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DooR to DooR's Acoustics of Care: Interrupting and Transforming the Biomedical Landscapes of Western Hospitals

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ABSTRACT

The present study was conducted at the University of North Carolina Hospitals. Data were collected from DooR to DooR (D2D), a healing arts program that brings professional artists into the hospital. Drawing from ethnographic data, we forefront music in health communication literature by exploring its performance by D2D artists in hospital settings that range from in-patient oncology wards, waiting rooms, and even burn units. From a narrative theoretical approach, we situate art programming in the historical development of the contemporary hospital system in the U.S. and our analysis amidst growing bodies of literature on the narrative and aesthetic potentials of healthcare. We offer an in-depth analysis of how D2D's music disrupts the soundscape of UNC hospitals, distracts patients from troubling exigencies, and fosters self-expression and storytelling among participants.

Joy knocked on the door of Room 711 and waited with cautious optimism. Most patients and family members are happy to see her and the accompanying artists, although some choose not to accept the gift she offers. "It's ok if patients prefer to not have company. They have so little agency and choice in hospital settings," shared Joy. "If they don't want to interact with us, then I do not view that as an insult. I view that as an important exercise of choice on their part." I hope Mason and his mom Jenna invite Braima, a West African drummer and storyteller, to enter their room and their lives, if only for a few moments. Jenna opened the door and spoke to Joy in hushed tones. I saw Mason crawl toward the end of the bed and whisper to his mom, shaking his head up and down. Braima offered him a smile, a hint of what was to come.

In a manner of moments, Braima transformed the sterile, even somber, setting of the in-patient oncology ward into a rice field in Sierra Leone. Through a combination of drumming and oral storytelling, Braima narrated life in West Africa and invited Mason to join in by strumming to his own beat. Twenty minutes later, Mason was no longer lying in bed. He was standing next to a Djembe, a common drum used to make West African music, and beating in rhythm with Braima, following his tempo and cadence. In the background was the steady drip and beep of the IV, a machine delivering an infusion of vitamins and antioxidants to Mason. I was struck by the juxtaposition of these sounds, both life-giving in their own ways. The administration of fluids intravenously is a common part of cancer treatment and often used to maximize the body's absorption of nutrients. Such treatments, though necessary, aren't designed to address the socio-emotional needs of patients. With patient and practiced hands, Braima invited Mason into a relational encounter through music and storytelling.

As he got up to leave, Braima promised to return the next day. "You actually drummed me out," exclaimed Braima. "Yeah, you are a very, very good drummer." As we left the room, I was reminded of John Dewey's (1980/1934) reflections on art as communication. For Dewey, the rhetorical power of art is not tethered to individual artists' expressions. Instead, it is the relational nature of an aesthetic encounter that renders it communicative. Those of us in the room this morning experienced art as communication, orchestrated by Braima in a setting once foreign to musicians and artists of all kinds. (Fieldnotes)

DooR to DooR: Healing Arts Program (D2D) brings professional artists like Braima into inpatient and outpatient settings at the University of North Carolina (UNC) Hospitals in Chapel Hill, North Carolina. Founded in 1991, D2D seeks to contribute to healing by "bringing inspiration and solace through the arts" (www.doortodoornc.com). Professional artists visit these hospitals three times a week, spending time with patients, family members, and healthcare personnel in every area of the hospitals. Its philosophy and practices enlarge an otherwise narrow biomedical approach that focuses on the experience of illness as something that needs to be "fixed" through medical technology (Harter, Quinlan & Shaw, 2017) and direct attention to the resilience of patients during difficult health journeys and illnesses. Braima did not address the uncertainties surrounding Mason's diagnosis or the potential long-term late effects of treatment. That said, he addressed the family's suffering in a way that too often lies beyond the scope of biomedicine and in so doing served as a complement to traditional care practices.

Hospital-based arts programs are on the rise (Americans for the Arts, 2018; Lane, 2006). According to Americans for the Arts (2018), D2D is one of the hundreds of organizations in the US and abroad that bring artists into healthcare settings. At the same time, narrative scholars have begun to explore the communicative capacities of art programming in health contexts (see Harter & Rawlins, 2011; Pangborn, 2017a, 2017b; Willer, 2018) and elevated the role of storytelling in health contexts (e.g., Sharf, 2017; Sharf, Harter, Yamasaki, & Haidet, 2011). In this essay, we join this scholarly dialogue by reporting on ethnographic fieldwork conducted with D2D over a five-year period and as part of a larger documentary project (see also Harter et al., 2017; Harter, Quinlan, & Ruhl, 2013; Hurdle & Quinlan, 2013; Quinlan, Harter, & Okamoto, 2014). We extend the conversation by focusing specifically on how music functions as communication in hospital settings. As noted by Harwood (2017), “Communication scholars have paid relatively little attention to music” (p. 3) despite its ubiquitous presence in our lives.

From a narrative theoretical approach, we bring music to the forefront of health communication literature by exploring its performance by D2D artists in settings that range from inpatient oncology wards, waiting rooms, and even burn units. We begin by situating art programming in the historical development of contemporary hospitals in the U.S. We then articulate the narrative and aesthetic sensibilities we brought to this project. Finally, we offer an in-depth analysis of how music functions as communication in the work of D2D artists. Specifically, we explore how D2D’s music disrupts the soundscape of UNC hospitals, distracts patients from troubling exigencies, and fosters self-expression and storytelling among participants.

The rise of art programming in contemporary U.S. hospitals

The U.S. witnessed a revolutionary shift from home to hospital care in the late 19th and early 20th centuries, and then the rise of the institutional hospital, characterized by a sterile environment and efficiency (Rosenberg, 1987; Starr, 1982; Stevens, 1989). In part, these changes emerged from the modernization of America itself, making the hospital a place people went to get well, instead of a place people went to die (Breslaw, 2012; Starr, 1982; Stevens, 1989). As Stevens (1989) noted, “The hospital, like the hotel, the factory, the club, and the symphony, was a manifestation of modern America” (p. 2). At the end of the 19th century, when medicine became more science than art, the hospital reflected the technological advances of the day: hydraulic elevators, steam power, aseptic operating rooms and the new bureaucracy of patient records (Morantz-Sanchez, 2005; Rosenberg, 1987; Stevens, 1989). The introduction of bacteriologically based sanitation measures, more effective medicines (including pain relief), professional nursing, clean beds, and fresh air wards exemplified America’s golden age of medicine, along with antitoxins and hopes for effective vaccines.

American hospitals by and large maintained a Judeo-Christian ethos, grounded in middle-class, “white” values. The scientific changes drastically improved patient outcomes, while the cultural changes (e.g., religious efforts and white

supremacist culture) left little space for the artistry and creativity encouraged in other spaces (e.g., the theatre; Morantz-Sanchez, 2005; Rosenberg, 1987; Starr, 1982; Stevens, 1989). By the 1930s, the arts were largely reserved for National Hospital Day, when community visitors and hospital patrons might hear “beneficial music” over the loudspeakers while indulging in tea and sandwiches at the end of a tour (MacEachern, 1931). The period from 1900 to 1930 also marks the solidification of the modern medical profession in America (Morantz-Sanchez, 2005). Today in the U.S., medicine generally seeks to cure illness and save individuals’ lives irrespective of the costs (Wolf & Wolf, 2013).

The integration of art and medicine represented by D2D exemplifies some recent shifts in assumptions about “quality” healthcare – moving away from a narrow focus on efficiency, aseptic treatment and corporate organization and toward the treatment of the entire patient, body, mind, and soul (Sharf, Geist-Martin, & Moore, 2013). Research points to the health benefits of art programming in hospital settings (Byrock, 1994; Trevisani et al., 2010). Arts have the power to meet patients’ emotional needs and to help them forget pain as well as the power to resolve fears about their future and boost their immune system (Longman, 1994; Stuckey & Nobel, 2010). Cromie (1997) claimed that when patients participate in arts activities, their psychological, emotional and spiritual well-being improve. Participating in arts can improve mood, induce deep meditation, and cause the body to release endorphins that can “ease pain and facilitate healing” (Longman, 1994, p. 66), which ultimately improve health outcomes. Staricoff, Duncan, Wright, Loppert, and Scott (2001) stated that in a London-based program that is similar to D2D, having visual arts and live performances in public areas and wards, a majority of the hospital staff, patients, and visitors reported the arts improved moods and morale, decreased stress levels, and distracted from fears in the process (e.g., Kennett, 2000; Lane, 2006; Rollins & Riccio, 2002; Staricoff, 2006; Stickley et al., 2017).

We are interested in the communicative nature of art-programming, and specifically, the impact of music programming in health contexts. In the next section, we articulate the theoretical sensibilities we brought to our fieldwork.

Narrative theorizing in healthcare contexts

In taking a narrative theoretical approach to understanding a health arts program, we invoke Fisher’s (1984, 1985) assumption that human beings are *homo narrans*, or natural storytellers who use stories to understand and create their worlds (Bruner, 2002; Somers, 1994). Fisher (1984) argued that when we create meaning from symbols and communicate them as stories, we do so to “give order to human experience and to induce others to dwell in them to establish ways of living in common” (p. 7). Narratives serve as a way for people to communicate knowledge, feelings, values, and beliefs (Burke, 1969). Storytelling is also an act of witness (Frank, 1995, p. 40). Illness often turns the body into an object body (Brody, 2003). Therefore, stories are one way to rescue that body. Frank (1995) argued, “Bodies are realized – not just represented but created – in the stories they tell” (p. 52).

Rather than fitting bodies into existing dominant cultural narratives, individuals connect with others in a “reciprocity of witnessing” (Frank, 1995, p. 143). Bearing witness to the lived experience of others is not an easy act, particularly when individuals speak from the chaos of illness, but listeners have a moral responsibility to resonate with others (Frank, 1995).

Hospitals provide lifesaving treatment, operations and ongoing care for serious health issues, but the human capacity to order and embody lived experiences in narrative form helps patients make sense of and contend with their hospital stays. Some scholars have positioned narrative as a vital resource for understanding and then addressing health-related problems (Charon, 2006, 2009; Frank, 1995; Harter, 2018; Harter, Japp, & Beck, 2005; Sharf et al., 2011). Medical scholars and practitioners have become receptive to the value of narrative in the practice of medicine (Charon, 2001, 2005, 2006; Frank, 1995; Kleinman, 1988; Mattingly, 1998). Narrative medicine has focused on the role of physicians and invited them to bear witness to the experiences of medicine through the learning and practice of health (Charon, 2006). Charon (2001) introduced a practice of narrative medicine in which the clinician is competent to recognize, interpret, and then be moved to action by the dilemmas of others. The literature on narrative in medicine focuses on illnesses in patients and how patients and clinicians narratively present and interpret illnesses (Carmack, 2010; Charon, 2005, 2006; Hunter, 1991; Mattingly, 1998).

The process of storytelling – both narrating and witnessing – is an aesthetic act that requires creativity on the part of all participants (Harter, 2009). Consider Charon’s (2006) argument: “The boldness of imagination is the courage to relinquish one’s own coherent experience of the world for another’s unexplored, unplumbed, potentially volatile viewpoint” (p. 112). In this study, we sought to understand how musicians engage in narrative co-creation with patients through aesthetic exchange. Narratives ask individuals to expand our imagination to understand the events facing another individual. To use our imagination is to sustain our capability to move past the limits of our own bodies and to appreciate others’ storied representations of reality. Artists couple imaginative, aesthetic, and narrative rationalities (Harter, 2009) as they bear witness to patients’ experiences and share their own stories.

There is scant medical research on how artists in hospital environments may narratively interact with individuals in the healthcare environment. Most narrative medicine literature is written from the perspective of narrative co-creation between patients and physicians (see Charon, DasGupta, Hermann, Marcus, & Spiegel, 2017, for an overview). How other staff (e.g., nurses and technicians), volunteers, and artists interact, share, and listen to other practitioners’ and patients’ stories and share their own can be viewed as narrative medicine. At the same time, communication scholarship on storytelling and art has failed to foreground how music functions as communication. “Much as we might seek to understand how narratives are constructed and what leads to expect events at particular times in a story,” argued Harwood (2017), “so we also should seek to understand how musical works are constructed to establish expectation, and

occasionally surprise” (p. 56). D2D is unique context that afforded us the opportunity to foreground the role of music and storytelling in hospital-based art programming. This essay answers a general research question:

RQ1: How does music function as communication in D2D hospital performances?

Methods

Our methodological practices consisted of qualitative methods inspired by ethnographic principles. We collected data from participant observations of the D2D performances, in-depth interviews with performers/artists, volunteers, and the founder of D2D. Because this research informed the development of a documentary, we filmed some of the participant observations in regional Emmy nominated documentary, *The Acoustics of Care* (Harter, Quinlan, & Shaw, 2017). Additionally, we completed short in situ interviews with healthcare providers and administrators, patients, and family members who were present during our participant observations (Patton, 2015). Due to ethical constraints, we did not perform in-depth interviews with patients and family members, which may have disrupted medical care in a hospital setting. As a result, this manuscript privileges the voices of artists/performers.

Data collection

Data were collected during a five-year period. The research sites included the UNC hospitals in Chapel Hill, NC. We received written permission to conduct this study from D2D’s founder and coordinator, Joy Javits. We also received Institutional Review Board approval from the University of North Carolina at Charlotte and UNC hospitals. Additionally, all participants completed Public Broadcasting Service (PBS) consent forms granting permission for footage to be distributed internationally in documentary form.

Participant observation. While engaged in participant observation, we took on the role of observers as participants (Lindlof & Taylor, 2002). We assisted artists by carrying instruments, opening doors, and pushing art carts. Our work was conducted in ways that allowed us to observe the interactions between artists and patients, family members, and other staff. We paid particular attention to how scenes were set up, how participants interacted, and the temporal sequencing of events. We observed relational communication patterns (e.g., between patients, performers, staff, and family members), primary scenes of interaction, dilemmas or challenges, and how those were managed (see Morse & Field, 1995). We observed a combined 100 hours of performances, including 28 performing artists, and took 50 typed single-spaced pages of field notes from Quinlan and Harter’s observation of performances.

In-depth interviews. During our fieldwork, we were struck by how the artists’ musical performances shifted the acoustics of the hospital settings. Thus, we included questions in the interview protocol about artists’ perceptions of sound in hospitals, what sound communicated, and how (if at all) they perceived themselves as shifting the typical sounds of hospital settings. All in-

depth interviews were digitally recorded and conducted at the participants' convenience either in their homes, the hospital, or a coffee shop near the hospitals. We interviewed a total of 15 participants including the founder of D2D, hospital administrators, and artists. Participants ranged in age from 31 to 65 years. We did not collect more demographic information (e.g., sexual orientation, ethnic background) as many of the interviews took place in the hospital halls outside patients' rooms or near nurses' stations or in hospital library. Interviews lasted between 45 minutes and 2 hours. After each interview, Quinlan took notes on conversations and events before and after the interviews and aspects of the interview that were surprising or noteworthy. All interviews were transcribed by Quinlan and resulted in 250 single-spaced typed pages.

Data analyses

A qualitative analysis of the data was completed in two steps. The first step was a content analysis with open, substantive coding of each interview and the fieldnotes. In the second step, categories were identified. The analysis of categorical content began with preliminary codes that were refined and then categorized into themes in relation to performers' expressed beliefs about themselves, their art, hospital experiences, and healing (Frank, 2004). After completing five interviews and approximately 20 hours of observations, we used open coding and the constant comparative method to develop themes that are labeled and defined through the participants' own words; these themes provided a framework for analysis of further 10 interviews (total of 15 interviews) (Corbin & Strauss, 2008; Glaser & Strauss, 1967). Once the codes were developed, axial coding was used to track the relationship between key themes and propositions (e.g., disruption of space of the hospital, elicitation of memories) and aided in analyzing of subsequent interviews. Quinlan and Harter met on several occasions (either by phone or when we recorded for the documentary) to discuss initial analysis of interview transcripts and fieldnotes/observations. Quinlan conducted phone "member checks" with six participants after the analysis had taken place in order to confirm that each narrative was well represented and to gather feedback (Janesick, 2000). Later after Quinlan and Harter had completed data collection and the documentary, a medical historian, Johnson, was given access to our data set (e.g., interview transcripts, fieldnotes, all the video footage for the documentary) to further contextualize the findings. All authors met to discuss the data. Our analysis produced a coherent set of analytical themes that responded to the research question. In the following section, we offer a co-constructed account that privileges the voices of participants but also recognizes our position (and power) in selecting and interpreting participants' experiences (Ellingson, 2009).

Findings

Our analysis focuses on how music functions as communication in D2D performances by disrupting and transforming the traditional soundscapes of hospitals, distracting patients from health-related exigencies, and fostering self-expression.

Disrupting and transforming the landscapes of hospitals

In patients' rooms and in surgical theaters, cardiac monitors beep while green lines graph heartbeats. Respirators hiss as tubes supply oxygen. Monitoring and life-sustaining technologies click, whirl, drip and occasionally erupt with warning signals, auditory reminders of patient health and safety. We witnessed D2D interrupt this soundscape and enlarge the acoustics of care. Meanwhile, D2D artists described how they provided disruptions for patients in terms of how the space and routines of the hospital are organized. In this way, music, like other forms of communication, brings into existence different ways of knowing about and experiencing our surroundings. The social construction of hospitals and the roles performed by inhabitants are shaped in part by sounds that are present (or not).

Hospitals are organized with the expectation that patients are passive. Due to their bureaucratic nature, hospitals are highly structured and routinized (Hunter, 1991; Montgomery, 2006). As Morantz-Sanchez (2005) noted, bureaucratization and professionalization were hallmarks of social change and modernization in early 20th century America. Hospitals sought to reflect advancements in both medicine (as science rather than art) and bureaucratic institutional models. Thus, advancements in bacteriology and lab science, new diagnostic procedures (e.g., the x-ray), and surgical advancements were buoyed by an increasingly complicated paperwork and filing system, including individual patients charts and payment plans (Morantz-Sanchez, 2005; Rosenberg, 1987). As technology improved and bureaucratic systems expanded, the biomedical model calcified, making considerations of the patient's environment and the patient as an individual less useful and less pressing.

Given the particular history of hospitals in America over the last century, the co-creation of narratives, rooted in an aesthetic experience, are inherently acts of institutional disruption, by using storytelling to create an alternative order (e.g., a pleasing aesthetic experience) from disorder (e.g., illness and hospitalization; Charon, 2006). For patients, being in a hospital is very difficult because they often feel as if they have no control over their bodies, schedules, routines, and time; their very presence there is a personal disruption. Some routines are very predictable, such as having their blood drawn in the morning to help doctors decide what to do during the day. In addition to blood tests, a patient's vital signs (e.g., blood pressure, temperature, oxygen saturation, heart rate) are taken regularly. Many patients in the hospital have had or will have a painful surgery or procedure. D2D artists bore witness or attended to patients' pain, loss of control, fear, and anxiety and, thus, disrupted the power of that narrative. Helen, a musician and certified music practitioner who plays hammer dulcimer, remembered playing for a young patient during a painful respiratory therapy:

I remember one time someone saying to me... that she could feel the baby's heart rate go down... I've had nurses come in and say that a baby's pulse hasn't been that low all day... one time [I] had a chaplain say to me "You've just performed a medical miracle." This child slept through... the therapy where they bang their chest, respiratory therapy... [music] is effective. It was amazing

the pulse and the measure of the heart rate actually showed a decrease...based on the music.

Helen's hammer dulcimer provided a disruption by relaxing and calming the child and allowed for a lower heart rate and falling asleep during a painful procedure. Callie, a singer and guitarist, gave an example of a child whose crying ceased so that a phlebotomist could draw blood. She said:

...two or three notes into [the song], this always makes me cry, the child stopped crying, like completely stopped crying, and they [mother and child] smiled through their tears and the mother was incredulous because nothing would soothe this poor child. The entire time that I played, [the child] didn't cry... and it allowed the technician to finish taking [the child's] blood.

This disruption created harmony for the child during an uncomfortable, likely frightening procedure in the unfamiliar space of the hospital.

Hospital employees also spoke to the way music and art disrupted sights and sounds now common in the American hospital. Chaplain Carl Clark noted that hospital sounds "are stressful and it's amazing how many different sounds are clamoring for our attention." Director of Patient Relations Shane Rogers noted that many of these sounds "are meant to catch someone's attention – remember they're meant to be intrusive...having an artist come in...is very different." Rodgers also noted the benefits to the staff: "It was nice to have the artist come in and not for the patients' sake so much for the staff." Art and music disrupt the sights and sounds of the hospital landscape for both patient and provider, allowing each a respite from the stress of their roles.

A second way artists narrated disruption was by complicating the notion of the passive patient. "Patients are expected to play a 'sick' role in which they passively and cooperatively submit to the expert opinions of the professionals" (Eisenberg, Baglia, & Pynes, 2006, p. 205; see also Parsons, 1951). This expectation emerged as patients began to choose the hospital for treatment (instead of hospice) and doctors were able to offer more effective treatments and produce increasingly positive outcomes (Morantz-Sanchez, 2005; Rosenberg, 1987; Starr, 1982). D2D artists bore witness to how patients lack agency in a hospital setting. Joy Javits recalled:

Patients, young and adult, rarely have the opportunity to say to whomever is knocking on their door, "No, you may not come in." Generally, it is a nurse who cannot even spare the time to wait for an answer, if one could be heard through the door, or food services with a meal to bring in or a visitor.. but I ask my artists to wait for an answer... then tell the patient, with my artist visible behind my shoulder, who we are and what we would like to do and then pause. Sometimes there is a longish silence while they try to figure out who on earth would be bringing ... What? Music? Into their room? When they choose to say..."No, thank you," I think it is empowering. At last, a decision they can make, not one told to them, demanded of them. A relief to be in charge again as they likely are at their home, a moment of decisiveness... a moment of power... And then they often thank you for the offer. This too puts them in charge.

It is unusual for patients to be able to decline or refuse much in a medical setting, and D2D offers an occasion for agency, freedom, and choice – again, a disruption of the typical hospital-based patient experience. Young and Flower (2002) coined the term

"rhetoric of passivity," which is the idea that patients should obey what caregivers say to do. Young and Flower (2002) suggested a different model of communication based on the "rhetoric of agency" that acknowledges patients as co-agents in health encounters. Their model of collaborative interpretation (CI) advised that health communication is most successful when patients are decision makers and problem solvers and when caregivers function as friends who work together with patients to help them complete common objectives. CI cannot happen if patients are unwilling to share their stories or take an active role in healthcare transactions. Also, CI will not happen if providers cling to patriarchal (e.g., power as "top-down") ideas of what is best for patients. This model does not privilege caregivers or patients. The goal of the D2D experience is to confirm the experience of both patient and provider while respecting the patient's wishes.

In literary narratives, a villain usually creates the disruption (Propp, 1968). However, artists do not envision themselves as villains. Instead, artists discuss the ways in which illness is a disruption of the equilibrium for patients. Artists can enter into the scene and recognize the disruption and attempt to reinstate balance for the patient. Charon (2009) proposed that narrative medicine is a means of bridging the "chasms and divisions and discontinuities" of healthcare and the experience of being ill (p. 197). Even when there is nothing a professional can do to cure a patient, the act of being present with the patient is therapeutic and affirming. Charon (2006) noted, "One knows, one feels, and one responds, and one *joins with* the one who suffers" (p. 12, also cited in duPré, 2014, p. 71).

Given that musicians partner with the person who is ill, the "passive patient" role is disrupted through the social process of *musicizing* (Small, 1999). We argue that this benefits the patient-provider relationship as it provides an opportunity to help patients use voice and gain legitimacy and agency (Sharf & Vanderford, 2003). As patients, providers, and artists co-create new narratives, more embodied, human medical procedures and experiences can result for all involved.

Providing distractions from health exigencies

Music also functions as communication by focusing patients' attention away from health exigencies. Artists told stories of the ways they provided a distraction for patients from physical and psychological pain. Many healthcare professionals consider pain management critical not only to patients' recovery but also to their own positive engagement with a healthcare facility. A healthcare provider's ability to understand and respond appropriately to patients' pain affects those patients' overall experience with their care provider. Music has been widely studied as a cost-effective way to reduce depression and pain levels, making it an art form well suited to the goal of physical and psychological pain reduction (Anderson Schorr, 1993; Angus & Faux, 1995; Chan, Wong, Onishi, & Thayala, 2011; Longman, 1994; Nauert & Johnson, 2011; Silverman, 2011; Wang, Wang, & Zhang, 2011).

Artists told stories of patients being distracted by the music from physical pain after an interaction with a D2D artist. For example, Helen, musician, hammer dulcimer, and certified music practitioner recalled: "Someone told me the whole hour I was

playing for her ‘I’m constantly in pain, but the hour you played for me, I felt no pain at all.’” Joy shared another memory of when she observed Helen interacting with a patient with her hammer dulcimer:

[D2D] brings healthy life into the patient’s room, and encourages them – to deal, to think – to go somewhere else with their minds and emotions away from the worry and the pain. [A] gentlemen had a lot of pain in his hips after surgery... the nurse arrived when I was there with a dancer who was having him move his hands and arms just a little bit. He said to the nurse, “I don’t need the pain medicine. Take it away.”

In both above examples, a musical experience with D2D led to a decreased need for biomedical intervention. In one very powerful exchange, Dawn, a musician and pianist, recalled a severely injured child who was distracted by a lullaby:

I visited a toddler in the burn unit. He was between 1 and 2 years old and crying inconsolably. I had a keyboard and as I played the beginning notes of “Twinkle, Twinkle Little Star,” he stopped crying immediately and didn’t cry as long as I continued to play. His mother danced with him in her arms, and you could see her smiling and tears streaming down her cheeks (presumably relief at his stopping crying). As a person with strong faith, and a strong belief in the power of music, even I was awed by the effect of this simple song on a young child in pain.

This simple nursery rhyme played again and again on a piano provided respite from the severe pain stemming from fourth-degree burns (see also Ryan, 1994). D2D artists told us that they were most needed where there is the greatest physical and emotional pain. Laura “Lulu” has her doctorate in education focusing on Arts and Education. She is an actress, dancer, musician, and singer, who often appears at the UNC hospital dressed Mother Goose singing for patients with the D2D program. Lulu said:

I know from experience that it touches them with some form of joy... If you put a smile on someone’s face – ah – that is a joyful experience, I tell you – especially the worse off they are health wise or emotionally, the more important it is. But if you can just see a peace, see the worry lines just relax... it’s just so important.

In addition to physical pain, artists narrated that their presence in a hospital setting draws patients’ attention away from psychological pain such as stress, depression loneliness, anxiety, and worry (Cromie, 1997; Daykin, Byrne, Soteriou, & O’Connor, 2008; Nauert & Johnson, 2011; Staricoff et al., 2001). Leslie and Suzanne shared:

[Patient said] “I feel so much better now that you’ve been here you know I was feeling lonely or I was hurting.” (Leslie, musician, cellist)

In November 2009, in the ICU, a 51-year-old woman diagnosed with pneumonia and sepsis received a 25-minute therapeutic session with my lyre...the nurse said, “Go ahead and give it a try but if she becomes agitated, stop.” The patient stayed calm throughout the session and all her vital signs improved: Heart Rate 117 to 109; Oxygen 91 to 94; Respiration 40 to 24 and Blood Pressure 172/85 to 125/62. This was a remarkable testament to the value and efficacy [of music]. (Suzanne, a certified music practitioner, musician)

We found that the narratives created between the D2D artist and patients often provided a therapeutic lens through which individuals make sense of “inner hurt, despair, hope, grief, and moral pain” (Greenhalgh & Hurwitz, 1999, p. 48). There

is also the physical effect mentioned here, suggesting that art has a biomedical impact as well, disrupting pain and agitation with the relief of aesthetic comfort.

The “success” of narrative as a therapeutic activity depends on individuals’ ability to construct a narrative of healing and coping (Launer, 1999). Interestingly, Leslie and Suzanne did not speak about psychological pain in isolation from physical pain. Suzanne used biomedical indicators to attest to the benefit of music for the patient’s vital signs. Indeed, pain management must address both the physical and emotional aspects of pain. Research is consistent that effective communication can modify people’s experience of pain. In an emergency department, while about 98% of abdominal pain sufferers told a provider they were in pain, only one-third of them asked for pain medication (Yee, Puntillo, Miaskowski, & Neighbor, 2006). Patients may be afraid of bothering staff or appearing weak. Also, nurses reported being less stressed and burned out when their patients experience less pain (Fuchs-Lacelle, Hadjistavropoulos, & Lix, 2008). As we discovered, integrating artists into a medical encounter may help patients and providers build a relationship where patients experience less pain due to distraction and redirection, even improving their vital signs.

The benefits of D2D artists bearing witness and providing artistic distractions from physical and psychological pain for the patient are numerous. For example, arts programs can help shorten hospital stays and lessen patients’ need for pain medication (Lane, 2006), both which positively impact patient-provider relationships within the hospital. Providing artistic intervention is a relatively inexpensive way to foster a healing process for patients with fewer addictive potentialities.

Fostering self-expression

D2D artists recalled the ways in which patients were encouraged to share narratives of self-expression after musical interactions. Narrative medicine involves compassion, engagement, and a respect for the uniqueness of each (Charon, 2006). Harter et al. (2013) argued art “can be a powerful vehicle for expression” (p. 33). Narratives and by extension experience can be liberated by providing space for storied expression. D2D artists bore witness to patients’ need, through art, to tell stories. Hospitalized individuals often struggle to maintain an identity beyond or outside their illness while they attempt to reconcile their previous identity (or identities) with present circumstances (Charmaz, 1987). Artists shared how patients were given space to merge identities. Kim, a singer, songwriter and poet said that participating in the creative process allows patients to be reminded of their identities. She articulated:

... [patients] deserve to come in contact with a person who doesn’t blame them for their illness but understands that I believe everything can be healed and when I say that I mean healed even if it’s just accepting mortality. Or if you go into remission, or if you accept whatever is your fate and I think reminding you of who you are helping in that process.

Individuals use narratives not only to make sense of experiences and change, but also to claim, express, and enact

multiple and sometimes divergent identities (Langellier & Peterson, 2004). Even when curing is not possible, music can improve the healing process (Lane, 2006; Olson, 1998). Others noted that D2D provides a space for individuals to move beyond the submissive patient role. Joy Javits remembered a time when a patient said “Thank you!!.. for treating me like a person instead of like a patient.”

Artistic forms invited patients to share their identities. Callie, a singer, told of a patient with Alzheimer’s Disease (AD) who was also a singer:

Music seems to really transform a situation, and it heightens their level of experience... when I sing to Alzheimer’s [patients]... a woman came in, she had taken her lipstick and had dotted all these dots all over her cheeks, and it was hot pink lipstick and I thought well poor thing she is completely out of it. She sat down and we started doing these Jazz standards, she knew every single lyric of every single song. I was just so blown away by how she knew every single lyric, more than I know the lyrics, and I went over to her afterwards and I said were you a singer? And she said “yes I sang, I sang all over the world”... she can’t remember her name, she can’t remember anything and in her daily [life] there is no connection, but when music starts... I have seen that over and over again.

Without a musician in the room, care providers may not have had the opportunity to learn about the patient with AD and their musical background. Similar studies have reported that in patients with AD, music and other forms of art cause physical and emotional responses that energize the mind and body (e.g., transcending memory loss; Holmes, Knights, Dean, Hodkinson, & Hopkins, 2006; Kneafsey, 1997).

Another artist shared a patient’s experience of music providing an escape even while heavily medicated during a surgical procedure:

Well because [of] very powerful sedative, the doctor said it could be very difficult for [the] patient. But what [the patient] told us... was that he had this incredible dream the whole time he [the patient] was underneath, that he was on a Caribbean vacation. [The patient] was born in the [Florida] Keys...I made my living playing the Keys music. So these are the songs that I played. I was sending him [the patient] on this voyage, not with words...When we sing or when I sing, it opens the door to a whole other level of communication. (Richard, singer and musician)

In this instance, a shared cultural knowledge allowed for a uniquely individualized, positive patient experience during treatment (see also Charon, 2006; Quinlan et al., 2014).

Other artists told stories about how engaging in the artistic experience provided emotional support, which allowed patients to vent feelings, share concerns, and feel safe.

Callie, a singer, said:

... those moments for me have been the most powerful because I have realized they probably haven’t shared that with anybody else. They may not be sharing that pain with a nurse or a doctor or whatever, but because a song has triggered a memory...it draws them out to share it. [Music is the] quickest most immediate way to get to the heart of what it is you most are moved by, are struggling with... people share really intimate things and need to feel safe to do that.

Callie revealed how artists listen and bear witness to patients’ emotions and feelings and provide a safe place for them to illicit emotions and express them. As she indicated, art allowed this patient to explore suffering (Byock, 1994), a part of self-expression that may help relieve stress. Not all individuals can tell their story. In a medical setting, patients may be silenced or not have the vocabulary through which to express their experiences (Clair, 1993; Giddens, 1991). Some patients’ stories may be forbidden (e.g., stories that include medical errors or highlight potential hospital liability; Carabas & Harter, 2005). Limitations in forms of self-expression, the power to communicate, or via censure all curtail individuals’ abilities for self-reflection and the potential for organizational change in healthcare. Aesthetic means may allow individuals an opportunity to wrestle with tensions that are difficult to express (e.g., limited language to talk about death and pain).

Narratives may provide a space for moving past experiences and may allow patients to tell hidden truths. Patients desire to be heard and respected and tend to be more satisfied when caregivers are concerned and have empathy for what they are feeling (Jadad & Rizzo, 2003; Jangland, Gunningberg, & Carlsson, 2009). Narrative provides an important “road toward empathy and reflection” (Charon, 2006, p. 113) and can provide opportunities for individuals to co-create a new reality.

Other artists described patients as having “communication breakthroughs.” Joy shared a memorable moment:

... [there were] three adult children of an older woman. I brought a group of six or eight [singers]. They gathered all around the bed of this woman, invited by the daughter to come in. They were all around the bed, and they sang to her...Later [the daughter] came to find me and she said, “My mother hasn’t talked for days and days... She started talking right after the singers went away.” That was a pretty phenomenal time.

Stories are told in and through the body (Sparkes & Smith, 2008) and can function as a conduit, leading to greater understanding of how a person’s notion of the self is changed by illness. The patient is communicating with her family after an aesthetic experience shows that narrative is inherently dialogic (Harter et al., 2005) and involves “mutual interplay of telling and listening” that constructs ongoing interaction” (Carmack, Bates, & Harter, 2008, p. 92).

Self-expression through aesthetic storytelling has numerous benefits, such as communication of identity and emotions and communication breakthroughs, unlike the traditional biomedical model that limits communication about an illness, marginalizes patients’ feelings and social experiences, and regards patients as impersonal collections of symptoms. Including D2D artists in the hospital setting can allow patients to share narratives that reflect upon their own experiences, lives, and relationships. D2D artists were supporting the biopsychosocial model (which simultaneously considers biological, psychological and, social factors), and considers patients’ physical conditions and their thoughts, beliefs, and social expectations. D2D artists embraced the idea that illness is not solely a physical phenomenon.

Conclusions

The artist knows when the patient needs a warm smile, reassuring words, or a gentle hug... artists who make every patient feel welcome, comfortable, secure, hopeful. The artist sees the anxiety and reassures the new mother that her baby's fever is nothing to worry about. The artist...helps the patient and family cope with end of life. What the artists does is why I became a physician. (Dr. Denis Corese, physician; Berry & Seltman, 2008, p. 1-2)

As Morantz-Sanchez (2005) posited, hospital care shifted as “doctors...gradually [started] to overlook treatment of the whole patient, concentrating instead merely on the disease. The nurturing aspects of nineteenth-century practice, with its heavy emphasis on intuition, sympathy, and art” gave way to the biomedical model familiar to us today (p. 202). This transformation of both medical and hospital care in the wake of the bacteriological revolution in medical science improved treatment, outcomes, and survival rates, but flourished “at the expense of a holistic approach to the problem of illness” (Morantz-Sanchez, 2005, p. 202). As a result, disruption, distraction, and self-expression are necessary practices that “re-humanize” the hospital space, particularly as holistic approaches to disease treatment become popular once again.

Our analysis points to how music communicatively functions as disruption, distraction, and self-expression. Illness interrupts the storyline we imagined for ourselves and “sickness summons” stories (Harter, 2009, p. 141; also cited in duPré, 2014, p. 70). In turn, we observed how music disrupts the often otherwise sterile and foreign settings of hospitals and musicians’ performances invited patients and families to express themselves. Music is ubiquitous in our everyday lives. We hear music when we watch television or at the theater. We turn on music when while we drive or exercise or cook. Music can elevate our mood, console us, and even anger us (see Harwood, 2017). Most of us can even identify soundtracks that mark key chapters of our lives. The communicative power of music rests not simply in the content but in social experience of *musicing* (Small, 1999), a process that involves participants whose interactions in specific settings are informed by tempo, rhythm, and lyrics.

Charon (2009) reminded us that narratives help bridge the gap between people and also what she called “the unstable gap between the body and self” (p. 122), facilitating the union between a person’s body and one’s “totality of being” (p. 124). Narrative medicine requires acknowledging and having respect for people’s stories; it is predicated on the assumption that storytelling unites the teller and the listener through shared experience with profound implications for life and healing (Charon, 2006). Narrative medicine involves a commitment to deep and sincere listening, a belief in the power of stories to heal and reveal what needs healing, and the courage to inhabit another person’s point of view for a while. As we witnessed with D2D musicians who embraced narrative medicine practices, storytelling is a natural way of making sense of the world, and can positively affect patients by offering them the space and a process through which to make sense of the hospital world.

Patients are “wounded storytellers” who attempt to heal by sharing stories with others (Frank, 1995). Artists articulate the ways in which narratives are a source of healing and comfort

for patients. Kennett (2000) wrote that ill patients often suffer from a “social death” (p. 419). By integrating musicians in hospitals we can improve patient–provider relationships by interrupting the hospital space as it emerged in the late 19th and early 20th century, and as it calcified into a corporate structure in the mid-20th century (see also Rosenberg, 1987). As interest in and scientific support for holistic models emerge within medical praxis in the 21st century, the disruption of the technocratic hospital structure requires narrative medicine, aesthetic care, and the co-creation of meaning, allowing for an engaged treatment experience for patient, practitioner, staff member and artist alike. This engagement can include music, which positively impacts the experiences and sensory world of both patient and provider. By sharing illness experiences, with the support of artists, we can create opportunities for individuals (e.g., patients and healthcare provider) to disentangle their illness narratives with music as they become partners in care.

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