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JOURNAL OF NURSING SCHOLARSHIP

EDITORIAL

Publishing Success: Rules to Live By

I was recently asked to speak with a group of students about my tips on getting published. At the risk of appearing trite, I offer you these six slogans that I have found helpful.

1. Old formulas don't give new solutions (Avivor, 2016). Before you start to write, it is important to make sure you have something new to say. What is the unique contribution that your work will make to the discipline? If you can answer this question and write your manuscript with the answer in mind, your chance of getting published greatly increases.

2. If you're not in you can't win (New York City lottery poster). This slogan on how to win the lottery holds equally true for how to get published. It seems obvious that if you don't submit your work for publication it will remain unpublished. However, countless authors who wish to publish do not submit.

There are numerous reasons or excuses that lead to not submitting, but it is important to recognize the barriers we impose on ourselves. Many people with important new ideas to contribute will say that they can't find the time to write up their work. There are many other authors who find the time to write but can't stop rewriting. A trick I use to comfort myself is to think that perhaps no one will really read what I am writing. On the other hand, I care passionately about the topics about which I write. So why am I hesitant about people reading my work?

Each of us has our own vulnerability about sharing our written thoughts with the world. We need to examine the barriers stopping us from submitting a manuscript and do as much as possible to address them. Once we have discovered new knowledge we need to share it. If we are in it we can win it. So, each of us needs to commit to submit.

3. "I get by with a little help from my friends. Gonna try with a little help from my friends" (Beatles, n.d.). The Beatles 1967 song "With a Little Help From My Friends" makes it clear that one way to overcome barriers and vulnerability is to rely on the support of friends. I have found that having a writing team or a group of friends who will critique my written work is an invaluable resource. When other people find my thoughts interesting it gives me courage to continue. When other people don't understand my thoughts, their confusion helps me gain clarity.

4. You never get a second chance to make a first impression (Rogers, n.d.). Will Rogers said it best. First impressions are important. Clarity is crucial in creating a first impression. Read author guidelines, proofread often, and ensure that you submit the best manuscript you can. I have only submitted one manuscript in my life that I didn't write with others or give to others to read. I quickly learned that what makes perfect sense to me is not necessarily sensible. That manuscript—although eventually published—had unnecessary problems that could have been fixed if I had used the writing support available to me. This might sound counter to what I just said about not spending all my time rewriting but it isn't. I am all for rewriting and we each need to make the best possible first impression. Then we need to submit our work.

5. Who made you the boss (a favorite saying of my children growing up)? When one of my children told the other to do something, a frequent response was: "Who made you the boss?" It is also a common question I get from authors (albeit not phrased quite so bluntly).

You finally get the manuscript submitted, your writing team is happy, and you have taken the excellent and helpful critique from your support group. Then you submit: you are in it to win it. But you don't win! You have to revise or (horrors) your manuscript is rejected.

As you read critiques from reviewers you might be outraged and wonder how in the world they ever got to be reviewers. Who made them the boss over whether this manuscript is published or not? Well, actually, the editor is the boss, so you might be mad at me for listening to the thoughts of the reviewers. Either way, I would ask you to take a deep breath and realize that if two, three, or four other scholars agree that something can be better, there probably is room for improvement.

Remember your earlier hesitations about letting your work get out in the world? Now there are even more people ready and willing to help you make your work better than it already is. What a true blessing that there are people interested in helping you succeed.

6. Energy and persistence conquer all things (Franklin, n.d.). As usual, Benjamin Franklin provides a simple but profound thought. It is persistence that ensures publication. Sometimes manuscripts have to be revised and resubmitted. Sometimes they need to go to another journal. If one is persistent in the process, the outcome is generally publication.

I have only written three manuscripts that didn't get published but I have had many, many manuscripts that needed to be revised and resubmitted more than once. Persistence made all the difference in having many of those manuscripts published.

The very first manuscript I ever wrote wasn't published. I didn't realize that I was writing on a topic that had already been well covered and I wasn't saying anything new. That manuscript did not deserve to be published. I co-wrote another manuscript that didn't get resubmitted after we were asked to revise and resubmit. Time got in the way and I regret that I didn't make the time to get that manuscript resubmitted. My third unpublished manuscript was another case of not having a sufficient amount of new information to convey.

All my other work has been published, and publication was helped because I had something new to share, had the courage to submit, and had writing colleagues. These factors resulted in my being able to have an easier path to publication, but it didn't mean that I didn't need to be persistent and to revise or find a new journal to which I could submit. I have learned how to be very responsive to reviewers' comments, and I honestly do believe that peer review has improved my work greatly.

I attribute success in writing to the help of my friends, the generosity of reviewers willing to give me their best critique, and my own persistence in being able to stay in the process. I hope these slogans help you in your quest to be a successful author.

Susan Gennaro
Editor

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Behavioral Economics: A New Lens for Understanding Genomic Decision Making

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Abstract

Purpose: This article seeks to take the next step in examining the insights that nurses and other healthcare providers can derive from applying behavioral economic concepts to support genomic decision making. As genomic science continues to permeate clinical practice, nurses must continue to adapt practice to meet new challenges. Decisions associated with genomics are often not simple and dichotomous in nature. They can be complex and challenging for all involved.

Design: This article offers an introduction to behavioral economics as a possible tool to help support patients', families', and caregivers' decision making related to genomics.

Methods: Using current writings from nursing, ethics, behavioral economic, and other healthcare scholars, we review key concepts of behavioral economics and discuss their relevance to supporting genomic decision making.

Findings: Behavioral economic concepts—particularly relativity, deliberation, and choice architecture—are specifically examined as new ways to view the complexities of genomic decision making. Each concept is explored through patient decision making and clinical practice examples. This article also discusses next steps and practice implications for further development of the behavioral economic lens in nursing.

Conclusions: Behavioral economics provides valuable insight into the unique nature of genetic decision-making practices.

Clinical Relevance: Nurses are often a source of information and support for patients during clinical decision making. This article seeks to offer behavioral economic concepts as a framework for understanding and examining the unique nature of genomic decision making. As genetic and genomic testing become more common in practice, it will continue to grow in importance for nurses to be able to support the autonomous decision making of patients, their families, and caregivers.

As genetics and genomics advance with the development of additional screening and testing procedures, it is imperative to understand how their expanding capacities can be integrated into and influence nursing practice. Further, as translational science comes to the forefront in genetics and genomics, scientists and clinicians alike must assess the social, ethical, and familial implications of the increased power, availability, and perplexing quandaries of genomic testing (Green, Guyer, & National Human Genome Research Institute [NHGRI], 2011). Over the past 20 years access to genomic information has increased in many ways, and there are a growing number of clinical and nonclinical (direct-to-consumer) applications (Boccia & Zimmern, 2015; Calzone et al., 2013). More specifically, clinical genetic testing can be used to screen for a disease or carrier status (e.g., aneuploidy, sickle cell), for help in supporting or confirming a diagnosis (e.g., alpha-1-antitrypsin deficiency), or to possibly guide treatment decisions (e.g., some cancers). The rapid growth of genetic testing requires diligent work in research and scholarship to ensure that the very best applications are understandable, safe, and equitably available for those affected (Green et al., 2011). Just as nursing care covers the entire lifespan, the future of genomics will range from cradle to grave.

With the amount of intellectual energy being focused globally on the inclusion of genetics and genomics in nursing education at all levels, the growing importance of genetics and genomics in nursing science research and practice is undeniable (Calzone et al., 2013; Kirk, Tonkin, & Skirton, 2014). It is imperative that nurses be able to understand and apply genetic and genomic information in their daily practice. Genetics and genomics are not equivalents; genetics refers more to a single gene approach, and genomics encompasses the entire genome and gene–gene interactions (Green et al., 2011; Lander, 2011). Nursing involvement with genomics includes activities such as direct, nurse–patient interaction (e.g., informed consent processes, specimen collection); patient, family, or caregiver education related to genomic testing decision making; or dealing with genomic testing results that may be ambiguous in the known clinical context. There are also the interactions with other healthcare professionals related to patient advocacy, interprofessional research collaboration, ethics, and treatment or intervention decision making. Nursing has maintained a high level of public trust globally, 89% of respondents having a high level of trust in nursing (GfK Verein, 2016). The relationships that nurses have with their patients and their patients' families are imbued with trust, and they often rely on nurses for information and guidance when making difficult decisions (Joseph-Williams, Elwyn, & Edwards, 2014; Stacey et al., 2008).

The field of behavioral economics, the study of forces and principles behind the decision-making behaviors of humans, is growing rapidly (Ariely, 2009; Thaler, 2015). The field is highly focused on economic contexts; however, applications outside of a strictly economic environment are promising. Many opportunities for the application of behavioral economics have been aligned with incentivized health outcomes and health behavior changes (Hostetter & Klein, 2013; Hough, 2013). These concepts may also prove very useful in helping nurses and other healthcare providers better understand and support patient engagement in decision making in various situations. In the realm of genomic decision making there are several opportunities for the application of behavioral economics in clinical practice that bear exploration. Although recent articles have discussed behavioral economics and genomics, they have not fully explored the mechanisms related to genomic decision making (Blumenthal-Barby, McGuire, Green, & Ubel, 2015; Blumenthal-Barby, McGuire, & Ubel, 2014).

It is in the setting of the patient–nurse relationship where behavioral economics could prove to be valuable. Understanding the relationship as a continuum ranging from laissez faire to authoritarian approaches, behavioral economics, when applied to decision making, can offer a middle ground between these approaches (Bayles, 2010). Each participant enters into the patient–nurse relationship with an information asymmetry—the nurse brings the expertise and the knowledge of the clinical situation while the patient brings an abundance of knowledge about the context of their personal situation. Ethical and appropriate use of behavioral economics can help to navigate the middle ground, balancing the clinical and evidence-based knowledge of nurses with the very personal needs of the decision makers (Hough, 2013). Behavioral economic approaches can open the door to conversation, which will allow for the identification and elimination of the information asymmetry that often exists in genomic decision-making encounters. Behavioral economic approaches are key to better supporting the growing use of decision support intervention models like Shared Decision Making (Elwyn et al., 2012). In order to better prepare nurses to support the autonomy and self-determination that are key to best practices in decision support, this article aims, first, to introduce nurses to key behavioral economic concepts, and second, to explore next steps and practice implications for behavioral economics and genomic decision making for nurses and other healthcare professionals. While these concepts are new to nursing, they complement the many roles that nurses fulfill in the care of patients. Understanding these concepts of behavioral economics can help nurses to better support patients in a respectful and balanced decision-making process.

Genomic Decision Making in a Behavioral Economic Context

Several key framing concepts from behavioral economics are important for a better understanding of the unique and often complex nature of genomic decision making. Chiefly, it is important to understand the concepts of relativity, deliberation, and choice architecture to adequately contextualize genomic testing decisions within behavioral economics. These concepts are explored by providing current, literature-based practical examples to illustrate the types of genomic decisions that may be faced by patients and their families. These examples are relevant to nurses and healthcare professionals that are relied on by patients and their families for information, guidance, and support in times of uncertainty and decision making.

Relativity

Relativity, a central part of the human decision-making construct, allows for understanding the relative advantages of one option compared to others (Ariely, 2009). In exploring relativity, it is important to note that the comparison must be among similar and available alternatives. Genomic testing may offer similar alternatives; for example, healthcare providers and patients can choose among different panels of genetic tests offering a range of levels of information, including testing for additional (often related) genomic variations. This choice could be limited by insurance coverage and financial constraints, but sometimes a similar choice is available. However, genomic testing often has no alternative for relative comparison, and thus there is no comparable methodology that offers the opportunity to obtain the same level of information.

The initial question for those facing decisions about genomic testing is whether to test at all. Absent alternatives, the decision is between knowing or not knowing genomic-level information and the possibility of that genomic information changing the course of care. In applying relativity to these situations there is an increase in the amount of information that is needed, specifically the type, amount, and nature of the information provided by the proposed genomic tests and how the results may influence next steps in patient care.

There are situations where there are much more affordable and clinically expedient choices that can be made. One example is testing serum cholesterol levels rather than doing genetic testing related to familial hypercholesterolemia (FH). Current guidelines do not recommend genetic screening evaluation of patients for FH due largely to cost (Robinson, 2013). Since there are, currently, no gene-specific treatments related to treatment of FH, knowing the specific genotype has limited value, so treatment with lifestyle, statins, and close clinical monitoring is still recommended, regardless of genetics.

Another example is the use of regular colonoscopies rather than screening for familial adenomatous polyposis (FAP)-related genes. A finding of several polyps in a colonoscopy may lead to further testing, but does not establish a diagnosis of FAP. Patients tested for FAP-related genes might be able to better inform their colonoscopy screening intervals. Those with genetically confirmed increased risks for FAP would be served best not by general screening guidelines regarding regular use of colonoscopies, but by the use of more frequent screening from an earlier age (Syngal et al., 2015).

These two examples highlight how, in terms of relativity, comparison is very important in making genomic testing–related decisions. Currently, genomic testing information has limited influence on the course of treatment for FH; however, with FAP the screening trajectory for a patient with a confirmed increased genetic risk for FAP is different than one without increased genetic risk.

Just as relativity is built on comparisons, a related concept of importance is anchoring, the strong behavioral influence produced by first impressions (Ariely, 2009). While often applied in an economic context, where initial prices are found to influence willingness to spend a certain amount of money on an item, the concept of anchoring can also be applied to healthcare decision making. If a patient or a family member has had a positive experience with genomic testing, then it might encourage them to engage in future genomic testing. If they have had a negative experience, then the opposite influence may be observed. Anchoring based on previous experiences may change the approach that decision makers take to addressing the options available.

Deliberation

Deliberation, the effort by an individual to identify alternatives, or new rules, for solving a problem, is important if practical problem solving or heuristics-based decision tactics have failed in supporting decision making regarding a dilemma (Gigerenzer & Gaissmaier, 2011; Mantzavinos, 2001). Heuristic decision making is the application of experiences of self or others to decision making. In deliberation as the mind seeks new alternatives, there is opportunity to address a problem through selection of one of several presented options or to apply the anecdotal knowledge of those who have encountered similar situations (Elwyn, Frosch, Volandes, Edwards, & Montori, 2010). This alternative is viable for decision making in genomic testing, but it is important to realize that, as with relativity, decisions are taken in context. The situation that one person faces in a diagnosis and testing decision is likely to differ, subtly or grossly, from anecdotal solutions. Contextually, genomic decisions are rarely identical from patient to patient, even within families. Even though test panels and results may be the same for several people, their lives and familial, environmental, emotional, and socioeconomic contexts vary, making the application of ready-made solutions difficult or impossible (Sweeny, Ghane, Legg, Huynh, & Andrews, 2014).

It seems relatively clear that there is limited potential for identifying a simple ready-made solution for decision making in genomics. In this regard, behavioral economics, when applied to the general situation of genomic testing decision making, may prove valuable in helping patients to make the best, most informed decision. The way to best shape these processes must rely heavily on choice architecture and requires a clear understanding of several of the dynamics at play (Thaler & Sunstein, 2008).

Choice Architecture

Choice architecture is the art of shaping decisions by designing choices within a framework that will encourage a certain choice. It is one mechanism that can be explored in attempting to best assist patients and families as they engage in genetic decision making. While it may seem like a limitation of autonomy, there is a clear difference between choice architecture and manipulation in that choice architecture merely provides guidance through information and support for decision making without attempting to limit a person's autonomy (Sunstein, 2015). Nondirective counseling is central in the profession of genetic counseling, and it is imperative that nurses and other healthcare professions support patients without manipulating them. Choice architecture can address some of the external and internal contexts of decision making. Thaler and Sunstein (2008) offer some insight on choice architecture that, when applied to genomics, further supports the unique nature of the decisions to be made.

The application of choice architecture is very well suited to encouraging patient choices regarding wellness and preventive health. In such situations, choice architects employ "nudges" to frame decisions about the most appropriate route as the easiest one without limiting options. There are numerous ways to nudge decision makers, and often the processes are subtle because of their reliance on probable human behaviors; context is key. The scope and level of information involved in decision making in genomics requires further exploration when contemplating nudges and choice architecture. Understanding the unique nature of genomic information will help sharpen nudge methods but also improve our understanding of their applicability in aiding patient and family member decisions—and the ethical implications of employing such methods. Key nudge tactics that warrant further exploration in the setting of genomic testing decisions include default choices and mapping (Thaler & Sunstein, 2008).

Default choices. When no action is taken by the patient in genomic decision making, the result may be some kind of default choice. This path can be a slippery slope. Because the impact of genomic information can extend beyond the decision maker or patient, default choices should be respectful of all parties potentially affected. The sheer ability to obtain genetic testing is not a reason to do it, and the use of a strict default to test limits the autonomy that patients and decision makers must have. If choice architects were to use nudges in genomic decision making to prompt a default choice, then perhaps the safest default would be the null, no testing, choice, one with the potential to affect the fewest people and not to impose effects on others, inadvertently or not. There are some examples where the default to test is established in law, such as the use of newborn screening to test for a panel of specific genetic variants that can lead to various serious diseases (NHGRI, 2015). In this case, the default is set up to ensure early identification and intervention in patients with the selected genetic variants to ensure quality of life. Some of the selected variants have potential implications for other people beyond the patient (e.g., the tested child's biological parents and other biological family members). The policy is designed to protect the perceived best interests of the child through early identification, early treatment, and improvement of outcomes. In other situations, such as where the proband is an older adult, a testing default choice is not a logical standard; it would be a nudge that discourages exploring other options. Because the implications of genomic testing results with regard to patient and family life are even less clear when testing in older populations, there is no clear path to a default choice for later life genomic testing.

Mapping. Mapping can be used as a way to nudge patients when making decisions regarding genetic testing. Mapping draws on a person's knowledge and experiences to establish, by analogy to prior decision situations, a pathway to a decision in previously unexplored territory. However, as with most attempts to help shape a decision, there are some drawbacks. Not all genetic testing may lend itself directly to mapping, so it is important to be aware of the variables that may limit the ability to map out a decision pathway. These variables, fairly consistent in genomic decision making, include the context and timing of the decision, provider biases toward one type of testing or toward not testing at all, information asymmetry creating an increased patient dependence on nurses and other healthcare providers for appropriate information, and the social-emotional and financial costs of genetic testing. Those patients and families considering genetic testing may need more time to make decisions, increased knowledge sharing between nurses and patients and families to limit information asymmetry, and an opportunity for deeper exploration of implications with patients to ensure that post-testing effects on patient and family lives are at least acknowledged if not mitigated in some way.

The BreastCARE intervention studies (Kaplan et al., 2014; Livuadais-Toman et al., 2015) provide an excellent example of how mapping might be helpful with genomics. BreastCARE sought to increase awareness and communication among patients and healthcare providers by using appropriate and validated measures of risk for breast cancer to structure a risk-assessment intervention. This strategy helped to increase communication of breast cancer–related information without increasing concern among patients. This intervention did not lead to a genomic testing decision per se, but it used existing knowledge to help shape the decision to speak with healthcare providers about breast cancer. Those who undergo this intervention may, in turn, need to be assisted in making the decision to seek testing for the genes associated with breast cancer, and this too could be mapped using a similar intervention.

Next Steps for Behavioral Economics and Genomic Decision Making

As genomic testing becomes more mainstream and as more people are faced with making decisions about testing and results, it will bring new challenges to old procedures and policies. Studies of decision-making processes and concerns will be crucial in adapting existing processes and developing new approaches. Understanding genomic decision making through a behavioral economic lens allows for the exploration of the nuanced factors at play in the rapidly emerging fields of genetics and genomics. While the personal and varied nature of genomic information makes restrictive and finely detailed descriptions of processes used in genomic decision making less likely, there is a need to have a clearer understanding of any processes that are undertaken.

Incorporation of behavioral economics elements can also help to create a more decider-friendly decision-making environment for those who are faced with difficult genomic testing decisions than the environment offered through the use of authoritarian approaches. There are a wide range of variables that each person will uniquely encounter, but there are also many commonalities that must be accounted for and further explored (Lerner, Li, Valdesolo, & Kassam, 2015). Nursing, based in holistic care, is uniquely equipped to inform the study of the decision-making processes as the complex intermingling of familial, contextual, emotional, environmental, and socioeconomic factors—all things that influence nursing care of patients. This unique nature makes studies seeking to identify ways to better support decision making imperative, and behavioral economics may be one path for reaching this goal. Exploring possible decision pathways or other tools that could be used to help patients contemplate the multiple variables of genomic testing is key for future steps in supporting patient decision making.

Contextual forces can disproportionately influence genomic decisions, resulting in a choice that may not fully reflect patient or family values or a full deliberation of the situation; nurses should be aware of these varied forces involved in decision making. Identifying the importance of assessing the utility of options and awareness of situational perspective, Kahneman and Tversky elucidated some of the initial applications of concepts that underpin those discussed in this article (Kahneman, 2002; Kahneman & Tversky, 1979, 1992). There are numerous veins of inquiry related to behavioral economics and decision making that have relevance to health care; Game Theory, partially derived from the Nash Equilibrium, and other theories of conflict, bargaining, and outcomes, have also been applied to healthcare decision making (Djulbegovic, Hozo, & Ionnidis, 2015).

Behavioral economics does not rest solely on the belief that humans will always act rationally in a given situation, but rather accounts for contextual influencers such as emotions, cognitive biases, and other internal and external pressures (Ariely, 2009). This is growing in importance as patients are often turning to easily accessed resources for information, such as Internet resources of varied reliability, accuracy, and quality (Foster, 2016; Fox, 2008; Perazzo, Haas, Webel, & Voss, 2017). One behavioral economic concept that has been noted to shape decision making is present bias, or present-centeredness (Hostetter & Klein, 2013). Awareness of present bias is also important in understanding how decisions may be perceived. Understanding the value of information at the moment of testing and understanding the possible implications for future decisions of the patient and their family is imperative in genomic decision making.

It is important to consider how behavioral economic concepts can be applied in clinical nursing practice. Even before the blossoming of decision science as a part of nursing science, nurses have been a part of patient decision making (Pierce & Hicks, 2001). In the current patient-centered care environment, nursing has a unique role in patients' decision-making processes. Relationships with patients and their families in times of both illness and wellness position nurses in contexts where important decisions are made. Often nurses are seen as sources of information and clarification when communication with other healthcare providers is limited. Nurses should seek to support decision making in a balanced manner, avoiding information asymmetry when at all possible and finding common ground from which to work. Behavioral economic concepts discussed here are important for informing nurses about how they can better support patient decision making within a shared or other decision-making model.

Interdisciplinary, collaborative exploration of decision making is an important part of assuring that patient decision making with regard to genomics is supported to the highest possible level. Understanding the core concepts of behavioral economics and choice architecture is key, and implementing these concepts to inform future studies will allow for improvement of the patient experience in genomic decision making. Nurses and other healthcare professionals must seek to better understand the context of the care that they deliver to their patients. The behavioral economic concepts described in this article offer a good start for better understanding decision making, specifically in a genomic context. Beyond the genomic focus of this article, nurses can benefit from further exploring these concepts and incorporating some of these approaches in supporting patients and families as they make difficult decisions.

These behavioral economic concepts do not replace the key concepts that underpin ethical practice and high-quality nursing, but are meant to complement nursing care. Patients are more than the sum of their complaints, diseases, or syndromes, and the process of diagnosis and treatment of illness is complex and multifaceted, possibly even more so when genomics are involved (Gorovitz, 2010). When engaging in supporting patient decision making, it is important that all parties involved fully understand the implications of decisions that they make, and these implications should be seen as a reason to further question processes. The use of behavioral economic mechanisms to support patient decision making is helpful in managing the complexities of these decisions through the use of information and expertise while still respecting autonomy. This is the essence of the marriage of behavioral economics with the nurse–patient relationship—the use of these approaches to overcome information asymmetry through thoughtful and deliberate support of patient decision making. Nurses will continue to provide high-quality care and support for patients, families, and caregivers; however, it is in that same vein that nurses must seek ways of understanding the new complexities of decisions faced by patients when deciding about genomic testing. While the question of whether to test or not may be dichotomous—either answer has effects on more people than just the patient at hand—nurses may be caught up in the mix as patients, families, and caregivers seek to reach a decision. Comfort, knowledge, and support are key aspects of the nursing care provided in times of need—nurses must remain unbiased and seek ways to bring balance in an unbalanced relationship between healthcare providers and patients.

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Clinical Resources

- National Institutes of Health, National Human Genome Research Institute. Genetic and Rare Diseases Information Center. https://www.genome.gov/10000409/genetic-and-rare-diseases-information-center/
- National Institutes of Health, National Human Genome Research Institute. Genetic health professional education resources. https://www.genome.gov/17517037/health-professional-education/
- National Institutes of Health, U.S. National Library of Medicine. Genetics home reference. https://ghr.nlm.nih.gov/

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The Global Landscape of Nursing and Genomics

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Abstract

Purpose: Nurses have a pivotal role in bringing the benefits of genomics and precision medicine to everyday health care, but a concerted global effort is needed to transform nursing policy and practice to address widely acknowledged deficits in nurses' genomic literacy. The purpose was to conduct a global country and organization review of nursing engagement with genomics, informing a landscape analysis to assess readiness for integration of genomics into nursing.

Design: Global nursing leaders and nursing organizations were recruited using a purposive sampling strategy to complete an online survey that assessed the scope of genomic integration in practice and education, challenges and barriers, and priorities for action.

Methods: The survey was administered online following an orientation webinar. Given the small numbers of nurse leaders globally, results were analyzed and presented descriptively.

Findings: Delegates consisted of 23 nurse leaders from across the world. Genomic services were offered predominantly in specialty centers consisting mostly of newborn screening (15/18) and prenatal screening (11/18). Genomic literacy and infrastructure deficits were identified in both practice and education settings, with only one country reporting a genetic/genomic knowledge and skill requirement to practice as a general nurse.

Conclusions: These data provide insights into the commitment to and capacity for nursing to integrate genomics, revealing common themes and challenges associated with adoption of genomic health services and integration into practice, education, and policy. Such insights offer valuable context and baseline information to guide the activities of a new Global Genomics Nursing Alliance (G2NA). The G2NA will use the landscaping exercise as a springboard to explore how to accelerate the integration of genomics into nursing healthcare.

Clinical Relevance: Genomics is relevant to all healthcare providers across the healthcare continuum. It provides an underpinning for understanding health, risks for and manifestations of disease, therapeutic decisions, development of new therapies, and responses to interventions. Harnessing the benefits of genomics to improve health and care outcomes and reduce costs is a global nursing challenge.

As the largest single healthcare professional group worldwide, nurses have a pivotal role in bringing the benefits of genomics to everyday health care; however, a global effort is needed to transform nursing policy, practice, education, and research (World Health Organization [WHO], 2016). Embracing genomic health care requires a prepared workforce. This represents a significant challenge, since deficits in genomic literacy in nursing and other health professions are widely acknowledged (Calzone, Jenkins, Culp, Caskey, & Badzek, 2014; Skirton, O'Connor, & Humphreys, 2012). Therefore, there is a need to assess existing genomic integration, as well as challenges or barriers, and to gauge readiness for a collaborative global effort to increase nursing capacity to integrate genomics into practice.

Background

Developments in genomics and its translation to improve healthcare continue unabated (Davies, 2017). Genomics advances have implications worldwide, across the healthcare continuum, and impact all nurses regardless of academic preparation, role, or clinical specialty (Umberger, Holston, Hutson, & Pierce, 2013). Embracing genomic health care requires a prepared workforce that can inform, educate, and empower people, address existing and novel ethical issues, and anticipate any potential negative impact on vulnerable populations (Badzek, Henaghan, Turner, & Monsen, 2013; Seven, Eroglu, Akyuz, & Ingvoldstad, 2017; Tekola-Ayele & Rotimi, 2015). Nurses have a pivotal role in leading change to advance health, integrating research discoveries into ethical healthcare practice benefiting individuals and societies (Salmon & Maeda, 2016). However, there is substantial evidence that many nurses worldwide lack confidence and competence in genomics, and education provision is inconsistent (Calzone et al., 2014; Skirton et al., 2012). A survey of 10 countries, including the United States, United Kingdom, Israel, Brazil, Pakistan, and South Africa, found that genetics competence is not included within the regulatory standards of six countries and is explicit in only one, defined as "only at the basic level" (Kirk, Calzone, Arimori, & Tonkin, 2011). The conclusion was that concerted and strategic global effort is needed to prepare and enable nurses to drive progress, influence policy, and maximize existing resources to promote nursing literacy in genomics that includes associated ethical, legal, and societal challenges (Kirk et al., 2011). This was echoed by Williams and colleagues, who acknowledge the critical role of nursing in implementation of genomics (Williams, Feero, Leonard, & Coleman, 2017). Nursing policy, education, practice, and research in genomics needs to be strengthened worldwide, and policy initiatives in some countries, such as England, may inform how this could be achieved elsewhere (Health Education England [HEE], 2017). Motivated by the need to embrace this challenge, the authors facilitated an interactive event to harness influence and knowledge, with the aim of creating a Global Genomics Nursing Alliance (G2NA; https://www.g2na.org) to accelerate integration of genomics into everyday professional practice. This article presents the first phase of that wider initiative.

Aims

As a starting point for the establishment of the G2NA, we conducted a country- and organization-specific landscape analysis to assess the factors likely to impact readiness for and scope of genomic integration into nursing policy, practice, and education. We sought to identify the range of genomic services available, the healthcare contexts within which they operate, and the challenges, barriers, and areas of action for nursing. The aim was to provide context and insights into the commitment, capacity, and challenges around the integration of genomics into nursing, and to inform a framework for action for the G2NA. This project was reviewed and approved by the Faculty of Life Sciences and Education Ethics Committee, University of South Wales.

Methods

Recruitment

This project utilized a purposive sampling strategy. Survey participation was limited to delegates attending the inaugural 2017 G2NA meeting. The number of delegates was constrained by available grant funding and meeting space. Country delegates were selected based on their expertise in nursing, health care, services, policy, and leadership within their country. Expertise in genomics was not required. Some delegates were not nurses but represented the nursing community in their country or provided a critical perspective to inform the work of the G2NA. There was an effort to have a broad geographical representation. We also strived to achieve a gender balance similar to the international nursing workforce, which is approximately 16% men (WHO, 2017a). Organizational delegates represented international nursing and genetic organizations: International Council of Nurses (ICN), Sigma Theta Tau International (STTI), International Society of Nurses in Genetics (ISONG), European Society for Human Genetics; two large national genomics and health organizations (U.S. National Human Genome Research Institute and HEE Genomics Education

Programme), and a national advocacy group for individuals and families affected by genetic disorders (Genetic Alliance UK). Delegates were identified via international nursing networks and an iterative process by the authors to identify the optimal representative at the most appropriate and highest level (e.g., current president).

Instrument

The WHO describes a landscape analysis as a review of positive and negatives factors that might influence the likelihood of adoption of a new development, initiative, or technology (WHO, 2010). The survey instrument was developed specifically for this project, and questions were designed to ascertain the country- and organization-specific context. Questions were adapted with permission from Manolio et al. (2015) and leveled for nursing by the authors, drawing on previous work assessing critical success factors in genetics/genomics integration in nursing (Kirk et al., 2011). The survey was pilot tested by the authors and other genomics and nursing experts, then revised prior to administration. Questions solicited information based on the delegate representation: country versus organization. Country questions sought information on the healthcare system, nursing, and genomics in mainstream and specialist services, as well as challenges and priorities in integrating genomics into nursing. Organization questions requested information on the scope of the organization (national or international), type and size of membership, existing genomic learning resources, and the organization perspective of challenges and priorities in integrating genomics into nursing. All delegates were asked to identify minimal needs to enable and ensure the integration of genomics across nursing practice, education, research, and policy, and to prioritize a list of nine areas for action. The nine areas for action were established through group discussion and anonymous voting at a plenary session at the ISONG Annual 2016 Congress. The survey was administered online in November 2016 following an explanatory webinar. Other demographics and indicators used to assess readiness and inform landscape analysis were obtained through review of routinely available data from the WHO and United Nations (2017).

Analysis

Data were exported into Excel for analysis. Results were tabulated and analyzed using descriptive statistics. There are very few global nurse leaders, so the sample size is necessarily small. Given the small sample we have chosen to not provide percentages.

Results

Population

Nineteen countries were represented at the meeting, of which 18 completed the survey. One country was invited after the survey following a late cancellation and did not complete the survey. Seven organizations were represented, of which four were international, three were not restricted to nursing but had interprofessional membership, and five completed the survey, with two completing the survey from a country perspective. Five men were among the respondents. All delegates were fluent in English.

Country delegates were predominately nursing leaders within their country but did not always have genetics expertise, and most held academic positions. Delegates came from countries with populations (in thousands) ranging from 2,380 (Australia) to 319,929 (United States). The number of nurses and midwives per 1,000 population varied widely from 0.6 (Pakistan) to 17.8 (Switzerland; **Table S1**; WHO, 2017b).

Half the country delegates (9 of 18) reported that the main source of healthcare services was health insurance systems funded by the government, citizens, employers, or a combination of those entities. Of the remaining, 8 of 18 reported they had a government funded system of which 5 included additional user fees at the time of use. Only one country, Pakistan, reported a decentralized, private system. Country-specific gross domestic product spending on health care was as low as 3% (Pakistan) to as high as 17% (United States; WHO, 2017c; see **Table S1**).

Nursing Qualifications to Practice

Most countries reported that the qualification most nurses obtain to practice is a bachelor's degree (9 of 18) or associate degree (4 of 18), with fewer reporting obtaining a diploma (3 of 18) or certificates (2 of 18). Despite this variation in qualification, most countries reported that entry-level training was 3 or 4 years (16 of 18), with 2 of 18 countries reporting 5 years. Most indicated that training occurred in universities or colleges (13 of 18). While hospital-based training was still prominent in three countries, one reported tertiary institutes, and one was transitioning from hospital- to university-based training. Five countries required examination such as a licensure or registration examination to practice. Four countries indicated there was no statutory regulatory body responsible for maintaining a nursing register and setting standards for education and practice. One country reported they do not have a national professional organization to represent nurses' interests.

Required Genomic Training for Nurses

Only one country, Israel, indicated a requirement for all nurses to reach an agreed standard of knowledge and skills in genetics/genomics to practice, via a mandatory 28-hour course. Otherwise, the integration of genomics into nurse training was ad hoc and varied widely based on the country, with some countries reporting no genetic or genomic content included in training. Three countries indicated existence of genetic/genomic competencies applicable to all nurses regardless of clinical role, level of training, or specialty: Japan (Arimori et al., 2007); United Kingdom (Kirk, Tonkin, & Skirton, 2014); United States (Consensus Panel on Genetic/Genomic Nursing Competencies 2009; Greco, Tinley, & Seibert, 2012). Building on U.K. work, interprofessional competencies are available for European countries for primary, secondary, and tertiary (defined as genetic specialist) care (Skirton, Lewis, Kent, & Coviello, 2010). Only 6 of 18 countries reported visible leadership driving developments in nursing to incorporate genomics.

Specialist in Genomics

All 18 countries reported the existence of a specialist genetics service, often in centers of excellence and consisting of genetic testing and counseling provided by trained or accredited individuals whose positions varied by country but included physicians, genetic counselors, and some nurses. Only 5 of 18 indicated there was a recognized specialist genetics nursing role (nurses with specialized training in genetics). Of those countries, four indicated they had agreed standards for specialist genetics nurses. A few countries reported that some genetic counselors are also nurses.

Availability of Genomic Services

The scope of genomic services offered globally varied (**Table S2**). The most widely available genetic services consist of newborn screening (15 of 18) and prenatal screening (11 of 18), though not prenatal testing (5 of 17). Genomic services were mostly offered in specialized centers only. Some countries reported not having one or more of the following genomic services: risk assessment and genetic testing for disease susceptibility; tumor sequencing; targeted therapies; or sequencing of infectious agents. One country reported the only genomic service was newborn screening. Only a few countries reported that genomics of common disease services, when offered, were widely available outside a specialty center: disease screening (2 of 16), disease prognosis (1 of 16), pharmacogenomics (2 of 14), and sequencing for infectious agents (5 of 15).

The nursing roles delivering genomic services were a mixture within and between countries of specialist genetic nurse, specialist nurse, and advanced practice nurse (data not shown). Newborn screening, systematic family history taking, and prenatal screening were interventions where "any nurse" was most likely to be involved (eight, six, and five countries, respectively).

Key Challenges

Several potential challenges to clinical practice and nurse education were considered by both organization- and country-specific delegates. The most significant challenges or barriers to genomic integration into clinical practice consisted of (a) limited access to point of care educational information and clinical decision support; (b) lack of genomic expertise with limited training opportunities; (c) access to critical resources for training; and (d) resources that could link genetic variation to clinical implications (see **Table S3a** for specific data). High cost or lack of reimbursement and the need for resources to link genetic variation to clinical implications also ranked as significant challenges or barriers. Confusion over consent and privacy issues were considered as only a minimal challenge or barrier.

Delegates identified a need for a cultural shift in the role of nurses in genomics. Comments included the need for development of clear career pathways in genomics for the registered nurse and the wider nursing workforce. Recommendations focused on demonstrating the relevance to nursing leaders such as directors of nursing and those responsible for setting standards.

Education key challenges and barriers identified as the most significant included (a) insufficient curriculum time to cover genomics, (b) insufficient numbers of educators able to teach genomics, and (c) absence of required genomic competency assessments to practice nursing (see **Table S3b** for specific data). The absence of standards for genomic nursing education was viewed as significant by 12 countries as well as by ISONG, HEE, and ICN. Reluctance to consider different approaches to nurse training that facilitate integration of new knowledge and clinical advances, and the absence of national leadership in driving nursing genomics integration, were also important. Establishing relevance for nursing leaders involved in setting curricula was deemed critical as otherwise there is no incentive to prepare practitioners.

More than three fourths of the countries (14 of 18) reported other significant or major competing priorities, including financial and political uncertainty. The absence of national leadership driving genomics integration into nursing was considered a significant issue.

Policy Initiatives

Country-specific policy initiatives have largely surrounded investments in large-scale genomic biomedical research. These include National Call for Research into Preparing Australia for the Genomics Revolution in Health Care; Brazil's National Institutes of Science and Technology and its creation of the Family Cancer Network and Institute of Oncogênomica; China Kadoorie Biobank; Japan's Genomic Medical Realization Promotion Council; the U.K. 100,000 Genome Project; and the U.S. Precision Medicine Initiative, now renamed the All of Us Research Program. Initiatives have also focused on specific health issues or ethical and regulatory considerations, such as Pakistan's Punjab Thalassemia Prevention Program; Germany's Genetics Diagnostics Law; Switzerland's National Criteria for Centers of Excellence in Rare Diseases; Taiwan's recommendations for prenatal and newborn screening; the German Ethics Council's position on genetic diagnosis; Turkey's regulation of Genetic Disease Diagnosis Centers; and the U.K. Rare Disease Strategy. However, only 10 of 18 reported these national initiatives acknowledge the implications for nurses. Fewer still include genomic training for nursing and other healthcare professions, although the United Kingdom's Genomics Education Programme is one exemplar (HEE, 2017).

Priority Areas for Action

The top three priority areas for action included raising awareness (22 of 22); education (21 of 22); and resources to support genomics in nursing (20 of 22). The creation of national and international collaborations also ranked highly. High priority areas identified in the survey included efforts to improve the status and visibility of nurses and nursing, generally and in relation to role in genomics as well as to facilitate the organization and delivery of genomic healthcare.

Discussion

To the best of our knowledge, this study represents the first landscape analysis of genomic healthcare services and nursing (education and practice) across multiple countries. Our aim was to conduct a landscape analysis that assessed the nursing and genomic trends in genomic literacy, clinical practice integration, and country-specific context inclusive of challenges and barriers. The current landscape revealed many global commonalities. National genomic sequencing initiatives are being implemented across the globe, and yet despite this, the largest single healthcare professional group, nurses, do not yet have genomics fully integrated into their practice, education, and policy. Genomic nursing literacy globally appears to be low given only one country requires genomic training, which is narrow in scope. Improvement may be limited, since the three primary education challenges were insufficient curriculum time for genomics, insufficient educators capable to teach genomics, and the absence of required genomic competency assessments to practice nursing. This contributes to limited genomic translation into practice, with most available services restricted to specialty clinics and not integrated into the general healthcare environment. Understanding this context informs priorities for action and identification of key strategies to influence change, including engagement and education of nursing practice and education leadership, an approach that may be useful for invigorating and sustaining any initiative (Calzone, Jenkins, Culp, & Badzek, in press). All of this can be greatly facilitated by global collaboration, the potential to learn from countries further along, and the sharing of expertise and resources to minimize duplication of effort.

Unsurprisingly, the availability and complexity of genomic-based health services varies between countries, with a range of nursing roles involved in their delivery. Most services are located within specialized centers, with more established activities like prenatal and newborn screening, available for many years, being more widely available and being delivered by the nonspecialist nurse. We anticipate that the transition from specialized center to services that are more widely available will occur over time as technology becomes increasingly accessible and genomics becomes embedded within mainstream healthcare practice. However, it is important to be realistic about the scale of the challenge and what this entails. Davies (2017) remarked on the need to reform professional attitudes towards genomics and for a new genomic paradigm to be integrated into all training curricula for all clinicians. According to Davies, adopting genomic technologies requires changes in the design, operation, and workforce of healthcare organizations and raises concerns about the international shortage of skills and expertise. Davies' comments highlight the importance of education, leadership, and willingness to change, the need for appropriate infrastructure, and the value of pooling international expertise.

The education challenges presented here resonate with those identified in the literature. The engagement of nursing leadership is vital to establishing genomics competency as a workforce priority (Calzone et al., in press;

Jenkins et al., 2015; Leach, Tonkin, Lancastle, & Kirk, 2016). To achieve engagement, relevancy of genomics must be established, which requires that nursing leaders attain competency in genomics sufficient to inform their decisions on competency standards and infrastructure priorities, such as point of care decision supports (Jenkins et al., 2015). Targeting nursing leadership is challenging as nursing leaders often view genomics as a niche specialty (Jenkins et al., 2015), but genomics represents a healthcare quality, safety, and cost issue in which larger policy mandates are needed to prioritize training in genomics for the practicing workforce (Calzone et al., in press). This is challenging given that most genomic initiatives globally focus on evidence generation, with limited attention paid to expanding the capacity of the existing healthcare workforce or the infrastructure necessary for effective translation of discoveries into practice. However, with the right government attitudes and investment, such as the U.K. 100,000 Genomes Project, evidence generation can be linked with increasing health professional capacity (HEE, 2017). Hoping that the solution will lie in the future nursing workforce is not realistic. The data from this landscape analysis document common global challenges that are well described in the literature, including lack of faculty capacity to teach genomics, a packed curriculum, and the absence of genomic educational standards (Jenkins & Calzone, 2014; Read & Ward, 2016). Addressing these deficits is hindered by the absence of regulatory bodies globally mandating some form of genomic nursing competency assessment.

The trajectories of genomic translation (outlined above) in both nursing practice (from specialized to widely available) and nurse education lend themselves to measurement. A tool that can capture country-specific and, in turn, global progress in integrating genomics into practice could be of great use to prioritize G2NA ongoing efforts and assess effectiveness.

Genomics epitomizes a complex competency. The global workforce has little underpinning in the science of genomics, limiting capacity to understand the relevancy and even the literature given some of the terminology used. Many of the health or disease outcomes achieved by using genomics are not readily observable in terms of health or disease outcomes and can also consist of psychosocial outcomes, such as the value of knowing (Garrison, Mestre-Ferrandiz, & Zamora, 2016). For example, identifying an individual with a genetic predisposition to a disease such as cancer provides an opportunity to implement strategies aimed at risk reduction or early detection. Utilizing a pharmacogenomic test to inform treatment options may help alleviate adverse drug events and improve efficacy, superior to the trial and error approach most often utilized (Ciardiello et al., 2014). Rogers' *Diffusion of Innovations* (2003) documents that this complexity and lack of observability all slow adoption. Policy approaches, the involvement of critical healthcare leaders, and the utilization of opinion leaders, such as the G2NA delegates, can help facilitate adoption (Leach et al., 2016). But those G2NA country delegates alone will not be sufficient. The contribution of critical nursing organizations such as the ICN and STTI, which have considerable respect and position in the global healthcare arena, are positioned to influence nursing leaders and policy internationally, and were specifically targeted for participation in this effort. Genomics integration into practice is absolutely an interprofessional issue (Passamani, 2013). Nursing, through global collaboration and interface with critical nursing leaders, can be a catalyst for all health professions to achieve the capacity to integrate genomics into practice and education to realize the healthcare benefits.

The findings from our landscape analysis underpin the future work of the G2NA. This alliance is not targeting the genetic specialist, but is aimed at genomic integration in everyday nursing practice and education though the sharing of resources, expertise, and mobilization of organizations that can help influence nursing leaders and policy directions.

Limitations

These findings have some limitations that need to be considered. The instrument used to collect the data was developed by the project leadership team. Apart from content validity using expert reviewers, the instrument was not otherwise tested for construct validity and reliability as that was not appropriate given the very narrow target audience for this survey.

Given funding constraints, not all countries and international nursing organizations were represented, though the G2NA provides a platform for growth in this arena. Furthermore, the data are based on the knowledge and views of just one individual from each country or organization. This project utilized a purposive sampling strategy. While the authors attempted to identify people optimally positioned to address the state of nursing in their country or organization, a single individual may not have the full details associated with every survey item. There are very few high-level nurse leaders globally who can comment on the state of nursing practice in their country; thus, the numbers we could involve are limited. We do not claim that those involved were representative in any way of the entire nurse leader population.

Given these limitations, our findings may not accurately reflect the global state of nursing and genomics. Therefore, these findings should be considered as one initial snapshot of a potential state of nursing in genomics that will inform the next steps in establishing the G2NA to facilitate and accelerate the integration of genomics into nursing practice.

Conclusions

The findings from this landscape analysis provide a foundation to inform the development of strategies to address common challenges and prioritize collaborative activities to accelerate the integration of genomics into nursing. The findings also support the concept of global commonalities of pathways to genomic adoption amenable to the development of a tool to guide and track progress. Now more than ever before, nursing exists in a global environment. By working together, we can mobilize information, resources, and strategies to realize the benefits of genomics for the patients that we serve.

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Clinical Resources

- Genetic and Genomic Competency Center for Education: http://genomicseducation.net/
- Health Education England. Genomics Education Programme: https://www.genomicseducation.hee.nhs.uk/
- Your Genome: http://www.yourgenome.org/

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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. Country Specific Landscape (*N* = 18 Countries; United Nations, 2017, World Health Organization, 2017a, World Health Organization, 2017b)

Table S2. Genomic Services Available Across 18 Countries

Table S3. Country and Organization* Ranking of Challenges or Barriers With Genomic Integration Into Nursing Practice

JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Determinants of Quality of Life in Lung Cancer Patients

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Key words
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Abstract

Purpose: To examine the relationships of self-care, symptoms, and a variety of demographic factors to quality of life (QOL), and to identify determinants of QOL in lung cancer patients undergoing chemotherapy.
Design: A cross-sectional, correlational study.
Methods: 159 patients with lung cancer undergoing chemotherapy were recruited from three southern hospitals in Taiwan. Four instruments were used: the Quality of Life Questionnaire Core 30-item (QLQ-C30), M.D. Anderson Symptom Inventory (MDASI), Memorial Symptom Assessment Scale-Short Form (MSAS-SF), and Self-Care Behavior Scale (SCBS).
Findings: Lung cancer patients rated lower scores of self-care behaviors on food choice and nutrition maintenance, regular exercise and sleep, and medical compliance. Being younger, having spouses as main caregivers, having food choice and nutrition maintenance, and getting regular exercise and sleep were associated with better QOL. Degree of interference with life, age, food choice and nutrition maintenance, and psychological symptoms were found to predict functional QOL and accounted for 43% of total variance.
Conclusions: The findings identified factors influencing QOL and provided evidence for designing an intervention to enhance QOL in lung cancer patients undergoing chemotherapy.
Clinical Relevance: The findings may be useful for guiding intervention development for early detection and management of symptom interference with daily living, and place greater focus on patient self-care to promote food choice and nutrition maintenance, especially in older patients and those whose caregivers are not their spouses.

Lung cancer is the leading cause of cancer deaths, accounting for approximately 26% of all cancer deaths (Siegel, Miller, & Jemal, 2017). Chemotherapy is the most common and important treatment for lung cancer. During treatments, patients not only experience the symptoms caused by lung cancer itself, but also suffer from the side effects of chemotherapy, such as fatigue, nausea, and vomiting; these symptoms interfere with patients' self-care abilities and daily life functions, and affect their quality of life (QOL; Lin, Chen, Yang, & Zhou, 2013). QOL is a predictor of mortality among lung cancer patients (Browning, Ferketich, Otterson, Reynolds, & Wewers, 2009). However, the main reason for lung cancer patients seeking medical help is the development of symptoms; hence, most of them are diagnosed at an advanced stage and have limited prognosis (Petrosyan, Daw, Haddad, & Spiro, 2012). Due to delayed diagnosis, the 5-year survival rate is only 18% (Siegel et al., 2017). Additionally, lung cancer patients have lower QOL in comparison to those who suffer from other malignancies (Polanski, Jankowska-Polanska, Rosinczuk, Chabowski, & Szymanska-Chabowska, 2016).

Although QOL research has been limited, previous studies have reported QOL perceptions and its relationship to symptoms or characteristics variables. Gupta, Braun, and Staren (2012) conducted a QOL study on 263 lung cancer patients; the results indicated that the mean cognitive function score was highest ($M = 74.6$), and the mean global health status/QOL score was lowest ($M = 56.2$). Larsson, Ljung, and Johansson (2012) conducted a QOL study on lung cancer patients in Sweden using the same questionnaire and had no consistent findings; the mean cognitive function score was highest ($M = 83$), and the mean role function score was lowest ($M = 51$). Several factors positively influence the QOL of lung cancer patients, including family and social support, independence, physical comfort, and spirituality, whereas fatigue has the most negative effect (John, 2010). Lung cancer patients undergoing treatment with more severe symptoms have a worse QOL (Iyer, Roughley, Rider, & Taylor-Stokes, 2014; Kurtz, Kurtz, Stommel, Given, & Given, 2000). QOL is better in patients who are male (Larsson et al., 2012), are older (Akin, Can, Aydiner, Ozdilli, & Durna, 2010; Larsson et al., 2012), and have a high educational level (Akin et al., 2010). Additionally, unemployed patients have poorer QOL than employed patients (Akin et al., 2010; Lee et al., 2011). However, inconsistent findings have been reported on gender (Akin et al., 2010; Henoch, Bergman, Gustafsson, Gaston-Johansson, & Danielson, 2007; Mohan et al., 2007; Svobodník et al., 2004), age (Henoch et al., 2007; Mohan et al., 2007; Yang, 2009), educational level (Lee et al., 2011; Yang, 2009), marital status (Svobodník et al., 2004; Yang, 2009), and lung cancer types (Akin et al., 2010; Henoch et al., 2007; Wong & Fielding, 2008).

Self-care is the ability of necessary human regulatory function, and a primary form of care for patients with chronic conditions. According to the World Health Organization (2013, p. 15), self-care is defined as "the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support of a health-care provider." For lung cancer patients undergoing chemotherapy, self-care behaviors include (a) infection prevention (Lyman, Lyman, & Agboola, 2005); (b) nutrition maintenance; (c) adequate amount of rest and activity (National Comprehensive Cancer Network, 2014); and (d) perception and management of chemotherapy side effects (Murphy-Ende & Chernecky, 2002). Self-care behaviors have been found to alleviate chemotherapy side effects, reduce symptom-related interference in daily living, increase independence, and improve QOL (William & Schreier, 2004). No other studies were found that examined self-care on QOL in lung cancer patients; previous studies have only focused on leukemia patients (Chuang, Chung, Chen, & Ho, 2005) and breast cancer patients (William & Schreier, 2004).

In view of the contradictory and limited results from previous studies, the aim of this study was to examine the relationships of self-care, symptoms, and a variety of demographic factors to QOL, and to identify determinants of QOL in lung cancer patients undergoing chemotherapy.

Methods

This was a descriptive, correlational, cross-sectional study using self-administered questionnaires to collect data.

Participants

The sample included patients from two medical center hospitals (one university hospital with 1,469 beds and the other with 1,250 beds) and one regional hospital (331 beds) in southern Taiwan. The inclusion criteria were (a) diagnosed lung cancer by physicians; (b) received chemotherapy once and continued receiving treatment; (c) age above 40 years, with clear consciousness, and capable of expressing themselves in Mandarin or Taiwanese; and (d) Karnofsky Performance Status (KPS) score over 60, and able to take care of themselves. Lung cancer patients with encephalopathy, neuromuscular diseases, severe congestive heart failure, or mental problems were excluded. The a priori sample size calculation was set with $r = .25$, $\alpha = .05$, and power level of .8 using G-power statistical software, and the estimated minimum of sample size was 126 (Faul & Erdfeler, 2007).

Data Collection

After receiving approval from the institutional review boards (IRBs) from three hospitals, the first author (H-Y.H.) contacted the chest physician in each hospital and explained the purpose of the study. The physician provided a list of eligible participants. Participants were approached at chest wards or clinics and explained the purpose of the study. After obtaining informed consent, participants were asked to fill out four questionnaires in a quiet and private room. The first author (H-Y.H) collected disease-related information via chart review and scored the KPS for each participant.

Ethical Considerations

The IRBs of the participating hospitals approved the study. Participants received a full explanation before participating and were reassured that their medical care would not be affected whether they agreed to participate or not. All data were deidentified, and no names or identifying information were revealed.

Measurements

Demographics. The characteristics of the participants included age, gender, education, marital status, employment status, and main caregivers. Medical information was collected regarding their cancer stage, treatment regimens, and coexisting chronic illness.

Karnofsky Performance Status. The KPS is designed to measure the level of patient functional status and contains 11 items that are rated from normal functioning (100) to death (0; Yates, Chalmer, & Mckegney, 1980). KPS scoring was above 60, which indicates individuals were able to mostly take care of themselves, and its construct validity and reliability (interrater reliability $r = .69$, test-retest reliability $r = .66$, all $P < .001$) were examined (Yates et al., 1980).

Quality of Life Questionnaire Core 30-item (QLQ-C30). The QLQ-C30 contains 30 items that are examined by construct validity (Aaronson et al., 1993). The QLQ-C30 incorporates three multi-item scales: functional scales (physical, role, cognitive, emotional, and social), cancer-related symptom scales (fatigue, pain and nausea/vomiting, dyspnea, insomnia, appetite loss, constipation, and diarrhea), and a global health status scale (Aaronson et al., 1993). The functional scales and symptom scales are rated from 1 (*not at all*) to 4 (*very much*). Global health status is measured on a scale of 1 (*worst*) to 7 (*best*). Scale scores are linearly transformed to 0–100 scores (Fayers, Aaronson, Bjordal, Groenvold, Curran, & Bottomley, 2001). High scores on the functional scales and global health status scale indicate a better QOL, but high scores on the symptom scales represent a high level of problems (Fayers et al., 2001). The Cronbach's α coefficient is .7, and validity was examined in a previous study (Aaronson et al., 1993). The Cronbach's α coefficient for the Chinese version of the QOL-C30 was over .7 (Chie, Yang, Hsu, & Lai, 2002). In this study, the Cronbach's α coefficient was .88.

Self-Care Behavior Scale (SCBS). The SCBS is designed for lung cancer patients and contains 24 questions, rated from 1 (*never do it*) to 5 (*always do it*) and a Likert scale, for assessing avoidance behaviors (AB), infection prevention (IP), food choice and nutrition maintenance (FCNM), regular exercise and sleep (RES), medical compliance (MC), and awareness of chemotherapy-related side effects (ACRSE; Tsai, 2009). A higher score indicates a higher level of self-care. The validity and reliability (Cronbach's $\alpha = .86$) have been reported previously (Tsai, 2009). The Cronbach's α coefficient was .77 in this study.

M.D. Anderson Symptom Inventory-Taiwan Form (MDASI-T). The MDASI-T was designed to assess the severity of symptoms and the degree of interference with daily living in cancer patients. The scoring method is on a scale of 0 to 10. The higher the score, the worse the symptoms. The Cronbach's α coefficients for symptom severity and degree of interference with life were shown to be .85 and .82, respectively (Cleeland et al., 2000). In the current study, the Cronbach's α coefficient for the MDASI-T was .93, and those of its subscales ranged from .88 to .94.

Memorial Symptom Assessment Scale, Short Form, Chinese Version (MSAS-SF Ch). There were four questions to assess how often patients felt symptoms on a scale of 0 (*none*) to 4 (*very severe*). The internal consistency reliability was 0.87 for the English version (Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000) and 0.91 for the Chinese version (Lam, Law, Fu, Wong, Chang, & Fielding, 2008). The Cronbach's α coefficient was .83 in this study.

Data Analysis

SPSS version 19 software was used for data analysis (IBM Corp., Armonk, NY, USA). All QLQ-C30 scores were calculated following the European Organization for Research and Treatment of Cancer scoring guidelines (Fayers et al., 2001). Demographic data and scale scores were reported with descriptive statistics, including percentages, means, standard deviations, and ranges. Pearson's correlation was used for inferential statistics to analyze correlation of age, symptoms, self-care behaviors, and QOL. The indicators of QOL were examined by a stepwise regression analysis. The variance inflation factor (VIF) was used as an indicator for multicollinearity effects; the acceptable level of VIF is less than 10 (O'Brien, 2007). A P value of <.05 was considered as statistically significant. All variables were examined for normality and homoscedasticity to avoid multicollinearity effects.

Results

Demographic Data

One hundred sixty-six participants were approached to participate in the study, and 159 were recruited, with a rejection rate of 4.4%. **Table 1** reports characteristics of participants. Over half the participants were men (56%) and cared for by their spouses (62.9%). Their age distribution was 42 to 86 years, and the mean age was 65.03 ($SD = 11.05$) years. Moreover, 58.5%

Table 1. Participants' Characteristics ($N = 159$)

Variables	Range	Mean	*SD*	*n*	%
Age (years)	42–86	65.05	11.05		
Gender					
Male				89	56.0
Female				70	44.0
Diagnosis					
Adenocarcinoma				126	79.2
Squamous cell carcinoma				13	8.2
Small cell carcinoma				13	8.2
Others				7	4.4
Tumor stage					
I				2	1.3
II				3	1.9
III				19	12.0
IV				135	84.9
Operation					
Yes				4	3.1
No				155	96.7
Treatments					
Traditional cytotoxic chemotherapy				83	52.2
Target chemotherapeutic				76	47.8
Education level					
Illiterate				14	8.8
Primary school or junior high school				73	45.9
Senior high school graduate or above				72	45.3
Marital status					
Married				123	77.4
Single				36	22.6
Employment					
Yes				20	12.6
No				139	87.4
Caregivers					
Spouse				100	62.9
Others				59	37.1
Smoking					
Yes				66	41.5
No				93	58.5

of the enrolled patients did not smoke. Most of them were unemployed (87.4%), diagnosed with inoperable stage IV lung adenocarcinoma (84.9%), and married (77.4%).

QOL, Symptoms, and Self-Care

Table 2 presents the descriptions of the QLQ-C30, SCBS, MDASI-T, and MSAS SF-Ch. The mean score on the QLQ-C30 was 50 ($SD = 7.32$). Among the three scale types, the functional scales had the highest mean score ($M = 79.60$, $SD = 16.24$), followed by the global health status and cancer-related symptom scales. Of the five subscales of the functional scale, physical functioning had the highest mean score ($M = 85.53$, $SD = 17.42$), whereas role functioning had the lowest mean score ($M = 70.23$, $SD = 28.02$). Among the subscales of the MDASI-T, the average scores for severity of symptoms and degree of interference with life were 1.76 and 2.1 ($SD = 1.42$ and 2.25, respectively). On the MSAS-SF Ch, the mean psychological symptoms subscale score was 0.89 ($SD = 0.83$). The average SCBS score was 4.00 ($SD = 0.34$), and the mean subscale score was highest for infection prevention ($M = 4.42$, $SD = 0.46$) and lowest for food choice and nutrition maintenance ($M = 3.57$, $SD = 0.51$).

Table 2. Descriptive Data of the QLQ-C30, Self-Care, MDASI-T, and MSAS-SF Ch ($N = 159$)

Scales	Items	*M*	*SD*
QLQ-C30 (0–100)	30	50.00	7.32
Functional scales	15	79.60	16.24
Physical functioning	5	85.53	17.42
Role functioning	2	70.23	28.02
Emotional functioning	4	84.07	15.50
Cognitive functioning	2	82.60	17.02
Social functioning	2	75.58	25.35
Cancer-related symptom scales	13	18.42	13.39
Global health status	2	51.99	17.95
MDASI-T (0–10)		1.87	1.58
Symptom severity	13	1.76	1.42
Degree of interference with life	6	2.10	2.25
MSAS-SF Ch (0–4)			
Psychological symptoms	4	0.89	0.83
Self-care (1–5)		4.00	0.34
Avoidance behaviors	3	4.23	0.65
Infection prevention	6	4.42	0.46
Food choice and nutrition maintenance	6	3.57	0.51
Regular exercise and sleep	2	3.95	0.83
Medical compliance	4	3.64	0.53
Awareness of chemotherapy-related side effects	3	4.35	0.49

Note. MDASI-T = M.D. Anderson Symptom Inventory-Taiwan; MSAS-SF Ch = Memorial Symptom Assessment Scale-Short Form Chinese; QLQ-C30 = Quality of Life-Core 30-item.

Relationship Between QOL and Related Factors

Table 3 displays the relationship between QOL and its related factors (patient characteristics, symptoms, and self-care). QOL in lung cancer patients undergoing chemotherapy had a positive correlation with the type of caregiver, FCNM, and RES ($r = .17$, $r = .17$, $r = .40$, respectively; all $P < .05$). QOL had negative correlations with age ($r = -.18$, $P < .05$), tumor stage ($r = -.16$, $P < .05$), severity of symptoms ($r = -.44$, $P < .01$), degree of interference with life ($r = -.58$, $P < .01$), and psychological symptoms on the MSAS-Ch ($r = -.41$, $P < .01$). Furthermore, gender, educational level, marital status, employment status, and treatment regimen showed no correlation with QOL ($P > .05$).

Table 3. Relationships Between the QOL-C30 and Its Related Factors

		QLQ-C30						
		FS						
	QLQ-C30	PF	RF	EF	CF	SF	CRSS	GHS
Age	−.18*	− .31**	.01	.03	−.13	.1	−.04	−.08
Gender	−.06	.13	−.06	.04	.02	−.01	−.07	−.03
Education level	−.02	.11	−.08	−.09	.07	−.09	.04	.04
Marital status	.03	.05	−.02	.03	−.05	−.04	−0.1	.07
Employment	.13	.17**	.05	.1	.05	.01	−.05	.05
Caregivers	.17*	.17*	.04	.05	−.03	−.03	−.02	.13
Tumor stage	− .16*	−.14	− .16*	−.24**	−.14	−.23**	.24**	−.14
Treatments	.03	.12	.09	.11	.01	.22**	−.20*	.06
Diagnosis	− .07	− .29**	− .08	− .02	.05	− .07	.13	−.09
MDASI-T								
SS	−.44**	−.48**	−.58**	−.56**	−.42**	−.65**	.86**	−.54**
DIL	−.58**	−.58**	−.75**	−.54**	−.34**	−.70**	.75**	−.57**
MSAS-SF Ch								
PS	−.41**	−.26**	−.40**	−.83**	−.35**	−.54**	.55**	−.37**
Self-care								
AB	.12	.12	.1	.03	.09	−.05	−.03	.11
IP	.03	.03	.16*	−.01	.03	.07	−.12	.07
FCNM	.17*	.14	.12	.01	.08	.1	−.12	.19*
RES	.40**	.54**	.49**	.19*	.14	.36**	−.49**	.44**
MC	−.11	−.32**	−.25**	−.30**	−.27**	−.25**	.34**	−.08
ACRSE	.08	−.04	.01	.03	.03	.02	−.01	.1

Note. AB = avoidance behaviors; ACRSE = awareness of chemotherapy-related side effects; CF = cognitive functioning; CRSS = cancer- related symptom scales; DIL = degree of interference with life; EF = emotional functioning; FCNM = food choice and nutrition maintenance; FS = functioning scale; GHS = global health status; IP = infection prevention; MC = medical compliance; MDASI-T = M.D. Anderson Symptom Inventory-Taiwan Form; MSAS-SF Ch = Memorial Symptom Assessment Scale Short Form-Chinese; PF = physical functioning; PS = psychological symptoms; QLQ-C30 = Quality of Life Questionnaire Core 30-item; RES = regular exercise and sleep; RF = role functioning; SF = social functioning; SS = symptom severity.
*$P < .05$; **$P < .01$.

Determinants of QOL

The significantly correlated variables in **Table 3**, including age, caregiver type, tumor stage, severity of symptoms, degree of interference with life, psychological symptoms, food choice and nutrition maintenance, and regular exercise and sleep, were analyzed in a regression equation. The regression equation was = 57.14 − 1.63 × (degree of interference with life) − 0.16 × (age) + 2.30 × (food choice and nutrition maintenance) − 1.58 × (psychological symptoms). As a result, the predictors of QOL were degree of interference with life (33%), age (6%), food choice and nutrition maintenance (2%), and psychological symptoms (2%), which together explained 43% of the total variance of QOL (**Table 4**).

Discussion

The results of our study show that lung cancer patients have poor global health status and perceived the lowest role functioning. The reduced QOL with dyspnea, fatigue, coughing, insomnia, appetite loss, and pain as prominent symptoms among lung cancer patients has been confirmed (Larsson et al., 2012; Lin et al., 2013). A previous study also indicated that independence, interaction with others, emotional stability, and psychological comfort are important components of QOL in lung cancer patients (John, 2010). Therefore, patients might lose their role functions when they are cared for by their families, and they might have limitations on what they can freely eat and do because of treatments. Additionally, culture is a main factor affecting patient autonomy. For instance, in Chinese society, once an individual is suffering from an illness, his or her family members normally make decisions for the individual (Hsu, 1999). Therefore, even if the patient has the capacity for medical decision making, it is common for him or her to lose autonomy because of considerations of family values and harmony (Tsai, 2005). Ideally, patients should retain their autonomy and execute their role functions. Future studies could explore how cultural issues impact changes in role functioning in

Table 4. Stepwise Regression Analysis of Functional Scale of Quality of Life

Variables	β	βeta	R^2	VIF	F	P
Constant	57.14				78.46	.01
MDASI-T						
Degree of interference with life	-1.63	-0.50	0.33	1.42		
Age	-0.16	-0.25	0.39	1.03		
Self-care						
Food choice and nutrition maintenance	2.30	0.16	0.41	1.00		
MSAS-SF Ch						
Psychological symptoms	-1.58	-1.80	0.43	1.45		

Note. β = nonstandardized regression coefficient; βeta = standardized regression coefficient; MDASI-T = M.D. Anderson Symptom Inventory-Taiwan; MSAS-SF Ch = Memorial Symptom Assessment Scale-Short Form Chinese; R^2 = coefficient of determination; VIP = variance inflation factor.

lung cancer patients to find ways to improve their role functions.

The highest QOL score (85 ± 17.42) in this study was found on physical functioning, which is compatible with a previous study conducted on 53 patients (mean age 63 years, range 47–76 years) by Nowak, Stockler, and Byrne (2004). However, other studies by Larsson et al. (2012) showed that the highest mean score was on the cognitive functioning subscale (83 ± 21). This difference may be due to the older age of the participants in this study. Aging can decrease cognitive function and affect QOL (Akechi et al., 2017). In addition, traditional cytotoxic chemotherapy treatment may cause more side effects that affect physical function (Zhang et al., 2015). In this study, only 52.2% of participants received traditional cytotoxic chemotherapy treatment in comparison to 100% of patients in the study by Larsson et al. (2012). Therefore, this difference may explain why the physical functioning score in our study was better.

Our study demonstrated that lung cancer patients, who had their spouses as caregivers and higher self-care scores, had better QOL. Furthermore, the self-care of food choice and nutrition maintenance is a predictor for QOL. Marriage represents intimacy and responsibility, and spouses could provide patients with more assistance and care in daily life (Johnson, 1983; Stetz, 1987). The caregiver has been reported to experience stress and burden due to the workload and challenges (Chen, 2007). In addition, a balanced diet may promote optimal functioning of the body (Amarantos, Martinez, & Johanna, 2001). With a better understanding of food choice, patients can cooperate more readily in treatment and improve their self-care ability (Hsu & Lin, 2011). Additionally, good nutritional support not only prevents patients from cachexia but also helps them experience a better QOL (Chou, 2000). Therefore, lung cancer patients should be encouraged to strengthen self-care behaviors, which can help maintain their roles and reduce the burden on the caregiver. Future studies may be focused on designing the self-care intervention to improve QOL in lung cancer patients.

Our findings identified four predictors—degree of interference with life, age, psychological symptoms, and food choice and nutrition maintenance—for QOL in lung cancer patients undergoing chemotherapy. The degree of interference with life accounted for up to 33.3% of the total variance for QOL, which is higher than the symptom cluster (28.8%) in a previous study (Yang, 2009). Having a symptom is an event, which does not affect functional QOL. For instance, feeling nauseous might not be a severe symptom, but it could affect the QOL of the patient by reducing appetite and activity. These results may explain why the symptom cluster poorly relates to QOL. In this study, symptom interference was evaluated based on responses regarding "enjoying life" and "regular activity." Clinically, assessments of symptom interference with daily living and its causes could help enhance QOL in lung cancer patients. Hence, continually assessing and improving symptom interference in patients may be essential to enhance QOL.

Study Limitations

Chemotherapy medications, dosages, and treatment times may affect QOL in lung cancer patients. Future studies that examine the aforementioned variables along with laboratory data, such as white blood cell counts and measurements of hemoglobin levels, are suggested.

Conclusions and Implications

Lung cancer patients gave lower scores to food choice and nutrition maintenance, regular exercise and sleep, and medical compliance on the SCBC. Additionally, several factors were identified that related to QOL in lung cancer patients undergoing chemotherapy. More focus should be placed on those who had lower QOL due to severe physical or psychological symptoms that interfere with patients' daily life, while development of intervention plans for empowering lung cancer patients to have food choice and nutrition maintenance, enhance self-care behaviors of regular exercise and sleep, observe medical compliance, and manage psychological symptoms undergoing chemotherapy (especially in those who are older and not cared for by their spouses) is also highly recommended. Additionally, it is imperative that healthy providers routinely assess symptom-related interference in daily living to develop an individual intervention to enhance QOL.

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Clinical Resources

- American Cancer Society. https://www.cancer.org/cancer/lung-cancer.html
- Cancer Research UK. http://www.cancerresearchuk.org/about-cancer/lung-cancer
- Lung Cancer Organization. https://www.lungcancer.org/

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JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

The Roles of Social Support and Health Literacy in Self-Management Among Patients With Chronic Kidney Disease

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Key words
Chronic kidney disease, health literacy, nursing, self-management, social support

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Abstract

Aims: To investigate the relationships among social support, health literacy, and self-management, and the factors influencing self-management of chronic kidney disease (CKD).
Design: Cross-sectional study.
Methods: A random sample of 410 patients was recruited from nephrology clinics. Data were collected using structured questionnaires and chart reviews from January 2013 to February 2014. Hierarchical regression analysis was used to determine the predictive factors of self-management behaviors and ΔR^2 to determine each variable's explanatory power.
Findings: Health literacy and social support were positively correlated with self-management behaviors. Furthermore, social support, health literacy, and marital status were significant predictors of self-management behaviors. Social support had a relatively greater explanatory power for self-management behaviors than did health literacy. Particularly, healthcare provider support had the greatest influence on patients' self-management behaviors.
Conclusions: Health literacy and social support play independent positive roles in self-management behaviors of patients with CKD, with social support having a particularly dominant role. Further research using a systems approach to improving self-management behaviors is necessary to clarify the role of social support.
Clinical Relevance: Health literacy and social support are independently and positively related to self-management. Social support, which is a system-level factor, is a relatively stronger and crucial predictor than is health literacy. Nurses have to refine self-management programs to focus on families and adopt a systems approach to help CKD patients improve their self-management behaviors.

Chronic kidney disease (CKD) has become a global health issue. According to a World Health Organization report (WHO; 2014), about 8.1 million people died from CKD in 2011, with a mortality rate of 12% per 100,000 population. The death toll and mortality rate for 2030 are expected to rise to 11.5 million and 14%, respectively. Globally, Taiwan consistently reports the highest incidence of end-stage renal disease (ESRD), followed by

Mexico's Jalisco region, and the United States (458, 421, and 363 per million people, respectively; Saran et al., 2016; U.S. Renal Data System [USRDS], 2015). CKD is a very important health problem that is characterized by poor health outcomes and health-related quality of life, and very high healthcare costs (Chen, Hsu, Yamagata, & Langham, 2010). High incidence and prevalence rates of CKD are likely due to poor control of chronic disease and population aging. Once such patients begin long-term dialysis, they often develop complications requiring treatment while continuing to receive dialysis to sustain their lives. This can be highly costly to both the patients and the healthcare system, and it has a heavy impact on the lives of patients and their families (Chen et al., 2010). Although CKD cannot be cured, appropriate medication combined with self-management, often via lifestyle modifications, can mitigate and delay its progression and complications (Bonner et al., 2014).

Self-management behaviors promote individuals' adaptation to the disease, including improvement of treatment adherence, disease control, quality of life, and self-perceived health status (Bonner et al., 2014; Sattoe et al., 2015). Self-management for CKD is rather practical—it comprises problem solving, managing daily life according to medication regimens, and engaging in health promotion behaviors. However, the nature of the disease, coupled with its progression and the fact that CKD patients are often older and have multiple diseases, makes daily self-management a complicated task (Bonner et al., 2014; Ong, Jassal, Porter, Logan, & Miller, 2013). Despite advances in medical therapy and case management, CKD patients continue to demonstrate inadequate self-management, leading to poor management outcomes (Chen et al., 2011, 2015; Ong et al., 2013). Thus, to perform optional self-management, patients require a certain degree of health literacy (Fransen, von Wagner, & Essink-Bot, 2012).

Health literacy is the ability to access, process, comprehend, utilize, and effectively communicate with healthcare providers about health information, including disease knowledge, to make appropriate healthcare decisions (Devraj & Gordon, 2009; Nutbeam, 2008). Evidence for a relation between health literacy and self-management behaviors remains inconsistent. Some studies have found that inadequate health literacy is independently associated with worse self-management behaviors and poorer health outcomes among individuals with chronic illness (Mantwill & Schulz, 2015; Suka et al., 2015). Others, however, have found no association between health literacy and self-management behaviors (Londoño & Schulz, 2015). Fransen and colleagues (2012) conducted a systematic review to confirm this inconsistency and further indicated that there is limited evidence for a significant association in diabetes patients. More research is needed to confirm, however, whether health literacy is related to patients' understanding of treatment options and self-management behaviors (Devraj & Gordon, 2009; Fransen et al., 2012), and to identify what other factors determine self-management behaviors. Such research would inform programs seeking to improve and sustain self-management behaviors in patients with CKD. Understanding the crucial determinants of self-management behaviors prior to formulating such a care program is important.

Social support is defined as resources provided by a network of individuals and social groups. Members of one's social network who provide support include peers, family, religious group members, professionals, etc. The members of social networks provide emotional, tangible, informational, and companionship support (Chen & Ku, 1998; Lee, Arozullah, & Cho, 2004; Lora et al., 2011). Higher levels of social support can improve one's ability to acquire and understand medical information, and to negotiate in the healthcare system, which would be particularly important for people to facilitate the establishment of healthful attitudes and behaviors (Chen & Ku 1998; Lee et al., 2004; Lora et al., 2011). Several studies of social support on chronic diseases have found that social support can be instrumental in improving self-management behaviors and reducing factors affecting the progression of diseases (Koetsenruijter et al., 2016; Lora et al., 2011; Vaccaro, Exebio, Zarini, & Huffman, 2014). Furthermore, patients with CKD in Taiwan are predominantly over the age of 65 years (i.e., approximately 80%) and generally have comorbidities. Social support has also been found to influence patients' health behaviors and disease management outcomes (Chen et al., 2010; USRDS, 2015). In general, social support represents a modifiable factor and may serve as a therapeutic target for CKD patients. Therefore, understanding the role social support plays in self-management behaviors is essential in the development of medical standards of care practices.

A useful framework for studying the determinants of self-management is the social ecology theory, which posits that self-management behaviors are determined by multilevel factors. In this theory, health literacy would be conceptualized as an individual-level factor, whereas factors such as health resources or social support would be considered system-level factors (Fisher et al., 2005; Koh, Brach, Harris, & Parchman, 2013). Health behaviors are affected not only by individual factors, but also by system factors. Indeed, individual factors are insufficient in explaining self-management (Koh et al., 2013;

von Wagner, Steptoe, Wolf, & Wardle, 2009). A particularly important system-level factor in Eastern cultures involves social support, given that significant others, such as family members and healthcare providers, tend to perform most of the disease care and management for patients with CKD (Li, Jiang, & Lin, 2014). However, the majority of previous studies have investigated the effects of health literacy (Bohanny et al., 2013; Fransen et al., 2012; Lai, Ishikawa, Kiuchi, Mooppil, & Griva, 2013) and social support (Koetsenruijter et al., 2016; Li et al., 2014; Soto et al., 2015; Vaccaro et al., 2014) on the predictors of self-management separately. Those results did not represent the whole picture of the predictors' effects on self-management. Even though others have tested the mediators of the self-management and health literacy relationship (Bennett, 2016; Edwards, Wood, Davies, & Edwards, 2013; Lee, Arozullah, Cho, Crittenden, & Vincencio, 2009), there is little consistency in these results. Thus, clarifying the association between health literacy, social support, and self-management behaviors could help healthcare providers devise better strategies to engage patients with CKD in their self-management behaviors.

Nursing care managers are the first line of contact with patients. Peeters and colleagues (2014) reported that nurses who provided sufficient care and education could attenuate the decline of kidney function and improve renal outcomes in patients with CKD. However, the growth in the number of patients with CKD is rapidly outstripping their ability to provide patient self-management education and preventive efforts, which is an important concern for nursing care and research (Bennett, 2016; Kao, 2015). To further clarify this association and to uncover the predictors of self-management behaviors, this study sought to empirically investigate two research questions. First, this study aimed to investigate the correlations among health literacy, social support, and self-management behaviors. Second, this study aimed to determine the factors influencing self-management behaviors, particularly with regard to the independent effects of health literacy and social support among patients with CKD. We hypothesized that individuals with a higher level of health literacy and social support would have greater self-management behaviors. Moreover, because the majority of CKD patients are elderly who need assistance from family and healthcare providers to implement their disease care, we also hypothesized that social support would exhibit greater effects than health literacy on self-management behaviors. In other words, the system-level factors would demonstrate a greater association with self-management behaviors than the individual-level factors among CKD patients.

Methods

Design

The study applied a cross-sectional design. The analysis was drawn from a larger prospective research project that examined the effects of the health literacy intervention on CKD management. In this article, we used the baseline data to address the hypotheses related to health literacy, social support, and self-management behaviors.

Participants and Sampling

The study population consisted of patients diagnosed with CKD. Inclusion criteria included CKD patients who had received CKD case management services for more than 3 months, were over 20 years old, had intact cognition, and were able to communicate in Chinese or Taiwanese. CKD is defined as abnormalities in kidney structure or function that have persisted for at least 3 months and have physical complications. Its classification is based on glomerular filtration rate (GFR; Inker et al., 2012). In this study, we classified CKD into four stages based on health insurance reimbursement regulations in Taiwan: (a) early stage, GFR ≥45 mL/min per 1.73 m^2; (b) Stage 3b, GFR 30 to 44 mL/min per 1.73 m^2; (c) Stage 4, GFR 29 to 15 mL/min per 1.73 m2; and (d) Stage 5, GFR <15 mL/min per 1.73 m^2. We excluded all patients with paralysis, dementia, intellectual disabilities, or cancer.

G∗power 3.1.5 (Faul, Erdfelder, Buchner, & Lang, 2009) was used to calculate the required sample size. According to the results of previous studies (Lai et al., 2013; Li et al., 2014), we estimated that an appropriate sample size for the analysis was 98 patients for each CKD stage, based on alpha level = .05, conventional medium effect size = 0.3, and power = 0.8 in multiple regression analysis. Furthermore, to account for the representative numbers of patients considered at each CKD stage and 20% nonresponse rate, we approached 120 eligible patients from each CKD stage, respectively. Of the 480 eligible patients who were approached, 410 agreed to participate in the present study (85.4% response rate), including 106 in early stage, 116 in Stage 3b, 103 in Stage 4, and 85 in Stage 5. Finally, we calculated the power, which was 0.95 in this study.

A random sample was recruited from nephrology clinics in two medical centers and two regional hospitals in northern Taiwan. Participants were selected via stratified random sampling from each CKD stage. A list of patients who were using nursing case management services was obtained through CKD care programs in four hospitals by the first and second authors (Y-C.C. and L-C.C.). After reviewing the patient list, the sample pool was first divided into four categories according to the patient's GFR level. Second, because the patients were initially assigned a chart number that cannot be used for random assignment, we randomly reassigned each patient a new number with three digits, starting with 001 in each category. This gave us a better understanding of the different subsample size in each subcategory. Finally, we used simple random sampling to draw out three numbers ranging from 0 to 9 as the selected numbers. If the last digit of the patient's new number matched the selected numbers, the patient was invited to participate in the study. This allowed us to randomly select the participants from the total subsample pool to obtain the minimum required subsample size without the influence of the different subsample size in each subcategory.

Data Collection

The study was approved by the relevant institutional review boards (IRB numbers 2013-01-019ACY, 2013109R, and TCHIRB-1011210-E). Before data collection, CKD patients received written and verbal information by well-trained research assistants regarding the purpose and procedure of the study, their voluntary participation, the possibility to quit at any time, and the confidentiality of their responses. CKD patients were welcome to ask questions before they agreed and signed the informed consent. Data were collected via self-report questionnaires and chart reviews from January 2013 to February 2014. When the selected participants visited the clinic for their regular appointments, their case managers notified them of the invitation to participate in this study. Then, research assistants explained the study aims and the questionnaire content. Individuals who agreed to participate and signed the consent form subsequently completed the questionnaires either by themselves or with the help of a research assistant.

Measures

The structured questionnaires included items regarding the independent variables (i.e., personal characteristics, subjective health condition, social support, and health literacy) and the dependent variable (i.e., self-management behaviors). We used well-developed scales to assess social support, health literacy, and self-management behaviors, as described below. All scales have been tested and validated in Chinese adults or CKD patients, and have demonstrated good reliability and validity. Nevertheless, we confirmed their content validity via a panel of nine experts in the field of CKD patient care and education. The content validity indexes for all instruments were 0.87 to 1, indicating good content validity.

Personal characteristics and subjective health condition. We collected data on personal characteristics, including gender, age, marital status, living condition, education level, employment status, length of time using the case management service, and CKD stage. Subjective health condition, including perceived severity of renal disease and overall health status, was measured using 3-point Likert scales, with higher scores reflecting more severe renal disease or better-perceived overall health.

Health literacy. The Short-form Mandarin Health Literacy Scale (s-MHLS) contains 11 items to assess functional health literacy in terms of the person's ability to read, comprehend, and utilize basic health information when making individual health decisions (Lee, Tsai, Tsai, & Kuo, 2012). The s-MHLS is a shortened version of the Mandarin Health Literacy Scale (MHLS; Tsai, Lee, Tsai, & Kuo, 2011). The MHLS was developed and validated to assess functional health literacy in people who use the Mandarin Chinese language. The s-MHLS is strongly correlated with the MHLS ($r = .97$, $P < .001$; Lee et al., 2012). Confirmatory factor analysis supported the unidimensionality of the s-MHLS. The psychometric analysis shows that the s-MHLS is valid and reliable, and yields a better fit than the MHLS. The internal consistency of the s-MHLS was Cronbach's $\alpha = .94$ in the original study (Lee et al., 2012) and .89 in this study. Items are presented in multiple-choice format, with eight items assessing reading and comprehension skills, and three items assessing numeracy skills. Correct responses are given 1 point, and no points are given for incorrect responses. Total scores range from 0 to 11, with higher scores reflecting better health literacy.

Social support. The Social Support Scale developed by Chen and Ku (1998) measures the amount of social support received by ESRD patients. The 16-item scale comprises two subscales assessing support sources (family and healthcare providers) and social support function (emotional, informational, tangible, and esteem), and it can thus assess support from a systems level. The content validity was at acceptable levels as rated by the expert panel (content validity index ranging from 0.85 to 0.96). The original scale demonstrated good internal consistency for both the total score (Cronbach's $\alpha = .90$) and the two subscales (Cronbach's $\alpha = .87$ and .93). It has also demonstrated reliability among patients with CKD and diabetic nephropathy (Cronbach's $\alpha = .93$; Chen, 2010). Its Cronbach's α was .91 in this study. Each item is rated on a 4-point Likert scale, and the total scores range from 32 to 128, with higher scores reflecting a greater amount of perceived social support.

Chronic kidney disease self-management. The original chronic kidney disease self-management instrument (CKD-SM) was developed by Lin, Wu, Wu, Chen, and Chang (2013) to assess CKD patients' self-management behaviors, including illness adaptation, decision making, and illness control. It comprises 29 items and contains four subscales: self-integration, problem solving, seeking social support, and adherence to recommended regimens. In the current study, these four factors accounted for 60.51% of the total variance. Each factor demonstrated acceptable internal consistency (Cronbach's α ranging from .77 to .92), and the test-retest correlations for the CKD-SM were 0.72. Chen (2010) revised the CKD-SM using an expert panel, which added another item about diet. This revised version of the CKD-SM also demonstrated good reliability for both the total scale and the subscales (Cronbach's α ranging from .81 to .95). It was also shown to be adequate in this study, with Cronbach's α of the total scale at .95, and subscales ranging from .87 to .94. Items are rated on 4-point Likert scales, with response options ranging from 1 (*never*) to 4 (*always*). Possible total scores range from 30 to 120, with higher scores indicating greater self-management behaviors.

Data Analysis

All statistical analyses were performed using SPSS Statistics 20.0 for Windows (IBM Corp., Armonk, NY, USA). $P < .05$ was considered significant. Data were coded, and a descriptive analysis was performed using percentages, means, and standard deviations on all variables. Independent t tests, one-way analysis of variance, and post-hoc testing were used to examine the relationships between demographics, health literacy, and self-management behaviors. We also calculated Pearson's correlations between social support, health literacy, and self-management behaviors. We conducted further analyses for variables with correlations above .6.

Hierarchical regression analysis was used to determine the factors predicting self-management behaviors. Before conducting the regression analysis, the following variables were dummy coded: age, education level, marital status, living condition, and subjective health condition. Subsequently, assumptions of normality and independence were examined through standardized residual plots. Neither assumption was violated, and collinearity statistics indicated that there was no multicollinearity among the independent variables. In model 1, we included demographics and subjective health condition as predictors of self-management behaviors. In models 2 and 3, we added health literacy and social support, respectively. We examined ΔR^2 to determine the explanatory power of each independent variable.

Results

Participant Characteristics and Descriptive Statistics of Health Literacy, Social Support, and Self-Management Behaviors

Participants' characteristics are shown in Table S1. A total of 410 participants were recruited. There was a low response rate for participants in Stage 5 CKD because of the relatively low subsample pool and some patients did not return for follow-up to receive renal replacement therapy. The majority of the participants were male (63.2%), married (78.5%), unemployed (80%), and living with their children (37.1%). Their average age was 70.43 years ($SD = 13.10$), with most being in the age range of 65 to 79 years (38.8%). Most participants were in CKD Stage 3b (28.3%) and had utilized case management services for 36 months (42.9%). The proportion of participants who perceived their renal disease as moderate severity and average overall health was 53.3% and 46.6%, respectively. Notably, 31.7% of the participants reported perceiving their renal disease as "not severe." These results indicate that most participants had low awareness of CKD.

The mean health literacy and social support scores were 7.1 ($SD = 3.4$, range 0–11) and 104 ($SD = 20.3$, range 32–128), respectively, indicating that participants had moderate to high health literacy and social support. The participants scored the highest for emotional support ($M = 28.0$, $SD = 5.1$) and lowest for tangible support ($M = 24.5$, $SD = 5.2$). The participants also received more support from healthcare providers than from family ($M = 54.0$, $SD = 10.8$ vs. $M = 50.0$, $SD = 13.0$). Healthcare providers provided more information and esteem support, while family members were the major source of tangible support. Self-management behavior scores ranged from 30 to 120, with a mean of 88.73 ($SD = 20.53$), indicating that participants performed most of the self-management tasks for CKD. According to the subscales, the mean scores were highest for self-care ($M = 3.39$, $SD = .70$) and lowest for adherence to recommended regimen ($M = 2.28$, $SD = .93$).

Health Literacy and Self-Management Behaviors by Participant Characteristics

We found that health literacy was significantly related to gender, age, education, employment status, marital status, living condition, CKD stage, and subjective health condition (see Table S1). Post hoc tests indicated that health literacy scores were higher in participants who were younger, male, single, living with spouse, had higher education levels, and at early-stage CKD. Regarding self-management behaviors, we found that participants who were younger, had higher education levels, were single, perceived their health status as good, and had very severe renal disease engaged in more self-management behaviors. However, CKD stage was not significantly related to self-management behaviors.

Social Support, Health Literacy, and Self-Management Behaviors

The correlations among health literacy, social support, and self-management are shown in Table S2. Consistent with our expectations, social support ($r = .64$; $P < .001$) and health literacy ($r = .33$; $P < .001$) were both positively correlated with self-management behaviors. Social support from healthcare providers and from family were strongly correlated with self-management behaviors (total score; $r = .60$ vs. $r = .50$). Moreover, social support from family was significantly correlated with adherence to recommended regimen, which is a subscale of self-management behaviors ($r = .62$ vs. $r = .44$). Notably, social support and health literacy were positively, but nonsignificantly, correlated ($r = .09$; $P = .088$). Social support from family was also significantly correlated with health literacy ($r = .12$).

Predictors of Self-Management Behaviors

Table S3 shows the results of the hierarchal regression of self-management behaviors. Social support, health literacy, age, and marital status together explained 52.1% of the variance in self-management behaviors ($\beta = .59$, $P < .001$). More specifically, in model 2, health literacy individually explained 5.5% of the variance in self-management behaviors (F-change = 26.874), while in model 3, social support explained 32.4% of the variance (F-change = 262.754). As it had the highest explanatory power, social support was deemed the strongest predictor of self-management behaviors.

Discussion

To our knowledge, this is the first study to compare the influences of health literacy and social support on self-management behaviors. Our findings support the hypotheses that social support and health literacy were significantly correlated with self-management behaviors, and social support had a higher explanatory power than health literacy. In other words, system-level factors are a more crucial determinant of self-management behaviors compared to individual-level factors. Our results demonstrated that both individual and system factors are vital for self-management behaviors, but the social support from family and healthcare providers is more important to individual healthcare ability. Wittenberg, Goldsmith, Ferrell, and Ragan (2017) also reported that self-management behaviors for CKD are complex social phenomena and are deeply affected by the context of social environment. Both Naranjo, Mulvaney, McGrath, Garnero, and Hood (2014) and Fisher and colleagues (2005) adopted a social-ecological approach and proposed that healthcare providers might shift the focus of self-management enhancement programs from individuals to families or the social context. Thus, patients might modify their daily activities to ensure that they have a supportive environment, good social network, and good support sources to achieve their disease management goals (Ansmann et al., 2014; Koetsenruijter et al., 2016; Mansyur, Rustveld, Nash, & Jibaja-Weiss, 2015; Rowlands, Shaw, Jaswal, Smith, & Harpham, 2015). In summary, social support appears to be an essential, modifiable factor for self-management behaviors, making it a suitable therapeutic target for patients with CKD.

The present study shows that health literacy was positively correlated with self-management behaviors, but it had comparatively weak predictive power. Suka and colleagues (2015) reported that health literacy was linked to health behaviors via health information access. Patients with low health literacy would be shy to ask questions and have difficulty in reading and learning health knowledge and skills (Fransen et al., 2012; Lee et al., 2004; Tsai, Lee, & Tsai, 2013). Therefore, they need assistance to understand that information (Lee et al., 2009). It is important that nurses have the sensitivity to detect patients' needs and provide sufficient support to help them. Moreover, from an individual-level perspective, the relationship between health literacy and self-management behaviors might be mediated by psychological factors. For instance, several studies have found that empowerment and self-efficacy are mediators in this relationship (Bohanny et al., 2013; Fransen et al., 2012; Lee et al., 2016; Londoño & Schulz, 2015). Lee and colleagues (2016) demonstrated that self-efficacy is linked to health literacy and self-care behaviors. When combining this with Lin and colleagues' (2012) findings that late-stage CKD patients had especially low self-efficacy, the weak relationship we found may be due to low self-efficacy in our participants, given that they tended to be older, had more comorbidities, and had late-stage CKD (later than Stage 3b). However, Tsai and colleagues (2013) failed to find an indirect effect of health literacy on health behaviors via individual attitudes and motivation in a Taiwanese population study. Thus, we cannot draw definite conclusions on this relationship, which necessitates further research to confirm if those psychological factors can play a mediator role in improving CKD patients' self-management behaviors.

Early stage CKD patients had better health literacy than did pre-ESRD patients, but they had the worst self-management behaviors of all types. The correlation between health literacy and self-management behaviors did not seem consistent. Those patients were also younger. This is probably because early stage CKD is typically asymptomatic, which means that patients have low awareness and could easily ignore their condition, thus leading to delayed treatment (Burke, Kapojos, Sammartino, & Gray, 2014; Hsu et al., 2006; Navaneethan, Aloudat, & Singh, 2008). In addition, younger populations with good health literacy, competency, and autonomy relied less on health providers' consultations, thus leading to poor or misinformed self-management behaviors (Londoño & Schulz, 2015). Therefore, patient-centered service is an important strategy to provide suitable and acceptable information to improve patients' health behaviors. Londoño and Schulz (2015) also reported that health literacy did not significantly influence self-management behaviors overall, but only critical health literacy was key to the utilization of health information, which is an aspect of self-management behaviors. Similarly, Heijmans, Waverign, Rademakers, van der Vaart, and Rijken (2015) also demonstrated that only communicative and critical health literacy were related to some aspects of self-management behaviors, while functional health literacy was less important to self-management behaviors. The measurement tools used may be a reason for the discrepancy in results. Another possible reason that health literacy was weakly associated with self-management behaviors is that the s-MHLS focuses on reading and communication, which refer to functional health literacy abilities.

Social support was the stronger determinant of self-management behaviors. Previous studies have indicated that social support likely mediated the relationship between health literacy and health behaviors, or interacted with health literacy to influence health behaviors (Fransen et al., 2012; Lee et al., 2004). However, we observed no association between health literacy and social support, suggesting that neither mediation nor moderation was likely. Instead, these variables appeared to be independent predictors of self-management behaviors, echoing Lee and colleagues' (2009) findings. In Chinese culture, most patients with chronic diseases rely on healthcare providers and family to manage their care tasks, which likely explains the strong influence of social support in our study. Health literacy and social support, notably, are on different levels according to the social ecological model (Fisher et al., 2005; Mansyur et al., 2015). Our results suggest that system-level factors might have stronger influences on self-management behaviors for CKD than individual-level factors.

Social support sourced from healthcare providers and family both had strong association with self-management behaviors in our study. CKD care is more complex than is care of other diseases because it presents an array of concomitant risk factors. Thus, patient care must consider the patient's social circumstances over the lifetime. Patients with CKD engage in long-term cooperation and close interaction with healthcare providers (Lora et al., 2011; Ong et al., 2013). Furthermore, the CKD case management program, which is covered by national health insurance, provides regular follow-up education and consultation in Taiwan. The outcomes of this program have shown that healthcare providers play important roles in instructing patients in disease management care skills and providing advice for patients' individual health conditions and lifestyles, which improve their self-management behaviors and CKD management outcomes (Ansmann et al., 2014; Chen et al., 2011, 2015). Therefore, the healthcare provider is an important social support resource for patients to learn self-management behaviors according to their individual situation. On the other hand, family members play a different role to help patients carry out disease management tasks. Family caregivers provide more hands-on, day-to-day care than do any other individuals. As such, they not only need access to information, but also the ability to process and act upon information in order to provide the best quality care. Therefore, family caregivers are expected to be helpful in encouraging self-management behaviors and thereby ensuring better health outcomes (Sperber, Sandelowski, & Voils, 2013; Vaccaro et al., 2014). When healthcare providers provide the disease care, family caregivers cannot be ignored, especially in the elderly population. Moreover, previous studies have shown that caregivers' health literacy influenced health management outcomes (Levin, Peterson, Dolansky, & Boxer, 2014; Paschal, Mitchell, Wilroy, Hawley, & Mitchell, 2016; Wittenberg et al., 2017). Wittenberg and colleagues (2017) and Levin and colleagues (2014) mentioned that caregivers with higher health literacy obtained more health information and had a better ability to act affably and maintain effective roles. Unfortunately, our study did not measure caregivers' health literacy, so we could not draw conclusions in this relation. Thus, further research needs to explore the effects of caregivers' and patients' health literacy in relation to patients' health behaviors or health service utilization at the same time.

The study has several limitations. First, although we used random sampling, participants tended to be older, had lower education levels, and had late-stage CKD. Thus, our results might not be generalized to all patients with CKD. Second, because most participants received a CKD case management program for over 24 months, they had better relationships with case managers in our study. Participants were referred by case managers, meaning that they might be more willing to comply with healthcare providers than individuals who declined to participate. Additionally, participants might overestimate their self-management behaviors and social support in front of case managers. Third, the questionnaires were self-reports, and we lacked objective measures of self-management behaviors, caregiver health literacy, and health outcomes. Thus, reported self-management behaviors might have been biased. However, this bias could have been partly mitigated by using an anonymous questionnaire, thus increasing participants' openness. Finally, the cross-sectional design precludes causal inferences, so we can only speculate on the mechanisms underlying the effects of social support and health literacy.

Conclusions

We found that patients with early-stage CKD who are elderly, live alone, and have inadequate social support might have the poorest self-management behaviors. Furthermore, health literacy and social support play independent positive roles in the self-management behaviors of patients with CKD, with social support having a stronger influence. To improve patients' self-management of their CKD, care services should refine self-management programs to focus on families and adopt a systems approach. Nurses and case managers should not only provide adaptive health-literacy education programs, but also build up supportive environments, strengthen social support function, and connect social support resources to improve patients' self-management behaviors. Further research using a systems approach to improving self-management behaviors is necessary to clarify the role of social support.

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Clinical Resources

- Agency for Healthcare Research & Quality. Self-management support. https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/self/index.html
- Self Management UK. http://selfmanagementuk.org/
- Self-Management Resource Center. Chronic Disease Self-Management Program (Better Choices, Better Health® Workshop). http://patienteducation.stanford.edu/programs/cdsmp.html
- World Health Organization. Track 2: Health literacy and health behavior. http://www.who.int/healthpromotion/conferences/7gchp/track2/en/

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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. Participant Characteristics and Comparisons by Health Literacy and Self-Management Behaviors

Table S2. Correlations Between Self-Management Behaviors, Social Support, and Health Literacy

Table S3. Hierarchical Regression Analysis of Self-Management Behaviors

JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Biomarkers as Common Data Elements for Symptom and Self-Management Science

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Abstract

Purpose: Biomarkers as common data elements (CDEs) are important for the characterization of biobehavioral symptoms given that once a biologic moderator or mediator is identified, biologically based strategies can be investigated for treatment efforts. Just as a symptom inventory reflects a symptom experience, a biomarker is an indicator of the symptom, though not the symptom per se. The purposes of this position paper are to (a) identify a "minimum set" of biomarkers for consideration as CDEs in symptom and self-management science, specifically biochemical biomarkers; (b) evaluate the benefits and limitations of such a limited array of biomarkers with implications for symptom science; (c) propose a strategy for the collection of the endorsed minimum set of biologic samples to be employed as CDEs for symptom science; and (d) conceptualize this minimum set of biomarkers consistent with National Institute of Nursing Research (NINR) symptoms of fatigue, depression, cognition, pain, and sleep disturbance.

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Design and Methods: From May 2016 through January 2017, a working group consisting of a subset of the Directors of the NINR Centers of Excellence funded by P20 or P30 mechanisms and NINR staff met bimonthly via telephone to develop this position paper suggesting the addition of biomarkers as CDEs. The full group of Directors reviewed drafts, provided critiques and suggestions, recommended the minimum set of biomarkers, and approved the completed document. Best practices for selecting, identifying, and using biological CDEs as well as challenges to the use of biological CDEs for symptom and self-management science are described. Current platforms for sample outcome sharing are presented. Finally, biological CDEs for symptom and self-management science are proposed along with implications for future research and use of CDEs in these areas.

Findings: The recommended minimum set of biomarker CDEs include pro- and anti-inflammatory cytokines, a hypothalamic-pituitary-adrenal axis marker, cortisol, the neuropeptide brain-derived neurotrophic factor, and DNA polymorphisms.

Conclusions: It is anticipated that this minimum set of biomarker CDEs will be refined as knowledge regarding biologic mechanisms underlying symptom and self-management science further develop. The incorporation of biological CDEs may provide insights into mechanisms of symptoms, effectiveness of proposed interventions, and applicability of chosen theoretical frameworks. Similarly, as for the previously suggested NINR CDEs for behavioral symptoms and self-management of chronic conditions, biological CDEs offer the potential for collaborative efforts that will strengthen symptom and self-management science.

Clinical Relevance: The use of biomarker CDEs in biobehavioral symptoms research will facilitate the reproducibility and generalizability of research findings and benefit symptom and self-management science.

This position paper is the third in a series, authored by the Directors of National Institute of Nursing Research (NINR) Centers of Excellence (P30) and Exploratory Centers (P20) that focus upon advancing symptom and self-management science through the utilization of common data elements (CDEs). The goal is to conceptually define, operationalize, and measure outcomes across research studies. The first paper focused upon the identification and development of CDEs for self-reported symptoms, their use, data-sharing platforms, benefits and challenges of CDEs in symptom science, and future research implications of CDEs for symptom science (Redeker et al., 2015). The second paper focused upon CDEs for research addressing self-management of chronic conditions (Moore et al., 2016). This third paper proposes biochemical biomarkers as CDEs for symptom and self-management science as a means by which to integrate biological with behavioral characterizations of symptoms and self-management. Once biological mechanisms for symptoms can be discerned, treatment efforts can focus on these biological mediators and moderators. This is an important endeavor given the National Institutes of Health (NIH) NINR strategic emphasis on symptom science. In 1998, the NIH Biomarkers Definitions Working Group defined a biomarker as “a characteristic that is objectively measured and evaluated as an indicator of normal biological processes, pathogenic processes, or pharmacologic responses to a therapeutic intervention” (Strimbu & Tavel, 2010, p. 463).

The purposes of this paper are to (a) identify a minimum set of biomarkers for consideration as CDEs in symptom and self-management science, (b) evaluate the benefits and limitations of such a limited array of biomarkers with implications for symptom science, (c) propose a strategy for the collection of the endorsed minimum set of biologic samples to be employed as CDEs for symptom science, and (d) conceptualize this minimum set of biomarkers consistent with NINR symptoms of fatigue, depression, cognition, pain, and sleep disturbance and aligned with a framework of the biobehavioral characterization of sickness behavior, a longstanding heuristic model that is of reasonable complexity with regard to brain and behavior interactions.

Best Practices for Selecting and Using Biological Common Data Elements

Several principles warrant consideration when planning for the integration of biological and behavioral outcomes in symptom and self-management science and more specific recommendations of biomarkers as CDEs. The first principle is analytic validity, that is, determining whether specific biomarkers are consistently reflective of a given symptom such that changes in biomarker levels are accompanied by changes in report of that symptom. Depending upon the approach, it would also be theoretically and conceptually important to evaluate whether interventions that alter symptoms also alter biomarker levels in a consistent way. If a biomarker is hypothesized to underlie the symptom or self-management phenomenon under study, it should be altered by the intervention if the biomarker mediates the symptom. Adding to the complexity of these relationships, however, is the recognition that individual biomarkers may mediate or moderate multiple pathways or multiple biomarkers may impact a single pathway (Miaskowski, 2016). The second principle is the quality of the evidence for each biomarker as it relates to the behavioral phenomenon, particularly with regard to the consistency of the "pairing" between behavioral and biomarker findings. Meta-analytic and rigorous experimental design are the most desirable approaches for building scientific support for these relationships. The third principle relates to our ability to measure biomarkers with precision, sensitivity, and specificity in any appropriately equipped laboratory. This principle also assumes appropriate sample collection, processing, and preservation before measurement, assuring sample quality as well as administrative precision and appropriate attribution of sample to participant. Continuing validation of biomarker and behavioral relationships contributes to their usefulness as CDEs. These three principles guided the deliberations of the writing team throughout the 8 months of meetings during which the recommendations for biomarker inclusion in symptom science were developed and consensus was reached. Compared to self-management science, there is a much greater body of literature supporting biomarkers for symptom science.

Sickness behavior offers an exemplar of relationships among a constellation of symptoms that accompany infection in both humans and animals. Symptoms including fatigue, sleep disturbance, reduced appetite, anhedonia, fever, myalgia, depressive symptoms, and pain emerge along with the immune activation mounted in response to the infection (Dantzer, 2001; McCusker & Kelley, 2013). Although it remains unclear exactly how a localized or systemic inflammatory response is transmitted to the central nervous system and initiates the sickness symptom response (Poon, Ho, Chiu, Wong, & Chang, 2015), studies in rats and mice have demonstrated that this symptom constellation is caused by increased pro-inflammatory cytokine levels in the brain. Mechanisms by which this may occur are several, including (a) entry of peripherally elevated cytokines into the brain through the blood–brain barrier; (b) activation of the afferent arm of the vagus nerve, which then conveys an inflammatory signal to the brain; or (c) cytokine production in the brain as a consequence of the immune activation in response to the infection (Poon et al., 2015). Pro-inflammatory tumor necrosis factor alpha (TNF-α) or interleukin (IL)-1 beta (IL-1β) are necessary for the development of sickness behaviors (McCusker & Kelley, 2013). Human experimental endotoxemia via the administration of small doses of lipopolysaccharide (LPS), cell wall components of Gram-negative bacteria, is a strategy to study inflammation-induced changes in cognition and motivation. The exemplar of sickness behavior is consistent with the NIH Symptom Science Model (Cashion & Grady, 2015) that describes how complex symptoms reflect the outcome of an individual's phenotype, including biological, genetic, psychosocial, and behavioral factors. Sickness behavior likewise reflects a constellation of symptoms that arise in an individual based on an inflammatory phenotype, overlaid on personal factors. As such, sickness behavior offers a mechanistic framework to better predict, track, and target the biology underlying individual symptom experiences.

Identifying and Selecting Biological Common Data Elements

Identifying and selecting biomarkers to include in a given research study ultimately depends upon the research question and the evidence in the literature. For nurse scientists, such biomarkers might include those known or suspected of playing a role in mechanistic pathways associated with symptoms or symptom clusters of acute or chronic illness, or stress. Within the sickness symptom framework described above, biomarkers associated with inflammation are often a choice for study inclusion given the reported associations between inflammation and fatigue (Kim, Miller, Stefanek, & Miller, 2015; Louati & Berenbaum, 2015; Morris, Berk, Walder, & Maes, 2015), pain (DeVon, Piano, Rosenfeld, & Hoppensteadt, 2014; Diatchenko, Nackley, Slade, Fillingim, & Maixner, 2006; Ji, Chamessian, & Zhang, 2016; Klyne, Barbe, & Hodges, 2017), depressive symptoms (Cai, Huang, & Hao, 2015; Huang & Sheng, 2010; Kiecolt-Glaser, Derry, & Faqundes, 2015; Miller &

Raison, 2016) cognitive function (Harden, Kent, Pittman, & Roth, 2015), and sleep disturbance (Harden et al., 2015; Kamath, Prpich, & Jillani, 2015).

Biomarkers associated with exposure to acute or chronic stress are also often measured in nursing science protocols, reflecting the recognition by many that emotional, physical, neighborhood, financial, relational, and societal stressors have a significant impact on health and well-being. Studies focusing upon self-management of symptoms and including biomarkers have been conducted, but are less common in the literature. For example, an abbreviated progressive muscle relaxation stress-management technique yielded reductions in psychological stress measures and diurnal cortisol secretion among first year university students (Chellew, Evans, Fornes-Vives, Pérez, & Garcia-Banda, 2015); and a 10-week guided imagery intervention in women with fibromyalgia improved self-reported self-efficacy and reduced perceived stress, fatigue, pain severity, and depressive symptoms compared to usual care, although immune biomarkers were not significantly impacted (Menzies, Lyon, Elswick, McCain, & Gray, 2014). Biomarkers that are more specifically linked to a given symptom or condition are also included in many research protocols. For example, investigators may measure specific hormones or neuroimaging biomarkers to explore mechanisms, risks, or treatments for hyperalgesia (Matic, van den Bosch, de Wildt, Tibboel, & van Schalk, 2016; Maurer, Lissounov, Knezevic, Candido, & Knezevic, 2016). Likewise, measuring changes in levels of brain-derived neurotrophic factor (BDNF), a peptide involved in neurogenesis, may be useful to evaluate how interventions such as exercise improve cognition (Meeusen, 2014), which, in turn, may improve self-management.

Immune and Inflammatory Markers

The immune response includes both innate and specific reactions driven by the increased production of white blood cells (WBCs) and the secretion from those cells of chemical products, including cytokines (Paul, 2013). Cytokines, defined as small peptides secreted by WBCs drawn to sites of injury or infection (Dinarello, 2007), provide communication between different types of WBCs. By this means, cytokines direct the immune and inflammatory response, and play a key role in host defense. Since normal or abnormal levels of cytokines remain imprecisely defined, cytokine levels are typically compared between groups or within one group before and after an event or intervention. Often cytokines are grouped as pro- or anti-inflammatory, or as contributing to the innate or active immune response.

The innate immune response involves the secretion of pro-inflammatory cytokines, including IL-1β, IL-2, IL-6, interferon-gamma (IFN-γ), and TNF-α, from type 1 T helper (Th1) lymphocyte activation of peripheral blood mononuclear cells, including macrophages, monocytes, and natural killer cells (Dinarello, 2007). Elevated levels of pro-inflammatory cytokines initiate cell-mediated and phagocytic-protective responses, and have been linked to the development of sickness symptoms (Dantzer & Kelley, 2007) as well as a variety of chronic and acute disease states (Godbout & Glaser, 2006; Wang et al., 2014). Other cytokines, including IL-4, IL-10, and IL-13, are generally considered anti-inflammatory and are responsible for various aspects of the specific immune response such as antibody production and eosinophil accumulation. The release of anti-inflammatory cytokines is primarily under the control of a different subset of T lymphocytes called T helper 2 (Th2) cells. Th2 responses are characteristic of humoral, or B cell, immunity. These cytokines are considered anti-inflammatory to a large extent because of their ability to inhibit the production of the pro-inflammatory cytokine transcription factor nuclear factor-kappa beta (NFkappaB), thereby suppressing pro-inflammatory cytokine gene activation and cytokine production. Measuring levels of pro- and anti-inflammatory cytokines, or the ratio of pro- to anti-inflammatory cytokines, provides a sensitive measure of cytokine equilibrium or disequilibrium (Petrovsky, 2001).

Cytokines are typically measured in plasma or serum samples collected from a study participant using sterile technique and processed according to specific protocols. Cytokine levels have also been reported in urine and saliva.

Markers of Stress

Biomarkers of acute and chronic stress of interest to nursing scientists often include the hormones of the hypothalamic-pituitary-adrenal (HPA) axis: corticotropin-releasing hormone (CRH), adrenal corticotropin hormone (ACTH), and cortisol. Elevation in any of the HPA axis hormones may occur with exposure to acute or chronic stress, and each has been associated with sickness symptoms, including depressive symptoms (Raison & Miller, 2013), heightened pain sensitivity and sleep disturbance (Dantzer, O'Connor, Freund, Johnson, & Kelley, 2008). Moreover, given the accumulating evidence that chronic stress interferes with cognitive functioning, exposure to chronic stress may interfere with an individual's ability to self-manage his or her health or a caregiver's ability to be an effective contributor to the self-management of another's health (Allen et al., 2017; Arnsten, 2015). Collection and analysis of plasma, serum, or cerebral spinal fluid levels of CRH and ACTH require strict consideration of sample collection methods, sample processing, and bioassay techniques. Cortisol levels are easily measured in plasma, serum, hair, or saliva, but consideration of free (salivary) versus bound (blood) cortisol, and of the strong diurnal rhythm of all HPA axis hormones, must be considered when planning studies involving these biomarkers (Segerstrom, Boggero, Smith, & Sephton, 2014). If serum or plasma samples are chosen, separation of free versus bound cortisol or concurrent measurement of cortisol-binding globulin would be required.

Also, frequently studied when considering biologic responses to chronic stress is the interaction between the inflammatory response and cortisol levels. Pro-inflammatory cytokines, released in response to infection, trauma, or psychological stress, are potent stimulators of the HPA axis, leading to increased levels of circulating cortisol (Petrovsky, 2001; Steptoe, Hamer, & Chida, 2007). Circulating cortisol binds to the cytoplasmic glucocorticoid receptors of WBCs, and once bound, the cortisol-receptor complex translocates to the nucleus where it inhibits the production of key cytokine transcription factors, effectively halting pro-inflammatory cytokine production (Pace & Miller, 2009; Ratman et al., 2013). This cytokine-glucocorticoid negative feedback cycle is an important homeostatic mechanism by which the inflammatory response is controlled. This negative feedback cycle can be disrupted in persons exposed to chronic stress due to a decreased sensitivity of the glucocorticoid receptor to chronically elevated cortisol, contributing to overproduction or dysregulated production of pro-inflammatory cytokines (Corwin et al., 2013; Pace & Miller, 2009). Biomarkers measured in studies of glucocorticoid resistance may include cortisol and pro-inflammatory cytokine ratios or levels of cytokine transcription factors such as NFkappaB. NFkappaB can be measured in blood samples using enzyme-linked immunosorbent assay (ELISA) kits.

Other Biomarkers of Frequent Interest to Nursing Science

BDNF is a peptide required for brain neurogenesis, including axonal growth and synaptic plasticity. BDNF is linked to fetal and infant neurodevelopment, as well as memory, neuronal plasticity, cognition, and affect across the lifespan (Angelucci, Brenè, & Mathè, 2005). The BDNF locus is on chromosome 11, and a relatively common single nucleotide polymorphism within the BDNF gene, Val66met, has been linked to the development of depressive symptoms in response to stress exposure (Gatt et al., 2009). Serum BDNF protein levels vary depending upon genotype (Lang, Hellweg, Sander, & Gallinat, 2009), and have been reported to increase with exercise in a sex-dependent manner (Szuhany, Bugatti, & Otto, 2015), but decrease with chronic stress (Gatt et al., 2009), inflammation (Tong et al., 2012), and aging (Patterson, 2015). Compared to a control group, older heart failure patients undergoing a cognitive training intervention, Brain Fitness, improved working memory and exhibited increased BDNF protein levels (Pressler et al., 2015). Recently, epigenetic changes in the BDNF gene were identified as possible links between environmental stressors and psychological disorders (Mitchelmore & Gede, 2014). BDNF upregulation in the spinal dorsal horn following noxious stimulation plays an important role in the development of central sensitization, a maladaptive neuroplasticity that drives long-term and persistent pain (Merighi et al., 2008; Nijs et al., 2015; Smith, 2014). As a biomarker in nursing research studies, BDNF may be measured before and after an intervention such as exercise, or in patients with chronic disease, or may be compared across populations. BDNF protein can be measured using an ELISA method, and BDNF mRNA can be measured via quantitative polymerase chain reaction (qPCR) in serum, leukocytes extracted from serum, or plasma samples. The decision of how and when to measure BDNF, however, can be complex, as there are other factors, including time of blood draw, sex, blood storage time, food intake prior to blood draw, smoking status, and other sociodemographic factors, that are critically important for consideration prior to designing the experiment (for review see Cattaneo, Cattane, Begni, Pariante, & Riva, 2016).

Another category of biomarkers frequently evaluated in nursing research is genetic polymorphisms. As with BDNF, genetic polymorphisms have been identified that influence whether and to what degree an individual might experience a particular symptom, and thus their presence or absence may be considered a risk or protective factor for symptom development. For example, polymorphisms of genes coding for cytokines have been linked to increased risk of fatigue (Lee, Gay, Lerdal, Pullinger, & Aouizerat, 2014), sleep disturbance (Miaskowski et al., 2012), depressive symptoms (Kim et al., 2013; Tartter, Hammen, Bower, Brennan, & Cole, 2015), and pain hypersensitivity among cancer patients (Oliveira et al., 2014; Shi et al., 2015). Other studies have linked genetic polymorphisms of the BDNF gene to pain and depressive symptoms in older adults (Klinedinst, Resnick, Yerges-Armstrong, & Dorsey, 2015), to dysmenorrhea (Lee et al., 2014), and to chronic musculoskeletal pain (Generaal et al., 2016). These and similar examples emphasize the range of clinically relevant research studies utilizing genetic biomarkers.

Measuring genetic polymorphisms requires first isolating the DNA and then sequencing the samples using PCR. Each of these steps requires careful consideration of the sample source (whole blood or serum) and access to DNA sequencing technology.

Platforms for Sample Outcome Sharing

Identifying and selecting biomarkers in symptom and self-management research is extremely important; however, equally important are electronic platforms by which stored sample sets can be explored and leveraged, and expert collaborators can be identified to enhance research.

NINR center collaboration involves identifying and leveraging opportunities within universities and clinical centers and potentially across other NIH centers or other universities (Dorsey et al., 2014). Big data science is an exploding field in which data sharing and collaboration have become the norm, and awareness of where to find these opportunities is key. There are many informative and comprehensive web-based platforms that are now available for obtaining biospecimens or datasets, or finding other scientists with whom to collaborate in utilizing profiling platforms, research collaboration platforms, and biorepository platforms (Redeker et al., 2015). Table S1 offers examples of these platforms.

Sample Quality and Administrative Oversight

The ability to utilize biological CDEs across studies depends upon the quality of the samples and the rigor by which they are collected, maintained, and assayed. Key to ensuring sample quality is consideration of, and strict adherence to, the methods by which each sample is collected. This may include time of day if the biomarker has a diurnal rhythm, may require subjects to be fasting, or may or may not require that a sample be kept on ice prior to processing and may or may not need to adhere to certain time constraints. For many types of biological sample collections, specific tubes with additives may be required (e.g., Tempus Blood RNA tube [Fisher or Paxgene Blood RNA tubes would both be viable tubes for measurement of DNA]). The sample may need to be centrifuged prior to aliqoting and freezing. In some cases, a sample may need to be incubated at a certain temperature, for a specified period of time. Similar detail will be required to ensure consistency in assay procedures. For example, if a commercial kit will be used in assaying a particular analyte, the same kit is recommended to be used by other investigators if possible, and details on all procedures need to be consistent across laboratories. These and other considerations must be discussed a priori, based on best practices from the literature. It will also be essential that collected samples are cataloged as they come into a laboratory and as they are assayed there or sent to other laboratories. Tracing the course of a sample from its collection, to processing, to storage, to assay or transport also contributes to the scientific rigor, transparency, and reproducibility of the data generated from that sample.

Challenges to the Use of Biological Common Data Elements for Symptom and Self-Management Science

Challenges in selecting and using biomarkers for symptom and self-management science include identifying and selecting relevant biomarkers that are components of the biological pathways of interest, and careful operationalization of symptom and self-management phenotypes, including multidimensionality, clustering, and temporal patterning.

Multiple biological pathways may contribute to symptoms and self-management, and each of these may have multiple biomarkers. Examples as described above may include the HPA axis stress pathways, inflammatory pathways, and sickness behavior. In some cases, little may be known about underlying pathways, or competing explanations may need to be tested. Understanding of putative pathways is needed to identify relevant biomarkers of interest. In the event that multiple biomarkers are examined, this may be associated with significant cost.

Distinct phenotypes of symptoms and the impact of self-management interventions must be selected with care to sensitively detect associations of biomarkers with these phenomena or to examine the effects of symptom and self-management interventions on biology. Challenges to phenotyping symptoms and self-management include the wide variety of operational definitions of symptom and self-management concepts; the inherently multidimensional, temporal, and perceptual characteristics of these phenomena; overlap and multicollinearity among symptoms; cultural, linguistic, developmental, and cognitive differences in the expression of these self-reported phenomena; and their meanings to respondents. For example, depressive symptoms have cognitive and somatic dimensions, such as sleep disturbance and fatigue (Schaakxs, Comijs, Lamers, Beekman, & Penninx, 2017), while pain and other symptoms have sensory, affective, and functional dimensions. Care must be taken to elicit relevant dimensions because biomarkers may be differentially related to various dimensions of these self-reported phenomena, although these possible differences are not yet well described. Although CDEs for symptom (Redeker et al., 2015) and self-management science (Moore et al., 2016) have been identified, further specification is needed to fully understand how multiple dimensions interact with biomarkers of interest. Standardization across studies is also needed to make the most efficacious use of data.

Symptoms also often occur in clusters during everyday life in individuals suffering with chronic conditions, such as cancer (Dong, Butow, Costa, Lovell, & Agar, 2014) and heart disease (Moser et al., 2014). Recent evidence suggests that biomarkers, such as cytokines, are associated with membership in specific symptom clusters (e.g., Illi et al., 2012). If a single symptom is actually part of a cluster, the specificity of the biomarker to one particular symptom may be compromised. Because symptoms are also temporal phenomena, with diurnal (Van Onselen et al., 2013; Wright et al., 2015) or seasonal rhythms, these patterns should be accounted for in relation to biomarkers that may also fluctuate (e.g., salivary cortisol). Symptoms also depend upon the context in which they are perceived. For example, a symptom that may be considered mild while an individual is interacting with loved ones may become much more unpleasant or burdensome when the individual is alone or in the hospital (Corwin et al., 2014). A mismatch between the timing of symptom measurement and the biomarker may also obscure associations or effects.

Culture (Moser et al., 2014; Park & Johantgen, 2016), language, reading level, aging, sex, and developmental level (Schaakxs et al., 2017), among other factors, influence how symptoms and self-management are reported and measured (Redeker et al., 2015). Factors such as aging, race, sex, and gender may also influence biomarkers, genes, and gene expression. Therefore, these factors should be considered in analyses and selection of measures to contextualize findings and minimize bias.

The causal nature of symptoms and biomarkers must also be considered and may be bidirectional (Corwin, Meek, Cook, Lowe, & Sousa, 2012). For example, sleep disturbance may be either a cause or a consequence of sympathetic arousal and HPA axis activation; and limitations in self-management (e.g., inability to exercise or adhere to medical treatment regimens) may contribute to changes in biological pathways and relevant biomarkers as well as behavior. These challenges suggest the ongoing need for experimental and longitudinal studies to understand causal relationships.

Implications for Future Research and Use of Biological Common Data Elements for Symptom and Self-Management Science

An intended outcome of this third paper in the series is, as with the previous two, to identify a short list, minimum set, of CDEs, in this case, biological CDEs, to be recommended for inclusion in appropriate symptom and self-management research studies. These recommendations, along with brief measurement guidelines are presented in Table S2.

The Benefits of Biological Common Data Elements to Symptom and Self-Management Science

There are multiple benefits to incorporating biological CDEs into symptom and self-management science. First, measuring biological CDEs can provide insights into the mechanistic underpinnings of patient symptoms, including symptom clusters. For example, data showing that IL-6/IL-10 ratios increase over time in patients with worsening heart failure compared to patients with stable disease, while at the same time, cognitive deficits and fatigue increase as well, potentially provide insights into the mechanisms by which cognitive deficits and fatigue develop in those patients, that is, that these symptoms may be driven by a similar increase in the pro- or decrease in the anti-inflammatory response (Petrovsky, 2001). Second, when developing an intervention to relieve or manage a given symptom, investigators often propose a theoretical or conceptual model that includes a pathway by which the intervention is hypothesized to work. When testing the intervention, measuring a biomarker known to be associated with that pathway before and after the intervention could provide evidence of both the efficacy of the intervention and the applicability of the model (Corwin & Ferranti, 2016). For example, again considering cognitive deficit and fatigue in heart failure patients, if a 6-month exercise intervention hypothesized to improve cognitive function and reduce fatigue by reducing inflammatory pathways does indeed lead to an improvement in symptoms compared to baseline and if that improvement is accompanied by a corresponding decrease in the IL-6/IL-10 ratio pre- to postintervention, this would suggest that the intervention is effective and the proposed model is supported. However, if there is symptom improvement in the absence of change in the cytokine ratio, the hypothesized mechanism by which the intervention is thought to be effective might need to be reconsidered. Other studies have been published recently as well, wherein biomarker status at baseline has been reported to predict the efficacy of an intervention, potentially allowing clinicians the ability to identify individuals up front who might or might not respond to the intervention in the future. For example, baseline levels of certain cytokines were identified as predictive of who would respond to a mindfulness-based stress reduction intervention and who would not (Reich et al., 2014), and in a separate study, baseline levels of certain cytokines were identified as predictive of which patients with treatment-resistant depression would benefit from the addition of an anti-inflammatory drug to their standard depression therapy and who would not (Raison et al., 2013). These latter examples demonstrate the power of measuring biomarkers to advance precision health care. Lastly, and perhaps most importantly, including biological CDEs offers the potential for collaboration across nursing research studies, which in turn will increase sample size, generalizability of findings, and data reproducibility. This is especially true if the biological CDEs are used in conjunction with the previously suggested NINR CDEs for behavioral symptoms and for research addressing self-management of chronic conditions. In this way the scientific impact of nursing research will continue to grow, and patients, families, and communities will benefit.

Clinical Resources

- National Institute of Neurological Disorders and Stroke. NINDS common data elements. https://www.ninds.nih.gov/Funding/Apply-Funding/Application-Support-Library/NINDS-Common-Data-Elements
- National Institute of Nursing Research. Common data elements at NINR. https://www.ninr.nih.gov/site-structure/cde-portal
- National Institutes of Health, U.S. National Library of Medicine. Summary Table for NIH CDE initiatives. https://www.nlm.nih.gov/cde/summary_table_1.html

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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. Examples of Profiling Platforms, Research Collaboration Platforms, and Biorepository Platforms

Table S2. Biomarkers Recommended for Inclusion in Symptom Science and Self-Management Research (Pain, Fatigue, Cognition, Depression, and Sleep)

JOURNAL OF NURSING SCHOLARSHIP

CLINICAL SCHOLARSHIP

Children’s Perceptions About the Quality of Pediatric Nursing Care: A Large Multicenter Cross-Sectional Study

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Abstract

Introduction: This study explored children’s perceptions about the quality of nursing care and the determinants of their evaluations according to different categories of children’s ages.
Design: Multicenter cross-sectional study carried out on 692 pediatric patients in eight large Italian regional hospitals.
Methods: We used a validated questionnaire, translated and adapted to the Italian context, consisting of 49 items (5-point Likert scale) exploring nurse characteristics, nursing activities, and nursing environment.
Findings: The mean score of children’s perceptions of their overall experience of hospitalization was 3.96; the nurse characteristics factor obtained the highest score (mean = 3.79), and it was in positive correlation with the satisfaction level across different age categories: 4 to 6 years, $\beta = .37$; 7 to 11 years, $\beta = .31$; and 12 to 14 years, $\beta = .32$.
Conclusions: Nurse characteristics is the only significant factor contributing to children’s satisfaction across the three different age categories.
Clinical Relevance: In pediatric nursing care, it is important to emphasize that nurses’ personal characteristics and the ability to connect with children are essential compared to the ability to perform tasks.

Quality of care is a multifaceted concept, together with organizational indicators. Many researchers agree that patient satisfaction is a core indicator of quality of care (Johansson, Oléni, & Fridlund, 2002; Mpinga & Chastonay, 2011; Suhonen et al., 2012). Patient satisfaction with nursing care is defined as the individual evaluation of the cognitive and emotional reaction related to the interaction between patients’ expectations of ideal nursing care and their perceptions of the actual care (Eriksen, 1995).

Patients’ perspectives regarding the quality of care have often been investigated in patient satisfaction surveys; in the context of pediatric care in particular, the quality of nursing care has been explored from parents’ perspectives, and children’s perceptions of pediatric nursing care have not been systematically taken into account in developing the quality of care. Several studies have highlighted that to date children are less likely to be consulted and involved in health care (Coyne, Hallström, & Söderbäck, 2016; Coyne & Kirwan, 2012; Hill, Davis, Prout, & Tisdall, 2004), and children usually have greater difficulties in expressing their evaluations of quality of nursing care (Ygge & Arnetz, 2001). Therefore, parents are often asked to evaluate the quality of care instead of their children. However, the extent to which parents can appropriately express their children’s opinions may be limited, and factors that affect satisfaction could differ between children and their parents; for example, children’s feelings of fear and their perceptions of interpersonal relationships are different because their experience of hospitalization is characterized by the interaction with unknown people in unfamiliar environments (Pelander & Leino-Kilpi, 2010).

In a pediatric healthcare setting, the children's right to information and participation in medical and nursing care is fundamental (Coyne, 2006), and it is one of the key principles of hospital standards that ensure that the child's view is taken into account to provide child-centered services, responsive to their needs and preferences (Department of Health, 2003). Children's opinions and perceptions regarding their experiences of hospitalization play a pivotal role in monitoring and evaluating the effectiveness and quality of healthcare services (Coyne & Kirwan, 2012). In the past 2 decades, many researchers have emphasized the importance of encouraging hospitalized children to participate in clinical decision making (Coyne, 2008; Coyne, Amorya, Kiernan, & Gibson, 2014; Moore & Kirk, 2010; Runeson, Enskar, Elander, & Hermeren, 2001), promoting children to express their own views in accordance with their age and maturity (Department of Health 1993, 1997; Runeson et al., 2001); more recently, researchers have recognized the importance of also including children as research participants (Coyne, 2010). However, very few studies have investigated pediatric patient valuations (Mah, Tough, Fung, Douglas-England, & Verhoef, 2006), and few studies have explored, as a primary outcome, the quality of pediatric nursing care from the children's points of view (Pelander, Leino-Kilpi, & Katajisto, 2007, 2009). Moreover, to our knowledge, no available studies have explored the variation of children's perceptions of nursing care quality across different age groups.

Background

Patient evaluations are often expressed with the term "satisfaction" (Pelander & Leino-Kilpi, 2004); most research concerning the quality of pediatric nursing from the children's view has been based on patient satisfaction studies, exploring children's satisfaction and the experience of hospitalization from the parents' perspectives (Bragadottir & Reed, 2002; Byczkowski et al., 2013; Homer et al., 1999; Schaffer, Vaughn, Kenner, Donohue, & Longo, 2000; Ygge & Arnetz, 2001,), and few studies included children's perspectives (Chesney, Lindeke, Johnson, Jukkala, & Lynch, 2005; Magaret, Clark, Warden, Magnusson, & Hedges, 2002) or adolescents' perspectives (Mah et al., 2006). Moreover, such studies demonstrated that parent satisfaction ratings were higher than those of their children (Chesney et al., 2005; Mah et al., 2006), and children differed from their parents on the lowest satisfaction items (Chesney et al., 2005).

Different tools have been used to analyze children's perceptions of nursing care, but often these instruments were not specifically tailored for use by children themselves (Stewart, Lynn, & Mishel, 2005) or were not tested and published internationally (Pelander et al., 2009). Among available validated questionnaires, only the Child Care Quality at Hospital (CCQH) instrument was developed on the basis of children's expectations and the definitions of the quality of pediatric nursing. Therefore, there is a need for further research to explore children's views of nursing care quality in different cultural contexts and clinical settings (Pelander et al., 2009). The purpose of this study was to evaluate quality of care as perceived by children in the Italian context, and to identify the determinants of the evaluation according to different categories of children's ages.

Methods

Design and Setting

This multicenter cross-sectional study was carried out from November 2013 to June 2015 on a convenience sample of pediatric patients from eight large Italian regional hospitals in four regions of central and southern Italy (Abruzzo, Marche, Sicily, and Puglia). Data were gathered from hospitals with pediatric units that agreed to participate in the study. In each hospital, data were collected from all pediatric wards with the same level of "entertainment" for children (possibility to have games, toys, books, places to be with parents or friends, and places to play with other hospitalized children), excluding intensive care, psychiatric, and neurological units.

Study Population

We asked for the participation of eight hospitals within the Italian national healthcare system. No restrictions in terms of number of beds or complexity were applied. We used a convenience sample to recruit hospitalized pediatric patients. Eligible participants included all children between 4 and 14 years of age. The choice to recruit children from 4 to 14 years of age was made to better represent the hospital experience of the majority of patients involved in pediatric care. Scale reliability was tested in this sample because, at present, scale reliability was only tested in the 7- to 11-year-old population. Eligible participants also included children with no mental impairment or psychiatric disorders, who were able to speak and read Italian, and to self-administer the questionnaire with either a parent's or legal guardian's support (Pelander et al., 2009). Children were excluded if they were unable to speak or read Italian; to complete the questionnaire due to the presence of acute disease or mental or psychiatric disorder; in cases of the absence of parents or legal guardians; and if they had not provided assent or their parents or guardians had not given permission.

Data Collection Procedures

In each participating hospital a trained researcher was responsible for participant recruitment. All researchers were previously trained to ensure the same recruitment protocol approach in all study centers. After enrollment, the researcher administered a validated instrument (Pelander et al., 2009) to each participant, who filled out the questionnaire before being discharged and deposited the completed questionnaire in an envelope inside a special box to ensure anonymity. Data from patients under 6 years of age were collected with parents' help. Specifically, parental presence helped to increase the child's trust in the researcher, and parents helped by reading questions and writing answers indicated by preschool children; however, parents were not allowed to interfere with the child's answers, since this would have affected the reliability of our results. In fact, the questionnaire items were rated on Likert scales with both words and graphic representations (smiley faces and teddy bears) to make the questionnaire more suitable for children and to facilitate obtaining a child's perspective, even from the youngest patients.

Instrument Description

In this study, we used the Italian version of the previously validated CCQH instrument (Pelander et al., 2009). The questionnaire consisted of 49 items divided into three main quality factors: nurse characteristics (5 items, which assessed nurses' humanity, competence, sense of humor, and trustworthiness), nursing activities (25 items, which assessed entertainment, caring and communication, supporting initiative, education, and physical care and treatment), and nursing environment (19 items, which assessed the physical, social, and emotional environments). Preliminary questions were included to describe demographic characteristics (gender and age), background data regarding the reason and duration of their hospitalization, parents' presence during the hospital stay, previous experiences of hospitalization, and characteristics of the hospital room. Moreover, the questionnaire included two open-ended questions to explore children's perceptions of the best and the worst things during their hospitalization.

Finally, children were asked to give their overall rating of the satisfaction with care, answering the following question: "How would you grade your hospital experience (from 1 = *worst experience* to 5 = *best experience*)?"

The items concerning nurse characteristics and nursing activities are rated on a 5-point Likert scale to measure frequency, using both words and graphic representations (from 1 = *never* = :(to 5 = *always* = :)). The nursing environment items are rated using a 5-labeled agreement/disagreement scale using teddy bear icons. The higher the score, the better the perceived quality of nursing care.

Validity and Reliability of the Instrument

Previous researchers have tested the psychometric proprieties of the CCQH instrument in pediatric settings, demonstrating the validity and reliability of the questionnaire (Pelander, 2008; Pelander et al., 2009). The CCQH questionnaire is the only validated instrument specifically designed to measure the quality of pediatric nursing from children's points of view (Pelander & Leino-Kilpi, 2004; Pelander, Leino-Kilpi et al., 2007).

In this study, the overall scale reliability was 0.93, and it varied from 0.76 to 0.93 among the three factors: In detail, the nurse characteristics factor (5 items) had a Cronbach's α of .91, the nursing activities factor (22 items) had a Cronbach's α of .93, and the nursing environment factor (19 items) had a Cronbach's α of .77. To date, the scale has been tested in a population of 7- to 11-year-olds; in the Italian sample, the reliability was stated in a wider age range. To better test the scale's reliability in the different age categories, Cronbach's α was tested in the 4 to 6 years, 7 to 11 years, and 12 to 14 years age groups. In the 4- to 6-year-old participants, the overall reliability was 0.89; in detail, reliability was 0.69 for the nurse characteristics factor, 0.87 for the nursing activities factor, and 0.79 for the nursing environment factor. In the 7- to 11-year-old category, the Cronbach's α was .94 (overall), and .79, .94, and .74 for the three nursing factors, respectively. In the 12- to 14-year-old sample, the Cronbach's α was .94 (overall), and .70, .93, and .81 for the three nursing factors, respectively. Content validity was confirmed by the translation process. Confirmatory factor analysis was not performed due to sample size.

Translation Procedures and Adaptation of the Questionnaire to the Italian Context

After the author's permission to translate and use the questionnaire, a forward-backward translation of the original version of the instrument (Pelander et al., 2009) was performed to establish semantic and conceptual equivalence with the Italian context. First, the CCQH was translated from English into Italian by two Italian researchers. Secondly, the Italian version was translated back into English by two bilingual researchers who were blind to the original questionnaire (White & Elander, 1992). Finally, the back-translated version was reviewed by the authors of the original instrument (Pelander et al., 2009) to check the accuracy of the translation (White & Elander, 1992).

Some items were adapted to the Italian hospital context, and consequently, three items were omitted because they did not fit adequately to the context of this study. In a pilot phase to test the instrument in the Italian context, many participants did not respond to the items "help with eating," "help with bathing," and "help with toileting," probably because in Italian hospitals parents often take care of these issues rather than nurses. Moreover, in the pilot study a 5-point Likert scale was preferred instead of the 4-point Likert scale, in line with the panel of expert opinion. This was because other tools used in pediatric care were rated on a 5-point scale, and both patients and nurses were more confident using this kind of rating.

Data Analysis

Preliminary data analyses were performed to assess instrument reliability. The internal consistency of the Italian version of the CCQH questionnaire was measured with Cronbach's α: If α values are over .70, the reliability of the scale is acceptable (De Vellis, 2003). If the proportion of missing data in the total amount of variables for each respondent was more than 7%, the case was deleted listwise (Graham, 2009). In the pilot study, three items reported a lot of missing data due to the characteristics of pediatric care in Italy, so the items were deleted from the final data analysis.

Sample description and data on children's perceptions of quality of nursing care were first analyzed using descriptive statistics. To test study aims, regression analysis was performed. Each factor's tool has been regressed on the perceived overall hospital experience as a dependent variable to identify the factors that better explain children's evaluations. The statistical significance was set at $p < .05$. All statistical analyses were performed with the Statistical Package for Social Science version 20 for MacOS (SPSS Inc., Chicago, IL, USA)

Ethical Considerations

The study protocol was approved by the ethics committees of the coordinating center. To be enrolled, all included children gave their consent, and then parents or legal guardians gave their permission and signed informed consent was obtained. All participants were informed both verbally and with an informative letter.

Table 1. Overall Characteristics of the Sample ($n = 692$)

Variables	*n* (%)
Mean age in years (*SD*)	9.82 (2.41)
Age categories	
4–6	50 (7.2)
7–11	458 (66.2)
12–14	184 (26.6)
Gender	
Male	351 (50.7)
Female	341 (49.3)
Duration of hospitalization (night)	
1	64 (9.2)
2	185 (26.7)
3	183 (26.4)
4	115 (16.6)
≥5	145 (21.0)
Previous hospitalization	
Yes	379 (54.8)
No	275 (39.7)
Do not know/remember	29 (4.2)
Parents' present during hospitalization	
All the time	639 (92.3)
During daytime	40 (5.8)
During admission and discharge	13 (1.9)
Hospital room	
Private	152 (22.0)
Private and shared with children	330 (47.7)
Shared with other children	210 (30.3)

Results

Characteristics of the Sample

A total of 712 questionnaires were administered, and 692 children completed the questionnaire (response rate: 97.2%). The mean age of the sample was 9.82 ($SD = 2.41$) years. Most participants had spent two or three nights in hospital ($n = 185$, 26.7%; and $n = 183$, 26.4%, respectively) and in 639 cases, their parents were with them for the entire duration of hospitalization (92.3%). None of the participants had a personal nurse who cared for them. Demographics and children's characteristics are reported in **Table 1**.

Evaluations of the Quality Categories

The children were asked to evaluate their overall hospital experience on a scale from 1 to 5: the mean score was 3.96 ($SD = 0.93$). The highest score among the main categories was obtained for nurse characteristics (mean = 3.79, $SD = 1.07$). The mean score for

Table 2. Regression Model Overall

	Quality of care[a]			
Regression model	*β*	*t*	*p*	R^2 *(p-value)*
Nurse characteristics	.326	6.911	.000	0.250
Nursing activities	.145	2.951	.003	(.000)
Nursing environment	.106	2.697	.007	

[a]Dependent variable.

the nursing activities category was 3.03 ($SD = 0.96$), and the mean score for nursing environment was 2.78 ($SD = 0.64$).

Factors Connected With Perceptions of Quality

A first regression model of correlation between children's perceived overall hospital experience and the main categories of the instrument to measure the quality of care (nurse characteristics, nursing activities, nursing environment), revealed that 25% of the variance in children's perceptions of the overall hospital experience was explained by the model ($p < .001$).

The quality of nursing care perceived in the nurse characteristics category ($\beta = .326$, $p = .000$) had the greatest correlation with the children's perceptions of their overall hospital experience; all correlations were statistically significant. The overall results of the regression model are reported in **Table 2**.

Three regression models were performed according to the different age categories of the sample, in order to better target nursing interventions to improve children's evaluations. In detail, the regression model of the three factors on the perception of the overall hospital experience was performed on children under 6 years of age, from 7 to 11 years of age, and from 12 to 14 years of age.

The three factors that were studied regarding children's perceptions of their overall hospital experience were best exemplified among the 7- to 11-year-old sample ($R^2 = 0.26$). In the children under 6 years of age, the variance explained by the factors' scale is 0.20, while in the 12- to 14-year-old category it was 0.23. Among the three age categories, the factor that most related to good care was nurse characteristics ($\beta = .37$, $\beta = .31$, and $\beta = .32$, respectively). The nursing activities factor had a negative correlation among children under 6 years of age ($\beta = -.12$) and, compared to the other age categories, it had the strongest correlation with children's perceptions of their overall experience of hospitalization among 7- to 11-year-olds ($\beta = .19$). The nursing environment factor had a stronger correlation among children under 6 years of age ($\beta = .27$), while it did not contribute to perceived good care among 7- to 11-year-olds. Looking at the statistical significance of correlations, the nurse characteristics factor was significant for the three age categories, while nursing activities was significant in contributing to perceived good care only in the 7- to 11-year-old category. The nursing environment factor did not show significant correlation in the three age categories. **Table 3** summarizes the detailed results by age category.

Table 3. Variation of Children's Perception of Quality Across Different Age Categories

	Quality of care[a]			
Regression model Age categories	*β*	*t*	*p*	R^2 *(p-value)*
4–6 years				
Nurse characteristics	.368	2.371	.022	0.199
Nursing activities	−.121	−0.803	.426	(.004)
Nursing environment	.267	1.737	.089	
7–11 years				
Nurse characteristics	.315	5.503	.000	0.257
Nursing activities	.186	3.095	.002	(.000)
Nursing environment	.080	1.654	.099	
12–14 years				
Nurse characteristics	.319	3.220	.002	0.231
Nursing activities	.120	1.164	.246	(.000)
Nursing environment	.125	1.613	.109	

[a]Dependent variable.

Discussion

The quality of care in hospitalized children is a challenging issue both in research and in clinical practice. While wide research has been developed regarding adult quality of care, it is a core challenge in research to develop a more child-centered (and age-centered) nursing approach, and to improve the overall quality of pediatric care (Pelander et al., 2009). In particular, analyzing children's perceptions of the quality of nursing care by considering the differences across age groups could be useful to make children's care more appropriate and responsive to different children's needs. The document Health 2020, the World Health Organization (WHO) policy framework for health and well-being in Europe, sets out the key strategic directions for health policy development and also emphasizes the importance of developing child-centered approaches based on true engagement of children and adolescents in the current healthcare system (WHO, 2013).

In this study, we assessed children's evaluations of nursing care in an Italian study using the CCQH questionnaire (Pelander et al., 2009), and to better target nursing interventions to improve patients' perceptions of the quality of nursing care, we performed three regression models according to the different samples' age categories: children under 6 years of age, 7 to 11 years of age, and 12 to 14 years of age.

On the basis of previous studies carried out by the authors of the CCQH (Pelander, Lehtonen et al., 2007; Pelander, Leino-Kilpi et al., 2007; Pelander et al., 2009), in our sample we considered a wide age range of children. It is obvious that it was easier for older children to answer the questionnaire; however, as confirmed by our empirical data and according to previous research (Pelander et al., 2009; Rebok et al., 2001), we observed that the use of both words and graphic representations as response options yielded good results, and even the youngest participants, with fewer languages skills, were able to express their own points of view. Children can be actively involved in research in health care to a larger extent than is currently seen, for example, if the methods used are adapted to facilitate taking a child's perspective (Nilsson et al., 2015).

Children's Perceptions of the Quality of Nursing Care

In accordance with previous results (Magaret et al., 2002; Pelander, Lehtonen et al., 2007; Simonian, Tarnowski, Park, & Bekeny, 1993), children reported an overall high level of quality with nursing care, in particular with all aspects related to nurse characteristics (mean = 2.79, *SD* = 1.07; Coyne & Kirwan, 2012; Pelander & Leino-Kilpi, 2010), such as kindness, sense of humor, trustworthiness (honesty), sympathy, and competence.

Regression analysis has confirmed that the greatest contribution to children's perceptions of their overall experience of hospitalization was from the quality of nursing care perceived in the nurse characteristics category. Notably, these findings are consistent with the results of the study carried out by Pelander, Lehtonen et al. (2007), who performed an in-depth exploration of the elements of quality in children's drawings of an ideal hospital: The nurse was a smiling and friendly person, and was an important reference in the children's experience.

Regarding the nursing activities and nursing environment categories, our findings were slightly different from those of previous studies (Pelander, Lehtonen et al., 2007; Pelander & Leino-Kilpi, 2010; Pelander, Leino-Kilpi et al., 2007). In detail, this study (Pelander, Leino-Kilpi et al., 2007) showed that most of the children had a rather negative perception of the nursing environment, reporting a low level of perceived quality (mean = 3.18). The nursing environment factor explored the physical, social, and emotional environments in terms of the possibility for children to have enough games, toys, books, a place to be with parents, and the opportunity to spend time with relatives, friends, and nurses as a part of the social environment. In fact, playing represents an important component of children's lives, and playing with hospitalized children can support nurses in providing effective nursing care (Hall & Reet, 2000). However, in pediatric settings, the availability of entertainment objects is not enough, but it is fundamental that nurses use them in connection with everyday clinical practice (Pelander & Leino-Kilpi, 2010). Other key findings confirm what has already been pointed out in previous research (Chesney et al., 2005; Pelander, Lehtonen et al., 2007), and they underline the important role of entertainment for hospitalized children, the lack of which can be a stressor during their stay in hospital (Boyd & Hunsberger, 1998; Pelander, Lehtonen et al., 2007; Pelander & Leino-Kilpi, 2010), contributing to children's dissatisfaction (Chesney et al., 2005). This is not surprising given that several procedures and treatments are an obvious source of stress for children (Pelander, Leino-Kilpi et al., 2007). Therefore, although it may be difficult due to the high workload in health care, nurses should continue to develop new strategies involving entertainment to reduce children's discomfort and negative experiences as much as possible.

The Quality of Nursing Care According to Children's Different Age Categories

In pediatric settings, nurses have to take account of the individual needs that come with different ages of children, and this is one of the main challenges for nursing. To better target nursing interventions to improve patients' perceptions of the quality of nursing care, we performed three regression models according to the different age categories of the sample: children under 6 years of age, 7 to 11 years of age, and 12 to 14 years of age.

The results seem to suggest an age affect in children's perceptions of quality. Interestingly, the nurse characteristics factor is significant in contributing to children's evaluations across the three different age categories, with no differences between younger and older children. Therefore, the findings revealed a general perception among children about the importance of the nurses' character, which should be trustworthy, happy, nice, and friendly. In terms of content, our results emphasize the role of human aspects of nurses in enhancing children's perceptions of their overall experience of hospitalization regardless of the child's age, and emphasize the importance of nurses' personal characteristics as essential elements of the perceived quality of care in pediatric settings (Coyne & Kirwan, 2012). Similar to other studies, children have perceived nurses' humanity (Pelander, Leino-Kilpi et al., 2007; Pelander, Leino-Kilpi,

& Katajisto, 2007; Pelander & Leino-Kilpi, 2004, 2010) as the most important aspect of a good nurse during their hospitalization. As regards the other factors of the scale, in younger children there is a negative correlation with nursing activities factors, while a strong positive correlation with nursing environment factors emerged. A higher age in the children is associated with less anxiety and stress (Roohafza et al., 2009); therefore, we can assume that during hospitalization, children under 6 years of age perceived nursing activities, such as treatment, medications, and procedures, as more traumatic and stressful compared to older children. On the other hand, the nursing environment factors, such as the possibility for children to have enough games, toys, and to spend time with parents, are important characteristics that affect satisfaction in younger children, who experience the separation from parents as a major source of anxiety and stress.

Nursing activity factors have the strongest correlation with children's perceptions of their overall experience of hospitalization in the 7- to 11-year-old category, and they are significant in contributing to perceived good care only in this age category, whereas nursing environment factors do not contribute to their evaluations in the same age group (7–11 years). Nursing activities factors explored all aspects related to caring and communication, supporting initiative, education, procedures, medication, and treatment. Probably, at this stage of a child's development, they are more curious about nurses' activities and show more interest in what happens during their hospitalization. Moreover, older children could be easily involved in playful and learning activities, which can reduce the stress experienced during treatment, procedures, and medications. Certainly, older children are better able to understand the information they receive during nursing activities, and can play a constructive role in discussion with health professionals, so that it may be easier for nurses to promote the involvement of children in the participation with their own care and decision making (Runeson et al., 2001). However, it is important to point out that children's age and maturity do not necessary have any influence on the degree to which they are able to participate in the nurse–patient interaction in terms of communicative process (Lambert, Glacken, & McCarron, 2008); in fact, even though of different developmental degrees, children's views could be regarded in most research (Nilsson et al., 2015).

Limitations

This study was quantitative in design; however, further research using observation to collect data along with interviews could be important to deepen and better understand children's experiences during hospitalization (Moore & Kirk, 2010). A qualitative perspective also could be useful to highlight other expectations of nursing care that contribute to children's evaluations, and to suggest other factors to enrich the available quantitative tools for data collection in pediatric settings.

Conclusions

Especially in pediatric care, the personal characteristics of nurses are important, and should be improved during educational training. Pediatric nurses need to develop several skills and knowledge in the psychosocial and biological development of children to better recognize the different needs of constantly growing patients (Brady, 2009). While nurse characteristics are constantly important through the different ages, nursing activities and nursing environment change their contributions to children's evaluations together with children's growth. This finding illustrates the relational approach as a core competence in pediatric nursing, while other factors could depend on children's growth and expectations. This evolutionary view is important in focusing nursing intervention in pediatric care. The evaluation of children's perceptions of their overall experience of hospitalization according to different children's age groups could be useful to provide focused guidance for pediatric nursing practice and to better target interventions to improve children's satisfaction. Integrating new evidence into practice may improve the nursing care quality of child and family health outcomes (Christian, 2013, 2014a, 2014b).

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Clinical Resources

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CLINICAL SCHOLARSHIP

A Systematic Review and Integration of Concept Analyses of Self-Care and Related Concepts

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Abstract

Purpose: This systematic review identified, synthesized, and integrated concept analyses on self-care and related concepts.
Design: The guidelines for systematic literature reviews of the Joanna Briggs Institute were followed.
Methods: The Cumulative Index to Nursing and Allied Health Literature (CINAHL), PubMed, PsycINFO, and EMBASE databases were searched for concept analyses published in the past 20 years.
Findings: A total of 26 concept analyses were identified that had been published on self-care, self-care agency, self-monitoring, self-management, self-management support, symptom management, and self-efficacy. Differences and commonalities in the examined literature were identified, and a model was delineated, explaining the relations among the various concepts from the nursing perspective.
Conclusions: The healthcare literature has broadly described self-care and related concepts; however, consensus on the definitions remains beyond our reach and should not be expected, due to the different perspectives and paradigms from which the concepts are interpreted. From a nursing perspective, self-care can be considered a broad concept encompassing the other concepts, which describe more specific individual levels of activities and processes.
Clinical Relevance: Nurses are actively involved in disease management and self-management support as well as in promoting self-care in healthy and sick people. Referring to a model on self-care and related concepts could avoid misinterpretations in nursing practice, research, and policy.

The term self-care has been broadly used in healthcare literature, and many disciplines have provided definitions of self-care from their specific perspectives (Gantz, 1990; Godfrey et al., 2011; Lommi, Matarese, Alvaro, Piredda, & De Marinis, 2015). The use of different definitions and terms to indicate self-care can lead to misinterpretations among healthcare providers and researchers and could generate confusion in patients and caregivers. Wilkinson and Whitehead's review (2009) highlighted the historical, social, economic, and political factors that have influenced the current knowledge of self-care and concluded that a consensual definition is not identifiable. In addition, they pointed out that the concept of self-management is related to self-care and is often interpreted as a subset. Richard and Shea (2011) identified commonalities and differences among self-care and the concepts of self-management, self-monitoring, self-efficacy, and symptom management. Based on their review, they proposed a model describing the relationships among these concepts. A clear identification of similarities and differences among self-care and the other associated concepts could bring a more conscious use of the concepts to clinical practice, research, and policy (Godfrey et al., 2011; Richard & Shea, 2011).

In the past, many concept analyses of self-care and related concepts have been conducted, aimed at enhancing the understanding of their meanings. In fact, a concept analysis endeavors to produce a definition of a concept and to identify its attributes, antecedents, consequences, and boundaries (Morse, Hupcey, Mitcham, & Lenz, 1996). Concept analysis offers a broad investigation of a concept within the context of the examined literature; consequently, it can be considered a summary of the literature on the identified concept, which permits identifying common elements, gaps, and inconsistencies (Hupcey & Penrod, 2005). Thus, a systematic review of concept analyses can represent an appropriate method to describe and synthesize the relevant literature. The specific aims of this systematic review, which updates previous literature reviews, were (a) to identify and synthesize the literature on self-care and the related concepts that used a concept analysis method, (b) to delineate the differences and commonalities among the concepts, and (c) based on the review results, to propose a model explaining the relations among the concepts.

Methods

A systematic literature review was carried out using the guidelines of the Joanna Briggs Institute for systematic reviews (Joanna Briggs Institute, 2014).

Search Method

A three-step search strategy was used to identify relevant literature. After an initial search undertaken on the PubMed and Cumulative Index to Nursing and Allied Health Literature (CINAHL) databases to identify the key words and index terms associated with self-care, a second search using the identified key words and terms was conducted on PubMed, CINAHL, EMBASE, and PsycINFO databases. The reference lists of all identified papers were searched to retrieve additional relevant studies. The search was limited to studies published in English, Spanish, Catalan, Portuguese, French, and Italian, and in peer-reviewed journals from January 1996 to July 2016. The search was limited to the literature published in the past 20 years to identify the most current literature produced on the concepts. Theses, dissertations, abstracts in proceedings, and other unpublished papers were excluded, as they are not subjected to a peer review process. The main key words searched were "self-care," "self-management," "self-care management," "self-management support," "self-monitoring," "self-care monitoring," "self-maintenance," "self-care maintenance," "symptom management," "disease management," "self-efficacy," "self-care confidence," "self-care agency," "self-care ability," AND "concept," AND "analysis" OR "development" OR "clarification" OR "delineation" OR "synthesis." A professional translator service was used to ensure the accurate comprehension of the abstract or full text retrieved in languages in which the reviewers were not fluent.

Inclusion and Exclusion Criteria

Phenomenon of interest. Self-care and the related concepts, including self-management, self-care management, self-monitoring, self-care monitoring, self-management support, self-maintenance, self-care maintenance, symptom management, disease management, self-efficacy, self-care confidence, self-care agency, and self-care ability, were taken into consideration.

Types of studies. Concept analyses using any kind of method were included. Review, discussion, and theoretical articles were excluded.

Context. Any cultural context was considered, as were any health conditions or healthcare settings in which self-care and the related concepts were analyzed.

Sampling frame. A 20-year period was used to ensure inclusion of all the relevant articles on the topics, as the concepts started to be broadly used in the medical literature at the end of 1990 (Godfrey et al., 2011; Lommi et al., 2015).

Data Extraction

The following data were extracted from each paper and summarized in a table: (a) authors and year of publication, (b) concept analysis method, (c) type of literature searched, (d) context, (e) antecedents, (f) attributes, (g) consequences, (h) concept definition, and (i) description of related and surrogate terms. A surrogate term is a term used to express the same concept, and a related term is a term that has some form of relationship with it (Morse et al., 1996). Two reviewers independently extracted the data from the identified studies; any discrepancy between reviewers was resolved through discussion. No quality assessment of the articles was performed, as no standardized instrument for quality appraisal of concept analysis work is available.

Data Analysis and Synthesis

Two reviewers separately read the extracted data, searching for commonalities and differences in antecedents, attributes, and consequences for each concept. In case of a concept analyzed in different clinical conditions or populations, common structural elements were extracted indicating the recurrence. The outcomes were classified as individual, clinical, and societal. Individual outcomes regard the subjective effects as perceived by the individual and are typically self-reported measures, such as quality of life, satisfaction, and empowerment. Clinical outcomes are objective indicators used by healthcare providers to measure the achievement of the results, such as modifications in physiological functions (i.e., glycemia, blood pressure), psychological status (stress, anxiety), and behaviors. Societal outcomes are measures of the impact on healthcare systems, such as healthcare costs or use of healthcare services. The antecedents were classified as internal (inherent to the individual) and external (related to healthcare professionals, services, or community resources). The reviewers compared their findings, and any discrepancy was solved through discussion.

Findings

In total, 4,883 records were identified after removing duplicates. After reading titles and abstracts, 4,834 records were excluded. Among 49 articles that were retrieved in full text, 23 were excluded, as they were not concept analyses, or the concept analyzed was not related to self-care (**Table S1**). Of the remaining 26 articles, 3 analyzed the concept of self-care, 1 of self-care agency, 9 of self-management, 2 of self-monitoring, 2 of symptom management, 2 of self-management support, and 7 of self-efficacy. No concept analyses were found on the following concepts: self-care confidence, disease management, self-care management, self-care monitoring, self-maintenance, or self-care maintenance. All the articles were in English except for one written in French (Mailhot, Cossette, & Alderson, 2013). The identified concept analyses, published from 2002 to 2016, used the following concept analysis methods: Walker and Avant ($n = 10$), Rodgers ($n = 10$), hybrid ($n = 2$), Norris ($n = 1$), Weaver and Morse ($n = 1$), integrated approach ($n = 1$), and integrative review ($n = 1$). The concepts were analyzed in different populations, such as adolescents, adults, and older adults, and in different health conditions. We could not analyze the evolution of the concepts over time because for the same concept, different contexts, clinical conditions, and databases were analyzed in the identified articles. Study characteristics are reported in **Table S2**. The syntheses of the concept analyses for each concept are described in the next paragraphs and reported in **Table S3**.

Self-Care

We identified three articles that analyzed self-care in an older population (Høy, Wagner, & Hall, 2007), in nursing (Mailhot et al., 2013), and in the Islamic literature (Marzband & Zakavi, 2017).

Attributes. Self-care was seen as an activity, capability, and process. As an activity, self-care entails physical, mental, social, and spiritual activities, which are learned and consciously performed by an individual; these activities are under individual control, situation driven, and directed toward specific goals (Mailhot et al., 2013; Marzband & Zakavi, 2017). As a capability, self-care is an action capability directed toward universal needs, goals, and health problems. As a process, self-care is a health developmental process related to illness and well-being (Høy et al., 2007).

Antecedents. Self-care is influenced by internal factors (such as self-efficacy, learning, motivation, perception of imbalance, religious beliefs and precepts, commitment, and ability to make judgments; Høy et al., 2007; Marzband & Zakavi, 2017) and external factors, such as availability of social support and resources (Høy et al., 2007; Mailhot et al., 2013). In the Islamic religion, caring for oneself is a moral imperative and a right. In fact, the body has dignity and value since it is a tool and platform for spiritual perfection. Participation in collective religious rites, avoiding custom corruption, and pursuing good are considered self-care activities (Marzband & Zakavi, 2017).

Consequences. Self-care is performed to maintain health, life, and well-being, to reach autonomy (Høy et al., 2007; Mailhot et al., 2013) and empowerment, to eliminate disease symptoms (Mailhot et al., 2013), to prevent and cope with disease, to obtain social support, and to achieve self-esteem, self-transcendence, and a meaningful life (Høy et al., 2007; Marzband & Zakavi, 2017).

Related and surrogate terms. The related terms are self-management, self-monitoring, and self-control. Self-control differs from self-care as it refers to the efforts to perform an obligated duty, regardless of any external control or commitment (Marzband & Zakavi, 2017).

Self-Care Agency

The concept of self-care agency, addressed in Sousa's article (2002), is defined as the capabilities of an individual to recognize his or her own needs and to assess personal and environmental resources.

Attributes. The identified attributes are cognitive, physical, and psychosocial capabilities to perform self-care action.

Antecedents. Self-care agency depends on the physical, cognitive, and psychosocial developmental levels of a person and on his or her needs and desires to perform self-care actions.

Consequences. The exercise of self-care agency leads to the performance of self-care actions aimed at reaching a specific goal.

Related and surrogated terms. The identified surrogate terms are self-care, power, self-care ability, and capabilities. Self-care entails two components, the practice of activities (self-care actions) and the capabilities to perform such actions (self-care agency), with self-care actions depending strictly on the person's capabilities. The related term self-efficacy differs from self-care agency as it is not general in nature but is related to specific activities. Further, it refers to the belief of an individual (judgment) in his or her capabilities to perform a specific action, whereas self-care agency refers to the individual's capabilities (power) to identify his or her needs, select the appropriate actions, and perform the activities (Sousa, 2002).

Self-Management

In the nine identified concept analyses, self-management was examined in chronic diseases (Blok, 2017; Mammen & Rhee, 2012; Miller, Lasiter, Ellis, & Buelow, 2015; Udlis, 2011) and in specific health conditions, such as prediabetes (Rothenberger, 2011) and diabetes (Schilling, Grey, & Knafl, 2002), epilepsy and diabetes (Unger & Buelow, 2009), hypertension (Balduino, Mantovani, Lacerda, & Meier, 2013), asthma (Mammen & Rhee, 2012), and postpartum weight (Ohlendorf, 2013).

Attributes

Although the definitions of self-management vary among the studies, due to different characteristics of the health conditions considered, some common attributes are recognizable. Self-management is seen as a process by which the individuals with a health problem intentionally perform a set of activities planned in partnership with healthcare professionals. The activities can be proactive and reactive (Balduino et al., 2013; Blok, 2017; Mammen & Rhee, 2012; Miller et al., 2015; Rothenberger, 2011; Schilling et al., 2002; Udlis, 2011). Proactive or preventive activities are aimed at maintaining a healthy lifestyle, preventing the occurrence of symptoms, evaluating physical and psychological changes, following the therapeutic regime, monitoring symptoms, and coping with the effects of a disease. Reactive or response activities are aimed at responding to an event or symptom, such as taking medications, treating the effect of a disease, or seeking help from healthcare providers.

Antecedents. The prerequisites of self-management most frequently identified are information and knowledge (Mammen & Rhee, 2012; Miller et al., 2015; Rothenberger, 2011; Schilling et al., 2002; Udlis, 2011), self-efficacy (Miller et al., 2015; Rothenberger, 2011; Udlis, 2011; Unger & Buelow, 2009), motivation (Miller et al., 2015; Schilling et al., 2002), and social support (Miller et al., 2015; Rothenberger, 2011; Schilling et al., 2002; Udlis, 2011). Moreover, self-management is influenced by the individual's developmental stage, as evidenced by studies that analyzed the concept in children and adolescents (Mammen & Rhee, 2012; Schilling et al., 2002): the responsibility of disease management is initially assumed by parents, subsequently shared, and later assumed fully by adolescents.

Consequences. The clinical outcomes are modifications of physiological parameters (i.e., glycemia, blood pressure, body weight; Balduino et al., 2013; Ohlendorf, 2013; Rothenberger, 2011; Schilling et al., 2002). The individual outcomes are improvement of quality of life, self-worth, satisfaction, and empowerment, whereas societal outcomes are reduced healthcare expenditures derived from reduced use of healthcare services (Blok, 2017; Mammen & Rhee, 2012; Miller et al., 2015; Udlis, 2011).

Related and surrogate terms. Self-management surrogate terms are self-care, self-care management, management of treatment regimens, disease management, and illness management. The term self-management is more often found in medical literature, while self-care management is used in nursing literature (Balduino et al., 2013). Other terms closely related to self-management are self-monitoring, compliance, and adherence. Self-monitoring, in particular, is considered a subdimension or attribute of self-management (Mammen & Rhee, 2012; Rothenberger, 2011). Adherence and compliance are considered components of or means for self-management; however, several researchers argue that self-management requires a shift from the traditional concepts of patient compliance and adherence to the new paradigm of mutual relationship or partnership of healthcare professionals with the individuals with a chronic disease (Rothenberger, 2011; Udlis, 2011).

Self-Monitoring

The concept of self-monitoring was analyzed in the context of chronic diseases (Wilde & Garvin, 2007) and in type 2 diabetes mellitus (Song & Lipman, 2008). It was defined as the awareness, measurement, and interpretation of signs and symptoms (Wilde & Garvin, 2007), and the response to disease manifestations (Song & Lipman, 2008).

Attributes. Self-monitoring characteristics are awareness of symptoms, and measurement, recording, interpretation, and response to signs and symptoms (Song & Lipman, 2008).

Antecedents. To perform self-monitoring, knowledge about the manifestations of a disease, skills in detecting variations of health status and measurements, skills in problem solving, and the ability to set goals are required (Song & Lipman, 2008; Wilde & Garvin, 2007).

Consequences. Self-monitoring leads to improvements in self-management, control of symptoms and signs of a disease, and improved quality of life.

Related and surrogate terms. Self-monitoring is related to the terms of self-management, symptom management, self-care, self-regulation (Wilde & Garvin, 2007), self-care maintenance, and self-care management (Song & Lipman, 2008). The term self-regulation is seen as a broader construct that includes self-monitoring (Wilde & Garvin, 2007). Self-monitoring is also seen as a component of self-management or symptom management. Self-care is described as a component of self-management or used as a synonym. According to some researchers, self-care differs from self-management, as self-care focuses on autonomous health/illness-related activities initiated by people without the need for the assistance of healthcare providers (Wilde & Garvin, 2007). Other researchers consider self-care to be a broad and multidimensional construct (Song & Lipman, 2008). Self-care maintenance refers to routine health behaviors, daily symptom monitoring, and treatment adherence, whereas self-care management entails symptom recognition, treatment, and treatment evaluation (Song & Lipman, 2008).

Symptom Management

Two concept analyses described symptom management in cancer (Fu, Le Mone, & McDaniel, 2004) and pain management in older people (Stewart, Schofield, Elliott, Torrance, & Leveille, 2014). Symptom management is defined as a dynamic and multidimensional process by which an individual intentionally performs activities by himself or herself, or others perform such activities, to relieve or decrease the distress derived from the perception of a symptom (Fu et al., 2004).

Attributes. Symptom management entails a collaborative relationship between an individual and the healthcare providers, who give information and support in treatment choices. The level of involvement of the individual in treatment decisions and in performing activities can vary, depending, for example, on the individual's age or on the presence of multimorbidity (Stewart et al., 2014).

Antecedents. Symptom management requires self-awareness of the need, disposition, and ability to manage symptoms, and support from healthcare providers and family (Stewart et al., 2014).

Consequences. At the individual level, symptom management leads to relief or reduction of the symptoms, prevention of symptom occurrence (Fu et al., 2004), improved performance in daily activities, and better quality of life. At the societal level, it leads to reduction in the use of healthcare resources (Stewart et al., 2014).

Related and surrogate terms. The related terms are self-monitoring, self-care, self-help, self-regulation, self-treatment, and coping. Symptom management requires the ability of an individual to recognize and interpret the symptoms before treatment. For this reason, it can be considered an element of self-management, focused on the management of disease symptoms. In addition, symptom management differs from the other concepts, as healthcare providers can also perform it. Coping strategies are considered the means used by an individual to manage the symptoms (Stewart et al., 2014).

Self-Management Support

Two studies addressed the concept of self-management support in chronic illnesses (Kawi, 2012) and in palliative care (Johnston, Rogerson, Macijauskiene, Blaževičienė, & Cholewka, 2014). It encompasses collaborative approaches directed at improving chronic illness outcomes with the involvement of healthcare professionals and healthcare organizations together with the patients (Kawi, 2012): patients make decisions and perform behaviors to improve their health; healthcare professionals provide support to help patients understand their role in managing the disease, making informed decisions about care and engaging in wellness-oriented behaviors; and healthcare organizations provide the infrastructure and resources needed for the patient to self-manage the disease.

Attributes. As self-management support involves three components, different attributes can be identified at the patient, healthcare provider, and organizational levels. The patient is considered a partner in identifying and prioritizing needs, setting goals, and planning actions with participatory decision making. To support patients, healthcare providers are required to possess adequate knowledge, communication skills, cultural sensitivity, and attention to disparities (Kawi, 2012). Finally, the healthcare organization must use an organized system with a multidisciplinary team approach to provide instrumental and emotional support to increase the patient's ability to self-manage (Kawi, 2012). In palliative care, nurses support patients and their families by helping them maintain normality and independence as long as possible, teaching physical and emotional self-care strategies, and preparing them for death (Johnston et al., 2014).

Antecedents. Self-management support is activated when the patient, or a member of the healthcare team, identifies a need to manage a chronic disease (Kawi, 2012). In the context of palliative care, nurses are required to possess appropriate skills, knowledge, and expertise, to be able to work in teams, and to refer to other healthcare providers or support services when needed (Johnston et al., 2014).

Consequences. Self-management support permits patients to control symptoms, change behaviors, increase their self-management skills, achieve satisfaction (Kawi, 2012), feel cared for, and have their needs met (Johnston et al., 2014). At the healthcare provider level, it leads to satisfaction for the care provided. At the organizational level, it contributes to improving quality of care and reducing healthcare costs (Kawi, 2012).

Related and surrogate terms. Surrogate terms are not identified, whereas related terms are partnership, collaborative management, and coordinated care (Johnston et al., 2014).

Self-Efficacy

Seven articles analyzed the concept in general (Zulkosky, 2009), in self-care (Eller, Lev, Yuan, & Watkins, 2018), in health promotion (Asawachaisuwikrom, 2002), in smoking cessation (Heale & Griffin, 2009), in older people with diabetes (Liu, 2012), in the prevention of sexual risk behaviors (Jenkins, 2015), and in promotion of physical activities (Voskuil & Robbins, 2015). All the definitions provided in the articles were derived from Bandura's social cognitive theory (1977). Self-efficacy is defined as the person's perception of or confidence in his or her capabilities to perform specific actions for preventing or treating health conditions.

Attributes. Characteristics of self-efficacy are, for example, cognitive and affective processes (Liu, 2012; Voskuil & Robbins, 2015; Zulkosky, 2009), locus of control (Zulkosky, 2009), motivation to perform a task (Heale & Griffin, 2009; Jenkins, 2015), and self-appraisal (Voskuil & Robbins, 2015).

Antecedents. Self-efficacy is influenced by previous mastery experiences, vicarious experiences, verbal persuasion or social influence, and physiological and affective states (Asawachaisuwikrom, 2002; Heale & Griffin, 2009; Jenkins, 2015; Liu, 2012; Voskuil & Robbins, 2015; Zulkosky, 2009). Other antecedents identified are self-confidence, values, beliefs, and spirituality (Eller et al., 2018). External factors, such as family support and availability of resources, can also influence a person's self-efficacy.

Consequences. Individual outcomes are, for example, improved quality of life, successful coping strategies, physical and mental health, increased level of confidence, and attainment of goals (Asawachaisuwikrom, 2002; Eller et al., 2018; Zulkosky, 2009). Clinical outcomes are engagement in the desired health behaviors, disease management and prevention, and improved physical functions (Heale & Griffin, 2009; Liu, 2012). Societal outcomes entail increased use of community resources and social support (Eller et al., 2018; Jenkins, 2015).

Related and surrogate terms. A surrogate term is perceived self-efficacy: as the term perceived is implied in the definition of self-efficacy, the term self-efficacy is preferred to perceived self-efficacy (Zulkosky, 2009). Related terms of self-efficacy are self-esteem, self-confidence, locus of control, competence, and motivation. Both self-esteem and self-confidence refer to personal characteristics of an individual, and they have a stable influence on his or her behaviors. Instead, self-efficacy is situation specific and task oriented. Thus, self-esteem refers to a global feeling of self-worth or self-value of a person, whereas self-efficacy regards the judgment of being able to accomplish a specific goal (Zulkosky, 2009). Locus of control refers to the person's belief regarding the determination to achieve a result (Asawachaisuwikrom, 2002; Zulkosky, 2009). People with an internal locus of control believe that their outcomes derive from their actions, while people with an external locus of control believe that their results are controlled by external forces (Zulkosky, 2009). Competence captures one dimension of self-efficacy, as it considers the personal evaluation of capability but does not include the dimension of power to select specific behaviors, despite barriers (Voskuil & Robbins, 2015). Motivation is a required component of self-efficacy, but the motivation to perform a behavior does not consider a person's level of confidence to attain a goal (Heale & Griffin, 2009).

Discussion

We identified 26 concept analyses on self-care and associated concepts, with most of the articles ($n = 14$) published in the past 5 years, showing the growing interest of researchers in these concepts. No concept analyses were identified addressing self-care confidence, self-maintenance, self-care maintenance, self-care management, self-care monitoring, or disease management. The concept of self-care confidence was initially identified by Riegel and colleagues (2004) as a contributor to self-care in the situation-specific theory of self-care in heart failure; later, self-care confidence was considered as a moderator or a mediator between self-care and its effects (Riegel & Dickson, 2008). In this theory, self-care confidence is interpretable as a synonym of self-efficacy, since it was defined as the confidence of an individual in his or her ability to perform specific self-care action. The concept of self-care maintenance was first used in the situation-specific theory of self-care in heart failure (Riegel et al., 2004). Subsequently, self-care maintenance, together with self-care monitoring and self-care management, formed the three dimensions of self-care in the middle-range theory of self-care of chronic illness (Riegel, Jaarsma, & Strömberg, 2012). In healthy individuals, self-care focuses on self-improvement, but in people with chronic illness most of the self-care maintenance behaviors reflect adherence to the advice of healthcare providers regarding the treatment plan and a healthy lifestyle (Riegel et al., 2012).

Although we did not find any concept analysis on disease management, this term is often used in the context of chronic diseases. The absence of the term self places the concept in the area of responsibility of the health professionals and the healthcare system (Richard & Shea, 2011).

In our review, many commonalities among examined concepts were identified, illustrating their close relationship and confirming the difficulties identified previously in the literature to delineate the concepts (Richard & Shea, 2011). In fact, a well-developed concept should have clear, recognized characteristics, definite antecedents, outcomes, and demarcated boundaries that distinguish it from other concepts (Morse et al., 1996). Our review identified common general outcomes for many relevant concepts, such as improvement of quality of life, maintenance of health, life, and well-being, and reduction of healthcare costs. Some concepts had other concepts as outcomes; for example, self-management was an outcome of self-monitoring and self-management support, and self-care an outcome of self-care agency and self-monitoring. Moreover, self-efficacy was considered an antecedent of self-care, and self-management an attribute of self-care, self-management, symptom management, and self-monitoring. Such overlapping terms and commonalities are due to the use of the same terms in different disciplines. In fact, the databases examined in the concept analyses included many disciplines, such as nursing, medicine, psychology, sociology, education, business, economics, and pharmacology. Each of them offers different perspectives and paradigms on self-care and related concepts. The effort to achieve a common definition is burdensome and perhaps unnecessary, as differences among the disciplinary paradigms are not conceivable (Godfrey et al., 2011; Wilkinson & Whitehead, 2009). Obtaining common definitions and identifying shared conceptual attributes leads to a level of generalization not useful when applying the concepts in clinical practice (Hupcey & Penrod, 2005). Therefore, we believe that nursing should be aware of the differences across disciplines but should take a disciplinary position to describe self-care and related concepts guided by existing nursing theories.

Based on the results of this systematic and integrative review of concept analyses and theoretical literature on self-care, we propose a model that updates and integrates that proposed by Richard and Shea (2011; **Figure 1**). In our view, self-care is a broad concept that encompasses all the other related concepts. It entails capacities, activities, and processes directed toward maintaining health, preserving life, and monitoring and managing acute and chronic conditions. In a healthy person, self-care is aimed at maintaining physical, psychological, social, and spiritual well-being, identifying changes in well-being, and implementing all the

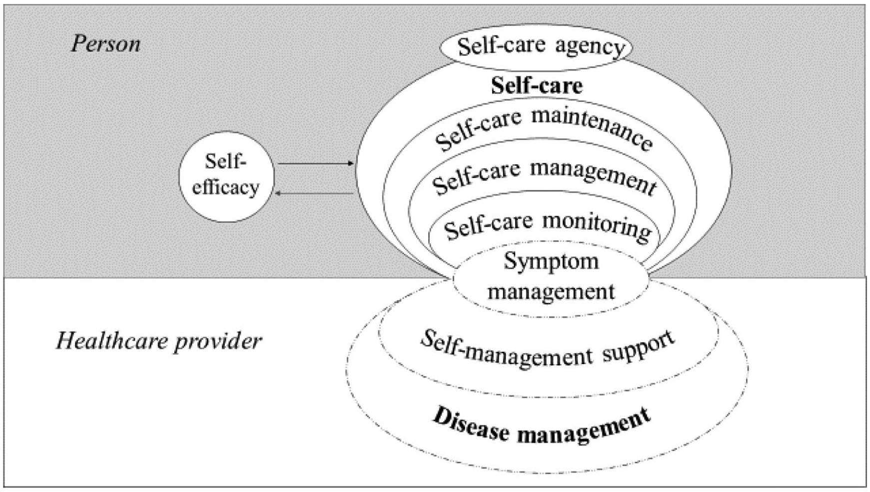

Figure 1. Model of self-care and related concepts. There is a shift in responsibility with the progression from the top (full responsibility of the person) to the bottom of the figure (full responsibility of the healthcare providers). The overlaps of the concepts are represented by the different circles inserted one inside the other. The progressive reduction of the circle size identifies the increasingly specific activities that are included in each concept.

activities needed to maintain and resume a desired level of well-being. People are supported in this natural process by their self-care abilities (self-care agency), which are prerequisites to care for one's self, and by self-efficacy, which facilitates the achievement of desired outcomes. People's family and healthcare professionals can support them in self-care. Healthcare professionals, especially nurses who are focused on holistic care, can educate individuals, for example, to maintain basic, instrumental, and advanced activities in various stages of life, and to adopt healthy lifestyles. When an acute or chronic illness occurs, the person's care will move on two different fronts: on one hand, the person will continue to perform self-care activities for promoting and maintaining well-being for the aspects of his or her life that are not influenced by the illness; on the other hand, the person will carry out activities that keep the disease stable (self-care maintenance), control the occurrence of signs and symptoms attributable to the illness or its treatments (self-care monitoring), and intervene with actions decided autonomously or recommended by healthcare providers to treat the disease (self-care management) and manage symptoms (symptom management). Self-efficacy can mediate the relations between influencing factors and the practices of self-care or can facilitate the achievement of the expected outcomes functioning as moderator. The use of the terms self-care monitoring and self-care management instead of self-management and self-monitoring supports the idea that they belong to the broader concept of self-care, according to the middle-range theories of self-care of chronic illness (Riegel et al., 2012).

Two new concepts are added to the previous model, which are external to individual control but important for the care of people with health problems: self-management support and disease management. They clarify the different roles and responsibilities of healthcare providers and the shared responsibility. Health professionals provide information to people on therapeutic treatments, educate to integrate therapeutic recommendations into people's lives, and train them to acquire psychomotor skills (self-management support), or they directly manage the symptoms or side effects of the treatments (symptom management) by using the resources of the healthcare systems (disease management).

This review presents a few limitations. Although a careful screening of the literature using a broad range of terms was performed, concept analyses could have been missed if the researchers did not explicitly identify them, or if they were indexed with other key words. Moreover, only four databases were searched, limiting our ability to identify all the literature produced. Although a broad range of languages was included in the search, articles written in other languages were omitted, reducing the contribution of other cultural contexts in the description of the concepts. Moreover, the quality of the studies was not assessed, as no approved criteria or specific standardized tool exists for quality appraisal of concept analysis; for this reason, all the identified studies were included in the review. To reduce the risk of including poor methodological quality studies, only articles published in peer-reviewed journals were considered, as they are submitted through a process of study quality appraisal before publication. Moreover, we included articles using all concept analysis methods, although some of them have drawn criticism regarding their rigor and validity (Weaver & Mitcham, 2008). Despite the weaknesses presented by concept analysis, the findings express the best efforts of the researchers to synthesize and interpret what is known about the identified concepts (Hupcey & Penrod, 2005).

Conclusions

Our review synthesized and interpreted the literature regarding self-care and related concepts and suggested an explanatory model that can help nurses and others to select, apply, and assess self-care in a variety of populations and conditions. The findings of this review have strong implications for research, practice, and policy. Precision in our terminology is essential to move the field forward. Research in this general area has exploded in recent years, so identifying shared terminology would allow us to search the literature more effectively so that we can focus on appropriate interventions, identify the factors that are modified by the intervention, and achieve specific outcomes. At this point, clinicians who search for literature on self-management may miss the large body of literature on self-care. Moreover, a clear identification of the diverse components of self-care can encourage the development and use of instruments that measure the specific attributes of the self-care dimensions. Together, progress in research and clinical practice will help to influence policy driving communities to promote self-care for the good of their local populations. Further studies are needed to confirm the utility of the proposed model in identifying and integrating the different dimensions of self-care.

Clinical Resources

- Agency for Healthcare and Quality. Self-management support: https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/self/index.html
- Royal College of Nursing. Self care: https://www.rcn.org.uk/clinical-topics/public-health/specialist-areas/self-care

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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. Literature Research Process on Self-Care and Related Concepts

Table S2. Description of The Concept Analysis Articles of Self-Care and Related Concepts

Table S3. Synthesis of Antecedents, Attributes, Consequences and Surrogate or Related Terms of Self-Care and Related Concepts

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HEALTH POLICY AND SYSTEMS

CE

The Relationship Among Change Fatigue, Resilience, and Job Satisfaction of Hospital Staff Nurses

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Key words
Change fatigue, nursing job satisfaction, resilience, organizational change

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Abstract

Purpose: The purpose of this study was to examine relationships between change fatigue, resilience, and job satisfaction among novice and seasoned hospital staff nurses.

Background: Health care is typified by change. Frequent and vast changes in acute care hospitals can take a toll on nurses and cause change fatigue, which has been largely overlooked and under-researched.

Design and Method: A descriptive correlational design was employed with 521 hospital staff nurses in one midwestern state. Participants completed three online surveys: (a) Change Fatigue Scale, (b) Connor-Davidson Resilience Scale, and (c) McCloskey/Mueller Satisfaction Scale.

Findings: In a multiple regression model, job satisfaction had a statistically significant negative association with change fatigue ($p < .001$) and significant positive association with resilience ($p < .001$). A linear trend was found with hospital size (number of beds) and change fatigue ($p = .001$) and education level and resilience ($p = .03$).

Conclusions: The results are consistent with job satisfaction among hospital nursing staff being negatively influenced by change fatigue and positively influenced by resilience, although reverse causal connections are also possible. Change fatigue may be increased by larger hospital size (number of beds), and resilience may be increased by higher educational level of hospital staff nurses.

Clinical Relevance: The study advanced the nursing knowledge on change fatigue, resilience, and job satisfaction of staff nurses working in acute care hospitals. Engaging in strategies aimed at preventing change fatigue in nursing staff can enhance workplace environments, job satisfaction, and retention of nurses.

Health care is typified by change. Hospitals constantly engage in change to become more competitive and cost effective, and actions taken to achieve these types of goals can exert tremendous impact on employees. Nurses working in acute care hospital settings are particularly vulnerable to the effects of organizational change. Rapid and vast changes in the working environment of hospitals have increasingly become the norm and impact all aspects of nurses' work (Verhaeghe, Vlerick, Gemmel, Maele, & Backer, 2006). A consequence is the risk for negative outcomes, which are heightened when the rate of organizational change is perceived as too frequent (Bernerth, Walker, & Harris, 2011).

The relationship of organizational change to the physical and psychological well-being of nurses has been largely overlooked and under-researched (Delmatoff & Lazarus, 2014; McMillan & Perron, 2013). There are studies using worker populations from occupations other than health care that support an influence of organizational change on increasing perceptions of stress

(Yu, 2009), and increased sick time away from work, job-related disability, loss of productivity, and reduced organizational commitment (Bernerth et al., 2011). In a longitudinal study of nurses, organizational change was associated with a greater perception of a stressful work environment and reduced job satisfaction (Kuokkanen, Suominen, Harkonen, Kukkurainen, & Doran, 2009). Studies on nurses (McMillan & Perron, 2013) and other occupations (Bernerth et al., 2011) have suggested that organizational change can lead to change fatigue, which is the overwhelming feeling of stress, exhaustion, and burnout associated with rapid and continuous change in the workplace. Frequent organizational changes can also cause the saturation effect, which occurs when a period of recovery following one change is not allowed (Ead, 2015).

In addition to personal stress, organizational change results in decreased job satisfaction and increased turnover of nurses (Applebaum, Fowler, Fiedler, Osinubi, & Robson, 2010; Caricati et al., 2014; Kuokkanen et al., 2009; Larrabee et al., 2010; Teo, Pick, Newton, Yeung, & Chang, 2013). Nursing turnover is both costly for healthcare organizations and can negatively affect quality of care and patient safety (Li & Jones, 2013). In the United States alone, the average turnover rate of bedside registered nurses (RNs) has increased every year, from 11.2% in 2011 to 17.2% in 2015 (Nursing Solutions Inc., 2015).

Resilience is an individual trait that enables one to thrive in the face of adversity (Connor & Davidson, 2003), and in the workplace, resilience can help one withstand significant disruption and change (Jackson, Firtko, & Edenborough, 2007). A study of Korean information technology workers showed that resilience is positively related to employees' commitment to organizational change, while commitment to change is negatively related to turnover (Shin, Taylor, & Seo, 2012). In a small study of psychiatric nurses, resilience was positively associated with job satisfaction (Matos, Neushotz, Quin Griffin, & Fitzpatrick, 2010).

Much of the research on organizational change to date has focused on change resistance, which is theoretically different from change fatigue. Behaviors associated with change resistance are intentional and disruptive, while change fatigue behaviors are often passive and staff become increasingly disengaged, apathetic, and passive about organizational changes over time. Change fatigue often goes undetected by nurse managers and organizational leaders (McMillan & Perron, 2013), especially among vulnerable groups, such as new graduate nurses and newly transferred nurses from one specialty area to another (Vestal, 2013). Thus, research aimed at uncovering phenomena related to organizational change and its sequelae are needed to design leadership interventions that will effectively reduce the negative impacts of organizational change. The purpose of this study was to examine the relationship between change fatigue, resilience, and job satisfaction among novice and seasoned hospital staff nurses.

This study was guided by Lazarus and Folkman's Model of Stress and Coping. The model proposes that stressors and ways individuals cope with stress be considered jointly in explaining the stress and coping process because they are interdependent (Lazarus & Folkman, 1984). Aligned with this framework is organizational change as a frequent stressor in nurses that may lead to change fatigue and a decrease in job satisfaction, and the resilience of nurses in coping with stress related to organizational change.

Methods

Design and Sample

A descriptive correlational design was employed to examine associations between change fatigue, resilience, and job satisfaction among novice and seasoned staff RNs working in the acute care hospital setting. The study population was recruited from a list of RNs obtained from a midwestern state board of nursing. A link to an online survey (developed using QuestionPro Software [QuestionPro Inc., San Francisco, CA, USA]) was sent via an e-mail to 4,000 randomly selected RNs from a database of over 10,000 RNs. A one-time reminder email was sent 1 week after the first e-mail inviting nurses to participate in the study. To be included in the study, the respondent nurse had to be employed as a staff nurse in an acute care hospital setting. The final study population consisted of 521 full- and part-time staff nurses who had a diploma, associate degree, baccalaureate degree, or master's degree. Benner's Novice to Expert Model was utilized to develop the categories of nursing experience (Benner, 1982). RNs who were employed less than 2 years were categorized as novice, and RNs with more than 2 years of experience were categorized as seasoned nurses. This study was approved by the university institutional review board, and online submission of completed questionnaires served as implied consent.

Measures

The Change Fatigue Scale is a 6-item Likert scale that measures well-being, organizational commitment, and turnover intentions in employees who experience multiple organizational changes. A panel of 14 experts, using a minimum content validity ratio of .51 for each item, tested content validity. Cronbach's alpha with non-nurses, is .85 (Bernerth et al., 2011) and .94 in this sample of nurses. The Connor-Davidson Resilience Scale (CD-RISC) is a 10-item Likert scale that measures resilience during the previous month. Cronbach's alpha is .85 (Campbell-Sills & Stein, 2007), and in this sample .86. Construct validity was tested by comparing the CD-RISC scores to childhood maltreatment and current psychiatric symptoms. The CD-RISC scores moderated the relationship between childhood maltreatment and psychiatric symptoms ($p < .001$; Campbell-Sills & Stein, 2007). The McCloskey/Mueller Satisfaction Scale (MMSS) is 31-item Likert scale and measures hospital nurses' job satisfaction. The scale measures eight types of satisfaction: extrinsic rewards, scheduling, family and work balance, co-workers, interaction, professional opportunities, praise and recognition, and control and responsibility. Cronbach's alpha for the global scale is .89 (Mueller & McCloskey, 1990), and in this sample .91. Construct validity was determined by moderate positive correlations of the MMSS subscales to the Job Characteristics Inventory and intent to stay on the job. Criterion-related validity was tested by comparing the subscales to the Brayfield-Rothe general satisfaction scale (.41) and Oldham's Job Diagnostic Survey (.56; Mueller & McCloskey, 1990).

Data Analysis

Questionnaire data were exported from QuestionPro as an SPSS file (Statistical Package for the Social Sciences, version 22, IBM Corp., Armonk, NY, USA). Bivariate analyses were conducted using correlations (Pearson's r) and t tests to examine associations among change fatigue, resilience, and job satisfaction between novice and seasoned staff RNs. Multivariate associations were evaluated using multiple linear regression in separate models for the outcome variables change fatigue, resilience, and job satisfaction measures as the dependent variable. To provide adjusted associations between the outcome variables, the regression model for a given outcome variable included the other two outcome variables as predictors (e.g., resilience and job satisfaction were predictors in the model for change fatigue). For all models, the independent variables included age, gender, marital status, number of children, educational level, full- or part-time employment status, hospital unit of employment, years employed as an RN, hospital size (number of beds), and designated Magnet accreditation status of the hospital. Since 97% of the sample indicated Caucasian race, a race variable was not included in the regression models. Tests for linear and quadratic trend were conducted for ordinal predictors. A 5% level of significance was used for all hypothesis tests.

Results

The total survey sample consisted of 521 non-union staff nurses, and complete data for the multiple regression analyses were available on 68.1% of the total survey sample. The distributions for demographic characteristics of both the total survey population and multiple regression population are shown in **Table 1**. There were no significant differences between the total survey population and the multiple regression population. These populations were predominantly White females working as full-time nurses. The majority were baccalaureate prepared (62%–64%) and employed at a facility with Magnet designation (64%). There were no significant differences in mean job satisfaction and change fatigue measures between the total survey population and multiple regression population (**Table 2**). The mean resilience was slightly higher in the multiple regression population, but the difference was very small.

The beta-coefficients in **Table 3** describe the adjusted associations between change fatigue, job satisfaction, and resilience. Job satisfaction had a statistically significant negative association with change fatigue ($p < .001$) and statistically significant positive association with resilience ($P < .001$). Change fatigue and resilience were negatively associated, but not statistically significant ($p = .28$).

Statistically significant bivariate associations were found between nursing experience (novice versus seasoned nurses) and all three outcome measures, change fatigue ($t = -2.9$, $p = .003$), resilience ($t = -2.4$, $p = .02$), and job satisfaction ($t = -2.0$, $p = .04$). However, no significant associations of nursing experience and the three outcomes were observed after adjusting for other factors in the multiple regression models (see **Table 3**). Instead, hospital size (number of beds) was a significant predictor of change fatigue among hospital staff nurses such that, as number of beds increased, change fatigue increased ($p < .001$; see **Table 3**). Gender was a significant predictor of change fatigue ($p = .02$), with males having higher change fatigue scores compared to females. Education was a significant predator of resilience such that, as educational level increased, resilience scores increased. There was a significant association of age and job satisfaction such that job satisfaction initially decreased with age and then returned to higher levels for older nurses (p value for quadratic trend = .03). There was weak evidence that nurses who were single had higher job satisfaction than married nurses ($p = .07$), but not divorced nurses. In addition, nurses employed in critical care units (ICU or CCU) had lower job satisfaction ($p = .02$) compared to the category for other types of hospital units, but not any of the specific types of hospital units listed on the questionnaire. Magnet designation was a significant predictor of job satisfaction ($p = .03$). Lastly, there was weak evidence that novice nurses had lower job satisfaction than experienced nurses ($p = .08$).

Discussion

The primary focus of this study was to examine associations between change fatigue, resilience, and job satisfaction among novice and seasoned RNs working in the acute hospital setting. Characteristics of this sample were similar to other hospital-based nursing samples (Nursing Solutions Inc., 2015). Organizational change can result in increased stress, decreased job satisfaction, increased turnover, and change fatigue (Applebaum et al., 2010; Bernerth et al., 2011; Kuokkanen et al., 2009; McMillan & Perron, 2013; & Yu, 2009). Nursing turnover and healthcare changes are at an all-time high, and job satisfaction is a major factor in the retention of nurses (Caricati et al., 2014). Given the high turnover rates and high demand for nurses, it is important that nurse leaders understand factors that affect change fatigue, resilience, and job satisfaction among hospital nurses. At a time of increasing nursing turnover, it is important to identity ways to enhance job satisfaction. Several researchers found a negative association between organizational change and job satisfaction (Dool, 2009; Kuokkanen et al., 2009; Rafferty & Griffin, 2006; Teo et al., 2013).

This study was an initial step in expanding the current knowledge on change fatigue among nurses practicing in acute care hospitals. No studies on change fatigue in nurses were located to date. With change fatigue, employees become disengaged and apathetic to the change and do not express their dissent even though it is explicitly felt (McMillan & Perron, 2013). Because these behaviors are passive, change fatigue is frequently unnoticed by nurse managers. It is imperative that nurse leaders understand the negative effects of change fatigue and monitor for the passive behavior so that change fatigue does not go unnoticed and under-researched.

In this study, the more resilient nurses were, the higher their job satisfaction. Similar to the findings of this study, previous investigators found a positive association between resilience and job satisfaction (Larrabee et al., 2010; Matos et al., 2010). In addition, Shin et al. (2012) found that resilience was positively related to employees' commitment to organizational change and commitment to change was negatively related to turnover. The association of resilience with commitment to organizational change was found to be mediated by organizational inducements that Shin et al. (2012) termed state positive effect and social change. In the present study, after adjustment for job satisfaction, the association of resilience and change fatigue was no longer significant, although

Table 1. Descriptive Statistics for Characteristics of Survey Sample and Multiple Regression Sample

	Counts (%)		
Characteristic	Total	Regression	p value[a]
Gender			
Female	469 (90.5)	317 (89.3)	.153
Male	49 (9.5)	38 (10.7)	
Race/ethnicity			
Caucasian	504 (97.3)	345 (97.2)	.102
Other	6 (1.2)	6 (1.7)	
American Indian	5 (1.0)	3 (0.8)	
Hispanic	2 (0.4)	0 (0)	
Black	1 (0.2)	1 (0.3)	
Age (years)			
25–35	174 (33.4)	121 (34.1)	.947
>55	136 (26.1)	89 (25.1)	
<25	93 (17.9)	63 (17.7)	
46–55	81 (15.5)	56 (15.8)	
36–45	37 (7.1)	26 (7.3)	
Marital status			
Married	328 (63.2)	227 (63.9)	.449
Single	145 (27.9)	94 (26.5)	
Divorced	46 (8.9)	34 (9.6)	
No. of children			
None	213 (40.9)	147 (41.4)	.642
1–2	168 (32.2)	117 (33.0)	
3 or more	140 (26.9)	91 (25.6)	
Education			
Bachelor's	322 (62.2)	226 (63.7)	.198
Associate	120 (23.2)	73 (20.6)	
Diploma	52 (10.0)	38 (10.7)	
Master's	24 (4.6)	18 (5.1)	
Employment			
Full-time	450 (86.9)	310 (87.3)	.653
Part-time	68 (13.1)	45 (12.7)	
RN experience			
>2 years (seasoned)	346 (66.8)	232 (65.4)	.303
≤2 years (novice)	172 (33.2)	123 (34.6)	
Hospital unit			
Other	211 (40.5)	132 (37.2)	.392
Medical/surgical	91 (17.5)	62 (17.5)	
ICU/CCU	78 (15.0)	59 (16.6)	
Maternal/child health	47 (9.0)	35 (9.9)	
Pediatrics/neonatal	26 (5.0)	19 (5.4)	
Trauma/ER	22 (4.2)	17 (4.8)	
Oncology	20 (3.8)	14 (3.9)	
Psychiatric/mental health	18 (3.5)	13 (3.7)	
Rehabilitation	8 (1.5)	4 (1.1)	
Magnet status			
Yes	324 (64.4)	228 (64.2)	.891
No	179 (35.6)	127 (35.8)	
Hospital Size (no. of beds)			
>250	250 (48.6)	181 (51.0)	.422
<50	140 (27.2)	94 (26.5)	
51–100	63 (12.3)	40 (11.3)	
101–250	61 (11.9)	40 (11.3)	

Note. CCU = critical care unit; ER = emergency room; ICU = intensive care unit; RN = registered nurse.

[a] p value for chi-square test.

Table 2. Descriptive Statistics for Job Satisfaction, Resilience, and Change Fatigue for Survey Sample and Multiple Regression Sample

	Mean ± *SD* (*n*)		
Factor	Total	Regression	*p* value[a]
Total job satisfaction	104.81 ± 16.97 (393)	104.83 ± 16.95 (355)	.939
Total resilience	40.71 ± 5.03 (470)	40.99 ± 5.09 (355)	.036
Total change fatigue	22.83 ± 8.97 (488)	22.51 ± 8.96 (355)	.197

[a] *p* value for two-sample *t*-test.

the association of job satisfaction and change fatigue was still significant. A possible explanation is that job satisfaction measures characteristics similar to organizational inducements, and that mediation by job satisfaction would attenuate an association between resilience and change fatigue. The multiple regression analysis of this study showed that Magnet designation was a significant predictor variable of job satisfaction; specifically, nurses who are employed in a facility with Magnet designation have higher job satisfaction. These findings are consistent with previous research demonstrating that Magnet designation correlated with higher levels of clinical nurses' job satisfaction (Upenieks, 2002). Magnet hospitals have been acknowledged as good places for nurses to work and are associated with greater professional autonomy, greater control over the practice environment, and the use of nursing systems that promote accountability and continuity of care (Adams & Bond, 2000).

This study also examined differences between novice and seasoned nurses with change fatigue, resilience, and job satisfaction. No prior research studies were found that examined change fatigue and the relationship with years of employment. Vestal (2013) suggested that new graduate nurses are more vulnerable to the effects of change fatigue. Two studies examined nursing experience and nurses' age with organizational change. Stensaker and Meyer (2012) found that employees with more change experience demonstrated less resistance and more positive reactions to the change. Moore, Kuhik, and Katz (1996) found that older nurses coped better with constant organizational changes. However, the present study did not find a significant association of nursing experience with change fatigue after adjustment for resilience, job satisfaction, and other nurse and employment characteristics.

There are some previous research studies addressing the association with resilience and nursing experience (Gillespie, Chaboyer, & Wallis, 2009; Kornhaber & Wilson, 2011; Lee et al., 2015). In the study by Gillespie et al. (2009), a significant positive association was found, but only operating room nurses were studied, and adjustments were made only for age and education. In the present study, confounders of the bivariate association of nursing experience and resilience were marital status, children, unit, job satisfaction, and change fatigue (data not shown), and there was no association of nursing experience and resilience after adjustment for these factors. In addition, Gillespie et al. (2009) found that age and education did not predict resilience. This study found that education was a significant predictor of resilience, but age was not a predictor of resilience.

Research findings have shown conflicting results with nursing experience and job satisfaction. Some studies have found no association with longevity in practice and job satisfaction (Adams & Bond, 2000; Cummings, Olson, & Hayduck, 2008; Larrabee et al., 2013; Murrells, Robinson, & Griffith, 2008). One study did report a positive association between age and nurse's job satisfaction (Chan & Morrison, 2000), but only bivariate associations were evaluated. Our study found that age had a nonlinear relationship with job satisfaction, with younger and older nurses having greater job satisfaction. There was weak evidence that years of experience and job satisfaction were associated. Whether this is real will require replication with other populations.

Limitations

Findings of this study might not be generalizable to the population for several reasons. Although the recruitment of nurses for the study population was based on a random sample, differences in response across population characteristics makes the study population less representative. This study employed a descriptive correlational design to describe relationships of variables of interest, and the temporal relationship between many of the variables cannot be determined, which prevents defining causal relationships. Also, there was potential for unmeasured confounding variables to affect the findings of this study, and the resulting potential for bias cannot be ruled out.

Additional research is needed to further understand the role of change fatigue to job satisfaction and retention of nurses. Bernerth et al. (2011) recommended

Table 3. Associations of Nurse Individual and Work Characteristics With Change Fatigue, Resilience, and Job Satisfaction

	Change fatigue		Resilience		Job satisfaction	
Characteristics	β	*p* value	β	*p* value	β	*p* value
Change fatigue			−.03	.28	−.55	<.001
Resilience	−.10	.28			.73	<.001
Job satisfaction	−.16	<.001	.07	<.001		
Marital status						
Divorced	−.64	—	.76	—	−1.0	—
Single	−.24	—	−.54	—	5.3	.07[a]
Married	R		R		R	
Education						
Master's	2.2		2.7		−1.5	
Diploma	2.8	> .05[b]	.07	.03[b]	−3.7	.45[b]
Associate	2.8		−.13		2.9	
Bachelor's	R		R		R	
Gender						
Male	3.6	.02	1.2	.16	−2.9	.31
Female	R		R		R	
Unit						
Psychiatric/mental health	−5.6	—	−1.8	—	−4.8	—
Maternal-child	−.22	—	−1.7	—	−3.4	—
Pediatrics/neonatal	−3.1	—	−1.1	—	−4.0	—
Trauma/ER	−1.2	—	.30	—	−2.3	—
ICU/CCU	−2.4	—	−.02	—	−8.9	.02[a]
Oncology	−1.6	—	−2.6	—	−11.0	—
Medical/surgical	.01	—	−1.3	—	−2.1	—
Rehabilitation	−4.3	—	3.6	—	−21.0	—
Other	R		R		R	
Employment						
Part-time	.70	.61	−.64	.42	1.6	.54
Full-time	R		R		R	
RN experience						
≤2	1.85	.18	.72	.36	−4.4	.08
>2 years	R		R		R	
No. of beds						
<50	−5.2		.49		−.14	
51–100	−3.0	.001[b]	1.8	> .05[b]	−3.1	.87[b]
101–250	.35		.33		−1.9	
>250	R		R		R	
Magnet status						
Yes	−1.5	.24	−.14	.85	5.1	.03
No	R		R		R	
Age (years)						
<25	1.7		−1.5		−.72	.54[b]
25–35	−1.6		1.1		−4.8	.03[c]
36–45	0.1	> .05[b]	−1.6	> .05[b]	−7.8	
46–55	1.2		.24		−.57	
>55	R		R		R	
No. of children						
None	R		R		R	
1–2	.15	> .05[b]	.89	.09[b]	−.78	.88[b]
3 or more	−.82		1.5		−.45	

Note. β = regression coefficient; CCU = critical care unit; ER = emergency room; ICU = intensive care unit; R = reference category; RN = registered nurse; — = $p > .05$ for paired comparisons with all other categories with Sidak adjustment.

[a] $p < .05$ for comparison to the reference category.

[b] *p* value for linear trend test of ordinal categorical variable.

[c] *p* value for quadratic trend test of ordinal categorical variable.

further research comparing change fatigue and individual differences, including self-efficacy, openness to experience, and tolerance for ambiguity. Future studies need to include a more diverse sample, and a qualitative study would be valuable in understanding change fatigue and individual coping strategies used during organizational change. Lastly, research is needed to test interventions that promote resilience and the effects on change fatigue.

Conclusions

Health care is typified by change, and in the current healthcare milieu, the pace, direction, and intensity of change challenge nurses to adapt and cope. Change fatigue is the overwhelming feeling of stress, exhaustion, and burnout associated with rapid and continuous change in the workplace, and there is limited research on change fatigue in nursing. This study was an initial step in advancing nursing knowledge on change fatigue, resilience, and job satisfaction in nurses working in acute care hospitals, which can be used by nursing leaders to enhance workplace environments, job satisfaction, and retention of nurses.

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Clinical Resources

- American Association of Colleges of Nursing. Nursing shortage factsheet. https://www.advantagern.com/hospitals/aacn-nursing-shortage-fact-sheet/
- Department for Professional Employees. Nursing: A profile of the profession. http://dpeaflcio.org/programs-publications/issue-fact-sheets/nursing-a-profile-of-the-profession/

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PROFESSION AND SOCIETY

A National Survey Examining Manuscript Dissertation Formats Among Nursing PhD Programs in the United States

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Abstract

Purpose: Among research-focused nursing doctoral (PhD) programs in the United States, the traditional dissertation format has recently given way to a series of publication-ready manuscripts, often bookended by introduction and conclusion chapters. To help programs make decisions about the use of these formats, this study undertook a national survey of programs offering PhDs in nursing. The purpose of this study was to explore the advantages and disadvantages of the traditional format versus manuscript option for dissertations among nursing PhD programs in the United States.

Design: Cross-sectional census survey of U.S. nursing PhD programs.

Methods: A web-based survey was administered to all U.S. nursing PhD programs. Respondents indicated formats offered, factors contributing to decisions of which formats to offer, and lessons learned. Descriptive statistics and inductive content analyses were used for analysis.

Findings: Of 121 eligible institutions, 79 provided eligible responses (66.7%). The majority (59%) offered both formats; 11% offered the manuscript option only, and 24% offered the traditional format only. Faculty support (or lack thereof) contributed to adoption (or not) of the manuscript option. Respondents' approaches to the manuscript option (e.g., number of papers) and advice are summarized.

Conclusions: Manuscript option dissertations are commonly offered and provide benefits to students and faculty; however, thoughtful implementation is critical. Programs need to agree upon clear expectations and have graduate school support (e.g., formatting). Faculty need mentorship in advising manuscript option students who choose to use this format, and the time and support. Finally, students need additional writing skills that could be provided through coursework or via individual work with mentors.

Clinical Relevance: As nursing education continues to expand further into doctoral research, programs must examine dissertation formats in order to both prepare future nurse scholars and disseminate nursing research that is critical to improving nursing education, patient care, and clinical practice.

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In 2010, fewer than 1% of nurses in the United States held a doctorate degree in nursing or a nursing-related field (Institute of Medicine, 2011). As demands for doctorally prepared nurse educators, healthcare providers, and researchers increase, the Institute of Medicine Future of Nursing Committee issued a call to “double the number of nurses with a doctorate by 2020” (Institute of Medicine, 2011, p. 13). In recent years, major incentives have been developed to increase the number of doctorally prepared nurses, including funding from the Jonas Center for Nursing and Veterans Healthcare, Rita & Alex Hillman Foundation, and the Robert Wood Johnson Foundation (National Academies of the Sciences, Engineering, and Medicine, 2016). In the United States, an estimated 5,290 students were enrolled in research-focused nursing doctoral programs in 2014, a growth of 53.8% since 2004 (American Association of Colleges of Nursing, n.d.). The number of nursing programs that offer research-focused doctor of philosophy (PhD) degrees has increased concomitantly (National Academies of the Sciences, Engineering, and Medicine, 2016).

Globally, the shortage of doctorally prepared nurses parallels the shortage in the United States (Nardi & Gyurko, 2013). PhD programs are of special concern due to the shortage of qualified faculty (Comiskey et al., 2015). As in the United States, nursing PhD programs are also increasing worldwide (McKenna, Keeney, Kim, & Park, 2014). The structure of these programs may differ from the United States with doctoral education that is more individualized and focused on students’ independent research; however, programs with coursework and dissertations or theses are becoming more common (Ketefian, Davidson, Daly, Chang, & Srisuphan, 2005).

Along with the growth in the number of nursing PhD students and programs in the United States, a shift in the format of dissertations is occurring (Robinson & Dracup, 2008). Traditionally, nursing dissertations in the United States present exhaustive scholarly research in the format of five chapters (i.e., introduction, literature review, methods, results, conclusions) unified as a single document. Recently, the “manuscript option” dissertation format has gained popularity. This format consists of a series of related manuscripts appropriate for submission to peer-reviewed academic journals, typically bookended by introduction and conclusion chapters. Notably, as early as 2001, nursing doctoral programs in Brazil required that students submit a manuscript for publication in a peer-reviewed journal in addition to defending their dissertation in the traditional format (Ketefian, Neves, & Gutiérrez, 2001). Students in Australia and Thailand are expected to publish their papers by the time they graduate (Kim, McKenna, & Ketefian, 2006). In the United Kingdom and Northern Ireland, some universities grant students their degree based on their publications (McKenna & Cutcliffe, 2001). In Sweden, a PhD by publication involves a thesis consisting of a number of peer-reviewed papers (five to six) with introductory and concluding chapters (McKenna & Cutcliffe, 2001). The advantages of the manuscript option include early preparation for tenure-track nursing faculty positions, experience with manuscript preparation, and familiarity with the article submission process. However, lack of depth, greater need for student writing help, and faculty burden have been cited as disadvantages of this alterative format (Robinson & Dracup, 2008).

The purpose of this study was to explore the use of the manuscript option dissertation format among nursing PhD programs in the United States, to help or assist nursing programs make decisions about the use of this format. Specifically, we sought to estimate the proportion of programs employing each dissertation format, factors contributing to adopting (or not adopting) the manuscript option, and advantages and disadvantages of the manuscript option.

Methods

Study Design

This was a cross-sectional study of all U.S. nursing PhD programs based on findings from a web-based census survey. We used descriptive statistics (e.g., chi-square tests) and inductive content analyses to examine data.

Sampling and Administration

A web-based survey was administered to a census sample of all U.S. nursing PhD programs from April to June 2016. The study sample was identified from the list of American Association of College of Nursing (AACN) member institutions identified on the AACN website (https://www.aacn.nche.edu/about-aacn/member-schools). Included in the study were AACN member institutions with a PhD program and academic collaborator institutions with PhD programs partnered with the Nursing Education Xchange (NEXus; http://www.winnexus.org/). Universities with nursing PhD programs directed from more than one campus were treated as separate institutions because the faculty members across the programs may vary, as may the policies. Once the sampling frame was established from AACN and NEXus sources, website searches were conducted to confirm the existence of the PhD program and obtain the name and contact information for the PhD program director. If information could not be found online, institutions were contacted by telephone.

Potential participants were contacted by email and asked to complete the survey through a web-based platform (Qualtrics®, Provo, UT, USA). Following the initial email contact, up to five reminders were sent weekly. No incentives were offered for participation.

Survey Design

The survey was investigator designed. Questions were chosen by the authors and vetted with members of a nursing PhD program advisory committee at the author's institution. Questions were designed to elicit information to understand what dissertation option each PhD program was using and perceptions of advantages and disadvantages of the manuscript option. The goal was to develop a survey that could help inform a PhD program that was considering various dissertation options. The latter was the specific motivation for the open-ended questions incorporated into the survey. A team of 15 subject matter experts (nursing faculty, staff, and administrators) reviewed the items and agreed by consensus that all survey items addressed key questions that were required to answer our research questions.

Respondents were asked to indicate whether they offered the traditional, manuscript option, or both dissertation formats. Respondents from programs that offered the traditional format only were asked whether they considered the manuscript option, and if so, they were asked about factors that contributed to the decision not to adopt it (categorical question). An open-ended response was offered as well. Respondents from programs that offered the manuscript option were asked to indicate factors contributing to adoption (categorical and open-ended questions), as well as open-ended questions about advantages, disadvantages, and advice for programs considering adoption of the manuscript option. They were also asked to provide details about the nature of their requirements for that option. Skip logic was employed for some items to reduce respondent burden and to avoid irrelevant questions; no respondent completed all questions. The maximum number of items possible was 16.

Analysis

Descriptive statistics were calculated for categorical and continuous responses. For open-ended questions, we conducted an inductive content analysis with a qualitative descriptive approach. First, two members of the research team read all of the open-ended questions. The questions were then divided and each of the two members conducted further readings and coding of data. Categories were formed and shared. Through an iterative process the categories were developed into themes and exemplar quotes reviewed. Sharing the results with the team and making additional clarifications of the themes and quotes concluded the analysis. Rigor was assessed during the analysis and writing for confirmability and credibility (Lincoln & Guba, 1985). In this study, confirmability was judged by maintaining records of all data collection and analysis steps (audit trail) and reporting results in narrative form that could be judged by researchers and readers for credibility. This study was reviewed and deemed exempt from human subject review by the Washington State University Institutional Review Board.

Results

A total of 130 institutions were identified from the AACN list (accessed January 29, 2016), of which 9 institutions were identified as not having a PhD program (after searching institutional websites). One institution was updating their curriculum and not admitting PhD students in 2016. Therefore, 120 eligible institutions were identified through AACN. Among NEXus schools with PhD programs ($n = 21$), 20 were already included in the AACN list and 1 was identified that was not identified through AACN. The final sample size for this study was 121 PhD programs (**Figure 1**).

Of eligible programs, 80 responded, 1 of which indicated they did not have a PhD program (and was therefore identified as ineligible post hoc), resulting in a 66.7% response rate (American Association for Public Opinion Research Response Rate 4). Most respondents were from the South ($n = 28$) and Northeast ($n = 18$); fewer were from midwestern or western institutions ($n = 15$ and $n = 9$, respectively; based on U.S. Census regions). Respondents did not differ from nonrespondents in terms of census region (chi-squared test = 3.82 [3 *df*], $p = .28$).

Of the 79 respondents, 66 (84%) offered the traditional format and 56 (71%) offered the manuscript option format. The majority of programs ($n = 47$, 59%) reported offering both the manuscript option and traditional dissertation formats. Few programs offered only one format: 19 (24%) offered only the traditional format and 9 (11%) offered only the manuscript option.

Among programs offering both dissertation formats ($n = 47$), 14 (30%) reported that less than half of their students choose the manuscript option. Eleven programs indicated that 50% to 74% of their students choose the manuscript option, and 9 reported that 75% or more students choose that option.

Decision-Making Considerations

Among the 19 programs that offered only the traditional format, half ($n = 10$) reported previously

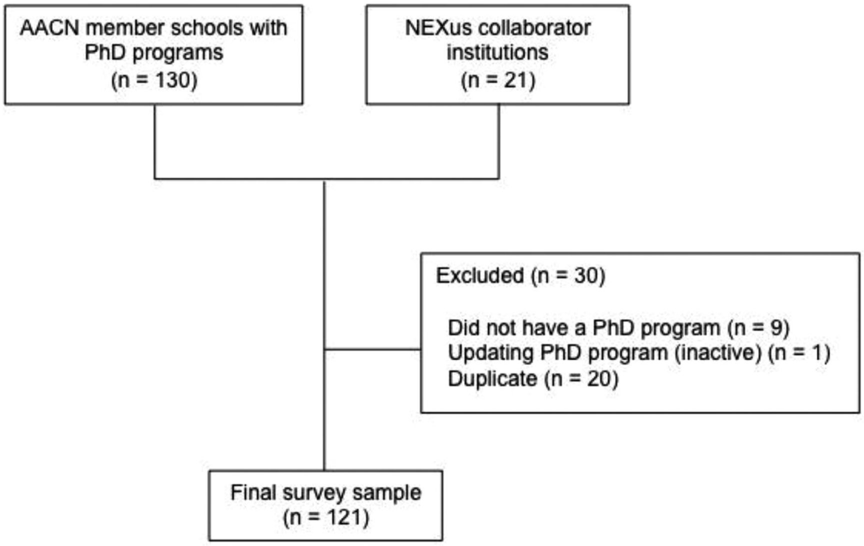

Figure 1. Flow diagram of sample determination.

considering the manuscript option. The most common reason for not adopting the manuscript option (based on categories provided in the survey) was lack of PhD program faculty support (**Table 1**). Seven respondents provided additional qualitative information by choosing the "other [write-in]" category. These responses included concerns that the manuscript option "watered down the process." Additionally, the lack of "control over when manuscript is reviewed, accepted and published" and "poor scholarly, scientific writing skills of admitted students" played a role in their decision. One program's graduate school policy not allowing the manuscript option was also cited as influencing the decision not to adopt the manuscript option. Four of the 19 programs indicated they were considering the manuscript option at the time of the survey.

Six respondents provided additional feedback on considerations that led to their institution not including the manuscript option for PhD nursing dissertations (after deleting responses such as "no"). Editor fatigue, described as "flooding journals with manuscripts that burden editors and reviewers," was noted by two respondents as an important factor. Other responses included the following: time that manuscript submission takes; unclear policies and procedures regarding manuscript rejection; external factors in following other university programs; "faculty educational philosophy;" limiting depth in the topic area, described as "artificially dividing the student's work into arbitrary milestones and we worried that they would not appreciate the 'whole' of their research dividing it up along the way"; and concern regarding the lack of publication opportunities in PhD programs focused on nursing education.

Factors contributing to adoption of the manuscript option format in the 56 programs offering this format included faculty support of the manuscript option and potential to increase the transition of student nurse scholars to academic positions (see **Table 1**). In addition to the categories provided in the survey, respondents who chose the "other [write-in]" option stated that external players, such as outside consultants ($n = 2$) or the basic science faculty in their institution ($n = 1$) played a role in their decision to adopt the manuscript option. Faculty benefits, including better use of their time and co-authorship, were also cited as contributors. Finally, one respondent noted that the manuscript option could aid in their students' progression as a scholar:

> Graduates may fail to publish manuscripts from their traditional format dissertation for a variety of reasons, including lack of time after assuming a full-time paid position and lack of appropriate mentoring. Being allowed or encouraged to write manuscripts while still a student was thought to increase their scholarly productivity while being effectively mentored.

Advantages and Disadvantages

Overall, respondents were in favor of the manuscript option, although several disadvantages were noted in text responses. Advantages, based on open-ended questions, centered on future career opportunities for students, such as the ability of having publications before or shortly after graduation aiding in finding postdoctoral fellowships or academic positions. Comments citing disadvantages

Table 1. Decision-Making Considerations Among Nursing PhD Programs Regarding Adopting the Manuscript Option Dissertation Format

Factors playing a role in decision not to adopt the manuscript option dissertation format[a]	% of PhD programs
Lack of PhD program faculty support for the manuscript option	30
Challenges with university/college regarding issues such as copyrights	20
Perception that alternative dissertations (such as the manuscript option) are less rigorous than traditional formats	20
Concerns about ambiguous requirements for manuscript option dissertations	20
Concerns about quality	20
Not all dissertations are suitable for manuscript option format	20
Potential burden on the committee to help with writing	10
Loss of creativity and exploration associated with the in-depth writing experience of a dissertation	10
Possible increased workload for faculty	10
Perceived difficulty in balancing faculty contribution with student independence (for authorship)	10
Desire to maintain tradition	10
Manuscript option format may be a long process (may lengthen the program)	10
Concerns about intellectual property rights	10
Concerns about self-plagiarism	0
Considerations leading to adoption of the manuscript option dissertation format[b]	
PhD program faculty supported the manuscript option	79
Potential to increase the transition of student nurse scholars to academic positions	75
Students gain firsthand experience in publishing	73
Better prepare students for a career in academia	68
Increased competitiveness for students when searching for future jobs/positions ("jump start")	59
Increases public's access to research by efficiently disseminating dissertation findings	39
Potential to decrease "thesis"-type journal submissions with faculty helping students learn to write for publication	39
Potential gains in student self-esteem	20
Facilitation of stronger or lasting collaborations between mentors and students	18
Support among students	14
More discrete tasks for students may help them finish	5
Increase student motivation (leading to fewer ABDs)	0

Note. Categories are not mutually exclusive.
[a] Among nursing PhD programs that considered but elected not to adopt the manuscript option ($n = 10$).
[b] Among nursing PhD programs that adopted manuscript option ($n = 56$).

focused on faculty time and need for careful policies and procedures.

Advantages. Thirteen of the programs that reported offering both dissertation formats provided input on advantages of this format (after deleting responses such as "no"). Generating publications was identified as a benefit by six respondents, not only for the student and faculty members, but also external members of the dissertation committee. Student publications could also serve as a tool for PhD program recruitment. Learning the publication and writing process (e.g., succinctness; $n = 2$) and strengthening expectations for publications and scholarly productivity on the part of the student ($n = 2$) were noted as advantages. Finally, one respondent noted that other programs in the United States have begun to offer this format as a reason for their consideration of the manuscript option.

Disadvantages. Twenty-two of 47 respondents provided open-ended responses (after deleting responses such as "no"). Disadvantages for including the manuscript option were multifold:

- challenges with formatting ($n = 6$);
- students' lack of writing skills ($n = 5$, 2 of whom mentioned students for whom English was their second language);
- limitations in exploring the topic fully, or not reaching the depth that a traditional dissertation does ($n = 3$);
- faculty resistance to making the change ($n = 2$), which included increased workload;
- the time that writing manuscripts takes in terms of editing and refining the work ($n = 1$);
- length of time and low manuscript acceptance ($n = 1$);
- increased faculty mentorship ($n = 1$).

Lack of faculty preparedness in the manuscript option as a new approach was also cited ($n = 1$); also cited was that not all faculty have strong publication records or writing skills themselves ($n = 1$).

Two respondents noted that copyright infringement was a concern, referring to the "need to embargo the dissertation for up to 3 years to avoid copyright infringement." In other words, journals may copyright the content of an accepted, dissertation manuscript, creating an issue when universities make dissertations accessible through clearinghouses and repositories. A respondent also noted that "some work may not need to be published ahead of time because copyright or patent may be pending and so the publication option, especially data-based papers ahead of completion of final work, may interfere with academic ownership." Negotiating co-authorship, especially among faculty coauthors, and potential conflicts between committee and reviewer feedback were also noted as disadvantages of the manuscript option by one respondent.

In terms of the number of manuscripts to be submitted, one respondent stated that three manuscripts might be unrealistic for some dissertation topics, noting "a purely qualitative dissertation may generate only one data-based paper.” Unclear expectations were also noted by one respondent as a factor contributing to the difficulty of adopting the manuscript option.

Finally, when asked about other considerations that led their program to offer the manuscript option, three respondents stated that generating publications for the graduate student ($n = 2$) and helping students learn the publication process ($n = 1$) were benefits. External factors were considered, such as support for the option through the graduate school ($n = 2$). Time was a consideration in that the dissertation “required substantial time on the part of the student and faculty” ($n = 1$).

Number of Manuscripts and Submission Requirements

Of the institutions that offered the manuscript option, the majority (61%) required three manuscripts in order to graduate, irrespective of publication status (submitted or accepted). Fewer required two (22%) or one (6%) manuscripts. One respondent noted that the “number . . . varies depending on particular study and content,” and another respondent stated “one to three manuscripts in lieu of chapters for the dissertation.” In terms of the submission status of the publications, 12% of institutions indicated that no manuscripts must be submitted, accepted, or published before defense. Many institutions (45%) reported that students may submit one or more manuscripts before defense, whereas 10% of respondents required that one or more manuscripts must be accepted or published before defense. Approximately one fifth of the schools (22%) required that one or more manuscripts be submitted before graduation, compared to 8% that required manuscripts be accepted or published before graduation. Overall, there was no agreement between programs on number of manuscripts or status (e.g., submitted, reviewed, or published) needed for graduation.

Advice to Other Institutions

Over half ($n = 44$, 56%) of respondents offered advice for other institutions considering the manuscript option (after deleting responses such as “no”). Many respondents had advice from “just do it” or a variation of strong encouragement to proceed ($n = 15$, 34%) to warning of the increased workload to faculty (16%). The five themes that emerged under advice were (a) admitting PhD students; (b) writing; (c) willing and experienced faculty; (d) providing clear policies and procedures; and (e) warnings.

Admitting PhD students. Respondents often noted that the manuscript option was not for all students. One participant suggested a limited trial run “with a few motivated faculty and students to guide program decision making.” Another suggested only admitting students with research and publishing experience and preferably “with scholarships that can devote to full-time studies and research experience simultaneously.” The same respondent emphasized student fit:

> Students electing to pursue the manuscript option will be best served by the following: an early run at publishing, documented fit with future career decisions (a statement making the case for choosing the manuscript option), self-confidence, good writing skills, selection of a topic early and sticking to it, and buy in to the faculty advisor’s research in a manner that is synergistic with moving the student and faculty research forward with ease and efficiency.

Another participant thought the manuscript option was the “best tool for ensuring that students are really ready for a career as a nurse scientist.”

Writing. Up to 60% of respondents emphasized the need to help students and faculty with writing. Included in this theme are recommendations for both student and faculty mentors: “Both need to understand the work that is involved in writing this type of dissertation. Many view it as easier when in fact it is not. It is not just three manuscripts bound together.” They also suggested that only faculty with strong writing backgrounds and track records with publications be involved. Another suggestion was to design coursework to support publications and to allow students to use their predoctoral fellowship proposals (i.e., Ruth L. Kirschstein National Research Service Award) as a dissertation proposal. These measures help to speed up the writing process.

Willing and experienced faculty. Faculty who undertake the manuscript option with students need to have their own research programs with related publications where they can include students. Faculty need to understand and accept that the manuscript option is more work than a traditional dissertation. One participant suggested that the manuscript option is better not only for students but for faculty:

> The outcomes are student scholarship, experience with writing different types of manuscripts and a more thoughtful and useable dissertation format. I believe the time investment is more over time with this option and as such my students often write the first paper in year one, the second in year two and the third for the defense. The investment is just better for all.

A second respondent reinforced the notion that "the investment is better for all."

Providing clear policies and procedures. Most respondents in the study who answered this question suggested clear policies and procedures as a primary ingredient for success. For instance, one respondent stated, "Be clear in expectations such as do manuscripts have to be published, submitted or in review to satisfy requirements? What QA [quality assurance] will you have on the quality and depth since there are page requirements for manuscripts?"

Suggestions also covered defining how many manuscripts are required and what each should contain. For example, respondents suggested "not just three random manuscripts," "not requiring publication before graduation," "one accepted and two submitted," or "one manuscript ready for submission at time of defense." Another respondent noted as an advantage that the manuscript option was consistent with other disciplines such as psychology and physiology. In summary, guidelines should be specific so that students, faculty, and committees understand what is required.

Noted concerns. As noted, respondents stressed the difficulty of the option and the need for faculty and students to be ready. Institutional readiness was seen in the previous theme on policy and procedures. Another concern mentioned by three of the respondents was that the option did not dive deeply enough to provide the foundation that scholars need to build their program of research. As noted by one respondent,

> The dissertation is like a care plan for a fundamentals student. It is the place where you learn about how to think about doing a research study. Just as a practicing nurse never does a care plan in practice, only as a student, the researcher does not write another dissertation. However, the habits developed during the writing of the traditional dissertation is a valuable experience.

The theme of student fit and abilities arose, as one respondent noted, "For rare students the five chapters may be the better option due to their abilities, topic, or other constraints." Two institutions noted that international students may face challenges with the manuscript option, due to speaking English as an additional language. In one case, a respondent revealed that at their institution, "some international students are required to complete a traditional dissertation" format and do not have the manuscript option as a choice.

Discussion

In this study, we found that the majority of nursing PhD programs in the United States offer the manuscript option dissertation format to their students. Respondents to our survey provided many comments on advantages and disadvantages and offered advice to other programs considering the manuscript option. The concerns cited by programs that considered and elected not to offer the manuscript option and programs that currently offer the manuscript option are consistent with published commentaries and research studies. The manuscript option is perceived to provide students with publication experience that prepares them for future employment (De Jong, Moser, & Hall, 2005; Gross, Alhusen, & Jennings, 2012; Lee, Clark, & Thompson, 2013; Morton, 2015; Nolan et al., 2008); however, a tension was revealed in this study between these advantages and the possible loss of the deep exploration that the traditional format affords (Robinson & Dracup, 2008).

Students electing the manuscript option will require support to develop their manuscripts and submit to a journal for publication; it should be the responsibility of the PhD program and its faculty to prepare the student in this way. Poorly written or prepared article submissions burden journal editors and reviewers, as highlighted by one respondent and noted frequently in the literature (Becker, 2012; Chyun & Henly, 2015; De Jong, Moser, & Hall, 2005; Gross et al., 2012). It is critical that the quality of dissertation-related manuscripts be on par with more experienced researchers. As a result, students require preparation, guidance, and assistance throughout the manuscript writing and submission process, which may currently be lacking in nursing PhD programs (Morton, 2015).

For international students completing graduate work in countries other than their own, language barriers may pose significant challenges in communication and stress related to writing. Producing publishable manuscripts can be overwhelming (McKenna, Robinson, Penman, & Hills, 2017). In their review of U.S. doctoral students' experiences across disciplines, Evans and Stevenson (2010) noted that international "students struggle not only with the intellectual exposition to be critical and questioning but also with its practical demonstration, i.e. how to demonstrate these qualities in their writing" (p. 246). Faculty advisors may need to consider taking extra steps to support international students in writing manuscript option dissertations, including providing clear writing examples and providing frequent feedback (Evans, 2007; Evans & Stevenson, 2010).

The increased time needed for faculty to assist students in writing publication-ready manuscripts should not be overlooked, as this can contribute significantly to their workload (Robinson & Dracup, 2008). Yet, these challenges can be offset by the benefits of co-authorship (Gross et al., 2012; Robinson & Dracup, 2008) and the establishment of lasting collaborations (De Jong, Moser, & Hall, 2005). Further, through mentoring PhD students through the manuscript drafting and submission process, faculty can model a collaborative, scholarly approach that more closely resembles research teams, rather than a lone academic moving their program of research forward in isolation (Morton, 2015).

The high (and growing) prevalence of nursing PhD programs offering the manuscript option can contribute to improved dissemination and translation of research findings (Chyun & Henly, 2015; De Jong, Moser, & Hall, 2005; Morton, 2015), in addition to preparing graduates for future academic positions (Gross et al., 2012; Lee et al., 2013; Robinson & Dracup, 2008). Nursing PhD programs considering this option should proceed carefully in developing policies and procedures that correspond with the needs and abilities of their students and faculty. Programs should agree upon clear expectations for the quality of the manuscript option dissertations and have support from their graduate school or university to address copyright issues that may arise. Additionally, faculty in PhD programs that offer or expect the manuscript option need mentorship in advising students who choose to use this format and supported time to do so. Students who chose the manuscript option require additional writing skills that could be provided through coursework or via individual work with mentors. However, if faculty are not well prepared to assist students in preparing manuscripts for publication, programs should consider offering support and guidance through continuing education or faculty advancement workshops. Institutions with nursing PhD programs will need to be supportive and able to provide additional resources such as faculty time and training, developing policies consistent with the university if needed, and potential increases in student support services such as writing labs and tutors.

Limitations

This study has several limitations. First, findings are based on self-reported responses to an online survey. It is possible that respondents may have misrepresented the dissertation formats available to their students; however, this is unlikely. The survey asked for input from a single respondent at each PhD program, which may not have been representative of the opinions of all faculty. We focused this study on PhD program directors, who we envisioned could provide the most accurate assessment of their dissertation formats and issues surrounding them.

In this study, we did not examine how alternative dissertation formats might influence the structure or content of final dissertation defenses, which may be an area for future exploration. In addition, we did not assess the publishing productivity of PhD students who completed each type of dissertation format or their career trajectory. It is assumed that students who complete the manuscript option will publish more quickly or frequently than students who choose the traditional format (De Jong, Moser, & Hall, 2005; Robinson & Dracup, 2008); however, we did not assess this, and this provides an opportunity for future research. We did not ask respondents about institutional practices or policies regarding the resubmission of manuscripts (from a manuscript option dissertation), including the time it takes to receive reviewer feedback and revise drafts. Furthermore, to address the potential conflict between the productivity and career readiness afforded by the manuscript option with the depth and process associated with the traditional format, which was noted both in our study and in the literature (Robinson & Dracup, 2008), qualitative research to explore the perspectives of recent PhD graduates who completed each type of dissertation format may be warranted. It is not currently known whether completing a PhD program with a manuscript option actually leads to more publications or to increased academic career competitiveness. While individual programs may collect data on time to graduation (defense) for their students, it may be relevant to compare time to graduation between both dissertation formats, as this has not yet been explored. Finally, this study summarizes various dissertation approaches within the United States, which may differ from models in other countries.

As noted by Chyun and Henly (2015) as a word of warning, the manuscript option should be considered as just that—an option. Respondents to our survey noted that some dissertation topics and methodologies may be more amenable to traditional dissertation format. These preferences might impact the timely publication of dissertation findings from certain types of studies; future studies could be conducted to examine this association. The decision of an individual's dissertation format should be made together with the student and dissertation committee, as several factors may contribute to the preferred approach, including the writing and publishing experience of the student and faculty and the faculty's program of research.

In conclusion, the manuscript option for nursing PhD dissertations is growing more common in the United States. While there are benefits to this format, it is not without its disadvantages and challenges, both for the student and faculty. For programs considering this option, thoughtful implementation is critical, and for programs that currently offer the manuscript option, ongoing faculty and student support may be needed to ensure the success of the future nurse scholars. Research is needed to understand if the primary reasons programs take on the manuscript option, publication productivity, and career competitiveness are improved.

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Clinical Resources

- Sigma Theta Tau. Learn and Grow: Education. https://www.sigmanursing.org/learn-grow/education
- National League for Nursing. Scholarly Writing Retreat: An NLN Mentoring Program. http://www.nln.org/centers-for-nursing-education/chamberlain/scholarly-writing-retreat
- American Association of Colleges of Nursing. PhD Education. http://www.aacnnursing.org/Nursing-Education-Programs/PhD-Education

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PROFESSION AND SOCIETY

Case Studies of Interprofessional Education Initiatives From Five Countries

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Collaborative practice, communication, interprofessional education, nursing student, patient outcomes, teamwork

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Abstract

Background: Although teamwork and interprofessional collaboration are critical to patient safety, nursing, medical, and allied health graduates often feel ill-prepared to confidently communicate and collaborate with other team members. While interprofessional education (IPE) has been advocated as a way of addressing this issue, there are multiple barriers to its systematic and sustained integration in undergraduate healthcare programs. Despite these challenges, examples of effective IPE initiatives have emerged.
Innovation: This article profiles seven case studies of innovative interprofessional education activities that have been successfully implemented across five countries, for a variety of learners, using different delivery modalities, and with evaluation results attesting to their success.
Conclusions: The case studies demonstrate innovative ideas that have the potential to overcome some of the barriers to IPE through the use of creative and targeted approaches. This article provides a wealth of ideas for the successful design and implementation of IPE initiatives and will be of benefit to educators wishing to expand their repertoire of teaching approaches.
Clinical Relevance: A body of research attests to the relationship between interprofessional communication, teamwork, and patient outcomes. IPE is imperative for facilitating the development of nursing graduates' communication and teamwork skills; however, innovative approaches are needed to overcome the perceived and actual impediments to its implementation.

A wide body of research attests to the relationship between interprofessional communication, teamwork, and patient outcomes (Levett-Jones, Oates & MacDonald-Wicks, 2014; Reeves, Pelone, Harrison, Goldman, & Zwarenstein, 2017). Yet, too often nursing, medical, and allied health graduates lack the confidence and skills needed to communicate and collaborate effectively as members of interprofessional teams (Gilligan, Outram & Levett-Jones, 2014). Interprofessional education (IPE) has been proposed as the most appropriate educational strategy for facilitating the development of these skills (Teodorczuk, Khoo, Morrissey, & Rogers, 2016). However, multiple barriers to the efficient, effective, sustained, and systematic integration of IPE in undergraduate education programs have been described (Lapkin, Levett-Jones, & Gilligan, 2012). Despite these challenges, examples of successful and innovative IPE initiatives have emerged.

The aim of this article is to profile seven case studies of creative IPE activities that have been successfully implemented across five countries. These case studies used both online and face-to-face teaching approaches and were conducted in classrooms, clinical and community settings. The IPE initiatives targeted a range of specific learning outcomes and practice issues for undergraduate and postgraduate nursing, medical, and allied health students.

Background

Healthcare professionals are required to work both autonomously and collaboratively in complex and dynamic clinical environments. Interprofessional collaboration is defined as members of the healthcare team working together to improve the quality and safety of patient care using complementary knowledge and skills, and with respect for each other's expertise (Rogers et al., 2017). An effective interprofessional team requires knowledge and understanding of each member's roles and responsibilities as well as mutual valuing of the unique contributions made by each professional group to patient care (Wilson, Palmer, Levett-Jones, Gilligan, & Outram, 2016).

When teams communicate and collaborate effectively, knowledge and information is shared, joint decision making is enabled, and team members feel more confident and empowered to assume leadership for patient care issues appropriate to their scope of expertise (World Health Organization, 2010). A recent systematic review identified that interprofessional collaboration has a significant impact on patient outcomes and use of healthcare resources (Reeves et al., 2017). However, too often deeply entrenched cultures, power differentials, and the hierarchical nature of healthcare environments can present barriers to interprofessional collaborative practice. Thus, many healthcare graduates enter clinical environments where the rhetoric of teamwork contrasts markedly with workplace realities (Rice et al., 2010).

Thistlewaite (2015) suggested that the opportunity for healthcare students to learn together prepares them to work within interprofessional teams, ultimately leading to improved patient care. IPE occurs when learners from two or more professions learn about, from, and with each other to enable effective collaboration and improved health outcomes (Centre for the Advancement of Interprofessional Education, 2002). However, contemporary teaching and learning approaches in higher education do not always facilitate the development of healthcare students' communication, collaboration, and teamwork skills, and formal teaching and assessment in these areas are often neglected (Leonard, Graham & Bonacum, 2011). Additionally, when educational opportunities are offered, they tend to focus mainly on communication with patients, and much less attention is given to communicating with other health professionals. As a result, graduates and their employers often report that they are not well equipped to communicate and contribute effectively as team members (Gilligan et al., 2014).

The IPE agenda emerged more than 30 years ago, but its importance was recognized following multiple international patient safety reports detailing adverse patient outcomes resulting from poor interprofessional communication and collaborative practice. Consequently, these concerns led to changing policy directions with regard to IPE. For example, in Canada there is a clear policy supporting the incorporation of IPE into health professional education, with the Health Council of Canada recommending that each university health sciences program offer an IPE subject (Bandali, Niblett, Yeung, & Gamble, 2011). Similarly, the Institute of Medicine Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing at the Institute of Medicine (2011) in the United States advocated that healthcare professionals should be educated to deliver person-centered care as members of interprofessional teams. In the United Kingdom, outrage at the findings of the Bristol Royal Infirmary inquiry, which attributed a significant proportion of clinical errors to poor interprofessional teamwork (Department of Health, 2002), led to IPE becoming a mandatory inclusion in preregistration training in health and social care programs (Department of Health & Quality Assurance Agency, 2006). In Australia, the importance of IPE came to prominence in reports such as Towards a National Primary Health Care Strategy (Department of Health and Ageing, 2008) and Garling's Special Commission of Inquiry into Acute Care Services in NSW Public Hospitals (Garling, 2008). Both of these reports recommended that university education should be undertaken in a manner that supports interprofessional teamwork and collaboration. However, these recommendations have not yet translated into the implementation of systematic and sustainable IPE initiatives in all healthcare programs (Lapkin, Levett-Jones, & Gilligan, 2012). It is evident that, despite the progress that has been made, strategies to overcome the barriers to IPE and examples of having done so are still needed.

In the following section of this article, seven diverse case studies of innovative but practical IPE activities from five countries are profiled. These examples were selected following a review of relevant literature and conference papers, and because they each included nursing students and one or more other healthcare groups, demonstrated the essential elements of IPE (Centre for the Advancement of Interprofessional Education, 2002), and used innovative and creative approaches to overcome recognized barriers and challenges to IPE (Lapkin et al., 2012).

Interprofessional Education for Quality Use of Medicines (Australia)

In Australia, opportunities for healthcare students to engage in IPE are often limited by the constraints imposed by timetabling and large student cohorts. To overcome these issues, academics from the University of Newcastle designed a set of e-learning IPE modules to enable nursing, medical, and pharmacy students to learn from and about each other's roles in the medication team (www.ipeforqum.com.au). Evidence suggests that online IPE experiences can contribute to an improved understanding of professional roles and responsibilities, enhancement of students' attitudes towards each other, and improved interprofessional communication and teamwork skills (McKee, Goodridge, Remillard, & D'Eon, 2010)

The project targeted medication safety and quality use of medicines (QUM) in the IPE modules because (a) prescribing, dispensing, and administering medications are interdependent processes that require collaboration between all members of the medication team; (b) safe medication practices are a focus of the global strategy to improve patient safety (Sears, Ross-White, & Godfrey, 2012); and (c) the prevalence of adverse patient outcomes associated with medication errors remains unacceptably high, with the World Health Organization (2011) estimating that more than 50% of all medications are prescribed, dispensed, or administered inappropriately.

Each of the five IPE for QUM e-learning modules includes a video recording of a patient journey that is based on an authentic representation of an actual clinical situation. A number are reenactments or adaptations of publicly available critical incident reports or coronial inquests. They present patients, nurses, pharmacists, and doctors of different genders, ages, and ethnic backgrounds. The IPE modules have been designed for flexible use, and educators can select the most appropriate resource to align with the particular learning objectives of their subject. Although these IPE modules provide an ideal platform for students from two or more professions to learn together, they are also effective when used for teaching single disciplines as they illustrate the roles and contributions of all members of the medication team. The modules can be used online for self-directed learning or as stimulus materials for lectures or tutorials. A facilitator guide is provided to support educators in their integration of IPE into their teaching (Levett-Jones, Gilligan, Lapkin, & Hoffman, 2012).

Findings from a quasi-experimental study attest to the effectiveness of the IPE modules. Three hundred and twenty nursing, pharmacy, and medical students were allocated to either an experimental ($n = 155$) or control group ($n = 165$). Participants in the experimental group who completed the modules demonstrated a significantly higher intention to practice in a manner that enhances collaborative practice and medication safety than those in the control group who did not have access to the modules ($p < .001$; Lapkin et al., 2015).

Learning With Other Healthcare Students in Population Practice (United States)

Many IPE initiatives focus on co-learning in the classroom; however, the School of Nursing at Oregon Health and Science University developed the Interprofessional Care Access Network (I-CAN), an authentic interprofessional clinical experience. Students were allocated to a neighborhood with vulnerable and underserved populations and a high prevalence of poverty or complex health needs. There were three neighborhoods where students served: (a) an inner-city neighborhood with many people who are homeless and live in single room occupancy (SRO) hotels; (b) a rural community, served by a large Spanish-speaking clinic; and (c) an urban neighborhood with large numbers of recent immigrants and refugees, primarily Bhutanese, Congolese, and Syrian.

Throughout the term, nursing students carried a caseload of two to four clients who required care coordination services and were referred by partner agencies within these neighborhoods. Nursing students worked side by side with medical, dental, and/or pharmacy students visiting clients in their homes or a common meeting place. Typical examples of these services included a pharmacy and nursing student working together to provide education and support to a homeless client with mental health issues who had difficulty obtaining and using prescribed medications; and nursing, dental, and medical students addressing issues associated with poor nutrition and dentition in neighborhoods where unstable housing and food scarcity were common (Wros, Mathews, Voss, & Bookman, 2015).

Students were supported by nursing faculty-in-residence (FIRs) who provided continuity for clients and the project as a whole. The FIRs also facilitated ongoing population health projects in which nursing students participated and served as resources in the neighborhoods with interprofessional teams. Findings from a qualitative study (Gordon, Lasater, Brunett, & Dieckmann, 2015) that explored the impact of the I-CAN IPE demonstrated the benefits of this learning experience from students' perspectives, for example:

> *I really enjoyed working amongst teams of nursing, dental, physician assistant and medical students to share ideas, learn from each other, and develop plans to best serve the needs of the clients. [pharmacy student]*
>
> *Over the 10 week I-CAN program it was rewarding to see how clients were able to accomplish or make strides towards many of their healthcare goals with the help of their I-CAN team. [physician assistant student]*
>
> *We had the opportunity to work with medical students to provide care to patients in the community. This collaborative education gave us practice working as a member of an interprofessional team. Our group came up with the analogy of a football team; the most effective offense is one where each teammate knows each other's role. Likewise, in order to provide best patient care, physicians, nurses, and other members of the healthcare team should have an understanding of each other's roles and responsibilities. [nursing student]*
>
> *By working with students from different professional backgrounds we are able to apply our own knowledge towards a common goal and also learn from each other. [pharmacy student]*

Like many IPE initiatives, the major challenge for the I-CAN project was scheduling and provision of appropriate opportunities for students to learn together in the same place at the same time (Gordon et al., 2015).

Interprofessional Education in a Ward Setting (Sweden)

Students from Lund University participated in mandatory ward-based IPE activities during the latter part of their educational programs, with learning outcomes focused on teamwork, professional collaboration, and preparation for future professional roles. Previous experience indicated that opportunities for students to learn about interprofessional collaboration and cooperation varied considerably between clinical settings. Therefore, this ward-based educational activity was specifically designed to facilitate quality IPE experiences for all students.

IPE teams consisting of nursing, medical, and physiotherapy students undertook 8-day (4 days per week) clinical placements. During this time students were encouraged to learn with, from, and about each other to develop knowledge and skills beyond their own professional role. Supervisors were on hand at all times; nursing supervisors worked day and night shifts 7 days a week, and the medical and physiotherapy supervisors worked weekdays.

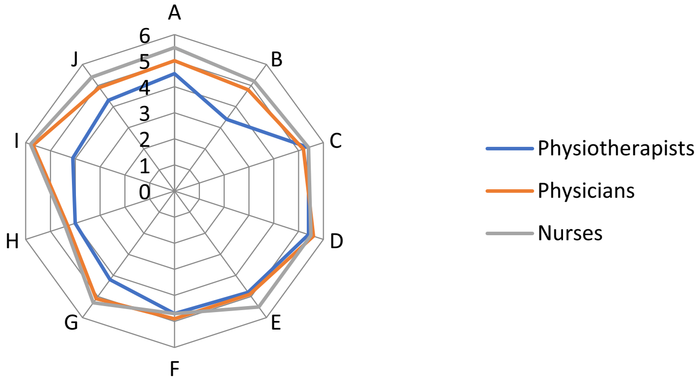
The IPE activity took place in a 14-bed hospital ward that specialized in the care of older people with conditions such as heart failure, pneumonia, and diabetes. Patients and their families were informed on admission that undergraduate students would be caring for them during their hospital stay, and their verbal consent was obtained. Each IPE team had the responsibility for providing care for three to six patients. Provision of routine personal care, for example, provided opportunities for the students to gain to gain a deeper understanding of each other's roles, responsibilities, knowledge, and skills.

Following the IPE experience, students met with their supervisor and a lecturer from the university to reflect on issues associated with their own profession and the transition between their role as students and their professional roles. They were also required to submit a written reflection about their IPE experiences, focusing specifically on team collaboration, their role in the professional team, what they learned, and how they will make use of their IPE experiences in their future practice. The reflections were graded on both content and quality.

This IPE activity has been running, in its current form, since 2013, and the ward has hosted approximately 60 students per semester. Although patient feedback is not routinely sought, several patients specifically ask to return to the student ward on re-admission. Students evaluated the IPE experiences using a 10-item questionnaire that uses a 6-point scale. Feedback has been highly positive with regard to the three domains of teamwork, communication, and supervision, with the exception of physiotherapy students who did not always feel that the IPE experience allowed them to develop their professional competence (see **Figure 1**).

An IPE Activity to Enhance Understanding of Compassionate Care, Ethical Practice, Teamwork, and Professional Roles (United Kingdom)

At Keele University, first-year nursing, midwifery, medicine, physiotherapy, pharmacy, and biomedical science students participated in an IPE initiative designed to enhance understanding of different healthcare roles, and the importance of collaboration and teamwork.



A: I developed a new perspective on my role in the team
B: I have developed my professional competence
C: I have developed my understanding of other professional competence
D: I have developed my understanding of the importance of team communication
E: I have developed my ability to communicate as a team member
F: The overall supervision was good
G: The specific professional supervision was good
H: I felt informed after the joint introduction
I: The team simulation task was considered meaningful
J: This placement was an essential element of my education so far

Figure 1. 2015 evaluation results from the ward-based interprofessional education activity ($n = 58$).

Situating the IPE initiative in the first year aimed to address students' preconceived stereotypes about the roles of other team members (Derbyshire & Machin, 2010; Lewitt, Ehrenborg, Scheja, & Brauner, 2010). This approach also helped to develop a sense of professional identity, empathy towards other members of the team, and understanding of the importance of effective teamwork and communication (Anderson & Lennox, 2009; Baker, Egan-Lee, Martimianakis, & Reeves, 2011).

Students attended an introductory plenary session that outlined the structure, concepts, and content of the IPE activity. They then divided into smaller interprofessional groups of no more than 15 students to discuss the concepts of compassionate care, ethical practice, teamwork, and professional healthcare roles. The stimuli for this activity were cases from the Mid Staffordshire National Health Service Foundation Trust Public Enquiry into patient neglect, safety, and death (Francis, 2013). To support the discussion and to help facilitate students' understanding of relevant concepts, the six Cs (care, compassion, competence, communication, courage, and commitment); (Cummings, 2013) and ethical principles of care (Beauchamp & Childress, 2009) were provided electronically as prereading. This activity took place over two afternoons, with online discussions in between. At the end of the IPE activity, each group developed a poster depicting key issues associated with their case. The poster was then presented by the group to other students, academic staff, and service users.

The interprofessional nature of the learning experience facilitated interesting discussions about the content and professional training requirements of the different healthcare disciplines. Students ($n = 562$) welcomed the opportunity to learn alongside healthcare students who they would not otherwise interact with during their courses. Feedback from staff was also positive; they valued the unique opportunity to work with colleagues from other schools and the sharing of ideas about learning and teaching practices.

Students expressed a marked increase in their understanding of how poor teamwork, ineffective communication, and lack of compassionate care can result in poor patient outcomes. The IPE experience also dispelled many preconceived ideas that students had previously held and resulted in an enhanced appreciation of the roles of other healthcare professionals. Biomedical science and pharmacy students shared insightful comments acknowledging that, although they would not be at the forefront of care, they nevertheless made a valuable contribution to the work of the team. They also recognized the relevance of the six Cs and ethical principles to their roles, that patient dignity and respect were integral to managing prescriptions and samples, and that effective communication was essential to prevention of errors. Following the IPE activity, students expressed a determination to apply their learning to their future practice, particularly with regard to effective communication, teamwork, respecting other healthcare professionals, and ensuring that patients and family members remain at the center of care provision.

This IPE activity has been conducted for two consecutive years. Enabling first-year healthcare students to analyze actual cases from the Francis Report together has proven to be a powerful influence on their educational and professional development. Feedback from students who completed the activity in previous years has demonstrated how their learning from this activity has influenced their clinical placements, with patient safety and compassionate care remaining top priorities.

Building Connection Between Researchers From Different Disciplines (Australia)

When students study in silos, they can gain a limited appreciation of the diverse research agendas, approaches, and worldviews of different disciplines. However, exposure to different philosophies, ontologies, epistemologies, and methods can open up new and illuminative ways of thinking about social phenomena, global issues, and disciplinary perspectives. Learners can also gain an understanding of the critical thinking skills that tend to be emphasized and developed in different research traditions.

In this example of IPE the aim was to enhance communication, collegiality, and interdisciplinary understandings between research students. The philosophy, ontology, epistemology, and methods (POEM) activity was a creative way to facilitate conversations between students about their similarities and differences. It was used at Central Queensland University as a critical thinking activity, with nursing, education, and creative writing research students participating as part of a research training activity.

The rationale for, and background to, this activity was explained to students and they were given two examples of POEMs previously constructed by a social worker and an occupational therapist (McAllister et al., 2012). Pairs of students from the same discipline were asked to reflect on their research approach and philosophy and to develop a POEM that represented their worldviews. The POEMs were then shared with the entire group and interdisciplinary similarities and differences were discussed. The ensuing discussions were illuminative and engaging.

Students began to recognize the diversity of approaches used in different disciplines, and that research questions and designs are shaped by underpinning knowledge traditions and methods of data collection and analysis. Students said that the activity expanded their understanding of methodologies and how different approaches emerged from a discipline's particular interest and worldview. For example, ethnography emerged from the sociology and anthropology disciplines to take a broad and unobtrusive examination of culture; but ethnography is now being utilized by many other disciplines such as nursing and creative writing students.

Students stated that this IPE activity assisted them to match their research question with an appropriate methodology. For example, one student discussed the historical inquiry approach taken to tell the story of a group of First World War nurses. She argued that historical research has its own conventions and traditions (philosophy), and requires researchers to be impartial but also curious (ontology), take a rigorous approach to discerning fact from hearsay to identify truths (epistemology), but that the retelling of history is always partial, incomplete, and dependent on the researcher's interpretation of events (methods).

Evaluation results from this IPE activity demonstrated that following the IPE POEM activity students ($n = 17$) felt they had an enhanced understanding of the research process (71%) and confidence in themselves as researchers (76%). Importantly, they also reported that a key highlight of the activity was the opportunities to communicate with and learn from students from other disciplines.

IPE Patient Safety Workshops (Singapore)

In recognition of the relationship between patient safety and effective interprofessional communication and collaboration (World Health Organization, 2010), the Yong Loo Lin School of Medicine at the National University of Singapore implemented a 1-day IPE patient safety workshop focusing on the six International Patient Safety Goals identified by the Joint Commission International (2011). These included correct patient identification; effective communication; medication safety (high-alert medications); correct patient, site, and procedure for surgery; reduced healthcare-associated infections; and reduced falls. By focusing on these issues as an interprofessional group, it was hoped that the medical, nursing, and pharmacy students would identify teamwork strategies that could influence their future professional practice.

Each workshop was facilitated by trained academic staff and practitioners from different disciplines. In order to encourage interactivity, a variety of teaching and learning strategies were employed, for example, brief lectures, videos, root-cause analyses from real case scenarios, role plays, and posters. To date 554 students have participated in the workshops. As with many IPE initiatives, there have been challenges. Foremost among these were the logistical and scheduling issues associated with coordinating a large number of students from three different schools and the resource-intensive nature of the workshops.

Students' ($n = 527$, response rate 95%,) evaluations of the workshops have been positive, and an average of 86% of the participants found the six IPE sessions to be "good" or "very good." Suggestions for improvement included the use of teamwork games and refined in-house videos.

An IPE Activity to Achieve Integrated Care (United Kingdom)

The integration of health and social care is at the heart of health policy in England (Department of Health, 2014). It involves care that is individualized and person centered (National Voices, 2013), with effective communication and coordination between members of the interprofessional team. Importantly, integrated care aims to ensure that the level of control over the planning of care is determined by the patient or service user. When implemented effectively, integrated care helps reduce confusion, repetition, duplication, and delays (Department of Health, 2014).

Workforce preparation for integrated care requires the bridging of gaps within and between health and social care services through the promotion of positive attitudes that overcome boundaries between professions and organizations. The core competencies of integrated care include interprofessional working and an understanding of whole systems networking, person-centered care, shared decision making, and care pathways (Shaw, Rosen, & Rumbold, 2011).

Bournemouth University provides IPE focused on integrated care for all undergraduate nursing, occupational therapy, paramedic science, midwifery, and physiotherapy students. Approximately 200 students attended each IPE event, where they collaboratively examined case examples that impacted negatively on patients and their family. They then identified strategies to alleviate or prevent this type of error occurring in the future with the support of expert practitioners, and presented their emergent ideas to the wider group.

Students worked in small and large groups that formed, reformed, splintered, and enlarged on an ongoing basis. This meant that they had the opportunity to learn with students from a range of disciplines over the course of the event. This interworking and cross-disciplinary engagement enhanced patient safety by providing opportunities for students to work together towards a person-centered outcome (Ndoro, 2014).

The integration event is just one of a series of IPE activities that occur throughout the 3-year undergraduate programs at Bournemouth University. Others look at issues such as safeguarding, dementia, and learning disabilities. The reported learning outcomes for the IPE events include an increased knowledge about the subject itself, an increased capacity to work together, enhanced creativity, and a broadening understanding of each other's roles.

Discussion

A body of research speaks to the relationship between interprofessional communication, teamwork, and patient outcomes (Rogers et al., 2017). Healthcare graduates' ability to work effectively as members of interprofessional teams is therefore critical, both to patient safety and to work satisfaction (Reeves et al., 2017), and IPE has been identified as a key strategy for developing these skills (World Health Organization, 2011). However, although IPE is integral to the preparation of future health professionals, there are many pragmatic constraints that can impede implementation (Lapkin et al., 2012). This article has demonstrated that despite the acknowledged challenges, integration of IPE is not only possible, but in many environments has already been successfully achieved through shared commitment and the use of creative educational approaches.

The IPE activities profiled in this article illustrate the impact of various online and face-to-face teaching approaches, conducted in classrooms, clinical settings, and community settings, for both undergraduate and postgraduate healthcare students (including nursing, medical, pharmacy, dental, physiotherapy, occupational therapy, paramedic science, midwifery, and biomedical science students) across five countries. Key to the success of these initiatives was a shared purpose and commitment of all team members; the determination to overcome perceived barriers to IPE; the willingness to take a risk with innovative and novel IPE approaches; support from all levels of the organization; and, lastly, a scholarly approach with a clear evaluation framework. What is clear from the examples provided is that there is no one ideal IPE approach; instead, each of the initiatives purposively addressed a specific need within a specific context, taking into account available resources and learning objectives. While a number of the IPE interventions were undoubtedly resource intensive (e.g., the Interprofessional Care Access Network and the ward-based IPE activities), others required up-front funding but then became cost neutral over time (e.g., the IPE for QUM e-learning module). It is hoped that the seven examples provided will motivate educators to recreate, adapt, and implement these innovative and practical IPE activities within their own educational context.

Conclusions

The case studies profiled in this article demonstrate that the very real barriers to IPE can be overcome when committed educators work together to develop creative and targeted approaches. This article has provided a range of ideas for the design and implementation of IPE and will be of benefit to nurse educators, as well as educators from other health disciplines, who want to expand their repertoire of teaching approaches. Ultimately, the investment in IPE has the potential to enhance graduate employability and lead to improved teamwork and safer health care.

Clinical Relevance

A body of research attests to the relationship between interprofessional communication, teamwork, and patient outcomes. Interprofessional education is imperative for facilitating the development of nursing graduates' communication and teamwork skills; however, innovative approaches are needed to overcome the perceived and actual impediments to its implementation.

Clinical Resource

- Interprofessional Education for Quality Use of Medicines: http://www.ipeforqum.com.au/modules/

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JOURNAL OF NURSING SCHOLARSHIP

PROFESSION AND SOCIETY

Quality of Author Guidelines in Nursing Journals

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Abstract

Purpose: The aims of this study were to (a) describe the information provided in author guidelines in nursing journals, (b) assess the completeness of this information, and (c) identify the extent and types of reporting guidelines used in nursing journals.

Design: Content analysis of author guidelines for 245 nursing journals included in the Directory of Nursing Journals maintained at the International Academy of Nursing Editors website.

Methods: Using Research Electronic Data Capture, data on 19 criteria for completeness were extracted from published author guidelines. Additional details about journal requirements, such as allowed length of manuscripts and format for the abstract, were also recorded. Reliability was established by simultaneous review of 25 journals (10%) by the research assistant and a senior member of the research team.

Findings: Author guidelines were easily accessible at journal websites or through links to download the information. A majority (73.5%) had completeness scores of 75% or higher; six journals had guidelines that were 100% complete. Half of the journals used the American Psychological Association reference style, and 26.3% used the American Medical Association style. Less than one fourth had stated requirements to use reporting guidelines such as Consolidated Standards of Reporting Trials (CONSORT) and Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Conclusions: Author guidelines for nursing journals are generally complete and informative. Although specific reporting guidelines such as CONSORT and PRISMA improve the accuracy and completeness of manuscripts on various types of studies, most nursing journals do not indicate use of these for manuscript preparation. Editors who want to improve their author guidelines should use the 19 criteria for completeness as a gauge for updating and revision.

Clinical Relevance: Nurses rely on the published literature to inform their practice and ensure that it is based on evidence. Guidelines for publishing in the scholarly literature assist clinicians and scholars to ensure that published articles are complete, current, concise, and accurate.

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When writing for professional communication, authors rely on the guidelines published in a journal to ensure that their manuscripts are clear, complete, and formatted according to the style of the journal. Editors rely on guidelines so that they receive appropriate manuscripts for peer review. Author guidelines, also called information for authors, should contain essential information about the journal, types and formats of articles that are published, specifics on manuscript preparation, reporting standards and guidelines to use, disclosure of conflicts of interest (COI) and criteria for authorship, and other requirements of the journal. These instructions are the link between authors, editors, and peer reviewers and the main channel of communication during the manuscript submission and review process. Instructions should be clear and comprehensive and provide guidance to the author who is writing a manuscript for submission. Not preparing a manuscript according to the journal's requirements delays the review process and in some cases, may lead to rejection of the paper. Detailed and complete author guidelines for a journal result in fewer questions among authors and may lead to higher quality of manuscripts submitted to the journal. Complete and comprehensive content in the author guidelines also confirms the credibility of the journal.

Although a few studies have been done on authorship of nursing articles and adherence of nursing journals to standards for reporting clinical trials and systematic reviews, no studies have examined the content of author guidelines of nursing journals. Thus, the aims of this study were to (a) describe the information provided in author guidelines in nursing journals, (b) assess the completeness of this information, and (c) identify the extent and types of reporting guidelines (e.g., Consolidated Standards of Reporting Trials [CONSORT]) used in nursing journals. This review of author guidelines reveals characteristics of nursing journals, which have not been previously described.

Literature Review

The Uniform Requirements for Manuscripts Submitted to Biomedical Journals, first published in 1979, has expanded from an outline of required components of a manuscript to a more robust set of guidelines that address ethical concerns, provide greater transparency, and emphasize editorial preferences of journals as outlined in instructions for authors (Kojima & Barron, 2010). The guidelines, developed by the International Committee of Medical Journal Editors (ICMJE, 2017) are now referred to as the *Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals*. They cover roles and responsibilities (e.g., defining author contributions, COI); publishing and editorial issues (e.g., scientific misconduct, overlapping publications); and manuscript preparation (http://www.icmje.org/recommendations/). There are more than 600 journals that follow these recommendations, and of those, 39 have the word "nurse" or "nursing" in their titles (http://www.icmje.org/journals-following-the-icmje-recommendations/). The ICMJE suggests that journals incorporate the recommendations into their author guidelines.

Several studies have analyzed the completeness of author guidelines, although none have provided a comprehensive analysis in nursing journals (Horvat, Mlinaric, Omazic, & Supak-Smolcic, 2016; Meerpohl, Wolff, Niemeyer, Antes, & von Elm, 2010). A few studies have addressed ethical issues within the nursing literature. Kennedy, Barnsteiner, and Daly (2014) surveyed corresponding authors of 422 articles published in 10 nursing journals to determine whether their coauthors met the authorship criteria outlined in the ICMJE Recommendations. They found that 42% of articles reported honorary authors, or those who are named as authors without having met the authorship criteria, and an additional 28% of articles had instances of ghost authorship in which those who met authorship criteria were not named as authors. A study on COI statements published in the supportive and palliative oncology literature, including some in the *International Journal of Palliative Nursing*, found 51% of 848 studies did not report COI related to the study, and 88% did not report COI outside the study (Hui et al., 2012).

Guidelines have been developed to improve the reporting of varied types of studies: these are referred to as reporting guidelines. Reporting guidelines include the CONSORT, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA), Standards for Quality Improvement Reporting Excellence (SQUIRE), and Strengthening the Reporting of Observational Studies in Epidemiology (STROBE), among others. The Enhancing the Quality of Transparency of Health Research (EQUATOR) Network is a portal of guidelines to use when conducting and reporting different types of study designs. Currently there are 370 reporting guidelines, with more under development (EQUATOR Network, 2017). These guidelines help authors in preparing a manuscript that accurately describes the study and is complete. All relevant information about a study needs to be reported for readers to assess its validity (Meerpohl et al., 2010).

A few studies have demonstrated a need within the nursing literature for more detailed reporting of systematic reviews and clinical trials. A study of nursing journals' endorsement of the PRISMA statement indicated that only 30 of 107 journals recommended or required the statement (Tam, Lo, & Khalechelvam, 2017). While there were no significant differences in adherence to the PRISMA statement between systematic reviews and meta-analyses published in journals endorsing PRISMA versus those in journals that did not, Tam et al. (2017) recommended that journals require authors to follow these guidelines.

In a study analyzing the requirement of and adherence to the CONSORT statement and trial registration for randomized controlled trials (RCTs), Jull and Phyu Sin (2015) found that 7 of 15 nursing journals promoted the use of CONSORT, and 3 of those also endorsed trial registration. Those RCTs published in journals endorsing CONSORT had a lower risk for bias for blinding and more complete follow-up, while those published in journals promoting trial registration were three times more likely to be registered. The authors found an inadequate reporting of trials and recommended a stronger editorial position on adherence, such as by only publishing trials that have been registered and involving reviewers in checking for trial reporting (Jull & Phyu Sin, 2015). In a similar study of 96 trials published in four nursing journals, 37% of the RCTs did not meet at least half of the criteria of the CONSORT checklist used to determine adherence to the standards. One journal began recommending the use of CONSORT during the study, and this caused a significant increase in CONSORT scores for RCTs published within that journal (Smith et al., 2008).

Methods

Review Process and Form

The author guidelines of all of the journals ($n = 249$) in the Directory of Nursing Journals at the International Academy of Nursing Editors (INANE) website (https://nursingeditors.com/journals-directory/) were reviewed. The directory is a collaborative venture between INANE and the publication, *Nurse Author & Editor*. This list was selected as the journals are vetted based on the Committee on Publication Ethics (COPE) Principles of Transparency and Best Practice in Scholarly Publishing (COPE, 2014). The directory includes journals that are published in print, online only, or a combination of print and online. It also includes journals that require a subscription to access content, are open access (authors pay to publish and for their article to be freely available on the Internet), and are hybrid, that is, subscription journals that offer an option for open access. The vetting process ensures that there are no journals that are described as predatory (Oermann et al., 2016). The directory is updated in real-time as new or revised information is received by the list maintainers.

Table 1. Completeness Criteria for Evaluation

Criteria
Instructions for authors available at the website or link to download
Purpose of the journal stated
Description of audience/journal readers
Types of articles published in the journal
Guidelines about required sections/content
Abstract required
Key words required
Specification of the length of manuscript in words or pages
Specification of maximum number of tables and figures
Identification if the journal is peer reviewed
Description of the peer review process
Style for references identified
How citations are to be presented in the manuscript is stated
Examples of citations in proper format are presented
Guidelines for permission to use copyrighted material identified
Guidelines for authorship identified
Guidelines related to originality/proper attribution identified
Guidelines related to conflict of interest identified
Clear procedure for transfer of copyright identified

Using the ICMJE Recommendations, COPE best practice guidelines for editors (COPE, 2011), and the literature review, a data capture form was developed to record the information provided in the author guidelines for the 249 journals. The form listed 19 content areas that were considered important to be included in author guidelines (**Table 1**). These content areas were consistent with a study by Nambiar, Tilak, and Cerejo (2014) on the quality of author guidelines of journals in the biomedical and physical sciences. If the information was present, it was answered as a yes or no question. For some areas additional details were recorded, for example, the maximum length of a manuscript in pages or words, reference style used in the journal and other information provided to authors about citations, reporting guidelines required by the journal, and fees (if any) for publication.

Data Collection and Analysis

A database was created in Research Electronic Data Capture (REDCap; Harris et al., 2009) for the study. For each journal, the research assistant (RA) located the author guidelines using the link at the Directory of Nursing Journals. The RA reviewed the guidelines and entered the information into REDCap. For the first five journals, the RA and a senior member of the research team reviewed the author guidelines together to establish a baseline of consistency for data entry. For the next 25 journals (10%), the same person reviewed the data entries made by the RA and verified their accuracy to ensure reliability, at which point the entry was verified in REDCap. After that, the RA entered data independently. If the RA had any questions or concerns about an entry, the second author reviewed and corrected the entry before it was marked as complete in REDCap. The RA also contacted the second author with any questions about the status of a journal, information about the editor or publisher, or availability of author guidelines. Through this process, four entries were deleted from the Directory of Nursing Journals and the REDCap database. The final number of journals reviewed was 245.

A completeness score was calculated for each journal based on the number of required content areas ($n = 19$) that were present in the author guidelines, with scores ranging from 0 to 19 (see **Table 1**). Items that comprised the completeness score were not weighted; all were considered equally important. Categorical variables were described with frequency and percent, and continuous variables were described using mean, standard deviation, median, and range (minimum, maximum). Data were analyzed using SAS/STAT software version 9.3 (2010; SAS Institute Inc., Cary, NC, USA).

Results

Of the 245 nursing journals in the final sample, the majority of publishers were from the United States ($n = 149$, 61.6%), followed by the United Kingdom ($n = 61$, 25.2%). All but five of the journals (97.9%) included author guidelines (instructions for authors) at the journal website or via a link to download them.

Manuscript Preparation

The vast majority of the author guidelines of nursing journals described the purpose or mission ($n = 210$, 88.2%) and readers ($n = 203$, 85.3%) of the journal. Nearly all of the journals also specified the types of articles that would be published ($n = 228$, 95.8%) and provided guidelines for preparing each of those manuscript types ($n = 226$, 95.0%).

Most of the journals reviewed required an abstract and used two formats: a structured abstract with headings ($n = 104$, 48.2%) or narrative (without headings; $n = 80$, 37.0%). Thirty-two journals that required an abstract, however, did not provide any information about its format. The maximum word length for abstracts ranged from 40 to 500, with a median of 200 words. Key words are critical for indexing articles, and the majority of journals ($n = 174$, 75.0%) asked authors to provide these terms with their submission. The median number of key words to be provided by authors was 6 and ranged from 3 to 20.

Table 2. Reporting Guidelines Used in Nursing Journals

Guideline	*n* (%)
Consolidated Standards of Reporting Trials (CONSORT)	57 (23.9)
Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)	47 (19.7)
Standards for Quality Improvement Reporting Excellence (SQUIRE)	33 (13.9)
Strengthening the Reporting of Observational Studies in Epidemiology (STROBE)	29 (12.2)
Consolidated Criteria For Reporting Qualitative Research (COREQ)	18 (7.6)
Enhancing the Quality of Transparency of Health Research (EQUATOR)	14 (5.9)

The majority ($n = 197$, 83.1%) of the author guidelines specified the maximum length of manuscripts allowed by the journal, which is critical information for authors. Typically, the maximum length was stated in words ($n = 125$, 63.5%) versus pages ($n = 72$, 36.5%). Word length ranged from 1,200 to 8,500 words (median 4,000 words), and number of pages ranged from 8 (briefs) to 40 (median 20 pages). In preparing a manuscript, authors need to know not only the length allowed but also how many tables and figures can be included with the paper. Only 43 (18.2%) of the author guidelines included this information.

Reference style is an important issue for authors. Reference styles that were specified in the author guidelines included the style manual of the American Psychological Association (6th ed.; APA, 2009; $n = 105$, 50.2%), followed by the style manual of the American Medical Association (10th ed.; AMA, 2007; $n = 55$, 26.3%) and Harvard style ($n = 37$, 17.7%). Journals tend not to limit the number of references that can be included with a paper: only 44 (18.1%) of the author guidelines stated a limit on the number of references, ranging from 3 to 150 (for a systematic review) with a median of 40.

Reporting Guidelines

Although specific reporting guidelines such as CONSORT and PRISMA improve the accuracy and completeness of manuscripts on various types of studies, most instructions for authors did not require their use for preparing manuscripts. For journals that did, the three most common were CONSORT, PRISMA, and SQUIRE (**Table 2**).

Editorial Processes and Ethical Requirements

Nearly all ($n = 232$, 96.2%) of the journals stated in their author guidelines that they were peer reviewed,

Table 3. Ethical Requirements Stated in Author Guidelines

Ethical requirement	*n* (%)
Disclosure about conflicts of interest	189 (79.4)
Criteria for authorship (who can be named as author)	138 (58.2)
Guidelines related to manuscript originality/proper attribution	204 (85.7)
Guidelines for permission to use copyrighted material	204 (85.7)
Clear procedure for transfer of copyright to publisher	194 (81.5)

and half of the journals ($n = 131$, 57.2%) described their peer review processes. Descriptions of ethical requirements such as disclosure of COI should be included in all author guidelines. However, there was variability across nursing journals regarding this information (**Table 3**). All journals should indicate criteria for authorship or refer authors to these criteria, but only 138 (58.2%) of the journal guidelines addressed this.

More than half ($n = 139$, 59.2%) of the author guidelines of nursing journals specified fees for publication ranging from $83 to $4,000 (median $2,640). The majority of the fees were for open access ($n = 126$; 90.6%); of this group, the fee was optional for 119 (94.4%) of the journals, designating them as hybrid journals. Only 7 (5.6%) of the nursing journals were solely open access. The remainder of the fees that were identified were for printing color pictures or figures ($n = 6$; 4.3%); a “submission or publication fee” ($n = 4$; 2.9%), and other miscellaneous fees, such as exceeding the maximum number of pages or color images ($n = 3$; 2.2%).

Completeness of Author Guidelines

The completeness score was based on the number of required content areas (out of 19) that were present in the author guidelines. A total of 238 journals had sufficient information to calculate a completeness score, which ranged from 3 to 19 with a median of 15 ($M = 14.67$, $SD = 2.97$). Six journals (2.5%) had a completeness score of 19. However, perfection is an elusive goal, and perhaps it is better to consider journals that had 14 or more elements (75%) that recorded yes for a completeness score. Using that criteria, 175 (73.5%) had completeness scores of 14 or more. By contrast, there were only 3 journals (less than 1%) with a completeness score of 3 (2.5%).

Discussion

Overall, findings of this study revealed that scholarly nursing journals have information for authors that is easily accessible on the journal website or through a link that allows guidelines to be downloaded. In addition, the majority of guidelines reviewed meet completeness criteria at a standard of 75% or better, with a small number of journals ($n = 6$) achieving 100% completeness. As noted earlier, the items comprising the completeness score were not weighted; all were considered equally important. At the individual journal level, an editor may have certain criteria that are considered to be more important or essential, while others are not relevant to the types of article the journal publishes. This may be a basis for some journals having less than 100% completeness in their author guidelines. On the other hand, missing items may reflect an unintentional omission, which would benefit from correction. Editors who want to enhance their author guidelines should review their current requirements against the 19 criteria in **Table 1**. Revisions can then be made based on criteria that are missing or weak, resulting in increased clarity in their guidelines.

Nambiar et al. (2014) assessed the completeness and clarity of author guidelines in biomedical and physical science journals. The primary categories of information to be included were grouped into five areas: aims and scope of the journal, submission and postsubmission processes, formatting instructions, ethical requirements, and authorship. No journal provided all of the information in their instructions for authors. The mean combined completeness and clarity score was 47.5%. Formatting instructions were the most complete category (60.2%), but information about authorship was the least complete (only 42.5% of the author guidelines provided information about authorship criteria, resolution of authorship issues, and copyright). Similarly, in a study of 25 medical laboratory technology journals, all defined the scope of the journal, and 92% defined their editorial policies (Horvat et al., 2016). However, only half (52%) of the author guidelines explained the peer review policy and process. Most of the journals required disclosure for COI ($n = 24$, 96%). The author guidelines for the nursing journals reviewed in this study exceeded all of these thresholds.

Ethical issues related to publication are important and an ongoing area of concern for editors, peer reviewers, authors, and publishers. Of the five ethical requirements listed in **Table 3**, it was a positive finding that the majority of journal guidelines include this information, at levels close to or exceeding 80%. One area for improvement, however, is in the “criteria for authorship,” with only 58.2% of the guidelines including this information. Based on the findings of Kennedy et al. (2014) reporting honorary (42%) and ghost (28%) authorship in nursing publications, it is clear that many authors do not understand the guidelines put forth by the ICMJE and perhaps are not aware of them. We recommend that editors review their guidelines carefully for information about authorship and consider adding more detail on this topic. It might be useful to reference journal policy regarding who qualifies for authorship versus who should be thanked in an acknowledgement, thus providing additional guidance for authors.

Most nurse authors are familiar with the reference style they used in their nursing programs for papers, research projects, theses, and dissertations. This study confirmed that APA style is predominant in nursing journals (51%) followed by AMA style (26%). Harvard style was third at 18%. It should be noted that Harvard is not really a style but rather a format of (author, date) citations similar to APA (Chernin, 1988). The fact that over 75% of journals reviewed use one of two styles should be reassuring to authors—there is no need to believe that it is necessary to learn or master multiple styles to publish in the nursing literature. A working knowledge of APA and AMA styles will probably suffice in most authorial situations. Use of reference management software to format references and style papers also will help authors to prepare their citations accurately (Chinn, 2016).

A study of 70 instructions for authors in pediatrics journals revealed 78% required disclosure of COI (Meerpohl et al., 2010). Our findings showed similar results, with 79.4% including a COI statement. Likewise, in the Meerpohl et al. (2010) study, endorsement of reporting guidelines in pediatric journals was limited; only 14 journals (20%) mentioned the CONSORT standards, and of these, only 3 required authors to use them. The other reporting guidelines were mentioned infrequently. Findings in our study were similar, with less than one fourth referring to the CONSORT guidelines and lower numbers for the others (see **Table 2**).

In a study by Sims, Henning, Wayant, and Vassar (2016) of 27 emergency medicine journals, 11 (40.7%) did not mention any reporting guideline in their instructions for authors. The ICMJE guidelines ($n = 18$, 66.7%) and CONSORT ($n = 15$, 55.6%) were included most often. Tunis, McInnes, Hanna, and Esmail (2013) evaluated whether the reporting of systematic reviews and meta-analyses improved in radiology journals since the publication of PRISMA and if use of PRISMA was associated with study quality, measured by the Assessing the Methodological Quality of Systematic Reviews (AMSTAR) criteria. They evaluated 130 studies from 11 journals. Prior to PRISMA, articles included a mean of 20.9 of the 27 items that should be reported. After publication of PRISMA, this number increased to 22.6, a slight improvement. Completeness of reporting using PRISMA, however, was associated with a higher quality of studies based on AMSTAR. The value of suggesting or requiring that authors use reporting guidelines to structure their manuscripts and report their findings must be balanced against the type of manuscripts published in the journal and the potential confusion presented to authors by suggesting "guidelines within guidelines." This study revealed that reference to reporting guidelines in the information for authors in nursing journals at this moment is somewhat low. This finding might be interpreted as editors proceeding cautiously with regard to guideline recommendation versus lack of awareness that guidelines exist. Editors and authors who have limited knowledge about the various reporting guidelines should make this a priority for learning.

An additional consideration about reporting guidelines is their use on a voluntary versus required basis. For example, a journal might not suggest or require use of the SQUIRE guidelines for reporting a quality improvement study. However, an author may choose to follow these guidelines to ensure the report is complete and there is sufficient detail for readers to replicate the study and implement the intervention in their own settings. Authors should refer to relevant reporting guidelines when writing their manuscripts. The EQUATOR Network (http://www.equator-network.org/), with its database of 370 reporting guidelines, is an excellent resource for authors.

In a study of 600 journals, Resnik, Tyler, Black, and Kissling (2016) found that 62.5% included a policy on authorship. The most frequent types of policies related to criteria for authorship (99.7%) and acknowledgments (97.3%). In this study, 138 journals (58.3%) had guidelines for authorship. A higher percentage (85.7%; $n = 204$) had guidelines for originality and proper attribution.

In an interesting footnote, one of the four journals that was removed from the Directory of Nursing Journals through the review process had changed publishers, and the new publisher was, in fact, one that had been identified previously as predatory. A review of articles from this journal revealed a dramatic downward shift in quality pre- to post-purchase in 2014 (Oermann et al., 2016, 2018). This is mentioned as a reminder that all authors need to be vigilant to carefully assess journals prior to manuscript submission and not get caught by publishing in a predatory journal, as no one is immune to this problem (Cobey, 2017; Nicoll & Chinn, 2015).

Conclusions

The findings of this study suggest that author guidelines for the 245 scholarly nursing journals that were reviewed are, in general, complete and provide sufficient guidance for authors to prepare manuscripts in accordance with required editorial policies. In addition, an interesting finding is that there is not a plethora of reference styles required by different journals—an author with a working knowledge of APA and AMA styles will be well served in the majority of cases when writing for publication in nursing.

An area of consideration is the suggestion or requirement to use reporting guidelines, such as CONSORT or PRISMA. This review found that the suggestion to use such guidelines is low at less than 25%. Editors need to carefully consider whether adding this information will make their author guidelines longer, and potentially more confusing, or will add value to authors who seek to publish in their journals.

Editors of nursing journals face the complex challenge of balancing the pragmatic considerations of publishing with the more erudite purposes for which the journal exists. Length of manuscripts, numbers of references, formatting styles, reporting standards, and other requirements reflect the editorial quality of the publication but also place limitations on the journal's substantive content. The requirements of the journal, such as allowed word or page length or number of references, should be considered by authors when selecting a journal for submission of a manuscript. Some studies and topics may not be adequately communicated in a shorter paper or in a journal that limits the number of references. Authors can send a query to the editor asking if these requirements can be waived for their particular manuscript; if not, another journal might be more appropriate. All who participate in the process of publishing—editors, authors, publishers, and consumers—contribute to the development of the professional literature, which ultimately aims to advance the discipline.

Clinical Resources

- Committee on Publication Ethics: https://publicationethics.org/
- EQUATOR Network: http://www.equator-network.org/
- International Academy of Nursing Editors. Writing for publication: https://nursingeditors.com/resources/writing-for-publication/
- International Committee of Medical Journal Editors. Recommendations: http://www.icmje.org/recommendations/

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