

In Sickness and in Health:
Museum Programming for People with Life-Threatening Illness

Anna H. Bennett

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Committee:

Kristine Morrissey

Frances M. Lewis

Meena Selvakumar

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Abstract

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Anna H. Bennett

Chair of the Supervisory Committee: Kristine Morrissey

Museology

Experiencing a serious illness can cause physical, social, and psychological suffering for both patients and their families. Some museums offer programming for people with life-threatening illness; these programs include art-making workshops, support groups and even live video from animal enclosures. This paper addresses the question “How, with whom, and why are museums offering programming for people with life-threatening illness?”

To address this question, I interviewed six museum professionals involved with these programs and whose institutions appeared in the 2013 American Alliance of Museums publication *Museums on Call*. Those interviews suggested that a variety of institution types are involved in this work. They fund their programs in a wide range of ways and consider the programs mission-fulfilling. Each program in this study included a partnership with a geographically close health care institution. The most common intended outcomes were fun and distraction along with empowerment and often some type of knowledge related to the museum’s disciplinary focus. The interviewees were all able to identify ways in which these programs advanced their mission and their visibility within the community. All programs valued evaluation although not all programs were able to evaluate their programs. The museum professionals included in this study connected personally and emotionally with the programs and their participants.

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Foreword

My name is engraved on a brick at the Minnesota Zoo right outside the *Discovery Cove* exhibit. My parents got to know my then-fiancé's family at the Philbrook Museum of Art in Tulsa, Oklahoma. Later, my husband and I celebrated our marriage with friends and family at the University of Michigan Museum of Art. I've made life-long friends from colleagues and fellow Museology students. Most of my museum memories are happy and social. But I've also cried in museums. I've been personally touched and moved to action in museums. Museums can affect people's lives. But what about the not-so-good times? Do museums engage with people in sickness as well as in health?

Chapter 1: Introduction

Americans live longer lives and experience more long-term illness today than in the past (Quill & Miller, 2014). Experiencing illness (whether the illness of oneself or of one's loved ones) can cause physical, social, and psychological suffering. Half of patients with terminal illnesses exhibit anxiety or depression, and half of those experience suicidal thoughts or behaviors. The suffering that these patients experience affects their caregivers and loved ones, and that shared pain can worsen the suffering of the patient themselves (Krikorian et al., 2011). The fields of hospice and palliative care developed in response to these trends (Quill & Miller, 2014).

Elaine Gurian has suggested that museums have always seen themselves as “instruments of social responsibility” (Gurian, 2006). Some museums provide what might be considered direct social services, such as literacy classes, parenting classes, and even medical screenings (Gurian, 2006; Silverman, 2009). Lois Silverman (2009) has suggested that one of the ways that museums can fulfill a socially responsible role in their communities is by offering therapy and therapeutic programming.

In order to study this role, Silverman and her colleagues at Indiana University formed a collaborative which designed and implemented three therapeutic programs at different museums which targeted three separate client groups. This project suggested that museums have the potential to successfully collaborate with community organizations to improve public mental health (Silverman & McCormick, 2001). Other researchers have found that handling museum objects can improve life satisfaction and health status of elderly patients in hospital (Chatterjee, Vreeland & Noble, 2006).

Today, some museums offer therapy and therapeutic programming for a variety of audiences, including people with PTSD and those with life-threatening illness (AAM, 2013). These programs are offered by a multitude of museological disciplines including art museums, natural history museums, zoos, and children's museums. These programs include art-making experiences facilitated by museum educators in and out of the hospital, art therapy, family therapy, and support groups, among others (AAM, 2013).

In 2013, the American Alliance of Museums published a report, *Museums On Call*, which provided an overview of the ways in which museums engage with health-related topics. As part of this publication, AAM developed an appendix of museums engaged in this work and a brief description of their activities. This publication provided brief overviews of these programs, their audiences and partners. What isn't clear from this publication is what goals and intended outcomes institutions have for these programs and what role the programs fill within the organization.

The goal of this research is to answer the question "How, with whom, and why are museums offering programming for people with life-threatening illness?" By answering this question, the museum field will better understand this growing trend and its relationship to mission statements. Additionally, other museums may consider the potential role of therapeutic programming within their own organizations.

Chapter 2: Literature Review

Illness

Americans are living longer lives, experiencing more long-term illness, and dying in institutions like hospitals and palliative care facilities more today than they did in the past (Quill & Miller, 2014). Between 1940 and 1990, the percentage of the U.S. population surviving from age 21 to age 65 rose from 53.9% (males) and 60.6% (females) to 72.3% (males) and 83.6% (females), respectively (Social Security Administration, 2014). While average life expectancy rose quickly, maximum life expectancy has remained relatively stable (Fries, 1980).

In response, beginning in the 1960s in England and the 1980s in the United States, hospice care and the field of palliative care developed (Quill & Miller, 2014). Hospice and palliative care are end-of-life services provided to patients who are facing a life-limiting illness and have stopped curative interventions (Mayo Clinic, 2013). Life-limiting illnesses are those in which premature death is usual; life-threatening illnesses are those through which premature death is likely but full recovery is possible. Terminal illness is used to describe life-limiting and life-threatening illnesses that have progressed to a point at which death may be inevitable (Gullo, 2011).

In 2012, 1.5-1.6 million people received hospice care in the United States, a number which has steadily increased each year (NHPCO, 2012). Patients receive care anywhere from less than a week (35.5% received services for less than seven days) to more than 180 days (11.5%). Two-thirds of those patients received care in their place of residence, and up to 16% of patients were non-death discharges (NHPCO, 2012).

While most hospice patients are aged 65 and older, 16% of patients served in 2012 were younger than 65 (NHPCO, 2012). The growth of the hospice and palliative care fields has been accompanied by an increased emphasis on the psychosocial suffering of patients, their families, and their caregivers (Quill & Miller, 2014).

Nurses and doctors have also begun to treat more than just the patient's physical suffering. These health care professionals have called for attention to and treatment of the patient-family dyad in place of the patient in isolation due to the fact that a patient's physical and psychological suffering often affects the suffering of their loved ones and vice versa (Krikorian, Limonera & Maté, 2012). Smith & Longo (2012) have suggested that doctors should be more direct about patients' prognoses so that they can cease unnecessary medical procedures and enter hospice care earlier. Ahn, et al. (2006) found that patients who were aware of their terminal illness had significantly better deaths than those who were not aware.

Therapy for People with Life-Threatening Illness

The hospice care industry has grown quickly and will continue to grow (NHCPO, 2012). As part of both traditional medical and palliative or hospice care, patients' psychological and social suffering (and the suffering of their families) is being addressed in both terminal and life-threatening illness (Silverman & McCormick, 2001; Quill & Miller, 2014).

Many different types of psychotherapy, psychoeducation and support groups have been used to lessen the shared psychological suffering of patients facing terminal illness and their families. Psychotherapy involves speaking with a mental health provider to learn about "mood, thoughts, behaviors, and how they influence their lives." Psychoeducation "teaches people about their illness and how they'll receive treatment." Self-help and support groups can "help address

feelings of isolation gain insight into their mental health condition.” Psychotherapy, psychoeducation and support groups can be used to successfully address the needs of both the patient and their loved-ones (NAMI, 2015).

Many of these therapeutic interventions focus on the relationships between the patient and their caregivers and loved ones. Dr. Ira Byock defined four phrases (“Please forgive me,” “I forgive you,” “Thank you,” and “I love you”) which can assist in this relationship completion (Byock, 2014). Different types of therapy have been used to successfully facilitate these phrases, including both music and art therapy (Clements-Cortés, 2009).

Group therapy and support groups have also been used to address patient-family suffering, especially in children (Kirk & McManus, 2002). Clinic-based educational counseling for spouse-caregivers of breast cancer patients has been successful in enhancing the spouse’s ability to support their wives and in improving the spouse’s own well-being (Lewis, et al., 2008). Another program offered educational counseling sessions for mothers with breast cancer which not only improved both the mother’s depressed mood and anxiety but significantly decreased their child’s behavioral problems, worries, and depressed mood and anxiety (Lewis, et al., 2006).

Museums & Therapeutic Programming

Museums have offered therapy and therapeutic interventions for more than a decade. Chatterjee, Vreeland and Noble (2006) conducted a quantitative study to examine the impact of object loan boxes as part of University College London’s (UCL) Heritage in Hospitals program. As part of this program, facilitators displayed a number of objects from UCL’s collections (including geological specimens, archaeological artifacts and works of art), asked the patient to choose an object to handle, and conducted a semi-structured interview with the patient about

their knowledge of and relationship to the object. The authors found that patients scored higher on both the Life Satisfaction and Health Status scales after handling the objects (Chatterjee, Vreeland & Noble, 2006).

Art therapy uses art to “explore their feelings, reconcile emotional conflicts, foster self-awareness, manage behavior and addictions, develop social skills, improve reality orientation, reduce anxiety, and increase self-esteem” (AATA, 2014). Some museums offer art therapy at their institutions; many of these programs target veterans with PTSD (AAM, 2013). Museums like the National Veterans Art Museum in Chicago and the Minneapolis Institute of Arts offer art therapy programs for veterans which make use of both the existing art work in their collections and the creative process by providing veterans with studio time (AAM, 2013).

In addition to serving veteran audiences, a growing number of museums are offering programming for people with dementia and their caregivers (AAM, 2013). For example, the Frye Art Museum in Seattle, Washington, offers discussion-based gallery tours that don't rely on short-term memory, after which the participants are invited to create their own art pieces (Frye Art Museum, 2014). The American Alliance of Museums (AAM) (2013) had identified these and other programs as part of a trend within the museum field of museums engaging with public health. AAM identifies this trend to include a variety of museum activities including healthy living exhibits, medical student education, and community health clinics (AAM, 2013).

Museums as Therapeutic Agents

In 1997, researchers and staff at Indiana University in Bloomington, Indiana developed a collaborative to study the therapeutic potential of museums for adults and families. This collaborative included three museums: Wylie House, the William Hammond Mathers Museum

of World Cultures, and Hilltop Garden and Nature Center. It also included three mental health agencies that served the following populations: adults living with HIV/AIDS, older adults, and adults with persistent behavioral health issues. This group received initial funding from the Institute of Museum and Library Services for their research. In 1998, eight additional social service programs joined the group and formed the Museums as Therapeutic Agents collaborative (MATA) (Silverman & McCormick, 2001).

These programs were evaluated using pre and post-intervention structured interviews that featured previously-developed numerical scales. MATA found that most changes observed were related to self-concept, while social connection showed no change in any group. The collaborative felt that these results were encouraging for the potential of museum involvement in therapy. They recommended longer interventions (none in this study included more than four contacts) and a stronger emphasis on the special roles that the client-visitors filled. (Silverman & McCormick, 2001).

Inclusion

The term “social exclusion” originated in France in the 1980s in order to describe the process of certain groups of people’s systemic disadvantages in a variety of experiences including political participation, poverty, and health outcomes (Sandell, 2003). The term “inclusion” has been used to describe the process of expanding programs, actions and benefits to cover people at risk of social exclusion (GLLAM, 2000). This term has been used especially in the United Kingdom (Sandell, 2003).

Richard Sandell has listed characteristics, or risk factors, for social exclusion. These factors include: unemployment, poor skills, low income, poor housing, high crime, *bad health*

[emphasis added], poverty, and family breakdown (Sandell, 2003). As mentioned earlier, long-term and life-threatening illness can also contribute to intra-family problems. It seems that families experiencing these illnesses might often display at least two of these characteristics (bad health and family breakdown). These families may be at risk of social exclusion, including from museums and their programming.

In 2000, the UK-based group GLLAM (Group for Large Local Authority Museums) commissioned a study on the ways and extent to which their member institutions were contributing to social inclusion. The final report noted the importance of community partnerships to the success of these programs (GLLAM, 2000).

Health-Related Museum Programming

Museums around the United States have developed a wide variety of programs for people with life-threatening illness. The American Alliance of Museums (2013) has identified these programs as part of the larger trend of museums engaging with health issues in general. AAM also identifies museum programming for people with dementia, people with Autism, people with mental health issues, and visual impairment. They also note in-museum training programs for health care professionals, in-museum health screening days, and exhibits about disease and healthy living (AAM, 2013).

The Great Plains Zoo (GPZ) and Delbridge Museum of Natural History in Sioux Falls, South Dakota partners with Sanford Children's Hospital and Sanford USD Medical Center to bring ZooTV and as well as live presentation featuring live animals to children with cancer.

Children's Museum of Manhattan sends museum educators with sterile art supplies to Memorial Sloan-Kettering's Cancer Treatment Center to facilitate art-making activities with pediatric cancer patients and their families.

At the Cummer Museum of Art and Gardens (Cummer Museum), clinical social workers partner with museum art educators and a local day school to offer a quarterly five-week workshop for children with cancer and their families.

The Museum of Fine Arts Boston offers MFA Artful Healing, a program which offers art activities to children, teens, and young adults and their families that are undergoing medical procedures at three area hospitals: Boston Children's Hospital, Massachusetts General Hospital, and Dana-Farber Cancer Institute.

At the Leigh Yawkey Woodson Art Museum, adult breast cancer survivors and those current undergoing treatment for breast cancer have partnered with Marshfield Oncology and local art therapists to create art pieces which were displayed at the Woodson. The Mulvane Art Museum at Washburn University also offers art-making classes for cancer patients of all ages.

Chapter 3: Methods

Research Question:

The goal of this research was to describe how, with whom, and why museums are offering programming for people with life-threatening illness. This goal was broken down into the following three questions for the purposes of analysis:

1. How are museums offering programming for people with life-threatening illness?
2. With whom are museums offering programming for people with life-threatening illness?
3. Why are museums offering programming for people with life-threatening illness?

Methods & Analysis

I conducted semi-structured, recorded phone interviews with individuals who were involved with museum programming for people with life-threatening illness. These interviews were then analyzed using emergent coding.

Instrument:

The interview questions were developed around five separate themes: “How?,” “Partnerships,” “Mission,” “Outcomes,” and “Why museums?” Between three and four questions were developed which touched on each of these themes. The instrument was pilot-tested with a local colleague in order to ensure that the interview remains under one hour in length and that the questions elicit the type of responses desired.

Sampling Procedures:

The phenomenon investigated in this paper is not restricted to one type, size or discipline of museum, so participant sites were selected to represent a range of institutional discipline,

audience, and partners and geographic location. The sample population was not meant to be a representative sample.

A list of potential sites was identified using a single publication by the American Alliance of Museums in 2013 titled *Museums on Call: How Museums are Addressing Health Issues*. This publication included an appendix which listed museums nation-wide that were engaged in health-related exhibits or programming without focusing on one particular region or institutional discipline (AAM, 2013). Fifteen museums included in this publication seemed to fit the necessary characteristics for this study: an audience that experienced life-threatening illness (not including dementias).

Using the 2013 AAM publication as a data set, each museum which offered programming for patrons experiencing life-threatening illness was placed in a matrix which identified: institutional discipline, program audience, partner organizations, and location. Using this matrix, six institutions were identified which included a range of institutional discipline, program audience, partner organizations and location. These six institutions include mostly museums on the East Coast and in the Midwest, but not in the Southwest or West Coast.

The participant museums selected include: The Great Plains Zoo and Delbridge Museum of Natural History in Sioux Falls, South Dakota; The Children's Museum of Manhattan in New York City; Cummer Museum of Art and Gardens in Jacksonville, Florida; the Museum of Fine Arts, Boston; the University of Pennsylvania Museum of Anthropology and Archaeology in Philadelphia, Pennsylvania and the Leigh Yawkey Woodson Art Museum in Wausau, Wisconsin.

Two institutions I contacted did not respond to requests for an interview. The first of these institutions was unique because of its institution type and therefore was not replaced. The

second of these institutions was selected based on its relationship to a University system and was partially replaced by the Penn Museum. One interviewee chose to participate in this study by email.

Research Subjects:

I selected the interviewees by cold-calling each institution's front desk and asking to speak to someone who could answer questions regarding their program. I was typically transferred to either someone in the Education or Marketing departments who helped me identify the best individual to speak with. These participating individuals ranged from volunteers to museum educators to the institution's CEO. I offered a phone or Skype interview to each interviewee. Five respondents chose phone interviews; one requested an email interview; none chose to use Skype.

Analysis

First, I uploaded the recording of each interview to NVIVO. Once in NVIVO, I completed an edited transcription of each interview. I then coded each answer based on the question it was a response to. I printed out all the answers to each interview question and examined each answer for major themes. I then identified which of those themes were unique to that institution and which themes were exhibited by multiple museums.

Institutional Matrix

Institution	Discipline	Program Audience	Partner Organizations	Location
Great Plains Zoo & Delbridge Museum of Natural History	Zoo, Natural History	children (and adults)	Children's hospital	Sioux Falls, South Dakota
Cummer Museum of Art and Gardens	Art, Gardens	Children w/cancer & their families	clinical social workers, local school	Jacksonville, FL
Museum of Fine Arts, Boston	Art	children, teens, young adults and their families in hospital	Children's hospital, adult hospital, oncology center	Boston, MA
Museum of Fine Arts, Houston	Art	children in hospital	Children's hospital, family medical resource	Houston, TX
Leigh Yawkey Woodson Art Museum	Art	Adult survivors or people currently with breast cancer	Oncology clinic, art therapist	Wausau, WI
University of Pennsylvania Museum of Anthropology and Archaeology	Anthropology, Archaeology	Children in hospital	Children's hospital	Philadelphia, PA

Phone Interview Protocol

A. How?

1. What is your job title and responsibilities to the program?
 - a. Probes: Were you involved in the development of the program? Do you personally administer the program? How long was it from when planning began to running the first program?
2. Please describe your institution's program.
 - a. Probes: What is the audience of the program? Who are partner organizations? What is the structure of the program? What activities make up the program? What is the monetary cost to the participants?
 - b. Why did your museum decide to offer this program?
3. How is this program funded?
 - a. Probes: How do you think it will be funded in the future?

B. With Whom

1. What organizations assist or assisted with this program?
 - a. Probes: In what ways did they help design the program? In what ways do they help administer the program?
2. What specific skills, competencies or resources do these partners bring to the program?
3. Why did you chose to partner with these particular organizations?
 - a. Probes: What was your thinking when you chose to partner with these organizations? What was your hope for the program?

C. Mission

I obtained your organization's mission statement, which I'll read aloud and ask you some questions about it.

[insert mission statement here]

1. In what ways might this program help fulfill your museum's mission statement?
2. To what extent is this program similar to others that your institution offers?
 - a. Probe: If so, in what ways?
3. What is the benefit of this program for your institution?

D. Outcomes

1. What are the intended outcomes of this program for the participants?
2. What are the intended outcomes for the staff?
3. What are the intended outcomes for the organization?
4. What do you hope that participants gain through this program?
5. What evaluation of this program have you been able to do so far? What were the results?

E. Why Museums?

1. What other programs like this one exist in your community?
 - a. How is your program different from those other programs?
2. How does this program build upon your institution's strengths?
3. If another museum practitioner were interested in offering a program similar to yours, what advice would you give?
4. What do you feel you as a professional gain from a program like this?

Email Interview Protocol

A. Theme: How?

4. Please briefly describe your institution's program.
 - a. What is the audience of the program? What activities make up the program?
What are your responsibilities to the program?
5. Why did your museum decide to offer this program?

B. Theme: With Whom?

4. What organizations assist or assisted with this program?
5. What specific skills, competencies or resources do these partners bring to the program?
6. Why did you chose to partner with these particular organizations?

C. Theme: Mission

These next few questions pertain to your organization's mission, which I have provided here: *[insert mission statement here]*

4. In what ways might this program help fulfill your museum's mission statement?
5. What is the benefit of this program for your institution?

D. Theme: Goals

6. What do you hope that participants gain through this program?
7. What evaluation of this program have you been able to do so far? What were the results?

E. Theme: Why Museums?

5. How does this program build upon your institution's strengths?

6. If another museum practitioner were interested in offering a program similar to yours, what advice would you give?
7. What do you feel you as a museum professional gain from a program like this?

Chapter 4: Results and Discussion

Research Question 1: How do museums offer programming for people with life-threatening illness?

Program Audiences

All of the programs involved in this study included cancer patients as a major part of their intended audience, but for some museums this was not a requirement. Program audiences included children experiencing illness; children experiencing illness and their families; children, teens and young adults experiencing illness, their families, and care givers; families experiencing the cancer of a parent, grandparent, or caregiver; women who have or have had breast cancer. Only one of these program did not include children as part of their audience.

Program Structure

Program structure varied from institution to institution. One institution offers a single annual art-making workshop. Another led the art-making portion of a larger program. The zoo included in this study offered in-hospital live video feed from animal enclosures and supplemented that program with monthly in-person educator visits. Three of the programs included the following structure: look at objects or pictures of objects; learn about those objects; create art related to those objects.

Most programs made use of their institution's collections in some way. However, the way that the collections were used was diverse. One institution streamed video of their live collections while some museums used photos of art and art objects in their collections. Others brought objects into hospital settings, while some brought participants to the museum itself. Often a combination of these arrangements was used.

Funding Models

The funding models for these programs are diverse. None of the museums characterized their programs as money-making endeavors. All of these programs were offered free to participants. Funds for the programs came from grants, from general operating budgets, individual donor support, and two institutions received some amount of remuneration from their partner organizations for supplies and staffing hours. One institution expressed interest in procuring an endowment so that their program might continue in perpetuity.

Special Considerations

There were a number of special considerations that interviewees noted when offering this type of programming. One of those considerations was the compromised immune responses of participants. Protocol related to this differed institution to institution and sometimes participant to participant. Some interviewees noted that they were required as hospital volunteers to maintain certain vaccinations. In addition, one program noted that when working with pediatric bone marrow transplant patients, who are often kept in isolation for weeks at a time, museum educators are required to wear masks, gowns, and bring brand new art-making materials with them, leaving those materials behind when they leave.

In addition, some institutions work with hospital staff to determine appropriate topics for their workshops. For example, some patients might be on special medical diets. Because of this, they were asked to avoid the topic of food.

Working in a hospital setting can also require specialized training of museum educators. Two interviewees noted that they were required to become fully-trained hospital volunteers. This not only required that they maintain certain vaccinations (see above), but that they received training regarding how to act during a medical emergency.

Finally, one institution noted that as part of their hospital volunteer training they completed a workshop with another local non-profit that taught them about grief that they might experience while working with critically ill children and gave them skills and tools in order to handle their grief.

Research Question 2: With whom do museums offer programming for people with life threatening illness?

Partners

The most common type of partner was a hospital. However, within the hospitals themselves, partners included oncology clinics, social workers, psychologists, and child life specialists (people trained to work with families in a hospital setting). In addition, other partners included Ronald McDonald House, a licensed art therapist, and other area non-profits. Some institutions were initially approached by their partners to form some kind of programming, while others approached their health partners.

Partner Responsibilities

Each program included in this study involved a partnership with a health care provider. The responsibilities of the partners in these relationships and the duration of the partnerships varied from institution to institution. One of the interviewed institutions moved from partnering with a health institution to put on programs and transitioned to offering an independent program whose health partners help recruit participants.

All of the interviewees found that the health care providers offered important insight into the unique needs of patients and their families. Many of these partnerships involved hospital social workers or Child Life staff who provided further support to patients and families when

needed. An important theme of these partnerships is geographic proximity as well as a city-wide culture of healthcare partnerships.

Research Question 3: Why are museums offering programming for people with life-threatening illness?

Participant Outcomes

The most common intended outcome for participants was fun and distraction. Interviewees noted the importance of offering an activity which wasn't centered on disease or medical need and which allowed caregivers a respite, maybe even long enough for a parent to shower or grab a quick nap. Another outcome was empowerment. One interviewee noted the importance of participants seeing themselves in a role other than "patient." The participants are encouraged to see themselves as students, artists, and creators.

Another participant outcome was facilitation of communication and the development of interpersonal relationships. One program's main goal was to facilitate communication among family members using art. Other interviewees noted the importance of family relationships and relationships among patients themselves.

Finally, many interviewees noted that they wanted their participants to come away with knowledge. This knowledge might be about the particular subject area they teach, the ways in which their institution can be a resource, or the healing nature of art making.

Mission

Each museum was able to identify ways in which these programs might help fulfill their museum's mission statement. Some museums' mission statements specifically mention their physical collection, which many programs use while offering these programs. Other interviewees mentioned that their program fulfilled the main verb. For example, one institution

noted that their mission was to “engage and inspire,” and she believed the program did indeed both engage and inspire its participants.

Another theme among responses was a focus on access or inclusion. Interviewees noted that their programs weren’t really *doing* anything unique, but they allowed the museum to reach those that they might not otherwise be able to. One interviewee noted that the program allowed them to “reach beyond the ... museum,” and another person felt that their partnerships let them “reach as many people as possible.”

Building Upon Our Strengths

One institutional strength mentioned by multiple museum was public programming. These museums described their programs for people with life-threatening illness as very similar to other programs they offer. Museums offer programs in many different places and formats for different audiences, and interviewees described using lessons learned from those experiences.

Some museums noted their institutions’ collections as an important strength which these programs utilize. As noted above, some interviewees mentioned that using these collections even helped fulfill their mission statement.

Another institutional strength was visibility within their community. Their museum is a well-known community resource, so partnering with another well-known institution allowed their programs to flourish.

The idea of access and inclusion also came up when describing institutional strengths. Some of the institutions included in this study see working with non-traditional museum audiences as an important part of their work. These museums in particular offer programming for people with dementia, children with disabilities, people with low or no vision or with hearing loss, and first-generation college-bound English as a Second Language students.

Multiple institutions noted that they were located in cities known for both world-class cultural institutions and world-class health institutions. Subsequently, they often found interpersonal connections between the museum and hospitals through staff members, prominent donors and even board members.

Personal Connection

Each interviewee spoke with emotion-centered words about their involvement with these programs. They used words like “humbling,” “sense of accomplishment,” “sense of purpose,” “compassion,” and “empathy.” One museum educator was inspired to pursue a degree in Art Therapy and design a program curriculum as part of her internship experience. After her hospital partnership stopped, another interviewee went on to work with adults in hospitals as a Caring Clown, giving out smiles. The interviewee from the Museum of Fine Arts, Houston had the following to say: “When we’re making a work of art and they have their final piece, that piece is either going to be a trophy that they get to take home when they’re well or it may be a tangible object that their family can remember them by if they do pass on. So that’s a beautiful thing that I get to help a family with.”

Each museum expressed value in evaluating these programs, whether or not they were able to conduct evaluation of their programs. The institutions that had been able to conduct evaluation found that their programs had positive, valuable effects on individual participants and participating institutions.

Implications

It seems possible for a variety of institutions with a variety of mission statements to offer programming for people with life-threatening illness. These programs would most likely involve a partnership with a local health care provider and include extra training and emotional

considerations for the staff members involved with it. There is a variety of ways in which institutions might fund these programs as appropriate for their budget and community. These partnerships can be highly rewarding for the individual staff, museum, partners, and participants.

Limitations

The institutions I chose to interview were listed in the appendix of the 2013 AAM publication *Museums on Call*. This document was not meant to be comprehensive, but presented a “snapshot of the ways museums are serving their communities” during 2013 (AAM, 2013). The institutions included in this study are not a representative sample of the institutions offering this type of programming. I chose to include a sample which hoped to show variety in institution type, program audience, partner institutions, and geographic location.

Notably, the only institutions without “art” in their name were the Great Plains Zoo and Penn Museum. In addition, only two institutions interviewed were located West of the Mississippi, and none that might be considered “West Coast.” There were no science centers listed in the publication, although one interviewee mentioned conversations with a science center in her city that plans to begin offering hospital-based programming. The only children’s museum listed in the appendix did not choose to participate in this study.

I also chose to exclude programming for people with dementia and their caregivers from this list. Some dementias (especially Alzheimer’s) can be considered life-threatening or terminal illnesses (Wolf-Klein, et al., 2007). However, there seems to be an extant literature regarding museum programming for people with dementia, and that this audience has specific needs that other audiences might not (Rhoads, 2009).

Chapter 5: Conclusion and Recommendations

Conclusion

Today, Americans live longer lives, experience more long-term disease and die in hospital more than in the past (Quill & Miller, 2014). Experiencing illness in any way (whether it's the illness of oneself or of one's loved one) can cause social, psychological, and even physical suffering (Krikorian, Limonera and Maté, 2012). In response, multiple therapeutic and psychoeducational tools and programs have been used to lessen this suffering (Kirk & McManus, 2002; Lewis, et al., 2006; Chatterjee, Vreeland & Noble, 2006; Lewis, et al., 2008; Clements-Cortés, 2009). Some museums have begun to offer programming for people experiencing life-threatening illness and their families (AAM, 2013).

To study the question "How, with whom, and why are museums offer programming for people with life-threatening illness?" I used AAM's 2013 publication *Museums on Call* as a data pool to interview museum professionals involved with these programs. The sample institutions were chosen to reflect a variety of institution type, program audience, partnerships, and geographical location.

A variety of institution type, including art museums, gardens, zoos, and children's museums currently offer programming for people with life-threatening illness. Each of these programs involves partnerships with geographically close health care providers. Every institution was able to specify the ways in which offering such a program might help fulfill their mission statements. The ways each of these programs was funded was diverse and ranged from gifts from individual donors to the museum receiving some amount of remuneration for supplies from their partner organization. Staff used strong emotional words like "sense of purpose" to describe their experiences with these programs.

Recommendations

It seems possible for a variety of institution types and sizes to develop programs for people with life-threatening illness which fit the needs of their mission, budget, staff strengths, and community. Although some evaluation has been conducted of these programs, more evaluation is needed in order to more closely identify and perhaps quantify patient outcomes. Perhaps this evaluation should be done with social workers or psychologists in order to identify psychosocial outcomes that museums might not be able to identify or evaluate.

Some interviewees saw the unique nature of these programs not as novel ways to use museum collections but as ways to include new audiences. More research into the ways in which these programs fit into the museum field-wide trend of *inclusion* is needed to understand this viewpoint better.

Finally, there should be discussion within each institution, with healthcare partners and field-wide regarding the training and expertise of the people designing and implementing these programs. How will museum educators know when a patient is shutting down emotionally or might need a referral for counseling? Is the volunteer training at the partner institutions enough? Should these programs be offered in the presence of social workers or psychologists?

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