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The Meaning of Evidence and Nonmaleficence: Cases from Nursing

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ABSTRACT

In our increasingly diverse environment, nurses are obligated to question the meaning of “evidence” when history has shown that our emphasis on the empirical and quantitative data has shaped our biases against knowledge unknown to us. This bias has limited our ability to provide patient or person-centered care, and can be harmful to patients. Nurses are encouraged to reflect on what evidence means in their practice and to make sure harm is not caused to patients by dismissing evidence yet unknown to us or accepting “truths” not fully understood by us. The authors use composite case studies to share experiences from their clinical practice on how “evidence,” or lack of, can challenge our obligation to “do no harm.” Curiosity and skepticism should guide nursing practice, and every nurse should strive to contribute to questioning accepted practice and finding answers to the unknown to meet the needs of our diverse patients.

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Introduction

For many of us who were raised in multi-cultural environments, coming to terms with the recent emphasis on evidence-based practice can prove to be an ethical dilemma. The issue has grown in significance as our societies become more ethnically and socio-economically diverse. Many a nurse can relate a story when a practitioner tells a patient that a non-Western practice is “wrong” because it is “not evidence-based.” It has been eighteen years since the publication of *The Spirit Catches You and You Fall Down*, Fadiman’s seminal 1998 book that contributed to mandatory cultural competency education in the United States (U.S.) healthcare field. However, nursing as a profession has not made significant progress in understanding, nor truly reflected on, the meaning of culture, evidence, and patient care. We seem to believe that class lectures, surveys, and multiple choice tests are enough to create culturally competent practitioners (Long, 2012), even as it is recognized that this approach to culture and evidence has contributed to continued poor healthcare outcomes among minority and marginalized populations in the U.S. (Agency for Healthcare Research and Quality [AHRQ], 2013; AHRQ, 2014).

The purpose of this paper is to discuss the meaning of evidence in nursing practice with the aim of encouraging practitioners to reflect on how they approach practices outside the norms of the dominant culture, especially the current push for quantification and empirical evidence in clinical practice. We wish to make this paper easy to read and to stimulate thinking on evidence-based practice, an issue that so many seem to take for granted as beneficial. By using composite cases from our clinical experience, we want to share how evidence or the lack of evidence from

our biases has harmed our patients. As Harvey (2013) points out, research is of little value not only if it cannot be effectively translated, but also if it is “lost before translation” when our prejudices and biases influence who, what, and how we study (p. 188).

The purpose is not to deny the importance of evidence-based practice but to question the meaning and extent of the practice in our daily lives as nurses, particularly when judgments are made against unfamiliar belief systems. Trust and faith in, and harm to patient-provider relations are significantly impacted when patient belief systems are minimized or dismissed all together (AHRQ, 2013; AHRQ, 2014). Our practice should be guided by both curiosity and skepticism while maintaining respectful communication, as the history of science has consistently shown that many a matter deemed unscientific, taboo, an “old wives tale,” or an impossibility, has been later “discovered” and proven worthwhile to add to our knowledge base. Understandably, this fine line of distinguishing “good” from “bad” evidence is not an easy task, but nurses must be prepared to question all evidence including those governing their own practices, and strive to contribute towards discovering the unknown.

Evidentialism and Evidence

Evidentialism, the existence of evidence or the meaning of evidence, as a philosophical matter, has been discussed from the days of Aristotle, Plato, and Socrates in their search for “truth” (Chignell, 2016). It is a discussion that continues today as to how truth is defined. Evidentialism affects belief systems as ancient as the argument on the existence of God. If one believes something to exist, does that mean there is sufficient “evidence” for the belief to be considered “true”? Is belief equivalent to knowledge? This situation may best be exemplified in the case of the boson particle, the existence of which was “proven” in 2013 even though it was theorized to exist as early as the 1920’s (Pillai, 2012). In healthcare, the use of quinine, foxglove, morphine and many other plant-based drugs may be the equivalent to physics’s boson particle: known to be effective by non-conventional medicinal traditions for centuries, these treatments were later adopted by Western medicine after these plants were “evidently” found effective (Ventola, 2010).

Without making this paper into a thesis on evidentialism, the discussion of evidence is simplified to focus on the empirical versus non-empirical. A reliance on empirical evidence was adopted by much of Western science after the “discovery” of gravity by Newton. Henceforth, science that can be empirically proven is true science, and what is unknown to our consciousness and five senses is somehow “unproven” and therefore, untrue (Smith, 2008). This limiting approach is confounded by the fact that many practitioners in the Anglo-centric world begin their scholarly pursuits by searching databases in one language: English, further restricting knowledge of other research and evidence conducted and disseminated in other languages. We should not forget that there are more than 6,900 languages in the world today. Even if these languages may not have a written tradition, we cannot dismiss the importance of the oral tradition in disseminating knowledge (Anderson, 2010). “Knowing” must incorporate evidence outside of Western empirical research; by accepting the hierarchy of evidence based on the medical approach where the randomized control trials rule, we put patient safety at risk by minimizing the humanness from our evidence, diminishing the purpose of what the evidence is purported to do (Christopher, Wendt, Marecek, & Goodman, 2014; Fawcett, Watson, Walker, & Fitzpatrick, 2001; Harvey, 2013).

In these times where multicultural diversity is increasingly the norm in healthcare, and where patient care is supposedly “patient or person-centered,” it is imperative that healthcare providers ask if the emphasis on evidence-based practice, without a more inclusive perspective of

what constitutes evidence, is compatible to the our obligation of “do no harm.” The authors share stories of composite patients to accentuate the point of “evidence” and how a lack of knowledge or evidence in our practice have negatively impacted minority and marginalized populations. These selections are purposefully broad to reach as many nurses as possible.

Composite Case Studies

One: The Transgender Patient

The first author grew up in a society where gender identity was not perceived in strict binary terms. Those who fell in the spectrum of gender between male and female were largely accepted as “different.” In 1994, upon her introduction to transgender individuals in the West who sought healthcare in a clinic at which she worked, she was surprised at the discrimination and abuse transgender individuals encountered. The result of this discrimination and abuse is the creation of a group of people outcast from the mainstream. Many resorted to prostitution to make a living, had to obtain hormones from the black market, and injected themselves with shared, reused, or dirty needles. Healthcare practitioners added to the ostracization of these individuals, calling them “freaks,” and refusing them treatment for even basic medical needs. This reality, sadly, persists today.

The story is about a young trans-woman, who will be referred to as Martina in this article. Martina was an 18-year old self-identified female who was born with male genitalia but had identified as a girl since age four. She was homeless and had come to the clinic’s attention for an abscess in her gluteus from a hormone shot she had self-administered. Martina ran away from home at age 14 because of incessant bullying at school and a lack of parental support. She had survived on sex work for the last four years, usually picked up by gay men with whom she would have unprotected anal sex.

Martina had originally come to a drop-in center for homeless youths where she was given a safe place in the daytime to get mental health support, activities, and food. Even though she was told of the free clinic services, Martina would not see any practitioners for preventive care. We later learned about her story which was not unique to Martina—her family had subjected her to a physician who informed her and family she was mentally ill, and she was admitted to a psychiatric hospital at age 12 for attempting to castrate herself. Martina only accepted a case manager’s offer to take her to the clinic when she experienced a fever and chills from her abscess. Martina was successfully treated with antibiotics, and she continued to come see the clinicians for primary care including vaccinations and screenings for sexually transmitted diseases. Her test results came back positive for the Human Immunodeficiency Virus (HIV). She began counseling with a psychiatrist for her depression associated with her traumatic childhood and her situation at that time, being homeless and HIV positive.

Her positive status made her eligible for housing. Martina moved in, and through intensive case management, returned to school. She believed she was heading in the right direction. Without informing anyone, Martina left for home one day believing that she was ready to see her family and that they would be ready to accept her. She returned in a week, withdrawn and depressed. Her father chastised her for returning home, and told her that she had brought the family shame. He had called the police on her, and the police put her in jail overnight. Her father had called Martina’s medical team “fraudulent” for practicing “voodoo” science since there was “no evidence” to support what we were doing.

Martina reported that she was glad to be back to her new home. She resumed school and found a part-time job in a café. Two weeks upon her return, we received a call from her case manager that Martina had been found dead in her room; she had hanged herself.

Martina's story is still very much the reality for many transgender individuals today. Due to provider ignorance or judgment that transgender identity is somehow not real and a creation in a person's head, too many transgender people have experienced discrimination in the hands of healthcare providers (Grant, Mottet, Tanis, Harrison, Herman, & Keisling, 2011). The "lack of evidence" is apparent since it is a population that had been judged and deemed unworthy of research. Nor has the dominant culture, and in this case, providers with a binary view of gender, taken the effort to go beyond what is known to study other cultures "hidden" from view. Transgender identity has been deemed a mental illness by the medical profession for decades—if one cannot physically "see truth," the "abnormality" must in be in the "disturbed" minds of transgender individuals. It is this cultural arrogance that dismisses what is a lack of knowledge as a lack of evidence that will continue to harm people who are different from us.

Two: Herbs and Breast Milk Production

Another area considered to be "lacking in evidence" is the use of non-Western methods such as herbs to promote breast milk production in new mothers. Herbal use is based on many cultural traditions (Damanik, Wahlqvist, & Wattanapenpaiboon, 2006), but very few studies of "quality" have been done (Budzynska, Dugoua, Low Dog, & Gardiner, 2014). In many instances, a randomized control trial would be difficult to conduct and could be unethical with infants involved.

The use of herbs is not considered evidence-based practice in the U.S., leading to most practitioners in the mainstream discouraging patients from using supplements for safety reasons (Budzynska, et al., 2014). The following story tells of a lactation specialist going against her colleagues' objections to encourage the use of herbs for a young mother.

For purposes of this article, the young mother shall be known as Belle. She is 28 years of age, identifies as Caucasian, and she had her first baby at 37 weeks by Caesarean section due to preeclampsia. Baby boy, John, was born at 37.1 weeks; Belle had more than usual blood loss but no transfusion was given. Baby was immediately placed skin to skin. Within 60 minutes of birth, Belle was taught hand expression. She successfully expressed a few drops of colostrum, which were given to baby John.

Within the first four hours of birth, Belle began to pump her breasts. Everything extracted was given to her baby. In spite of these interventions, there was a 36-hour delay in lactogenesis II; when it did happen, the amount seemed inadequate for the baby's needs. During the 74-hour hospital stay, due to extenuating circumstances, Belle was not referred to a lactation consultant. At discharge, the baby's bilirubin was "high intermediate" with Belle feeding the baby every three-four hours.

At the first post-discharge examination, when baby John was 98-hours old, the situation was unchanged. The young parents were concerned because the baby was awake all night and would only settle when latched to mom's breasts. Baby's weight on the day of the examination was 12% less than birth weight. Belle thought her breasts were starting to feel fuller and the family was discharged with a plan to recheck bilirubin levels the next day. When there is no blood incompatibility, inadequate milk is often a cause of persistent elevated bilirubin. Belle started

pumping every two hours and was offering baby her breast at least 10 times in 24 hours. On day five, baby remained jaundiced. His blood level of bilirubin remained “high intermediate.”

The lactation consultant instructed Belle on how to supplement baby at breast using a supplementary nursing system. Belle was also encouraged to start an herbal regimen. The supplementary feeding helped reduce the bilirubin to “low intermediate” over the next 24 hours, and the baby’s weight increased but remained below his birth weight. Over the next two weeks, Belle continued with supplementary feeding while using the herbs. At week five, milk production increased, and by week eight, baby was breastfed exclusively.

As it is believed that breast milk production peaks at week four and stays at the peaked level through six months post-partum, a mother with low milk production is typically advised to stop breastfeeding and bottle feed her baby with formula (West & Marasco, 2009). A “lack of evidence” does not mean that herbs do not help augment milk production in mothers. In Belle’s case, if she had been given conventional advice based on “evidence,” she would have likely been told that she cannot produce enough milk. The consequence would be that Belle would have stopped breastfeeding, and baby John would not have received the benefits of his mother’s milk. Belle’s use of herbal supplement cannot be proven nor disproven as the cause of her increase in milk production. However, our lack of knowledge or the lack of “evidence” on a regimen that has worked for cultures outside of our own does not justify dismissing the potential of giving the full benefits of breastfeeding to a baby.

Three: Cardiac Care for Women

The third case study addresses the continued lack of knowledge among physicians and health care providers in diagnosing women with heart disease. In 1948, the Framingham Heart Study followed more than 5,000 men and women and was instrumental in identifying major risk factors for cardiovascular disease (CVD)(Dawber, Meadors, & Moore, 1951). The findings provided valuable data on the incidence, prevalence, and prevention of CVD. The findings, however, were on a predominantly white male population, but the “evidence” was generalized to other populations. The impact of the Framingham study is such that the medical community and the general public believed women do not develop heart disease, and if they did, they experience the same clinical symptoms as men (Wenger, 2010). However, more recent data have indicated that, compared to men, women presented differently when they experienced cardiac symptoms (O'Donnell, McGee, Mooney, O'Brien, & Moser, 2014), showing atypical symptoms such as extreme fatigue, shortness of breath, chest pressure and abdominal pain which may be misunderstood and lead to the incorrect diagnosis (McSweeney, Cody, O'Sullivan, Elberson, Moser, & Garvin, 2003).

The following is a case of a black woman’s presentation in the emergency department (ED). We will refer to her as Mary for this article. Mary arrived to the ED with chest pressure accompanied with abdominal pain and found herself explaining in great detail what she was experiencing. The response she received was expressed as non-concern and trivialization of her experience. Mary was admitted to the hospital for a series of tests and discharged after 24 hours with a diagnosis of constipation. Not knowing what was really going on, she accepted this temporary diagnosis, but knew instinctively there was something wrong. She could not give a name to it, but this was a drastic change from what she normally experienced. The Institute of Medicine reveals that the medical community has historically overlooked, and in some cases

ignored, the health needs of women, with the exception on their reproductive concerns (Committee on Women's Health Research, 2010).

After 24 hours, Mary was discharged and told to return to the hospital if the same symptoms persisted. She returned three days later after subjecting herself to many hours of unnecessary pain and persistent chest pressure. She had tolerated the discomfort. Mary's self-image and confidence about being seriously ill was shaken by the prior experience of being discounted by the doctors. She did not want to encounter the same experience as before, and wanted to be sure that she was sick enough to be taken seriously. When Mary arrived at the hospital by ambulance for the second time, it was clear to the healthcare professionals that Mary was critically ill, and she was subsequently diagnosed with congestive heart failure. Mary was relieved on one hand, that her fears were vindicated, but in a state of shock on the other, knowing that she could have died waiting for the correct diagnosis.

Mary's uncertainty and lack of awareness about heart disease is not unusual. In 2012, only 56% of white females and 36% of black females viewed heart disease as a health risk (Mosca, Hammond, Mochari-Greenberger, Towfighi, & Albert, 2013). But more importantly, half a century after the Framingham study, the emphasis on classic signs of chest pain experienced by men continue to take precedence in the minds of healthcare providers over women's presentation of symptoms for cardiac illness. The "evidence" taken as "truth," combined with the historical dismissal of women's health needs, led to severe consequences for Mary. Her experience is not unique, as heart disease in women continues to be understudied, underdiagnosed, and undertreated (Mehta, Beckie, DeVon, Grines, Krumholz, Johnson et al., 2016).

Evidence and Nonmaleficence: Our Obligation

These composite case studies, created from the decades of experience of the three nurse authors, demonstrate how healthcare providers and nurses have accepted the "evidence," or lack of, as best practices with potential harmful consequences to our patients. All three cases attest to the unfortunate realities that are a result of our lack of acceptance of things unknown and unfamiliar to us, and a trivialization of marginalized populations. The evidence from outside our dominant Western scientific views was not accepted in the case of the transgender woman and the use of herbs to augment post-partum milk production. Our prejudices have also impacted the population we study. If studied, results published outside the U.S. have not been given our attention, especially if the publications are not in English. The premise can be applied to other examples: for example, the use of acupuncture; the benefits from meditation; human hibernation and the control of our autonomic nervous system; and the ability of our neurons to grow new pathways. Newton's suspicions and argument that truth in science must be observable has, indeed, influenced Western science greatly (Smith, 2008).

Psychologists Christopher, Wendt, Marecek, and Goodman (2014) argued that dismissing other realities and beliefs can only point to our own ignorance, and in the blindness of our dominant view, patients are being harmed. They reflected on their own experiences as Western psychologists trying to help patients from non-Western cultures only to understand later that they were trapped in their own truths, and that labeling those they were supposed to help ended up causing more harm than good. It is imperative that we critically examine our culture-bound "evidence" so as to stay true to our oath of nonmaleficence. Christopher, et al (2014) also called for caution in healthcare's prioritization of quantitative research, as qualitative methods remain more suited in capturing the nuances of language and culture.

The challenge for nurses, and healthcare providers in general, is how to find a balance in our practice when we say that what we do is “evidence-based.” It is our moral obligation to understand that evidence in science is only as good as what we do not yet know, and that outright dismissal and belittling of people and practices from cultures unfamiliar to us do not serve us well. If we are to truly “do no harm,” we need to start infusing our practice with fewer negative judgments of things unknown, and questioning the assumption that “evidence” is automatically “scientific” and therefore, true. As critical practitioners, we need to instill curiosity and skepticism in our work for the sake of patient or person-centered care and our ethical obligation to nonmaleficence.

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