Social Science & Medicine 133 (2015) 77–84

Contents lists available at ScienceDirect

Social Science & Medicine

journal homepage: www.elsevier.com/locate/socscimed

Visualizing harm reduction: Methodological and ethical considerations

S. Switzer [a, *], A. Guta [b, f], K. de Prinse [c], S. Chan Carusone [c, d], C. Strike [e]

[a] Faculty of Environmental Studies, York University, Toronto, Canada
[b] Faculty of Arts & Social Sciences, Carleton University, Canada
[c] Casey House Hospital, Toronto, Canada
[d] Department of Clinical Epidemiology and Biostatistics, McMaster University, Canada
[e] University of Toronto, Dalla Lana School of Public Health, Toronto, Canada
[f] Department of Gender, Sexuality, and Women's Studies, Simon Fraser University, Canada

ARTICLE INFO

Article history:
Available online 19 March 2015

Keywords:
Canada
Photovoice
Photo-elicitation
Community-based research
Harm reduction
Hospitals
People living with HIV
Engagement

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.

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 (S. Switzer).

http://dx.doi.org/10.1016/j.socscimed.2015.03.040
0277-9536/

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. Interprofessional 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 narcan 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 policymakers" (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

design with action outcomes (advocacy, enhanced understanding of community needs and individual empowerment) (Catalani and Minkler, 2010; Gubrium and Harper, 2013).

Despite this initial fit, as we began recruitment, we learned that photovoice required significant adaptation in order to meet the needs of the community we were working with. Similar to Baker and Wang (2006)'s work with older adults who experience chronic pain, we discovered that a conventional photovoice project premised on the principles of collective dialogue and group-oriented capacity-building, while important in theory, would hinder our process. While clients expressed interest in the study, and were eager to discuss issues in groups, some clients disclosed that they did not feel they could speak openly about drug use amongst other clients because of stigma and ongoing tensions related to drug use in the house (see Strike et al., 2014). Since many clients would continue to access hospital services together following the project, photovoice's focus on group dialogue and collective empowerment became a challenge for both maintaining confidentiality and preventing potential conflict between clients during or after the study. While other photo-based projects with PLHIV have discussed the difficulty of stigma and disclosure (Teti et al., 2012) these challenges are often articulated in relation to disclosing one's HIV status *outside* the research, vs. disclosing one's status within the research (i.e., drug use). Although clients initially told us that a group-oriented approach would be useful, neither they nor we anticipated these challenges.

In response to client feedback, we adapted our research design to include a blended approach of photovoice and photo-elicitation. Developed by Collier (1957) and more recently re-defined by Harper (2002), photo-elicitation can be described as "a method in which photographs (taken by the researcher or by research participants) are used as a stimulus or guide to elicit rich accounts of psychosocial phenomena in subsequent interviews" (Frith and Harcourt, 2007, p. 1340). Commonly used in clinical nursing (Riley and Manias, 2004), photo-elicitation has been used when working with participants recovering from, or experiencing, intensive health concerns, often within clinical environments and chronic disease management (Bugos, 2014). We combined the action-oriented and community-based approach of photovoice with photo-elicited interviews to respond to early concerns about confidentiality, the stigmatizing nature of drug use and the small space. To keep the capacity-building element of photovoice, we organized two group photography sessions to orient participants to the study (and ourselves), and introduce the basics of camera operation and picture-taking. Participants were shown examples of images as a way to discuss implicit and explicit imagery, discuss ethics and photo-taking guidelines, and to strategize on how to take photos of people while preserving their anonymity. We used a multi-step informed consent process at every level of participation (first verbally by phone, then at the photo orientation, and finally at the interview). We provided participants ($n = 16$) with a disposable camera, 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." As this was a project to assess the feasibility for future work, the photovoice prompt was intentionally broad. The research coordinator arranged reminder calls to participants to assist with camera retrieval and scheduling. This helped participants stay engaged in the project and facilitated their involvement when support was needed.

Once cameras were returned, we conducted semi-structured interviews ($n = 11$) to ask participants about the meaning behind their photos, the photography process, and their understandings of harm reduction within the space. Because we were interested in the potential of the arts to engage Casey House clients in conversations about harm reduction, we asked participants to tell us what they enjoyed, or found challenging about the process, why they wanted to participate, and if they would do it again. During the interview, in order to attend to the restrictions of time, participants were provided with a copy of their photos and asked to select five photos they would like to discuss. At the request of participants, these photos were exhibited anonymously at two separate photography exhibits for staff and clients.

4. Methodological insights: opportunities and constraints of photo-based methods

4.1. Engaging with photography

Visual methods scholars often speak to the role of images in identifying details that might not otherwise be available (Pink, 2013; Weber, 2008). Images can help to capture the ineffable, helping us pay attention to things in new ways (Weber, 2008). Photo-elicited interviews facilitated our ability to capture the complexity of drug use by building trust and encouraging participation among clients on a sensitive topic. Participants also expressed a keen interest in taking photographs. While specific findings from this study are presented elsewhere (Strike et al., 2014) an examination of *how* participants engaged with photography can illustrate how the act of photography can tell us as much about a study topic as the content of the photographs and accompanied narratives (Guillemin and Drew, 2010).

Photographs taken by participants served as prompts for a range of temporal and/or spatial memories, as well as concrete, abstract, symbolic or geographic experiences (Frith and Harcourt, 2007; Van Auken et al., 2010). Whereas hospital spaces are often characterized as being clinical and sterile, participants (especially those who had accessed Casey House for years) imbued these spaces with shared meaning to become important, albeit differently understood, places (Tuan, 1977). Participants used the photos to 'walk us through' the way domestic and clinical spaces framed their thoughts on substance use and/or the harm reduction policy and how drug use was negotiated both within and outside of the hospital – either through participant's own substance use, or the substance use of other clients. While some participants may have been able to express these ideas without photographs, the photography process helped us, as researchers, to understand the spatial relationship between clinical, domestic and recreational space and the harm reduction policy from the clients' perspective. For example, one participant depicted his choices in relation to substance use through a series of images of doors and a bench – all entry points to places he had attributed

Fig. 1. Participant Photograph, door to Casey House.

Fig. 2. Participant Photograph, door to a club.

Fig. 3. Participant Photograph, back door to Casey House.

Fig. 4. Participant photograph, bench.

meaning to: the front door to Casey House (Fig. 1); a door to a nightclub (Fig. 2); the back door of Casey House (Fig. 3), the bench across from the back door where people smoke (Fig. 4); and a cemetery (not depicted). As he explained,

> This is a series of doors and choices I made, [Figs. 1–3] which door I wanted to go in. […] This is the first one, with Casey House's door [Fig. 1]. And when I chose to come in here, it was a decision to get better. […] So that was the beginning, you know, there's all the other doors, there's the one [Fig. 2] where I went, and you know, all the trouble I got into. It was a real utopia and everything you needed and didn't need came in that door.

As he continues, "This is, this is, you know my choice. I could either go through that door, or this door. And if I go through that door [the club], I'd probably end up coming out that door, which is where the morgue (Fig. 3), where the people from Casey House die, come out the back door."

Understandings of drug use were articulated through a continual negotiation as participants constructed meaning in relation to both individual photos and the relationship *between* photos and places. As this participant flipped through photos and re-arranged them on the table, he used the images to organize his interview response as he visually mapped the choices he had made in relation to substance use and his current relationship to Casey House. Here, the photo process became a way "to represent what I see": "I um, just had to think about what direction I wanted to go with. And I did. I just followed my first instinct. […] I wanted to show the process of what it did for me and my choices, since I left here. [..] I thought there was a process here of my thinking."

The photography process also helped us look at otherwise mundane objects or spaces in new ways, by identifying spaces that might otherwise go unnoticed – a tool that was important for an exploratory study. For example, the fourth photograph in this series, a bench (Fig. 4) "where I smoked, this is the back, where I could see that door ["the morgue" - Fig. 3] " and "where everybody goes and they're all screwed up on crystal and crack and everything" helped us understand the vulnerability clients faced in relation to substance use, and their chronic health issues. As he continues, "Like I'd be sitting on the bench, people are coming in to buy crack next door, or here even. […] But, you know what I mean? And people know to come there. […] And then, being sick, they take ah, they look at you a little different, right? You'd be the prey."

While photographs were often of quotidian or banal items, we must not overlook these photos for more visually interesting photos. After all, the literal content of the photograph is less important than how participants use the image to make sense of their experiences (Clark-Ibanez, 2004; Mitchell, 2011; Pink, 2013). For example, another participant took a photograph of her kitchen and her partner to represent the range of harm reduction strategies she learned at Casey House to manage her health and substance use (Fig. 5). When describing the photo, she explains,

> This is my partner who reminds me to laugh and reminds me to um, not to take myself so seriously, and he's holding a big bag of weed. That's my weed. […] My food is in here, it reminds me to eat. […] My schedule to make sure I'm on track; my art work to not forget to be creative. […] I can't be healthy if I don't eat. I won't be healthy in my mind, if I don't create. I won't be healthy in my body if I don't keep appointments. And I won't be healthy in life, if I don't remember to love.

As the participant explained, although her narrative was

Fig. 5. Participant photograph, man in kitchen.

deliberatively comprehensive, it was only when she took the photo that she realized "that's really where I have my stuff, but I just realized how much was actually in the picture." Here it is through the *act* of photographing the space (and subsequently describing and interpreting the image), that the participant was able to connect all of the elements into a cohesive narrative about how Casey House's harm reduction policy supported her health. As Radley and Taylor (2003) note in their study on space in hospital wards:

> [P]hotographs partially gained their meaning from the act that produced them; they [photographs] were not meaningful only in the sense of their pictured content. The act of photography is one separation of self from surroundings – even if only briefly – so that what is picked out defines boundaries, transitions, and preferred and disliked orderings and invocations. To be given a camera in this situation is to be invited to turn on one's setting, to objectify a relationship that one has so far been living out. To photograph things is to detach oneself from them – even for a moment – and to do this while you are in hospital is to make small breaches in one's ongoing engagement as an ill person (p. 82).

The act of photographing places and objects can provide participants with a degree of distance from their daily lives, as participants must make decisions (intentionally or unintentionally) on what to include within the frame. As another participant explained when talking about the process, "seeing each photo, there's always something different. … But they all tie in."

4.2. On participation: navigating daily health realities

Arts-based methods often require a high level of participation in the research process (Boydell et al., 2012). Methods such as photovoice may require multiple sessions (photo orientation and focus group), camera retrieval, and additional consent processes. In a systematic review by Catalani and Minkler (2010), authors note that while the scope of participation can vary in photovoice projects, studies that contain a more action-oriented approach (program or policy change) often require higher levels of participation. While community participation is understandably heralded by CBPR practitioners, the type of participation may need to be modified for clinical settings when working with participants whose illnesses limit their ability to participate in more demanding forms of data collection (i.e., long focus groups, scheduled meetings, etc.) (see also: Frith and Harcourt (2007); Baker and Wang (2006); Drew et al. (2010)). Although HIV is sometimes considered a manageable health issue in Canada, during our one year study, two of the sixteen participants passed away, and in the front hall of Casey House, a candle sits, ready to be lit for each client who passes. This is not to paint a stereotypical image of "AIDS as a death sentence" (some of our clients spoke openly about accessing Casey House services in the 80's) but rather, to illustrate what complex health issues look like in our practice of CBPR. Participants' unanticipated appointments, ongoing substance use and fluctuating levels of wellness often resulted in re-scheduling interviews, working around other appointments and strategizing with participants on accessible transportation and photo-taking. Photo-elicited interviews (vs. photovoice's group-oriented approach) not only allowed us to tailor research activities to appropriate participation levels, but allowed us to work individually with participants to attend to specific needs (i.e., competing medical appointments).

Photo-elicited interviews have also been identified as a way to bridge cognitive limitations, as participants can use photographs to prompt their memory and "show" while also tell (Erdner and Magnusson, 2011; Lorenz, 2011). In interviews, photographs acted as tangible artifacts and a sparking point for discussion as they were passed back and forth between participant and interviewer, turned around, and sorted on the table with other photos. Given some of the cognitive, mental and physical health challenges experienced by Casey House clients, the accessibility of our method was a key concern. Individual interviews also provided us with extra time to (re-)assess consent. Many participants were very creative in their use of photography to articulate their understandings and concerns about harm reduction, and spoke to the usefulness of the method. However, while photos could spark a story or bring a conversation back on track, for some participants struggling with cognitive limitations, the task of articulating a link between their photos (concrete representations of their daily lives) and the harm reduction policy (an approach implemented by the hospital) was a struggle. For this reason, some interviews yielded richer data (at least for our purposes) than others. This discrepancy in interview data has been noted by other researchers as a limitation of photo-based methods (Castleden et al., 2008; Drew et al., 2010).

While clinicians recommended over-recruiting to deal with high levels of attrition commonly associated with hospital programming, unexpected issues such as the weather inhibited participation. Despite unseasonably warm temperatures that winter, participants frequently referenced the weather as providing challenges for taking photographs, or getting to interviews. The holidays – a difficult time for many individuals struggling with poverty, mental health issues and social isolation – also provided barriers to participation. Several participants talked about their health restricting them from taking photos due to feelings of personal safety (e.g., a place where someone had used substances) or not being able to lift objects for their photos. To respond to these challenges, we asked participants what was missing in the photos, or if there were any photos they wanted to take but could not. Here, as forms of data, photographs become tools for what was both present and absent (Mitchell, 2011). Similar to Teti et al. (2012), the research coordinator also strategized with participants around places they could go, or alternate images they could take where their safety was not a concern. Nonetheless, similar to studies by Radley and Taylor (2003) and Frith and Harcourt (2007), participants expressed that they enjoyed taking photos, and that it gave them something to do at a time when illness limited other social activities. This is particularly important (and should not be underemphasized) given feelings of isolation experienced by participants who were struggling with their health and had limited mobility in winter months.

4.3. Confidentiality, anonymity and stigma

Arts-based methods, such as photovoice and photo-elicitation complicate traditional understandings of confidentiality and consent (Clark et al., 2010; Gubrium et al., 2013). First, they often require additional consent processes (i.e., photo release) that increase research burden on already marginalized communities. Second, participants may take photographs of people who have not provided consent, or may photograph illicit or illegal activity. As many visual scholars note, the possibility of complete anonymity is a challenge in visual research and researchers should acknowledge the possibility that someone may recognize an individual or space in a photo – despite participants' or researchers' best intentions to conceal identities (Clark et al., 2010; Gubrium and Harper, 2013). During the photo orientation, research team members provided participants with guidelines such as not taking photos of people, or activities that could depict illegal activity. While in some cases participants disregarded (or forgot) these guidelines and photographed people (Fig. 5), these 'slips' were somewhat expected. Without consent to reproduce images, researchers must choose to

either eliminate the photo (which may cause conflict if the photo is important to the participant) or blur faces in attempt to conceal an individual's identity. Representation of pixilated images can cause more harm, as pixilation might unintentionally connote illegal or stigmatizing activity (Bagnoli, 2009). Blurring photographs can also remove evocative details that are often the strength of photo-based methods. Given that people who use drugs are already highly stigmatized, the blurring of (Fig. 5) was not an option, and speaks to the complications of anonymity and regcognizability in practice. Photographs are more than their content, and must be understood within a larger system of circulation and the context of looking (Hall, 1997; Mitchell and Allnutt, 2007).

Third, the aims of photovoice projects can be a challenge when discussing issues that may evoke conflict or stigma within a group. Participatory visual methods like photovoice may not be appropriate for studies that explore sensitive issues within communities, and where conflicts may arise *during or after* the research has been completed. Because not all Casey House clients used drugs, or were open about their drug use, the sensitive nature of the research and the intimate nature of the space complicated the way the research was framed, discussed, and implemented. Long and recurring in-patient stays and regular in-house programming for community clients meant that what might be disclosed within a photovoice session could cause tension or conflict outside the study. Given this backdrop, it was important to select a medium that provided participants with some degree of control over the process. Photo-elicited interviews provided participants with control over *what* photographs to take, *when and how* to take them (Frith and Harcourt, 2007; Oliffe and Bottorff, 2007; Radley and Taylor, 2003) as well as which photographs they would describe in the confidential space of an interview (vs. the shared space of a focus group). Interviewers asked open ended questions to help participants narrate/explain photos such as "Tell me about this photo" versus pre-determined interview questions about the harm reduction policy and/or drug use. This not only allowed participants to set the agenda for what was discussed, but broke down the question and answer format of a traditional interview where researcher (as 'expert') is set-up to ask the questions (Lapenta, 2011). In this way, the photo-elicited interview model of our study matches well with some of the principles of CBPR, in building trust, and allowing participants to identify and define priorities in relation to their health (Teti et al., 2012).

Last, photo-based projects in hospitals can add additional complications in relation to anonymity and space. The issue of anonymity of clinical spaces was raised by Radley and Taylor (2003) who describe challenges experienced in a hospital-based photo-elicitation study about patient recovery from surgery or illness. In their study, hospital administration was concerned with photographing a hospital space. The team resolved this issue by asking hospital administration to pre-approve the spaces/objects participants' wanted to photograph and then accompanying participants' in taking the photos. In our project, we were not constrained in this manner. Provided participants did not take photos of other clients, the administration did not have any concern with participants photographing clinical areas. Instead, we experienced challenges with the blurring of community clients' domestic space versus clinical space. Initially we envisioned the clinical space to be bound only by the physical geography of the hospital. It was only after community clients took photos in their homes, that we realized issues of confidentiality and clinical care could become compromised *outside* of the hospital. Since Casey House delivers clinical care in home environments, photos of participants' homes and any associated interview data became instantly recognizable to clinicians who had visited these participants in their homes. Since many of the community clients are unable to leave their homes due to concerns around mobility and the weather, asking participants to take photographs outside of their homes was not always an option. This presents a particular challenge for health researchers interested in using photo-based methods with people experiencing complex health issues on home-based clinical services. To resolve this issue, the research coordinator contacted each of the participants following the interview, described the way their anonymity might be compromised by images of their home, and asked participants if they wanted to re-visit the conditions of their photo consent (e.g., images removed from any public or staff exhibition). This step was in addition to a thorough photo release process that researchers and participants signed off on during the interview.

5. Discussion

These methodological insights offer a case study on the complexity of image-based research in clinical settings, and the importance of applying a "situated visual ethics" (Clark et al., 2010) that takes into account many of the contextual factors that frame this work. Duff's (2007) work on the importance of theorizing context when thinking about drug use spaces is useful when applied to visual methods. Duff argues that researchers often speak to context in descriptive vs. theoretical terms. Citing the work of Thrift, he argues that context is often described structurally, as an "impassive backdrop to situated human activity" (qtd. on p. 506). In contrast, a post-structural approach to context may

> view context as "a necessarily constitutive element of interaction, something active, differentially extensive" (Thrift 1996, p. 3). This approach insists that contexts are never merely the passive and malleable product of exogenous forces, but rather embody their own constitutive and active rhythms, forces and energies (Duff, 2007, p. 506).

While the suitability of matching a method to context is widely accepted in visual methods literature, methods are often viewed as being applied *to* the context, rather than seeing context as being a constitutive element in the research. Researchers are advised to remember that photo-based methods, their processes and products will not only be constrained by the larger research context (e.g., a hospital, harm reduction, PLHIV) (Guillemin and Drew, 2010), but also constitutive of these constraints. There is no prescriptive recipe for doing visual research in hospitals, or on stigmatized issues, and any study using photo-based methods will need to understand context as not just being a neutral backdrop, but as something that actually shapes or influences the research process. In our study, issues of stigma, the small hospital setting and participants' daily realities all interacted to shape the way participants were able to engage with the photography process and the research.

In hindsight, we learned that many more questions need to be asked and answered about the study population, the desired/required level of participation, frequency and duration of participation, and group advocacy intentions to best determine if and what photo-based methods are to be used. We also learned how context and spatial relations will effect how participants and researchers engage with visual methods. Once modified, photovoice served as an effective community engagement tool for research on a sensitive topic. Participants expressed a keen interest and enjoyment in taking photographs, vocalized the importance of the project in sparking dialogue on an important issue, and often discussed the project at subsequent research events. Photo-elicited interviews also facilitated participants' control and confidentiality over the data collection and interview process, and assisted research team members in unearthing new ways of thinking about the study topic.

However, despite participants strong interest in photography and the research team's commitment to modifying study methods to address barriers to participation, the added elements of visual research (photo-consent, camera retrieval, multiple sessions) were too demanding for some clients – particularly more marginalized clients who were actively struggling with advanced HIV and substance use. While a larger sample size may have helped us work around the range of complex health needs of clients, this is a clear limitation of photo-based methods, as it meant these important voices were not captured by the study. These challenges are not unique to our study, and are reflected in other arts-based projects when working with participants with complex health care issues (Cabassa et al., 2013; Lorenz, 2011; Schrader et al., 2011). Challenges concerning confidentiality in small spaces, temporal or seasonal barriers, and stigmatized topics may also apply to research projects employing more conventional data collection tools. When engaging participants who are chronically-ill, added supports and flexibility need to be introduced for project logistics; consent; communication between participants and research team members; mobility issues and confidentiality. These may extend the length of research projects in ways that can threaten the feasibility (and completion) of arts-based projects that are not sufficiently resourced.

Studying *how* participants engage with a particular method can shed valuable insights on the topic being studied. In her text, *Doing Visual Research*, Mitchell (2011) reminds us that community-based visual research must always balance community rights and responsibilities with protection and advocacy. Here, researcher reflexivity to ethical issues, the production process, and what she describes as the "pedagogy of visual ethics" is crucial – especially when doing research that could cause controversy or harm. Without an awareness of this larger social context, participatory visual methods – because of their attention to collective dialogue – can actually augment community tensions or micro-politics within a setting (Low et al., 2012; Prins, 2010). In our project, regular team meetings, detailed field notes, and continuous consultation with clients allowed us to reflect on and adapt our photo-based process. Participatory visual methods, such as photovoice, are just the ends, not the means to creating collaborative research relationships (Gubrium and Harper, 2013), and researchers may want to reflect on the range of ways power plays out in CBPR (Guta et al., 2014). Drawing on both the literature and our own experiences, we identify questions researchers might consider when assessing the use of photo-based methods for their study (Fig. 6).

6. Conclusion

Literature on participatory visual methods has been critiqued for being too descriptive (Drew and Guillemin, 2014) and not critically engaging with the limitations of the methods (Gubrium and Harper, 2013; Luttrell and Chalfen, 2010). Understanding both the opportunities and constraints of photo-based methods are essential when researchers are considering the appropriateness of a method for a study. The above methodological insights reinforce the importance of not just attending to the content and narratives that accompany photographs, but rather, the entire process of engagement with photography: the act of taking photographs (and the visualizations and breaches of engagement that ensue); issues of participation; and issues of confidentiality, anonymity and stigma. Researchers are also wise to document the process of selecting, implementing and modifying methodological decisions. This contributes to photo-based research that can be more readily evaluated for its rigor, and will expand the possibilities (and limitations) of using photo-based methods in a range of settings and research contexts.

Project Phase	Questions for Consideration
Method Selection	• Why do you want to use photographs? • Is the community interested in photography? • How will you balance the importance of participation with participants' capacities and needs? • Considering resources, project focus, and feasibility, which photo-based methods are suitable for your project? • Does the method involve participation in collective dialogue? Will community members feel comfortable discussing this issue with others, or disclosing their identity/practices to others within the research? • Do you have the experience on your team to use this method? • What are the constraints of this method?
Implementation	• What does the selected method require of participants (e.g. time, resources, energy levels)? • How much do participants want to participate? Have you asked them? • How do you create opportunities for participation (e.g. advisory board, data collection, analysis, dissemination) that are commensurate with the project *and* community's resources? • How can you include what people cannot photograph? Is there a way to include this into the interview or focus group guide? • What challenges might you encounter in relation to confidentiality, anonymity and space? How can you account for this in your project?
Modification	• What processes will you enact with your team and/or your REB to be able to attend to ethical or methodological challenges as they arise? • How can you proactively structure your project to attend to unanticipated changes or challenges? • How will you document these issues throughout the process?
Analysis	• What can you learn about your research question by focusing on process of engagement? • How do participants make sense of the process of taking photos? Did the act of photography yield any insights about the subject? • What do photographs exclude? What is missing in photographs?

Fig. 6. Methodological considerations for researchers considering participant-generated photo-based methods.

Acknowledgments

Thank you to Casey House clients who shared their time, photographs and voices on this project and to Casey House staff for providing extra project support and feedback for the project – including Bill O'Leary. Sarah Flicker and Ciann Wilson provided generous feedback on this paper. Funding support provided by Ontario HIV Treatment Network (CBR G68); Knowledge exchange funding from the Evidence Exchange Network for Mental Health and Addictions, Centre for Addiction and Mental Health. Sarah Switzer is supported by the Elia Scholars Program, York University. Adrian Guta is supported by a Canadian Institutes of Health Research (276123) postdoctoral fellowship.

References

Bagnoli, A., 2009. Beyond the standard interview: the use of graphic elicitation and arts-based methods. Qual. Res. 9, 547–570.
Baker, T.A., Wang, C.C., 2006. Photovoice: use of a participatory action research method to explore the chronic pain experience in older adults. Qual. Health Res. 16, 1405–1413.
Barndt, D., 2001. Naming, making and connecting: reclaiming lost arts—the pedagogical possibilities of photo story production. Particip. Pract. Adult Educ. 31.
Boydell, K.M., Gladstone, B., Volpe, T., Allemang, B., Stasiulis, E., 2012. The Production and Dissemination of Knowledge: A Scoping Review of Arts-based Health Research (Forum Qualitative Sozialforschung/Forum: Qualitative Social Research).
Bugos, E., 2014. Practical guidance and ethical considerations for studies using photo-elicitation interviews. Prev. Chron. Dis. 11.
Cabassa, L.J., Parcesepe, A., Nicasio, A., Baxter, E., Tsemberis, S., Lewis-Fernandez, R., 2013. Health and wellness photovoice project: engaging consumers with serious mental illness in health care interventions. Qual. Health Res. 23, 618–630.
Cannuscio, C.C., Weiss, E.E., Fruchtman, H., Schroeder, J., Weiner, J., Asch, D.A., 2009. Visual epidemiology: photographs as tools for probing street-level etiologies. Soc. Sci. Med. 69, 553–564.
Castleden, H., Garvin, T., Nation, Huu-ay-aht First, 2008. Modifying photovoice for community-based participatory indigenous research. Soc. Sci. Med. 66, 1393–1405.
Catalani, C., Minkler, M., 2010. Photovoice: a review of the literature in health and public health. Health Educ. Behav. 37, 424–451.
Clark, A., Prosser, J., Wiles, R., 2010. Ethical issues in image-based research. Arts Health 2, 81–93.
Clark-Ibanez, M., 2004. Framing the social world with photo-elicitation interviews. Am. Behav. Sci. 47, 1507–1527.
Collier Jr., J., 1957. Photography in anthropology: a report on two experiments. Am. Anthropol. 59, 843–859.
Drew, S.E., Guillemin, M., 2014. From photographs to findings: visual meaning-making and interpretive engagement in the analysis of participant-generated images. Vis. Stud. 29, 54–67.
Drew, S.E., Duncan, R.E., Sawyer, S.M., 2010. Visual storytelling: a beneficial but challenging method for health research with young people. Qual. Health Res. 20, 1677–1688.
Duff, C., 2007. Towards a theory of drug use contexts: space, embodiment and practice. Addict. Res. Theory 15, 503–519.
Erdner, A., Magnusson, A., 2011. Photography as a method of data collection: helping people with long-term mental illness to convey their life world. Perspect. Psychiatr. Care 47, 145–150.
Flicker, S., Savan, B., Kolenda, B., Mildenberger, M., 2008. A snapshot of community-based research in Canada: who? what? why? how? Health Educ. Res. 23, 106–114.
Fraser, K.D., al Sayah, F., 2011. Arts-based methods in health research: a systematic review of the literature. Arts Health 3, 110–145.
Frith, H., Harcourt, D., 2007. Using photographs to capture Women's experiences of chemotherapy: reflecting on the method. Qual. Health Res. 17, 1340–1350.
Gubrium, A.C., Harper, L., 2013. Participatory Visual and Digital Methods. Left Coast Press, Walnut Creek, CA.
Gubrium, A.C., Hill, A.L., Flicker, S., 2013. A situated practice of ethics for participatory visual and digital methods in public health research and practice: a focus on digital storytelling. Am. J. Public Health e1–e9.
Guillemin, M., Drew, S., 2010. Questions of process in participant-generated visual methodologies. Vis. Stud. 25, 175–188.
Guta, A., Strike, C., Flicker, S., Murray, S.J., Upshur, R., Myers, T., 2014. Governing through community-based research: lessons from the Canadian HIV research sector. Soc. Sci. Med. 123, 250–261.
Hall, S., 1997. Representation: Cultural Representations and Signifying Practices. Sage.
Halman, M., Chan Carusone, S., Stranks, S., Schaefer-McDaniel, N., Stewart, A., 2013. Complex care needs of patients with late-stage HIV disease: a retrospective study. AIDS Care 26, 320–325.
Harper, D., 2002. Talking about pictures: a case for photo elicitation. Vis. Stud. 17, 13–26.
Hergenrather, K., Rhodes, S., Clark, G., 2006. Windows to work: exploring employment-Seeking behaviors of persons living with HIV. AIDS Educ. Prev. 18, 243–258.
House, Casey, 2008. Casey house approach to harm reduction: harm reducation and policy implementation Plan. In: Hospital, C.H. (Ed.). Toronto.
Israel, B.A., Schulz, A.J., Parker, E.A., Becker, A.B., 1998. Review of community-based research: assessing partnership approaches to improve public health. Annu. Rev. Public Health 19, 173–202.
Knowles, J.G., Cole, A.L. (Eds.), 2008. Handbook of the Arts in Qualitative Research : Perspectives, Methodologies, Examples, and Issues. Sage Publications, Los Angeles.
Lapenta, F., 2011. Some theoretical and methodological views on photo-elicitation. SAGE Handb. Vis. Res. Methods Lond. 201–213.
Lorenz, L.S., 2011. A way into empathy: a 'case' of photo-elicitation in illness research. Health (London) 15, 259–275.
Low, B., Rose, C., Salvio, P., Palacios, L., 2012. Re:framing the scholarship on participatory video: from celebration to critical engagement. In: Milne, E.-J., Mitchell, C., De Lange, N. (Eds.), Handbook of Participatory Video. AltaMira Press, Lanham, Maryland, pp. 49–64.
Luttrell, W., Chalfen, R., 2010. Lifting up voices of participatory visual research. Vis. Stud. 25, 197–200.
Margolis, E., Pauwels, L., 2011. The SAGE Handbook of Visual Research Methods. SAGE, Los Angeles.
Mitchell, C., 2011. Doing Visual Research. SAGE, Los Angeles.
Mitchell, C., Allnutt, S., 2007. Photographs and/as social documentary. In: Cole, A., Knowles, J.G. (Eds.), Handbook of the Arts in Qualitative Research, pp. 251–263.
Oliffe, J.L., Bottorff, J.L., 2007. Further than the eye can see? Photo elicitation and research with men. Qual. Health Res. 17, 850–858.
Pink, S., 2013. Doing Visual Ethnography. Sage Publications, Thousand Oaks, CA.
Prins, E., 2010. Participatory photography: a tool for empowerment or surveillance? Action Res. 8, 426–443.
Prosser, J., 1998. Image-based Research : a Sourcebook for Qualitative Researchers. Falmer Press, London ; Bristol, PA.
Radley, A., Taylor, D., 2003. Images of recovery: a photo-elicitation study on the hospital ward. Qual. Health Res. 13, 77–99.
Riley, R.G., Manias, E., 2004. The uses of photography in clinical nursing practice and research: a literature review. J. Adv. Nurs. 48, 397–405.
Rose, G., 2012. Visual Methodologies : an Introduction to Researching with Visual Materials. London. Thousand, Oaks, Calif.: SAGE.
Schrader, S.M., Deering, E.N., Zahl, D.A., Wallace, M., 2011. Visually storying living with HIV: bridging stressors and supports in accessing care. Health Educ. Res. 26, 638–652.
Shinebourne, P., Smith, J.A., 2011. Images of addiction and recovery: an interpretative phenomenological analysis of the experience of addiction and recovery as expressed in visual images. Drugs: Educ. Prev. Policy 18, 313–322.
Strike, C., Guta, A., de Prinse, K., Switzer, S., Chan Carusone, S., 2014. Living with addiction: the perspectives of drug using and non-using individuals about sharing space in a hospital setting. Int. J. Drug Policy 25, 640–649.
Tapajos, R., 2003. HIV/AIDS in the visual arts: applying discipline-based art education (DBAE) to medical humanities. Med. Educ. 37, 563–570.
Teti, M., Murray, C., Johnson, L., Binson, D., 2012. Photovoice as a community-based participatory research method among women living with HIV/AIDS: ethical opportunities and challenges. J. Empir. Res. Hum. Res. Ethics 7, 34–43.
Tuan, Y.-F., 1977. Space and Place: the Perspective of Experience. U of Minnesota Press.
Van Auken, P.M., Frisvoll, S.J., Stewart, S.I., 2010. Visualising community: using participant-driven photo-elicitation for research and application. Local Environ. 15, 373–388.
Wallerstein, N., Duran, B., 2010. Community-based participatory research contributions to intervention research: the intersection of Science and practice to improve health equity. Am. J. Public Health 100, S40–S46.
Walsh, S., Mitchell, C., 2004. Artfully Engaged: Arts Activism and HIV/AIDS Work with Youth in South Africa. Provoked by Art : theorizing arts-informed research pp. 191–202). Toronto, Ont.: Backalong Books/Centre for Arts-informed Research.
Wang, C., 1999. Photovoice: a participatory action research strategy applied to Women's health. J. Women's Health 8, 185–192.
Wang, C., Burris, M.A., 1997. Photovoice: concept, methodology, and use for participatory needs assessment. Health Educ. Behav. 24, 369–387.
Wang, C., Morrel-Samuels, S., Hutchison, P.M., Bell, L., Pestronk, R.M., 2004. Flint photovoice: community building among youths, adults, and policymakers. Am. J. Public Health 94, 911–913.
Weber, S., 2008. Visual images in research. In: Cole, A.L., Knowles, G. (Eds.), Handbook of the Arts in Qualitative Research. Thousand, Oaks, California: SAGE, pp. 41–53.