



## Visualizing harm reduction: Methodological and ethical considerations



S. Switzer <sup>a,\*</sup>, A. Guta <sup>b,f</sup>, K. de Prinse <sup>c</sup>, S. Chan Carusone <sup>c,d</sup>, C. Strike <sup>e</sup>

<sup>a</sup> Faculty of Environmental Studies, York University, Toronto, Canada

<sup>b</sup> Faculty of Arts & Social Sciences, Carleton University, Canada

<sup>c</sup> Casey House Hospital, Toronto, Canada

<sup>d</sup> Department of Clinical Epidemiology and Biostatistics, McMaster University, Canada

<sup>e</sup> University of Toronto, Dalla Lana School of Public Health, Toronto, Canada

<sup>f</sup> Department of Gender, Sexuality, and Women's Studies, Simon Fraser University, Canada

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### ABSTRACT

The use of visual methods is becoming increasingly common and accepted in health research. This paper explores the opportunities and constraints of using photo-based methods in the context of a community-based participatory research study on how to engage people living with HIV in conversations about a hospital's recently introduced harm reduction policy. Using a blended approach of photovoice and photo-elicited interviews, we provided participants ( $n = 16$ ) with cameras and asked them to take a series of photos that "show how you feel about or have experienced harm reduction as a Casey House client." We reflect on methodological insights from the study to think through the process of doing photo-based work on a stigmatized topic in a small hospital setting by foregrounding: 1) how the act of taking photos assisted participants in visualizing connections between space, harm reduction, and substance use; 2) expectations of participation and navigating daily health realities; and 3) issues of confidentiality, anonymity and stigma in clinical settings. These reflections provide a case study on the importance of critically examining *the process* of engaging with photo-based methods. We conclude the paper by re-thinking issues of context and photo-based methods. Rather than viewing context as a neutral backdrop to apply a method, context should be viewed as an active force in shaping what can or cannot be done or produced within the space. Photo-based methods may offer an effective community-engagement strategy but may require modification for use in a clinical setting when working on a stigmatized topic with individuals with complex health care needs. Given the potential of visual methods as a community engagement strategy, research teams are advised to understand the entire process as a data collection opportunity so that these methods can be further explored in a variety of contexts.

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### 1. Introduction

The use of visual methods is becoming increasingly common and accepted in health research (Fraser and al Sayah, 2011; Mitchell, 2011). Photography has emerged as a particularly popular visual medium wherein researchers use images to elicit conversation with/or amongst participants; as data artefacts ripe for analysis; as a way of documenting the research process; and/or as a dissemination tool (Weber, 2008). Photography has been used in

health intervention research (Shinebourne and Smith, 2011), clinical nursing research (Riley and Manias, 2004); epidemiological research (Cannuscio et al., 2009); and community-based participatory research (CBPR) (Catalani and Minkler, 2010). However, how and why health researchers use photography varies significantly depending on the study, context, and disciplinary frames of the researchers. While there are a number of source books documenting different ways of selecting a visual method (Knowles and Cole, 2008; Margolis and Pauwels, 2011; Rose, 2012), literature merging both theoretical and applied approaches to visual methods in community-based health research is limited (for a notable exception see Castleden et al. (2008) and Drew and Guillemin (2014)), especially when it comes to CBPR in clinical spaces.

\* Corresponding author. Faculty of Environmental Studies, HNES 137, York University, 4700 Keele St, Toronto, ON M3J 1P3, Canada.

E-mail address: [switzers@yorku.ca](mailto:switzers@yorku.ca) (S. Switzer).

Systematic reviews on arts-based methods in health research (Boydell et al., 2012; Catalani and Minkler, 2010; Fraser and al Sayah, 2011) have noted that researchers employing visual or arts-based methods often fail to describe how they arrived at methodological decisions, leading to a field that Fraser and al Sayah describe as lacking “theoretical clarity.” Similarly, as Mitchell (2011) explains in a chapter on *looking at looking*, studies using visual methods most often report on the “products” of research or the stories embedded in the art work (e.g., this is what the photos show us) however, community-based visual researchers should be encouraged to examine the way participants engage with photographs, or the act of photography itself, especially in the context of HIV CBPR where the principles of meaningful community engagement are paramount (Flicker et al., 2008; Israel et al., 1998).

This paper explores the opportunities and constraints of using photo-based methods in the context of a CBPR study on how to engage people living with HIV (PLHIV) in conversations about a hospital's recently introduced harm reduction policy. We discuss our team's process of selecting, implementing and modifying photovoice – a method in which participants are given cameras and asked to identify and represent issues and solutions in their community – with photo-elicited interviews. In particular, we reflect on key methodological insights from the study to think through the process of doing photo-based work on a stigmatized topic in a small hospital setting. We begin with a description of the research study and setting, a sub-acute HIV hospital in Toronto, Canada; our initial rationale for selecting photovoice as a methodology; and our subsequent adaptations to meet both study- and importantly, community-needs. We foreground the opportunities and constraints of engaging with photo-based methods in our study by highlighting the following: 1) how the act of taking photos assisted participants in visualizing connections between space, harm reduction, and substance use; 2) expectations of participation and navigating daily health realities; 3) issues of confidentiality, anonymity and stigma in clinical settings. Together, these methodological insights allow us to re-think issues of context when applying photography in health research. Rather than viewing context as a neutral backdrop to apply a method (are arts-based methods appropriate?), context should be viewed as an active force in shaping what can or cannot be done or produced within the space (Duff, 2007). These reflections respond to a call by Castleden et al. (2008) for researchers to thoroughly explain *how* and *why* visual methods were selected and implemented so that visual methods can be assessed for rigor.

## 2. Research setting and study

Casey House is a sub-acute 13-bed specialty hospital located in Toronto, Ontario, which provides both in-patient and home care services to people living with HIV/AIDS. The hospital has approximately 110 admissions and 140 community clients annually. Inter-professional services include sub-acute rehabilitative care (e.g., pain management), medical and psychiatric symptom control, post-hospitalization discharge support, end-of-life palliative care, respite care, and recreational therapy. For the purpose of this paper, we use ‘clients’ to refer to both in-patient and community clients. Clients admitted are typically coping with multiple medical diagnoses, complicated medication regimes and psycho-social challenges, including mental health issues, substance use and poverty. The average length of stay is 45–60 days, however, clients often return to Casey House after discharge, moving from in-patient to community client and back again (Halman et al., 2013).

In 2008, Casey House adopted a harm reduction policy to respond to an increasing number of clients who used substances and were also living with complex medical conditions, and poverty.

Core to this policy is an acceptance of substance use as an aspect of clients' lives, however, due to provincial legislation, non-prescribed illicit substance use, or misuse of prescribed medications (including administering substances by a route other than prescribed) within the hospital environment is prohibited. The harm reduction policy promotes “utiliz[ing] a range of practical strategies which are relevant to harm reduction, including: ... counseling, relapse prevention, education to maximize safety for clients, staff and environments of care, needle exchange, methadone bridging therapy, opiate replacement therapy ... and connect[s] clients to community programs that offer distribution of safer crack kits, needle exchange and naran kits” (Casey House, 2008). In 2010, Casey House invited Carol Strike and Adrian Guta to assess the feasibility of conducting a CBPR study on the impact of harm reduction at the hospital. CBPR has been identified as a promising approach that engages affected communities in the development, planning and implementation of health care interventions and policies (Israel et al., 1998; Wallerstein and Duran, 2010). We consulted with clients and staff to establish the need for a project, appropriate methods, and desired levels of engagement. Casey House has a long tradition of successfully incorporating the arts into programming and services. We used feedback from our consultations to develop a research project to investigate the feasibility of using arts-based models of engagement to explore clients' experiences of harm reduction at the hospital, and collect exploratory data to inform a larger study. At the request of clients, both formal and informal advisory structures (e.g., advisory sessions, individual consultations) were created for client input and feedback into study design and analyses.

## 3. Selecting and adapting photo-based methods

Arts-based methods are increasingly promoted as an effective strategy to engage PLHIV in research and program evaluations (Hergenrather et al., 2006; Schrader et al., 2011; Tapajos, 2003; Walsh and Mitchell, 2004). During advisory sessions, clients vocalized a strong interest in photography as a preferred art medium for the study. Because we were interested in understanding the varied (and sometimes conflicting) perspectives of clients, photo-based methods offered a potential way to help us ‘see’ how different clients understood harm reduction, and how these visually mapped onto different clinical spaces. This is not to say that meaning is embedded within an image, however, our hope was that photographs might be an accessible site on to which participants could project and interpret meaning (Drew and Guillemin, 2014).

There are many ways researchers use images within the research process; some researchers use photos taken by themselves or by participants, while others rely on secondary photographs (Prosser, 1998). There are also different ways researchers might use participant-generated images such as “photo-elicitation” (Harper, 2002), “photovoice” (Wang, 1999), or photo-production stories (Barndt, 2001). Photovoice's focus on participatory policy change and on community engagement made it an appealing methodological fit for our study. Emerging from the seminal works of Wang (1999) and colleagues (Wang and Burris, 1997; Wang et al., 2004), photovoice is a community-based participatory method which has three objectives: “(1) to enable people to record and reflect their community's strengths and concerns, (2) to promote critical dialogue and knowledge about important issues through large and small group discussion of photographs, and (3) to reach policy-makers” (Wang and Burris, 1997, p.369). While the scope of photovoice projects vary considerably, photovoice projects tend to include a capacity-building component; an iterative process of photo documentation, critical dialogue and collective analysis (most often in the form of group discussions); and last, a research

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