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Navigating Ethical Challenges in Arts-Based Research in Medicine

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ABSTRACT

Arts-based research (ABR) in medicine provides innovative ways to understand and communicate health-related experiences, using methods such as photography, poetry, and filmmaking to explore complex patient narratives. However, the integration of artistic methodologies into medical research introduces unique ethical challenges, including informed consent, confidentiality, emotional safety, and power dynamics in participant-researcher relationships. This paper examines these issues in the context of arts-based participatory action research with Canadians living with rheumatological diseases. It emphasizes the need for reflexivity, collaborative partnerships, and cultural competence to ensure equitable representation and participant agency. By fostering interdisciplinary dialogue, this study aims to establish a robust ethical framework for arts-based methodologies, ensuring their transformative potential in health advocacy, education, and policy-making.

Keywords: Arts-based research, Ethics in medicine Participatory action research, Narrative medicine, Reflexivity in research.

INTRODUCTION

Arts-based research, a methodology increasingly popular in the social sciences, asserts that artistry and creative activity can provide alternative ways of knowing, understanding, and representing human experiences. Arts-based researchers in the field of health have taken up this methodology to communicate more complexly about aesthetically rich renditions of the health, illness, and disability experiences of their respondents. This paper discusses photograph-making, poetry writing, and filmmaking process activities used within arts-based research to investigate the health and healthcare experiences of Canadians with rheumatological diseases. This artistic research process was facilitated by and for patients and participants [1, 2]. There is an emerging trend in medical research—evident in critical analysis, medical humanities, and narrative medicine—that seeks to engage more critically and creatively with medicine, active clinical practices, and the practicalities of patient care and experiences. Many of these initiatives are oriented toward educational outcomes; that is, they aim to re-jig the structures of institutional medicine from the inside out. Not unlike our effort to gain a better understanding of the health, illness, and disability healthcare experiences of Canadians, narrative medicine looks today at the clinical encounter, asking practitioners to withhold diagnosis, observe the frame, and question the story to gain clinical insight through altered perception rather than to focus, immediately, on patient care. Our project, like narrative medicine, attempts to uncover meanings contained within or obfuscated by art and to break down categories of knower/known in an effort to let new knowledge emerge through the transformative power of empathy and engagement with the story. The subsequent narratives and images presented throughout this paper are part of a much larger collection that we are currently curating and analyzing. The goal of this review is to open up a dialogue about the ethical challenges we encountered in conducting arts-based participatory action research—an analysis, that is, structured around the processes, as opposed to outcomes, of our work of knowledge generation with healthcare users [3, 4].

Ethical Considerations in Research Design and Implementation

Arts-based research in medicine raises several ethical challenges throughout the life cycle of a research project, requiring thoughtful consideration at each stage to responsibly navigate concerns. Ethical frameworks for research emphasize the importance of procedural ethical considerations, such as informed consent, confidentiality, and safety, but also broader ethical considerations addressing, in part, the researcher's commitment to initiatives that promote integrity, social responsibility, and concern for the public welfare. However, arts-based research is not well-suited to the steps of biomedical research that have become the gold standard, and so the widely accepted procedures must be reimagined. Consent, for example, cannot anticipate data that might hurt particular research participants, confounding the single form or protocol that typifies standard research, and confidentiality falters when consent is relational [5, 6]. In addition, the unique characteristics of artistic expression in the context of arts-based research in medicine can challenge research norms. Therefore, specific ethical challenges arise in the context of arts-based research in medicine that require further exploration. A series of positions and authorship are offered to foster interdisciplinary research, and here we draw from the spirit of that document to argue that collaborative reflection and dialogue are equally essential to the advancement of arts-based research in health advocacy, education, and research, grounded in disciplinary expertise and theoretical understandings. Those keen to undertake arts-based research in the context of medicine should also be attentive to their own subjective experiences and those of the individuals with whom they are engaging. Any profound ethical inquiry extends well past a discrete focus on the research participant to include the researcher in a reflexive study of how they have come to believe this problem should be addressed. By considering such questions on the continuum of ethical inquiry, we are working to extend our understanding not only of what it means to create knowledge but also of the broader aesthetic grounds of that knowledge creation. Revisiting the existing ethical research guidelines on a regular basis to critique how they are manifest in the research process from start to finish provides a model of responsible arts-based research, enabling a continual re-engagement with methodological and ethical commitments all along the way. The importance of reflexive ethical considerations throughout the planning and implementation of arts-based research in medicine cannot be overstated [7, 8].

Safeguarding Participant Rights and Well-Being

Respect, autonomy, and justice should guide researchers' protection of participant rights and well-being. Informed consent is a key aspect of that respect. Participants' rights to self-determination, to not be coerced, and to withdraw without repercussions should also be upheld. Some are particularly vulnerable, and several best practices are used to protect participants' rights. The consent process provides an opportunity to convey respect by taking participants and their contributions seriously. In arts-based research with participants who are not primarily artists, consent needs to use accessible rather than academic jargon. Participants identifying as artists still face important ethical considerations in making informed choices, especially those who use art to explore highly personal and possibly psychologically and emotionally charged topics such as their personal experiences with mental illness [9, 10]. Researchers can respect autonomy by adopting a flexible approach to participation rights. They can, for example, allow participants to choose which pieces to include or give them control over how their pieces are used. Conversely, the emotion inherent in trauma art may be intellectually appreciated but experienced in different ways. Findings from focus groups similarly suggested that some participants are familiar with art's emotional risks, such as that writing poetry might retraumatize them. Researchers should also consider the relative sense of emotional safety in different art forms, with art forms that are faster to create requiring less emotional investment. Emotional and psychological risks inherent in creating art are ethical issues to weigh in authorizing, regulating, or rejecting arts participation, even when the outcomes of these interviews have no medical applications. Researchers should also ensure that participants feel safe in the interview, debrief participants where appropriate, or conduct interviews in a therapeutically supportive manner. In some cases, researchers extend this support for as long as the participants feel they need it. At the same time, a rigorous researcher protection approach risks exacerbating any vulnerability research participants feel by perpetually reiterating the badness of their emotions. Recognizing the existence of heavy emotions without indulging them is part of the mentorship provided to second-year Indigenous students in preparation for their art performance in front of an audience [11, 12].

Addressing Power Dynamics and Representation in Arts-Based Research

The power relations between researchers and participants are integral in arts-based methods research and imperative to ameliorate to avoid reproducing hegemonic patterns, thus positioning the 'other' as a production for and in favor of the 'experts.' As such, researchers need to acknowledge and address the

intricacies of these relationships, as well as the multimodal and integrative approaches that accompany interpretative arts-based research. In reflecting on the ethical implications, a critical question complicated by participation becomes, 'Who gets to tell the story?' As the overrepresentation of stories within public and policy discourses shapes societal perceptions of illness, these stories need to be authentic and inclusive of people living at the margins. A participatory framework offers some guidance on addressing such dilemmas by working to challenge dominant research practices and making research participants the primary agents of the research process. The purpose of participation in arts-based research methods is to support collaboration with participants in their own stories. By making the participant's voice a primary focus of inquiry, power is shifted from the researcher to the participant. A commitment to the participatory framework extends further than showcasing visual art, as researchers need to foster a spirit of cultural competence to value all forms of artistic expression and experience. The use of diverse artworks also needs to be interpreted through partnership and cultural competence. Researchers also face the ethical challenge of protecting participants from misrepresentation and being objectified as having a sensational narrative or exemplifying a specific ethos. In navigating these intersections, researchers need to continually check their intentions. Adopting a co-participant and/or collaborative partnership approach means prioritizing the role of the participant as the co-producer of the narrative. Researchers aim to elicit new understandings of narratives and collaborative techniques. The intentions of the researcher are hence to visibly support their capacity to provide authentic stories of art and everyone involved, regardless of cultural or racial background, and how cultural, artistic, and socio-political statements are shaped within a collaborative space. The researcher's approach is to visibly support the co-producer by providing visual and emotional support, especially when their voice is often marginalized in an attempt to address power dynamics in the area of narrative, power, and knowledge production. The introduction to *Seeing the Light* is that researchers aiming to respect artistic and personal expression and integrity do not wish to conform to Western narratives of medical practice and research [13, 14, 15].

Future Directions

Insight. Our findings affirm the importance of ethical vigilance at all stages of the arts-based research process, from the participants' first encounter with a call for research participants to the final exhibition of findings. Future directions would benefit from an ongoing dialogue among members of arts-based research teams and with collaborators about the approach. Such a process could form an ethical practice that should be subject to continual refinement as participation in arts-based research is subject to ethical review. As a way forward, we believe the field needs to engage in discussions about the ethical implications of conducting arts-based research in medicine and other academic disciplines. This could result in a theoretical and practical framework for arts-based research that might be used as a guide for decision-making in future research projects [16, 17, 18]. At the outset of this article, we proposed that the potential impact of arts-based research on policy and practice in the field of healthcare and medical research cannot be realized if it is developed without acknowledging conceptual difficulties and emerging ethical responsibilities. People's narratives offer the opportunity for medical sociologists to develop new knowledge through research that embraces new qualitative methodologies, specifically those that embrace the arts. Furthermore, empirical study has shown that participation in these arts-based research projects may offer participants a space from which to challenge normative perceptions of their inevitably political bodies and identities. However, the ever-evolving philosophy surrounding the arts and humanities' value in research poses challenges for the academic embarking on arts-based research projects and raises methodological and especially ethical questions that are not easily addressed. This challenges the notion: "Do what I want, and in doing so we will transform your life." However, it is our ambition that offering the above analysis can provoke questions, debate, and reflection for those embarking on their revelatory quest [19, 20].

CONCLUSION

Arts-based research offers a transformative approach to exploring health and healthcare experiences, emphasizing empathy, storytelling, and participant empowerment. However, navigating the ethical complexities of such research demands a commitment to reflexivity, participant collaboration, and cultural competence. The dynamic interplay between artistic expression and medical research challenges conventional research ethics, necessitating continual dialogue and adaptation of ethical practices. By addressing issues such as informed consent, emotional safety, and representation, researchers can ensure that ABR fosters authentic, inclusive narratives that contribute to both academic inquiry and practical healthcare advancements. Future endeavors should focus on developing standardized ethical guidelines and fostering interdisciplinary collaborations to maximize the impact of arts-based research in medicine and beyond.

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