

## The Production and Dissemination of Knowledge: A Scoping Review of Arts-Based Health Research

*Katherine M. Boydell, Brenda M. Gladstone, Tiziana Volpe,  
Brooke Allemang & Elaine Stasiulis*

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exchange

**Abstract:** The use of arts-based research is shifting our understanding of what counts as evidence and highlights the complexity and multidimensionality involved in creating new knowledge. A scoping review of arts-based health research was undertaken to identify the breadth of peer-reviewed literature, summarize findings and identify gaps. A literature database search identified 71 original studies meeting our criteria for review. Studies were characterized by diverse art genres, designs, and substantive health topics. The arts in qualitative research were considered an opportunity for enhanced engagement of participants and audiences alike, a way to enrich communication and make research accessible beyond academia, and a method for generating data beyond the scope of most interview-based methods. Three central gaps were identified: the need for critical dialogue regarding the impact of arts-based health research, the need to focus on how the quality of such projects is judged, and the need to address the ethical challenges of engaging in this work. We suggest that the broadening of qualitative methodologies to include arts-based approaches offers more than simply adjuncts to typical data collection and dissemination approaches, and instead, presents different ways of knowing. We believe that this may be a significant moment in the field in which to question whether or not we are witness to a paradigmatic shift in the ways we approach inquiry into the social world and/or the emergence of an innovative set of techniques that researchers can draw upon to enhance traditional methods of conducting qualitative inquiry.

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## 1. Background

Arts-based health research initiatives are emerging as a new approach for social inquiry and a fruitful avenue for innovation in qualitative research (BOYDELL & JACKSON, 2010; KONTOS & NAGLIE, 2007). The growing use of arts-based knowledge creation and dissemination strategies is driving an important shift in our understanding of what counts as evidence, as well as appreciation for the complexity and multidimensionality involved in creating new knowledge (BOYDELL, 2011a, 2011b; NISKER, MARTIN, BLUHM & DAAR, 2006; WAINWRIGHT & RAPPORT, 2007). These changes are promising as they begin to address the use of arts-based approaches as a legitimate way of conducting research and representing knowledge in the health sciences, social sciences and humanities. [1]

Although these methods are well-established in other fields, particularly in adult education (KNOWLES & COLE, 2008), they are relatively new to the field of health. The literature suggests that social scientists, artists and health care practitioners recognize the potential of arts-based methods to elucidate human dimensions of health and illness in ways that augment our understanding of health and social care (PAUWELS, 2010). The arts are posited to offer alternative ways of producing and communicating research findings and best practices in health care (KEEN & TODRES, 2007). JONES (2006) argues that by incorporating art forms in the research process it is possible to evoke emotional responses and to construct alternative forms of representation that promote dialogue and shared storytelling. The use of artistic formats are said to inform and enrich the research process. COLANTONIO et al. (2008) note that knowledge conceptualized in this way is more accessible to diverse stakeholders. [2]

The emergence of arts-based approaches in health research has caused us to reflect on the ways in which qualitative research methodologies emerge and change over time, with assorted taxonomies reflecting attempts to (re)think and categorize what we know and how we come to know it (see for example, LINCOLN & GUBA, 2000; GIACOMINI, 2009; KONTOS & POLAND, 2009). We recognize that many factors are common to both qualitative research and the arts—primarily, valuing of the subjective nature of human experience, an interpretive philosophy *vis-a-vis* knowledge production, including a creative process wherein experience is translated and transformed through this interpretive process and a representation of that experience is made available to others. Those working from an arts-based perspective argue that a fundamental difference in this type of health research includes, for example, an expansion of representational possibilities because a more fully embodied response is invited from research participants and the audiences of such work (BOYDELL & JACKSON, 2010; KONTOS & NAGLIE, 2007). Further, there is an implicit goal of making scholarship more accessible by reaching multiple audiences (COLE & KNOWLES, 2001). GERGEN and GERGEN (2010) argue that arts-based dissemination strategies are able to effectively create interest in and action around substantive areas that require change by directing critical dialogue

towards social issues; they note that traditional written forms of social science communication are limited as models for change. [3]

We consider a scoping review an ideal way to investigate the claims being made in this new field of arts-based health research as the evidence in the field is relatively recent and the method is designed to quickly and systematically identify the breadth of literature, and clarify boundaries and definitions in the field of focus. It can be used to determine the feasibility of conducting a more systematic review, summarize and disseminate research findings and identify gaps in research evidence (ARKSEY & O'MALLEY, 2005; LEVAC, COLQUHOUN & O'BRIEN, 2010; RUMRILL, FITZGERALD & MERCHANT, 2010). The objectives of a scoping review are broader and more comprehensive than is typical of systematic review because the focus is not narrow or limited to particular research questions (GLASZIOU, IRWI, BAIN & COLDITZ, 2001). [4]

Our definition of arts-based research is in accord with that used more specifically in educational research (KNOWLES & COLE, 2008). Arts-based research is an emerging qualitative research approach; it refers to the use of any art form (or combinations thereof) at any point in the research process (COLE & KNOWLES, 2001; KNOWLES & COLE, 2008) in generating, interpreting, and/or communicating knowledge. In this article, we refer to arts-based health research as: 1. a process to produce knowledge, and 2. a product to disseminate results<sup>1</sup>. While art genres are used in health promotion and community development projects to promote health literacies, empower participants and change health-related behaviors, we do not include this extensive literature in our review because empirical research is often not their primary goal (see for example, CARSON, CHAPPELL & KNIGHT, 2007). In contrast, it is argued that audiences of health care practitioners are often said to be more oriented toward empiricism and therefore, appear to be more receptive to arts-based projects in which data has been generated via traditions of inquiry considered scientific (KONTOS & NAGLIE, 2007). This article reports results of a scoping review in which we identify and examine the extent, range and nature of arts-based health research; summarize key concepts in the field; and identify existing gaps<sup>2</sup> in the literature. [5]

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- 1 Arts-based research as process refers to researcher and/or participants using an artistic format to develop, explore, analyze or collect data. Arts-based research as product indicates that the research results are communicated in some type of artistic format. There are variations of the above and many arts-based research projects are a combination of the two.
  - 2 Gaps where research itself is of substandard quality are not the focus, as assessment is not typically within the rubric of scoping studies (ARKSEY & O'MALLEY, 2005).

## 2. Methods

Our scoping review uses an adapted version of the ARKSEY and O'MALLEY (2005) framework<sup>3</sup>, involving the following steps: [6]

### 2.1 Identification and development of the research questions

The overall research questions are as follows: What is the extent of published evidence on the use of the arts as process and product in health research? What is known from the existing literature about the use and impact of the arts in the production and dissemination of health research? What are the gaps in the knowledge base in this emerging field? [7]

### 2.2 Location, screening and selection of relevant publications

Numerous terms were used to search six electronic databases of published scientific literature. Search terms included diverse art genres, as well as terms related to health, knowledge translation and qualitative inquiry<sup>4</sup>. The electronic databases searched included [PsyCHINFO](#), [CINAHL](#), [ASSIA](#), [EMBASE](#), [MedLine](#) and [Web of Science](#). Articles were included if they were published in English, from 2000 to June 2010. These dates reflect the emergence and further development of published literature in this area. This search procedure yielded 4,729 abstracts. Titles and abstracts were scanned to determine whether or not they used arts-based research methods in the health field and to eliminate those focusing on art as therapy, those not related to health, and those not research based. As described earlier, much of the literature reports efforts to promote specific health behaviors and to educate the public about general health issues—these papers did not have a research component<sup>5</sup>. The team agreed to these criteria, which was applied to all 108 citations identified for inclusion in the review. Full articles were obtained for these studies and read by at least two team members. After further inspection, 74 articles were deemed relevant and selected for inclusion. Following further scrutiny, two papers were excluded as they were not research-based, and one paper was found to be a review of an included paper, leaving 71 papers in the review. The review process is outlined in Figure 1.

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3 LEVAC and colleagues (2010) suggest that best practice in scoping reviews should explicitly specify their framework.

4 A sample of search terms includes health, mental health, art, photography, drama, theater, knowledge translation, knowledge production, information dissemination, qualitative methods, to name a few.

5 The decision was made to exclude health promotion articles as their intent was to raise awareness about health issues using art genres as method, however, the art was not based on research, and was not producing new knowledge.

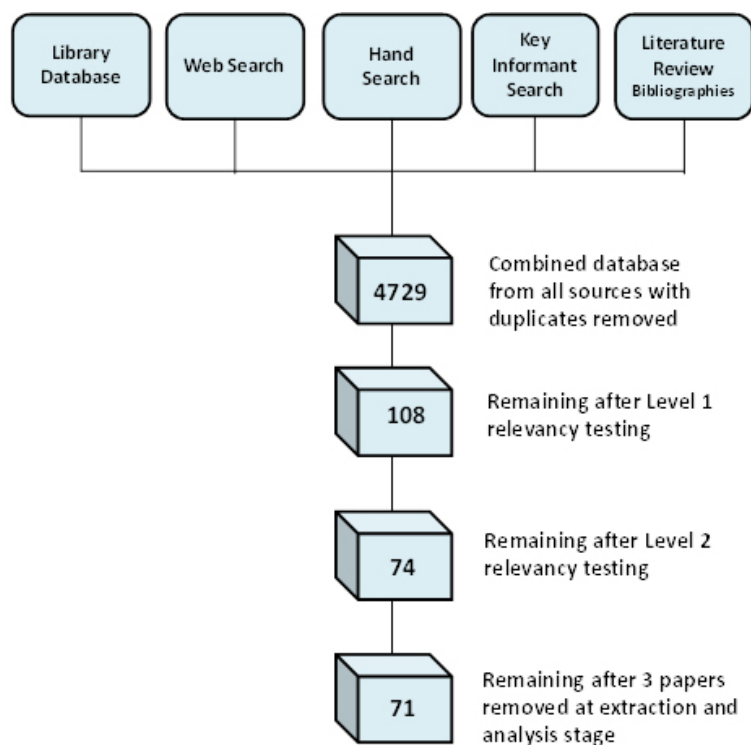


Figure 1: Results of the search strategy [8]

### 2.3 Charting and collating results

Articles were organized according to a primary focus of the research in which arts were used either to produce data (process) or disseminate findings (product) and analytic questions were developed to interrogate the data set. A data charting form was developed to organize our analysis. We asked questions pertaining to the study purpose and whether or not the authors describe using a theoretical approach or conceptual framework. We examined how methods related to data generation, analysis and rigor were described and how the findings of these studies were represented, including discussion related to study limitations and future research directions. Answers to these questions were collated, summarized and reported as results of our scoping review. [9]

## 3. Results

Results of our study include both a descriptive numerical summary as well as a thematic analysis, based on the questions we asked during the charting process (ARKSEY & O'MALLEY, 2005). [10]

### 3.1 Descriptive numerical summary

A full listing of the 71 publications obtained through our systematic search is provided in Table 1. Most papers were published relatively recently, with the

majority appearing in the five-year period immediately preceding this review (see Figure 2).

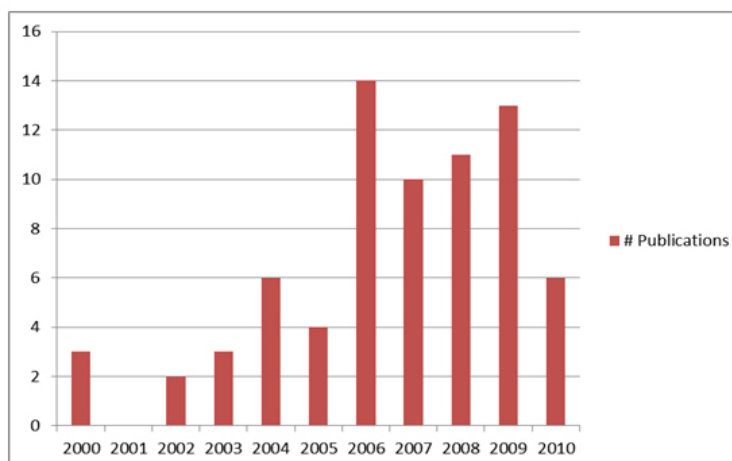


Figure 2: Year of publication [11]

Publications emanate largely from researchers in the US (48%, n=34), Canada (28%, n=20), and the UK (13%, n=9), with the remaining eight articles from researchers located in Australia, New Zealand, Poland, Hungary, Bolivia and Africa. Although many art genres are represented, the majority included photography (n=23) (photovoice, photo-elicitation, visual intervention analysis) and theater (n=21), followed by drawing (n=8), film/video (n=8), poetry (n=3), dance (n=1) and the remaining representing more than one type of art form (n=8). The health care issues examined in these studies are diverse and include articles focusing on general health care (n=17), cancer (n=10), autoimmune diseases (diabetes, HIV/AIDS, lupus) (n=10), mental illness (n=6), cognitive issues (Alzheimer's disease, dementia, acquired brain injury) (n=6), and others. Authors represent various academic disciplines, including nursing (n=15), public health (n=11), psychology (n=5), sociology (n=5), dramaturgy and performance arts (n=3) and social work (n=2). Table 1 displays the descriptive characteristics of the literature, including the art genres studied, country of origin and the academic discipline of the main author.

Author, Year	Author's Discipline(s)	Art Genre	Country	Health Issue
BAKER & WANG (2006)	Education	Photo	USA	Chronic pain in older adults
BENDER, SANTANDER, PATINO & WASSERMAN (2008)	Health policy & administration	Photo	Bolivia [USA & Bolivian researchers]	Reproductive care
BOSOMPRA (2007-2008)	Not indicated	Drama, theater	Ghana	AIDS education

<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
BOXALL & RALPH (2009)	Sociology	Photo	UK	Intellectual disability
CATALANI & MINKLER (2010)	Public health	Photovoice (review)	USA	General health and public health
CHUNG et al. (2006)	Psychiatry; public health	Multi-genre	USA	Depression
CLARKE, FEBBRARO, HATZIPANTELIS & NELSON (2005)	Sociology; psychology	Poetry	Canada	Homeless mentally ill
COAD (2007)	Participatory research in child health settings	Multi-genre	UK	Children and young people
COAD, PLUMRIDGE & METCALFE (2009)	Child and adolescent health; health sciences	Multiple (drawing, mapping, collage, photographs, graffiti, etc.)	UK	Children and young people
COLANTONIO et al. (2008)	Public health	Drama, theater	Canada	Acquired brain injury
COOPER & YARBROUGH (2010)	Nursing	Photo	USA	General health issues
COX, KAZUBOWSKI-HOUSTON & NISKER (2009)	Medicine	Drama, theater	Canada	Genetics, preimplantation
DYCHES, CICHELLA, OLSEN & MANDLECO (2004)	Education	Photo	USA	Developmental disability
EAKIN & ENDICOTT (2006)	Sociology	Drama, theater	Canada	Workplace injury
FLEMING, MAHONEY & CARLSON ENGBRETSON (2009)	Nursing	Photo	USA	Mental illness

<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
FRITH & HARCOURT (2007)	Social psychology; health psychology	Photo	UK	Cancer
FURMAN (2006)	Social work	Poetry	USA	General health
GAVARAVARAPU & THANGIAH (2009)	Nutrition science	Dance	UK	General health, nutrition education
GRAY, FITCH, LABRECQUE & GREENBERG (2003)	Psychology	Drama, theater	Canada	Cancer
GRAY et al. (2000)	Psychology	Drama, theater	Canada	Cancer
GUILLEMIN (2004a)	Public health; sociology of health, illness	Drawing	Australia	General health
GUILLEMIN (2004b)	Public health [as above]	Drawing	Australia	Heart disease
HAINES, OLIFFE, BOTTORFF & POLAND (2010)	Nursing; public health; health and social development	Photo	Canada	Tobacco use
HENARE, HOCKING & SMYTHE (2003)	Occupational therapy; nursing, midwifery	Drawing; sketching; magazine collage	New Zealand	Chronic pain
HERMAN & LARKEY (2006)	Psychology	Decoupage	USA	Cancer
KEEN & TODRES (2007)	Social work; psychology	Ethnodrama, theater; Internet	UK	Multiple
KONTOS & NAGLIE (2007)	Rehabilitation science	Drama, theater	Canada	Alzheimer's disease
LAPUM (2005)	Nursing	Poetry	Canada	Heart disease



<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
LEVIN et al. (2007)	Computational neuroscience	Photo	USA	Stroke
McINTYRE & COLE (2008)	Education	Drama, theater	Canada	Alzheimer's disease
MITCHELL, JONAS-SIMPSON & IVONOFFSKI (2006)	Nursing	Drama, theater	Canada	Dementia
MORGAN, McINERNEY, RUMBOLD & LIAMPUTTONG (2009)	Public health; nursing; social science; counseling psychology	Drawing	Australia	Chronic vaginal thrush
MOSAVEL & THOMAS (2009)	Social and behavioral health	Drama, theater	USA	Lupus
NISKER et al. (2006)	Medicine; health policy, management and evaluations; public health sciences	Drama, theater	Canada	General health; health policy
NOWICKA-SAUER (2007)	Psychology; family medicine	Drawing	Poland	Lupus
OLIFFE & BOTTORFF (2007)	Nursing; health and social development	Photo	Canada	Tobacco use
OLIFFE, BOTTORFF, KELLY & HALPIN (2008)	Nursing; health and social development	Photo	Canada	Tobacco use
PICARD (2008)	Nursing	Creative movement (choreography)	USA	Mid-life women; bipolar disorder
PIETRZYK (2009)	Anthropology	Poetry, fiction	USA	HIV/AIDS

<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
PIKO & BAK (2006)	Psychiatry, behavioral sciences	Drawing	Hungary	Children's beliefs about health, illness, disease prevention and health promotion
POUDRIER & MAC-LEAN (2009)	Sociology	Photo	Canada	Cancer
RADLEY & TAYLOR (2003)	Social sciences	Photo	UK	General health hospital ward
RICH (2004)	See below	Video	USA	Health literacy
RICH, LAMOLA & WOODS (2006)	Medicine; adolescent, young adult medicine	Video	USA	Asthma
RICH, POLVINEN & PATASHNICK (2005)	Medicine; adolescent, young adult medicine	Video	USA	Pediatric illness
RICH, LAMOLA, AMORY & SCHNEIDER (2000a)	Medicine; adolescent, young adult medicine	Video	USA	Asthma
RICH, LAMOLA, GORDON & CHALFEN (2000b)	Medicine; adolescent, young adult medicine	Video	USA	Adolescent illness
ROBERTS et al. (2007)	Performance arts; rehabilitation psychiatry; sociology	Drama, theater	UK	Mental illness; early psychosis
ROSENBAUM, FERGUSON & HERWALDT (2005)	Medicine	Drama, theater	USA	General health; multiple illnesses
ROSSITER et al. (2008a)	Dramaturgy	Drama, theater	Canada	Various (e.g. Alzheimer's disease, cancer)
ROSSITER et al. (2008b)	Dramaturgy	Drama, theater	Canada	Brain injury

<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
SANDELOWSKI, TRIMBLE, WOODARD & BARROSO (2006)	Nursing	Drama, theater	USA	HIV
SHAPIRO, TOMASA & KOFF (2009)	Humanities	Video, film	USA	Medical students
SINDING, GRAY, FITCH & GREENBERG (2002)	Public health; nursing	Drama, theater	Canada	Cancer
SINDING, GRAY, GRASSAU, DAMIANAKIS & HAMPSON (2006)	Social work: health studies	Drama, theater	Canada	Cancer
SMITH, FROST, ALBAYRAK & SUDHAKAR (2006)	Information sciences & technology	Photo	USA	Type 1 diabetes
SMITH, FROST, ALBAYRAK & SUDHAKAR (2007)	Information sciences & technology	Photo	USA	Type 1 diabetes
STEWART, RIECKEN, SCOTT, TANAKA & RIECKEN (2008)	Indigenous counseling; education; health education, promotion	Video	Canada	General health, health literacy
STRENG et al. (2004)	Public health	Photo	USA	General health, immigration
STUCKEY (2009)	Medicine and education	Drawing, photo	USA	Diabetes

<b>Author, Year</b>	<b>Author's Discipline(s)</b>	<b>Art Genre</b>	<b>Country</b>	<b>Health Issue</b>
STUCKEY & TISDELL (2010)	Medicine and education	Photo and imagery	USA	Diabetes
STUTTAFORD et al. (2006)	Geography; applied theater; social sciences; neurology; epidemiology; public health	Drama, theater	UK and South Africa	General health, health research
THOMPSON et al. (2008)	Nursing	Photo	USA	Mental illness; chronic mental illness
VAUGHN, ROJAS-GUYLER & HOWELL (2008)	General and community pediatrics and emergency medicine; sociology, anthropology, philosophy	Photo	USA	General health; girls perception of health
WALKER, CAINE-BISH & WAIT (2009)	Human development; family studies; nutrition, dietetics	Drawing	USA	Overweight children
WALLIS, WINCH & O'CAMPO (2010)	Epidemiology; public health	Photo	USA/Canada <sup>6</sup>	General health
WANG (2006)	Public health	Photo	USA	General health; multiple, related to community and well being
WANG & PIES (2004)	Public health; family, maternal and child	Photo	USA	General health; family, maternal and child health

6 Study in USA; first investigator is Canadian.

Author, Year	Author's Discipline(s)	Art Genre	Country	Health Issue
WASHINGTON & MOXLEY (2008)	Nursing; social work	Art exhibit (photo, videography, etc.)	USA	General health; homelessness
WILLIAMS, ANDERSON, LEE, WHITE & BAKER (2009)	Community health sciences	Drama, theater	USA	Lupus
YI & ZEBRACK (2010)	Social work	Photo	USA	Cancer

Table 1: Descriptive characteristics of the literature [12]

### 3.2 Thematic analysis

We organize our thematic findings according to the analytic questions we asked: 1. rationale for the use of arts-based strategies, 2. theoretical frameworks, 3. methods, 4. findings, 5. limitations, and 6. future directions. [13]

#### 3.2.1 Rationale for the use of arts-based strategies

Authors describe the limitations of traditional qualitative research methods to communicate subjective experience and the consequent need for alternative methods (see for example DYCHES et al., 2004; KEEN & TODRES, 2007) that move beyond forms of dissemination that typically cater to academic audiences. Authors also assume that aspects of art-based research, such as increased participant control in producing arts-based work, help to highlight features of lived experience otherwise overlooked or ignored (e.g. GUILLEMIN & DREW, 2010). Reminiscent of qualitative inquiry in health more broadly, the most common rationale given for using arts-based methods is to highlight the illness experience by eliciting subjective experience. There are numerous references to the way that these methods can provide a rich and detailed picture of the illness experience (BAKER & WANG, 2006; FLEMING et al., 2009; MORGAN et al., 2009; RICH et al., 2000a, 2000b; THOMPSON et al., 2008; WANG & PIES, 2004; WASHINGTON & MOXLEY, 2008), thereby enhancing our understanding (STRENG et al., 2004), as well as empowering and engaging participants (CHUNG et al., 2006; COOPER & YARBROUGH, 2010; COX et al., 2009; HENARE et al., 2003; NISKER et al., 2006; OLIFFE & BOTTORFF, 2007; OLIFFE et al., 2008; PICARD, 2008; STUCKEY & TISDELL, 2010; VAUGHN et al., 2008; WANG & PIES, 2004). The use of arts-based methods is supposed to account for the skills and abilities of vulnerable populations (COAD, 2007; GUILLEMIN, 2004a; PIKO & BAK, 2006; RICH et al., 2005; WALKER et al., 2009) in order to address, challenge and rebalance power relationships (CLARKE et al., 2005; COAD et al., 2009; GAVARAVARAPU & THANGIAH, 2009;

POUDRIER & MAC-LEAN, 2009; WILLIAMS et al., 2009). The intent of many studies is to move both participants and audiences to critical awareness of health-related issues and allow them to reflect on and become sensitized to aspects of the illness experience (HAINES et al., 2010; LAPUM, 2005; ROBERTS et al., 2007; ROSSITER et al., 2008a, 2008b). [14]

Although authors provide a rationale for the use of arts-based strategies in general, they are less likely to give specific details about why they chose a particular art genre. Those who discuss their choice include GUILLEMIN and DREW (2010), who justify the use of photography as fostering a sense of participation for those who may be reluctant to take part in research. Like qualitative methods more generally, they argue that photography can be empowering because it provides young people with a voice. The use of theater (GRAY et al., 2003; KONTOS & NAGLIE, 2007; ROSENBAUM et al., 2005) is often rationalized as an opportunity for health care professionals to reflect on the care they provide and enhance their understanding of the patient's lived experience through the concept of embodiment. For example, KONTOS and NAGLIE (2007) state that performance more vividly depicts how selfhood is manifested in habits, gestures, and actions of the body than is achieved with traditional text-based dissemination strategies alone. [15]

### *3.2.2 Theoretical frameworks*

Description of the theoretical approaches and conceptual frameworks used in these studies is diverse. This is likely the result of scholars' disciplinary training and the influence of different theoretical orientations toward research. Although ontological and epistemological assumptions are often implicit in these studies, one third of the publications described taking a particular approach to their work. For example, at a paradigmatic level, authors describe using a constructivist approach to focus on understanding the meaning of health phenomena in accounts participants gave of their illness experience (see for example, HENARE et al., 2003; SINDING et al., 2006; WALKER et al., 2009). Study authors also report taking a more critical perspective to confront issues of power at a structural level for the purpose of making social change (see for example, COOPER & YARBROUGH, 2010; WILLIAMS et al., 2009; YI & ZEBRACK, 2010). Several studies report, for example, the use of feminist frameworks (LAPUM, 2005; McINTYRE & COLE, 2008, MORGAN et al., 2009, POUDRIER & MAC-LEAN, 2009, and STUCKEY, 2009) and draw on particular theorists (HAINES et al., 2010; RADLEY & TAYLOR, 2003). [16]

### 3.2.3 Methods

The papers reviewed did not distinguish between the use of methods or methodology in discussing these various studies<sup>7</sup>. Most authors described methods to collect data<sup>8</sup> (for example, using participant observation methods and interview techniques) and manage it for the purposes of analysis (WALLIS, WINCH & O'CAMPO, 2010). Data analysis often consists of content and thematic analysis (e.g. COOPER & YARBROUGH, 2010; YI & ZEBRACK, 2010) as well as narrative analysis (MORGAN et al., 2009). Photo studies typically rely on content or thematic analysis of photos in studies which focus on a number of health problems, including developmental disabilities (DYCHES et al., 2004), stroke (LEVIN et al., 2007), and mental illness (THOMPSON et al., 2008). A structured technique for analysis of photos (SHOWeD<sup>9</sup>) is mentioned in four articles (STRENG et al., 2004; VAUGHN et al., 2008; WANG & PIES, 2004). GUILLEMIN (2004b) uses ROSE's (2001) critical visual methodology for analysis of drawings in her work on menopause and heart disease. One article involves participants in the thematic analysis of drawings depicting the experience of Type 1 diabetes (STUCKEY & TISDELL, 2010). [17]

With articles primarily focusing on the use of the arts as product (research dissemination), the description of methods involves details of the actual presentation, performance, photographic exhibit (HALVERSON, 2008; NISKER et al., 2006; ROBERTS et al., 2007) or installation (McINTYRE & COLE, 2008). Authors describe the ways in which they document audience response (e.g. MOSAVEL & THOMAS, 2009; STUTTAFORD et al., 2006). This most frequently takes the form of participant observation (ROBERTS et al., 2007), thematic analysis of field notes and documents (CLARKE et al., 2005; FLEMING et al., 2009), group discussions (STRENG et al., 2004), questionnaires (HERMAN & LARKEY, 2006), and post-performance sessions with audiences (SHAPIRO et al., 2009; SINDING et al., 2002; STUTTAFORD et al., 2006). [18]

Methods used to evaluate the effects of using the arts to create and/or disseminate research include, for example, pre-post interviews with an audience of prostate cancer patients and their families (GRAY, FITCH, LaBRECQUE & GREENBERG, 2003); Likert type questionnaire with health care professionals in the traumatic brain injury field (COLANTONIO et al., 2008; KONTOS & NAGLIE, 2007; MITCHELL et al., 2006); and focus groups with individuals with HIV/AIDS (BOSOMPRA, 2008) and dementia (KONTOS & NAGLIE, 2007). [19]

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7 *Methodology* refers to the beliefs regarding knowledge that emerge from the study's philosophic framework or theoretical framework that guides how the research should unfold (CAELLI, RAY & MILL, 2003; HARDING, 1987). Methods refer to the tools, techniques or procedures used to gather the evidence (HARDING, 1987). Recently, *methodology* has been increasingly used as a substitute for *method* in the scientific context. This misuse obscures an important conceptual distinction between methods and methodology.

8 Articles did not routinely provide justification for the sample size used—whether research participants were involved in the creation of knowledge or were involved as audience members.

9 The mnemonic "SHOWeD": What do you See here? What is really Happening here? How does this relate to Our lives? Why does this problem, concern, or strength Exist? What can we Do about it?

The issue of research rigor as method is seldom discussed. When specifically stated, it refers to procedural qualitative criteria of trustworthiness achieved via independent coding (THOMPSON et al., 2008), inter-rater agreement (DYCHES et al., 2004; VAUGHN et al., 2008), screening (RICH et al., 2000b), regular team meetings to debrief, compare and achieve consensus (FLEMING et al., 2009; THOMPSON et al., 2008; OLIFFE et al., 2008), and member checking to confirm accuracy and make modifications (STRENG et al., 2004; STUCKEY, 2009; VAUGHN et al., 2008). [20]

### 3.2.4 Study findings

The findings of reviewed articles are grouped into the following key categories<sup>10</sup>: 1. the illness experience; 2. benefits of participation in knowledge production; 3. audience response; 4. programmatic and policy implications; and, 5. extension of existing methods.

1. *The illness experience*: Most articles focus on explicating the illness experience, hence one of the key findings centers on the illness experience itself and enhanced awareness and knowledge of the health phenomena being examined. The underlying meaning of illness is explored (e.g. FLEMING et al.'s [2009] photovoice study of mental illness; NOWICKA-SAUER's [2007] study of lupus and the use of drawing), enabling expression of emotions (e.g. STUCKEY's [2009] study on diabetes), and offering an insider view of treatment (e.g. FRITH & HARCOURT's [2007] study of experiences following chemotherapy for breast cancer). Greater understanding of the illness, as well as new information and insights (ROBERTS et al., 2007; FURMAN, 2006; COAD, 2007) are also reported. In one example, SHAPIRO and colleagues (2009) demonstrate that student filmmakers learn about the impact of chronic illness on relationships, the role of health care professionals, the availability of community resources, insurance challenges and the financial impact of care.
2. *Benefits of participation in knowledge production*: Arts-based methods are posited to be more engaging and empowering than traditional qualitative methods; the therapeutic or individual benefits of participation are frequently reported in articles that focus primarily on using arts-based research as process. Manuscripts report access to deeper emotion through arts-based work, enabling patients to express their feelings (STUCKEY, 2009; STUCKEY & TISDELL, 2010; THOMPSON et al., 2008). MORGAN et al. (2009) report that the drawing method of storytelling provides opportunities for participants to reflect on their experiences and acquire new insights about feelings of disconnection from their body. Much of the literature notes that involvement in research using art genres empowers participants (CATALANI & MINKLER, 2010; THOMPSON et al., 2008; FRITH & HARCOURT, 2007; STEWART et al., 2008; WANG, 2006; STRENG et al., 2004; YI & ZEBRACK, 2010) and enhances confidence, self-esteem, individuality, passion, team building, collaboration, and creativity (BAKER & WANG, 2006; RICH et al., 2006).

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10 These categories are by no means discrete; overlap among articles did occur.



ROBERTS et al. (2007) in their study of the use of drama to enhance understanding and awareness of psychosis, demonstrate an improved willingness among research participants to access help. Using art to generate research knowledge is also noted to increase patient trust in health care providers (NOWICKA-SAUER, 2007), participant trust in the research process (MOSAVEL & THOMAS, 2009; STRENG et al., 2004) and enhance strategies for coping with the illness (BAKER & WANG, 2006). RICH and his colleagues (2006) claim that their use of video increases adherence to physical activity, improves overall quality of life and activity levels for those with asthma. Additionally, more confident self management of diabetes is reported by STUCKEY and TISDELL (2010).

3. *Audience response*: The audience is represented as a key stakeholder in arts-based research, albeit more explicitly in the dissemination of research findings than in the production process. In the literature, explicit references to audience include health care practitioners, patients and the general public.

Many articles feature health care practitioners as the target audience. Telephone interviews conducted by GRAY et al. (2003) reveal that practitioners reflect on a new level of awareness and understanding resulting from their attendance at a theatrical production of research on prostate cancer. They report the humanizing effect of engaging with patients' lives on the stage and increased insight into, and empathy with, the experiences of patients and their families. GRAY et al.'s (2000) theatrical production based on cancer research also targets health care practitioners and reports similar effects. COLANTONIO and her colleagues (2008), in their study of a dramatic production about traumatic brain injury, demonstrate short-term impact in terms of imparting new knowledge to health care practitioners and increased recognition of patient needs. In their evaluation of a play based on living with dementia, MITCHELL et al. (2006) identify practitioner disclosure of intent to change practice based on new knowledge and understanding. Also noted was the opportunity for audiences of both patients and physicians to engage in unique dialogue and thoughtful discussion, for example, in SMITH et al.'s (2006, 2007) study on Type 1 diabetes.

Findings related to patient-based audiences demonstrate the benefits to audience members via their own changes in perspectives. For example, SINDING et al. (2006) show that their theatrical production of research on breast cancer eases the sense of isolation for survivors as well as normalizes their ongoing struggles. Behavior change is evident in BOSOMPRA's (2007-2008) use of drama and songs to communicate his research on HIV/AIDS as he documents changes in audience reported sexual behavior resulting from his dissemination strategy. There is a specific appreciation for the patient perspective of illness/health issue as demonstrated in ROBERTS et al.'s (2007) study of the experience of psychosis and FRITH and HARCOURT's (2007) study of the experience of chemotherapy. STEWART et al. (2008) report that the process of video making enhances confidence and self esteem and offers a space for redefining youth problems. MORGAN et al. (2009) report on the therapeutic impact of storytelling on patients with chronic thrush. In their dramatization of research results on work-related injury, EAKIN and

ENDICOTT (2006) demonstrate that an audience of injured workers identifies with the play's content and are given hope that their individual experiences are translated broadly.

Arts-based research is also demonstrated to enhance general public knowledge of health resources in local communities, as in the review of photovoice by CATALANI and MINKLER (2010). Several articles also document the use of the arts to foster a sense of community among the general public (CATALANI & MINKLER, 2010; WANG & PIES, 2004; LEVIN et al., 2007; VAUGHN et al., 2008).

4. *Programmatic and policy implications:* Articles report that the use of the arts in knowledge production has the potential to assist in the development and design of programming (prevention) and has implications for practitioners and policy makers, for example, WALKER et al.'s (2009) design of a program to enhance children's physical activity. Use of the arts to produce and disseminate new knowledge is also recognized as having the potential for cultural activism (BENDER, SANTANDAR, WILSON & WASSERMAN, 2008; PIETRZYK, 2009), to provide recommendations to health education programs, as in PIKO and BAK's (2006) study of children's drawings of their conceptions of illness and health, as well as the potential to change opinion from baseline conceptions of breast health (HERMAN & LARKEY, 2006). KONTOS and NAGLIE (2007) further support arts-based health research as a knowledge translation strategy and identify its potential to positively affect health care policy and practice. Stimulation of public engagement is noted in NISKER et al.'s (2006) and COX et al.'s (2009) study of the use of research based theater in policy development.
5. *Extension of existing qualitative methods:* Many articles make explicit the use of the arts in the research enterprise as expanding upon and extending conventional qualitative methods (CLARKE et al., 2005; COLANTONIO et al., 2008; OLIFFE & BOTTORFF, 2007; OLIFFE et al., 2008; WANG & PIES, 2004). For example, while COAD et al. (2009) state that participatory arts-based methods offer a new approach to research with children, GUILLEMIN (2004a, 2004b) argues that strategies like drawing can be used effectively with adult participants as well. WASHINGTON and MOXLEY (2008) suggest that their use of multiple arts-based methods leads to powerful portrayals of lived experience that other forms of inquiry cannot. STUCKEY (2009) notes that because of the opportunity for creative expression, participants feel aspects about their diabetes not previously explicated, particularly regarding spiritual dimensions of the body. Additionally, the contribution of arts-based research to the research enterprise itself is highlighted. For example, an arts-based project was found to increase willingness to enroll in trials and help people engage in clinical research (HERMAN & LARKEY, 2006). Arts-based strategies are reported to enable research teams to understand community perceptions of research and health and are useful in the teaching of medical students (MOSAVEL & THOMAS, 2009). [21]

### 3.2.5 Challenges

Authors highlight the challenges encountered in their research; many of which are identified more broadly in the literature on qualitative methodologies and are not specific to arts-based methods. For example, authors report the possibility of increased distress as a consequence of reading transcripts on which their drama was based (GRAY et al., 2000). Others describe the lack of longitudinal outcomes (WANG, 2006), or refer to ongoing contentious issues related to the problem of small sample sizes and the need for generalizability typically associated with approaches that use statistical analyses (HERMAN & LARKEY, 2006; RICH et al., 2006; YI & ZEBRACK, 2010) and methods that have the ability to quantify and measure change (RICH et al., 2006). [22]

Challenges specific to arts-based methods are also raised, such as ethical issues regarding privacy (SINDING et al., 2006) and consent to be photographed (COAD, 2007). There is also recognition of the "dangerous emotional terrain" (GRAY et al., 2000) and potential negative consequences of asking people to participate in communicating their health issue in a more embodied and representational manner (BAKER & WANG, 2006; MORGAN et al., 2009). Such activities can be perceived as demanding and a "risky" process that can result in painful, unexpected feelings (MORGAN et al., 2009; NISKER et al., 2006; SINDING et al., 2002). The problem of validity is raised (GUIELLEMIN, 2004) as an issue for visual research as some view multiple interpretations over time and with multiple audiences as a threat to validity (PIKO & BAK, 2006; MORGAN et al., 2009). [23]

Authors note that balancing the artistic and scientific components of the project is difficult (ROSSITER et al., 2008a; SANDELOWSKI et al., 2006), and that the aesthetic components of such projects are unexamined (ROSSITER et al., 2008b). Difficulties in coherence in styles of appraisal and in identifying what to examine in terms of evaluation are also acknowledged (ROSSITER et al., 2008b). [24]

A number of costs associated with arts-based research—monetary, temporal and academic—are identified (COAD, 2007; LEVIN et al., 2007). Articles address the costs of equipment, particularly photovoice camera equipment and the production of photos (LEVIN et al., 2007; RICH et al., 2000b). The extraordinary length of time to prepare installations, performances, and exhibits based on research is often noted (COAD, 2007; McINTYRE & COLE, 2008; VAUGHN et al., 2008). The time-consuming nature of arts-based research (SMITH et al., 2006) is explicitly linked to the pressure on academics to meet research deadlines (CHUNG et al., 2006) as well as intellectual property issues and the minimal academic value associated with this work (EAKIN & ENDICOTT, 2006). The lack of funding or very limited resources for this type of research is also mentioned (CHUNG et al., 2006; EAKIN & ENDICOTT, 2006; THOMPSON et al., 2008). [25]

### 3.2.6 Future directions

Authors point to the need for further work to examine the impact of arts-based research on research participants and audiences alike. They argue for rigorous impact studies to evaluate arts-based dissemination strategies (COX et al., 2009; GRAY et al., 2000; KEEN & TODRES, 2007; STUTTAFORD et al., 2006; WALKER et al., 2009), and sometimes this refers more specifically to designs that include randomization to ensure rigor (HERMAN & LARKEY, 2006), the need for multi-site studies (RICH, 2004) and comparative work (PIKO & BAK, 2006). Additional design issues were identified by those who expressed a need for larger numbers and longer term data collection (PIKO & BAK, 2006; RICH et al., 2006), as well as a desire for more detailed analyses of the process of knowledge creation (GRAY et al., 2000; ROSENBAUM et al., 2005), and of analysis more generally (CATALANI & MINKLER, 2010). Future directions also focus on thinking about the ethical considerations required when engaging in arts-based health research (WANG, 2006; KEEN & TODRES, 2007), which includes the need to educate research ethics boards about arts-based health research (BOXALL & RALPH, 2009). [26]

## 4. Discussion

Our discussion corresponds to the three research questions that formed the basis of our scoping review: What is the breadth of the literature? What are the key findings? And what are the research gaps in arts-based health research? [27]

### 4.1 Breadth of literature

Our review identified a range of arts-based strategies used to both create and disseminate health-related research knowledge. The scope of this literature pertained to both the type of health issue examined in the studies and the art genre used to conduct the research. Although the majority of papers focus on general health and well being, cancer, autoimmune disorders, mental health and illness and cognitive difficulties, the remainder were scattered across disease categories pertaining to chronic pain, asthma and heart disease. This distribution leads us to query whether the arts lend themselves to some health issues rather than others. For example, we wondered how stigmatizing conditions might also figure into design choices where innovation might be considered a good way to encourage participation and a method for delving deeper into the illness experience and in ways that could address sensitive issues. [28]

We found that the most widely used art genre is photography, following closely by theater, with relatively little use of other methods such as poetry, dance and mural art. However, we do not know why there is a concentrated use of particular methods in the literature and there is little clarity found here as investigators rarely reflected explicitly on their design choices. We would be keen to know for example, why researchers may have selected a certain art form to explore a particular health phenomenon. In qualitative research more broadly, it is likely that the choice of method are personal and often based on scholarly interest,

disciplinary training, and political and/or moral commitments, epistemological beliefs, and casual and informal observation made in a particular substantive area of inquiry (see, for example, SCHRAM, 2006). etc. This review raises questions about methodological choices and suggests that it would be of value to compare different genres and explore their particular benefits and challenges in various contexts. As this field is only in its nascent stages, we think it worth considering how a methodological literature in this area might develop and mature, including a more fully reflexive account of the methodology as we have seen in qualitative inquiry more broadly (MAUTHNER & DOUCET, 2003). [29]

#### 4.2 Thematic findings

Our review indicates that the most common rationale for using arts-based methods is similar to that of qualitative inquiry more generally—that is, to provide rich description, highlight lived experience and meaning, attend to contextual factors and enhance understanding. However we are struck by the fact that many authors considered the arts in social science research as a method for extending what is possible with qualitative methods on their own and we question how the arts infuses qualitative methods with something more. Do they reveal, produce and represent data in ways that traditional qualitative methods do not? While the authors in our review seldom indicate the *unique* contribution of the arts, those who did, did so in a number of ways. The arts in qualitative health research was considered: 1. an opportunity for enhanced *engagement* for participants and audiences alike (e.g. LEVIN et al., 2007); 2. a way to enrich communication and make research *accessible* beyond academia (e.g. KEEN & TODRES, 2007; COLANTONIO et al., 2008); and, 3. a method for facilitating conversation and reflection during individual interviews, generating data beyond what was considered the normal scope of most interview-based methods alone (e.g. DYCHES et al., 2004; OLIFFE & BOTTORFF, 2007). However, many authors fail to attend to why the arts matter, hence the need for reflexivity. Those that make the claim that the arts matter, need to demonstrate this—we believe that further research is required to examine the ways in which this may be so. [30]

When describing the rationale for using arts-based methods, we suggest that the emphasis be on the unique contribution that the specific art form being used makes. A more reflexive account of arts-based methods might emphasize the unique contribution of a particular method but only if it is not conflated with qualitative methods more generally. Moreover, a critical dialogue amongst those working across genres might contribute to further understanding whether or not arts-based health research is in fact a new paradigm for inquiry or a methodology that might be categorized under any of the current taxonomies for qualitative research that describe a range of realist, interpretive and critical ontologies and epistemologies and the issues that arise within them (LINCOLN & GUBA, 2000; GIACOMINI, 2009). These issues are seldom addressed in the extant literature, with a few exceptions (GUILLEMIN & DREW, 2010; GRAY et al., 2003; ROSENBAUM et al., 2005; KONTOS & NAGLIE, 2007). We also document the frequent failure to conceptually distinguish between methods and methodology and encourage reflexivity amongst individuals working in this field to differentiate

between the tools of scientific investigation and the principles that determine how such tools are utilized and interpreted (MAUTHNER & DOUCET, 2003). [31]

Findings from the few studies that explicitly evaluate the impact of using the arts in knowledge production and dissemination are promising, highlighting the *potential* to impact health care positively and for attitude and behavior change. These articles rely primarily on the use of pre–post questionnaires and post performance audience feedback. We argue that further research could add significantly to the extant work; specifically, to explore in greater depth how and in what ways using the arts as process and product has an immediate and long term impact on health care practitioners, consumers of health services, families and the general public. [32]

#### 4.3 Research gaps

We focus here on three central gaps identified in our review: 1. the need for critical dialogue<sup>11</sup> regarding the impact of arts-based research; 2. the need to focus on how the quality of arts-based research is judged; and, 3. the need to address the ethical challenges of engaging in this work. [33]

According to our review, one of the most conspicuous gaps is the lack of critical dialogue regarding the examination of the impact of this work. Authors suggest that impact can be measured in a manner rooted in positivism. They are likely responding to deep-seated assumptions about science; the current emphasis on evidence-based health care and the call to employ rigorous designs and provide "hard" evidence of the efficacy of arts-based health research (PUTLAND, 2008). This raises questions for us about innovative options for addressing impact and what they may in fact be. Does the call for rigorous evaluation reduce the value and meaning of art to narrowly defined functions wherein art is viewed as the mechanism to achieve social outcomes and address public policy agendas? Do arts-based methods call for a distinct way of dealing with impact, notions of rigor and ways of evaluating assertions or not<sup>12</sup>? [34]

Although articles often allude to the impact of using the arts in health research, it is only a smaller group of articles that focus *explicitly* on determining the impact on participants and audience, including patients, their families, and health care practitioners. Authors in our review replicate the expectations of a positivist worldview and argue for rigorous evaluation of dissemination strategies (COX et al., 2009; GRAY et al., 2000; KEEN & TODRES, 2007; STUTTAFORD et al., 2006) and several suggest that what is required to address issues of quality and impact are randomized controlled trials (for example, see GRAY et al., 2000). We question whether or not there may be alternative ways to address quality if arts-

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11 By "critical" is meant the capacity to inquire "against the grain": to question the conceptual and theoretical bases of knowledge and method, to ask questions that go beyond prevailing assumptions and understandings of phenomena, to acknowledge the socio-political dimensions of health and health research.

12 We acknowledge here the enduring issues in qualitative methodology more generally, in which these issues are debated and have frequently given rise to paradigmatic shifts and differences in ways of considering what we know and give evidence for knowledge.

based health research is viewed as a different way of doing research. That is, positivist ways of evaluating impact may be at odds with the methods and methodologies used to conduct such work. [35]

Articles in our review often report on issues of rigor in the work and follow the conventional standards of reporting on research trustworthiness in qualitative inquiry (see ERLANDSON, HARRIS, SKIPPER & ALLEN, 1993). We agree with GERGEN and GERGEN (2010), who take issue with traditional standards for evaluating research in general (e.g. validity and reliability in quantitative work and trustworthiness in qualitative work) and their lack of transferability to arts-based projects. Similarly, EAKIN and MYKHALOVSKIY (2003) critique the form of judgment put forward by guidelines used in the health sciences for appraising qualitative research and posit an alternative evaluative stance. They argue that by judging quality exclusively via execution of proper method, guidelines tend to over-simplify and inappropriately standardize the complexities and non-formulaic nature of qualitative inquiry, and tend to divert attention away from the analytic content of the research. They instead propose augmenting procedural considerations with a "substantive" orientation that focuses on the relationship between the practice of research and substantive findings and interpretation. Consequently, one would not merely ask about which research procedures were used, whether they were the correct ones to use and whether they bear out validity of the findings. Instead, judgment emerges from a deeper engagement in and understanding of the interpretations offered and assessment of how they are (or are not) rendered convincing by the utilized research practices. [36]

In a similar vein, in the case of arts-based health research, constricted frames of academic excellence and criteria are considered inappropriate and new criteria are recommended. As one example, JONES (2007) posits that arts-based philosophies—aesthetics—should be considered when judging research processes and products using the arts. He draws upon BOURRIAUD's (2002) "Relational Aesthetics" as a potential resource and one example to address this issue. BOURRIAUD's (2002, p.14) relational art takes as its theoretical horizon "the realm of human interactions and its social context, rather than the assertion of an independent and private space." JONES (2006, 2007) identifies this work as a starting point to allow social scientists to ponder issues of aesthetics and strategies for research using the arts. He notes that the key components of relational aesthetics include intersubjectivity, the encounter, and the collective elaboration of meaning; the goal of which is to bring people together and to increase understanding. [37]

The ethics of engaging in arts-based health research have, in large part, been neglected. Consequently, methodological and theoretical frameworks that can provide direction for other researchers and artists interested in this breakthrough work are lacking. So too is guidance in the form of accepted standards or policy for members of research ethics boards charged with reviewing arts-based research. There is a critical need to bring individuals engaged in arts-based health research together to reflexively 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. [38]

Ethical questions must be addressed in any qualitative study; however, some issues are peculiar to arts-based methods (COX et al., 2009; WHITE & BELLIVEAU, 2010; NISKER et al., 2006). These ethical concerns can be encountered at any stage of the research process: the creation of the artistic works, the live performance and/or display, and other strategies of dissemination such as performance recording or publication in academic journals. There are currently few guidelines specific to arts-based research to draw from (NISKER & DAAR, 2006), and the challenge is to acknowledge that such research clearly involves a broader and very different range of human participants than more traditional research disciplines, which influenced the development of extant ethical guidelines. [39]

#### **4.4 Limitations**

Since a scoping review is not meant to be exhaustive—but rather to provide a good sense of the literature in a particular area and identify potential research gaps—it is likely that other relevant publications were not included. Further, due to time and cost considerations we include only English language publications and exclude books and grey literature, although we recognize that they constitute an important source of research information. Application of the inclusion criteria used in selecting studies for review reflects the interpretivist position of our research team and our approach to decision making. In keeping with more critical and interpretive traditions in qualitative research, we recognize that our approach to review is subjective and that this influences our consideration of studies relevant for the study purpose. [40]

#### **5. Conclusions**

We postulate that the broadening of qualitative methodologies to include arts-based approaches offers more than simply adjuncts to typical data collection and dissemination approaches. As WAINWRIGHT and RAPPORT (2007, par.2) report, it instead represents "alternative epistemic positions from which to view the world." We believe that this may be a significant moment in the field in which to question whether or not we are witnessing a paradigmatic shift in how we approach inquiry into the social world and/or the emergence of an innovative set of techniques researchers can use to enhance more traditional methods for doing qualitative research. [41]

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## Authors

*Katherine M. BOYDELL* is a senior scientist whose program of research focuses on child and youth mental health. Her academic background is in community health epidemiology and qualitative sociology and she has an interest in studying arts-based forms of knowledge translation and exchange.

Contact:

Katherine M. Boydell, MHSc, PhD  
Senior Scientist, Learning Institute  
Scientific Director of Qualitative Inquiry

Child Health Evaluative Sciences  
The Hospital for Sick Children  
Associate Professor  
Department of Psychiatry  
Dalla Lana School of Public Health  
University of Toronto  
555 University Avenue, Toronto, Ontario M5G  
1X8, Canada

Tel.: +1 416-813-8469  
Fax: +1 416-813-7258

E-mail: [katherine.boydell@sickkids.ca](mailto:katherine.boydell@sickkids.ca)  
URL: <http://www.sickkids.ca/>



*Brenda M. GLADSTONE* is an adjunct lecturer in the Lawrence S. Bloomberg Faculty of Nursing at the University of Toronto where she teaches graduate courses in qualitative methodology. She is also a research manager at the Community Health Systems Resource Group at the Hospital for Sick Children. Her research involves the use of critical discourse analysis and ethnography with respect to children of parents with a mental illness.

Contact:

Brenda M. Gladstone  
555 University Avenue  
Toronto, Ontario M5G 1X8  
Canada

E-mail: [brenda.gladstone@sickkids.ca](mailto:brenda.gladstone@sickkids.ca)

*Tiziana VOLPE* is a research manager at the Community Health Systems Resource Group at the Hospital for Sick Children. Her research interests are focused on the use of photography with young people identified as at risk for developing psychosis.

Contact:

Tiziana Volpe  
555 University Avenue  
Toronto, Ontario M5G 1X8  
Canada

E-mail: [tiz\\_volpe@yahoo.com](mailto:tiz_volpe@yahoo.com)

*Brooke ALLEMANG* is a student at the University of Western Ontario with an interest in combining research and the arts.

Contact:

Brooke Allemang  
555 University Avenue  
Toronto, Ontario M5G 1X8  
Canada

E-mail: [balleman@uwo.ca](mailto:balleman@uwo.ca)

*Elaine STASIULIS* is a research manager at the Community Health Systems Resource Group at the Hospital for Sick Children. She is pursuing doctoral studies at the Institute of Medicine at the University of Toronto. Her doctoral work involves the use of institutional ethnography in the context of an early intervention for psychosis clinic.

Contact:

Elaine Stasiulis  
555 University Avenue  
Toronto, Ontario M5G 1X8  
Canada

E-mail: [elaine.stasiulis@sickkids.ca](mailto:elaine.stasiulis@sickkids.ca)

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