Health Research: Ethics and the Use of Arts-based Methods in Knowledge Translation Processes

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Abstract

In this article, we situate arts-based health research in the contextual background of evidence-based medicine, knowledge translation and qualitative health research to explain why the ethics of doing arts-based health research has received little attention until now. Then, we present an overview of the ethical issues reported in scientific publications by arts-based health researchers. Finally, we discuss the utility of the literature on ethics and arts-based health research for guiding practice in this type of research.

Contextual background

Evidence-based medicine

Knowledge translation is presently a major theme in health research. The concept emerged in the aftermath of the evidence-based medicine (EBM) movement which can be traced back to the mid-1980s (Estabrooks et al., 2008). EBM aims at integrating individual clinical expertise with the best available clinical evidence from systematic research (Sackett et al., 1996). Despite forceful criticism regarding, for instance, the belief that EBM can identify "the" "rational", "decisive" (Borgerson,

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2009), "objective", and "scientific" (Britten, 2010) answer to a specific question, and that it creates the most valuable knowledge in health research (Broader, 2010; Holmes et al, 2006), EBM supporters continue to promise that standardization, certainty and consistency in practice will lead to better decision making, higher quality of care and avoidance of clinical errors (Mantzoukas, 2009).
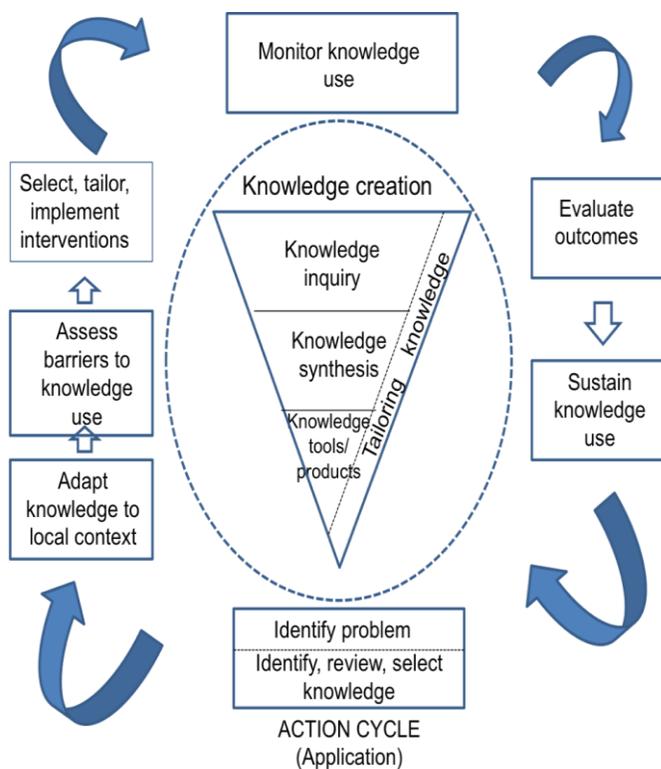
Knowledge translation

However, promises in that regard are taking time to materialize (Curran, 2011 ; Kahn, 2009). Is it due to health practitioners unawareness about availability of new evidence, their "indifference" to research-based evidence (Lewis, 2007), or is it because « something » in the process from knowledge creation to knowledge uptake is not working? For almost a decade now, knowledge translation research has been trying actively to answer these types of questions, as it studies scientifically the determinants of knowledge use and the methods to promote uptake of research findings. The process of KT is well depicted by the "knowledge-to-action framework" (*Figure 1*) designed by Graham et al. (2006), which encompasses two main components : a knowledge creation process and a knowledge application cycle made of seven action phases. Knowledge creation can come from individual research studies (e.g., a study on the validity and reliability of various tools for assessing and managing cancer pain), through the synthesis of knowledge across different studies (e.g., a systematic review of the literature on pain management in hospitalized cancer patients), or from tools allowing knowledge to be implemented (e.g., clinical guidelines on the management of pain in adult patients who have cancer). At the knowledge application stage, the attention is on identifying, reviewing, and selecting the knowledge to implement ; adapting the knowledge to the context where it will be implemented ; identifying and addressing local or system barriers to create changes ; selecting, tailoring, implementing intervention (knowledge dissemination) ; monitoring the knowledge dissemination

intervention ; assessing the outcomes/impacts of using the knowledge ; and establishing strategies to make sure that the use of knowledge will be sustained (Strauss et al., 2011).

Insert *Figure 1 : The knowledge-to-action framework*

Figure 1 : Knowledge-to-action framework (Graham et al., 2006)

It is worth noting that the concept of evidence is presented differently in the field of knowledge translation than in EBM where evidence constitutes, in most cases, the product of systematic reviews, ideally of randomized controlled trials (Nunn, 2011 ; Tricco et al., 2011). Promoters of KT rather talk about « research findings » or even more generally, refer to knowledge translation as « the process of

moving from what has been learned through research to application in different decision-making contexts » (Curran et al., 2011). If this definition can lead to believe in a broadened conception of evidence, in practice, KT adherents too implicitly promote research findings that come ideally from high-quality practice guidelines or systematic reviews (Kitson & Straus, 2009).

Despite that some authors criticize the fact that until now knowledge translation research has been rooted almost exclusively in a positivist approach (Cornelissen et al., 2011 ; Rycroft-Malone, 2007), there is no doubt that KT research is in the process of permeating the whole health research community and its practice. Most health research national funding organizations have endorsed the knowledge translation philosophy (Reimer-Kirkham et al., 2009) and use their strategic position to influence health researchers employing either a positivist or an interpretivist approach, to integrate the KT principles in their research process, for instance, when submitting grant proposals (Tetroe et al., 2008). They might require, for example, that end-users be closely involved in defining, conducting and implementing the research. Infrastructures to support the expanding field of KT, such as education and training programs, research networks, and research groups, are burgeoning across academia, and specialized publications are launched.

Given that general picture of health research, wherein quantitative research occupies a significant space, one can wonder: Then, where is the place of qualitative approaches, and more specifically of arts-based research in that context?

Development of qualitative research in the health research realm

Until the mid-1980s the way of seeing in health research was that of quantitative methods. Qualitative health research was dismissed, or at best judged, with the criteria applicable to quantitative health research. This was reflected, for instance, in the content of research textbooks published in the health sciences at that period which presented almost exclusively quantitative methodologies (Morse, 2012; Hutchison, 2001).

From the mid-1980s, qualitative health researchers became more successful at publishing their work. Their advice on the use of qualitative methodologies were highly sought-after at conferences by individuals keen about integrating these approaches in their work (Hutchison, 2001). Students and faculty members, particularly in Nursing, were more and more interested in the non-numerical approach to research and the emphasis on human experience (Morse, 2012; Hutchison, 2001). Nevertheless, at the time, qualitative experts on review panels of health research funding agencies were still rare (Wuest, 2011).

The decade 1990-2000 witnessed a greater visibility of qualitative health research in journals, at conferences, and in the curriculum of graduate programs. A critical mass of health researchers with qualitative expertise was growing.

In the last decade, qualitative researchers could not but observe that the EBM philosophy was integrated itself deeply into the health research community. Therefore some of them perceived that to be taken seriously, the truthfulness of their research findings had to be assessed with criteria similar to the ones used in quantitative research. They thus decided, for instance, to use software and have the coding and analysis of their data checked by a second researcher to show objectivity and reliability (Pope & Mays, 2004; Mauthner & Doucet, 2003). Hence, some authors feared that the very roots of qualitative research could be affected by the EBM paradigm and endanger its quality (Grypdonck, 2006). Many express discontent with having, still today, to convince people in charge of research funding, curricula and mainstream journals that their work is important and that it answers questions that quantitative research cannot address (Morse, 2012; Britten, 2010).

It is in that general context that arts-based research is entering qualitative health research with the aim of being recognized as an innovative, useful, effective, and thus legitimate means of creating and disseminating knowledge.

Arts-based health research

Arts-based research is « the systematic use of the artistic process, the actual making of artistic expressions in all of the different forms of the arts, as a primary way of understanding and examining experience by both researchers and the people that they involve in their studies » (McNiff, 2008, p. 29). It can also be defined as « a mode and form of qualitative research in the social sciences that is influenced by, but not based in, the arts broadly conceived. The central purposes of arts-informed research are to enhance understanding of the human condition through alternative (to conventional) processes and representational forms of inquiry, and to reach multiple audiences by making scholarship more accessible » (Cole & Knowles, 2008, p. 59). In the present article, we refer to arts-based health research as the use of artistic methods for research purposes in health sciences (e.g. as a knowledge creation method, as a knowledge dissemination method, as an evaluation tool for a knowledge dissemination intervention). Thus, doing arts-based health research and using arts-based methods in health studies, in the context of this article, means the same.

Arts-based research entered slowly the health research realm at the end of the 1990s-begining of 2000s. In countries such as Australia, the United Kingdom and the United States, it emerged out of a concern for evaluating arts-based programs implemented in healthcare settings or community organizations (Wreford, 2010 ; Clift et al., 2009 ; Sonke et al., 2009). Research was then done to provide evidence about the impact of arts on health. The objective was to obtain quantitative evidence of measurable change, although qualitative data could also be gathered (Clift et al., 2009). We are thus talking less here about doing arts-based research, and more about assessing with traditional methods the effectiveness of arts programs.

In Canada, the portrait differed. Arts-based methods were first introduced to represent the illness experiences of people, in particular of those living with various forms of cancer, through the production of theatrical performances (Cox et al., 2010). Since the mid 2000s, literature shows that the

use of arts-based methods in health research has increased significantly with the introduction of a broad array of artistic forms (e.g. dance, drawing, photography, poetry, song) to both create knowledge and disseminate research data (Boydell et al., 2012).

Indeed, the bulk of the literature in arts-based research describes research initiatives that used arts-based methods. Health researchers interested in arts-based research first focused on importing in health sciences artistic methods of inquiry that until then were used mainly in educational research and social sciences (Gergen & Gergen, 2011; Cahnmann-Taylor, 2008; Gray et al., 2000). They are now working at the same time to justify the importance of arts-based methods as a complement to quantitative and traditional qualitative methods promoting, for instance, the capacity unique to arts-based methods, at the knowledge creation stage, to access deep and emotional experiences (Frith & Harcourt, 2007; Clarke et al., 2005), and at the knowledge dissemination phase, to engage audiences affectively and cognitively (Fleming et al., 2009; Colantonio et al., 2008), and to reach various publics (Gray, 2003).

Arts-based researchers are currently facing the same challenges encountered by other qualitative researchers given the context described above. They must advocate for a broaden conception of knowledge, one that supplements other forms of analytical information (Washington & Moxley, 2008; Baker & Wang, 2006), ascertain that their methods generate representative and valid data (Bender et al., 2008; Colantonio et al., 2008; Furman, 2006; Gray et al., 2000), demonstrate the effectiveness of their interventions (Lafrenière & Cox, 2012; Eakin & Endicott, 2006). Further to those concerns, arts-based research needs to develop theoretically and methodologically. Indeed, the extent of the work that must be accomplished in the field is colossal, and there are relatively few health researchers involved in arts-based research. Hence, questions of form, content and legitimacy of artistic research methods have been scrutinized in the last few years, but clearly other important matters have been overlooked

(Lafrenière & Cox, forthcoming). The ethical aspects of doing arts-based research is certainly one of them.

Ethics in arts-based research

The recent reviews focusing on the use of arts in health research performed by Boydell et al. (2012) and Fraser and al Sayah (2011) served as a basis for our reflection on ethics and arts-based research. All the articles that were reviewed by these authors, and that we could access from the electronic resources of our university (n=69), plus three others (Bombard et al., 2011; Clark et al., 2011; Sinding et al., 2008) were examined in order to identify explicit content about the ethical issues encountered by researchers who used arts-based methods in health research. Indeed, the authors of nine of these 72 articles (12%) discussed ethical issues actually encountered in the course of their study. In five articles (7%) authors reported that they provided research participants with some rules to follow in the study in order to avoid ethical issues (e.g. ask permission before taking someone's picture). Authors offered comments or raised general questions on ethical issues in ten articles (14%) (e.g., "What happens when research findings are altered for theatrical or communicative effect, or when research ideas that are too hard to stage are left out?", (Eakin & Endicott, 2006, p. 57)). Thus, a total of 24 articles (33%), out of the 72 that were reviewed, actually referred to ethical issues either explicitly or implicitly. However, substantive discussions on the topic are rare. The results of this review are summarized below.

o *Ethics at the knowledge creation phase in arts-based research*

All but one of the reviewed articles (n=11) implicitly or explicitly addressing ethical issues used photographs or theatre in specific contexts to *generate* research data (which considerably differs from the use of photographs or medical imaging to document, for instance, the physical appearance of a particular disease studied in a given research project).

Several ethical issued described by the authors pertains to the protection of research participants' autonomy. Cooper and Yarbrough (2010) paid significant attention to the distribution of power between the researchers and the research participants in a "photovoice" project aimed at gathering information about health-related conditions in rural Guatemala. Photovoice is a participatory action research method in which individuals photograph their everyday health and work realities (Baker & Wang, 2006). Cooper and Yarbrough (2010) emphasized that researchers should not be giving photographs other meanings that were not intended by the photographer. If they do, they ought to make clear to others the difference between their meanings and the views originally expressed or implied by the photographer, i.e. the research participant. Truthfulness can also be an issue at stake as selection of material to include in an artistic production can alter patient meaning (Shapiro et al. 2009).

Le Clerc et al. (2002) and Oliffe and Bottorff (2007) arrange so that, in photovoice projects that they conduct, research participants can view alone and select the photographs that they took prior to showing them to members of the research team. Allowing participants to decide on the end-product (and thus on the research data) is not without creating a tension between the concept of respect for participants' autonomy, practical considerations (e.g., space or time available in a given medium), and truthfulness of the resulting data. What degree of control or power should participants have over the final arts-based work? This question uncovers the tension that exists between the researcher's ethical obligation to create a representation that will not deny participants' voices while also respecting artistic license (Cox et al., 2009; Rossiter et al., 2008 ; Sandelowski et al., 2006; Gray, 2000), research purposes and "truthfulness" of data. Simply selecting or creating text for 'dramatic impact' should be avoided (Stuttaford et al., 2006).

Other authors have addressed the concept of power from a different angle by stressing the ethical acceptability of constructing or taking pictures that could knowingly misrepresent an individual or a situation, as well as by questioning the morality of manipulating a photography with technical devices

to make a more attractive statement (Clark et al., 2010). These authors also mentioned the risks involved by such practices for the veracity or truthfulness of research data.

Besides the ethical issues raised by the protection of participants' autonomy and the truthfulness of research data, other authors reminded that researchers have the obligation not to put their research participants at risk by taking photographs in unsafe areas (Vaughn et al., 2008; Frith & Hardicourt, 2007; Baker & Wang, 2006). In addition, Cooper and Yarbrough (2010) stressed that because visuals are powerful tools of expression, researchers must be extremely cautious to preserve the dignity of those who appear in pictures.

Some ethical issues raised by the use of theatre as a means to generate research knowledge were addressed in seven of the reviewed articles. Rossiter et al. (2008) and Gray et al. (2000) explicitly acknowledged that the protection of people from harm is a concern that playwrights and researchers must have in mind when collecting, writing about, and then staging painful personal moments pertaining to experiences with illness. The risks are that both patients disclosing their experiences and members of the script development team will go through anxiety and distress during that period. They must be informed of the disturbing process that they will likely experience before deciding on engaging or not in such a project (Sinding et al., 2008; Mitchell et al., 2006).

o *Ethics at the knowledge dissemination phase in arts-based research*

The articles which explicitly addressed potential ethical issues raised by the use of arts-based methods in the knowledge dissemination phase of health research focused on the protection of participants' privacy.

Not all authors agree on how (and to what extent) participants' privacy should be protected when arts-based methods are used. Some authors claim that researchers must make sure that there are no signs in visuals which could deny individuals' anonymity and allow to identify them in the community (Boxall & Ralph, 2009 ; Vaughn et al., 2008; Oliffe & Botorff, 2007; Rich, 2000). Conversely, some

research participants question the need or even the legitimacy to be anonymised, and request to have their experiences and opinions publicly attributed to them (Clark et al., 2010 ; Poudrier & Thomas Mac-Lean, 2009 ; Sinding et al., 2002). Bombard et al. (2011) found out that contrary to what they expected about the sensitivity of showing photographs of persons affected with a degenerative disease, it was the absence of images of specific individuals that was deplored by participants of that illness community in a research findings dissemination workshop. But one may worry that participants might feel differently at a later date about letting the world know that they once experienced a particular situation (e.g. substance abuse, mental health problems). In this regard, it is worth noting that we did not identify any article that addressed the potential challenges raised by the traditional right of participants to withdraw at anytime from any research project, when arts-based methods such as theatre, for instance, are used. In any case, researchers must ensure that participants are fully aware of what they are consenting to and the potential consequences for themselves. As stressed by some authors, while participants may give consent to having their photograph taken (knowledge creation), they may not agree to subsequent presentation of those images (knowledge dissemination) (Clark et al., 2010 ; Oliffe & Botorff, 2007; Wang, 2006). These issues are particularly challenging when vulnerable populations, such as young participants or people with intellectual disability, are involved (Boxall & Ralph, 2009 ; Wang, 2006).

In the use of drama, researchers and playwrights must be conscious that the audience might be comprised of people closely related to the actors-patients-participants and that the performance might cause emotional distress or even harms to relationships depending on the subject covered (Sinding et al., 2008; Mitchell et al., 2006; Gray, 2000). Genetics-related topics are particularly delicate ones to manage. Given the familial nature of genetic information, disclosure of personal information by the actor-patient-participant might also mean disclosure of information about, or to, other family members (who can be part of the audience) (Nisker et al., 2006). If actors play their own role, the script must

avoid referring to family members or friends and to the latter's experiences with illness, in order not to infringe their privacy (Nisker et al., 2006; Stuttaford, 2006). We may suggest that the same recommendations apply for the discussion period that often follows theatre performance used in knowledge dissemination interventions.

Surprisingly, no reviewed article explicitly commented on the potential ethical issues raised by authorship when using arts-based methods, except for Clark et al. (2010) who mentioned that researchers (and research participants) should be cautious when using copyright images from magazines or from internet pages. They should make sure to give appropriate credit to the original copyright owner. While authorship is an issue sitting both on the knowledge creation and the knowledge dissemination stage of the research process, it may be particularly challenging in the latter phase. Should an artist involved in a research project keep the right to authorize the publication, performance or reproduction of his/her artistic creation (Lafrenière et al., submitted)? Indeed, attribution of authorship can become a real puzzle. Should the authorship lie with the participants who provided the raw material for the artistic piece to be created, with the artist (e.g. playwright, filmmaker, poet, writer, singer), with the artist and the development group, if sessions with fellow artists took place prior to creating the final product, or with all of the previously mentioned stakeholders?

Is literature about ethics and arts-based research useful for guiding practice?

Is the information about ethical issues such as provided in the literature useful for guiding the design and implementation of arts-based knowledge creation methods and knowledge dissemination interventions in a specific health study? We went through this reflection recently, as we are currently developing a knowledge dissemination intervention for a research project conducted in the field of nutrigenomics/nutrigenetics (Ngx). We will share some general comments on the topic without any objective of being exhaustive in our analysis as our dissemination intervention is still in the process of

being drawn up. Thus, we will briefly explain our project and comment on if, and how, the current literature can help us foresee and address the ethical issues that could arise in the implementation of our project.

The objective of our knowledge dissemination intervention is to share the results from a research project entitled: *A Foundation for Evidence-Based Management of Nutrigenomics Expectations and ELSIs*[1]. The study aims at uncovering the socio-ethical issues associated with Ngx research and its potential applications. In the first phase of this project, an extensive analysis of 173 clinical studies, published in the field of Ngx, between 1998 and 2007 inclusively, was performed. This analysis highlighted scientific challenges and significant ethical concerns in the field of Ngx (Hurlimann et al., 2011). These issues notably pertained to the potential impact *(i)* of a concentration of Ngx clinical studies in Europe and North America, *(ii)* of a focus on middle-aged populations in a majority of studies, *(iii)* of a lack of representation of ethnic minorities in such research, and *(iv)* of the current methodological limitations encountered in Ngx research on the interpretation of study results and the risks of biohype. Our knowledge dissemination intervention aims at sharing these findings with researchers in the field of Ngx and researchers in research ethics, as well as members of research ethics boards (targeted audiences). We plan to use four Web pages with a combination of interactive original cartoons and texts for that purpose. Each Web page will contain a cartoon illustrating one of the four aforementioned issues. When clicking on icons located at various positions on the cartoon, information about the study results will pop up. A « Food for thought » component will be included on each Web page for presenting the potential ethical issues associated with the findings on this theme.

Firstly, the question arose as to whether arts-based methods of dissemination could be appropriate to communicate our findings, exclusively constituted of aggregated data extracted from

[1] *A Foundation for Evidence-Based Management of Nutrigenomics Expectations and ELSIs* is a research project funded by the Canadian Institutes of Health Research and conducted at the Université de Montréal. http://www.omics-ethics.org/project.cfm?pid=23

scientific publications of Ngx studies, as well as of an analysis of their potential ethical impact. Despite numerous concrete examples on the creation and dissemination of knowledge through arts-based methods in the literature, none of them disseminated similar research data. Similarly, most ethical issues addressed in the previous section were associated with a sensitive type of data (such as personal experiences of illness) that could, for instance, generate emotional distress among participants or family members. In addition, our research project did not involve participants and the nature of our data does not raise comparable concerns as those described in the previous section in terms of protection of confidentiality or privacy.

Similarly, the ethical issues pertaining to the targeted audiences that are highlighted in the literature refer generally to publics "affected" by a specific issue, either because they were research participants in the study, because they are research participants' relatives, or because their work is closely related to the topic of the study. Furthermore, most ethical issues addressed in publications refer to publics attending a theatrical performance presented in a specific location, or a precise site where research-based visuals are displayed. In both cases, the target audience is physically present. This is not the case in our project, where Web pages will be visited by audiences who are geographically dispersed worldwide, work in diverse research areas, and in different organizational and national cultures. It is thus clear that our literature review in the field of arts-based research did not provide us with useful resources in order to foresee the potential issues associated with our targeted audiences, even though our audiences are also "affected" by the topic given that their work is closely related to the issues discussed in the dissemination intervention. The same is true to identify potential issues raised by the use of cartoons and Web pages to illustrate our findings. While some ethical challenges resulting from the use of visual methods (e.g. photovoice) are discussed in the literature, a picture and a drawing are certainly different artistic genres. We can expect that our cartoons will be scrutinized by people from different cultures, and thus by members of publics with different values and

beliefs. Is it possible to foresee how each of them will interpret the cartoons and to prevent feelings to be hurt? (E.g., in a cartoon illustrating the underrepresentation of ethnic minorities, how to represent "ethnic minorities" without hurting anyone's feelings?)

Ultimately, we could not find much information in the literature about specifics that would be readily applicable to our knowledge dissemination intervention. Clearly, we will pursue our reflection on these issues and the potential other ethical challenges that could arise in the course of our dissemination intervention.

Concluding remarks

No doubt, any research involving human beings is framed by national and international ethical guidelines that should apply in any case, including in arts-based research. Yet, it remains to be seen whether such guidelines that do not focus on or even consider the potential particularities of arts-based methods may always be appropriate or practicable given the many different contexts in which such methods may be used. The lack of resources and literature addressing ethical issues associated with arts-based methods may be problematic for researchers. It is thus important for them to add to the current knowledge and feed the debate on this topic, by explicitly addressing and documenting the ethical issues that they may encounter when conducting their study.

Clearly, arts-based health research is an emerging field that is growing in the dynamic environment of health sciences, wherein an interplay of forces (e.g. dominant EBM paradigm) and factors (e.g. quantity of arts-based researchers) interact and impact on how the field develops, according to which priorities, and at what pace. Ethics is concrete and contextual in arts-based research, just like in any type of research should we add. As seen in the review of the literature above, some research participants want to be anonymized in pictures, others not. Some want the power to participate in decisions about the conduct of the study that they enrolled in, others not. Some want to

be acknowledged for their artistic creation, others not. Context matters. We cannot limit ourselves to formulate abstract and general ethical principles. Ethical issues encountered will undoubtedly differ across contexts and they must be reported in the literature as part of the descriptive assessments of arts-based research projects. The more descriptions of arts-based projects including their ethical pitfalls, the more ethical issues critically discussed in all sorts of forums, the more effective and competent will arts-based researchers be at recognizing and reflecting upon potential ethical issues arising in their own projects.

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