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**Arts-based Approach for Knowledge Dissemination: Lessons learned**

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**Arts-based Approach for Knowledge Dissemination: Lessons learned**

**Background:** Once a study has been completed, the final step of dissemination of findings is crucial. In this paper, we explore the benefits of bringing nursing research into public spaces using an arts-based approach.

**Aim:** To present a case example of using an arts-based approach developing an art exhibit to disseminate research findings from a narrative research study.

**Data Sources** Findings from a qualitative narrative inquiry exploring peoples’ experiences of living with life-threatening illnesses.

**Review Methods** Semi-structured in-depth interviews were conducted with 32 participants living with cancer, chronic renal disease, or HIV/AIDS. Participants were invited to share a symbol representing their experience of living with life-threatening illness and the meaning it held for them.

**Discussion**: The exhibit conveys experiences of how people story and re-story their lives when living with chronic kidney disease, cancer, or HIV. Photographic images of symbolic representations of study participant’s experiences and poetic narratives from their stories were exhibited in a public art gallery. The theoretical underpinning of arts-based approaches and the lessons learned in creating an art exhibit from research findings are explored.

**Conclusion:** Creative art forms for research and knowledge dissemination offer sites for new ways of understanding and knowing that are under-utilized in nursing.

**Implications for practice/research** Arts-based approaches make visible patients’ experiences that are often left unarticulated or hidden. Creative dissemination approaches such as art exhibits can promote insight and new ways of knowing that communicate nursing research to both public and professional audiences.

Key words: arts-based research, narrative inquiry, knowledge translation, aesthetic

*The date for the art exhibit of our research findings was fast approaching and we were excited to see how it would unfold. All details seemed to be in place. The invitations to the Opening had been sent and we were curious which study participants, colleagues, and stake holders would attend. It seemed straightforward enough. And then everything shifted. I received a call from one of our study participants whose photo was in the exhibit. She was in the process of making extensive plans and adjustments to medical appointments to be able to attend. She surprised me by asking, “What should I wear?” Her question revealed her feelings of vulnerability in attending this public event to share our research with a larger audience. It triggered my awareness of a deeper sense of responsibility and desire to look for her and to keep a watchful eye during the event. I felt a sense of duty and ethical obligation to ensure that my eyes met each participant on arrival at the gallery and that each felt visible, welcomed, and safe. [R. Beuthin, doctoral research fellow].*

 As nurse researchers, it is common to disseminate results of our research through peer-review publications and formal presentations at professional and academic conferences. However, using creative, arts-based approaches to conduct and translate research findings was new territory for our research team. In this paper we share an innovative way to disseminate nursing research with a broader audience using an art exhibit. Our aim is to define arts-based research, summarize the narrative study and findings unpinning the art exhibit and to describe the steps and lessons learned for researchers considering this approach to research dissemination.

Knowledge Dissemination

 Knowledge dissemination is the final and crucial phase of research. A study cannot contribute to new knowledge, critically challenge taken-for-granted understandings, or convey the voices of marginalized populations if the study findings are not communicated. (Loiselle & Profetto-McGrath, 2011). Conventional approaches to sharing knowledge from nursing research include peer-reviewed publications in professional journals and conference presentations that are effective in reaching academic and professional audiences. Increasingly however, publically funded researchers are encouraged to make research outputs more accessible through open-access journals, public venues and accessible technologies (CIHR, 2013). The rationale is that with greater ease of access, policy makers and the public will use research more effectively and thereby increase the overall benefit of new knowledge (CIHR). However reaching a broader population including patients, families, and the greater public requires innovative and diverse dissemination approaches. Increasingly, more creative arts are used to extend the reach of nursing research and to communicate findings to broader audiences and stakeholders. We believe approaches such as art exhibits, offer open and evocative platforms for nursing research.

What is art based research?

 Arts-based research is described as a process that uses expressive qualities of form (images, sound, movement, poetics) to transcend the limits of language and call forth what cannot be articulated (Eisner, 1995). The aim is to foster insight, nondiscursive understanding, and to reveal “what someone can feel” about some aspect of life (Barone & Eisner, 2012, p. 9). These approaches provide ways of communicating that move people towards new ways of understanding and knowing. Scholars in nursing and health research are turning to aesthetic forms such as research-based theatre (Rossiter et al., 2008; Quinlan, 2010), dance productions (Boydell, 2011) and art exhibitions (Lapum et al., 2012) to evocatively share study findings. Through imagery, movement, music, and poetry researchers can holistically represent knowledge and generate emotional as well as cognitive understandings. Boydell (2011) illustrates this by creating a dance performance from findings of a study that explored first time episodes of psychosis for teens. The intent was to “condense information into a story-like dance that would educate, rather than overwhelm, an audience” (p. 15) of teenagers, parents, and the public. In the art exhibit we developed, our intention was also aimed at incorporating visuals and peoples’ stories to promote understanding of what it is like to live with the uncertainty of life-threatening illness. As you will see, we used arts based approaches in the data collection, analysis, and the knowledge dissemination phases of this research..

Summary of Narrative Research Study

 The art exhibit entitled, *Symbols of living in-between: Re-stor(y)ing life within life-threatening illness* (Authors, 2012) is part of a larger study exploring the experiences of people living with chronic kidney disease, cancer and HIV. The study uses a narrative approach (Reissman, 2002, 2008) to explore peoples’ experiences of living with life-threatening illnesses and how they story and re-story their lives in the face of uncertainty. The word re-stor(y) is used to convey dynamic, non-linear, and multiple experiences. According to Frank (2005), it is the perpetual generation of storying for people with life threatening illness that offers a means of living with uncertainty. The term, re-stor(y)ing conveys several possible interpretations: restoring life, re-storying life, or something in-between the two. The research is based in the need for greater understanding of how people make sense of living in-between the hope for prolonged life and the eventual decline as life-threatening illness progresses. The aims of the study were to further understand these in-between or liminal spaces. Participants were invited to participate throughposters and advertisements that were placed in community newspapers and newsletters. Word of mouth and snowball sampling/recruitment were also used as participants came forward.

 Thirty-two people diagnosed with chronic kidney disease (CKD), cancer or HIV participated with a balanced representation across disease populations: (a) ten people living with cancer, (b) fourteen with CKD, and (c) eight people living with HIV/AIDS. Participants included 14 women and 18 men from 37 to 83 years in age and a range of 1 to 50 years post-diagnosis. Seven participants had a dual-diagnosis of cancer and either CKD or HIV/AIDS. The types of cancer varied including breast, ovarian, prostate, colon, and bladder cancers. For those with cancer alone, the date since diagnosis at the time of the first interview ranged from 1 to 20 years; three participants with CKD were lost to the study due to death. All aspects of the study were approved by a University Human Research Ethics Board.

 Participants were interviewed four times over a period of three years. In the first meeting rapport was established and exploratory, descriptive questions were posed including, “can you tell me about your experience of living with (cancer, CKD, or HIV)” and “how do you make sense of having this illness?” During the second interview, we invited participants to share a symbol that represented their experience of living with life-threatening illness. Participants were asked to identify a symbol and share what meaning it held for them. Our aim was to shed light on the complex ways people experience and make sense of living with a life-threatening illness. Through incorporating symbols we hoped to access aspects of experience that were difficult to put into words. The third and fourth interviews explored changes participants were experiencing over time, clarification of topics, and closure of the data collection phase. Copies of transcripts and instructions for accessing future study findings were provided. A decision was made to create an art exhibit in order to display the images of participants’ symbols, narratives and analyses in an innovative way that would educate and make visible experiences that are often left unarticulated or hidden.

Art Exhibit - Symbolic Representations and Poetics

 The art exhibit combines photographic images of the symbolic representations accompanied with participants’ narratives in the form of poetry and direct quotations. Sixteen images with narratives were selected to provide a window into their experiences (see Figure 1- Art Exhibit wall and Figure 2- Sample of image and poetry). What follows is a description of the steps taken in generating the visuals and poetic narratives along with other aspects of the exhibit.

**Images**

 All participants were invited to identify a symbol that represented their experiences of living with a life-threatening illness and the meaning of their symbolic representations. When possible, the symbols were photographed in the natural setting during the interview, and then photographed against a uniform gray background sheet. Participants were also invited to take a photograph of their symbol so that they could participate in the construction of the image. The researchers conducting the interviews were not professional photographers and the cameras were of varying qualities.

 Participants’ symbols are diverse and personal. They range from family pictures, to personal treasures (jewelry, drawing of an Egyptian ankh, letters received during chemotherapy), to objects of everyday life (coffee maker, cluster of apples, hook for peritoneal dialysate). There are a few symbols that are specific to illness (a graph tracking prostate specific antigen [PSA] levels, a wig) and as well two pieces of music (Beethoven’s Ninth Symphony, “Choral” [Finale], Tchaikovsky’s First Violin Concerto). The symbols express meaningful aspects of the everyday lives of participants – and yet, often the meaning of a person’s illness is not immediately evident in the symbol alone. Symbols, like illness, are interwoven into the fabric of people’s lives. Therefore the participants’ accompanying words were important in interpreting and understanding the symbolic meaning.

 Approximately half of the photographs of participants’ symbols were selected for enlargement in the art exhibit. The criteria for image selection were based on whether it was visually stimulating from an artistic perspective (for example, those with dynamic compositions) and if it was of high quality resolution. Ethical consideration of confidentiality also played a role in selecting which symbols to display. Consent was ongoing and negotiated with both the participant and those whose identities are revealed (usually people in a family photograph). If participants had since passed away during the course of the study, permission was sought from their next of kin. As a way of acknowledging participants who had died, we placed small white ribbons beside their symbols**.**

**Participant Narratives**

 Narrative analysis using text from participant interviews was identified to accompany the images. Both narrative poems and interpretive or lyric poems were created by two researchers. Faulkner (2007) identifies a distinction within ‘research poetry’ which we adopted. “Narrative poetry… are most interested in storytelling and lyric poetry the goal is to stress moments of subjective feeling and emotion in a short space” (p. 220). Both forms include analytic interpretation while lyric poetry fuses researcher and participant perspectives more explicitly. We drew primarily from Glesne’s (1997) methodology to create poems based on identified storylines while staying grounded in participants’ words from the transcripts.

 Representing findings in poetic form has been used by a number of nurse researchers (Malinski, 2008; Lapum et al., 2012). Evocative writing such as poetics recreates experiences that can pull into awareness the habitual and taken-for-granted. However, Faulkner (2007) cautions that closer attention to the craft of poetics and establishing criteria for a shared understanding of what constitutes ‘good research poetry’ is needed. While some researchers argue that such criteria will constrain creativity and freedom (Bochner, 2000), others call for clear criteria for assessing rigor versus standardization that might threaten creativity (Faulkner, 2007; Barone & Eisner, 2012). Current criteria for judging research poetry include artistic concentration, discovery and/or surprise, narrative truth, embodied experience, and the ability of poetry to transform (see Faulkner, 2007).

**Other Aspects of the Exhibit**

 We felt the intersection of research and art could be better highlighted by also foregrounding the research process. Therefore, in addition to hanging selected images and poetic narratives, we included a display case containing 16 images of symbols that we could not enlarge due to one or more of the reasons described above. The display case also contained artifacts including a selection of advertisements used to recruit participants, an example of the research team’s participant consent form, and brochures created from knowledge generated through the study.

 The exhibit was free and open to the public, running from April 13th to June 4th, 2012. As with many gallery events, an opening reception was hosted by the research team with brief introductory remarks about the research aims, process, and findings. The event was widely publicized and invitations were sent to 80 special guests. These included all of the study participants and their family/friends, representatives from the cancer agency, kidney foundation, AIDs organization, the research advisory group, university members, and members of the media.

 And finally, a comment book was placed on a table in the gallery with a sign inviting viewers to add their reactions, thoughts, and feedback about the exhibit. Examples of viewer feedback include, “Thanks for these exhibits. I was so moved by that living in between; I have not known how it is difficult. God Bless” and “The exhibit is very moving and powerful. I felt that time was eliminated and every symbol made me feel very present.”

Lessons Learned

 Three key areas of learning are highlighted for those considering an art exhibit approach to dissemination: 1) ethical considerations; 2) curatorial support; and 3) recommended resources.

Ethical Considerations

 Ethical considerations were central, time intensive, and ongoing. As illustrated in the opening narrative of this paper, a variety of unforeseen ethical obligations continued to arise. As nurses and researchers, we were sensitive to the need for ongoing consent at each step in the project. Even though a formal consent form was reviewed prior to each of the four interviews (and included consent for dissemination strategies), new dilemmas arose. For example, anonymity was no longer possible because participants or family members could be identified in the exhibited images. Permission of family members or friends who appeared in the photographs on public display was required. When a participant died, locating contact information for family members, and contacting the next of kin added other layers of complexity. Participants and family had the final say about whether they wished to have the symbol and narrative included in the exhibit. During this phase of the project, one of the researchers was frequently in contact with participants through multiple phone and email communications. When there were ethical concerns, permissions were needed before production of the images and poems could proceed.

Curatorial Support

 It became clear early on that the knowledge, skills and abilities of installing an art exhibit were necessary to ensure the artistic success of the project. To this end, a staff member at the School of Nursing who had previous experience as a curator was hired. The curatorial responsibilities (see Table 1) included consulting with the research team, overseeing and managing the installation and publicity of the exhibit.

Table 1: Curator duties:

* Work with team to identify compelling images for display purposes
* Identify venue and assist with the exhibit proposal for gallery
* Organize and connect content into an accessible and evocative display
* Develop layout of images in gallery
* Build specialized audio displays (music as symbolic representation).
* Develop, oversee, and install exhibit.
* Liaise with gallery staff
* Assist with publicity, opening ceremony, and exhibit documentation and report.

 With a large team, it is important to clearly define the role and scope of artistic considerations along with the research and KT intentions of the researchers. Tensions between the artistic aims of an exhibit and the educational needs of researchers for knowledge translation and academic accountability are cited elsewhere in the literature (Boydell, 2011; Gladstone, Volpe, & Boydell, 2007). In our experience, for example, the research team felt participants should be shielded from media coverage, while the gallery and publicity planners urged radio and print interviews with participants to promote interest in the exhibit. In addition, questions of intellectual property needed to be discussed where research findings and artistic translation intersected. The co-creation of artistic projects requires cross-disciplinary collaboration that can provide enriching experiences and outcomes.

Recommended Resources

 An art exhibit requires significant human and financial resources to plan, organize, publicize and install in a timely manner. In our case, the idea of an exhibit emerged during the analysis process. Consequently we were able to use funds from the original qualitative study but were also constrained by the funding timelines. Galleries often require proposals describing the goals, rationale, and structure before agreeing to host an exhibit. This means plans must be made months in advance when the conceptualization is still underway. Specific budget considerations related to the exhibit included: material costs of block mounting images and text panels, creating audio stations, art opening invitations and reception, publicity posters, and parking vouchers for invited guests. In addition, there were salary costs for the curator and research assistant to liaise with participants and families. In summary, important lessons learned include ethical issues of confidentiality, the need for curatorial support, and attention to pre-planning for material resources and exhibit venues.

Discussion

 Creative platforms for disseminating nursing research hold untapped potential. The place of arts-based research in health care continues to evolve and our experience has been both positive and, we hope, encouraging for others. Arts often function by projecting an image that resonates, unsettles, or connects with the viewer in some way (Barone & Eisner, 2012). According to these scholars good arts based research “has ‘legs’, allowing you to go someplace… it invites you into an experience that reminds you of people and places…” (p. 152). While empirical research is needed to assess the impact of arts-based dissemination strategies, we offer a reflective narrative written by one of the researchers (AB) following the opening reception:

 *I was standing by the punch bowl at the reception and asked the women next to me how she found the exhibit. She laughed sheepishly and said that her mother (who was a participant in the study) had asked her to come with her to the opening event. She then told me about her experience….As she was viewing one of the exhibit images her eye landed on the white ribbon discretely placed, almost invisible, against the cream colored wall. There was a moment of recognition and then she suddenly reacted-- as if abruptly struck by the impact of what the white ribbon meant. She explained, “I almost left at that moment. I couldn’t take it that Mom will die too”. One of the researchers must have seen this and gently approached her. They began talking about the exhibit and what it’s like for her family since her mother has been diagnosed.*

 *As she recounted her story it was clear by her nervous laughter that the experience had been unsettling. Barone and Eisner (2012) remind us how powerful symbols can be in calling forth feelings and spaces that often stay hidden. For this daughter, accessing a pool of fear beneath her everyday knowing that her mother will die some day was a wake-up call. I wondered if the exhibit has helped her to re-consider her mother’s mortality and perhaps even to act differently….*

Conclusion

 By bringing research findings into public spaces such as galleries we hope to foster dialogue and education about living with chronic kidney disease, cancer and HIV. In this exhibit, 16 large format photographs of the symbols were displayed alongside brief text panels. Poetic renderings based on participants’ words conveyed meanings and the multiple ways of sharing illness experience. Through symbols and narratives, we displayed intimate knowledge of life-threatening illness for others in healthcare, academic, and public communities. For further information about the exhibit and other related knowledge dissemination projects, access the website [www.uvic.ca/illnessnarratives](http://www.uvic.ca/illnessnarratives). The place of arts-based research in nursing is only beginning; we hope the lessons learned described here will support other nurses wishing to creatively share research that fosters diverse ways of understanding and knowing.

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