

Ethical Challenges in Arts-based Health Research

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This special issue of [The International Journal of The Creative Arts in Interdisciplinary Practice, IJCAIP](#), explores some of the ethical challenges of using arts-based methods in health research. It resulted, in part, from a workshop held by members of the Arts-based Health Research Consortium in response to the growing interest in the ethical issues and debates surrounding current practice in using the arts to create and disseminate research.

This article describes the workshop, held in Toronto, Ontario, September 2011, supported by the Canadian Institutes for Health Research. The meeting was chaired by Katherine Boydell¹ and attended by 22 participants, representing a range of professional, academic and artistic backgrounds from Canada and beyond. The objective of the meeting was to share experiences about the types of ethical issues encountered while conducting arts-based research, identify gaps and priorities – for the researcher, artist, the research participant, and the audience – and develop a research project for submission for external funding.

Background and Context

Interdisciplinary collaboration among the arts, humanities, health and social sciences is receiving much attention, characterized by enthusiasm for the creation of new knowledge and new forms of knowledge translation and exchange. There is a burgeoning of arts-based research in various fields including education, nursing and other health sciences, sociology, and communications studies (Gray, 2003, 2004, 2007; Knowles & Cole, 2008; Kontos & Naglie, 2006; McIntyre, 2004; Mitchell, Jonas-Simpson, Ivanoffski, 2006; Pink, 2007; Rossiter, Kontos, Colantonio et al, 2008), crossing traditional boundaries and forms of academic writing including autoethnography, poetry, performance texts, and visual representations (for example, see Belliveau, 2006, 2007; Boydell, 2011a, 2011b; Keen & Todres, 2007; Moffit & Volmann, 2004; Nisker, Martin, Bluhm, et al., 2006; Parsons & Boydell, 2012; Plummer, 2001; Saldana, 1998).

To date, literature in the field is primarily concerned with describing the conditions,

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particularly content and form, of arts-based research (Knowles & Cole, 2008). While different methodological perspectives on engaging the arts in research have been advanced, questions of ethics have, in large part, been neglected (Sinding, Gray & Nisker, 2008). Consequently methodological and theoretical frameworks for other researchers and artists interested in this breakthrough work are lacking. Those engaged in visually based ABHR have, however, been able to look to guidelines available from the field of visual sociology (Harper, 1990; Papademas, 2009). A special chapter was recommended for the second edition of the Tri-Council Policy Statement (TCPS2)², as the result of a working committee chaired by Blackstone et al (2008) in recognition of researchers from a wide range of disciplines—not just traditional Fine Arts disciplines—currently using creative practices in their research. It appears that the creative practices chapter was not selected for inclusion in the TCPS2, despite the 2008 report recommending it be included, along with a chapter on qualitative research; only the latter made it into the final 2010 edition.

Our trans-disciplinary workshop was planned in recognition of this critical need to bring individuals engaged in arts-based health research (ABHR) work together to discuss the unique and common ethical challenges they face and, in turn, share the findings of such dialogue with policy-makers and research ethics board members. As Cox and her colleagues (2009) note, systematic scrutiny of a wide variety of viewpoints allows for comparisons, similarities and differences to be identified, revealing key challenges for ethical oversight of [in our case, arts-based] health research involving humans.

In response to the growing use of ABHR and the lack of ethical guidelines to guide researchers, a subgroup of the ABHR Consortium organized a workshop that would bring

² The TCPS2 regulates the ethical conduct of research involving humans in Canada.

together an international group of scientists working in the field of ABHR. In preparation for the workshop, an organizing committee was formed, whose first task was to read the peer-reviewed empirical literature on issues of ethics in arts-based health research. Three review articles on arts and health were located, two of which were written by our participants (Cox, Lafrenière, Brett-MacLean et al., 2010; Boydell, Gladstone, Volpe et al., 2012; Fraser & al Sayah, 2011). Cox and her colleagues (2010) provided an overview of work that covers health policy, healthcare practice, individual and community health promotion, health professional education and ABHR. They noted that our knowledge about the actual methodology involved in ABHR is increasing rapidly; however, new attention needs to be directed to the ethical aspects involved in this work. Fraser & al Sayah (2011) conducted a systematic review of 30 ABHR studies. They found a paucity of critical inquiry into, reflection on or debate about, the use of arts in research and note that ethical considerations in using arts-based research methods are not explicit. They identify ethical issues as an important area for development – especially regarding data ownership, appropriate ways to analyze arts-based data, and participant anonymity.

In a scoping review of 71 studies, Boydell, Gladstone, Volpe et al. (2012) found few guidelines about ethical issues are specific to ABHR. Furthermore, the review identified a need to focus on how the quality or trustworthiness of ABHR is “measured”. White & Belliveau (2010) examined ethical considerations that influence how we develop, present and respond to performed research. They cautioned that ethical implications should not be regarded as potential distractions or obstructions, nor as a responsibility solely addressed prior to research never again to be considered once the process is underway. They noted the need for researchers to maintain a critical awareness of emergent ethical dilemmas throughout the process and to explicitly bring to surface issues with performers and audience as an integral part of the research.

Key issues in arts-based health research

To structure the workshop for maximum efficiency and output, organizers conducted an environmental scan by asking workshop participants to identify and submit examples of ethical concerns they have encountered in their own arts-based research. These examples were collated and taken together with our learnings from the literature review; five key issues emerged and were used to structure the discussion at the workshop:

- authorship/ownership of the work
- “truth” , interpretation and representation
- informed consent/anonymity/confidentiality
- dangerous emotional terrain
- issues of aesthetics

The workshop included *graphic recording* a visual arts-based method for capturing the content of a meeting, discussion, or conversation in real time. This enabled the group to clarify the five key issues and identify concerns and questions related to each of them.

Graphic Recording of the Event



As a graphic recorder I work silently on the chart while the conversation unfolds. As the group discussion moves forward, I create a visual record of the key points and concepts within a composition that captures the experience and meaning of the workshop. Individuals are drawn into the recording process as their comments, questions and direct dialogue are incorporated into the chart. However, what makes this work both challenging and deeply rewarding for people is how rapidly the ideas and concepts are transformed into a configuration of colour and imagery. (Reilly Dow, Artist)

To help stimulate workshop discussion and creativity, conference organizers invited a local artist to graphically record the proceedings. While the conversation unfolds, the recorder [RD] works silently on the chart, using icons, words, images and other visual tools to capture the key points and concepts. A composition emerges, documenting not only content but human experience and meaning. The participants find themselves drawn into the recording process as their ideas, questions and quotes are incorporated into the chart. There is room on the page for all their voices and the intention is for everyone to feel that they have been heard. The charts should typically be large enough for individuals to view their ideas as interconnected entities rather than fragments, incorporating information, patterns, colour and higher level concepts. Rather than capturing every word, the goal is to provide an aesthetically pleasing visual representation of central points that engages people in an emotional and intellectual way.

In the case of our workshop, the graphic recording captured the process of the conversation, resulting in a visual record that could then be juxtaposed with the more linear text-

based notes on the five workshop themes. In particular, the graphic recording documented what was said and felt and captured temporal patterns that reflected which themes were more challenging and required greater time for reflection. This technique enabled attention to be paid to those ethical challenges and tensions that were most salient for participants and therefore required most evidence-based scrutiny through our future research.

As made art, visual recording is a way for the artist to reflect and ‘make visible’ the words, phrases and images of the participants, and provide a sense of what is being exchanged amongst them. The graphic recording does not seek to represent one ‘truth’ but to juxtapose multiple voices and navigate what is at stake for those who speak and for those who listen. Several questions arose from our workshop and from subsequent conversations. What happens when made art is brought into the room, moment by moment? What are the ethical responsibilities of the recorder as they choose what and how to record? We explored this last question in some depth when the group engaged in a reflecting process, under the guidance of a *facilitator* [AK], who has used this process in clinical work and research practice (Katz, 1991, 1997, 2000). A key part of the process involved preparing the participants. AK began by asking the recorder [RD] for her consent and then invited everyone to re-view the visuals that had been created and to reflect on them in facilitated dialogue. RD listened and captured these reflections in a separate chart, after which she reflected on the reflections. This could have been an unusual situation for the graphic recorder, but two elements were especially important in reducing any potential vulnerability: the context-setting by the *facilitator*, and the positive attitudes of the other participants, perhaps based on their familiarity with various arts-based methods. The recorder found it engaging and helpful to know how her work was being received and interpreted—not knowing could be more unsettling than hearing feedback. Questions were raised

about whether the graphic recording, as a symbolic representation, has the power to reshape the original stories.

We concluded that graphic capture can be used at several levels of engagement: as a stand-alone artifact as something to be observed silently, and as a tool for making meaning together as a group in dialogue, in real time. By adding this new level of reflection amongst the recorder and the group, we had the opportunity to embody what we had been discussing in the workshop: how artists and researchers can enter into a meaningful dialog and navigate multiple meanings.

Five key themes

(1) Authorship/ownership of the work

This theme was characterized by the question ‘whose story is it anyway’? Attendees felt that one key ethical issue they grappled with in their arts-based work related to questions of authorship. Some central questions posed included: What are ethical practices related to collaborative authorship or best practices when deciding who takes the lead in creating different kinds of project outcomes? What are the authorship/ownership issues encountered in the use of various art genres? Who ultimately ‘owns’ the work? For example, in the case of a poem created from a research interview, Lafrenière, Cox, Belliveau & Lea (2012), in a manuscript currently under review, ask whether the poetic text belongs to the research participant, to the artist, or to the researcher. Other situations lend themselves to additional questions such as, have participants consented to the use of interview material by artists to create an artistic piece? Who owns the photographs, and in which format (originals, negatives, enlargements, digitized copies)?

One workshop participant reported that, according to their university's legal department, after an artist has been granted permission from a researcher to artistically engage with the research data, he/she is granted artistic ownership; that is, the artist now possesses the rights of the creative research piece. This stance was resisted by some academics in the workshop, indicating the need for more safeguards to be put in place to protect participants.

(2) ***“Truth”, interpretation and representation***

When drawing on art genres to create and disseminate research, the workshop attendees recognized that art conveys multiple meanings that can be used to evoke the complexity of our work and the contradictions that are inherent to it (see Gladstone et al., this issue). A number of questions were raised regarding the issue of representation, including: How much discretion should be given to artists to select which research messages they will convey? What if artists focus only on aspects that can be easily dramatized? Does the selection process allow research participants to challenge the interpretation that the artists have given to their words? Would leaving the performance open to a greater level of interpretation result in a product that is less ‘true’ to the research? How do we deal with different interpretations of data by artists and researchers? Specifically, what are the potential risks of misrepresentation? What are the ethical implications of divergent interpretations? These questions all point to the central importance of clarifying the roles and responsibilities as well as varying degrees of autonomy that characterize particular research relationships (i.e., between researchers and artists, artists and research participants, etc). Although such issues will likely need to be revisited frequently as arts-based research collaborations evolve, it seems prudent to adopt a pro-active stance acknowledging that the inherently fluid nature of the artistic creative process will manifest itself as specific tensions

between the intended messaging of core research questions or findings and the aesthetic and other goals which may be more germane to artists.

(3) *Informed consent/anonymity/confidentiality*

It is a cornerstone of research ethics that all research involving human subjects be respectful of individual autonomy. This requires that participants give their informed consent to all procedures. This highlights the importance of clearly articulating what is being asked of participants and identifying the possible positive or negative effects research participation may have for them. Traditionally, it is assumed that researchers will protect the identity of research participants. One of the areas of ethical uncertainty in arts-based research, however, is the consequence of being publicly identifiable, whether it is through one's likeness in an image or through explicit co-authorship.

Attendees identified the need to engage in a process of thinking about the longer term consequences of using the arts in the research process – do research participants understand what it means to be identified in the future? For example, in mental illness research, there is a tension between the goals of anonymity and protecting vulnerable participants on the one side, and the desired goal of stigma reduction strategies that promote speaking out and putting a name to mental illness on the other (Corrigan, 2000). Moreover, when preserving anonymity in work using photography, the standard method of blinding which uses a black bar across the eyes to protect identity makes participants look unsavory or criminal, which exacerbates the potential for stigma and discrimination. Importantly, there are some research ethics boards who resist allowing researchers to give research participants the choice of whether to be 'public' – total anonymity is sometimes demanded – and this produces difficulties in participatory emancipatory

research projects. Several workshop participants shared examples of successful efforts in educating ethics review boards in the area of ABHR.

Further, it is critical that researchers are cautioned against overemphasizing the need for anonymity/confidentiality. In some cases, researchers do need to forego artistic needs in favour of protection. Just because researchers or ethics review boards may perceive research participants to be vulnerable or marginalized, does not necessarily mean that confidentiality is required. For example, if the central purpose of the research is to empower individuals and provide a venue where they can (and want to) speak to the community, then to insist on anonymity would contradict that goal and be inappropriate. Workshop attendees concluded that there is a need for explicit discussion about when and for whom it is appropriate for a research participant to be identified – and that this discussion should include the academic and artistic community as well as participants.

(4) Dangerous emotional terrain³

Art is a heightened experience, one that simultaneously engages our senses, our emotions, and our intellect. As such, arts-based approaches engage our senses in a way that provokes something differently than many written texts are and therefore more likely to have influence (Parsons, Heus & Moravac, 2012). Images or experiences that have emotional overtones stay with us, even if hidden for a time in the recesses of our consciousness, only to return and provoke at a later time. Using artistic modes of representation allows for participation in a different way and may thus increase the likelihood of making an impact (whether negative or positive) on the reader/ viewer/ community and, of course, on the artist and researcher.

³ This term is used by Gray and his colleagues (2006) in their discussion of the potential negative impact of using theatre in dissemination of cancer research.

However, the emotional proximity and persuasiveness of arts-based research also raises the question of the potential for participants to find it ‘troubling’, ‘unsettling’, even ‘disturbing’ at times. Furthermore, sometimes there are unintended consequences for audiences. Do we characterize this as harm or a failure of the ‘work’?

Asking people to participate in communicating their health issue in a more embodied and representational manner has the potential to be perceived as being too demanding, or too ‘risky’ - a process that can result in uncomfortable or unexpected feelings. Because the arts open up the audience/viewers or readers to emotional moments, feelings enter into the work. It’s a key characteristic of the arts to tap into the cognitive & emotional and not to separate them as they often work in tandem. However, researchers and research ethics boards are often ill-prepared to examine protocols for arts-based research where there are these types of unknowns in terms of the emotional risks of engaging as a participant in research. Other concerns related to the emotionality of arts-based research are raised by arts methods that engage audiences. For example, ethically, should members of audiences be made aware in advance of the emotional or other effects an artistic work could have for them (most obviously, the potential for distress). Recent work utilizing theatre as a tool for engaging the public in health policy development suggests that there is an ethical responsibility to provide advance knowledge of the potential for distress and also have a plan in place to respond to participants who require debriefing and/or support (Cox, Kazubowski-Houston & Nisker, 2009)

Finally, the potential for harm to performers who engage in arts-based research requires careful consideration. Actors and other artists and their experiences of depicting suffering and violence, for example, remain relatively unexplored. For example, in one of our research projects using dance to communicate the experience of psychosis, some dancers themselves had

experienced mental health issues and embodying or “dancing” the experiences of those with first episode psychosis had unintended affects on them (Boydell, 2011a, 2011b).

(5) Issues of aesthetics

Workshop attendees repeatedly raised the notion of the aesthetic component of ABHR, the problem of evaluating what is “good”, and who gets to determine what “good” art is. Aesthetics in ABHR highlight problems of emphasis in representations of complex human experience and whether the weight of judging the quality of ‘goodness’ of the work should rest with aesthetic principles and/or those of research (see Gladstone et al., this issue). Gladstone and her colleagues (this issue), for example, take up the ‘process’ piece – judging goodness in the context of producing data is linked to the ‘ethics as process’ literature. They cite Guillemin’s (2004) work in this area where she identifies ‘ethically important moments’ - those factors that are key to everyday practice of research where even when it is clear what ‘should be done’ there remains the possibility for harm. She and her colleagues query whether a participant can become vulnerable during the process and the ways in which we should think about that ethically. This is connected to their own process of trying to create something ‘good’ and having to evaluate this in terms of what is good art, or what is a good representation of individual experience or that of the others in the project as they worked together. Gladstone et al.’s paper is an attempt to be reflexive about these kinds of moments and the link between goodness and ‘micro’ ethics as Guillemin has referred to it. Determining the goodness of art (or moment of art) is complex as it is. Determining the goodness of art in terms of its role in research is even more complex, requiring attention to the aims of the research and the context in which the research is being conducted. Beck and colleagues (2011) suggest that artists and researchers engage in this type of

work for different purposes and with different audiences in mind. They also come with different experiences and expertise.

The workshop attendees agreed that the five key themes – ownership, representation, confidentiality, emotional risk, and aesthetics – require critical scrutiny, with the objective of re-making research ethics guidelines to effectively accommodate ABHR.

Concluding Comments

This Special Issue of *the International Journal of the Creative Arts in Interdisciplinary Practice* is an important outcome of the Ethics and Arts-based Research workshop and an effort to reach others who are engaged in this work to participate in the conversation. Three papers written by workshop participants highlight some of the conversations we engaged in during the two-day discussion. The first paper focuses on what it means to judge quality in ABHR. Brenda Gladstone and her colleagues use as an exemplar their work involving the creation of mural art. In considering the case of the ‘*Ugly Baby*’, their short-hand for an ABHR project described during the ethics workshop, they raise questions about the challenges encountered in thinking about what makes ABHR ‘good’ and how this is tied to ethical concerns more generally. In the second paper, Darquise Lafrenière and her colleagues situate ABHR in the contextual background of evidence-based medicine, knowledge translation and qualitative health research to explain why the ethics of doing ABHR has received little attention until now. They then present an overview of the ethical issues reported in the literature by arts-based researchers. Finally, they discuss the utility of the literature on ethics and arts-based research for guiding practice in this type of research. In the final paper Kaisu Koski details her experience in medical education and the ethical challenges encountered when using art-based methods. Also discussed is the notion of dispersed loyalty, caused by the dual position occupied by the artist-researcher, and how it can

raise ethical issues during the research project. Koski also highlights the ways ethics protocol can constrain artists by the emphasis on avoiding so-called dangerous emotional grounds.

Our workshop on ethical challenges addresses a significant gap in arts-based health research. A key outcome of the proposed initiative is the preparation of a grant proposal focused on the ethical challenges of engaging in arts-based health research. We collectively believe that a focus on research ethics in ABHR (Cox et al, 2009) will make a significant contribution to the development of an evidence-based ethics as empirically driven studies, rather than principle-driven approaches alone, assist in enhancing our awareness of the key issues as they are experienced by the full range of salient participants. This will inform the development of new research ethics policy and will also play a role in evolving research and creative practice.

(McDonald & Cox, 2009).

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