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CONTENTS

EDITORIAL

435 Mistakes to Avoid in Scientific Writing
Susan Gennaro

CLINICAL SCHOLARSHIP

437 Recommendations of Common Data Elements to Advance the Science of Self-Management of Chronic Conditions
Shirley M. Moore • Rachel Schiffman • Drenna Waldrop-Valverde • Nancy S. Redeker • Donna Jo McCloskey • Miyong T. Kim • Margaret M. Heitkemper • Barbara J. Guthrie • Susan G. Dorsey • Sharron L. Docherty • Debra Barton • Donald E. Bailey Jr. • Joan K. Austin • Patricia Grady

448 Caring for the Unseen: Using Linking Social Capital to Improve Healthcare Access to Irregular Migrants in Spain
Deanna Marie Mason

456 Understanding Compassion Fatigue in Healthcare Providers: A Review of Current Literature
Claire Sorenson • Beth Bolick • Karen Wright • Rebekah Hamilton

466 The Lived Experiences of People With Chronic Obstructive Pulmonary Disease: A Phenomenological Study
Yi-Ya Chang • Yu-Tzu Dai • Nai-Hui Chien • Hui-Ya Chan

472 A Focused Ethnography of Baccalaureate Nursing Students Who Are Using Motivational Interviewing
Lisa M. Howard • Beverly A. Williams

482 The Experience of Men Caring for a Partner With Multiple Sclerosis
Chiara Rollero

490 Integrated Review of Barriers to Cervical Cancer Screening in Sub-Saharan Africa
Ditsapelo M. McFarland • Sarah M. Gueldner • Keitshokile D. Mogobe

499 Provider Perspectives on Safety in Primary Care in Albania
Jonila Cyco Gabrani • Wendy Knibb • Elizana Petrela • Adrian Hoxha • Adriatik Gabrani

508 An Audit of Nursing Documentation at Three Public Hospitals in Jamaica
Jascinth Lindo • Rosain Stennett • Kayon Stephenson-Wilson • Kerry Ann Barrett • Donna Bunnaman • Pauline Anderson-Johnson • Veronica Waugh-Brown • Yvonne Wint

WORLD HEALTH

517 Volunteer Service and Service Learning: Opportunities, Partnerships, and United Nations Millennium Development Goals
Safiya George Dalmida • Roxanne Amerson • Jennifer Foster • Leila McWhinney-Dehaney • Mabel Magowe • Patrice K. Nicholas • Karen Pehrson • Jeanne Leffers

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JOURNAL OF NURSING SCHOLARSHIP

EDITORIAL

Mistakes to Avoid in Scientific Writing

As an editor I have read thousands of manuscripts. Most of these manuscripts have taught me something that I have enjoyed learning. So I am grateful to each and every author who has submitted their work to the *Journal of Nursing Scholarship*. Your excellent work is the reason why *JNS* has had such a steady rise in our Impact Factor (now at 2.128).

Some manuscripts, sadly however, have features that grate on my editorial nerves and I worry that the worth of these manuscripts might be masked, in part, because of unnecessary distractions. So I'd like to share a list of those things that are annoying to me and to our reviewers in the hope that this list helps all potential authors avoid unnecessary literary missteps. Here is my top 10 list of things to studiously avoid when writing a manuscript for *JNS*. I have to admit they are in no particular order but all manuscripts would benefit from not containing these common errors. I also believe that avoiding these common missteps might help an author be successful in publishing irrespective of the journal to which a manuscript is being submitted. Here then are the 10 most common mistakes to avoid in scientific writing.

Number 10: Titles That Are Very Long

Inevitably titles that are longer than 10 or so words are from manuscripts that lack focus. Very long titles seem to indicate that the author hasn't really decided the main points they wish to convey in their manuscript. Sometimes it seems that the author chooses a very long title because the author can't quite adequately communicate what the manuscript is primarily conveying. Sometimes I am wrong, but over 90% of the time I find reviewers are not enthusiastic about manuscripts with a very long title. Think about the purpose of the manuscript and the key words that you are going to use to index your work. Make sure the title matches your purpose and key words so that it will be easy for interested readers to search for your work. Perhaps in seeking clarity around the title of your work and matching key words with the purpose you will help improve the overall quality of the manuscript.

Number 9: Manuscripts That Do Not Follow Our "Author Guidelines"

We clearly state that all manuscripts have to contain a list of clinical resources (Websites) for people who are interested in the topic of your manuscript and want to learn more. I hate to have to ask for a new submission because this piece is missing or because there is not a statement of clinical relevance. Our mission is to improve the health of the world's people. So if your manuscript does not have a statement of clinical relevance, it is likely you can't tell us how you are helping to meet our mission. And please, don't use footnotes or any referencing system that is not APA. Your manuscript is not going to get accepted if it does not follow the simple rules for publication that we explain in the author guidelines.

Number 8: Manuscripts That Are Too Long

I continually get queries from authors telling me how important their work is and how impossible it is to encapsulate it into 20 manuscript pages. It is true that sometimes there are additional features that you would like to share but you can put additional data, tables, figures etc. on our Website and refer to them with a link in your manuscript. Most of the time a request for more space means that authors are not able to be succinct. We would love to give everyone as much room as they need, but this would decrease the number of manuscripts overall that we can publish and that just doesn't seem fair.

Number 7: Manuscripts That Are Geographically Limited

All research is only done in a finite number of settings. But we get lots of manuscripts that say that the purpose is to determine if what is generally known in nursing holds true in their country. We are read by nurses in over 103 countries. If the sole purpose of a study is only applicable for nurses in one of those 103 countries, then it is not a good fit for *JNS*. Replicating studies to make sure their findings are applicable in a specific country is a worthy purpose, but then this work seems best suited to a journal in the country of interest.

Number 6: Self-Duplication

Most journals run all manuscripts through software to make sure that the information in the manuscript has not been published elsewhere. Copyright is very important, and if I find that 40% of your manuscript has appeared in print (or online) elsewhere, I have to wonder why I want to publish something that clearly contains a lot of self-duplication or copying of someone else's work. It is inevitable that there is some duplication. It is impossible not to use common phrases in science (like "the purpose of this study is" or certain methodologic or statistical phrases). More and more universities have duplication software that you can use as an author to ensure that your work does not have a high duplication index. You can't publish something word for word that has already been published, so as an author you must think about how to say things differently or to refer readers to already published work for further information. Sometimes, unfortunately, there is not enough new information being provided to warrant another new manuscript. Commonly referred to as "salami slicing," you have to carefully examine whether the information you are trying to provide in a study has in fact already been published.

Number 5: Manuscripts That Don't Provide Any Information as to Why the Study Is Important for Nursing Practice

Manuscripts that don't contain information that is important to nursing practice really don't fare well with reviewers. A manuscript might be well written and a study might be well executed, but if it is not clear to the reviewer what nurses will do with the information, they are likely to suggest that the manuscript be rejected. So authors whose work is focusing on population health or on improvements in methodology or statistics really need to make sure that they are making a case for how the information being presented will benefit practicing nurses.

Number 4: Manuscripts That Come With Cover Letters to a Different Journal

This is self-explanatory but unfortunately is rather consistent. Before you submit to *JNS*, please make sure that this is where you wish to submit.

Number 3: Manuscripts in Which the Conclusion Has Nothing to Do With the Findings of the Study

Often I read a really excellent study that I think makes a great contribution to the body of science, but I get to the conclusion section and the authors include many, many conclusions that have nothing to do with the actual study they conducted. It is tempting to generalize beyond one's findings, but it devalues your work because it raises questions as to how careful you are as a scholar. Please be very careful to ensure that anything you are concluding is something that is based on what you found in the study and not something you are suggesting that is only tangentially related to what your study found.

Number 2: Manuscripts That Wander

If your manuscript is supposed to be about one topic (let's say stress) and you start talking about airline travel (which is indeed stressful these days but is not directly related to stress), you confuse your reader. Some manuscripts recover and get back to the case in point, but it is infinitely better to tell your reader the purpose of your work, to describe your work, and then to tell them how this work can help them as nurses. I am sure your peripheral thoughts on the stress of air travel in my example are interesting but best saved for a different article.

Number 1: Studies That Didn't Really Need to Be Conducted as We Already Know the Outcomes

This is my greatest pet peeve. I can't tell you how many manuscripts I read in which an educational intervention was performed on nurses and a pre- and post-test was given and the findings show that nurses learned the content presented. This is not at all surprising to me. Nurses are smart people. If you teach us something, we learn. This is the most common example of the kind of study where reviewers suggest rejecting the study because nothing new is learned. I have said this before, but it bears repeating: your time is precious, so please do a study that is firmly based in our global nursing knowledge and that extends that knowledge.

I hope that these 10 points are helpful. I know that, on the other side of the editorial process, there are equally things that are done by reviewers or editors that are annoying. As an author myself I can even easily list my top 10 annoyances in the review process. So please know this list is not meant to be a diatribe against authors' foibles. Our authors for *JNS* are the best, and you continually allow us to publish research that is truly making a difference in our mission to improve the health of the world's people. My hope, however, is that your publishing experience will be easier when understanding what simply puts your work in a less appealing light. We know with your help we will continue to publish clinically relevant and globally significant research. Thanks for all you do (and honestly thanks for not doing any of the 10 things listed above).

Sincerely,
Susan Gennaro
Editor

JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Recommendations of Common Data Elements to Advance the Science of Self-Management of Chronic Conditions

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Key words
Common data elements, research data harmonization, self-management

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Abstract

Purpose: Common data elements (CDEs) are increasingly being used by researchers to promote data sharing across studies. The purposes of this article are to (a) describe the theoretical, conceptual, and definition issues in the development of a set of CDEs for research addressing self-management of chronic conditions; (b) propose an initial set of CDEs and their measures to advance the science of self-management; and (c) recommend implications for future research and dissemination.

Design and Methods: Between July 2014 and December 2015 the directors of the National Institute of Nursing Research (NINR)-funded P20 and P30 centers of excellence and NINR staff met in a series of telephone calls and a face-to-face NINR-sponsored meeting to select a set of recommended CDEs to be used in self-management research. A list of potential CDEs was developed from examination of common constructs in current self-management frameworks, as well as identification of variables frequently used in studies conducted in the centers of excellence.

Findings: The recommended CDEs include measures of three self-management processes: activation, self-regulation, and self-efficacy for managing chronic conditions, and one measure of a self-management outcome, global health.

Conclusions: The self-management of chronic conditions, which encompasses a considerable number of processes, behaviors, and outcomes across a broad range of chronic conditions, presents several challenges in the identification of a parsimonious set of CDEs. This initial list of recommended CDEs for use in self-management research is provisional in that it is expected that over time it will be refined. Comment and recommended revisions are sought from the research and practice communities.

Clinical Relevance: The use of CDEs can facilitate generalizability of research findings across diverse population and interventions.

The science of self-management is focused on the need for strategies to help individuals with chronic conditions and their caregivers better understand and manage their illnesses, control their symptoms, and improve their health behaviors (Intercultural Cancer Council, 2011). Self-management encompasses both the maintenance of wellness and the management of chronic conditions (Grady & Gough, 2014). Self-management research, including research supported by the National Institutes of Health (NIH)–National Institute of Nursing Research (NINR), supports the development, testing, translation and dissemination of interventions that help individuals from diverse backgrounds and their families use self-management to live with chronic conditions to improve health outcomes, while reducing the burden for caregivers and the healthcare system.

Use of common data elements (CDEs), which are fundamental logical units of data pertaining to one kind of information that are clearly conceptualized (Warzel et al., 2003), promotes effective leveraging of resources by facilitating data sharing across studies within and across institutions (Cohen, Thompson, Yates, Zimmerman, & Pullen, 2015; Redeker et al., 2015). CDEs facilitate generalizability of research findings across diverse populations and interventions, and their use may reduce the cost and complexity of conducting self-management studies. Researchers in a number of disciplines, including nursing (Cohen et al., 2015; National Cancer Institute, 2014; National Institute of Neurological Diseases and Stroke, 2014; National Institute on Drug Abuse, 2014; Redeker et al., 2015), are increasingly using CDEs. To date, however, CDEs have not been developed or extensively used to support self-management science. The NINR currently supports four exploratory (P20) and six centers of excellence (P30) designed to advance the science of self-management and symptoms (**Table 1**). This article is a report of the consensus of the NINR Center Directors (July 2014 to August 2015); the purposes are to (a) describe the theoretical, conceptual, and definition issues in the development of a set of CDEs for research addressing self-management of chronic conditions; (b) propose an initial set of CDEs and their measures to advance the science of self-management; and (c) recommend implications for future research and dissemination.

Self-Management Definitions and Frameworks Influencing the Development of Common Data Elements

Definitions

For the purposes of this article, self-management is considered either or both a process or an outcome. Definitions of self-management have varied widely, but these definitions generally describe processes that are often complex in chronic conditions, usually occur on a daily basis, and require confidence to regulate and take action that result in specific self-management behaviors and health. Definitions have evolved from early definitions by Creer, Renne, and Christian (1976), who described self-management as the patient's ability to actively participate in his or her treatment or care, and Corbin and Strauss (1988), who expanded the definition to include specific content areas such as medical, behavioral, role, or emotional management. More recently, Lorig and Holman (2003) emphasized self-management processes (self-efficacy, skill building, emotional management), and Grey, Schulman-Green, Knafl, and Reynolds (2015) posited that individual and family self-management were interactive in influencing outcomes for chronic conditions.

The terms self-management, self-care, and self-regulation have been used interchangeably, and as a result, the definitions are blurred and often inconsistent. Self-care definitions share similar conceptual overlap with self-management. For example, Levin and Idler (1983) described self-care as "Those activities individuals undertake in promoting their own health, preventing their own disease, and limiting their own illness and restoring their own health without the assistance of a health professional" (p. 181). Lawson, Bundy, Lyne, and Harvey (2004) described the medical perspective of self-care as management of treatment and disease, with specific aspects of care being the responsibility of the patient. Psychologists, on the other hand, have

Table 1. Current National Institute of Nursing Research (NINR) Exploratory Centers: Building Research Teams for the Future (P20) and Centers of Excellence (P30)

NINR P20 Exploratory Centers: Building Research Teams for the Future			
Type	Center PI	Center Title	Center Website
P20	Redeker, Nancy (contact); Yaggi, Henry (MPI)	Yale Center for Sleep Disturbance in Acute and Chronic Conditions	http://sleep.yale.edu/yale-center-sleep-disturbance
P20	Barton, Debra (contact); Dinov, Ivo (MPI)	Center for Complexity and Self-management of Chronic Disease (CSCD)	http://www.socr.umich.edu/CSCD/
P20	Guthrie, Barbara	Northeastern Center for Technology in Support of Self- Management and Health	http://www.northeastern.edu/nucare/
P20	Schiffman, Rachel	Self-Management Science Center at UWM	http://uwm.edu/nursing/about/centers-institutes/self-management/
NINR P30 Centers of Excellence			
P30	Dorsey, Susan G (contact); Fadan, Alan (MPI); Greenspan, Joel (MPI)	Center for the Genomics of Pain	http://ruinpain.org/center-faculty/susan-g-dorsey-phd-rn-faan
P30	Waldrop-Valverde, Drenna	The Center for Cognition and Affect in Chronic Illness	http://www.nursing.emory.edu/cns/
P30	Docherty, Sharron (contact); Bailey, Donald (MPI)	Center for Adaptive Leadership in Symptom Science	http://nursing.duke.edu/centers-and-institutes/adapt/adapt-center
P30	Page, Gayle (contact); Smith Michael (MPI)	Center for Sleep-Related Symptom Science	http://nursing.jhu.edu/faculty_research/research/centers/sleep/
P30	Moore, Shirley M.	SMART Center II: Brain Behavior Connections in Self-Management Science	http://fpb.case.edu/SMARTCenter/
P30	Kim, Miyong	Center for Transdisciplinary Collaborative Research in Self-Management Science	http://www.utexas.edu/nursing/tcrss/

Note. MPI = multiple principal investigators; PI = principal investigator; SMART = Self-Management Advancement through Research and Translation; UWM = University of Wisconsin-Milwaukee.

defined self-care in terms of the internal processes of health that include self-concept, health belief, and cognitive behaviors (Penning & Keating, 2000). From a nursing perspective, Orem (McLaughlin Renpenning & Taylor, 2003) described self-care as being either universal (essential demands of daily living that included air, fluids, food, elimination, rest, active, solitude, interactive relationships with others, and protections from hazards) or a health deviation. More recently, Riegel, Dickson, and Faulkner (2015) described a self-care framework in which self-management is a subset of activities within the overarching concept of self-care.

Similarly, the term self-regulation has emerged over the past several decades within the fields of psychology and health. The discipline of psychology definitions of self-regulation have several common elements, including the importance of being goal-directed and changing attitudes and behaviors through supportive mechanisms and deliberate processes (e.g., using problem solving and motivation; Karoly, 1993; Leventhal, Leventhal, & Contrada, 1998). Bandura (2005) expanded the definition of self-regulation by relating the construct to health promotion through self-monitoring of health behaviors and social support.

Self-efficacy is another term closely related to self-management. Bandura (1977) first introduced the term self-efficacy as a critical component of social cognitive theory related to motivation and defined it as the personal judgment of one's capability to organize and to execute a plan of action geared toward attaining a selected goal. He indicated that self-efficacy referred to an individual's performance capabilities and that the levels of self-efficacy were based on the difficulty of a particular task or behavior ranging from the simplistic to the more complex of a selected task. A similar but different concept closely related to self-efficacy is patient activation, the definition of which also includes one's judgments regarding capability to perform a set of self-management activities, but also includes judgment about skill building and actual execution of those behaviors. Thus, there is some conceptual overlap in the definitions of self-efficacy and patient activation.

Self-Management Frameworks

The most frequently used contemporary self-management frameworks are summarized in **Table 2**. One or more of these frameworks undergird the current NINR-funded self-management centers. Although these frameworks use a variety of terms, they share many commonalities, such as antecedents or predisposing factors or contexts, processes, and outcomes related to

Table 2. Comparison of Selected Self-Management (SM) Frameworks and Their Characteristics

	Definition		Scope				
Framework/Model	Process	Outcome	Individual	Family	Components	Outcomes	Comment
Lorig & Holman (2003) Self-Management Education	x		x		SM tasks: (1) medical/behavioral management (2) role management, (3) emotional management SM skills: (1) problem solving (2) decision making (3) finding and utilizing resources (4) forming partnerships with healthcare providers (5) taking action Self-tailoring (using SM skills and knowledge and applying these as appropriate) Self-efficacy enhancement: action planning, modeling, reinterpreting, social persuasion	Improved SM behavior Improved health status Healthcare utilization	SM: person/patient responsible for day-to-day management of health-promoting activity or living with a chronic disease.
Grey et al. (2015) Self and Family Management (revision of Grey et al. [2006] framework)	x		x	x	Facilitators and barriers: personal/lifestyle, health status, resources, environment, healthcare systems Processes: focusing on illness needs, activating resources, living with the condition	Proximal outcomes: behaviors, cognitions, biomarkers, symptom management Distal outcomes: health status, individual outcomes, family outcomes, health care	SM is in context of family management of the condition.
Knafl & Deatrick (2003) Family Management Style Framework (revision of Knafl et al. [1996])				x	Sociocultural context: Perceived influences on management Major: (1) definition of situation (2) management behaviors (3) perceived consequences Family members: child, mother father, sibling Family management style	Individual functioning Family functioning	Family management style is the family response to childhood illness.
Ryan & Sawin (2009) Individual and Family Self-Management Theory	x	x	x	x	Context: risk and protective factors (condition specific, physical, social and environmental, individual and family) Process of SM: knowledge and beliefs, self-regulation skills and abilities, social facilitation	Proximal outcomes: SM behaviors, cost of healthcare services Distal outcomes: health status, quality of life/well-being, cost of health	SM involves the use of specific processes, can be affected by specific programs and interventions, and results in specific types of outcomes.

the individual's or family's management of the chronic condition. For example, context sometimes comprises risk and protective factors (Ryan & Sawin, 2009), facilitators and barriers (Grey et al., 2015), or sociocultural context (Knafl & Deatrick, 2003). Self-management processes (Grey et al., 2015; Ryan & Sawin, 2009) are also called self-management tasks and core self-management skills (Lorig & Holman, 2003). Processes, tasks, and skills include some actions and factors related to taking actions. Lorig and Holman (2003) use tasks and skills but focus on how individuals apply these in ways that are appropriate for them. Grey et al. (2015) include integration into one's lifestyle, "ownership" of the need, using resources. Ryan and Sawin (2009) include many elements of action taking and regulating or modifying action. Knafl and Deatrick (2003) identify behaviors and approaches ("management styles") that indicate the type of engagement of the parent or family in management and the characteristics that define those engagement styles.

Several factors commonly associated with self-management are present in these contemporary frameworks as either context or process. The most common individual-level psychological factors include self-efficacy, attitudes, health beliefs, and perceptions about the severity of chronic condition or risk factors (Grey et al., 2015; Lorig & Holman, 2003; Ryan & Sawin, 2009). Knowledge or skills is another factor known to improve self-management processes and outcomes; however, it is well known that level of knowledge often is not sufficient to translate to the desirable self-management behaviors or outcomes (Dickson & Riegel, 2009). Depressive symptoms are another individual factor that has been shown to influence both the self-management process and self-management outcomes (Chew, Shariff-Ghazali, & Fernandez, 2014). There also are family- or community-level factors that influence self-management, including perceived social support (Graven & Grant, 2014), family support (Kara Kaşlkçl & Alberto, 2007), social isolation (Wada, Akiyama, Takeda, Nakamura, & Takizawa, 2014); neighborhood factors such as food insecurity, safe walking environment, and violence (Merom et al., 2015); and cultural values and practices (Lemacks, Wells, Ilich, & Ralston, 2013). These factors are identified either directly or indirectly in the Grey et al. (2015) and the Ryan and Sawin (2009) frameworks and can be inferred from Lorig and Holman (2003) and Knafl and Deatrick (2003).

Our review of self-management frameworks showed that all included outcomes. In two frameworks (Grey et al., 2015; Ryan & Sawin, 2009), outcomes are categorized as proximal (usually short-term) outcomes, such as self-management behaviors specific to the condition or recommended treatment regimen, or distal (long-term) outcomes, such as health status (Grey et al., 2015; Lorig & Holman, 2003; Ryan & Sawin, 2009) and quality of life (Grey et al., 2015; Ryan & Sawin, 2009). Since these frameworks primarily focus on management of chronic conditions, health status outcomes are often reported as disease- or condition-specific variables such as improvement in HbA1c for people with diabetes. In addition, an improved overall or global health status, sense of well-being, or improved health-related quality of life are also identified distal outcomes of self-management (Grey et al., 2015; Ryan & Sawin, 2009). Utilization of health care and costs are included as outcomes in most frameworks (Grey et al., 2015; Lorig & Holman, 2003; Ryan & Sawin, 2009). Family-specific outcomes are identified in Grey et al. (2015) and Knafl and Deatrick (2003). The mechanisms for achieving the outcomes are portrayed as linear models with potential moderating or mediating factors (Grey et al., 2015; Ryan & Sawin, 2009).

The frameworks propose varied mechanisms of action to achieve self-management behaviors and outcomes. For example, Lorig et al. (1999) have relied heavily on Social Cognitive Theory and self-efficacy, arguing that it is the increase in one's confidence to carry out a given behavior or skill that explains the change in self-management behavior. Others have suggested that motivation—or self-regulation—is a mechanism driving self-management behavior. More recently, patient activation has been shown to be a primary mechanism in the self-management process (Hibbard, Mahoney, Stockard, & Tusler, 2005). In addition, self-management itself can be considered a mechanism for improving health. For example, Grey and colleagues (2013) found support for self-management as a mediator of the relationship between family functioning and depression and HbA1c and quality of life among adolescents with type 1 diabetes.

The work of Lorig and colleagues (Lorig, Ritter, Laurent, & Plant, 2006; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001; Lorig et al., 1999) illustrates an approach to self-management of chronic illness more broadly through their Chronic Disease Self-Management Program. By focusing on processes or mechanisms, in this instance, self-efficacy and problem solving, decision-making and confidence building, these authors do not limit self-management to a specific condition or population, but rather view overall health status as the major outcome of chronic illness self-management. Although not all centers use the same unifying framework, there were sufficient commonalities across the self-management perspectives to identify elements that were deemed important and were common to all centers.

Process to Develop Common Data Elements for Self-Management Science

We developed a systematic process for choosing CDEs for use in self-management research by following the best practices outlined in previous work done by the P20 and P30 center directors (Redeker et al., 2015). Our process started in July 2014 with a series of monthly conference calls among center directors and NINR staff. Within each NINR-funded center, investigators had developed common measures that each pilot project was using in order to harmonize data across center studies. These measures are internal to each self-management and symptom center. Each center has a different focus (see **Table 1**), making the list of measures diverse and quite lengthy. The iterative process began with an initial list of over 80 measures that were used across centers and considered possible candidate self-management CDEs, duplicates were removed, and a list of 50 was agreed upon in preparation for the annual Center Directors meeting in May 2015. During this meeting the Directors held discussions, using a consensus process, to work through a theoretical analysis of self-management with the aim to develop conceptual consistency between chosen data elements, measures of the concepts, and self-management theoretical positions. At the 2015 meeting, Directors divided into small working groups to delve into issues related to operationalization of three areas of self-management science: outcomes associated with self-management, basic self-management behaviors and processes, and mediators and moderators of self-management. Each working group produced a draft list of concepts, variables, and measures, and this list was further reduced during a series of cross-center telephone conference calls after the annual meeting. Criteria used to make the selection of the initial set of four recommended CDEs included parsimony, cost, subject burden, potential for use across different chronic conditions, and consistency with measures from the symptom science CDEs (Redeker et al., 2015).

Recommended Common Data Elements for Use in Self-Management Studies

The list of proposed CDEs, their recommended measures for use in self-management studies, and information of where to access the measures is provided in **Table 3**. Although a lengthy list of possible candidate CDEs was originally considered, it was decided to limit the number of recommended CDEs to only a few. With the recent development of the CDEs for symptom science, we realized that the total set of CDEs for nursing science potentially could be quite large. In general, the acceptance and use of CDEs by researchers in a scientific field is more successful if the list of recommended CDEs is parsimonious (Redeker et al., 2015); thus, we decided to constrain our proposed CDEs for self-management science to four CDEs that are frequently used in self-management studies across multiple populations and chronic conditions and where expanded use of these measures has the potential to advance self-management science. The CDEs selected represent core constructs across existing self-management frameworks. All measures selected have good psychometric properties and have been used in multiple adult populations. The recommended CDEs include measures of three self-management processes: activation, self-regulation, and self-efficacy for managing chronic conditions, and one measure of a self-management outcome, global health.

Activation

Activation is a recommended CDE because it includes the broad range of elements involved in self-management, including the knowledge, skills, beliefs, and behaviors that a person needs to manage a chronic illness (Hibbard et al., 2005; Hibbard, Stockard, Mahoney, & Tusler, 2004). Activated individuals also have better health outcomes and lower rates of emergency department use and hospitalizations (Hibbard et al., 2005). We recommend that activation be measured using the 10-item Patient Activation Measure® (PAM®; Hibbard et al., 2004), a self-report scale that predicts self-management behaviors, including self-monitoring, goal setting, medication management, health information seeking, and healthy living behaviors (e.g., healthy diet and being physically active). A total score can be obtained using the PAM® and it also can be used to segment people into one of four progressively higher levels of activation. Advantages of the PAM® include its applicability across a broad range of chronic conditions, its availability in multiple languages, and the availability of a version to assess caregiver activation. There currently is not a version for assessment of activation in children. A major limitation of the PAM® is that there is a cost for its use in large studies. For healthcare researchers, however, it can be obtained at a reduced fee for use in large studies, and there is no fee for use in studies of less than 250 unique participants (with a signed agreement). Permission to use the PAM® must be obtained exclusively at Insignia Health® located in Portland, OR (see **Table 3**).

Self-Regulation

Another recommended CDE for self-management research is self-regulation. Although there are numerous definitions and measures of self-regulation in the

Table 3. Recommended Common Data Elements (CDEs) for Self-Management Studies

CDE	First choice CDE recommendation	Internet access site
Activation	Patient Activation Measure (Hibbard) Caregiver Activation Measure (Hibbard)	www.insigniahealth.com/products/pam-survey
Self-regulation	Index of Self-Regulation (Yeom; Fleury)	http://www.ncbi.nlm.nih.gov/pubmed/9769608
Self-efficacy for managing chronic conditions	Self-efficacy for Managing Chronic Disease (Lorig)	http://patienteducation.stanford.edu/research/secd6.html
Global health	PROMIS SF v1.1 Global	http://www.assessmentcenter.net/documents/Scoring%20PROMIS%20Global%20short%20form.pdf

Note. PROMIS = Patient-Reported Outcomes Measurement Information System.

literature, we selected the Index of Self-Regulation (ISR; Fleury, 1998; Yeom, Choi, Belyea, & Fleury, 2011) because it assesses an individual's effort to make behavioral changes and modulate thoughts, emotions, and behaviors to achieve goals. The ISR can be used to assess general behavior change or specific changes. This nine-item self-report scale has been tested across several populations and is available in Spanish. There currently is not a version for assessment of self-regulation in children.

Self-Efficacy for Managing Chronic Conditions

Although numerous instruments exist to assess self-efficacy for specific self-management behaviors (e.g., self-efficacy for exercise; self-efficacy for medication adherence), we recommend that studies of the self-management of chronic illness include a measure that addresses the management of chronic conditions in general, the Self-efficacy for Managing Chronic Illnesses Scale (Lorig et al., 2001). This brief, six-item self-report measure can be used in addition to a measure of self-efficacy specific to a condition or behavior (e.g., self-efficacy for healthy living behaviors in persons with human immunodeficiency virus infection). Thus, with little increased subject burden, the role of self-efficacy in self-management studies can be assessed across studies of adult populations and numerous chronic conditions. The Self-efficacy for Managing Chronic Illnesses Scale is available in numerous languages and has been used in studies of numerous cultural groups and chronic conditions (Lorig et al., 2001). It has not been used with children.

Global Health

The recommended CDE outcome measure for self-management research is global health as measured by the Patient-Reported Outcomes Measurement Information System (PROMIS) Global Health short form. This 10-item instrument assesses an individual's perception of health over the past 7 days in multiple domains. Measures of both global physical health and global mental health are obtained. Similar to other PROMIS measures, it can be administered and scored electronically if desired. Another advantage of using this PROMIS measure is that it is widely used across scientific disciplines. It is recommended for use only in adults.

Relationship Between Common Data Elements for Self-Management and Common Data Elements for Symptom Management

As the NINR Center Directors represented both self-management and symptom management centers, it was quickly acknowledged that the constructs of self-management and symptom management have overlapping, complementary, and synergistic attributes and processes that would be helpful to consider in identifying and using self-management CDEs. Specifically, symptom management can be conceptualized as a task of self-management (part of the process; Grady & Gough, 2014; Ryan & Sawin, 2009), as a moderator of the self-management process (Disler, Gallagher, & Davidson, 2012), or even as an outcome (Grey et al., 2015).

Chronic symptoms are prevalent in people with chronic conditions. Symptoms can occur that are signs of progression or exacerbation of a health condition, side-effects of treatment, or chronic effects of a health condition and its treatment (e.g., cancer, chronic obstructive pulmonary disease). The relationship between symptom management and self-management can change depending on their respective roles. One example of symptom management as a critical task in the process of self-management can be illustrated in people with chronic heart failure. Changes in the severity of dyspnea or fatigue (key symptoms) often herald the need for self-management regarding adherence to medication regimens and management of fluids and sodium, which then directly improve the management of the disease.

On the other hand, when the disease is not active but long-term symptoms persist as a sequelae of the disease, such as cancer-related fatigue in long-term survivors, the self-management of the specific symptom may be the objective. For example, fatigue can be a long-term symptom resulting from cancer treatment, being present in some survivors up to 10 years after anticancer therapy (Bower et al., 2006). Learning to monitor fatigue levels, understand the context in which fatigue is exacerbated, increase activity, and practice energy conservation strategies when needed can reduce fatigue levels (Barsevick et al., 2004). In this instance, self-management may be the mediator through which fatigue is lessened.

Finally, symptoms can moderate the ability of a client to successfully self-manage. In diabetes mellitus, a goal of self-management is diet and exercise to keep insulin and glucose well balanced and improve circulation. Sleep disturbance or pain could negatively impact a person's ability to exercise, either because of being in too much pain or too sleepy to engage in exercise behavior. In this example, successful management of the symptom (pain or sleep) could then lead to the ability to exercise and thereby keep the diabetes mellitus appropriately controlled.

Given the complex but intertwined relationships among symptoms, symptom management, and self-management, improved understanding of the concepts and mechanisms underlying self-management (e.g., self-efficacy, motivation, activation, self-regulation) through careful use and selection of self-management CDEs is likely to enhance understanding of symptom management. A broad view of self-management and its interrelationships with symptom management will provide a more comprehensive approach than a singular focus on self-management without considering the role of symptoms (and vice versa).

When evaluating behavioral interventions to improve symptom management, understanding adherence to the behavior and reasons for lack of adherence to the behavior can provide insight into how an intervention may be working, or if not found to be effective, why it may not have been helpful. Concepts related to self-management would contribute to understanding behavior adherence. Also, symptoms can affect the ability to self-manage. For example, fatigue, sleep disturbance, and cognitive dysfunction may influence the ability to self-manage. Therefore, the use of a parsimonious list of CDEs from both self-management and symptom management fields can advance both fields.

Implications for Future Research and Dissemination

Several considerations should be taken into account in the future use of these recommended CDEs for self-management research. First is the context in which these recommendations were formulated. As described, the selection of the CDEs was done by the directors of the NINR-funded self-management and symptom management centers. Each of these centers has a different self-management or symptom management research focus (see **Table 1**) and currently uses its own set of CDEs. Thus, the full range of possible CDEs for self-management research may not be represented in this recommended list. Although the existing literature on self-management is well known by this group of center directors, it may be that representation on the development team of more and different types of self-management research foci may have resulted in a different set of CDEs. This list of CDEs is considered provisional in that it is expected that over time the list will be refined by the larger self-management scientific and practice communities. To facilitate this "vetting" process, a series of sessions have been convened at regional research conferences and will be presented at national conferences to share the recommended CDEs and invite comments from the nursing research and practice communities. The vetting and revision activities of a CDE set, however, are an ongoing process in which multiple venues for comment and recommended revisions are sought from the scientific and practice communities.

Another important consideration as investigators begin to use the CDEs is the limitations in their conceptual and practical applications. Consistent with the literature, we are aware that there is some conceptual overlap among the three self-management process CDEs (activation, self-regulation, and self-efficacy for managing chronic illness). We decided, however, that each of these three variables represents sufficiently different and important dimensions of self-management processes. There also were other constructs associated with self-management that were considered but are not included on this list, such as patient use of and reliance on healthcare services and the predisposing factors influencing self-management. We also did not include CDEs and measures for specific self-management behaviors, such as exercise, eating behaviors, and medication taking. This was primarily because the goal was to recommend a set of CDEs that could be used across a wide range of self-management studies addressing different populations, chronic conditions, and behavioral targets. It is noted that our focus in this set of CDEs is on the self-management of chronic illness and does not take into full account the self-management of wellness promotion. There is likely a considerable overlap in a set of CDEs for self-management of chronic illness and CDEs for self-management of wellness promotion. The focus to develop the CDEs for self-management of wellness may be a next step in the advancement of the use of CDEs for self-management science. Lastly, biologic markers of self-management are not included in this initial set of proposed CDEs. This is in part because of the current lack of knowledge about common biological markers of self-management, as well as our decision to limit ourselves to only four CDEs. The development of biological CDEs for self-management research is an important area for future development of CDEs to advance the science of self-management.

To date, measures of the CDEs selected have not been designed for use with children. Given the need for the development of self-management skills in children with chronic conditions, CDEs of relevant constructs of self-management in children are needed. In addition to their usefulness in different age groups, a general limitation of the CDEs is a lack of information about their appropriateness for use in studies of different cultures, ethnic or racial groups, and sexual identities.

Summary and Conclusions

The use of CDEs in self-management research can advance the science of self-management in several ways. The use of common constructs and their measures in self-management research studies can facilitate data sharing across studies and increase generalizability of research findings across diverse populations and interventions. Their use may reduce the cost of conducting self-management studies as well as speed up knowledge production. The four recommended CDEs for self-management research (activation, self-regulation, self-efficacy for managing chronic conditions, and global health) described herein represent a first step in the design and use of CDEs for self-management research. Several steps and processes in the development and subsequent use of a final set of CDEs are yet to be completed. Next steps include submitting the CDEs for public review and then revising the CDEs based on the feedback from this review, education of nursing scientists regarding their use, and developing protocols for CDE collection, use, and management. The availability of infrastructure to support CDE use, including a national data repository for sharing study data that includes the CDEs and links to other CDEs developed in other institutes at the NIH, is needed. These recommendations, therefore, include a call to action from the nursing scientist community to use, add to, and help refine the proposed CDEs for self-management of chronic conditions.

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Clinical Resources

- Available common data elements: https://www.ninr.nih.gov/researchandfunding/available-cdes# (includes progress of the National Institute of Nursing Research to develop a set of common data elements for use in nursing research)
- Common data elements for use in neuroscience clinical research: https://commondataelements.ninds.nih.gov
- National Collaborative on Childhood Obesity Research measures registry: http://tools.nccor.org/measures/ (a registry of dietary behavior and physical activity measures suggested by the National Collaborative on Childhood Obesity Research)
- PROMIS: Dynamic tools to measure health outcomes from the patient perspective: http://www.nihpromis.org (a system of item banks measuring patient-reported health status for various domains of physical, mental, and social health across clinical populations; i.e., not disease-specific)
- Summary table for National Institutes of Health common data element tools and resources: https://www.nlm.nih.gov/cde/summary_table_2.html

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Caring for the Unseen: Using Linking Social Capital to Improve Healthcare Access to Irregular Migrants in Spain

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Key words
Irregular migrants, social capital, community health, education, homelessness, health disparities, case study

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Abstract

Purpose: To describe a novel strategy using linking social capital to provide healthcare access to irregular migrants with low literacy, low numeracy, and limited cultural assimilation in a European metropolitan area.
Organizing Construct: Public data show numerous shortcomings in meeting the healthcare needs of refugees and irregular migrants surging into Europe. Many irregular migrants living in European communities are unable to access information, care, or services due to lack of social capital. An overview of the problem and traditional charity strategies, including their barriers, are briefly described. A novel strategy using linking social capital to improve healthcare access of irregular migrants is explored and described. Information regarding the impact of this approach on the target population is provided. The discussion of nursing's role in employing linking social capital to care for the vulnerable is presented.
Conclusions: Immigration and refugee data show that issues related to migration will continue. The novel strategy presented can be implemented by nurses with limited financial and physical resources in small community settings frequented by irregular migrants to improve health care.
Clinical Relevance: The health and well-being of irregular migrants has an impact on community health. Nurses must be aware of and consider implementing novel strategies to ensure that all community members' healthcare needs, which are a basic human right, are addressed.

Nursing is a profession concerned with the needs of vulnerable populations and the recognition of social, economic, and political determinates of health (Sigma Theta Tau International, 2005). Violence, conflict and extreme poverty are uprooting millions of people in the Middle East (Syria, Iraq, and Afghanistan), Eastern Europe (Ukraine), Sub-Saharan Africa, and Southeast Asia (United Nations High Commissioner for Refugees, 2015). As a result, record numbers of refugees and migrants are entering Europe (United Nations High Commissioner for Refugees, 2015). However, not all refugees and migrants use formal routes to obtain residency or asylum. Irregular migrants live in a precarious position of low social capital in the countries in which they reside.

Social capital is the relationship an individual has to a group that allows them to access resources, such as money, health care, information, or services (Szreter & Woolcock, 2004). A sociological health principle describes this relationship well:

> Social inequality affects health in direct and indirect ways. High inequality entails a larger proportion of the population living in relative poverty and governmental policies that neglect human investments (such as in education, health, and an array of services). Inequality also affects health indirectly through psychosocial factors related to our place in the social hierarchy. Social capital (trust and civic participation) declines with greater inequality. (Wermuth, 2003, p. 66)

Irregular migrants in Europe have limited access to basic human needs, such as education, health care, and housing, while being excluded from any civic involvement, which makes them exceptionally vulnerable. The close physical proximity between rich and poor enhances the harmful effects of inequality on a physical, mental, and social level (Massey, 1996). Together the lack of equality, social capital, and being excluded from civic involvement permit the reinforcement of hindrances to perpetuate isolation of the irregular migrant.

Background Factors

Clear data are available on refugees and migrants who take formal routes to gain asylum and residency. More than 625,000 asylum applications were submitted in the European Union in 2014 (Bitoulas, 2015). The makeup of asylum applicants in 2014 was 18–34 years of age (53.7%), 35–63 years of age (19.9%), 0–13 years of age (18.8%), 14–17 years of age (6.7%), 65 years of age and over (0.8%), and unknown (0.1%), with the majority being men (Bitoulas, 2015).

However, less information is available regarding irregular migration. Irregular migration is defined as “the movement of persons to a new place of residence or transit that takes place outside the regulatory norms of the sending, transit and receiving countries,” and an irregular migrant is defined as “a person who, owing to irregular entry, breach of a condition of entry or the expiry of their legal basis for entering and residing, lacks legal status in a transit or host country” (European Migration Network, 2014, pp. 172–173). European Union member countries have less access to data on irregular migrants and generally base estimates on sanctions against employers for employing irregular migrants (European Migration Network, 2011). This type of data collection does not include irregular migrants who are present without employment or who are employed with employers who have not been sanctioned. The most recent data estimates on irregular migrants in Europe were collected by the Clandestino Project, commissioned by the European Union, which was terminated in 2009 (Clandestino, 2012). Estimates of irregular migrants, both working and nonworking, from data collected from 2007 to 2009, were between 1.9 million and 3.8 million for the 27 member states of the European Union (Eurostat, 2011).

Irregular migrants are at higher risk for health impairments because they do not have valid authorization to reside in the country where they live and therefore try to make a living in jobs that are typically dangerous or degrading while experiencing challenges in accessing health care, education, and housing (European Union Agency for Fundamental Rights, 2011). Not all European Union states recognize the rights of irregular migrants to claim compensation for accidents in the workplace or provide a means to seek judicial redress when discriminatory or abusive practices occur in the workplace (European Union Agency for Fundamental Rights, 2011). Access to health care for irregular migrants is variable between European Union states, and even in States that provide healthcare services there are obstacles of unawareness of entitlements and fear of information exchange between service providers and immigration enforcement authorities (European Union Agency for Fundamental Rights, 2011). Education access for irregular migrant children is complicated by rules that require documentation for enrollment or to receive diplomas; as education levels increase, access becomes increasingly restrictive (European Union Agency for Fundamental Rights, 2011). Housing is also problematic for irregular migrants who lack appropriate documentation to secure housing or lack sufficient financial resources to maintain a place of residence (European Union Agency for Fundamental Rights, 2011).

International human rights should be applicable to every person, as a consequence of being human, regardless of immigration status (United Nations, 1948, 1966a, 1966b). The Universal Declaration of Human Rights states that everyone is entitled to the rights and freedoms set forth in the Declaration, “without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, or other status” (United Nations, 1948, Article 2). Recommendations for European Union member states from sources such as the Universal Periodic Reviews and the European Center for Disease Prevention and Control have focused on assurance of access to basic social services for irregular migrants, which includes health care (European Center for Disease Prevention and Control, 2015; European Union Agency for Fundamental Rights, 2011; United Nations, 2015).

Spain, where this public health project took place, had a unique process within the European Union for irregular migrants. Irregular entry was not considered a crime in Spain (European Union Agency for Fundamental Rights, 2011). Spain was the only European country that allowed and fostered the registration of irregular migrants through a registration process called *Padrón*, which gave irregular migrants access to free medical care and public education on the same basis as Spaniards or regular migrants (Clandestino, 2009). Many South American immigrants, African, and Eastern Europeans entered the country as false tourists and used irregular migration as part of the process to gain residency or citizenship (Clandestino).

Irregular migrants in Spain could access other basic human needs, in addition to health care, via a broad charitable organization called Cáritas, which is the official charity group of the Catholic Church in Spain. Food, clothing, and other necessary supplies are distributed to those in need through offices located within Catholic churches; the physical address of a person or family corresponds to a specific church or dioceses where the person or family must go to receive services (Cáritas Española, 2009a, 2009b). The requirement to have a physical address, verified by a utility bill or government paper, to locate and receive services may be a barrier to irregular migrants who do not have access to stable housing, are not listed on utility bills, or do not receive government papers.

Due to an extended economic crisis, new legislation Real Decreto-Ley 16/2012, 2012 was passed on April 20, 2012, that restricted access of irregular migrants, as well as other sections of the population, to the national healthcare system (Gobierno de España, 2012). In response, a nongovernmental organization (NGO), Yo Sí Sanidad Universal, was formed to denounce and work on the retraction of the law through civil disobedience by accompanying community members, including irregular migrants, who are excluded from healthcare services to seek assistance within the national healthcare system (Yo Si Sanidad Universal, 2015). The groups of accompaniment are most often organized and enacted with Spanish speakers (European Commission, 2012), which can be a barrier for irregular migrants who do not speak Spanish.

The right of the independent European states to enforce immigration law may have a negative indirect impact on the ability of migrants to access basic rights in the host country and may discourage irregular migrants from accessing support services from NGOs or charity organizations for fear of arrest (European Union Agency for Fundamental Rights, 2011). A common method of policing for irregular migrants within the European Union are routine identity checks that are often carried out on routine traffic stops, on public transportation, or in public spaces (European Union Agency for Fundamental Rights, 2011). Identity checks carried out near schools, health centers, or religious buildings have an indirect effect of discouraging migrants from accessing charitable services and can be frightening, humiliating, or traumatic for the juxtaposition of seeking charitable services and being suspect at the same time (European Union Agency for Fundamental Rights, 2011). Social circumstances shape the quality of one's life (Kawachi, 2001). Irregular migrants live with persistent fear and distrust because they reside in a society that does not recognize them (Skiba-King, 2016). Enforcing immigration law at points of charitable service or resources for irregular migrants only deepens the fear and distrust while additionally building barriers to receiving fundamental basic rights.

Role of Social Capital in Irregular Migrant Health

Social capital has been linked to health outcomes in public health literature (Islam, Merlo, Kawachi, Lindstrom, & Gerdtham, 2006; Murayama, Fujiwara, & Kawachi, 2012). The concept of social capital has continued to evolve to include the nuances of "bonding," "bridging," and "linking" social capital. Bonding and bridging social capital are both horizontal in nature; bonding social capital involves trusting relationships between a network of people (e.g., family, friends) who view themselves as similar, while bridging social capital is based on mutual respect and support between group members who may not be alike in social identity or demographic (e.g., banks, police; Putnam, 2000). Linking social capital is a vertical strategy that links individuals in positions of high social capital with those individuals who lack social capital to open up and provide access to services or relationships that were previously inaccessible (Woolcock, 2001). Linking social capital is important in the health of poor communities where access to formal institutions, such as hospitals and clinics, must be based on trust and respect in order to improve access and health outcomes (Szreter & Woolcock, 2004). Although linking social capital can be led by disadvantaged community members, trusting relationships are usually successfully formed when those with greater social capital reach out to those with less social capital (Gittell & Thompson, 2001; Noguera, 2001). Concisely, the burden resides with community members who have social capital to both recognize and create trusting relationships with those who lack social capital. Together, the action of high social capital community members initiating and interacting with vulnerable community members embodies the application of linking social capital to create change.

Meeting the needs of irregular migrants in the communities in which they live is an essential component of community health. Nurses, through the nurse–patient relationship, are well prepared to meet the needs of irregular migrants (Skiba-King, 2016). Nurses are prepared academically to be change agents who can enter communities of irregular migrants and work as mediators to provide linking social capital to the unseen members of society through the intentional creation of trusting relationships. Individuals are only able to change their lifestyle habits and improve health if they are able to learn from honest and truthful individuals (Afzali, Shahhosseini, & Hamzeghardeshi, 2015). Linking social capital must be carefully constructed in order to create feelings of mutual respect and shared goals between group members and minimize the effects of the inherent power differential between those with high social capital and those with low social capital (Szreter & Woolcock, 2004). Irregular migrants are outside the formal systems of society and lack social capital, which may impair them from seeking assistance through NGOs or charity organizations out of fear of deportment or lack of understanding due to low literacy, low numeracy, or insufficient language skills. Nurses can intercede on their behalf through the use of linking social capital.

Nurses as Change Agents

Nurses are viewed favorably in most societies (Shattell, 2004). Nursing's role in providing care to society's most vulnerable members through linking social capital has been clearly demonstrated since Lillian Wald and Mary Brewster began the Henry Street Settlement in New York's Lower East Side in 1893 and pioneered public health nursing (Yost, 1955). After a random, brief encounter with the living conditions of the immigrants inhabiting the Lower East Side of New York City, Wald became an activist to improve the health and well-being of those who were on the fringe of society through public health initiatives and advocacy (Wald, 1915/2014). She noted during her first encounter with a family living in poverty, squalor, and social exclusion that "they [the immigrants] were not without ideals for the family life, and for society, of which they were so unloved and unlovely a part" (Wald, 1915/2014, p. 7). She linked the immigrant family's current condition with a lack of knowledge that could be rectified through education to help them avoid the natural consequences of their ignorance and promote health (Wald, 1915/2014).

In order to meet the needs of those at risk, Wald and Brewster moved into the Henry Street Settlement house in the Lower East Side to live near and directly attend to the issues of those living there (Wald, 1915/2014; Yost, 1955). Wald and Brewster navigated successfully to link social capital between privileged, educated, high-status women and immigrants living in squalid conditions to build trust and construct mechanisms to meet community needs, which then improved health for both the immigrant community members and the larger community around them.

A Novel Approach Using Social Capital

An analogous public health nursing approach was employed as the foundational structure to identify, address, and assist a community of irregular migrants attending English-speaking worship services at a multicultural church in central Madrid. The majority of irregular migrants are sub-Saharan African and South American. Adult males make up 70% of the population, with 30% being women and children. All irregular migrants attending worship services report being Christian; no data were collected to differentiate between Catholic and Protestant faiths. The irregular migrant community socializes routinely amongst themselves before and after church services as well as outside of church services (bonding social capital). The influential members of their community, such as spiritual leaders and tribal chiefs, interact with the religious leader of the church and the church's council members (bridging social capital). Interaction between church members of both regular and irregular status occurs during church services, religious education classes, bible study classes, language classes, and a coffee hour after church. Through these formal and informal activities, the church has become a place for spiritual, social, and emotional support as well as a location to access food and clothing for irregular migrants through Cáritas.

When Spanish law banned irregular migrants from healthcare services in the national healthcare system, the church community witnessed the negative effect of limited healthcare access. Irregular migrants are part of the social community of the church, so being unable to access health care posed a threat to not only the irregular migrants' health but the church community's health as well. Therefore, the decision was made to use linking social capital to improve access to healthcare services for irregular migrants to maintain community health.

Work for the program began with bridging social capital to identify civic groups for collaboration. The parish nurse scheduled meetings with local NGOs (e.g., Yo Si Sanidad Universal), humanitarian organizations (e.g., Red Cross), and charity organizations (e.g., Cáritas) to identify systems already in place. Conversations addressed available services, distribution of services, and perceived barriers that kept targeted populations from accessing services.

Following the use of bridging social capital at the professional level, bridging social capital was employed again at the church level between the church leaders and the irregular migrant leaders. Gaining entrance into the community and creating a trusting relationship were the main objectives of these meetings. Discussions involved the perceived needs of the irregular migrant community, which services were most valued by the community (primary, secondary, or tertiary care), and perceived barriers in accessing the services. Meetings were continued until an agreed process, location, time, and access point were mutually determined by all parties. The religious leader of the church, who evokes trust and respect among the irregular migrants, was a significant gate keeper, allowing access to the spiritual and tribal leaders as well as access to a physical location to distribute services.

The bridging social capital meetings informed and directed further meetings to assess strategies and resources to meet the needs of the communities involved. Main themes included ways to address and eliminate or reduce the barriers identified by the service providers and the irregular migrant community. Based on these conversations, an inventory of resources available, the volunteers present, and anticipated financial needs were collected.

Funding was secured through private donations. A charitable foundation was legally structured, according to local law, to manage the financial and legal issues related to the program. Initial ideas for the program included: (a) appointments on Sunday mornings at the church, before worship services to lower transportation costs; (b) an appointment sheet posted in a private area where interested parties could sign up for 10-min appointments slots; (c) a private office space for appointments with an external entrance to allow private entrance and exit; (d) an office space located next to a restroom for access to water; (e) no financial handouts for medication or supplies would be distributed, but the physical distribution of necessary medication and supplies would be given directly to the client; and (f) intentional and specific collaboration with NGOs, humanitarian agencies, and charities would begin on the bridging social capital level and move towards linking social capital as trust and respect increased between the organization and individuals seeking assistance.

Overview of the Program

The program provides direct assessment for basic health ailments that can be managed on an outpatient basis with immediate distribution of medications or supplies for symptomatic treatment. Monitoring of health conditions, such as high blood pressure, is also performed. Each office visit includes health education as a health support. Additionally, health promotion seminars, which are adapted to the needs of low-literacy and low-numeracy learners, are created and implemented on a regular basis. After the seminar, individual bags containing supplies referenced in the seminar and a low-literacy, low-numeracy teaching sheet are distributed to participants.

Finally, through linking social capital, the program acts as a triage and referral to link irregular migrants with NGOs, humanitarian groups, and charity organizations. After trust and mutual respect have been cultivated between the nurse and client, the suggestion to access appropriate services and charities is considered safe by the irregular migrant. As Skiba-King (2016) clearly wrote, “when nurses listen to the . . . undocumented migrant, we are establishing caring connections—we are creating new stories to flood the community” (p. 325).

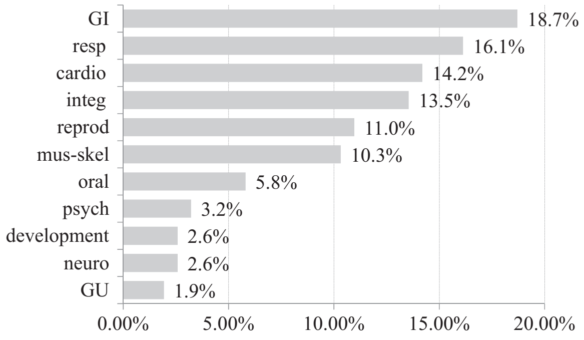

Figure 1. Distribution of chief complaints by body system.

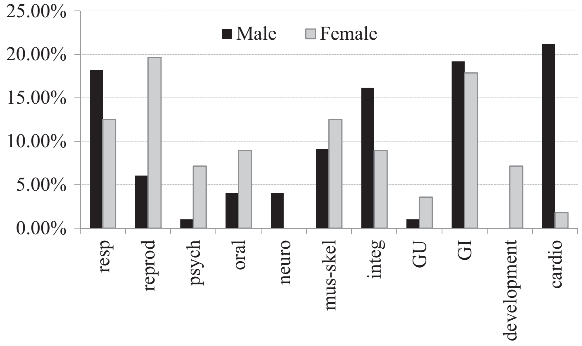

Figure 2. Chief complaint by body system separated by gender.

The program began in November 2012. Initially, only a few irregular migrants came. Culturally, there was a huge divide between the White, educated women providing services and the irregular migrant men seeking services. A warm, inviting presence was necessary while maintaining a professional approach. A white coat was worn by providers and a desk separated the provider from the client to discuss the issue of concern before the examination. Confidentiality was reinforced at each visit, truth keeping was a requirement, as was honoring the needs of the client before our assessment of needs by listening and seeking understanding.

The program sees approximately 10 families per week. Twenty percent of visits each week are to address chronic conditions or are follow-up visits. Males make up 64% of the clients; 76% of the clients are adults, 5% adolescents, and 19% infants and children. The majority of visits are related to common ailments such as gastrointestinal concerns, respiratory infections, hypertension, and skin infections. **Figure 1** shows the distribution of visits by body system. The nature of visits by gender and age are described in **Figures 2** and **3**, respectively.

Irregular migrants are referred to outside resources for more severe health impairments, such as suspected broken bones, abnormal growths, uncontrolled

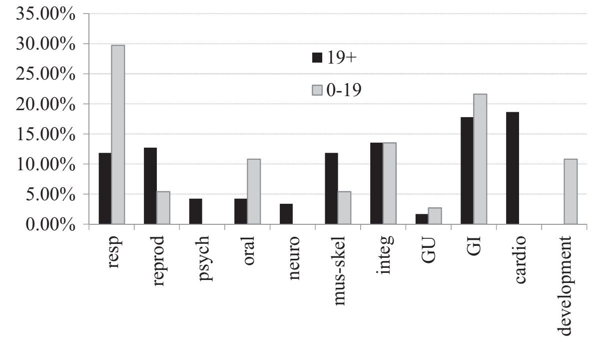

Figure 3. Chief complaint by body system separated by age group.

hypertension, severe lacerations, sexually transmitted diseases, unwanted pregnancy, birth control, and psychiatric issues. Nineteen percent of clients are referred for further evaluation or treatment. Of that 19%, 15% require continued follow-up.

Through linking social capital, irregular migrants feel confident seeking outside resources to meet their needs. A specific process is employed when clients are referred to outside resources because most irregular migrants do not have sufficient language skills to communicate their needs. Additionally, there can be fear and distrust of seeking services beyond the church. To begin, a note is written at the sixth grade English level and read to the client so they understand what information they are carrying. An opportunity is given to clarify doubts or add additional information. Then, this information is rewritten in Spanish to assist the person receiving the client at the referred location. Finally, an email is sent to the receiving organization to make them aware that a client will be arriving with limited language skills, but carries a letter from our program to help them access the services he or she needs. This is possible because formal lines of communication were created during the development of the program through bridging social capital. The last step is to inform the irregular migrant of the exact location of the service provider and specific directions on how to use the public transportation system to arrive at the location at the right time and on the right day. A follow-up visit is encouraged with the client after his or her referral to learn more about his or her experience and to provide information to improve the process. Most clients are happy to participate in the improvement process and share positive experiences readily with their community members through bonding social capital.

Lessons Learned

Not all initial ideas worked due to cultural issues. The sign-up form for appointments was never used. Instead, there is an informal "line" for appointments. When irregular migrant community members were asked why the sign-up sheet did not work, two reasons were given: (a) not all members could write their English name clearly, and (b) there is a cultural norm of not showing weakness. The irregular migrants did not want other members of their community to know they were seeking support. Another issue related to privacy arose around the distribution of medication and medical supplies. The clients wanted the medications and supplies needed for treatment, but did not want others to see what they were receiving. Having a pharmacy bag to put the medications in, for privacy reasons, was very important to the community.

Beyond physical health needs, irregular migrant community members actively seek information on secondary health issues such as nutrition, child development and discipline, grief and loss, exercise and healthy behaviors, and clarifying culturally learned health behaviors (i.e., questions such as: How long do you have to wait between users of public restrooms to allow the air to change?). This prompted the need to connect with other health professionals to find appropriate resources and information.

Challenges

There are still issues that have not been resolved. One issue is the hierarchy between men and women; women will be in the invisible line, but men will jump ahead of them. The last meetings of the morning are always women and their children. Additionally, there have been issues of trying to seek more medication than necessary, seeking medications for afflictions not being experienced, or bringing in an empty medication container and demanding the exact same medication to be distributed.

Another challenge is guiding the expectations of the client. Educating clients that health impairments are not always resolved with the first medical appointment or first therapy is critical to maintaining a trusting relationship and avoiding skepticism of the program. Correspondingly, follow-up can be difficult among a transient population, which can affect medication therapies, monitoring health conditions, or knowing if certain procedures were effective.

There has been a rotation of volunteer providers. Working with irregular migrants is demanding. Issues that influence volunteers are: (a) a lack of a shared native language between the nurse and client so there can be misunderstandings about what is being expressed; (b) power differential can be uncomfortable when strong personalities interact; (c) power struggles can arise; (d) fairness is culturally assessed and clients can complain about services; and (e) when a service is "free" there can be feelings of entitlement, which can be demoralizing for the providers.

Positive Outcomes

Despite the challenges, there are rewards. The irregular migrant community reports feeling supported and is better able to access services it previously did not know were available or were uncertain how to access. Specific examples include: (a) two women and one man being successfully treated for sexually transmitted diseases from a foundation specializing in sexual health education; (b) a woman was able to access services to address an unwanted pregnancy and obtain birth control by two distinct foundations providing women's health services; (c) a man was able to receive appropriate diagnostic testing, treatment, and follow-up for a cerebral vascular accident related to uncontrolled hypertension from a humanitarian organization. This individual now has his daily medication purchased and distributed by the program as well as weekly follow-up to prevent a reoccurrence; and (d) a man with an abdominal tumor was able to access an evaluation and treatment within the national healthcare system through the assistance of an NGO that accompanied him to his doctor visit and assured he was adequately evaluated. In all these cases, the irregular migrants were previously unaware of available services, were unable to access the services due insufficient language skills, or did not have sufficient trust to visit these services without the direct and repeated assurance of the program members. Linking social capital was integral in helping the irregular migrants know, understand, and access services that are available in the community to meet their healthcare needs.

Additionally, the parish community is better protected from preventable communicable disease. Health promotion seminars on proper handwashing use and technique help lower the spread of gastrointestinal illnesses. Prompt and appropriate treatment of intestinal worms limits the spread between household members and other community members outside the household. Health promotion seminars on healthy eating are well attended by both irregular migrants and local community members to improve health and well-being. Through these shared experiences and shared concern for each other, increasing networks of bonding and bridging social capital among church community members reinforce the benefits from providing linking social capital to the irregular migrant community.

Conclusions

This novel strategy of employing Wald's grassroots approach can be recreated by nurses in their local communities to start caring for the unseen. The Universal Declaration of Human Rights (United Nations, 1948, 1966a, 1966b) clearly entitles all humans, regardless of status, to basic human rights, which includes health care. Violence, conflict, and extreme poverty continue to force migration globally; migrants who choose irregular entry are at higher risk for health impairments due to lack of social capital (European Migration Network, 2014; Wermuth, 2003).

Nurses have the ability to build positive relationships with irregular migrants based on safe interactions in order to assist them in meeting their healthcare needs (Skiba-King, 2016). The use of linking social capital between nurses and irregular migrants, stemming from a trusting and respectful nurse–patient relationship, can improve access and healthcare outcomes for both the irregular migrant community and the larger community as a whole (Szreter & Woolcock, 2004). Furthermore, nurse-led efforts to meet irregular migrant health needs and scholarly documentation of these efforts directly support the global nursing research priorities set by Sigma Theta Tau International (2005) which include health promotion and disease prevention as well as advocacy and promotion of health of vulnerable and marginalized communities.

Clinical Resources

- European Migration Network: http://ec.europa.eu/dgs/home-affairs/financing/fundings/migration-asylum-borders/asylum-migration-integration-fund/european-migration-network/index_en.htm
- European Union Agency for Fundamental Rights: http://fra.europa.eu/en

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Understanding Compassion Fatigue in Healthcare Providers: A Review of Current Literature

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Key words
Advanced practice registered nurse, burnout, compassion fatigue, compassion stress, healthcare providers, nurse, nurse practitioner, physician, secondary traumatic stress

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Abstract

Purpose: The purpose of this integrative review was to identify, review, synthesize, and analyze the existing literature addressing compassion fatigue (CF) in healthcare providers (HCPs), with careful attention to provider role and practice area. CF needs to be better understood to identify, prevent, and treat it before it becomes problematic for HCPs. CF is representative of the cost of caring and results in physical, emotional, and psychological symptoms that contribute to the decision of the HCP to leave the profession.

Methods: A literature search, guided by search terms related to CF, was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed encompassing publications between 2005 and 2015. The selected literature was then systemically reviewed and synthesized for this narrative review.

Results: These preliminary searches resulted in 307 articles, of which 43 met inclusion criteria. These 43 articles were reviewed and reported that CF and related concepts (CF and RCs) were pervasive and affected a wide variety of HCPs working in many clinical settings; however, advanced practice registered nurses (APRNs), respiratory therapists, physical therapists, and occupational therapists were not well represented. The literature provided information regarding prevalence, risk factors, prevention measures, and symptoms of CF and RCs.

Conclusions: While CF and RCs have been explored in a myriad of medical professionals, there is little published regarding APRNs, respiratory therapists, physical therapists, and occupational therapists. More research is needed to evaluate for the presence of CF in HCPs working in a variety of settings and the degree to which it affects personal and professional well-being, including interactions with patients, patient outcomes, and the quality of professional life. Additionally, as the definition and use of the term compassion fatigue has evolved, a need for a well-developed concept analysis has also become evident.

Clinical Relevance: A better understanding of current research on CF through narrative review, development of a concept analysis, and further exploration of its impact on HCPs has the potential to improve the overall well-being of HCPs, ultimately leading to better patient care and retention within the profession.

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Compassion fatigue (CF) is often thought of as the caregiver's cost of caring and results when caregivers are exposed to repeated interactions requiring high-levels of empathic engagement with distressed clients; it can be a significant contributing factor in caregiver burnout (Figley, 2002). CF leads to an acute onset of physical, emotional, and work-related symptoms that affect patient care and relationships (Lombardo & Eyre, 2010).

CF is often conflated with burnout, secondary traumatic stress (STS), and compassion stress. While the terms are used interchangeably in the literature, it is unclear whether they are in fact synonymous. Some of this overlap occurred due to the evolution of the concept of CF. CF originated from the understanding that post-traumatic stress disorder could also affect individuals who know about a traumatic event that impacted someone close to them; this was also known as secondary catastrophic stress reaction (American Psychiatric Association, 1980; Figley, 1993). This understanding led to Figley's further research and conceptualization of STS to explain the costs of caring many supportive parties experienced when they learned of someone else's trauma (Figley, 1993). Joinson renamed the cost of caring phenomenon compassion fatigue, and both parties conceded that the terms could be used interchangeably, with STS offering a better clinical description and CF providing a more user-friendly term for the experience (Figley, 1995; Joinson, 1992).

CF and burnout have similarities and are closely correlated ($r = 0.769$, $p < .001$), yet they have unique symptomology, with CF occurring more abruptly than burnout and as a direct result of exposure to another person's trauma (El-bar, Levy, Wald, & Biderman, 2013; Todaro-Franceschi, 2013). While both result in mental, physical, and psychological exhaustion, CF mirrors post-traumatic stress disorder in that most of the symptoms and distress are related to traumatic memories, hyperarousal or numbness, avoidance of same or similar situations, and exhaustion (El-bar et al., 2013). Conversely, burnout is the result of powerlessness and low job satisfaction, and leads to gradual worker disengagement (El-bar et al., 2013). However, continued overlapping and interchanging of these terms in recent research suggests the need to differentiate them in the form of a thorough concept analysis (Coetzee & Klopper, 2010; Figley, 2002; Jenkins & Warren, 2012; Sabo, 2011). Until such time, CF and related concepts (CF and RCs) will be used as an overarching term in the discussion to present a comprehensive analysis of the literature.

Aims and Research Questions

The aim of this literature review was to analyze published research in the past 10 years that addressed CF and RCs in healthcare providers (HCPs) with attention to provider role and practice area. To do this, the current literature for CF in all HCPs was reviewed. Ultimately, this review aims to answer (a) What does the recent literature report regarding CF and RCs in HCPs, and (b) Are there any gaps in the current literature related to specific HCP roles?

Methods

This literature review employed Whittemore and Knafl's (2005) integrative review methodology. It deviated slightly as no official data evaluation stage was included due to lack of clearly defined concepts in the literature. While recommended, Whittemore and Knafl (2005) acknowledged that quality data evaluation is complex and more helpful when the sample of literature is small and includes similar or identical research designs. The use of a quality scoring system would not have been particularly beneficial because this review covered an extensive sample and a wide variety of research designs.

The literature search spanned 2005–2015 and was conducted using the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and PubMed. While restricting the search to online databases can be self-limiting, as detailed by Whittemore and Knafl (2005), including databases that are inclusive of all healthcare professionals minimized this limitation. The search was limited to the past 10 years of literature because of the evolution of the concept in healthcare research and the need to find the most current definition and use of the concept in healthcare research. Search terms included compassion fatigue, compassion satisfaction, secondary traumatic stress, burnout, healthcare providers, and bad news. These search terms were used because they are closely related and are often used interchangeably during discussions regarding CF; these are also the terms listed as related by the primary authors of the papers included. Whittemore and Knafl (2005) encouraged hand searching the literature to increase results; thus, the reference lists of papers identified in the primary search were reviewed for possible additional publications to include. Unpublished materials, such as dissertations, were included provided they otherwise met inclusion criteria; this was intended to decrease publication bias (Whittemore & Knafl, 2005). Theoretical papers were

Table 1. Study Sample Provider Role

Provider role	$N = 43$
Mixed healthcare providers	14 (32.6%)
Staff nurses	16 (37.2%)
Genetics workers	3 (7.0%)
Emergency workers	3 (7.0%)
Physicians	2 (4.7%)
Midwives	2 (4.7%)
Students	2 (4.7%)
Child protection service workers	1 (2.3%)

Table 2. Study Sample Practice Area

Practice area	$N = 43$
Mixed/unspecified	8 (18.6%)
Pediatrics	7 (16.3%)
Emergency/trauma	6 (14.0%)
OB/fetal/abortion	5 (11.6%)
Oncology	4 (9.3%)
Genetics	3 (7.0%)
Intensive care	3 (7.0%)
Hospice	3 (7.0%)
Well-baby care	2 (4.7%)
Transplant	1 (2.3%)
Military medicine	1 (2.3%)

Note. OB = obstetrics.

not included, as they were outside of the scope of the research questions for this narrative review.

A priori inclusion criteria required that studies be published in the time span previously noted, written in English, and included only formal HCPs. Studies were excluded if they were not the primary source of information or original research. This was intended to increase the quality of data included in the narrative review.

Results

Search terms were identified in 307 articles, 275 of which were available as full-text articles. Abstracts were evaluated for inclusion and exclusion criteria, resulting in 43 articles. **Tables 1** and **2** and **Figures 1** and **2** provide details of the articles' study samples and research design. A table representation of all literature included in this review may be found in this article's online supplemental materials.

The results section that follows will present the literature review findings using the authors' original language for clarity; however, many of these concepts are used in tandem, which again highlights the need for an effective concept analysis of CF to differentiate it from RCs. In addition, advanced practice registered nurses (APRNs) were conspicuously missing from the current body of research, despite their growing numbers and roles in the healthcare force, thus resulting in a gap in the literature and an area for future research. Many HCPs, though, were well represented in the literature; thus, results will be presented based on professional group.

Mixed Professional Groups

Many of the studies used a mixed sample of HCPs or did not specify the participants' professions. A variety of healthcare settings were represented.

One study found that HCPs working in critical care units scored lower on burnout and CF than did HCPs working in the general medicine setting ($t = 2.23$, $p = .031$; Smart et al., 2014). A higher average number of hours of sleep was linked to decreased burnout and helpful in predicting STS ($F[1,133] = 4.211$, $p < .05$, $r^2 = 0.031$; Smart et al., 2014). HCPs who scored higher on emotional intelligence and emotional management scores reported a decreased incidence of CF (Zeidner, Hadar, Matthews, & Roberts, 2013). Finally, a study examining a mixed group of military HCPs caring for wounded soldiers showed that CF was a significant problem that could be reduced using resilience training (coping scores before training $M = 86.46$, $SD = 27.89$; coping scores following training $M = 80.61$, $SD = 22.92$; $t[27] = -1.20$, $p = 0.240$; Weidlich & Ugarriza, 2015). Although these results were not statistically significant in the sample ($n = 93$), they support a need to follow up with a larger study for validation.

Three studies looking at a mixed professional group of hospice workers found that workers with higher levels of compassion satisfaction, or positive feelings resulting from caring for others, had lower levels of CF ($r = -0.300$) and burnout ($r = -0.612$), noting a positive correlation between CF and burnout ($r = 0.761$; Alkema, Linton, & Davies, 2008; Slocum-Gori, Hemsworth, Chan, Carson, & Kazanjian, 2011). The findings also suggested that improved self-care can decrease CF and burnout while increasing compassion satisfaction ($p < .05$; Alkema et al., 2008). An additional study noted that although hospice workers reported high levels of stress, a small minority reported symptoms of CF or burnout, far lower than published norms (Whitebird, Asche, Thompson, Rossom, & Heinrich, 2013).

Clinicians working in oncological inpatient settings had higher rates of CF when compared to their outpatient colleagues (53% vs. 37%), and higher levels of burnout (44% vs. 33%; Potter et al., 2010). One team of researchers likened oncology work to a Mount Everest expedition, citing the need for teamwork to overcome challenges and to prevent or delay the onset of CF through open communication, mutual trust, interdependence, and strong team support (Rohan & Bausch, 2009).

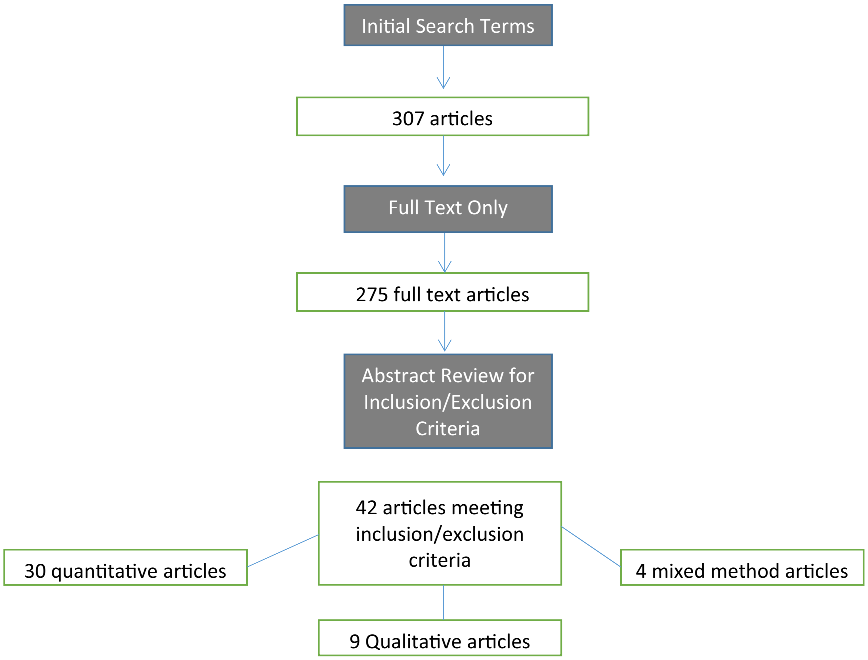

Figure 1. Literature search process.

Pediatric nurses and physicians were evenly distributed among the various levels of CF severity; however, the majority of chaplains (72%) reported high levels of CF (Meadors, Lamson, Swanson, White, & Sira, 2009). Branch and Klinkenberg 2015 compared CF, compassion satisfaction, and burnout across a variety of inpatient pediatric units. The only statistically significant finding was that clinicians in the pediatric critical care unit reported lower levels of compassion satisfaction and higher levels of CF and burnout than providers in other pediatric units (Branch & Klinkenberg, 2015). These results were similar to McGarry's (2013) study, which reported that providers in traumatic brain injury and burn units had more symptoms of CF and lower levels of compassion satisfaction than published norms, and providers younger than 25 years or with nonproductive coping mechanisms had higher levels of burnout, STS, depression, and anxiety than other providers on the same unit. HCPs working in fetal medicine reported the negative emotional impact and personal and professional effects of caring for women with adverse pregnancy outcomes (Menezes, Hodgson, Sahhar, & Metcalfe, 2013).

Staff Nurses

Inpatient nurses working in emergency, oncology, critical care, progressive care, and medical-surgical units, and outpatient nurses working in home health settings and oncology infusion clinics were found to be at risk for CF (Potter et al., 2013; Yoder, 2010). Emergency department (ED) nurses were at particularly high risk for CF and burnout (Hinderer et al., 2014). The vast majority of nurses working in EDs reported symptoms of traumatic stress within the past week, with 33% of them meeting all criteria for STS (Dominguez-Gomez & Rutledge, 2009). Another report revealed that 86% of ED nurses had high CF scores, and 82% reported high burnout scores (Hooper, Craig, Janvrin, Wetsel, & Reimels, 2010). Despite high scores for CF, these nurses also reported high compassion satisfaction in more than one study (Hinderer et al., 2014; Hunsaker, Chen, Maughan, & Heaston, 2015). CF and burnout in ED nurses may be related to feeling unsupported by management (Hunsaker et al., 2015). In addition, the emotional stress and disruptive memories of caring for patients, specifically victims of intimate partner violence, contributed to high CF and burnout scores (Van der Wath, van Wyk, & Janse van Rensburg, 2013).

Critical care nurses were also extensively studied. Nurses working in intermediate and critical care vascular units experienced average to high levels of compassion satisfaction, and low to average scores of STS and burnout (Young, Derr, Cicchillo, & Bressler, 2011). Mason et al. (2014) differentiated various concepts and reported them separately. Participants in those studies reported high burnout, with 58% reporting average levels of CF and 28% reporting average levels of STS; none of the participants reported high levels of CF or STS (Mason et al., 2014). Similar to their ED nurse colleagues, critical care nurses stated that low managerial support

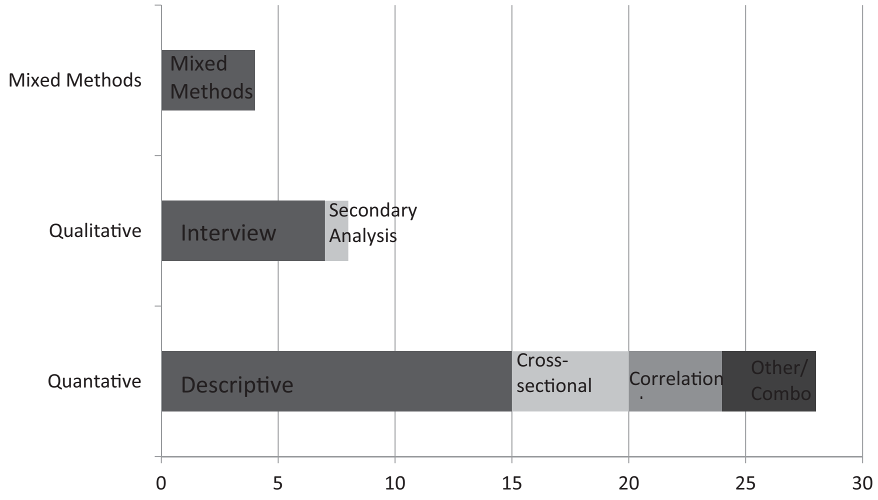

Figure 2. Literature search results by study design.

contributed to CF (Mason et al., 2014). Critical care nurses also reported feelings of powerlessness; physical distress; values conflicts; medication errors; and violence, death, and suffering in the critical care units as factors leading to CF and RCs (Maiden, Georges, & Connelly, 2011; Mason et al., 2014).

Oncology nurses' unique experiences revealed five themes of CF, including the causes, definition, factors that worsen it, factors that lessen it, and outcomes (Potter et al., 2013; Yoder, 2010). There was also a significant gap in nurses' knowledge regarding CF (Perry, Toffner, Merrick, & Dalton, 2011). But the risk and incidence of CF among nurses could be decreased with education regarding its existence, prevention, and coping strategies (Potter et al., 2013; Yoder, 2010).

Almost 30% of pediatric nurses reported high levels of burnout and more than 27% reported high levels of CF (Berger, Polivka, Smoot, & Owens, 2015). Nurses working on pediatric medical-surgical units reported the highest levels of burnout but the lowest levels of CF (Berger et al., 2015). Similar to prior work, Berger et al. (2015) also found that younger nurses experienced the highest levels of burnout. Canadian home health nurses, completing well-baby visits to homes with first time mothers, and nurses working in well-baby clinics in Israeli war or terrors zones both reported STS (Berger & Gelkopf, 2011; Dmytryshyn, Jack, Ballantyne, Wahoush, & MacMillan, 2015). Each reported that concern for the babies and mothers contributed to their STS and CF despite different community environments.

Nurse caring, job satisfaction, and compassion satisfaction were all positively related, while nurse caring was negatively related to stress and burnout with other inpatient nurses (Burtson & Stichler, 2010). CF was positively related to burnout ($r = 0.37$, $p < .001$) and inpatient nurses' intention to leave the profession ($r = 0.55$, $p < .001$; Sung, Seo, & Kim, 2012). CF was reported in 29.6% of Korean nurses intending to leave the nursing profession (Sung et al., 2012). Transplant nurse coordinators had average or above compassion satisfaction scores and low to average scores for STS and burnout as measured by the Professional Quality of Life Scale Version 5 (Kim, 2013).

Genetics Workers

Genetics workers, including nurses, doctors, and counselors, all reported CF, compassion distress, and burnout. Bernhardt's large-scale study of 214 genetics workers aimed to identify the nature, causes, and consequences of compassion distress, another concept related to CF, and burnout (Bernhardt et al., 2009). Bernhardt et al. (2009) found that the greatest sources for compassion distress included professional responsibility for the test results, negative patient experiences, and worry for bias in the information presented to patients and families. Genetic counselors had higher rates of conflict and personal responsibility for the information provided to patients than their physician and nurse colleagues did, often leading to compassion distress (Benoit, McCarthy Veach, & LeRoy, 2007; Bernhardt et al., 2009; Bernhardt, Silver, Rushton, Micco, & Geller, 2010). Triggers for the counselors included delivering bad news; but effective coping mechanisms, such as establishing clear professional boundaries, decreased CF, compassion distress, and burnout (Benoit et al., 2007; Bernhardt et al., 2009, 2010).

Trauma Workers

Trauma therapists in Europe who had low levels of working through their own feelings resulting from caring for traumatized clients had frequent symptoms of CF, compassion distress, and burnout (Deighton, Gurris, & Traue, 2007). Seventy-two percent of the trauma therapists believed it was necessary or often justified to work through the trauma with their own trained therapist (Deighton et al., 2007). Alternatively, emergency responders in South Africa reported lower levels of CF and burnout (although higher levels than comparative groups in Sweden and United States), with high compassion satisfaction scores (Pietrantoni & Prati, 2008). Self-efficacy and sense of community were identified as predictors for compassion satisfaction levels, whereas self-efficacy alone was a predictor for CF (Pietrantoni & Prati, 2008).

Physicians

Of 914 junior doctors in Australia, 69% met the criteria for burnout, and 554% met criteria for CF (Markwell & Wainer, 2009). Seventy-one percent of respondents reported below average job satisfaction and a concern for their health and well-being; however, 98% of respondents intended to continue practicing medicine (Markwell & Wainer, 2009). These results were similar to those found in a study of 1,000 gynecologists in the United States in which one third of respondents reported emotional exhaustion, with more symptoms reported from those who experienced conflict with patients or colleagues (Yoon, Rasinski, & Curlin, 2010).

Midwives

Midwives were the only APRN group specifically represented in the current literature on CF, though it is important to note that midwives are not necessarily APRNs in some countries. Midwives and obstetrics or gynecology nurses in Japan working in abortion centers had the highest CF scores if they believed that an aborted fetus was viable or if they had a difficult time controlling emotions during a procedure (Mizuno, Kinefuchi, Kimura, & Tsuda, 2013). The authors of the study concluded that abortion was a particularly distressing experience for providers that may lead to CF (Mizuno et al., 2013). Midwives who were present during traumatic births also reported emotional distress, stating that they felt a sense of womanly and professional responsibility to their patients and their babies (Rice & Warland, 2013).

Child Protective Workers

In a sample of 363 Colorado child protective services staff, half of the sample experienced high or very high levels of CF despite 70% reporting high levels of compassion satisfaction (Conrad & Kellar-Guenther, 2006). Even though half of the participants reported high levels of CF, there was a low report of burnout, leading the authors of the study to conclude that compassion satisfaction may have served as protection against burnout (Conrad & Kellar-Guenther, 2006).

Students

Midwifery students were at risk for CF if they were not able to cope with or move past their feelings regarding a traumatic birthing event (McKenna & Rolls, 2011). Undergraduate nursing students did not show any signs of CF at the time of evaluation; however, the students' interviews revealed their concern for burnout later in their careers despite role actualization skills learned in advanced clinical rotations (Michalec, Diefenbeck, & Mahoney, 2013).

Discussion

The aim of this narrative review was to identify, review, synthesize, and analyze the existing literature addressing CF and RCs in HCPs. CF and RCs have the ability to take a toll on HCPs and on the healthcare profession as a whole. One of the challenges of conducting research on CF is delineating it from several RCs, such as burnout, STS, compassion distress, and compassion satisfaction, because the terms have developed overlapping and conflated meanings over time. While evaluating for the quality of data is a vital part of completing an integrative review, this cannot be accomplished with any degree of validity without first providing a clearer understanding of CF through concept analysis. For this discussion, the abbreviated "CF and RCs" will be used to convey the variety of concepts reported throughout the literature.

The majority of studies assessed CF and RCs in various subgroups of HCPs using self-report surveys. In addition, a subset of the research identified risk factors and preventative measures for CF and RCs. CF and RCs were identified in various providers across multiple practice settings, countries and community environments, age groups, and experience levels. Although multiple professional roles are represented in the literature, respiratory therapists, physical therapists, occupational therapists, and APRNs are conspicuously absent from the recent CF and RC literature and represent an opportunity for additional research. Few studies specifically discussed the validity of their results. In addition, there is a paucity of data regarding the specific causes or triggers of CF and RCs that again represents an opportunity for additional work.

Significance of Understanding Compassion Fatigue

This review demonstrates the difficulty in completing a thorough and accurate review of the literature without clearly conceptualizing CF. It also offers a comprehensive understanding of the effects of CF in HCPs. CF and RCs lead to physical (headache, gastrointestinal issues, sleep disturbances), emotional (mood swings, irritability, depression, poor concentration, judgment), and work-related (avoidance of particular situations or patients, decreased ability to feel empathy, lack of meaning in work) symptoms that can affect patient care and relationships with coworkers and patients (Lombardo & Eyre, 2010). Emotional exhaustion and its effects on personal life were the most commonly cited results (Mason et al., 2014; Menezes et al., 2013; Rice & Warland, 2013; Van der Wath et al., 2013; Yoon et al., 2010). Physicians specifically reported a concern for their health and overall well-being as a result of CF and RCs (Markwell & Wainer, 2009). Further, physicians reported job dissatisfaction related to CF and RCs, though denied a desire to leave the profession (Markwell & Wainer, 2009). Conversely, CF and RCs were reported in nurses' intention to leave the nursing profession (Sung et al., 2012). These findings are worrisome in light of the continued nursing shortage and growing population.

Risk Factors for Developing CF and RCs

The intensity of the patient setting is related to development of CF and RCs. HCPs caring for traumatized individuals, including traumatized or stressed infants, children, mothers, and victims of intimate partner violence, are at risk for developing CF and RCs (Berger & Gelkopf, 2011; Dominguez-Gomez & Rutledge, 2009; Hooper et al., 2010; Van der Wath et al., 2013). HCPs working in general medical-surgical units had a lower incidence of CF and RCs than providers working in critical care units (Berger et al., 2015; Branch & Klinkenberg, 2015; Smart et al., 2014).

Conflicting family and patient interactions are also a risk factor for CF and RCs, with many providers reporting that the simple act of providing patient care and interacting with patients and their families contributed to symptoms (Benoit et al., 2007; Bernhardt et al., 2009, 2010; Dmytryshyn et al., 2015; Mason et al., 2014; Van der Wath et al., 2013; Yoder, 2010; Yoon et al., 2010). While patient care and interactions are the essence of health care, they are also the chief stressors for many providers. Other workplace factors contributing to CF and RCs include particular job duties, such as delivering bad or uncertain news to patients and their families, and lack of perceived managerial support. Genetics workers reported a high occurrence of CF and RCs, triggered delivering uncertain or bad news resulting in emotional stress (Bernhardt et al., 2009). Presumably, this finding could be applied to any HCP sharing bad or uncertain news with patients and families.

Junior providers with limited experience and poor coping strategies are at higher risk for developing CF and RCs (McGarry, 2013). The inability to work through one's feelings regarding a traumatic event or providing care for traumatized individuals, to identify effective coping mechanisms, or to improve emotional intelligence through education or experience all contribute to CF and RCs (Deighton et al., 2007; McGarry, 2013; McKenna & Rolls, 2011; Mizuno et al., 2013).

Prevention of CF and RCs

Self-care was reported to be the most significant preventative measure HCPs could take to protect themselves from developing CF and RCs. Education and teamwork also contributed to the prevention of CF and RCs in HCPs. Coping with emotionally trying situations and self-efficacy, or an individual's perceived ability to have some control over one's own behavior, task, and environment, decreased the risk for CF and RCs (Benoit et al., 2007; Pietrantoni & Prati, 2008). Educational programs that taught recognition and prevention of CF and RCs were effective in teaching resilience and coping mechanisms to HCPs when implemented in interventional studies or through professional training (Berger & Gelkopf, 2011; Meadors & Lamson, 2008; Michalec et al., 2013; Potter et al., 2013; Weidlich & Ugarriza, 2015).

In addition to educational interventions, researchers found other workplace characteristics that may help prevent CF. Managers should aim to create a professional environment that promotes teamwork and positive working relationships because poor administrative leadership was a contributing factor to developing CF and RCs (Hunsaker et al., 2015; Mason et al., 2014; Rohan & Bausch, 2009). Compassion satisfaction decreases the likelihood of experiencing CF and RCs; so, HCPs should strive to foster behaviors that improve compassion satisfaction (Alkema et al., 2008; Conrad & Kellar-Guenther, 2006; Smart et al., 2014).

Conclusion

CF and RCs are a pervasive concern in HCPs working in a wide variety of clinical settings and practice settings. While the presence of CF and RCs has been well established in many HCPs, some providers are absent from current literature, including respiratory therapists, physical therapists, occupational therapists, and APRNs. The literature shows that CF and RCs contribute to burnout, HCPs leaving the profession, and HCPs' ability to interact with patients; therefore, a better understanding of the effects of CF and RCs and effective prevention and intervention need to be explored. Unfortunately, the lack of a well-constructed concept analysis for CF has created limitations to understanding its effects and identifying strategies to prevent or treat it. A concept analysis will provide much needed differentiation among CF and RCs and allow for better evaluation of data quality and an enhanced ability to compare study findings. Ultimately, clarifying the definition of CF and addressing gaps in research will help clinicians and administrators identify, intervene, and prevent CF in HCPs.

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Clinical Resources

- Compassion Fatigue Awareness Project: www.compassionfatigue.org
- Green Cross: http://www.greencross.org
- Support: Dealing with Stress in the Workplace: http://toolkit.ahpnet.com/Dealing-with-Stress-in-the-Workplace/Introduction-Compassion-Fatigue-and-Burnout/Compassion-Fatigue/Compassion-Fatigue-Resources-and-Papers.aspx

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Supporting Information

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

Table S1. Overview of reviewed quantitative studies.

Table S2. Overview of reviewed mixed methods studies.

Table S3. Overview of reviewed qualitative studies.

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CLINICAL SCHOLARSHIP

The Lived Experiences of People With Chronic Obstructive Pulmonary Disease: A Phenomenological Study

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Key words
Chronic disease, long-term care, phenomenology, qualitative research, respiratory

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Abstract

Purpose: This study explored the lived experiences of people with chronic obstructive pulmonary disease (COPD) following hospitalization for acute exacerbation or pneumonia.
Design and Method: A phenomenological approach was adopted to collect data through semistructured interviews. Fourteen participants were recruited from a medical center in northern Taiwan. Data were collected from January 2013 to January 2014. Giorgi's phenomenological methodology was adopted to analyze the interview content.
Findings: Three phenomenological themes emerged: trapped in an invisible cage, torments in the winter, and striving for wellness.
Conclusions: This study sought to elucidate the lived experiences of people with COPD, who perceived themselves as feeling an overwhelming sense of confinement. The interviewees displayed positive attitudes, indicating that people with COPD are willing to cope with their disease. Health practitioners should focus on educating people with COPD about their needs, encouraging them to be more positive, and assisting them in engaging in self-management.
Clinical Relevance: People with COPD can cope with the disease and seek alternative methods to improve their health. These positive attitudes could be used to encourage self-management in the future.

Chronic obstructive pulmonary disease (COPD) is a growing threat to global population health because of smoking, air pollution, and population aging. COPD was the fifth leading cause of death in 2002, and it is estimated to rise to the third largest cause of death in the world by 2030 (World Health Organization, n.d.). The burden of COPD is projected to increase in the coming decades.

Earlier researchers emphasized that people with COPD have a prevalence of depression, anxiety, and poor quality of life (Al-Gamal, 2014; Asuka et al., 2013; García-Rio et al., 2011). Pulmonary rehabilitation and self-management were used to improve quality of life by medical practitioners (Billington, Coster, Murrells, & Norman, 2015; Jácome & Marques, 2014). It is unclear why people with COPD continue to have a poor quality of life and in an unhealthy mood.

Previous qualitative research on the lived experiences of people with COPD focused on their self-care, self-management, or final stage (Chen, Chen, Lee, Cho, & Weng, 2008; Ek, Sahlberg-Blom, Andershed, & Ternestedt, 2011; Hayle, Coventry, Gomm, & Caress, 2013). More evidence and different views of lived experiences other than self-management and life during the final stage are needed for understanding life with COPD. Further, lived experiences of patients may differ under different health care systems, social cultures, and living conditions.

Table 1. Interview Guide

1. Would you like to talk about how you feel about COPD?
2. How has COPD affected your life?
3. How do you feel when you feel breathless or have difficulty breathing?
4. How do you deal with COPD?
5. What concerns you the most in your daily life?

The purpose of this study was to explore the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia. This article extends knowledge about what it is like to live with COPD after being hospitalized for acute exacerbation or pneumonia by highlighting the lived experiences of these persons.

Methods

A qualitative approach was designed for data collection through semistructured interviews. A phenomenological methodology was adapted for analyzing the interviews to extract the meaning of the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia.

A purposive sample of 17 participants was recruited from the thoracic and geriatric wards of a medical center in northern Taiwan by one of the authors. Three of the 17 participants declined participation, and 14 participants were included in this study. Eligibility criteria were: (a) clinical diagnosis of COPD, (b) had hospitalization due to acute exacerbation or pneumonia within the past year, (c) were over 18 years of age, (d) were Mandarin- or Taiwanese-speaking, (e) were willing to be interviewed and digitally recorded, and (f) were provided informed consent. Exclusion criteria included: (a) lung cancer or pulmonary tuberculosis, (b) heart disease, or (c) cognitive impairment. As no new themes emerged at the 11th interviewee, the results were considered saturated and were stopped at the 14th interviewee in this study.

Data were collected from January 2013 to January 2014. Six of 14 interviews were conducted in clinical settings, and eight took place at the patients' homes. Semistructured, face-to-face, digitally recorded interviews were conducted and ranged in length from 42 to 120 min. The interview guide was developed and modified from previous studies (Chen et al., 2008; Tsou, Lu, Lin, & Maa, 2009), as outlined in **Table 1**. This study was approved by the Research Ethics Committee of the National Taiwan University Hospital (Reference No. 201211017RIC) and related departments before commencement. Subjects who met the recruitment requirements were invited to participate in this study and were informed about the aims and procedures of it in both oral and written form. Before the interviews, all participants were told that they were free to withdraw from the interview at any time and for any reason.

The data analysis and interview processes of this study were carried out simultaneously. After an interview recording was transcribed, the first author (interviewer) checked for accuracy by listening to the recordings while reading the transcripts. All data were analyzed using Giorgi's (1997) method for extracting the meaning of their lived experiences. This method is based on the philosophy of Husserl. The researcher must "bracket" to analyze a person's phenomenal status (Giorgi, 1997). Procedures used included reading all of the transcripts that described the experiences and listed the feelings described, rereading the description, confirming the lived experiences transcribed in the transcripts, clarifying and carefully connecting related relationships, carefully considering what was mentioned by all the interviewees, translating what was expressed by all interviewees into scientific terminology and concepts, and combining all observations into a meaningful description of their lived experiences. After repeated readings of the transcripts, the researchers grouped similar meaningful experiences from the transcripts into key words. Key words with similar meanings or concepts were then grouped into a subtheme. Lastly, the main meaning behind each of these subthemes was then formed into the theme.

This study adhered to credibility, dependability, transferability, and confirmability (Lincoln & Guba, 1985) for maintaining rigor. Each interview was conducted by the first author who is not a staff member at this hospital and shared no health care provider relationships with the participants. The interviewer is a doctoral candidate who has more than 15 years' experience as a nursing lecturer and who received qualitative research training in her master's and PhD courses. In order to achieve credibility, the interviewer tried to avoid using her experiences and ideas to guide the participants to talk about their minds and feelings. All the transcripts, data coding, and theme formulation were reviewed by another author (first author's advisor). A precise transcription of all interview recordings was read several times and confirmed by the first author to achieve dependability. Transferability was met through a rich description of the context of participants from different levels of severity in COPD. Conformability was enhanced with a rigorous audit trail of data and procedures.

Findings

Fourteen participants (12 men and 2 women) were recruited from a medical center in northern Taiwan. The average age of the participants was 77.1 years (range 63–86), and the mean duration of COPD was 5.8 years (range 1–11). According to the Global Initiative for Chronic Obstructive Lung Disease (2015) severity classification of COPD, seven participants were in the mild stage, two participants were in the moderate stage, and five participants were in the severe stage. Eleven participants were former smokers, two were nonsmokers, and one was a current smoker. Their lived experiences following hospitalization for acute exacerbation and pneumonia were analyzed to develop subthemes and themes.

Theme 1: Trapped in an Invisible Cage

All participants perceived being trapped in an invisible cage as having a great impact on their daily life after being hospitalized for acute exacerbation or pneumonia. Participants experienced a derailed life because of the symptom of breathlessness. Breathlessness is difficult to avoid and manage for participants, discouraging them from going outside, so they would choose to stay at home for a sense of security. These feelings are linked to debilitation and a sense of confinement.

Derailed life. Their lifestyles changed dramatically and they endured significant differences, especially with respect to exercise capability, sleep patterns, and eating habits. From their descriptions it was obvious their quality of life was affected by COPD: "I used to go hiking before, but I could not go hiking anymore after the exacerbations again and again. All I can do is to walk around my house" (Participant 09). "It is hard to breathe when I lie down in the bed. I like to sit in the chair when I feel breathless at night" (Participant 13). "My appetite was affected by breathlessness. I lost a lot of weight within 2 years because I didn't eat much" (Participant 13).

Debilitated. Breathlessness is difficult to avoid for people with COPD, which frustrates participants as it becomes difficult to manage. From the participants' descriptions, it appeared they lacked energy to move around. This is linked to feelings of debilitation. One participant expressed his situation: "I am just like a withered flower. I have no energy to go outside so I choose not to go outside" (Participant 07).

Sense of confinement. Participants became breathless and fatigued easily due to their COPD, which resulted in participants narrowing their range of activities. Participants described their concerns: "I didn't like to go outside when I lived in the old apartment without an elevator, because it was difficult to return if I went outside. I was locked up in the house all day" (Participant 03). "I used an oxygen machine at home for nearly 4 years. When I went outside, I had to carry a small oxygen cylinder so I couldn't go far away from my house" (Participant 02).

Theme 2: Torments in the Winter

Participants suffered torments from unpredictable and uncontrollable pneumonia or acute exacerbations in the winter. Winter acts like a time bomb that could explode and cause destruction to their daily life. They expressed their fears, worries, and concerns. Their airways are sensitive to the low temperature, and acute exacerbation is more likely to occur in the winter. They experienced a great fear of death when they struggled for oxygen. Further, they worried about becoming a burden to their families when they were hospitalized.

Sensitivity to the cold. The low temperature in the winter led to coughing for many people with COPD, which was often quickly followed by feelings of breathlessness. One man described his experiences in the winter: "I have been hospitalized for acute exacerbation in the winter almost every year due to the weather change. When the weather changes in the winter, the breathlessness comes with coughing . . . they never stop" (Participant 04).

Fear of death. The fear of struggling with oxygen was not only related to death, but also the complications or outcome of hypoxia. One participant described his fears: "I couldn't breathe ... It was just like my neck was squeezed ... I was afraid that my heart might stop beating ... I needed oxygen right away" (Participant 03).

Family burden. When the time bomb of pneumonia or acute exacerbation exploded, it caused not only suffering for the people with COPD, but also for their families. One man described his concerns:

> I am in a state of bliss if the next generations show their filial piety. My son came with me when I needed to go to the emergency room because of an acute exacerbation. The daily routine of my son's family was disrupted ... I don't want to be a burden to my son and daughter in terms of medical costs or care. (Participant 03)

Theme 3: Striving for Wellness

Participants suffered from discomfort because of the symptoms from COPD. Participants strived for their wellness by preventing the flu, smoking cessation, and using folk medicine in their daily life to improve their well-being.

Preventing the flu. Participants were afraid of contracting the flu because of the complications that could immediately arise. Participants have their own methods for preventing the flu in their daily life. One participant shared his experience: "I am afraid of contracting the flu. In order to avoid contracting the flu, I receive a flu vaccine every year and I prefer to stay at home most of the time when the cold weather comes" (Participant 01).

However, one participant described the uncomfortable experience of wearing a mask: "It is suggested to wear a mask. However, I am not used to wear it because it is difficult to breathe when I wear a mask" (Participant 03).

Smoking cessation. It is hard for people to quit smoking. A patient's motivation determines if he or she is successful in ceasing smoking. It is important to know why people with COPD stop smoking. One man described his reason for stopping smoking: "My physician suggested that I stop smoking to live a longer life. I want to live longer so I decided to quit smoking. I quit smoking without any help from smoking cessation outpatient services" (Participant 07).

Using folk medicine. In Asian culture, there is a belief that "medicine and food are from the same source." This belief encourages traditional medicine to be combined with daily food intake. Participants in this study also followed this ideology in their lives. They paid particular attention to the properties of their food to reduce COPD symptoms. Experiences shared by participants include the following: "I found that I have more sputum within 2 days after eating more tomatoes. Therefore, I am eating fewer tomatoes now" (Participant 09). According to Chinese medicine, swallows' nest soup has beneficial properties for healing the lungs. A subject described her hope: "I eat swallows' nest soup with chicken stock every day. I think it will be helpful to combat my breathlessness" (Participant 11).

Discussion

This study presents participants' subjective feelings about their lived experiences as people with COPD following hospitalization for pneumonia or acute exacerbation. Our participants felt that they were trapped in an invisible cage and their lives were no longer the same after suffering from COPD. Previous research revealed that persons with COPD who were severely ill at home with oxygen therapy built their lives around limited space during their final stage of life (Ek et al. 2011). We found that participants had a tendency to narrow their range of activities. However, in our study, participants were not seriously ill during their final stage of life, indicating that people with COPD following hospitalization for acute exacerbation or pneumonia would be limited mainly to their home, regardless of their stage of disease. Health practitioners can focus on working towards educating and serving people with COPD on how and what to use to deal with breathlessness for increasing their sense of security to go outside and be able to extend their range of activities. Portable oxygen systems are more regularly used in some Western countries. In the present study, the participants who required oxygen used nonportable oxygen, which is one reason why people experienced restricted activity areas.

Influenza has been predicted as a risk factor for the exacerbation of COPD (Montserrat-Capdevila, Godoy, Marsal, Barbé, & Galván, 2015). The highest number of admissions for patients with COPD occur during winter, as exacerbation and temperature are related to the number of COPD hospitalizations (Almagro, Hernandez, Martinez-Cambor, Tresserras, & Escarrabill, 2015; Tseng et al., 2013). Our study supports these findings, as the participants described their fears of contracting the flu, which could progress to acute exacerbation or pneumonia, and in turn could lead to hospital admission. Therefore, our interviewees were particularly wary of the need to keep warm on a daily basis to reduce the chance of acute exacerbation. This is also a reminder to all health practitioners to advise people with COPD to stay warm, as well as to supply information on how to avoid contracting the flu. In addition, this study revealed that people with COPD who experienced breathlessness found it more difficult to breathe after wearing a mask, which was uncomfortable. Alternative methods are needed for preventing respiratory tract infections and protecting against respiratory pollutants.

A previous study found that the Chinese cultural ideology of filial piety and the modernization of society placed the family caregivers of people with COPD in a caring dilemma situation in Hong Kong (Yu, Lee, & Wu, 2007). Taiwan is similarly a place of Chinese culture. We found that when children helped take care of their parents with COPD, parents felt that there was sufficient respect from their children. However, parents with COPD were worried about their children bearing too much of the burden if they were to be hospitalized. These results show that people with COPD were also in a dilemma—while they appreciated being respected by having their children visit and care for them in the hospital, they also worried about increasing the burden on their children. Therefore, health practitioners need to evaluate the mental support needs of people with COPD.

Clancy, Hallet, and Caress (2009) found that COPD patients shared very negative experiences. Our study supports this finding since most participants had very negative feelings towards having COPD. However, some participants tried hard to be healthier and show a positive attitude, suggesting people with COPD can cope with the disease and seek alternative methods to improve their health. These positive attitudes could be used to encourage self-management in the future. This research showed that participants believed eating functional foods was very important to them, but they also suffered from a poor appetite, malnutrition, and weight loss. Therefore, health practitioners should try to introduce evidence-based nutritional information to people with COPD and find ways to improve their appetites. This study also revealed that participants tried to avoid all foods that had "cold" and "cool" attributes. According to traditional Chinese medicine, foods have four different attributes not defined by their temperature: cold, cool, warm, and hot. From a modern medicine viewpoint, foods with cold and cool attributes can reduce body metabolism, while foods with warm and hot attributes can increase body metabolism (Chen, 2000). Many interviewees believed that foods with "cold" and "cool" attributes, such as melons, radishes, and tomatoes, would increase mucus production. This resulted in reduced intake of these vegetables by the interviewees. We suggest that a randomized controlled trial be performed to investigate if avoiding these vegetables can control COPD symptoms to provide a more scientific basis for this belief.

Chen and Wang (2011) found that the quality of sleep for COPD patients was not ideal. Our study supports this finding, since our participants mentioned that they experienced breathlessness, increased mucus expelling, and coughing, leading to poor sleep quality or an inability to sleep. Except for the recommendations of noninvasive ventilators and medicines for sleeping, the literature or educational brochures lack information on ideal sleeping positions, which healthcare experts need to address and further research is needed to explore.

Furthermore, the majority of participants were ex-smokers (11 of 14, with 1 current smoker and 2 non-smokers). This indicates that people with COPD in this study were more successful at quitting smoking than a previous qualitative study showing that two out of three COPD interviewees were unable to quit smoking (Schofield, Kerr, & Tolson, 2007). Participants in this study indicated that they did not receive any treatment to help them quit smoking. Coughing and breathlessness contributed to these people successfully quitting smoking, as did consistent encouragement from health practitioners. The reason and process behind the high success rate in Taiwanese people with COPD in quitting smoking without any treatment should be explored further. This study also showed that it was very helpful for health practitioners to correctly remind people of the need to quit smoking.

Study Limitations

The results of this study only presented the experiences of people with COPD who were hospitalized at a medical center in northern Taiwan. People in other parts of the world may experience living with COPD differently. The participants in this study were only interviewed on one occasion, and the data were not sought from multiple sources. The findings may be unable to describe the phenomenon to a full extent, and it is difficult to interpret participants' experiences about the changing process of the disease without further follow-up.

Conclusions

This study described the lived experiences of people with COPD following hospitalization for acute exacerbation or pneumonia. Participants described their experiences on how to live with COPD. These participants went outside less because of their fear of breathlessness. They felt insensibly trapped in an invisible cage. Health practitioners can focus on working towards educating and serving people with COPD on how to deal with breathlessness and offering information to assist them to choose a more suitable oxygen delivery device for improving their activities. In addition, people with COPD found that wearing a mask actually increased their breathlessness, so alternative methods are needed for preventing respiratory tract infection and protecting against respiratory pollution. The positive attitudes observed in some people indicated that they were still willing to cope with their disease. Health practitioners should encourage people with COPD to be positive and responsible by educating them to self-manage.

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Clinical Resources

- COPD Foundation: http://www.copdfoundation.org/
- Self-management tools: https://www.blf.org.uk/Page/Self-management-tools

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CLINICAL SCHOLARSHIP

A Focused Ethnography of Baccalaureate Nursing Students Who Are Using Motivational Interviewing

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Abstract

Purpose: The purpose of this article is to describe how nursing students learned and used motivational interviewing (MI) in a community-based clinical context at a primary care vascular risk reduction clinic focused on health promotion.

Design and Methods: A focused ethnography was used to access a sample of 20 undergraduate nursing students, 16 patients, and 2 instructors. Data were generated from participant observations, field notes, student journals, and interviews (one-on-one and focus group).

Findings: Central to the students' experience was their transformation because of learning and using MI. Three sub themes describe the social processes that shaped the student experience: learning a relational skill, engaging patients, and collaborating as partners.

Conclusions: It is feasible for nursing students to learn MI and use this approach to enhance collaborative care in a primary care setting. The experience can be transformative for students.

Clinical Relevance: Supporting patients to adopt healthy lifestyles is a significant role for nurses in practice. The findings provide key insights and strategies for nurse educators teaching students a collaborative communication approach, such as MI, to engage patients in health behavior change.

Patient teaching is a large part of nurses' roles, and much of this education is about changing behaviors for improved health (Whitehead, 2007). Traditional lifestyle education includes giving information on healthy lifestyle behaviors, instructing patients on managing conditions, and targeting risk reduction. These approaches are typically didactic and intended to work through transferring illness knowledge to effect a change in patient behavior (Whitehead & Russell, 2004).

The literature provides a mixed impression of the effectiveness of health education, and authors posit this may be due in part to the preparation of undergraduate and practicing nurses as educators or the lack of time or priority given to health education activities (Holt & Warne, 2007; Miller & Beech, 2009; Wiley, Irwin, & Morrow, 2012). Some authors identified that traditional health teaching may not provide the collaborative problem solving that patients need to make the complex adaptations accompanying the uptake of new behaviors (Miller & Rollnick, 2013; Montgomery-Dossey & Keegan, 2013). With a focus in health care on patient-centered approaches, nursing students would benefit from developing skills, such as motivational interviewing (MI), to work collaboratively with patients on health behavior change. This article reports on themes from a focused ethnography of how undergraduate nursing students learned and used MI as a collaborative approach to engage patients in behavior changes targeted at vascular risk reduction. We report on the patient experiences of MI by nursing students in another article.

MI is a patient-focused approach to behavior change that is distinct from health education because it explores and addresses values, beliefs, and worries about change (Miller & Rollnick, 2013). The clinician uses open-ended questions, affirmative statements, reflective statements, and summary statements (OARS skills) to engage patients to talk through the ambivalence associated with adopting different lifestyle patterns. Despite considerable research activity, questions remain about how MI works from a patient's perspective as well as the best way to prepare practitioners and determine their competence (Rouleau et al., 2015; VanBuskirk, & Loebach Wetherell, 2014). Some scholars have suggested MI is a good complement to nursing practice because its key principles align with a collaborative and holistic view of patients (Maissi et al., 2011; Southard, Bark, & Hess, 2013). While nurses in primary care settings have successfully used MI to support patients with behavior change (Brobeck, Bergh, Odencrants, & Hildingh, 2011; Noordman et al., 2012), little is known about undergraduate nurses using MI in practice. Thus, the aim of this study was to describe how nursing students learned and used MI in a community-based, primary care clinical context with the intent that our account can help nurse educators better prepare students to work with patients on changing health behaviors.

The research on undergraduate students using MI primarily focused on skill acquisition and involved research participants from dental hygiene (Croffoot, Krust Bray, Black, & Koerber, 2010) medicine (Martino, Haeseler, Belitsky, Pantalon, & Fortin, 2007; White, Gazewood, & Mounsey, 2007), nursing (Carpenter, Watson, Raffety, & Chabal, 2003; Czart, 2014) and pharmacy programs (Goggin et al., 2010). The studies identified that students should learn theoretical material on MI principles, then develop skills using a variety of modalities, including role play, standardized patients, or high-fidelity simulation (Carpenter et al., 2003; Croffoot et al., 2010; Czart, 2014; Goggin et al., 2010; Martino et al., 2007; White et al., 2007). These recommendations are consistent with synthesis research on MI training for clinicians in practice (Schwalbe, Oh, & Zweben, 2014; Soderlund, Madson, Rubak & Nilsen, 2011). There is some evidence that high-fidelity simulation is a feasible strategy to teach nursing students MI and that they achieve proficiency with basic principles and techniques (Carpenter et al., 2003; Czart, 2014). However, in these studies, the aim of the encounter was smoking cessation, and this neither reflects a collaborative approach to care (Gottlieb & Feeley, 2006) nor is consistent with the spirit of MI where the patient should identify the focus of discussion (Miller & Rollnick, 2013).

Methods

A focused ethnography is an adaptation of traditional ethnography that addresses a phenomenon as it is experienced by a particular group in a specific context (Erickson, 2011; Knoblauch, 2005). Since the aim of this research was to understand how undergraduate nursing students learned and used MI in their clinical work, a focused ethnographic approach was selected for its emphasis on social context, participant interactions, and subjective experiences. Focused ethnography is distinct from traditional ethnography by specific attention to a selected phenomenon, and therefore the researcher should be familiar with the area of investigation (Knoblauch, 2005). In our research, the primary author had extensive knowledge of MI, undergraduate clinical teaching, and patient education for health promotion and secondary prevention. The ability to both converse with and observe the students as well as those with whom they interacted, such as instructors and patients, provided a multidimensional view of how students learn and apply this relational skill. Both authors had professional backgrounds in nursing education. The primary author had training at the graduate level in field observation techniques and consulted with peers who were experienced in ethnographic research.

Throughout the course of the research study, the investigators adhered to the procedures outlined in the Tri-council Policy Statement: Ethical Conduct for Research Involving Humans. The study protocol, accompanied by interview guides, received ethical approval from two research ethics boards at universities in western Canada. Recruitment occurred through third parties not affiliated with the nursing students' activities or the patients' health care. The primary author collected the data and was not associated with the students' academic progression or patients' care.

Context and Participants

The study occurred at a postsecondary institution in western Canada and took in activities as part of a 13-week community-based clinical experience in a primary care setting where students used MI to support patients with health promotion and vascular risk reduction. The students worked in pairs during the patient encounters and had direct supervision by an instructor. Debrief sessions for student feedback on skill development took place following the patient visits. The community experience occurred in year 3 or 4 of an undergraduate nursing program.

In a focused ethnography, the sample is drawn from the setting and informed by the participants' relationship to the phenomenon of interest (Roper & Shapira, 2000); therefore, we sampled to obtain diverse views of how learning MI unfolds for students in the setting. The sample included nursing students who learned MI, instructors who taught students MI in the clinical setting, and patients who received MI from nursing students. All student participants were in the third year of a 4-year nursing program. There were 38 participants (20 students, 16 patients, 2 instructors); 9 identified as male and 29 female, and they ranged in age from 23 to 55 years.

Data Collection

The authors had no association with the students prior to their being contacted to participate in the study. Eligible students ($n = 48$) and instructors ($n = 3$) each received an information letter describing the study sent by e-mail from an administrative support person. Students and instructors received an email invitation sent by an administrative professional not connected with academic or clinical activities. Potential patient participants ($n = 100$) received a letter describing the study from administrative personnel (not affiliated with care delivery) in the location where they accessed health promotion services. Potential participants notified the primary author of their interest using an email address in the invitation letter. The primary author contacted potential participants, answered questions about the study, reviewed the consent form, and discussed the range of activities involved in the research. The consent form was reviewed and signed prior to the first observation, and participants were aware they could withdraw or modify participation. In the case of one patient where an observation did not occur, the consent form was reviewed and signed prior to the one-on-one interview. Data collection occurred over two 13-week academic terms.

Ethnographic approaches are grounded in a constructivist philosophy that perceives the nature of reality as something socially constructed by human beings rather than naturally given (Roper & Shapira, 2000). To support coherence between method and question, we used data collection strategies that included field observations and notes, student journals, one-on-one interviews with patients and instructors, and focus group interviews with students.

Unstructured field observations, a distinguishing feature of the ethnographic approach (Germain, 2001; McCurdy, Spradley, & Shandy, 2005), provided direct exposure to participants' actions relative to MI. The observations took place in weeks 5 through 12 of the 13-week community-based clinical experience. Thirty-five clinical observations occurred. These included 15 student–patient encounters and 20 student–instructor debrief sessions. An observation did not occur with one patient due to a scheduling conflict; however, this individual participated in an interview. The cumulative time in the field was 46 hr, and each observation lasted between 45 and 180 min. Field notes were taken discretely during the observations and updated immediately following with descriptions of the context, unique events, typical routines, as well as the primary author's reflections.

Spontaneous, unstructured interviews occurred during field observations, and these clarified elements that surfaced during observations. We received 10 student journals that each contained a 3- to 6-page reflective summary on either community health nursing in general (six journals) or MI in particular (four journals). The primary author completed all participant interviews (one-on-one interviews with patients and instructors, focus group interviews with students) after field observations in order to expand on experiences that surfaced during fieldwork. Interview questions for the two instructors focused on their approaches to and experiences with teaching students MI. The one-on-one patient interviews ($n = 16$) were 30 to 60 min in duration and covered what it was like to have motivational support from a student as well as how this compared to the typical experience with a health provider. The student focus group interviews explored the timing, techniques, experiences, and insights associated with their learning and using MI. We used a focus group format with the nursing students because they worked in pairs or threes during the clinical experience and were uniquely positioned to build on insights from their debrief sessions in a focus group setting. Students had the option of a one-on-one interview; however, all took part in the focus groups. There were four student focus group interviews: two groups had two participants each and eight students attended each of two other focus groups. The focus group interviews were 60 to 90 min in length, took place in a private but familiar area, and happened at the end of the school term.

With the concurrency of data collection and analysis, the interview questions evolved as the research progressed over two academic terms to gain a better understanding of how students used MI in clinical practice. The instructor and patient interviews took place in a private space, and all but one, where a patient participant declined for personal reasons, were audio-recorded. The primary author took notes during the nonrecorded interview.

Data Analysis

The diverse data collection strategies (observations, field notes, interviews, student journals) provided material to alert us to the fit between the data and research question, triangulate developing themes, and recognize patterns. Consistent with an inductive approach to qualitative research, we concurrently collected and analyzed data (Germain, 2001; Knoblauch, 2005; Morse

Table 1. Undergraduate Nursing Students and Motivational Interviewing (MI)—Themes and Features

Central theme: Transforming as Nursing Students
  Through using MI, students experienced transformation in their nursing practice

Subthemes:
Learning a Relational Skill
  Timing—students ready to integrate MI into practice at Year 3
  Feedback—instructors use MI when supporting students' skill development
Engaging Patients
  Releasing the "expert stance"—students resist giving advice on what patients "should" do
  Meeting patients "where they are at"—students discern cues of what is important for patients
Collaborating as Partners
  Patients as partners—students and patients collaborating on approaches to change
  Doing critical thinking—students tailoring knowledge to patients' unique situations

& Richards, 2002). Through this verification process, we assessed accumulating data to ensure a comprehensive description of the students' experiences. Interviews were the primary source of data for this research. The field observations and student journals provided context and insights to support the understanding of what students "thought about" and how they "enacted" MI relative to verbal accounts of their experiences. The interviews were transcribed verbatim (over 200 pages of single-spaced text) as they were completed, assessed for accuracy, stripped of identifiers, and annotated with observations made from the interviews. There were 30 double-sided, single-spaced pages of handwritten field notes transcribed for analysis. Due to the flexible nature of the journal assignment where students self-selected topics for reflection, we used only 4 of 10 student journals because they addressed MI in particular. The student journals were submitted in electronic format; after removing identifiers, we had 12 double-sided, double-spaced pages of text that we managed similar to the interview data. We reviewed all data line by line; identified consistent words, phrases, and events; organized these into categories; and formatted them into tables according to data type. All categories were derived from the data and represented distinct symbols that shared common relationships or meanings (McCurdy et al., 2005). This approach also supported the comparison of developing patterns across the different types of data (interviews, field notes, observations, and student journals).

Categories were reevaluated (discussed, reviewed, refined) as the data collection progressed to assess the data fit within the categories, the comprehensiveness of the categories overall, and the developing themes. We continued the process of concurrent data collection and analyses until we identified that the categories were rich in detail, replicated in several cases, and uncovered no new information. The instructor themes aligned with the themes in the student data providing credibility to our analysis. From the data-generated categories, we noted salient features from which we identified themes (Morse, 2008). The themes represent contextual features that influenced students' use of MI in their clinical practice and distinguished the substantive elements that constituted the overall experience. Two student participants reviewed the analysis and reported that our account resonated with their experience.

Findings

We identified a central theme of transformation that was supported by three subthemes to describe how students learn and use MI in clinical practice: learning a relational skill, engaging patients, and collaborating as partners (**Table 1**).

The findings describe the shared understandings and social actions organized around how nursing students use MI in clinical practice. A central finding was that the students identified that the experience of learning and applying MI transformed them as health professionals. Subthemes of learning a relational skill, engaging patients, and collaborating as partners describe the social processes that influenced student transformation. Specifically, learning a relational skill like MI was shaped by introducing the skills at the right time in their academic program and providing ongoing feedback on skill development. The application of MI skills pushed the students to focus on engaging patients, and this entailed letting go of an expert stance and meeting patients "where they are at." As students became experienced using MI to discern what was important for patients, the students collaborated with patients as partners to understand the context of patients' lives and used critical thinking to tailor health messages. Altogether, the growth that occurred through learning MI—using the skills to engage with patients and subsequently collaborate as partners—created a transformation in the nursing students.

Transforming as Nursing Students

With learning MI, students adopted a way of being that enhanced patient connection, collaboration, and ultimately the students' personal transformation. Through using MI, students experienced a transformation in their nursing practice and it became "how I nurse." Transformation is a deep, structural shift in thinking, feeling, and acting (O'Sullivan, Morrell, & O'Connor, 2002). We identified diverse accounts of transformation. Students talked about the impact of using MI, such as how they behave with patients: "it is part of my nursing practice; it is the way I am with people—respectful and collaborative" and "I use these skills all the time because they show what professional caring looks like." The students' transformation included changed thinking about knowledge: "there is a feeling of confidence that patients will still trust us and see us as professionals even if we don't have all the answers" and "it's not just about reading articles to know things, we 'read' patients and put those together."

A significant transformation was in attitude: "[we] had to take a hard look inwards so now there is more softness in our approach" and "we stopped fighting with patients to make them do what we want and learned to guide them along." Indeed, using MI influenced students' confidence in their patients: "for many of us who were skeptical about people changing it happened that using these skills brought out huge potential in patients and we became a lot less cynical." Overall, learning and using MI in a clinical setting was both educational and formational for undergraduate nursing students.

Learning a Relational Skill

Both instructor and student participants identified that the timing of learning MI as well as the approach to feedback were significant determinants of skill acquisition. The students indicated they would not have been interested in using MI in years 1 and 2 because they were preoccupied with "doing things to patients," such as developing their skill with nursing procedures. Students described feedback sessions with their instructors as "motivating experiences that inspired [us] to build on what worked and strategize to build up what didn't work."

Timing. From the students' perspective, the best time to learn MI was in year 3 because the students' focus was expanding beyond hands-on clinical skills towards relational skills: "in those first 2 years it was a challenge to even talk with the patient while doing nursing tasks; in year 3 came the ability to focus on both skills and communication." The field observations confirmed that students started the clinical experience with only basic interpersonal skills and it was noted how "students talked at rather than spoke with patients." The students linked the timing of teaching MI to their professional formation: "third year is when a lot comes together and the 'light bulb' moment was that communication is as significant to the patient care as doing the tasks." The clinical instructors recognized MI was an advanced helping skill, yet believed in teaching MI early and "nurturing concurrently throughout their program alongside psychomotor skills so students develop relational techniques to enhance hands-on care." Instructors who teach MI should be sensitive to when they introduce the skill and establish clear linkages for students to the role MI has in accentuating nursing care.

Feedback. Feedback sessions, or "debriefings," were instructor-facilitated, student-centered conversations where students reflected back on the patient encounter and described how MI skills unfolded, discussed what aspects worked well, and self-identified areas to strengthen. During field observations, it was noted that instructor participants used MI to draw out students' self-assessment of how things went and provide feedback. Indeed, the student participants appeared enthusiastic to participate in the feedback sessions and did most of the talking. When the influence of the instructors demonstrating MI during debrief was raised in the focus group interviews, the student participants shared "the instructor using MI during debrief made the feedback on what I was doing sink in because I saw how it could be done." The interviews, journals, and field observations confirmed the value of feedback. There were examples of how the students' self-awareness of their skill performance progressed to self-correction in subsequent patient encounters: "as I got better at it, I found myself thinking 'how could I be doing this differently' so the debrief was about that moment when I realized that and modified the approach."

Some students, however, struggled with incorporating MI into a natural conversation. In these cases, the instructors would demonstrate MI skills with the student role-playing a patient. The role reversal was a turning point because it gave students a "personal experience" of MI with a skilled professional and "first-hand feedback" of how to integrate MI into the conversational flow. A frequent student comment on the role of feedback was "getting beyond the initial clumsiness of communicating differently, recognizing what I'm doing with a patient and adapting to take those skills further." The findings in this theme provide guidance to the timing of introducing MI to nursing students and the importance of feedback on skill development. Instructor-guided, student-centered feedback on MI use with real patients prepared the students to be self-reflexive as they incorporated this advanced relational skill into their communication repertoire.

Engaging Patients

When using MI to engage patients in conversations about modifying health behaviors, nursing students unlearned the "expert stance" and created an opening to "meet the patient where they are at." Miller and Rollnick (2013) identified that when clinicians transition from being the expert, they have embodied both the spirit and style of MI. In this research, the turning away from an expert stance changed the conversation's direction from students telling patients standardized information and towards students using MI skills to discern patients' needs.

Releasing the "expert stance." The students described how using MI changed their communication, specifically using the OARS skills to have patients discuss their preferences for health behavior changes rather than providing unsolicited, expert advice on what "should" be on the change agenda. Field observations, journal reflections, and focus group interviews consistently identified that "students acting like the expert and giving advice" resulted in the patient "disengaging" and "zoning out" of the conversation. Students learned to recognize patients' physical and verbal cues: "you see their eyes glaze over and you notice their answers get more abrupt" or "it became like 'talk to the hand,' they just weren't with you anymore." The students described how releasing an expert stance ameliorated the expectations of them "having all the answers" and got them to trust patients' personal knowing. The MI skills enabled students to tune in to what was important for a patient, reflect these observations in the conversation, and sustain patient interest: "it was about using OARS to get at what the patient wanted rather than me proving how smart I was by telling them what I thought they needed to know." Students described how MI repaired instances of "patient zone out" that came about from defaulting into an expert role: "the patient just faded out until I stopped talking and started listening—well they just perked right up."

Meeting patients "where they are at." The students discussed the importance of MI for patient engagement because it also helped them "connect with what was meaningful to the patient." Meeting the patients "where they are at" included using MI skills to discern the covert cues of what was important for the patient and build an agenda around the patient's needs. Students enacted engagement as "moving from telling to probing to show the patient I was there for and with them." This feature of engagement reflects field observations of student–patient encounters where using MI made the student attend to the person, rather than the chart with patient results, in front of them. The process of engaging with patients presented as a turning point in the student's ability to appreciate both the wholeness and uniqueness of the patient: "learning MI made us pay attention to the person and not just the numbers and it gave us skills to talk with patients about anything—including numbers." As students used their motivational skills to attune to the patient, they moved beyond a detached, expert stance and created an opening for a collaborative partnership.

Collaborating as Partners

During their clinical experience of learning and applying MI to support patients with vascular risk reduction, students realized their potential to collaborate with patients as partners in health. With the patient as a partner, the application of MI made critical thinking tangible for students. The synergy between MI and critical thinking was evident in students' ability to draw out the patient's perspective, deliberate with patients about potential change, tailor information to unique situations, and develop goals within a collaborative partnership.

Patients as partners. During field observations of student–patient encounters, a visit routine evolved where students asked patients about potential topics to discuss, supported patients to prioritize areas, invited them to share personal knowledge, and validated past experiences to guide future goals. The instructors interpreted this routine as "becoming a partner by helping the patient get in the driver's seat." Instructors described partnership to their students in feedback sessions as "demonstrating an interest to be an affiliate in the relationship." In focus group interviews, students perceived partnership as a change in the relationship dynamic: "it's less one-sided because when patients see we want to get to know them they are interested to work with us." Students believed partnership was distinct from engagement because "it means we trust each other and that comes from going past connecting to sharing ideas and getting out of our boxes to do things differently." As partners, students and patients collaborated on customized approaches to behavior change.

Doing critical thinking. The students described how MI engaged their critical thinking as they identified and considered multiple approaches to respond to an array of patient situations. MI made critical thinking visible as students discerned relevant health issues, tailored information to the patient's unique situation, and supported patients to begin to navigate the complex processes of planning change. As one student summarized,

> MI is me doing critical thinking. I'm putting together what I've learned in school with what I'm hearing from patients and together we make sense of their big picture and the little steps they can work on for their health.

The patient encounters involved a review of laboratory results, and, without exception, patients wanted to know if their lab values were "normal." A student's poignant account resonated across many patient encounters: "normal is not the same for everyone and we owe people more than telling them they are normal." In making sense of the laboratory results, the students used MI and critical thinking to move beyond a situational focus on "normal" and towards individual capacity building. MI facilitated a back-and-forth exchange between student and patient about health based on personal relevance and ability to engage in change: "we're using MI to move 'blocks' of ideas around, to help patients 'build' their version of health." Students described this as "probing beyond the normal to get patients thinking about what is important to them and how they might act on that." In many cases it was identified that "patients wanted to change everything at once," and the students seized the opportunity to use their MI skills to "work together to understand patients' hopes and refine those lofty aspirations to something that works for them and fits for their health." Assessment of the importance a patient places on making a change, and clarification of an ability to change, constitutes proficient MI practice (Miller & Rollnick, 2013) and reflects a collaborative approach to care (Gottlieb & Feeley, 2006).

In this research, the application of MI skill and spirit enabled students to engage patients in conversations about what is important about health, tailor information to the patient's needs, and engage in collaborative patient partnerships to explore health behavior change. The experience of learning MI, engaging patients, and collaborating as partners enabled students to demonstrate critical thinking skills, and this had a transformative effect on students.

Discussion

MI presents as a promising approach to prepare nursing students to work collaboratively with patients. Using MI in a collaborative partnership has the potential to change how nursing students go about their work and shift from a habitual practice of "doing to" patients toward a different way of "working with" patients. This research answers important questions about whether, how, and why MI has a place in undergraduate nursing education. Indeed, nursing students can become proficient with MI provided they can practice with real patients and have ongoing, personalized feedback from a skilled instructor.

This research described both how nursing students learned MI and the transformative influence the experience had for their practice. It is an original finding to both identify learning MI as transformative and describe how transformation took place through reorienting to a new way of being as a professional, connecting with patients as people, and collaborating with patients on problem solving. Our findings are consistent with current recommendations on MI teaching that performance assessment by a skilled provider after the initial training is necessary for clinician skill development (Rouleau et al., 2015; VanBuskirk & Loebach Wetherell, 2014). MI unfolds in two distinct phases where the clinician uses OARS skills to help patients explore areas for change and then establishes goals consistent with patients' beliefs and capacity (Miller & Rollnick, 2013). The themes of engaging with patients and collaborating on change parallel these phases and show how students initially used OARS skills to "meet patients where they are at" and then worked collaboratively to tailor goals to the patients' unique context and ability. Authors highlight the relevance of MI "spirit," especially for clinicians who are more accustomed to adopting an expert stance when supporting patients with lifestyle change (Everett, Davidson, Sheerin, Salamonson, & DiGiacomo, 2008; Miller & Rollnick, 2013). Similarly, the students recognized an expert attitude disengaged patients and found when they used OARS skills to draw patients out there was opportunity for sharing mutual expertise. Addressing the complex interplay between patients' values, beliefs, and social practices involves a high degree of collaboration to tailor support to the patient's needs (Miller & Rollnick, 2013). Our research demonstrated that MI supports a student–patient collaborative partnership for exploring health behavior change and makes critical thinking visible. In addition, the experiences of learning MI transform students in their practice. We provide some recommendations for instructors interested in teaching MI and decision makers interested to incorporate MI in undergraduate nursing education.

Recommendations

In this research, students identified feedback as instrumental in their formation as proficient nurses in MI, and feedback had a significant role in helping students to adapt the skills to fit their unique style. Verbal feedback should occur immediately after the patient encounter; an instructor who interrupts to give correction potentially creates disruption (Beukes & Nolte, 2013). Both instructors in this research study accompanied students as they used MI and provided feedback immediately following unless the student invited feedback concurrent to patient care. Instructors should provide feedback that is relevant to the student, linked to behavior, and associated with the student–patient collaborative process because this is easiest for students to assimilate (Plank, Dixon, & Ward, 2014). A feedback session is an opportunity to engage the student in self-reflection and target specific areas for reinforcement and modification.

In this research, there appeared to be something reinforcing the students' view of themselves as "experts," and this served neither the aims of conversations about health behavior change nor the purposes of a collaborative nurse–patient relationship. Our observation may be isolated to the present research context; however, we advise instructors to be alert to practices embedded in nursing education programs that reinforce an expert stance because this could undermine the collaborative spirit of MI.

Based on our research, it is feasible for nursing students to learn MI, and the best timing for learning MI is when students are proficient with basic communication skills, comfortable in their clinical knowledge to support patient problem solving, and in a clinical course that gives them opportunity to practice techniques with real patients. The clinical setting is an ideal place to develop MI proficiency (Miller & Rollnick, 2013) and critical thinking skills because direct patient care supports application and transfer of knowledge from an abstract theoretical level to a unique situation (Brunt, 2005). MI involves a high degree of interaction and an ability to tailor support to the patient's needs. These conditions are best suited to a clinical placement at a time in the student's program when he or she has sufficient knowledge, skill, and experience to exercise critical thinking. We recommend that MI be part of nursing education and that instructors introduce MI to support integration of critical thinking into patient communication.

Limitations

The findings are unique to the research context because of the synergies among participants and setting such that the account may vary when different instructors teach MI or apply it in alternate clinical placements. The addition of another setting and a different group of nursing students at a similar point in their studies could strengthen the research findings. In our study, nursing students used MI with a population of patients who agreed to receive support from nursing students on health-promoting behaviors that would reduce vascular risk. The interest on the part of our patient participants to help students with learning MI or the nature of behavior change associated with risk reduction and health promotion may have positively influenced the students' experiences with learning a complex relational skill. Using MI for chronic illness management, for example, requires supporting a patient to address multiple behaviors over the course of a lifetime; some behaviors are pleasurable and not perceived as problematic (Everett et al., 2008; VanBuskirk & Loebach Wetherell, 2014). Therefore, further research is needed on how undergraduate students use MI in more complex clinical situations.

Conclusions

This study identified that students can learn and apply MI to evoke problem solving around health-promoting behaviors and support patients to explore change. The spirit of MI is a process of formation where students require targeted feedback on their ability to connect meaningfully with the patient and work collaboratively as partners. The exposure to MI as part of a collaborative partnership in undergraduate education is an opportunity to embed this relational style into routine nursing care. Because of learning MI, students experienced a deep transformation in themselves and their nursing practice. Furthermore, MI, as part of a collaborative partnership, contributes to meaningful nurse–patient encounters that enhance patient capacity for problem solving.

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Clinical Resources

- California Healthcare Foundation. Video with techniques: http://www.chcf.org/publications/2006/08/video-with-techniques-for-effective-patient-selfmanagement
- Heart and Stroke Foundation (Ontario). Counselling tips for motivational interviewing: http://www.heartands.on.ca/atf/cf/%7B33C6FA68-B56B-4760-ABC6-D85B2D02EE71%7D/HSFBLP%20counselling%20tips%20for%20web.pdf

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The Experience of Men Caring for a Partner With Multiple Sclerosis

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Key words
Multiple sclerosis, gender issues, caregiving, qualitative study

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Abstract

Purpose: The aim of this study was exploring the experience of male caregivers living with a partner with multiple sclerosis (MS).
Design and Methods: A qualitative study was conducted following a grounded theory approach. Twenty-four men–husbands or partners of a woman diagnosed with MS–were interviewed in-depth. A thematic analysis was carried out and involved line-by-line coding with codes deriving from narratives.
Findings: Five major themes emerged: caregiving as a full-time job; changes in the couple; the importance of social support and social life; gender specificities; and fear of the future.
Conclusions: Results highlight the complexity of issues surrounding this specific form of caregiving. Social expectations referring to the marital relationship and to gender norms play a central role.
Clinical Relevance: Findings can help in developing ad hoc interventions to support male spousal caregivers to care for their partners.

Multiple sclerosis (MS) is a progressive neurodegenerative disorder of the central nervous system affecting more than 2.1 million people around the world (Buchanan & Huang, 2012). It is at least two to three times more common in women than in men, and most people are diagnosed between the ages of 20 and 50 years (Starks, Morris, Yorkston, Gray, & Johnson, 2010). MS is considered a polysymptomatic disease, whose progress, severity, and specific symptoms vary from time to time and from person to person. It is characterized by episodes of neurological symptoms that are often followed by fixed neurological deficits. Such deficits may involve motor and sensory functions (e.g., muscle weakness, paraesthesia, fatigue), cognitive functions (e.g., memory, attention, verbal fluency), and behavioral functions (e.g., anxiety, depression, emotional lability).

Because of their clinical condition, people with MS often experience limitations in their ability to do everyday tasks and thus require demanding support from others. Their need for personal assistance increases as the disease progresses and disability becomes more severe and permanent (Kouzoupis, Paparrigopoulos, Soldatos, & Papadimitriou, 2010). More than 50% of people with MS require some form of assistance with daily activities, most of which is offered by informal caregivers (Buchanan, Radin, & Huang, 2010).

An informal caregiver has been defined as an unpaid person providing needed care to a friend or a family member who cannot manage everyday living without help or support because of sickness or disability (Giovannetti, Cerniauskaite, Leonardi, Sattin, & Covelli, 2014). Informal caregivers provide several services to people with MS, including personal care, homemaking, mobility, emotional support, and leisure activities (Buchanan & Huang, 2012). Although psychological research on MS has focused primarily on patients, there is increasing literature on caregivers and caregiving burden (Corry & While, 2009; Kleiboer, et al., 2007; Kouzoupis et al., 2010; Labiano-Fontcuberta, Mitchell, Moreno-García, & Benito-León, 2014). Literature highlights that caregivers report more stress symptoms than the general population. They also experience a decrease in their physical health, psychological well-being, and social life (Corry & While, 2009; McKeown, Porter-Armstrong,

& Baxter, 2003). Frequently, caregiving has an adverse effect on their work activity and financial situation (Opara, Jaracz, & Brola, 2012). Studies have also shown that caregivers perceive an inner conflict between desiring independence in their role as carer and wanting others to offer them assistance, although in general they report receiving little social support (McKeown, Porter-Armstrong, & Baxter, 2004). Additionally, the specific characteristics of MS, such as the unpredictability of its course and the lack of specific treatment, seem to increase caregiver burden (Corry & While, 2009). Recent studies demonstrate that cognitive impairment in patients significantly affects health-related quality of life of caregivers (Labiano-Fontcuberta et al., 2014). The decreased cognitive function associated with MS is often more difficult to cope with than the physical deficits. The caregiver not only has to provide augmented surveillance, but also experiences the loss of the individual he or she once knew (Starks et al., 2010).

Despite this abundance of negative consequences of the caregiving role, caregivers can also report positive emotions related to assisting a person with MS, such as satisfaction, pride, and gratification (Opara et al., 2012). The identification of benefits in such difficult situations can help the caregiver cope with adversity (Pakenham, 2007). Some caregivers gain personal reward from their caring, and those who experience personal growth in providing assistance are exposed to less burden (Buchanan & Huang, 2012; Corry & While, 2009). A greater effort assisting the person with MS increases the feeling of caregiver accomplishment, especially for low-educated caregivers (Buchanan & Huang, 2012). Other benefits of caregiving include increased feelings of closeness, recognition of inner strengths and abilities, and reprioritizing life goals (Starks et al., 2010).

Gender and Caregiving

Several factors influence the experience of caregiving, the most significant being gender (Li, Mak, & Loke, 2013). Researchers who have analyzed gender differences in caregiving found that women not only provide a greater amount of care, but also show higher levels of burden and depression and lower levels of well-being and physical health than men (Akplnar, Küçükgüçlü, & Yener, 2011; del-Pino-Casado, Frías-Osuna, & Palomino-Moral, 2011; del-Pino-Casado, Frías-Osuna, Palomino-Moral, & Ramón Martínez-Riera, 2012; Vitaliano, Zhang, & Scanlan, 2003). Consistently, recent literature reviews on spousal caring experience for cancer patients found that women report more distress and lower mental health and life satisfaction than men (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Li et al., 2013). These gender differences seem to be exclusively attributable to caregiving activities and could indicate a diverse appraisal of the caregiving situation in men and women, which is culturally rooted (del-Pino-Casado et al., 2012). Indeed, due to the traditional societal norms concerning gender roles (Eagly & Karau, 2002; Rollero, 2013), women are more likely to be regarded as caregivers and assume more over-responsibility and self-sacrifice than men for the care of other family members (Hsiao, 2010; Rollero, Gattino, & De Piccoli, 2014).

Although the factors discussed in the preceding text suggest that caregiving is affected by gender, little work concerning MS has been devoted to this area (Lopez, Copp, & Molassiotis, 2012). The very few studies on gender differences in caregiving reported that men and women differ in how they protect themselves and their lives. Women are more likely to feel guilty if they set limits to preserve their own lives, while men tend to clearly establish such protections (Boeije & Van Doorne-Huiskes, 2003). Moreover, husbands and wives of people with MS experience different coping strategies. Women tend to help their partner to maintain his independence and role, whereas men tend to express anger and to become protectors of their wives (Courts, Newton, & McNeal, 2005). However, as a consequence of the traditional societal norms about gender behaviors and of the prevalence of women as caregivers, the experiences of men are notably overlooked (Denby, Brinson, Cross, & Bowmer, 2014).

It is clear that important gaps remain in our understanding of caregivers' experience, particularly those of male caregivers (Lopez et al., 2012). The present research is aimed at illuminating such experiences. Specifically, the purpose of this qualitative study is to provide insight into the meaning of the experience of male caregivers living with and providing care for a partner with MS.

Method

Participants and Procedure

Participants were recruited through the Italian sections of the Multiple Sclerosis International Federation. They were identified using purposive sampling techniques. By snowballing through contacts between the Federation and people diagnosed with MS, the author identified potential participants and invited them to take part in the research. To be included in the study, participants needed to be the husband or partner of a woman diagnosed with MS and the woman he assisted should have been diagnosed for at least 1 year. On the basis of previous research

(Boland, Levack, Hudson, & Bell, 2012; McKeown et al., 2004), this last criterion was formulated to exclude subjects new to the role of caregiving.

Ethical approval for this study was obtained from the author's University's Research Ethical Committee. The author provided the Ethical Committee with a detailed description of the study, the list of the primary interview questions, and a copy of the consent form for participants. When the ethical approval was obtained, the author contacted the Italian sections of the Multiple Sclerosis International Federation to gain access to potential participants. Consenting caregivers were informed about the study, and written informed consent was obtained. Participants were assured that they could discontinue the study at any time. They were told that to protect confidentiality all information provided by them would be de-identified.

A grounded theory approach was selected as a general framework (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Following Charmaz's constructivistic perspective (Charmaz, 2006), theoretical sampling was applied to elaborate and refine categories founding a theory. Consistently, caregivers were involved in this study until a repeated pattern of conceptual and theoretical dimensions emerged and their experience was fully described.

A total of 24 male caregivers participated in the study. None of those contacted refused to participate. All participants were Italian (Caucasian) and 37 to 68 years of age (mean age 52 years). Twenty were spouses and the remaining were partners or fiancés. All participants lived in the same house with their wives or partners. Most of the participants had completed high school (*n* = 14) or college (*n* = 2), whereas the others had lower levels of education. Eight participants were retired, one was given time off, one was working part time, and the remaining 14 were employed full time.

Data Collection

Data were collected using face-to-face in-depth interviews. The interviews were conducted by one female psychologist with experience in qualitative research. All interviews took place in the patients' homes but separately from the patients. They were carried out between June and September 2015 in the caregivers' native language. Citations reported here were translated into English.

Each interview began with brief sociodemographic questions. Caregivers were then asked, "Could you please describe your experience after the diagnosis?" During the interview the researcher used additional prompts to encourage the in-depth description of the lived experience, such as questions that sought greater detail on topics already spoken about or questions aimed at exploring what impact the diagnosis may have had on their life and their family (**Table 1**). Interviews lasted between 35 min and 1 hr and 45 min, with an average length of 55 min. The interviews were audiotaped and subsequently transcribed verbatim for analysis.

Table 1. Primary Interview Questions

Could you please describe your experience after the diagnosis?
What are the main challenges you encountered?
What impact did the diagnosis have on your everyday life?
What impact did the diagnosis have on your social life, your family and friends?
Could you describe what your intimate relationship was like before the diagnosis?
How did your relationship change after the diagnosis?
What do you support your caregiving work on?
What are the main problems you have to cope with now?
What do you think about the future?

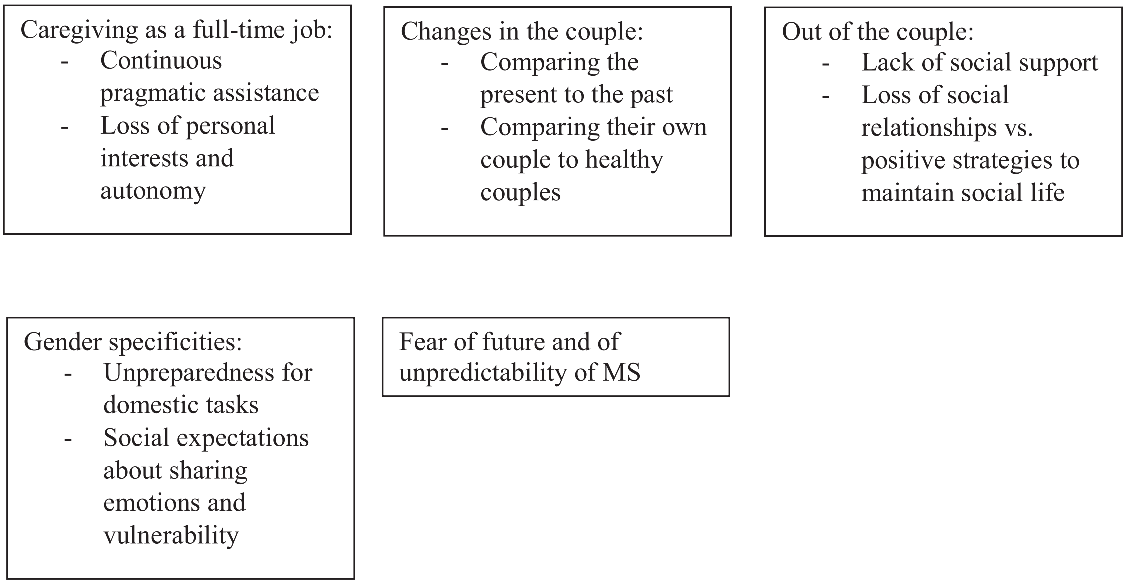
Data Analysis

Since a grounded theory approach was chosen as the framework for this research, interviews and data analysis were conducted simultaneously. After 21 interviews were completed, no new topics emerged and saturation was obtained for the main themes identified. Such saturation was confirmed with three subsequent interviews, and thus no more participants were contacted (Guest, Bunce, & Johnson, 2006).

A thematic analysis was carried out without a predetermined coding scheme. Analysis was inductive and involved line-by-line coding with codes deriving from narratives. A three-step coding procedure was used (Corbin & Strauss, 2008; Giovannetti et al., 2014). In step 1, the words used by caregivers were considered and used for generation of meanings and indications for further data collection. In step 2, data were aggregated to identify the emerging codes and categories. In step 3, theoretical coding was applied to explore relationships between categories. All interviews were double coded and the coders (the psychologist who conducted the interviews and a researcher in psychology) met to discuss codes and their definitions. Discrepancies were resolved through discussion until agreement was reached.

Results

Figure 1 shows a graphic representation of the key themes and subthemes that emerged during the interviews: caregiving as a full-time job; changes in the couple; social support and social life; gender specificities; and fear of the future.



Caregiving as a full-time job:
- Continuous pragmatic assistance
- Loss of personal interests and autonomy

Changes in the couple:
- Comparing the present to the past
- Comparing their own couple to healthy couples

Out of the couple:
- Lack of social support
- Loss of social relationships vs. positive strategies to maintain social life

Gender specificities:
- Unpreparedness for domestic tasks
- Social expectations about sharing emotions and vulnerability

Fear of future and of unpredictability of MS

Figure 1. Key themes and subthemes emerged during the interviews.

Caregiving as a Full-Time Job: Continuous Assistance and the Loss of Autonomy

After the diagnosis, the caregiver's role became a new role and in most cases the predominant one. As his partner got worse, caregiving came to be the focus of his life. This implied two different outcomes: continuous pragmatic assistance and heavy physical workload, and the loss of personal interests and autonomy.

Most men indicated that they cared for their partner night and day: "I think this is a full-time job . . . maybe more . . . even at night I do not feel completely relaxed: when she can't sleep and gets up, I get up too" (P 17). "I know she prefers not being alone, so I try to be present every moment I don't have to work" (P 3). Assistance is physically demanding, especially for those who are older: "I have to move her, to wash her, to do domestic tasks: it is a hard work. My backache is permanent by now" (P 5).

When caregiving played this all-consuming role, partners experienced the loss of autonomy:

> Everything has changed. My life has become totally different . . . but little by little: sometimes I feel a bit like a prisoner . . . I would need someone to come here to take care of her just for a couple of hours, just to go for a walk alone. (P 12)

Consistently, some caregivers reported difficulties in enjoying relaxation and restorative activities: "Sometimes one would need more freedom: I would like to go away knowing that she's all right. For example, last year I never went skiing because leaving her and organizing assistance would have been too complicated" (P 21).

Changes in the Couple: "Our Love Is Different"

Another core issue of the caregivers' experience pertains to the changes affecting the couple. Such changes are reported mainly with two terms of comparison: the past of the couple and the everyday life of the other "healthy" couples. Almost all participants reported relevant changes within the couple after the diagnosis, with different degrees and intensity: "Our love is completely different now, it is more care-based . . . or maybe only care-based" (P 11). "Our relationship has changed: she has become more a patient than a partner" (P 21).

As the dimension of care became predominant, the partner suffered an absence of sexual life: "For us sex was really important, but now, you know, we can't have sex because she becomes too tired after that" (P 8).

Other caregivers emphasized that they were not prepared for their partner's cognitive impairment and to its consequences in their relationship:

> The most important things have changed in our couple. I was quite prepared to see her in a wheelchair, but I was not prepared at all about cognitive deficiency, I was not prepared to the fact that we cannot talk each other as we did before. (P 5)

Moreover, a number of partners referred to social expectations concerning their care roles within the couple:

> You're expected to do it: you're her husband. (P 2)
>
> I know one man whose wife had MS and got divorced, and I understand him: it's hard to live with it. But I've heard very blaming comments toward him, because he was her husband and should have been with her in sickness and in health. (P 21)

For some couples social expectations were interconnected with comparisons with healthy couples:

> My parents are very sad because they have no grandbabies. They are always talking about their friends who spend their time with grandsons and granddaughters. I know, it can be hard to accept, but they don't do any effort to hide their sorrow, even when my wife is present. (P 19)

Making comparisons with healthy couples resulted in grieving for what might have been had MS not become center to their lives:

> I have to admit that sometimes I'd like to be as the couples you see all around. We are young, as they are, but we are different, even if I try to let her do anything she would like to. We are different from other couples. (P 16)
>
> We got married after her diagnosis. We wanted to fight against this damned disease, but during these years quite often I have wondered whether ... well, what would have happened if she would have been healthy? If we would have been as the other normal and healthy couples? (P 12)

Out of the Couple: Social Support and Social Life

Most partners discussed the lack of constant social support. A common experience was strong support from people just after diagnosis, but an increased feeling of loneliness as this support was withdrawn over time:

> At the beginning relatives and friends were all supportive sympathetic. However, once we came back home we were alone and I felt the complete responsibility ... I was alone with my hard caregiving work. (P 21)
>
> When people know that your wife is ill they offer their help and support. But my experience taught me that probably they offer their help because they feel they have to but this does not mean that you can actually rely on them. Indeed, now just me and her parents are taking care of her. (P 19)
>
> The friends and neighbors have been good at the beginning, but there's a limit to what they can do. (P 5)

Another relevant issue for participants concerns social life. Two different positions emerge. First, the accounts from the interviews showed the progressive limitation of social contacts, mainly due to the lack of social support described in the preceding section and to practical difficulties:

> In the end you lose your friends. Before, we still went out sometimes, but since she is in a wheelchair it is actually impossible. She has also difficulties in eating, and going out for dinner is not funny at all. ... (P 13)
>
> When you organize something to do, they don't think about all the problems we can deal with: architectural barriers, schedules, her tiredness. ... People don't understand. People can't understand. (P 22)

However, on the other hand, a number of partners (along with patients) tried to adopt positive coping strategies in order to maintain a pleasing social life:

> In the first year after the diagnosis, she was a bit depressed and didn't want to see anyone. Now it's better ... we are going out again, we even organize dinners at home with other patients. (P 12)
>
> We try to live as normally as we can. We go out, even to have a pizza: you just have to cut it in small pieces. Her mother does not agree, but I always tell her that we don't have to care about her mother's opinion, we have to care about her life and her pleasure, if it's possible. (P 19)

Gender Specificities: "I Feel Like a Housewife and I Have to Be Strong"

Caregivers often mentioned traditional gender roles that specify which behaviors are expected by an individual on the basis of his or her sexual identity. Since domestic tasks and caregiving are usually associated with female roles, most men mentioned being unprepared to take on "female" work:

> Since her illness, I have started doing domestic tasks ... it's a very different side of myself ... I feel like a housewife sometimes! (P 17)
>
> I have to do the domestic jobs. I had to learn many things, as before she did almost everything at home. I had to become cook, gardener, cleaner .... (P 5)

Besides the unpreparedness for traditional female tasks, social expectations concerning gender specificities also affected the emotional dimension of caregivers' experiences. They found it difficult to express their emotions and concerns to other people and tried not to look too vulnerable:

> I see women who are married to a man with MS who create groups. They support each other. They chat about their everyday challenges. For men I think it's a bit different. We are not used to sharing with others our emotions and our difficulties. (P 12)
>
> You know, men are supposed to care for. If I look weak and vulnerable, how can she rely on me? (P 20)
>
> I am a man. I am her man. I have to be strong. It doesn't matter how I really feel. I have to keep her spirits up. (P 11)

Fear of Uncertainty: The Future

The unpredictability of MS and the related fear of the unknown were also reported. Caregivers were particularly worried about the uncertainty of the illness's course and the lack of information concerning specific trajectories and treatments. They felt uncomfortable and powerlessness in the face of such unpredictability:

> When I notice things getting worse, I start thinking what is going to happen and I get a little bit nervous. (P 19)
>
> I try to take it day by day, but this illness is so unpredictable that I can't ... horrible thoughts about the future come to my mind ... I know it's progressive. (P 20)
>
> I would like to know what to expect ... someone who tells me: "Ok, this is what it's gonna be" ... it will help me in feeling a sort of control of the situation. (P 5)

The long-lasting course of MS had often discouraged both caregivers and patients: "At the beginning we were more optimistic about new drugs and treatments. We fought. Now we just fear the future" (P 17).

Other partners used active coping strategies in order to prevent future troubles:

> I always think about [the] future, about what I can do. In this period, I am planning to buy another home, on the ground floor, so that she will be able to move freely and easily even if she will be in a wheelchair. (P 7)
>
> When I think about the future, I think "if something happens to me, what will become of her without me?" I am getting old. For this reason, I have written anything she needs and I have shared this document with friends and relatives. I say to myself: "You have to be ready." (P 9)

Discussion

The literature about caregiving presents a lack of knowledge about experiences of male caregivers because females have been thrust more often into the caregiver role (Hsiao, 2010). The in-depth examination of interviews employed in this study has enabled an exploration of men's experiences caring for a partner with MS. Taken together, the findings of this study highlight the complexity of issues surrounding this form of caregiving.

As a consequence of becoming a caregiver, men felt that their everyday lives were progressively disrupted, with several repercussions. All participants experienced caregiving as demanding, as a "full time job" where no break is allowed. Consistently, as previous studies showed (Covelli et al., 2014), caregivers expressed a need for leisure time for themselves, which is often missing, due to their responsibility in caregiving. The uncertainty of the disease appeared to be another relevant source of stress: the unpredictable relapses, disease progression, or even the everyday functional capacity of the patient may account for the overwhelming feelings of responsibility (McKeown et al., 2004).

After the onset, significant changes affect marital intimacy. When one partner is diagnosed with such a chronic illness, the ill partner becomes more dependent on the healthy partner, not only for assistance, but also for emotional support (Kleiboer et al., 2007). Indeed, in our study caregivers seemed to take it upon themselves to protect their partners throughout the illness, providing both emotional and pragmatic support. This is in line with previous research on male caregivers of women with breast cancer (Lopez et al., 2012). At the same time, our participants reported low marital satisfaction due to the shift to a care-based relationship (Starks et al., 2010). Partners felt obligated to stay together due to beliefs that they must remain true to their marriage vows. Social expectations play a relevant role in this process, as they make caregivers sensitive to duties and responsibility that are socially rooted, such as not leaving the partner, being strong and supportive, and avoiding any form of burden.

Social and cultural expectations refer not only to the marital relationship, but also to specific gender roles. Most male caregivers have assumed a role they were not familiar with. Spending time taking over the patient's personal care and household tasks is often understood as female gendered and can foster feelings of discomfort and strain. Gender expectations also significantly affect the emotional level. Caregivers revealed the need to show and share their emotions, such as fear for the future, sadness, discomfort, worries, and everyday difficulties. However, expressing emotions and showing vulnerability can be seen as not appropriate for the male gender. This represents a relevant impasse and can contribute to caregivers' burdens. As reported earlier in this article, the scarce research on caregiving from a gender perspective has demonstrated that women show lower levels of well-being than men (del-Pino-Casado et al., 2012; Vitaliano et al., 2003). This may be due to the fact that women provide a greater amount of care than their male counterparts. However, the present study suggests that such gender differences may also be related to different ways of showing weaknesses and sharing emotions and difficulties, which are socially and culturally rooted.

Regarding the identification of positive aspects of the experience of caregiving, in our study, participants expressed few positive benefits from the caregiving experience, whereas other studies found greater benefits. Differently from other studies (Buchanan & Huang, 2012; Corry & While, 2009; Opara et al., 2012; Pakenham, 2007), caregivers reported neither positive emotions related to assisting a person with MS nor the impression of personal growth. The most positive aspects of their experience seem to be related to preserving the status quo. They felt proud and satisfied when they were able to help their partner maintain her everyday life and social relationships.

In sum, the theory that seems to emerge involves both the pragmatic and the emotional level. At the pragmatic level, it posits a significant relationship between the demanding characteristics of caregiving (i.e., the continuous pragmatic assistance) and the loss of personal autonomy. At the emotional level, three aspects are assumed to decrease caregivers' well-being: comparing the present to the past (or their own to those of healthy couples), the perception of lack of social support, and the fear of the future.

The data from this study can provide useful considerations for healthcare professionals working with people with MS and especially with their male caregivers. Health professionals should pay particular attention to the impact caregiving has on the emotional health of caregivers and understanding the psychosocial dimensions of caregiving in case of MS is necessary to alleviate family burden. In this perspective, the present findings can help nurses in developing interventions to support male spousal caregivers to care for their partners. One of the most pressing aspects to be considered is the necessity to deconstruct social expectations, in order to give men the chance to share their emotions and to show their vulnerability. Interventions aimed at developing positive emotion-focused strategies could be particularly helpful to this aim. Moreover, nurses who are aware of these social expectations can take them into consideration when assessing the needs and concerns of people with MS and their caregivers.

Some limitations of this study need to be taken into account and considered as recommendations for future research. One of the most significant issues pertains to the importance of the cultural context. All caregivers recruited for this study came from Italy, which is one of the less egalitarian European countries according to the Gender Empowerment Measure index (i.e., a rank of 21 among 91 world nations; United Nations Development Programme, 2007). Since expectations concerning gender roles appear to be particularly relevant, generalizing our results to other cultural contexts requires caution. Rather, future research should investigate the replicability of these findings in different countries. Another limitation was that this study did not address the experiences of men who were no longer able to provide care to their partner, and as such it does not shed light on the possible sources of burn-out and breakdown. Further research is needed to examine these processes.

Despite these limitations, it is hoped that the present results can contribute to a better understanding of the experience of male caregivers, leading to a more sensitive approach to support them and to a better management of welfare services devoted to the care of patients with MS.

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Clinical Resources

- Family Caregiver Alliance: https://www.caregiver.org/
- International Organization of Multiple Sclerosis Nurses: http://www.iomsn.org/
- Multiple Sclerosis International Federation: http://www.msif.org/
- Multiple Sclerosis Italian Association: http://www.aism.it/home.aspx

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Integrated Review of Barriers to Cervical Cancer Screening in Sub-Saharan Africa

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Abstract

Purpose: The aim of this study was to review published studies to identify and describe barriers to Papanicolaou (Pap) smear screening among women in sub-Saharan Africa.

Design and Methods: Guided by Cooper's integrative review methodology, studies published between 2006 and 2015 were identified by searching electronic databases: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, MEDLINE, ProQuest, and PsycINFO using specified search terms. Using this strategy, 224 articles were identified and screened for duplication and by reading titles, abstracts, and full texts. Seventeen articles met the inclusion criteria and were appraised using relevant tools for qualitative and quantitative designs. No relevant articles published in 2006, 2007, and 2014 were found.

Findings: All 17 articles had good methodological quality and were included in the review. The studies were from 10 sub-Saharan countries and from different settings. Content analysis of the data revealed three major themes coded as client, provider, and system barriers. The most common client barriers were lack of knowledge and awareness about Pap smear screening, fear of cancer, belief of not being at risk for cervical cancer, and that a Pap smear is not important unless one is ill and cultural or religious factors. Provider barriers were failure to inform or encourage women to screen. Major system barriers were unavailability and inaccessibility of the Pap test.

Conclusions: The review provided evidence of barriers to Pap smear screening among sub-Saharan women. Although there were some variations from country to country, sub-Saharan countries share similar constraints to Pap smear screening. These findings have important implications for practice and policy.

Clinical Relevance: Understanding the client, provider, and system barriers to cervical cancer screening could guide development of effective interventions.

Cervical cytology screening using a Papanicolaou (Pap) smear has played a significant role in reducing the mortality and incidence of cervical cancer in developed countries since its introduction in the 1940s (Mbulaiteye, Bhatia, Adebamowo, & Sasco, 2011). Despite this evidence, the success has not yet been achieved in sub-Saharan Africa. Therefore, cervical cancer remains the leading cancer in women in sub-Saharan Africa. It is estimated that 34.8 new cases of cervical cancer are diagnosed per 100,000 women annually, and 22.5 per 100,000 women die from the disease, compared to 6.6 and 2.5 per 100,000 women, respectively, in

North America (World Health Organization, 2013). The incidence of cervical cancer in sub-Saharan Africa is reported to be even higher in rural areas. It is noted that 60% to 75% of women in sub-Saharan Africa who develop cervical cancer live in rural areas, and that many of these women go untreated, mostly due to lack of access to health care (Parkin, Whelan, Ferlay, Teppo, & Thomas, 2002).

The link between cervical cancer and sexually transmitted human papillomavirus (HPV) has been clearly established (Bosch, Lorincz, Muñoz, Meijer, & Shah, 2002). Evidence has shown that sub-Saharan women are at risk for infection by HPV as a result of early marriages and polygamy in some societies and high parity (Bayo et al., 2002). It has been noted that in some societies, girls as young as 15 years are married to older men, which exposes them to early sexual activity, increasing their risk for contracting HPV (Anorlu, 2008). The rising incidence of cervical cancer in sub-Saharan Africa may also be fueled by the human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) epidemic. Research has shown that cervical cancer progresses faster in women whose immune systems have been compromised by HIV infection, and that survival rates for these women are poor (Denny et al., 2014). Research has also found that HPV types 16 and 18 are the most common in women with invasive cervical cancer, and were the most common infections in HIV-positive women (Denny et al., 2014). It is further noted that sub-Saharan women tend not to seek medical attention until their cancer is in advanced stages, leading to high mortality. Such deaths could be prevented by early detection with Pap smear screening. Other screening techniques, specifically visual inspection with acetic acid wash, could also be used as alternatives for the Pap smear.

Cervical cancer screening in developing countries is very complex and has been hampered by many barriers. For instance, it has been found that most women in developing countries do not screen regularly because the screening services are either unavailable or ineffective (Denny, Quinn, & Sankaranarayanan, 2006). Evidence further suggests that where services are available, they are largely accessible to younger women through postnatal and family planning services, or to a smaller percentage of women through private practitioners (Sherris, Herdman, & Elias, 2001). It is also noted that barriers to establishing screening programs and the pitfalls encountered may differ from country to country. In many sub-Saharan countries, cervical cancer screening programs have not been effective due to a number of barriers, including inadequate health services, poor laboratory infrastructure, and a myriad of service delivery challenges (Moodley, Med, Kawonga, Bradley, & Hoffman, 2006). Researchers also indicate that the magnitude of the problem in sub-Saharan Africa has been under-recognized and underprioritized compared to competing health priorities such as HIV/AIDS, tuberculosis, and malaria. The aim of this integrative review was therefore to review published studies to identify and describe barriers to Pap smear screening among women in sub-Saharan Africa. The information obtained could guide effective interventions and further research. The review was conducted from August 2015 to December 2015.

Methods

The integrative review methodology described by Cooper (1998) guided this review. An integrative review is the broadest category of review, and it facilitates the inclusion of both qualitative and quantitative research to gain a full understanding of the topic. Therefore, an integrative review was considered to be the most appropriate methodology to examine and describe the available literature pertaining to barriers to Pap smear screening in sub-Saharan Africa. Cooper’s methodology encompasses five stages: (a) problem formulation, (b) data collection or literature search, (c) data evaluation, (d) data analysis, and (e) interpretation and presentation of results.

Problem Formulation

The review started with a clear identification of the problem, and was guided by the question: “What are the barriers to Pap smear screening among women in sub-Saharan Africa?”

Literature Search

To answer this guiding question, the first author conducted an electronic search of the following databases covering the years 2006 to 2015: Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, MEDLINE, ProQuest, and PsycINFO. Combinations of the search terms, using the Boolean operations “AND” and “OR” were as follows: “Cervical cancer OR Neoplasm,” AND “Screening OR Pap smear,” AND “Barrier*” AND “Developing countries” OR “Sub-Saharan Africa.” Web-based Google and a reference list of the retrieved articles were searched for possible inclusion in the study. The article selection was based on the following inclusion criteria: (a) the topic addressed barriers to Pap smear screening, (b) studies included sub-Saharan women, (c) studies were conducted in English, (d) articles were peer reviewed, (e) the design was either qualitative or quantitative, and (f) the studies reviewed were published

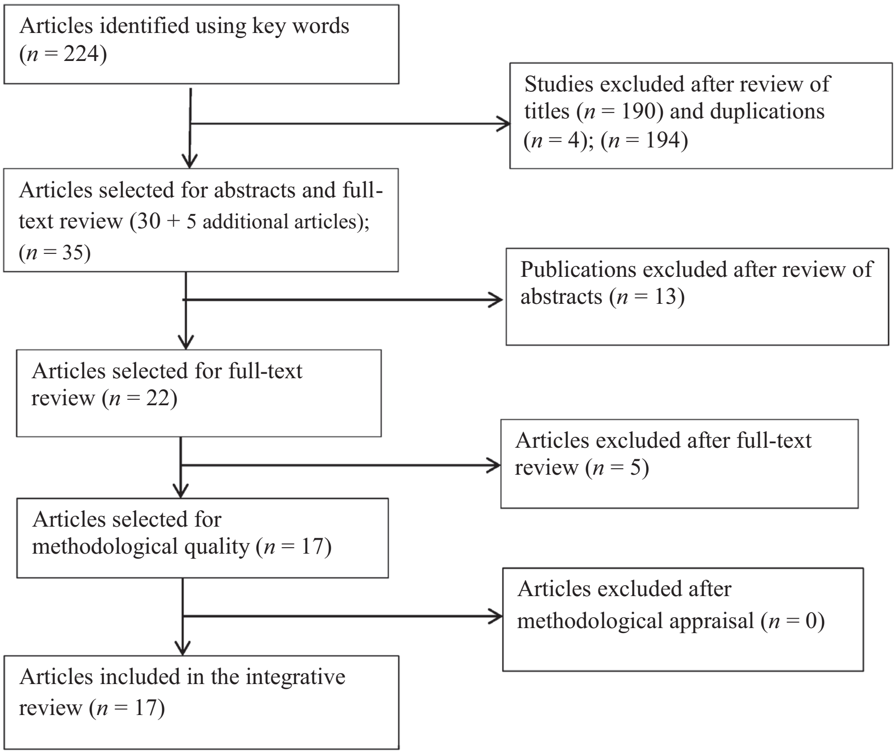

Figure 1. Flow chart of article selection.

from 2006 to 2015. The exclusion criteria included secondary research articles and dissertations. Through this process, 224 articles were retrieved as follows: CINAHL ($n = 96$), MEDLINE ($n = 10$), PubMed ($n = 42$), ProQuest ($n = 5$), PsycINFO ($n = 56$), and Google ($n = 15$). Five additional articles were identified through a hand-search of the reference lists of identified journals.

Data Evaluation

During this phase, the quality of the primary studies was evaluated against the identified standards. First, the first author examined the retrieved articles for duplicates and read the titles. This process led to the exclusion of 194 articles. All three authors then independently read the abstracts and full texts of all the remaining articles to determine if they met the inclusion criteria. The findings were compared, and any disagreements were resolved through consensus. Through this process, several studies were excluded either because they had different foci or used different methodologies. The remaining 17 studies were each evaluated using relevant appraisal tools. The quantitative studies were assessed using the 11-item checklist for evaluating descriptive and cross-sectional studies (Guyatt, Sackett & Cook, 2010). The 10-item critical appraisal checklist (Critical Appraisal Skill Program, 1997) was used for assessing the methodological aspects of the qualitative studies. This checklist asks the reviewer to select "Yes," "Can't tell," or "No" in response to the posed question about the study purpose, methodology, and findings. Based on the high prevalence of "Yes" responses in the checklist, all 17 articles adequately met the selection criteria and were included in the review. The selection process is depicted in **Figure 1**.

Data Analysis and Interpretation

Content analysis was used for this integrative review. Content analysis is a method of analyzing narrative or word responses to questions, and either counting similar responses or grouping the responses into themes or categories (Lobiondo-Wood & Haber, 2014). The first author read and reread each article to identify emerging themes. Eventually, all the barriers were extracted and categorized as client barriers, provider barriers, and system barriers. These categories were further recoded to identify various aspects of the client, provider, and system barriers. To facilitate visualization and comparison of the responses across the cases, descriptive grids were developed for each subcategory. The inter-reliability of the codes was verified by the other two authors, who are competent in content analysis.

Table 1. Profile of Studies ($N = 17$), 2006–2015

Author, year, site	Sample and sampling	Design	Major barriers
Abotchie & Shokar, 2009, Ghana	A random sample of 140 university college students. Age: 20–35 years.	Quantitative: using questionnaires	Limited knowledge about Pap screening and where to go for the test. Partner would not allow. Fear of loss of virginity. Fear of being thought of as sexually active. Not at risk.
Adetola, 2011, Nigeria	A random sample of 261 women attending primary health care clinics. Age: 25–50 years.	Quantitative: using questionnaires	Religious values and beliefs against women's body exposure to persons other than their husbands. Cervical screening less important. Not at risk for cervical cancer.
De Abreu et al., 2013, South Africa	21 disadvantaged women from two informal settlements. Age: 21–53 years.	Qualitative: using four focus group discussions	Limited knowledge about screening. Absence of health education. Not eligible for screening due to younger age. Cost and time. Fear of the procedure. Fear of stigmatization in attending screening.
Ebu et al., 2015, Ghana	392 sexually active females selected from the community using cluster and random sampling. Age: 10–74 years.	Quantitative: using structured interviews	Limited knowledge of cervical screening and where to go for the test. Partner would not allow. Difficult to schedule a test appointment. Screening sites are too far or not available. Screening is embarrassing and painful. Not at risk for cervical cancer. Fear of cancer diagnosis. Screening is against religious beliefs and cultural values. Cost of the Pap smear.
Eze et al., 2012, Nigeria	360 rural women attending antenatal and gynecological clinics. Mean age: 36.2 years.	Quantitative: using questionnaires	Lack of awareness of cervical cancer and screening. Nonavailability of screening centers locally. Cost and time. Fear of the positive outcome. Beliefs of being faithful and not needing the test.
Fort et al., 2011, Malawi	20 rural women attending outpatient clinics. Age: 20–50 years.	Qualitative: using semistructured interview guides	Low knowledge levels, low perceived susceptibility, low perceived benefits from the service. Cervical screening viewed to be not critical.
Hoque & Hoque, 2009, South Africa	389 university students selected by stratified random sampling. Mean age: 20 years.	Quantitative: using questionnaires	Fear of the screening test. Cultural and religious reasons. Not ill so screening is not necessary. Poor attitude of providers. Discouraged by partner/others. No access to a clinic where Pap smear is done.
Kahesa et al., 2012, Tanzania	396 urban women selected by multistage cluster and random sampling. Age: 25–59 years.	Quantitative: using questionnaires	Access to health service difficult. Reluctant to go for any test in absence of disease. Lack of medical advice. Prohibitive cost of the test. Fear of cancer diagnosis and pain of the test.
Lyimo & Beran, 2012, Tanzania	354 rural women selected using multistage and simple random sampling. Age: 18–69 years.	Quantitative: using questionnaires	Limited knowledge of cervical cancer and prevention. Low level of education. Embarrassment and pain of screening. Distance to the screening services. Husband approval needed.
McFarland, 2013, Botswana	A convenience sample of 353 asymptomatic urban women. Age: 30–60 years.	Quantitative: using questionnaires	Limited information about Pap smear screening. Cervical screening not considered as important. Financial constraints. Low perceived susceptibility. Low motivation. Negative attitude of providers.

Continued

Table 1. *Continued*

Author, year, site	Sample and sampling	Design	Major barriers
Mosavel, Simon, Oakar, & Meyer, 2009 South Africa	A convenience sample of 228 urban women from two events on World Cancer Day. Age: 21–84 years.	Quantitative: using survey questionnaires	Limited knowledge about a Pap smear test. Lengthy waiting times to get an appointment for a test. Embarrassment. Fear of cervical cancer diagnosis. Cervical cancer cannot be prevented and is fate. Family responsibilities.
De Abreu et al., 2013, Zimbabwe	A random sample of 514 women from traditional rural and resettlement villages. Age: 12–84 years.	Quantitative: using questionnaires	Limited knowledge about cervical cancer and screening. Lack of advice/encouragement by health professionals. Not at risk. No screening in nearest health center. Long walking distances. High cost of screening. Fatalistic view of cervical cancer.
Ndikom & Ofi, 2012, Nigeria	A purposive sample of 82 urban women attending antenatal clinics. Mean age: 27.6 years.	Qualitative: using eight focus group discussions	Fear of having a positive result. Ignorance. Illiteracy. Not at risk for cervical cancer. Financial constraints. Having many contending issues.
Terefe & Gaym, 2008, Ethiopia	A convenience sample of 276 women attending clinics at urban hospitals. Age: 18–53 years.	Quantitative: using structured questionnaires	Limited awareness of the Pap test and where it is done. No gynecologic symptoms. Pap smear not important. Wait till older age. Level of education.
Twinomujuni et al., 2015, Uganda	416 women in the district selected using cluster sampling. Age: 25–49 years.	Quantitative: using semistructured questionnaires	No cervical cancer symptoms. Not at risk. Fear of cancer diagnosis and pain from the test. Distance from screening facility. High transport costs.
Utoo et al., 2013, Nigeria	A convenience sample of 172 women attending a hospital outpatient gynecological clinic. Mean age: 35 years.	Quantitative: using questionnaires	Limited awareness of cervical cancer and screening. No screening centers. Cervical screening not necessity. Prohibitive cost. Physician's nonrecommendation.
Were et al., 2011, Kenya	219 non-pregnant women attending urban health clinics. Mean age: 31.3 years.	Quantitative: using questionnaires	Lack of awareness about the service. Lack of finances. Not at risk. Fear of abnormal results. Fear of genital exam.

Note. Pap = Papanicolaou.

Presentation of Results

Finally, all of the barriers were synthesized and interpreted. The synthesis table was drawn identifying the following characteristics: authors (in alphabetical order), year of publication, location, study focus, sample, design, and major findings. This information is supplied in **Table 1**.

Results

Profiles of the Studies

Seventeen articles that met the inclusion criteria were classified as follows: quantitative studies ($n = 14$), qualitative studies ($n = 3$). These articles were from 10 different countries, including Botswana ($n = 1$), Ethiopia ($n = 1$), Ghana ($n = 2$), Kenya ($n = 1$), Malawi ($n = 1$), Nigeria ($n = 4$), South Africa ($n = 3$), Tanzania (n = 3), Uganda ($n = 1$), and Zimbabwe ($n = 1$). The studies were conducted in different settings, including educational settings, clinics, and workplaces, as well as in rural and urban areas. Age of the participants ranged from 10 to 80 years. Sample sizes ranged from 172 to 514 for the quantitative studies, and 6 to 82 for the qualitative studies. Most articles were published in 2011 and 2012. There were no relevant papers published in 2006, 2007, and 2014. These studies are listed in **Table 1**.

Barriers to Screening

Barriers to Pap smear screening are presented below under the following headings: client, provider, and system barriers. Client barriers are individual factors that directly prevent women from participating in Pap smear screening. Provider barriers are factors that prevent healthcare providers from effectively offering the Pap smear services. System barriers are factors related to inaccessibility and unavailability of the screening services and screening policies.

Client Barriers

Lack of knowledge and awareness of cervical screening. Lack of knowledge and awareness of cervical screening was cited as the most common barrier (Abotchie & Shokar, 2009; De Abreu, Horsfall, & Learmonth, 2013; Ebu, Mupepi, Siakwa, & Sampselle, 2015; Eze, Umeora, Obuna, Egwuatu, & Ejikeme, 2012; Lyimo & Beran, 2012; McFarland, 2013; Mosavel, Simon, Oakar, & Meyer, 2009; Mupepi, Sampselle, & Johnson, 2010; Terefe & Gaym, 2008; Utoo, Ngwan, & Anzaku, 2013; Were, Nyaberi, & Buziba, 2011. Some women also reported lack of knowledge about cervical cancer as barriers to cervical cancer screening (Eze et al., 2012; Lyimo & Beran, 2012; Mupepi et al., 2010; Utoo et al., 2013). Other studies reported not knowing where to go for the Pap smear (Abotchie & Shokar, 2009; Ebu et al., 2015; Terefe & Gaym, 2008).

Fear of cervical cancer and the Pap smear test. A number of women reported a fear of cancer and hesitancy to be tested. Some women expressed fear of the possibility of receiving positive test results (Ebu et al., 2015; Kahesa et al., 2012; Mosavel et al., 2009; Mupepi et al., 2010; Ndikom & Ofi, 2012; Twinomujuni, Nuwaha, & Babirye, 2015; Were et al., 2011). They believed that if the test is positive they would die, and some said that they would rather not know if they had cervical cancer (Mosavel, 2009). For some women, fear of undergoing the screening test was a barrier (De Abreu et al., 2013; Hoque & Hoque, 2009; Were et al., 2011). Some younger women expressed fear of losing their virginity (Abotchie & Shokar, 2009). Others reported fear of stigmatization for attending screening (Abotchie & Shokar, 2009; De Abreu et al., 2013). They expressed concern that they might be viewed by others as being sexually active if they engaged in cervical cancer screening.

Beliefs and Attitudes

Beliefs commonly reported included those of not being at risk for cervical cancer (Abotchie & Shokar, 2009; Adetola, 2011; Ebu et al., 2015; Eze et al., 2012; Fort, Makin, Siegler, Ault, & Rochat, 2011; Mupepi et al., 2010; Ndikom & Ofi, 2012; Twinomujuni et al., 2015; Were et al., 2011), and of being healthy and having no gynecological symptoms to warrant screening (Hoque & Hoque, 2009; Terefe & Gaym, 2008; Twinomujuni et al., 2015). Other beliefs included not perceiving Pap smear as beneficial, because cervical cancer cannot be prevented (Mosavel, 2009). The following attitudes were also reported: cervical screening not viewed as important or necessary (Adetola, 2011; Eze et al., 2012; Fort et al., 2011; McFarland, 2013; Terefe & Gaym, 2008; Utoo et al., 2013) and the embarrassment of the test (Ebu et al., 2015; Lyimo & Beran, 2012; Mosavel, 2009).

Cultural and Religious Factors

Some women expressed that they did not go for the test because screening is against their cultural and religious beliefs (Adetola, 2011; Ebu et al., 2015; Hoque & Hoque, 2009). Other women held religious values and beliefs that did not encourage them to expose their bodies to men (i.e., physicians) other than their husbands (Adetola, 2011).

Sociodemographic Variables

Age: In one study, free screening was available only to women who were over 30 years of age (De Abreu et al., 2013). In another study, younger women said that they waited until they were older to get a Pap smear (Terefe & Gaym, 2008). Education: some studies identified low levels of education or illiteracy as a barrier to screening (Lyimo & Beran, 2012; Ndikom & Ofi, 2012; Terefe & Gaym, 2008). Marital or relationships: barriers related to marital or relationship status included needing husband's or significant other's approval for a Pap smear (Lyimo & Beran, 2012), their husband or partner not allowing them to screen (Abotchie & Shokar, 2009; Ebu et al., 2015), and their husband or partner being unsupportive and discouraging them from participating in cervical cancer screening (Hoque & Hoque, 2009). Other factors included distance to the screening facility (Ebu et al., 2015; Lyimo & Beran, 2012; Mupepi et al., 2010; Twinomujuni et al., 2015), cost and time of travel to a health facility that offers the Pap screening (Eze et al., 2012; De Abreu et al., 2013; Twinomujuni et al., 2015), and having family and work responsibilities (Mosavel, 2009).

Provider Barriers

Provider barriers included providers not providing health education (Abotchie & Shokar, 2009; De Abreu et al., 2013), providers not advising or encouraging women to screen for cervical cancer (Kahesa et al., 2012; Mupepi et al., 2010), physicians not recommending Pap smears (Utoo et al., 2013), and negative attitudes of providers toward patients (McFarland, 2013; Hoque & Hoque, 2009).

System Barriers

Inaccessibility: the most common access barrier cited was cost of the Pap smear test. The majority of the women reported that the Pap smear test was too expensive (Ebu et al., 2015; Eze et al., 2012; McFarland, 2013; Mupepi et al., 2010; Ndikom & Ofi, 2012; Utoo et al., 2013; Were et al., 2011). Other access barriers included (a) having no access or having difficult access to facilities where test is done (Kahesa et al., 2012) and (b) lengthy waiting times to get an appointment for a Pap smear (Ebu et al., 2015; Mosavel, 2009). Unavailability: Pap smear services were reported to be unavailable in some localities (Ebu et al., 2015; Eze et al., 2012; Mupepi et al., 2010; Utoo et al., 2013). Screening policies: In some societies, women had to be a certain age (over 30 years) to qualify for free screening (De Abreu et al., 2013).

Discussion

This review sought to understand the barriers to Pap smear screening among women in sub-Saharan Africa. The review included 17 primary articles published between 2006 and 2015. Through analysis of the articles, a large number of barriers to Pap smear screening have been identified and were categorized as client, provider, and system barriers. Inadequate knowledge and awareness of Pap smear screening was the most common client barrier identified. Inadequate knowledge and awareness of Pap smear screening could be related to the inability of the system to inform the clients about cervical cancer screening. Lack of information could also be related to illiteracy or low knowledge levels. Lack of knowledge and awareness of cervical cancer screening were reported by other reviewers as the most significant barrier to cervical cancer screening (Chidyaonga-Maseko, Chirwa, & Sinjani Muula, 2015). Most of the barriers have been derived from various quantitative studies using random sampling, and from qualitative studies, which offered further exploration and categorization of the barriers.

Evidence has also shown that the majority of sub-Saharan women do not screen for cervical cancer for fear of positive test results, which might indicate the possibility of death. This fatalistic view of cervical cancer could be a reason that the majority of the women in sub-Saharan Africa report to health facilities at a late stage of cancer. Fear of cancer and death is not unique to the sub-Saharan samples. In their review of the literature, Austin, Ahmad, McNally, and Stewart (2011) reported that Hispanic women held fatalistic attitudes of cervical cancer, and they believed that getting cervical cancer is fate and cannot be changed. As such, the fear of finding cancer also deterred Hispanic women from screening. Fear of loss of virginity was also a barrier to screening by some women. This fear could indicate that women in some cultures hold important beliefs about preserving their virginity, which indicated the need for sensitivity by providers. Younger women reported fear of stigmatization for using the services as an impediment to screening. This finding indicates lack of information about cervical cancer screening.

In this review, most women did not view cervical screening as important or necessary, because they did not believe they were at risk for cervical cancer. Rather, they believed that they were healthy and had no gynecological symptoms to warrant screening. This could be why the Pap smear is generally used as a diagnostic rather than as a preventive tool. As such, women do not consider it necessary to go for testing when they have no symptoms. It is also worth noting that African traditional explanatory models of disease causation and illness prevention may be somewhat different from the biomedical explanatory models of the Western world. While the focus of biomedical preventive health services is directed toward preventing specific diseases such as cervical cancer, traditional preventive health aims to prevent misfortune and general ill health rather than specific diseases (Staugart, 1985). The fact that disease-specific preventive health services such as Pap smear screening have never been part of the African tradition may explain why sub-Saharan women do not readily use biomedical preventive health services for the prevention of cervical cancer.

In this review, for women to participate in Pap smear screening, they must get the approval of their husbands or partners, suggesting that if the husband or partner does not approve of this test, a woman may not go against these cultural expectations and values. The findings of this review further indicate that religious values and beliefs did not encourage women to expose their bodies to men other than their husbands. It also suggests that women may not participate in screening for cervical cancer because it violates their religious practices and values. Major health system barriers included unavailability and inaccessibility of the Pap smear services. Access barriers could be explained by the fact that in most sub-Saharan countries, the healthcare systems use referral systems, which could act as a serious barrier for women because they prolong the process of accessing health care and transport costs.

Limitations

It is acknowledged that this study has several limitations. The researchers included only peer-reviewed qualitative and quantitative articles, and had very specific inclusion criteria. As such, some articles satisfying these criteria could have been missed. Further research is needed to examine the possibility of the inclusion of other articles that could also be valuable sources of information.

Conclusions and Implications

The review has provided some important highlights regarding the barriers to screening for cervical cancer among women in sub-Saharan Africa. The review also highlights implications for education, policy, and further research. Although there were some variations from country to country, and from rural to urban settings, sub-Saharan countries share similar constraints to cervical cancer screening related to the client, provider, and healthcare system. Understanding the client, provider, and system barriers to cervical cancer screening is necessary and could guide development of effective interventions. Therefore, there is a great need for women in sub-Saharan Africa to be informed about cervical cancer and the need for regular screening so that they can make informed choices about whether or not to screen. Policies are needed to facilitate availability, accessibility, and affordability of the screening services for women of all ages. It is also important that men, as well as religious leaders, be involved as important partners in the struggle to end cervical cancer. Further research is needed to explore barriers to screening for cervical cancer in sub-Saharan Africa.

Clinical Resources

- Cervical cancer: The sub-Saharan African perspective: http://www.ncbi.nlm.nih.gov/pubmed/19027621
- World Health Organization. (2013). Latest world cancer statistics. International Agency for Research on Cancer. Press release no. 223: https://www.iarc.fr/en/media-

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

An Audit of Nursing Documentation at Three Public Hospitals in Jamaica

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Abstract

Purpose: Nursing documentation provides an important indicator of the quality of care provided for hospitalized patients. This study assessed the quality of nursing documentation on medical wards at three hospitals in Jamaica.
Methods: This cross-sectional study audited a multilevel stratified sample of 245 patient records from three type B hospitals. An audit instrument which assessed nursing documentation of client history, biological data, client assessment, nursing standards, discharge planning, and teaching facilitated data collection. Descriptive statistics were conducted using IBM SPSS, Version 19 (IBM Inc., Armonk, NY, USA).
Findings: Records from three hospitals (Hospital 1, $n = 119$, 48.6%; Hospital 2, $n = 56$, 22.9%; Hospital 3, $n = 70$, 28.6%) were audited. Documented evidence of the patient's chief complaint (81.6%), history of present illness (78.8%), past health (79.2%), and family health (11.0%) were noted; however, less than a third of the dockets audited recorded adequate assessment data (e.g., occupation or living accommodations of patients). The audit noted 90% of records had a physical assessment completed within 24 hr of admission and entries timed, dated, and signed by a nurse. Less than 5% of dockets had evidence of patient teaching, and 13.5% had documented evidence of discharge planning conducted within 72 hr of admission.
Conclusions: This study highlights the weakness in nursing documentation and the need for increased training and continued monitoring of nursing documentation at the hospitals studied. Additional research regarding the factors that affect nursing documentation practice could prove useful.
Clinical Relevance: The study provides valuable information for the development of strategic risk management programs geared at improving the quality of care delivered to clients and presents an opportunity for nurse leaders to implement structured interventions geared at improving nursing documentation in Jamaica. In light of Jamaica's epidemiologic transition of chronic diseases, gaps in nurses' documentation of client assessment, patient teaching, and discharge planning should be addressed with urgency. Patient teaching and discharge planning enable the clients to participate more effectively in their health maintenance process.

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Documentation is an essential tool in the nursing profession, providing the structural, consistent, and effective communication required for the delivery of quality patient care that meets professional and legal standards (Jefferies, Johnson, & Griffiths, 2010; Urquhart, Currell, Grant, & Hardiker, 2009; Wang, Hailey, & Yu, 2011). Scholars have defined nursing documentation as a written or electronic communication tool that generates information about a patient and is typically used to describe the patient's care and response to treatment (Wang et al., 2011). It is estimated that nurses spend approximately 15% to 25% of each shift documenting patient care (Wang et al., 2011). Multiple factors can affect the quality of nursing documentation, including the level of staffing, and education and training of nurses (Blake-Mowatt, Lindo, & Bennett, 2013; Wang et al., 2011).

Information gathered or mined from nursing documentation may be used as a proxy of the quality of care given (Collins et al., 2013), particularly the use of elements of the nursing process (Wang et al., 2011). Advocates of Universal Health Coverage suggest the selection of measurable indicators such as nursing documentation to assist in determining the overall quality of care delivered to clients (Dye et al., 2013). Additionally, the Joint Commission, has listed patient and family education outcomes as essential focus areas for quality of care surveys (Joint Commission on Accreditation of Healthcare Organizations, 2009). Regulatory bodies in the United States continue to advocate for electronic health records, citing benefits of increased patient safety, quality of care, and opportunity for research (Adler-Milstein et al., 2014). Notwithstanding, more than half of U.S. hospitals continue to use paper-based documentation (DesRoches et al., 2013). Likewise, paper-based documentation remains common in sections of countries such as Germany, the United Kingdom (Ammenwerth, Mansmann, Iller, & Eichstädter, 2003; Nursing and Midwifery Council, 2010), and most low- and middle-income countries (Nakate, Dahl, Petrucka, Drake, & Dunlap, 2015).

The Jamaican healthcare system primarily employs a paper-based health record system and is burdened by the high prevalence of diabetes, cardiovascular diseases, and other chronic diseases, often requiring prolonged and or repeated hospital admissions (Boyne, 2009). Nurses must therefore play a critical role in advancing the health of the population by providing a high quality of care that enables optimal patient outcomes. Policy development regarding the monitoring of nursing documentation and buttressing the importance of "documentation and record keeping qualities in nursing practice, nursing education, and continuing education of nurses" cannot be underemphasized (Inan & Dinç, 2013, p. 87).

National policy should be driven by generalizable evidence. Local evidence garnered from a review of 90 patients' records at a public hospital in Western Jamaica revealed inadequacies in the use of the nursing process, and identified significant weaknesses regarding patient education and discharge planning (Blake-Mowatt et al., 2013). The singleness of the institution studied and the limited study sample size prohibit inferences about nursing documentation at the national level. This follow-up study sought to describe paper-based nursing documentation of the care of adult patients admitted on medical wards at three Type B public hospitals across Jamaica.

Methods

Study Design

A descriptive cross-sectional audit of nurses' documentation was conducted. An audit entails a systematic, independent, and documented process of evaluation through which one can objectively determine whether the audit criteria are fulfilled (Domingues, Sampaio, & Arezes, 2011). This process allows health workers to determine the need for changes in current practice (Kirrane, 2001).

As in other low- and middle-income countries, research mentorship and financing for nursing research can be challenging (Edwards, Webber, Mill, Kahwa, & Roelofs, 2009). Through a mutually beneficial partnership, the study allowed research capacity building among junior faculty who were mentored during the research process and facilitated the learning experiences of undergraduate students enrolled in a research methods course (data collectors).

Setting and Population

Type B public hospitals were selected from three of the four health regions in Jamaica. A Type B health agency offers medicine, general surgery, obstetrics and gynecology, and pediatric services and refers high-risk patients to larger specialist hospitals (The Health Sector Task Force, 2009). Hospitals selected were located in proximity to the three schools of nursing and had a combined total of seven adult medical units. Each unit had a bed capacity of 70 to 109, with a combined total of 276 beds at full capacity. Hospital policy requires only licensed personnel to participate in nursing documentation and an average staff patient ratio of 1:4–6 on medical wards at government-operated hospitals. However, in the presence of the persistent nursing shortage, nurses are often assigned many more than six patients. Typically, the units are staffed primarily with registered nurses; however, across hospitals the nursing staff often included up to 25% enrolled assistant nurses (similar to a licensed practical nurse).

Sample and Sampling Strategy

Using a margin of error of 5%, confidence level of 95%, and response distribution of 50%, the recommended minimum sample size was 187. To account for clustering and variations at the hospital level, a design effect of 0.3 was added, resulting in a final sample of 244. A multilevel sampling strategy was employed. Three hospitals were purposely selected based on their Type B status, the health regions, and their capacity to facilitate nursing students' senior clinical experience. All seven adult medical units (female, male, and mixed) were selected, and a proportionate sample was then calculated to determine the number of patient records to be audited: 100, 66, and 78 from Hospitals 1, 2, and 3, respectively. The criteria for selection included medical records of patients admitted to the adult medical units at the hospitals during the period February 1 to April 30, 2015, with a hospitalized stay of 4 or more days. Records of patients admitted to the medical units at the institution over the 3-month period were made available by the medical records clerks, and records were then selected based on the stated inclusion criteria.

Data Collection Measures

The records were reviewed using an audit instrument from the Nursing Policy Manual, Ministry of Health Jamaica (Ministry of Health Jamaica, 2008) that was strengthen base on a review of the literature (Björvell, Wredling, & Thorell-Ekstrand, 2003; Blake-Mowatt et al., 2013; Jefferies, Johnson, & Nicholls, 2011; Paans, Sermeus, Nieweg, & Van Der Schans, 2010; Wang et al., 2011). The audit instrument included four sections (A–D): Section A described nursing history and assessment at admission. Section B ascertained the nursing care framework (SOAPIE/SOAPIER or ADPIE) used in the nursing documentation. The SOAPIE/SOAPIER framework is a problem-oriented approach to documentation that allows the nurse to organize the nursing notes and is recommended by the Ministry of Health, Jamaica. The College of Registered Nurses of British Columbia (CRNBC, 2013, p. 14) describes the elements of the SOAPIE documentation: "S = subjective data, O = objective data,A = assessment, P = plan, I = intervention, E = evaluation and R = revision." This section also sought answers to questions relating to the use of the nursing process, which includes the assessment, diagnosing, planning, implementation, and evaluation (ADPIE) of the patient and is commonly used by nurses caring for patients (CRNBC, 2013) and closely resembles the SOAPIE method. Section C of the tool assessed the meeting of the standard requirements for documentation in nursing such as the presence of date and time (mainly applicable to paper-based records; Wang et al., 2011). Section D reviewed the presence of patient teaching and discharge planning within 72 hr of admission. The documentation entries were rated based solely on the absence or presence of the specific entries, reducing the probability of interrater reliability issues.

Validity and Reliability

The Ministry of Health Jamaica has developed and validated an audit tool for nurses' documentation, which is used in the country's hospitals (Ministry of Health Jamaica, 2008). Furthermore, Blake-Mowatt et al. (2013) described pretesting of the instrument in a similar setting and reported adequate reliability and validity. However, a primary concern of the study was interrater reliability. Consequently, multiple strategies (described in the ensuing Data Collection section) were employed to successfully address same.

Data Collection

Final year undergraduate nursing students enrolled in a research methods course were trained as data collectors. Students attended a 1-day training workshop that included a lecture on nursing documentation, a review of the nursing process, role play, demonstration, and return-demonstration using two mock records for which data extraction was successfully completed by each student as assessed by faculty.

The probability of duplication of data collection was reduced by inserting green slips of paper in the record, indicating the date when the record was audited by the team. Data extraction was done at the institutions and always in the presence of at least one of four nursing faculty members who monitored the process, acted as resource persons, and audited a minimum of 10% of the records. All data extraction sheets were then centrally collected and reviewed by the lead researchers. This process highlighted variances in data collection and extraction at one of the three study sites and resulted in a re-audit of all records selected at that site.

Data Analysis

Data were analyzed using the IBM SPSS Statistics version 19 (IBM Corp., Armonk, NY, USA). Descriptive statistics were used to summarize the data and nurses'

Table 1. Distribution of Documented Nursing History and Assessment by Hospital

Assessment variables	Hospital 1 *n*/119 (%)	Hospital 2 *n*/56 (%)	Hospital 3 *n*/70 (%)	Total *n*/245 (%)	*p*
Documentation of patient history by the nurse					
Chief complaint	89 (74.8)	47 (83.9)	64 (91.4)	200 (81.6)	.015
History of present illness	95 (79.8)	39 (69.6)	59 (84.3)	193 (78.8)	.126
Past health history	92 (77.3)	46 (82.1)	56 (80.0)	194 (79.2)	.749
Family health history	18 (15.1)	0 (0.0)	9 (12.9)	27 (11.0)	.010
Psychosocial history	13 (10.9)	0 (0.0)	11 (15.7)	24 (9.8)	.011
Biographical data					
Age	108 (90.8)	55 (98.2)	65 (92.9)	228 (93.1)	.193
Sex	103 (86.6)	55 (98.2)	57 (81.4)	215 (87.8)	.014
Marital status	43 (36.1)	2 (3.6)	30 (42.9)	75 (30.6)	.0001
Number of children	3 (2.5)	1 (1.8)	3 (4.3)	7 (2.9)	.672
Occupation	26 (21.8)	1 (1.8)	17 (24.3)	44 (18.0)	.001
Education	2 (1.7)	0 (0.0)	1 (1.4)	3 (1.2)	.630
Religious affiliation	23 (19.3)	2 (3.5)	15 (21.4)	40 (16.3)	.012
Living accommodations	13 (10.9)	1 (1.8)	25 (35.7)	39 (15.9)	.0001
Patient assessment					
Physical assessment	98 (82.4)	56 (100.0)	68 (97.1)	222 (90.6)	.0001
Method of physical assessment					
Systemic	29 (27.6)	16 (30.2)	8 (11.4)	53 (23.2)	.013
Focused	29 (27.6)	25 (47.2)	30 (42.9)	84 (36.8)	
Head to toe	35 (33.3)	9 (17.0)	23 (32.9)	67 (29.4)	
Combination	12 (11.4)	3 (5.7)	9 (12.9)	24 (10.5)	
Checklist used	3 (2.8)	0 (0.0)	6 (8.6)	9 (3.9)	.035

adherence to hospital guidelines. The chi square test was used to compare variables across hospitals.

Ethical Considerations

Ethical approval was obtained from the university's institutional review board and from the Ministry of Health, Jamaica. Permission to conduct the audit was obtained from the administration of all relevant institutions. Informed consent was not required to conduct the audit of the nursing documentation within the institution (Björvell, Thorell-Ekstrand, & Wredling, 2000). Confidentiality and privacy of patient records were maintained and records were not removed from their primary locations. Finally, data extraction forms were assigned consecutive numbers and hospital codes, void of the clients' names or medical record numbers.

Results

A total of 245 medical records from seven adult medical wards at three Type B hospitals across Jamaica were audited. This included 119 records (48.6%) from Hospital 1, 56 (22.9%) from Hospital 2, and 70 (28.6%) from Hospital 3, which reflects oversampling of 19 records at Hospital 1 and shortfalls of 10 and 8 from Hospitals 2 and 3, respectively.

Patients' History

More than 69% of the records had evidence of documentation relating to chief complaint (81.6%, $n = 200$), history of past illness (78.8%, $n = 193$), and past health history (79.2%, $n = 194$; **Table 1**). In contrast, documented evidence related to patients' family health history and psychological history were infrequently present (11.0% and 9.8%, respectively). Chi-square analysis revealed that there was a significant relationship between hospitals and four elements of client history documentation (nursing history documented by nursing, $p = .0001$; chief complaint, $p = .015$; family history, $p = .010$; psychological history, $p = .011$).

Biographical Data

Table 1 also shows a distribution of medical records with documented evidence of the patient's biographical data by hospital. Age (93.1%) and sex (87.8%) were the most frequently documented demographic data. The number of children, marital status, occupation,

Table 2. Distribution of Medical Records With Nursing Documentation Adhering to Selected Ministry of Health Standards of Nursing Documentation

Standard (Ministry of Health)	Hospital 1 *n*/119 (%)	Hospital 2 *n*/56 (%)	Hospital 3 *n*/70 (%)	Total *n*/245 (%)	*p*
Writing of the record is legible	109 (92.4)	45 (80.4)	59 (88.1)	213 (88.4)	.069
Erasure line present	87 (75.0)	47 (83.9)	14 (28.6)	148 (67.0)	.0001
Error(s) properly corrected	35 (46.1)	18 (40.9)	35 (68.6)	88 (51.5)	.012
All documentation					
Timed	116 (98.3)	56 (100.0)	67 (100.0)	239 (99.2)	.350
Dated	118 (99.2)	52 (92.9)	67 (100.0)	237 (97.9)	.009
Printed name	33 (28.7)	6 (10.7)	36 (59.0)	75 (32.3)	.0001
Signed	118 (100.0)	56 (100.0)	67 (100.0)	241 (100.0)	—
Designation of recording nurse	65 (56.5)	41 (73.2)	39 (73.6)	145 (64.7)	.031

education, religious affiliation, and living accommodations were observed in less than a third of the records.

Documentation of Patients' Assessment

The study sought to determine whether nurses documented the physical assessment of patients within the first 24 hr of admission. Ninety percent of records had evidence of physical assessment being done and reflected varying types of assessment (focused 36.8%; head to toe 29.4%; systemic 23.2%; combination 10.5%), with 3.9% indicating the use of a checklist.

Nursing Care Framework

The instrument sought to determine the organizing framework that governed the nurses' documentation. Less than 10% of notes had the explicit subjective and objective statements of SOAPIE, and 29% included a nursing diagnosis. Eleven dockets (4.5%) reflected nurses' goal, intervention, and evaluation in documenting client care in the first 24 hr of admission.

Nursing Documentation Standards

Almost all of the records assessed had been timed (99.2%), dated (97.9%), and signed (100.0%) by a nurse, whilst only a third of records had a printed name present (**Table 2**). Some variations were found in nursing documentation standards, as the use of erasure lines at the institutions reflected rates of 29% to 83% and improperly corrected errors (41%–69%).

Discharge Planning and Teaching

As shown in **Table 3**, only 4 (1.7%) of the medical records audited reflected evidence of patient teaching within 24 hr of admission (all were from Hospital 1). Topics taught included medication, patient safety,disease process, and plan of care. Finally, less than 15% of medical records audited reflected evidence of discharge planning within 72 hr of admission. The stark weaknesses in the documentation of discharge planning and patient teaching at the institutions studied has negated the relevance of further analysis at this level.

Discussion

The results of this study reflected statistically significant differences in specific elements of nursing documentation at the institutional level. For example, at Hospital 1, 15% of records reflected the clients' family history, while none of the records audited at Hospital 2 had the family history recorded. Both were woefully inadequate, with major implications for the quality of client assessment and subsequent plan of care. Consequently, the trends noted across institutions were summarized to create a national perspective of the strengths and weaknesses in the nurses' documentation among hospitals across Jamaica.

The complex task of nursing documentation is often guided by the nursing process, a framework for solving patient care problems, and ensuring the provision of high quality nursing care (Yildirim & Ozkahraman, 2011). In the current study, less than 5% of the dockets reflected a goal, intervention, and evaluation in documenting client care in the first 24 hr of admission. Nurses are required to determine whether the desired outcomes are achieved, the effectiveness of the interventions, and whether changes need to be made in the proposed plan of care (Yildirim & Ozkahraman, 2011, p. 261). Paans et al.

Table 3. Documentation Entries Related to Patient Teaching and Discharge Planning

Documentation	% Within 24 hr (*n*)	% Within 72 hr (*n*)
Patient teaching	1.7 (4)	4.2 (10)
Discharge planning	—	13.5 (33)

(2010, p. 2486) hypothesize that "expert nurses know what steps can be safely skipped, combined, or delayed." However, the lack of comprehensive documentation could present a challenge to junior nurses, has significant legal implications, and may affect communication among members of the healthcare team (Jefferies et al., 2010; Wang et al., 2011).

The records reviewed revealed high rates of documentation of the patients' physical assessment as more than 90% of the records demonstrated the conduct of a patient assessment within 24 hr of admission. These findings are consistent with those of the review of 90 patients' records in Western Jamaica (Blake-Mowatt et al., 2013), a Brazilian hospital based audit (Borsato, Rossaneis, Haddad, Vannuchi, & Vituri, 2011), and a review done in the Netherlands (Paans et al., 2010) in which 74% to 90% of records reflected documented admission data. Nurses have been shown to demonstrate a preference for documenting patient assessments and interventions (Kirrane, 2001).

Patient assessment influences the quality of care provided for patients as clinicians rely on assessment data to make appropriate patient diagnoses and treatment decisions (Munroe, Curtis, Considine, & Buckley, 2013). Likewise, changes in the patient's condition are detected through the assessment process and has obvious implications for the timeliness of care (Hoffman, Aitken, & Duffield, 2009). Recent evidence has identified links between patient mortality outcomes and nursing documentation patterns and underscores the importance of patient assessments, particularly in inpatient settings (Collins et al., 2013). In the current study, the majority of records audited reflected a focused assessment; this is in contrast to hospital policy, which requires a head-to-toe assessment, and appeared to differ from the nurses' notes written in Ghana, where a narrative form is typically seen (Asamani, Amenorpe, Babanawo, & Ansah Ofei, 2014).

The incompleteness of patients' admission assessment data was notable as nurses tended to document patients' age, sex, chief complaint, history of present illness, and past history but were less inclined to document family and psychosocial history, number of children, and education. Jasemi, Zamanzadeh, Rahmani, Mohajjel, and Alsadathoseini (2012) reported insufficient information in 71.1% of nursing assessment records audited in an Iranian hospital. In first-world settings, successful efforts to improve the completeness of nursing documentation to address this issue included the implementation of electronic documentation systems (Björvell et al., 2003). Nurses in developing countries must strive to understand the factors that influence nurses' attitudes towards documentation (Asamani et al., 2014), since the cost of implementation of computerized systems may be prohibitive in these practice settings.

Although nurses are aware of the importance of documentation, gaps in this area of practice have been described in studies conducted in Iran (Dehghan, Dehghan, Sheikhrabori, Sadeghi, & Jalalian, 2013; Jasemi et al., 2012), Ghana (Asamani et al., 2014), Turkey (Inan & Dinç, 2013), Australia, the United Kingdom, and the United States (Wang et al., 2011). The failure of nurses to adequately document patient teaching and discharge planning noted in this study has been reported in other settings (Ehrenberg, Ehnfors, & Ekman, 2004; Paans et al., 2010). Flagrant absences of documentary evidence regarding patients' achievement of shared understanding about their treatment may be viewed as a lack of patient centeredness (Flink et al., 2015) and is unfortunate given the importance of self-management among patients living with chronic diseases (Boyne, 2009).

Failure to communicate via documentation is likely to contribute to poor health outcomes and increased levels of patient dissatisfaction (Goodman, Fisher, & Chang, 2013; Knier, Stichler, Ferber, & Catterall, 2015), as incomplete or unclear documentation impedes communication process among health practitioners (Törnvall & Wilhelmsson, 2008). It is therefore commendable that the majority of the records reviewed were deemed legible, dated, and signed, thus meeting international standards (College of Registered Nurses Association of Nova Scotia, 2012; College of Registered Nurses of British Columbia, 2013; Ministry of Health Jamaica, 2008). This is expected to facilitate continuity of patient care and maintain safety, especially in case of emergencies (Inan & Dinç, 2013), and reduce errors related to miscommunication (Inan & Dinç, 2013; Törnvall & Wilhelmsson, 2008). These findings present a sharp contrast to other developing settings where the majority of nurses' notes were unsigned (Asamani et al., 2014). Nevertheless, errors made were appropriately corrected in only half of the records; this could lead to unwarranted exposure to liability (Austin, 2011).

Audit exercises should consider the historic evolution of subsystems and must be contextualized (Domingues et al., 2011). There is consensus that "nurses bear a large burden in both managing and implementing the interdisciplinary team's plan for the patient" (Keenan, Yakel, Tschannen, & Mandeville, 2008, p. 1). Nurses may find it necessary to neglect the comprehensiveness of documentation in order to administer direct patient care (Gugerty et al., 2007); therefore, nurses may have conducted patient teaching but failed to document these activities. The nurses' level of experience may influence the completeness of nursing documentation (Hoffman et al., 2009). A high patient:staff ratio amid the shortage of experienced nurses due to migration to first-world countries has been seen in Jamaica, and this could contribute to the gaps described in the current study (Brush, 2008; Salmon, Yan, Hewitt, & Guisinger, 2007). Finally, the absence of adequate amenities such as available seating and forms or charts (Björvell et al., 2003, p. 213), inadequate time, and staffing issues (Blake-Mowatt et al., 2013) are issues common to the Jamaican practice setting.

Limitations

This study did not explore the factors affecting nurses' documentation, and this would have strengthened the study. Based on the level of experience of the data collectors, the study was limited to the absence or presence of the variables of interest and did not adequately examine the quality of the documentation. The study concedes the limitations associated with a convenience sampling technique and the fact that patient teaching and discharge planning may have been conducted outside of the period of review of this study.

Implications for Practice

These hospitals facilitate nursing students' learning experiences and therefore appropriate standards must be maintained. Continuing education is necessary to ensure staff are familiar with institutional documentation guidelines. This study provides baseline information that could guide the development of national educational interventions for nurses in the public health system. Continuous monitoring of nursing documentation as a means of quality assurance is indicated and should be developed through a national consultative process led by nurse leaders.

Conclusions

This study highlights weaknesses in nursing documentation at the national level. While nurses' notes met many of the stated documentation guidelines, there is a need for re-education and reorientation on history taking and the appropriate legal correction of errors and use of the nursing process. The noted deficiency in discharge preparation is likely to contribute to increased incidences of readmission among patients with chronic conditions (Jack et al., 2009; Weiss, Yakusheva, & Bobay, 2011). These findings could affect the ability of Jamaica to enact Universal Health Coverage and the fight against the advancement of the chronic disease epidemic in the Caribbean region (Dye et al., 2013).

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Clinical Resources

- Nursing documentation: https://bibliomed.bib.uniud.it/novita/nursing/nursing_documentation.pdf
- Nursing documentation, record keeping, and written communication: http://www.intl.elsevierhealth.com/media/us/samplechapters/9780443073991/9780443073991.pdf
- Lippincott Nursing Center: http://www.nursingcenter.com/
- Practice standards: Documentation: http://www.cno.org/Global/docs/prac/41001_documentation.pdf

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Effects of Auricular Acupressure Therapy on Primary Dysmenorrhea for Female High School Students in South Korea

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Key words
Auricular acupressure, dysmenorrhea, nursing, student

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Abstract

Purpose: To examine the effect of auricular acupressure therapy on primary dysmenorrhea among female high school students in South Korea.
Design: A randomized controlled trial was employed.
Methods: The study sample consisted of 91 female high school students, with 45 participants in the experimental group and 46 in the control group in two regions of South Korea. The average age of the participants was 16.7 years, and the average age of menarche was 12.2 years. Auricular acupressure therapy including an auricular acupressure needle on skin paper tape was applied on an ear for 3 days during periods of extreme primary dysmenorrhea. The acupoint names were Jagung, Sinmun, Gyogam, and Naebunbi. For the placebo control group, only the skin paper tape without an auricular acupressure needle was applied on the same acupoints. Measures used were the Menstrual Distress Questionnaire to assess primary dysmenorrhea, and the visual analog scale to assess abdominal and back pain of participants.
Findings: There were significant differences on abdominal pain ($t = 24.594$, $p < .001$), back pain ($t = 22.661$, $p < .001$), and primary dysmenorrhea ($t = 32.187$, $p < .001$) between the two groups. Auricular acupressure therapy decreased abdominal pain, back pain, and primary dysmenorrhea of female high school students in South Korea.
Conclusions: Auricular acupressure therapy was an effective intervention for alleviating abdominal pain, back pain, and primary dysmenorrhea of female high school students in South Korea. For feasibility of the auricular acupressure therapy in practice, it is needed to train and learn the exact positions of acupoints in ear.
Clinical Relevance: Health providers should consider providing auricular acupressure therapy as an alternative method for reducing abdominal and back pain, and primary dysmenorrhea in female high school students in South Korea.

Primary dysmenorrhea is defined as a complex of symptoms with cramping pain in the lower abdomen, which occurs during menstruation or before it, where there are no other diseases, like endometriosis (Wang, Hsu, Yeh, & Lin, 2013). Primary dysmenorrhea occurs within 1 to 2 years of menarche after the ovulation cycle, particularly between 10 and 20 years of age, and can last until a woman's late forties (Davis & Westhoff, 2001; Kim, 2005; Strinic, Bukovic, Fajdic, Herman, & Stipic, 2003) and decreases with age. As such, the interest in efficient intervention for women's health before progression to a serious disorder is increasing (Kim & Kim, 2012; Yeh, Hung, Chen, & Wang, 2013).

Background

Primary dysmenorrhea is mostly caused by uterine contractions. When the uterus contracts, the intrauterine

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pressure is 200 to 300 mmHg. Due to the excessively frequent uterine contractions, the intrauterine blood flow decreases, and ischemic pain occurs in the uterus (Eby, 2007; Jeon, Cha, & Sok, 2014). In general, pain occurs right before or simultaneously at the start of menstruation. The pain lasts from several hours to more than a day. In many cases, it can even last during the entire menstrual period. In Korean women, and perhaps in women from other parts of the world, the prevalence rate is approximately 87% to 90%, and the proportion of serious cases is approximately 10% to 25.6% (Chang, 2002; Jeon, 2003; Jeon et al., 2014).

Primary dysmenorrhea can cause serious problems as well as negative emotions in everyday life by inducing lower abdominal pain, fatigue, back ache, loss of appetite, headache, diarrhea, and nausea (Cheng, Chung, Chen, Chang, & Yeh, 2012; Jeon, 2003). In South Korea, primary dysmenorrhea is the most frequent cause for work or school absences (Chang, 2002). Therefore, countermeasures and management of these problems are very important. Many women are aware of their physical and emotional stressors and daily personal experiences, but they are not willing to seek expert or medical advice in order to alleviate the discomfort and pain relevant to a menstrual cycle (Durain, 2004; Jeon et al., 2014).

To alleviate primary dysmenorrhea, drug therapies (e.g., analgesic and oral contraceptive pill) and nondrug therapies (e.g., relaxation, warmth, supportive, exercise, and diversional therapies) have been used (Hewison & VanDen Arker, 1996; Jeon et al., 2014). Among these therapies, analgesics are most frequently used for pain alleviation. The effectiveness of nonsteroidal anti-inflammatory drugs has also been reported (Dawood & Khan-Dawood, 2007; Eby, 2007). However, analgesics are only effective for temporary pain relief, and they need to be administered again when the blood drug concentration drops. Furthermore, using analgesics poses side effects and unnecessary medical expenses. There are different methods that are much more economical and safe, such as relaxation, sleeping, warm compresses, and massage. However, these alternatives need to be applied while primary dysmenorrhea is being experienced in order to alleviate the symptoms, and thus could interrupt a person's daily activities (Cheng et al., 2012; Kim & Kim, 2012; Nam, Bang, & Kim, 2013; Yeh, Hung, Chen, & Wang, 2013).

In auricular acupressure therapy (AAT), sticker needles are attached to specific stimulation points on the pinna, and these needles can last for up to 3 days. As a result, there is no inconvenience or interruption of everyday life, and the cost is minimal. Moreover, active self-management of abdominal pain and primary dysmenorrhea is available if one learns about the acupuncture points of the pinna. Since auricular acupressure self-therapy can be applied on the ear, accessibility is higher (Cha, 2008; Sok, 2001; Wang et al., 2013). It is an effective intervention method because of its effects on the entire body through the use of sticker needles to the ears (Cheng et al., 2012; Du et al., 2009; Sok, 2001; Wang et al., 2013; Yeh et al., 2013).

AAT has been commonly used for smoking cessation, obesity, and acne treatment (National Department of Meridian Acupoints, 2000; Wang et al., 2013). In South Korea, a few studies have been conducted on patients with cancer (Kim, 2002), senile insomnia (Kim & Sok, 2007), and dysmenorrhea (Cha, 2008). More studies have been performed in other countries (Terry, 1999; Wang et al., 2013; Wu, Zhang, & Lin, 2007; Yeh et al., 2013), but studies on primary dysmenorrhea remain insufficient. It has also been reported that gynecological diseases, such as menstrual irregularity, can be eliminated or reduced simply by stimulating the acupuncture points during AAT (Cheng et al., 2012; National Department of Meridian Acupoints, 2000; Wang et al., 2013; Yeh et al., 2013). Few studies on primary dysmenorrhea showed that intrauterine blood and qi flow to the uterine increases during AAT, and through the functional mechanism, the excessively frequent pain, discomfort, and primary dysmenorrhea can be reduced (Cha, 2008; Kim, 2005; Wang et al., 2013). Based on the available literature, research conducted on the effects of AAT on abdominal pain and primary dysmenorrhea is considered significant. Additionally, 82.7% of adolescents complain of primary dysmenorrhea (Jung & Kim, 2004), and 10% of them suffer from extreme pain. Because of the extreme pain they cannot attend school, resulting in reduced learning activities (Walsh, 1981). Its effect is worse on activities of daily living (Cha, 2008; Wang et al., 2013). If the effectiveness of AAT is confirmed, health management and the learning activities of female high school students can be improved. Consequently, a study was conducted to examine the effects of AAT on primary dysmenorrhea among female high school students in South Korea.

The theoretical framework of this study is shown in **Figure 1**. According to the meridian acupressure theory, acupressure stimulates the body's meridian pathways through which vital energy flows, causing the dynamic circulation of the retained qi and blood and thus maintaining and controlling the internal organs' functions and balancing the yin and the yang (Kang, Sok, & Kang, 2009; Shin, Song, & Seo, 2007). The main principle of its treatment of a disorder is centered on the qi, the basic substance that causes all the movements and mutations of all phenomena in the universe: keeping it at the correct level and then regulating its relationship with the

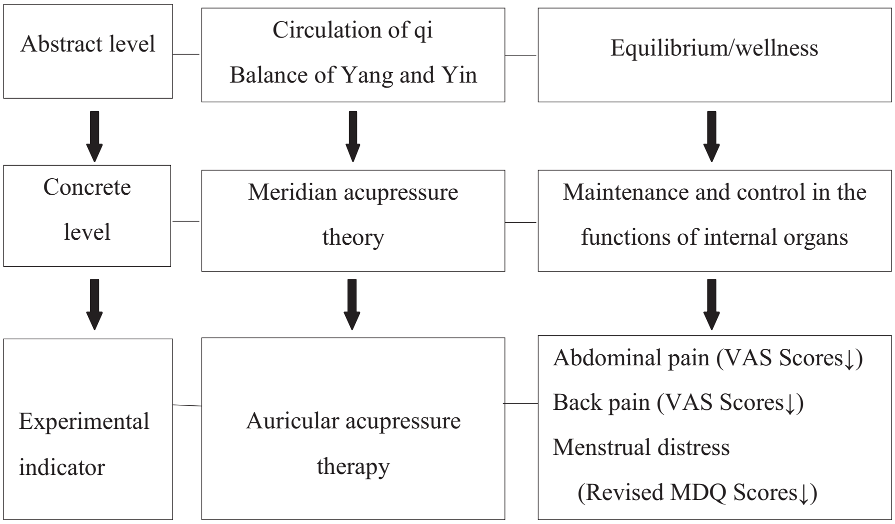

Figure 1. Theoretical framework in this study.

blood while also regulating the relationship between the yin and the yang (Gao, 1997; Sok & Kim, 2005). The foci of acupressure are the meridian points (Kyung-Hyul), certain spots on the body where acupuncture is applicable. Also, acupressure can be performed with the hands or fingers alone, without any drug or tool, based on Pascal's principle (when pressure is applied to an enclosed fluid, it is transmitted to every part of the fluid and to the container's walls in equal amounts) as well as the principle of acupuncture (Shin et al., 2007). In the case of acupressure, it can produce the effects of acupuncture by applying an appropriate amount of pressure to a painful spot on the body using the hands or fingers alone. However, this method, like auricular acupressure with needles, is more effective. Although there is a needle on the skin paper tape in AAT, AAT is generally called auricular acupressure because the size of the needle is smaller than a seed. According to Pascal's principle, AAT can make the internal organs function properly and can restore the body's physiological functions (Han, 1997; Shin et al., 2007). The four meridian points used for meridian acupressure in this study are Jagung (子宮), Sinmun (神門), Gyogam (交感), and Naebunbi (內分泌; East-West Nursing Research Institute, 2001; Han, 1997). Meridian acupressure using four meridian points on the ear balances the qi (the energy or life force) in the body, making positive energy enter the body from outside, particularly through the four meridian points. The balance between the yin and the yang in the body as well as the proper circulation of qi therein, especially the uterus, will decrease the abdominal pain, back pain, and primary dysmenorrhea in female high school students (Cha, 2008; Wang et al., 2013; Yeh et al., 2013).

Purpose

The aims of this study were to examine the differences of application of AAT in terms of (a) abdominal pain, (b) back pain, and (c) primary dysmenorrhea between the experimental and control groups.

Methods

Design

A randomized controlled trial was adopted.

Participants

The total study sample was composed of 91 female high school students (experimental group: 45 participants; control group: 46 participants) in two regions of South Korea. The number of recruits rejected was three female high school students. The dropout rate was 10% (five participants) in the experimental group and 8% (four participants) in the control group. The participants were secured through random sampling using a coin toss. During the toss coin, heads meant the subject becomes a participant of the experimental group in this study. Inclusion criteria were 16 to 19 years of age, with primary dysmenorrhea, consented to engage in this study, and above 70 score in the Menstrual Distress Questionnaire (MDQ) based on previous studies (Cha, 2008; Chang, 2002). The dropout rate in the inclusion was 5.7% (three participants). The exclusion criteria were as follows: persons who took medical diagnosis and treatments related to women's diseases in the past or at present; exposure to oriental medicine or traditional therapies during this study; or intake of contraceptive pills within 1 month.

Sample size adequacy ($n = 45$ for each group) was estimated based on an alpha level of 0.05, number of groups of 2, conventional medium effect size of 0.30, and power of 0.80 (Cohen, 1988). Therefore, the sample size of this study was appropriate.

Measures

The study questionnaire was designed to measure general and menstrual characteristics, abdominal and back pain, and menstrual distress. General and menstrual characteristics developed by the investigators consisted of significant variables found in a review of previous studies. The variables were age, menarche, menstrual regularity, menstrual cycle length, duration of menstruation, peak time of dysmenorrhea, family history, intervention methods, and regularity of diet. These variables were assessed with a total of nine items.

A visual analog scale (VAS) to measure the perceived abdominal and back pain of participants was used in this study. This is a 0- to 10-point scale, with 0 meaning *no pain* and 10 the *worst pain*. Although subjective, the VAS has wide application and can validly assess pain (Chao et al., 2007; Chung, Hung, Kuo, & Huang, 2003). The higher the score of the respondent, the higher her level of abdominal and back pain.

The MDQ, developed by Moos (1968), was revised by Kim (1995). The revised scale was used to measure the distress level of menstruation among the participants. It consisted of 35 questions using a 6-point scale. The validity for this scale was confirmed by factor analysis statistics and by two nursing professors. The possible score range was 35 to 210. The higher the score of the respondent, the higher her level of dysmenorrhea. This tool was chosen based on considerations of high reliability and generality.

Cronbach's alpha reliability coefficients in the studies of Moos (1968) and Kim (1995) were each 0.97. Cronbach's alpha reliability coefficient for this instrument in this study was 0.96. Content validity for this scale was confirmed by two nursing professors and a statistics expert; they determined that the items in this scale correctly measured the concept.

Intervention

AAT including auricular acupressure needle on skin paper tape was applied on an ear for 3 days during instances of extreme primary dysmenorrhea. AAT is designed to stimulate various acupoints such as those described by Jagung, Sinmun, Gyogam, and Naebunbi for 3 days (**Figure 2**; National Department of Meridian Acupoints, 2000; Sok, 2001). Auricular acupressure needles on skin paper tape were applied with pressure. At this time, the exact positions of acupoints are very important. For the control group, only skin paper tape without an auricular acupressure needle was applied on the same acupoints. The control group was given placebo auricular acupressure. AAT was chosen as an experimental treatment based on positive evidences from previous studies (Cha, 2008; Chang, 2002; Cheng et al., 2012; National Department of Meridian Acupoints, 2000; Sok, 2001; Wang et al., 2013; Yeh et al., 2013). These previous studies support that AAT is applied on only one ear because of discomfort experienced from having auricular acupressure needles on two ears. Both ears have the meridian points of AAT, but because of the discomfort experienced when applied to both ears, only one ear is generally used (National Department of Meridian Acupoints, 2000; Wang et al., 2013; Yeh et al., 2013). Also, the acupressure needles on skin paper tapes are sterile products, and the quality and safety of this intervention method has been confirmed (Cheng et al., 2012; National Department of Meridian Acupoints, 2000; Sok, 2001; Wang et al., 2013; Yeh et al., 2013).

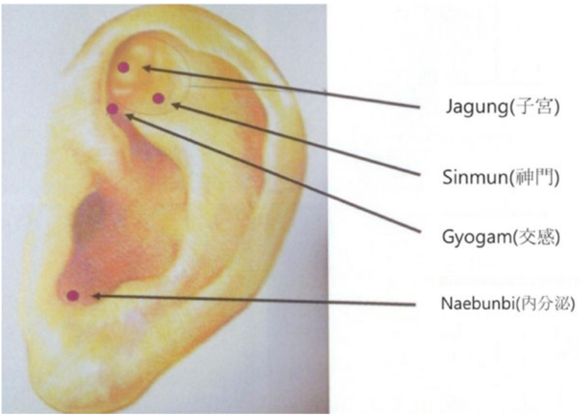

Figure 2. Meridian points of auricular acupressure therapy.

Data Collection

Data were collected by an assistant researcher from April to August 2013. The researcher visited female high schools to obtain permission and a list of phone numbers of female high school students. The researcher contacted the prospective female student participants and explained to them the study's purpose as well as the nature of their participation in the study and the instruments to be used in the study. The researcher received the completed written consent forms from the female students who agreed to participate in the study. AAT as an experimental

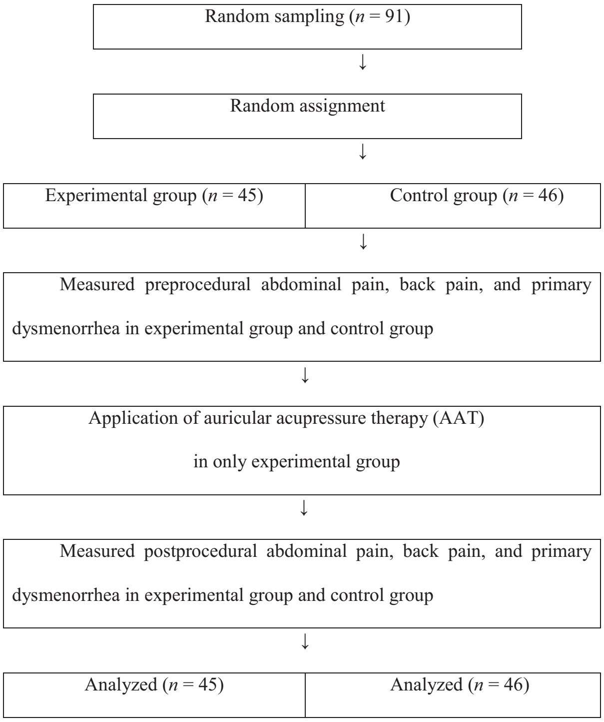

Figure 3. Participant flow diagram and study procedure.

intervention was applied by a researcher to the experimental group in a public health room in the high school. The students were informed about reporting to the public health room while having maximum menstrual pain. AAT including an auricular acupressure needle on skin paper tape was applied on an ear for 3 days during instances of extreme primary dysmenorrhea. For the control group, only skin paper tape without an auricular acupressure needle was applied on the same acupoints and for the same duration. Application with or without auricular acupressure needles on skin paper tape was carried out aseptically. Study variables were measured subsequently before the experiment and at 3 days immediately after removal of the tape in both groups. The questionnaire was given only to female students who agreed to participate in the study, after which the completed questionnaires were collected. Data were collected using the double-blind method. The questionnaires were self-reporting and were administered by an assistant. Each of the participants took approximately 20 min to complete the questionnaire. The researcher was trained in AAT by an expert in this area. The assistant was trained by the researcher for 6 hr in the use of the interview and assessment method.

A flow diagram of participants and the study procedure is presented in **Figure 3**. Study participants were selected by random sampling, and were randomly assigned to either the experimental group or control group. All study variables were measured at the preapplication of AAT. AAT was applied only on the experimental group. All study variables were then remeasured after the application of AAT.

Throughout the trial, there were no adverse effects, and no problems on participants' response of applying auricular acupressure needles were observed. Participants were satisfied during the application of AAT.

Data Analysis

The collected data were analyzed using SPSS version 19.0 (IBM Corp., Armonk, NY, USA). The general and menstrual characteristics of the study participants were analyzed using descriptive statistics, including frequency, percentage, mean, and standard deviation. Group differences at baseline were analyzed using the two-group t-test and the chi-square test of association. Differences on abdominal pain, back pain, and revised MDQ between the two groups were analyzed using the repeated measures analysis of variance. A *p* value of less than .05 was considered statistically significant.

Ethical Consideration

This study was approved by the ethical review boards at the authors' institution. For female high schools, the researcher obtained written permission from the schools. After this procedure, the researcher contacted each individual and their parents to obtain written consent. The researcher explained the purpose, sample criteria, participation details, and instruments of this study to all the schools and the study participants with their parents. The study participants and their parents were informed of the confidentiality of data. They were also informed that their participation was voluntary and that they had the right to withdraw from the study at any time. The study participants completed the written consent forms after their parents gave informed consent for this study.

Results

General and menstrual characteristics and the homogeneity test are shown in **Tables 1** and **2**. The average age of the participants was 16.7 (*SD* = 0.77) years (experimental group: 16.6 [*SD* = 0.92] years; control group: 16.8 [*SD* = 0.61] years), and the average age of menarche was 12.2 (*SD* = 1.18) years (experimental group: 11.8 [*SD* = 1.08] years; control group: 12.6 [*SD* = 1.27] years). In terms of menstrual cycle length, there were more participants whose period lasts for 28–30 days. Peak time of primary dysmenorrhea among most

Table 1. General and Menstrual Characteristics and Homogeneity Test ($N = 91$)

		Experimental group (*n* = 45)	Control group (*n* = 46)		
Variables		*n* (%)	*n* (%)	χ2	*p*
Age (years)		16.6 (0.92)[a]	16.8 (0.61)[a]	8.713	.083
Menarche (years)		11.8 (1.08)*	12.6 (1.27)*	10.125	.072
Menstrual regularity	Regularity	20 (44.4)	19 (41.3)	.092	.834
	Irregularity	25 (55.6)	27 (58.7)		
Menstrual cycle length (days)	∼27	6 (13.3)	8 (19.1)	5.758	.330
	28∼30	23 (51.1)	31 (69.0)		
	31∼	14 (31.2)	7 (16.7)		
Duration of menstruation (days)	3∼7	44 (97.8)	45 (97.8)	3.036[b]	.219
	8∼14	1 (2.2)	1 (2.2)		
Peak time of dysmenorrhea	3–4 days before menstruation	1 (2.2)	1 (2.2)	4.420[b]	.491
	1–2 days before menstruation	2 (4.4)	7 (15.2)		
		20 (44.4)	14 (30.4)		
	1 day after menstruation	18 (40.0)	18 (41.2)		
	2 days after menstruation				
Family history of dysmenorrhea	Mother	12 (26.7)	9 (19.6)	2.932[b]	.402
	Sisters	7 (15.6)	4 (8.7)		
	Mother + sisters	3 (6.7)	2 (4.3)		
	None	22 (48.9)	31 (67.4)		
Intervention methods	Analgesics taken	25 (55.6)	10 (21.7)	5.430[b]	.340
	Endure with no action	12 (26.7)	16 (34.8)		
	Sleeping with bed rest	7 (15.6)	8 (17.4)		
	Warming on abdomen	1 (2.2)	10 (21.7)		
	Others	—	1 (2.2)		
Regularity of diet	Regularity	22 (48.9)	27 (58.7)	.880	.403
	Irregularity	23 (51.1)	19 (41.3)		

[a]Values are means (*SD*). [b]Fisher's exact test.

Table 2. Homogeneity Test of Abdominal, Back Pain, and Revised MDQ Between Two Groups ($N = 91$)

	Experimental group (*n* = 45)	Control group (*n* = 46)		
Variables	Mean (*SD*)	Mean (*SD*)	*t*	*p*
Abdominal pain	6.11 (0.43)	5.76 (2.62)	6.549	.623
Back pain	6.04 (2.44)	5.56 (2.63)	7.164	.354
Revised MDQ	105.97 (32.51)	87.14 (35.55)	70.659	.265
Pain	19.79 (6.17)	15.42 (6.22)	26.887	.310
Concentration	21.68 (8.54)	16.77 (7.85)	21.073	.783
Behavioral change	18.70 (5.71)	15.60 (6.26)	26.992	.256
Autonomic reactions	8.71 (3.65)	8.13 (4.42)	12.678	.473
Water retention	10.68 (4.15)	10.02 (3.64)	15.647	.335
Negative affect	24.68 (10.18)	19.45 (9.53)	43.343	.104

Note. MDQ = Menstrual Distress Questionnaire.

participants was the day of and 1 to 2 days after menstruation starts. There were no differences in all general and menstrual characteristics between the two groups. Also, there were no differences in preprocedure degrees of abdominal pain ($t = 6.549$, $p = .623$), back pain ($t = 7.164$, $p = .354$), and revised MDQ ($t = 70.659$, $p = .265$) between the two groups.

The application of AAT shown in **Table 3** was found to be statistically significant on abdominal pain ($F = 7.524$, $p < .001$), back pain ($F = 8.247$, $p < .001$), and revised MDQ score ($F = 87.581$, $p < .001$) between the two groups. The mean scores in the experimental group on abdominal pain decreased from 6.11 to 3.01, and back pain decreased from 6.04 to 4.04. The mean scores in the experimental group on primary dysmenorrhea decreased from 105.97 to 80.38. Based on Cohen's (1988) criteria, effect size on abdominal pain was considered large if above 6.774, effect size on back pain was considered small if below 0.002, and effect size for the revised MDQ was considered medium at 0.681.

Discussion

For the experimental group, which received AAT, the decrease in perceived abdominal and back pain and primary dysmenorrhea was statistically significant. The outcome of this study supported the result of Kim (2005),

Table 3. Application of Auricular Acupressure Therapy ($N = 91$)

		Preprocedure	Postprocedure		
Study variables	Group *n*	Mean (*SD*)	Mean (*SD*)	Source *F*	*p*
Abdominal pain	Exp 45	6.11 (0.43)	3.01 (2.68)	Group .357	.525
				Time .560	.216
	Con 46	5.76 (2.62)	4.62 (2.54)	G*T 7.524	<.001*
Back pain	Exp 45	6.04 (2.44)	4.04 (2.51)	Group .321	.487
				Time .587	.158
	Con 46	5.56 (2.63)	3.41 (2.83)	G*T 8.247	<.001*
Revised MDQ	Exp 45	105.97 (32.51)	80.38 (35.22)	Group 15.478	.142
				Time 8.423	.067
	Con 46	87.14 (35.55)	83.70 (37.20)	G*T 87.581	<.001*

Note. Con = control group; Exp = experimental group; G*T = interaction between Group and Time; MDQ = Menstrual Distress Questionnaire. *$p < .05$

in which the effects of AAT on pubertal primary dysmenorrhea were investigated, and the findings of Cha (2008), in which AAT was applied to female college students. Furthermore, the results of this study were similar to the results of previous studies (Cheng et al., 2012; Kim & Sok, 2007; Lee & Choi, 2005; Wang et al., 2013; Yeh et al., 2013), in which the effects of the application of oriental medical nursing intervention on pain of primary dysmenorrhea were verified. However, they could not be directly compared with this study since there have been very few studies on AAT. It was theorized that abdominal and back pain was reduced by the principle of mutual correspondence, which suggested the importance of the ears as the passages of the 12 meridians and physiological reaction points (Chae, 2004; Estores, Chen, Jackson, Lao, & Gorman, 2016; Wang et al., 2013; Yeh et al., 2013). This also suggested that the parts of the ears reflect the entire human body because the internal organs are connected along the ears, and by the principle that the reaction points of the ears and organs of the human body correspond to each other (Cheng et al., 2012; Du et al., 2009; National Department of Meridian Acupoints, 2000; Sok, 2001; Wang et al., 2013; Yeh et al., 2013). Stimulation through AAT also enhances the natural healing power of the human body by promoting blood circulation and improving physiological functions (Sok, 2001; Terry, 1999; Wang et al., 2013; Yeh et al., 2013). In other words, it is thought that relief of the abdominal pain was because Naebunbijeom (the specific stimulation point of the pinna used in this study) promoted the excretion and metabolism of prostaglandin, which causes menstrual pain, by inducing uterine contraction. It was also due to the analgesic and anticonvulsant effects of the Jagungjeom, Sinmunjeom, and Gyogamjeom.

On the other hand, pain and primary dysmenorrhea also decreased when only tape (placebo) was applied, but its effectiveness is doubtful. It seems that slight stimulation of the passages of the 12 meridians by applying tape (placebo) may decrease the pain and primary dysmenorrhea of female high school students. The effect size on back pain might be smaller because of this reasoning. However, this study showed that AAT including an auricular acupressure needle on skin paper tape has considerably more effect. The clinical significance as well as the statistical significance of the findings of this study exist in the nursing practice. AAT can contribute to the alleviation of abdominal and back pain attributed to primary dysmenorrhea. Additionally, female students will be able to improve their learning experience. The effects of AAT will be meaningful in the lives of female high school students.

AAT is an easy and useful technique that is also convenient and inexpensive (Cheng, Lo, & Tzeng, 2015; Sok, 2001; Wang et al., 2013; Yeh et al., 2013) compared to taking prescribed analgesic drugs. AAT is preferred by those who are afraid of treatments that require the use of larger needles or who do not wish to take oral medications (Cheng et al., 2015; Sok & Kim, 2005; Wang et al., 2013).

Throughout the trial, no adverse effects were observed, and the response of the participants to the auricular acupressure needles was satisfactory.

Limitations

The generalizability of this study's results is limited since the participants were recruited only from female high schools in metropolitan cities such as two regions of South Korea. Therefore, replication of this study using larger samples drawn from middle schools or high schools or other educational institutions from both the same and different regions of the country are recommended. The study was conducted, however, mainly to furnish information that could serve as bases for future relevant studies.

Implications for Nursing Practice and Future Research

Based on the results of this study, AAT can be utilized as a nursing intervention method for alleviating abdominal and back pain, and primary dysmenorrhea in female students. Nurses and other health providers can apply AAT after training and learning the exact positions of acupoints in the ear. Training for AAT requires 24 hr of study (on average for 4 weeks, 3 hr per session, twice a week). This has significant implications in clinical practice and is expected to help female students overcome primary dysmenorrhea.

For future studies, replication of experimental nursing intervention studies is necessary to verify and complete the effectiveness of AAT.

Conclusions

In this study, AAT was found to be effective in alleviating abdominal and back pain and primary dysmenorrhea experienced by female high school students. This result can serve as the foundation for using AAT, which can be easily applied, as a convenient intervention method that enables women to manage their physiological problems. Furthermore, it is conveniently accessible in terms of time and economic feasibility.

Acknowledgments

We are thankful to all the participants who participated in this study.

Clinical Resources

- Association of Korean Medicine: http://www.akom.org
- Korea Acupuncture-Moxibustion Association of World Federation of Chinese Medicine Societies: http://www.chim.or.kr

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JOURNAL OF NURSING SCHOLARSHIP

WORLD HEALTH

Volunteer Service and Service Learning: Opportunities, Partnerships, and United Nations Millennium Development Goals

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Abstract

Purpose: This article explores approaches to service involvement and provides direction to nurse leaders and others who wish to begin or further develop global (local and international) service or service learning projects.
Approach: We review types of service involvement, analyze service-related data from a recent survey of nearly 500 chapters of the Honor Society of Nursing, Sigma Theta Tau International (STTI), make recommendations to guide collaborative partnerships and to model engagement in global and local service and service learning.
Findings: This article offers a literature review and describes results of a survey conducted by the STTI International Service Learning Task Force. Results describe the types of service currently conducted by STTI nursing members and chapters, including disaster response, service learning, and service-related responses relative to the Millennium Development Goals (MDGs). The needs of chapter members for information about international service are explored and recommendations for promoting global service and sustainability goals for STTI chapters are examined.
Conclusions: Before engaging in service, volunteers should consider the types of service engagement, as well as the design of projects to include collaboration, bidirectionality, sustainability, equitable partnerships, and inclusion of the United Nations Sustainable Development Goals.
Clinical Relevance: STTI supports the learning, knowledge, and professional development of nurses worldwide. International service and collaboration are key to the advancement of the nursing profession. Culturally relevant approaches to international service and service learning are essential to our global organization, as it aims to impact the health status of people globally.

The nursing profession in the 21st century is characterized by the development of collaborative partnerships with patients, providers, families, and communities to promote the health and well-being of all people. Nurses across the globe are actively engaged in voluntary service activities in local, national, and international arenas.

Sigma Theta Tau International (STTI) strongly encourages members to address the United Nations (UN) Millennial Development Goals (MDGs), now the Sustainable Development Goals (SDGs; UN, n.d.), with their service commitment. Community service, advocacy, and activism are a vital and important part of the social responsibility of the world's most trusted profession (Riner, 2011). Contemporary nursing is fully engaged in the social responsibility of caring in our global society. Tyer-Viola et al. (2009) view social responsibility as grounded in the American Nurses Association Code of Ethics and the International Council of Nurses Code of Ethics and steeped in social justice. As such, many schools of nursing incorporate service learning as a key component in their curricula. Increasingly, many institutions of higher education seek to develop international service opportunities for their students. However, many nurses still experience difficulty in identifying ways to engage in service activities in meaningful and sustainable ways, select organizations with whom to volunteer, and prepare for or complete service activities, especially in international contexts or in response to disasters.

This article is the result of 2 years of preparation, survey data collection, and analysis by nurse leaders with expertise in collaborative, sustainable service engagement who served on STTI's International Service Task Force (ISTF). These nurse leaders were selected by the STTI Board of Directors during the 2011–2013 Biennium. This paper (a) reviews common types of service activities, including disaster response and service learning; (b) discusses results from a survey of nearly 500 chapters of STTI that describe the types of service conducted by chapters and nursing members and their link to the MDGs, as well as the needs of chapter members for information about international service and MDGs; and (c) provides recommendations for service that promote global service and sustainability goals for nursing organizations and chapters. It is intended to provide direction to nurses, STTI chapter members, and others who wish to begin or further develop global (local and international) service or service learning projects.

History of Nursing Volunteerism, Social Responsibility, and Ethical Obligations

There are over 19.3 million nurses worldwide (World Health Organization [WHO], 2011), with a global density of 29.0 nurses and midwives per 10,000 population (WHO, 2013). However, according to the WHO (2010), greater than 70% of WHO member states report experiencing a shortage of nurses and midwives. There is a steady increase in available opportunities and a growing demand for nurse volunteers both in their home country as well as across international borders. Nurses volunteer their service in local communities in a variety of short- and long-term roles and in response to local, regional, or international disaster events.

Nursing as a discipline has focused on service since the days of Florence Nightingale. Notably, the call to nurses for service has never been greater than in this contemporary era of globalization. One of the central challenges facing all health professions today is that clinical excellence is diminished if it is out of reach of most of the people who require access to it (O'Neil, 2006). "Excellence without equity," Paul Farmer wrote, "looms as the chief human rights dilemma of health care in the 21st Century" (Farmer, 2001, p. 210). More recently, Farmer, Kim, Kleinman, and Basilico (2013) argued for global health equity through a model that includes partnerships, collaboration with the public sector, priority needs for women and children, and consideration of basic social needs using a biosocial approach. They emphasized that a global approach includes addressing disparities within countries as well as across international borders; focusing on health equity; and considering the cultural, social, political, and economic factors that impact health. Though not a nursing model, it serves to remind the nursing profession of the importance of models to guide practice and the importance of collaborative partnerships.

Nursing models offer insight into elements of global nursing service. In an integrative review of the literature for global health diplomacy, Hunter et al. (2013) noted that ethical issues are critical in framing any nursing involvement in global health initiatives. Leffers and Mitchell (2011) in their report on the conceptual model for partnership and sustainability noted that engagement and partnership are essential to sustainability of international programs. Partnership processes of mutual goal setting, cultural bridging, collaboration, and capacity building are critical to the development and continuation of partnerships. Riner's Global Engagement for Nursing Education model outlines important characteristics for the design, provision, and evaluation of global experiential education for nursing students (Riner, 2011).

Global Nursing Service Types and Contexts

Nurses volunteer their service in a variety of global settings and contexts. International service includes local, regional, national, and international aspects in nursing volunteerism. Service can occur in church buildings, clinics, and schools, and in programs for those who are homeless, victims of violence, or migrant farmworkers. Service can be offered on a short-term basis for a particular event, but also may be offered on a long-term basis over many years of involvement. Although numerous examples can be offered, one example of a long-term, sustainable service program is the Farmworker Family Health Program, which is an interprofessional, in-country cultural immersion service learning experience. Each summer in June, undergraduate and graduate students from the Emory University Nell Hodgson Woodruff School of Nursing, University of Georgia School of Pharmacy, Georgia State University Department of Physical Therapy, Clayton State University, and Darton College Departments of Dental Hygiene spend 2 weeks delivering vital health care services to farmworkers and their children in a farming community in southwest Georgia (Bail et al., 2012; Connor, Rainer, Simcox & Thomissee, 2007).

Disaster Response

Many nurses provide service with local or national emergency response teams for disaster relief. Therefore, it is vital that nurses receive the necessary training and that they connect with the national or federal emergency management authorities in their home countries before disasters occur. Training should be acquired from federally or nationally recognized sources, including the International Red Cross-Red Crescent or governmental agencies. Nurses can consult the International Council of Nurses (ICN, 2009) or the International Nursing Coalition for Mass Casualty Education (2015) for information about disaster preparedness and ethical considerations for disaster response. Nurses in the United States should connect with the U.S. National Disaster Medical System, a nationwide medical response system designed to (a) supplement state and local medical resources during disasters or major emergencies and (b) provide backup medical support to the military and Veterans Administration Medical Care systems during any overseas conflict. Interested U.S. nurses should contact the U.S. Medical Reserve Corps (MRC, www.medicalreservecorps.gov), which is a national network designed to engage volunteers to strengthen public health, emergency response, and community resiliency. Nurses trained in disaster response and emergency preparedness can contact the MRC, Red Cross, Red Crescent, or other disaster response organizations to determine how best to offer volunteer services consistent with the mission of the organizations. Globally, nurses are involved in disaster response in many ways, including roles in the Disaster Nursing Network, sponsored by the ICN, STTI's Disaster Nursing Community, WHO's Disaster and Nursing Collaborating Centers, in addition to other global response efforts.

International Service and Volunteer Service Involving Travel

Nurses also travel to other countries and significantly contribute to global health efforts by volunteering in international humanitarian settings in activities frequently referred to as "missions," "health brigades" (Leffers & Plotnick, 2011), or "service trips." It is important to note that not all "mission" trips are associated with a religious group or have a religious cause. Rather, mission often refers to "short-term trips that healthcare professionals embark on to meet the needs of people worldwide" (Leffers & Plotnick, 2011, p. 8). Many nurses also participate in longer service trips that may range in length anywhere from several weeks to several months or years as part of organizations that emphasize international service. Examples of organizations include the Peace Corps, Medicins Sans Frontieres (Doctors Without Borders), Health Volunteers Overseas, Volunteer Service Organization, and many others. *Volunteering at Home and Abroad: The Essential Guide for Nurses* (Leffers & Plotnick, 2011) provides many examples, models, and guidelines for nurse volunteerism.

Nursing service across international borders can take the form of direct patient care, consultation with nurses and healthcare professionals, or educational collaboration. Many forms of service provide nurses with opportunities to serve in well-established partnered and ethically responsible programs. Poverty, lack of access to care, or differences in power or cultural understanding can create ethical challenges in some service opportunities that nurses must consider. Critics have claimed that short-term overseas volunteer work in low-income countries by clinicians from high-income countries can be self-serving, raise unmet expectations, burden local health facilities, and be culturally irrelevant (Suchdev, Ahrens, Click, Macklin, Evangelista, & Graham, 2007). Further, these trips may provide temporary fixes that fail to address the root causes of problems and fail to follow current standards of public health delivery (Suchdev et al., 2007). In contrast, many nurses provide service through long-term, well-established partnerships that benefit the host country partners as well as nurse volunteers and organizations (Upvall & Leffers, 2014). Sustainable service partnerships can be facilitated through service learning and achieve bidirectional goals.

Service Learning

Service learning is a strategy to ensure that nursing service meets the needs of those in low-resource settings. Service learning is defined as "an educational methodology which combines community service with explicit academic learning objectives, preparation for community work, and deliberate reflection" (Purdue Center of Instructional Excellence, n.d., p. 1). Service learning must have benefits to primarily the community recipients as well as students/professionals from other settings, with learning opportunities that are integrated into the academic curriculum and allow students to be active participants in the planning and implementation of the service project. Shared goals from the community should be viewed as critical to any service learning project. This pedagogy moves beyond merely providing service to a recipient; thus, it requires reciprocity and bidirectionality between the community and students (Riner, 2011).

The benefits of engaging students in service learning include (a) improved skills in health education; (b) increased awareness of community needs and empathy; (c) improved abilities to work with diverse clients; (d) decreased stereotyping attitudes about disadvantaged populations; (e) increased civic awareness and responsibility; (f) personal and professional growth for cultural competency and critical thinking about real-life situations in unfamiliar environments; (g) greater flexibility, creativity, and innovation that later influenced both their personal and professional lives; and (h) increased self-efficacy related to cultural competency and a commitment to international service when students become registered nurses (Amerson, 2014; Edmonds, 2012; Levine, 2009; Murray, 2013).

Not only do students benefit from service learning; community recipients must also benefit from service learning. Reising, Allen, and Hall (2006) found that hypertension screening and counseling sessions conducted by the Indiana University School of Nursing resulted in community members taking actions to address hypertension goals, decrease their hypertension levels, and decrease their risks for future hypertensive episodes. The participants of a *promotora* (community health worker) program reported that the educational sessions provided by nursing students benefited people in their community (Amerson, 2013). As suggested by Amerson (2013), the establishment of relationships and long-term participation by community members in collaboration on service learning projects provides evidence that community recipients value the service of nursing students. Recent literature addresses the contributions of the partnerships in academic–community partnerships (Sanchez, Carrillo, & Wallerstein, 2011), but review of this extant body of literature is beyond the scope of this article.

International Nursing Excellence in Scholarship, Leadership, and Service

The Honor Society of Nursing, STTI is a global nursing organization whose mission is to advance world health and foster nursing excellence in scholarship, leadership, and service. STTI's active members number more than 135,000 residing in more than 90 countries, with more than 500 STTI chapters in six global regions: Africa, Asia, Europe, Latin and South America and the Caribbean, and North America and Oceania (**Figure 1**). More recently, the Middle Eastern Region has been developed as a unique region within STTI.

STTI's special consultative status granted by the UN provides the strongest nursing presence at the UN, and the organization works to help their nurse members understand the aims of the MDGs, and the goals subsequent to 2015, the SDGs (c.f. Sigma Theta Tau International, 2014). In 2012, there was agreement by UN member states that it was critical to launch a process to develop a set of SDGs that would build on the MDGs and integrate with the post-2015 development agenda (UN, 2015). STTI has strongly encouraged members to serve locally, nationally, and globally and to address the UN MDGs with their service commitment.

Millennium Development Goals and Sustainable Development Goals

The eight UN MDGs have served as the roadmap to guide the development of global nations from 2000 through 2015. As the deadline for achieving the goals approached, the Secretary General of the UN declared that the MDGs "have been the most successful global anti-poverty push in history" (UN, 2013). However, according to the WHO, critical health workforce shortages, inadequate skill mix, and uneven geographical distribution of the health workforce posed major barriers to achieving the health-related MDGs (WHO, 2014).

Nurses are pivotal in nation and capacity building. As nurses worldwide seek to offer roles critical to the MDGs, SDGs, and post-2015 era, the selection and planning of service activities must be reflective of meeting these goals both locally and internationally. Moving forward, the choice of service activities must be targeted, relevant, and achievable—as well as aligned with the SDGs. Identification of potential partners, stakeholders, and collaborators, and the choice of the level of service involvement, are critical to the process of selecting activities geared towards meeting these set goals.

Figure 1. Sigma Theta Tau International's global regions.

The following section describes findings from an STTI service-related nursing survey. These survey results are followed by the ISTF recommendations for service engagement.

A Baseline of Service Activities Within Chapters of STTI: The 2012–2013 International Service Taskforce Survey

As part of the work of the STTI ISTF, each STTI chapter was asked to complete a 76-item 2012 Annual Chapter Report Survey. Data from responses to 13 service-related questions on the 2012 STTI Annual Chapter Report were used and analyzed. A total of 488 chapters completed the 2012 Annual Chapter Report. Quantitative data and open-ended questions from the survey were reviewed by taskforce members. Quantitative data were analyzed via IBM SPSS version 20 statistical software package (SPSS Inc., Chicago, IL, USA). Descriptive statistics were used, including frequencies, means, and standard deviations, to describe the sample and responses. Cross-tabulations were also calculated to examine results by region and globally.

Service-Related Results

More than half (61%, $n = 300$) of all STTI chapters reported that they participated in volunteer community service. Chapter service activities were primarily conducted in the local areas of chapters (57.2%, $n = 279$), but 18.9% ($n = 92$) were conducted internationally, and 12.9 % of chapters ($n = 63$) conducted activities in national or regional areas. Many chapters engaged in volunteer service activities annually (30.3%, $n = 148$), or monthly, bimonthly, or quarterly (22.9%, $n = 112$). A few chapters (7.7%, $n = 38$) provided service activities less often than annually or that were a one-time event. Only 22.5% ($n = 110$) of chapters provided activities where nurses were able to provide health care, which primarily included direct patient care (50.0% [or 11.3% of total], $n = 55$) or consultation (23.6% [or 5.3% of total], $n = 21$). However, despite answering "no" (70.5%, $n = 344$) to the question regarding if the chapter's members provided health care during volunteer service activities, several of these chapters ($n = 23$) concurrently reported that their members provided or engaged in health education, health screening, first aid care, health fair activities, health histories, physical exams, or vaccinations during community service. Many chapters engaged in service activities in partnership with either schools of nursing (11.5%, $n = 56$), nongovernmental organizations (7.8%, $n = 38$), a clinic or hospital (3.1%, $n = 15$), or with another STTI chapter (0.2%, $n = 1$).

Chapter service activities were instrumental in addressing all of the MDGs. Over one fifth of the chapters reported volunteer service activities to address MDG 1: Eradication of extreme hunger and poverty (21.1%, $n = 103$ chapters) through activities such as providing food or supplies for homeless or underserved populations. More than 10% of chapters also reported service activities that addressed MDG 8: Global partnership for development (13.3%, $n = 65$), MDG 4: Reduction in child mortality (12.7%, $n = 62$), MDG 3: Promotion of gender equality (12.5%, $n = 61$), and MDG 5: Improvement in maternal health (10.5%, $n = 51$). Chapters also reported volunteer service activities that helped to address MDG 6: Combat HIV/AIDS, malaria and other diseases (8.4%, $n = 41$) through HIV screening and education and MDG 7: Ensure environmental sustainability (7.7%, $n = 38$) through water purification, donation to organizations (water.org), or through other activities. Some chapters (6.1%, $n = 30$) helped to address MDG 2: Promote universal primary education by activities such as promoting children's literacy, providing simple health education of elementary children, and donating back-to-school backpacks.

Despite documentation of numerous chapter service activities that addressed the MDGs, there were also many chapters that reported seeking additional assistance to better understand the MDGs and to develop service activities that addressed specific MDGs (**Figure 2**). More than 10% of chapters expressed interest in additional information on MDGs related to hunger and poverty, child mortality, global partnership for development, gender equality, maternal health, and environmental sustainability.

Many chapters also expressed interest in learning more about volunteer service-related activities for experienced nurses, including group service trips (28.2%, $n = 234$), particularly "out of home country experiences" (21.9%, $n = 182$), disaster response (27.0%, $n = 224$), and student service learning through exchange programs (22.9%, $n = 190$). Combining service with nursing student learning was identified as another important component of nursing practice.

Task Force Recommendations for Volunteer Service

Key Elements Necessary for Appropriate Service and Service Learning

The current global health equity paradigm reflects a reimagining of global health ethics to be bidirectional, and reciprocal, with equality embedded within culturally relevant, sustainable, collaborative partnerships. Significant investment of time, energy, and resources over multiple years is required to establish productive relationships, centered within mutual respect, which may result in improved health care and a strong commitment to bidirectional, reciprocal student and professional nursing commitments to global health. Without elements of mutual respect and trust to build partnerships, cultural humility to foster relationships, a commitment to a shared vision for service partnerships and collaboration, service programs are likely to fail, or worse, to perpetuate models of unequal power and cultural imposition. All service should lead to sustainable outcomes.

Ethics and Volunteer Service

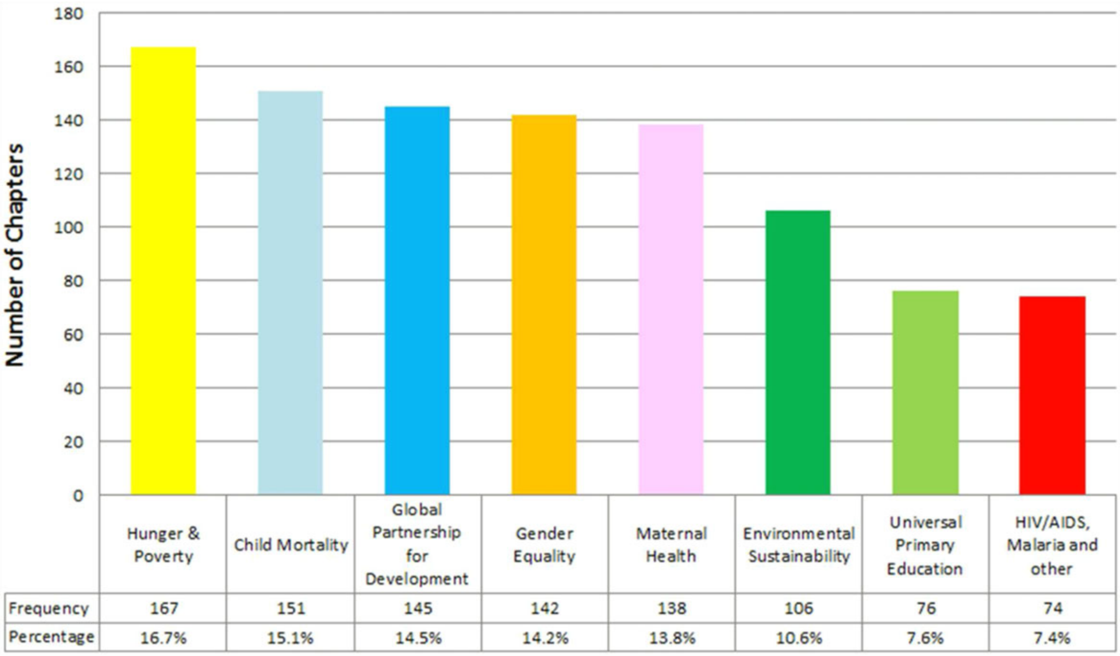
In *Reimagining Global Health*, Farmer et al. (2013) suggest that to achieve global health care equity, partnerships and collaboration must be the foundation of service in resource-limited areas, and that social justice is the only framework on which these partnerships can be built. The ethics of international service are a key element in global partnerships. Crigger (2008) emphasizes that all voices must be heard, that inclusion of all partners is essential, and that ethics underpins all aspects of care. Further, nurse volunteers must consider reflexivity to consider one's own as well as partners' perspectives and keeping human rights concerns at the forefront of all service endeavors. For example, it is critically important to avoid US—and North American—centric approaches when engaging in global service partnerships. Culturally sensitive approaches must be embraced to achieve successful milestones in international service. Grounding all volunteer service in the ethical foundations of nursing and social justice fosters respectful partnerships, successful programs, and global health equity (Crigger & Holcomb, 2007).

Types of Service Involvement

Ethical participation in service, globally or locally, requires a discernment process regarding the choice of types of service involvement. Short-term projects, social education, social action, and social justice require different commitments of time, skill sets, and capacities. We begin the discussion with the simplest form of service involvement and move to the higher order level of social justice that represents the most effective and responsible level of service.

Short-term projects are designed to assist in meeting the immediate or short-term needs of individuals, families, or groups of people. Project activities may include assisting in disaster relief, gathering and distributing supplies during emergencies and scarcity of resources, providing health screenings, and providing a specific time-limited service as a part of a long-term project. Collaboration with local partners is critical to ensure cultural relevance and need.

Social education service requires providers to become educated about a specific health issue, and then to



	Hunger & Poverty	Child Mortality	Global Partnership for Development	Gender Equality	Maternal Health	Environmental Sustainability	Universal Primary Education	HIV/AIDS, Malaria and other
Frequency	167	151	145	142	138	106	76	74
Percentage	16.7%	15.1%	14.5%	14.2%	13.8%	10.6%	7.6%	7.4%

Figure 2. With which Millennium Development Goals would your chapter most like assistance in service project development from Sigma Theta Tau International?

collaborate in providing sustainable, culturally appropriate education to individuals, families, or population groups to stimulate the change in beliefs, behaviors, practices, and customs that is necessary to improve the health outcomes of a target population. Activities might include community workshops, topic-specific awareness events such as Alzheimer walks, HIV education or outreach, education about safe water, or in-service seminars or workshops for healthcare providers, such as hunger assessment tools for elders living alone. Recent examples include professionally trained nurse-midwives providing clinical training for traditional indigenous midwives in Guatemala (Foster, Anderson, Houston, & Doe-Simkins, 2004) or teaching promotoras (community workers) about hygiene and the use of oral rehydration practices (Amerson, 2013).

Social action service requires becoming knowledgeable about specific healthcare issues and advocating for culturally relevant or culturally determined change, and taking collaborative, sustainable action through community, legislative, or political action. One example is the training of volunteers from a local hospital in the Dominican Republic to become doulas to provide women with emotional support during labor and delivery. The U.S. nursing partnership contributed to the stewardship and financing of the doula training and achieving optimal health outcomes (Foster & Heath, 2007).

Social justice service activities involve taking action, collaboratively, to address root causes of health issues through provision of long-term tools and strategies. There are several organizations whose mission is to address issues of social justice, including, but not limited to, the Carter Center, Heifer International, and Habitat for Humanity®. Another example is teaching community health workers in the Dominican Republic to become certified in research ethics to assist them in becoming members of the research team aimed at contributing to research projects related to quality of maternity care (Foster et al., 2012).

Research and community-based projects steeped in social justice have great value for service learning. It is important for nurses to understand the type and goals of the project they are undertaking. Short-term projects are the easiest to design and implement with local partners; however, achieving bidirectional goals is critical. Projects that involve social education, social action, or working for social justice require long-term partnerships and commitment to specific sites and long-term goals. Projects that promote social action and social justice, however, may have more long-term impact and are more likely to achieve sustainability goals, including SDGs. Critics have argued that some short-term projects are more likely to serve the needs of volunteers, rather than the long-term interests of the community. All projects that are well designed may be well served in achieving bidirectional goals and successful evaluation by the collaborative partners.

To provide ethically sound, culturally appropriate and sustainable volunteer service, the choice of partnership organizations must be a significant priority for nurses engaging in any form of service as individuals or as a group, locally, nationally, or internationally on behalf of the nursing profession. While nurses often volunteer as individuals or as part of small volunteer organizations, volunteer service with a well-established organization can be most beneficial to both the volunteer nurse and to the host partners. It is important to consider one's own interests, abilities, motives, passion, and details about potential organizations to achieve bidirectional goals. If a nurse considers service in response to emergencies and disasters, it is imperative that disaster preparedness training is included, such as registration with one's local Medical Reserve Corps. Nurses should choose to partner with like-minded organizations that share a similar mission, vision, and set of values. The organization should develop collaborative service partnerships and outreach to populations in local and international settings, promoting health worldwide, and explicitly address the achievement of specific SDGs.

Every experience of service involvement or engagement requires adequate preparation, inculcation of professional values, and an understanding of the critical goals of service. All nurses need to be realistic about their skills, stamina, and cultural adaptability. Knowledge of the project parameters and partner involvement, pre and post education, briefing, debriefing, and processing guidelines are all critical to the success of the experience. Perhaps most critical is the achievement of bidirectional goals and successful evaluation of these project goals.

Specific Service Recommendations

Therefore, in response to our review of types of service involvement and survey of STTI chapters, we recommend the following:

1. Nurses should choose a volunteer organization whose mission addresses relevance to health, and articulates the professional role of nursing.
2. Nursing service activities should address one or more of the SDGs.
3. Relationship formation and partnership building must be bidirectional and reciprocal.
4. Nurses must work in collaboration with host partners, identifying the host partners' key goals.
5. Volunteer nurses must ensure that the organization adheres to the host country's requirements for nursing licensure.
6. Volunteer nurses should use reflexivity to consider their own perspective and that of the host partners.
7. Volunteer nurses must practice cultural humility to provide culturally relevant service.
8. Volunteer service should be ongoing and sustainable through direct care or collaborative efforts to promote health.
9. Service activities should not only benefit local communities, but also have intent to serve the broader population.

Every experience of service involvement or engagement requires adequate preparation. All nurses need to be realistic about their skills, stamina, and cultural adaptability. Knowledge of the project parameters and partner involvement, pre and post education, briefing, debriefing, and processing guidelines are all critical to the success of the experience.

Conclusions

In response to the charge from the STTI Board of Directors, the ISTF reviewed types of service involvement, identified STTI chapter volunteer service activities, and made recommendations for volunteer service involvement. As nursing organizations and STTI chapters increasingly involve global participation, thoughtful and deliberate planning and ongoing evaluation must be a critical, requisite element to the involvement of individuals, chapter members, and students and faculty in service engagement. Volunteers should pay attention to the types of service explored in the service involvement model, as well as the design of projects to include collaboration, bidirectionality, sustainability, equitable partnerships, and inclusion of the UN SDGs.

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Clinical Resources

- International Council of Nurses: http://www.icn.ch/
- Medical Reserve Corps: https://www.medicalreservecorps.gov

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