

Qualitative Inquiries in Music Therapy
2022: Volume 16 (Monograph 4), pp. 103-109.
Barcelona Publishers

RE-STORYING EXPERIENCES OF VOICE AT THE END OF LIFE

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RE-INTRODUCTION

Solvitur ambulando.

This Latin phrase – attributed to early Christian theologian Saint Augustine and meaning *it is solved by walking* – comes to mind as I approach re-imagining my research, entitled “A Narrative Exploration of the Music Therapist’s Experience of Patient Voice in Hospice”. Navigating my research (imperfect as it was) required a willingness to walk an emergent path with each participant and the process as a whole. As I engage with the manuscript again in hopes of generating something new, I focus especially on (1) the limitations of my inquiry that point toward obscure potentials, and (2) three themes I might explore differently now. Through my writing, I also experiment with the possible meanings—personal or collective—of circuitous or topographic approaches to storytelling.

Worlds are spun as stories are told. Story, storyteller, and listener transform over time through voiced account. As in following a trail, narrative researchers, participants, and listener-readers yield to the terrain of the present moment in a wilderness of infinite paths. Thus, commitments to mutable meaning-making and embodied engagement inform my exploration/explanation. My writing structure emulates a hike wherein one sets out in a specific direction; wanders, loses, and rediscovers a way; then eventually finds or creates a route home.

It is solved by walking.

SETTING OUT

When I begin a hike, a subjective egoic experience is at the fore (“Here I am, and here I go to do this.”). That is how I find myself stepping into re-storying, too, grounding first in where I find myself since the research was published and my impressions from this location.

Trail limits

Circumstances at the time of my study applied considerable pressure to the inquiry process. I conducted the research for my graduate thesis, and initially imagined the study would be something very different from what it became. After planning an arts-based project with patient participants, I learned of a new regulation with my employer that made that study impossible to conduct. A narrative study with non-patient participants became the methodology to appropriately hold my research questions – which centered lived experiences of voice – given these limitations. The impact of these limitations helped me discover a latent interest in storytelling and interpretation, though; after the study, I found myself attending narrative medicine workshops, reading fiction and poetry after a hiatus, and seeking non-fiction writings from authors who speak in myth (Kenny, 2006; Pinkola Estés, 1992; Roth, 1998; Wall Kimmerer, 2013; Ward, 2003; Woodman, 1985). What seemed at the time a pragmatic decision to study story (a decision not lacking

frustration given the external demand to change my desired method) became a catalyst for later inspiration.

What mattered then? What matters now?

In my research, I asked participants to describe an encounter they deemed significant. At this juncture, I question what I deem and deemed significant in (re-)storying experiences of voice at the end of life. I still feel uncertain about the relevance of my research questions and the integrity of my process. Although art and research that privilege the unknown capture my attention, building up my tolerance for the unknown is still a challenge. As a first-time researcher and new clinician at the time of this study, I worried that my approach, findings, and motivation for asking questions was somehow wrong. Supervisors and colleagues helped me recognize that certainty and mastery – both easily-internalized vestiges of imperialist and patriarchal systems – are not prerequisites for sharing my voice.

Perhaps the development of researcher and participant efficacy is of equal value to the development of findings that advance theory or practice. The goal of my study was as much to complete it (and remain intact enough to go about other responsibilities) as it was to discover something meaningful. I imagine many student researchers can relate. This feels to me like a reasonable reality and a disappointing limitation that challenges my ideal image of why we research. Nevertheless, if a more engaged professional community results from more clinicians getting their hands in research and publishing, then student research has an important function independent of study results. Since validity and significance are more holistically determined in qualitative research than in quantitative research, perhaps broad engagements with qualitative inquiry among professionals of varied experience levels is an avenue toward re-storying the music therapy profession into a more inclusive field wherein many voices comprise our body of expertise. Perhaps the graduate student working to *get the thing done* symbolizes the potential of research labor to be developmentally meaningful in the life of a practitioner.

Switchback

Circumstances, people, and inner narratives in my life have changed since conducting the study. Colleagues, mentors, friends, therapists, my spouse and pets, the land I live on continue to teach me about potential and limitation. Personal and collective life at the time of this writing also teaches me to respond to limitation with creativity and acceptance.

FINDING AND LOSING THE WAY

Inquiry is made most generative when based in relationship and grounded in a resonant purpose. As I continue re-storying my research, I ask, *What current needs could this research engage?* and *What missing pieces, if recovered, could expand the meaning or impact of this research?*

I got lost repeatedly throughout the research and writing process. As I re-engage it now, my wandering/wondering replicates that sense of pathlessness. Like a hiker drawing attention away from their location on a map to direct experience of the flora and fauna

surrounding them (“Who/what else is here? How/what is the environment communicating?”), I will now try to move from initial introspection toward a more contextual, collective orientation. I highlight three themes that have cracked opened for me in response to unfolding experiences and relationships since the study ended, and that I would re-story or epilogize in the manuscript now.

On anxiety

A conversation with a QIMT editor emphasized for me the current anxiety in collective experiences with death and voice. The continued unfolding of a global pandemic in which respiration signifies danger and death is encountered at scale demands a deep reckoning with our relationship to breath, death, and truths therein waiting to be voiced. Further, systems of scarcity that fuel widespread interpersonal turmoil and ecological devastation threaten our biological and spiritual wellbeing with increasing speed. To not reckon with these realities metastasizes collective distress to which none of us are immune.

Languageing our experiences with voice or death in the face of distress is a powerful antidote to disconnection and dehumanization, but activates anxiety. Anxiety about voice among music therapy patients and practitioners sometimes seems as pervasive as the death anxiety described by Yalom (2009). To contemplate my voice or my death presses directly into my sense of identity. Without my voice, (who) am I? Without this life, (who) am I? One of the first things we do at birth is inhale and scream, and one of the last things we do while dying is exhale, sometimes with raspy or intoned breath. Vocal sound bookends the story of the body. Sharing stories of our observed and embodied encounters with voice and death *contain* the encounters such that surrounding anxiety can be reckoned with. The structure of story and the process of telling provides an ancient system to investigate forces beyond our capacity for direct experience. However, to *live* rather than only investigate unfolding stories of voice and death requires sustained, committed engagement with self and story. This is what Clandinin and Connelly (2000) call “living a life story” (p. 71). If we are to meet the challenges of this time in our planet’s story, we must not merely enter but must sustain the task of facing anxieties related to death and voice.

To sustain engagement with this difficult territory requires a story-space be mutually held by storyteller(s) and listener(s). While my study opened a temporary portal into story-space, the process was not slowed and stretched deeply enough to engage participants at the level where story is most psycho-socio-spiritually potent. If I conducted the project again, I would include systematic debriefing with participants following data collection. If time constraints were generous, I would change the procedure to include the debriefings as additional data, or interim texts (Clandinin & Connelly, 2000). Even without a chanced procedure, though, debriefings would improve study’s impact; an optional post-study follow-up with participants examining how they continued to live with the stories might have more fully expressed narrative inquiry’s potential to help participant, researcher, and even peripherally impacted persons like family make meaning of vulnerable experiences. Peer-supported reflection of this nature can also clarify for end-of-life clinicians the legacy of a deceased patient, which may then be shared with related bereaved persons if appropriate and/or internalized to support the clinician.

On Othering

The collective story we are living seems to be – from my location – one with increasing consciousness and urgency to recognize and dismantle the bodily hierarchies we have created, particularly racism. Each storyteller in my research referenced cultural intersections present in the therapeutic encounter; race was an explicitly named aspect of experience deemed significant by two participants and strikes me as acutely consequential. I wish I had posed more questions of myself and the participants about race in their stories.

I consider my own experiences hearing the voices of patients of different races (I am White). Although I have not narratively investigated my experiences with the Black, Latinx, or Asian patients I have seen, stories of these experiences live wordlessly in embodied memory. My experience as a privileged racial outsider in such experiences undoubtedly impacts my storying of the experiences. When, as a member of a socially dominant group, I story an experience with someone from socially Othered group, I risk exoticizing or superimposing prejudiced meaning onto the experience.

I wonder how culturally embedded notions of sameness or differentness impacted my sense as a researcher about whether I was encountering a story about *us* or about *them*. And I wonder whether participants heard themselves or heard Other in the stories told. I suspect there would be no cut-and-dry findings related to these curiosities, and I wish I had allowed my analysis to be further complicated by such vital complexities. Telling and hearing stories codifies reality and contours memory. Narrative research devoid of such complication perpetuates the harm of silenced truths and unvoiced actualities. To complicate my analysis would require gathering additional information on participants' cultural identities. Additionally, interim texts like those recommended in the previous section could explore the influence of self/other projections storied into each experience.

Narrative not only cultivates personal meaning-making but is an avenue by which communities co-create life stories. Rather than relying solely on two-way data exchange between me and each participant, I could have also gathered participants to engage with and respond to one another's stories. Listening and sharing in community might have provided an opportunity for the shared life story of music therapy in the United States in 2016 to be freshly engaged, reconsidered, and reimagined, even at the most micro level. Perhaps small and close dialogues grounded in story are a necessary part of rooting more culturally responsive life stories in our professional community.

On interpretation

A persistent thread in my own professional life story is the privileging of lived experience as the primary source for understanding truth. As a beginner student of phenomenological philosophy I recognize there are unexamined layers of my data that would have mutated differently by employing, for instance, a hermeneutic methodology. When I consider whether the meaning or impact of the research would be improved by using another related method, I am of mixed mind. While hermeneutic inquiry would have provided a more formal philosophical lens through which to interpret participant stories, "narrative inquirers tend to begin with experience as lived and told in stories" (pg. 128). The focus of narrative inquiry on *story* and *storying* subtly contrasts with the focus

of hermeneutics on *interpretation* and *interpreting*; my sense as a researcher is that de-emphasizing interpretation in this study endorsed the innate adequacy of raw participant data. The time and resource constraints that shaped my process rendered for me an unpolished, constructed quality to the experience, and in retrospect, allowing the data to stand without further interpretive efforts reflects that quality. Still, I am curious about what would have come had I utilized a hermeneutic approach.

RETURNING HOME

In her poem titled “The Return”, Mary Oliver (1992) references the Greek myth of Theseus and the Minotaur. The protagonist winds their way out of a labyrinth, following a thread unspooled during the journey inward. I took several walks while writing this, perhaps trying to find a thread. I seem to have found fibers, and don’t expect to stop searching. Perhaps the work of re-searching is staying with the dislocated fibers; for the reflexive inquirer, seemingly well-marked paths may only lead to dead-ends.

Tenuous though the thread, it heartened me to tread again the labyrinth. I hope there is something of use here for others who wonder what could come of re-imagining research. I hope we as music therapists continue to invite one another to look back, to reckon with potential and limitation, and to refine our attempts to understand this multifaceted work and the people engaged with it.

Retrospective engagement with former research can serve as a mirror for selves and systems. As posited by Clandinin and Connelly (2000), “narrative inquiries are always strongly autobiographical” (p. 121). Since re-imagining this inquiry comes at a time of personal and collective revelation as well as rapid change, the mirror feels more like a microscope or telescope. To remain responsive and responsible at this time in the global narrative, perhaps we need to re-story ourselves as researchers. And perhaps we begin by looking at where we have been. If research is a series of trails with no point of arrival, let us story journeys that sustain embodied engagement and meaning-making in the world within, around, and between us.

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