 2012) approaches guided data collection and analysis. Semistructured



**Figure 1.** Study CONSORT Diagram. Three participants were not included in the final survey analysis: one participant discontinued due to non-study-related medical reasons; one participant was enrolled and then was contacted by his primary care provider to cancel his new prescription; one participant answered "no" to "Did you fill your new prescription?" on study days 2–30 because it was filled on day 1, and thus no additional daily questionnaire data were gathered.

questions and thematic analysis of self-recorded thoughts, activities, and accounts were categorized, coded, and described, and in-depth textual analysis of storied interviews were interpreted for meaning. Categorical data were obtained using a real time ecological momentary assessment (EMA) approach (Bolger, Davis, & Rafaeli, 2003; Shiffman & Stone, 1998) that captured patient perceptions and experiences at the time of occurrence, providing a realistic representation of experience in the naturalistic setting. The combination of the qualitative tradition and its emphasis on rich data with EMAs that offer data from patients' perspectives in real time provided a philosophical and practical integration. Recall of past experiences using EMAs can be improved by minimizing the duration between a medication experience and the reporting episode, thereby reducing the likelihood of decay of the memory trace (Bjork, 1978; Blair & Burton, 1987; Burton & Blair, 1991). This technique allowed individuals to report periodically or "in the moment" when the experience occurred (Bolger et al., 2003). The complementary face-to-face hermeneutic interviews, done with half of the participants, provided comprehensive reflective

accounts that accessed deeper meaning and allowed us to generate interpretive commentary. This study was reviewed and approved by Washington State University Office of Research Assurance.

#### **Recruitment, Enrollment, and Data Collection**

Prospective participants were invited to participate in the study by their clinic healthcare professionals. In addition to the above characteristics, inclusion criteria included English speaking ability and ability to participate in interviews lasting up to 120 min. Participants were not screened for cognitive disorders. Thirty participants were enrolled over a 1-year period and were asked to use electronic diaries to record daily medication-taking thoughts and activities (Figure 1). Participants also answered a set of structured questions regarding their demographic information, medications and conditions, and medicationtaking practices. Fifteen of these participants were asked to participate in two in-depth interviews, initially upon their receiving a new prescription and again when they completed their 30-day electronic diary recording period. Key baseline characteristics for the enrolled cohort can be

**Table 1.** Baseline Characteristics (n=27 Completers Included in Full Analysis)

Variable	
Age (years)	69.6 ± 6.9
Gender	48% Female ( $n = 13$ )
	52% Male ( $n = 14$ )
Race/ethnicity	92% Caucasian ( $n = 25$ )
	4% Asian ( $n = 1$ )
	4% Hispanic ( $n = 1$ )
Self-rated health status	"Poor" = 7% (2/27)
	"Fair" = 26% (7/27)
	"Good" = $37\%$ (10/27)
	"Very good" = 22% (6/27)
	"Excellent" = 7% (2/27)
Mean number of diagnosed chronic medical conditions	$8.8 \pm 4.2$
Number of total medicines <sup>a</sup>	$11.9 \pm 4.4$

 $<sup>{\</sup>it a}\mbox{``Number of total medicines''} is inclusive of prescription, over-the-counter, and herbal medications taken regularly.$ 

**Table 2.** Primary Diagnoses Prompting Prescription of a New Medicine at the Time of Enrollment (n = 27 Completers Included in Full Analysis)

System	Diagnosis
Cardiovascular/renal	Hypertension ( $n = 10$ )
	Hyperlipidemia ( $n = 1$ )
	Focal segmental glomerulosclerosis ( $n = 1$ )
	Peripheral edema $(n = 1)$
Gastrointestinal	Gastroesophageal reflux disease $(n = 3)$
Endocrine	Type 2 diabetes mellitus ( $n = 2$ )
Urological	Urinary urgency/incontinence ( $n = 2$ )
Pulmonary	Chronic obstructive pulmonary disease ( $n = 1$ )
	Allergic rhinitis ( $n = 1$ )
Infectious disease	Urinary tract infection ( $n = 1$ )
	Bronchitis $(n = 1)$
Neurological	Peripheral neuropathy ( $n = 1$ )
-	Parkinson's disease $(n = 1)$
Musculoskeletal	Osteoarthritis ( $n = 1$ )

found in **Table 1**. Additionally, **Table 2** outlines the primary medical conditions enrolled participants were being treated for with their newly prescribed medication.

**Electronic diaries.** All participants were given instruction on the use of the iPads for completion of surveys. Using electronic diaries, participants were asked once if they filled their prescription, if not, why not, and, daily, whether they took their medication. In addition to discrete responses, participants could record short comments on their thoughts or feelings about medication taking. Electronic diaries were additionally used at baseline and at 30 days to collect self-rated health status in all participants. No prompts were provided to study participants regarding self-rated health categories.

**Interviews.** Hermeneutic interviews, informed by Continental philosophy (Gadamer, 1975; Heidegger, 1927/1962, 1999), require a deliberately unstructured style of questioning that is evocative, resulting in rich descriptions. The audio-recorded conversations began with a single initial directive: "Tell me a story about an experience that stands out for you because of what it means to take prescription medicines." The interviewer then listened intently, asked clarifying but not leading questions, and created the circumstances for the participant to speak unsolicited for 1 to 2 hr (Vandermause & Fleming, 2011). All intentions were for the participant to reveal storied, contextual accounts of experience.

**Data analysis.** The use of multiple qualitative methods, including survey methods, content analysis of self-recorded data, and interviews, informed a comprehensive understanding of the phenomenon of interest and helped us to answer questions of meaning.

**Survey analysis.** Basic demographic information was collected on our cohort and is reflected in **Table 1**. Additionally, findings from electronic diaries were logged using tables that compared participant demographic characteristics, whether or not the new medicine or all prescribed medicines were taken, and self-assessed level of wellness.

**Content analysis.** The spontaneous self-recordings were transcribed, coded, and summarized. Categorical comparisons across all self-recorded transcriptions were organized and described (Sandelowski, 2000). Responses to structured questions and self-recorded content analyses were examined alongside interview data in an iterative process, looking at the content summaries, then performing interpretive analyses, returning to the content summaries and back to interpretive discussions. This allowed for fluid and ongoing attention to various pieces of data during discussion sessions. In this way, new knowledge was consistently addressed as the participants provided real-time data. Such knowledge informed the ongoing collection of interview data, though the primary use of interview data was to develop a comprehensive interpretive analysis, following the philosophical tenets of hermeneutic research.

**Hermeneutic analysis.** The hermeneutic analysis was an exhaustive process of interpretation that included categorical data obtained in this study, extant research, and literature that informs the questions and patterns that were raised in the analysis. An analytic process well described in the literature (Crist & Tanner, 2003;

Diekelmann, Allen, & Tanner, 1989; Vandermause, 2012) was followed and involved an iterative and systematic approach to interpretation. The analytical team included one graduate student of qualitative research methods and the co-principal investigator; their interpretations were shared with select members of the research team and also with provider stakeholders and community members with knowledge of or experience with the phenomenon of interest. Team members reviewed de-identified transcriptions of the in-depth interviews, and wrote interpretive commentary based upon textual analysis of word choices, story structure, and manner of expression. Analysis sessions ran continuously (every 2-week sessions), reading across texts and writing text-substantiated interpretive commentary. In keeping with phenomenological traditions, the interpretive results were discussed alongside audit trails, analytical team member challenges, and the process of parallaxic praxis, below, to determine that the interpretations generated resonated with appropriate stakeholders and were trustworthy interpretive results. These procedures, rather than member checking, are used to ensure rigor in the interpretive process.

**Parallaxic praxis.** The final process of analysis included the combined insights of all research partners, including patient stakeholders, representative physicians, pharmacists. and nurses, in a comprehensive look at the data and analyses as rendered (Sameshima and Vandermause, 2009). This analytical process, informed by principles of participatory research (Israel, Eng, Schultz, & Parker, 2005; Small, 1995), was a way of enriching (not validating) findings (Seaton, 2005). Perspectives of various stakeholders were added to participant voices to expand the dialogue. Such summative analyses are compatible with content analysis and interpretive phenomenological approaches and comprise parallaxic praxis.

**Stakeholder participation.** Throughout the project, two "patient stakeholders," individuals who met criteria similar to those of our participants, worked as co-investigators in all phases of the project, including study design, data analysis, and dissemination planning. Additionally, providers (physicians, nurses, and pharmacists) were invited to assist us in the analytical process by discussing our interpretive findings and corroborating, modifying, or extending the results. These stakeholders were formally involved via focus groups, or informally involved as recipients of conference presentation proceedings. In this way, we were able to refine interpretive results and prepare for the generation of study implications.

# **Results**

Findings are presented here in the form of categorical results, interpretive patterns, and themes, with exemplars for illustration. An ancillary aim of the study was to determine if use of technology to provide real-time electronic surveys to older adults with MCMCs was feasible. For the 27 participants completing our study, all completed daily questionnaires, with a 30-day completion rate ranging from 40% to 100%. Study participants overall reported the process to be simple, though many had never used an electronic tablet prior to participating in this study.

# **Content Analysis of Survey Data**

Electronic survey data provided important insight into difficulties encountered by study participants related to medication taking. Common barriers to taking new medicines as prescribed could be categorized in two areas, one relating to problems with the prescription itself and one related to the process of taking medication. In each of these categories, there were particular common concerns. Relative to the prescription itself, access to medication was the common attributed barrier, including as reasons: (a) transportation difficulties, (b) the pharmacy was closed or out of pills, and (c) the insurance company was evaluating. Relative to the medication-taking process, barriers included: (a) the timing of taking medications, (b) the appearance of side effects, and (c) undifferentiated worry.

These categorical findings, based upon the daily responses and recordings, showed that patients needed more conversation with providers, especially early in the period following the new prescription, to answer questions, help them to adjust their lifestyle (diet, activity, timing of medicines), and process the symptoms they were experiencing. The addition of a new medicine appeared as a superimposed condition on top of several already diagnosed chronic conditions, and, consequently, required new understanding and also a readjustment to social and functional needs. The desire for a normal life with a medication regimen was ubiquitous. Thus, the issue of access alone was a concrete problem, compounded by social and functional problems better understood through the hermeneutic analysis.

#### **Hermeneutic Interpretation**

In the hermeneutical analysis, emerging patterns placed the focus on identity and self. Formative patterns and themes were presented to stakeholder groups and relevant audiences throughout the analytical process, resulting in the refinement of pattern naming and

explication. The overarching pattern, "preserving self" emerged and was supported by two patterns that subsume several themes: (a) engaging the powerful hold of my illness, including themes related to identity, function, and being with others; and (b) engaging providers in visioning health, related to claiming health and working with lifestyles.

# Preserving Self: Living With Chronic Conditions and Being With Healthcare Providers

The overarching pattern of "preserving self" was a surprising and clear finding. Taking medication was closely tied to self-identity and manifested in various ways, described in the ensuing sections. Taking multiple medications was significant and personal. The description of these findings is accompanied by the interpretations and implications as interpretive products. Exemplars are offered to support and illustrate the findings consensually identified.

Engaging the powerful hold of my illness. The mention of a new prescription to an older adult taking multiple medications and having multiple health problems brings a solemn response. Any discussion about medication is a reminder that one is in ill health, that the body is unable to sustain itself without medicine. A new medicine can thus be seen as another sign of impending mortality, and persons respond to this awareness variously. Some become despondent and see themselves as incapable; others call upon personal resiliency to manage moods and perception. For all, the prescription, even if seemingly innocuous, such as an antibiotic or anti-acid, added burden to health management. In all cases, it represented another manifestation of illness and was a powerful force in self-identity, perception of function, and ways of being with providers, friends, and family.

**Engaging the powerful hold of my illness.** *Who am I?* One gentleman, Rodney (names are pseudonyms), exhibited signs of dejection when speaking about his medication schedule. He was unable to describe his feeling in words: "You look at all the bottles up there and you just shake your head...." Although he talked about being slow and tired due to his medication regimen, he also wanted to show the interviewer his projects, mechanical and woodworking activities that filled his time. This aspect of the interview was telling because it signified Rodney's desire to be productive and active in his life. He did not want to identify as a sick or unproductive person, a perception of his medication regimen.

Marjorie said what others also voiced: "More medicines means older and a declining condition, whether or not it's true." Participants did not want to fall into the category of "taking multiple medicines." Many rejected this descriptor, though they fit the criterion of taking five or more medicines. No matter what their medicines, they did not want to be seen as medication users. The desire to be viewed outside this designation was commonly strong.

It was not uncommon to hear stories of confusion and dejection when participants described medicine side effects or compatibility problems, barriers to getting their prescriptions filled, and cost factors that were worrisome. All of these impediments affected their sense of who they were as persons. Their bodies were failing them, unless they could find a way to manage the problems they encountered.

And so it encouraged me to want to keep trying to trouble shoot through it in hopes that, oh, maybe it'll just take a little while for my body to get used to this new medicine and adjust to it. And so I'm left now having to wonder, okay, what will we add now? (Donna)

Being able to cope or adjust to a multimedication regimen signified a personal success, a part of one's identity, an aspect to fight for, if possible. These revelations provide insight into the gravity of the effects prescription medicine can produce in relation to persons' feelings of self-worth and, by extension, their senses of health and well-being.

**Engaging the powerful hold of my illness: What can I do?** Like Rodney, many participants wanted to discuss the activities they could do and the productive lives they could have, despite being regulated by medication schedules. Adjusting their daily routines around when their medicines were due and whether or not they needed to take food with medication structured the day for some. Those who chose to take the medicines as prescribed (most did) developed an attitude of acceptance and compromise. Joyce said:

These are all very conscious daily decisions that you have to make when you take multiple medicines.... If you want to look at it, it's a pain in the neck, but, you know, it's keeping me going and I feel very good because of it.

Some participants found they could manage by taking a medication box around with them; others came home to take medications when needed and worked their days around their medication-taking practice. This affected social interactions and required conscious maneuvering. Medication takers needed to think about how they wanted to be present in society.

**Engaging the powerful hold of my illness: Being with others.** The ideas that taking medication signaled illness and health depended upon taking medication led participants to feelings of dependency, recognition that they needed the prescriber to be a vital part of their lives. This is a significant finding because, though some social adjustments are expected when accommodating health management, the common attachment to the medication prescriber is often overlooked.

I feel a kinship with my physician ... it's hard if another doctor tries to give me a new medicine ... I'm not trusting them to know what I'm taking ... [to know me]." (Diane)

One of the most surprising findings from the study was the number of times participants told stories about the importance of their prescribers or primary physicians. One woman said that she could not move nearer to her daughters because her physician was "here." A gentleman kept a picture of his primary care nurse on his mantle. These kinds of statements and gestures were common, implying that the prescriber may actually hold a position equivalent to or higher than family. When these findings were shared with provider groups, they found this phenomenon to be a new insight, one they will consider as prescriptions are written. It is a profound responsibility prescribers bear. They proffer good news or bad news; their word is life changing. Every patient feels this profundity when entering the office for a routine or episodic clinic visit. The provider's response can offer comfort or pain. "He [either] knows my condition and cares, or does not care" (Mary). This interface was an important point of focus for each study participant.

### **Engaging Providers in Visioning Health**

The patient–provider relationship, known to be a key component in health and illness, showed itself in this study as central to patients' experiences. The depth of the analysis revealed an aspect of the relationship that was truly patient centered. That is, patients could manage their perceptions and behaviors variously as they engaged their providers, emphasizing an ontological characteristic that could be developed and supported.

**Engaging providers in visioning health: Claiming health.** Participants who identified themselves as "healthy" on their electronic diary surveys tended to speak more positively about their use of medicine. Even those who did not like taking medicine, calling it poison, had learned to make decisions with care providers and establish a kind of "new normal." They were proactive, like one gentleman who carried his medical records

with him, asked direct and specific questions of his doctors, and shared information with all of his physicians, making sure that all healthcare providers were informed. This is in contrast to the practices of other participants, who waited for providers to coordinate activities. An active stance included asking questions and taking charge of one's life and treatment, and was adopted by some, not all

Someone like Donna, for instance, a woman with a family history of severe diabetes and a personal history of dietary challenges, spoke about her disappointment whenever she saw her physician and was made aware of her laboratory values, blood pressure, weight, or other indicators. Donna actually anticipated disappointment when she visited her provider. Claiming health for Donna required a tremendous act of will. Claiming health, thus, is inconstant and requires skills that could be innate or taught. The particular ways medication takers perceive or act on the conditions of medication taking need to be considered by prescribers. Such recognition is relevant to the potential for improvement in helping patients access or exert best practices for managing their conditions.

Engaging providers in visioning health: Working with lifestyles. Lifestyle change was one of the more challenging practices noted in the study, especially when patients needed to alter long-term habits of diet, exercise, and other long-standing behaviors. Donna relayed a story that helps to put lifestyle adjustments in perspective. She talked about her medical history and current chronic illnesses, including diabetes. She said, "Lots of this is all my fault," relating her state of health to her own lifestyle management. However, she kept a very detailed log of all of her activities, food intake, exercise, and observations. Such diligent record keeping demonstrates a commitment to care for herself. "I worked hard on my diet-kept track...." When Donna went to her physician after working on her lifestyle plan she learned that "My A1C was in the normal range! So I celebrated and made a juicy cake!" After telling this story Donna became tearful, expressing self-recrimination for going against her diet. Yet, when the analytical team discussed this transcript, it was clear that Donna was responding "normally" to an exciting bit of news. In any other circumstance a cake is an appropriate celebratory element. This discussion is important because it highlights the atypical behaviors patients with MCMCs must exhibit to maintain adherence to medical recommendations and the expectations that healthcare providers, who want the A1C within range, place upon their patients. These social distinctions may not be consciously considered by healthcare professionals or by patients. Such challenges, when illuminated, could provide the possibilities for alternative interactions between prescribers or providers and patients. What is a normal response? What is expected? Both patients and providers, in redefining normalcy, need to be concerned about the effects of perception on identity and behavior.

In another example, Frank worked out a dosing schedule with his physicians that suited his lifestyle better, though it was not the usual or standard protocol. Frank needed to initiate this discussion, ask for information and conversation with his providers, seek other professional input from his pharmacist, and negotiate a plan that all could agree was appropriate.

I do the regimen the way I figure it will fit, trying to balance them on the 12-hour schedule. The [medication] is twice a day. But they agreed that I could take it with food, so.... (Frank)

Medication-taking practices are wholly within patients' control, and are foundational to reducing complications and improving outcomes for those with MCMCs. Many of the participants, like Frank, were able to converse with their providers and reconcile their healthcare management with the sense of identity they desired, building confidence and a sense of well-being.

#### Discussion

The healthcare literature includes analyses of barriers to appropriate medication-taking practices on the part of patients. There is recognition that nonadherence is associated with events that may be beyond the control of patients (such as availability of medicine or impediments to obtaining a prescription) and also factors related to patients' attitudes and beliefs (Chisholm-Burns & Spivey, 2008). Our study and others point as well to factors such as communication problems between providers and patients, many of which are unintentional consequences of delivery systems. For instance, multiple providers, reduced clinic time, and insurer differences can complicate prescribing patterns. However, findings from the electronic diaries pointed to issues that might have been resolved had patients been comfortable reaching out to providers for conversation.

The common emergent questions related to taking medications (timing, side effects, and other worries) required interaction with pharmacists, prescribers, or nurses. These issues were expressed even more deeply in the interviews, showing the needs and desires patients experienced that related to their ontological circumstances. The multiple data collection techniques used in this study thus added another level of complexity in understanding the phenomenon of medicine prescribing

and taking, pointing to the patient–provider interaction as a crucial target for potential intervention. Categorical findings from diary entries, elaborated considerably in the analysis of interview data, allowed us to move deeper into understandings that can produce change.

Findings closely resemble Townsend et al.'s (2003) work that explores the perspectives of patients with multiple morbidities in their approach to medication management. Consistent with their findings, patients in our study varied their regimens in response to symptoms, juggled social responsibilities with medication regimens, desired "normal" life, and associated their use of medications with morbidity. In our analyses we further recognized a common core practice driving patients or challenging their well-being. This practice was an ontological thrust, which we called "preserving self" amidst threats to identity and function.

# **Implications**

The provider–patient relationship is often cited as an area that needs to be addressed in healthcare practice. Our study emphasized the patients' voices and their profound needs around medication management. The emphasis on preservation of self is an important finding that focalizes the concern. Chisholm-Burns and Spivey (2008) summarized technical, behavioral, affective, and multimodal intervention strategies that have been disseminated in the literature. Their excellent overview of strategies and interventions that have been developed to improve pharmacoadherence offers recommendations by researchers, the American Public Health Association, and the American Psychological Association that can help patients.

Our study centers the focus on the need for tools for patients to engage providers and manage their care, especially in situations where a new medicine must be incorporated into a medication regimen. Using suggestions from our participants, and eliciting suggestions from others that address the patterns uncovered in this study, practical personal protocols can be developed for use in clinical settings, community-based events, and home care that vitalize patients' actions on their own behalf. We are developing these tools in response to findings from this study.

# **Strengths and Limitations**

It should be noted that the use of journaling via electronic diaries may have influenced participants' usual behaviors in taking medications. Their holistic experiences with the inclusion of a new medication, nevertheless, were elicited in this study. Our cohort is limited geographically, consisting of individuals of both sexes, with varying personalities, having a variety of medical conditions, and served by several specialists in one small region of the United States. Individual perceptions and responses were not associated with personal characteristics, nor were correlating factors to successful or unsuccessful medicine-taking practices derived. The study was strengthened by a multimethod qualitative design that allowed for a multiperspectival understanding of common experiences in a vulnerable group.

#### Conclusions

In this study, the perceptions and behaviors surrounding the medication-taking process by older adults with MCMCs were illuminated and an interpretation of the meaning of this process was generated. A deeper understanding of the impact of receiving a new prescription and of managing medication for MCMCs reveals the challenges patients experience in preserving a sense of self. This understanding can lead to interventions that practitioners may consider and patients may embrace. Older adults struggle with the ontological issues identified here and need tools to engage with healthcare providers so that they can manage their health satisfactorily. Healthcare providers of all disciplines need to understand the meaning of medication prescribing and medication taking so that the problem of nonadherence is mollified.

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#### **Clinical Resources**

- Adult Medication. A website dedicated to improving medication adherence in older adults: http://www.adultmeducation.com/
- Food and Drug Administration educational resources: Ensuring safe use of medicine. FDA website with tools and resources for patients to help facilitate provider interactions and optimize medication use: http://www.fda.gov/Drugs/ResourcesForYou/ucm079529.htm

- Patient-Centered Outcomes Research Institute (PCORI). Website outlining the mission of PCORI as well as results of funded research focusing on patient-centered outcomes: www.pcori.org
- Vignettes for discussion. These videos are being refined and used for discussions in teaching patients, students and providers about what is useful and what is not useful during the clinic interaction: https://vimeo.com/album/3778972

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#### **CLINICAL SCHOLARSHIP**

# **Experiences of Military Spouses of Veterans With Combat-Related Posttraumatic Stress Disorder**

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#### Key words

Spouse, posttraumatic stress disorder, phenomenology, military, Colaizzi

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#### **Abstract**

**Purpose:** To explore the experiences of military spouses living with veterans with combat-related posttraumatic stress disorder (PTSD).

**Design:** Husserlian phenomenology was chosen as the theoretical framework because it allowed a deeper understanding of the unfolding of the spouses' daily experience.

**Methods:** A purposive sample of 14 spouses living with veterans with symptoms of PTSD participated in unstructured interviews. Data were analyzed using a modification of the Colaizzi phenomenological method.

**Findings:** Spouses recognized that the veteran was no longer the same person, with life becoming one of living with the unpredictability of PTSD. The spouses bore the burden to maintain normalcy in the family and eventually created a new life.

**Conclusions:** Military spouses endure psychological stress and strain, while living with a veteran with PTSD. There is a need for more programs to support the resilience of military spouses.

**Clinical Relevance:** Life for military spouses of veterans with PTSD is everchanging and unpredictable. Practitioners need to be aware of the stress that spouses experience and develop programs and interventions that bolster the resilience of military families.

Spouses are a major support to married veterans who are experiencing symptoms of combat-related posttraumatic stress disorder (PTSD; Dekel, Goldblatt, Keidar, Solomon, & Polliack, 2005). Symptoms of PTSD may occur after exposure to a traumatic event, such as threatened death to oneself or others, the death of others, serious or threatened injury to oneself, or actual or threatened physical or sexual violence (U.S. Department of Veterans Affairs, 2015). Although there have been international studies (Ahmadi, Azampoor-Afshar, Karami, & Mokhtari, 2011; Dekel et al., 2005; Dirkzwager, Bramsen, Adèr, &

van der Ploeg, 2005; Franciskovié et al., 2007; McLean, 2006; Westerink & Giarratano, 1999; Woods, 2010) in spouses of veterans from previous combat operations, a recent review of the literature (Yambo & Johnson, 2014) revealed no published studies of the essence of the experience in U.S. spouses living with veterans who developed symptoms of PTSD from post-9/11 overseas contingency operations (OCO).

Veterans who supported OCO had unique experiences when compared to veterans from previous combat. What makes OCO unique is that they are the first sustained

ground combat, since the Vietnam War (Hoge et al., 2004), with 75% of veterans wounded by explosive devices (Helwick, 2011), more married veterans in families with more children, and accessible cutting-edge medical care (Glasser, 2011). Further what makes OCO different from previous operations for the spouses is that more military families are negatively impacted by PTSD, which contributes to weakened family bonds and hostility toward partners and military children (Peterson, Lester, Calohan, & Azad, 2014). To fill this gap in knowledge, the purpose of this study was to describe the experiences of military spouses living with a veteran with PTSD from OCO. According to the World Health Organization (WHO, 2013a), it is critical to not only meet the mental health needs of individuals, but to employ integrated strategies to coordinate holistic care to support mental well-being. Understanding the spouses' perspective will be useful to international clinicians and researchers who are funding, developing, and testing interventions that could potentially prevent mental health problems among military families. Further, this study may benefit mental health practitioners who care for veterans and their spouses as they manage the symptoms of PTSD.

# **Background**

Globally, PTSD prevalence rates span from 0.3% to 6.1% in the general population and 15.4% in conflictaffected populations (WHO, 2013b). In the United States, PTSD impacts about11% to 20% of the 2 million veterans returning from OCO (U.S. Department of Veterans Affairs, 2015) and almost 1.1 million military caregivers provide care to post-9/11 veterans (RAND Corporation, 2013). Living with a veteran with PTSD can have a negative impact on the mental health of military partners. Secondary traumatic stress, psychological distress, burden (Yambo & Johnson, 2014), marital and relationship dis-satisfaction, difficulty coping (Hamilton, Nelson Goff, Crow, & Reisbig, 2009), and domestic violence (Dekel et al., 2005) have been documented. Despite the emerging evidence in family resiliency (Peterson et al., 2014), most research is limited to investigations on the impact of trauma on the primary victim—the veteran with symptoms of PTSD. However, the spouse's perspective is critical to enhance family resiliency.

# **Philosophical Framework**

To investigate the phenomenon of interest, Husserlian phenomenology was employed. Phenomenology is a research methodology that is used to understand the essence of a phenomenon (Munhall, 2007), in this case,

the participant's perspective of living with a veteran with PTSD. This philosophical framework stems from Husserl's posit that consciousness is connected to human experiences. Thus, phenomenology refers to the study of the participant's perspective of their lived experience. The researcher must therefore strive to set aside his or her personal preconceptions, partialities, and beliefs to acquire consciousness of the experience (Munhall, 2007). Developing consciousness of the phenomenon as one who does not know is referred to as existential interaction. Existential interaction requires the researcher to participate in transcendental subjectivity (Wojnar & Swanson, 2007). When a researcher participates in transcendental subjectivity, he or she must make endeavors to relinquish presumptions and portray the genuine consciousness of the phenomenon. To achieve transcendental subjectivity, bracketing must occur. Bracketing is defined as purposefully surrendering previous encounters, beliefs, and prejudices to prevent obstruction of the phenomenon (Tymieniecka, 2003). Previous encounters, beliefs, and prejudices must be exposed by the researcher. Intentionally setting aside preconceptions is referred to as decentering, which allows the researcher to become an authentic and effective instrument of research. These concepts are essential for the researcher to acknowledge the essence of the participant's experience (Munhall, 2007).

# **Methods**

# **Recruitment Procedures and Participants**

Participants included in the study were married to Active Duty, Guard, Reserve, retired, or medically discharged veterans. The participants reported that their husbands had a presence of PTSD symptoms or were diagnosed with PTSD as a result of deployment to an OCO. Additionally, the inclusion criteria were (a) between the ages of 21 and 60 years, (b) English-speaking, and (c) having the capacity to reflect upon and discuss their personal experiences. Exclusion criteria included individuals who were unable to participate due to mental or physical illness, hospitalization, inability to communicate, residing outside of the United States, or unmarried partners.

A pilot study was conducted to refine the methodological issues (Yambo, Hamilton, & Johnson, 2014). Participants were recruited through purposive sampling. Further recruitment was conducted through social networking and participant referral. Each participant was asked to pass along the information to other spouses living with veterans with PTSD until the investigator reached study saturation. Recruitment ended when, via

**Table 1.** Participants' Sociodemographic Characteristics (N = 14)

Variable	n (%)	Variable	n (%)		
Age (years)		Length of marriage (years)			
21-29	4 (29)	<5	2 (14)		
30-39	6 (43)	5–10	6 (43)		
40-49	3 (21)	>10	6 (43)		
50-56	1 (7)				
		Number of deployments			
Ethnicity		1	6 (43)		
Caucasian	10 (71)	2	3 (21)		
Caucasian-Hispanic	2 (14)	3	4 (29)		
Hispanic	2 (14)	4	1 (7)		
Employment		PTSD symptoms	PTSD symptoms		
Caregiver	3 (21)	Diagnosed	12 (86)		
Employed*	8 (57)	Undiagnosed	2 (14)		
Homemaker	3 (21)				
Volunteer	1 (7)	Traumatic brain injury			
		Diagnosis	7 (50)		
		No diagnosis	7 (50)		
Children					
None	2 (14)				
1–5	11 (79)	PTSD symptoms (years)			
6–10	1 (7)	<3	2 (14)		
		3–5	9 (64)		
		>5	3 (21)		
Current health					
Fair	3 (21)				
Good	4 (29)	Relationship status			
Very good	3 (21)	Married	11 (79)		
Excellent	4 (29)	Divorcing	3 (21)		

Note. Caregiver = recognized as provider of personal care to the veteran. PTSD = posttraumatic stress disorder.

coding and examination of the interviews, it was determined that redundancy had been achieved (Morse, 2006).

The purposive sample (N=14) included 2 spouses of veterans with PTSD symptoms (without formal diagnosis) and 12 spouses married to a veteran with a diagnosis of PTSD. In this study, participants (n=7) reported living with a veteran with a codiagnosis of PTSD and traumatic brain injury (TBI). The TBI, as reported by the spouses, was the result of a traumatic event that occurred during the veteran's deployment. **Table 1** includes additional sample demographic characteristics. The participants felt that their participation in the study might aid others living with veterans with PTSD.

### **Ethical Considerations and Data Collection**

Rush University Institutional Review Board approval was obtained for this dissertational study. Before the interviews took place, each participant gave written informed consent. Data collection took place from

September 2013 to December 2014 until redundancy and data saturation were achieved after the 14th interview. Data were collected through interviews with each participant individually at a mutually agreed upon time. Twelve participants were interviewed face to face. Per their request, two participants were interviewed via telephone. Interviews were unstructured with openended questions that began by asking the participants to describe an experience that exemplified what it was like to live with a veteran with PTSD symptoms. For parts of the story that needed clarification, more detail, or deeper exploration, probing questions, such as, "Can you say more about that?" were utilized. Individual questions were used to further explore what makes living with someone with PTSD symptoms either more difficult or easier. The interviews were audio-taped and field notes were written following each interview. Recordings were transcribed verbatim by a professional transcription service. Each transcript was quality checked for accuracy by the first author.

# **Data Analysis**

The transcripts were uploaded into the qualitative data management program, ATLAS.ti (Scientific Software Development, Berlin, Germany). Data were analyzed using a modification of Colaizzi's phenomenological analysis (Colaizzi, 1978). The modification included contacting three participants for validation of the findings, rather than all participants, to ensure that their words had the same meaning as the investigator understood. The Colaizzi (1978) analytical steps involved (a) reading each participant's description of the experience, (b) formulating the meaning of each significant statement, (c) organizing the formulated meaning into clusters of themes, (d) integrating the results into a description of the phenomenon, (e) validating the findings by revisiting three participants, and (f) integrating modifications provided by the participants into the final description. Three participants compared their experience with a summary of the findings of the study. Participants reviewed the findings separately and expressed agreement that the findings accurately described their experiences. To preserve confidentiality, each participant was assigned a pseudonym.

#### **Findings**

Four major themes emerged. A description of the themes along with supporting quotes follows to reflect the essence of the spouses' experience.

Military spouses living with veterans with PTSD described the experience of reintegration, a period of time immediately following the deployment, as a time

<sup>\*</sup>One caregiver worked outside the home.

of noticing changes in their husbands. Outwardly, their husbands looked the same, but their reactions and behaviors were different. For instance, Sara, spouse of a veteran with PTSD and TBI, recalled how she initially noticed the change in her husband's behavior but only later realized that it was a symptom of PTSD. She stated, "We had a lot of fights over him just being self-absorbed with video games all the time. Now I know that that's a common symptom of PTSD, the isolating and withdrawal. It's still a struggle."

The spouses struggled to understand the change in their husbands' behavior and attitudes. These changes were often observed, but sometimes they were simply hunches that something about their husband was different. Over a period of time, the spouses began to realize that certain conditions or events triggered a memory of a traumatic experience from their husband's deployment. Alice, a spouse of a veteran with symptoms of PTSD, shared that the subtle changes in her husband's behavior made her aware that he was no longer the same. She said,

It started clicking to me, um, that he was having some PTSD because just like the locking of the doors. And later he told me that was because he felt like he was being followed or, you know, he got paranoid that people were after him.

When their husbands returned from deployment, the spouses expected their husbands to resume their previous roles and responsibilities and that life would return to "normal." However, the more time the spouses spent with their husbands, the more they recognized that their husbands were no longer the same. Recognizing their husbands were no longer the same made many of them realize that they, not their husbands, needed to readjust.

### **Living With Unpredictability**

Living with their veteran spouse was turning into a life of unpredictability. The spouses often referred to the predictability of unpredictability as "walking on egg shells." In other words, they knew their husband would react, but they did not know when or where the reaction would occur. Not knowing what new experience was going to trigger a reaction coupled with the uncertainty of their husbands' reactions was stressful to the spouses. Isabelle reflected on the unpredictability. She explained, "Sometimes, it feels like walking on eggshells. You don't know if he's having a good day or not. Small things could trigger him "

All of the spouses were trying to become more attuned to their husbands' moods and triggers. Although the spouses were feeling stressed from the continual

exposure to PTSD symptoms, this stress was compounded by the loss of predictability in their lives. Leah shared her viewpoint on the impact of unpredictability on her life. She explained,

It's very unpredictable because you don't know. We could be shopping and be fine and then somethin' catches his eye. Like I know crying children and women in balaclava or whatever the headdress. Certain things if he catches it, it puts him back there in whatever happened; the aggression comes out or whatever he needs to do to get out of the situation. It's a daily stress, unpredictable.

The spouses dealt with the daily challenges of unpredictability. Many of them recognized that their husbands would have good days that made everyone feel good. However, when their husbands had bad days, they felt the loss of predictability in their lives. The loss of predictability created an emotionally unstable environment that left the spouses wanting to recreate peace in their homes.

# **Bearing the Burden**

The spouses perceived two types of burdens, a tangible one from assuming the duties and responsibilities of their relationship, and an invisible psychological burden. With regards to the tangible burden, the spouses felt that it was their responsibility to manage the changes in their lives that were sparked by their husbands' medical condition. For example, shifting roles, assuming their husbands' chores, or reintegrating their husbands into the family became part of their responsibility. Megan, whose spouse had symptoms of PTSD, reflected on how shifting roles helped her to support her husband. She stated, "That sense of you're dealing with—you know that this person can't deal with the regular stuff. You step in. You take care of it for them. Cleaning, the dishes, all these little things. Even filling up the car."

In addition, three spouses bore the psychological burden of guilt for their husbands' traumatic deployment experience, the impact of PTSD on their life, or for starting a new life without their husband. Cassie, a spouse of a veteran with PTSD and traumatic injuries expressed her guilt for encouraging her husband to take the place of another military member when it was not his turn to deploy. She was feeling guilty for her husband's traumatic experience that resulted in PTSD and a traumatic injury. She shared, "I asked my husband to volunteer to go this third time to Afghanistan. I guess I feel guilty because he did go and 3 months later came home with 45% burns to his body, you know, PTSD."

Maintaining the peace. Ten of the spouses felt responsible for maintaining peace in the family. They tried to avoid conflict, but often felt unsuccessful in their endeavors. For those spouses with children, maintaining peace between their husbands and their children was emotionally exhausting because their husbands angered easily and quickly. One tactic they used to maintain the peace was to help the children understand their father's medical condition. The spouses also tried to model behavior for their children. Yet, keeping the peace was an ongoing challenge for them. Lily expressed concern about the emotional fragility of her family. She said,

I feel like I'm the peacemaker in our home and it gets exhausting. Sometimes you just want to lock yourself in the room and really just want to run away, but you can't because if you do then he might hurt himself or the kids will be scared.

**Dealing with spouse's emotions.** The spouses experienced a myriad of emotions as they tried to navigate the journey of PTSD with their husbands. Six of the spouses shared that they were struggling with dealing with their husbands' coexisting mental health concerns. Three spouses reported struggling with their husband's plan to commit suicide. To keep their husbands safe, each spouse described encouraging their husbands to seek mental health treatment. All three of these spouses discussed intervening at times to prevent their husband's suicide attempt. Maria was feeling afraid that she might not be able to keep her husband safe. She said, "I'm terrified of the snap. There's been a couple of times he's had to take himself to the [hospital] because he's suicidal. 'Cause he's suicidal and he snaps; things make him so angry that I can't calm him down." Many of the spouses were dealing with their husband's volatile emotions without seeking assistance from external sources. In other words, they were silently struggling with their own emotional needs, while tending to their husband's emotions.

**Protecting the children.** Twelve of the spouses had children and many of them expressed concern about how PTSD symptoms were impacting their children. Therefore, they were taking measures to shield their children from hostility and to prevent the children from triggering a symptom of PTSD. The mothers were also attempting to nurture the father–child bond. Six spouses noticed that their husbands were unable to relate to them or the children during a flashback. A flashback, the mothers expressed, posed a significant fear for their children's safety and their own. Thea, a spouse of a veteran with PTSD and TBI, recalled protecting herself and their children when her husband experienced a

flashback. She stated, "You had to clear all the kids to one room, and lock yourself in the room 'cuz your husband has a knife and he's trying to kill you, but he doesn't know that he's in that mind frame."

### **Creating a New Life**

The return to life before the deployment was not happening the way the spouses anticipated it would when their husbands returned home. Therefore, each spouse created new ways to function around the veteran's PTSD symptoms. Bree described how she altered the way she tended errands. She said, "We have to change our shopping schedule around a lot. He doesn't like to be where there's a lot of people. When we do, he just—he has anxiety." Kathy reflected on the changes in their social life. She recalled, "We could never go out, ever. We couldn't go out to crowded places. We couldn't go to restaurants or couldn't go even grocery shopping. Couldn't go anywhere where there were crying kids and babies because that set him off, too."

### Not seeing old friends; creating new friends.

Despite having a network of friends, six of the spouses described feeling alone in dealing with their husband's symptoms of PTSD. Lily described why she sought support from like-minded spouses. She remarked,

I enjoyed being around other spouses that were experiencing similar situations because they understood. They didn't judge and they didn't look down on you. They understood exactly what you were going through, and sometimes you'd hear their stories and you're like, "Oh, my day wasn't that bad today then." As silly as it sounds, it helps you get through.

All of the spouses were gravitating towards individuals who accepted their experience. The spouses cultivated relationships with individuals who shared ongoing emotional encouragement. Receiving emotional encouragement became a lifeline, linking them to those who understood their plight.

Making sense of the relationship. Restructuring ways of thinking and reacting was important to the spouses. Two spouses talked about structuring their "new normal." However, their new normal was not a destination, but rather an ongoing journey. Michelle, a spouse of a veteran with PTSD and TBI, recalled how she was able to accept her new way of living. She remarked, "Seeing that MRI made me realize there's no way he's ever coming back. We started our new normal that day that I was in [treatment facility]. He cannot multitask anymore. He can only do one thing at a time." Because

of the impact of PTSD symptoms on their marriage and family, the spouses altered their lifestyle to cultivate a way of living that fit their relationships.

Three spouses shared that they were contemplating divorce as their way of creating a new life. Megan described how struggling with her husband's medical condition impacted her decision. She commented, "I've actually filed for divorce just this month because it's something I've had to do. 'Cause I'm at the point with after many struggles with his PTSD and all the problems that have come with it." The three women perceived that their new normal was to be without their husbands. In spite of filing for divorce, two spouses felt that they would reconsider the divorce, if their husbands were willing to engage in treatment and make progress towards reducing self-destructive behaviors.

**Adjusting the environment.** As their lives unfolded, the spouses were learning to adapt their surroundings to their husband's condition. For instance, Isabelle, a spouse of a veteran with PTSD, discussed how she was creating structure for her husband. She mentioned,

I have a dry erase board to write everything down. If I'm gonna be working, I make sure to write it on there. I even text him reminders. I always have to keep reminding him about certain things, so he doesn't forget.

One spouse established rapport with her husband's medical practitioners to become active in her husband's treatment. Several women became advocates for their husband's care; they were helpful in creating processes to ensure their husbands were compliant with their medical treatment. Hence, spouses were finding ways to adjust the environment for their husbands.

**Understanding PTSD** and **TBI.** The spouses whose husbands were diagnosed with PTSD and TBI described feeling unprepared to deal with their husbands' dual medical disorders. Michelle shared her difficulty with understanding her husband's dual diagnosis. She said, "I wish, [my husband], I could have tattooed on your forehead 'PTSD' and 'TBI' because you look the same, but you do not act the same." Because the spouses were limited in their knowledge of how to deal with the veteran's dual diagnosis, they were experiencing difficulty with the complexity of PTSD and TBI symptoms and communicating with their husbands.

# **Discussion**

The essence of the experience of living with veterans with symptoms of PTSD is that spouses are struggling to find balance. Finding balance is a primary concern in postdeployment resiliency for spouses, because prolonged exposure to PTSD symptoms is a predictive factor of secondary traumatic stress (Ahmadi et al., 2011). The findings reported here highlight military spouses' perspective of their daily life with a veteran with PTSD symptoms. Further, this study adds to earlier descriptions of the experiences of military spouses living with veterans with PTSD (Dekel et al., 2005; Lyons, 2001; Maloney, 1988; McLean, 2006; Ray & Vanstone, 2009; Woods, 2010); supports marital adjustment findings revealed in PTSD research conducted with Vietnam veterans' partners (Evans, McHugh, Hopwood, & Watt, 2003; Jordan et al., 1992; Koenen, Stellman, Sommer, & Stellman, 2008; Riggs, Byrne, Weathers, & Litz, 1998), ex-World War II Prisoners of War (POWs; Cook, Riggs, Thompson, Coyne, & Sheikh, 2004), and former Israeli POWs (Dekel & Solomon, 2006); and provides a deeper understanding of the impact of combat-related traumatic stress on family relationships (Canfield, 2014; Frederikson, Chamberlain, & Long, 1996; Maguen, Stalnaker, McCaslin, & Litz, 2009; Ray & Vanstone, 2009). The findings of this study support the evidence that spouses struggle to balance their day-to-day life due to the symptoms of PTSD (Mansfield, Schaper, Rosen, & Yanagida, 2014).

Often, the military spouses struggle alone in silence. It is little surprise that many of the participants expressed loneliness amid the mental health resources that are available to them. Moreover, these findings are consistent with findings from research with U.S. Vietnam veteran spouses (Lyons, 2001) and Canadian peace-keepers' spouses (McLean, 2006). Researchers found that spouses readjust their lives around the veteran's symptoms without regard to their own personal physical and emotional well-being, and little is known about the cost of such resiliency.

This study is one of the few qualitative studies conducted to explore the essence of the experience of U.S. military spouses living with a veteran with PTSD symptoms from OCOs. In this investigation, the themes and significant statements described were comparable to the themes of previous research: feelings of anger, confusion, fear, and loneliness; thoughts of confusion to understanding PTSD symptoms; and descriptions of the complexity of their relationship with their husband (Woods, 2010). Furthermore, they were consistent with themes identified by Dekel and associates (2005) in wives of Israeli veterans: the illness as navigating living, between

merging and individuation, partners as present-absent, separation and divorce, and partners as empowers. The themes revealed that spouses perceived that navigating their husband's illness made it difficult to maintain their individuality, which created emotional dissonance in their relationship that led to thoughts of separation and divorce. However, despite the emotional dissonance, partners remained in their relationship. Remaining in the relationship meant assuming the responsibility of making household decisions on their husbands' behalf. Hence, the partners felt empowered when they made decisions that impacted the well-being of their family, while their husbands dealt with PTSD symptoms. This study, which focused on these women's lived experiences, detailed the myriad adjustments they make on many fronts to keep themselves and their children safe, to regulate their husband's emotions and affect and to preserve the threads of their relationships.

This research also provided insight to the spouses' perception of PTSD as ever-changing, unpredictable, and stressful to their family dynamics and relationships. According to the Substance Abuse and Mental Health Services Administration (2014), enhanced behavioral health clinical policy is necessary for families to receive tailored care to help them cope with the complexities of PTSD. Although, each spouse felt that living with a veteran with PTSD was an individual experience, their lives were interwoven in commonalities that cut across all the spouses, regardless of the veteran's PTSD symptom severity. The findings indicate that living with a veteran with PTSD is stressful for the spouses due to the complexity of the condition. On a positive note, five spouses reported gaining insight on how other spouses coped with a difficult situation and working to "normalize" their experience through the experiences of others. In other words, when the spouses connected with other individuals, they were able to make sense of their situation. When spouses made sense of their situation, they were able to identify common stressors and utilized their awareness of others' ways of coping to cultivate their own coping strategies. Unfortunately, two spouses, who were unable to connect with others, were feeling exceedingly stressed and lonely in their efforts to cope.

Although programs such as Families Overcoming under Stress (FOCUS project) are underway to address family resilience enhancement, most of the emphasis has been on deployment and has not targeted PTSD and spouse resilience (Saltzman, Bartoletti, Lester, & Beardslee, 2014). However, even when there are collaborative efforts like the FOCUS project, military spouses lack the tools to effectively cope with the stress of PTSD symptoms. Thus, it is paramount for community and

private organizations to link the spouses with resilience services early in the military separation process.

Limitations of the study include the absence of a male spouse in the sample. Although community organizations supported male and female spouses, we were unsuccessful with the recruitment of a male spouse. One male spouse intended to participate; however, his veteran wife had a co-occurring, incurable illness that prevented his participation. Therefore, findings cannot be generalizable beyond female spouses. In addition, it is not possible to control for the interaction of PTSD and the impact of multiple deployments.

# **Conclusions**

The experiences of these military spouses draw attention to the tremendous stress of spouses of veterans who suffer with PTSD and traumatic injuries. Community organizations are crucial to offering resources and connecting spouses to appropriate referral services. Yet, there remains a need to nudge collaboration among civilian, military, and federal components to support the health and well-being of military spouses. Respect and understanding of the spouses' unique position in the treatment of PTSD warrants the unveiling of obscure systematic processes to provide continual support for military families.

Reintegrating is a challenge for military families. Future studies are needed to understand the impact of traumatic stress on the spouse and military family. Clearly, we are on the cusp of transforming health care to acknowledge and care for the unsung heroes of military families—military spouses. It is our hope to keep military families together through educational efforts to increase awareness of their plight.

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#### **CLINICAL SCHOLARSHIP**

# **Provider Perspectives on Safety in Primary Care in Albania**

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#### Key words

Albania, general practitioners, medical errors, nurses, patient safety, primary healthcare, teamwork, Safety Attitudes Questionnaire

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#### **Abstract**

**Purpose:** The purpose of this study was to determine the safety attitudes of specialist physicians (SPs), general physicians (GPs), and nurses in primary care in Albania.

**Design:** The study was cross-sectional. It involved the SPs, GPs, and nurses from five districts in Albania. A demographic questionnaire and the adapted Safety Attitudes Questionnaire (SAQ)-Long Ambulatory Version A was used to gather critical information regarding the participant's profile, perception of management, working conditions, job satisfaction, stress recognition, safety climate, and perceived teamwork.

**Methods:** The onsite data collectors distributed questionnaires at the primary care clinics and then collected them. Descriptive statistics were used to summarize the responses. The significance of mean difference among SPs, GPs, and nurses was tested using analysis of variance.

**Findings:** Five hundred twenty-three questionnaires were completed. The concept of patient safety in relation to job satisfaction received the highest ratings. Stress recognition had low ratings. There was a high level of teamwork in SPs, GPs, and nurses. Healthcare staff agreed that it was difficult to discuss errors in their primary healthcare center. Physicians in contrast to nurses were most likely to affirm that they do not make errors in hostile situations.

**Conclusions:** Errors are difficult to discuss. It was clear that primary care staff, such as physicians, never considered the likelihood of errors occurring during tense situations.

Clinical Relevance: Staff at primary healthcare centers are used to adverse events and errors. Despite the demand for safety improvement and the existing evidence on the epidemiology of outpatient medical errors, most research has only been conducted in hospital settings. Many patients are put at risk and some are harmed as a result of adverse events in primary care. Adequate communication and technical skills should be utilized by primary care providers (PCPs) for improvement of patient safety. The patient safety measures should include assessment of the safety attitudes of PCPs.

The state of a patient's protection from preventable harm during the process of health care is referred to as patientsafety (World Health Organization [WHO], 2002). This is a result of integrated efforts to correct adverse results or prevent harm that may arise in the process

of health care (Council of Europe, 2005; Institute of Medicine, 2004; Suñol et al., 2009). A preventable harm that has the capacity to cause future complication to the patient is a patient safety incident (WHO, 2007). Unintentional injuries that lead to temporary or permanent

disability, prolonged hospital stay, or death are adverse events that are caused by the healthcare management (Brennan et al., 1991; Wilson et al., 1995).

Patient safety has been identified as a substantial global issue in the past decade (European Commission, 2014; Institute of Medicine, 2004; WHO, 2008). The available data suggest that harm from medical care poses a substantial burden in terms of morbidity and mortality on people around the world. The WHO (2002) report highlights that better understanding is required of the causes, frequency and harm of adverse events in developing countries and those with economies in transition.

Lack of effective teamwork and communication breakdowns are the major causes of errors in health care (Leonard, Graham, & Bonacum, 2004). These factors also highly influence the occurrence of patient safety incidents (Gawande et al., 2003; Joint Commission on Accreditation of Healthcare Organizations, 2004; Risser et al., 1999). In order to achieve high reliability, teamwork and effective communication are encouraged, which leads to a culture of safety (Leonard et al., 2004).

# **Hospital Safety**

With regards to the data from the European Union (EU) Member States, 8% to 12% of hospitalized patients experience healthcare-related adverse events and medical errors. Each year, 1 in every 20 hospitalized patients contract healthcare-related infections (approximately 4.1 million patients). According to the U.K. National Audit Office, this is approximately £1 billion per year (WHO, 2014). A range of occurrences in relation to healthcare errors directly cause 37,000 deaths every year, as reported in Patient Safety and Quality of Care, a recently released European Commission report (European Commission, 2014). Such healthcare errors also further influence 110,000 deaths every year, which incurs more than €5.4 billion in costs every year (European Commission, 2014, n.d.). Albania currently lacks an electronic system for monitoring errors in primary health care (PHC).

Hospital care represents only a small percentage of the patient's use of healthcare services (Degos, Amalberti, Bacou, Carlet, & Bruneau, 2009). There are low risks associated with primary care; however, it involves many procedures that raise the probability of fatal incidents occurring. Other studies focused on patient safety have proven primary care to be the origin of incidents in hospital care (Elder, Vonder Meulen, & Cassedy, 2004; Leendertse et al., 2011; Michel, Quenon, Djihoud, Tricaud-Vialle, & de Sarasqueta, 2007; O' Reilly, 2006). In the field of patient safety, hospitals have been the institutions most reviewed (Sorra et al., 2008). Due to

the level of risk, most studies should instead focus on primary care (Dovey et al., 2002; Rosser et al., 2005).

### **Albania**

Officially identified as the Republic of Albania, it is located in southeastern Europe and represents a postcommunist system in transition. In Europe it is one of the poorest countries, with about 14.3% of the population in absolute poverty (World Bank, 2012). Its population is estimated at 2,800,193, with a diversity of religion and ethnicity. The country is characterized by a peaceful religious coexistence (Hoxhaj, 2014). The latest census held in Albania in 2011 showed that 56.7% of the respondents were Muslims, 6.8% were Orthodox Christians, and 10.0% were Roman Catholics. Caution should be maintained while interpreting these findings because of the low response rate (Burazeri et al., 2014).

Despite the unreliability of the statistics, life expectancy increased to 70.0 years in the 1980s from 62.2 years in 1960s. The increase in life expectancy has been observed in both sexes (male life expectancy increased from 67 to 73 years, while female life expectancy increased from 71 to 75 years between 1990 and 2012; WHO, 2014). Eighty-eight percent of all deaths in 2010 were influenced by noncommunicable diseases (NCDs) in Albania (19% due to cancer and 55% due to cardiovascular diseases).

This identifies Albania as one of the European countries facing the NCD epidemic as their critical health issue. Infectious disease have shown a substantial decline in the past 20 years to 11% in 2012. This level of improvement might attain the actual European average of 5% in a decade. Ischemic heart disease in Albania exhibits the highest mortality rate in the southeast European region. Dietary risks, high blood pressure, and tobacco smoking are the three factors that contributed to the largest health burden in 2010.

Physicians and nurses in primary care clinics are the main providers of health services for NCDs (Kruk, Nigenda, & Knaul, 2015). The present PHC providers network (2,300 health posts, 421 autonomous health centers [HCs]) needs revision of its accountability mechanism, management, and package of services with regards to territorial and administrative reforms. HCs operate as autonomous units contracted for the health services offered through the mandatory plan for health insurance. Education, health promotion, mental health care, elder care, adult care, women's health and reproductive health, child health, and emergency care are included in the basic PHC service package (Arqimandriti et al., 2014).

HCs in Albania represent a primary publicly funded nonprofit health institution. Recent studies indicate that almost 95% of HCs lack the appropriate mechanism for service provision to disabled people (Arqimandriti et al., 2014). In general, there is high provision of these services. The health services provided by HCs at the national level are generally of a high percentage. Most HCs have the appropriate medical equipment. More than half have the appropriate supply of medications. Of the HC medication supplies, 75% are at an adequate or somewhat adequate level. In addition, 80% of HCs nationwide have proper documentation (Arqimandriti et al., 2014).

A revolution in nursing education is occurring in the Western Balkans and Albania. New methodologies, such as mergers with other industries and competence-based approaches, are emerging. One of the main challenges, however, is lack of consistency between the various forms of education (secondary school, post-secondary school, and bachelor's degree) and the approach in EU countries. The standard of programs offered for initial nursing education in private universities is different from that in public universities. Fragmentation of governance in the educational and health sectors is a limitation to the harmonic policy on nursing education. The programs are not holistic; nor are they biomedically oriented. The nursing faculty in the secondary and bachelor's level is composed of doctors of medicine rather than nurses. The new required competencies in nursing do not correspond with the theoretical information (Tempus Program, 2013).

There are very few physicians in Albania as a whole, which translates to a scarce number in remote areas. Based on the statistics of the WHO (2014), there were about 399 nurses and midwives and 115 physicians per a population of 100,000 in Albania between 2006 and 2013. GPs were estimated at 50 per 100,000 population between 2006 and 2012. Between 2006 and 2012, there were 43 pharmacists and 33 dentists per 100,000 population.

The healthcare systems in Albania are considered to be in transition. There was a 5.97% total expenditure on health with regards to the gross domestic product in 2012. The government spent \$227.51 on health per capita annually (this is the international dollar with regards to the purchasing power of the U.S. dollar in the United States). There was a 47.60% expenditure on public health based on the total health expenditure. The out-of-pocket expenditure was 99.69% (World Bank, 2014). The PHC facilities are estimated at 76 per 100,000 population in Albania (Burazeri et al., 2014).

Researchers in Albania are aiming to collect data for research on patient safety. Researchers note that there are direct relations between medical breaches and presumed medical corruption (Cipi, 2007), poor human resource management, and lack of staff capacity building interventions (Myers, 2012). Health reform initiatives in Albania are directed towards the introduction of PHC

based on family medicine for enhancement of health system performance and coping with a broader political agenda (Institute of Statistics, 2008; World Bank, 2005).

The issue of communication among doctors and patients is being resolved, and other fields are addressing the provision of quality healthcare services in Albania (Hoxha, Sarolli, Petrela & Gabrani, 2007). The results from this study indicate the high level of patient dissatisfaction with hospital service. The main reasons for dissatisfaction were staff attitude and long waiting. Study participants (43.8%) gave negative ratings to service provided by nurses. With respect to the study, most of the patients were not aware of where they could take their grievances. Other challenges exposed were inappropriate hospital environments and poor maintenance and unavailability of the prescribed medication.

However, it has been noted that there are no studies on safety attitudes in PHC. The Safety Attitudes Questionnaire (SAQ) has been used in other regions, which prompted its use in Albania. Two research questions were posed during the study: (a) Which SAQ domains exhibited the maximum and minimum positive perceptions by the providers? and (b) Do nurses have a positive response perception similar to that of general physicians (GPs) and specialist physicians (SPs) regarding the patient safety attitude on stress recognition, safety climate, team work, and job satisfaction? The main goal was assessment of the perceptions of patient safety based on the provider's view while attempting to determine the attitude that influences errors.

#### Methods

#### Design

This was a quantitative, cross-sectional study. Collection of data took place in PHC centers in the five main political districts in Albania from January to June 2011. The types of healthcare centers in Albania are preventive health services, immunization, family planning, maternal care (prenatal and postpartum), and outpatient care.

#### Sample

One-stage cluster sampling was used in this study, and it included SPs, GPs, and nurses as the only eligible healthcare staff.

#### Instrument

The SAQ was the instrument utilized for data collection, borrowed from the long and ambulatory version. The questions were about job satisfaction, stress, recognition, error, and perceived teamwork, in addition to the professional's profile data: sex, position held, main job, and years of experience.

Questionnaires are used to understand the employee's view of the different dimensions of patient safety. The results are helpful to frontline staff, clinical leaders, and quality safety officers to identify the strengths and weaknesses of a culture, plan strategic improvement, and track changes and provision of benchmark data (Kristensen, Sabroe, Bartels, Mainz, & Christensen, 2015).

The measurable elements of safety culture are assessed by the questionnaire through measurement of the caregiver's perception and attitude. Six critical dimensions of a safety culture are measured: stress recognition, working conditions, safety climate, perception of management, job satisfaction, and teamwork climate. This form of questionnaire is the only one that touches on all common dimensions, can be used for a variety of settings, is suitable for broad comparison, and can be performed psychometrically well (Buljac-Samardzic, van Winjingaarden, & Dekker-van Doorn, 2015). The instrument is evidently valid and reliable; previous studies have indicated a strong relationship between the positive outcomes of a patient and the favorable scores of the SAQ (Deilkås & Hofoss, 2008; Hutchinson et al., 2006; Modak, Sexton, Lux, Helmreich, & Thomas, 2007; Sexton et al., 2006).

#### **Procedure**

The respondents (healthcare staff) were identified by their roles in the PHC and if they worked full time. The aim of the study was clarified to the potential participants. It was also made clear that participation was voluntary and they were free to opt out without the need for a reason. Students from the School of Public Health in the Faculty of Medicine collected the data. Standard manual and audiovisual aids were used to prepare them in their week-long course.

#### **Ethical Issues**

Because of the lack of an experimental design in the study, there was no need for approval by the Ethical Committee. The head of the PHC centers also assured researchers that there was no need for an ethics approval. The aims of the study were clarified to the participants. The participants understood that it was voluntary, they would remain anonymous, and they were free to opt out without any explanation.

#### **Statistical Analysis**

An Excel database was used to contain the data. SPSS 19.0 (IBM Corp., Armonk, NY, USA) was used to

perform statistical analysis. Structural equation modeling conducted Confirmatory Factor Analysis (CFA) with the help of AMOS version 5.0 software for testing the degree of explanation of each SAQ, a dimension in addition to the degree of explanation of safety attitude by the six dimensions.

The acceptable model fit was demonstrated using a comparative fit index (CFI) value of  $\geq$ 0.95, relative  $\chi^2 < 5.0$ , a root mean square of approximation (RMSEA) <0.08, and a standard root mean square residual (SRMR) value of <0.09.

Internal consistency of the Albanian version of the SAQ was assessed with the help of Cronbach's  $\alpha$  coefficient. The reliability over time was tested using the Pearson r correlation. Mean scale scores and standard deviations were calculated for the three providers (SPs, GPs, and nurses). Analysis of variance (ANOVA) was used to compare the mean scores of the provider types.

ANOVA was used to test the differences in rating of subscale scores based on the positive response from the participants on a single item. The groups (SPs, GPs, and nurses) were paired and compared using Tukey-Kramer post hoc tests. The percentage rating for each caregiver type was then presented.

The associations between discrete variables were assessed using the chi-squared test. The substantial p value considered was  $\leq$ .05.

# Albanian Version of the SAQ

Native speakers translated the SAQ from English to Albanian. This version was then reviewed by faculty members, nurse experts, and physicians to ensure that the translation was clear and included the correct words. All the elements were assessed to ensure alignment with the Albanian culture.

The back-translation technique was applied to perform a linguistic validation of the translation. With regards to the analytical results, all six dimensions were sufficiently reliable. The authenticity of the context with regards to its relevance, significance, and appropriateness to the Albanian culture was determined using an expert's view.

The content validity index (CVI) and content validity ratio (CVR) were calculated for each item: 0.97 was the CVR for the total scale, while 0.83 was the mean CVI, which indicates satisfactory content validity.

#### **Internal Construct Validity**

Goodness-of-fit values were utilized in the evaluation of internal construct validity. The SRMR, RMSEA, and CFI values were 0.078, 0.049, and 0.98, respectively. These values are indicative of the appropriate model fit estimation of the translated version of the SAQ. A good

model fit was indicated by CFA for each dimension in addition to the whole safety construct. The CFI, Tucker–Lewis index, and goodness-of-fit index were >0.90, while the RMSEA was <0.10.

# **Internal Consistency**

Cronbach's  $\alpha$  values of the internal consistency of the six factors and the 30 elements of the SAQ translated version were 0.62 to 0.82. The highest value was seen with safety climate, while the lowest value was recorded for stress recognition.

The test regarding the hypothesized correlation between the factors and items indicated a range from 0.02 to 0.89 in addition to five of the six factor relationships being substantial. Safety climate was positively linked to teamwork climate (r = 0.57, p < .01), working conditions (r = 0.67, p < .01), and management (r = 0.69, p < .01), whereas there were no relations between stress recognition and other subscales.

# **Test-Retest Reliability**

The coefficient for test-retest reliability was 0.85.

# **Results**

# Sample

A total of 526 questionnaires were completed by PHC providers from five HCs from the main districts in Albania from January to June 2011. There were 523 valid responses. Forty-three percent of participants were from rural settings, and 57% were from urban settings. The overall response rate for the SAQ was 99.4%. Among the participants, there were 174 GPs (33%), 180 nurses (34%), and 169 SPs (33%). Table S1 (available with the online version of this article) shows characteristics of the sample. The mean age of the respondents was 37.88 years (*SD* 12.69).

SPs were substantially older (p < .02; mean age 43.46 years, SD 12.21) compared to nurses (mean age 34.92 years, SD 12.78) and GPs (mean age 35.52 years, SD 11.28). SPs were more experienced (mean years of experience 17.33, SD 13.52) in comparison to GPs (mean years of experience 10.95, SD 11.84) and nurses (mean years of experience 11.681, SD 3.08; p = .001). More respondents were female; there was no correlation between gender and provider type (p = .50).

# **Subscale Responses by Provider Type**

Job satisfaction had the highest proportion of positive responses (70%), followed by safety climate (60%), perceptions of management (60%), working conditions

(56%), and teamwork climate (55%); stress recognition had the lowest proportion of positive responses (30%; Table S2, available with the online version of this article).

Values related to teamwork were slightly low for GPs (M 68.7, SD 17.5) in comparison to nurses (M 69.9, SD 20.0) and SPs (*M* 69.5, *SD* 14.1), but the differences were not substantial (p = .92). The lowest positive responses among GPs were reported for stress recognition (23%, p < .01), working conditions (50%), and perceptions of management (54%). Less than half of the respondents showed positive stress recognition scores (positive scores show the greater affirmation of the impact of stress). The proportion of nurses (45%) with positive stress recognition was almost twice that of SPs and GPs reporting stress recognition. There was a lower positive response for nurses regarding safety climate and teamwork (Table S3, available with the online version of this article). Fiftyfour percent of SPs were in accordance that "the nurses and physicians worked in coordination as a team," which was higher in comparison GPs (36%) and nurses (47%). Forty-three percent of SPs, on the other hand, were in accordance that "it is difficult to discuss errors in this PHC," which was also affirmed by more nurses than GPs (52% vs. 46%).

More than 56% of GPs reported that "the culture present in their unit made it possible to learn from the mistakes of others." This statement was agreed upon by more SPs than GPs, in addition to nurses agreeing on adequate treatment in the PHC. More GPs compared to SPs and nurses agreed on knowing the appropriate channels for directing their constraints regarding patient safety in the PHC (GPs 46%, SPs 39%, nurses 26%).

#### **Attitudes About Stress and Fatigue Recognition**

There were identifiable differences between the positive response of nurses and physicians regarding the question on the stress recognition subscale. Eighteen percent of SPs and 23% of GPs affirmed that their performance was impaired when the workload was excessive, compared to 37% of nurses. Forty-seven percent of nurses and 43% of clinicians agreed that they were prone to make mistakes during tense situations. A smaller proportion of nurses and GPs (25% and 37%, respectively) affirmed that their performance was influenced by fatigue during routine care.

# Job Satisfaction, Working Conditions, and Perception of Management

Among all the professional groups, a high percentage agreed with the item "I like my job." With regards to information flow, there was a statistically substantial

difference between the views of physicians and nurses. For instance, based on the item "I am provided with adequate, timely information about events in the office that might affect my work," 42% of GPs agreed, compared with 58% of nurses and 70% of SPs. For the item "I am routinely provided with the necessary information for diagnostic and therapeutic decisions," 44% of GPs, 59% of nurses, and 65% of SPs agreed (Table S4, available with the online version of this article).

# Comparison With International Benchmarks and U.S. Findings

There is a need to measure the attitudes of healthcare providers on issues regarding patient safety (Sexton et al., 2006). We compared the obtained data with the results (Table S5, available with the online version of this article) based on the seminal work of Sexton and colleagues (2006). There were domains with high mean scores such as working conditions (76.9  $\pm$  21.4) and job satisfaction (76.9  $\pm$  21.4), while the stress recognition domain had a low mean score (46.4  $\pm$  22.7).

#### Discussion

Very little effort has been directed towards understanding medical errors and safety attitudes in primary care in Albania. The study revealed differences among the responses of SPs, GPs, and nurses. There were low agreement scores for SPs and GPs as compared to those of nurses for questions related to working conditions and stress recognition. A high percentage of GPs were noted to deny the negative effects of fatigue, hostile situations, and workload. Results on open communication were controversial. With regards to the flow of information, there was substantial difference between the perception of nurses and physicians, where the GPs felt they were not adequately provided with information. There was a pronounced difference between GPs, SPs, and nurses in the average level of responses to the scales of stress recognition and safety climate.

# **Comparison With Existing Literature**

Physicians and nurses have a major role in ensuring the maintenance of safety culture in health care. Nurses are discouraged from speaking up to doctors by the traditional hierarchy of physicians; hence, they hesitate to confront the physician regarding a patient's issue (Makary et al., 2006; Rosen et al., 2008; Thomas, Sexton, & Helmreich, 2003; van Noord, de Bruijne, & Twisk, 2010; Wiles & Robinson, 1994). However, the study revealed that nurses had an equal or higher score on

average in the SAQ subscales (see Table S2). The results indicated positive responsiveness towards job satisfaction, perception of management, information flow, stress recognition, safety climate, and teamwork by the nurses. The reason is still not clear, which shows the need for future research that would better explain the difference in attitudes across professional groups.

For five of the six safety subscales—working conditions, job satisfaction, perception of management, safety climate, and teamwork climate—Albanian PHC centers scored higher in comparison to the international benchmark (Sexton et al., 2006). It was also noted that the high scores were valued in relation to the international mean values. This is because life-threatening medical errors are not common in PHC institutions—hence the need to prioritize the identification of the perception of patient safety by the healthcare staff. Since medical risks are perceived to be lower in PHC centers, it might lead to the neglect of in these settings. The report bias may contribute to the high mean scores where the respondent supported high rates because he or she felt it was right.

# Safety in Primary Care in Albania

Errors are viewed as difficult to discuss, although nurses did not admit to errors in comparison to GPs and SPs. This shows the need for further research to find out if the nurses are professionally equipped for hostile situations. The nurses of Albanian PHC centers will have diverse roles in the future in order to strengthen care. This shows that nurses are in a capacity to provide services such as prevention and wellness services, diagnosis and management of many common mild acute illnesses, and management of chronic diseases like diabetes (Institute of Medicine, 2010). Issues relating to error should be stressed to indicate the attitude of nurses towards such a topic. There is no solid healthcare information system in Albania. Doctors do not use electronic prescriptions, which shows the need for a program of error record.

# **Implications for Research and Practice**

The scores for stress recognition were low. Tense situations contribute to error. Physicians in middle- and low-income countries work in both the private and public sector (Bir & Eggleston, 2003). The workload is increased by such activities, which in turn generates tenser situations, which in turn influences errors. The most essential requirement in health institutions is a positive safety culture that combats the adverse effects (WHO, 2007). Learning about the errors and redesigning the processes for the prevention of errors is essential for

health staff (Brennan et al., 1991; Institute of Medicine, 2004, Wilson et al., 1995).

There is insufficient data from the developing world in addition to little research exclusively on primary care (WHO, 2008), despite its essentiality as a safety measurement technique (European Commission, 2014; Leonard et al., 2004). Our results in Albania are the foundation of this critical information. Deeper research on middle-and low-income countries is essential for understanding the required safety in primary care, for the provision of quality health services, and for the increasing number of individuals in the world with NCDs.

# **Strengths and Limitations**

The use of a validated questionnaire was a major strength for this cross-sectional survey, as was the 99.4% response rate, which is above the convention for primary care clinicians (Bowling, 2002). Fear of job position harm or persecution discouraged some personnel from participating. There was the feeling from primary care providers that they were auditing rather than conducting research. The SAQ was reliant on self-reported behavior rather than direct observations. The participants have the capacity to act differently compared with their response. Responses can clearly indicate potential harm to patients even without formal monitoring data for errors if they show low awareness of the safety violations. In comparison to other multisite studies of safety culture, our study yielded a better response rate on average in addition to a higher positive attitude score. The information available might be biased. This is among the initial studies in the field of safety culture in PHC. This can be viewed as both a limitation and strength that goes beyond safety in the hospital settings to considering the primary care setting.

# **Conclusions and Recommendations**

Stakeholders should consider education programs, training, promotion of teamwork, open communication, stress recognition, and error self-report for the prevention and reduction of errors and adverse events. There should be implementation of continuous education on patient safety in PHC centers. There should also be a long-term national strategy on patient safety in place, such as the health workforce attitude surveys, which are essential in the control and prevention of adverse events in the care process. There should be the appropriate use of the SAQ in PHC, especially with the lack of established programs in patient safety and a culture of self-reporting errors, where the results should be analyzed appropriately by the directors.

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#### **Clinical Resources**

- Agency for Healthcare Research and Quality. Patient safety indicators: http://www.qualityindicators.ahrq.gov/modules/psi\_resources.aspx
- World Bank. World Bank to help improve quality, ikaccess, and efficiency of Albania's health care system: http://www.worldbank.org/en/news/pressrelease/2015/02/27/world-bank-to-help-improvequality-access-and-efficiency-of-albanias-healthcare-system
- World Health Organization. Europe, patient safety: http://www.euro.who.int/en/health-topics/ Health-systems/patient-safety

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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 \$1.
   Participant Characteristics.
- **Table S2.** Positive Responsiveness by SAQ Subscale and Provider Type.
- **Table S3.** SAQ Subscale Positive Responsiveness by Provider Type for Team Work, Safety Climate, and Stress Recognition by Provider Type.
- **Table S4.** SAQ Subscale Positive Responsiveness by Provider Type for Job Satisfaction, Working Conditions, and Perception of Management.
- **Table S5.** SAQ Subscale Scores: International Benchmark, Albanian PHCs, and US Ambulatory Care Clinics.
- **Table S6.** SAQ Subscale Positive Responsiveness by Provider Type (%-positive min-max).



#### CLINICAL SCHOLARSHIP

# Interpersonal Violence and Health in Female University Students in Spain

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#### Key words

Health, university students, violence, women

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# **Abstract**

**Background:** Most studies address the health impact of violence by an intimate partner; therefore, violence exerted by someone other than a partner in university students and its health effects are less known.

**Purpose:** This study aims to analyze the effect of different forms of interpersonal violence on female university students' health.

**Design:** Women 18 to 25 years of age enrolled at two schools of the University of Valencia in the academic year 2013–2014 (N = 540) were selected, with a participation rate of 82%. Students were grouped as follows: no lifetime violence, violence by an intimate partner (IPV), other personal violence (OPV), and by both (IPV and OPV). Adjusted logistical regression analysis was performed to assess the effects of the different forms of violence on students' health.

**Results:** As many as 92 students (20.6%) experienced violence at least once in their lives: 46 (10.3%) by an intimate partner, 24 (5.4%) by someone other than a partner, and 22 (4.9%) by both. Abused students are more likely to suffer psychological distress and poor health perception, and more regularly used psychoactive drugs than nonabused students, although the use of medication is higher for those abused by a partner and others. Women who experienced only IPV are more likely to suffer psychological distress (adjusted odds ratio [aOR] = 1.78, p < .05, 95% confidence interval [CI; 1.10-2.86]), while those who experienced only OPV are more than twice as likely to perceive their health as poor (aOR = 2.68, p < .05, 95% CI [1.38-5.22]).

**Conclusions:** The high prevalence of violence and its consistent association with a wide range of female university students' health problems suggest that violence seriously compromises women's health.

**Clinical Relevance:** Prevention programs that promote harmonious social relationships among university students should be implemented.

Violence against women is widespread and affects women of all ages, cultures, and economic and education levels (United Nations, 1995); constitutes a violation of human rights; and is a prevalent problem all over the world, with substantial physical and mental health consequences (Krantz, 2002). "Interpersonal violence against women" implies the infliction or threat of enforcement of physical, sexual, psychological, and/or emotional violence, which includes any kind of aggression carried

out by an individual intended to cause damage or apply supremacy and control over women or girls, in the public or private sphere (Kilpatrick, 2004).

The latest estimate of lifetime violence against women worldwide reveals that one out of every three women will experience some kind of physical or sexual abuse inflicted by an intimate partner or sexual violence by a nonpartner during their lives (Abrahams et al., 2014). The World Health Organization Multi-country Study of

women 15 to 24 years of age reported that physical and sexual violence is more prevalent in this age group than in older women, ranking from 19% (Serbia) to 66% (Peru; Stöckl, March, Pallitto, & Garcia-Moreno, 2014). The results of a study carried out by the European Union Agency for Fundamental Rights (FRA) revealed that 33% of the 42,000 women who participated in the research had suffered physical or sexual violence from the age of 15 years (FRA, 2014). Moreover, a previous study with a representative sample of 10,815 women 18 to 70 years of age attending school in primary health care in Spain estimated a prevalence of lifetime violence of 32.7%, where women younger than 30 years showed higher rates of violence by others than by an intimate partner compared with older women (Montero et al., 2011). Violence definition, how violence has been assessed, culture, age distribution of the study population, length of the observation period, and sample approach may explain the variability between studies (Ruiz-Pérez, Plazaola-Castaño, & Vives-Cases, 2007).

The severe adverse effects of aggressions on women's physical and psychological well-being in the short and long term have been indicated with great consistency (Romito, Molzan, & De Marchi, 2005). Common mental disorders such as anxiety and depression, post-traumatic stress disorder, chronic physical problems, and suicide attempts were detected much more frequently in women exposed to physical and sexual violence than in unexposed women (Ellsberg et al., 2008; Ludermir, Schraiber, D'Oliveira, França-Junior, & Jansen, 2008; Pico-Alfonso et al., 2006).

Reports in the literature indicate that the prevalence of intimate partner violence (IPV) and violence exerted by a family member, classmate, acquaintance, or stranger is higher in adolescents and young women (Vézina & Hébert, 2007) than in older women (Scarpa, 2003). Despite the evidence that IPV has an increasingly early onset and its prevalence is higher in dating relationships than in marriage (Jouriles, Garrido, Rosenfield, & McDonald, 2009), most research assesses the negative health consequences of IPV in married women with a mean age of 45 years (Garcia-Moreno et al., 2006).

For almost 40 years, there has been a firm growth in investigations aimed at identifying situations of aggressive behavior among adolescents and young individuals in educational establishments, especially in high school, ranging from 5% to 18% is a prevalence of aggressive behavior in previous studies (Lento, 2006; Saewyc et al., 2009), varying according to the source of sample extraction, the definition of violence, and the method used to assess violence. It was not until early this century that gender violence in the university context was addressed (Eyre, 2000; Gross, Winslett, Roberts, &

Gohm, 2006; Vazquez, Torres, Otero, Blanco, & Lopez, 2010). Although the prevalence of IPV is lower among university students compared to teenagers in high school or younger people in general practice, the adverse effects that violence has on physical and mental health, as well as on attention and performance, is similar between IPV and other personal violence (OPV) in college students (Durant et al., 2007).

In Spain, where university women outnumber men, violence against female university students has received little attention, and the few studies that have addressed the impact of interpersonal violence in younger people were based on samples of subjects from high school or adolescents, which are not representative of university students. This research offers new data on violence against Spanish female university students and its effects on their physical and psychological health. In particular, we intend to (a) estimate the prevalence of violence in different relational settings, (b) compare the sociodemographic profile and health status in those exposed and unexposed to violence, and (c) analyze the effect of different forms of violence in students' health outcomes.

#### Methods

# **Study Design and Sample Methods**

The sample was composed of 540 university students 18 to 25 years of age enrolled in nursing and teacher schools in the academic year 2013-2014. Sample size was calculated for a prevalence rate of at least 20%, according to data from a Spanish study, which addressed violence in Spanish young women and adolescents, with an accuracy of 3.373% and confidence level of 95% (Fernández-Fuertes & Fuertes, 2010). We requested the cooperation of the teaching staff to let us make use of the classroom and in order to agree on the schedule (day and time). The study purpose was explained, written informed consent requested, and confidentiality and anonymity guaranteed. Only 2 of the 540 students invited declined to participate in the study and were replaced by another 2 students of the same age and academic group. After excluding 93 students who decided not to answer the violence questions, the final sample for analysis was composed of 447 students, representing a participation rate of 82% (American Association for Public Opinion Research, 2015). The Ethics Committee of the University of Valencia approved this study.

#### **Survey Instrument and Measures**

Data were collected using a brief self-administered questionnaire composed of 20 items that included

questions on violence, health, and sociodemographic characteristics, and it could be answered in approximately 10 min. In order to assess whether the questions were formulated in a clear and understandable way, if it was drafted with adequate sensitivity to women, and if the time to complete the questionnaire had been suitable, we randomly selected 54 (10%) of the students involved in the study to obtain their opinions on the questionnaire. Most agreed or strongly agreed that the questionnaire was well organized (85%; n = 46/54); the question sequence was clear, consistent, and understandable (70%; n = 38/54); and the time for questionnaire completion was adequate (70%; n = 38/54). Eighty-two percent (n = 45/54) indicated that no questions were worded in a way that was insensitive to women.

# **Description of Variables**

Students were asked if they had experienced physical abuse (hit, slapped, kicked, pushed, etc.), psychological abuse (threatened, insulted, humiliated, harassed, or excessively controlled), or sexual abuse (unwanted or forced sexual experiences), sometimes or many times, in the past or the present. These three questions had shown high comprehensibility and acceptability and good reliability (Cronbach's  $\alpha = 0.82$ ) when used in a previous study (Ruiz-Pérez et al., 2006). The reliability coefficient (Cronbach's  $\alpha$ ) for the present study was 0.73. A list of potential perpetrators was provided: an intimate partner, relative, friend, classmate, neighbor, or stranger. Women were considered to have experienced violence if they reported any act of physical, psychological, or sexual violence. Given that IPV and OPV are not mutually exclusive, women who reported abuse by both a partner and by someone other than a partner were considered to have experienced both forms of violence (IPV and OPV).

#### **Health Outcomes**

After conducting a literature review analyzing the long-term adverse implications of violence, four well-being indicators were highlighted: self-perceived health, mental distress, somatic symptoms, and medication consumption (benzodiazepines, antidepressants, and analgesics).

**Self-perceived health.** This part of the study focused on the subjective aspect of health perception of the SF-36 Spanish version, recommended for samples of less than 500 individuals (Vilagut et al., 2005). This questionnaire is widely used in clinical practice and in general population research studies, and has been applied in Spain for decades. The reliability coefficient

(Cronbach's  $\alpha$ ) for the dimension of overall health in the SF-36 Spanish version was estimated at 0.82 (Alonso, Prieto, & Anto, 1995). Women were requested to report their overall health as "very good," "good," "fair," "poor," or "very poor." Combining the categories of "fair," "poor" and "very poor" to indicate perceived poor health enabled dichotomizing the variable. "Very good" and "good" categories were fitted together likewise. This variable also shows a good reliability coefficient (Cronbach's  $\alpha$ ) of 0.80 for the present study.

**Psychological distress.** Psychological distress was established by applying the General Health Questionnaire (GHQ-12) in its Spanish version (Lobo & Muñoz, 1996), with a reliability coefficient (Cronbach's  $\alpha$ ) of 0.80 (Sánchez-López & Dresch, 2008). The reliability coefficient (Cronbach's  $\alpha$ ) for the present study was 0.74. This questionnaire is used extensively with women and in studies that assess the effect of violence in women's health (Duncan-Jones, 1979). Its scale includes 12 elements with four multiple-choice answers, yielding an overall possible score of 0 to 12. The questionnaire assesses anxiety, depression, and self-esteem suffered during the past month. Psychological distress is considered to be present with scores of at least 3.

**Somatic symptoms.** Somatic symptoms are defined as the following complaints over the past or present year: headaches or migraines; gastrointestinal, renal, or urinary problems; neck, shoulder, or back ache; or gynecological disorders. Participants could choose from three responses to the questions on the presence of somatic symptoms: no somatic symptoms; one or two symptoms; three or more symptoms. Answers were dichotomized with values of 0 (*no symptoms*) and 1 (*one or more symptoms*) for the analysis. Internal consistency was calculated with a reliability coefficient (Cronbach's  $\alpha$ ) of 0.77.

**Use of medication.** The regular use of benzodiazepines/antidepressants or analgesics by women in the past year was assessed. Responses were classified for psychotropics and analgesics as 0 (*nonregular use*) and 1 (*regular use*). This variable also shows a good reliability coefficient (Cronbach's  $\alpha$ ) of 0.70.

#### **Adjusting Variables**

Given that IPV has been associated with sociodemographic factors, such as age and social support, these variables were considered as potential confounders for analysis. Social support was established by asking about the accessibility to active assistance in a certain situation (Blake & McKay, 1986): "How many people can you

**Table 1.** Lifetime Interpersonal Violence Against Female University Students in Spain (N = 540)

	n	%
Nonabused	355	79.4
Abused	92	20.6
Intimate partner violence	46	10.3
Other personal violence	24	5.4
Friend	6	1.4
Classmate	10	2.2
Unknown person	5	1.1
Family member	3	0.7
By both (partner and others)	22	4.9
Partner and classmate	13	2.9
Partner and friend	8	1.8
Partner and unknown person	1	0.2
Students who did not answer the questions on violence	93	17.2

apply to for aid if you are in trouble or if you have difficulties?" Answers were recorded as a dichotomous variable with the values 0 = Yes (one or more to ask for help) and 1 = No (no one to ask for help).

# **Statistical Analysis**

Lifetime violence of different possible aggressors was calculated and the sociodemographic characteristics and health of abused and nonabused women were compared; the chi-square test and independent t-test were used. Given the low incidence of some categories of OPV, three independent forms of lifetime violence were established: (a) violence committed by an intimate partner only (IPV), (b) by other than a partner only (OPV), and (c) by both (IPV and OPV). Adjusted logistic regression models were fitted to assess the effect of the different forms of violence for each health indicator. Results are considered statistically significant at p < .05. The explanatory power of the models was shown by Nagelkerke  $R^2$ . Data were analyzed with the IBM/SPSS version 20.0 statistical package (IBM Corp., Armonk, NY, USA).

# **Findings**

**Table 1** shows the prevalence of lifetime interpersonal violence against female university students. Of the 447 who completed the questionnaire, 92 (20.6%) experienced some form of abuse at least once in their lives: 46 (10.3%) only by a partner and 24 (5.4%) only by someone other than a partner. Although most of the violence was inflicted by people that the women knew (partner, classmate, or friend), in 5 (1.1%) the aggressor was an unknown person. Given that IPV does not exclude the possibility of having been abused by other than a partner, 22 (4.9%) were abused by both (IPV and OPV).

**Table 2.** Sociodemographic and Health Characteristics Among Nonabused and Abused Female University Students (N = 447)

	,	,	
	Nonabused $(n = 355)$	Abused $(n = 92)$	
	n (%)	n (%)	p value
Age (years)			.50
18–21	258 (72.7)	70 (76.1)	
22–25	97 (27.3)	22 (23.9)	
Nationality			.28
Spanish	338 (95.2)	85 (92.4)	
Others	17 (4.8)	7 (7.6)	
Habitual residence			.35
Family home	248 (70.3)	71 (77.2)	
Shared apartment/student residence	105 (29.7)	21 (22.8)	
Number of people at home <sup>a</sup> (mean, <i>SD</i> )	3.6 (1.1)	3.6 (0.9)	.89
Social support			.19
No	7 (2.0)	4 (4.3)	
Yes	347 (98.0)	88 (95.7)	
Health indicators			
Self-related health			.41
Very good/good	276 (78.0)	68 (73.9)	
Fair/poor/ very poor	78 (22.0)	24 (26.1)	
Psychological distress			.016
<3	181 (51.0)	34 (37.0)	
≥3	174 (49.0)	58 (63.0)	
Somatic symptoms			.99
One or two	155 (43.7)	32 (34.8)	
Three or more	176 (49.7)	54 (58.7)	
Medication use			
Benzodiazepines or/and antidepressants	41 (11.6)	22 (23.9)	.003
Analgesics	208 (58.9)	58 (63.0)	.47

at test was used.

Table 2 summarizes the health and sociodemographic characteristics of abused and nonabused colleagues. Most were Spanish and living with their parents, and the vast majority had someone able to support them. Abused students reported more psychological distress and a higher regular use of antidepressants or benzodiazepines than nonabused students. However, no significant differences were found for somatic symptoms and use of analgesics, although the percentages are somewhat lower than in abused students.

The results of the adjusted regressions analysis are shown in **Table 3**. Abused students were almost twice as likely to report poor health (aOR = 1.79, p < .05, 95% confidence interval [CI; 1.13–2.81]) and psychological distress (aOR = 1.37, p < .05, 95% CI [1.03–2.21]), and to use psychoactive drugs (aOR = 1.80, p < .05, 95% CI [1.05–3.09]) than nonabused students. However, the health impact differs according to the aggressor: if

**rable 3.** Lifetime Interpersonal Violence Against Female University Students and Health: Logistic Regression Models<sup>e</sup>

	Poor health $(n = 102)$		Somatic symptoms $(n = 230)$	oms	Psychological distress $(n = 232)$	tress	Use of benzodiazepines or/and antidepressants $(n = 63)$	pines sants	Use of analgesics $(n = 266)$	ics
	aOR (95% CI)	$R^2$	aOR (95% CI)	R <sup>2</sup>	aOR (95% CI)	$R^2$	aOR (95% CI)	$R^2$	aOR (95% CI)	$R^2$
Lifetime violence ( $n = 92$ )	1.79 (1.13–2.81) *	0.46	1.16 (0.79–1.71)	0.13	1.37 (1.03–2.21) *	0.35	1.80 (1.05–3.09) *	0.42	1.45 (0.97–2.15)	0.22
Intimate partner	1.22 (0.71–2.08)	0.28	1.44 (0.90–2.30)	0.18	1.78 (1.10–2.86) *	0.49	2.41 (1.34–4.33) *	0.43	1.24 (0.77–2.01)	0.13
violence ( $n = 46$ ) Other personal violence	2.68 (1.38–5.22) *	0.38	1.33 (0.70–2.51)	0.14	1.79 (0.93–3.44)	0.25	3.12 (1.52–6.41) *	0.39	1.27 (0.66–2.44)	0.29
(n = 24) Both $(n = 22)$	2.49 (1.08–6.34) *	0.47	1.00 (0.42–2.40)	0.12	2.27 (0.89–5.76)	0.19	4.59 (1.75–11.9) *	0.68	0.93 (0.38–2.24)	0.16

Vote. "Never abused" was the reference group. Abuse categories are mutually exclusive. aOR = adjusted odds ratio; CI = confidence interval; R² = Nagelkerke R² Models were adjusted for age, social support, and nationality.  $^*p < .05$  violence was inflicted only by an intimate partner, students were almost twice as likely to report psychological distress (aOR = 1.78, p < .05, 95% CI [1.10–2.86]), whereas if perpetrated by other than a partner, students were more likely to perceive their health as poor (aOR = 2.68, p < .05, 95% CI [1.38–5.22]) than nonabused students. Any kind of abuse increases regular use of psychotropic drugs. However, women who have experienced violence by a partner or former partner and by others show the highest odds for use of psychotropic drugs (aOR = 4.59, p < .05; 95% CI [1.75 11.9]).

#### **Discussion**

More than one in five female university students in Spain has experienced some form of violence at least once in their lives. This finding confirms that university students have fewer incidents of violence (20.6%) compared with the 27.6% estimated in Spanish women 18 to 25 years of age attending primary care services (Martín-Baena et al., 2015). The circumstance that current or previous partner events and most of the nonpartner assaults involved individuals known by the women supports other studies that showed interpersonal violence ranging from 20% to 60% (Montero et al., 2011; Moracco, Runyan, Bowling, & Earp, 2007; Romito et al., 2005). Definition of violence, how violence has been assessed, sample extraction method, and age may explain this variability between studies. In addition, most studies addressing violence in college students focused only on IPV (Durant et al., 2007); others included only incidents of violence exerted by a nonintimate partner such as a family member, classmate, acquaintance, or stranger (Scarpa, 2003); and still others included both male and female students (González-Sala & Mora-Valero, 2014). Therefore, direct comparison is rather inconsistent.

Our results in relation to the prevalence of IPV are higher than that of OPV, verifying prior research results of the accelerated premature beginning of IPV in students (Lento, 2006). The most common abuse inflicted by individuals other than partners was committed by a classmate only or in combination with IPV. This finding must alert Spanish university authorities to develop urgent measures to eradicate violence against female students in the university community and implement strategies that encourage women to report any situation of abuse and ensure that such reports are appropriately addressed.

Despite the health data collected corresponding to the study period, violence may have occurred sometime before. After a period of abuse, abused women reported significantly poorer health than nonabused women. The wide range of adverse effects reported differs according to the relationship that women had with the aggressors. The association between violence and psychological distress seems to be stronger when the aggressor is a partner than when the aggressor is a nonpartner. As IPV has an early onset and experiences of psychological and physical aggression in adolescent romantic relationships are linked to psychological distress (Jouriles et al., 2009), these women could be exposed for longer and suffer more psychological distress than other abused students.

Previous analyses exposed that the degree of the connection between IPV and unfavorable health rises as the amount of violence typologies grows (Gomez, 2011; Vézina et al., 2015), but few addressed the impact on well-being when very diverse kinds of agents perpetrated abuse. Our study shows that women experiencing violence by more than one kind of perpetrator undertake more mental distress and tend to use more antidepressants or benzodiazepines than those who suffered violence by only one kind of perpetrator. Given that experienced violence from multiple interpersonal settings have cumulative and differential health effects (Margolin, Vickerman, Oliver, & Gordis, 2010), the negative health consequences could be more pronounced in women who have experienced accumulated abuse by different types of perpetrators than in women who have experienced IPV only.

The high number of nonabused students reporting psychological stress (49.0%) and use of psychotropic drugs (11.6%) is striking. It is noteworthy that both abused (63%) and not abused (58%) women reported regular use of analgesics. The fact that early adulthood is a period of rapid physical, psychological, and cognitive changes, as well as stress and experimentation, which can involve an overwhelming psychological burden (Catallozzi, Simon, Davidson, Breitbart, & Rickert, 2011), may partially explain the poor physical and mental health status and regular use of drugs reported by nonabused students. Although the literature shows that psychological violence is the most prevalent type of violence against women (Thompson et al., 2006), the vast majority of studies have focused on severe physical and sexual assaults, as they are more visible than other types of violence. Given that psychological violence is a strong predictor of physical aggression (Lawrence, Yoon, Langer, & Ro, 2009) and violence tends to escalate, educational programs should be implemented to help female and male students to identify every act of violence, including controlling behaviors. Despite the deep process of gender role transformation in Spanish society in recent decades, young women still have serious difficulties detecting situations of violence in their dating relationships, especially harassment and excessive control over them (Rodríguez-Franco et al., 2012). The fact that 59 women were killed

by their intimate partners (three of them [5.8%] younger than 30 years and one 15 to 20 years old) is extremely worrying (Ministry of Health, Social Services and Equity, 2015).

#### Limitations

This study has a number of limitations that need to be taken into account for a critical evaluation of its results. The cross-sectional nature of the data means that the relationship between violence and health outcomes should not be taken as a cause-effect relationship. However, the strong association found between violence and health supports the hypothesis that violence is the cause and not the effect. The exclusion of the 93 students who did not answer the violence questions may reduce the power of the results. The fact that the questionnaire was not formally validated may also have affected its validity. Our inability to establish the different types of violence (physical, sexual, and psychological) experienced in each relationship setting requires cautious interpretation and should be considered in further studies. Furthermore, this study is not representative of all Spanish female university students, since it is based on a convenience approach where the profile of nursing and teaching students may be different from the profile of students of other university degrees.

## **Conclusions**

Notwithstanding these limitations, our research shows that the rates of violence against Spanish female university students remain high and confirms that all forms of violence seriously compromise university students' health. As most of the acts of violence involved people close to women, preventive programs should be tailored for every social context where young women and men interact which each other. Early adulthood is a period in which healthy and stable relationships are established. Therefore, ensuring that young women enjoy healthy and violence-free relationships is an investment for the future.

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# **Clinical Resources**

- European Union Agency for Fundamental Rights (FRA): http://fra.europa.eu/en
- Ministry of Health, Social Services and Equality: http://www.msssi.gob.es/
- United Nations: http://www.un.org/

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#### **CLINICAL SCHOLARSHIP**

# Differences in Symptom Distress Based on Gender and Palliative Care Designation Among Hospitalized Patients

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#### Key words

Patient-reported symptom distress, nursing documentation, palliative care designation

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#### **Abstract**

**Purpose:** To explore patient-reported symptom distress in relation to documentation of symptoms and palliative care designation in hospital inpatients.

**Design:** This cross-sectional study analyzed data from 710 inpatients at two large hospitals in Sweden using the Edmonton Symptom Assessment Scale and the Memorial Symptom Assessment Scale. Chart reviews focused on nurses' and physicians' symptom documentation and palliative turning point.

**Methods:** Descriptive statistics were calculated for all variables and provided summaries about the sample. Patients were grouped according to gender, age, palliative care designation, and symptom documentation. The *t* test and chisquare test were used to calculate whether symptom distress varied between groups. A two-way analysis of variance was conducted for multiple comparisons to explore the impact of gender and age on mean symptom distress.

**Findings:** Females reported higher levels of symptom distress than did males related to pain, fatigue, and nausea. When comparing symptom distress between males and females with documentation pertaining to symptoms, there were significant differences implying that females had to report higher levels of symptom distress than males in order to have their symptoms documented. **Conclusions:** Females need to report higher levels of symptom distress than do males for healthcare professionals to identify and document their symptoms. It can be hypothesized that females are not receiving the same attention and symptom alleviation as men. If so, this highlights a serious inequality in care that requires further exploration.

**Clinical Relevance:** Considering that common reasons why people seek health care are troublesome symptoms of illness, and that the clinical and demographic characteristics of inpatients are changing towards more advanced ages with serious illnesses, inadequate symptom assessment and management are a serious threat to the care quality.

The most common reasons why people seek health care are troublesome symptoms of illness (Kris & Dodd, 2004; Tranmer et al., 2003; Wadensten, Fröjd, Swenne, Gordh, & Gunningberg, 2011). The majority of those admitted

to hospital are 65 years of age or older, and about half have two or more chronic conditions (The National Board of Health and Welfare, 2015; World Health Organization [WHO], 2011). Those diagnosed with multiple chronic

conditions usually experience multiple symptoms concurrently (Dodd et al., 2001; Lenz, Pugh, Milligan, Gift, & Suppe, 1997), resulting in intermittent exacerbations and subsequent hospital admissions. In Sweden there has been a shift in healthcare delivery from acute hospital units into the homes of the patients through the development of advanced home healthcare services. The amount of healthcare services used by those 65 years of age or older is thus largely not driven by their age but rather by the sum of their chronic conditions (Christensen, Doblhammer, Rau, & Vaupel, 2009; Tseng, 2011). As a consequence of this development, the majority of patients admitted to hospitals are 65 years of age or older suffering from life-threatening and serious illness.

According to the literature, women consistently report more symptoms than men (O'Neill & Morrow, 2001). The differences are seen in all age groups regardless of the inquired time period, response format, or whether symptoms are assessed retrospectively or prospectively (Barsky, Peekna, & Borus, 2001). Generally, symptoms are experienced as multidimensional, including aspects such as symptom intensity and symptom distress (Fu, McDaniel, & Rhodes, 2007; Rhodes, McDaniel, Homan, Johnson, & Madsen, 2000). In addition to reporting more symptoms, studies also show that women report higher levels of symptom distress compared to men, and that patients tend to evaluate intensity and distress at dissimilar levels (Sarenmalm, Browall, & Gaston-Johansson, 2014). While symptom intensity pertains to degree of discomfort, distress relates to the degree of suffering experiences as a consequence of the symptom (Rhodes & Watson, 1987, November).

There is a large body of literature focusing on different aspects of symptom experiences in selected groups of patients. For example, patients with inoperable lung cancer during the first year postdiagnosis experience on average 13 distressful symptoms (Spichiger et al., 2011; Tishelman, Lövgren, Broberger, Hamberg, & Sprangers, 2010), with fatigue, pain, weakness, and appetite loss being the most frequent (Teunissen et al., 2007). In patients with heart failure, shortness of breath and fatigue are the most frequently self-reported symptoms (Falk, Patel, Swedberg, & Ekman, 2009).

As the clinical and demographic characteristics of admitted inpatients are changing towards more advanced ages with serious and life-threatening illnesses, adequate symptom assessment and management are significant aspects of patient care (O'Donovan, Painter, Lowe, Robinson, & Broadbent, 2015). Providing high-quality care at the end of life in hospital settings is reported to be a great challenge, although this is the most common place of death (Cohen et al., 2008; Jayaraman & Joseph, 2013; Murray, Wilson, Kryworuchko, Stacey,

& O'Connor, 2009). In Sweden, almost every second person dies at a hospital (Håkanson, Öhlén, Morin, & Cohen, 2015), where they mostly do not receive care designed to address their palliative care needs (Jakobsson, Gaston-Johansson, Öhlén, & Bergh, 2008). One reason to explain this might be the lack of identification of dying and, consequently, reorientation of care in daily clinical healthcare practices. The nonexistence of such palliative care designation, or its delay until very close to death, may lead to unnecessary symptom distress at the end of life due to invasive and unsuccessful treatments rather than comfort-based palliative care (Jakobsson, Bergh, Gaston-Johansson, Stolt, & Öhlén, 2006). When patients enter the palliative phase, the focus of care should be on symptom assessment and management as well as other forms of distress such as psychosocial stress and existential anxiety (Bailey et al., 2005). As such, studying patients' self-reported symptom distress in relation to documentation of patient care, including symptom assessment, management, and palliative care designation, might serve as a useful quality indicator. Retrospective chart reviews in cancer patients showed a positive association between higher patient-reported symptom scores and higher rates of clinical actions taken by healthcare staff (Basch & Abernethy, 2011; Seow, Sussman, Martelli-Reid, Pond, & Bainbridge, 2012).

Although symptom experiences in specific patient populations such as cancer or heart failure patients are well documented, no studies have been found that target selfreported symptom distress in relation to documentation of symptoms and palliative care designation in mixed and unselected groups of hospital inpatients. Thus, the focus of this study is to explore symptom distress as a quality indicator for care without regard to specific medical diagnoses, but rather gender and palliative care designation. We have previously reported that these patients describe extensive suffering due to illness and existential concern for the future (Fridh et al., 2014). We have also previously reported that a latent class analysis of patients' reported symptom distress revealed three distinct classes that were not differentiated by diagnoses but diverge in terms of level of distress and number of symptoms (Henoch, Sawatzky, et al., 2014). The purpose of this study was to explore patient-reported symptom distress in relation to gender, palliative care designation, and documentation of symptoms in patient records in hospital inpatients in Sweden.

## Methods

#### **Design and Procedure**

For this exploratory secondary analysis, we used crosssectional data from surveys at two hospitals in Sweden performed identically, each during the course of a single day. Data were collected by nursing students who were at the end of their third year of an undergraduate nursing program at the University of Gothenburg, Sweden. The students attended seminars and workshops on campus to receive training in the data collection techniques used in this study prior to the data collection days. On the data collection days, the research team was present at the hospitals to provide support to the students if needed. A pilot study was conducted 2 months preceding the data collection days in order to test the feasibility of the study design and refine the logistics surrounding the study. A more detailed description of the study procedure has been described previously (Henoch, Ung, et al., 2014). All participating patients gave their informed consent, and the Regional Ethics Committee at the University of Gothenburg approved the study.

#### Sample

The sample included patients on medical, surgical, oncological, orthopedic, and geriatric hospital wards at two hospitals—one university hospital (2,300 beds) with highly specialized care, and one county hospital (800 beds). In total, around 80 units were identified as sites for patient recruitment. Intensive care, psychiatric, pediatric, and obstetric wards were excluded from this study, as it was expected that for ethical or communicative reasons these units did not care for patients who would be able or eligible to participate in the study. On the data collection days, 1,874 patients had been admitted at the selected hospital wards. Of these, 1,141 patients met the inclusion criteria set for this study (i.e., ≥18 years of age, speak and understand Swedish, show no signs of dementia or cognitive impairment, and deemed able to participate in a short interview by a staff nurse) and were approached for participation in the study. Of 1,141 patients, 431 declined to participate in the study, leaving an effective sample of 710 patients (response rate 62%). The gender distribution was comparable between the sample (46.8% male) and the nonparticipating group (46.1% male). However, nonparticipants were older compared to participants (mean age 69 years vs. 67 years; p = .02) and had a significantly higher 1-year mortality rate compared to participants (29.3% vs. 18.5%; p < .001).

#### **Measures and Chart Review**

Patient demographic data included age, gender, marital status, living arrangements (i.e., living alone, in ordinary housing, or in residential care), highest level of education, employment status, and immigrant status. Cause of admission (i.e., planned, referred, symptoms,

accident, or other), length of stay, and main diagnosis according to the International Classification of Diseases, Tenth Revision (ICD-10; WHO, 2010) was obtained from medical records. Patients' dates of death were obtained from the Swedish Population Register (The National Board of Health and Welfare, www.socialstyrelsen.se/english). This is a complete national register of mortality data and includes the date and cause of death for all Swedish citizens both in Sweden and abroad.

A Swedish translation of the Edmonton Symptom Assessment Scale (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1994), which has previously been used in Sweden (Astradsson, Granath, Heedman, & Starkhammar, 2001), was used to assess the following symptoms: pain, dyspnea, fatigue, sleeping difficulties, appetite loss, mood disorder, and anxiety. The instrument was administered in a structured interview format. The patients were asked three questions in relation to each symptom where the first acted as a gateway question (i.e., symptom being either present or absent). When a symptom was present, patients completed the two additional questions in accordance with the Memorial Symptom Assessment Scale (Browall, Sarenmalm, Nasic, Wengström, & Gaston-Johansson, 2013; Portenoy et al, 1994). The first additional question measured symptom intensity, and the second additional question measured symptom distress on an 11-point numeric rating scale ranging from 0 (no intensity/distress) to 10 (worst possible intensity/distress). For the aim of this study we analyzed the results from the distress scale. If the patient indicated not having a symptom, then the corresponding distress score was set to zero.

Patient records were reviewed retrospectively according to a predefined protocol by two researchers to ensure inter-rater agreement. All entries describing assessment and management of symptoms one day prior to the data collection day to one day following the data collection day were included in the review. In this study, palliative care designation was defined as a record entry that described the reorientation of care from curative, life-extending treatment and rehabilitation to palliation (Jakobsson et al., 2006). All entries describing palliative care designation 1 week prior to the data collection day to 1 week following the data collection day were included in the review.

#### **Analysis Procedure**

Descriptive statistics were calculated for all variables and provided summaries about the sample. Patients were grouped according to gender, age, palliative care designation, and symptom documentation. The *t* test and chi-square test were used to calculate whether symptom distress varied between groups. A two-way analysis of

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Table 1. Demographic and Clinical Characteristics of the Sample Divided by Gender

	Male $(n = 332)$	Female ( $n = 378$ )	Significance (two-tailed)
Age group >65 years (%)	198 (59.6)	240 (63.5)	ns
Age, mean years (SD)	65.9 (16.6)	68.0 (17.7)	ns
Living alone, n (%)	123 (37.0)	212 (56.1)	p < .001
Ordinary housing, n (%)	294 (88.6)	340 (89.9)	p < .05
Tertiary education, n (%)	80 (24.1)	91 (24.1)	ns
Full-time employment, n (%)	84 (25.3)	59 (15.6)	p < .05
Retired, n (%)	202 (60.8)	255 (67.5)	p < .05
Admitted at a medical unit, n (%)	153 (46.1)	150 (39.7)	ns
Admitted at a surgical unit, n (%)	107 (32.2)	103 (27.2)	ns
Hospitalization, mean days (SD)	12.6 (15.7)	12.7 (17.4)	ns
Deceased <1 year after hospitalization, n (%)	66 (19.9)	60 (15.9)	ns

Note. ns = not significant.

Table 2. Mean Symptom Distress Divided by Gender

Symptom, mean (SD)	Male $(n = 332)$	Female ( $n = 378$ )	Significance (two-tailed)
Pain	3.48 (3.56)	4.26 (3.66)	p < .05
Dyspnea	1.73 (2.97)	1.64 (2.88)	ns
Fatigue	3.42 (3.35)	4.30 (3.40)	p < .001
Sleep disorder	2.71 (3.37)	2.92 (3.51)	ns
Nausea	1.02 (2.28)	1.79 (3.03)	p < .001
Mood disorder	2.20 (3.17)	2.66 (3.33)	ns
Anxiety	2.20 (3.16)	2.44 (3.27)	ns

Note. ns = not significant.

variance was conducted for multiple comparisons to explore the impact of gender and age on mean symptom distress. A probability value of <.05 (two-tailed) was considered statistically significant.

### **Results**

Demographic and clinical characteristics of the sample are presented in Table 1. The most prevalent reason for hospital admission was symptoms of illness (49%). Tumor diseases were more prevalent in women (19.8% vs. 14.2%; p < .05), whereas cardiovascular diseases were more prevalent in men (30.1% vs. 21.2%; p < .05). The relationship between symptom intensity and distress was investigated using Pearson correlation, showing a significant correlation coefficient for all symptoms in both males and females (pain 0.91, dyspnea 0.95, fatigue 0.80, sleeping difficulties 0.94, appetite loss 0.96, mood disorder 0.96, and anxiety 0.97). A two-way analysis of variance between groups was conducted to explore the impact of gender and age on mean symptom distress. Participants were divided into three groups according to their age (group 1: ≤65 years; group 2: 66–80 years; and group  $3: \ge 81$  years). The interaction effect between gender and age was not statistically significant. There was a statistically significant main effect for gender in symptom distress related to pain, F(1,704) = 9.01, p = .003;

small effect size (partial eta squared = 0.01), fatigue, F(1,704) = 11.25, p = .001; small effect size (partial eta squared = 0.02), and mood disorder, F(1,704) = 3.22, p = .001; small effect size (partial eta squared = 0.02). There was also a statistically significant main effect for age in symptom distress related to anxiety, F(2,704) =7.92, p = .001; small effect size (partial eta squared = 0.02). The analysis showed that, when controlling for age, there was still a significant difference between males and females in symptom distress related to pain, fatigue, and mood disorder (**Table 2**). The analysis also showed that when controlling for gender, those ≤65 years of age reported higher symptom distress related to anxiety than did those older than 66 years ( $\leq$ 65 years M = 2.02, SD 3.44; 66–80 years M = 2.02, SD 3.10; and ≥81 years M = 1.81, SD 2.92).

In the total sample of 710 patients, according to the Memorial Symptom Assessment Scale and Edmonton Symptom Assessment Scale, 463 patients reported pain, out of which 58.5% had documentation in their medical charts pertaining to the symptom; 541 patients reported fatigue, out of which 19.4% had documentation; 207 patients reported nausea, out of which 34.8% had documentation; and 332 patients reported mood disorder, out of which 7.8% had documentation. When comparing mean symptom distress between males and females with documentation pertaining to the symptom,

Table 3. Mean Symptom Distress Among Patients With Documentation Pertaining to Symptoms Divided by Gender

Symptom, mean (SD)	Male $(n = 158)$	Female ( $n = 180$ )	Significance (two-tailed)
Pain	4.56 (3.56)	5.33 (3.41)	p < .05
Fatigue	4.53 (3.54)	6.08 (3.19)	p < .05
Nausea	2.46 (2.86)	4.49 (3.76)	p < .05
Mood disorder	3.38 (4.17)	6.67 (3.25)	p < .05

Table 4. Mean Symptom Distress Divided by Documented Palliative Care Designation

	Palliative care designation		
Symptom, mean (SD)	Yes $(n = 96)$	No (n = 614)	Significance (two-tailed)
Pain	3.59 (3.63)	3.94 (3.64)	ns
Dyspnea	2.27 (3.28)	1.59 (2.85)	p < .05
Fatigue	4.47 (3.38)	3.80 (3.40)	ns
Sleep disorder	2.11 (3.14)	2.93 (3.48)	p < .05
Nausea	1.69 (2.93)	1.39 (2.70)	ns
Mood disorder	3.11 (3.49)	2.34 (3.22)	p < .05
Anxiety	2.81 (3.59)	2.25 (3.15)	ns

Note. ns = not significant.

there were significant differences related to pain, fatigue, nausea, and mood disorder, indicating that females had to report higher levels of symptom distress than did males in order to have their symptoms documented (**Table 3**).

When comparing mean symptom distress between males and females with a documented palliative care designation, there were no significant differences. However, there were differences between those with palliative care designation and those without. Patients with a documented palliative care designation reported higher levels of symptom distress related to dyspnea and mood disorder, while patients without a documented palliative care designation reported higher symptom distress related to sleep disorder (**Table 4**).

There was no difference between males and females in 1-year mortality. When comparing mean symptom distress between males and females in relation to 1-year mortality, there was only one significant difference among those deceased, with females reporting higher symptom distress in fatigue (3.77 in males vs. 4.95 in females; p=.05). However, among those still alive 1 year after the data collection day there were significant differences in symptom distress, with females reporting higher symptom distress in pain (3.53 in males vs. 4.43 in females; p<.001), fatigue (3.33 in males vs. 4.17 in females; p<.001), nausea (1.05 in males vs. 1.71 in females; p<.001), and depressed mood (2.08 in males vs. 2.71 in females; p<.05).

#### **Discussion**

This study aimed to explore patient-reported symptom distress in relation documentation of symptoms and a

reorientation towards palliative care in a mixed and unselected sample of hospital inpatients. Our findings show large gender differences, with females consistently reporting higher symptom distress than males, which is in line with previous findings (Barsky et al., 2001; O'Neill & Morrow, 2001). Several reasons for these gender differences have been presented in the literature. For example, gender socialization may influence the willingness to disclose and communicate symptom distress (Baron-Epel et al., 2005). On the other hand, our results can also be compared to those of Ravn-Fischer and colleagues (2012), who showed that in patients hospitalized due to chest pain, female sex was associated with an extended delay time until admission to a hospital ward, to administration of heart disease drugs, cardiac catheterization, and coronary angiography, indicating that men are given priority over women. But there are also studies showing that women have a higher probability of receiving treatment with palliative chemotherapy near the end-of-life compared to men (Randén, Helde-Frankling, Runesdotter, & Strang, 2013).

Our findings should also be seen in light of previous findings on symptom distress profiles in this sample (Henoch, Sawatzky, et al., 2014). In that study, latent class analysis identified three classes with different symptom profiles that varied in terms of number of symptoms and degree of distress. Compared to the other two classes, the third class included patients reporting the highest level of symptom distress, and were more likely to be female, to live alone or in residential care, and to be diagnosed with diseases from the musculoskeletal system.

This is in concordance with the gender differences seen in this study.

Quite surprisingly, about half of the total sample reported suffering from symptoms that were not found in their patient records. For example, the symptom of fatigue was reported by 76% of the total sample, of which 19% had documentation pertaining to fatigue. There might be several reasons for this low level of symptom documentation in relation to high level of patient reports. Fatigue accompanies most chronic illness and is common in life-threatening conditions. As a symptom, fatigue is difficult to recognize due to its indistinctness, with little or no chance for symptom alleviation (Falk, Granger, Swedberg, & Ekman, 2007).

Among those patients with documentation pertaining to symptoms, females had to report higher levels of symptom distress than males in order to have their symptoms recognized and documented by the healthcare staff as health problems that needed management. These findings indicate that gender differences possibly constitute larger problems in mixed and unselected groups of hospital patients than we anticipated. Considering the saying "not documented, not done" in relation to our findings, it can be hypothesized that females are not receiving the same symptom attention and symptom alleviation as males. If so, this highlights a serious inequality in care that requires further exploration.

When comparing mean symptom distress between males and females with a documented palliative care designation, there were no statistically significant differences. However, there were differences in symptom distress between patients with a documented palliative care designation and those without. Patients with a reorientation towards palliative care reported higher levels of symptom distress related to dyspnea and mood disorder. Although severity of illness and proximity to death might explain some of these differences, it is quite surprising that these patients reported higher symptom distress since symptom relief is considered paramount in palliative care (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002).

Our findings indicate that those ≤65 years of age reported higher symptom distress related to anxiety than did those 66 to 80 years of age and ≥81 years of age. Lindskog, Tavelin, and Lundström (2015) showed that systematic assessment of pain was more often done in younger patients. There might be several reasons for why younger patients appraise and assess their symptoms as more distressful than older patients. Age-related changes in coping suggest that different age groups may act similarly in response to severe and serious symptoms and differently in response to mild and chronic symptoms, since older patients attribute them to aging rather than to illness.

There are limitations in this study that need to be addressed. Students in their third year of an undergraduate nursing program collected the data, and it could be argued that they are not skilled data collectors, which might have influenced the data quality. In order to reach sufficient inter-rater reliability, students were trained in how to use the measures by the research team prior to the data collection. The research team was present at the hospitals and available for the students if support was needed during data collection. Other cross-sectional studies involving large samples have involved students in data collection with successful results (Westergren, Lindholm, Axelsson, & Ulander, 2008; Westergren et al., 2009). When comparing subgroups, there is always a risk of finding significant differences that do not exist (i.e., type I error). To minimize this risk, we performed the overall stratified test and, when significant, followed up with stratum-specific level

A significantly larger proportion of the nonparticipating patients was older and died within a year from the data collection day (Henoch, Sawatzky, et al., 2014). This indicates that the nonparticipating patients were more severely diseased than the participants. Presumably, if the nonparticipators were included in the study, levels of symptom distress would be even higher. The information gained from this study should increase awareness among healthcare professionals about symptom assessment and documentation and may help them to target patients for particular symptom-alleviating interventions. Our results indicate that there is a large discrepancy between how patients self-report when asked about their symptom distress and what the nurses and physicians identify as symptoms calling for action in terms of assessment and alleviation. If physicians and nurses do not observe patients' experienced symptoms, and if care differs because of gender, action must be taken to tackle these discrepancies. However, the fact that this issue arose in two hospitals and several clinics in our study demonstrates the necessity of processing the problem at an organizational level. Further research is needed about symptom experience and management in unselected patient populations to improve the awareness of inequality in symptom management.

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#### **Clinical Resources**

- EBSCO Nursing Resources: http://www.ebscohost. com/nursing
- The National Palliative Care Research Center: http://www.npcrc.ord
- The Swedish Society of Nursing: http://www.swenurse.se

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#### CLINICAL SCHOLARSHIP

# **Nurses' Use of Race in Clinical Decision Making**

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#### Key words

RACE (Racial Attributes in Clinical Evaluation) Measure, clinical use of race, clinical decision making, nurses

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#### **Abstract**

**Purpose:** To examine nurses' self-reported use of race in clinical evaluation. **Design:** This cross-sectional study analyzed data collected from three separate studies using the Genetics and Genomics in Nursing Practice Survey, which includes items about use of race and genomic information in nursing practice. The Racial Attributes in Clinical Evaluation (RACE) scale was used to measure explicit clinical use of race among nurses from across the United States.

**Methods:** Multivariate regression analysis was used to examine associations between RACE score and individual-level characteristics and beliefs in 5,733 registered nurses.

**Findings:** Analysis revealed significant relationships between RACE score and nurses' race and ethnicity, educational level, and views on the clinical importance of patient demographic characteristics. Asian nurses reported RACE scores 1.41 points higher than White nurses (p < .001), and Black nurses reported RACE scores 0.55 points higher than White nurses (p < .05). Compared to diploma-level nurses, the baccalaureate-level nurses reported 0.69 points higher RACE scores (p < .05), master's-level nurses reported 1.63 points higher RACE scores (p < .001), and doctorate-level nurses reported 1.77 points higher RACE scores (p < .001). In terms of clinical importance of patient characteristics, patient race and ethnicity corresponded to a 0.54-point increase in RACE score (p < .001), patient genes to a 0.21-point increase in RACE score (p < .001), and patient age to a 0.19-point increase in RACE score (p < .001).

**Conclusions:** Higher reported use of race among minority nurses may be due, in part, to differential levels of racial self-awareness. A relatively linear positive relationship between level of nursing degree nursing education and use of race suggests that a stronger foundation of knowledge about genetic ancestry, population genetics and the concept "race" and genetic ancestry may increase in clinical decision making could allow nurses to more appropriately use of race in clinical care. Integrating patient demographic characteristics into clinical decisions is an important component of nursing practice.

**Clinical Relevance:** Registered nurses provide care for diverse racial and ethnic patient populations and stand on the front line of clinical care, making them essential for reducing racial and ethnic disparities in healthcare delivery. Exploring registered nurses' individual-level characteristics and clinical use of

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race may provide a more comprehensive understanding of specific training needs and inform nursing education and practice.

More than 4 million healthcare professionals in the United States are nurses, making them the front line of health provision (National Council of State Boards of Nursing, 2016). Driven by the Patient Protection and Affordable Care Act of 2010, the discipline of nursing has entered a new era of clinical practice. The profession has been called upon to increase the number of baccalaureate-prepared and doctorate-prepared nurses, appropriately inform and educate the next generation of nurses, and aid in closing the health disparities gap (Fairman, Rowe, Hassmiller, & Shalala, 2011; Hassmiller, 2010; Institute of Medicine, 2010; Levin & Bateman, 2012). The growing utilization of nurses as primary care providers highlights their important role in bringing a precision medicine approach to health care (Calzone, Jenkins, Nicol, et al., 2013; Cheek, Bashore, & Brazeau, 2015).

Although precision medicine may allow a more accurate approach to patient care that moves beyond race, the complicated relationship between race and genetic ancestry continues to stir an ongoing debate around the clinical utility of race (Dankwa-Mullan, Bull, & Sy, 2015). Race is a fluid concept used to group people according to various factors, including ancestral background and social identity (Smedley & Smedley, 2012). Because race is a crude proxy for certain underlying genetic risk, it remains a commonly used indicator in disease prevention, screening, and treatment strategies.

# Differential Health Treatment and Outcomes by Race and Ethnicity

Persistent health disparities are apparent in the variation of disease incidence and mortality across racial and ethnic populations (Badve et al., 2011; Kaiser Family Foundation, 2015; U.S. Cancer Statistics Working Group, 2016). For example, complex diseases such as cardiovascular disease, type 2 diabetes, and prostate and colorectal cancer have disproportionally affected certain racial and ethnic minority populations (Centers for Disease Control and Prevention-National Center for Health Statistics, 2015). A debate has risen around whether race-based screening guidelines are needed to address these disparities and to what extent race has clinical utility, particularly as a proxy for genetic ancestry.

One facet of the debate involves common practice and healthcare guidelines that specifically include the use of race as a proxy for ancestry, genetic risk, and response in diagnostic and treatment decisions. For example, a recently approved test for the Lp-PLA2 biological marker to predict risk for coronary heart disease is reported by the U.S. Food and Drug Administration (2014) to predict risk better in Black women. Additionally, there is a long history of using race in clinical decisions about the most effective type of drugs to administer (Ramamoorthy, Pacanowski, Bull, & Zhang, 2015). Given the current treatment guidelines and ongoing contention around the role of race in clinical practice, scientific discoveries that are beginning to illuminate the contributions of genomic variation and environmental factors to health outcomes for persons with complex chronic diseases hold the promise of guiding development of effective health interventions.

#### **Nurses' Clinical Use of Race**

As research continues to clarify the contribution of social and genetic factors to racial and ethnic differences in health, disease, intervention choices, and outcomes, it is necessary to understand how healthcare providers use (i.e., collect, perceive, and interpret) race in public health practice and clinical care. Research indicates that individual background characteristics, personal beliefs, and biases influence the clinical encounter, often to the disadvantage of minority patients (Lawrence, Rasinski, Yoon, & Curlin, 2014; McKinlay, Piccolo, & Marceau, 2013; Sabin, Nosek, Greenwald, & Rivara, 2009). Research also indicates that patients receive differential treatment by race and may respond differently to treatment based on genomic profile differences (Keenan et al., 2015; Wandner et al., 2014).

There remains a dearth of literature focusing on nurses in the context of race, interpretation of genetic risk and response, and healthcare. A few studies have explored nurses' understanding and use of genomics (Calzone, Jenkins, Culp, Bonham, & Badzek, 2013; Coleman et al., 2014), while others have focused on race and revealed low levels of cultural competency with little awareness of personal biases in nurses (Haider et al., 2015; Hirsh, Jensen, & Robinson, 2010). However, huge knowledge gaps remain about nurses' behaviors and beliefs concerning race in clinical care. Given the importance of nursing practice and increased responsibilities of nurses in healthcare provision, our primary aim is to better understand nurses' clinical use of race, which can affect clinical outcomes. Specifically, although patient race

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along with other information can help guide diagnostic and treatment decisions in certain circumstances, it can also be used inappropriately, which could adversely influence patient care (Nelson, 2002).

#### **Methods**

#### **Eligibility**

Study eligibility consisted of registered nurses (RNs) at all levels of academic preparation, role, or specialty employed at participating institutions. Licensed practical nurses and licensed vocational nurses were excluded. This was the only exclusion criterion for study participation.

#### **Study Sample**

The study sample includes 5,733 RNs across three separately recruited groups. The largest group is composed of nurses employed by Magnet®-designated hospitals participating in the Method to Integrate a New Competency (MINC) study (Calzone, Jenkins, Culp, Caskey, & Badzek, 2014). MINC included nurses from 23 American Nurses Credentialing Center-designated Magnet Recognition Program® hospitals located in 17 U.S. states. The second group was recruited by member associations of the National Coalition of Ethnic Minority Nurse Associations (NCEMNA), a national collaboration of five ethnic minority nurse associations. Four NCEMNA associations participated in this study: Asian American/Pacific Islander Nurses Association, National Association of Hispanic Nurses, National Black Nurses Association, and Philippine Nurses Association of America (Coleman et al., 2014). The third group is a sample of nurses recruited by the American Nurses Association (ANA; Calzone, Jenkins, Culp, et al., 2013).

#### Instrument

Data were collected in all three groups using online survey methods and convenience sampling. The survey instrument, called the Genetics and Genomics in Nursing Practice Survey (GGNPS), was developed from a tool for family practice physicians, scaled for nursing and pilot tested with a sample of RNs (Calzone et al., 2012). Instrument validation was performed using structural equation modeling (SEM), which found that the instrument items aligned well with the Rogers Diffusion of Innovations (DOI) domains (Jenkins, Steven, Kahn, & McBride, 2010; Rogers, 2003). The items used in the present study were background demographic characteristics of the nurses and the Bonham & Sellers Racial Attributes in Clinical Evaluation (RACE) scale.

The RACE scale was adapted for nurses from an eight-item RACE scale for physicians designed to measure self-reported use of patient race in clinical decision making (Bonham, Sellers, & Woolford, 2014). Bonham et al. (2014) developed the RACE scale as a tool to measure healthcare providers' use of race in clinical care, without applying any value-laden assessment of the benefit or harm of its use. Higher RACE scores indicate greater self-reported use of race in clinical care.

Using a portion of the total nurses' responses (n = 577) for confirmatory factor analysis (CFA) of the 8 items, a final five-item version of the scale was developed for evaluation of nurses' clinical use of race (**Figure 1**). The five-item RACE scale had a Cronbach's alpha of .86, the loadings were all positive and statistically significant, and other measures (GFI = .99, AGFI = .95, CFI = .99, RMSEA = .08) all indicated adequate fit.

#### **Data Collection**

The GGNPS was voluntary, took 15 to 20 min, and did not collect any participant personal identifiers. Recruitment strategies varied across the three participating groups.

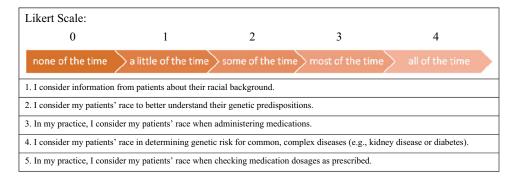
MINC institutions sent email announcements about the survey to their nursing staff. Some institutions employed recruitment methods such as advertising, supervisor encouragement, and intranet postings. Data were collected between July and October 2012, and the survey was open for completion 28 days at each institution (Calzone et al., 2014). Although there was no standard protocol for providing compensation, incentives were offered by some institutions when approved by their individual institutional review boards (IRBs).

Recruitment of NCEMNA study participants was done by each participating NCEMNA member association through email announcements and newsletter notifications (Coleman et al., 2014). The survey was open for completion from fall 2010 to early 2011, and a link to the survey was posted on the main NCEMNA website and each participating NCEMNA member association website. No compensation was provided for participation.

The ANA recruited study participants by posting announcements on the main ANA website ("nursingworld") and in *The American Nurse*, the official publication of the ANA (Calzone, Jenkins, Culp, et al., 2013). Additionally, study announcements were sent out to ANA SmartBrief and eNewsletter subscribers. The survey was open for completion from fall 2009 to early 2010. No compensation was provided for participation.

Survey development was approved by the National Human Genome Research Institute IRB (05-HG-N196). The IRB at West Virginia University approved the MINC

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**Figure 1.** Racial Attributes in Clinical Evaluation (RACE) Scale for Nurses, with score calculated as sum of responses (0–20), with higher scores signifying greater use of race in clinical practice.  $\alpha = .86$ . Adapted from Bonham et al.'s (2014) RACE scale for physicians.

(H-23491) survey, and the Cedars Sinai IRB approved the NCEMNA survey (PRO00018344). The National Institutes of Health Office of Human Subjects Research Protections considered the MINC (OHSRP#11366), ANA (OHSRP#4891), and NCEMA (OHSRP#4570) surveys to be exempt pursuant to 45 CFR 46 because respondents were anonymous and there were no risks to participants.

#### **Study Variables**

The outcome variable, use of race in clinical decision making, is measured using a five-item RACE scale (see **Figure 1**). Items in this 0- to 20-point scale gauge level of nurses' clinical use of race using a 0–4 rating scale, with 0 as "none of the time" and 4 as "all of the time." This measure was adapted from the RACE scale for physicians in order to measure clinical use of race by nurses (Bonham et al., 2014). As with the original scale, higher RACE scores indicate more self-reported use of race in clinical decision making; it measures the extent of clinical use of race without placing a positive or negative label on the phenomenon itself.

Predictor variables included age, portion of work time spent with patients, nursing education level, primary nursing role, race and ethnicity, and views on clinical importance of certain patient demographics. Age was measured by subtracting participant birth year from the year in which the survey was completed by the participant. Portion of work time spent with patients was presented as a percentage-based write-in question. Nursing education level, determined by highest nursing degree attained, was measured with the following categories organized low to high: diploma nurse, associate's, baccalaureate, master's, and doctorate degree. Primary nursing role was broken down into five categories: patient care, administration, education, research, and other (including students). Selfidentified race and ethnicity categories included American Indian or Alaska Native, Asian, Black or African

American, Native Hawaiian or Pacific Islander, Hispanic or Latino, and White. However, because there were only 26 American Indian or Alaska Native participants and 39 Native Hawaiian or Pacific Islander participants, these two racial and ethnic groups were combined into one category called "Indigenous Populations." Additionally, the racial and ethnic categories were simplified and combined into one variable with mutually exclusive categories, such that participants who identified as Hispanic or Latino were placed in that category and the other five categories are non-Hispanic in this study. The variables for opinions on clinical importance of certain patient characteristics are gender, race and ethnicity, genes, family history, and age, measured on a 1–7 Likert scale, with 1 meaning "not at all important" and 7 meaning "essential."

Survey group was included as a covariate, with MINC, NCEMNA, and ANA respondents as three categorical groups. This variable was created specifically to show and account for between-group differences of the three nursing study subgroups.

#### **Data Analysis**

Respondents who were not RNs and those who did not answer all five RACE scale items (and therefore could not receive a valid RACE score) were excluded from data analysis (35% of respondents dropped from analysis). Before dropping these data from the final analysis, assessment showed no pattern of the missing RACE scale items, so 35% was deemed an acceptable amount of exclusion.

Once cases that met the exclusion criteria were removed from the dataset, analysis was performed using IBM® SPSS® Statistics 19.0 (SPSS, Inc., Armonk, NY, USA). After basic evaluation of descriptive frequencies and means, the relationships between variables were assessed with bivariate analyses, namely correlation and one-way analysis of variance (ANOVA). The variables

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were then placed in an ordinary least squares (OLS) regression model for multivariate analysis.

#### **Results**

#### **Study Sample Description**

**Table 1** presents the characteristics of the 5,733 nurses in our sample. The average age in our study sample was 44 years, which is slightly younger than the national average of 50 years (Budden, Moulton, & Cimiotti, 2013). Nurses reported spending an average of 72% of their work time seeing patients, with the ANA and NCEMNA nurses averaging 52% and 53%, respectively, and MINC nurses averaging 75%. Nursing education level in the study sample shows a pattern similar to that of the national nursing workforce (i.e., relatively normal distribution curve with baccalaureate level as the mode), although the study sample has received more nursing education, with a higher percentage of baccalaureate, master's, and doctorate degrees than the general nursing population (Budden et al., 2013). Of the nurses in the study sample, 57% were at the baccalaureate level, 17% had received master's degrees, and 2% had their doctorates. Despite some variation in primary nursing role across the MINC, NCEMNA, and ANA survey groups, the general pattern is similar, with the highest percentage of nurses reporting patient care as the primary role and the lowest percentage of nurses reporting research as the primary role in all three groups. Of all the predictor variables, race and ethnicity varied most across survey groups, which was to be expected based on the nature of the recruiting organizations. Despite this variation, the total study sample has a racial and ethnic breakdown similar to that of the national nursing workforce, with slight oversampling of highly educated nurses and minority nurses (Budden et al., 2013).

#### **Clinical Use of Race Analysis**

As shown in **Table 2**, three predictors were significantly associated with RACE: higher nursing degree level, nurses' race and ethnicity, and views on clinical importance of patient demographic information.

Although there was no statistically significant difference in RACE score between associate degree-level and diploma-level nurses, the baccalaureate-level nurses reported 0.69 points higher RACE scores than diplomalevel nurses (p < .05), master's-level nurses reported 1.63 points higher RACE scores than diploma-level nurses (p < .001), and doctorate-level nurses reported 1.77 points higher RACE scores than diploma-level nurses (p < .01). This relatively linear relationship between

level of nursing degree and RACE score indicates that increase in education corresponds to increase in reported clinical use of race in our study sample.

Asian and Black nurses appear to be linked to higher reported RACE scores. Specifically, nurses who identified as Asian reported RACE scores 1.41 points higher than White nurses (p < .001), and those who identified as Black or African American reported RACE scores 0.55 points higher than White nurses (p < .05). Nurses in Indigenous Populations and nurses who identified as Hispanic or Latino did not have significantly different RACE scores than White nurses in this study.

The nurses' ratings of clinical importance of patient characteristics were significant for all attributes except gender. With a one point increase in clinical importance rating as the increment, patient race and ethnicity corresponded to a 0.54-point increase in RACE score (p < .001), patient genes to a 0.21-point increase in RACE score (p < .001), patient family history to a 0.15-point increase in RACE score (p < .001), and patient age to a 0.19-point increase in RACE score (p < .001).

Our covariate, survey group, also had a significant relationship with clinical use of race. Although there was no significant difference in RACE scores for NCEMNA-and MINC-recruited nurses, ANA-recruited nurses reported RACE scores 0.88 points higher than MINC-recruited nurses (p < .01). The overall model has an adjusted  $r^2$  of 0.20, suggesting that higher nursing degree, self-identified minority racial identity, and perceived importance of various patient demographics together provide a modest explanatory power in predicting RACE score. These variables do not tell the whole story, but they provide important insights into the clinical decision-making process.

### Discussion

When assessed in the bigger context of racial and ethnic health inequities, there are many implications of these findings. For highest nursing degree, the relatively linear positive relationship between education level and clinical use of race indicates that there could be differences in cultural competency and training associated with different levels of nursing education. This notion is supported by the presence of published and well-documented guidelines for cultural competency training in baccalaureate and higher degree nursing education that are not in place for associate or diploma levels (American Association of Colleges of Nursing, 2006, 2008, 2011). The linear positive relationship we found might be explained by increased depth, scope, and overall exposure to these topics in training required for baccalaureate and higher nursing degrees. Because the

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Table 1. Variable Means and Frequencies Across Survey Group

Variable	ANA	NCEMNA	MINC	Total	
		Mea	n $\pm$ SD		
RACE score	10.3 ± 4.7	11.3 ± 5.3	8.0 ± 4.7	8.3 ± 4.8	
Age at time of survey	$52.4 \pm 11.2$	$50.9 \pm 11.2$	43.7 ± 11.9	44.4 ± 12.1	
Portion of time seeing patients	$52.1 \pm 38.8$	$52.5 \pm 38.7$	$74.7 \pm 33.5$	$72.4 \pm 34.8$	
		Frequency (%)			
Education					
Diploma	5 (2.0)	4 (1.3)	300 (6.1)	309 (5.6)	
Associate's degree	41 (16.3)	25 (8.3)	1009 (20.4)	1075 (19.6)	
Baccalaureate degree	89 (35.5)	107 (35.7)	2911 (58.9)	3107 (56.5)	
Master's degree	94 (37.5)	120 (40.0)	693 (14.0)	907 (16.5)	
Doctorate degree	22 (8.8)	44 (14.7)	31 (0.6)	97 (1.8)	
Missing	1	8	229	238	
Nursing Role					
Administration	18 (7.1)	69 (22.4)	431 (8.3)	518 (9.0)	
Education	52 (20.6)	64 (20.8)	251 (4.9)	367 (6.4)	
Research	9 (3.6)	17 (5.5)	67 (1.3)	93 (1.6)	
Patient care	122 (48.4)	141 (45.8)	4002 (77.4)	4265 (74.4)	
Other/not specified	51 (20.2)	17 (5.5)	422 (8.2)	490 (8.5)	
Race and ethnicity					
American Indian/Alaska Native	4 (1.6)	0 (0.0) <sup>a</sup>	22 (0.5)	26 (0.5)	
Native Hawaiian/Pacific Islander	2 (0.8)	7 (2.5)	30 (0.6)	39 (0.7)	
Asian	5 (2.1)	123 (43.5)	357 (7.4)	485 (9.0)	
Black/African American	4 (1.6)	92 (32.5)	315 (6.5)	411 (7.6)	
Hispanic/Latino	5 (2.1)	56 (19.8)	221 (4.6)	282 (5.2)	
White	223 (91.8)	5 (1.8)	3903 (80.5)	4131 (76.9)	
Missing	9	25	325	359	

Note. "Survey group" indicates participant recruiting organization. Percentages may not total 100% because of rounding. The sample size was N = 5,733. ANA = American Nurses Association; MINC = Magnet®-designated hospitals participating in the Method to Integrate a New Competency; NCEMNA = National Coalition of Ethnic and Minority Nurse Associations; RACE = Racial Attributes in Clinical Evaluation. a Less than 0.5% was rounded to 0.

education for each degree comes with its own course and credit hour requirements, every additional degree earned increases exposure to and complexity of courses in population genetics, epidemiology, risk assessment, prevention, detection, symptom management, treatment strategies related to race, and other associated topics. In this case, a stronger foundation of knowledge about race and genetic ancestry in clinical decision making could allow nurses to more appropriately use race in clinical care.

Nurses who identified as Asian or Black reported more use of race in clinical decision making than nurses who identified as White. Given the sample size and potential limitations of our defined racial and ethnic groups, especially the Hispanic and Indigenous categories, we have focused on Asian, Black, and White as the primary racial and ethnic groups for interpretation of results. Generally, a significant difference in race scores was found between minority (Asian and Black) and White nurses, such that minority nurses reported higher clinical use of race than White nurses. This trend of higher reported use of race among minority nurses may be

due, in part, to racial self-awareness. White nurses are not often forced to be conscious of their own race or their use of race in day-to-day life, while minorities are continuously made aware of their own race (Dottolo & Stewart, 2013; Hall & Fields, 2012; Robinson, 2014). This suggests that the lived experience of minority nurses influences their perception of race and health care in a way that makes them more inclined to be explicit about their understanding and clinical use of race (Johansson, Jones, Watkins, Haisfield-Wolfe, & Gaston-Johansson, 2011). This differential experience and awareness of White nurses and nurses of color might be reflected in the higher RACE scores of minority nurses. The difference in racial awareness and everyday experience of race, which may be a key factor in RACE score differences across racial and ethnic groups, has also been found between White and Black physicians in previous qualitative research (Bonham et al., 2009; Snipes et al., 2011).

RACE scores were also significantly associated with reported clinical importance of patient characteristics. We found that nurses who identified patient age, race Sellers et al. Nurses' Clinical Use of Race

**Table 2.** Final Regression Model Predicting Use of Race in Nurses' Clinical Decision Making

Predictors	b <sup>a</sup>	(95% CI) <sup>b</sup>
Age at time of survey	0.011	(00, .02)
Portion of work-time seeing patients (%)	0.003	(00, .01)
Education level		
Entry-level diploma (Ref)	0	
Associate's degree	0.516	(10, 1.13)
Baccalaureate degree	0.686*	(.11, 1.26)
Master's degree	1.633***	(.99, 2.28)
Doctorate degree	1.770**	(.51, 3.031)
Primary nursing role		
Patient care (Ref)	0	
Administration	0.290	(23, .87)
Education	-0.006	(65, .64)
Research	0.036	(99, 1.06)
Race and ethnicity		
White (Ref)	0	
Indigenous Populations <sup>c</sup>	0.364	(88, 1.61)
Asian	1.411***	(.92, 1.90)
Black/African American	0.554*	(.04, 1.07)
Hispanic/Latino	-0.152	(75, .45)
Importance of patient demographics		
Gender	0.022	(09, .13)
Race/ethnicity	0.537***	(.42, .65)
Genes	0.206***	(.09, .32)
Family history	0.151**	(.04, .27)
Age	0.189***	(.10, .28)
Control: survey group		
MINC (Ref)	0	
ANA	0.882**	(.23, 1.53)
NCEMNA	0.307	(58, 1.19)

Note. Outcome variable: RACE score. After listwise deletion, n=4,205. Adjusted  $r^2=0.199$ . ANA = American Nurses Association; CI = confidence interval; MINC = Magnet®-designated hospitals participating in the Method to Integrate a New Competency; NCEMNA = National Coalition of Ethnic and Minority Nurse Associations; RACE = Racial Attributes in Clinical Evaluation.

and ethnicity, genes, and family history as important in clinical care had higher RACE scores. Surprisingly, patient gender was not associated with RACE scores. The significant association of RACE score with beliefs about the clinical importance of race and ethnicity is logical, and given the complicated relationships between race, genes, and family history, it is not surprising that importance ratings of all these patient demographics significantly predicted RACE score. The use of patient age, race and ethnicity, genes, and family history in clinical decision

making has been documented in previous studies (Doerr, Edelman, Gabitzsch, Eng, & Teng, 2014; Hirsh, Callander, & Robinson, 2011; Musunuru et al., 2015). However, findings concerning patient gender have been less conclusive, with some studies finding no gender difference at all in clinical care (Hajjaj, Salek, Basra, & Finlay, 2010; Wandner et al., 2014). Perhaps the ambiguity of the clinical role of patient gender in previous findings, as well as the nonsignificant relationship between perceived importance of patient gender and use of race found in this study, stem from another aspect of clinical decision making such as education or other related experience.

#### Limitations

Our study must be interpreted within the bounds of its limitations. First, the study employed a convenience sampling method for data collection, and rates of group membership and demographic features in the study sample were not congruent with rates in the national nursing population. For example, 90% of the nurses in this study were employed by Magnet®-designated hospitals, although only 6% of all hospitals in the United States have received Magnet® designation. Nurses at these institutions may be a unique subset of the nursing population with a higher percentage prepared at baccalaureate, master's, or doctoral levels (American Hospital Association, 2014; American Nurses Credentialing Center, 2015, February).

Second, grouping strategy for respondents' race and ethnicity is a limitation. There was considerable variation within both the Hispanic or Latino and Indigenous Populations categories, for which potentially unlike subgroups were combined in analysis; Hispanic or Latino included all nurses who identified as such, regardless of their other additional racial and ethnic identities, and Indigenous Populations was relatively small and included nurses who identified with any of four different groups (American Indian, Alaska Native, Native Hawaiian, and Pacific Islander).

Third, it is difficult to account for social desirability bias in survey responses. Social desirability bias is especially likely to have some effect on survey studies involving sensitive subjects, like race. In an effort to avoid seeming prejudiced, consciously or unconsciously, people tend to under-report their use of race, and the effect of this bias is stronger for members of the dominant racial group (Hall & Fields, 2013; Manns-James, 2015). Relatedly, because of the discrepancy between reported conduct and actual behavior, the findings of this study only reveal factors related to the self-reported level of clinical use of race.

a"b" shows change in RACE score for every 1-unit increase in predictor variable, or between the indicated group and reference group.

<sup>&</sup>lt;sup>b</sup>Less than 0.005 was rounded to 0.

 $<sup>^{\</sup>rm c}$ American Indian/Alaska Native and Native Hawaiian/Pacific Islander categories were combined into Indigenous Populations category due to small n.

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

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# **Conclusions and Implications**

To our knowledge, this is one of the first studies to examine background characteristics of nurses related to clinical use of race and to utilize the nurses' RACE scale. Replication of this study using a national probability sample of nurses would provide more generalizable insights into the issues addressed here. Another consideration for future studies would be inclusion of additional predictors in order to gain a more holistic understanding of the role of race in nurses' clinical decision-making processes. Additionally, in "A Blueprint for Genomic Nursing Science," health disparities issues are recommended as a component of any genomic nursing research (Genomic Nursing State of the Science Advisory Panel, 2013). Racial, ethnic, socioeconomic, and cultural influences on disease occurrence and response to treatment; genomic health equity (e.g., access); diseases that disproportionately affect specific groups (e.g., racial and ethnic minorities); and targeted therapeutics are specific topics for evidence development through research.

Healthcare providers are obtaining knowledge of tools to better understand complex biological, environmental, and psychosocial mechanisms relevant to clinical decision making and health outcomes (Dankwa-Mullan et al., 2015). As the precision medicine approach to health care advances, health providers' perception and use of race in clinical decision making should change accordingly. More specifically, nursing education and clinical practice must reflect new findings and knowledge in the field of genomics to continue improving patient care (Calzone et al., 2014). Both formal academic training and continuing education efforts that include a stronger foundation regarding knowledge about use of race and genetic ancestry in clinical decision making are encouraged. This foundation will stimulate translation of the science to practice, facilitating nurses' appropriate use of race in clinical care.

Given the important role of nurses in provision of health care, this study's focus on clinical practice and nurses' use of race contributes to the body of nursing research. Understanding how nurses use race in their practice provides key insights about the clinical encounter and may help inform the development of future cultural competency trainings and educational interventions.

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#### Clinical Resources

- American Anthropological Association RACE Project: http://www.understandingrace.org/home. html
- Centers for Disease Control and Prevention Fast-Stats: Health of Black or African American non-Hispanic population: http://www.cdc.gov/nchs/ fastats/black-health.htm
- Genetics/Genomics Competency Center (G2C2): http://g-2-c-2.org//
- Institute of Medicine report brief: Unequal treatment: What health care providers need to know about racial and ethnic disparities in healthcare: https://iom.nationalacademies.org/~/media/Files/Report%20Files/2003/Unequal-Treatment-Confronting-Racial-and-Ethnic-Disparities-in-Health-Care/Disparitieshcproviders8pgFINAL.pdf
- National Human Genome Research Institute: http://www.genome.gov/

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#### CLINICAL SCHOLARSHIP

# Influence of Gender and Care Strategy in Family Caregivers' Strain: A Cross-Sectional Study

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#### Key words

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#### **Abstract**

**Purpose:** To analyze the factors that influence the strain on family caregivers of elderly dependent people, relating it to the strategy of care, with a gender perspective.

**Design:** Cross-sectional study.

**Methods:** We interviewed 328 Spanish family caregivers in 2012. Main variable: Caregiver Strain Index (CSI). Independent variables: relationship, sex, age, marital status, education level, employment status, socioeconomic status, family and/or institutional supports, time they devote to care, and how long they have been giving care. Data were analyzed using bivariate procedures and multiple linear regression.

**Findings:** Caregiver profile: women around 60 years old, housewives, with primary education. CSI average:  $6.63 \pm 3.36$ . Female sex, kinship being a son or daughter, housewife employment status, service of home care, and the care recipient being female were significantly associated with the subjective strain.

**Conclusions:** Caregivers' strain has a strong gender component: women are more tired, primarily those that practice a partial care strategy.

**Clinical Relevance:** Knowing the factors that predict burden, nurses may help caregivers to provide better care. A risk profile for strain and burden: women who practice a partial care strategy; they are adult women and daughters who do not want to give up their professional role and combine it with their duty of caregiving.

When care, one of the most vital human functions, is naturalized and linked to women, it becomes a factor of injustice and inequality (Casado-Mejía et al., 2014). The dedication to care has been associated with age and gender (Del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Martínez-Riera, 2012) and is related to the ideology and attitude of potential caregivers.

This ideology associated with gender is supported by the typical familialism (Losada et al., 2010) of the countries in Southern Europe (Shurgot & Knight, 2005) that reinforce the caregiver role of women, hiding a completely inequitable structure in relationships between men and women (Serrano Pascual, Artiaga Leiras, & Dávila, 2013).

In our aging Western societies, there is an increase in dependency, accompanied by family and personal changes: women are entering the productive world, but men are not entering the reproductive world to the same extent. This highlights the crisis in the informal care system. And it is important to visualize the link between care and women's status as it reveals the impact on health of dependents who need care and the women who are sometimes caught between their traditional and new roles (Casado-Mejía et al., 2014).

In this context of crisis in the informal care system, different family measures arise to give new answers (progressive incorporation of men into care and external contracting of mostly immigrant caregivers) and Strain in Family Caregivers Casado-Mejía & Ruiz-Arias

institutional support (Casado-Mejía et al., 2014; Ley de la Dependencia, 2006).

Care management strategies have been described as an important factor related to the health status of both the caregivers and the person who is receiving care. The classification of these family strategies has been published before (Casado-Mejía & Ruiz-Arias, 2013), but the relationship between strategies and caregiver burden has not yet been examined. The different ways of organizing care depends on factors that cause a different impact on health, such as having or not having one's own life plan, age, gender, kinship, composition and size of the household, and socioeconomic status. Three different strategies of caring were identified and characterized by informal family caregivers with at least one dependent person at home: total assumption of care (the caregiver assumes all responsibility and the delivery of care), partial care management in coexistence (the caregiver takes responsibility for the care but keeps a personal lifeline, usually paid work), and independent management of care in separate homes (the caregiver is responsible for managing care, the direct care is shared; Casado-Mejía & Ruiz-Arias, 2013).

Family care for an elderly person is a stressful experience that may impair one's health. The subjective strain is often analyzed to measure the consequences of care (Pinquart & Sorensen, 2011). It is defined as the state of caregivers characterized by fatigue, stress, and the perceived limitation of social contact and adjustment to their role, which comes from a negative assessment of the care situation, which can jeopardize caregivers' emotional, physical, psychological, and functional health (Gort et al., 2007). Different measurement scales for detecting burden in caregivers of dependent people have been described (Martin, Domínguez, Muñoz, González, & Ballesteros, 2013), such as the Zarit Burden Interview (Zarit, Reever & Bach-Peterson, 1980) or Caregiver Strain Index (CSI; Robinson, 1983). At the present time, the CSI is the most successful one: Crespo and Rivas (2015) have considered the CSI to be one of the preferential tools for assessing burden. Several investigators agree that it is an easier and simpler instrument than others in identifying excessive burden on family caregivers (Crespo & Rivas, 2015; Odriozola Gojenola, Vita Garay, Maiz Alkorta, Ziatzeta Aduriz, & Bengoestxea Gallastegi, 2008). It can also be a useful tool to detect early signs or symptoms of caregiver's syndrome.

Although the caregivers' strain has been previously studied, the relationship with the various factors that influence it has not been clearly established. This requires further research and providing evidence of said relationship (Del-Pino-Casado, Millán-Cobo, Palomino-Moral, & Frías-Osuna, 2014). Care strategies in turn are influenced

by other factors, previously studied in family care, but not interconnected in this way. For example, the healthrelated effect of institutional support on caregiver burden has not been studied.

As strain affects health (Gort et al., 2007), knowing these factors will be important for nursing interventions that aim to promote the health and quality of the lives of primary home caregivers of older relatives (Del-Pino-Casado et al., 2014). The hypothesis is that female caregivers develop and feel a greater strain than men when giving care, but there are other factors, such as care strategy, marital status, employment status, kinship, institutional support, and age, that influence burden.

The purpose of this study was to analyze the factors that influence the strain on family caregivers of elderly dependent people, relating it to the strategy of care assumed by the family caregiver, with a gender perspective.

# Methodology

#### Design

A cross-sectional study was performed. The main variable was subjective caregiver strain, measured by the CSI. The CSI was validated by Robinson (1983) in an American population of caregivers of patients with atherosclerotic disease or hip replacement. It consists of 13 questions with a "yes" or "no" answer option. It was validated in Spain by López Alonso and Moral Serrano (2005).

Subjective caregiver strain was evaluated based on the relationship with the person cared for and the caregiver's sex, age, marital status, education level, employment status, and socioeconomic status. Subjective caregiver strain also depended on the presence and type of family or institutional support and caregivers' attendance at caregivers' workshops, the time they devoted to care, and how long they had been giving care.

#### **Study Sample**

To obtain a representative sample, a margin of error of 5% and a participation rate of 80% were assumed. People registered in the Seville Primary Care Health District (Spain) as caregivers of dependent persons for at least 1 year (9,689 caregivers) were considered as the study population. The source of the sample was this census.

The composite socioeconomic index (Consejería de Salud de la Junta de Andaluc, 2010), which socioeconomically classifies the five neighborhoods, was used to homogenize the social class. This neighborhood map was superimposed on the health map to determine the conglomerates by primary healthcare centers. Health centers were classified according to this superimposition.

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Census caregivers of each health center were chosen by proportional random sampling in order to reach the target sample size. The sample unit was from the primary healthcare centers, constituted as conglomerates within their area of influence, homogenized by social class and proportional to the census of caregivers (not to the general population).

The unit of analysis was the caregiver. Caregivers whose dependent relative had died in the first half of 2012 were excluded.

#### **Pilot Project**

Prior to passing the questionnaire to the entire sample in the second half of 2012, a pilot project and its validation were carried out with a representative sample of the population, 49 caregivers (Casado-Mejía et al., 2014). The research team analyzed the logical order of the questions, wording, categories of response, social desirability bias, tendency of opinion, and other biases such as memory; it assessed the reliability of the CSI (Cronbach's alpha 0.83) in the sample and determined the reproducibility of the questionnaire or reliability test-retest (0.87). Some corrections were made. These corrections allowed us to obtain a questionnaire that was reliable, valid, and free of androcentric bias (Ruiz-Cantero, Carrasco-Portiño, & Artazcoz, 2011).

#### **Data Collection**

Data collection was mainly carried out by telephone (90.7%), at home (5.0%), and at the primary health-care center (4.3%). The interviewers were trained by researchers during a 5-hr session to ensure high quality and uniformity of data collection (objectives, meaning of each item, how to interview, etc.).

The study was approved by the Ethics Committee of the Seville Primary Care Health District. Informed consent was verbally obtained from all the participants.

# **Data Analysis**

Data analyses were performed with the help of SPSS-20 software (IBM Corp., Armonk, NY, USA). The descriptive analysis was carried out using mean values, percentages, and standard deviation. Some additional analyses were performed: a correlation between quantitative variables for multivariate analysis, a one-way analysis of variance to verify the existence of differences between variables with more than two groups and normal distribution, nonparametric analysis such as the Kruskal-Wallis H-test and the Mann-Whitney U test in variables that did not present normality, and the

chi-square test to verify the differences between two categorical variables.

To apply the model of multiple linear regression, all the variables that were found to have a significant relationship with the CSI were included. Before applying multiple linear regression, the assumptions that the technique required to obtain powerful and unbiased conclusions were verified: absence of multicollinearity (tolerance indices >0.10 and inflation factor of variance <0.10), homoscedasticity (dispersion graphics), regardless of errors (Durbin-Watson 1.5–2.5), linearity (partial dispersion graphics), and normality (histogram and normal probability graphic or Kolmogorov-Smirnov test; Field, 2009).

# **Findings**

Twelve percent of the sample was not eligible because patients had died (n = 573), patients had been admitted to a nursing home (n = 201), or caregivers had died (n = 388), so the eligibility rate was 88%.

Four hundred five questionnaires were issued. The participation rate was 81%, so that 328 valid questionnaires for analysis were obtained. An average of 1.9 calls per questionnaire were made in order to contact and obtain a response.

The caregiver profile of the sample was: woman around 60 years old, housewives, with primary education, that take care of both men and women, primarily their parents; they had been giving care for 9 years. The care recipient profile was: woman around 78 years old. The characteristics of the sample are shown in **Tables 1** and **2**. The average CSI score was  $6.63 \pm 3.36$ . **Table 3** shows the CSI score depending on certain characteristics of caregivers.

Statistically significant differences were found through analysis with the Mann-WhitneyU text regarding the caregiver's sex (p < .001), showing that women experienced greater strain; divorcees experienced more tiredness than did those who were single or married or cohabiting (p < .05); daughter or son caregivers experienced greater strain than did those who cared for their partners or other relatives (p < .001); retired people and housewives who worked as caregivers were less tired than those who had jobs outside of caregiving. As for aid, attending caregiver workshops or enjoying institutional aid such as the home help service or day or night care centers led to an increase in strain (p < .05). Significant negative relationships between age and strain were also found, using the Pearson correlation: the older one is, the less strained one is (p < .05).

There were no statistically significant relationships in terms of socioeconomic status, while the caregiver was Strain in Family Caregivers Casado-Mejía & Ruiz-Arias

 Table 1. Sample Description I (Discrete Variables)

		Inter	viewee
Variables	Values	Men n (%)	Women n (%)
Care recipient	Man	14 (18.7)	113 (44.7)
	Woman	61 (81.3)	140 (55.3)
	Total	75 (100.0)	253 (100.0)
Socioeconomic status	Low	14 (18.7)	59 (23.3)
	Medium low	17 (22.7)	46 (18.2)
	Medium high	24 (32.0)	67 (26.5)
	Medium	15 (20.0)	62 (24.5)
	High	5 (6.7)	19 (7.5)
Marital status	Total Single Married/cohabiting Divorced Widower/widow No answer Total	75 (100.0) 20 (26.7) 48 (64.0) 6 (8.0) 1 (1.3) 75 (100.0)	253 (100.0) 45 (17.8) 174 (68.8) 10 (4.0) 24 (9.5) 253 (100.0)
Kinship	Son/daughter Partner Others Total Lost	32 (42.7) 33 (44.0) 10 (13.3) 75 (100.0)	128 (50.6) 81 (32.0) 43 (17.0) 252 (100.0) 1 (0.40)
Education level	They did not go to school	9 (12.0)	38 (15.0)
	Primary studies	33 (44.0)	156 (61.7)
	Bachelor's degree	24 (32.0)	37 (14.6)
	University	9 (12.0)	22 (8.7)
Employment status	Total	75 (100.0)	253 (100.0)
	Employed	9 (12.2)	45 (17.9)
	Retired	38 (51.4)	67 (26.6)
	Unemployed	23 (31.1)	26 (10.3)
	Housewife	3 (4.1)	113 (44.8)
	Other	1 (1.4)	1 (0.4)
	Total	74 (100.0)	252 (100.0)
Time the caregiver devotes to paid work <sup>a</sup>	Lost <20 hr 20–35 hr >35 hr Temporary work No answer Total	1 (1.3) 9 (18.4) 5 (10.2) 25 (51.0) 1 (2.0) 9 (18.4) 49 (100.0)	1 (0.4) 20 (19.2) 23 (22.1) 51 (49.0) 9 (8.7) 1 (1.0) 104 (100.0)
Receives or has received family support	Lost	26 (34.7)	149 (58.9)
	Yes	45 (60.8)	141 (57.3)
	No	29 (39.2)	105 (42.7)
	Total	74 (100.0)	246 (100.0)
	Lost	1 (1.3)	7 (2.8)
Sex of the person who helps	Man	4 (8.7)	52 (36.6)
	Woman	42 (91.3)	90 (63.4)
	Total	46 (100.0)	142 (100.0)
	Lost	29 (38.7)	111 (43.9)
"Dependency Law" support	Economic benefit Home help service Day/night care centers	40 (60.6) 24 (36.4) 2 (3.0)	127 (67.6) 51 (27.1) 6 (3.2) 4 (2.1)

Continued

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Table 1. Continued

		Inter	viewee
Variables	Values	Men <i>n</i> (%)	Women n (%)
	Lost	9 (12.0)	65 (25.7)
Obligation to modify employment situation for care	Yes	18 (29.5)	62 (49.2)
	No	43 (70.5)	61 (50.0)
	No answer		1 (0.8)
	Total	61 (100.0)	124 (100.0)
	Lost	14 (18.7)	29 (51.0)

<sup>&</sup>lt;sup>a</sup>Regardless of care.

Table 2. Sample Description II (Continuous Variables)

			Men		Women	Total
Variables		n	Average $\pm$ SD	n	Average $\pm$ SD	n
Recipient care age (years)		75	77.60 ± 12.44	253	79.05 ± 14.30	328
Caregiver age (years)		75	$63.24 \pm 13.84$	253	$62.32 \pm 12.08$	328
How long giving caring (years)		75	$9.09 \pm 9.20$	249	$8.99 \pm 8.74$	322
Time the caregivers devote to care	Hours/day	27	$20.59 \pm 5.51$	99	$19.10 \pm 6.70$	126
	Days/month	21	$22.05 \pm 11.20$	72	$19.46 \pm 12.06$	93
	Months/year	23	$6.57 \pm 5.42$	81	$6.72 \pm 5.60$	104

giving care or was devoted to care. As for aid received, neither family nor institutional help, such as the economic benefit or nursing home, was significant (p > .05).

To apply the multiple linear regression model, all the variables mentioned that had had a significant relationship with the CSI were included: caregiver's sex, marital status, kinship, work status, institutional aid, and age. Sex and age of the care recipients were also included. It was verified that the required assumptions were met. After this, we proceeded to apply the model. The female sex of the interviewee (p < .001), kinship, being a daughter or son (p < .001), housewife employment status (p < .001), home care service (p < .001), and the care recipient being female (p < .005) were significantly associated with the subjective strain. Through these independent variables, 20% of the variance of the subjective strain ( $R^2 = 0.20$ ) can be explained. The Durbin-Watson value was 2.026, which suggested the existence of independence of errors.

In relation to the regression line coefficients, we know that when all the independent variables are 0, the CSI score starts from 7.78 points. In **Table 4**, variables associated with caregivers' strain are expressed: being a woman increases the subjective strain by 1.90 points, being a daughter or son by 2.35 points, and using home care service by 1.90 points; however, to have housewife employment status decreases the subjective strain by 1.61 points, and if the care recipient is female, subjective strain is decreased by 1.21 points.

#### **Discussion**

#### **Descriptive Results**

The caregiver profile of the sample was similar to that in other studies (Moreno-Gaviño et al., 2008). Women take care of both men and women, primarily their parents. This contrasts with men who are joining caregiving, who mostly take care of women (81.3%), mainly their spouses. This result on male caregivers suggests that they do it out of necessity, when there is no woman who can take over and when they are already retired. Men and women receive help from others, although more men than women receive help (60.8% vs. 57.3%), and generally from a woman (70.21%).

Although a similar proportion of men and women in the sample had a paid job regardless of caregiving duties, more women had to change their employment status as a result of their caregiving duties (49.2%) as compared to men (29.5%). In this study, women were still responsible for family care, whatever their extra-family situation was, which seems to take second place when it is necessary to attend to family obligations. All this indicates that care remains a feminine nature.

#### Sex of Interviewee

The provision of care for a dependent person creates a source of chronic stress of various kinds for the caregiver's

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**Table 3.** Link Among Caregiver Strain Index (CSI) and Several Caregiver Characteristics

Variables	Values		n	CSI Average $\pm$ SD
Sex	Man		74	5.43 ± 3.18
	Woman		253	$6.98 \pm 3.34$
Marital status	Single		65	$6.25 \pm 3.59$
	Married/cohabiting		222	$6.65 \pm 3.34$
	Divorced		15	$8.47 \pm 3.07$
	Widower/widow		24	$6.37 \pm 2.96$
Kinship	Son/daughter		159	$7.36 \pm 3.24$
	Partner		114	$6.05 \pm 3.26$
	Other		53	$5.70 \pm 3.54$
Employment	Employed		54	$7.93 \pm 3.40$
status	Retired		105	$6.31 \pm 3.12$
	Unemployed		48	$6.67 \pm 3.65$
	Housewife		116	$6.26 \pm 3.31$
	Other		2	$6.62 \pm 3.35$
Aids	Economic benefit	Yes	122	$6.14 \pm 3.28$
		No	197	$6.88 \pm 3.31$
	Tele-aid	Yes	161	$6.53 \pm 3.20$
		No	160	$6.71 \pm 3.43$
	Home help service	Yes	69	$7.78 \pm 3.02$
		No	252	$6.30 \pm 3.32$
	Day/night care center	Yes	12	$8.92 \pm 2.91$
		No	308	$6.51 \pm 3.29$
	Caregiver Holidays <sup>a</sup>	Yes	8	$9.12 \pm 3.27$
		No	312	$6.54 \pm 3.29$
	Technical aids	Yes	127	$6.83 \pm 3.23$
		No	194	$6.478 \pm 3.37$
	Caregiver's workshop	Yes	37	$7.68 \pm 3.02$
		No	283	6.46 ± 3.32

<sup>&</sup>lt;sup>a</sup>Caregiver Holidays is an Andalusian Health System program based on the admission of patients in a chronic institution or long stay hospital in order to allow caregivers a period of rest.

Table 4. Caregiver Strain Index Predictive Model

Starting point CSI	7.78
Being a woman	+1.90
Being a daughter/son	+2.35
Housewife employment status	-1.61
The service of home care	+1.90
Care recipient being female	-1.21

health (García-Calvente, Del Río Lozano, & Marcos Marcos, 2011), although this stress is difficult to classify because of its subjective component and the influence of social roles and cultural factors (Ingersoll-Dayton, 2011). It has also been widely demonstrated that, among caregivers, women have poorer health than men. Being a female caregiver in our study proves to be one of the factors that increases the subjective strain most, which is consistent with the literature (García-Calvente et al., 2011).

The most important explanation is that behind this situation is the gender mandate (Bowlby, McKie, Gregory, & MacPherson, 2013). Women, socialized to care for others, ignore themselves to be available and caring (Lagarde, 2004). They become "sloppy caregivers" (Rogero García, 2010), who neglect self-care in favor of attention to another person.

In our study, men clearly had a lower CSI score than women. This could be due to male caregivers doing things differently (Robinson, 2014), such as protecting their personal space, performing the more instrumental tasks (Ducharme et al., 2006; García-Calvente et al., 2011), having less emotional involvement, and being less biased when asking for help. Women caregivers have assumed that care is their natural and moral obligation and take it as something of their own, so they have more difficulty in asking for help. They live it as an almost total dedication of themselves, dedicating more affection to the care tasks that they perform (García-Calvente et al., 2011), besides assuming heavier, more intense and complex tasks (Masanet & La Parra, 2011). The female experience carries more strain.

#### Sex of the Person Under Care

According to the aforementioned socialization, when women have to be caregivers they represent less burden than men to those they care for. Does that mean that dependent women have less need of care? Probably it is not the needs that are less but the demands, because women have learned not to ask for themselves.

On the other hand, the base of care is full of emotional elements: good relations that are equitable and satisfactory are an element of well-being. Women socialized as emotional beings have been responsible for maintaining relations, and they sustain emotions (perhaps that is why) when they have to be caregivers, facilitate relationships, and promote trust, reward-cost balance, and reciprocity (Del-Pino-Casado et al., 2014; Lai, 2010). These elements are necessary so that relationships are satisfactory and are maintained (Rogero García, 2010).

Such relationships favor the positive consequences of care (Zabalegui Yarnoz et al., 2007), for example, the experience of care that can be valued as "learning for life."

#### **Marital Status**

There are hardly any previous studies linking health with marital status. The ones that exist are attached to sex (Soria Trujano, Cielo Torres, & Vega Valero, 2010), and they identify worse mental health among divorced men due to the economic burden and children. This is a point for further research.

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#### **Employment Status**

Being retired or a housewife emerged as protective factors, decreasing the strain. It is clear that to reconcile care and work involves adding tasks, difficulties, and fatigue.

The requirements of care involve, in many cases, problems in meeting working hours, having to request a reduction in working hours, giving up work, or accepting that work will suffer in some way (Casado-Mejía & Ruiz-Arias, 2013). As reflected in the results, it is women who have to modify or give up their paid work if care demands it. This results in many women seeking assessment and social validation, an intense frustration (Rogero García, 2010).

Interpersonal relationships are important to the quality of people's lives, which is reflected in the use of time. Working (paid) and caring (unpaid) often reduce a person's free time (Bittman, Fisher, Hill & Thomson, 2005) because there are not sufficient hours in the day. This also reduces the possibility of establishing and maintaining social relationships (Bittman et al., 2005).

#### **Kinship**

Being a daughter or son increases fatigue. This result agrees with the findings of Del-Pino-Casado et al. (2014) and Conde-Sala, Garre-Olmo, Turro-Garriga, Vilalta-Franch, and Lopez-Pousa (2010), although other studies have not confirmed this relationship (Pinquart & Sorensen, 2011). These sons and daughters are adults who, due to circumstances, have had to take over the care of their dependent mother or father, but do not give up their paid work, responding to the social ideal model of independent men and women through work. In addition, they are basically daughters, as the male caregiver's profile is close to retirement age. That is, men usually join caregiving at the end of their working lives to care for their wives (Fernández Villanueva, Artiaga Leiras, & Dávila de León, 2013).

When women try to respond to the new ideal of an independent woman but cannot completely abandon the gender mandate (Bover Bover & Gastaldo, 2005), they add paid work to caregiving. Housework or caring is not replaced or shared, so the burden increases. This idea coincides with that of García-Calvente et al. (2011), who pointed out that strain is higher in women because the working days for them, inside and outside the home, are endless. Esteban (2003) underlined the uneven discriminatory distribution not only of material and economic resources, but in the time that men and women share due to the sexual division of work in which care is a women's specialty.

#### **Care Strategies**

If these variables are related to the previously predefined care strategies (Casado-Mejía & Ruiz-Arias, 2013), it can be concluded that being a housewife—devoted 24 hr a day to caregiving, undertaking a strategy of "full assumption of care," although it has a negative impact on health—does not affect women as much as the "partial management of care." In this research, being a housewife is a protective factor against the fatigue of caregiving.

Most people who undertake "partial care management" are children who care for their parents, not wanting to give up all their time and their own lives. To do this, they negotiate with themselves and their families and at least they keep some personal time, usually for their paid work, time in which someone, hired or not, is doing the caregiving. Work is added to caregiving, which introduces strain. A balance between satisfaction and the demands and consequences of the new (professional) and traditional (caregiver) roles has to be sought.

Women nowadays, with high cultural capital or working duties, carry out care with resignation or directly oppose it, considering it as an antiwill structural imposition that reduces or precludes the projection of their own personal and individual trajectory. Yet they have to lend a deaf ear to the social pressure they receive as they are blamed for the family changes, especially for these new roles, which bring problems resulting from inattention to people who need more care (Bover Bover & Gastaldo, 2005).

Economic, psychological, and social costs justify fatigue. Women, to become persons in the difficult path of equality, have not managed to divide it up but they have added burdens, tasks, and responsibilities, so that they have to carry a double burden.

In light of these results, we can continue to argue that the healthiest strategy is the one that came closest to the "ideal" of an autonomous person with an own project, that protects his/her life and managed care. It is the strategy known as "independent management of care."

#### **Institutional Support**

It may be surprising that getting the most out of institutional support (Ley de la Dependencia, 2006) supposes an increase in the CSI score, since it is designed to ease the burden of care. To understand the results, the measures in question, how they are designed, and how they are provided should be analyzed.

In a previous study (Casado-Mejía et al., 2014), it was verified that having to plan and manage time to get the most out of these aids added stress to caregivers. For

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example, the way a dependent person arrives and is picked up from the day center has to be organized; the time to go to caregivers' workshops has to be found (besides stimulation that sometimes involves becoming aware of one's own situation, although the workshops provide coping strategies). Del-Pino-Casado et al. (2014) found positive relationships when the perception of social support is satisfactory.

The home help service has significant relationships with the CSI score and proves to be a predictor for its increase. Families commented on their dissatisfaction, and they were greatly stressed by this help because they had to make efforts to adapt to different people coming each time and at different times. They also commented that these people were not personally involved in the care. All the aforementioned produced more stress than support (Casado-Mejía et al., 2014).

#### **Proposals**

It is necessary, as an ethical position, to relieve the strain that caregiving involves. This could occur by sharing caregiving duties. Men are increasingly lending more care, but not without resistance (Pérez-Orozco & López-Gil, 2011), and many of them do it as a last resort or because they are becoming identified with more feminine dimensions. On many occasions, they are motivated by their egalitarian relationship with women (Fernández Villanueva et al., 2013). Perhaps we should continue making an effort in building more egalitarian and healthy masculinity, supporting men with greater recognition in the caregiver role (Fernández Villanueva et al., 2013).

If care is not shared, and there is no coresponsibility (Pérez Orozco & López Gil, 2011), there will have to be support for women to make a free choice whether to give care or not give care (Esteban, 2003), but not based on feminine virtue that has traditionally made it mandatory. If the choice is to give care, perhaps women must learn from men and do so by protecting their own space (Casado-Mejía et al., 2014).

Health professionals, in general, play an important role, and nurses in particular, who often involve women in the care of other family members naturally, without questioning whether they are plunging them deeper into the negative consequences of this role.

# **Strengths and Limitations**

One of the great strengths of this work is to have identified the factors that can overburden or alleviate the impact of caregiving. The proposed new model for the increase or decrease in the CSI score will help health professionals, particularly nurses, to better understand the subjective care strain and influencing factors, to provide better care to these factors and establish a systematic care plan and to include early diagnosis and early care.

The sample, of probabilistic character, was broad and representative not only of the population of Seville, but it can be considered representative of the Spanish population and other European countries, as their characteristics are common to other contexts. However, it should be expanded in future works to include the rural population.

As a limitation, it has to be noted that during the completion of the questionnaire it was revealed that the census was not fully updated, having produced drop-outs in patients and caregivers from development to implementation. The characteristics of some patients (frailty, comorbidity, advanced age, patients in palliative care, etc.) and the advanced age of many caregivers who also have chronic health problems contributed to 12% of patients having died, being admitted to a nursing home, or the caregiver having died. This has affected the eligibility rate.

Having focused on the caregivers' characteristics for the CSI analysis is also considered a limitation. It would be appropriate in the future to consider other characteristics of the persons cared for, such as the degree of dependence, in addition to age and gender.

#### **Conclusions**

Findings support the hypothesis that the strain and burden of caring for a dependent elderly person by the family implies a strong gender component: women are more strained, primarily those who practice a partial care management strategy. They are adult women, daughters who do not want to give up their professional role and combine it with their duty of caregiving.

Nurses can use this risk profile for the early prevention of and intervention for subjective burden. A risk profile can also improve understanding of the caregiving process and help to develop plans for higher quality of care.

Assuming that care is a social responsibility, to move towards a more just and egalitarian society will require an active commitment from men at all levels, as well as from other family members, and unconditional support (from the professional and from the social) for women who do not now want to give care within the parameters defined by our society, encouraging the protection of personal space. In addition, we should continue investing in institutional measures that help families care, measures which, when revised, are really supportive.

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# **Clinical Resources**

- Australia: Carers Australia: http://www.carersaustralia.com.au/
- Canada: Carers Canada: http://www.carerscanada. ca
- Finland: The Central Association of Carers in Finland: http://www.omaishoitajat.fi/
- India/Nepal: Carers Worldwide: http://www. carersworldwide.org/
- Ireland: Care Alliance Ireland: http://www.carealliance.ie/
- New Zealand: Carers New Zealand: http://www.carers.net.nz/
- Sweden: Carers Sweden: http://www.anhorigasriksforbund.se
- United Kingdom: CarersUK: http://www.carersuk. org/
- American Association of Retired Persons: www. aarp.org
- Caregiver Network Action: http://www. caregiveraction.org
- Family Caregiver Alliance: www.caregiver.org
- National Alliance for Caregiving: http://www.caregiving.org

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#### **WORLD HEALTH**

# **How Factor Analysis Results May Change Due to Country Context**

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#### Key words

Health services research, nurses, PES-NWI, Poland, survey research, work environments

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#### **Abstract**

**Purpose:** To present how factor analysis results of a Practice Environment Scale of the Nursing Work Index (PES-NWI) translation changed due to country context.

**Design:** Validity and reliability analysis of a cross-culturally adapted, Polish translation of the PES-NWI came from a cross-sectional, national survey that included 2,605 registered nurses working in surgical (50.4%) and medical (49.6%) units of 30 Polish hospitals.

**Methods:** Exploratory factor analysis (EFA) using the principal component analysis (PCA) method with varimax rotation and confirmatory factor analysis (CFA) was used to examine factor structure of the instrument in the Polish context. Zero-order and partial Pearson correlation coefficients were used to establish the range of variance shared by the dimensions of the Polish version. The Cronbach's alpha coefficient determined internal consistency reliability. The internal consistency of the scale was also tested based on Kline's criterion. **Findings:** The PCA conducted in the sample of Polish nurses extracted six factors, explaining together 56% of the total variance. The varimax rotation, however, restricted results to five factors, explaining 52.7% of the total variance and generating a factor structure closer to that based on previous studies. The CFA model, based on a PCA solution with five nonorthogonal factors, fitted data better than the theoretically driven model.

**Conclusions:** Dimensions of the PES-NWI nurses' work environments remain conceptually consistent in Poland, but load differently. Health system or nursing profession factors related to the country context are potential explanations for these differences.

**Clinical Relevance:** When using a translation of the Practice Environment Scale of the Nursing Work Index-Revised to examine the influences of work environment quality on nursing and patient outcomes, it is important to consider contextual differences when using results to inform policy.

Research consistently demonstrates that nurses' work and the quality of the work environment influence several key health system outcomes in multiple countries around the world (Stalpers, de Brouwer, Kaljouw, & Schuurmans, 2015). As countries seek to improve their health system outcomes, reliable and valid measurement of nurses' work environments is an important part of that effort. Results from these assessments have the potential to produce better organizational, local, and national

policies around the healthcare workforce, aiming to promote optimum patient outcomes. For international research comparing countries, a reliable instrument that consistently measures a phenomenon is an important part of rigorous, comparative country research.

In a country like Poland, where research about nurses and associated patient outcomes is relatively new when compared to other European countries (Brzostek et al., 2015), the ability to cross-culturally compare related Brzyski et al. Context and PES-NWI Validation

research results helps provide context-specific direction for improving patient outcomes and addressing workforce issues. In this study, we sought to explore how country context may influence factor analysis results through an analysis of the Polish version of the PES-NWI. The exercise also aimed to determine its validity and reliability as a measure of work environment concepts in a dynamically changing Central European country.

# **Background**

Several instruments can reliably measure the nursing practice environment, but for the purposes of this article, this section will focus on the Practice Environment Scale of the Nursing Work Index (PES-NWI; Lake, 2002). A strength of the PES-NWI is that consecutive revisions have further refined and strengthened the instrument. It was developed on the basis of the 65-item NWI (Kramer & Hafner, 1989) by Lake, who reduced the NWI survey to a manageable 31 items, with five subscales emerging in the U.S. context (Lake, 2002). Two subscales are hospital specific: nurse participation in hospital affairs (named in this article as participation, which has 9 items), and nursing foundations for quality of care (shortened to foundations for this article, with 10 items). Three other subscales—managerial ability, leadership, and support of nurses (in short, support, with 5 items), staffing and resource adequacy (in short, staffing, with 4 items), and collegial nurse-physician relations at work (in short, relations, which includes 3 items)—are unit specific. The unit specific distinction is important because that means the instrument can hone in on how "problem" units skew organizational results.

Similar analyses were conducted by Li et al. (2007), who analyzed a 55-item NWI (Aiken & Patrician, 2000), and for 0.6 cut-off for factor loadings, she obtained the 21-item, four-factor solution, including the manager support and advancement opportunity factor (seven items), the relations factor (eight items), the staffing factor (three items), and nurse manager leadership factor (three items). The latest analysis concerning PES-NWI was conducted by Parker, Tuckett, Eley, and Hegney (2010), who used the 30-item PES-NWI, including six items not present in Lake's work (Lake, 2002). She obtained a fivefactor structure, including participation (eight items), foundations (five items), support (eight items), staffing (five items), and active quality improvement programme factor, which contains four items ascribed by other authors as the relations factor. The version of the PES-NWI used in the RN4CAST study (Sermeus et al., 2011) was based on works of Parker et al. (2010), complemented by results coming from Li et al. (2007).

Some analyses have shown that, in different contexts, the PES-NWI factor loading pattern varies (Warshawsky & Havens, 2011). Given the differences between health systems, this is not surprising but may concern some researchers who seek to cross-culturally adapt and translate the instrument in their own country. It is also a concern for creating internationally comparable research results.

Nursing research in Poland, for example, is "new" compared to many European countries (Brzostek et al., 2015). Many researchers began by studying nursing work and workforce dynamics. Several recent Polish studies indicate that the work environment is an essential element that impacts a nurse's professional and personal satisfaction, reinforcing findings from studies conducted in other countries (Kunecka, 2010; Wysokińska et al., 2009). According to some reports, professional satisfaction of Polish nurses is lower in comparison with nurses in other countries (Estryn-Behar et al., 2007). Moreover, it is also lower when compared to other professionals in Poland (Widerszal-Bazyl, 2005). Both domestic and foreign reports indicate that professional satisfaction among nurses is directly related to patient safety, quality of care, work productivity, organization commitment, and personnel fluctuation (Best & Thurston, 2006; Kosińska & Pilarz, 2005; Wild, Parsons, & Dietz, 2006).

Until now, a variety of tools prepared by various authors had been used to measure different aspects of the work environment in Polish studies (Klimak, Klimak, & Skorek, 2000; Kosińska & Pilarz, 2005; Kunecka, 2010; Wysokińska et al., 2009). The lack of a standardized tool made it impossible to compare the results of studies between institutions, and, consequently, researchers were unable to generalize the results at the national level. International comparisons were also hardly possible.

Currently, obtaining a standardized tool to systematically measure the work environment is a crucial research challenge for Polish nursing management policy. The reforms of the Polish healthcare system, diminishing interest of younger people in the nursing profession, reduced nurse-to-population ratios, and the concurrent increasing age of professionally active nurses make this issue a policy priority on the national level (Radkiewicz, Widerszal-Bazyl, Pokorski, & Ogińska, 2004; Council of Nurses and Midwives, 2015). Further complicating the Polish situation are generational dynamics as a growing number of young nurses give up the profession, emigrate, or do not start practicing after graduation. A combination of direct measures that address social and managerial efforts around recruitment and retention of qualified nurses is urgently needed.

Therefore, adapting an international tool to the Polish context is important to generate good evidence that will support the ongoing healthcare system transition, Context and PES-NWI Validation Brzyski et al.

domestic nursing workforce policy, and European Union cooperation. Many other eastern European countries face nursing workforce challenges similar to Poland's; therefore, this study will help inform research in those countries and others where nursing workforce studies are not common.

#### Methods

Poland was one of the countries participating in the European RN4CAST study, a 12-country comparative nursing workforce study that has yielded rich comparative results about the nursing workforce in that region of the world. The version of the PES-NWI used in the RN4CAST study was based on Parker's version of the PES-NWI and complemented by Li's work and includes five factors: foundations (nine items), participation (eight items), relations factor (seven items), staffing (four items) and support (four items; Bruyneel, Van den Heede, Diya, Aiken, & Sermeus, 2009; Li et al., 2007; Parker et al. 2010). The psychometric history of the instrument contributed to the theoretical foundation and integration of the PES-NWI scale into the RN4CAST final protocol (Sermeus et al., 2011). The translation and pilot testing of the instrument in Poland was detailed by Brzostek et al. (2015).

#### **Parent Study Sample**

The survey sample participating in the RN4CAST study consisted of 2,605 nurses (including 11 men) working at surgical (50.4%) and medical (49.6%) units of 30 Polish hospitals (Sermeus et al., 2011). The hospitals were selected according to the region, population density, and reference level to assure a representative sample of Polish hospitals that provide constant acute care. Nurses participating in the study were 20 to 70 years old (mean 40.6, *SD* 7.7). They obtained professional nursing degrees at age 18 to 39 (mean 20.7, *SD* 1.5), and 556 of them (21.3%) graduated with baccalaureate degrees. Almost all (2,529 nurses, 97.1%) were employed full time, and the length of their professional experience ranged from 1 to 50 years (mean 18.8, *SD* 8.5), including 1 to 50 years (mean 15.6, *SD* 9.2) working in their current hospital.

#### **Statistical Analysis**

Theoretical validity of the Polish adaptation of the PES-NWI was assessed using exploratory factor analysis (EFA) by means of the principal component analysis (PCA) method with varimax rotation (Nunnally & Bernstein, 1994). The criteria for the number of extracted factors were, firstly, eigenvalue greater than 1 (indicating the

factor explained more about total variance than a single item included in analysis), and secondly, a theoretically grounded interpretation of the factors, meaning using an approach described by Garson (2010) where the item was grouped based on the item's highest factor loading. Results of the PCA were presented as a matrix of factor loadings (a collection of standardized regression coefficients where the variables have fallen into principal component groups).

The empirical factor structure, obtained as a PCA solution, was compared against the theoretical one based on the work of Li et al. (2007) and Parker et al. (2010). In order to test how original factor structure was replicated in Polish cultural conditions, a confirmatory factor analysis (CFA) was conducted. Several models were tested: unidimensional and four five-dimensional models. Two of them tested the theoretical factor structure of the PES-NWI designed for the RN4CAST study. The first assumed the factors to be not correlated, while the other assumed correlation between factors.

Two other models tested the data-driven factor structure with respect to the existence of a correlation between factors. Evaluation of the goodness of fit of each model was primarily based on the root mean square error of approximation (RMSEA; Steiger, 1990), a populationbased index that measures discrepancy per degree of freedom that is relatively insensitive to sample size. Additional goodness-of-fit indices, such as chi-square statistics, the Normed Fit Index (NFI; Bentler & Bonett, 1980), and the Comparative Fit Index (CFI; Bentler, 1990), were inspected to provide additional evidence of the model fit. Based on recommendations from prior Monte Carlo studies (Hu & Bentler, 1998), the goodness-of-fit statistics were evaluated using arbitrary cutoffs of less than .08 as an acceptable fit, and less than 0.05 as a good fit for RMSEA; at least 0.90 for NFI and CFI was considered an adequate fit, whereas 0.95 was considered a good fit.

The zero-order and partial Pearson correlation coefficients were used to establish the range of variance shared by the dimensions of the Polish adaptation of the PES-NWI scale after controlling for other scale dimensions. Reliability of the scale and its subscales was evaluated in terms of internal consistency using the Cronbach's alpha coefficient (Cronbach, 1951). The values of the coefficients higher than 0.7 were regarded as acceptable, while the values of the coefficients higher than 0.8 were regarded as satisfactory. The internal consistency of the scale was also tested in terms of the Kline criterion, which demands the correlation between an item and a summary score (so-called discrimination power) to be higher than 0.4 (Kline, 1986). PCA and internal consistency reliability analysis were conducted using IBM SPSS Statistics 19 for Windows (IBM Corp.,

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Table 1. Factor Loadings Matrix of Five-Factor Structure of the Polish Practice Environment Scale of the Nursing Work Index

			Component		
Item	1	2	3	4	5
13. Physicians recognize nurses' contributions to patient care.	0.80				
21. Physicians respect nurses as professionals.	0.77				
30. Physicians hold nurses in high esteem.	0.77				
26. Collaboration between nurses and physicians.	0.75				
7. Physicians value nurses' observations and judgments.	0.74				
2. Physicians and nurses have good working relationships.	0.72				
17. A lot of team work between nurses and physicians.	0.52				
14. Praise and recognition for a job well done.	0.48				
10. A nurse manager who is a good manager and leader.		0.77			
22. A nurse manager who backs up the nursing staff in decision making, even if the conflict is with a physician.		0.72			
3. A supervisory staff that is supportive of nurses.		0.63			
23. Management that listens and responds to employee concerns.		0.55			
11. A chief nursing officer who is highly visible and accessible to staff.		0.47			
25. Registered nurses are involved in the internal governance of the hospital (e.g., practice and policy committees).			0.66		
18. Opportunities for advancement.			0.62		
29. Registered nurses have the opportunity to serve on hospital and nursing committees.			0.61		
5. Career development/clinical ladder opportunity.		0.46	0.59		
4. Active staff development or continuing education programs for nurses.		0.43	0.48		
6. Opportunity for registered nurses to participate in policy decisions.		0.42	0.46		
32. Patient care assignments that foster continuity of care (i.e., the same nurse cares for the patient from one day to the next).			0.43		
15. High standards of nursing care are expected by the management.				0.68	
20. Working with nurses who are clinically competent.				0.63	
19. A clear philosophy of nursing that pervades the patient care environment.				0.63	
24. An active quality assurance program.				0.63	
31. Written, up-to-date care plans for all patients.			0.39	0.52	
16. A chief nursing officer is equal in power and authority to other top level hospital executives.				0.46	
28. Nursing care is based on a nursing rather than a medical model.				0.41	
27. A preceptor program for newly hired nurses.				0.39	
9. Enough registered nurses on staff to provide quality patient care.					0.84
12. Enough staff to get the work done.					0.81
Enough time and opportunity to discuss patient care problems with other nurses.					0.62
Adequate support services allow me to spend time with my patients.					0.36

Note. Factor loadings lower than 0.35 were hidden for more clear presentation of results.

Armonk, NY, USA), whereas CFA was done using IBM SPSS AMOS 23 for Windows (IBM Corp.).

### Results

The PCA conducted in the sample of Polish nurses extracted six factors with eigenvalues greater than 1, which explained 56% of the total variance. After varimax rotation, each of the factors explained 14.9%, 9.3%, 8.3%, 8.2%, 7.7%, and 7.6% of the total variance of the analyzed set of items, respectively. However, the obtained structure was substantially different from the

theoretically driven factor structure of the PES-NWI based on the work of Lake (2002) and Li et al. (2007). Thus, we considered forcing the procedure to extract five factors, omitting the sixth factor with an eigenvalue of 1.06, while the factors with an eigenvalue greater than 1.2 were retained. The obtained factor structure then appeared to be closer to the theoretically driven structure of the PES-NWI. The five extracted factors explained together 52.7% of total variance of 32 items included in the PES-NWI used in the study.

According to the varimax rotated solution presented in **Table 1**, the first factor, explaining 14.9% of total

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variance, included eight items and may be defined as collegial nurse–physician relationships and collegial work (in short, relations). The second factor of the presented PCA solution explained 10.4% of total variance and was highly loaded by five items, which may be interpreted as nurse managerial ability, leadership, and support of nurses (in short, support). The third factor, explaining 10.1% of total variance, included seven items, which may be described as nurse participation in hospital affairs (in short, participation). The fourth factor, explaining 9.5% of the total variance, was defined by eight items and may be interpreted as the nursing foundation for the quality of care (in short, foundations). The fifth factor, explaining 7.8% of total variance, and may be described as adequacy of staffing and resources (in short, staffing).

The difference between this five-factor version and the initial six-factor one concerned different item locations mainly in the third (participation) and the fourth (foundations) factors of the five-factor version. The foundations factor was split into two factors, which could be defined as the nurses' competence factor (items 15, 16, 19, 20, and 24) and organization of work factor (items 27, 28, and 31). These were also complemented by items 25, 29, and 32, which were moved from the participation factor of the five-factor version.

## **Confirmatory Factor Analysis**

In order to test how the original factor structure was replicated in Polish cultural conditions, the CFA was conducted. In the case of both models, one theory based and the other data driven, the submodels with five nonorthogonal factors fitted data the best. What was expressed in lower chi-square and RMSEA statistics values and higher values of other goodness-of-fit measures further confirmed the results. The Polish models fitted data better, as expected, since they were based on the above PCA results. The highest values of CFI and NFI coefficients almost reached a level of 0.9, and the lowest value of RMSEA was close to 0.05. The differences in goodness-of-fit measures for the theory-driven model and the data-driven one were rather small: for the CFI coefficient they did not exceed 0.02, and for RMSEA they did not exceed 0.005. Since the two oblique models were not nested in each other, there was no way to test if the difference between them was significant (Table 2).

# **Reliability of PCA-Extracted Subscales**

The reliability of total score (including all 32 items), measured with the Cronbach's alpha coefficient, was estimated to be equal to 0.93, and further analysis showed that removing any of the items from the scale

**Table 2.** Selected Measures of Models' Goodness of Fit for Confirmatory Factor Analysis of Theoretically Driven and Data-Driven Factor Structures of the Practice Environment Scale of the Nursing Work Index

	RN4CAST	
	theoretical	Polish data-driven
Model/measure	structure	structure
	Chi-square/df/p	Chi-square/df/p
1 dimension	5871.17/464/.000	5334.44/464/.000
5 orthogonal factors	9454.86/464/.000	8633.29/464/.000
5 correlated factors	4645.72/454/.000	4068.82/454/.000
	RMSEA/90% CI/p	RMSEA/90% CI/p
1 dimension	0.067/0.065-	0.063/0.062-
	0.068/0.000	0.065/.000
5 orthogonal factors	0.086/0.085-	0.082/0.081-
	0.088/.000	0.084/.000
5 correlated factors	0.060/0.058-	0.055/0.054-
	0.061/0.000	0.057/.000
	NFI/CFI	NFI/CFI
1 dimension	0.82/0.83	0.84/0.85
5 orthogonal factors	0.71/0.72	0.73/0.74
5 correlated factors	0.86/0.87	0.87/0.89

*Note.* CFI, Comparative Fit Index; CI, confidence interval; NFI, Normed Fit Index; RMSEA, root mean square error of approximation.

did not cause an increase of the alpha value. The analysis of discriminative power of the items revealed that only in the case of three items (namely, 15, 20, and 31) did the corrected item total correlation not exceed 0.4, and the lowest one was equal to 0.3. Subscales based on extracted factors, as defined by location of the highest factor loading for a particular item, reached a reliability of 0.89 for the relations subscale, 0.81 for the support measurement, 0.80 for the participation dimension, 0.76 for the foundations subscale, and 0.72 for the staffing dimension.

All items from the nurse-physician relationships subscale correlated sufficiently high with the total score of the subscale; however, two items (14 and 17) did not cause any change in value of the Cronbach's alpha coefficient when removed from the subscale. This suggested that none of them brings any additional information about the variability of the latent variable measured by the subscale. The similar observation concerned items belonging to the support subscale, where all items correlated highly with the subscale's total score. One item, number 11, also caused no change in the Cronbach's alpha value when removed from the subscale. Concerning the participation subscale, all its items, except item 32, correlated with the subscale's total score higher than 0.4, but decreased the Cronbach's alpha value when removed from the subscale. Among items belonging to the foundations subscale, none of them increased the alpha coefficient when removed from the subscale, but

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item 20 correlated with the subscale's total score, with a value lower than 0.4.

Regarding the staffing subscale, item 1 correlated below 0.4 with its total score and led to an increase of the Cronbach's alpha coefficient when removed from the subscale. Exclusion of this item from the subscale led to construction of a three-item subscale, with the Cronbach's alpha coefficient equal to 0.76. However, the scaling properties of item 8 worsened simultaneously. Correlation of item 8 with the subscale's total score was still higher than 0.4, but its removal led to increase of the Cronbach's alpha coefficient value. Removing this item from the subscale would lead to construction of the two-item subscale, with the Cronbach's alpha equal to 0.82. Attempts to include these two items (i.e., 1 and 8) into other subscales showed that they improved the reliability of the foundations subscales only, but they correlated with its total score at a level lower than 0.4. Finally, both items were retained in the staffing subscale, as suggested by the results of the PCA.

For item 17, inclusion in the different subscales increased the reliability of the participation, foundations, and support subscales. In turn, items 14 and 32, when included in the support and foundations subscales, reinforced the theoretical assumptions behind the instrument; the reliability of the support subscale increased to 0.82. Removing item 14 slightly decreased the Cronbach's alpha value, whereas reliability of the foundations subscale increased to 0.78. The psychometric properties of item 20 improved, whereas removing it did not lead to an increase in the Cronbach's alpha value. Nonetheless, it still correlated with the total subscale's score lower than 0.4. The incorporation of item 11 in the participation dimension increased the reliability of this subscale to 0.82, and all item total correlations for this subscale were higher than 0.4; removing any of the items from this subscale did not increase the Cronbach's alpha coefficient.

### **Reliability of Theoretically Driven Subscales**

Since the factor structure of the Polish translation of the PES-NWI derived from the PCA differed from that based on the works of Lake (2002) and Li et al. (2007), we then estimated the reliability of measurement conducted using the original subscales of the PES-NWI. This analysis showed that all five subscales were, at least, characterized by acceptable reliability: 0.89 for the relations subscale, 0.78 for the support measurement, 0.82 for the participation dimension, 0.78 for the foundations subscale, and 0.72 for the staffing subscale, respectively. None of the items, except item 1, increased the Cronbach's alpha coefficient when removed from the subscale. Furthermore, items 14, 16, and 17 caused no

change in the Cronbach's alpha coefficient value of their subscales when removed from the subscale. As the reliability of theoretically driven subscales was checked in case the subscales' variation differed, we determined that the results were as good as those built on an empirical basis. Its internal consistency was even better: only items 1 and 20 correlated with their subscales' total scores at the level lower than 0.4.

## **Relationships Between Subscales**

The zero-order correlations between subscales based on the five-factor PCA solution (see Table 1) varied from 0.45 to 0.63, supporting the thesis that the scale measures five non-overlapping latent variables. The partial correlations (when controlling for all other dimensions of the PES-NWI) varied from 0.09 to 0.33, therein demonstrating that the real amount of variance shared by every two dimensions of the PES-NWI in the sample of Polish nurses did not exceed 10% (the value of the highest correlation squared). Similarly, the zero-order correlations between theoretically driven subscales varied from 0.41 to 0.61, whereas the partial correlations (when controlling for all other dimensions of the PES-NWI) varied from 0.06 to 0.33. The differences in values of correlation coefficients for the particular subscales' pairs—created based on the theoretically driven and empirically obtained factor structures—did not exceed 0.04 in most pairs; it reached 0.07 solely in the case of correlations between the relations and the participation subscales. The respective differences for partial correlations coefficients did not exceed 0.05, except for 0.11 for the correlation value between the relations and the participation subscales (**Table 3**).

# Discussion

The results represent the first trial of cross-cultural adaptation of PES-NWI to an Eastern European country and revealed some differences between theoretically driven and PCA-obtained factor structures of the PES-NWI, as Table 4 illustrates. The theory-driven structure of the scale was five-dimensional, and particular dimensions were measured based on following a number of items, namely, foundations (nine items), participation (eight items), relations (seven items), support (four items), and staffing (four items; Li et al., 2007; Parker et al., 2010). In the Polish PCA solution, the components may be interpreted the same way as theoretically driven ones, which included 8, 7, 8, 5, and 4 items, respectively. The differences between the number of items defining dimensions were also connected to changes in sets of variables highly loading on a particular principal component.

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Table 3. Zero-Order and Partial Correlations Between Subscales of the Practice Environment Scale of the Nursing Work Index

	Relationships	Participation	Support	Foundations	Staffing
Empirically derived factor structure					
Relationships	1.00	0.10	0.31	0.20	0.20
Participation	0.52	1.00	0.33	0.33	0.19
Support	0.59	0.63	1.00	0.17	0.14
Foundations	0.53	0.61	0.56	1.00	0.09
Staffing	0.50	0.51	0.50	0.45	1.00
Theoretically driven factor structure					
Relationships	1.00	0.21	0.26	0.16	0.24
Participation	0.59	1.00	0.29	0.33	0.22
Support	0.57	0.61	1.00	0.16	0.11
Foundations	0.51	0.60	0.51	1.00	0.06
Staffing	0.52	0.53	0.46	0.41	1.00

Note. The numbers under the diameter of each part of the table present zero-order Pearson correlation coefficients, whereas the numbers above diameter present partial correlation coefficients, obtained after adjustment on all other dimensions of PES/NWI.

**Table 4.** Reliability of Subscales Based on Empirically Derived and Theoretically Driven Factor Structures of the Polish Practice Environment Scale of the Nursing Work Index

	E	Empirical		Theoretical		
Factor	Reliability	Number of items	Reliability	Number of items		
Relations	0.89	8	0.89	7		
Suport	0.81	5	0.78	4		
Participation	0.80	7	0.82	8		
Foundations	0.76	8	0.78	9		
Staffing	0.72	4	0.72	4		

These might be attributed to several factors, including differences in cultural and historical background of the nursing profession in the compared countries, as well as differences between samples and measurement tools used for each of the studies mentioned in the current article.

Since the version of the PES-NWI used in the RN4CAST study was based on the work of Parker et al. (2010) and Li et al. (2007), in that study they used a stratified random sample of 1,192 members of the Queensland Nurses Union and used a 30-item (of 31 items proposed by Lake [2002]) version of the PES-NWI. Whereas a study conducted by Li et al. (2007) on a sample of 6,623 registered staff nurses from acute care of Veterans Health Administration hospitals used the 55-item Nursing Work Index-Revised, complemented by some additional questions, some of them were later included in the RN4CAST PES-NWI theory-based version. The Polish sample included nurses from medical and surgical wards and resembled the sample from Li et al.'s (2007) study, whereas it differed from Parker et al.'s (2010) study.

It seems that observed differences between theorydriven and Polish empirical factor structures do not affect the reliability of measurement performed in Polish conditions using the original version of the scale. Reliability of measurement assessed using data-driven subscales of the PES-NWI was equal to or higher than that assessed with subscales based on the PCA solution in all dimensions except for "support." This may be explained by the fact that in the Polish PCA solution, the support subscale included five items instead of four as it had in the RN4CAST version of the PES-NWI. This finding is important because the value of the Cronbach's alpha reliability coefficient depends on the number of items in the scale and its mean intercorrelation (Cronbach, 1951). Obtained results do not deny the stability of the instrument's factor structure over different cultural conditions and sampling contexts.

The differences in factor structures, therefore, may be attributed to cross-cultural differences reflected in the functioning of the healthcare system in studied countries. For example, items 11 and 23, which originally belonged to the participation factor, were located in the support factor in Polish conditions. This might be related to the situation quite common in Polish hospitals where staff nurses consider a chief nurse as the person responsible for providing support for adequate patient care on the hospital level, rather than as an executive participating in creating top hospital policy (Stychno, Wdowiak, & Kruk, 2004).

Also, item 16 ("a chief nursing officer is equal in power and authority to other top level hospital executives"), which was located on the PES-NWI participation factor in Lake's (2002) analysis, was defined as the foundations indicator in the Polish factor structure. Changes in nursing's scope of practice in Poland may be explained by the fact that, in Poland, a staff nurse is aware of the limited influence (including that of the hospital chief

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nurse) of nursing on the hospital managerial policy. The title "chief nurse" as a role descriptor also presented problems during the broader RN4CAST translation process (Squires et al., 2013). For some countries, the "chief nurse" descriptor refers to the national head of nursing who works in the ministry of health. It appears that this is an item that is highly subject to misinterpretation by respondents and, therefore, may affect its reliability as a measure of equitable management representation by nurses in organizational governance.

Item 14, originally included in the support factor of theoretically driven PES-NWI structure, was located on the relations factor in the Polish solution. This might be explained by the fact that, despite important recent changes of the Polish healthcare system, a system of nurse assessment by nurse managers still has not been implemented in practice in a significant number of hospitals. The work of staff nurses has been evaluated not only by the ward head nurse but also by other team members, including chief of the ward (senior registrar), physicians, and colleague nurses, which directly affects the relationship between them.

Item 4, which was included in the foundations factor in the theoretically driven structure of the PES-NWI, fell into the participation factor in the Polish version. This shift might reflect growing personnel awareness of the necessity to participate in the professional education process among studied nurses. Recent changes in the educational system open the possibility of obtaining a baccalaureate degree not only for new young university candidates, but also for already registered nurses who had been certified by previously existing education systems (Ministry of Health, Department of Nurses and Midwives, 2010; Pawłowska & Doboszyńska, 2012). Polish nurses, however, are aware that nurse managers at different levels (ward and hospital) should be responsible for creating conditions that facilitate continuing vocational education. Different types of support, including motivation systems, training organized at the workplace, information concerning education offers outside the hospital, along with financial support and training leave, are expected from the managers as a form of participation in the hospital structure. There is a consensus among Polish nurses is that good organization of work, including regulations, staffing, staff qualifications, documentation, resources, equipment, and supervision, are essential in ensuring the continuity and quality of patient care (Deregowska et al., 2013). This would explain the stronger correlation of item 32 to the participation factor rather than to the foundations one, where it was originally included.

Other differences in items belonging to the particular factors might also be related to the history of the nursing profession in Poland (Majda, Ziarko, & Zalewska-

Puchala, 2015). When compared to the United States, where university-level, postgraduate, and life-long education started in the mid-twentieth century, in Poland nursing was recognized as an independent profession only in 1996 (Act on the Professions of Nurses and Midwives, 1996), while the first nurses started modern university education at the end of the 20th century (Pawłowska & Doboszyńska, 2012). In general, nursing's professional development in Poland has been progressing relatively slowly in comparison with the country's social, economic, and political situation. Several studies have indicated that high professional requirements, especially when confronted with difficult work conditions and weak management, increase professional stress level, deprive employees of professional safety, and decrease professional satisfaction among nurses (Klimak et al., 2000; Kulczycka & Stychno, 2012). These interactions are negatively accentuated by relatively low wages and limited chances of professional development and promotion (Jakimowicz Wołoszczek, Jakubowska, & Leźnicka, 2011). Other studies indicated limited engagement of hospital healthcare managerial authorities in nurses' professional development (Kobos, Leńczuk-Gruba, Idzik, & Sienkiewicz, 2010; Kulczycka & Stychno, 2012). All above-mentioned arguments appear to have influenced the factor structure of the Polish version of the PES-NWI.

Our results, therefore, further demonstrate the importance of understanding the country context when explaining or accounting for variations in the factor structure of the PES-NWI. These results should not be interpreted as the instrument being unable to compare nursing work environments across countries, but rather as a signal that the items measuring particular dimensions of the nursing work environment may vary in different countries. The factor analysis results provide clues into where variation occurs. Reflecting upon the meaning of the sampling design when adopting an instrument from a different language and cultural background in the particular country settings is another important step.

## Limitations

The criteria for selecting the hospital samples included providing 24/7 acute care, hospital reference level, and density of the population in the *voivodeship*, a Polish term used to describe each of the 16 country's administrative provinces. Consequently, no hospitals lower than the *voivodeship* referral level, especially from low-population-density regions, were represented. Moreover, the study was conducted only among nurses working at medical and surgical wards, so it is difficult to say whether including nurses from other types of wards and from other

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hospitals would change the factor structure of the scale. It cannot be ruled out that including nurses from other hospital types or even from other types of wards in the studied hospital might change the factor structure observed in this study due to variations in specialized practice.

# **Conclusions and Implications**

The theoretically driven factor structure of the PES-NWI was stable and resulted in slightly higher reliability coefficients than those obtained for subscales defined on the PCA solution for Polish adaptation. Both PES-NWI versions, the theoretically derived one and the PCA based one, are adequate for use in Polish settings. The results of this study suggest that managers and researchers can have confidence that the results obtained with both versions of the Practice Environment Scale of the Nursing Work Index-Revised come from reliable and valid instruments capable of capturing the country-specific working conditions for nurses. They can use the findings to guide organizational changes supportive of nursing personnel. Implementing these evidence-based changes have the potential to positively affect patient outcomes, as many international studies have shown. We recommend, however, that researchers carefully compare the theoretically driven baseline factor structure. Finally, these results further support the need for rigor in the instrument translation approach as an important part of the cross-cultural adaptation process of any survey instrument, but particularly those that reflect a health system's "administrative" language.

### **Clinical Resources**

- RN4CAST Study: http://rn4cast.eu/en/
- "A Systematic Survey Instrument Translation Process for Multi-Country, Comparative Health Workforce Studies": http://www.sciencedirect.com/science/article/pii/S0020748912000600

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### **HEALTH POLICY AND SYSTEMS**

# **Employment and Wage Disparities for Nurses With Activity Limitations**

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### Abstract

**Purpose:** No studies quantify the labor market disparities between nurses with and without activity difficulties (physical impairment or disability). We explore disparate treatment of nurses with activity difficulties at three margins of the labor market: the ability to get a job, the relative wage rate offered once a nurse has a job, and the annual hours of work given that wage rate.

**Design:** Key variables from the American Community Survey (ACS) were analyzed, including basic demographic information, wages, hours of work, and employment status of registered nurses from 2006 to 2014.

**Findings:** Although there is relatively little disparity in hourly wages, there is enormous disparity in the disabled's employment and hours of work opportunities, and hence a moderate amount of disparity in annual wages.

**Conclusions:** This has significant implications for the nursing labor force, particularly as the nursing workforce continues to age and physical limitations or disabilities increase by 15-fold from 25 to 65 years of age.

**Clinical Relevance:** Physical or psychological difficulties increase sharply over the course of a nurse's career, and employers must heighten efforts to facilitate an aging workforce and provide appropriate job accommodations for nurses with activity limitations.

Though a few studies have examined the determinants of work-related illness and injuries on nurses (O'Brien-Pallas et al., 2004), no studies have quantified labor market disparities between nurses without long-term activity difficulties and nurses with long-term activity difficulties (i.e., with some sort of physical or mental impairment). The question of labor market disparities for this occupational group is especially interesting, as nursing is universally referred to as one of the caring occupations (England, 2005). So an interesting issue is how the "caring profession" cares for its own, especially in a profession where physical or psychological difficulties increase sharply over the course of their own careers (Wray, Aspland, Gibson, Stimpson, & Watson, 2009), and in a profession that faces additional stresses associated with treating an aging population (Kennedy, 2005).

Disparate outcomes for nurses with activity limitations does not necessarily imply market discrimination against such nurses, where discrimination means disparate treatment where productivity is equivalent. In this article, we examine the extent to which annual total wage or salary disparities are due to such discriminatory treatment, and the extent to which it is due to voluntary choice, by decomposing annual wages into work participation, hours, and hourly wage components. If annual wage disparities were due to discriminatory treatment of those with activity limitations, it is mostly likely to be exhibited in differences in hourly wage rates: discriminating hospitals (who have a demand for nursing services) would be paying lower wages to nurses with activity limitations. On the other hand, if such disparities were the result of supply differences—nurses with activity limitations choosing to work less—then the disparities would be reflected more in chosen hours of work rather than hourly pay. We examine both in this article.

Labor market discrimination is an important problem for persons with activity limitations across many occupations. Baldwin and Johnson (1994, 2000) found unexplained wage differentials (after controlling for factors relating to potential productivity differences) between non-disabled and disabled men that reduced the wages of working men and discouraged others from accepting employment. Employment opportunities were an even more significant problem than wage discrimination, as only a small fraction of the large differences in employment rates were attributable to wage discrimination.

Labor market discrimination for disabled persons, coupled with gender inequality in the U.S. labor market, may pose additional challenges for nurses, who are predominantly female. Whatever the cause, jobs dominated by females pay less on average than jobs dominated by males, and women's occupations pay less than male-dominated occupations in other countries as well (England, 2005). In this study, we explore and quantify the disparate treatment of nurses with activity difficulties at three margins of labor market activity: the ability to get a job, the relative wage rate offered once a nurse has a job, and the annual hours of work given that wage rate (or equivalently, total annual wage and salary income as a nurse).

### Methods

# Annual Wage and Employment Regressions, Data Sources, and Means

The American Community Survey (ACS; U.S. Census Bureau, 2014) is an ongoing, extensive governmental survey of the population that includes basic demographic information, wages, hours of work, and employment status, with consistently defined variables key to our analysis. A representative sample of about 30,000 registered nurses (RNs) is contained in each year's sample of the ACS. Moreover, these data also contain "difficulties with daily activities" measures, which we employ as our variable of principal interest, used to measure the impact of dressing difficulties, uncorrectable vision or hearing problems, difficulties with physical activities, difficulties with memory, and difficulties with independent living. Our sample, from 2006 to 2014, is limited to those whose occupation is self-identified as an RN in their current or most recent job, and whose ages are between 25 and 70 years.

To sort out the effect that "difficulties with daily activities" has on measures of annual wages, wage rate, and employment probability, we take advantage of the following relationships: since log(annual wages) =  $log(hourly wage rate \times number of annual hours) =$ log(hourly wage rate) + log(annual hours), if we know the regression of log(annual wages) and log(hourly wage rate) on our independent variables, then we automatically know the coefficients of the regression of log(annual hours) on the independent variables (since regressions are linear mathematical operators). For example, if the coefficient of males in the log(annual wages) regression is 0.2 (males make 20% more than females with similar sociodemographic status), and the coefficient of males in the log(hourly wage rate) were 0.05 (the male nurse wage rate is 5% higher than the female nurse wage rate), then the male coefficient in the hours regression is 0.15 (0.05 + 0.15 = 0.2). Hence, in the regressions below we present evidence on annual wages, hourly wages (so we can infer the regression on annual hours), and the likelihood of employment.

To anticipate those results below, where we estimate our models for every year the activities difficulties are consistently reported (2006 to 2014), we find that there is little disparity associated with activity limitations in the implied wage rate for our sample of nurses. The real disparities in outcomes are associated with differences in hours of work, which differences are highly correlated (in terms of regression coefficient signs and magnitudes) in the hours regressions and in the employment regressions. It is at these margins of work, employment at all and hours of work if employed, where the disparity really lies, and this in turn generates a substantial disparity in annual wage and salary incomes.

### **Means of the Key Variables**

Table 1 provides the most recent ACS data (U.S. Census Bureau, 2014) on RNs and reflects the following survey questions: "Is this person deaf or does he or she have serious difficulty hearing?" (ear or eye difficulty); "Is this person blind or does he or she have serious difficulty seeing even when wearing glasses?" (ear or eye difficulty); "Because of a physical, mental, or emotional condition, does this person have serious difficulty concentrating, remembering, or making decisions?" (memory difficulty); "Does this person have serious difficulty walking or climbing stairs?" (physical difficulty); "Does this person have difficulty dressing or bathing?" (dressing difficulty); "Because of a physical, mental, or emotional condition, does this person have difficulty doing errands alone such as visiting a doctor's office or shopping?" (independent living difficulty).

**Table 1.** Descriptive Statistics: 2014 American Community Survey Data (N = 30,035 Registered Nurses)

	Nurse	s only
	Mean	SD
Ln (annual wage)	10.783	0.774
Ln (hourly wage)	3.394	0.530
Employment	0.851	0.355
Dressing difficulty	0.003	0.063
Ear/eye difficulty	0.019	0.138
Independent living difficulty	0.006	0.078
Physical difficulty	0.018	0.133
Memory difficulty	0.007	0.087
Male	0.098	0.298
Number of children	0.726	1.069
Married	0.683	0.465
Black	0.090	0.287
Hispanic	0.053	0.225
Bad English	0.004	0.069

Note. "Bad English" = 1 if the nurse does not speak English or cannot speak it well. All data are from the American Community Survey, retrieved from Dataferrett (U.S. Census Bureau, 2015). Ln = natural logarithm transformation.

# **Findings**

### **Regression Results**

The most recent results (2014 American Community Survey panel; U.S. Census Bureau, 2015) are presented in **Table 2**: the log of annual wages and log of hourly wages are regressed on the detailed list of sociodemographic variables (including activity limitations) in the left-hand columns, and the right hand column of employment outcomes are estimated with a linear probability model (for ease of interpretation).

As seen in virtually all other studies of North American labor markets, some groups make more than others: male nurses have higher wages (17% more than female nurses), Blacks have lower wage rates (Black nurses make 5% less than White nurses per hour, but they work more hours so that total annual wages are not significantly different from White annual earnings), Hispanic nurses make 7.5% less than non-Hispanic Whites per hour, and those who speak good English make 23% more (the annual wage is 23% higher because the wage rate is 23% higher [there is no hours effect], but the employment rate of English speakers is 9.7% higher than that of non-English speakers). Not shown here, but included in the analysis: wage income increases with age (up to about age 55 years in the 2013 sample), while employment is highest in the mid-forties. This is consistent with data from the U.S. Census Bureau and Bureau of Labor Statistics (2010), which reported that nurses 45 to

54 years of age replaced those 35 to 44 years of age as the largest age group of RNs in the United States, reflected by the median RN age of 42.4 years in 2000 and 45.4 years in 2009 (Juraschek, Zhang, Ranganathan, & Lin, 2012). The effect of educational attainment, given that one is an RN and of a certain age, shows no particular trend.

Among working adults 25 to 70 years of age, in 2014 annual wages were lowest for those with dressing difficulties (40% lower), independent living difficulties (25% lower), and memory difficulties (30% lower). This is almost completely an hours effect, as the wage rate differentials are minimal. Moreover, the hours effect is duplicated in employment likelihood in our linear probability models: employment (about 85% of self-identified nurses are employed and at work) falls with dressing difficulties (7% lower), independent living difficulties (34% lower), and memory difficulties (24% lower).

**Table 3** presents only the difficult activities variable coefficients, year by year, but all specifications included all the variables as in **Table 2** for 2014 (including an exhaustive list of age and educational attainment dummy variables). Again, as for 2014, in all years since 2006, "memory difficulty" and "independent living difficulty" have large negative effects, all due to strong hours effects (reductions) and decreased employment opportunities. For example, in 2012, holding all other effects constant, a nurse who reported memory difficulties made 44% less and had a lower likelihood of being employed by more than 30% than a nurse without memory difficulties. Hourly wages were less variable; that is, a nurse who reported a memory loss made 1.4% less than a non-disabled nurse.

The several years of results reported in **Table 3** indicate how the recent business cycle might have affected those with activity limitations. For example, it is well known that blue collar and white collar workers experience quite different labor market outcomes in recessions. The deleterious outcomes for those with activity limitations does not appear to be cyclical, but rather a persistent structural phenomenon unlikely to improve much even if economic activity in the healthcare sector expanded substantially.

# **Regression Gini Index**

We believe the single best summary measure of disparity is the following: what would be the average percentile shift in the "disabled" (we use this term to capture "difficult activity" conditions in our discussion here) nurses' outcomes if they had similar wage and employment outcomes to the "abled" nurses' outcomes, when all sociodemographic characteristics, except the disability, are held constant. We call this the regression Gini index (RGI, when the percentile shift is multiplied by 2).

Table 2. 2014 Nurse Wage/Employment Regressions and the Activities Impairment Differential

	Annual v	vages	Hourly v	vages	Employment	
	Coefficient	р	Coefficient	р	Coefficient	р
Intercept	10.470	<.0001	3.626	<.0001	0.325	<.0001
Dressing difficulty	-0.396	<.0001	-0.106	.0436	-0.070	.0033
Ear/eye difficulty	-0.029	.3398	-0.056	.0074	-0.052	<.0001
Independent living difficulty	-0.252	<.0001	0.023	.5916	-0.345	<.0001
Physical difficulty	-0.147	<.0001	-0.067	.0049	-0.171	<.0001
Memory difficulty	-0.297	<.0001	-0.083	.0152	-0.243	<.0001
Male	0.170	<.0001	0.052	<.0001	0.024	<.0001
Number of children	-0.046	<.0001	0.001	.7351	-0.009	<.0001
Married	-0.053	<.0001	0.024	.0002	-0.022	<.0001
Black	-0.014	.3409	-0.051	<.0001	0.014	.0212
Hispanic	-0.028	.1425	-0.075	<.0001	0.024	.0023
Bad English	-0.229	.0002	-0.236	<.0001	-0.097	<.0001
$R^2$	.102	8	.121	7	.1992	
Sample size	30,05	53	30,0	53	33,0	48

Note. "Hourly wages" are annual wages divided by the product: weeks worked last years  $\times$  usual hours worked per week. "Bad English" = 1 if the nurse does not speak English or cannot speak it well. All regressions include dummy variables for each year of age, dummy variables for each year of educational attainment, and dummy variables for state of residence, which are not reported here. All data are from the American Community Survey, retrieved from Dataferrett (U.S. Census Bureau, 2015).

At one extreme, given their characteristics, perhaps a sample of the disabled had predicted employment probabilities of 49% or less (their predicted outcomes given their own regression coefficients). So the 49% probability of employment would be the 100th percentile given the distribution of their current outcomes. But suppose they then were shifted to receive abled nurses employment outcomes, in the sense that their employment prospects—given their sociodemographic characteristics (except for the activity limitation)—were improved to those of the abled body. Indeed, suppose that the shift was sufficiently great that the lowest predicted probability for the disabled now became, if they were treated just like the abled nurses (i.e., the disabled were shifted up from their current regression outcomes to the abled regression outcomes), a 51% chance of employment. Hence, there is no overlap between their current outcomes and their "as if" outcomes (outcomes as if they were treated like the abled nurses). Everyone's percentile would shift from its current level to the 100th percentile level; the average percentile shift would be 50% (0.5); and two times this average percentile shift would indicate the average degree of disparity (given the characteristics of the disabled). The RGI = 1 in this case would indicate complete disparity (i.e., once the disabled are treated just like the abled, every disabled person is better off now than the best disabled person was before). Similarly, 0 indicates no disparate treatment on average. RGI = -1would indicate no overlap between the disabled and abled, but in a way that favors the disabled group. RGI is bounded between -1 (the disabled, each, are doing better than the non-disabled, all) and +1 (the non-disabled are all doing better than the disabled, so there is no overlap in the disabled and the "as if" non-disabled distributions). As an RGI value of 0 indicates no disparities between the groups on average, the closer that RGI is to 0, the more equal the labor market treatment between the two groups.

**Table 4** presents these disparity calculations (controlling for all the variables in the regression, and the distribution of the disabled across those sociodemographic partitions) using the RGI from 2006 to 2014. The Gini index, without multivariate corrections, is the most common single index of welfare in the world. The RGI is the multivariate extension of the usual Gini index. The statistical foundation for the RGI, developed to control for differences between treatment and control groups when making comparisons, was explained in Butler and McDonald (1987) and applied (and further explained) in Butler, Wilson, and Johnson (2012).

As suggested by the regression results, there is relatively little disparity in the hourly wages between the abled and disabled. But there is enormous disparity in the disabled's employment and hours of work opportunities, and hence a moderate amount of disparity in annual wages. For example, a nurse who reported some sort of physical or mental impairment or disability in 2009 made, on average, 33.6% less and had a nearly 64% lower likelihood of being employed relative to nurses without physical impairments or activity limitations.

**Table 3.** Estimated Impairment Difficulty Effects by Year for Registered Nurses

	Annual v	vages	Hourly wages		Employ	ment
	Coefficient	р	Coefficient	р	Coefficient	р
2013 (n = 29,024)						
Dressing difficulty	-0.016	.8208	-0.120	.0133	-0.019	.4004
Ear/eye difficulty	-0.006	.8289	-0.004	.8189	-0.002	.8039
Independent living difficulty	-0.287	<.0001	0.062	.1059	-0.350	<.0001
Physical difficulty	-0.128	.0001	-0.046	.0382	-0.199	<.0001
Memory difficulty	-0.240	<.0001	-0.015	.6340	-0.219	<.0001
2012 (n = 28,585)						
Dressing difficulty	-0.064	.3821	-0.024	.6366	-0.089	.0002
Ear/eye difficulty	-0.080	.0185	-0.017	.4460	-0.040	.0021
Independent living difficulty	-0.273	<.0001	0.018	.6855	-0.304	<.0001
Physical difficulty	-0.094	.0069	-0.034	.1526	-0.196	<.0001
Memory difficulty	-0.442	<.0001	-0.140	.0002	-0.301	<.0001
2011 (n = 27,621)						
Dressing difficulty	-0.111	.1360	-0.056	.2700	-0.078	.0011
Ear/eye difficulty	0.042	.2177	0.025	.2900	-0.010	.4522
Independent living difficulty	-0.270	<.0001	-0.155	.0003	-0.330	<.0001
Physical difficulty	-0.075	.0277	0.009	.6947	-0.174	<.0001
Memory difficulty	-0.453	<.0001	-0.165	<.0001	-0.266	<.0001
2010 (n = 28,217)						
Dressing difficulty	-0.151	.0391	0.013	.7826	-0.070	.0028
Ear/eye difficulty	-0.008	.8164	0.017	.4449	-0.055	<.0001
Independent living difficulty	-0.248	<.0001	-0.009	.8166	-0.376	<.0001
Physical difficulty	-0.079	.0221	-0.063	.0073	-0.185	<.0001
Memory difficulty	-0.277	<.0001	-0.089	.0144	-0.212	<.0001
2009 (n = 29,824)						
Dressing difficulty	0.118	.1104	0.149	.0034	-0.080	.0009
Ear/eye difficulty	-0.010	.7470	-0.017	.4487	-0.012	.3616
Independent living difficulty	-0.222	.0003	0.007	.8534	-0.385	<.0001
Physical difficulty	-0.110	.0006	-0.051	.0207	-0.170	<.0001
Memory difficulty	-0.462	<.0001	-0.197	<.0001	-0.200	<.0001
2008 (n = 28,951)						
Dressing difficulty	0.089	.2572	0.109	.0396	-0.107	<.0001
Ear/eye difficulty	-0.064	.2002	-0.086	.0112	0.035	.0627
Independent living difficulty	-0.330	<.0001	-0.008	.8384	-0.355	<.0001
Physical difficulty	-0.149	<.0001	-0.071	.0008	-0.156	<.0001
Memory difficulty	-0.284	<.0001	-0.051	.1591	-0.209	<.0001
2007 (n = 14,163)						
Dressing difficulty	-0.159	.0551	0.019	.7527	-0.113	.0002
Ear/eye difficulty	-0.001	.9903	-0.026	.4976	0.033	.1508
Independent living difficulty	-0.174	.0166	0.094	.0740	-0.299	<.0001
Physical difficulty	-0.207	<.0001	-0.089	.0003	-0.195	<.0001
Memory difficulty	-0.370	<.0001	0.019	.6617	-0.228	<.0001
2006 (n = 13,817)						
Dressing difficulty	-0.271	.0085	-0.095	.1834	-0.154	<.0001
Ear/eye difficulty	-0.060	.2946	-0.004	.9092	-0.064	.0047
Independent living difficulty	-0.119	.1835	0.121	.0512	-0.273	<.0001
Physical difficulty	-0.102	.0055	-0.026	.3134	-0.177	<.0001
Memory difficulty	-0.312	<.0001	-0.096	.0411	-0.277	<.0001

Note. All specifications include the same variables as in Table 2, though only the "difficulties with respective activity" variables are reported here.

**Table 4.** Regression Gini Indices, 2014–2006: Activity-Impaired Nurses Relative to Nonimpaired Nurses

Year	Annual wages	Hourly wages	Employment
2014	.360	.228	.673
2013	.306	.115	.687
2012	.339	.101	.740
2011	.290	.121	.738
2010	.265	.139	.769
2009	.336	.146	.637
2008	.315	.133	.687
2007	.489	.215	.783
2006	.295	.084	.749

Note. The regression Gini indices are (twice) the percentile shift in the respective outcome, when those with "activity difficulties" are treated in the marketplace just like those without any activity difficulties. All specifications included dummy variables for states, individual ages, and individual years of education, as well as all the variables in Table 2 except the activity-difficulty variables (as these are accounted for by the separate regressions used in the analysis).

Finally, we examine the disability type by age group for nurses from 2006 to 2014 (available upon request) for this sample of U.S. nurses. Not surprising, as the nursing cohort ages, there is a significant increase in the probability of the nurse having some sort of physical or mental impairment or disability. For example, in 2014, less than 1.4% of working nurses 25 to 29 years of age were working with a disability. For nurses that same year 60 to 64 years of age, 11% were working with a disability, and for nurses 65 and older, nearly 13% were working with some sort of physical or mental impairment or disability. Likewise in 2006, 1.4% of nurses 25 to 29 years of age were working with a disability; for that same year, nearly 16% of nurses 65 and older were working with a physical or mental impairment or disability. Our data are consistent with other findings, where it is estimated that 10.4% of persons 21 to 64 years of age have a disability, and 25% of persons 65 to 74 years of age have a disability (Erickson, Lee, & von Schrader, 2014).

## **Discussion and Recommendations**

Nearly 40% of the RNs currently working are over 50 years of age (Auerbach, Buerhaus, & Staiger, 2015). Baby boomer RNs are continuing to work into their late fifties and sixties (Auerbach et al., 2015), which significantly increases the probability that nurses with activity limitations will be a substantial portion of the nursing workforce. In addition, employment among healthcare practitioner occupations is expected to increase by 21.4% and will result in almost 1.6 million new jobs, driven by an increasing demand for healthcare services (Bureau of

Labor Statistics [BLS], 2010). RNs will account for more than one third of the growth in this occupational group (BLS, 2010).

Nurses with a broad range of activity limitations are currently employed in the hospital setting (Wood & Marshall, 2010), although persons with activity limitations have historically been underrepresented in the nursing workforce. Matt (2008) reported that approximately 154,000 of the 2.2 million nurses surveyed in 2000 indicated they were employed in positions other than nursing because of disability or illness. For those nurses who do work with a disability, significant barriers can exist in getting and keeping jobs (Guillett, Neal-Boylan, & Lathrop, 2007), including acceptance by co-workers, supportive environment, organizational policies related to accommodations, and an understanding of how these physical limitations affect the nurse and the nurses' job performance (Guillett et al., 2007; Job Accommodation Network [JAN], 2011; Matt, 2008, 2011). Given the current data presented here, there is evidence that the issue of practicing nurses with physical or mental impairments or activity limitations will continue to grow in importance to the nursing workforce.

In the ACS data set, we find enormous disparity in the disabled's employment and hours of work opportunities, and therefore a moderate amount of disparity in annual wages. Hours of work and employment choice are determined by the interaction of supply (at what price does the nurse want to work, and for how long) and demand (what the hospital or healthcare institution is willing to do in employing the nurse, and under what circumstances; see Johnson, Butler, Harootunian, Wilson, & Linan [2016] for further elaboration of labor supply and demand in the nursing context). In this data set, as in other studies of disparity, we have no way of identifying exactly which it is—supply (want) or demand (willing to employ). However, because the wage rates are so close, there is some indication that at least some of the disparities in outcomes are due to the nurses' choices, given his or her disability.

We also have no way of determining whether nurses in the analysis are working 8- or 12-hr shifts. It is known that the likelihood of making a patient care error increases with longer nurse work hours (Rogers, Hwang, Scott, Aiken, & Dinges, 2004; Scott, Rogers, Hwang, & Zhang, 2006). Longer shifts also increase the likelihood of musculoskeletal disorders of the back, neck, and shoulder for nurses, as extended work hours increase exposure to the physical demands of patient care (Geiger-Brown & Trinkoff, 2010). Whether this ultimately relates to increases in nurses with activity limitations is possible but not completely understood.

# **Conclusions**

With nearly half of the current RNs over 50 years of age, annual retirements from the workforce will accelerate from 20,000 in 2005 to nearly 80,000 in the next 10 years. Although many nurses are retiring later than expected, nearly all of the baby boomer RNs will retire by 2030 (Auerbach et al., 2015). Until that time, according to the ACS data employed here, the likelihood of a nurse 65 or older developing a physical impairment or disability increases up to 15-fold compared to younger nurses entering the workforce (25–29 years of age). While the number of new graduates entering the RN workforce has more than doubled from 2001 to 2012 (U.S. Department of Health and Human Services, 2014), the changing of the RN demographics will take place only gradually over the next few decades.

In the meantime, there remain a substantial number of nurses who, as they continue to age, will experience increasing activity difficulties. Indeed, for nurses as a whole, these difficulties increase roughly 10-fold from the late twenties to the late sixties. Given that we now recognize this important shift in age-related difficulties, in addition to the healthcare industry's efforts to prevent nursing injuries, they can proactively—through explicit human resource agendas—provide job accommodations and counseling for nurses developing activity limitations. For example, employers can promote flexible schedules and alternative work assignments; create environments that foster acceptance and support of disabled nurses; and conduct a careful review of job descriptions to ensure essential job functions are accurately reflected and describe the professional nursing role (Guillett et al., 2007; Matt, 2011), including critical thinking and clinical judgment. Employers must also ensure all possible resources are being used to provide work accommodations, including consultation with the disabled nurse (JAN, 2011), and educate co-workers regarding how to interact with their peers with physical limitations (Matt, 2008). In so doing, the "caring" profession will begin caring for its own.

### **Clinical Resources**

- Americans with Disabilities Act: United States Department of Justice, Civil Rights Division: http:// www.ada.gov/
- Job Accommodation Network. Accommodating nurses ith disabilities: http://askjan.org/media/ nurses.html
- National Organization of Nurses with Disabilities: http://www.nond.org/

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### **HEALTH POLICY AND SYSTEMS**

# Rapid Response Teams: Is it Time to Reframe the Questions of Rapid Response Team Measurement?

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### Key words

Medical emergency teams, nurse–patient relations, nursing care, organizational culture, patient-centered care, rapid response system, rapid response team

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### Abstract

**Purpose:** The purpose of this article is to present an overview of rapid response team (RRT) history in the United States, provide a review of prior RRT effectiveness research, and propose the reframing of four new questions of RRT measurement that are designed to better understand RRTs in the context of contemporary nursing practice as well as patient outcomes.

**Organizing Construct:** RRTs were adopted in the United States because of their intuitive appeal, and despite a lack of evidence for their effectiveness. Subsequent studies used mortality and cardiac arrest rates to measure whether or not RRTs "work." Few studies have thoroughly examined the effect of RRTs on nurses and on nursing practice.

**Methods:** An extensive literature review provided the background. Suppositions and four critical, unanswered questions arising from the literature are suggested.

**Findings:** The results of RRT effectiveness, which have focused on patient-oriented outcomes, have been ambiguous, contradictory, and difficult to interpret. Additionally, they have not taken into account the multiple ways in which these teams have impacted nurses and nursing practice as well as patient outcomes.

**Conclusions:** What happens in terms of RRT process and utilization is likely to have a major impact on nurses and nursing care on general medical and surgical wards. What that impact will be depends on what we can learn from measuring with an expanded yardstick, in order to answer the question, "Do RRTs work?"

**Clinical Relevance:** Evidence for the benefits of RRTs depends on proper framing of questions relating to their effectiveness, including the multiple ways RRTs contribute to nursing efficacy.

The scientist is not a person who gives the right answers, he's one who asks the right questions.

-Claude Lévi-Strauss

For more than 20 years, we have been measuring whether or not rapid response teams (RRTs) are effective by asking, "Do rapid response teams reduce hospital mortality and cardiac arrest rates?" The answers, from numerous studies, have often been ambiguous and

contradictory (Bellomo et al., 2003; Hillman et al., 2005; Lee, Bishop, Hillman, & Daffurn, 1995; Offner, Heit, & Roberts, 2007). It is clear that RRTs are very much a part of the landscape of acute care hospitals today, representing an initiative that is here to stay. It is time to ask new questions that focus on how to obtain better value from these teams instead of questioning their validity.

This article utilizes our research and a literature review to launch us into asking more and different questions regarding RRTs. We will examine the RRT characteristics at 10 similarly functioning tertiary hospitals in Washington State (**Table 1**) that were a part of a large retrospective study of RRTs on hospital mortality, the full results of which are reported elsewhere (Salvatierra, Bindler, Corbett, Roll, & Daratha, 2014). We will review the history of RRT adoption in the United States, the studies conducted to date on the effectiveness of RRTs as measured primarily by survival criteria in one form or another. Finally, we will discuss the role of nurses in RRTs and the ways in which RRTs have an impact on nurses, patients, and patient families.

The current questions regarding RRT effectiveness that focus on patient outcomes have not begun to gauge the effect of RRTs on nurses and on nursing practice, despite the fact that nurses are at the bedside more than any other member of the healthcare team. Additionally, it is the nurse who almost always is the one to activate the RRT. Nurses are the major personnel that comprise RRTs in most facilities. Thus, we propose four new research questions that are designed to better understand RRTs in the context of contemporary nursing practice as well as patient outcomes.

# **Background**

RRTs represent one of the more visible and significant responses to the realization that some patients who should not die do die during hospitalization (Beaumont, Luettel, & Thomson, 2008; Berwick, Calkins, McCannon, & Hackbarth, 2006). The first rapid response system was launched in Australia in the early 1990s; these physicianled teams were known as the medical emergency team (MET; Bellomo et al., 2003; Hillman et al., 2005; Lee et al., 1995). Prior to the introduction of the MET or RRT, no option existed to provide the bedside nurse with additional expertise, consultation, and intervention for deteriorating patients.

Preceding RRT implementation in U.S. hospitals, when nurses at the bedside encountered a deteriorating patient they had three choices: call the patient's physician, deal with the patient's decline using institutional resources at hand, or if and when the decline worsened, call a code. There are problems with each of the three options: physicians can be slow to respond, or they may be inaccessible; most nursing units are not staffed to support care for deteriorating patients; and codes are reserved for cardiopulmonary arrests (Goldhill, Worthington, & Mulcahy, 1999).

Motivated by studies showing distressingly poor outcomes for patients who experienced cardiopulmonary arrest, and armed with the knowledge that there are premonitory signs prior to the arrest event, the intuitive appeal of a MET was undeniable. How could pre-arrest intervention by a team of critical care specialists not yield better outcomes? It seemed so obvious that by the time the concept of RRTs was first introduced in the United States, their implementation quickly led to rapid adoption despite conflicting clinical evidence. The Institute for Healthcare Improvement (IHI, 2009), The Joint Commission (2009), and the Robert Wood Johnson Foundation (2005) were all early endorsers and enforcers. However, their support was based on a handful of uncontrolled studies, most of them from other countries with medical delivery models that differed from those of the United States. Within a relatively short time span, two thirds of U.S. hospitals had an RRT in some form or another (Agency for Healthcare Research and Quality, 2013). Retrospectively, researchers asked, "Do RRTs save lives?" The answers were, "yes," "no," and "maybe." Some studies showed benefits, while others demonstrated no benefits or yielded ambiguous results (Bellomo et al., 2003; Bristow et al., 2000; Buist et al., 2002; Chan et al., 2008; Dacey et al., 2007; DeVita et al., 2004; Jolley, Bendyk, Holaday, Lombardozzi, & Harmon, 2007; Lee et al., 1995; Priestley et al., 2004; Salvatierra et al., 2014).

Until recently, attempts to resolve the literature gap of RRT effectiveness with meta-analyses have also been inconclusive. Earlier meta-analyses showed no improvements in adult hospital mortality following implementation of RRTs (Chan, Jain, Nallmothu, Berg, & Sasson, 2010; Winters & Weaver, 2013). However, the two most recently published meta-analysis found lower in-hospital cardiac arrest and mortality rates after RRT implementation (Maharaj, Raffaele, & Wendon, 2015; Solomon, Corwin, Barclay, Quddusi, & Dannenberg, 2016).

In response to the ambiguities about RRT outcomes that existed in the literature, we chose to examine in-hospital mortality rates from 10 similarly functioning large tertiary hospitals in Washington State. At the time of the study, it was the largest of its kind (Salvatierra et al., 2014). Utilizing data from the Washington State Comprehensive Hospital Abstract Reporting System (CHARS) database, we observed the mortality rate for 31 months prior to and following implementation of an RRT while controlling for a number of factors, including time, patient severity of illness, and other complexities of patient care (Salvatierra et al., 2014). Although we found reduced in-hospital mortality in the post-RRT implementation period in 6 of the 10 acute tertiary care hospitals examined, after adjusting for the long-term trend of decline in hospital mortality, the improved outcomes could not be attributed directly to RRT implementation (Salvatierra et al., 2014). Our study reflected the difficulty that other researchers have had in finding definitive evidence of RRT effectiveness.

Table 1. Select Rapid Response Team Characteristics Among Study Hospitals

Hospital ID	Year RRT started	Team members	RRT calls/ 1,000 discharges	Who can activate RRT	Calling criteria	Educational plan	Goal for response (min)	% annual D/C 2009
U	2007	CCRN RT	35	Anyone	Any Concern	Formal mandatory classes	5	2.8
Q	2006	CCRN, EDRN RT	263	Anyone	Clinical & qualitative indicator	Formal mandatory classes	Ŋ	4.7
ш	2006	CCRN, EDRN RT	52	Anyone	Clinical & qualitative indicator	Formal mandatory classes	15	3.2
	2006	CCRN, EDRN RT MD	17	Anyone	Clinical & qualitative indicator	Formal mandatory classes	S	2.5
<b>Y</b>	2005	CCRN RT	222	Anyone	MEWS	Formal mandatory classes	10	2.7
	2005	CCRN EDRN RT	16	Anyone	Clinical & qualitative indicator	Formal mandatory classes	15	5.7
В	2006	CCRN, EDRN RT	44	Anyone	Clinical & qualitative indicator	Formal mandatory classes	5	3.6
ш	2004	CCRN, EDRN RT	40	Anyone	MEWS	Informal, non-mandatory classes	10	2.6
エ	2004	Dedicated CCRN RT	80	Anyone	"Gut" of bedside nurse <sup>a</sup>	Informal classes	10	3.7
_	2005	CCRN, EDRN RT MD	33	Anyone	Clinical & qualitative indicator	Informal classes	5	3.0

Note. Shading indicates hospitals demonstrating reduction in risk of in-hospital mortality. Survey title: Timing and Processes Related to Implementation of Rapid Response Teams. CCRN = critical care registered nurse; D/C = discharge; EDRN = emergency department registered nurse; MD = medical doctor; MEWS = modified early warning systems; RT = respiratory therapist. <sup>a</sup>Results copied verbatim from survey.

**Table 1** provides information about the characteristics of the RRTs at each of the 10 hospitals included in our study (Salvatierra et al., 2014). Of interest is that the six hospitals demonstrating reduced mortality rates had only two process points in common: response time <15 min and a comprehensive, formal, and mandatory education plan for RRT implementation. Team composition and type of activation criteria did not appear to have any relationship with the reported results. The concept of "dose" within the context of the RRT domain implies that the greater the number of RRT calls (per 1,000 patients) within a hospital, the better the outcomes that are associated with RRT. However, our study did not support the previously reported results that a higher RRT dose is linked to improved outcomes and team composition (Jones, Bellomo & DeVita, 2009). In particular, having a physician on the team did not seem to have any influence on the outcome.

The varying results regarding RRT effectiveness as measured by in-hospital mortality and in-hospital cardiac arrests is hardly a surprise. RRTs are medically and organizationally complex undertakings subject to substantial variations in their implementation, adoption, and utilization within and between hospital cultures (Chan et al., 2008, 2010; Maharaj et al., 2015; Salvatierra et al., 2014; Winters & Weaver, 2013). Furthermore, despite each hospital's standardized assessment for identifying signs of deterioration, interinstitutional standardization in this area is lacking (DeVita, et al., 2006). Additionally, not all patients who are deteriorating can be saved; in fact, implementing life-saving interventions at the terminal phase of a patient's life can be painful and most often futile (Jones, Moran, Winters, & Welch, 2013).

# What Do RRTs Really Do?

The varying results of the multiple studies conducted on RRTs should cause researchers to step back and consider additional questions. The cumulative findings of previous RRT studies suggest that RRT research should be broadened to measure a far wider range of outcomes. It is now time to begin using a different measuring stick for deciding whether or not RRTs work. We should consider if we are missing key aspects of what RRTs really do.

Perhaps RRTs work in ways that contribute an indirect benefit to the patient and nursing staff, in addition to any direct effect. RRTs provide an option for higher-level assistance that did not previously exist in the hospital setting. RRTs are positioned to assure and reassure the nurses on the floor that they are not alone and do not have to wait until someone is so compromised that the only choice is to call a code. The fact that in many facilities, families can also activate the team has the potential

to provide families with a sense of autonomy and empowerment (Chen, Bellomo, Hillman, Flabouris, & Finfer, 2010). These factors have an impact on many aspects of the hospital ecosystem, yet several of these issues have not been well measured as they relate to RRTs. Research should be designed to discover all of the facets of what RRTs do, outside the measurement of survival statistics.

Whether the intuition that RRTs have an important role to play—in fact, several important roles—is not in question. What is in question is the way in which we have initially measured RRT success, because none of the previous measures have specifically assessed those roles. Perhaps it is time to ask different questions in order to more clearly understand the ways in which these teams influence nurses, nursing care, and patient outcomes. Instead of asking, "Do RRTs reduce in-hospital mortality from cardiac arrest?" maybe we should be asking—and researching—the following four crucial questions.

# Question 1: What Are the Best Measures of the Benefits That RRTs Provide?

Illness severity among hospitalized patients has increased significantly over the past 20 years. This increased patient acuity places a greater burden on existing nursing resources (Jennings, 2012; Jones, DeVita, & Bellomo, 2011). Of course, not all patients who are deteriorating can be or should be rescued. Rather, for many deteriorating patients who have a terminal illness, end-of-life care is needed. End-of-life care involves establishing a plan of care that provides a clear and valuable resource to provide safe care for acutely ill patients (Benin, Borgstrom, Jeng, Roumanis, & Horwitz, 2012; Cioffi, 2000; Donaldson, Shapiro, Scott, Foley, & Spetz, 2009; Shapiro, Donaldson, & Scott, 2010).

For a floor nurse, an RRT is situated below a code but above being left on one's own with what a nurse perceives to be a deteriorating patient. While there is no official diagnosis, medical or nursing, for "this patient doesn't seem right," nurses everywhere know the condition exists and is often detectable (DeVita & Winters, 2014; Donaldson et al., 2009).

Recognizing patient deterioration without having the resources to effectively address patient decline is futile and frustrating. Having reliable backup not only facilitates escalation of care in a patient experiencing deterioration, but it may also decrease perceived workload and increase nurses' satisfaction with their jobs. Nurses have described their satisfaction with RRTs in a variety of settings (Benin et al., 2012; Cioffi, 2000; DeVita et al., 2006; DeVita & Winters, 2014; Donaldson et al., 2009; Salamonson, van Heere, Everett & Davidson, 2006; Jones et al., 2006; Shapiro et al., 2010) and nursing care

environments have been linked to better patient outcomes and higher nurse satisfaction (Bagshaw et al., 2010).

The existence of an RRT has the potential to improve nursing workflow, because nurses have an option for higher-level assistance that did not previously exist in the hospital setting. However, the effects that RRT role has on nursing workflow (process) and outcomes are not well documented in the research literature.

RRTs enhance the importance of a floor nurse's decisions and autonomy. Their very existence should encourage nurses to intervene earlier and more aggressively, because now they have an option for doing so.

RRTs represent a patient-centered approach to care that depends on teamwork, collaboration, evidencebased practice, and informatics-key elements in the Institute of Medicine (IOM) report (Institute for Healthcare Improvement, 2009). The authors of the IOM report acknowledge the need for developing competencies within new care delivery models. RRTs represent a relatively new care delivery process whose effectiveness has the potential to be strengthened in almost every way, from standardization of calling criteria to the competencies of team members. This makes the role of both the RRT and the floor nurse more important, because they are linked in a tight feedback loop in which neither succeeds without the success of the other. The best measures of the benefits that RRTs provide include identifying and measuring changes in the care delivery process, measuring nurse satisfaction with RRTs, and establishing clear competencies.

# Question 2: Do RRTs Provide an Opportunity to Expand Nursing Skills and Improved Nursing Confidence?

By definition, the RRT team is composed of people with a high level of specialty expertise. RRTs can be composed of a variety of personnel; however, most include intensive care unit nurses. The clinical implications of the RRT from a nursing standpoint extend beyond "just assisting" in emergency situations. RRT nurses are in a position to also provide education and support for nurses on best responses to specific clinical situations. In this role, RRTs may serve as a mobile educational resource from which every nurse can learn, thus offering another real-life venue for skill improvement as well as bringing evidence-based practice to the bedside. From demonstrating infrequently used or new techniques to sharpening patient evaluation skills, every RRT call is a potential "teachable moment." Continuing education targeting the detectors, responders, and all persons involved in providing care has the potential to enhance

the skills of the RRTs and promotes the medical-surgical nurse's early recognition of patient failure.

RRTs have the potential to serve as a tool for helping nurses provide and deliver evidence-based treatment within the acute care environment. These teams should bring the latest evidence-based practice to the bedside, thus raising the knowledge and skill base of all nurses.

Several studies have identified the importance of having a well-defined triggering system or calling criteria by which nurses can base the decision to call the RRT. One of the frustrating aspects of the calling criteria relates to the inability of the different systems within the hospitals to communicate with each other. For example, nurses record patient vital signs into the nursing documentation area, while laboratory results commonly populate a different section of the electronic medical record (EMR); rarely have these two sections communicated with one another. Recently the capability to access fully automated, computerized data collection software that can analyze the triggers within different components of the electronic medical records (EMR) has been suggested. This capability would assist the bedside nurse and the RRT nurse in recognizing early clinical deterioration.

Ideally, RRTs should do more than just serve as a tool for helping nurses provide care and treatment to deteriorating patients within the acute care setting. We should be measuring whether RRTs provide an opportunity to expand nursing skills and improve nursing confidence through provision of education, application of evidence-based practice, and improvement in documentation that triggers RRT implementation.

# Question 3: What Criteria for Membership and Training Should Exist for RRTs?

One area regarding the RRT staff that is not well defined or described relates to team membership and the skills required to be a team member. Possessing excellent critical care skills does not translate to having excellent teaching skills, yet both are essential in the RRT role. One hospital found that the most effective RRT nurses were those who had excellent critical care clinical skills, as well as excellent communication and collaboration skills while also being comfortable teaching others (Aiken, Clarke, Sloane, Lake, & Cheney, 2008). Another study found that delays in activation were a result of poor interactions between the responding RRT nurse and the medical-surgical nurse (Braaten, 2015). Despite these findings related to the need for clinical expertise and communication skills, there is no standardized training or training requirement for RRT nurses and other personnel. Improving the function of the RRT calls for developing a standardized approach in the training and education of RRT members. Standardization of RRTs would provide a unified process for education, which would ensure that RRT members are not only critical care experts but also are strong communicators and collaborators (Caricati et al., 2016). Researchers should design studies that answer the question of what criteria for membership and training should exist for RRTs, and measure the outcomes on care and staff satisfaction.

# Question 4: Do RRTs Provide an Enhanced Level of Patient and Family Empowerment and Satisfaction?

Patient satisfaction is recognized as an important, quantified criterion for quality of care. Therefore, patientor family-activated RRTs provide a means for patients and their families to summon assistance if they feel the level of response by the floor or charge nurse is not satisfactory.

In our large, multicenter study (Salvatierra et al., 2014), all 10 of the hospitals supported family-activated RRT, which aligns with characteristics of patient- and family-centered care. Most patients expect a high level of autonomy and control over their treatment, and the option of summoning an RRT provides autonomy and control. While not all hospitals have instituted the practice of family-activated RRT, it is increasingly becoming the norm. Intuition or concern by staff or a family member has been cited as a common trigger and frequent reason for activation of the RRT (Benin et al., 2012). However, there is little research reporting how families are informed about their ability to trigger an RRT, how often their requests are appropriate, the feedback provided for families regarding outcome, or how the ability to call the RRT influences overall patient satisfaction. Researchers must design studies that measure whether RRTs provide an enhanced level of patient and family empowerment and satisfaction.

### Summary

RRTs have become an expected standard of care, are assumed to be an effective use of clinical resources, and their implementation has been linked to increased nurse and patient satisfaction. Despite what is known, many unanswered questions remain. There is a need for considerable additional research to understand RRT effectiveness related to an expanded view of its benefits, its effects on nursing skills and confidence, the need for standardization of RRT member training, and the relationship of the RRT to patient-family empowerment and satisfaction.

What happens in terms of RRT process and utilization is likely to have a major impact on nurses, healthcare

systems, and patient outcomes. What that impact will be depends on what we can learn from measuring RRT effects with an expanded yardstick. This article has suggested four new questions that will provide structure for research in order to answer the question, "Do RRTs work?"

# **Clinical Resources**

- Agency for Healthcare Research and Quality. Rapid response systems: https://psnet.ahrq.gov/primers/ primer/4/rapid-response-systems
- Institute for Healthcare Improvement. Rapid response teams: http://www.ihi.org/topics/ rapidresponseteams/pages/default.aspx
- Resuscitation Central. Rapid response and medical emergency teams: http://www.resuscitationcentral. com/documentation/rapid-response-medicalemergency-team/

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### PROFESSION AND SOCIETY

# **Study of Predatory Open Access Nursing Journals**

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#### Kev words

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### **Abstract**

**Purpose:** The purpose of this study was to identify predatory journals in nursing, describe their characteristics and editorial standards, and document experiences of authors, peer reviewers, and editors affiliated with these journals

**Design:** Using two sources that list predatory journals, the research team created a list of nursing journals. In Phase One, the team collected data on characteristics of predatory nursing journals such as types of articles published, article processing charge, and peer review process. In Phase Two, the team surveyed a sample of authors, reviewers, and editors to learn more about their experiences with their affiliated journals.

**Methods:** Data from the review of predatory nursing journals were analyzed using descriptive statistics. Written comments were summarized and categorized.

**Findings:** There were 140 predatory nursing journals from 75 publishers. Most journals were new, having been inaugurated in the past 1 to 2 years. One important finding was that many journals only published one or two volumes and then either ceased publishing or published fewer issues and articles after the first volume. Journal content varied widely, and some journals published content from dentistry and medicine, as well as nursing. Qualitative findings from the surveys confirmed previously published anecdotal evidence, including authors selecting journals based on spam emails and inability to halt publication of a manuscript, despite authors' requests to do so.

**Conclusions:** Predatory journals exist in nursing and bring with them many of the "red flags" that have been noted in the literature, including lack of transparency about editorial processes and misleading information promoted on websites. The number of journals is high enough to warrant concern in the discipline about erosion of our scholarly literature.

**Clinical Relevance:** Nurses rely on the published literature to provide evidence for high-quality, safe care that promotes optimal patient outcomes. Research published in journals that do not adhere to the highest standards of publishing excellence have the potential to compromise nursing scholarship and is an area of concern.

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Scholarly journals serve as a vehicle to communicate research findings, disseminate evidence to guide practice and teaching, and share innovations and new ideas. Journal articles provide information to answer specific clinical questions and are the critical link between research and practice, regardless of whether that practice is with patients, students, or other groups. Knowledge disseminated through scholarly journals builds the science base of a field and advances its development.

With the growth of the Internet, significant changes have occurred in scholarly publishing. Years ago journals were available in print form only. Today, many subscription journals now offer parallel electronic versions and frequently publish papers online ahead of print. There also are many journals that are published only online, including some specific to the discipline of nursing. As a result of these changes, a new model of publishing has emerged in the past two decades: open access. Articles published as scholarly open access are freely available via the Internet and not restricted by subscription or behind a paywall (Beall, 2016d). Offering articles in an electronic format, however, does not mean the journal is open access. Most nursing journals are not open access and continue to rely on a subscription model. To access the articles online or in print, individuals or libraries need to subscribe to the journal. Alternatively, readers who do not have access through a library can purchase an electronic version of an individual article for a fee

There are various models of open access. In one, often called gold open access (Harnad et al., 2004), authors pay a fee to the publisher, referred to as an article processing charge (APC), at the time of acceptance of a manuscript in the journal. These fees are what support the journal and its publishing processes, since there are no revenues from subscriptions or advertising. Other aspects of the publishing process, such as peer review, are the same as with a traditional print journal, although the turnaround time for peer review and publication of the article in electronic form is generally shorter. In the green open access model, authors are allowed to archive a manuscript or preprint version of their article in an institutional or other type of repository (Harnad et al., 2004; Shen & Björk, 2015). A hybrid model, in which traditional subscription journals offer open access, enables authors to pay the APC for their article to be freely available on the Internet in the electronic archive of the journal.

Unfortunately, the growth of open access publishing has led to a new phenomenon, termed "predatory publishing" and "predatory journals" (Beall, 2016d), also labeled as pseudo-journals (McGlynn, 2013). Predatory publishers have questionable practices and may be

in business only to collect the fees from authors for publishing their articles (Shen & Björk, 2015). These publishers typically charge an APC when the paper is accepted and provide a fast peer review and publication process. However, the peer review is often of low quality, and with some journals, papers are accepted without any peer review at all. Importantly, the articles published in predatory journals may not be digitally preserved. The publishers may be in business for a short period of time, and when they cease publication of their journals, the articles disappear.

Publishers also may falsely claim that articles are indexed in reputable bibliographic databases such as PubMed and the Cumulative Index to Nursing and Allied Health Literature (CINAHL) or misleadingly claim that articles are indexed in what are actually nonindexing or abstracting resources to make their articles appear to be stable and discoverable (Beall, 2015a). As a result, articles in predatory journals are not guaranteed to be available for others to easily locate as part of a literature search. To be indexed in PubMed or CINAHL, or to have a legitimate Thompson-Reuters Impact Factor, journals must complete a detailed application process and meet defined standards, which predatory journals are not able to demonstrate. If there is a claim on the website that a journal is indexed or has an "impact factor" score, typically these claims are either false or refer to fake indexes or scores.

These journals are growing at a fast pace: In 2011, there were 18 predatory open access publishers and now there are 923. In addition, there are 882 standalone predatory scholarly open access journals, up from 126 in 2013 (Beall, 2016a).

### **Purpose**

No studies have been done of predatory nursing journals. The purpose of this study was to identify predatory journals in nursing and describe characteristics of those journals and articles published in them, including the APCs, peer review and publication processes, and editors and editorial boards. In addition, a survey of authors, reviewers, and editors revealed more about their experiences with their affiliated journals.

# **Literature Review**

The available literature on predatory publishing is relatively small, with the majority centered on editorials, letters, and case studies to bring awareness to the issues concerning these journals and their practices. A few studies have attempted to describe the volume,

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characteristics, and influence of predatory publishing. The most comprehensive appeared in *BMC Medicine*, describing Shen and Björk's (2015) longitudinal study that examined the volume of predatory publishing. The authors estimated an increase in the number of articles published in predatory journals from 53,000 in 2010 to 420,000 in 2014 and an increase in the number of active predatory journals from 1,800 in 2010 to 8,000 in 2014. About three quarters of the authors published in predatory journals were from Asia and Africa.

Moher and Srivastava (2015) collected all emails that invited Moher to submit manuscripts to various journals over a 1-year period. Comparing the soliciting journals to the list of predatory publishers and journals maintained by Beall (2016b, 2016c), they found that 244 of 311 (78.5%) invitations were from predatory publishers, while the remainder contained predatory qualities, such as poor sentence structure and false claims. More than half (n = 179) of the invitations came from biomedical journals.

If predatory journals cannot be trusted in content or their review processes, what impact are they having on scholarly communication? A few researchers have approached this question from various angles, including citation counts. Nwagwu and Ojemeni (2015) performed a bibliometric analysis on two Nigerian predatory publishers and found that 32 journals had 12,596 citations in Google Scholar, with an estimated 394 citations per journal and 2.25 per paper. Worried about the possible presence of predatory articles in library databases available for student research, Nelson and Huffman (2015) studied the extent to which predatory journals were indexed in three library databases in 2014. They found six predatory journal titles in Gale Academic OneFile (0.04% of its content), 55 titles in EBSCO Academic Search Complete (0.4% of its content), and 299 titles in ProQuest Central (1.4% of its content). The most prominent subject areas of the indexed predatory journals included science (30.5%), medicine/health (21.8%), technology (20.1%), and business (14.2%).

Researchers also have studied the differences between predatory and traditional journals to improve the ability to differentiate between them. Wicherts (2016) developed an instrument to analyze the transparency of the peer review process in predatory, open access, and traditional journals. Raters then analyzed 31 journals and found that publishers of predatory journals had the least transparency of their peer review processes. Markowitz, Powell, and Hancock (2014, June) performed a language analysis of the About Us and Aim or Scope sections of 203 predatory journals and 203 authentic journals for comparison. The predatory journal sections contained more positive language but fewer articles, prepositions, and

quantifiers. The authors attributed these differences to predatory publishers' use of deceptive language but did not consider the publishers' countries or languages of origin.

Shen and Björk (2015) identified India as the country with the largest number of predatory publishers. In another study of 214 predatory journals, 72% specified the APC, with the Indian rupee being the most common type of currency followed by the U.S. dollar (Xia, 2015). Xia et al. (2015) examined author profiles in seven pharmaceutical predatory journals and found the majority to be from India, Nigeria, and Pakistan. Most of the authors had never published before, and those who did had fewer than five publications. This raises the question of awareness, which Christopher and Young (2015) addressed in a small study of 145 veterinary and medical authors: only 33 authors (22.7%) were aware of predatory journals. When asked to define them, 22 respondents (15.3%) provided definitions that described predatory journals, while 93 (64.5%) defined poor journal practices not necessarily indicative of predatory publishing.

# **Methods**

# **Identifying Predatory Nursing Journals**

The research team selected journals with the word "nursing" in the title from Beall's (2016c) list of predatory standalone journals. In addition, the team reviewed the websites of each of the predatory publishers on Beall's (2016b) list to identify journals with "nursing" in the title or "nursing" as a category. Journals removed from the Directory of Open Access Journals (DOAJ) because they were predatory also were considered (DOAJ, 2014a, 2014b). Of those titles, one was no longer open access, one was not in English, and the other three were on Beall's list.

### **Data Collection**

Data were collected in two phases. In the first phase, the research team developed a data collection form based on Beall's (2015a) criteria for determining predatory publishers. The form was developed to guide the review and assure that the same information was collected from every journal and that missing information about the journal was noted. The form included items about the volume and types of articles published in the journal, APC, the nature of the peer review process, length of time for peer review and publication, indexing claims, country of origin of authors and editorial board members, and information about the editor. Some of Beall's criteria were modified to capture data specific for nursing, such

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as statements that the journal was indexed in PubMed or CINAHL and whether the editor or members of the editorial board were nurses or were qualified to serve in those roles. The distribution of clinical specialties and topics of articles in each of the journals were recorded. Notes were made about misspelled words and grammatical errors on the journal's website, per Beall's advice that "poorly maintained websites" should be considered cautiously (Beall, 2015a).

Phase One data collection occurred from late December 2015 through mid-February 2016. Members of the team were assigned journal websites to review. Data collected from the review of each journal were recorded on the form. A different member of the research team then reviewed each journal a second time, thereby confirming the accuracy of the data collected about the journal and recorded on the form; if necessary, the information on the form was modified for accuracy.

For Phase Two, conducted in March 2016, the research team developed three surveys, one each for authors, reviewers, and editors who were listed on the journal websites as having nursing credentials. The surveys asked for the respondents' experience with the journal; how they came to be an author, a reviewer, or an editor with this journal; their understanding about the quality of the journal; and their understanding about the nature of the review process. These authors, reviewers, and editors were selected by the research team from the predatory nursing journals identified in Phase One to reflect a variety of publishers and countries, different types of journals, and authors from a diversity of academic settings and countries. The sample included a list of 39 potential participants. Invitations were sent asking the participants to complete a brief online survey, and reminder invitations were sent 10 days later. The study was approved by the authors' university institutional review board.

### **Data Analysis**

A database for the project was built and maintained in Research Electronic Data Capture (REDCap; Harris et al., 2009). A research assistant entered the data from each form in REDCap and then exported the data for analysis. Continuous variables were described using mean, standard deviation, median, and range (minimum, maximum) and categorical variables with frequency and proportion. Data were analyzed using SAS/STAT software (version 9.3, SAS System for Windows, SAS Institute Inc., Cary, NC, USA, 2010). Survey data from Phase Two were analyzed with descriptive statistics. Written comments were summarized and categorized.

## Results

# Number of Nursing Journals and Publishing Trends

There were 140 predatory nursing journals from 75 publishers, some of which published only one nursing journal while others, such as OMICS International, published many. Predatory journals are new in the nursing literature, with five journals beginning in 2011, six in 2012, nine in 2013, and the majority in 2014 (n = 27, 25.0%) and 2015 (n = 54, 50.0%). There were a few journals that published content prior to 2011, but these were initially from traditional publishers who were then purchased by a predatory open access publisher. The other nursing journals had not yet published any articles. The mean number of years in which predatory nursing journals were published was 2.20 (SD = 1.98).

One important finding was that many of these journals only published one or two volumes and then either ceased publishing or published fewer issues and articles after the first volume. Of the predatory nursing journals identified, 104 published a first volume, but that number decreased to 51 offering a second volume of the journal and only 26 publishing a third. Most of the journals published a median of two issues per volume.

There were 4,238 articles published in predatory nursing journals when the study data were collected. Most (n = 1,138) were published in volume 1 or 2 (n = 906) of the journal. There was a wide variability in the number of articles per issue: the mean number in the first issue of a predatory nursing journal was 11.3 (SD = 19.3), which decreased to 6.71 (SD = 16.17) in the second issue and continued to decrease with subsequent issues. These journals actively published in the beginning with a burst of articles but then the number declined rapidly.

## **Content of Articles**

The data collection form included identification of the type and content of articles published. One striking finding was the lack of focus of a journal on a particular clinical specialty or area of content regardless of its title. It was common for a predatory journal to publish papers on pediatrics, medical surgical nursing, midwifery, critical care, and nursing education in one issue of the journal. One original intent of this study was to identify the distribution of clinical specialties and other content areas across journals, but most journals published articles on varied clinical specialties and content areas. Some of the nursing journals included articles from other fields such as dentistry and medicine. **Table 1** provides a list of the types of articles in predatory nursing journals.

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Table 1. Main Content Areas of Articles in Predatory Nursing Journals

Medical surgical nursing

Obstetrics, gynecology, and women's health (including breast feeding) Medicine and dentistry

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Pediatrics

Community, public health, and global health

Nursing education

Nursing management

Geriatrics

End-of-life care

Patient education

Psychiatry

Other clinical topics

Advanced practice nursing, including nurse anesthesia

Health policy

Family and caregiving

Table 2. Most Common Article Processing Charges

Fee (US\$)	n
100	19
30-80 <sup>a</sup>	18
500	15
400–900	14
200–999	12
300	10
749	8
200	7
99–379	6
75	4
1,500	2

 $<sup>^{\</sup>rm a}{\rm Some}$  journals had a range of fees, depending on the type of article, country of the author, or special promotion.

## **Article Processing Charge**

As an open access journal, it is likely that all of the predatory journals had an APC. However, we were only able to locate the APC for 115 of the journals, and it was frequently difficult to find. The APCs ranged from US\$75 (4 journals) to US\$1,500 (2 journals), with the most common fee being US\$100 (19 journals; **Table 2**).

### **Peer Review and Publication Time**

Most journal websites indicated that manuscripts were peer reviewed (n = 94, 67.1%) and described the peer review process (n = 66, 71.7%). However, the legitimacy of the reviews was not clear based on descriptions at the websites. Ten journals indicated that the length of time for peer review was a mean of 2.7 days (SD = 3.2); 36 of the journals described their process as requiring about 3 weeks (M = 3.33, SD = 2.04).

Some journals stated the time from acceptance to publication in days and others in weeks. For journals that

specified publication time in days, the mean length of time was 3.47 days (SD = 2.12; 17 journals). Other journals (n = 12) reported their publishing speed in weeks, with a mean of 3.17 weeks (SD = 2.95).

# **Bibliographic Databases in Which Indexed**

Some of the journal websites claimed that the journal was indexed in PubMed (six of the websites), CINAHL (five websites), and EBSCO (six websites). However, when each of these databases was checked, the identified journals were not indexed. For that reason, articles published in a predatory nursing journal may not be easily discoverable through a traditional search. Articles published in a predatory journal might be found through Google Scholar, but even that is not guaranteed if the publisher is not using a journal hosting service or aggregator. Published articles were archived at the journal website. However, it was not clear if the articles were digitally preserved. With many journals publishing for only a short period of time, articles archived at journal websites may not be available beyond the life of the journal.

# Country of Authors, Editorial Board, and Editor

For each of the journals, the research team identified the predominant countries of authors and editorial board members. The majority were from India, followed by the United States. This is likely because India appears to have the largest number of predatory publishers (Shen & Björk, 2015). Less than half (n = 65, 46.4%) of the journals listed an editor, and only 39.6% (n = 21) of those editors were nurses. Because there was limited information on the website about the editors' professional affiliations and qualifications, only a small number were verifiable.

### **Phase Two Survey Results**

We sent invitations to 19 authors with eight respondents (42.1%), 12 peer reviewers or editorial board members with four respondents (33.3%), and 8 editors with four responses (50.0%).

**Author survey results.** Of the eight author respondents, six had prior publications, while for two, this was their first published article. For their journal selection process, three authors responded to email invitations, two followed recommendations of colleagues, and two authors were familiar with their selected journals, asserting that they were "well read" and "well known." One author selected a journal based on its past reputation and publisher; unbeknownst to her, it had been bought by a new publisher, which was part of OMICS International,

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included on Beall's list of predatory publishers (Beall, 2016b).

Authors indicated that their manuscript was peer reviewed by two (n = 3), three (n = 2), or an unknown (n = 3) number of reviewers. Quality of the reviews was rated as "average," with none selecting excellent or poor. Five of the authors reported that they were asked to make revisions to their manuscript. Publication decisions were made within a week (n = 1), a month (n = 5), or 3 months (n = 2). Journal publication occurred within a month (n = 3) or 3 months (n = 4). One author selected "other" but did not indicate the time frame for publication.

Four authors paid an APC, and three did not. One was asked to pay a fee of US\$850 but refused and commented, "I still get emails with them asking for payment." One author commented that the fee was paid "up front"; the others said it was requested at the time the article was accepted or before it was published. One author purchased a "membership" in the publishing company and can now publish a number of articles at no charge. For others, the fee was US\$130 (n = 1) or US\$200 (n = 2). One author was asked to pay a "withdraw" fee of US\$413, which was refused. This article was subsequently published without permission or fee payment. Communication with the editorial office ranged from being *satisfied* (n = 4) to *very unsatisfied* (n = 4); no one was neutral on this issue.

Peer reviewer or editorial board member survey results. Of the four peer reviewers or editorial board members who responded, two had no idea that they were listed on the journal website. One respondent wrote, "I didn't realize my name was put on an editorial board for this journal. I never gave them permission." Given that two people did not even know they were listed, they answered "no" to the questions about the process of peer review. The other reviewers were satisfied with the process and believed that their feedback was taken into account in the final editorial decision. One reviewer noted that she was listed as an editorial board member but stated, "I think we are misnamed. We are really only manuscript reviewers."

**Editor survey results.** All four respondents were aware that they were listed as editors of the journal. They indicated they were selected through a review process that included an evaluation of their experience and expertise. There was variation in initial review of the manuscript (with three editors reviewing the manuscripts before peer review), assigning of peer reviewers (with two indicating that was done by the publishing office), and final editorial decision of manuscript acceptance, revision, or rejection (with two replying that they made the

final decisions). By and large, communication with the authors, peer reviewers, and the editorial board was handled by the publishing office. None of the editors received any sort of compensation for their work; all indicated that it was totally voluntary.

## **Discussion**

The findings of this study confirm that predatory journals exist in nursing. While the numbers may seem to be small (140 journals from 75 publishers), if current trends continue, this number will continue to grow. The International Academy of Nursing Editors (INANE) maintains a vetted database of 244 nursing journals; the number of predatory journals is equivalent to 57.3% of the INANE directory, suggesting that predatory publishers are making inroads in the nursing scholarly literature.

The analysis of the journals included in this study affirms that there is no single "red flag" that earmarks a journal or publisher as engaging in predatory and deceptive practices. Rather, there are a number of indicators that nurses can use to perform due diligence when considering a journal as a possible outlet for their scholarship. The practices that are known and common are generally in the categories of deceptive, confusing, or false information about the journal, and lack of adequate editorial processes to assure the integrity of the material published. The unrealistic promise of rapid peer review is a particularly important compromise of editorial integrity; a peer review process by definition requires more time than the claims typically made. The nurse editor and reviewer responses confirmed anecdotal evidence that despite having the names of nurses associated with these journals, the journals lack adequate editorial responsibility and leadership to ensure their quality. Being supportive and encouraging creative initiatives in publishing is a worthy goal, but the practices identified in the journals analyzed are only creative in terms of gain for those who are representing themselves as publishers. These practices compromise the integrity of nursing science and ultimately can lead to serious consequences in clinical practice.

The second phase of this study contributes to an understanding of the dilemmas faced by all who engage in any aspect of publishing in the nursing literature. The findings of this study confirm much of what was suspected through anecdotal evidence. Nicoll and Chinn (2015a) wrote about author responses and consequences of publishing in predatory journals. For example, they described the "pendulum phenomenon" wherein an author's manuscript is rejected by one or two non-predatory journals; feeling discouraged, the author turns to a journal that invites their submission and without

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investigating the journal, submits the manuscript with revision based on the prior reviews. Once the manuscript is accepted by the predatory journal, the author discovers the consequences and learns that there is no recourse to withdraw the article. In the survey comments from our respondents, one author noted the published manuscript had been rejected previously by two top nursing research journals. Three of the authors responded to the flattering spam emails that are ubiquitous with predatory publishers, again confirming how authors easily fall prey to these deceptive practices.

Nicoll and Chinn (2015a) also described the "I'm just one person" phenomenon, where someone is associated with a journal without their knowledge, or, if they choose to be associated, they do not see the quality of the journal or its publishing practices as an issue. Interestingly, with the editor surveys, all four editors indicated that they were selected based on their experience and expertise. While this might seem to be a refutation of this principle, the fact that two of four respondents do not make the final editorial decision on publication begs the question of what they perceive their editorial role to be. This is further complicated by the fact that the editors of predatory journals, in general, do not communicate with authors, peer reviewers, and editorial board members. Two reviewers did not know they were listed on the journal website and were disturbed to learn this news; since they did not know they were listed, they did not do peer review. The roles of journal editors and peer reviewers in legitimate journals vary from journal to journal, but these roles always include specific responsibilities that assure the scientific quality and merit of the material published in the journal, and direct involvement in the journal's editorial processes. When people with these titles are not involved in the journal's editorial practices, the entire quality of the peer review process comes into question.

Two author respondents described the "article held hostage" phenomenon (Nicoll & Chinn, 2015a). One author refused to pay the APC, but the article was published anyway. A second author described an ongoing, unsatisfactory communication process with the editorial office to withdraw the manuscript. The author received emails from only one person saying there was no journal contact and no one to speak to. This same person requested a US\$413 "withdraw fee" (which was not paid) to halt publication. Even intervention from the university legal department did not stop the article from being published. The author described the experience as "horrible" and believes it is unethical and borderline illegal.

Beall (2015b) has described predatory publishers who are buying established journals as a way to appear legitimate, to gain access to indexing in databases such as PubMed, and to confuse authors who through past

familiarity with the journal may consider it a credible outlet for their article. The experience of one author who was caught in this situation was documented in this study. The author noted, "We contacted the listed editors from major U.S. universities who had no knowledge or contact with the journal since the new publishers took over." This practice also highlights the challenges facing authors to carefully vet a journal prior to submission—if prior editors "come over" to the new journal without their knowledge or consent, what process exists for an author to determine that this has happened? Further, as some predatory publishers expand their empires with multiple businesses working under various names, it is increasingly difficult for authors, many of whom have only a cursory knowledge of the "ins and outs" of publishing, to sort out what exactly is going on.

Nicoll and Chinn (2015a) also discussed consequences of predatory publishing, including lack of indexing, absence of long-term (or even short-term) archiving, and inability of authors to "liberate" their manuscript when it has been published against their wishes. All of these points were confirmed by the evidence in this study.

### Limitations

The results of this study are limited by use of Beall's lists and the DOAJ lists to identify possible predatory nursing journals. In addition, nursing content found in possible predatory journals that were not titled or labeled with the word "nursing" was missed.

# **Summary and Implications**

This study provides evidence that deceptive practices by certain publishers are real. The analysis of the journals revealed common deceptive, misleading, and inadequate editorial practices. The survey of authors, peer reviewers, and editors of these journals provides additional insight into the experience of nurses whose names appear on the websites in some capacity. While the survey respondents' reports were varied and not all experiences with these journals were negative, when viewed in the context of standards that assure the integrity of the literature in nursing, there is ample evidence for concern.

The question remains: what approaches should be taken to mitigate the problems that result from these practices? It is clear that deceptive publications in nursing and other fields are growing and are not likely to disappear. Therefore, it falls to individuals and organizations in nursing to assume responsibility for the quality of nursing literature. At the individual level, authors, reviewers, and editors must be aware of these issues and take action to prevent falling into the traps of deceptive practices.

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At the organizational level, policies and practices need to be in place to assure that scholarship produced from the institution represents the highest standards of scholarship and publishing.

Authors, in one sense, do the most work and receive the most benefit from a published article; therefore, it is in their best interest to thoroughly review and select a journal for submission. "Journal due diligence" as described by Nicoll and Chinn (2015b) is a systematic process to vet a journal. While it is important to verify the positive attributes of a journal, authors should also be aware of "red flags" such as inclusion on Beall's (2016a) list, poorly designed websites, and lack of transparency about the publisher. The website "Think. Check. Submit." provides a checklist authors can use in the process of selecting a trusted journal (http://thinkchecksubmit.org/). Nicoll (2012) offers helpful worksheets and Oermann and Hays (2016) identify questions for authors to use for a systematic approach to review and vet a journal.

Consulting with colleagues is always wise; authors might also contact members of the editorial board to ask questions about the peer review process and overall professionalism of the journal. Journal due diligence is also a key factor in a successful publication outcome—a poor fit between a journal's focus and article topic is a leading cause of manuscript rejection. Being strategic from the outset will do much to help authors find the best journal option for their manuscripts and avoid predatory publications.

Reviewers and editors contribute to the problem by lending their "good name" to a dubious journal, especially if they do not know their name is being used. Being invited to serve as a peer reviewer, editorial board member, or even editor can be flattering, but before accepting the invitation take time to review the journal and ensure that this is a publication that merits your affiliation and will be a positive addition to your résumé.

Committees, departments, and schools need to accept some responsibility for mentoring and teaching faculty about these issues. Peer review committees should fully vet journals appearing on a candidate's dossier. For faculty who are coming up through the tenure and promotion process, teaching them to understand what types of publications are appropriate is an important role for senior faculty. If a school or department has funds to pay APCs for open access publications, then clear policies should be in place regarding the criteria that will be used to determine disbursement.

# **Conclusions**

This study confirms the anecdotal evidence that has been published recently, warning nurses about the implications of deceptive publishing practices (INANE, 2014; Nicoll & Chinn, 2015a). Based on this study and other research analyzing the trends in deceptive publishing, these practices are growing in all disciplines and can lead to serious erosion of confidence in the veracity of scientific literature. If nursing is to resist the negative consequences of these practices, individuals and institutions must remain aware of the pitfalls and take action to ensure that legitimate standards of publishing are used to protect the reliability of the literature of the discipline.

# **Clinical Resources**

- International Academy of Nursing Editors: https:// nursingeditors.com/resources/
- Nurse Author & Editor: http://naepub.com/ predatory-publishing/2014-24-3-2/
- Scholarly Open Access: https://scholarlyoa.com
- Think. Check. Submit: http://thinkchecksubmit. org/

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