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ORIGINAL RESEARCH: PEER-REVIEWED ARTICLE

Arts-Based Research Methods to Explore Cancer in Indigenous Communities

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Abstract

Background: Indigenous peoples experience an inequitable burden of cancer compared with other populations. The arts can serve as a culturally relevant cancer intervention and research method.

Methods: A scoping review was conducted to determine how arts-based research methods have been used to address cancer in Indigenous peoples. Literature searches identified 129 publications; 32 were selected for review. The following data were extracted: communities employing arts-based cancer research, cancer control continuum stages, cancer types, art forms, and methodologies.

Results: Most studies were conducted in the United States. Art as research and sound art forms were the most utilized arts-based methods. Cancer types and control continuum stages were not often specified.

Conclusions: Culturally responsive, arts-based methods can enhance research and education across the cancer-control continuum with Indigenous populations.

Art as Data Sources

The arts can serve as the core of an intervention (eg, art therapy, narrative medicine) and as a method of research (ie, arts-based research). There is a growing movement to diversify the academic research environment by treating the arts as an empirical source of information and to expand our understanding of what art *is* to include what art *does.*¹ Arts-based research (ABR), a method of inquiry that recognizes artistic expressions as ways of knowing, uses artistic expression and the artistic process as a primary mode of inquiry to understand and examine the experience of both researchers and research participants.¹ In particular, ABR has been used to explore, illustrate, define, treat, and explain cancer across the control continuum.²,3,4,5

In health research, ABR is commonly utilized with Indigenous populations as a culturally appropriate means of engagement.^{6,7,8} A recent systematic review of Indigenous research methods (IRMs) found that the following most cited methods were general Indigenous frameworks: Western methods in an Indigenous context, community-based participatory research, storytelling, and culture- specific methods.⁹ ABR was not explicitly identified as an IRM; presumably, it was included under storytelling and culture-specific methods.⁹ Of the 47% of articles focused on health, one investigated cancer.⁹

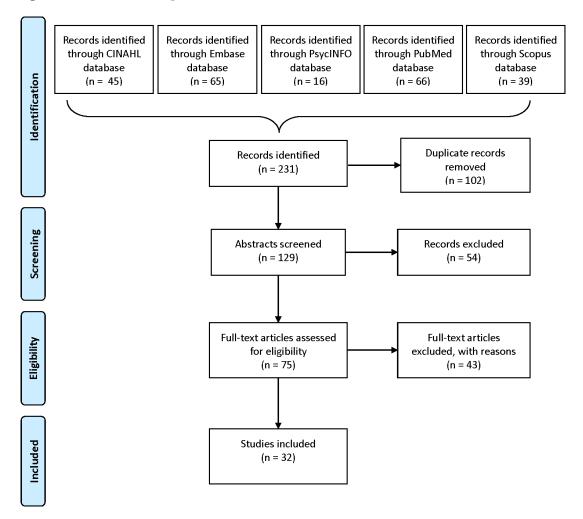
Although data are sparse, globally, some cancers, such as lung cancer and cervical cancer, disproportionately affect Indigenous populations. ^{10,11} Cancer is a leading cause of death for American Indian and Alaska Natives (Al/ANs). ¹² Over the past 20 years, death rates for many cancers increased for Al/AN while decreasing for all other groups, ¹² and gaps for many cancers continue to widen. ¹³ Despite the significance of this health disparity, there is a need for more community-focused and culturally appropriate cancer research and education specific to Indigenous communities. ^{14,15,16}

The objective of this scoping review was to identify literature reporting use of ABR methods with Indigenous populations to explore the ways that such methods are used across the cancer control continuum (CCC)—from cancer prevention through survivorship—in what we hereafter refer to as arts-based cancer research (ABCR).

Methods

This scoping review is reported in accordance with the preferred reporting items for systematic reviews and meta-analyses (PRISMA) guidelines. In October 2020, we used strategies designed by a medical librarian (ie, PRISMA) to search published literature for the concept of ABR in cancer research and health education with Indigenous peoples (see Figure). We limited our review to cancer, excluding other chronic illnesses, because cancer is a topic of interest to our local Indigenous community. Using a combination of subject headings and keywords (see Supplementary Appendix), we searched MEDLINE via PubMed, Embase, Scopus, PsycINFO via EBSCO, and CINAHL via EBSCO. Language filters were applied to limit retrieval to English and Spanish language articles. Published letters, comments, and reviews were excluded. The results were exported to the citation manager RefWorks (legacy), where the automatic duplicate finder removed duplicates.

Figure. PRISMA Flow Diagram



Adapted from Tricco, Lillie, Zarin, et al. 18

Literature selection was performed by 3 reviewers in 2 steps: (1) review of article title and abstract and (2) review of the full-article text. Each review required reviewer consensus meetings to resolve disagreements. Thirty-two of 129 articles screened were selected for inclusion in this review and evaluated by an analysis team to extract the following data: (1) communities employing ABCR, (2) stages in the CCC, ¹⁹ (3) cancer types, (4) art forms, and (5) methodologies employed. To classify ABR studies, we identified studies utilizing art as a method of inquiry as "art as research," studies utilizing art to support qualitative inquiry as "art in research" and investigations of artistic topics as "research about art." Terms describing the data extracted are defined in Table 1.

Table 1. Description of Data Extracted				
Data Extracted	Definition			
Demographics				
Indigenous community	Who participated in the study			
Country	Where the study took place			
Stages in CCC ¹⁹				
Etiology	Includes gene-environment interactions, infectious agents, environmental factors			
Prevention	Includes tobacco control, diet, physical activity, sun protection, HPV vaccine			
Early detection	Includes screening and testing			
Diagnosis, treatment ^a	Includes shared and informed decision making and treatment			
Survivorship	Includes coping and health promotion for survivors			
Nonspecific	Two or more CCC stages identified or discussed holistically			
Cancer types				
Type of cancer	Specific type of cancer identified			
Nonspecific	Two or more cancer types identified or discussed holistically			
Art forms ²⁰				
Visual	Includes 2- and 3-dimensional art forms			
Sound	Includes radio, soundscape, and storytelling			
Performing	Includes dance and theater			
New media	Includes digital media, such as virtual reality			
Literary	Includes poetry and short stories			
Multiple	Two or more art forms identified			
ABR methods ²⁰				
Art as research	Art utilized as a method of qualitative inquiry			
Art in research	Art to support qualitative inquiry			
Research about art	Inquiry into art-related topics without (re)creating the object or installation under study			

Abbreviations: ABR, arts-based research methods; CCC, cancer control continuum; HPV, human papillomavirus.

Results

The majority of the articles (60%) did not specify the Indigenous communities the researchers were working with; therefore, we report our findings by the country in which the ABCR took place. Twenty-one publications (65.6%) reported on research conducted in the United States. Five publications (15.6%) were specific to Australia and 4 publications (12.5%) were specific to Canada. Our results also included one publication specific to New Zealand (3.1%) and one publication specific to Peru (3.1%).

Many publications were not specific to one stage of CCC or cancer type (see Table 2). Publications dealing with survivorship (18.8%) and early detection (15.6%) were the most frequent, followed by publications dealing with prevention (6.3%) and diagnosis and treatment (3.1%). Etiology was not identified in any publications. The most frequently identified cancer types were gynecological, breast, and colorectal cancer.

^a Diagnosis and treatment were collapsed into one category, as literature that identified diagnosis also referenced treatment.

Table 2. Publications Categorized by Cancer Control Continuum Stage and Cancer Type **Publications** No. (%) CCC stage19 Not specific 18 (56.3) Survivorship 6 (18.8) 5 (15.6) Early detection 2 (6.3) Prevention Diagnosis and treatment 1 (3.1) Etiology 0 (0.0) Cancer type Not specific 14 (43.8) Gynecological 7 (21.9) 6 (18.8) Breast Colorectal 2 (6.3) Head and neck 1 (3.1) Lung 1 (3.1) Skin 1 (3.1)

Abbreviation: CCC, cancer control continuum.

In Table 3, it can be seen that publications dealing with sound art forms, such as telling yarns or stories, were the most frequent (34.4%), followed by multiple forms (21.9%), visual form (18.8%), and new media (15.6%). Publications dealing with performing and literary forms were the least frequent. Over half of the publications utilized art as research (59.4%) as their methodology. In these publications, portraiture, storytelling, and theater served as the inquiry method itself. Research about art was identified in 9 of the selected publications (28.1%). Examples include investigations into the use of video vignettes and informational art cards in interventions. Four publications utilized art *in* research (12.5%), including drawing accompanied by qualitative inquiry.

Table 3. Publications Categorized by Art Forms and Arts-Based Research Methods					
Publications	No. (%)				
Art forms ²⁰					
Sound	11 (34.4)				
Multiple ^a	7 (21.9)				
Visual	6 (18.8)				
New media	5 (15.6)				
Performing	2 (6.3)				
Literary	1 (3.1)				
ABRMs ²⁰					
Art as research	19 (59.4)				
Research about art	9 (28.1)				
Art in research	4 (12.5)				

Abbreviation: ABRM, arts-based research method.

 $^{\rm a}\,\text{Not}$ included in Wang et al. $^{\rm 20}\,$

A detailed description of all data extracted from each article can be found in Table 4.

Country	Indigenous Community	CCC Stage ¹⁹	Cancer Type	Art Form ²⁰	ABRM ²⁰	Reference
Australia	Aboriginal, Torres Strait Islander	Not specific	Not specific	New media	AAR	Ash 2010 ²¹
Australia	Aboriginal	Not specific	Not specific	Multiple	AIR	Bernardes 2020 ²²
Canada	First Nations, Metis	Prevention	Breast	Visual	RAA	Bottorff 2014 ²³
US	AI/AN	Not specific	Breast	Visual	AIR	Chilton 2013 ²⁴
Australia	Aboriginal	Not specific	Not specific	Literary	AAR	Clague 2010 ²⁵
US	AN	Not specific	Colorectal	New media	RAA	Cueva 2013 ²⁶
US	AN	Not specific	Colorectal	New media	RAA	Cueva 2014 ²⁷
US	AN	Not specific	Not specific	Multiple	AIR	Cueva 2014 ²⁸
US	AN	Not specific	Not specific	New media	RAA	Cueva 2015 ²⁹
US	AN	Not specific	Not specific	New media	RAA	Cueva 2016 ³⁰
US	AN	Not specific	Not specific	Performing	AAR	Cueva 2010 ³¹
Peru	Shipibo	Not specific	Cervical	Multiple	AAR	Darivemula
US	Chamorro	Survivorship	Breast	Sound	RAA	2018 ³² Duenas Manglon
NZ	Māori, Tangata	Survivorship	Not specific	Sound	AAR	2010 ³³ Egan
US	whenua, Pākeha Winnebago Tribe	Diagnosis,	Head, neck	Visual	AAR	2016 ³⁴ Gilbert
US	of Nebraska Comanche	treatment Not specific	Breast	Sound	AAR	2020 ³⁵ Haozous
Canada	First Nations	Early detection	Cervical	Visual	RAA	2010 ³⁶ Hislop
US	AI/AN	Early detection	Cervical	Sound	AAR	1996 ³⁷ Hodge
US	,	-				1996 ³⁸ Hodge
	AI/AN	Survivorship	Not specific	Sound	AAR	2016 ³⁹ Ka'opua
US	Native Hawaiian	Early detection	Breast	Sound	AAR	2008 ⁴⁰ MacDonald
Canada	Mi'kmaq	Early detection	Cervical	Sound	AAR	2015 ⁴¹ Margalit
US	Lakota	Prevention	Lung	Sound	AAR	2013 ⁴² McWilliams
US	Osage Aboriginal, Torres	Not specific	Skin	Visual	AAR	2020 ⁴³ Meiklejohn
Australia	Strait Islander	Not specific	Not specific	Multiple	AAR	2019 ⁴⁴ Pelusi
US	AI/AN	Survivorship	Not specific	Sound	AAR	200545
Canada	Aboriginal	Not specific	Breast	Multiple	AAR	Poudrier 2008 ⁴⁶
US	AN	Survivorship	Not specific	Performing	RAA	Sharma 2016 ⁴⁷
US	Yakama	Early detection	Cervical	Sound	AAR	Strickland 1996 ⁴⁸
US	AI/AN	Not specific	Not specific	Multiple	RAA	Vogel 2013 ⁴⁹
US	Lumbee, Cherokee, Coharie, Waccamau Siouan	Survivorship	Not specific	Visual	AAR	Warson 2012 ⁵⁰
US	Coharie, Waccamaw Siouan	Not specific	Breast	Multiple	AAR	Warson 2013 ⁵¹
Australia	Indigenous	Not specific	Not specific	Sound	AIR	Yerrell 2016 ⁵²

Abbreviations: AAR, art as research; AI/AN, American Indian/Alaska Native; AIR, art in research; AN, Alaska Native; RAA, research about art.

Discussion

Conducting health research and education in culturally relevant ways is vital to their success with Indigenous communities.⁵³ IRMs existed well before precolonization,⁵⁴ with their own theoretical constructs and protocols that should be respected and acknowledged in research conducted with Indigenous communities.^{55,56} ABCR aligns with Indigenous knowledge systems in exploring and generating knowledge through painting, drawing, crafting, and storytelling.⁵³ We have identified 4 areas of opportunity to support ABCR with Indigenous populations based on the results of this review.

Extension of ABCR to other Indigenous communities. In the majority of publications in this review, ABCR was conducted in the United States. According to the United Nations,⁵⁷ Indigenous peoples account for 476 million individuals across 90 countries worldwide. There is an opportunity to apply ABCR methods in other American (eg, the Mayans in Guatemala) or European (eg, the Basque in Spain) communities not found in this review. Furthermore, many publications did not specify the Indigenous communities involved in the research but instead stated the countries where the research occurred. Identifying and acknowledging Indigenous communities not solely by the geographical boundaries created postcolonization but as their own sovereign units of identity would decolonize research and recognize ABCR as an IRM.⁵⁸

Extension of ABCR to other cancer types. Over half of the articles reviewed were not specific to one cancer type. The conceptualization of cancer as a disease that can spread to many parts of the body is representative of Indigenous worldviews that we are all related. ^{55,59,60,61} This holistic perspective aligns with Indigenous approaches to healing, which include body, mind, and spirit. ^{62,63} There are more than 100 types of cancer, ⁶⁴ yet only 5 cancer types were studied. These included most of the leading causes of cancer deaths in Native Americans. Prostate cancer, however—a leading cause of cancer death among Al/AN men¹²—was not mentioned and is arguably worth exploration.

Extension of ABCR to all CCC stages. No publications were identified that used ABCR methods to explore cancer etiology. ABCR (eg, art *in* research) could be integrated in research on cancer etiology examining environmental factors, genetic factors, geneenvironment interactions, medication exposures, infectious agents, and health behaviors related to cancer. Following the transtheoretical model of health behavior change, arts could also be studied as a means to stimulate changes in health behaviors that could help prevent cancer. In this way, ABCR could support prevention efforts at this relatively uninvestigated CCC stage.

Extension of ABCR to other artistic mediums. Sound and multiple art forms were most often employed in ABCR projects with Indigenous populations. Only one article was found utilizing literary art forms. Poetry could be explored as a culturally responsive way to conduct literary-based research that honors Indigenous orality. 66,67 Two articles identified performing art forms. Theatre of the Oppressed, a methodology that explores non-oppressive experiences and discusses difficult social topics, 68 has been successfully employed with Indigenous populations 90 and could be utilized to address cancer. Tecno-sovereignty, an emerging ABR method that examines cross-cultural and intercultural Indigenous innovations from digital media, old electronic analog media, and traditional Indigenous media, is yet another possiblity. Integrating literary, performing, and media-based art forms into cancer research could create new methods that align with Indigenous values.

Limitations

Our search terms for ABR methods included prominent methodologies, such as photovoice and storytelling, and, for Indigenous populations, included common regional terms (see Supplementary Appendix). It is possible that not all publications were identified based on the search terms, as these terms are not standardized internationally. Similarly, publications in languages other than English or Spanish were excluded. The CCC model selected did not include end-of-life care and instead included noncurative care in the treatment stage. The literature could be further analyzed to determine ABCR uses in palliative care.

Conclusion

This review details culturally responsive methods of cancer inquiry and education that can be employed with Indigenous populations to enhance research across the CCC. Understanding existing ABCR studies and their effectiveness can guide researchers in designing projects that acknowledge Indigenous knowledge systems and support more ethical ways of generating knowledge. Integrating ABCR can increase the cultural relevance of cancer research, education, and interventions for Indigenous communities. Future qualitative studies to address cancer in Indigenous populations should consider integrating ABCR.

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