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Examining the artist-patient relationship in palliative care. A thematic analysis of artist reflections on encounters with palliative patients

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Abstract

Background.—Although therapeutic arts are used in the palliative care setting, little has been described about what happens during the artist-patient encounter and how these interactions can complement and integrate into the interdisciplinary model of palliative care. The objective of this study is to describe the artist-patient encounter and how artists can function in the palliative interdisciplinary model of care.

Methods.—Authors reviewed 229 reports written by artists about encounters with palliative patients, and performed thematic analysis on 95.

Results.—Artists describe physical, emotional, and spiritual responses by patients including relaxation, invigoration, and accessing spirituality, some of which were unique to the artist-patient interaction. Artists also described personal reactions including themes of professional fulfillment, kinship and empathy with patient suffering. Themes surrounding the artist-patient bond and trust also emerged.

Conclusions.—The artist-patient encounter has an effect on both patients and artists, and can create a therapeutic relationship between them. Artists provide unique perspectives and care paradigms to the palliative team.

Keywords

palliative care; therapeutic arts and music; integrative medicine; arts and humanities; therapy; qualitative research

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Introduction

The use of arts in healthcare has increased substantially over the past few decades (Clift, 2012; Rhondali, Lasserre, & Filbet, 2013). A variety of both arts- and humanities-based approaches, including dance, music, creative writing and visual art, serve as adjuvant and supportive therapies (Kellman, 2004). Research to date involving therapeutic arts interventions largely focuses on patient-centered outcomes (Gallagher, Lagman, Walsh, Davis, & Legrand, 2006). For example, music therapy can improve shortness of breath and anxiety in the palliative population (Bolwerk, Mack-Andrick, Lang, Dorfler, & Maihofner, 2014). Among cancer patients, creative or expressive writing enables participants to express their ideas and feelings, fosters personal growth and provides a positive distraction from their illness (Corner et al., 2015). Visual art improves the physiological function of the brain and may be an important tool in managing the burden of chronic diseases in older adults (Howell, Gaies, & Saint, 2013).

Despite the demonstrated benefits of using arts in healthcare, art modalities are rarely integrated into patient care plans, even in practices that include multidisciplinary perspectives such as social work, psychology or psychiatry, palliative care, and internal medicine (Crone et al., 2012). In addition, little has been described about what goes on inside the artist-patient encounter and how the artist can function as part of the interdisciplinary team. Here we describe a novel arts program explicitly integrated into patient care as part of the Palliative Arts and Humanities Program at MedStar Georgetown University Hospital. We present a retrospective review of 95 artist reports of encounters with hospitalized palliative patients. The purpose is to illustrate the artist-patient interaction and examine its contribution to interdisciplinary palliative care.

Methods

The Lombardi Arts and Humanities Program

The Georgetown Lombardi Comprehensive Cancer Center's Arts and Humanities Program was established in 1990 to encourage the use of the arts as a tool for coping with illness. Among one of the first university medical centers to feature arts in healthcare, the program is comprised of 15 artists-in-residence who offer a variety of art modalities as therapeutic tools, including visual art (painting, fabric arts, beadwork, guided imagery, word art and knitting), music (violin, harp, vocals, flute and cello), literary art (weekly writing workshops and writing prompts) and movement (yoga and dance). All artists are mid-career professionals with training and experience working in healthcare settings, however they are not certified art therapists.

Model of care

In January 2015, the Lombardi Arts and Humanities Program teamed with their palliative care colleagues to create the Palliative Arts and Humanities Program to provide care for hospitalized patients (Figure 1). The palliative providers (MDs and NPs) screen patients during their initial inpatient consultation to assess their ability to benefit from a visual art, music, writing or movement-based intervention. At weekly interdisciplinary rounds, the

Palliative Care team provides detailed referrals to artists including patient's medical condition and psychosocial assessments. This information helps artists target their interactions to the needs of the patient. After each interaction, the artist writes a detailed report of the patient-artist interaction, which is shared with the Palliative team at the next weekly rounds. This 360-degree model is designed to foster communication and promote individualized interventions.

Design of retrospective artist report review

We conducted a retrospective review of artists' reports from January 1, 2015 through December 31, 2015. Of the 15 artists on staff, eight consented to participate in the review, representing a range of modalities, including music (e.g., cello, flute, violin, harp, singing), fabric art, knitting and guided imagery. Artists hand-wrote or typed reports describing patient encounters including specifics on modalities delivered, patient responses, and personal reactions and insights. Reports were written for each encounter, including repeat encounters with the same patient. Roughly 10% of the reports were different encounters with the same patient who requested multiple visits from artists. A member of the study team typed notes and removed identifiers for analysis. Artists wrote a total of 229 artist encounter reports between January 1 and December 31, 2015.

Data analysis

Qualitative data.—We analyzed written artists' reports using thematic analysis and qualitative description approaches. Guided by empirical research on use of the arts and humanities in medicine and palliative care (Gallagher et al., 2006; Rhondali, Barmaki, Laurent, & Filbet, 2012), and the clinical and programmatic experiences of the palliative care physicians (KA; KTO) and Arts and Humanities Director (JL), we searched for themes related to psychological impact, physiological impact and patient-artist connection from artists' observations and notes following encounters with patients in palliative care.

First, two raters read through all 229 artist encounter logs and collaboratively identified 95 as appropriate for inclusion in the current analyses. Entries were excluded if they a) were too brief (less than 20 words) or b) identified that no interaction with a patient occurred (if the patient declined a visit).

Following identification of the 95 encounter entries that met criteria for inclusion, two raters independently read and reviewed each entry's content and separately characterized themes based on the text. The two raters shared identified themes with the research team for discussion to discern commonalities and differences from each coder. We used an iterative process to refine the themes until consensus was reached between the two raters; discrepancies were resolved with input from a third team member. We concluded that data saturation was achieved when no new themes emerged. Individual raters identified quotes that exemplified our themes.

Results

Nine unique themes emerged from the patient-artist encounter notes written by the artists, which were grouped into three categories (Table 1, Figure 2). *First, patient-centered* themes

were identified where patients were described as experiencing relaxation, animation, spirituality, and gratitude. Second, *artist-centered* themes were identified where artists experienced fulfillment, kinship, and empathy. Finally, themes describing the *patient-artist* interaction involving creating bonds and establishing trust. Artists' notes often described elements from different themes concurrently (e.g., relaxation, spirituality and gratitude). For clarity in coding the qualitative data, we separated out themes that may have been referenced in a single artist encounter.

Theme 1 – Patient-centered themes: Relaxation, Animation, Spirituality and Gratitude

Artists evaluated how their encounters affected patient anxiety, pain, boredom, depression and restlessness. Their reports indicated that some patients appeared to relax while other patients appeared to be invigorated. Patient relaxation was conveyed either verbally and/or through body language. Animation appeared to be evidenced by a renewed sense of energy shown by the patient. Several artists noted that patients referenced God or heaven during an artist encounter. More than a quarter of the patients visited showed gratitude for the artist's visit. Less than 10% of patients visited did not show any reaction, positive or negative, to an artist's visit.

Relaxation—A musician described a patient who hummed along to music performed on a harp. The patient 'commented on how soothing the music was and how it helped her relax.' Another musician noted that a man, who initially grimaced frequently as a sign of pain, calmed and relaxed his brow while listening to the cello, then began falling asleep. When the cellist stopped playing the patient woke up and said the music had 'taken him to another place.' Another patient 'slipped into a deep relaxation,' during a session with the guided imagery artist. The artist reported that, 'Her breath transformed from an effortful, uneven breath to a calmer, even one.'

A fabric artist spent time with a patient who was anxiously awaiting surgery. The artist held her hand through a guided imagery exercise and then gave her a quilted square to keep. She noted before leaving that the patient's 'breathing was calmer.'

The flutist wrote about playing a slow and relaxing song for a patient in the midst of a busy unit, '[The unit] was busy and noisy, but the patient looked relaxed, almost caught in a trance as I played.'

Animation—Artists' notes suggested that many patients were invigorated by their encounters with the artists. This appeared to be particularly true of encounters with the musicians. The flutist, for example, wrote of a patient who asked her to play *Danny Boy*. When she played it, the patient was, 'ecstatic and restful at the same time, reclining on her bed and closing her eyes, taking in the melodies.' When the chorus came, the patient 'pumped her fist in the air.' Then she asked for the song to be played again. A similar type of encounter took place when the singer visited a patient. 'While I was singing he bopped his head and moved his feet to the rhythm. He made facial expressions and we were engaged through eye contact and smiles,' she wrote.

Music was not the only art form to invigorate patients. The fabric artist reported that a patient became engaged during her visit. ‘She was distracted from the pain, interested in the buttons, the colors, [she] showed me her fashion drawings and talked about making doll dresses with her grandmother.’

Spirituality—In addition to relaxation and invigoration, spirituality and gratitude were expressed in a number of artist encounters with patients. Patients expressed their spirituality by talking about God in relation to the music they heard. The singer reported that, ‘The patient was asleep but was delighted to be awoken by singing. During the song, she repeatedly exclaimed, “Oh! Beautiful! I feel like I am floating in heaven.”’

One patient, who was seen over time by several artists, talked about the healing power of music. ‘She said the visits from the artists have definitely helped her with her disease. “There’s something about music that just moves me...more than literature, even more than the Bible...they say it’s because I got the rhythm inside.”’

Gratitude—Gratitude for artist visits ranged from grunts and statements to smiles and requests for the artists to return. The singer was pleased to be presented with a musical CD prepared by the patient especially for her. She was ‘humbled by [the patient and his wife’s] appreciation and willingness to share.’ The fabric artist paid a return visit to a patient and noted, ‘She is hopeful about going home and happy to be remembered.’

After visiting a patient who was hard of hearing and had slurred speech, the guided imagery artist wrote, ‘I guided him slowly and loudly through relaxing his body,’ she wrote, ‘He was smiling when I left.’

Descriptions from the artists’ notes suggest that their encounters with patients helped some patients to relax and others to become animated. In both situations, the artists’ notes reflect that the mood of the patients appeared to be improved after their encounters. Patients expressed appreciation for the visits through direct statements of gratitude, talking about God and healing and sometimes even through an expression of emotion such as smiles or tears.

Negative or null-responders—A few notes indicated negative patient reactions. Patients were categorized by coders as having a negative reaction if they demonstrated anxious or distracted behavior while interacting with artists. ‘The entire time I was there,’ a musician wrote, ‘he was trying to re-arrange the food, moving food from one container to another...I changed the style of music, but nothing seemed to help him relax.’ The guided imagery artist tells of a patient who ‘did not stop tossing/turning’ as she spoke so, ‘I left. I didn’t want her to feel startled by me.’ When the flutist went to visit a patient she found her to be writhing in pain. She tried to play some ‘calming songs,’ but the patient did not respond.

Responses in non-verbal patients—Artists also described effect on those who could not participate in care. ‘The patient is non-verbal. I sang Amazing Grace. There was one part of the song where I noticed tears came to her eyes.’ The singer told of a patient who was

unresponsive at first but then, as she began to sing the patient, ‘grunted through the song. I got the impression she was humming/singing along.’

Theme 2 – Artist-centered themes: Fulfillment, Kinship, Empathy

Working with patients had a profound impact on the artists who reported feeling fulfilled and that they had developed a connection with patients.

Fulfillment—Of her work, one artist wrote excitedly, ‘I left feeling really good, not just about that days’ visit but also about the positive impact that our type of program can have for people who embrace the opportunities of the moments we share.’

Kinship—The flutist, who was unable to use her music stand in a crowded patient room, reported that she was glad she did not have the stand in this instance because, ‘I felt more exposed, more personally connected to the patient without a barrier between us.’ In another encounter the flutist noted she was asked if she had any hymnals. She played *Amazing Grace* from memory, as the patient sang along. ‘Having this communal moment made me feel connected to [the patient] more than any other instance I’ve played *Amazing Grace*.’

The violinist reported that he played for a woman who was a singer and whose vocal abilities had been diminished by her condition. Nevertheless, they played and sang together. ‘The enhancement of the patient’s energy during this was profound and delightful to behold,’ he wrote. ‘She told me that ‘it made her day’ while at the same time I felt that it had made mine.’

Empathy—Through their work, the artists showed empathy for the patients. This is evidenced by the ways in which the artists tailored their patient visits to the cues they received from the patients themselves.

The knitter visited a patient who was making a sweater. ‘The patient wanted to learn something new,’ reported the knitter. ‘We started a cotton dish cloth...It make a difference for her (and for me) to teach her something new.’

The violinist began playing ‘tranquil’ music (*The Ash Grove*) for a patient, but moved onto the livelier *Sway/Quien Sera* as the patient began to respond. Next, the violinist played *Take a Walk on the Sunny Side of the Street*. ‘I took it at a fast tempo and improvised wildly on the melody while the patient tapped his foot and smiled broadly,’ reported the violinist.

Theme 3 – Patient-artist interactions: Bonds, Trust

The patient-artist interactions appeared to create moments when patients and artists shared stories about themselves, their challenges and their friends and families. Descriptions in the artists’ reports suggested that bonds are formed between the artists and patients, along with an enhanced sense of trust. A pronounced sense of empathy is evidenced during and after the artist and the patient interaction. Artists described insight into the patients’ lives as individual humans, beyond their lives in the hospital.

Bonds—The fabric artist visited a patient for the second time. When she entered the room the lights were off. Then, she wrote, ‘Recognition prompted turning on light in the room. [The patient] chose fabrics for project, buttons and thread – as selection progressed she brightened, shared about family, a close friend, situation.... Bright and hopeful at end of visit... Thanked me for seeing her as a person. We are sisters.’ Similarly, one artist wrote about an encounter with a patient, ‘We discovered we have mutual friends. We laughed.’

Trust—Artists reported patients asking to share information about their condition. The violinist wrote about a patient who ‘managed to tell me about his prognosis and his long shot hope for a genetic-based therapeutic intervention. He is very well informed and rational about his situation, so I praised him for being proactive in learning about treatment options and about the way in which he can partner with his care team.’

During a different encounter the violinist said the patient requested that the artist play a lament ‘given the situation.’ Finding a mutual interest in Scottish music, the patient and artist formed a connection and their ‘shared laughter changed the mood.’ This was demonstrated when the nurse and then the respiratory therapist visited the room and were told by the patient that, ‘we were trying to figure out a more appropriately cheerful song for me to play!’ By the end of the encounter the artist selected a Scottish dance tune that he describes as one of the happiest songs that he knows how to play and ‘a world away from being a lament!’

Discussion

Patient response

Artists described their patients as having varied responses to art interventions. A frequent physical response in this study was observed signs of patient relaxation such as stillness, soft speech, and dropped shoulders. These observed findings are consistent with patient-reported outcomes of relaxation after music therapy in other palliative populations (Warth, Kessler, Hillecke, & Bardenheuer, 2015). Further, many patients in this study seemed to respond to art interventions in the opposite way. They demonstrated activating effects of the interventions such as sitting up, fist-pumping, and dancing. This response is particularly useful in a palliative population where lethargy, fatigue, and hypoactivity are common adverse symptoms. The artists also appeared to access and foster spirituality in patients. This aspect of patient care can be neglected in the inpatient setting, but is essential to the palliative care model. There are several instances in the quotes where patients are overcome with emotion. In these cases the artists’ visits can be seen as cathartic for the patients.

Null or negative responses to art interventions may be related to the patient experience, the art modality, or the brevity of the artist visit. In fact, as this study excluded short reports and those who declined an artist visit, null responders may have self-screened out of this analysis.

An unexpected result in this study came from artist interactions with patients considered ‘non-verbal’ before the artist encounter and who then communicated with artists during their encounter. These patients required a type of *slow listening* not often experienced in a

hospital setting where care providers are pressed for time. Factors such as artist perception and quality of interaction and art modality played a role in evoking patient response.

Artist reactions

The artists appeared to be highly impacted by their interactions with palliative patients. Most entries about personal emotional reactions described developing a connection with patients and a sense of fulfillment in serving the sick. High levels of empathy allow experienced artists to quickly assess the mood and tenor of the hospital room and respond appropriately. A few entries, however, referred to the emotional weight of caring for severely ill or dying patients. This type of emotional strain presents a challenge in the palliative setting where disease burden is high and highlights the need to teach and provide space for self-care skills in these team members.

Patient-artist relationship

Artist encounters with patients appeared to enable meaningful bonds and trust to form. This is likely a result of intimacy experienced during the encounter. The patient and artist are in close proximity, usually sharing a small hospital room (although artists sometimes play from the doorway for patients on contact precautions). Trust can stem from physical touch, as in the case of the fabric artist, where both people are manipulating textiles. Musicians described constantly assessing and reacting to the patients, for example changing their volume or tempo, to match or guide patients' activity levels or emotions. These encounters were more than just unidirectional 'performances' - the artists discouraged the use of this word - and were instead an interaction between parties sharing expression and emotion. Intimacy transforms the encounter into an interaction, where both parties respond to the other and personal connections are formed. This subtle interplay between patient and artist is the key to creating the patient-artist relationship and developing a therapeutic encounter.

Artist as interdisciplinary team member

This study elucidates the role of the artist as a member of the interdisciplinary care team. The patient-artist interaction is not related to clinical issues or illness and accesses the 'well aspects of patients.' As a result, several patients shared personal, relevant information that helped the palliative team provide better care. In addition to passing along information, artists added useful insights into patients' state of mind, which were brought back to the physicians. Our results highlight the artist's role as liaison, bridging clinical teams and patients, bridging the sick and non-sick aspects of self, the mundane and the spiritual.

Study limitations

Although the size of this qualitative study is robust with 95 entries analyzed, our study is limited in that it analyzes only artists' perspectives on encounters. These were observations of patient's response and not self-reported outcomes. Observations of physical responses are likely accurate such as signs of relaxation (dropping shoulders, normalized breathing, etc.). However, internal and emotional reflections may be a less accurate (for example, interpreting moaning sounds as joy or pleasure). Future studies will include 360 degree

semi-structured interviews with multiple members of the care team including patients, family members, and other practitioners.

Implications

The Palliative Arts and Humanities Program provides a unique and novel model of care that integrates artists onto existing care teams to work directly with patients using a variety of art modalities as therapeutic tools. The inclusion of artists as team members opens up a new channel for communication between patients and their care teams. Understanding the patient-artist relationship and its effect on both parties has clinical value to overall patient well-being. It also allows for highly personalized care to be delivered. Artists, who are trained and available to listen slowly, receive information that busy medical professionals do not know. Their reports back to the care team may include valuable information psychological, social and/or economic issues that were previously unknown. Our 360 degree care model (Figure 1) between patients, artists and palliative clinicians is a unique paradigm.

Conclusions

The therapeutic arts can play an important role in caring for patients with severe illness and high symptom burden. The arts access the creative and whole aspects of patients, a critically important part of delivering high quality, interdisciplinary palliative care. We examined a large sample of artist reports reflecting on patient encounters with hospitalized palliative patients in a major university hospital. Our results suggest that the artists' visits had a meaningful impact on both artists and patients and created bonds between them.

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Figure 1.
Care model of the Palliative Arts and Humanities Program

Figure 2.
Themes from patient-artist encounters

Table 1.

Themes, Subthemes and Quotes from patient-artist encounters

Theme/Subtheme	Quote
Patient-Centered Themes	
Relaxation	'After the guided imagery, with her eyes closed, she said "Boy, I really needed that."'
Animation	'He closed his eyes and smiled broadly while rocking back and forth with the beat of my jib. He raised his hand and started conducting the music.'
Spirituality	'At the time he didn't want to be bothered. However, when he heard the sound [of the cello] he said it was like God sent him a gift.'
Gratitude	'They were thrilled to have live music. At one point the patient cried. She said how undervalued music is in this society. They very much appreciated the music.'
Patient-Artist Relationship	
Bonds	'It turns out that the patient is a singer whose vocal abilities have been diminished by her health condition. She was really enthusiastic to sing now...she pulled up the lyrics on her phone and we did it together. She has talked down her current vocal abilities, but I thought she sounded really good.'
Trust	'She talked the whole time about her son and living situation, her illness, about retaining her sense of personal identity.'
Artist-Centered Themes	
Fulfillment	'Her response to my words was to smile. I loved seeing that.'
Kinship	'This offer opened up a gateway to conversation and further sharing. The patient told me about his Scottish heritage and started to tell me stories.'
Empathy	'"I've been in the hospital for four months now and this reminded me of home." My heart went out to him hearing the four months thing.'