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Mailing Address:

Philippine Nurses Association
of America, Inc.
7725 Gateway Boulevard, #4448
Irvine, CA 92618
Tel: 443-340-7352
<http://www.mypnaa.org>

Send inquiries and manuscripts
for consideration to
TheJNPARR@gmail.com

Editor's Perspective

Epistemology: On Knowing and Knowledge

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The philosopher Jiddu Krishnamurti once said: *"We never see anything completely. We never see a tree, we see the tree through the image that we have of it, the concept of that tree; but the concept, the knowledge, the experience, is entirely different from the actual tree."*

In the JNPARR, many empirical manuscripts that have been published in past issues, and in this current edition, have focused on literature review. Examples of these empirical reviews appearing in this issue include the *Electronic Diaries in Healthcare* written by Ladores and *Disclosing a Child's Difficult Diagnosis to Parents* written by Sethi and Ladores.

Literature review is a significant part of any research endeavor. It is important to conduct a literature review to assess what information is available about a particular topic of interest. Literature review allows the researcher to identify the gaps in the literature and enables the investigator to narrow down the research topic. Conducting a literature review is a skill learned at all levels of education, beginning as early as in elementary school, with increasing expectations in high school, and a critical skill for undergraduate and graduate studies.

There are primary and secondary literature sources. Primary sources are found in refereed journals as a result of an original study. It can also be found in unpublished master's theses and doctoral dissertations. Secondary sources are summaries or critiques of primary sources on specific topics. Secondary sources are helpful when a topic is extensive; these sources provide a compendium of information regarding the subject of interest. Secondary sources provide readers a different perspective in understanding the literature especially when analysis of the literature collected has taken place.

There are different approaches when conducting literature reviews, including narrative-, systematic-, meta-analysis-, meta-synthesis- and integrative reviews.

Narrative review is an older approach to literature review. The topic is oftentimes broad and does not have a defined search strategy. The review is purely descriptive in nature. Because of its lack of focus or the lack of a clinical question when doing a search, it does not provide a compelling evidence for practice change. It is sometimes referred to as scoping the literature and may land into selection bias when experts try to comb the literature to find information that would support their opinions (Whitehead & Maude, 2016).

Systematic review is not simply a literature review. It is focused on a single question with clear objectives. Inclusion and exclusion criteria are laid out before the literature search begins. The search is conducted in a systematic approach whereby the selection and evaluation criteria of the articles are clear and explicit (Ebling Library, 2017). Systematic reviews combine the evidence of numerous studies regarding a clinical problem. It has become the basis of evidence-based practice initiative most particularly known as the Cochrane initiatives (Whittemore & Knafl, 2005).

Meta-analysis is a subset of a systematic review. It uses quantitative methods to synthesize and summarize the results of several studies that have related research hypotheses. Meta-analysis has the ability to be completely objective in evaluating research findings. The desired output of a meta-analysis is the identification of the common measure of the sample size which is derived from the weighted average of all the research studies (Ebling Library, 2017; Whitehead & Maude, 2016). The integration of findings from large pool of research studies makes meta-analysis the golden standard in literature review.

Meta-synthesis is putting together and examining the results of qualitative research studies and transforming it to a new interpretation. Qualitative findings are snapshots of interpretations of events or phenomena. Meta-synthesis combine these interpretations to strengthen the findings to make the topic of interest more substantive and informative. Meta-synthesis leads to theory building and theory explication (Ebling Library, 2017).

Integrative review is the only literature review approach that draws from a variety of sources, both from qualitative and quantitative studies as well as theoretical papers. Integrative review addresses related or identical research question or hypotheses. Subjectivity is minimized through careful application of the criteria for selection and evaluation of available literature. Integrative reviews that are well conducted meets similar rigor as in primary research and it can be replicated

(Ebling Library, 2017; Whittemore & Knafl, 2005). An example of integrative review in this journal edition is *Barriers to the Patient Advocacy Role* by Oliveira and Tariman.

JNPARR continues to publish diverse types of manuscripts. Aside from the reviews of literature, there is a variety of empirical studies using different research methods. In this edition, these studies include a quantitative research on *Pre-Licensure BSN Students' Attitudes Toward Evidence-Based Practice: A Longitudinal Study* authored by Thiel and Ko; a qualitative research on *Caring and Cultural Diversity Behaviors of U.S. Nursing students on a Study Abroad Program* written by Mahmoud and Schuessler; and a theoretical paper on *Addressing Health Disparities in Rural Populations: The Case of Hawaii* written by Ayers-Kawakami and Paquiao.

In our ongoing effort to share timely and relevant information, ideas and opinions, I have invited Dr. Dula Paquiao to write on op-ed on the Affordable Care Act with her piece on *Commentary on the GOP's Effort to Repeal and Replace ACA*.

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Leo-Felix M. Jurado, PhD, RN, APN, NE-BC, CNE, FAAN
Editor-in-Chief, JNPARR

Op-ed
Commentary on the GOP's Effort to Repeal and Replace ACA
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The Republican Party's proposal to repeal and replace the Patient Protection and Affordable Care Act (PPACA 2010) otherwise known as 'Obamacare' is met with enormous public pressure. While the proposal is far from being finalized, it is instructive that every American, particularly health professionals need to have an in-depth understanding of the political ideologies that undergird the design, financing and outcomes of the proposal. PPACA was established for the purpose of increasing access to healthcare services by an estimated 41 million uninsured Americans in 2013 (13% of the total population). While the replacement bill is touted as a panacea for rising healthcare premiums, the underlying purpose of the GOP proposal is to cut down the massive deficit by decreasing federal support for healthcare particularly for the most vulnerable (poor, disabled and older Americans) on Medicaid. PPACA's method of healthcare financing emphasized mandating health coverage for all Americans and increased taxes for high-income earners. By contrast, the GOP proposal removes this mandate and places millions of the most vulnerable group for losing healthcare insurance.

After World War II, the US was one of the signatories of the UN Declaration of Human Rights (1948) that upheld the *Right to Health* as a fundamental and inalienable right of all people. Health is basic to becoming a productive member of any society by preventing one's dependence on the state. Yet, the US remains as the only developed country that does not provide universal access to healthcare for all its citizens. The US spends the most for health care than any other developed country in the world - 2.5 times more than the OECD (Organization for Economic Cooperation and Development comprised of 35 of the world's richest countries) average, 16.4% vs. 8.9% of GDP, respectively (OECD, 2017). Despite having the most expensive healthcare (per capita and total expenditures), the US lags behind most OECD countries in terms of health outcomes as life expectancy, health related behaviors (alcohol abuse, obesity) and chronic disease such as asthma. Indeed, other nations have managed to provide universal access to their citizens, and achieved better health status of their populations with much lower cost (OECD, 2015).

Healthcare financing and infrastructure reflects the dominant political ideology of a nation. The US has a capitalistic system that has proven good for businesses and treats health as a commodity to be traded for profit. Health is in fact a form of human capital but attainment and maintenance of health is differentially conditioned by the social conditions in which one is born, live and grow (Marmot & Bell, 2009). Worldwide, individuals with higher socioeconomic status/SES based on indicators such as income, education and occupation, have better access to healthcare services and health status compared to those with low SES (Babones, 2010). Countries with wide disparities in SES such as the US where the top 1% earn the equivalent of 90% of the total earnings of the rest of the population, are plagued by the greatest health inequities between the rich and the poor (Wilkinson & Pickett, 2010).

Employment-based access to healthcare services breeds health inequity as *not all jobs are created equal*. Many employers do not provide nor are able to offer health benefits for their employees. Low-income workers are unable to afford healthcare premiums for themselves or their families. In fact, most of the uninsured Americans are under 65 years of age (ineligible for Medicare unless they are disabled) and have at least one family member working. It is interesting to note that majority of personal bankruptcies occur because of medical reasons particularly among those with employer-sponsored health coverage. Because of chronic and catastrophic illnesses, they are unable to maintain employment thus, forfeit employer-sponsored insurance.

People are most vulnerable when they are sick. They are unable to negotiate healthcare services nor choose insurance plans that fit their needs. The United Nations' (1978) Alma-Ata Declaration emphasized "Health Care for All" as a world initiative to be achieved through "Primary Health Care" for all (WHO, 2008). Access to healthcare should not be a left to an individual's wherewithal and free choice. One does not plan to be sick and the causes of illness are usually beyond ones' ability to control (e.g., aging and exposure to unhealthy environments) (Miranda, Messer & Kroger, 2012). Health and illness are common life struggles for all Americans, regardless of income.

Universal and equal access to healthcare is the hallmark of a *just* society. The philosopher, John Rawls (1999) stated that a *just* society is one in which the vulnerable are rendered less vulnerable. It is a truism that healthcare is expensive and a major financial burden to any society. But balancing the budget should not be on the backs of the vulnerable population as in the GOP's proposed cuts to Medicaid. Health should be in *all* policies. Poor health outcomes are an economic, social and political burden that should be addressed at the federal, state and local levels. Geronimus, Hicken, Keene, & Bound

(2006) have documented that cuts in social programs result in poorer health outcomes years later especially among the vulnerable women, children and families. The proposed withdrawal of funding from Planned Parenthood and shifting of funds from public to private schools can increase health vulnerability of this group in the future.

There are effective approaches from other countries and healthcare experts worldwide that we can adopt to decrease healthcare expenditures. Universal health insurance through effective management by a single-payer can ensure quality of services and cut costs. All countries with a single payer system have recognized the obligation of the government to ensure healthcare for all its citizens. As a single payer, the government plays a major role in cutting costs by negotiating with drug companies, laboratories and health providers; eliminating multiple insurance administrative costs that could save billions of dollars; setting systems of care that are uniformly monitored through standardized data bases and protocols; preventing expensive duplication of services; and allocating care services in areas determined by the needs of the population rather than profitability of the enterprise. The central tenet of capitalism that competition is best, has minimized the commitment of the government to take an active role in the nation's healthcare. For example, Medicare Part D, a program promoting access to prescription drugs by Medicare recipients essentially prohibited the government from negotiating drug prices with pharmaceuticals unlike Medicaid and the Veterans Administration that are also run by the government. Special interest groups such as Pharma have strong political lobbies that put their business profits above the welfare of the people. Americans have been paying much higher prices for the same drugs that are purchased at much lower costs in other countries such as Canada. PPACA's push for electronic medical records to be shared among health providers in order to prevent expensive duplication of services and promote efficient follow-up of consumers, has been marred by secrecy and protectiveness of service-contracts between insurance organizations and vendors. Single payer systems establish guidelines for pricing of drugs and other services to ensure universal access to affordable health care. As a single payer, the government has greater power to negotiate with vendors and businesses in health care. As a single payer, the government is the sole guardian for the nation's health.

Universal health care is funded by everyone's taxes. Progressive taxation requires that the wealthy contribute a bigger share of healthcare financing. The French philosopher, Voltaire aptly stated, *the rich get richer because of the abundance of the poor*. A successful state is characterized by fairness rather than exploitation. With universal health care, no one is identified by SES based on the health insurance card he/she carries. Medicaid, the program for the indigent has always been the brunt of political scapegoating. Medicaid is often associated with lower quality care and differential treatment in healthcare. Having Medicaid is tantamount to carrying a badge saying, "I am poor and don't deserve the same care as those who pay for their care." While the poor are often seen as an economic burden, they need a safety net to lift them from poverty and become productive members of society. By keeping them in poor health, they are doomed to a state of dependence and incapacity. According to WHO (2008), health is enabling and empowering individuals, families and communities to control their lives. Being healthy is enabling and empowering.

WHO (2008) emphasized primary healthcare as the system of care that is planned, organized, implemented and evaluated based on the needs of the population and communities served. Healthcare infrastructure and services are established based on the people's needs rather than profitability of the enterprise. Primary health care is focused on the living and working conditions of the people, keeping them healthy and preventing illnesses. The US healthcare system is skewed towards expensive disease-based care. There is little incentive in keeping people healthy as more money is made when they are sick. Compared to other OECD members, the US does poorly in keeping people out of the hospital – the setting where care is most expensive. Disease-based care is expensive with poorer outcomes and PPACA has attempted to shift incentives towards health promotion. Studies have shown that to keep people healthy, countries must focus on the social determinants of health (Marmot & Bell, 2009). Access to care explains only about one-third of keeping people healthy. The physical and social environments have greater impact on risk behaviors and health status. People living in high crime, polluted neighborhoods that are deprived of basic, affordable and quality social and health services, experience chronic stress predisposing their engagement in high-risk behaviors with consequent negative impact on their mental and physical health (McEwen, Nasca & Gray, 2015; Miranda, Messer & Kroger, 2012). Investment in public health and improvement of living conditions of the people have greater impact on their health as compared to mobilizing services when they are already sick. Public health receives a paltry 13% of the total US healthcare expenditure of 3.2 trillion dollars in 2015. In 2015, the federal government contributed 29% to health care spending as compared to households (29%), private businesses (20%) and state and local government (17%) (CMS, 2015). The GOP proposal is shifting greater responsibility for managing the care of the indigent to the state governments, creating consequent disparities in access to healthcare among different states and further burdening those states with limited revenues. In addition, it dismantles the many provisions of PPACA targeting health promotion and disease prevention.

Right to health as a fundamental human right is actualized by universal access to healthcare services that are equitably allocated in amount and quality. Right to health should not be based on one's ability to pay for services. Healthcare access is by necessity conditioned by a nation's economic capacity. The US is one of the most successful economies in the world but riddled with health disparities based on SES. While some Americans enjoy the best and most responsive healthcare, millions have no access. The responsibility for healthcare should not be left solely on the capacity of the individual especially if that ability is so constrained. It is the government's ethical and moral obligation to create a healthcare infrastructure that allows equity in access and remediation of health disparities across population groups.

Health professionals particularly those representing racial and ethnic minority groups need to be proactive in order to influence social policies that largely impact the health of vulnerable populations. Across the globe, vulnerable populations comprise those that experienced cumulative disadvantages from discrimination, isolation and oppression (Alwin, 2012). In the US, the most vulnerable sectors comprise racial and ethnic minorities who experience greater rates of poverty, being uninsured, shorter lives and suffering from disease and death (Seith & Kalof, 2011). The current GOP proposal has excluded the voices of experts and the people in its deliberations. It is high time that we make a unified stand to inform policy makers and participate in deliberations on an issue that we have direct experience and expertise.

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Dula F. Pacquiao, EdD, RN, CTN-A, TNS

Professor (Retired), School of Nursing
Rutgers University, Newark, NJ

PNAA President's Corner

Inspirational Leadership

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There are many talented executives and leaders with the ability to manage operations, but great leadership is not based solely on great operational ability (Sinek, 2011). Leading is not the same as being the leader. Being the leader means holding a rank or a position. Leading, however, means that others willingly follow the leader – not because they have to, not because they are paid to, but because they want to.

Inspirational Leadership is about energizing and creating a sense of direction and purpose for employees or members of an organization. It does involve generating excitement, enthusiasm and momentum for change to strive towards a compelling vision of the future. It offers clarity around goals and objectives and ensures a shared purpose among the people. Some of the greatest inspirational leaders of the past and present time possess three common denominators: trust, enthusiasm, and optimism.

- They earn trust. Trust does not emerge simply because a leader makes a rational case and promises change. Trust is a feeling, not a rational experience. Some people and companies are trusted even when things go wrong, and some are not even though everything might have gone exactly as it should have. Trust begins to emerge when there is a sense that another person or organization is driven by things other than their own self-gain. Leaders like the late Nelson Mandela had so much influence because people knew they could trust him. His word was his bond. This same sentiment can be carried over into any organization, where people want their leaders to be more trustworthy and transparent.
- They show enthusiasm. Great leaders are able to generate excitement, enthusiasm and commitment by translating the organization's vision, mission and values into terms that are relevant to the members. The key to inspiration is about showing interest and putting a stamp of approval on ideas that excites the leader and the members. If the leader is not enthusiastic, then the team will not be. The most detailed vision will not be realized if a leader cannot create enthusiasm and enlist the help of the members. Inspirational leaders rarely just take a walk but they walk with a purpose and eager enjoyment.
- They air optimism. The workplace atmosphere plays a big role in how well a team performs. It involves energizing individuals to strive towards a compelling vision of the future by embracing and embodying the values in all aspects of their work. Leaders communicate positively why change is needed, the benefits of change, what is at stake, and how the change will impact the members and the organization. A leader encourages optimism, insists on it but does not run from challenges. He addresses problems head on and continues to seek positive solutions and outcomes.

Dr. Martin Luther King once said he had a dream and he inspired people to make his dream their own. He didn't change America alone but with millions of others whom he inspired that changed the course of history. His vision and charisma as a leader were great factors that significantly influenced the people to create a movement. Trusting their guts and their intuition, these people made greatest sacrifices to help see the vision become a reality.

As President of the Philippine Nurses Association of America (PNAA), I am always in awe of the rewarding non-tangible privileges it has afforded me. The very core of PNAA is its dynamic and service-oriented members. Discharging my duties in serving the organization and its members has never been more inspiring. The genuine generosity and infectious enthusiasm each has contributed to expedite our agenda is priceless. PNAA has certainly paved the way for our coming together and we prudently use it to serve our many purposes in the nursing profession.

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Dino Doliente III, MBA, BSN, RN

President, 2016 – 2018

Philippine Nurses Association of America, Inc.



Barriers to the Patient Advocacy Role: An Integrative Review of the Literature

Caroline Oliveira & Joseph D. Tariman

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Correspondence to:
Joseph D. Tariman
phdinseattle@gmail.com

Authors' Affiliation

Caroline Oliveira, MSN, RN
Registered Nurse, Emergency
Department
Advocate Trinity Hospital
Chicago, IL

Joseph D. Tariman, PhD, RN,
ANP-BC, FAAN
Assistant Professor, Nursing
College of Science & Health
DePaul University
Chicago, IL

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Abstract

Background: Nurses must be competent patient advocates according to the American Association of Colleges of Nursing. In order to be effective advocates, nurses need to understand all aspects of patient advocacy as well as identify the barriers to patient advocacy encountered in contemporary nursing practice.

Objectives: This review aimed at describing the barriers to the patient advocacy role performed by nurses in clinical practice.

Methods: Computer databases at DePaul University Library – CINAHL Complete, PubMed, PsycInfo, and ProQuest Nursing and Allied Health Source were used to find relevant studies on barriers to patient advocacy by nurses.

Results: This review revealed many barriers to patient advocacy, which are thematically categorized into administration barriers, nursing role barriers, institutional barriers, physician-nurse power imbalance, and personal barriers. These barriers pose significant problems in the areas of personal, professional, and job satisfaction among nurses.

Conclusion: Patient advocacy remains a challenge for nurses. Barriers to patient advocacy must be systematically addressed and patient care outcomes related to patient advocacy should be consistently evaluated.

Keywords: *professional issues, nurse competencies, nursing ethics, patient advocacy, patient's rights*

Introduction

The American Nurses Association (2014) defines nursing as the protection, promotion, optimization of health, and advocacy in the care of individuals, families, communities, and populations. The American Association of Colleges of Nursing (AACN) requires that every nurse must be a competent patient advocate (AACN, 2008; 2010a; 2010b; 2012). Patient advocacy is the process of speaking on behalf of the patient and acting in the patient's best interest (Hanks, 2005). Patients who are generally vulnerable while dealing with a terminal illness like cancer can benefit from the care of highly trusted professional nurses who can advocate for them while they are unable to do so themselves.

A nurse spends more clinical contact hours with the patient than any other member of the healthcare team and is known to be one of the patient's trusted sources of health-related information (Tariman, Doorenbos, Schepp, Singhal, & Berry, 2014). Thus, patient advocacy is an essential part of day to day clinical nursing practice. Every nurse is expected to provide the best possible care for the patient's medical condition while effectively protecting the patient's basic rights and safeguarding their safety. Competency in patient advocacy can help in gaining a patient's trust and can have an impact on the long-term nurse-patient therapeutic relationship (LaSala, 2009).

As an advocate for the patient, the nurse must be alert to and take appropriate action regarding any instances of incompetent, unethical, or illegal practice that places the rights or best interests of the patient in jeopardy (American Nurses Association, 2014). Unfortunately, not all nurses feel capable to serve as a vocal advocate for their patients. This paper examines the barriers to patient advocacy among nurses.

Aims

This integrative literature review aims to examine the barriers to patient advocacy in contemporary clinical nursing practice. By identifying barriers specific to patient advocacy, nurses can develop and implement interventions that address the root cause of the problem.

Conceptual Model

The theoretical model that guided this integrative literature review is the Sphere of Nursing Advocacy (SNA) model by Hanks (2005). The SNA model can be used in the practice setting to visually depict the concept of patient advocacy on the part of the practicing nurse and can also be used as a teaching model for patient advocacy and decision-making. The model assumes that patients can either advocate for themselves (if physically or emotionally able) or they cannot and therefore the nurse will advocate for them.

The SNA model guided the analysis and interpretation of the results derived from this integrative literature review.

According to Hanks (2005, p. 76), the nurse provides a semipermeable sphere of advocacy for the patients while they are in a vulnerable situation and unable to advocate for themselves. However, when patient is able to speak for himself or herself, the nurse should allow the patient to freely self-advocate despite any limitations brought about by the medical condition.

Methods

Design

Whittemore and Knaf's (2005) methodology was followed during the conduct of the entire integrative literature review process. Qualitative data provide rich, thick, detailed descriptions on the nurse perspective related to the barriers to patient advocacy. The quantitative data provide information on the frequency of actual occurrences of patient advocacy barriers that nurses encountered in clinical practice. Initial themes emerged from the review. The two researchers first discussed the initial themes that were derived from study findings of the articles included in this review. Any disagreement with thematic analysis was resolved using consensual validation, where the two researchers aimed at 80 percent agreement of all the deductively produced major themes. The data were first organized by alphabetical order of key words and initial themes to easily group the same word or themes together. The two researchers then grouped the words and initial themes that best represent the major themes. The two researchers had 100 percent agreement during the final phase of major themes development.

Literature Search Strategy

Articles for this review were retrieved from the following computerized database sources: CINAHL Complete, PubMed, Health Source: Nursing Academic Edition, and SAGE Journals. CINAHL Complete search using keywords barriers, patient advocacy, and nurses yielded 74 articles using year 2003-2015 parameter. A PubMed search using same keywords resulted in 79 articles and Health Source resulted in 33 articles. Finally, Sage Journals search resulted to 160 articles (Table1).

Number of studies found using key words	PubMed N=79	CINAHL Complete N=74	Health Source: Nursing/Academic Edition N=33	Sage Journals N=160
Number of studies meeting inclusion criteria	35	19	16	19
Number of studies after excluding duplicates	35	12	13	15
Number of studies after using exclusion criteria	26	11	12	13
Number of studies meeting inclusion and exclusion criteria after reading full text articles	19			

Inclusion and Exclusion Criteria

The inclusion criteria included peer-reviewed journal articles published from 2003-2015, written in the English language, with abstracts that included information related to barriers to patient advocacy as reported by nurses. The exclusion criteria included studies involving healthcare providers other than nurses and study settings other than hospitals and clinics. A total of 19 articles met these inclusion and exclusion criteria (Table 1).

Data Synthesis and Analysis

Whittemore and Knaf's (2005) methodology was used. Analysis began by researching relevant data concerning barriers to patient advocacy. The framework of the SNA model posited by Hanks (2005) guided the data analysis. Qualitative data were thematically categorized into five major themes described in the results below. Table 2 presents information on the author and year of publication, study aim/s, study population, methods, and barriers to patient advocacy.

Table 2. Synthesis Table on the Barriers to Patient Advocacy by Nurses

Source Author/Year	Study Aim/s	Sample and Study Population	Research Design	Barriers to Patient Advocacy	Major Theme/s
Beagan & Ellis (2009)	Explore the moral experience of nursing in their working lives	N=20 nurses in Canadian city	Qualitative study, qualitative interviews	Administration failed to seek frontline input into decision making, poor staffing, lack of time, lack of resource, professional hierarchies	Administration barriers; institutional barriers; nursing role barriers; physician-nurse power imbalance
Blignaut, Coetzee, & Klopper (2014)	Investigate nurses' perceptions of safety and quality of care in South Africa	N=1117 nurses from medical and surgical units	Cross-sectional survey	Half of participants were doubtful of administration willingness to address problems, nurses felt they couldn't question authority	Administration barriers; physician-nurse power imbalance
Browne, Macdonald, May, Macleod, & Mair (2014)	Examine barriers and facilitators to improved care	N=30 patients, 65 professionals	Qualitative study, semi-structured interviews and study groups	Lack of knowledge, opportunities or adequate support from administration to improve situation	Administration barriers; personal barriers
Bull & Fitzgerald (2004)	How nurses in Australian operating room experience the role of patient advocate	N= 5 nurses in Australian operating dept. over 9 months	Ethnographic study, semi-structured interviews and observation	Personal assertiveness, relationships between team members, lack of support from administration.	Administration barriers; physician-nurse power imbalance; personal barriers
Choi, Cheung, & Pang (2013)	Nurses' advocacy role and practices that affect patient safety	N=28 nurses	Relevant documents and semi-structured interviews	Short staffing, lack of experience	Nursing role barriers; personal barriers
Davis, Konishi & Tashiro (2003)	To discover what these nurses thought about advocacy as part of the nursing role	N=24 graduate student nurses and clinical teachers at Japanese nursing college <40years w/ median of 10 years' experience	Pilot study, questionnaire	Second form of advocacy mentioned entails possible risk-taking behavior of the nurse for advocating for patients and nurses feared these could damage their relationship with the physician or patient/family and physician.	Nursing role barriers; personal barriers
Festic, Wilson, Gajic, Divertie, & Rababatin (2012)	Perspectives of physicians and nurses regarding End-of-Life care in the ICU	N=331 nurses	Cross sectional survey	Nurses felt they were unable to safely voice concerns over policy and practices, lack of communication, moral stress	Nursing role barriers; personal barriers
Gaudine, LeFort, Lamb, & Thorne (2011)	Nurses and physicians organizational ethics conflicts	34 Registered Nurses, in four Canadian hospitals	Qualitative descriptive study, interviews	No support from administration, lack of resources, not agreeing with organizational policies, lack of investment in nursing development	Administration barriers; institutional barriers
Hanks (2008)	Describe experiences of nursing advocacy by registered nurses	N=3 registered nurses practicing medical surgical nursing	Qualitative pilot study	Lack of confidence, lack of experience on patient advocacy	Personal barriers
Jimenez-Herrera & Axelsson (2014)	Analyze situations that generate ethical nurses.	16 ER nurses	Qualitative analysis, interviews and focus groups	Lack of autonomy, lack of communication, reification of injured body, pain	Nursing role barriers; personal barriers
Josse-Eklund, Jossebo, Sandin-Bojo, Wilde-Larsson, & Petzall (2014)	Describe Swedish nurses' perceptions of influencers on patient advocacy	18 nurses from different Swedish clinical contexts	Qualitative study with a phenomenographic method, interviews	Lack of support from nurse managers, time constraints, limited communication	Administration barriers; nursing role barriers
Lyndon (2008)	To identify processes affecting agency for safety among perinatal nurses, physicians, and certified nurse-midwives	12 RN, 2 certified nurse-midwives	Grounded theory	Lack of resources, lack of organizational/administrative support, exclusion from teaching rounds, lack of communication, physician/nurse relationship, lack of confidence	Administration barriers, institutional barriers; nursing role barriers, physician-nurse power imbalance; personal barriers
Negarandeh, Oskouie, Ahmadi, Nikravesh, & Hallberg (2006)	Explore the barriers and facilitators influencing the role of advocacy among Iranian nurses	N=24 Iranian registered nurses working in a large hospital in Tehran, Iran.	Prospective study, semi-structured interviews	Powerlessness, lack of support from administration, law, code of ethics and motivation, limited communication, insufficient time, physicians leading	Administration barriers; nursing role barriers; institutional barriers; physician-nurse power imbalance
O'Connor & Kelly (2005)	Nurses' perceptions of patient advocacy in Ireland	N=20 nurses	Qualitative interviews	Avoidance of conflict/ confrontation	Personal barriers
Sorlie, Jansson, & Norberg (2003)	The meaning of being in ethically difficult care situations	N=20 female RN in pediatric hospitals	Interviews	Limited time, nurse/physician relationship, heavy demands of work	Nursing role barriers; physician-nurse power imbalance; personal barriers
Thacker (2008)	To describe nurses' perceptions of advocacy behaviors in end-of-life nursing practice	N=317 from 3 regional hospitals in moderately sized urban areas of the mid-Atlantic region of the USA	Comparative descriptive study, self-administered 38 item instrument with four sub instruments	Lack of communication, lack of knowledge, time, lack of support from administration, patient/family	Administration barriers, nursing role barriers; personal barriers
Walden, Elliott, & Gregurich (2009)	Determine the perceived barriers and organizational factors that influence nurses' participation in patient care rounds	Pediatric hospital in Texas: all-inclusive sample of interdisciplinary team members	Descriptive study using Delphi technique, descriptive surveys	Nurses busy with other patients, no standard time for rounds, RNs input was not valued or respected	Nursing role barriers; institutional barriers; personal barriers
Ware, Bruckenthal, Davis, & O'Conner-Von (2009)	To determine the educational needs for and barriers of advocacy for nurses working with patients experiencing pain	188 nurses from the American Society for Pain Administration Nursing	Descriptive correlational study, online survey	Lack of time, lack of employer support, professional obligations, power struggles, no mentor	Administration barriers, nursing role barriers, physician-nurse power imbalance; personal barriers
Zuzelo (2007)	Identify types and frequencies of patient care situations that evoke moral distress	Convenience sample of 100 RN's employed by health care network full time	Quantitative, descriptive study, open ended questions	Physician/nurse relationship, frustration with family members, inadequate staffing, accessibility of support limited during off business hours	Administration barriers; institutional barriers, physician-nurse power imbalance

Results

Nineteen studies met the inclusion and exclusion criteria for this integrative literature review. The barriers were thematically categorized into five major themes: administration barriers, nursing role barriers, institutional barriers, physician-nurse power imbalance, and personal barriers. Examples of administration barriers include lack of support from managers, less optimal milieu for discussion of ethical dilemmas, and perpetuation of hierarchical power structure and organizational cultures that hinder nurses from advocating for their patients (Beagan & Ells, 2009; Blignaut, Coetzee, & Klopper 2014; Browne, Macdonald, May, Macleod, & Mair 2014; Bull & Fitzgerald 2004; Festic, Wilson, Gajic, Divertie, & Rabbatin, 2012; Gaudine, LeFort, Lamb, & Thorne, 2011; Josse-Eklund, Jossebo, Sandin-Bojo, Wilde-Larsson, & Petzall, 2014; Lyndon, 2008; Negarandeh, Oskouie, Ahmadi, Nikravesh, & Hallberg, 2006; Thacker, 2008; Ware, Bruckenthal, Davis, & O'Conner-Von, 2009; Zuzelo, 2007). The nursing role barriers pertain to lack of time; nurses felt they didn't have time to be engaged in the advocacy process or be involved with bioethics committee (Beagan & Ells, 2009; Josse-Eklund et al., 2014; Negarandeh et al., 2006; Thacker, 2008; Ware et al., 2009; Walden, Elliott, & Gregurich, 2009; Sorlie, Jansson, & Norberg, 2003) and lack of healthcare team communication about end of life in the intensive care unit (Festic et al., 2012; Josse-Eklund et al., 2014; Lyndon, 2008; Thacker, 2008; Jimenez-Herrera & Axelsson 2014). Institutional barriers included poor staffing (Beagan & Ells 2009; Choi, Cheung, & Pang, 2013; Zuzelo, 2007) and administration's failure to seek frontline input into decision making, poor staffing, and lack or inadequate resources to promote safety (Beagan & Ells, 2009; Gaudine et al., 2011; Lyndon, 2008). Physician-nurse power imbalance was reported in five studies, where nurses felt unable to successfully speak up to or in the presence of a physician on behalf of a patient (Davis, Konishi, & Tashiro, 2003; Lyndon, 2008; Sorlie et al., 2003; Ware et al., 2009; Zuzelo, 2007). Lastly, personal barriers to patient advocacy pertain to lack of knowledge and/or experience on patient advocacy (Browne et al., 2014; Choi et al., 2013; Davis, Konishi, & Tashiro, 2003; Hanks, 2008; Thacker, 2008) and personal avoidance of conflict (O'Connor & Kelly, 2005). Table 3 lists the occurrence frequencies among the five major barriers to patient advocacy.

Discussion

Lack of support from the administration was the most common barrier identified by nurses. Many narratives supported this theme such as report of administrators who were more apt to act on requests from physicians than from nurses (Gaudine et al., 2011). Nurses also expressed that they felt misunderstood and disrespected, and that managers and administration were not investing in nurses' education and training on patient advocacy. These barriers illustrate opportunities for nursing administrators to improve upon.

Table 3. Frequencies and Percentages of Barriers to Patient Advocacy

Barriers to Patient Advocacy	Total Barriers	Percentage Based on Total Responses
Management Barriers	12	28%
lack of support	12	
Nursing Role Barriers	12	28%
time	7	
communication	5	
Personal Barriers	7	16%
Lack of knowledge/experience	5	
personal assertiveness	1	
personal confidence	1	
Institutional Barriers	6	14%
staffing	3	
resources	3	
Physician/nurse relationship	5	12%

Limited time was reported as a major barrier to patient advocacy. Nurses expressed extreme frustration due to time constraints. This barrier prevents nurses from getting to know their patients well, decreasing their ability to effectively speak on behalf of their patient's specific interests and needs and nurses feared these could damage their relationship with the physician or patient/family and physician. Higher workloads lead to decrease amount of time nurses have to spend with their patients. The adequacy of clerical support staff, nurse-patient ratio (1:8 as a bare minimum in the general medical inpatient setting; approximately 1:2 in ICU), and acuity of patients should be closely monitored and maintained using evidence-based guidelines (Keogh, 2014).

Lack of resources and staffing issues were the most frequently reported institutional barriers. The current health care system was cited as a constant source of frustration due to inadequate nurse staffing and lack of funding for professional development to increase knowledge and competency in patient advocacy skills. There is a need for nurse leadership team members to represent the voice of nurses to the administration and advocate strongly for adequate nursing and auxiliary staffing levels at all times, so that nurses retain the capacity to routinely advocate for their patients.

The perception of physician-nurse power imbalance was reported in studies in this review as a barrier to patient advocacy. Nurses remain fearful of confrontation from physicians, and report concerns about retaliation and powerlessness. A model of hospital shared governance where nurses have equal footing with physicians is now taking hold. This model can empower nurses to advocate more for their patients and improve nurses' job satisfaction and retention (Fisher, Jabara, Poudrier, Williams, & Wallen, 2016). An interdisciplinary and collaborative approach to patient care

should be cultivated from the top of the leadership structure to the bottom.

Personal barriers include the nurse's personal lack of assertiveness, lack of confidence, and lack of knowledge and/or experience on the ability to act as a patient advocate. An assessment of personal traits, preferences and values such as the use of Temperament and Character Inventory or TCI (Cloninger, Przybeck, Sverakic, & Wetzel, 1994), and knowledge level on patient advocacy is an example of a tool that could be used early in a nurse's employment to guide future professional development activities. TCI has been used in assessing personality traits of individuals entering nursing and the tool has been found to have adequate reliability (Eley, Eley, Bertello, & Rogers-Clark, 2012). Competency on patient advocacy can also be part of the annual performance evaluation for nurses using Hanks' (2010) Protective Nursing Advocacy Scale or PNAS.

Implications for Research

More research studies are needed on how the barriers reported in this review actually affect patient care outcomes, such as patient satisfaction. Moreover, patient advocacy and its relationship to nurses' personal and professional satisfaction should be further studied. Patient care outcomes related to patient advocacy by nurses also remain to be established.

Limitations

Most studies that met the inclusion and exclusion criteria in this review were conducted in the hospital setting and very few were conducted in clinic or outpatient setting. Study conclusions should be interpreted within this context.

Conclusion

Patient advocacy remains a challenge for nurses. Barriers to patient advocacy must be systematically addressed and patient care outcomes related to patient advocacy should be identified and consistently evaluated. Nursing leadership must support nurses who are engaged in patient advocacy and bioethics committee.

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Electronic Diaries in Healthcare: A Review of Literature

Sigrid Ladores & Leigh Ann Bray

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Correspondence to:

Sigrid Ladores
sladores@uab.edu

Authors' Affiliation

Sigrid Ladores, PhD, RN, PNP,
CNE
Assistant Professor, School of
Nursing

Leigh Ann Bray, MSN, CNL
PhD Student, School of Nursing

University of Alabama at
Birmingham
Birmingham, AL 35294

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Conflict of Interest

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Abstract

Purpose:

As the world continues to become highly technological in nature, electronic diaries are emerging as vital additions to healthcare research and practice. Electronic diaries are mobile devices used as research and clinical aids to collect data on patients' experiences and assist with diagnosis, treatment planning, implementation, and evaluation. The purpose of this paper is to critically examine the literature related to the use of electronic diaries in healthcare.

Method:

A comprehensive review of the literature was undertaken to extricate relevant articles on electronic diaries used in healthcare. The approach recommended by Whittemore and Knafl was used to guide the analysis. Health-related databases, truncated keywords, and date parameters were used to identify the 30 articles included in the review.

Findings:

Advantages and disadvantages of using electronic diaries were extracted. Notable advantages include improved compliance rates, satisfactory usability results, and high quality data due to the elimination of hoarding, forward-filling, and back-filling which plague paper diaries. Notable disadvantages include cost of purchase, installation, maintenance and repair of electronic diary systems, technical malfunction leading to data loss, and challenges in user interface.

Discussion:

The use of electronic diaries has implications for both research and practice. Compared to paper diaries, electronic diaries have the capacity to collect more reliable and valid data in research. Additionally, electronic diaries can be designed as part of an interactive algorithm that logically leads the user to appropriate interventions that promote one's well-being and potentially prevent disease. The future for electronic diaries is rich in terms of its diffusion and application in healthcare.

Keywords: *electronic diaries, paper diaries, healthcare, research*

Introduction

As the world continues to become highly technological in nature, electronic diaries (EDs) are emerging as vital additions to healthcare research and practice. EDs are mobile devices used as research and clinical aids to collect data on patients' experiences and assist with diagnosis, treatment planning, implementation, and evaluation. Compared to traditional paper diaries (PDs), EDs have certain properties that make them attractive and feasible for use in healthcare. This paper provides a review of the literature related to EDs and discusses their implications and applications in healthcare.

Electronic Diaries versus Paper Diaries

No one can dispute the utility and importance of gathering patient data through the use of diaries. Before the advent of EDs, paper diaries played an integral part in various monitoring and intervention studies, as well as clinical and medication trials. However, PDs were found to be riddled with inaccuracies that affected the validity and reliability of study findings. Consequently, researchers and scientists developed EDs to combat PDs' internal flaws.

Most of the discussion surrounding notable problems related to the use of PDs in healthcare revolves around recall bias. Paper diaries rely on retrospective recollection of events and associated conditions. Evidence shows that memory is fallible and is not simply a straightforward process of retrieval. Memory, in fact, undergoes a series of mental "short-cuts" or heuristic maneuvers to reconstruct past experiences. Each step is vulnerable to errors, and although unintended by the participant, recall bias can introduce inaccuracies in the data provided (Piasecki & Hufford, 2007).

Other handicaps related to the use of PDs include illegible data and noncompliance in completing required monitoring entries, both of which result in poor quality data available for analysis. Researchers coined the terms "parking lot compliance" and "white coat compliance" after realizing that study participants completed their PD entries minutes before seeing their study investigators (Stone, Shiffman, Schwartz, Broderick, & Hufford, 2003). This social desirability bias leads to infected data that are rendered unusable. In comparison with PDs, EDs, usually created within a software to be run via a palmtop computer, tablet, or smartphone, are programmed to elicit multiple entries per day as study participants live their daily lives.

Review of Literature

To ascertain the current state of usage of EDs in healthcare, a comprehensive search of the literature was conducted using Whittemore and Knaff's (2005) approach. The following databases were accessed: CINAHL, PubMed, PsycINFO, Google Scholar, Health and Psychosocial Instruments,

and Scopus. Certain limiters were imposed to capture appropriate sources: English language, full-text available, data-based, and date parameters 2000-2017. Using truncated words, "electron", "diar", and "health", 5,399 articles surfaced. Additional limiters were used to specify "diary" or "diaries" and "health care" or "healthcare" to further narrow the results. After deleting duplicates and reviewing for appropriateness and relevance, 30 articles remained for review (See Table 1).

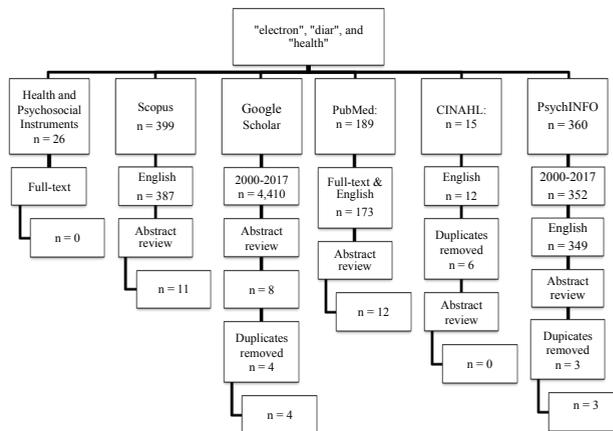


Figure 1
Detailed Search Strategy

Advantages of EDs

When compared to PDs, EDs' major positive attribute is the overwhelming evidence of an improved compliance rate, which is, the patient's (or study participant's) act of adhering to a prescribed frequency of data entry as required by the clinician (or researcher). A seminal study by Stone & Shiffman et al. (2003) found that the reported compliance rate by PD participants was 90%; whereas, the actual compliance rate was only 11%. In comparison, the reported and actual compliance rate by ED participants was 94%. This study was unique in its design because it used a paper diary system that was instrumented with photosensors, which unbeknown to the participants monitored the frequency and duration of the opening and closing of each diary. The staggering difference in reported versus actual compliance rates among the PD participants demonstrated the pervasive problem of back-filling and forward-filling of diary entries. Faked compliance is a major detriment in the integrity of any study findings.

Compliance rates in other studies were comparable. Most had 80% - 90% compliance rates (Allena, Cuzzoni, Tassorelli, Nappi, & Antonaci, 2012; Giffin, Lipton, Silberstein, Olesen, & Goadsby, 2016; Hensel, Fortenberry, Harezlak, & Craig, 2012; Schöndube, Bertrams, Sudeck, & Fuchs, 2017; Williams et al., 2015). However, as noted in Table 1, several studies had monetary incentives based upon the number of diary entries submitted, which could lead one to question true compliance rates if remuneration were not included.

On the other hand, usability reports were also favorable. Participants of all ages, ranging from 8 to 75 years voiced praises for the ease in using EDs (Aaron, Turner, Mancl, Brister, & Sawchuk, 2005; Begg, Drummond, & Tiplady, 2003; Gaertner, Elsner, Pollmann-Dahmen, Radbruch, & Sabatowski, 2004; Litcher-Kelly, Stone, Broderick, & Schwartz, 2004; Palermo, Valenzuela, & Stork, 2004; Peters et al., 2000; Roelofs, Peters, Patijn, Schouten, & Vlaeyen, 2004; Stinson et al., 2006; Stone & Broderick et al., 2003; Williams et al., 2004). They range in their experience and exposure to electronic equipment; thus, usability was not directly correlated to past computer use. A qualitative usability study of Canadian adolescents with arthritis showed that all were very satisfied with EDs, and reported that using EDs was “better than just getting a book full of blank paper and writing about your pain each day” (Stinson et al., 2006, p. 301). Gaertner et al. (2004) showed that 75% of participants used EDs more frequently than PDs because they were fast and easy to handle.

Other studies demonstrated support for the two-way messaging capabilities found in EDs where participants felt as though there were someone supportive on the other end of the terminal who monitored data and answered questions (Jamison et al., 2001). In a more recent study, participants gave the readability and design of EDs’ screens positive subjective ratings (Allena et al., 2012). Participants rated EDs as both easier to understand and easier to use when compared to PDs. Similarly, physicians found EDs to be convenient and helpful in monitoring patients’ headaches. The one participant, out of 85, who preferred the paper version, explained that it was due to being unfamiliar with technology (Allena et al., 2012).

Another advantage of EDs was the high quality and veracity of the data collected from study participants. Electronic diaries were equipped with time and date stamps so that each entry was recorded; eliminating the possibility of manipulation (Aaron, Mancl, Turner, Sawchuk, & Klein, 2004; Aaron et al., 2005; Begg et al., 2003; Bromberg, Connelly, Anthony, Gil, & Schanberg, 2014; Gaertner et al., 2004; Jamison et al., 2001; Jamison, Raymond, Slawsby, McHugo, & Baird, 2006; Litcher-Kelly et al., 2004; Palermo et al., 2004; Peters et al., 2000; Roelofs et al., 2004; Stinson et al., 2006; Stone & Broderick et al., 2003; Stone & Shiffman et al., 2003; Turner, Mancl, & Aaron, 2005; Williams et al., 2004). Data were not tainted by hoarding, back-filling, or forward-filling. Additionally, the completeness of data obtained was noted as an advantage of EDs over PDs. The palmtop computers, tablets, or smartphones used as vehicles for EDs were designed so that participants must answer a question completely before being allowed to proceed to the next one. This ensured that there were no omissions in the data being collected. Inspection of previous entries was also not permitted by the software design so

that current assessments were not influenced by past events. Also, the high quality data gathered by EDs were seamlessly transmitted to the investigators’ mainframe for efficient analysis. This is in contrast to the PDs’ need for transcription and manual data entry, which may be prone to human errors and pose additional costs (Stinson, 2009). When not immediately transmitted to the investigator, a memory card was used and returned for analysis (Crosby et al., 2012). Lastly, alarms were set on the ED to remind participants at the specified time contributing to the completeness of data (Bouwman, Bos, Hoenders, Oldehinkel, & Jonge, 2017).

Electronic diaries can offer more detailed information in real time when compared to questionnaires (Anttila, Anttila, Kurki, & Valimaki, 2017; Bray, Bundy, Ryan, & North, 2016). For example, in a study by Anttila et al. (2017), the use of an ED allowed the differences in people who have anxiety to be clearer than questionnaires alone. ED data collection methods can offer richer information on complex processes, such as post-traumatic stress disorder, and on how symptoms change in real time (Dewey et al., 2015). When dealing with highly personal areas of study, such as sexual behavior, EDs can enhance self-awareness and reflection and can be therapeutic (Felsher, Wiehe, Gunn, & Roth, 2017).

Disadvantages of EDs

While there was overwhelming evidence supporting the use of EDs in healthcare research and practice, there were also disadvantages that needed to be considered. The primary issues were the cost of purchase, installation, maintenance, and repair of ED systems, which can be prohibitive especially for small-scale research groups and clinical areas that might be interested in using EDs for their patient populations.

As with any technology, the possibility of malfunction and technical misfortune is a real concern. Several studies encountered such difficulties and resulted in data loss (Fisher, Wiehe, Gunn, & Roth, 2016; Quilty, Watson, Toneatto, & Bagby, 2017; Suveg, Payne, Thomassin, & Jacob, 2010). For example, Quilty et al. (2017) reported that 731 diary entries were labeled missed due to technological malfunction. Hensel et al. (2012) reported that 5% of their participants were unable to access the survey at one point during the study, and as many as 20% had issues transferring completed data to the remote server.

Other disadvantages discovered with the use of EDs involved user interface. Several participants noted that the palmtop computer screen was small and difficult to see (Gaertner et al., 2004; Stinson et al., 2006), the stylus and touch-screen were challenging to manipulate (Peters et al., 2000; Stinson et al., 2006), and the use of reminder alarms was bothersome (Gaertner et al., 2004; Stinson et al., 2006).

In summary, EDs used in healthcare have several advantages over traditional PDs. These include increased compliance and positive usability reports among users and overall higher quality of data obtained. The cost, maintenance, and potential for technology malfunction have been identified disadvantages when using EDs.

Table 1
Review of 30 Studies Involving Electronic Diaries (EDs)

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Aaron et al. (2004)	N = 62 Age = 38.6 mean Gender = 84% female Race = 81% white Education = 50% with some college Disorder = Temporomandibular disorder pain Country = USA	RCT comparing cognitive-behavioral therapy-based pain management program versus self-care manual education. Duration = 8 weeks. Monetary incentives = Yes	Palmtop computer using Palm OS (Santa Clara, CA) with 3 measurements (morning, afternoon, and evening) per day predetermined by participants with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 91%. Most common reasons for missed entries = failure to hear alarm and inconvenient time. Afternoon and evening entries most commonly missed.
Aaron et al. (2005)	N = 71 Age = 38 mean Gender = 86% female Race = 93% white Education = 78% with some college Disorder = Temporomandibular disorder pain Country = USA	RCT comparing cognitive-behavioral therapy-based pain management program versus self-care manual education. Duration = 2 weeks. Monetary incentives = Yes	Palmtop computer using Palm OS (Santa Clara, CA) with 3 measurements (morning, afternoon, and evening) per day predetermined by participants with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 91%. Participants took 2-3 minutes to complete each entry. No reactivity found between completion of EDs and pain-related variables (i.e., pain monitoring did not change participants' appraisals or management of pain).
Allena et al. (2012)	N = 85 Age = 39.73 mean Gender = 80% female Race = Not provided Education = 69.4% secondary school or higher Disorder = medication overuse headaches Country = Italy	Aim was to evaluate acceptability of and compliance to electronic diaries compared to traditional diary chart in inpatients with medication overuse headaches. Duration = 30 days. Monetary incentives = Not reported	The Palm device (ATC Service—Pavia, Italy) is a PDA with 32 MB RAM and Windows CE version 3.0 operating system. Data collected on medication use, trigger factors, and headache factors. Diary filled out daily.	Compliance rate for EDs = diaries completely filled out by 98% of patients. Usability = Instructions were rated clear by 97%. EDs were rated easier to understand ($p < 0.01$) and easier to use ($p < 0.001$) than PDs.
Anttila et al. (2017)	N = 70 Age = 15.9 mean Gender = 96.7% female Race = Not reported Education = 48.3% were in high school Disorder = Social relationships in adolescents Country = Finland	Mixed methods study to compose broad picture of adolescent social relationships. Duration = 2 years (2008-2010). Monetary incentives = Not reported	Depis.Net support system website – Participants first described social relationships by creating a visual network map and identifying people close to them through plotting smiley face symbols. Then in reflective texts, participants reflected on their social relationships. Frequency of reporting not specified.	Compliance rate for EDs = Only 41% (n = 29) of 70 adolescents used EDs to depict social relationships.
Begg et al. (2003)	N = 27 Age = 48.9 mean Gender = 100% female Race = not provided Education = not provided Disorder = post-gynecological surgery symptoms Country = UK	Longitudinal monitoring after hospital discharge. Duration = 4 weeks. Monetary incentives = No	Palmtop computer using Apple Newton Message Pad 120/130 or Psion Series V (Cupertino, CA), with 2 measurements (morning and evening) initiated by participants, with no reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 74.7%. 96% of participants found EDs “very easy” or “quite easy” to use. None found EDs difficult to use.
Bouwman et al. (2017)	N = 54 Age = 34 mean Gender = both groups 74% female Race = Not reported Education = 46% were classified as highly educated Disorder = Sleep quality in depressed and healthy individuals Country = The Netherlands	Replicated single-subject time-series design with pair-matched depressed patients and healthy controls to see how sleep and affect are associated throughout the day. Duration = 30 days. Monetary incentives = Not reported	PysMate BV (Maastricht, Netherlands) was the electronic device. Monitoring occurred 3 times per day. Assessments were fixed with 6 hours in between. Assessments took place at approximately 10am, 4pm, and 10pm. An alarm sounded 30min prior to assessment time. An hour window was provided to complete the diary. After that, entry was considered missing.	Compliance rate for EDs = 62 participants began the diary study. Four participants dropped out before the study ended, four other participants did not have enough valid measurements ($T > 60$) diary entries. The remaining 54 participants had enough valid entries and were included.
Bray et al. (2016)	N = 35 Age = 12.5 mean Gender = 100% male Race = 100% Caucasian Education = 91% were in the mainstream schooling system Disorder = Duchenne Muscular Dystrophy Country = Australia	Study to investigate whether real time diary reporting of daily experience is valid in representing health-related quality of life. Duration = 7 days. Monetary incentives = Not reported	Personal Digital Assistant (PALM z22) with ESP software. Boys responded to alarms 8 times/day for 7 days. Alarms were randomly generated by experience sampling diary method.	Compliance rate for EDs = Mean compliance rate was 70%.
Bromberg et al. (2014)	N = 59 Age = 13.30 mean Gender = 74.6% female Race = 73% Caucasian Education = School-age, 93% attended public schools Disorder = Juvenile arthritis Country = USA	Longitudinal monitoring of pain experience related to juvenile arthritis in those being treated with pharmacotherapies after hospital discharge. Duration = 4 weeks. Monetary incentives = Yes	Completed the diary 3 times per day for 28 days via a T-Mobile Dash smartphone. Pain was monitored using a visual analog scale. Alarms were programmed according to each participant's schedule to sound 3 times per day (morning, afternoon, and evening) to avoid school hours.	Compliance rate for EDs = There was a total of 3,258 diary entries showing a 66% completion rate.
Crosby et al. (2012)	N = 929 Age = 29.2 mean Gender = 55.1% female Race = 66.5% African American Education = 65.7% earned less than \$1,000/month Disorder = non-viral sexually transmitted infections Country = USA	Prospective longitudinal study to compare consistent condom use with sexually transmitted infection incidence. Duration = 6 months. Monetary incentives = Yes	Personal digital assistant (PDA) programmed with Configurable Electronic Real-Time Assessment System (Reston, VA) with one measurement per day. If they answered yes to having sex that day, they were asked questions about each act of sexual intercourse.	Compliance rate for EDs = Not reported
Dewey et al. (2014)	N = 32 Age = 51 mean Gender = 78.13% female Race = 88% European-American Education = not provided Disorder = Posttraumatic stress Country = USA	Quasi-experimental study to evaluate the potential impact of ecological momentary assessment on severity of posttraumatic stress. Duration = at least 2 weeks. Monetary incentives = Not reported. Course credits and entry into a raffle	Randomly prompted participants within 6 two-hour time blocks between 10 am and 10 pm. With each prompt, the same 22 items were completed in the same order. An Android device was used to assess post-traumatic stress symptoms and negative emotions 6 times per day.	Compliance rate for EDs = Overall response rate was 67.5% with participants completing an average of 56 out of 84 possible entries. It took an average of 1 minute and 14 seconds to complete an entry.
Felsher et al. (2017)	N = 25 Age = 42.5 mean Gender = 100% women Race = 75% Black Education = Not reported Disorder = Mental health Country = USA	Longitudinal study of the sexual lives of women engaging in transactional sex to explore how weekly interviews and the use of the electronic ecologic assessment facilitated positive mental health outcomes. Duration = 4 weeks. Monetary incentives = Yes	Participants were provided an internet-enabled smartphone. Information was collected about behavior and emotions surrounding sexual events twice/day. Participants were allowed up to 240 minutes to complete diary entries. Mean completion time was 19.6 minutes for those reporting sexual behavior and 11.3 for those who did not.	Compliance rate for EDs = Not reported

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Bouwman et al. (2017)	N = 54 Age = 34 mean Gender = both groups 74% female Race = Not reported Education = 46% were classified as highly educated Disorder = Sleep quality in depressed and healthy individuals Country = The Netherlands	Replicated single-subject time-series design with pair-matched depressed patients and healthy controls to see how sleep and affect are associated throughout the day. Duration = 30 days. Monetary incentives = Not reported	PysMate BV (Maastricht, Netherlands) was the electronic device. Monitoring occurred 3 times per day. Assessments were fixed with 6 hours in between. Assessments took place at approximately 10am, 4pm, and 10pm. An alarm sounded 30min prior to assessment time. An hour window was provided to complete the diary. After that, entry was considered missing.	Compliance rate for EDs = 62 participants began the diary study. Four participants dropped out before the study ended, four other participants did not have enough valid measurements ($T > 60$) diary entries. The remaining 54 participants had enough valid entries and were included.
Bray et al. (2016)	N = 35 Age = 12.5 mean Gender = 100% male Race = 100% Caucasian Education = 91% were in the mainstream schooling system Disorder = Duchenne Muscular Dystrophy Country = Australia	Study to investigate whether real time diary reporting of daily experience is valid in representing health-related quality of life. Duration = 7 days. Monetary incentives = Not reported	Personal Digital Assistant (PALM z22) with ESP software. Boys responded to alarms 8 times/day for 7 days. Alarms were randomly generated by experience sampling diary method.	Compliance rate for EDs = Mean compliance rate was 70%.
Bromberg et al. (2014)	N = 59 Age = 13.30 mean Gender = 74.6% female Race = 73% Caucasian Education = School-age, 93% attended public schools Disorder = Juvenile arthritis Country = USA	Longitudinal monitoring of pain experience related to juvenile arthritis in those being treated with pharmacotherapies after hospital discharge. Duration = 4 weeks. Monetary incentives = Yes	Completed the diary 3 times per day for 28 days via a T-Mobile Dash smartphone. Pain was monitored using a visual analog scale. Alarms were programmed according to each participant's schedule to sound 3 times per day (morning, afternoon, and evening) to avoid school hours.	Compliance rate for EDs = There was a total of 3,258 diary entries showing a 66% completion rate.
Crosby et al. (2012)	N = 929 Age = 29.2 mean Gender = 55.1% female Race = 66.5% African American Education = 65.7% earned less than \$1,000/month Disorder = non-viral sexually transmitted infections Country = USA	Prospective longitudinal study to compare consistent condom use with sexually transmitted infection incidence. Duration = 6 months. Monetary incentives = Yes	Personal digital assistant (PDA) programmed with Configurable Electronic Real-Time Assessment System (Reston, VA) with one measurement per day. If they answered yes to having sex that day, they were asked questions about each act of sexual intercourse.	Compliance rate for EDs = Not reported
Dewey et al. (2014)	N = 32 Age = 51 mean Gender = 78.13% female Race = 88% European-American Education = not provided Disorder = Posttraumatic stress Country = USA	Quasi-experimental study to evaluate the potential impact of ecological momentary assessment on severity of posttraumatic stress. Duration = at least 2 weeks. Monetary incentives = Not reported. Course credits and entry into a raffle	Randomly prompted participants within 6 two-hour time blocks between 10 am and 10 pm. With each prompt, the same 22 items were completed in the same order. An Android device was used to assess post-traumatic stress symptoms and negative emotions 6 times per day.	Compliance rate for EDs = Overall response rate was 67.5% with participants completing an average of 56 out of 84 possible entries. It took an average of 1 minute and 14 seconds to complete an entry.
Felsher et al. (2017)	N = 25 Age = 42.5 mean Gender = 100% women Race = 75% Black Education = Not reported Disorder = Mental health Country = USA	Longitudinal study of the sexual lives of women engaging in transactional sex to explore how weekly interviews and the use of the electronic ecologic assessment facilitated positive mental health outcomes. Duration = 4 weeks. Monetary incentives = Yes	Participants were provided an internet-enabled smartphone. Information was collected about behavior and emotions surrounding sexual events twice/day. Participants were allowed up to 240 minutes to complete diary entries. Mean completion time was 19.6 minutes for those reporting sexual behavior and 11.3 for those who did not.	Compliance rate for EDs = Not reported

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Fisher et al. (2016)	N = 152 Age = 53 mean Gender = 100% female Race = 65% white Education = 53.4% had a college education Disorder = Hot flashes Country = USA	Cohort of women from a larger observational study of hot flashes and cardiovascular risk. Aim was to collect a prospective hot flash data using an electronic phenomenon diary. Duration = 3 days Monetary incentives = Not reported	Electronic digital diary via the Palm z22 (uses flash memory, the Palm OS Garnet 5.4.9 operating system, and 32MB NVRAM) data uploaded by Thacker Network Technologies – Alberta, Canada.	Compliance rate for EDs = 96% reported no issues in using the diary. 2% had battery issues and 1% issues filling out diary. 1 participant had device failure and 1 participant had difficulty using the diary. Participation rate of the study was 71%.
Gaertner et al. (2004)	N = 24 Age = 49.9 mean Gender = 54% female Race = not provided Education = 45% with high school diploma Disorder = chronic cancer and non-cancer pain Country = Germany	RCT, crossover study comparing paper and electronic versions of pain diary (PDs vs. EDs). Duration = 4 weeks. Monetary incentives = No	Palmtop computer using Palm OS (Santa Clara, CA), with 1 measurement daily predetermined by participants, with reminder alarms. Other system specifications not provided.	75% of participants stated that they used EDs more frequently than PDs. 83% preferred using the EDs vs. PDs. 62% stated that the EDs provided better support of their healthcare (e.g., taking analgesics regularly). Participants took less than 15 minutes to complete either PDs or EDs. 6 participants criticized the EDs' poor legibility due to insufficient contrast and brightness. 54% found EDs more complicated to use; 42% found PDs more complicated to use.
Griffin et al. (2016)	N = 97 Age, Gender, Race & Education = Not reported Disorder = Migraine headaches Country = UK	Prospective daily electronic diary study using visual analog scales to report migraine postdrome symptoms in those who report non-headache symptoms as part of their migraine episodes. Duration = 3 months incentives = Not reported	One random alarm per day during waking hours. Questions asked were related to non-headache symptoms before, during, and after a migraine. Entries could not be altered once confirmed by the participant.	Compliance rate for EDs = All participants included in the final sample recorded diary entries on at least 80% of the study days.
Hensel et al. (2012)	N = 243 Age = 45.27% 20-24 years Gender = 60.91% female Race = 87.65% African American Education = Not reported Disorder = Sexually transmitted infections/ HIV Country = USA	Part of a larger prospective clinical study on sexual risk behavior and sexually transmitted infections in order to understand sexual risks and sexually transmitted infections in adults. Duration = 12 weeks Monetary incentives = Yes	Internet enabled Palm Centro cellular phone equipped with a digital camera, touchscreen navigation, QWERTY keyboard, and stylus using Pendragon SyncServer software Availability of the diary was 30 minutes before to 4 hours after scheduled start time. Up to 4 SMS text message reminders were sent: at scheduled time, 1 hours after start time, 2.5 hours after start time, and 15 minutes before availability window closed. Participants completed three entries per day at one of 4 pre-set 8-hour data entry schedules to best fit their lifestyle.	Compliance rate for EDs = Over the entire 12 weeks, 89.7% of the diary entries were submitted. On average 85.7% of the expected diaries were completed each week.

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Jamison et al. (2001)	N = 36 Age = 42.1 mean Gender = 45% female Race = not provided Education = 100% with high school diploma Disorder = chronic low back pain Country = USA	Longitudinal comparative study: 20 participants used both EDs and PDs; 16 used PDs only. Duration = 1 yr. Monetary incentives = No	Palmtop computer using Apple Newton MessagePad 100 (Cupertino, CA) with 2-way messaging features. Participants are requested to initiate at least one measurement per day, with no reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 89%. Compliance rate for PDs = 55.9%. Participants who used EDs monitored their pain an average of 261.1 days over 1 year; those who used PDs monitored their pain an average of 46.2 days over 1 year.
Jamison et al. (2006)	N = 21 Age = 42 mean Gender = 42.9% female Race = not provided Education = 100% with high school diploma Disorder = chronic low back pain Country = USA	Longitudinal comparative study using EDs daily versus weekly telephone interview. Duration = 1 yr. Monetary incentives = No	Palmtop computer using Apple Newton MessagePad 100 (Cupertino, CA) with 2-way messaging features. Participants are requested to initiate at least one measurement per day, with no reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Participants completed EDs an average of 7.8 times per week over 1 year. Pain ratings between recalled weekly pain and daily pain via EDs were in high agreement (p<.001)
Litcher-Kelly et al. (2004)	N = 66 Age = 51 mean Gender = 84.9% female Race = 93.9% white Education = not provided Disorder = chronic arthritis pain Country = USA	Longitudinal momentary pain study to examine relationship between pain intensity and sensory characteristics, affective qualities, and activities limited by pain. Duration = 2 weeks. Monetary incentives = No	Palmtop computer using Sony Clie (Japan) with pre-programmed multiple random alarms for multiple measurements (3, 6, or 12 times) per day. Other system specifications not provided.	Compliance rate for EDs = 94%. Participants took an average of 2 minutes to complete EDs.
Palermo et al. (2003)	N = 60 Age = 12.3 mean Gender = 70% female Race = 66% white Education = elementary to high school Disorder = chronic headache and juvenile idiopathic arthritis pain Country = USA	RCT comparing EDs and PDs in children, examining issues of compliance, accuracy, and acceptability. Duration = 7 days Monetary incentives = Yes	Palmtop computer using Hewlett Packard Jornada 548 with 1 preset measurement (evening), and with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 83.3% completed all 7 days, versus 46.7% for PDs. Accuracy rate for EDs = 100% (no errors or omissions), versus 5.3% for PDs. Acceptability rate for EDs = 83.3% found EDs very easy or easy to remember to fill out, versus 53.3% for PDs. 61.1% of ED group very much liked the diary presentation, versus 33.3% of the PD group.

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Peters et al. (2000)	N = 80 Age = 40.6 mean Gender = 78% female Race = not provided Education = 43% with trade school/business Disorder = chronic pain Country = Netherlands	Longitudinal measurement of pain, disability, and psychological adaptation. Duration = 4 weeks. Monetary incentives = Yes	Palmtop computer (brand not specified) with 4 preset, random measurements between 0800 and 2130 hours, and with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 88%. Participants took an average of 5 minutes to complete each ED entry.
Quilty et al. (2017)	N = 30 Age = 44 mean Gender = 70% female Race = 90% white Education = 43% completed post-secondary education Disorder = Mood disorders (Depressive disorder and Bipolar disorder) Country = USA	Prospective study to examine relationship between affective states, desire to gamble, and gambling behavior in adults diagnosed with depressive disorder or bipolar disorder. Duration = 30 days Monetary incentives = Yes	Palm One Zire 22 (PDA) with software pre-installed. PDA beeped at random times 3 times per day. Ten questions on desire to gamble, gambling activity, motivation for gambling etc. were asked. If questions not completed within 5 minutes, data was considered missed. A maximum of 2700 PDA entries could be collected during the study.	Compliance rate for EDs = 73.1 PDA responses were either labeled as missed or lost due to PDA malfunction leaving 1,969 valid diary entries.
Roelofs et al. (2004)	N = 40 Age = 46.4 mean Gender = 57.1% female Race = 100% white Education = not provided Disorder = chronic low back pain Country = Netherlands	Longitudinal assessment of relationship between pain-related fear, attention to pain, and pain intensity in daily life. Duration = 1 week Monetary incentives = Yes	Palmtop computer using Palm OS (Santa Clara, CA) with 8 preset random measurements per day between 0800 and 2000 hours, with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 76.4%. Most commonly cited reason for not completing entries: inopportune timing. None of the participants stated that they could not complete EDs due to their back pain.
Schondube et al. (2017)	N = 63 Age = 23.5 mean Gender = 66.67% female Race = Not reported Education = all participants were university students Disorder = self-control strength and physical exercise Country = Germany	Electronic diary study to look at association between self-control strength and physical exercise in individuals who exercise regularly. Duration = 20 working days (Monday-Friday) Monetary incentives = Yes	Google Nexus 5: LG - Seoul, South Korea) using the app "movisenseXS." Four random measurement points per day an alarm prompted participants to complete an entry. It random alarms occurred within 4 pre-programmed time periods: morning (9:30 am-10:30 am), midday (12:30-1:30pm), evening (4:30-5:30 pm), and bedtime (10:00-11:00 pm). Participant could decline an entry or delay for up to 20 minutes.	Compliance rate for EDs = compliance rate was 86.75% producing an average of 17 out of 20 entries per participant.

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Stinson et al. (2006)	N = 20 Age = 13.55 mean Gender = 80% female Race = not provided Education = elementary to high school Disorder = juvenile idiopathic arthritis pain Country = Canada	Two-phase qualitative usability testing with semi-structured interviews and observation. Duration = one-time Monetary incentives = No	Palmtop computer using Tungsten W, Palm OS. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	All participants reported that EDs were "very easy to learn" and "very easy to use". Participants in phase one voiced difficulties with technical aspects of EDs ("tricky to use" and "too touchy" slider). Changes to address above were made prior to Phase 2, no further problems with ease-of-use were noted. Participants took an average of 9 minutes to complete ED entry, and voiced satisfaction with using EDs (i.e., "really cool", "just liked using it", and "better than just getting a book full of blank paper and writing down about our pain each day"). 80% of participants agreed to pilot EDs at home for a 2-week period.
Stone et al. (2003a)	N = 91 Age = 50.9 mean of 4 sample groups Gender = 85.2% female Race = 93.9% white Education = 33.6% college graduate Disorder = chronic pain Country = USA	Longitudinal, randomized study with control group to determine relationships between momentary monitoring of pain and pain levels over time and assess participants' compliance and reactions to EDs. Duration = 2 weeks. Monetary incentives = Yes	Palmtop computer using Sony Clie with multiple preset random measurements (3, 6, or 12 depending on randomization) per day, with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 94%. Almost all, even those who received 12 alarms per day, stated that they did not have difficulties with using EDs, and would participate in a similar study in the future if asked.
Stone et al. (2003b)	N = 80 Age = 43 mean Gender = 47% female Race = 90% white Education = 38% with high school diploma Disorder = chronic pain Country = USA	Longitudinal comparative study of patient compliance in samples assigned to PD or ED group. Duration = 3 weeks Monetary incentives = Yes	Palmtop computer using Palm OS (Santa Clara, CA) with 3 preset measurements (1000, 1600, and 2000 hours) per day, with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed. PDs were a DayRunner Organizer with unobtrusive instrumentation that detects when the diary was opened and closed.	Compliance rate for EDs = 94%. Reported compliance rate for PDs = 90%; actual compliance rate for PDs = 11%. PDs were not opened on almost 1/3 of all study days, however, diary entries were completed for these days. 75-80% of PDs entries were falsified.
Suveg et al. (2009)	N = 38 Age = 9 mean Gender = 51% male Race = 79% Caucasian Education = School-age children; 33% had household income between \$40,000-\$59,000 Disorder = Emotional states of youth Country = USA	Feasibility study to see if EDs are a feasible method of monitoring emotional states in school-age children. Duration = 1 week. Monetary incentives = Yes	Palm Tungsten E2s, 4 measurements per day (between 4 and 8pm to avoid school conflicts) via randomly programmed prompts. Prompts unanswered after 20 min were considered missing.	Compliance rate for EDs = 60% of the total responses were considered valid, 30% were participant error, and 10% were technical errors.

Author (year)	Sample	Study design / aim	ED system specifications	Compliance and/or usability results
Turner et al. (2005)	N = 126 Age = 39.3 mean Gender = 88.1% female Race = 86% white Education = 39.7% with some college Disorder = TMD pain Country = USA	RCT to evaluate short-term efficacy of brief cognitive-behavioral therapy versus education/attention control using EDs. Duration = 8 weeks. Monetary incentives = Yes	Palmtop computer using Palm OS (Santa Clara, CA) with 3 measurements (morning, afternoon, and evening) per day predetermined by participants with reminder alarms. Each question must be completed before proceeding to the next one. Participants cannot return to previous question once completed.	Compliance rate for EDs = 90%. Use of EDs in studying outcome and process variables in chronic pain intervention trials is feasible.
Williams et al. (2004)	N = 14 Age = 46.5 mean Gender = 93% female Race = 86% white Education = 72% with some college or completed college Disorder = fibromyalgia syndrome Country = USA	Pilot feasibility study of using EDs to assess clinical pain in fibromyalgia syndrome. Duration = 12 weeks. Monetary incentives = Not reported	Palmtop computer (Palm OS) with 4 - 6 preset, random measurements per day, and with reminder alarms. Other system specifications not provided.	Compliance rate for EDs = 85%. Participants took at most 3 minutes to complete each ED entry.
Williams et al. (2015)	N = 59 Age = 47.71 mean Gender = 88% female Race = 76% white Education = not reported; 85% employed and 54% reported household income > \$50,000/year Disorder = being overweight or obese Country = USA	Randomized pilot study to test recommending a self-paced exercise program in overweight adults. Duration = 6 months Monetary incentives = Not reported	Handheld device (HP iPAC 111) to complete the diary. Participants were asked to report in real time when they began and ended a session of walking for exercise. Each morning, they were asked if they exercised the previous day and if so, had they reported it in real time.	Compliance rate for EDs = Participants completed 87% of the daily morning reports over the 6-month period. 81% of the exercise reported on morning reports was also recorded in real time.

Implications of Using EDs in Healthcare Research and Practice

The review of literature revealed a homogeneous participant population that lacked diversity. The majority were white, female, and in the studies including adults, had at least a high school diploma or college; hence, the need to recruit a more diverse population related to gender, race, education level, for future studies in order to increase generalizability. Although there have been older studies involving EDs in monitoring compliance in various clinical trials, the ED system used at the time did not have the same capabilities and lacked the adherence-enhancing features that were constructed in more current ED vehicles. Furthermore, out of the 30 research studies reviewed, all but six involved adult participants. Electronic diaries have the potential to be used on children with various chronic illnesses such as inflammatory bowel disease, cystic fibrosis, and cancer, but will need further study and application.

Although EDs have been primarily used in research, this technology also has implications for clinical practice. For example, EDs can be designed as part of an interactive algorithm that logically leads the user to appropriate interventions depending on the entries submitted. Proliferation of positive study findings related to the use of EDs, along with demonstrated use in practice, are mandatory to propel diffusion of this innovation across a variety of healthcare settings.

Increased Application of ED

In order to expand usage and fully implement EDs, vendors must continue to enhance the capabilities of the system to promote compliance and achieve quality data. Palmtop computers, tablets, or smartphones to be used as vehicles for EDs must be designed with the end-user in mind; therefore, intuitiveness in their navigation must be carefully planned. This is where user feedback plays a critical role in continuous product development. Furthermore, since the small screen and use of the stylus have been identified as barriers in using EDs, technology options may be widened to accommodate mobile devices and personal computers (PC) that have larger monitors and a navigable mouse for those with sensory and mobility deficits. Participants can be given a username and password to access a secure website to enable them to complete EDs similar to the other smaller devices noted above. The primary drawback in this approach is the PC's lack of portability.

Future Directions and Conclusion

Compared to PDs, EDs yield more comprehensive, valid and reliable data that can help inform the patient and clinician's decision-making process in treatment initiation and evaluation. Additionally, EDs are easy to use, especially as new technologies continue to emerge and previous product iterations are refined. There are a few potential issues to consider if EDs are to be used in research and clinical areas. These include costs related to purchase, installation, monitoring, maintenance, and repairs of EDs, as well as risks of malfunction or failure, which translate to lost data.

The future for EDs is rich in terms of their application in research and practice. Future research in EDs must include a diverse group of populations and health conditions. There is also a need to promulgate the use of EDs beyond the research arena. Electronic diaries can be integrated into health activities that promote well-being and prevent disease. The ultimate goal is to use EDs as one step in an iterative cycle of informed decision-making by both patients and clinicians.

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Baccalaureate Nursing Students' Attitudes Toward Evidence-Based Practice: A Longitudinal Study

Linda M. Thiel & Arthur Ko

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Correspondence to:

Linda M. Thiel
thiellm@udmercy.edu

Authors' Affiliation

Linda M. Thiel, OP, PhD, RN
Faculty, McAuley School of
Nursing
University of Detroit Mercy,
Detroit, MI

Arthur Ko, PhD, RN
Faculty, Graduate School
University of Detroit Mercy,
Detroit, MI

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Abstract

Introduction: Evidence-based practice (EBP) is well recognized as an essential standard of care for healthcare professionals. As a core competency, schools of nursing are expected to graduate students ready to provide evidence-based care to patients, families, and communities. Integration of EBP competencies in nursing curricula is an expectation. One aspect of student preparation is the progression toward positive attitudes pertaining to evidence-based practice.

Objectives: This descriptive longitudinal study presented an approach for assessing students' EBP attitudes, at the start of program (freshman) and end of program (senior), in a pre-licensure BSN program in an accredited school of nursing located in Midwest United States.

Methods: A descriptive longitudinal survey was conducted to assess pre-licensure BSN students' attitudes pertaining to EBP. Data were collected from the same cohort of students at two time periods. First survey data were gathered from freshman level students in 2014 and follow-up survey data from senior level students in 2017. Participant selection was based on purposive sampling. Descriptive and inferential statistics were used to analyze first and follow-up survey data.

Results: One hundred twenty one students participated in the longitudinal study. Sixty-three students participated as freshman and 58 as seniors. Freshman participants' attitudes toward EBP were 'uncertain' as the overall mean score was 3.6. This mean score tended toward positive EBP attitudes (positive EBP attitude = 4.0 to 5.0). There was a significant difference between attitudinal mean scores of freshman and seniors ($M = 50.11$, $M = 56.25$, $p < 0.001$).

Conclusions: The longitudinal study reported first survey and follow-up survey EBP attitudinal data of pre-licensure BSN students. At program end, there was a significant change in attitudinal scores. As it is important to measure EBP program outcomes related to EBP attitudes, the researchers of this study have recommended interventions such as: a) Collection of EBP data at start-of-program, mid-program, and end-of-the program; after graduation and in the workplace; b) Utilize data to drive course and curricular evaluation and revision; and c) Collaborate with other schools of nursing and disciplines in developing external EBP benchmarks.

Keywords: evidence-based practice; attitudes; pre-licensure BSN students; longitudinal research

Background

Evidence-based practice (EBP) is an effective decision-making process which incorporates the best available research. Sackett et al (1996) defined EBP as “the conscientious, explicit and judicious use of current best evidence in making nursing decisions about the care of individual patients.” (p. 71). One of the strong emphases on EBP by Sackett and colleagues was on integration of best research evidence with clinical expertise and patient values.

Educating student nurses to be prepared to be utilizers of EBP has been strongly emphasized in the nursing programs. In academia, EBP program alignment and program outcomes are well known (AACN, 2010; Institute of Medicine (IOM), 2011; Mazurek-Melnyk, Gallagher-Ford, English-Long & Fineout-Overholt, 2014; Stevens, 2013). The American Association of Colleges of Nursing (AACN) document, *Essentials for Baccalaureate Education, Essential III*, (AACN, 2008) directs Baccalaureate schools of nursing to incorporate core EBP content in curricula. Additionally, the global Quality and Safety Education for Nurses (QSEN) project articulates six competencies directed toward nursing education to prepare students in matters of patient safety and quality in the practice setting, one of which is EBP (AACN, 2010; Dolansky & Moore, 2013).

EBP has been elevated as an essential for schools of nursing (AACN, 2008), and schools of nursing have responded. Nursing scholars have clearly articulated EBP competencies to guide programs of nursing (Stevens, 2009; Mazurek-Melnyk, Gallagher-Ford, English-Long, & Fineout-Overholt, 2014) and educators have responded positively to the imperative with ongoing expansion of EBP program indicators and expansion of course content (Bloom, Olinzoch, Radjenovic, Trice, 2013; Finotto, Carpanoni, Turrone, Camellini, Camellini, Mecugni, 2013; Stiffler, Cullen, 2010; Mouch, Cronje, Branson, 2010). Despite the elevation of EBP as an essential, EBP curricular alignment and content expansion, the assessment of students' EBP attitudes has rarely been published in the nursing literature. Measuring EBP indicators of achievement, such as students' attitudes toward EBP during a program of study is beneficial, as it allows educators to direct strategies to ensure EBP curricular outcomes are met and students are prepared to enter the EBP workplace upon graduation.

Literature

A literature search of studies written between January 2000 and June 2015 directed toward nursing students' attitudes toward EBP was conducted by the researchers of this study. The CINAHL and Pubmed databases were used along with the keywords, ‘nursing students attitudes toward EBP’, and ‘EBP literature review.’ Few studies addressing nursing students' attitudes toward EBP were found (Brown et al., 2010; Llasus et al., 2014). Common areas of interest among the

studies were EBP attitudes (EBP skills, knowledge, skills or competency), and current and future intent to use EBP. Brown and colleagues (2010) examined EBP perspectives among 436 BSN nursing (sophomore, junior, senior) students at two universities in California. The study examined source of EBP, knowledge, attitudes, and use (current and future) of EBP. Their findings indicated EBP knowledge and attitudes toward EBP mean scores “increased from sophomore to junior levels but declined slightly in the senior year.” (p. 524). Preparedness was found to be a predictor of EBP knowledge; however, predictor variables for attitudes toward EBP did not reach statistical significance. Students with high confidence in clinical decision-making and clinical preparedness were found to most likely use EBP and intended to use it in the future. Florin and colleagues (2012) conducted a “cross-sectional” study to examine capability beliefs (ability to engage/knowledge) regarding EBP skills among nursing students (n = 1440) in their final semester before graduation at 26 universities in Sweden. Findings indicated a high level of capability beliefs; however, there were large differences between universities regarding some skills, such as stating research questions and seeking relevant knowledge. Overall, students felt adequately prepared for EBP. A study conducted by Llasus et al. (2014) examined 174 graduating BSN students' actual EBP knowledge, self-perceptions of EBP readiness and EBP implementation. They found that even though students had a higher than average readiness score, EBP knowledge scores were low. Confidence to implement EBP was found to be less than adequate. Findings from these studies indicate variance in EBP knowledge, beliefs, and skills (competence) between sites.

Currently there is a gap in the literature on BSN pre-licensure students' attitudes toward EBP (e.g., knowledge, beliefs, skills or competencies) as there are few studies, despite the articulation of its importance. It is vital for nursing schools to examine students' attitudes toward EBP, so that educators can evaluate EBP program outcomes, assess students' level of progression, and consider curricular changes that could improve student EBP attitudes in undergraduate nursing curricula.

The conceptual framework used in this study was a modified version of the knowledge-to-action process presented by Graham and colleagues (2006) and the premise that translation of EBP to the workplace begins at the onset of a nursing program.

Purpose

The purpose of this longitudinal study was to assess BSN pre-licensure students' attitudes toward EBP. The research question for this study was: What are the attitudes toward EBP of pre-licensure BSN students at start of program (freshman level) and end of program (senior level)? In this

study, the concept attitudes toward EBP, was defined as the overall belief, skills, and knowledge one holds about EBP. Measurement over time was operationalized as fall semester of freshman year (2014) and winter semester of senior year (follow-up, 2017).

Method

Study Design and Sample

A descriptive longitudinal survey was conducted to assess students' attitudes toward EBP overtime. The same cohort of students was surveyed as freshman in 2014 (first survey) and as seniors in 2017 (follow-up survey). The population included approximately 600 BSN pre-licensure students in a private, Commission on Collegiate Nursing Education (CCNE) accredited program. In 2014, the available population to the researchers included a total of 75 freshman level nursing students. Sixty-three students participated in the first survey. The same freshman cohort was resurveyed as seniors in 2017 (follow-up survey). Seventy senior level students were invited to participate. Fifty-eight seniors participated in the follow-up survey. Participant selection was based on purposive sampling. The eligible participants were: 1) full-time or part-time nursing students enrolled in the university, 2) freshman level students enrolled in the BSN pre-licensure program in fall of 2014 and 3) senior level students enrolled in the BSN pre-licensure program in winter of 2017.

Data were collected from eligible students at the end of the class period. The course professor (who is one of the study researchers) invited students to participate; however, was not present during the distribution, completion and collection of the surveys.

Procedure and Ethical Consideration

Study participants consisted of nursing students enrolled in a CCNE accredited, private university located in Midwest United States. The survey included a cover letter, which explained the voluntary nature of the study, along with the purpose and anonymity of responses from participants. One of the faculty researchers explained the purpose of the study, in addition to providing participants with an opportunity to ask questions. Participants were informed that participation or lack of participation in the study would not impact their grades or status at the university. After explaining the purpose of the study and responding to participants' questions. Student volunteers distributed and collected the completed questionnaires. To reduce the possibility of bias, the faculty researcher was not present in the room during completion or collection of the questionnaires. Participants completed the survey within the 10-minute time period. Monetary incentives were not provided to participants in the study. All returned surveys were placed in a locked cabinet. Only one researcher (faculty) had access to a private password protected computer. SPSS software was

used to upload the completed data. The study was granted institutional review board (IRB) approval at the university where it was conducted. Respondents' implied consent to participate in the survey was granted upon the respondents' completion of the survey.

Survey Instrument

The 18 first survey contained three demographics (i.e., age, gender, program of study) and one EBP characteristic (i.e., familiarity with the term EBP) (see Table 1) in addition to the 14-item Nurses' Attitudes Toward Evidence-Based Practice Scale (NATES©) tool (Thiel & Ghosh, 2008). The follow-up survey contained three demographics (i.e., age, gender, program of study) and two EBP characteristics (i.e., familiarity/competency with EBP, comfort in using EBP at the bedside) items (see Table 1) in addition to the 14-item NATES tool. Psychometrically, the 14-item NATES tool measures attitudes and consists of two domains, or subscales. These domains include beliefs and behaviors (i.e., skills and knowledge) toward EBP, which is conceptually categorized as attitudes. Participants rated their level of disagreement and agreement with each item on a 5-point Likert rating scale (strongly disagree=1, strongly agree=5), resulting in a summative score between 14 and 70 points; higher scores indicated a more positive attitude toward EBP. All negatively stated questions in the NATES© tool were reverse coded. The NATES© reliability (Cronbach's alpha 0.80 to 0.93) and validity have been previously reported (Thiel & Ghosh, 2008). The developers of the NATES have received feedback from faculty in academic settings indicating the usefulness of the NATES instrument in classroom settings with BSN pre-licensure students, even though the tool was developed initially for use with registered nurses.

Analysis

Statistical data entry and analysis was completed using the IBM® Statistical Package for Social Scientists® (SPSS, version 23.0) software. The researchers calculated the percentage of respondents completing the survey (return rate). The first survey's return rate was 84%. The follow-up survey's return rate was 83%. As the completion rate was high (>90%) for each survey, all cases were included in the data analysis. Descriptive statistics were computed for all study variables. Frequency and percentage were generated for nominal and ordinal level data, and means and standard deviations for interval (continuous) level data. The researchers used the NATES© tool to determine students' attitudes toward EBP. Inferential statistics (t-test) were generated to compare attitudinal mean score differences between first survey and follow-up survey data. Internal consistency (reliability) was assessed using Cronbach's alpha. An alpha of 0.80 or greater was desirable as an alpha <0.80 limits interpretation of findings (Nunnally & Bernstein, 1994). P-values less than 0.05 were considered as statistically significant.

Results

Demographic and EBP Characteristics

One hundred twenty one nursing students participated in the longitudinal study. The demographic characteristics of both surveys are presented in Table 1. Out of the 75 freshman students invited to participate, 63 participated (84% return rate). The typical freshman respondent was female (85.7%, n = 54) and 19 years (73%, n = 46) of age. The mean age of participants was 21 years (SD = 6.90) and ranged between 18 and 48 years. Nearly 50% (47.6%, n = 30) of the freshman participants indicated they were “somewhat” familiar with the term EBP, and 17.5% (n =11) reported being ‘very’ familiar. Only one respondent indicated having no familiarity with the term EBP.

At follow-up, 70 seniors were invited to participate in the study. Fifty-eight seniors participated (83% return rate). The typical respondent was female (93%, n=53) and 22 years of age (63.4%, n=35). The first survey’s EBP demographic item, ‘Familiarity with EBP’, was revised for the follow-up survey. The researchers decided to revise the item to obtain more substantive information from the senior level participants. As students had progressed from the freshman to senior year, information regarding EBP competences related to standards for BSN graduates was needed. The revised item asked, “Are you familiar with the term EBP? Five options with descriptors were offered and respondents were asked to ‘select all that apply’. Three of the options addressed EBP competency progression (see Table 1). Nearly 75% (75.8%) of senior participants indicated being able “...to routinely apply EBP in clinical decision making when working at the bedside (direct patient care).” Due to the longitudinal nature of the study and establishing end-of-program benchmarks, one item was added to the EBP demographic portion of the follow-up survey: “On a scale, from 0 (not at all) to 10 (completely), how comfortable are you in using EBP at the bedside?” The mean was 7.22 (SD=1.57).

	First (2014) (n=63) % (n)	Follow-up (2017) (n=58) % (n)
Age (years)	M=21, SD=6.90	M=22.6, SD=4.75
<20	84 (53)	0 (0)
21-30	9.6 (6)	94.5 (52)
31-40	(0)	5.4 (3)
41 - 50	6.4 (4)	1.8 (1)
Gender		
Male	14.3 (9)	7 (4)
Female	85.7 (54)	93 (53)
Program of Study		
BSN	100 (63)	100 (58)
Familiarity with the term EBP		
1. “Not” familiar with the term EBP	1.6 (1)	
2. A “little” familiar with the term EBP	33.3 (21)	
3. “Somewhat” familiar with the term EBP	47.6 (30)	
4. “Very” familiar with the term EBP	17.5 (11)	
Familiarity/competence with EBP (item was revised based on the first survey)		
1. No, I have not heard the term EBP		0 (0)
2. Yes, I have heard the term EBP but I’m not clear about what it is.		0 (0)
3. Yes, I’m familiar with the term EBP and can teach another student about EBP		43 (25)
4. Yes, I’m familiar with the term EBP and can correctly select the best evidence to include in my written nursing assignments		62 (36)
5. Yes, I’m familiar with the term EBP and can routinely apply it in clinical decision-making when working at the bedside (direct pt. care).		75.8 (44)
Comfort in Using EBP at the Bedside		M=7.22 (SD=1.57)

Attitudes toward EBP

Respondents' attitudes were assessed using the 14-item Nurses' Attitudes Toward Evidence-Based Practice Scale (NATES©) tool summative scores on the 5-point scale could range between 14 and 70 points. The same NATES tool was used for both surveys. No revisions or modifications were made to the NATES tool.

Freshman (first survey) attitudinal scores (NATES) ranged between 38 and 70 with summative mean of 50.11 (SD = 6.61) and a statistic mean score of 3.60 (on a 1-5 interval level scale) (see Table 2). When asked if they have "enough knowledge to engage in EBP" (item # 6), 6.3% (n=4) 'strongly disagreed', 17.5% (n=11) 'disagreed', and 46.0 % (n=29) 'neutral/uncertain'. When asked "EBP ignores the holistic aspect of nursing" (item 8), 50.8% (n=32) of freshman respondents selected the 'neutral/uncertain' option. Descriptive statistics revealed that many freshman participants scored items as 'neutral/uncertain'. The selection of the option 'neutral/uncertain' for the NATES ranged between 14.3% and 50.8%.

Senior (follow-up survey) summative NATES actual scores ranged between 42 and 70 with a mean of 56.25 and a statically mean score of 4.01 (on a 1-5 interval level scale) (see Table 2). When asked if they have "enough knowledge to engage in EBP" (item # 6), 0% (n=0) 'strongly disagreed'; 5.3% (n=3) 'disagreed', and 22.8 % (n=13) 'neutral/uncertain'. When asked, "EBP ignores the holistic aspect of nursing" (item 8), 17.5% (n=17) of respondents selected the 'neutral/uncertain' option. The selection of 'neutral/uncertain' ranged between 0% (n=0) and 24.6% (n=14). The frequency of 'neutral/uncertain' section decreased from 2014 (freshman participants, first survey) to 2017 (senior participants, follow-up survey).

The attitudinal (NATES) mean score difference between the freshman (first survey) (Mean=50.11, SD=6.61) and seniors (follow-up survey) (Mean=56.25, SD=6.11) was found to be statistically significant ($p < 0.001$). Cronbach's alpha for the NATES tool in this study was 0.85; first survey 0.86, follow-up survey 0.83.

Table 2. Percentage, Frequency and Mean Scores for Each 14 Items From at First Survey (2014) and Follow-up Survey (2017).

Attitudes	Strongly Disagree	Disagree	Neutral / Uncertain	Agree	Strongly Agree	Mean (SD)
	% (n) First Follow-up	% (n) First Follow-up	% (n) First Follow-up	% (n) First Follow-up	% (n) First Follow-up	First Follow-up
1. EBP...fad and will pass with time ^a	27 (17) 59.6 (34)	42.8 (27) 38.6 (22)	27.0 (17) 0 (0)	1.6 (1) 0 (0)	1.6 (1) 1.8 (1)	3.92 (0.86) 4.54 (0.63)
2. I believe in EBP	1.6 (1) 1.8 (1)	1.6 (1) 0 (0)	15.9 (10) 0 (0)	49.2 (31) 40.4 (23)	31.7 (20) 57.9 (33)	4.07 (0.86) 4.52 (0.68)
3. EBP disregards clinical experience ^a	4.8 (3) 19.3 (11)	57.1 (36) 54.4 (31)	34.9 (22) 19.3 (11)	3.2 (2) 3.5 (2)	0 (0) 3.5 (2)	3.63 (0.62) 3.82 (0.90)
4. ...EBP will help me provide quality nursing care	0 (0) 3.5 (2)	1.6 (1) 1.8 (1)	14.3 (9) 1.8 (1)	55.6 (35) 47.4 (27)	28.5 (18) 45.6 (26)	4.11 (0.69) 4.29 (0.88)
5. EBP ignores the 'art' of nursing ^a	4.8 (3) 14.0 (8)	46.0 (29) 54.4 (31)	41.3 (26) 24.6 (14)	7.9 (5) 7.0 (4)	0/0 0/0	3.47 (0.71) 3.75 (0.78)
6. I have enough knowledge....	6.3 (4) 0/0	17.5 (11) 5.3 (3)	46.0 (29) 28.8 (13)	28.6 (18) 54.4 (31)	1.6 (1) 17.5 (10)	3.01 (0.88) 3.84 (0.77_)
7. I have enough access to resources...	1.6 (1) 0 (0)	15.9 (10) 1.8 (1)	36.5 (23) 12.3 (7)	36.5 (23) 64.9 (37)	9.5 (6) 21.1 (12)	3.36 (0.92) 4.05 (0.62)
8. EBP ignores the holistic aspect of nursing ^a	7.9 (5) 15.8 (9)	36.5 (23) 54.4 (31)	50.8 (32) 17.5 (10)	4.8 (3) 10.7 (6)	0 (0) 0 (0)	3.47 (0.71) 3.76 (0.85)
9. Previous nursing experience is more important.... ^a	5.3 (4) 10.5 (6)	33.3 (21) 49.1 (28)	44.9 (27) 22.8 (13)	17.5 (11) 15.8 (9)	0 (0) 1.8 (1)	3.28 (0.83) 3.50 (0.94)
10. Nursing is about people...not statistics ^a	12.7 (8) 21.1 (11)	50.8 (32) 70.2 (40)	25.4 (15) 7.0 (9)	11.1 (7) 1.8 (1)	0 (0) 0 (0)	3.65 (0.84) 3.96 (0.84)
11. I have enough skill to engage in EBP.	1.6 (1) 0 (0)	20.6 (13) 1.8 (1)	41.3 (26) 21.1 (12)	34.9 (22) 68.4 (39)	1.6 (1) 8.8 (5)	3.14 (0.82) 3.84 (0.59)
12. EBP ignores patient values ^a	1.1 (7) 21.1 (12)	54.0 (34) 59.6 (34)	28.6 (18) 10.5 (6)	6.3 (4) 8.8 (5)	0 (0) 0 (0)	3.69 (0.75) 3.96 (0.84)
13. Using EBP increases certainty...meeting outcomes	0 (0) 0 (0)	3.2 (2) 8.8 (5)	31.7 (20) 10.5 (6)	54.0 (34) 56.1 (32)	11.1 (7) 24.6 (14)	3.73 (0.70) 3.96 (0.84)
14. It is importantfacility utilizes EBP...	0 (0) 0 (0)	3.2 (2) 7.0 (4)	27.0 (17) 0 (0)	50.8 (32) 54.4 (22)	19.0 (12) 38.6 (22)	3.85 (0.75) 4.24 (0.78)

^aNegatively written item score was reverse coded

Discussion

The restructuring of healthcare toward an evidence-based practice (EBP) milieu pervades health systems and academic settings. Ensuring nurses graduate with positive attitudes toward EBP has been frequently articulated and elevated to core competencies and program outcomes (IOM, 2003; Stevens, 2009; Mazurek-Melnyk et al., 2014) therefore, assessment of students' EBP attitudes at baseline and periodically prior to graduation is needed to ensure graduates are prepared for the EBP healthcare arena.

This longitudinal study confirmed the benefit of assessing nursing students' EBP attitudes at two points in time, program onset and program end. Our findings establish EBP attitudinal data for nursing students in the first semester (freshmen) and last semester (senior) of study. Results indicate students' attitudes toward EBP (using NATES) significantly increased over time. The first survey's (freshman) attitudinal mean score of 3.60 (neutral/uncertain category) was not surprising, as the study participants did not have previous classroom EBP content. The frequency of participants selecting the 'neutral/uncertain' option in each NATES item decreased from the first survey to the follow-up survey. The follow-up survey suggest senior students are engaged in EBP decision making and activities at the bedside during the senior year; however, there is opportunity for further growth in this area, as 24% of the seniors are not involved in this activity. Additionally, senior participants' comfort level in using EBP at the bedside requires further attention and study (rating of 7 out of 10). The brevity of the instrument (approx. 5 minutes to complete) lessened the likelihood of survey-fatigue and lack of missing data, and the response rates of 84% (first survey) and 83% (follow-up survey) may have positively impact user response validity. The reliability (Cronbach's alpha, internal consistency) for the NATES in this study was good (Nunnally & Bernstein, 1994), and may be considered for future studies with student nurses.

Limitations and Generalizability

As nonprobability (purposive) sampling was used, selection bias was a concern in this pilot study. Consecutive sampling would have ensured a more representative sample. As with any self-administered survey, validity issues pertinent to item interpretation and response bias exists. The NATES© tool has limited use with nursing students and therefore further psychometric analysis with students is needed. Caution must be taken in generalizing the findings beyond this study as it is not representative of the larger population and is not amenable to generalizability.

Future Research

Further research is needed to expand the assessment/evaluation strategies of nursing students' attitude toward EBP and its application and relationship to EBP program outcome criteria. Longitudinal studies are needed to determine

nursing students' EBP attitudes throughout a program of study; start-of-program, mid-program, and upon graduation. In addition to determining students' attitudes toward EBP (perceptions), future research needs to include students' actual EBP knowledge and EBP competencies. Additionally, frameworks such as the Ace-Star Model (Stevens, 2009) can be incorporated into future EBP readiness studies. There is also a need to develop national and global benchmarks among and between schools of nursing. Further studies need to be conducted using a national sample (i.e., various U.S. regions) to determine the state of attitudes toward EBP in US nursing students.

Recommendations

This descriptive longitudinal study offers an approach to measuring the attitudinal dimension of EBP during a program of study in an accredited school of nursing located in the Midwest United States. Recommendations for measuring attitudinal-EBP from baseline to program completion are offered.

- Decide on concept measures: a) EBP attitudes b) EBP actual knowledge c) attitudes and knowledge
- Select an instrument with established reliability and validity. Validity of $\geq .80$ for an established tool and $\geq .70$ for a new tool;
- Consider survey-fatigue when developing or selecting a tool.
- Conduct a baseline assessment for the establishment of internal benchmarks for ongoing measurement.
- Other Considerations:
 - Utilize attitudinal data to drive course and curricular evaluation and revision
 - Incorporate EBP attitudinal (knowledge, skills, and beliefs) data to enhance the teaching-learning process (formative and summative evaluation)
 - Collaborate with other schools of nursing in developing external EBP-attitudinal benchmarks
 - Collaborate with other disciplines and institutions in developing processes to evaluate EBP program outcomes.

Conclusions and Implications

Achieving positive attitudes toward EBP prior to graduation is an expectation throughout nursing and healthcare programs. Although EBP as a core competency and program outcome has gained attention among nursing administration, faculty and curriculum committees, the literature is remiss in reporting approaches to measuring EBP program outcomes throughout a program of study. There is minimal available literature addressing EBP attitudes of BSN nursing students. EBP is an area of study that is a major focus in the healthcare industry in improving health outcomes. In line with this, it is important for educators to examine students' attitudes toward EBP during a program of study, so as to ensure the students are prepared to enter the workforce as competent providers of care based on EBP. Attitudinal data

allows for ongoing content and course refinement, benchmarking, and program evaluation and revisions.

Metrics have important implications for educators and curriculum or program developers who are in key positions to ensure student achievement of program outcomes pertaining to EBP. Faculty and curriculum committees must be equipped with evidence to assess students' EBP attitudes throughout a program of study and to ensure students are well prepared to enter the EBP workforce. The study contributes to the nursing literature in that it highlights the importance and value of assessing students' attitudes toward EBP at the start and end of a program of study.

The researchers of this study suggest strategies such as: a) Collection of EBP data throughout a program of study, such as mid-program; after graduation and in the workplace; b) Utilize data to drive course and curricular evaluation and revision; and c) Collaboration with other schools of nursing and disciplines in developing external EBP benchmarks.

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Caring and Cultural Diversity Behaviors of U.S. Nursing Students on A Study Abroad Program

Rita Marie Wi Mahmoud & Jenny Schuessler

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Correspondence to:

Rita Marie Wi Mahmoud
marierita83@yahoo.com

Authors' Affiliation

Rita Marie Wi Mahmoud, PhD,
RN, PMHCNS-BC
Assistant Professor
University of West Georgia
Tanner Health System School of
Nursing
Carrollton, GA

Jenny Schuessler, PhD, RN, CNE
Dean & Professor
University of West Georgia
Tanner Health System School of
Nursing
Carrollton, GA

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Abstract

Introduction: Investigators have assessed how US nursing students demonstrate caring behaviors and improve cultural understanding in the study abroad programs. However, sparse literature focusing on how US nursing students demonstrate caring and cultural diversity behaviors in a country other than US exists.

Objective: The purpose of this study was to describe the caring and cultural diversity behaviors of US nursing students studying abroad.

Methods: A descriptive exploratory cross sectional design with secondary analysis of data using purposeful sampling was employed. The data were comprised of 12 journal summaries and 12 clinical evaluation tools.

Results: Thematic analysis was used to analyze the data. Caring behaviors were categorized into self-caring and caring presence. Self-caring involves indoor and outdoor activities. Caring presence includes touching or holding hands, hugging or embracing, smiling, and helping. Cultural diversity behaviors were categorized into enhancing interactions, learning something new, and appreciating another culture.

Conclusion: Students were able to report caring and cultural diversity behaviors in a different environment. The study abroad programs may facilitate the students' appreciation of the universality of caring and cultural diversity. This study provides the foundation for future dialogue and inquiry about study abroad programs.

Keywords: *caring behaviors, cultural diversity behaviors, study abroad, secondary analysis, thematic analysis*

Introduction

Theorists and nurses support caring as a critical attribute of the nursing profession (Siviter, 2008; Smith, 2012; Wood, 2014). Caring serves as the conceptual framework for some nursing schools and is reflected in their philosophy, mission, and vision. For example, the faculty at South Florida State College (SFSC) developed the Seven C's of Caring. The Seven C's of Caring includes critical behaviors integrated throughout their educational programs and reflected in the mission and vision of the college (SFSC, n.d.). At another school, the University of West Georgia Tanner Health System (WGTHS) School of Nursing's caring philosophy is reflected in the course objectives as well as in selected course activities (WGTHS, 2012).

Cultural diversity is valued by the nursing profession, particularly because of the globalization in healthcare. In the US, nurses provide care for an increasing number of clients from other cultures (McClimens, Brewster, & Lewis, 2013). Recognizing the need to help students gain an understanding of global health issues and increase cultural competency, many schools of nursing have developed study abroad programs (Carpenter & Garcia, 2012; Dudas, 2012; Parker & Hyrkas, 2011).

Investigators have assessed how US nursing students demonstrate caring behaviors (Minnesota Baccalaureate Psychomotor Skills Faculty Group, 2008; Sitzman, 2010; Wilson & Grams, 2013). Investigators have found some evidence of improving cultural understanding in the study abroad programs (Anderson, Friedemann, Büscher, Sansoni, & Hodnicki, 2012; Edmonds, 2012). However, few have examined how nursing students demonstrate caring and cultural diversity behaviors in cultures and countries removed from their own. The purpose of this study was to describe the caring and cultural diversity behaviors of US nursing students studying abroad.

Background

Caring behaviors have been assessed quantitatively using various instruments in nursing education such as the Caring Behaviors Measurement (Lee-Hsieh, Kuo, Tseng, & Turton, 2005) and the Modified Caring Attributes Questionnaire (Jimenez et al., 2013). Investigators have assessed caring behaviors in China (Chen, Yen, Lin, Lee, & Lu, 2012; Ou & Lin, 2006), Iran (Khademian & Vizesfar, 2008), and Thailand (Udomluck, Tonmukayakul, Tiansawad, & Srisuphan, 2010). The most common nursing caring behaviors identified in the literature were a) being attentive to safety, b) providing comfort, and c) showing respect and sensitivity to the patients' cultural and spiritual beliefs (Dunnington & Farmer, 2015). Other investigators have focused on understanding theories in caring (Ranheim, Karner, & Bertero, 2012; Sumner, 2012) such as Watson's theory of human caring. Leininger (1988) developed the nursing theory of

cultural care diversity and universality which has a fundamental goal to provide culturally competent nursing care to patients and families.

Many investigators have combined looking at caring and cultural competence in nursing (Canales & Bowers, 2001; Leininger, 2002; Shapiro, Miller, & White, 2006). Investigators who examined cultural diversity behaviors and transcultural theories have emphasized the need to integrate cultural education in the curricula. Providing care to the patients and being culturally competent are linked together (Ayaz, Bilgili, & Aken, 2010; Hall, Guidry, McKyer, Outley, & Ballard, 2014; Mareno & Hart, 2014). A common goal to be a caring and culturally competent nurse is being able to connect to the patients. From an educational perspective, a major focus of study abroad programs is fostering an increased appreciation for cultural diversity (Bohman & Borglin, 2014; Carpenter & Garcia, 2012; De Natale, & Waltz, 2015; Kokko, 2011). Edmonds (2012) has found that most of the existing research on nursing study abroad programs used quantitative methods and samples comprised of non-American nursing students. More qualitative studies are encouraged to obtain data about US nursing students' experiences studying abroad as they interact with people from diverse ethnic and sociocultural backgrounds (Edmonds, 2012).

Kent-Wilkinson, Dietrich Leurer, Luimes, Ferguson, and Murray (2015) have concluded that students prefer to study abroad in countries such as Australia, New Zealand, Western Europe, South America, and the Caribbean mainly due to costs and availability of funding. A dearth of information remains in describing study abroad in Eastern and Central European countries such as Hungary. Currently, no published research study describing the two complex phenomena of caring and cultural diversity behaviors has been conducted on US nursing students in the study abroad program in Hungary.

Hungary

Hungary is a landlocked country in Eastern Europe bordered by Slovakia, Romania, Serbia, Croatia, Slovenia, Austria and Ukraine. Budapest is the largest city and considered the country's cultural and economic capital. Hungary has an estimated total population of almost 10 million with ethnic Hungarians or Magyars comprising the majority of the population. Other ethnic groups include Roma, Jewish, and Germans. The Hungarian language originated from the Finno-Ugric group and considered unique in Europe as it was written in Latin characters. Christianity is the primary religion with Roman Catholics making up the largest group ("Hungary", 2016; Nagy, 2016; Stalcup, 2005). Stalcup (2005) described Hungarians as hospitable, well mannered, creative, ambitious and extremely polite people.

Guests are typically greeted by a handshake or a kiss on the cheeks and offered Palinka or fruit brandy at any time of the day (Commiceo Global Consultancy Ltd, 2017; Stalcup, 2005). Hungarians take pride in their traditional folk culture that includes music, art, dance, embroidery, books, leisure, wine, and food (Guillain, 2012). Private or intimate topics and romantic stories are shared among friends but money is an inappropriate topic of conversation (Commiceo Global Consultancy Ltd, 2017; Stalcup, 2005).

The family is the center of the Hungarian society and provides emotional and financial support for its members. Grandparents play important roles in raising grandchildren, thus generations of extended family live in one household. A typical family has one or two children but Hungarian Gypsies or Romanies have three or more children. Close ties, connections and celebrations are highly valued within the family. Children are raised through strict parental discipline and expected to work hard (Commiceo Global Consultancy Ltd, 2017; Guillain, 2012; Stalcup, 2005).

Western cultural influences shaped Hungarian culture with the introduction of Christianity in AD 975 and its subsequent establishment as the state religion. In 1990, Hungary became a parliamentary democratic country after 40 years under communism. In 2004, Hungary was one of the post-communist countries that became a member of the European Union. This event contributed to the marked advancement of its educational system ("Hungary", 2016; Nagy, 2016). In 2006, Hungary's economic crisis has negatively impacted life expectancy, employment, and mental and physical health conditions of the people (Egedy & Uzzoli, 2016) as well as tourism (Hajdu & Liptak, 2016). Ujvarine et al. (2016) found that the Hungarian nurses' intention to leave the profession and migrate to other European countries was prevalent.

Method

Design and Sample

An exploratory descriptive cross sectional design using secondary analysis of data was employed. A purposive sample was used (Palinkas et al., 2015). The sample was comprised of 12 female students in the junior year of a southwest region university in the US who participated in the study abroad program. Students' age ranged from 21 to 34 years old, 50% (n=6) were Caucasian, and 50% (n=6) were first time travelers outside of the US. The study was deemed exempt by the WGTHS Institutional Review Board (IRB).

Clinical Setting

The study abroad program in Budapest was initiated by a nursing professor of Hungarian ancestry who teaches at the university where the US students attend. This evolved into a mutual agreement between the partner universities in the US and Hungary. Prior to the trip, students were encouraged

to read about Hungary and provided a four-hour overview of the course including an orientation to the country and its culture. The orientation included a presentation on the hostel/dormitory type accommodations and clinical sites.

The students experienced clinical observations in different clinical facilities and cultural excursions at selected sites. Students were in clinical five days per week from Monday to Friday with weekends as free time, for a total of 120 clinical hours. They interacted with staff, patients and families. Though students did not provide direct patient care, they were exposed to a variety of patients and clinical situations. The cultural excursions involved a total of 20 hours visiting cultural landmarks including the Hospital in the Rock, Thermal Bath, Buda Castle, Shoes on the Danube Bank, Matthias Church, Heroes Square, House of Terror, and the Parliament Building. Hungarian student volunteers studying health sciences and public services served as interpreters and guides during the clinical rotations and cultural excursions.

The first week consisted of classroom lectures (e.g. history of Hungary in European context, socio-cultural context of the Hungarian health system, health issues, and nursing leadership, education and resources), and clinical site visits (e.g. partner university's simulation/skills lab and cardiovascular center, military hospital, and orphanages). The second and third weeks started with one hour of case study presentation in the morning relevant to general aspects of critically sick patients, critical metabolic and endocrine situations, and critical neuro-psychiatric situations in intensive care units. The rest of the day was spent in clinical observations with the preceptor.

Students were able to observe patient care by multidisciplinary health workers in the cardiovascular intensive care unit, operating room, recovery room, emergency room, and outpatient clinics in one large military hospital. The partner university's cardiovascular center exposed students to specialized cardiac care. Clinical rotations at the orphanages provided observations on the care for children with special needs and healthy infants.

Data Collection Instruments

The data assessed in the study were composed of the journal summaries and clinical evaluations submitted as part of the course requirements by the 12 students who participated in the study abroad for 23 days period. The two nursing professors who participated in the study abroad did not have access to the daily journals or daily clinical evaluations of the students. Each of the students submitted a journal summary and four weekly clinical evaluation tools that provided the data for assessing the students' caring and cultural diversity behaviors.

Journal Summary. Students were asked to discuss four topics in their journal summary: 1) awareness of self, 2) cultural diversity appreciation, 3) caring towards self and others, and 4) environmental health enlightenment. Students completed their daily journal during the 23 day study abroad period, generally at the end of the day either in their hostel room or at another comfortable site such as the hostel's common room conducive to self-reflection and writing. The students had a week upon arrival in the US to submit the journal summary to the faculty professors.

Clinical Evaluation Tool. The weekly summary of clinical performance consisted of student ratings on eight concepts: 1) safety, 2) education, 3) informatics, 4) competency, 5) communication, 6) teamwork and collaboration, 7) critical thinking and reasoning, and 8) caring, and cultural diversity. Each concept consisted of one to nine items. For example, caring, and cultural diversity were considered as one concept and consisted of four items: 1) preserves a caring, nurturing, helping environment for client, self, peers, and the health care team, 2) provides holistic care that recognizes the interaction of mind, body and spirit for clients across the lifespan, 3) respects and cares for clients in non-judgmental manner, and 4) participates in quality caring as the essence of nursing for persons of diverse cultures, values, beliefs, and lifestyles procedures and incorporates the action into their student practice. This clinical evaluation tool (CET) has been used in all courses in the program, and was developed based on caring philosophy and concept-based curriculum.

The twelve students completed their daily clinical performance at the end of the day but were only required to submit their weekly summary of CET. The two nursing professors who participated in the study abroad completed the CET on their assigned six students at the end of each week while in the clinical setting. Both nursing professors and students rated the clinical performance.

Data Analysis

The students' written descriptions of caring and cultural diversity behaviors were copied and pasted into two separate documents. One document contained the clinical evaluation tool where caring and cultural diversity behaviors were described. The other document contained the summary of the clinical journal entries where caring towards self and others and cultural diversity appreciation were described. Students' names were removed to maintain anonymity and confidentiality. The researcher read and re-read the two documents, underlined important words or phrases, noted significant phrases on the sides of the copied documents, categorized and created a schema, and defined the main themes.

Trustworthiness of the qualitative study was established

to ensure rigor and validity using five criteria: credibility, dependability, confirmability, transferability and authenticity (Cope, 2014; Guba & Lincoln, 1994; Lincoln & Guba, 1985). Credibility was supported by the researcher's engagement in the students' experience in study abroad program as she was also involved in the travel when data were collected and by repeatedly reading the students' submitted documents. Dependability was ascertained by triangulation (Guba & Lincoln, 1994; Lincoln & Guba, 1985) and achieved by having two experienced researchers compare the themes and acquire similar findings from previous studies with the current study in relation to the experiences of nursing students studying abroad. Confirmability was ensured through constant comparison (Guba & Lincoln, 1994; Lincoln & Guba, 1985) and attained by providing direct quotes from the students and having an audit trail in place. Transferability was recognized by having the thick descriptions give meaningful impact to nursing students who have been or plan to be in the study abroad as well as students who have opportunity to take care of culturally diverse people. Authenticity was established by reflection of all critical interpretations of data without bias and validation of data by another researcher (Cope, 2014; Lincoln & Guba, 1985).

Results

Thematic analysis was used to analyze the data (Boyatzis, 1998; Braun & Clarke, 2006). Themes were taken from the two concepts, caring behaviors and cultural diversity behaviors in the clinical evaluation tools. Two themes emerged in the caring behaviors: self-caring and caring presence. Three themes emerged in the cultural diversity behaviors: enhancing interactions, learning something new, and appreciating another culture.

Caring Behaviors

Self-caring. Self-caring behaviors emerged as the most common demonstration of caring behaviors. Self-caring behaviors involved both outdoor and indoor activities. Self-caring behaviors involving outdoor activities were caving, boat cruising, running, pub crawling, eating a gelato, relaxing at a thermal bath, and shopping. Self-care behaviors involving indoor activities were listening to music, having "alone" time, praying, and sleeping.

Four students who went *spelunking* (caving) and explored a local cave have expressed a lot of fun and had unique adventure. Several students went boat cruising for the first time and expressed their excitement about the experience. Two students went to an island and had a morning mile run as a form of exercise. All of the students went out on the weekend evenings and experienced pub crawling. Eating a gelato on the way to the hostel was a form of a "small treat" for the students. All students but one went to the thermal bath resort and expressed that it was relaxing and a once in a lifetime experience. Lastly, shopping was another way of

self-care for the students.

Although not considered as typical self-care behaviors, several students expressed praying and sleeping as the most important demonstrations of self-care. Statements by the students on praying and sleeping were noteworthy. A student stated, "In order to take care of myself, I have been incorporating my prayers into my daily routines for my own sanity". Another student stated:

The one saving grace for that day was getting the opportunity to go into the mosque with a Muslim student on the trip. The guy at the mosque led us up to the prayer room and he explained how people are to be positioned during prayer. He also explained that during prayer all people were brothers and sisters on equal standing, completing their prayers together. The thought of this equality was very comforting for me and for the first time, I understood why people believe that all roads lead to God. It was enlightening and I felt calm and peaceful in the mosque. It was a welcomed moment in an otherwise hectic day.

Several students expressed the importance of having the opportunity on the weekend to be able to "sleep". One student stated, "I care for myself by taking a long nap after I finish working on my assignments". Another student stated:

It felt so good to sleep in. We have been on the go the entire week, and I needed this rest day so much. I didn't leave my bed one time today other than getting food down the street. I needed my sleep!

Caring presence. Another aspect of caring was the interaction of students with another person. Students demonstrated caring presence by means of touching or holding hands, hugging or embracing, smiling, praying, and helping.

Touching or holding hands. One student stated:

Each patient requires different care in regards not only to his/her admitting complaint but also to his/her personality. Some required more attention and felt comforted by touch like hand holding.

Another student stated, "Every time she would move her hands to try and reach for it (tube out of her nose), I would hold her hand so she knew that someone was there and that she was okay." Additionally, a student stated, "lean in closely and use reassuring touch when speaking with the patients." One student stated, "Nursing is more than simply going through the motions; it is about being there for someone and being a hand to hold when they have no one else".

Hugging or Embracing. One student stated:

I expressed caring by providing a comforting hug to the family member who was at the bedside of a patient who was gravely ill. The family member's English was limited but she received my hug and said "thank you" when I said to her and her family member "God bless you".

Another student stated:

There was a woman crying over her dying relative. It was a very sad moment. I offer to give her privacy but she declined. After the medical professionals took us outside the room, I found her in the hall and gave her a big hug to show compassion to her.

Yet another student stated, "Before we left the orphanage, I hugged a couple of the caregivers, and one of the residents said he wanted to hug me as well. That hug truly made my day!" Another student stated:

Sadly a patient next to me was in the process of dying. It was so hard for me not to cry while the patient's adult child was crying. I embraced her to show compassion. I hope I did not disrespect her by being in her personal space without permission. I hope she took my compassion positively".

Smiling. Another caring behavior displayed by four students was smiling. One student stated, "Even though there is a language barrier and we are not allowed to do a lot with our patients. I still have been able to give a patient a friendly smile". Another student stated, "I had the opportunity to speak with a man as he woke up from anesthesia. I asked if he spoke English and he replied 'yes' and told me how beautiful my smile was after greeting him".

Yet another student stated, "By the end of the week I am more accustomed to the stares and usually to smile breaks the ice and the one staring will shyly greet me in some way". Still another student stated, "The patient did not speak much English but we communicated some during her surgery. I comforted her as best I could by stroking her head and smiling at her to reassure her".

Helping. One student stated, "The ability and willingness to care for others is why I chose nursing. One example of caring for others is when I helped a pair of girls on the trip become familiar with reading a map and following the routes of the trains and buses". Another student stated, "Even though there are a lot of things that we do differently in the USA, at the end of the day we have the same jobs as the nurses here with the passion to help those in need!" Another student stated, "Although I did not do much on this day, I can say that I did care towards myself and others. I did this

by helping out different classmates with their journaling and papers”. Lastly, a student stated, “I saw an elderly man with a walker having a difficult time opening a heavy door to his doctor’s office. I kindly left the group and helped the elderly man in. This was a very selfless act of kindness and it made me feel very fulfilling”.

Cultural Diversity Behaviors

The three themes for cultural diversity behaviors were enhancing interactions, learning something new, and appreciating another culture. Significant statements from the students were obtained in order to elaborate the themes on cultural diversity behaviors.

Enhancing interactions. A student stated, “I have interacted more with the patients in the hospital this week and have realized that communication is more than just verbal, it includes touch, visual/facial expressions, and even body language”. A student stated, “I have used a caring, holistic, and culturally sensitive approach when meeting new people, interacting with the healthcare professionals, patients, and even within our group”. Another student stated, “I appreciated the interactions with the population, it made me more open to various cultures that I may come across one day”. Yet another student stated, “I have learned how to really communicate with individuals on this trip. Not only the people that I enjoy talking with, but also the people who I may not be interested in having conversation with”.

Learning something new. Students were able to learn different words with the same meaning, new language, special dance, the money exchange, use of the public transportation system, and try new food. A student learned that different words with same the meaning were used, for example she stated, “When we landed in the airport, I noticed that instead of calling the public restrooms a ‘restroom’ or a ‘bathroom’ they call it ‘toilet’”. A student expressed her learning the new language as she stated:

I didn’t feel an instant culture shock as we stepped foot in this new territory, and I have been having a great time learning the new language and interacting with the people here.

Another student learned the traditional dance for that country. She stated:

We learned about the traditional dance. For me it was really amazing for the students to dress up and show us their dances. The traditional dances were very fast pace so at first it was difficult for me to stay on beat with the music. Eventually I was able to master the dance and enjoy myself.

Another student learned about the money exchange and

stated:

Inside of the store was where I felt a little frustrated because not only did I not understand the weight of the money, I did not know how to spend it. I did not understand how much I was supposed to give or how much I was supposed to get back. Once we got back to the hostel I quickly went online and understood how the money works.

Another student learned the new way of transportation and stated, “I am also getting used to having to walk so much and taking public transportation. This is an adjustment”. Two students expressed trying new food. A student stated, “I also walked through the festival near our hostel and tried chimney cake and took in the local culture. There were so many things to see in the different booths at the festival. I got to see traditional dancing, clothing and listen to traditional music”. Another student stated, “I experienced cultural diversity by stepping out of my comfort zone and trying new types of food...langos” (Deep fried flatbread or Hungarian pizza).

Appreciating another culture. Students appreciated the culture other than their own. A student stated:

I am very appreciative and understanding of the culture here. I like to learn about different cultures. I enjoy comparing this culture with the American culture to notice the differences. A lot of the people that I have met have been really nice and have introduced some of their culture to me. I have gained an appreciation for this population and I think that proves that I could care for culturally different patients in a non-judgmental manner.

Another student stated:

The lecturers were all very nice and welcoming throughout the day which was well appreciated. It was very interesting to learn about the culture and how it has changed over the centuries. I am still in awe about the shortage of health care professionals, especially nurses. I am shocked at how little they are paid because I know that it is far from an easy job. It made me appreciate the passion that I have for nursing and applaud those nurses who do choose to stay in the country to care for others despite the low pay.

A student stated:

I also learned that I enjoy living out of my comfort zone; it makes life more fun. Although it was difficult adjusting to a new culture, it made me appreciate it even more. It was rewarding to interact with a culture

other than my own because it gave me perspective... When we were at thermal bath this week, I noticed people of all different shapes and sizes, and no one was being judged! I really appreciate that about their culture.

Still another student stated, "I feel as if I am adjusting well to some of the culture shock I have been experiencing. I am really starting to appreciate a culture other than my own."

Discussion

Nursing students in this study were able to report both caring and culture diversity behaviors. Caring behaviors were exemplified through self-caring and caring presence. Cultural diversity behaviors were exemplified through enhancing interactions, learning something new, and appreciating another culture. The themes gleaned from this study were consistent with the transpersonal theory of caring (Wade & Kasper, 2006) and transcultural nursing (Leininger, 2002). Presence, appreciation, and interactions were concepts explicated in both of these theories.

Conveying genuine respect, warmth, and caring, and competence were identified as caring behaviors (Minnesota Baccalaureate Psychomotor Skills Faculty Group, 2008). Similarly, caring behaviors were demonstrated through caring presence. Caring differs across culture. Caring is influenced by the nurses' cultural background and cultural competence (Wikberg & Eriksson, 2008). In this study, students recognized and respected the differences of how patients were taken care of. However, the students also appreciated another culture and the similarities of providing nursing care by means of a caring presence (e.g. touching, hugging, smiling and helping).

Caring and cultural diversity behaviors appear to overlap. The categories for caring and cultural behaviors have similarities (Bohman & Borglin, 2014; Carpenter & Garcia, 2012; Hegedus et al., 2013). In this study, the themes of caring behaviors, self-caring and caring presence, could be inferred as cultural diversity behaviors. Likewise, the themes of cultural diversity behaviors, enhancing interactions, learning something new, and appreciating another culture, could be inferred as caring behaviors. Nursing students in the study abroad program have merged their descriptions of caring behaviors and cultural diversity behaviors in the journal summary. Additionally, caring and cultural diversity have been used as one concept in the student's clinical evaluation tool.

Despite no direct patient care being provided by the US nursing students, an appreciation of Hungary's socio-cultural, political and historical richness, as well as an understanding of the healthcare system was evident in the students' journals. The US nursing students developed an

appreciation of the advantages they have in terms of family support, access to transportation and the US health care system. This understanding and appreciation was possible through the establishment of a new social network by studying in a post-communist country such as Hungary.

From a personal perspective, the US nursing students learned about Hungarian specific nursing care phenomenon. The reflections of US nursing students revealed that self-caring and caring presence were imperative and congruent with Hungarian nurses' demonstration of their own self-care and care of their patients. Hungarian nurses showed their caring by treating their patients as their own family members. In the orphanages, nurses and caregivers were all females. Hungarian societal norms include mothers responsible to raise their children as the fathers were not expected to be caretakers or were employed as childcare workers. Gender norms, caregiving and childrearing have been ingrained among the majority of Hungarian family (Brayfield & Korintus, 2011)

Synergistic relationships were observed among the Hungarian multidisciplinary workers. Piko (2003) found that despite low salaries, long working hours, and low social status, the only significant factor associated with psychosomatic complaints among Hungarian nurses was the lack of peer social support. The proximity and accessibility of the socio-cultural landmarks and activities in Hungary are beneficial to use in times of burnout.

The US nursing students in this study listened to lectures on Hungarian history, did cultural excursions and interacted not only with Hungarian patients and families but also with Hungarians living in the community. The nursing students also used touching or holding hands, hugging or embracing, and smiling to communicate with the Hungarians who were non-English speaking patients. Touching or holding hands, hugging or embracing, and smiling are examples of psychomotor skills to use as alternative methods of communication with non-English speaking patients in transcultural nursing. Additionally, developing cultural competence to promote health in diverse cultural groups included learning about the history of the culturally diverse population, spending as much time as possible within the community, attending local events, being familiar with health care practices related to religion, food preferences, and family traditions; and understanding the cultural values and ways of life (Andrews, Boyle, & Carr, 2003). Noticeably, body contact among Hungarians in public places is customarily accepted ("Hungary", 2017) hence Hungarians were accustomed to the US nursing students' way of communicating through touch, hug, and smile.

The nursing students were immersed in experiential learning, which led to an appreciation about the differences be-

tween individualistic culture such as in the US and collectivistic cultures like that of Hungary. The US nursing students were able to observe the Hungarian nurses demonstration of their commitment to their job, working together in harmony and treating their patients just like their own family members regardless of the low pay. The students' completion of the journals was a venue to gaining insight into their own caring and cultural diversity behaviors as well as overcoming ethnocentric tendencies and cultural biases. This study abroad program in Hungary not only gave the students an opportunity to travel but also the chance to engage in a culture other than their own.

Study abroad programs not only offer lasting memories of being in another country but also entail different clinical experiences when providing care locally with diverse populations and communities. Students who were traveling for the first time outside of US and away from their families and friends have expressed struggles in adapting to food, language, public transportation, and people. Additionally, in order to connect with their families and friends, the use of technology to establish communication was important. Phone connectivity or internet access may not be available at all times in the country where the students were for the study abroad, thus their focus may be distracted or may result in homesickness and perplexity (Napolitano & Duhamel, 2017).

Study abroad programs have positive outcomes in the caring and cultural diversity behaviors of nursing students (East-erby et al., 2012; Edmonds, 2012; Greatrex-White, 2007; Koskinen & Tossavainen, 2004; Thompson & Johns, 2009). Caring behaviors' themes (self-caring and caring presence) and cultural diversity behaviors' themes (enhancing interactions, learning something new, and appreciating another culture) have remarkably been viewed as students' exceptional learning experience. A longitudinal study or more in-depth phenomenological approach on the lived experience of the US nursing students in the study abroad program in Hungary is recommended for future studies to provide an elaboration of the experience and behaviors reflecting caring and cultural diversity.

Limitations of the Study

The researcher's personal biases and idiosyncrasies may have influenced the interpretation of findings, as the researcher was part of the study abroad program in Hungary. Having the students verify the findings would strengthen the study. Another limitation of the study was the use of journal and clinical evaluation summaries instead of the daily student journal logs and daily clinical evaluations. Data analysis may have been obscured as variability of the data was dependent on how students provide raw descriptions of their actual daily observations and participation in

the patient care. Overall, the use of secondary analysis inherent in a qualitative study could be challenging (Tripathy, 2013). In addition, the length of study abroad (one month versus one semester or 3-4 months) may have an impact on the students' perspectives (Rahikainen & Hakkarainen, 2013).

The students' reflections may have been limited due to their inability to provide direct patient care and the language barrier.

Conclusion

US nursing students were able to report caring and cultural diversity behaviors in a foreign environment. Nursing students have the opportunity to care and be culturally sensitive to a multicultural population through study abroad programs. Study abroad programs serve as a mechanism to enhance care and cultural diversity behaviors.

The findings of this study may assist nurse educators and nursing students in redefining caring and cultural diversity behaviors. Caring and cultural diversity are interrelated concepts that have connections and overlapping similarities. The themes of caring behaviors, which are self-caring and caring presence reinforce the importance of building self-confidence and enhancing team-building skills when taking care of a diverse group of patients. The themes of cultural diversity behaviors, which are enhancing interactions, learning something new, and appreciating another culture augment knowledge awareness related to caring and cultural diversity which are beneficial to patient outcomes and satisfaction. Given that caring is at the heart of the nursing profession (Wood, 2014), the challenge for the nursing student of today is to demonstrate caring behaviors irrespective of cultural boundaries. This study provides the foundation and catalyst for future dialogue and inquiry about study abroad programs.

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Addressing Health Disparities in Rural Populations: The Case of Hawaii County

Jeanette Ayers-Kawakami & Dula F. Paquiao

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Correspondence to:
Dula F. Paquiao
dulafp@yahoo.com

Authors' Affiliation

Jeanette Ayers-Kawakami,
DNP(c), RN
Assistant Professor, University of
Hawaii at Hilo School of Nursing
Hilo, Hawaii

Dula F. Paquiao, EdD, RN,
CTN-A, TNS
Professor of Nursing (retired),
Rutgers University School of
Nursing
Adjunct Lecturer, University of
Hawaii at Hilo School of Nursing

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Abstract

Rural communities bear a greater burden of health disparities and lack of access to health-care services. In the state of Hawaii, the population of Hawaii County, also known as the Big island experiences higher morbidity and mortality compared to other groups in the state. The area in which they live is considered medically underserved. Using Kaplan's model, this article explores the social determinants of health disparities in this rural community and approaches that mitigate these social and geographical disadvantages. Doctor of Nursing Practice graduates with advanced practice preparation can help mitigate the shortage of physicians and lack of access to primary healthcare by rural populations.

Keywords: rural health, Advanced nursing practice, health disparities, community health, primary healthcare

Health Disparities in Rural Populations

Health disparities are differences in the health status of individuals when compared to the general population which may be indicative of increased incidences of disease and disability, mortality rates, lower life expectancies, and increased rates of pain and suffering (Healthy People 2020, 2017). Rural communities are considered vulnerable because of their isolation and lack of access to basic services, including health promotion, disease prevention and healthcare during illness. In addition to geographic isolation, rural dwellers have lower socioeconomic status, because of limited job opportunities. Compared to urban populations, rural residents have a higher prevalence of chronic conditions (HRSA, 2015) and experience higher rates of infant mortality and deaths from chronic obstructive pulmonary disease, ischemic heart disease, unintentional injuries, and suicides. Higher rates of chronic illness and poorer overall health occur in rural communities as compared to urban populations (Rural Health Reform Policy Research Center, 2014).

Access to health care plays a critical role in the health of individuals and populations. In the United States, thousands of additional primary care providers (PCPs) are required to meet the demand in rural communities. It is estimated that in the next decade, tens of thousands of additional PCPs are required to meet the healthcare needs of a growing rural population (Pellegrin, Surber, & Vitousek, 2011). This paper uses Kaplan's model (1999) to explain the determinants of health of a rural community in the state of Hawaii and argues for the use of advanced practice nurses to help mitigate health disparities in the rural population.

While health disparities may be attributed to differences in access to health services, this was found to have limited impact on population health. The seminal Whitehall I and II studies of white British civil servants who were poor and had equal access to health services found a social gradient in their health outcomes (heart disease, some cancers, chronic lung disease, gastrointestinal disease, depression, suicide, sickness absence, back pain and general feelings of ill-health) (Marmot, Rose, Shipley, & Hamilton, 1978; Marmot et al., 1991). The social gradient was conditioned by one's social position, status syndrome; higher social position was linked with better health (Marmot, 2006). The Whitehall studies confirmed that access to healthcare services does not guarantee equity of health outcomes, suggesting that health status is more significantly shaped by life conditions.

Social Determinants of Health

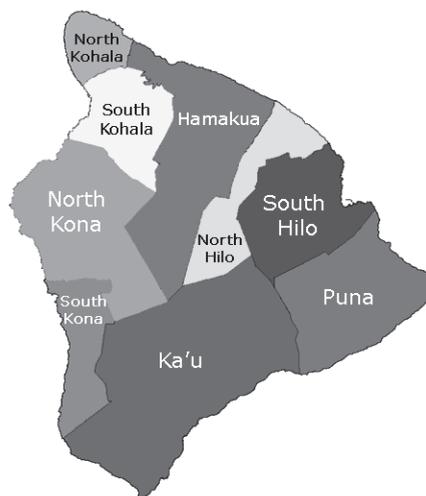
The World Health Organization's Health Impact Assessment (2015a) defines social determinants of health (SDH) as factors in which people are born, grow, live, work, and age. SDH are primarily responsible for health inequities which result in health status differences that are framed by

the distribution of money, power, and resource availability at the global, national, and local levels. Socioeconomic and political structures may influence living conditions and social circumstances that support or hinder health by creating conditions resulting in wealth or poverty, job stability or instability, educational opportunities or insufficient education, discrimination, and community trauma and deprivation. SDH have a huge impact on the overall health of communities.

Hawaii County

The Big Island is one of eight main islands that make up the state of Hawaii. It is comprised of nine districts (see Figure 1). Hawaii County is coterminous with the Big Island. The district of Puna is nestled on the windward coast (eastern side) of the Big Island of Hawaii, bordered by the South Hilo district in the north and the Ka'u district in the west (Hawaii, The Big Island, 2016). As of July 1, 2015, Hawaii County's population was 196,428 with a growth rate of 6.1%, as compared to 5.2% for the state of Hawaii (U.S. Census Bureau, 2016). The district of Puna has become the fastest growing district in the State of Hawaii with a population increase of 44% since 2000 that is expected to increase considerably from 45,326 to 75,000 in the next 15 years (U.S. Census Bureau, 2015).

Figure 1. Map of the island of Hawaii depicting the nine districts.



Like many communities across the globe, Hawaii faces an increasingly aging population, thus contributing to a growing number of residents with chronic illnesses. However, the Puna district faces more challenges in access to healthcare because of its more rural landscape. Hawaii County is the least healthy county in the state with some of the highest morbidity and mortality rates from cancer, stroke, diabetes, obesity, smoking, infant mortality rate, and less than adequate prenatal care utilization (Kaiser Permanente, 2010). Hawaii County has the second highest rate of chronic conditions in the state and residents of the Puna district comprise

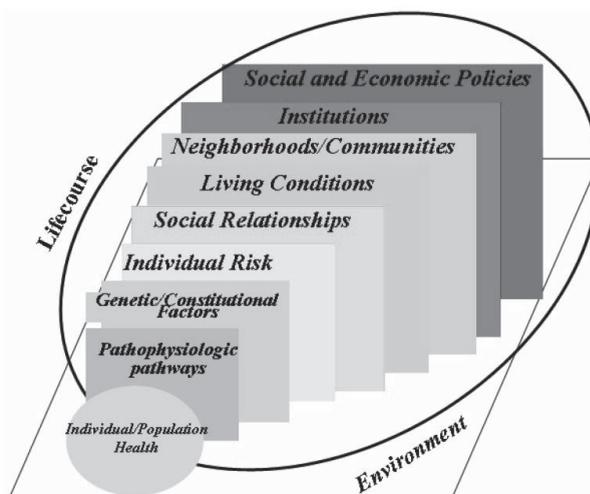
the majority of people with chronic diseases (HHDW, 2015). In 2013, hypertension was one of the primary contributing causes of death in the nation (CDC, 2015). In 2015, the state of Hawaii ranked fourth nationally for high blood pressure and Hawaii County had the highest prevalence in the state with 29.1% (United Health Foundation's America's Health Rankings, 2016). Puna residents had a 30.3% prevalence of hypertension and the second highest mortality rate from stroke (48.1%) in the state (Family Health Services Division Hawaii Department of Health, 2016).

Pathway to Health Disparities

Kaplan (1999) developed a comprehensive framework for explaining the determinants of population health. Population health is affected by micro-determinants that set the pathophysiologic pathways secondary to a) genetic and constitutional factors, and individual risk factors, b) interpersonal systems and local conditions (social relationships, living conditions, and neighborhoods and communities), and c) macrosocial factors (institutional and social and economic policies). As shown in Figure 2, health determinants are clustered in three levels. The first cluster includes micro-determinants at the individual level including pathophysiologic pathways, genetic and constitutional factors and individual risk factors. For example, smoking predisposes health risks such as asthma, COPD, cancer and cardiovascular diseases. Genetic changes are generally associated with environmental factors and may increase susceptibility of individuals to certain diseases such as sickle cell anemia, Huntington's disease, myotonic dystrophy, cystic fibrosis, etc. The second level of health determinants includes interpersonal processes and local conditions. Poor neighborhoods lack basic services such as healthy food venues, safe parks, adequate public transportation, primary health care services, quality schools and adequate deterrents to crimes. At the third level are the macro-determinants involving institutional and broad social and economic policies. Poor neighborhoods lack social capital, social cohesion and collective efficacy to influence local policies that impact their communities.

Disempowerment and social discrimination create disparities in allocation of public goods and services that disadvantage the poor and minorities. Inadequate access to quality schools perpetuates poverty in certain communities impacting their social and economic mobility. Poor neighborhoods bear a greater burden of environmental pollutants predisposing them to a life course of poor health. Exposure to neighborhood and societal level disadvantages create chronic stress that result in high-risk behaviors, and poorer physical and mental health (Thomson, Mitchell & Williams, 2006).

Figure 2. Comprehensive framework of the determinants of health proposed by George Kaplan (Thomson, Mitchell, & Williams, 2006).



As the model shows, social determinants of health include a broad array of societal conditions and psychosocial factors. Social determinants can impact individual and community health as an independent influence interacting with other determinants, or indirectly by influencing health-promoting behaviors. For example, low educational attainment limits employment to low-income jobs without support for employee health insurance thus minimizing access to health-care services. Low education affects one's ability to cope with stressors and navigate health systems that requires higher level of health literacy. Education, income, and occupation may mutually influence and interact with each other over an individual's life course influencing health outcomes among individuals, families, neighborhoods, and communities. Each level in the model may provide opportunities for interventions to improve health and reduce disparities through policies and other interventions influencing the factors affecting social determinants.

Central to Kaplan's model are the concepts of cumulative experience of social and economic disadvantages in one's life course and environmental exposures to these disadvantages resulting in poorer health status across generation. These factors occur in an environmental context across the life course. The principles of the life course theory posit that events occurring in life, particularly in childhood can manifest as risk factors for health disorders and diseases later in life. According to Seabrook and Avison (2012), exposures to severe episodes of stress (i.e., childhood or adolescent violence) are not random events; neither are the social status into which we are born (e.g., having poor single mothers). The chain of negative events can spiral into a domino effect creating cumulative disadvantages particularly among those with lower socioeconomic status (SES). These cascades of negative effects result in poor mental and physical

health because of the direct relationship between traumas accrued over a lifetime with mental disorders and psychological distress.

Such events may be referred to as sentinel events from which diseases emerge but with preventable episodes. The ability to identify a sentinel event allows intervention to occur in the early stages with higher success of better outcomes. Social circumstances occurring early in one's life may influence a multitude of lifelong health outcomes, including cardiovascular disease, obesity, diabetes, and disability, all which have the potential to affect mortality in an individual (Russ, Larson, Tullis, & Halfon, 2014). Research on significant events altering the course of one's life suggests that early intervention can decrease the rates of poor outcomes through adulthood (Zlotnick, Tam, & Soman, 2012). Individuals who are disadvantaged may experience an increased health risk due to harmful factors affecting their health at each level of determinants. The constructs of Kaplan's model are used to demonstrate the social determinants of health/SDH that influence the health status of residents of Hawaii County particularly those in the Puna district.

SDH of Hawaii County Population

Microsocial and Interpersonal Level Factors

In 2015, Hawaii County reported the highest rate of unemployment at 4.5% as compared to 3.3% statewide. This was an improvement from the unemployment rate of 9.8% in 2011 for Hawaii County compared to 6.8% statewide (United States Bureau of Labor Statistics, 2017). Hawaii County has the lowest per capita income in the state, and the highest number of individuals living below the poverty level in the past 12 months based on per capita income of \$24,395. Hawaii's high cost of living creates a financial burden for many individuals and families struggling to meet basic necessities such as food, rent, transportation and healthcare. More than 18% of residents are living below the poverty level compared to 11.2% in the state (U.S. Census Bureau, 2015). Hawaii County has a higher number of households receiving financial aid and food stamps (Kaiser Permanente, 2010). Puna District has the highest percentage of children living in households receiving assistance in the state (43%) (Family Health Services Division Hawaii Department of Health, 2016). In 2015, rural populations on the Big Island held a poverty rate of 16.5% compared to 9.2% in urban areas (USDA Economic Research Service, 2017).

Lack of income can prevent individuals from making healthy choices. Socioeconomic factors may play a major role in teen pregnancy rates due to lower education and income levels; low income communities have fewer opportunities for positive youth involvement (CDC, 2016). In 2013, 25.6% of Hawaii County residents had a bachelor's degree or higher compared to the state's 30.1% (US Census

Bureau, 2015). According to WHO's Health Impact Assessment Report (2015), low education levels are linked with poor health, more stress, and lower self-confidence. Education plays a crucial role in improving health outcomes and reducing health inequities. There is strong evidence that mothers with higher education have better maternal and child health outcomes. The pattern of association between maternal education and infant mortality has shown higher mortality risks occur with successively lower levels of educational attainment (Institute of Medicine, 2006). Poverty is more common among families headed by single mothers and teen mothers. The Puna district's percentage of births to teen mothers under the age of 18 from 2008-2013 was 3.0% compared to 1.8% for the entire state (Family Health Services Division Hawaii Department of Health, 2016). Experiences occurring in early childhood, such as lower educational attainment and SES, can have a long-term impact on the mental and physical health of individuals, affecting their future school performance.

Better access to nutrition and healthcare services can improve attendance rates in school and scholastic performance of children living in poverty. Improving health of early school-aged children has a lasting impact on their educational outcomes by reducing school absences, increasing motivation to attend schools and improving scholastic performance. Improved education provides increased economic opportunities for individuals while promoting overall social development (CDC, 2012; World Health Organization, 2015b).

Macrosocial Factors

Water is an important aspect of health contributing directly to a household's food and nutrition. Clean water and sanitation are essential for maintaining a healthy lifestyle. Decreased access to clean water directly affects socially and economically vulnerable populations (Institute of Medicine Forum on Microbial Threats, 2009; World Health Organization, 2015b). Most Puna residents have access to catchment water, not county water; many are unable to afford high-end ultra violet filtration systems to ensure clean water. According to Macomber (2010) an estimated 30,000 - 60,000 people in the State of Hawaii are dependent on rainwater catchment systems for their water needs particularly those in the Puna, Kau, and Hamakua districts of Hawaii County.

Water catchment systems can provide soft, clear and odorless rainwater that is almost free of contamination for drinking, bathing, and for other household needs. However, if the system is not properly maintained, it poses serious health risks. Water catchment tanks need to be cleaned periodically to remove sludge build-up on the bottom, or dead animals, requiring decontamination. Leptospirosis, giardiasis, and cryptosporidiosis are the three common diseases from catchment water contaminated by animals. Other health

risks include bacterial and viral diseases, parasitic worms and protozoans, chemicals and lead. Acid rain can destroy water pumps, lines, and the tank itself as well as cause illness by drinking or using the water. While special pumps and filters or chemicals such as baking soda or bleach are used to disinfect and purify the water, not all microorganisms are killed or filtered by filtration systems (Macomber, 2010).

Hawaii County has the highest rate of medically uninsured residents (8.2%) in the state. Individuals between 18-24 years old comprise the largest group of people without health insurance (Kaiser Permanente, 2010). In 2003, Hawaii County was designated a Medically Underserved Area (MUA) (U.S. Department of Health and Human Services, 2015) and a Health Professional Shortage Area (HPSA) (U.S. Department of Health and Human Services, 2015). Medically underserved areas are designated by the ratio of PCPs per 1,000 population, percentage of populations with incomes below the federal poverty level, percentage of population age 65 and over, and the infant mortality rate (Health Resources and Services Administration, 2016). The residents have very limited access to medical professionals because they are located in excessively distant locations inaccessible to the population. Access barriers prevent residents from using primary medical care providers.

In 2010, the School of Medicine Workforce Study at the University of Hawaii reported that Hawaii County had a shortage of 177 physicians including 61 primary care physicians. The study predicted that the shortage will increase to 331 physicians by 2020 (Pellegrin, Surber, & Vitousek, 2011). Hawaii County has 14% of the population, but only 10% of the state's licensed physicians, and the lowest ratio of physicians/1,000 population (2.1 compared to 3.4 for Honolulu County). Hawaii County has a shortage of 34% primary care providers. The healthcare shortage has been attributed to the large gap between the high cost of living and doing business, and the low reimbursement rates from Medicare, Medicaid, and private insurers across the county. In general, the cost of living in Hawaii County is higher than in Oahu, yet both counties receive the same medical reimbursement rates (Pellegrin et al., 2011).

Hawaii County ranks as the least healthy county in Hawaii. In 2012, the county had 17.5% of adults without a PCP (State of Hawaii Department of Health, 2016a). During the previous 12 months, 63.4% of individuals in the county had not received care from a physician (State of Hawaii Department of Health, 2016b). In the State of Hawaii, there are only two rural health clinics and 14 Federally Qualified Health Centers providing services at 71 sites across the state (National Association of Community Health Centers, 2015).

The consequences of inadequate access to healthcare include higher costs from greater utilization of emergency services and hospitalization, and poorer health outcomes. The healthcare provider shortage is most severe in Hawaii County and is a key barrier to healthcare access which results in higher morbidity and mortality and healthcare costs. Evidence shows that growing the healthcare workforce will reduce mortality and reduce potentially avoidable Emergency Department visits and hospitalization. One analysis showed that for every increase of one Primary Care Provider (PCP) per 10,000 population, there is a related reduction in the average mortality by 5.3% (Pellegrin et al., 2011).

Recommendations

Macrosocial Approaches

Mitigation of the disproportional health burden of rural populations requires interventions addressing microsocial, interpersonal and macrosocial level factors (Kaplan, 1999). At the macrosocial level, local, statewide and national policies must address the social determinants of health, and healthcare access of rural populations. Health service infrastructure should improve equitable access of rural populations to needed services. Rural areas in Hawaii are considered medically underserved with shortage not only of health facilities but also of health professionals. Lack of universal coverage is a big policy gap in the United States that further disadvantages low income and unemployed rural residents. When health services availability is conditioned by the local community's economic wherewithal, rural residents living in isolated and less profitable neighborhoods are more likely to be deprived access to adequate, timely and quality services. Greater incentives need to be provided to attract more health professionals (doctors and dentists) to establish practice in Hawaii County.

Improving access of rural residents to safe water supply requires statewide policy and resource allocation. Environmental policies protecting the ocean and wildlife have created barriers to cheaper transportation of agricultural products from Hawaii County to profitable markets in Honolulu. Transportation subsidies should be made available to local farmers to improve income generated from their land produce. Access to quality education is significant in promoting economic mobility of local residents. Statewide and local planning should facilitate equitable educational opportunities for rural residents. Graduates however will not remain in the Big Island without adequate opportunities for gainful employment.

There is need for collaborative planning and development of policies for equitable distribution of resources and services among the different islands in Hawaii. Currently, Honolulu in the island of Oahu is the center for political, educational, health and social services. Greater investment is needed in Hawaii County to develop its economic, social

and cultural capital. Long term commitment by local and state policy makers is needed for sustainable development supportive of population health in the Big Island.

Improving Healthcare Access

In 1978, the World Health Organization's Alma Ata Declaration emphasized the need for health care for all (WHO, 2017). It launched primary health care as an initiative to achieve health equity worldwide. Primary health care moves health care emphasis from a medical model of disease-based care to a more holistic view of health. Primary health care recognizes the many root causes of ill health and disease that are beyond the control of the health sector and need a broad societal approach. The goals of primary health care are to promote better health and health equity by improving the performance of health systems.

According to WHO (2017), health systems have made remarkable strides to improve health, combat disease and lengthen life spans, but people worldwide are dissatisfied with existing health systems, and concerned with the cost of health care. A great number of people are unable to access any health care or quality health services. Health systems tend to be fragmented, offering a patchwork of specialty care emphasizing curative care and neglecting prevention and health promotion.

According to WHO (2008) primary health care reorients health care systems to better respond to people's needs through delivery points embedded in communities. Health care systems should be people-centered which are planned, developed, implemented and evaluated based on the needs of communities. Primary health care systems are guided by the four core principles of universal coverage for all, people-centered services, healthy public places and leadership. Fair and efficient health systems provide all the people access to services according to their need, regardless of their ability to pay. Lack of access results in health inequities that produces decades of differences in life expectancies and health risks. Health systems should be embedded in their communities, providing services that are responsive, accessible and appropriate to the needs of the population. Health should be considered in all policies in order to build healthy communities as some of the greatest health impacts can be achieved through policies like early childhood development programs and education of women. Primary health care requires collaborative leadership engagement and commitment among private, governmental, business and health sectors with local communities. Wise leaders are well-informed by others, and evidence-based practices that can produce desired outcomes.

Primary care is defined as healthcare provided by physicians and other non-physician providers, such as Nurse Practitioners (NPs), including health maintenance and pro-

motion, disease prevention, counseling, patient education, and diagnosis and treatment of acute and chronic illnesses (American Academy of Family Physicians, 2017). PCPs are the primary source for regular medical care, providing continuity of care across the patient's lifespan.

There is research evidence that non-physician practitioners, such as advanced-practice registered nurses (APRNs) or Nurse Practitioners (NPs), play a significant role in providing access to individuals in underserved communities. The Institute of Medicine (2010) has found that increased access to primary care occurs when more NPs provide healthcare services, particularly in rural communities. Many studies have shown patients experiencing similar outcomes when they receive primary care from APRNs compared to physicians, oftentimes with lower cost and increased patient satisfaction (American Nurses Association, 2011). Increasing the healthcare workforce with NPs will greatly increase access for Hawaii County's under- and uninsured residents. NP and DNP-prepared nurses have the skills necessary to meet the complex and challenging demands of rural practice while reshaping the future of primary healthcare in rural settings. They can provide comprehensive primary care services at lesser cost and can close the gap in the shortage of PCPs in underserved areas. NPs have a track record of providing safe, cost-effective and quality care that can mitigate the shortage of physicians in vulnerable communities. The time required to become a licensed NP is significantly less than the time necessary to obtain a medical license, thus the costs of training NPs are much lower than physicians (Zand, 2011).

The American Association of Colleges of Nursing (AACN) (2006) has recommended the upgrading of APRNs/NPs from a master's degree to a doctoral degree. According to AACN doctoral education for advanced nursing practice (DNP) curriculum emphasizes the following: a) scientific underpinnings for practice, b) organizational and systems leadership for quality improvement and systems thinking, c) clinical scholarship and analytical methods for evidence-based practice, d) information systems/technology and patient care technology for the improvement and transformation of health care, e) health care policy for advocacy in health care, f) interprofessional collaboration for improving patient and population health outcomes, g) clinical prevention and population health for improving the nation's health, and h) advanced nursing practice.

The National Organization of Nurse Practitioner Faculties (NONPF, 2012) defines the independent practice competencies of APRNs/NPs as licensed independent practitioners who independently manage previously diagnosed and undiagnosed patients (provide full spectrum of health care services including health promotion, disease prevention, health protection, anticipatory guidance, counseling,

disease management, palliative, and end of life care; use advanced health assessment skills, screening and diagnostic strategies in the development of diagnoses; prescribe medications within their scope of practice and manage the health/illness status of patients and families over time), and provide patient-centered care that recognizes cultural diversity and the patient or designee as a full partner in decision-making.

The University of Hawaii at Hilo School of Nursing has established a post baccalaureate FNP/DNP (Family Nurse Practitioner/Doctor of Nursing Practice) program to increase primary care providers in Hawaii County (School of Nursing, 2011). The program has a transcultural emphasis and a concentration in rural health promotion. The program was established with much collaborative planning with community stakeholders (community leaders, businesses, health facilities, health providers and politicians). Students and faculty have a keen awareness of social and cultural norms of the rural community because of the sustained mutual engagement between the university and the local communities. Such engagement promotes mutual trust conducive to building partnerships and collaboration for health. Graduates of the program can provide comprehensive health care services and assume leadership roles in health promotion in the community. DNP nurses have the educational preparation to support and lead the transformation of healthcare to improve health outcomes for patients across community settings (Lathrop & Hodnicki, 2014). DNP nurses have the leadership capacity to engage in multisectoral and interprofessional collaboration to establish policies to mitigate the social and environmental inequities in rural communities (IOM, 2010; Douglas et al, 2011).

A number of private and governmental entities have emphasized the need for cultural competencies of all health professionals. AACN (2009) has proposed the integration of cultural competence in graduate nursing education to support the development of patient-centered care, focusing on identifying, respecting, and addressing variations in patients' values, preferences, and needs. The U.S. Department of Health and Human Services' Office of Minority Health promotes cultural competence of healthcare systems by emphasizing culturally and linguistically competent healthcare services (Jackson & Gracia, 2014). The FNP/DNP program at the University of Hawaii in Hilo has a transcultural nursing focus that aims to develop culturally competent graduates. Cultural competency requires the ability of healthcare providers to perform effectively within the context of cultural differences in order to improve healthcare services and outcomes for racial and ethnic minority groups. This is especially significant as Hawaii does not have a majority group; it is comprised of comparable representations of Asians (Japanese, Chinese, Filipinos), Hawaiians, Whites and other Pacific Islanders.

Previous research has demonstrated that medical students and physicians from rural areas are more likely to practice in rural settings. Recruiting students and health providers from rural areas and increasing the desirability of rural practice settings through favorable lifestyles, working environments, and employment opportunities can help in expanding the workforce in the rural areas of Hawaii (Schiff et al., 2012). Graduates from the University of Hawaii's DNP program at Hilo who work in the community have implemented their capstone projects to create practice innovations in their agency.

NP and DNP graduates can help address the shortage of PCPs in Hawaii County and promote health care particularly for under- and uninsured populations. Nurses practice in a variety of settings outside of hospitals including home health/Visiting Nurses, Long term care, Hospice, Community Health, School Nurse, Public Health and Ambulatory/Outpatient Clinics. Because of their exposure to various practice settings in addition to advanced knowledge and skills, DNP-prepared advanced practice nurses can effectively provide primary care services in underserved areas. Their background in holistic care enables them to address the full spectrum of preventive, health promotion and disease-management care. FNPs can deal with health promotion across the life span. More significantly, DNP graduates can assume leadership roles in designing care services and forge partnerships and collaboration to promote accessible and affordable care to remote populations. Availability, affordability, and the appropriateness of healthcare services targeting the most vulnerable and disadvantaged populations can help decrease health disparities. Indeed, NPs and DNP graduates have the background preparation to help address the multilayered factors that affect vulnerable populations in rural communities (Kaplan, 1999).

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Disclosing a Child's Difficult Diagnosis to Parents: A Review of Literature

Nidhi Sethi & Sigrid Ladores

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Correspondence to:
Nidhi Sethi
nidhisethi@mail.usf.edu

Authors' Affiliation
Nidhi Sethi, BSN, RN
DNP-FNP Student
University of South Florida
Tampa, FL

Sigrid Ladores, PhD, RN, PNP,
CNE
Assistant Professor
School of Nursing
University of Alabama at
Birmingham
Birmingham, AL

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Abstract

Background. For the health care provider, disclosing a pediatric patient's difficult diagnosis to the parents is a challenging task. Most healthcare providers often feel unprepared when disclosing the patient's diagnosis, and parents feel equally unprepared upon hearing it.

Objectives. This literature review examined the various communication techniques in disclosing a pediatric patient's diagnosis, and the effectiveness of techniques in increasing parental satisfaction when first learning of their child's diagnosis.

Method. Inclusion criteria included: 1) neonatal and pediatric population (0 -18 years); 2) healthcare providers (physicians, physician assistants, and nurse practitioners); 3) any acute or chronic condition; and 4) articles written in English. Exclusion criteria included: 1) articles written before 1990; and 2) communication of a difficult diagnosis between the parent and child. Databases used to extract relevant articles included CINAHL Plus with Full Text database, MEDLINE, PsycINFO and PubMed.

Results. Three commonly occurring communication themes identified from the studies were: 1) parents desired privacy during the disclosure and having an available support system present; 2) diagnosis must be disclosed as soon as the healthcare provider suspected it; and 3) the healthcare provider must emphasize the positive characteristics of the pediatric patient (such as mentioning the child being physically healthy) as well as the patient's prognosis.

Conclusions. Parents and providers agreed that further research is needed to identify effective communication techniques used during disclosure. Furthermore, all healthcare providers need collaborative and interdisciplinary training in delivering a difficult diagnosis and supporting the parents during disclosure to increase perceived parental emotional support.

Keywords: *truth disclosure, bad news, parents, healthcare provider*

Introduction

The birth of a child is a joyous and memorable occasion. However, in the case of a child born with an acute or chronic disorder, the experience can be difficult and stressful for the parents or caregivers involved. This literature review asked the question: What are the most effective means of communication when relaying a difficult diagnosis to the parents of a pediatric patient?

Background and Significance

Up to 10% of children are expected to have a moderate or severe long-term health problem (Harrison & Walling, 2010). The news is presented in various ways, including face-to-face, over the telephone, or have interdisciplinary members of the healthcare team present. The healthcare provider is faced with a challenging task when relating the news of a difficult diagnosis because parents often remember years later whether the experience was a positive or negative one (Wright, 2008).

The time of disclosure is stressful for parents, and the delivery of the difficult diagnosis is often dreaded by healthcare providers. A difficult diagnosis can be defined as an acute or chronic disorder that affects the future of the child (Ahmann, 1998). The disclosure has been described by parents as realizing the loss of a perfect child and is a life-altering experience (Boyd, 2001). In the literature, the delivery of a difficult diagnosis is also termed truth disclosure (Blake, 2013). The method by which the news is disclosed affects the parents' ability to cope and can have future implications in regards to the parents' relationship with the child (Krahn, Hallum, & Kime, 1993).

Few studies have examined the effectiveness of previously employed communication techniques when relaying a difficult diagnosis, and most remain qualitative in method. Since little is known about the topic, this review will focus on the most effective means of communicating a difficult diagnosis to the parents of neonatal and pediatric patients for the first time.

Method

This review of the literature was conducted to examine the most effective communication techniques used when disclosing a child's difficult diagnosis to the parents. Databases used to extract relevant studies included CINAHL Plus with Full Text database, MEDLINE, PsycINFO, and PubMed.

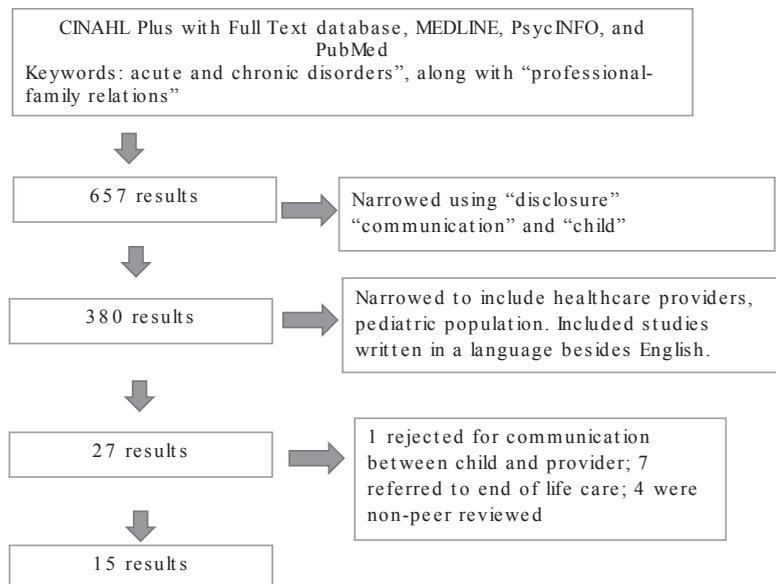
Search Terms

A search that included the terms "acute and chronic disorders," along with "professional-family relations" yielded 1,217 results.

The search results were narrowed by using the following relevant terms: "truth disclosure", "sad news", "bad news", "pediatric* disease", "pediatric condition", "pediatric illness", "therapeutic communication", "verbal communicat*", "nonverbal communicat*", "communicat*", "child*", "pediatri*", "family; nurs*", "role", "healthcare", "effective communicat*", "doctor" and "provider". From the 657 results found, the search was further narrowed to include only "truth disclosure or sad news or bad news or communicat*" and "child or pediatric or family and nurs*" to yield 380 studies. A subsequent search to include a more cross-cultural audience was conducted. The same search terms and inclusion/exclusion criteria were employed with the difference of including studies written in a language besides English.

Inclusion and Exclusion Criteria

From these 380 studies, inclusion and exclusion criteria were employed. Inclusion criteria included: 1) neonatal and pediatric population (0 -18 years); 2) healthcare providers (physicians, physician assistants, and nurse practitioners; 3) any acute or chronic condition; and 4) articles written in English. Exclusion criteria included: 1) articles written before 1990; and 2) communication of a difficult diagnosis between the parent and child. Twenty-seven studies were identified, and of those, one was excluded because it referred to the communication between the healthcare provider and the child, and did not focus on communication between the healthcare provider and the parents. Seven were also excluded because the focus was on communicating end-of-life care to the parents; the focus of this literature review was on communicating acute and/or chronic conditions. Additionally, four studies were excluded due to non-peer review. In addition to the databases mentioned above, the reference list from each article obtained was reviewed for other relevant articles.



Level of Evidence

After employing the inclusion and exclusion criteria to narrow down the results, 15 articles were selected for this literature review. Next, the level of evidence of each of the articles was determined to find one level II study (randomized control trial), six level V studies (synthesis of descriptive or qualitative studies), seven level VI studies (descriptive or qualitative studies), and one level VII study (expert opinion). Fourteen of the 15 studies were either qualitative studies, or evaluations of qualitative studies, and one was a quantitative study (East Carolina University, n.d.).

Findings

In the 15 studies, one of which was quantitative and fourteen qualitative, parents suggested a total of 19 communication techniques to the healthcare provider to improve the disclosure process. Of those 19 communication techniques, the three most common effective recommendations were selected as the themes for further analysis. These themes were recommended in the majority of the studies. These themes were: 1) privacy with support present, 2) timing of the interview, and 3) emphasizing the positive characteristics of the child.

Privacy with Support Present

Krahn, Hallum, and Kime (1993) interviewed the parents of 24 children with a developmental disability to determine the parents' satisfaction with the disclosure process. The authors' research questions asked what aspects of the disclosure process the parents liked and disliked, when the parents preferred to receive the disclosure, advice to the healthcare providers for future disclosures, and how the disclosure process could be modified to increase parental satisfaction. A majority of the parents interviewed suggested that the disclosure be relayed privately, such as in a family meeting room, with the fewest number of healthcare professionals present (e.g., only those directly involved in the child's care) (Havermans, Tack, Vertommen, Proesmans, & de Boeck, 2015). Another recommendation is ensuring that disclosure remain uninterrupted. Parents also recommended for the disclosure to occur face to face. Boyd (2001) explained that privacy and few distractions during the disclosure process allowed the parents to feel more accepted by the healthcare provider, and created a comfortable atmosphere where parents could ask questions freely. Some parents wished that only the diagnosing physician be present, stating that white-coated team members in such an emotional situation would only add to the stress that was already felt (Wright, 2008). Krahn et al., (1993) found that parents wanted the informing physician to personally know the child, and not necessarily be an expert in the field. Aside from the physician, other acceptable healthcare members include a perinatal nurse educator familiar with the family who could help the physician with more specific questions in the case of Down syndrome (Wright, 2008). The con-

cept of privacy also extended to after the interview, when parents reported that if needed, a private room should be made available for them to discuss and reflect on the meeting (Boyd, 2001; Wright, 2008). This could ultimately help increase parental satisfaction with the overall disclosure process.

Parents also stressed that some form of a support system should be present. In the study by Krahn et al., (1993), 46% of the families interviewed suggested that this would be one of the biggest improvements when receiving bad news. The support made parents feel less alone, as well as reduced the burden of informing the other parent. Other reasons for support (especially spousal) was the reduction in information distortion (if one parent was not present during the interview), as well as being able to start the grieving process together (Boyd, 2001). In the case of a married parent, a spouse was preferred (Ponte et al., 2012) and in the case of a single parent (usually a mother), a family member or close friend was preferred. Interestingly, one study found that even if the father was not available to attend the interview, mothers should be given the diagnosis first, and the physician should review the information once again when the father became available (Skotko, 2005). Mothers of children diagnosed with Down syndrome were surveyed to inquire about how they felt at the time of diagnosis. A total of 930 mothers responded, and a majority stated that under no circumstances should the father be informed before the mother unless the mother was unconscious and unable to understand the information. Overall, the presence of a support system significantly reduced the feelings of parental stress during the disclosure process (Skotko, 2005).

Sloper and Turner (1993) interviewed 103 parents of children with severe physical disabilities. Of these, only 37% of the parents were satisfied with the way the news was disclosed by the medical professional.

Timing of the Interview

The disclosure of a diagnosis can be relayed either before or after the birth of the child. Most of the studies found that parents preferred that the diagnosis be delivered as soon as the healthcare provider suspected it (Hasnat & Graves, 2000). If the diagnosis could be made and confirmed prenatally, then that is when it should be disclosed. In cases where the diagnosis was suspected postnatally, timing was also important. The suspected diagnosis should be given as soon as it was discovered, but only after the mother had time to recover from the birthing process (Skotko, 2005). Sheets, Baty, Vasquez, Carey, and Hobson (2012) interviewed 14 mothers whose children were diagnosed with Down syndrome at the time of birth. The survey questions were open-ended and focused on what the mothers felt upon first learning the child's diagnosis, and later what the mothers thought would be the best case scenario during a disclosure. Mothers who

had been informed of the diagnosis after the baby was born wished the news had been communicated sooner (i.e. as soon as it was suspected). Another reason for wanting the information as early as possible was that mothers often felt betrayed and in the dark about the child's health (Krahn et al., 1993 p. 580). Mothers felt afraid when the child was taken away for testing without prior communication. This stress was made worse because parents often felt the impact of nonverbal cues or communication. This added to the already escalating stress on the parents who now felt that bad news was imminent (Skotko, 2005; Wright, 2008).

Another suggestion is the inclusion of a short-term therapeutic conversation after the disclosure. Svavarsdottir, Tryggvadottir, & Sigurdardottir (2012) conducted an experimental study in which 76 families were divided into two groups: the control group whose children were admitted in the hospital for an acute or chronic condition, and who did not receive a therapeutic communication intervention; and the experimental group, who received a therapeutic communication intervention afterwards to determine whether the short-term communication increased perceived family support. The conversation, initiated by the nurse, asked the following questions: 1) current challenges they were facing secondary to the child's hospitalization; 2) the impact of the hospitalization; 3) what had been most and least helpful in similar situations; 4) how the family could be helped best; and 5) what the families wished for at the time of disclosure. Although this study did not focus on first-time disclosure of a difficult diagnosis, its findings can be extended and applied to the topic at hand. The study found that caregivers in the experimental group reported significantly higher perceived cognitive support after the conversation ($p = .037$), although the family did not report significantly higher emotional support. This information can be useful when relating a difficult diagnosis as it significantly increased perceived cognitive support.

Positive Characteristics of the Child

Fifty percent of the parents in the study by Krahn et al., (1993) wanted the informing physician to relay the diagnosis positively and mention the positive characteristics of the child. Along with being positive, parents wanted physicians to keep negative opinions to themselves and instead focus on remaining positive (Wright, 2008). In one case, a physician told a mother that her child with Down syndrome would never hold a job or live without assistance. Instead, it was recommended that the discloser help the parents feel well informed of the diagnosis and comforted. An example of a positive comment was a physician informing the mother of a child newly diagnosed with Down syndrome that children with Down syndrome are usually good and very loving (Skotko, 2005). One mother suggested that the informing healthcare professional use words like normal, and put less emphasis on the negative outcomes of the disorder (Sheets et al., 2012).

In conjunction with the theme of emphasizing the child's positive characteristics, parents wished for the child to be present during the interview (Skotko, 2005). This way, parents could witness the interaction between the physician and the child. This activity accomplished the following: 1) it showed that the physician was positive and comfortable in handling the child's disclosure of diagnosis (making the parents more comfortable); and 2) it made it easier for the physician to point out characteristics of the child and dispel any misconceptions. Referring to the child as disabled was considered less desirable to the parents than using the phrase infant with a disability. However, the best way to refer to the infant was by using the infant's name. In the case of an unborn child, parents preferred using either infant or baby (Wright, 2008).

Aside from stating the positive aspects of the child and the child's future, parents also recommended that the physician communicate current and up-to-date information regarding the diagnosis. Skotko and Bedia (2005) surveyed 467 mothers with children newly diagnosed with Down syndrome. The study revealed that the mothers reported feeling more emotionally positive when receiving up-to-date information than when the information presented was not current. This emotionally positive experience at the time of disclosure eventually led to a better parent-child relationship and better emotional and psychosocial development of the child (Skotko & Bedia, 2005).

Discussion

Disclosing the news of a pediatric patient's difficult diagnosis to the parents for the first time should be a learned skill that improves over time, and is individualized to each situation. Horwitz and Ellis (2007) sent surveys to 206 doctors in Ireland who specialized in pediatric consulting, including disclosing a difficult diagnosis. Of the 113 doctors who responded, most reported feeling competent in delivering a patient's diagnosis of Down syndrome to the parents. However, out of the 113 doctors, only 55 had personally delivered a diagnosis, with only 21% receiving feedback from the parents in regards to the experience of receiving a difficult diagnosis related to their child.

Medical and nursing students do not receive enough training in delivering a difficult diagnosis later in their careers. Although techniques exist to aid students with the process, few guidelines have been established in disclosing a difficult diagnosis. One model for teaching students regarding this skill is demonstrated at the University of South Florida's College of Medicine. Students in their oncology rotation are required to participate in a two-to-three hour session focused on communicating bad news to patients (Kiluk, Dessureault, & Quinn, 2012). The students are expected to deliver a difficult diagnosis to a patient, and the

session is videotaped for a post evaluation. Afterwards, the recording is reviewed by both students and the instructor to highlight the positive and negative communication techniques employed by the students. A majority of the students (98.3%) agreed this exercise was helpful. Participating in training programs early on in their medical careers aid students in becoming more comfortable in disclosing difficult diagnoses later on (Kiluk et al., 2012).

Disclosing a difficult diagnosis to a parent is generally the physician's responsibility, but increasing perceived parental support is a collaborative effort between physicians, nurses, and other healthcare professionals (Boyd, 2001). Wakefield, Cooke, and Boggis (2003) conducted a study in which 34 students (22 nurses and 12 medical students) participated in two sessions spanning two-and-a-half days that focused on how to deliver a difficult diagnosis. Groups were formed that consisted of at least one medical and nursing student. Before each disclosure session, the group discussed the disclosure's content and the best way of disclosure. The first session involved a 45-minute demonstration by a facilitator showing what was expected of the students, followed by students practicing disclosing bad news for two to two-and-a-half hours. During the second session, the facilitators demonstrated another patient scenario, and the students were given practice simulated patients. After the first and second sessions, the students were debriefed regarding their performance. Although both medical and nursing students found the role-play beneficial, the nursing students reported having had less practice in this area as compared to the medical students. Thus, while simulations are beneficial, learning to communicate difficult news should be integrated into the medical curriculum, while nursing students should be trained in supporting parents and caregivers after receiving a difficult diagnosis.

Farrell and Langrick (2001) evaluated a workshop aimed at teaching healthcare providers to deliver bad news. In the workshop, 45 healthcare members (mostly nurses) were given scenarios to act out involving the delivery of bad news in a pediatric setting. The scenarios involved the members (i.e., nurses and doctors) working collaboratively to deliver the news, and later receiving feedback from the patients. Seventy-seven percent of the participants had not received any training in this field, but all agreed that training in this field was important. After completing the training, the participants were asked to evaluate the effectiveness of the training. Both doctors and nurses found the training was very helpful, with the majority stating that it should become a mandatory requirement in their respective curricula. However, aside from learning how to effectively disclose a difficult diagnosis during formal education, training to disclose a difficult diagnosis to improve perceived parental emotional support should be offered to continually improve the disclosure of a difficult diagnosis.

Although nurses may not communicate the diagnosis itself, nurses can be of great support to both the disclosing physician and the families. Nurses often spend the most time with a patient and family during the hospital stay and can assist with individualizing the disclosure to that family's needs. Few studies selected for this literature review mentioned the importance of individualizing the interview. This can mean having the information given in a parent or caregiver's native language, or allowing the presence of family members and friends if this increases perceived parental or caregiver emotional support. Aside from making the necessary arrangements for the disclosure interview (i.e., written materials and keeping the area private), nurses can be available to provide emotional support before, during, and after the disclosure. Because of the difficult nature of the disclosure process, parents often feel overwhelmed and shocked upon first learning the diagnosis. Nurses can continue to educate the family after receiving the diagnosis by recording and repeating information missed by the family (if permissible by the state, the family, and the disclosing physician) and using therapeutic communication techniques to increase parental satisfaction with the disclosure process.

Recommendations

Although healthcare providers may feel comfortable in delivering a difficult diagnosis, the disclosure of the diagnosis may not be effectively communicated. Aside from the education and training the healthcare providers receive during their formal education, disclosure training should be done on a regular basis and evolve based on new available evidence. A continuing education for effective delivery of difficult diagnosis can be developed and offered to health care providers. The continuing education includes interprofessional collaboration of the healthcare team (pediatricians, specialists, pastoral care, nurses) since the delivery often involves several team members. Nurses are well positioned to conduct research on this area and educate other healthcare providers on the most effective communication techniques preferred by parents during the disclosure process. Today, the majority of research has been qualitative in nature, with few quantitative studies conducted due to the subjective nature of this topic. Researchers could employ mixed method designs that incorporate both the qualitative (perceived parental satisfaction) and quantitative (parental satisfaction based on a scale) aspects of this important phenomena.

Limitations

Not many quantitative studies were found on effective communication techniques when disclosing a pediatric patient's difficult diagnosis to the parents. The majority of the studies were either qualitative in nature, or literature reviews. Furthermore, the majority of the studies conducted were surveys, sent out months or years after the diagnosis was disclosed, thus introducing the likelihood of recall bias. Additionally, of those studies that proposed techniques to improve communication during disclosure, only one was

evaluated. Also, the studies did not include the role of interdisciplinary team members in improving perceived parental support. Another limitation was that several of the articles found are older than ten years, thus the findings may not be applicable today. Further, the studies focused mostly on Down syndrome, and do not refer to other acute or chronic conditions. In addition, there were no assessments used to help parents understand the medical diagnosis. Similarly, none of the studies objectively assessed the family's response to the diagnosis. Finally, the research is mostly from the United States, with little cross cultural consideration. It would be beneficial to see whether members of different cultures have different preferences during and after the disclosure process.

Conclusion

Disclosing a difficult diagnosis to the parents of a child is not an easy task. The most commonly occurring themes from the review of the literature are: 1) that the information be relayed privately with parental support present; 2) that the information be shared as soon as a diagnosis was suspected; and 3) parents preferred that the disclosing healthcare provider focus on the positive characteristics of the child. Although the stress of receiving a difficult diagnosis cannot be eliminated, measures can be taken to lessen parental and caregiver stress during disclosure. To achieve this, more research needs to be conducted to identify the most effective ways to engage in disclosure that best meets parental needs.

1

Table of Evidence: Quantitative Study

Name, Year, Source	Method/ Sample Size	Type of Condition	Purpose	Results/Themes	Limitations
1. Svavarsdottir, E.K., Tryggvadottir, G. B., & Sigurdardottir, A.O. (2012). Knowledge translation in family nursing: Does a short-term therapeutic conversation intervention benefit families of children and adolescents in a hospital setting? Findings from the Landspítali University Hospital Family Nursing implementation project. <i>Journal of Family Nursing</i> , 18 (3), 303-327.	Clinical trial using family interviews, 76 families	Acute and chronic illnesses	To evaluate the effectiveness of a short-term therapeutic conversation intervention with families who were receiving healthcare services at the Children's Hospital at Landspítali University Hospital in Iceland.	Although this study did not focus on the time of diagnosis, it still focused on the importance of therapeutic conversations with caregivers of a child with an acute or chronic condition. It was found that caregivers who got therapeutic conversation felt a lot more perceived cognitive support as compared to the control group ($F = 6.742, p = 0.011$), but not much more perceived emotional support ($F = 1.74, p = 0.074$). Caregivers of children with acute illnesses felt more cognitively supported ($F = 7.433, p = 0.003$) as compared to the control group.	-Measures used were new and not previously evaluated in any other settings.

2

Table of Evidence: Qualitative Studies

Name, Year, Source	Method/ Sample Size	Type of Condition	Purpose	Results/Themes	Limitations
1. Ahmann, E. (1998). Review and commentary: Two studies regarding giving "bad news." <i>Pediatric Nursing</i> , 24 (6), 554-556.	Review of two studies in which bad news was given	Chronic illness or disability	To compare two studies in which bad news was given.	Both studies: It is important to: provide a private setting; many caregivers prefer to have someone who knows their child to be told the diagnosis, not an expert in the field; simple, direct language; give the caregivers positive aspects about the child and then deliver the negative information. In this article, the nurse's role is more of setting up the environment and giving family support during and after the diagnosis.	-Literature review, not quantitative data. -Review is on two articles written over 15 years ago.
2. Abdelmontader, A.M., & Abd Elhamed, K.A. (2012). Egyptian mothers' preferences regarding how physicians break bad news about their child's disability: A structured verbal questionnaire. <i>BMC Medical Ethics</i> , 13.	20-item questionnaire listing different preferences regarding the disclosure process.	Pediatric patients with Down Syndrome.	To determine Egyptian mothers' preferences when learning of their child's Down Syndrome diagnosis.	Top three preferences: -That the diagnosis be delivered once it deemed final, and not preliminary. -To be informed by the doctor. -To be informed of others with a similar condition.	-Only one hospital was used, thus limiting generalizability.
3. Boyd, J.R. (2001). A process for delivering bad news: Supporting families when a child is diagnosed. <i>Journal of Neuroscience Nursing</i> , 33(1), 14-20.	An analysis of previous studies to determine what caregivers want when bad news is delivered.	Neurodegenerative Disorders	To find the nurse's role during and after diagnosis of a pediatric patient with a neurological disorder, and to find what the caregivers want.	Caregivers want: empathy, sensitivity, and caring; allow caregivers to show their feelings; provide time to talk and ask questions; provide privacy; arrange for both caregivers to be present; limit the number of professionals to be present; provide information (straightforward, honest, detailed); refer to other caregivers, support groups, and community resources; individualize the approach (most important).	-Literature review with no quantitative data. -Literature review involves cancer patients (and the protocols presented in the review have not been evaluated), not delivering bad news to caregivers or children. -Interventions in this article have not been evaluated. -Article was written over ten years ago.

4. Farrell, M., Ryan, S., & Langrick, B. (2001). 'Breaking bad news' within a paediatric setting: An evaluation report <i>Journal of Advanced Nursing</i> , 36 (6), 765-775.	Workshop. 34 Nurses, 10 Doctors	Any pediatric illness	To evaluate a workshop to prepare health professionals for breaking bad news in the paediatric setting.	Seven themes, including development of practice, the value of sharing, benefit of feedback, and teamwork, emerged from responses. All responses indicated that the workshop had been beneficial and an effective training method, with most participants (40 of 45 = 89%) indicating that it would be strongly recommend to their colleagues to attend a similar workshop.	-Was only an evaluation of a training workshop for delivering bad news. -Article was written over ten years ago.
5. Hasnat, M.J., & Graves, P. (2000). Disclosure of developmental disability: A study of parent satisfaction and the determinants of satisfaction. <i>Journal of Paediatrics and Child Health</i> , 36(1), 32-35.	Disclosure interviews in which parents were asked how they found out about their child's disability, and how satisfied they were with the process.	Patients with autism spectrum disorders.	To determine how the disclosure process was for parents, and to note their preferences during the disclosure process.	-Parents preferred being overly informed versus being adequately informed about the details of the diagnosis.	-Limited size and sample, hence less generalizability.
6. Havermans, T., Tack, J., Vertommen, A., Proesmans, M., & de Boeck, K. (2015). Breaking bad news, the diagnosis of cystic fibrosis in childhood. <i>Journal of Cystic Fibrosis</i> , 14(4), 540-546.	Semi-structured interview of 38 parents regarding their child's cystic fibrosis diagnosis.	Patients with cystic fibrosis.	Asking parents about the time of diagnosis and how they coped with the news, using a semi-structured interview.	-Parents were generally happy with the disclosure process. -Parents preferred having both parents and the doctor present.	-Small size (n=38 parents). -Validity of interview questions was not assessed.
7. Horwitz, N., & Ellis, J. (2007). Paediatric SpRs' experiences of breaking bad news. <i>Child: Care, Health & Development</i> , 33(5), 625-630.	Questionnaire-based survey Physicians. N=112, 78 females and 34 males.	Down Syndrome	To ascertain the level of support and training available to paediatric specialist registrars (SpRs) in breaking bad news and their self-reported confidence in this task.	This article took a different take on the matter. It asked qualified healthcare professionals about the thought of breaking bad news to families. It was found that even these healthcare professionals found that caregivers were dissatisfied in the way that news was related to them. The individuals who related the bad news were trained in doing so, but according to the caregivers, their competence in doing so was not enough.	-A survey of the specialists who delivered the bad news, as compared to the caregivers or child who received it. Thus, it can only be assumed what the caregivers or child want as compared to having quantitative data on this question.
8. Krahn, G.L., Hallum, A., & Kime, C. (1993). Are there good ways to give 'Bad news'? <i>Pediatrics</i> , 91(3), 578-582.	Interviewing the caregivers	Any disability	To find what the caregivers preferred when being told (for the first time) that their child has a disability	Caregivers were interviewed after learning that their child had a disability. It was found that caregivers appreciated straight-forward information (no "beating around the bush"), no medical terminology or negative portrayal ("many anomalies"), given by a single professional, empathetic approach, privacy during talk, and should be <i>in person</i> and not over the phone, another support person present (i.e. not just one person: mom and dad, or someone else), holding or touching their baby before or during interview (both pediatrician and family members), wanting information for support groups and another family who is going through something similar.	-Small sample size (caregivers of 24 children) -Article was written over ten years ago. -Did not touch upon specifics of how to give bad news, such as words to avoid or use, etc.
9. Pirie, A. (2012). Pediatric palliative care communication: Resources for the clinical nurse specialist. <i>The Journal for Advanced Nursing Practice</i> , 26 (4), 212-215.	Literature Review	Palliative Care	The purpose of this article was to highlight the lack of communication skills pediatric practitioners have when delivering bad news and introducing pediatric palliative care to a family with a child with a life-limiting condition.	There are three phases of delivering bad news: Preparation, Delivering, and Planning. The article also mentioned that not enough research has been done on communicating with pediatric patients diagnosed, (and in this case) those who will go through palliative care.	-Literature review that talks more about what the nurse faces when delivering bad news as compared to how s/he should deliver the bad news. -Mainly references something the American Academy of Pediatrics and the World Health Organization published over ten years ago.

10. Ponte, J., Perpinan, S., Mayo, M.E., Milla, M.G., Pegenaute, F., & Poch-Olive, M.L. (2012). Study on the professional procedures, experiences and needs of parents when they are told their child has a disability or developmental disorder. <i>Breaking the news. Revue Neurologique, 54</i> (1), S3-S9.	Questionnaire with 43 items asking about ways to deliver bad news.	Disability or developmental disorder.	To understand the practices currently used to deliver bad news to families, and to determine what can be improved about the process via the use of a 43 item questionnaire.	-The discloser must know the family. -Care should be observed as to where, when, and how the news is delivered. -Parents must be present upon disclosure. -Type of disability and intensity of disability must be addressed.	-Survey focused on qualitative not quantitative aspects.
11. Price, J., McNeilly, P., & Surgenor, M. (2006) Breaking bad news to caregivers: The children's nurse's role. <i>International Journal of Palliative Nursing, 12</i> (3), 115-120.	Literature examination	Palliative Care	To find the nurse's role when delivering bad news. Also, forms of communication that are useful when delivering bad news.	This article indicates that the nurse's role in delivering bad news is not well understood. Because the nurse is probably the one who developed a therapeutic relationship with the family and patient, that the nurse should be the one to deliver the bad news.	-Literature review, not quantitative data. -Although a framework for delivering bad news has been offered, it has not yet been evaluated.
12. Sheets, K., Batty, B., Vázquez, J., Carey, J., & Hobson, W. (2012). Breaking difficult news in a cross-cultural setting: A qualitative study about Latina mothers of children with Down Syndrome. <i>Journal of Genetic Counseling, 21</i> (4), 582-590.	Semi-structured qualitative interviews. 14 mothers	Down Syndrome	To determine how to deliver bad news in a cross-cultural setting.	The mothers desired the news in a more positive, balanced light and with more complete explanations about the condition. Mothers felt excluded from the diagnostic process and wanted to be better informed about the need for diagnostic studies. 13 of the 14 mothers wanted the diagnosis before birth. Mothers needed a support person (mostly their spouses), did not like to hear medical jargon, and wanted time with their doctors in order to ask questions.	-Small sample size (n = 14). -Only mothers were included, not any other members of the family. -Focus was on Latina mothers, thus decreasing the ethnic diversity of the participants.
13. Skotko, B. (2005). Mothers of children with Down Syndrome reflect on their postnatal support. <i>Pediatrics, 115</i> (1), 64-77.	Survey 2,945 people on Down Syndrome organization membership lists (response rate = 49.4%)	Down Syndrome	To document, in the most robust comprehensive way, the reflections of mothers in the United States who received diagnoses of DS for their children.	Mothers think that physicians should emphasize the positive aspects of Down Syndrome (p < 0.001), and not give statistics that do not pertain to their child. However, the doctor's way of delivering the diagnosis has improved a lot since the 70s and 80s. Mothers liked or preferred being told sooner (when the doctor suspected Down Syndrome) rather than later; mothers want a support person available with them. Mothers did not like it when doctors used negative language to describe the diagnosis. Finally, receiving written information is a must, as well as being given the names of other caregivers with a child with DS (p = 0.0001).	-Risk of recall bias: the mothers received this survey at an average of 11 years after the diagnosis of Down Syndrome was disclosed. -Selection bias: only mothers who are members of a Down Syndrome support group were given the survey, of which only 42.4% of people responded, suggesting that only mothers with difficult experiences answered the survey. -Because only those mothers enrolled in a support group were given the survey, certain socioeconomic and ethnic classes were not represented; for example, this study was completed mostly by middle to upper-class white females.
14. Wright, J.A. (2008). Prenatal and postnatal diagnosis of infant disability: Breaking the news to mothers. <i>Journal of Perinatal Education, 17</i> (3), 27-32.	Any disability	Any disability	To define the role of the perinatal educator when news of a disability is being delivered to mothers.	When delivering bad news to a new mother, it is important not to diminish "the joy of birth." The nurse should encourage the mother (in this case) to seek care and support; this is especially useful when finding a mother of another child with the same illness: has excellent bonding.	-Literature review, not quantitative data. -Focuses more on perinatal education thereby making it less broad when it comes to age groups of children. -Focused on how to give bad news to only the mother as compared to other members of a family.

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Peer Reviewers of the July 2017 Issue of JNPARR

Cynthia Ayres, PhD, RN, FNAP

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Rutgers, School of Nursing
Camden, NJ

Rose P. Estrada, DNP, RN, BC, CPN

Assistant Professor & Specialty Director Nursing Informatics,
MSN Program
Rutgers, School of Nursing
Newark, NJ

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Massachusetts General Hospital
Boston, MA

Jill Nocella, PhD, RN

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William Paterson University of New Jersey
Wayne, NJ

Dula F. Pacquiao, EdD, RN, CTN-A, TNS

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Adjunct Professor, University of Hawaii at Hilo and
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San Antonio, TX

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