

# Visual Embodiment of Psychosis: Ethical Concerns in Performing Difficult Experiences

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## Research Article

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### ABSTRACT

Arts-based health research has increased dramatically in recent years. Many academics are collaborating across disciplines including health and social sciences, humanities and the arts. Using artistic modes of research representation allows for a different way of participating and may enhance the likelihood of making an impact (negative or positive) on the audience and, consequently, on artists and researchers. This paper focuses on the concept of 'dangerous emotional terrain', used to describe the potential negative impacts of using the arts, in this case dance, in research dissemination. We focus on a seldom-explored area – the impact on artists embodying research results of difficult lived experiences. The potential for harm to performers engaging in arts-based research requires consideration. Actors and other artists and their experiences of depicting suffering and pain, for example, remain relatively unexplored. What are our responsibilities to performers taking on this role? What are the ethical implications of engaging in such work? This paper explores these questions and identifies four strategies to tackle emotional impact: reflexive practice, creation of a safe and supportive environment, address issues of audience, and focus on balance between types of performance, and between work and home.

*Keywords:* Dangerous emotional terrain; embodiment; ethics; arts-based research; emotionally difficult roles; knowledge translation.

## Introduction

Drawing upon artistic expression as a knowledge translation<sup>1</sup> strategy to generate and disseminate evidence-based research has become a multidisciplinary means to impact health care professionals, patients, artists, policy makers and the general public. Arts-based knowledge translation involves communication, but embodiment is what makes it a unique and distinct form (Archibald, Caine & Scott, 2014). Visual images often have immediacy and an affective power that can evoke strong emotions from emotionally distressing images (Gray et al., 2003). Arts-based research refers to a wide array of artistic forms including music, visual arts, photography, poetry and dance/theatre (Parsons & Boydell, 2012). Arts based therapy has been used in pediatric medicine and child mental health for many years (Sinding, Gray, Damianakis et al., 2006; Gray et al., 2003). However, it is only recently that the arts have been added to the qualitative investigator's toolbox as a mode of research production and dissemination (Boydell, 2011a). In Canada, arts based methods have burgeoned as a method employed in health research for representation and dissemination of research findings (Fraser & Al Sayah, 2011). Arts-based research has become an important strategic tool for knowledge translation, community awareness and public health programs (Boydell, 2011a; Boydell, Gladstone, Volpe et al., 2012).

The field of knowledge translation has increased in health and social care in an attempt to advance uptake and implementation of potentially beneficial knowledge (Graham, Logan, Harrison et al., 2006). The most effective knowledge translation incorporates research evidence, practitioners' knowledge, patient experience, and knowledge of local context (Sinding, Gray, Damianakis et al., 2006). Other forms of knowledge can be gained via the role of the health practitioner in managing and treating patients; researchers working with patients in arts-based research; and, choreographers directing patients and performers in arts-based research (Sinding, Gray, Damianakis et al., 2006). The use of arts-based research in knowledge transfer has the potential to assist in the development of public awareness, community programs and dissemination of knowledge through media and the arts (Boydell, 2011a; Boydell, Gladstone, Volpe et al., 2012; Cox, LaFreniere, Brett-Mclean et al., 2010). Knowledge translation via arts-based research has stimulated public engagement, increased knowledge about health issues, allowed for dissemination of scientific knowledge to the broader community and reduced mental health stigma (Goldner, 2011).

Arts based methods are used to enhance awareness and knowledge of the illness experience (Boydell, 2011a), and have been demonstrated to engage and empower participants to enhance confidence, express emotions and acquire insight compared to traditional qualitative knowledge dissemination (Boydell, 2011b). Despite the current excitement in the field with respect to the power of the arts to share evidence-based research and reduce the knowledge to practice gap (i.e. evidence to impact on changes in awareness, attitudes and behavior), there are still unexplored challenges. One central challenge is the notion of 'dangerous emotional terrain'<sup>2</sup> coined by Ross Gray and his colleagues (2003), and used to refer to the potential of using the arts in the research process to have negative effects on the individuals performing and on the audience

members viewing (Goldner, 2014; Boydell et al., 2014). It has been recognized that visual research methods have the potential to generate unanticipated types of harm or discomfort, which may lie outside of the harmful experiences normally considered by ethics committees (Cox, Drew, Guillemin et al., 2014).

In a recent publication outlining ethical guidelines for visual research methods, Cox, Drew, Guillemin and colleagues (2014) note the importance of reducing the harm that may be experienced by researchers and members of the audience who are privy to the stories shared via visual and other arts based methods. They recognize that these narratives are frequently highly personal with the potential to both evoke and provoke. They further state: "While it can be important and empowering for participants to share their stories, it could be distressing to researchers and audience members who are confronted with evocative imagery on sensitive topics", p. 11. Whilst this is certainly true, there is also the potential distress experienced by those who perform research results via dramatic performance or dance. However, there is very little in the current literature that explores the impact of using the arts on the actors/performers/health care consumers who embody these lived experiences of a health issue (Boydell, Gladstone, Volpe et al., 2012; Sinding, Gray, Damianakis et al., 2006; Gray et al., 2003). This paper provides an overview of our current knowledge base in this area and draws upon our recent research-based dance project to reflect on the impact of embodying experiences of psychosis on the choreographer, dancers and musician involved in the study<sup>3</sup>. We follow with some suggestions for addressing this issue in future arts-based health research.

## Overview

The use of the arts in the knowledge translation process (creation and dissemination) has been reported (Boydell, Gladstone, Volpe et al., 2012). As one frequently described example, theater is posited as an extremely effective method for knowledge transfer; though its use is not without risk to the actors involved in emotionally difficult roles (Colantonio, Kontos, Gilbert et al., 2008). Research based theatre holds both academic credibility and validity, with a unique emotional impact on audiences at the cognitive level (Parsons & Boydell, 2012; Colantonio, Kontos, Gilbert et al., 2008). Theatre allows audiences to assimilate knowledge by observing, hearing and feeling rather than traditional forms of passive knowledge transfer from journals and pamphlets (Colantonio, Kontos, Gilbert et al., 2008). The use of theatre is often described as an opportunity for healthcare professionals to reflect on the care they provide and enhance their understanding of the patient's lived experience through the concept of embodiment (Boydell, 2011a; Boydell et al., 2012a). Multiple studies are consistent with the findings that dance and theatre have a greater impact on the emotions of the audience and performers (Rossiter, Gray, Kontos et al., 2008). A small number of articles focus on determining the emotional impact on participants and audiences (Boydell, Gladstone, Volpe et al., 2012a).

Embodied research is based on the traditional phenomenon of the "lived body" and "lived experience" which suggests that knowledge has to do with the lived experience (Todres, 2007). Embodied inquiry focuses on the relationship between language and the

body (Boydell, 2011a; Winters, 2008; Andres-Hyman, Strauss & Davidson, 2007; Thomson & Jaque, 2012). An actor embodies the physical life and emotions of the character; the initial task of an actor is similar to that of a psychologist/physician taking a history, understanding the experiences and behaviors to acquire cognitive understanding of the patient's well-being (Thomson & Jaque, 2012; Colantonio et al., 2008). After researching the character's emotions and life experiences, the actor embodies the character in dance or theatrical performance (Andres-Hyman, Strauss & Davidson, 2007; Thomson & Jaque, 2012). In recent years it has become evident that embodying conflicted characters has the potential to emotionally affect the actor outside the theatrical role (Thomson & Jaque, 2012). Emotionally difficult roles involving the embodiment of mental illness or psychosis may pose a psychological risk to the performer (Jackson, Meltzoff & Decety, 2005). Are actors more vulnerable to performing difficult roles? Does the embodiment of emotionally difficult roles impact the actor/dancer more than other forms of art?



Figure 1. The embodiment of emotionally difficult roles<sup>4</sup>

*Method Acting* is described as a form of acting where the actor 'becomes' the character or tries to embody the character outside of the theatrical role (Thomson & Jaque, 2012; Colantonio, Kontos, Gilbert et al., 2008). Method acting was created by Constantin Stanislavsky in Russia; and further developed by Lee Strasberg (Thomson & Jaque, 2012). This form trains actors to use their imagination, life experiences and emotions to create performances as if they re-experienced the emotions and experiences of the character (Colantonio, Kontos, Gilbert et al., 2008). An actor is required to research and understand

the difficult emotions and experiences in order to fully embody the character. Once the actor has embodied such emotions, they may experience difficulty in separating themselves from the character (Andres-Hyman, Strauss & Davidson, 2007; Thomson & Jaque, 2012).

Actors with a history of depression, traumatic past experiences and unstable relationships are reportedly more likely to be affected by emotionally sensitive character roles (Thomson & Jaque, 2012). Specifically, it has been noted that there is an emotional and psychological impact to the performer after embodying characters with mental illness and psychosis (Andres-Hyman, Strauss & Davidson, 2007; Thomson & Jaque, 2012). The observation and re-enactment of delusional or depressive emotions affects the emotional stability of the performer (Winters, 2008; Gallese, 2005). There is a psychological risk of depression and dissociation in vulnerable actors who perform characters experiencing psychosis and other forms of mental illness (Winters, 2008). Depression and mood changes are associated with sleep deprivation; further intensifying negative mood and impulsivity (Gryglewska-Orzel, 2010; Anderson & Platten, 2011; Tempesta, Couyoumdjian, Curcio et al., 2010; Hemmeter, Sernal-Hemmeter & Kreig, 2010). On occasion, actors may be at risk of using alcohol or pharmacological sleep aids, such as benzodiazepines, to relieve depressive thoughts and emotions induced by embodying a particular character (Gryglewska-Orzel, 2010; Anderson & Platten, 2011; Goel, Rao, Durmer et al., 2009). Sleep deprivation affects the prefrontal cortex, limbic system, anterior cingulate cortex; thereby affecting empathy and emotions (Anderson & Platten, 2011; Tempesta, Couyoumdjian, Curcio et al., 2010; Guadagni, Burles, Ferrara et al., 2014). Such deprivation also leads to impaired neurological prefrontal and limbic system functioning, similar to that expressed by patients with acute psychosis (Anderson & Platten, 2011; Tempesta, Couyoumdjian, Curcio et al., 2010; Hemmeter, Sernal-Hemmeter & Kreig, 2010; Goel, Rao, Durmer et al., 2009).



Figure 2. The vulnerability of performative artists to difficult emotional roles

Thomson and Jaque (2012) used personality tests to compare the psychological vulnerability of actors with a control group. They found that actors had a greater distribution of unresolved mourning, psychological distress and the potential for dissociative disorders as compared to the control group. Further, artists with healthy attachment experiences, secure family relationships and mindfulness proved to be resilient to psychopathology. The actor group had a higher frequency of fantasy, imagination, and daydreaming than the control group. It was demonstrated that artists may use the embodiment of emotionally difficult character roles to distract themselves from their own memories and experiences.

Dance is a powerful means of interpreting lived experience (Boydell, 2011a, 2011b) and is reported to have a greater effect on the audience and artist than other forms of art (Winters, 2008). The audience response to a performance reveals ways that dance may ease isolation and engage the community (Goldner et al., 2014). Dance allows the dancers to use their body to express pain, emotions and gain a deeper level of insight at the unconscious level (Winters, 2008). Dance therapy has also been found to have a greater therapeutic effect for the patient than other forms of arts-based therapy due to the stimulation of neurological areas related to emotion and memory (Boydell et al., 2012a; Winters, 2008). The combination of body movements and facial expressions in dance therapy enhance emotional expression and release stress (Winters, 2008). Few studies have examined the effect on the healthy dancer after the embodiment of painful and angry emotions.

Giacomo Rizzolatti discovered mirror neurons while he was studying the motor activities of monkeys (Winters, 2008; Gallese, 2005). Mirror neurons are located in the extrastriate body, limbic system and lateral occipital cortex (an area of the brain stimulated by emotions and memories). These neurons equally respond to audio, visual and somatosensory stimuli while performing and observing the actions (Winters, 2008; Berrol, 2006). Gallese (2005) studied the effect on humans, and discovered that humans had similar neurological stimulation in performing and observing actions. He found that the same neurological mechanisms are stimulated when embodying an action as when watching someone else embody the same action. Gallese has contributed numerous research articles on the activation of mirror neurons in facial expression and body posture. Mirror neurons have been linked with the development of social conscience and empathy (Berrol, 2006).

There is evidence that the perception of emotion activates mechanisms responsible for the generation of emotion. Viewing facial expressions on others stimulates an unconscious facial reaction on the observer (Jackson, Meltzoff & Decety, 2005; Colantonio, Kontos, Gilbert et al., 2008). Many studies have documented that witnessing and experiencing pain or antipathy in another person activates the anterior insula and anterior cingulate cortex; areas of the brain stimulated by pain (Jackson, Rainville & Decety, 2006). Observing facial expressions of pain and anger activate mirror neurons; supporting the explanation of how one is affected by another's emotions and behavior (Jackson, Meltzoff & Decety, 2005; Jackson, Rainville & Decety, 2006).



Figure 3. How do we perceive pain and suffering in others?

Dancers and patients in dance therapy identify anger at higher levels when embodying postures than when observing postures (Winters, 2008; Jackson, Meltzoff & Decety, 2005; Colantonio, Kontos, Gilbert et al., 2008). The processing of anger is activated in the limbic system in association with emotion and memory; thereby stimulating the fight-flight response and cortisol release to stimulate body sensation and movements (Winters, 2008; Jackson, Meltzoff & Decety, 2005). The brain is able to perceive pain and anger through body posture even if the facial expression is in disagreement with the body movement (Winters, 2008). Embodying certain body postures to express emotion and experience has a greater effect on the cognitive and emotional states of the dancer (Winters, 2008; Gallese, 2005; Berrol, 2006).

The theatrical artist and dancer research their roles by reading manuscripts, watching videos and observing others to fully embody the emotions and experiences of the character (Andres-Hyman, Strauss & Davidson, 2007; Boydell, 2011a; Lafreniere & Cox, 2012). Mirror neurons support evidence that observing and experiencing emotions produce the same emotional response (Jackson, Rainville & Decety, 2006; Gallese, 2005; Berrol, 2006). The continuous embodiment of difficult emotions and experiences by the dancer has the potential to lead to an increased risk of dissociation and mood changes (Thomson & Jaque, 2012). The effect of dissociation is evident when the performer is no longer able to separate themselves from the embodied character, leading to negative thoughts and relationships (Anderson & Platten, 2011; Hemmeter, Sernal-Hemmeter & Kreig, 2010; Goel, Rao, Durmer et al., 2009). Individuals who simply observe others moving in dance experience similar emotions to those of the dancer (Winters, 2008; Berrol, 2006). As the goal of arts-based research is to expose viewers to varied perspectives and experiences in a meaningful manner (Cox & Boydell, in press), the example of using dance to depict research on the experience of help seeking in first psychoses exposes the audience and performers in potentially dangerous emotional terrain.



## Our Research-based Dance Project: Using dance to embody the experiences of help seeking by youth experiencing psychosis

Given these findings regarding the link between overall wellbeing and performing/ embodying difficult experiences, we reflect on an arts-based study where we used movement and music in the form of a dance performance to disseminate empirical research based on case study of the pathways to mental health care from the perspectives of youth experiencing psychosis (Boydell, 2011a, 2011b; CIHR, 2010). When we began to co-create the dance, we realized the challenges associated with taking the topic of psychosis and the genre of dance and combining them to communicate the experience of young people (Boydell, Jackson & Strauss, 2012). Many discussions ensued regarding the ability of dance to explore knowledge physically, emotionally and mentally, allowing the audience to enter into the experience. Todres's (2007) work on embodied inquiry that attends to the relationship between language and the experiencing body became extremely important to us throughout the process of co-creation (Boydell, 2011b). We asked ourselves what difference does it make to co-create embodied narratives to share the lived experience of psychosis?

Our reflections on the impact of embodying the experience of seeking help for mental health issues draw upon audio-recorded conversations between the research team and dance choreographer, Siona Jackson. Siona describes dance as a unique form that allows the audience to become engaged and emotionally stimulated. The use of dance incorporates music, visual aids and body movements. The music, critical to the dance performance, is created and adapted to the dancer's body movements. The use of facial expressions and body movements is very powerful. Sinclair (2015) encompasses this notion in her statement that "the researcher/performer's body in physical and symbolic action, within an aesthetic space, contributes to the production of understanding, through an embodied knowing" (p.90).

The main focus of the dancers in our project was to read the anonymized transcripts of in-depth interviews with young people and their significant others, listen to the music and represent an emotional event in character all the while attempting to be 'true' to the individual experience and without misrepresenting the research data. Dance performers, who auditioned for the role, were engaged as co-researchers and were involved in the co-creation of the performance in a profound manner; they participated in research-creative team meetings to discuss the findings and the ways in which we wanted to highlight the central themes, both universal themes depicting the pathways to mental health care identified across all narratives as well as the very particular and unique individual stories. The music was created with each dance posture; the music producer was also provided with summaries from the case studies and he created an original score based on the words of our participants. The music was then adapted to the dance postures and movements on stage. The use of "spoken word" along with body movements show continual growth and reflected each individual's journey in their pathway to mental health care. The final performance represented the key themes that describe first-

episode psychosis and help seeking, and has been presented to thousands of people internationally: academics, clinicians, policy makers, educators, students, and community members (Canadian Institutes of Health Research, 2010). This arts based knowledge translation strategy increased awareness of, and empathy toward, the issues youth face when seeking mental health care. A condensed film clip of the performance is available for viewing at [www.katherineboydell.com](http://www.katherineboydell.com).

Dancers are trained as professionals to balance their performative roles and personal life. Specifically with respect to arts-based health research, it was critical that experienced dancers were asked to participate; dancers who had previous experience with emotionally difficult roles and were mature dancers with a wide variety of performative experience were specifically selected, as it was assumed they would be better-equipped to handle the difficult content. We acknowledged that performing difficult material has an impact across non-research and research performances; however, in this case we believe there were differences. The dancers displayed an intensity of wanting to "get the story right" and were extremely concerned about authentically depicting the experience of psychosis. The team worked together over six-months, reading and discussing verbatim transcripts of pathways to care. This represented an intense and much longer period of training than is the norm. The dance team selected for the project was multicultural, with an equal ratio of male and female dancers; this was important as it allowed the audience to more broadly relate to the dancers. Importantly, during our talkback sessions with the various audiences, we heard feedback that the fact that there was diversity among the dancers was greatly appreciated.

The dancers were known to the choreographer and in fact, were a fairly close-knit group with very supportive families and partners. Consequently, they felt they were supported and were comfortable with one another. This environment of trust was readily apparent to the research team, who noted that the dancers disclosed past experiences with their own or friends' substance abuse or mental health issues during the research and creative team co-creation meetings. Our research team was present at co-creation sessions to develop the dance performance and assist with understanding the results of our research and the ways in which the key messages could be translated using movement and music. We also attended all performances and training sessions.

We asked Siona to reflect on the impact of performing and embodying an emotionally difficult role on a dancer. Our conversation follows below and is recreated in the form of our questions and her responses.

Do you think that dancers embodying emotionally difficult roles such as psychosis experienced any negative sequelae such as emotional stress, insomnia, or depression?

I noted that insomnia often occurred in the dancers, which I believe was associated with the stress and intensity of the training process. All dancers were fully dedicated to the training and production during the six months of co-creation. Roles were emotionally exhausting because the dance movements and reading the case study summaries were

both physically and emotionally demanding. The dancers were intent on representing and honoring the lives of young people experiencing psychosis to the best of their abilities and were extremely concerned about the possibility of misrepresentation.

*How is choreographing in an arts based research project different?*

Choreographing roles for academia have been very different than typical productions for entertainment. The artistic team has so much more work to do with respect to learning about the research project, its specific intent, what the research team wanted to convey, and the best way to do that. The performance was created based upon the intended audience(s); this necessitated choreographic changes based on each audience, which resulted in extended rehearsal sessions to accommodate these adaptations. For example, when we were performing in secondary schools to students, changes were made to the dance to interest young people. The production was reduced to 10 minutes and more hip-hop and pop music were featured. For young people in particular, we found that short performances were more effective than longer performances; there was greater attention and impact in a short performance. However, short performances were more challenging to choreograph due to the complexity of representing two particular cases in addition to some of the universal aspects of the help-seeking process that occurred across all interviews. Further, the continual adaptation to new stage settings was difficult because the 'stage' was often in a noisy or cluttered area such as a school cafeteria, as opposed to a theatrical stage. This required the dancers to adapt and maintain composure and poise during the many distractions. These changes had an impact on the dancers, who had to rehearse different choreography based on the audience and continue to adapt to new settings, which were very different from those they typically performed in.

*What was the most difficult role to choreograph?*

The emotional role most difficult to choreograph was empathy. It is important as a choreographer (and researcher) to represent each particular narrative/story and reflect the individual experience of help seeking. In order for a dancer to embody empathy, they must understand the emotions and experiences of the young person experiencing psychosis. This required a great deal of time, understanding and reflecting on each of the case study summaries. The research team did not anticipate the need of the dancers to have more information; the summaries of each young person prepared for them were often not enough, as they wanted to know much more about each young person in order to depict their experiences through dance.

*Have you implemented strategies to help overcome challenges with emotionally difficult roles? If so, can you talk a bit about these?*

During our performance we had a strong support group from myself as the choreographer and music producer as well as the researchers that were present during rehearsal and productions. The research team explained in detail the objectives of the study, and the emotions and experiences of young people experiencing psychosis. A comprehensive guideline of the overall purpose of the research and specific objectives

was outlined to the choreographers and dancers prior to their involvement. It also helped that there were always researchers present and available to talk to any of the dancers on a one-on-one basis about any questions they might have about the study, and in particular, the illness itself. I believe that this occurred quite frequently.

*Do you have any suggestions regarding what arts-based researchers should do to address the emotional effect on dancers that embody psychosis and other difficult experiences?*

First, I would recommend that reflexive practice be an essential component of any project, offering the opportunity for continued discussion throughout, not just at the beginning and end of a project. I think that a successful strategy for us was the work we engaged in individually with each case; dancers were encouraged to reflect on their own life experiences, as well as the emotions each young person was going through. Key words and emotions were taken from the cases; and then, in a group situation, the dancers and choreographers discussed the emotions and impact that might have on an individual's life.

Second, the creation of a safe and supportive environment is critical. Dance is a social art where dancers are interacting together in a team during rehearsals and performances; therefore they become a "family". Other art forms such as acting may be very isolating. Our ongoing and frequent group discussions created a supportive and safe environment to discuss personal experiences, and provided a forum where we all felt comfortable acknowledging our vulnerable experiences. The dancers were never personally asked whether or not they were experiencing any difficulties; rather, a cohesive supportive environment was created where the dancer felt that they were a part of the greater dance family. They were supported by the entire dance team and validated to perform for education and awareness of mental health in general, and psychosis specifically.

Another suggestion would be to address the issue of audience with the performers. Discussing the varied types of audience and why they were targeted to view the performance helped the dance team cater their performance to specific audiences. Unfortunately, dance does not touch all audiences because most who watch dance performances are often from the more elite demographics. There needs to be opportunities to impact more audiences, and those who may not typically encounter such dance performances. All dancers were aware that dance is a very powerful tool, and one in which an audience is in a receptive listening and viewing position, with an opportunity to immediately engage in the dance performance. The dancers were keenly aware that they were embodying sensitive and emotional material and worried about the impact that this might have on varied audiences, but in particular, those comprising young people.

Finally, the focus on balance is an important strategy to mitigate negative impacts of involvement in research-based dance. It is important for a dancer and choreographer to balance different types of dance performances. Performing emotionally difficult roles continuously has an emotional effect on the dancer, creating feelings of fatigue and insomnia. Emotionally difficult roles are more emotionally and physically demanding on

the dancer and choreographer. I always emphasize the critical importance of balancing their work and personal life as an integral part of releasing stress and any negative emotions that might ensue from the emotionally difficult role.

## Discussion: Ethical implications of engaging in emotionally difficult roles

Research ethics have been developed to protect research participants from harm (Gray et al., 2003). Ethical research guidelines include avoiding physical and emotional harm and protecting research participants' anonymity and confidentiality (Guillemin & Gillam, 2004). According to the World Medical Association, 2008, The Declaration of Helsinki states that considerations related to "the well-being of the individual research subject must take precedence over all other interests" (Cox, Drew, Guillemin et al., 2014). One strategy that helped to minimize conflict was reliance on the guidelines, professional and ethical codes of conduct and broader research policies that govern the ethical conduct of clinical and community based research (Cox, Drew, Guillemin et al., 2014). Researchers must maintain a critical awareness of emergent ethical dilemmas and explicitly raise the issues with participants as an integral part of the research (Goldner et al., 2011). Researchers attempt to incorporate arts based methods of dissemination by attempting to represent authentic patient experiences and incorporating aesthetic qualities to the artistic performance (Boydell, Volpe, Cox et al., 2012). Greater awareness and commitment to the unique ethical implications of arts-based health research has recently been advocated (Boydell, Volpe, Cox et al., 2012).

It is interesting that Siona addressed the need to be reflexive with her dancers on an ongoing basis. This very much supports the work of Guillemin and Gillam (2004) who argue that reflexivity is intricately bound up in the ethical practice of research, which is viewed as an active and ongoing process throughout the entire research enterprise. They note that engaging in reflexivity as a central component of research practice includes recognizing the ethical components of the everyday (or microethics), being sensitive to 'ethically important moments' in research practice, and, strategizing with respect to a response to ethical concerns that may arise. We extend the notion of reflecting on how research might affect research participants to include reflecting on how the research affects the performers throughout the project.

The ethical implications of dramatizing certain health topics to vulnerable audiences must be considered (Goldner, Jeffries, Bilsker et al., 2011). Given our experience working together with the creative team, we feel that artists working on arts-based performative research projects should be informed on the potential negative effects of embodying difficult and traumatizing experiences, prior to involvement in the project (Gray, Fitch, Labrecque et al., 2003). Evidence suggests that the risk of emotional fatigue and dissociation are manifest in healthy actors that embody emotionally difficult roles. Actors that have a healthy family relationship and emotional support are less likely to be at risk when embodying difficult roles (Lafreniere & Cox, 2012; Thompson & Jacque, 2012). Performers should be encouraged to embody a character while maintaining their own identity and cognitive thoughts. During performances the researchers and choreographer

should consider encouraging mentorship and emotional support for actors that may be at risk of depression.

According to Cox and her research colleagues (Cox, Drew, Guillemin et al., 2014), it may be necessary for arts-based researchers to document the performer's long-term emotional effects of difficult roles as well as the emotional effect on the audience. There is an ethical imperative to ensure that research participants are authentically represented and involved in the process of knowledge translation (Gray, Fitch, Labrecque et al., 2003). Knowledge translation efforts are important in the field of mental health; implementing the development of community programs and new research ethics policy (Cox & Boydell, 2015).

It is important to consider our responsibilities to performers taking on this role. Our experience in co-creating a research-based dance performance to disseminate empirical research findings and subsequent reflections on the impact of doing so have allowed us to identify a number of strategies that we would incorporate in future work in this area. We draw on Hunt et al.'s (2014) work on the ethics of an engaged presence as a model to follow. This model acknowledges the limits and risks related to contributions of health professionals, but we believe that it is equally applicable to artistic performers. It supports the notion of reflexive practice, described above, as well as developing, sustaining and promoting collaborative partnerships.

It is essential to provide adequate preparatory material for the dancers and associated cast, ensuring an explanation of the nature of the research and the role they are expected to embody and perform. Rossiter, Gray, Kontos et al. (2008) provide a good example of the ways in which they incorporated knowledge translation at the outset of their project, ensuring that in the very early stages of rehearsal, the actors were informed of the research process, and began to experiment with methods of translating the themes and codes from the research into scenes and narratives. It is important to ensure a high degree of sensitivity to the experience of the performer in the hopes of better understanding what negative and positive impacts of engagement in this work might ensue. Also included in our lessons learned is the importance of attending to issues of authorship and ownership and credits to the artists and performers involved in the co-creation process, addressing the issue of artistic license and ensuring a balance between the scientific veracity and aesthetic quality of the artistic performance. Lafreniere and her colleagues (2013) have noted that tension associated with balancing both may pose difficulties to researchers and artists working together on arts based research projects. It is also critical to be explicit regarding ways to access the necessary supports and services to resolve any difficulties that may be encountered in embodying difficult emotions and experiences. The importance of reflexive practice cannot be underestimated and we believe this is a central feature of ethics in practice. We also acknowledge the implications of this work for ethics review committees, who are likely unfamiliar with some of the unique ethical challenges associated with performing data in this way. There is no need to reinvent the wheel as excellent work has begun with the publication of the ethical guidelines for visual methods (Cox, Guillemin et al., 2014), in addition to other relevant texts. As researchers, we must take it upon ourselves to provide the appropriate guidance



and reassurance to the Research Ethics Boards that we have considered issues unique to engaging in this work and have ways to address them.

Given the paucity of literature, there is a need to address and assess the impacts, both positive and negative, of artists' involvement in arts-based health research projects. Following the lead of other academics (Lafreniere & Cox, 2012) who have assessed the impact of arts based performances as research dissemination tools, we propose asking performers open-ended questions about the effects of their presentation/performance on understanding of the topic, the specific emotions generated, questions arising, and prompts leading to altered understanding of or opinions about their participation. We concur with Lafreniere and her colleagues (2013) who note that in arts based health projects, researchers should always incorporate dialogue with their participants with respect to the ways in which they are impacted by the research. We would extend this to include the performers themselves.

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#### Endnotes:

- 1 The Canadian Institutes of Health Research (CIHR) defines Knowledge Translation as a dynamic and interactive process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system (CIHR, 2010).
- 2 Gray and his colleagues (2003) used this term in their discussion of the potential negative impact of using theatre in dissemination of cancer research.
- 3 Although not the focus of this paper, we acknowledge the previous work focused on the impact and the ethical challenges of such performative work on the audience (see for example, Cox and Boydell (2015); Boydell (2011 a, 2011b)).
- 4 The photographic images used in this paper are taken by Ashley Hutchison, and are for illustrative purposes only. Permission has been granted from Ashley Hutchison to use the photos in presentations and publications.