Full-Length Article

Shame and its Soundscapes

Zoe Tao[1]

[1]*The University of Texas Southwestern Medical Center, Texas, United States of America*

Abstract

This essay comprises an experience creating a collaborative musical artwork with a resident of a community hospice that serves the needs of primarily HIV-positive individuals. In this essay, I provide a reflection as to how experiences of social marginalization may become embedded in one's sense of self, such that that they see themselves as shameful, less human, and the societal "other." I utilize a combination of first-person reflections and critical third-person interpretations of this experience and this artwork via literature in Psychology, Epidemiology, Music Therapy, Queer and Gender Theory, and the Medical Humanities to contextualize affective and social conditions that tend to produce experiences of shame.

Keywords*: medical humanities; hospice; community art; shame; minority health*

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Introduction

The reflections and analyses in this essay explore issues of shame, musical artworks, and healing primarily through informal and experiential perspectives. In this setting, I was a college senior entering medical school the following year, having been a volunteer in this hospice for nearly 4 years. My role in the experience described in this essay was to share an artistic and musical experience via personal accompaniment and psychosocial support while the patient was a resident, given the pseudonym Oscar. In this artwork, Oscar expresses themes of both love and shame relating to spirituality, familial exclusion, immigration status, and HIV-positive status.

While for this artwork, I aimed to elicit and validate an individual's voice to express shame and create possibilities for transforming the hurt and suffering accompanying this shame, I am not a therapist and do not yet have professional healthcare credentials. I was a volunteer who saw a window of opportunity to create an artwork with a patient who shared my love of music, and with the blessing of the hospice staff, proceeded to write a song with them. My work is based on the perspective of art as an informally human rather than a clinical phenomenon. *Art in Action: Expressive Arts Therapy and Social Change* introduces the concept of *poiesis,* which stipulates that art is "an extension and development of the basic capacity of human beings to shape their worlds."[1] Art grants and expands upon this "world-building" capacity, and accounts for the ways in which individuals are profoundly shaped and misshapen by social and cultural phenomena.[1] In this sense, the process of creating art was a window into the world of a person who otherwise would not have had the means or materials to write music and record a song.

Methods: why musical artworks for shame?

My own efforts to humanize experiences of shame are through "assisted artworks," defined by MD Anderson Palliative Care Artist-in-Residence Marcia Brennan as poetic artworks which encompass a patient's words verbatim in a structure curated by the bedside artist, and can embody experiences ranging from spirituality and well-being to loss and social isolation.[2] Building from this method of creating assisted artworks, I conceptualize myself as accompaniment, both musical and interpersonal, to create tangible representations of experiences of shame. While the musical and psychosocial accompaniment I do is not music therapy, I believe that these assisted artworks embody several basic principles of music and art therapy by virtue of co-creating the artwork itself; from my standpoint, this act gestures to the person that a fellow human being wants to help capture them in a tangible form, and wants to do so by listening to them describe their lives and their self in their own voice. The affective power of creating art can come from the "aesthetic response," when the art – which lives in an "imaginal" form – comes to "touch people's literal reality" as they see or hear what they have created.[1] A given person's beauty may remain unknown to themselves without accompanying artists to capture these voices, words, and portrayals of life, especially if this person has been marginalized by society-at-large.

The impact of illness on identity loss extends more broadly to medical diagnoses that carry with them disability

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Zoe Tao, E-mail: zoetao1@gmail.com| COI statement: The author declared that no financial support was given for the writing of this article. The author has no conflict of interest to declare.

and complex psychosocial difficulties. In an article on the role of music therapy in the lives of patients with terminal cancer, the authors discuss that cancer has adverse effects on not only one's physical wellbeing but also on one's identity, describing patients' lives as "denuded" by a terminal diagnosis.[3] The authors' role in these music therapy sessions were to grant "choice, enrichment and so forth" amidst conditions of "limitation, restriction, isolation and disempowerment."[3]

The question of how to grant voice to someone who has experienced several blows to his sense of self – physical, social, political, and emotional – emerged as I came to know Oscar. This artwork encompasses both my words and the words of a person I became close to through volunteering in hospice care. Oscar's medical difficulties form a significant portion of his narrative. We wrote a song together in a hospice, but this was not a professional healthcare intervention; while formal music therapy encompasses music explicitly for purposes of therapeutic change, my process of creating a musical artwork in this case did not incorporate formal therapeutic outcomes nor explicitly take into account the man's specific disease or diagnosis in tailoring the artistic process.[3] Rather than working toward any measurable therapeutic objective, the process was based entirely on what this man wanted to write a song about, with my occasional suggestions during pauses in the process.

I will introduce the artwork and then delve into my interpretation of both the other person's words and psychosocial circumstances. I created a musical artwork with a person who loved music all his life but did not know any musical instruments, so we wrote the lyrics and the tune to the song together.

The artwork: "I love music in all languages"

Oscar had entered hospice care feeling certain that he would never be able to leave. Having lived in the streets as an undocumented immigrant for much of his life, he had lacked basic medical care for his physical and psychosocial needs. He told me that he felt that he did not deserve care, and that he would die in the streets without treatment. Additionally, while he was not queer-identifying, there were subtle cues indicating his non-heterosexuality, such as his describing to me that he didn't need love and that the thought of being with a female repulsed him.

After having been in hospice care for a few weeks Oscar made a rapid physical recovery, what he described as a miracle. We first completed a non-musical poetic artwork together in Spanish and English, with his words verbatim and me as a scribe (the original words come first, and the translations in parentheses):

Dios nos hace segundas oportunidades (God creates second chances for us)

Poder descubrir que se puede volver a empezar. (It is possible to discover one can return to start again)
God.
Amoroso, cuidadoso, protector. Todo. (Lover, caregiver, protector. Everything.)
All the good.
I almost felt like dying-
One night before I came here, I felt like it was my last night in the world.
Then I'm surrounded by loving people, caring people.
It feels like I'm surrounded by angels.
Creía que no lo merezco. (I thought I didn't deserve [this care]).
Estaba muy mal, en la calle. (I was very sick, in the streets).
Now that I'm older, I try to do something for my future.
Maybe it's too late, but I feel like God gives me another chance.
Con lo que queda de mi vida, (With the rest of my life)
Quiero lo que es suficiente para vivir. (I want only what is necessary to live)
Make a living on my own.
Ser independiente, trabajar. (To be independent, to work.)
No matter how many times you fall.
Even when you feel like you are alone in this world.
You feel like something bigger is taking care of you.

From week to week I would find Oscar singing and dancing in his room in the hospice whenever I passed by, and we would talk about the poems he wrote, his love of learning languages, and the time he tried to learn the guitar. Finally, I asked him if he'd like to write a song together, and he told me he had wanted to create a song all of his life. We then moved the hospice's piano keyboard temporarily into his room for this purpose. The song is as follows:

God is Love

God.
Amoroso, cuidadoso, protector.
Todo.
I feel like God gives me another chance
Reasons to believe
There can be a better future tomorrow

When you feel like you're alone
When you fall a lot of times
You can feel there's someone there
Taking care of you

But deep inside you know
Who can take care of you and all
Who will show His love to all
From the beginning, you know, it's God
'Cause God is love

When you feel like all is gone
He always gives you hope
And the strength to make you know
You're not alone

He sends angels to surround you
For His love
God is love
God is love

Oscar was intent on writing all but the introduction to the song in English, and had a very strong idea of how he wanted to phrase the verses. He came up with the melody and rhythm to the song while I accompanied him on the piano keyboard. While he came up with majority of the words, I suggested some whenever he felt stuck. After several iterations of drafting and playing out the song, we made a few recordings—one for his phone, and one for mine—and he animatedly showed it to his pastor and his church group in the days to come.

While we created this song together, he insisted that if he sung, I had to sing as well – so we alternated verses of the song. He told me that his voice was not good, and I insisted that it defined the song. The song itself is technically off from any regular rhythm, at least partially improvised at the time of recording on both of our parts, and with questionable intonation. But as we went on, the technical aesthetics of who "can" and "can't" sing became increasingly irrelevant. An article on music therapy in cancer care states, "…what people get out of music therapy seems to depend to some extent on socially constructed notions of healing and music as well as concepts of the 'creative' (or uncreative) self."[3] While Oscar held reservations as to whether he "could sing," this became a peripheral concern as we created the artwork together.

Discussion

An important note to make about this artwork is the strong emphasis on spirituality, which in turn is connected to Oscar's sense of both shame and humanity. A study on music therapy, spirituality, and cancer describes spirituality as a construct which "differs from the concept of religion and the linked emotional and psychologic state of 'religiosity,' as it encompasses a broader set of meanings."[4] Other than "God," the artwork depicted here does not make explicit religious references—rather, Oscar references feelings of hopelessness turning to forgiveness, feeling alone to feeling accompanied by something "bigger," and illness giving way to the possibility of leaving medical care to "start again." Recounting his illness reminds him of feeling less than human and on the literal verge of death, but also gives way to expressions of renewed life and feelings of worthiness. Songwriting in Music Therapy, used as a clinical tool with hospice patients, has been conceptualized as a process of both "life review" and "enhancement of spirituality," where expressions of what one has done and their sense of purpose in the world emerge while creating music.[5] There is a pivotal expression of Oscar's feelings of unworthiness toward the middle, where he states that he did not believe he deserved the medical care he received. This was accompanied by his expression that he brought his dire medical circumstances upon himself with his own life choices.

There were many instances in the process of creating the artwork depicted in this essay when Oscar revealed an experience or a feeling to me, and it was so heartbreaking or stunning that I had no idea what to say in response. In retrospect, I think that this very silence and speechlessness provided a space for the other person to be, to feel heard and accompanied, and to have room to share their hurt and their shame. In the words of Judith Butler, the element of "unknowingness" which comes with largely unconscious methods of implementation in musical improvisation allows room for a "condition of possibility for the subject," therefore creating a space in which an individual person may speak or sing without fear of social castigation.[6] While proposing the music was my idea, the ultimate goal was to foster togetherness and make meaning out of our shared humanity, moment by moment.

As in the end, both of our voices are in this musical recording, I wondered if my vocal presence in the song ever took away from Oscar's agency in expressing himself and his experiences. However, in retrospect, I believe that our alternating the verses allowed for another individual—myself—to sing in momentary connection with Oscar's experiences of suffering. The particular inflections of the singing or reading were done on my part with great care, and I believe that this song reflects to him in writing and sound that his experiences of abandonment and spirituality, hope and hopelessness, and isolation and belonging are deeply human and worthy of care. As he says, "I love music in all languages."

Attempting to defer to Oscar's voice and therefore his subjectivity while making the music was my way of gesturing that I do not have the language nor the place to speak of what he has experienced. Siddall and Waterman define subjectivity as a "complex negotiation of lived embodied experience and social forces that work to regulate behavior and therefore shape that experience," indicating that the process of expanding one's subjectivity is socially and relationally dependent.[7] A person can attain agency not only via moment-by-moment choices in the vocalization itself, but also via "moments of transgression and unpredictability" which take place in relation to social norms that work against the capacity to self-shape or self-express.[7] Within this small hospice space in which we created music, Oscar gained momentary agency in shaping his soundscapes if not his external social circumstances.

According to social and developmental psychologists, shame and guilt are internalizations of social norms and rules of social deviance, serving as affects which signal to us when we have broken such norms and rules.[8] Feelings of shame in particular occur when one has failed their "ego ideal," an amalgamation of socially and personally constructed ideas of who they should be.[8] While feelings of guilt can be rectified through "prosocial and reparative behaviors" in response to acts of social transgression, shame implies not just transgressive acts, but a transgressive self.[8] By this definition, feelings of guilt can arise and dissolve when one demonstrates remorse to others for acting in socially deviant ways, while shame remains a part of their sense of self regardless of whether they have demonstrated such "prosocial" remorse.

My work was situated in a hospice with strong community ties to LGBTQ communities through both their patients and volunteers, the intersections of Psychology and Queer and Gender Theory are applicable to parse the impacts of social stigma on self-concept, a term defined by clinical psychologists as "an integrated set of beliefs about one's personal qualities and attributes."[9] Affect theorist Eve Sedgwick articulates that for people with queer genders or sexualities, shame is often the first permanent, structuring part of identity.[10] Sedgwick introduces the concept of shame as performance, where one's behavior is molded by experiencing habitual shame and conveys to self and others that they have transgressed social norms.[10] In this sense, openly expressing one's sexual or gender identity is intertwined with anticipation of social stigma and potential castigation. Because of this, individuals may be apt to appraise themselves as "other" and integrate shame as a part of their identity. All this to say, an LGBTQ individual may not openly identify themselves as queer. I vividly remember meeting another hospice resident, who lost the ability to speak due to esophageal cancer. Before I approached him, I was told by a nurse that he had been disowned from his family for his "homosexual lifestyle." I asked if he would like to tell me about himself and his life. He immediately wrote down on a notepad that this was a bad idea; that sometimes he went into bouts of depression, and wanted to be left alone. To me, this interaction signified the resident's experience of stigmatized personhood, resulting fear of vulnerability, and accustomedness to social isolation. His family abandoning him established his being as "other," as someone who did not belong; his aversion to self-disclosure seemed to parallel this.

Also essential to discussing how shame manifested throughout Oscar's experiences, as well as those of many patients in the hospice I worked in, are the intersections of HIV-positive status and immigration status on his experience. In a literature review on mental health and undocumented Mexican immigrants, Sullivan and Rehm discuss that being an undocumented immigrant frequently leads to feelings of shame and guilt relating to societal conceptions of undocumented immigrants as politically controversial.[11] Additionally, in a qualitative study on barriers to HIV care for undocumented Latinx immigrants, Dang, Giordano, and Kim articulate that societal intolerance toward HIV-positive individuals leads to feelings of secrecy and shame among undocumented Latinx immigrants, which emerge from complex psychosocial circumstances such as familial rejection, lack of access to healthcare, and fear of disclosing their HIV-positive status due to disease stigma.[12] Individual experiences of illness are impacted by a widespread social impetus toward self-obscuration and treading as lightly as possible to avoid being "other"-ed further. Additionally, the majority of undocumented Latinx immigrants who are HIV-positive are diagnosed only after seeking emergency care for severe symptoms, an epidemiological finding that relates directly to the circumstances under which Oscar ended up in hospice care with end-stage illness without having previously received any form of regular medical attention.[12] Oscar's words in the first artwork reflect this tendency toward self-obscuration and perceiving oneself as social "other," as they express shame through language such as "I believed I did not deserve this care."

Lastly, this position in creating collaborative musical artworks highlights a disparate position of social privilege between myself and the individual portrayed in the artworks. On one hand, my lack of professional credentials establishes a relationship between myself and the other person with little disparity in formal expertise regarding health, medicine, and music. At the same time, I still understand my position as a hospice volunteer and student to be privileged in terms of affective and physical wellbeing and musical tools (having the piano keyboard in the first place, for example), reflecting that making art is inseparable from "'real' social processes involving power and resources."[4] A relevant term in professional Music Therapy is *intrasubjective countertransference*, which describes conflicts between the therapist's and the client's respective social positions and relationships before a therapeutic encounter has taken place.[13] I aim to be mindful of the various socioeconomic, educational, and health-related privileges that allow me to facilitate projects such as the artwork in this essay, and how they may influence my interactions with hospice residents.

The artwork illuminates that social marginalization has deep-rooted consequences for one's sense of self, but also emphasizes that the individual's voice in the artwork can resist a fixed position of shame and stigma via self-expression. In Susan Finley's model of arts-based research, art possesses a "communal, dialogic function" which erases divides between disciplines and explores social relationships not just for answers to pressing human needs but also for potential modes of transforming the flawed systems and institutions that generate these gaps and needs.[14] This conceptual model of arts-based projects aims to give voice to people who have been underprivileged, unwanted, and underappreciated as subjects

of beauty and power on a systemic level, opening spaces for them to potentially transform their social situation and sense of personhood. While my goal at the time of creating this artwork was to be present with the person portrayed, I believe that sharing this art and the psychosocial circumstances from which it was born can validate individuals as human, as beautiful, and as worthy of care – both to the subjects of the art themselves, and those who interact with it. As a mode of resistance against stigmatized personhood, healing through artistic creation can arise from the combined voices of people who have been socially marginalized and those who stay physically and emotionally present to be with them. Little by little, experiences of shame and hurt can become speakable, tangible, and accompanied by the love, care, and acceptance of someone who may be an outsider to these experiences.

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Biographical Statements

Zoe Tao is a medical student at the University of Texas Southwestern Medical Center in Dallas, Texas. She has a B.A. in Religion and Psychology from Rice University and has a vested interest in both community medicine and community music. Her most recent projects include planning an American Medical Association panel on immigration health, designing and implementing a medical school elective on end of life topics, and starting a "legacy project" program with the palliative care office at Parkland Memorial Hospital that pools together students with various artistic skills to provide accompaniment at the end of life for patients and their loved ones.