In their essay, *Nursing Research and the Transformative Value of Art*, nursing researchers Bergum and Godkin (2008) trace a history of the tension between the art of nursing and an overarching emphasis on science, suggesting that those fixed boundaries in nursing research are disappearing—a proposition, they note, that was also traced by other nursing researchers (Mitchell & Halifax, 2005; Newman, 2003). Their essay proposes that:

the transformative value of art within our research environment is found in the intermediate space (Behar, 1996), or relational space (Bergum & Dossetor, 2005), that exists between the researcher and the researched, between the question that is asked and the answer that evolves, between the research done by the researcher and the public for whose benefit the research is carried out. (Bergum & Godkin, 2008, pp. 603-604)

As a point of intersection between nursing, the visual arts, and the performing arts, this intermediate (or liminal) space is precisely the space we can inhabit through multiple forms of practice, whether performative or visual.

BACKGROUND

The current authors recently launched an artist-in-residence program between the Colleges of Nursing and Arts and Architecture at Penn State University. The residency centers on the art of caring for individuals amid some of life’s most difficult experiences so that we might create a forceful interface at the nexus of the science and art of nursing. Our aim is the purposeful infusion of artistic representation into the science of nursing to establish new ways of understanding the complexities of living through altered states of health. For the purpose of collaboration, we combined the backgrounds of nurse researchers with that of a performing and visual artist who makes work about death and dying as well as anxiety and depression (Doan, 2016a,b,c; 2018a,b). We discussed an initial collaboration using Story Circles as a methodology (access https://roadside.org/asset/story-circle-guidelines) to investigate the potential for enhancing research aimed at improving illness representation, communication (art as data), and potentially art as intervention.

The art of nursing includes fostering an understanding of patient and family experience to inform care. With this in mind, artistic expression holds important implications for enhancing nursing education, practice, research, and even the ways nurses cope with the stress and emotional burden that caregiving may bring. Story Circles maximize our ways of looking at individuals’ health experiences, moving beyond traditional paradigms of representation, thereby increasing potential for broader interpretation and action. Story Circles are reflective and dialogic, offering the chance to observe body language, tone of voice, and follow-up reflection for clarity. They bring individuals together to answer questions using stories drawn...
from their own lives. We are testing the feasibility and utility of Story Circles as a methodology to enhance understanding in three main areas of focus: (a) everyday experiences of older adults who report cognitive problems; (b) illness perceptions of individuals with advanced heart failure; and (c) home health nurses’ and family caregivers’ experience with delirium superimposed on dementia (DSD).

Story Circles

First, we will engage community-dwelling older adults who report cognitive problems in a Story Circle to explore the nuances of their experiences as well as influences on self-perceptions, daily activities, and well-being. Older adults’ everyday concerns related to cognition are associated with negative health-related behaviors, such as withdrawal from social activities, and negative emotional impact, such as depression or anxiety symptoms. Approximately 25% of older adults report cognitive problems (Fritsch, McClendon, Wallendal, Hyde, & Larsen, 2014). Although these reports are associated with an increased risk for future cognitive decline, daily functional difficulties, and decreased well-being, the phenomenon has not been well studied from the perspective of older adults themselves (Hill et al., 2017; Reisberg, Shulman, Torossian, Leng, & Zhu, 2010). Qualitative studies have examined early cognitive problems among older adults, but findings to date are unable to differentiate between those who will and will not experience progressive cognitive decline (Buckley, Saling, Frommann, Wolfsgruber, & Wagner, 2015). There is a need to better characterize the phenomenon, and a more thorough understanding will help guide clinical assessment and development of preventive interventions.

Second, we will use Story Circles with individuals with advanced heart failure to explore their experiences and illness perceptions, and how these perceptions might influence goals of care and decision making. Individuals with advanced heart failure face a 5-year mortality rate of 50% following diagnosis (Benjamin et al., 2018). Considering the high mortality rate, there is a growing body of evidence on the importance of goals for care conversations between individuals with advanced illness and their health care providers (Doorenbos, Levy, Curtis, & Dougherty, 2016). An understanding of an individual’s wishes is a foundational cornerstone of person-centered care and an individual’s perception of his/her illness has profound implications regarding goals of care and decisions regarding advanced treatment options, such as mechanical circulatory support, especially at the end of life. A recent study examined illness perceptions in individuals with advanced heart failure and found that 80% of participants with a predicted life expectancy of less than 2 years did not perceive the severity or terminality of their heart failure (Hupcey, Kitko, & Alonso, 2016). There is a gap in our current understanding of how individuals with an advanced life-limiting illness, such as heart failure, perceive their illness and how this might influence decision making. New knowledge regarding an individual’s illness perceptions has important implications for future work, including goals of care conversations and decision making for heart failure throughout the illness trajectory and especially at the end of life.

Finally, we will explore the experience of delirium and DSD in older adults and their caregivers. Recalling experiences with delirium and DSD can be difficult, and little is known about the recognition of delirium by home health workers and community nurses, despite work that has shown that many older adults are admitted to the hospital with delirium and experience distress with delirium (Fick, Steis, Waller, & Inouye, 2013; Morandi et al., 2015; Racine et al., 2018). Under-recognition of delirium leads to poor outcomes, but recent evidence suggests that if DSD is promptly recognized and correctly managed, these poor outcomes can be improved. Art has been used increasingly in work with individuals with dementia, but much less work has been conducted in the area of delirium (Deshmukh, Holmes, & Cardno, 2018; Werner & AboJabel, 2018). This work will use Story Circle methodology to explore the experiences of community-dwelling older adults with delirium and their informal and formal caregivers (i.e., home health nurses), with a focus on capturing rich details of these experiences. The long-term goal of this research will be to develop informed and pragmatic interventions for delirium at home.

IMPLICATIONS FOR NURSING AND HEALTH CARE

Richard Blanco, the 2013 Presidential Inaugural Poet, spoke recently about the importance of art in health care. Blanco is an engineer and a poet; therefore, in addition to reading his poems, he talked about the importance of breaking out of our silos in education and the “work of art” in the world, emphasizing the importance of being able to tell a story and communicate well (Fick, 2018). Blanco notes that when we use the arts with our science, “We get the best results when we are using both sides of our brain” and that art “helps us ask the questions we are not asking…” (Blanco, 2018). This is also true in nursing and health care. Patricia Flatley Brennan (2018), the Director of the National Library of Medicine, recently spoke about the importance and growth of team science, stressing innovations in how we communicate our research (e.g., videos, podcasts, access to datasets). When imagining research and publications of 2020, she emphasized the need to move health care to more of a conversation, with a clear responsibility to explain our work and research to the public. In her blog, Brennan also refers to the value of nurses’ ways of knowing and understanding the human response (access https://nlmdirector.nlm.nih.
The collaboration of the arts and nursing is a critical piece of team science and has implications for better understanding how nurse researchers and bedside nurses can tell our story and the story of nursing and health care. Art is a universal language, and the merging of art and nursing can help us understand the human experience and improve our qualitative approach by capturing and telling our story with richer detail and, importantly, can help us appreciate the context and humanness of the world and what we do as health care professionals (Yoder-Wise, 2018). We look forward to sharing our experience with the artist-in-residency program. In addition to being an innovative program and methodology that should yield rich data to inform our science, the infusion of artistic representation into nursing should make us better communicators of our work and profession and build a bridge between our increasing reliance on technology and numerical quantitative data in health care with the human side of the arts and nursing.

REFERENCES


William J. Doan, PhD, MFA, BA
Donna M. Fick, PhD, RN, FAAN, FGSA
Nikki L. Hill, PhD, RN
Lisa Kitko, PhD, RN, FAHA, FAAN
The Pennsylvania State University State College, Pennsylvania

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