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Treena Orchard

Remembering the Body

Ethical Issues in Body Mapping Research

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This book is dedicated to the women and men whose lives and artful creations are featured in these pages.

We'd talk
Or sit silently
And listen to our thoughts
Illusions of someday
Casting a golden light
No dress rehearsal
This is our life.

The Tragically Hip- Ahead by a Century (1992).

Acknowledgements

Writing this book has been a labour of love and trepidation, which in the original Latin context refers to both fear and 'trembling movement.' Throughout the process I have been concerned about capturing lives of the women and men, whose experiences and artful expressions constitute the data upon which this book is based, fully and with sufficient 'truth' or clarity. These feelings run through most creative endeavours and in this instance they kept me thinking, albeit somewhat 'trembly' at times, and actively remembering the powerful things they shared with myself and the other team members during the research. I am deeply grateful to the six women in Vancouver, British Columbia, and five men in London, Ontario, who engaged in this intense experience with courage, dedication, good humour, and astonishing strength. Their body maps are moving testaments to the systemic and everyday challenges they have encountered, and often continue to face, and they also capture the beauty, love, and hope that colour their lives.

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About the Author

Treena Orchard is Associate Professor in the School of Health Studies and Affiliate in Women's Studies and Feminist Research at Western University in London, Ontario, Canada. An anthropologist with cultural and medical expertise, she has conducted ethnographic research with women in sex work, people with HIV/AIDS, Indigenous populations, and those of sexual minority status across Canada and in India. Her areas of special research interest include sexuality and sex work, gender, marginalization, and the politics of health and her work has been published in academic journals such as *Social Science & Medicine*, *Culture, Health & Sexuality*, *Critical Public Health*, and *Anthropologica*. She has delivered over 75 conference papers, is regularly consulted by international journals and funding bodies for her expertise as a peer reviewer. She is also involved in local and national activism related to the rights of women and other marginalized populations and had her first poem published in 2014 in a collection by the Poetry Institute of Canada, *From the Cerulean Sea* (National Library of Canada, Ottawa). Treena lives in London, Ontario with her two cats Shiva and Mr. Marbles, who provide much love and grounded support in the navigation of the everyday.

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Abstract

This book explores body mapping, an arts-based methodology that originated in the Global South as a means of community mobilization and advocacy regarding women's reproductive health and HIV-related care needs. Increasingly popular with qualitative researchers, health practitioners, and community agencies, the unique challenges and benefits of employing body mapping in diverse research and cultural settings have not yet been examined. Using data from an ethnographic study with HIV-positive women and men who struggle with addictions, HIV stigma, and historical traumas stemming from colonialism in two Canadian cities, the author analyzes three key issues that shaped the body mapping research experience for the participants and herself as a researcher. Chapter 1 discusses the emergence of the approach and its operationalization in different research settings. Chapter 2 provides an overview of the research project upon which this book is based and participants' perspectives on body mapping. Chapter 3 focuses uses on the problems associated with the lack of a systematic framework to analyze body mapping data. Chapter 4 explores the powerful effects of this research approach on study participants and herself as a researcher and seeks to make theoretical sense of this transformative experience. Chapter 5 examines the cultural appropriation of body mapping by different researchers and community practitioners and its implications for participants' well-being and the integrity of the methodology. The author offers unique and useful insights to address these important ethical issues, with an eye to further refining the approach, ensuring the safety of those taking part, and contributing to research that is culturally respectful.

Chapter 1
Introduction

> *Nothing is materially hidden and the creative process is fully available, yet the whole is not perceived at any one time. These paintings rely on a process of looking and remembering.*
>
> Tiffany Bell (2015: 27)

Artful Research and Ways of Being: Opening the Space

The growing interest in arts-based methodologies in research, therapeutic practice, and community settings signals a shift in how we approach the elicitation of human experience, knowledge generation, and use the arts to infuse these facets of life with uniquely powerful meaning and purpose. Arts-based methods include poetry, narratives, music, dramatic performance, dance, and a range of visual arts (i.e., photography, film, drawing, painting) that are employed in various academic and applied fields, including health, psychology, anthropology, education, talk and cognitive therapy, as well as community mobilization and activism (Boydell et al. 2012; Fraser and al Sayah 2011; Futch and Fine 2014; Guillemin 2004; Ingold 2011; Knowles and Cole 2008; Kontos and Poland 2009; Leavy 2009; Pink 2001). The rising popularity of these approaches coincides with increased scholarly interest in the interiority of human experience and subjectivity (Hogan and Pink 2010), embodied forms of expression, sensory research (Pink 2009; Rice 2013), and our increasingly 'visual' global culture (Rose 2014; Spencer 2011). With a focus on small-scale, intimate interactions that open up new creative spaces within which to understand the experience of being in the world, arts-based methods can be used to challenge the boundaries imposed by traditional research paradigms, especially quantitative projects that depend on large samples and multiperson/site teams. They can also disrupt the unequal power relations that structure many research studies given the focus on participant-generated data, versus researcher-driven methods; thus producing research experiences that can be emancipatory and more closely represent participants' lives.

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As the field of arts-based research takes shape certain approaches have risen to prominence, especially those involving art practices that are well-defined methodologically and more easily accessible to participants (i.e., telling a story or painting a picture). Photography, in particular the method of Photovoice,[1] is the most commonly used arts-based approach and studies employing this technique dominate the research literature (Guillemin and Drew 2010; Hartman et al. 2011; Wang and Redwood-Jones 2001). An exciting approach with potentially empowering outcomes, the insights gleaned from Photovoice projects are somewhat unique to this methodology and may not be applicable to researchers or others interested in using different arts-based methods. This is particularly true in projects that involve the body, as the primary and most complex medium through which we express human experience, and mapping, a multivalent technique that helps to situate, guide, and visually plot our journeys past and present.

This book is about body mapping, a unique approach that combines visual arts and therapeutic practice to guide participants in the artful communication about their embodied life experiences in ways that are safe and supportive. I used this methodology in an ethnographic study that explored how women and men living with HIV navigate their struggles with addictions, health, sexuality, gender-based violence, and historical trauma in aftermath of colonialism. This was my first time using an arts-based approach and I encountered numerous challenges as I sought to probe the depth, range, and kinds of data featured on the maps (i.e., textual, symbolic, temporal), which receive somewhat limited attention in the thematic analyses that dominate the literature. I also grappled with how to make theoretical and methodological sense of the research experience itself, which was deeply transformative for participants and myself. Questions about cultural appropriation also surfaced as I wondered about the implications of using body mapping, which was developed in the context of HIV with women from the Global South, in Canada with women and men whose lives and gendered identities differed substantially from the original participants.

I did not find answers to these questions in the body mapping or attendant arts-based literature and this book is a meditation on analysis, research experience, and cultural appropriation. These issues highlight important ethical tensions related to body mapping, which may be useful to other researchers or community groups who are interested in refining or tailoring their own artful praxis. Before turning to additional details about body mapping, ethical issues within arts-based literature, and an overview of the book I want to touch upon the act of remembering. The first part of this book is entitled ‘Remembering’ and the opening quote of the book mentions remembering. The process of recalling, remaining aware of, and thinking again about certain events, people, and things was central to the creative process the study participants engaged in, and it was integral to the conceptual steps I put

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[1] An action-oriented processes intended to be directed by participants, who take pictures of various aspects of their lives with the purpose of critically reflecting on them and working towards making positive change (Wang and Burris 1997).

myself through when trying to fully understand this research experience. Remembering can also be political, as a way to commemorate and render real that which has been silenced or oppressed, important considerations given that this book is as much about research and art as it is about HIV/AIDS—perhaps the most painful signifier of inequality of our times.

Body Mapping

Body mapping was first developed by anthropologist MacCormack (1985) in a study about fertility and the body in rural Jamaica, and it was employed to learn how women understand their reproductive systems and internal biologies. These insights shed new light on indigenous systems of embodiment and health, which had been ignored in the rural context western due to the dominance of biomedical knowledge and health practices (MacCormack and Draper 1987). Another early example is from Cornwall (1992), who used body mapping to generate conversations about sexuality, reproductive health, and anatomy with women in southern Zimbabwe, who found the exercise a safe and cathartic way to share their knowledge and raise questions about these sensitive topics. Recognizing the unique attributes of body mapping, as a way to bridge the gaps between biomedical systems, popular knowledge, and lived experience (Cornwall 2002) and provide safe, potentially empowering opportunities for people to share their embodied knowledge, many researchers, advocacy groups, and clinical practitioners have since adopted the method. Although the focus of these projects vary tremendously, they most often involve issues related to the body, health, trauma, and occupational safety among marginalized groups—primarily women (see Jager et al. 2016 for a comprehensive review).

In the context of HIV/AIDS, body mapping first emerged in Uganda in the early 1990s. At this time many women, in particular, were becoming infected with HIV and in the absence of antiretroviral medications and social supports for women and their families, the National Association of Women Living with HIV and AIDS developed an arts-based approach to respond to their needs. Envisioned as a way for women to share personal histories, memories and discuss the issues of death and succession planning with their children, they began with an outline of their bodies that served as the starting point for the women's storytelling. This arts-based approach served a vital role in the transmission of cultural and familial knowledge between women and their children, who might never otherwise learn these important things given that so many parents were taken by the virus (Ward 2006).

In 2002 South African artist Jane Solomon and psychologist Jonathan Morgan adapted the Ugandan approach and sought to use body mapping to generate stories that focused less on memorializing and more on renewed health and hope for the future. This shift was in response to changes in the HIV treatment landscape in South Africa, specifically the distribution of free antiretrovirals by Médecins San Frontiers to a select number of health clinics in the country (Coetzee et al. 2004).

Driven to celebrate this milestone and draw attention to the fact that many South Africans were still without access to these life-saving medications, Solomon and Morgan's approach combined healing activities with a political message that reflected local health inequities (MacGregor 2009). Their first body mapping initiative, the 'Long Life' Project, was conducted with 13 women from the Khayelitsha Township in Cape Town and generated significant interest from local and international researchers as well as community groups (Morgan and The Bambanani Women's Group 2003).

In response to the interest generated by their body mapping work Solomon developed a facilitator's guide called 'Living with X' (a subversion of the term 'People Living with HIV/AIDS'), which was made available online in 2007. The guide provides instruction and guidance to those leading the body mapping workshops, whose aim is to ensure that participants feel safe as they explore their lives through drawing/painting life-size pictures of themselves, talking in groups, and engaging in quiet thinking and reflection. This text is the most comprehensive resource available to guide facilitators and participants through the body mapping process and it has been used in studies focusing on HIV/AIDS (Betancourt 2015; Brett-MacLean 2009; Devine 2008; De Lange et al. 2006; Flicker et al. 2007; MacGregor 2009; MacGregor and Mills 2011; Maina et al. 2014; Nostlinger et al. 2015; Smith 2015; Smith and Miller 2015) and a range of other health issues (See Jager et al. 2016). However, 'Living with X' has since been removed from these websites because of its inappropriate use and adaptation by different agencies/researchers, many of whom did not take the time to follow the therapeutic aspect of the process and inadvertently (re)traumatized their participants (Smith, 2016). I discuss this in detail in Chap. 5, which explores the cultural appropriation of body mapping and ways to resist these troubling practices.

But what does body mapping 'looks like'? The following is an overview of what transpires in body mapping workshop using the Solomon and Morgan model. The workshops take place over four consecutive days and participants use artistic materials (i.e., acrylic paints of various colours and shades, markers, crayons, pastels, glitter) to respond to questions introduced by the facilitator. Their responses are placed on a large piece of paper measuring six feet by four feet, which is their body map. Using the 'Living with X' guideline, a trained facilitator walks participants through four or five different exercises per day, and each day begins and concludes with a check-in/out so that they can share their feelings and reflections about the workshop as it progresses. Importantly, the facilitator does not tell participants how to create symbolic images or where to put them on their maps,[2] but helps them prepare their thoughts and plan their creative expression. This

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[2] This includes a pre-mapping discussion of colour and how it can be used to convey particular events or experiences, which are recorded on a large piece of paper and hung in the mapping space during the workshop. The facilitator also shares insights about the use of symbols to capture complex experiences and provides some examples, which are also hung in the mapping space for the duration of the workshop.

supportive and mindful aspect of the approach is critical given the difficult, often traumatic experiences related to HIV and other issues that often arise.

The mapping begins with participants tracing their body outline on the six feet by four feet sheets of paper and then the outline of another participant is added, which represents a ‘support figure’—about which specific questions are asked during the workshop. These two figures, along with the background space, constitute the three distinctive layers within the maps. The next series of items marked on the map ‘emplace’ their lives within the body outline, and they include: family/place origins, memories of childhood (good and bad), life goals and ambitions, and life journeys from past to present. Participants are then asked to mark where they generate power and strength from and to reflect on emotional difficulties they have encountered, physical scars or marks on the body, and the impact of life’s stresses on their internal bodies and organs.

Specific questions regarding HIV are then asked, including what it was like to receive their HIV diagnosis, how it affected them and their loved ones, their experiences with HIV medications, how they take care of themselves, and a symbol that represents HIV. In the final stage the facilitator and attendant helpers arrange the maps within the workshop space as though it was an art gallery, and participants sit in front of their maps and receive supportive insights and comments from the others in attendance about their maps and often themselves. These comments are recorded on pieces of paper, which are then given to participants as a keepsake. During the follow-up interviews held two or three weeks after the workshops, participants create a one-page story that captures their body mapping experience and what they hope viewers ‘see’ in their maps.

Ethical Issues in Arts-Based Research

The ethical issues encountered in arts-based research are shaped by the contexts in which the projects are based (i.e., health, social work, therapeutic, community) and the kinds of art produced, and most discussions are based on projects that use photography, drawings, narratives or writing, the performative arts (i.e., plays, dance), and to a lesser degree body mapping (Fraser and al Sayah 2011). A predominant theme explored is the challenge that arts-based researchers face when trying to get their projects approved by high-ranking funders and ethics review boards, which are typically dominated by quantitative researchers and ‘hard science’ approaches to knowledge production, dissemination, and evaluation (Boydell et al. 2012; Clark et al. 2010; Leavy 2009; Wiles et al. 2008). Often faced with questions like ‘Yes, but is this research?’ (Barone and Eisner 2011: 45) or recommendations to embed the ‘artistic part’ of the study within more substantiated theoretical or methodological paradigms (Smith 2013), many researchers write about the ethical and emotional struggles they experience when trying to make their research ‘fit’ institutional parameters without sacrificing their artistic and intellectual integrity. Others have approached these issues by creating guidelines, for researchers and ethic review board members, to assist the former in manoeuvering through the review process more successfully and the latter in having a more concrete understanding of what arts-based research is and the kinds of research it generates (Cox et al. 2014).

A second theme explored pertains to the conditions in which arts-based work is produced. Unlike other qualitative methodologies, like individual interviews performed on a single occasion, many aspects of arts-based research are done collectively and involve different stages of production. In Photovoice, for instance, participants are trained in the basics of photography, camera operation, the interpretation of their images, and how to prepare them for public showings or to be used in presentations (Sutton-Brown 2014; Wang and Burris 1997). While it can be empowering and generate data that closely represents participants' lived realities, this degree of engagement can also be stressful because it adds 'work' to their already full lives (Guillemin and Drew 2010; Packard 2008). Some participants feel added pressure to measure up to the art created by other participants and may be shy or unable to discuss their lives and their work in a group setting. These issues thread through the research process, which means researchers need to check-in with participants in an ongoing way to gauge where they are at and to determine what can be adjusted to help them feel more at ease (Laliberte Rudman et al. 2016).

Ethical considerations regarding consent, confidentiality, anonymity, and ownership of the research process are also raised in arts-based studies, and while there are variations depending upon the kind of art work and populations[3] involved the basic principles of autonomy, beneficence, and non-maleficence are integral (Boydell et al. 2012; Jager et al. 2016; Leavy 2009). Operationalizing these principles according to official ethical guidelines, which typically focus on individual activities or relationships between individual participants and researchers (Clark et al. 2010), can be challenging in arts-based research because of its hybrid nature. It is a process and set of activities that involve individual creativity and group work, whereby participants develop their own creations alongside each other, provide feedback on each other's work, and contribute to the project collaboratively. Ensuring anonymity, for instance, can be difficult because while participants can ensure their art does not contain identifying information, their identity is known by others taking part who may share this information accidentally or otherwise. This does not cancel out the need for anonymity, it just means that the conversations about it and attendant issues like confidentiality need to be different. Many in the field advocate for an approach to ethics that is situated within the mutable

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[3] Referring to particular copyright and privacy laws regarding photos of people (Wiles et al. 2008), illegal activities, and especially vulnerable groups like undocumented workers (Gastaldo et al. 2012). Although rarely mentioned in the literature, literacy and the symbolism associated with official paperwork deserve ethical reflection as well given the reliance on written forms in virtually all ethical review processes—which may exclude populations who are not literature and who may associate official documents with government surveillance.

framework of arts-based research and conceived of as a set of reciprocal relations of care and support, which need to be revisited regularly with participants versus the fixed, one-size-fits-all parameters often mandated by institutional ethics review boards (Clark et al. 2010; Guillemin and Gillam 2004; Liamputtong and Rumbold 2008).

The creation of photographs, drawings, stories, and body maps that reflect people's lives and embodied identities is an intensive process that can cause participants considerable emotional strain (Boydell et al. 2012; Guillemin and Drew 2010; Jager et al. 2016; Packard 2008; Sinding et al. 2008). This is true in many kinds of research, however, it takes on special significance in arts-based research because these studies are typically conducted with marginalized populations (i.e., youth and children, those suffering with addictions, mental health, eating disorders, and other health issues). Researchers have a responsibility to know as much as possible about the lives of the people they work with and what kinds of issues can be triggering, and how to respond to these situations safely,[4] a fine line best traversed in dialogue with participants and other support staff or assistants. These responsibilities extend to the analysis and dissemination phases of a project, when researchers need to engage in discussions with participants about the potential for their work to be interpreted differently than their initial vision and how to be emotionally prepared to deal with having the work displayed publicly (Cox et al. 2014; Guillemin and Drew 2010). Finding a way to prepare audience members about the content of the work, which typically reflects 'hard life stuff' (Sinding et al. 2008: 462), has also been suggested to reduce the potential for the public or others viewing the art to be triggered or caught off-guard by the content (Chilton 2013).

Chapter Overview and Format

Although arts-based approaches are used in an array of research and community settings, the ethical challenges encountered by the researchers, artists or participants, and trainees engaged with body mapping have received very little attention (Hodgins and Boydell 2014: 4). This is important because arts-based research varies tremendously, as do the kinds of ethical issues and research experiences they engender. Taking photographs or constructing a written narrative are not only different from each other, they are quite distinct from a 4-day body mapping workshop that involves the unearthing of difficult, albeit deeply meaningful, embodied experiences and life events. Moving through the project upon which this

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[4] Above and beyond dispensing a brochure with locally available psychological services or crisis hotline phone numbers, which Smith (2012: 17) refers to as 'pamphlet knowledge'.

book is based I found myself questioning certain aspects of the body mapping methodological design. I wondered about using this approach with participants whose sexual identities and cultural backgrounds differ substantially from the women among whom the methodology was first designed. Should I ask different or new questions for men? How or should the issues of colonialism and historical trauma be approached among the Indigenous participants? Additional questions emerged during the analysis of the maps, which contain richly layered, complex symbolic and textual meanings that seemed to be largely untapped in the descriptive thematic analyses in other body mapping studies. Is there a way to more fully account for the depth and breadth of these data? The research experience itself proved to be transformative and life-changing for participants, and myself as a researcher, and I wondered how to unpack and account for this without making 'too much' of it or appearing self-aggrandizing.

Exploring these questions and thinking through the different ethical tensions they raise is the focus of this book, which contributes new theoretical and methodological insights with which to further refine body mapping as a distinctive arts-based approach in its own right. Chapter 2 begins with an overview of the research project upon which this book is based, which was a qualitative exploration of how gender and the body shape the medication practices of HIV-positive women and men who struggle with drug addictions, homophobia, racism, and other forms of social exclusion. Following a discussion of the study context, methodologies, and theoretical orientation, an overview of the study participants and their insights about doing body mapping are presented. Chapter 3 explores the analysis of body mapping data and the 'axial embodiment' approach I developed to infuse the interpretation of these data with more depth and analytical rigour.

Chapter 4 examines the transformative nature of the body mapping research process, which the participants identified as therapeutic and as generating meaningful, positive change into their lives. I also discuss how my life was changed by this project, through reference to my fieldnotes that document particularly memorable study moments. Chapter 5 focuses on cultural appropriation, namely how researchers and community agencies selectively borrow certain aspects of the methodology and rarely acknowledge the cultural context within which body mapping emerged. I also explore the topics of culture, sexuality, addictions, and trauma, which are seminal issues in the lives of our participants that impacted their body mapping work and overall research experience. These issues have not yet been addressed in the body mapping literature and I include them not because they need to be worked into the methodology, per se, but because they are important for researchers/practitioners to be mindful of in their efforts to engage in culturally sensitive and responsive work with similarly complex populations. The chapter concludes with a discussion of six particularly important lessons learned during the project, from the planning stage through to dissemination, 'real-life' insights that will be useful to others wishing to incorporate body mapping into their research, clinical, or community-based projects.

This book follows the customary academic format of incorporating research literature and theory with primary data collected in the field, and it includes suggestions for others who may be interested in doing body mapping. It also features reflexive insights about myself as a researcher and woman, primarily in Chaps. 1 and 3. There is much written about reflexivity in qualitative research, which is used as a measure of study validity and for some it seems to be opportunity to explore how the research changed them (Berger 2013; Bott 2010; Clayton 2013; Lovell 2007). Issues of quality control and self-analysis are of less interest to me than the larger political goal of pushing myself to develop and do research that is ethical, equitable, contributes new knowledge, and can enhance people's lives (Freire 2000). This is a task I was involved in alongside the men and women in this study, as a flesh and blood researcher with my own failings and particular cultural lenses through which I see the world. Instead of writing myself out of this text I adopt what Pillow (2003: 188) calls 'reflexivities of discomfort', which involve wrestling with the unfamiliar, different, and sometimes unknowable in true critical fashion.

See Maps 1.1, 1.2, 1.3, 1.4, 1.5, 1.6, 1.7, 1.8, 1.9, 1.10 and 1.11.

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Map 1.1 Abby's map

Map 1.2 Tarah's map

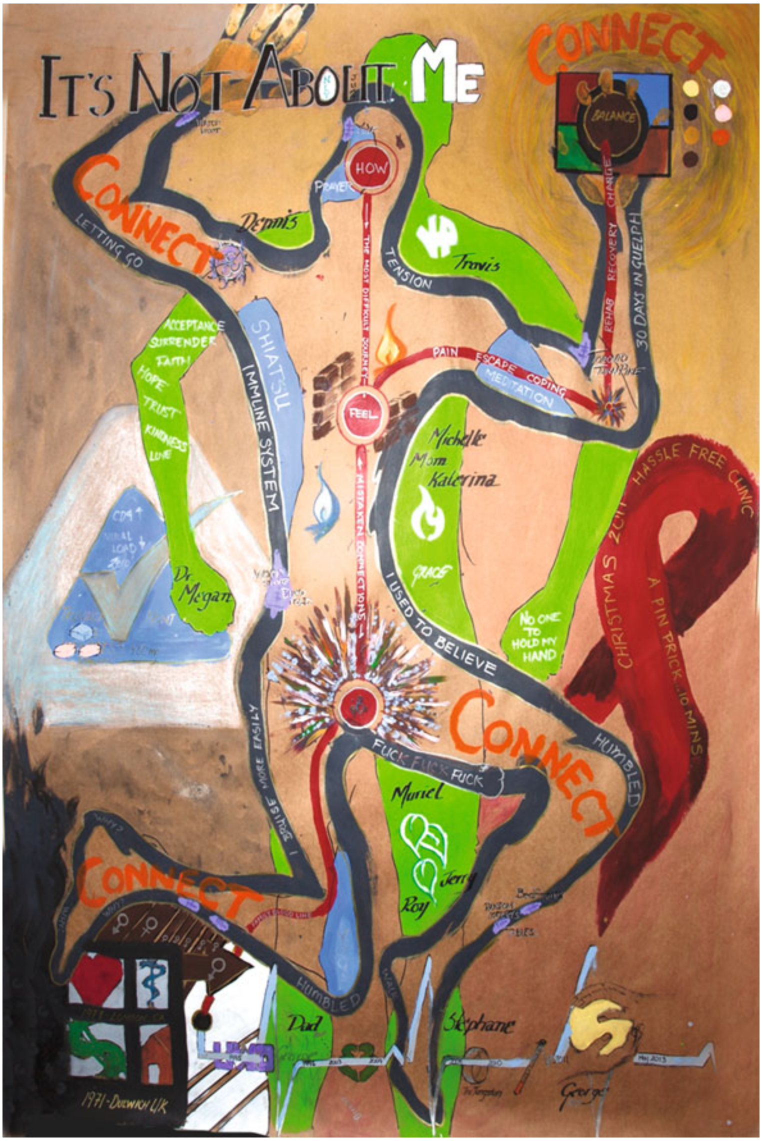
Map 1.3 Georgia's map

Map 1.4 Sue's map

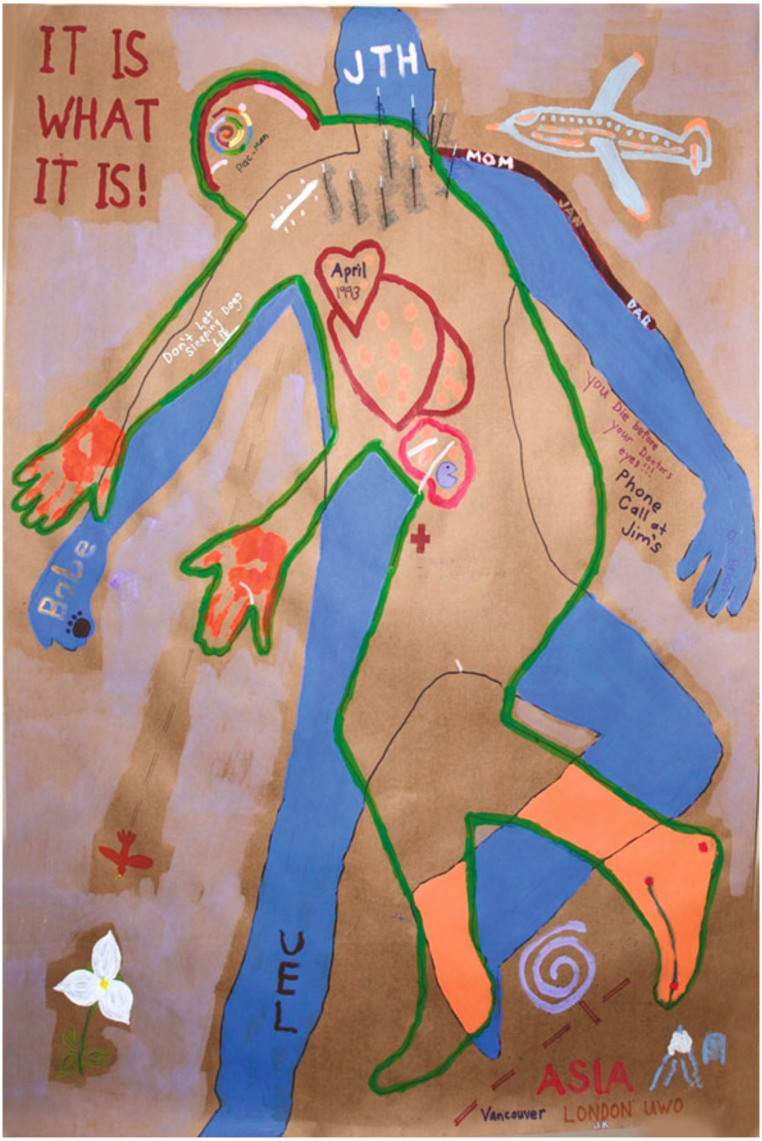
Map 1.5 Rayna's map

Map 1.6 Isabel's map

Map 1.7 Ted's map



Map 1.8 Andrew's map



Map 1.9 Evan's map

Map 1.10 Luke's map

Map 1.11 Nolan's map

Chapter 2
Project Overview and Insights About Body Mapping

> *As we critically imagine new ways to think and write about visual art, as we make spaces for dialogue across boundaries, we engage in a process of cultural transformation that will ultimately create a revolution in vision.*
>
> Bell Hooks (1995: xvi)

The Anatomy of Adherence Project

The conceptual seeds of the Anatomy of Adherence study, the project upon which this book is based, emerged during my postdoctoral work at the British Columbia Centre for Excellence in HIV/AIDS in Vancouver (c. 2008). Although productive in all facets of clinical and behavioural HIV-related research, Centre researchers had not yet qualitatively explored the medication practices of marginalized groups of people living with HIV/AIDS. Of key interest were 'polysubstance users' or people who use a range of licit and illicit drugs for recreational, medicinal, and psychosocial reasons. In the medical research literature and clinical discourse, these individuals are described as being the least adherent in the management of their medications, which is often explained through reference to high risk lifestyles, disengagement from health care systems, and the crippling effect of addictions on their ability to take medications as prescribed (Binford et al. 2012; Lambers et al. 2011). Such assessments shed little light on the intersecting systemic and everyday factors that shape people's decisions to take, or not to take, their medications and are often internalized as highly stigmatizing. In addition, these medicalized framings of adherence and non-adherence focus on people's behaviour as though it is divorced from the broader political context and forces that shape their lives, particularly those of the disadvantaged whose bodies have often been the site of pharmaceutical exploitation (Biehl 2005; Martin 2006).

I wanted to design a project that would involve marginalized women and men in a more meaningful exploration of these broader forces and the more localized, everyday factors that shape their decisions about HIV medications. I was particularly interested in how their embodied health practices are shaped by gender, issues

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that remain underexplored among marginalized populations. Before describing the Anatomy of Adherence study in more detail, I provide an overview of the relevant research literature on adherence, gender, and the body.

Adherence, Gender, and the Body: An Overview of the Literature

The successful management of HIV/AIDS is dependent upon near perfect adherence to HIV medications, namely HAART (highly active antiretroviral therapy), which is critical to preventing adverse health outcomes like developing resistance to HIV medications, immune system collapse, and death (Bangsberg et al. 2001; Lima et al. 2009; Wood et al. 2004). Most medical and epidemiological research on adherence examines the degree to which HIV-positive people follow prescribed medical advice (Harrigan et al. 2005; Osterberg and Blaschke 2005). Through this lens, non-adherence among marginalized groups like polysubstance users is often chalked up to chaotic lives, lack of engagement with health systems, addictions, and other individualized behaviours are used to explain why they are unwilling or unlikely to take their medications. Missing from this approach is an understanding of how medical information about adherence is incorporated into these women and men's daily lives and personal health care practices. In particular, relatively little is known about how gender and bodily responses to HIV medications, such as side effects and body image, structure medication practices and decision-making (Puskas et al. 2011). In addition, this decision-making has not yet been contextualized in terms of the meanings patients attribute to HAART (Conrad 1985) and the complex institutional relationships that shape personal health care practices (Bresalier et al. 2002; Orchard et al. 2015b).

This contextualization is important because of the disjuncture between biomedical and lay assessments of adherence, which are both mediated through the body but in very different ways. From a biomedical perspective, health decisions are individualized processes made by rational patients who obey instructions from medical experts (Di Matteo et al. 2012; Shiavo 2013). In the case of HIV, the degree to which people adhere to prescribed medical information can be measured, through pill counts and virus levels in the blood. Making these decisions is not so linear or straightforward for most people living with HIV, who must negotiate taking these medications for the rest of their lives while simultaneously navigating side effects, stigma, and the demands of socially situated, environmentally constrained everyday life (Mykhalovskiy et al. 2004). For the more marginalized, such as those struggling with addictions, this balancing act is further complicated by potential interactions between HAART and illegal drugs and the impact of social determinants like poverty, homelessness, homophobia, and sex trade involvement.

This disjuncture regarding the body exists not only between HIV-positive people and their health and social service providers, but also between different groups of people along the gender continuum. Access to HAART is not universal yet.

Eligibility for this expensive treatment is determined by clinical markers based mainly on the bodies and experiences of White men and may not reflect the particular needs of women or other groups (Broyles et al. 2005; Floridia et al. 2008; Mrus et al. 2005; Pinn 2003). Although HIV-infected women and men progress to AIDS at an equal rate, women's CD4 counts—critical indicators of immune function and prime determinants of treatment eligibility—are typically higher than men's are for longer periods of time (Napravnik et al. 2002; Nicastri et al. 2005). This means that women could be living with HIV longer than men by the time they are permitted to access this life-saving treatment.

The Anatomy of Adherence project was designed to generate in-depth insights about how marginalized women and men[1] think about HAART and how gender and the body shape their medication practices. I was also interested in the perspectives of health and social service providers who work with marginalized groups and often face systemic barriers that impede their ability to deliver comprehensive support and treatment for HIV-positive people with addictions. The insights of practitioners are rarely featured alongside those of the people they seek to help, however, because they are critical in the management of HIV medication practices and overall health of the people they work with I included them in this study. It is my hope that our study data can inform the development of gender-sensitive treatment and support programmes for HIV-positive women and men struggling with addictions and adherence, and contribute to the growing body of work that explores the relationships between health and gender more broadly (Johnson et al. 2007).

Methodology

The research team was composed of two lead investigators (myself and Dr. Robert Hogg) and additional researchers who have expertise working with HIV-positive populations and service providers, in Canada and internationally. Given the research connections established between the British Columbia Centre for Excellence in HIV/AIDS and local community agencies, the project was originally set in Vancouver. However, by the time we received funding for the study I had moved to London, Ontario, which brought about several logistical challenges. Ultimately, most of the study data were collected in Vancouver, with different project coordinators and myself contributing to the data collection. The body mapping with the women took place in Vancouver and the workshop with the men occurred in London, where I had taken a job and made strong connections with a local HIV service organization. The project was approved by the Ethics Boards at Simon Fraser University, Western University, and Providence Health Care (Table 2.1).

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[1] Which includes men who have sex with men (MSM), the preferred term given that many men who sleep with other men do not necessarily identify as being gay or homosexual.

Table 2.1 Total data collected

Participant group	Preliminary interview	Body mapping	Post-mapping interview	Treatment workshop	Total research activities ($N = 45$)
Women	7	6	6	6	25
Men	2	5	5		12
Service providers	8	–	–		8

Preliminary interviews with HIV positive participants of approximately one hour were conducted with seven women and two men in Vancouver,[2] who learned about the study through recruitment posters distributed at health and social service agencies with whom the team had fostered strong relationships. These discussions focused on the ways that drug use, gender, and the body impact adherence to HAART and overall health management, and the questions included: Do you have a routine that helps you organize taking your medications? How do your medications impact your body and how you feel? Do you talk about this with service providers? and Does your drug use affect your ability to stay on track with your medications/appointments? These interviews were also used to determine whether participants were interested in the body mapping workshop, which was the case for all but one of the female participants. Participants received a $25.00 honorarium for taking part in the interviews, each of which were audio-recorded with the participants' written consent and transcribed verbatim for analysis. These interviews were conducted by Kate Salters, who was the primary Vancouver-based study coordinator.

Interviews with service providers were conducted with HIV physicians ($n = 3$), social service providers ($n = 3$), and pharmacists ($n = 2$) on one occasion for approximately one hour. These interviews were designed to ascertain the adherence and addictions-related resources available for their MSM and female clients, and the kind of training they have received to work with these populations. We were also interested in their ideas about how gender and bodily responses to HAART impact their different client groups. Questions for these participants included: How important is a client's adherence to HAART? What kind of approaches do you use to promote adherence? Do you tailor these methods to different client populations? How do you respond to patients who are not adherent? These interviews were conducted by Kate Salters.

Body Mapping was conducted with six women in Vancouver (May 2012) and five men in London (May 2013). During each of the four-day workshops participants created individual body maps on a large piece of heavy paper that measured six feet by four feet, onto which they painted/drew textual and symbolic items in

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[2] Pursuing additional research with male participants in Vancouver was difficult following the loss of a research assistant, who had completed interviews with the women, service providers, and the first two male participants. I decided to continue working with MSM participants in London, Ontario and partnered with an HIV/AIDS agency that has many MSM clients. The five men who took part in the body mapping were selected by this agency and did not complete a preliminary interview.

response to a series of questions. The workshops were facilitated using the body mapping approach developed by Solomon (2007), which was described in Chap. 1. Digital photographs were taken of each map, which the participants all consented to, and each participant received $50.00 per day as an honorarium and were reimbursed for any travel costs. Tricia Smith facilitated and led all aspects of the body mapping and in the women's workshop she received assistance from myself, Kate Salters, and team member Alexis Palmer. I also helped in the men's workshop, which was attended by two members of the Regional HIV/AIDS Connection—the service agency through which the male participants were recruited.

Post-Mapping Interviews with the women and men who took part in the mapping exercises were held approximately 2 weeks after their respective workshops were completed. These individual interviews ran around one hour in length and participants were asked to describe what they included on their maps, the experiences and ideas that informed the creative process, and their perspectives on the mapping process itself. The participants also created one-page summaries of their mapping experience and what they hope prospective viewers of the maps 'see' in their creations. These interviews were audio-recorded with the participants' written consent, transcribed verbatim,[3] and participants received an honorarium of $25.00 for taking part. Tricia Smith conducted these interviews with the women and I completed this part of the project with the men.

A Treatment Workshop was held with the women participants in August of 2012. This one-day workshop featured information about how HAART and living with HIV/AIDS can impact women's health and bodies. During the body mapping workshop, the women expressed confusion about these health issues and responding to their desire to learn more about them was important. The issues of particular concern to them were lipodystrophy (the redistribution of abdominal, breast, and bum fat, loss of bum fat), diabetes, heart disease, dyslipidemia,[4] gastrointestinal issues, peripheral neuropathy, and forgetfulness/brain fog. A 'women's treatment guide' was prepared that featured information about these health issues, the most common HAART medications and their side effects, and allopathic and natural medical approaches for dealing with the uncomfortable effects of these toxic medications. The women were very receptive to the workshop and they engaged in productive group discussions and brainstorming sessions, which featured their own ideas and suggestions for how to deal with their everyday health challenges, as women. The workshop was led by Tricia Smith.

Fieldnotes were also recorded during the project, approximately sixty double-spaced pages. Excerpts from these notes are included throughout the book to help to bring the reader into the project setting and provide important, often

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[3] All of the project interviews were transcribed by a professional transcriptionist and editor based in Vancouver, British Columbia.

[4] The elevation of plasma cholesterol, triglycerides (TGs), or both, or a low high-density lipoprotein level that contributes to the development of atherosclerosis or hardening of the arteries.

intimate accounts of certain aspects of the research experience that did not arise during the interviews or workshops.

Analysis

A constant comparative method was used during the analysis of the interview data, and as is often the case with projects that take unfold over time, data collection and analysis occurred simultaneously (Sandelowski 1995). Verbatim transcripts prepared from the interviews were reviewed multiple times and a line-by-line open coding method was employed. This involves looking for common themes that inform the study objectives and grouping them into ‘master’ categories (i.e., HAART, adherence, HIV, addictions, gender, the body), which are refined through the creation of subcategories that contain insights that flesh out the information in the ‘master’ categories. The analysis of the interview and other study data was led by myself, in consultation with other team members.

The data analysis has also been shaped by work from scholars who explore HIV/AIDS, drug use, and other health issues among marginalized populations through critical medical anthropology, third-wave feminism, and postcolonial theory. These researchers examine how the lives of disenfranchised groups, including women, Indigenous populations, and men of sexual minority status, are shaped by their unequal access to different socio-economic, cultural, and political resources. Their exclusion from meaningful participation in society can, in complex ways, reinforce the idea that they are to blame for the ill-health and embodied forms of suffering they experience, including poverty, addictions, sexual discrimination, racially motivated and gender-based violence, and intergenerational abuse stemming from colonization (Bourgois and Schonberg 2009; Kelm 1998; Knight 2015; Sterk 2000; Truth and Reconciliation Commission of Canada 2015). However, marginalized people do not passively accept the role of ‘the victim’ ascribed to them, as reflected in many studies and arts-related projects that illuminate how members of disenfranchised groups resist oppression with and create meaning in their lives (Barone and Eisner 2011; Conrad and Campbell 2008; Huss 2007, 2011). This includes the move towards self-determination, healing, and social justice among Indigenous groups globally through reclaiming control over the knowledge that is produced about them as sovereign peoples recovering from colonization (Smith 2012).

When talking about their experiences related to HIV/AIDS, addictions, stigma, gender-based violence, and the effects of historical traumas resulting from colonialism, our participants oscillated between self-blame and recognizing how various sociostructural systems limit their meaningful participation in society. They also discussed how they resist the systemic and everyday exclusion they regularly experience, thus revealing their agential potential. These insights align with critically informed studies with similar populations, but the depth to which they are explored here is unique within the arts-based literature. Additional details regarding the analysis of the body mapping data is the focus of Chap. 3.

Knowledge Translation

The data gleaned from the interviews conducted with service providers revealed that instead of the binary framework through which adherence is typically assessed (i.e., adherent or non-adherent), they used 11 different social typologies to capture the spectrum of medication practices they observed among their clients with addictions (Orchard et al. 2015a). These participants also shed light on how addictions and the structure of the environments where they work impact their adherence-related work with these groups. It was revealed that while addictions complicate adherence to HAART, this is not a universal reality and the kinds of drugs used as well as the individual capacities of patients also impact adherence success. The organization of the HIV care environment, which is highly stratified and provides certain professionals with more resources and structural capabilities than others (i.e., physicians and HIV specialists), also shapes their ability to address the health needs of their clients (Orchard et al. 2015b).

The body mapping data yielded rich insights about how gender, the body, and different social and structural factors shape the medication practices and everyday lives of HIV-positive men and women with addictions issues. In the arts-based literature, knowledge translation is consistently cited as a challenge given the tradition of recording research findings in textual mediums and the tendency for mainstream academic venues (i.e., journals, conferences) to question whether or not arts-based research is indeed research (Barone and Eisner 2011; Liamputtong and Rumbold 2008). Our dissemination strategies unfolded in unique ways in the two sites and were informed with the input of the participants (see Chap. 5 for more details). With the women's group we held an art show and dinner in Vancouver to celebrate the project and made t-shirts, postcards, and booklets, that featured their maps and one-page stories created during the follow-up interviews. Their maps stayed for a week in the host restaurant and yielded a great deal of positive feedback from patrons and staff, one of whom said they made her 'weepy'.[5] Copies of the women's maps were also installed in Vancouver's women's-only pharmacy and at a women's clinic where many of the participants receive their services, where they still hang today. With the men's group, we also created booklets and their maps were featured at the AIDS Vigil in London, Ontario and the Annual General

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[5] She shared these feelings with me when I took down the maps and we chatted about the pride she takes in participating in community projects designed to combat stigma and promote healing among Downtown Eastside residents, most notably the amazing *Hope In Shadows* project (Cran and Jerome 2008).

Meeting held at the Regional HIV/AIDS Connection, our community partner in the men's body mapping group.

Locating Our Participants

The participants in our study are the experts in their own lives and while I am writing this text, as Barone and Eisner (2011: 134) contend, "The voice of the writer should not overpower those of her informants-turned-characters in the text-the people with whom she is collaborating." To that end, throughout the book I use direct quotations from the women and men in our study to ensure that they are 'heard' and I have organized each chapter around their lived experiences. The sociodemographic overview below is included to provide a preliminary sense of the women and men who took part in the project.

Five of six women participants identify as Indigenous[6] and are originally from communities in British Columbia as well as other Western Canadian provinces. The majority of them have lived or are currently living in the Downtown Eastside area of Vancouver, one of Canada's poorest neighbourhoods. Their experiences with colonialism feature prominently on their maps and in our discussions, including residential schools, intergenerational traumas, and struggles with addictions, street life (including sex work, homelessness), and poor health resulting from the everyday and structural violence they experience.[7] All of these women have had children, most of whom live with them but some have been given to institutional care systems and three children have passed away. The non-Indigenous woman, Rayna, was born in Hong Kong and moved to Vancouver as a teenager in the 1990s. However, her parents did not move to the city with her and she was left to fend for herself, which she described as contributing to feelings of loneliness, drug use, and other coping behaviours she developed. The women ranged in age from their early 30s to 60 years of age and they have lived with HIV for varied lengths of time living, from almost 30 years to six years. All of the women are on HAART and have taken many kinds of pills over the years, which has led to physical, neurological, and socioemotional side effects stemming from long-term use of these toxic medications.

The five male participants are from London or nearby rural/semirural areas, and with respect to cultural identity three identify as White, one man as Black, and one man is of mixed race. The men range in age from their late 20s to just under 60 years old, and the average age was around 35. Their length of time living with HIV is slightly less than that of the women, ranging from two years to 22 years. Of

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[6] Which includes First Nations, Inuit, and Metis peoples in the Canadian context. In our study four of the Indigenous women participants identify as First Nations and one as Metis or of blended racial descent.

[7] See Acoose (2015) for an incredibly powerful first-hand account.

the five men, three were on medication at the time of the study. One of the men in our study has children, two of whom are with him and one passed away. All of the men have experienced addictions, including different kinds of drugs (i.e., pharmaceutical, illicit) and/or alcohol, which emerged as one of their most defining life challenges and ways of coping with struggles related to family, mental health, and HIV/AIDS. At the time of the workshop, most of the men had been in or were actively involved with support/treatment programmes to help ease the pain of their addictions and work through their underlying issues.

Participants' Perspectives on Body Mapping

The data below feature the participants' perspectives on the body mapping experience and how this approach compares to other studies that they have participated in, typically survey-based or individual interviews conducted over a brief period of time. Each section opens with an excerpt from my fieldnotes recorded during the workshops, beginning with the women.

Women

> As women trickled in, it was clear from the big "hi's", hugs, and familiarity among them that many of the women knew one another. I sat in the cluster of chairs closest to the doors, across from the supplies table, and adjacent to the neatly plasticked and taped edge of the carpeted floor. It was interesting because many of the women began, like you would, by asking one another how they were doing. This quickly led to discussions of health, specifically, many of them began to speak the language of HIV numbers and procedures: CD4 counts, blood work, appointments, and commenting on what they share with each; with impressive experiential knowledge honed from many years, often decades, of living with the virus.
>
> Four or five out of seventeen total exercises were done today: tracing the support figure, tracing the woman's body, fingering the outline of each woman's own body tracing, painting their outline, creating images relating to "where they are from", creating images relating to "where they are going", creating images that link the roots to the fruits (so to speak!). After these exercises we all regrouped in a circle and each woman's map was put in front of her, and then she discussed what she wanted to about the day, the map, the colours, the symbols, and so forth. Tears were shed by two women and one spoke about the power of finally being able to shed tears that she could feel and understand. All of the women said that they really enjoyed the process so far, complimented one another on how unique and interesting the maps were, and looked forward to the progression of the workshop. One woman said that she felt vulnerable and opened up, and following upon that (or trying to) I mentioned that I thought they were all very courageous because what they are doing is baring their lives in the open. The other team members spoke about being thankful to be a part of the workshop and spending time with the women (Fieldnotes, May 3, 2012).

The women expressed a range of feelings about the body mapping experience and many highlighted how interesting, thoughtful, and supportive it was: "It was a new experience for me and I'm glad I did go…It was quite interesting. I was quite impressed with what we learned and what people think…you know, about each other's maps. It was touching" (Georgia). Sue emphasized how important the process was, which was informed by the quiet and thoughtful environment that gave her time to think about what she wanted to express: "It was very quiet. It was very thoughtful…I really took my time to get what I really wanted to say. Because I knew it might be important. Well, it's important for me to say what I really see, and what I really feel too." Rayna focused on the power of art to inspire and bring people together by tapping into our shared struggles and feelings of loneliness: "This kind of thing is not just piece of art. I think it's inspiration for everybody, you know. I've been through this and I want you to look at this. I don't know how they feel about it, but I hope they know that they are not alone."

Tarah also found the experience positive, such that saying goodbye at the end was hard: "I was sad it was finished! It was like, 'There's gotta be more to this!' Yeah, it was kind of like, it was a good trip! It was a good trip!" Isabel discussed how gentle and feminine[8] the process was, emphasized through her repeated use of the word 'soft', and offered suggestions for other groups of women who might benefit from the body mapping experience:

> I really think this would be good for use with teenage girls who are HIV because it's really pretty! I felt very…it's very soft and very womanly… Because you've got all the colors and it's more of a gentle way of doing it…I can honestly say I felt like… it's really kind of feminine and really, just soft. It brings out the woman-ness in me!

Given the women's extensive involvement with research projects in Vancouver's Downtown Eastside, namely survey-based behavioural questionnaires, I was curious about how they would perceive this arts-based approach. They all indicated that body mapping is very different and more meaningful because of the personal and humanizing experiences it generated. As Georgia shared: "I think it's very different… This is personal, here, you know?…It is quite amazing to see, you know, how people put their own life down there and…. Then look at it again and see." In a similar vein, Isabel said:

> You feel like a specimen rather than a person wanting to do a survey. This is not like that. I like surveys like this! Surveys with paint – for four days! How are you supposed to know somebody if you don't get to know them?!…This was more meaningful. It feels like it's going to be used in a good way, in a healthy, safe way.

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[8] Given that she referred to herself and some of the other participants as "hard core", these descriptions were particularly powerful. Also telling is how Isabel begins to say, at two points in the excerpt above, "I felt" when providing these descriptors and then switched to "it's very soft" or "it's really kind of feminine", which may reflect her difficulties with ascribing these gentle qualities to herself.

Abby draws attention to the lack of genuine engagement with and understanding of research participants in many Downtown Eastside project, which she did not experience in our study:

> It was just the way you taught it…We had those days to get comfortable with each other… I've been to [other research projects]…I find them actually quite snotty. If you can't be around addicts, then you shouldn't be down here doing this…I feel a lot of them just want it for the government grant.

Other women highlighted the unique attributes of the arts-based approach and how it enabled them to see their lives and what they have created, which was described as being emotive, substantial, and real to them. Take the following excerpt from Rayna:

> Normally [surveys] go after certain things, like, knowledge about certain things or what you're believing or stuff like that. But this is research – wow! Research for a person who lives with HIV and has to take medication. How do they affect their lives from the beginning to now? And what do you see, how do you feel? On one single piece of paper!

Tarah uses the visual image of 'having her eyes opened' when talking about how different and important this experience was, compared to projects that rely strictly on writing things down:

> I'm able to open my eyes and see what I've done!…Better than questions because…if you just put it on paper, I may have just passed it and said 'Ah, maybe!'…I mean, you can write and talk forever, and not really know what you're talking about. But when you actually see it on paper, then it actually becomes a something. I believe we did something. Something important enough that I would do again.

Sue describes how visual research produces a more immediate and 'real' account of peoples' lives compared to standard academic research and dissemination practices of reading and talking about study findings:

> I believe it has to be [personal]…I like Visual Research…When somebody talks, or you put it on paper, like written word, it's not as visual as looking at the real thing. And I don't know. I think it opens a lot more people's eyes than just, you know, speaking from a podium and reading documents.

Men

> I was excited to begin and we started things around 10 am or so, with introductions, ethical/confidentiality issues and consent forms, an overview of what body mapping is and how the next 4 days will unfold, and when and what to expect in the way of food. Despite the numerous smoke breaks throughout the day the men got a lot done: tracing their image and that of their support figure, outlining their own figure with paint, symbols about where they're from, symbols about what their goals/aims for the future are, their journey from their past to their future aspirations, and colouring in their support figure.
>
> On our way for a smoke, Evan and I ran into the other men and Luke decided to join us. As we walked up the stairs to the room, Luke asked if this building is where the medical students are. I said no, and he told us that a friend of his is in medical school and he doesn't

> want to run into her because then she'd know he has HIV. He said he'd be embarrassed not because he has HIV, but because he hasn't told her. We ended before 4 pm, with a profoundly moving and fascinating check-out, where the men each explained the different stages they accomplished and what it all meant to/for them.
>
> I asked Tricia at the end of the day if she observed any differences, thus far, about this group of men compared to the women we worked with in Vancouver. The first thing she commented on was that there is WAY more talk about sex, totally!!! She also said that they moved through the steps quicker too, and I agreed. I said that they seem more intimate/supportive of one another, which might be because we recruited all of them from the same agency. I wondered what other folks in Elborn College (where the workshop was held) thought of the guys and we sure found out what one woman thought about Luke brushing his teeth in the water fountain. She informed him, and I can't imagine why (!!!) that there is a men's bathroom around the corner. I noticed that a few people seem to be rather unimpressed with the fact that the crew of us were smoking by an entrance, fair enough (Fieldnotes May 23, 2013).

While the women spoke about the introspective and healing nature of the body mapping process this was the case among only two of the men, Nolan and Andrew. For Nolan the mapping process enabled him to think about himself in new, positive ways: "It really helped me to take a good look at myself and to see that things aren't as bad as they seem, and it helped me look at myself in a different way. I'm definitely going to put this up on my wall because I need to remind myself that, you know, I am a beautiful person." Andrew went into detail about how meaningful the mapping experience was and initially focused on the process, saying: "Landing there and going through the process, I found it really interesting that I went inward. And it didn't really matter what everybody else was doing, or saying even…The process actually drew me into itself." He then shared a moving reflection about the story his map tells, which is about suffering as well as his movement through pain to the other side towards recovery and healing:

> It does tell a story. I think that red blood line is the central story. From that point of feeling isolated and different…through lots of sexual activity and other expressions…The career, the schooling, making mistaken connections to heart. For a long time I lived in that part that goes out into the arm… which is pain, escape and coping. And then on the other side 'Rehab, Recovery, Change'. But I couldn't get to change and recovery without having gone through the pain. My attempts to escape… It is my story.

The other participants used less intense images and language to describe the mapping experience and here Luke says that it had nothing to do with his story or significant life events: "I don't really think it tells a story. It's just kind of like, a map! With stuff on it! It's kind of like 'Here I am! Here's some things that have happened in my life!' The main things." Ted enjoyed the mapping and described it in the following way: "I talk about the overall experience being really cool." Evan framed his account of the workshop through reference to the omnipotent processes of life and death, yet does not provide a tremendous amount of personal insights regarding his individual experiences: "I guess it talks about the Circle of Life and the human journey… from birth to death. And I'm somewhere in between!"

Among the men with previous research experience, like behavioural surveys that document behaviours quantitatively, body mapping enabled them to express themselves and assign meaning to life events/people in ways that were far more personal:

> I've done studies for, like 'man on man sex' or 'living with HIV'…And it's, like, "Yes", "No", "Yes", "No"….It's painstaking! It's just so boring, and it's like 'Fuck, can I speed it up?' Like, you kind of half-read and they don't pay as good. This was great and it was a lot more personal, there was a lot more interaction with people. Other studies aren't so long, but they don't pay as well and they are very boring. They just want answers. This has a little more facets to it… You guys are trying to get more of us out of it" (Luke).

These sentiments were echoed in Ted's account of different research approaches:

> My parents, who obviously played a big role in my life…wouldn't necessarily come out in an interview or a Survey Monkey. And being able to add people… and explain, like…. My son is up her, and my daughter is here!…You have to explain that to people. One of the things that I think is cool about it is that you can assign value to different aspects of your life that totally makes sense to you, right? As opposed to 'A, B, C, D' ….Oh, 'It doesn't fit' you know? Or ranking something. This is just very different (Ted).

While Nolan had not taken part in other studies he made reference to other arts-oriented activities he has participated in and how they align with his interests: "In treatment centres… there was a lot of looking at my past, looking at what I want in the future and stuff like that… For some people, like for me, my personality, I'm more of an artsy kind of person. You know, so I really took to this."

Locating Myself

I am a white (English and Irish descent) anthropologist with cultural and medical expertise and at the time of writing (August 2016), I am 43 years old. I grew up in the city of Saskatoon in the Canadian prairie province of Saskatchewan, which has left many indelible marks on me, as a woman and a researcher. Among the most lasting have been the influence of artists, political figures, and others from the land of the big sky, including Buffy Sainte-Marie (Indigenous singer, songwriter, activist), Tommy Douglas (the father of social medicine in Canada), Joni Mitchell (singer, song writer, painter), Neil Stonechild (an Indigenous man whose 1990 murder helped change racist policing practices in Saskatoon), and countless members of my family from whom I continue to learn. Being encouraged from a young age to stand beside and sometimes for those pushed to the outskirts of society has had a dramatic impact on the kind of work I do as an anthropologist. Since beginning my academic career in the late 1990s I have consistently worked with people who have been mistreated and deeply misunderstood, mainly rural and urban Indigenous communities, women and transgender people in sex work, gay men and others affected by HIV/AIDS, and youth.

My first foray into body mapping occurred when I was working on a project with women in sex work in Vancouver, while completing my postdoctoral position at the Centre for Excellence in HIV/AIDS. I wanted to introduce arts-based methodologies into what was predominantly an epidemiological study. I met with approximately ten women who expressed an interest in body mapping and using Solomon's (2007) facilitator's guide I set about purchasing supplies and began structuring the workshop. However, due to unforeseen conditions surrounding the study I was unable to see the workshop through and it was taken over by other team members who were not as committed to or familiar with the therapeutic structure of the process. Interestingly, one of the women featured in this book (Abby) took part in that failed attempt and rightly described it as a 'gong show'.

Thankfully, my second experience with body mapping has been infinitely different than the first. Over years of researching and thinking, I have remarked on numerous occasions that this project has changed my life. This is due to a series of factors that came together in a particular way around the time of this study. The most salient being the beginning of my sobriety and healing journey in 2012, having the opportunity to conduct research that focuses on the connective power art, and meeting the incredible women and men in our study. These issues are discussed in more detail in Chap. 4, which focuses on the transformative nature of this research experience, but I think it is important to 'show' a little bit of who I am at the outset just as I have tried to do with our participants.

Discussion

This chapter opened with a description of the project upon which this book is based, which was designed to examine how gender and the body structure medication practices among HIV-positive women and men who struggle with drug addictions and multiple forms of socio-economic, cultural, and sexual marginalization. A brief overview of the literature on adherence, gender, and the body in the context of HIV/AIDS adherence research was provided, which illuminated some of the limitations of the quantitative methods commonly used to investigate these issues. As discussed, these approaches can determine whether people take their medications, but they provide few insights into the individual conditions or structural factors that shape the ways that people think about HAART or living with HIV (Browne et al. 2012; Penn et al. 2011; Puskas et al. 2011). I designed a different kind of project that involved marginalized women and men in a more meaningful exploration of these broader forces and everyday factors that shape their decisions about HIV medications. Learning how social and health providers who work with these populations approach addictions and adherence, given their critical role in the management of these health issues, was also of significant interest. To that end, myself and other team members conducted individual interviews with HIV-positive women and men who struggled with addictions as well as adherence, along with HIV providers who care for these populations and seek to improve their uptake of HAART (Orchard et al. 2015a, b; Orchard et al. 2014). Our team used body mapping with the HIV-positive participants, which aligns well with the study aims and generated participant-generated data that is unique within the adherence/addictions research literature.

The second half of the chapter features ethnographic insights from our study, specifically our participants' thoughts about body mapping and how it compares to other research they were familiar with. They saw many unique benefits of the approach, which included providing a creative alternative to understanding the lives and experiences of people with HIV and enriching their lives beyond the frame of the project. The women's insights were remarkably cohesive and they all spoke about the personal nature of this research, which included feeling as though their whole lives were of interest and free to be documented as they saw fit. This is very different than their experiences with surveys or one-time interviews, which often made them feel like 'specimens' or as though only very specific aspects of their lives or behaviours were up for discussion. Two of the men also commented on this, including Luke who said: "They [surveys] just want answers. This has a little more facets to it…You guys are trying to get more of us out of it." From Ted's perspective, one of things that made the experience 'cool' is that "You can assign value to different aspects of your life that totally makes sense to you, right? As opposed to 'A, B, C, D.'"

The research environment and process were also identified by participants as unique aspects of the body mapping approach. Several women talked about having quiet time to think and reflect upon their lives while engaging in the artistic process, which becomes more complex with each passing day as more and more of their lives are revealed. While this can make them feel vulnerable our participants spoke about being relieved and thankful for the opportunity, albeit intense and very hard at times, to release certain experiences they had been holding inside for a long time. Releasing these experiences and having them materialized through the creative process helped make them real and dealt with in a therapeutic way. Visualizing these experiences was an essential part of this, as Tarah said: "When you actually see it on paper, then it actually becomes a something." Rayna went into more detail about the collaborative, artful power of what they were producing: "This kind of thing is not just piece of art…It's inspiration for everybody, you know. I've been through this and I want you to look at this…I hope they know that they are not alone."

While most of the men did not speak at length about the uniquely visual or inspirational aspects of the process, Nolan and Andrew did. For Nolan, the body mapping experience allowed him the space and emotional security to be kind to himself and to see that he is a beautiful person. He discussed using his map as a reminder of these personal facts, thus revealing the double powerful of body mapping in this context: map as mirror and map as eyes, through which he can see himself in a new light. Andrew talked about how the process pulled him in and guided him in the creation of the story of his life, which is traumatic, painful, and beginning to be shaped by human connection and self-love/respect.

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Chapter 3
The Forest and the Trees: Pushing the Analytical Envelope

> *Invention is mostly this kind of subtle, inevitable thing. People get closer to the beauty of their invention. They get narrower and more particular in it…It's a million choices you make. It's luck in a sense. The thing that's important to know is that you never know. You're always sort of feeling your way.*
>
> Diane Arbus (1972: 10, 14)

Analytical Issues in Arts-Based Research

The analysis of arts-based research findings is among the most variable aspect of the field, due to the very diverse range of methodological approaches, artistic activities involved, subjects explored, and uses or purposes of the resulting data. The ways that a theatre performance or a collection of writings, for instance, are interpreted varies tremendously from the analytical approach used to understand a series of photographs or a single painting. The context in which such methods are used also shapes how and the degree to which they are analysed, which may be more important or certainly different in research-based studies compared to a program evaluation or social justice initiative. The divergent values assigned to the particular arts-based activities employed, as an adjunctive or primary method, as a means for community mobilization or therapeutic treatment (Knowles and Cole 2008; Viega 2016), also contributes to rather muddy analytical waters. While this heterogeneity can make data analysis challenging, especially for those working with the more fringe methodologies that have few interpretive frameworks from which to draw, it is also exciting because it pushes researchers to find new ways to make sense of things.

Given that it is the most widely used and adaptable arts-based method, the analytical procedures related to Photovoice are quite well established, particularly in small-scale participatory projects designed to generate critical reflection among participants and sociopolitical change in their lives. In this context the analysis is approached collaboratively and begins with participants selecting images, contextualizing them, codifying them in ways that inform the study objective, and they

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may also assist with the prioritization and validation of the findings (See Wang and Burris 1997 for details). The following questions are shared among the group to assist participants and researchers during interpretation: “What do you see here?”; “How does this relate to our lives?”; “Why does this situation, concern, or strength exist?”; and “What can we do about it?” (Wang 1999). When documenting the analytical process and attendant findings, researchers using Photovoice typically focus on individual storytelling as well as group narratives (Sutton-Brown 2014).

In studies that employ drawings, as in the case of Guillemin and Westall’s (2008: 125) work with women experiencing post-natal depression, researchers often use a thematic analytical framework guided by questions about image production (colour, composition), the relationship between images, whether they are contradictory (i.e., to other data collected), and the kinds of knowledge that are included or excluded. In some projects, participants are relied upon to direct the analysis (Guillemin and Drew 2010: 183), which may be empowering but also stressful given their already full lives and potential disinterest in this activity (Packard 2008). Different modes of interpretation emerge from visual anthropology, which overlaps with arts-based research but is also quite distinct given the focus in this sub-field on photography, film, material culture, and the history of visual arts within the discipline (Banks and Ruby 2011; Hockings et al. 2014). Leading visual anthropologist Pink (2003: 186) argues that researchers “should attend not only to the internal “meanings” of an image, but also to how the image was produced and how it is made meaningful by its viewers”; a wide-ranging set of principles that highlight content, context, and the relationality of artful production.

Sociologists have also contributed to these discussions and Spencer’s (2011) exploration of visual research methods in the social sciences is a noteworthy resource. While most of the studies he examines employ similar kinds of intertextual approaches, namely critical semiotics and discourse analysis, that he discusses how these paradigms can be applied in different projects makes his book unique and useful- particularly for those working with image-based art (i.e., media, photos, archival materials, and cartographic as well as hand drawn maps). Place/space mapping has also been used to generate visual narratives that represent participants’ relationships to place, people, time, and themselves; a “mediational method” (Futch and Fine 2014) that produces data which are qualitatively coded and categorized into thematic groups that reflect the research focus. McIntosh (2010: 167) suggests that a more systematic approach to the analysis of arts-based research can be found by paying closer attention to metaphor and dialogue within the given artful creation, thereby producing “a kind of mixed methodology if you please, with the prospect of deepening understanding and developing theory through conjunctions with what is found”. Another compelling example comes from artist practitioners who documented their physiological responses to various artistic activities, with an eye to developing a measure of the artistic experience and/or process (Learmonth and Huckvale 2012). Here, they describe their original approach:

> Ripples, eddies or whirlpools, inseparable from the currents they arise in. These properties embody what matters about the arts. Reductionist interrogation can be like collecting waves in a bucket and taking them home for a closer look…Our experiment did not capture any waves, but we certainly felt them go by… Our bucket kept coming up full of frogs, slippery amphibians who move between the worlds (106–107).

As a tripartite method that combines research with art and therapeutic process body mapping occupies a complex and somewhat slippery position within arts-based approaches, a kind of "hybrid or third space" (Leavy 2009: 232). The divergent processes and outcomes associated with this method are its key strengths but they can make the systematic analysis of the findings challenging, and of all the arts-based methods body mapping is among the least well-developed in this regard. When first created with women in South Africa as a tool for community mobilization and political advocacy, the maps were documented in ways that highlighted the primary issues or themes in their lives, which included living with HIV, gender, violence, HIV treatment, family, health, and survival (Morgan 2003; Solomon 2007). These expressive elements speak with considerable force about women's everyday realities and the need for sociopolitical change, and the tradition of drawing attention to the most powerful or readily accessible themes in the maps runs through many studies. This is not to say that all body mapping studies merely replicate the practices developed by Morgan and Solomon or that they focus on the same kinds of issues. Indeed, research teams and community agencies from around the world have adapted the original methodology to fit their needs/interests related to wide-ranging issues, including motherhood, sexuality, HIV disclosure (MacGregor and Mills 2011), individual and transactional narratives in pedagogical settings (Maina et al. 2014), post-colonial realities and struggles (Lu and Yuen 2012), exploitation and solidarity among undocumented workers (Gastaldo et al. 2012), and sociocultural constructions of the body that challenge biomedical knowledge and surveillance practices (MacGregor 2009).

The point I wish to make is that while the maps are central to these and other studies, they are framed as vehicles through which different kinds of lived experience are transmitted and are rarely the subject of in-depth analysis in and of themselves. This is an important issue that threads into the ultimate goal of body mapping and ethnography itself—that of understanding participants' lived experiences or 'emic' perspectives. On our participants' maps I saw so much more than insights about the primary themes that informed the study (i.e., HIV, addictions, gender, the body). I saw multifaceted stories within stories in the different layers within each map (i.e., the background, support figure, and main body figure of the participant), different modes of communication across these layers (i.e., symbolic and textual) and between participant groups, and the intense psychosocial and emotional work demanded of our participants as they went through the creative process. This illuminated the complexity of not just the method but the maps themselves, the breadth and depth of which I did not see analysed in the literature. This is particularly true for the men's experiences, which are rarely examined given that body mapping is a largely feminized methodology.

This chapter introduces the approach I developed to more fully account for the multiplicity of art data contained in our participants' maps, a task that was fueled, in part, by a sense of obligation. I felt like I owed it to our participant to push the analytical envelope, given the tremendous effort, time, and expanse of lived experience they poured into their creations, which represent nothing less than—as Georgia said—"Your life on a map. You know…From birth to now!" This task was also undertaken in the spirit of demonstrating the strength of this arts-based approach, alongside more established forms of scholarly inquiry that rely on textual or print-based knowledge. Arts-based ways of knowing are grounded in active, hands-on participation and personal connection that challenge dominant forms of knowledge, which is why they are often ascribed the status of 'subjugated' (Foucault 1980) or 'non-serious' knowledge, or simply ignored (Conquergood 2002). The inequities that structure the hierarchical world of knowledge classification need to be pushed in order to make new spaces for meaning making that can, as Conquergood (2002: 151) eloquently argues, "bridge segregated and differently valued knowledges, drawing together legitimated as well as subjugated modes of inquiry".

Ethnographic Insights: The "Axial Embodiment" Approach and Key Findings

The remainder of this chapter is devoted to unpacking the new approach to interpreting the body mapping findings that I developed, which I refer to as "axial embodiment". Along with a detailed discussion of the different constituent parts of this model, I include the participants' thoughts about how to make sense of body mapping, insights that are rarely seen in the literature. These data are followed by a discussion of the key study themes of HIV and HIV medications, taken from the interviews with participants, which rounds out this discussion.

The axial embodiment approach is influenced by pioneering anthropologist Douglas (1970), who argued that the body is not a natural symbol but our ideas about the body have become naturalized in particular ways depending upon the cultural context in which they are situated. This is due to the symbiotic links between the individual and the social body, which she describes as "a continual exchange of meanings between the two kinds of bodily experience so that each reinforces the categories of the other" (1970: 69). Going beyond the structural–functional theoretical frameworks of her time that generated interesting but somewhat lateral explanations of relationships between individual and social bodies, Douglas asserted that the vertical dimensions of analysis or those that focus on the structural axis of lived experience must be given more serious consideration.[1] To

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[1] Alongside more 'traditional' horizontal analyses that highlight relational themes within a given pattern, which she identified as different than her "analysis in depth" model (Douglas 1970: 75).

operationalize this approach she developed schematic, grid-like diagrams to capture the degree to which certain groups valued particular cultural phenomena, sometimes in relation to each other and at other times in relation to the social organization of the societies in question; thus bringing visual form to her innovative, in-depth approach to the analysis of symbolic and embodied experience across the social and individual body (see example below; Douglas 1970: 60).

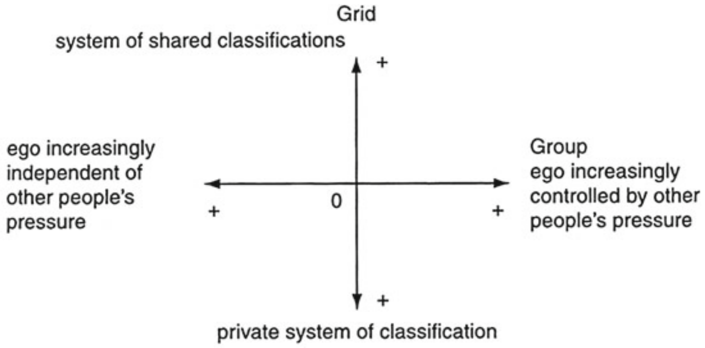

Diagram 4 Grid and group

Reflecting upon the sheer volume[2] of items contained in each of the body maps and their incredibly diverse content and distribution across the layers of the maps, I was driven to develop an analytical approach that captures and makes sense of these data. In the absence of anything beyond the 'horizontal' or thematic/relational interpretive focus in the body mapping literature, I developed a more rigorous system that considers the numerical/vertical (i.e., number of symbols and textual references across the different layers of the maps) and content/horizontal analytical axis of the mapping items. To achieve this, I counted each textual and symbolic item within each map layer, for each of the maps, and completed a numerical and content analyses of these data. During the analysis I reflected upon what the participants were communicating about, and how, an iterative process that was informed by feminist, critically oriented inquiries into the body as symbol and vehicle of expression (e.g. Farnell 2011; Martin 1994; Sontag 2001; Treichler 1999; Wolf 1992) as well as the relationship between the body, gender, and HIV/AIDS.

Being attentive to the multiplicity of embodied representations within the maps, including Douglas's individual and social body, as well as the body politic or "third body" was also central to the analysis (Schepher-Hughes and Lock 1987). Related to this is destabilizing the notion that there exists a singularly normative or complete corporeality and that the body is but a bounded, physical phenomenon or

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[2] A staggering 561 textual and symbolic references on the women's six maps and 325 for the men's five maps, including those related to HIV/AIDS (see Table 3.1).

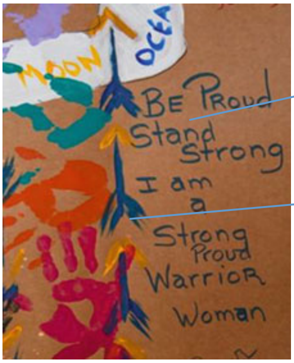
Table 3.1 Numerical distribution of textual and symbolic images on the body maps

Name	Text on map	Text on body	Text on support	Text total	Images on map	Images on body	Images on support	Image total
Women								
Abby	21 [8]	4 [1]	6 [0]	31	3 [2]	9 [0]	5 [1]	17
Georgia	21 [11]	0 [0]	16 [2]	37	20 [8]	10 [2]	3 [0]	33
Sue	23 [15]	11 [3]	46 [2]	80	14 [4]	6 [0]	3 [0]	23
Tarah	12 [5]	4 [1]	11 [2]	27	15 [4]	9 [2]	3 [0]	27
Isabel	20 [1]	5 [1]	22 [3]	47	10 [1]	12 [0]	1 [0]	23
Rayna	6 [0]	0 [0]	8 [0]	14	10 [1]	5 [1]	3 [0]	18
Women total Average	**103** (17)	**24** (4)	**109** (18)	**339** (56)	**72** (12)	**51** (9)	**18** (3)	**141** (24)
HIV/AIDS [ ] Average	40 (6.7)	6 (1)	9 (1.5)	55 (9.2)	20 (3.3)	5 (0.8)	1 (–)	26 (4.3)
Men								
Ted	6 [2]	13 [4]	14 [2]	33	11 [1]	12 [3]	6 [0]	29
Luke	7 [0]	8 [0]	12 [1]	27	10 [1]	8 [0]	3 [0]	21
Andrew	7 [1]	25 [10]	21 [1]	53	25 [5]	8 [2]	4 [0]	37
Nolan	4 [1]	7 [0]	7 [1]	18	6 [3]	12 [1]	1 [0]	19
Evan	7 [2]	3 [2]	6 [0]	16	10 [0]	13 [2]	4 [0]	27
Men total Average	**31** (6)	**56** (11)	**60** (12)	**147** (29)	**62** (12)	**53** (11)	**18** (4)	**133** (27)
HIV/AIDS [ ] Average	6 (1.2)	16 (3.2)	5 (1)	27 (5.4)	10 (2)	8 (1.6)	0 (–)	18 (3.6)

productive system (Martin 1992) that “ends at the skin” (Haraway 1990: 220). The body is created and known through a myriad of socio-economic, political, and sexual practices that are realized through the experience of embodiment, a transformative agential process through which subjectivity emerges both materially and emotionally (Shildrick 2015). Our participants have had to confront many oppressive and deeply stigmatizing experiences, stemming from colonialism, homophobia, poverty, addictions, and the acquisition of HIV/AIDS, and being attentive to how they express, sought to make sense of, and resist them through their art was also important.

I use the term “axial embodiment” to describe this approach because it reflects an attention to the vertical and horizontal analytical levels and because the metaphor of the axis, which denotes movement, relativity, and simultaneous moments of light and shadow, captures the complex embodied experiences our participants documented on their body maps. The philosophical study of axiology has an interesting place within qualitative and arts-based research, which was a discovery I made after developing the term “axial embodiment.” It is a branch of inquiry that centres on ‘values’, specifically ethics and aesthetics, and is variously defined among the researchers who employ it. For some axiology emerges alongside ontology and epistemology as an additional tool with which to validate arts-based research as 'real', 'true', and as having legitimate meaning within the arts and the sciences (Piantanida et al. 2003; Viega 2016). For other researchers the axiological lens focuses more pointedly on the ethical nature and conditions of relationships that structure research initiatives, particularly those with vulnerable populations (Liamputtong and Rumbold 2008). My particular rendering of axial embodiment is unique because it is intended to capture several axes of experience versus enhancing the status or evaluation of our participants' work. It also aligns with the insights of visual artist and pioneering arts-based scholar McNiff (2013: 3), who assesses the value of artistic inquiry by determining whether it is useful to other people and whether or not it sparks subsequent phases of "creative contagion and professional change".

To operationalize the analytical process, I begin with the textual and symbolic data on the three distinctive story levels contained within each map: *the map itself* (i.e., the background space); *the body* (i.e., the participant's body map), and the *support figure* (i.e., the second body on the maps). The textual and symbolic items on each story level are then counted and organized by content. The same is done for the HIV-specific textual references and symbolic imagery across each map layer. Thus, each map contains 12 locales of analysis: Text on map; Text on body; Text on support; Image on map; Image on body; Image on support; HIV text on map; HIV text on body; HIV text on support; HIV image on map, HIV image on body; and HIV image on support. When tabulating the number of textual and symbolic images on the maps, I counted '1' for each stand-alone word, phrase or sentence that constitutes a single or unified idea/statement/subject. For instance, "Darcy, Stew, Cary, Alexa & Me" count as '5' entries because each person is distinct, whereas the sentence "My son and myself have been undetectable for over 15 years" counts as 1 entry because these words are part of a singular statement. Similarly, a depiction of a house with trees around it or a series of arrows counts as '1', but closely clustered images of a cigarette, crack pipe, a bottle count as '3' because they are each unique items. The image below, which is a portion of the background layer of Sue's map, illustrates these principles:



Textual (n=3)

Be proud (n=1), Stand strong (n=1), I am a strong warrior woman (n=1)

Meanings: Indigenous ideologies, gender, strength

Images (n=4)

Indigenous symbol of arrows (n=1)

Hands (n=3)

Meanings: Movement, strength, connection

When discerning the text and images related to HIV/AIDS, I used obvious references like ‘HIV’, the names of agencies and physicians who are in the HIV field, and red ribbons. I also relied upon the knowledge gleaned in the two workshops, in which some participants marked things that were specific to HIV/AIDS discretely or in highly symbolic format, which would not be immediately discernable (i.e., the white paint on Isabel’s map that captures the idea of HIV as a “white man’s disease” and Ted’s “Desert Storm” reference that refers to a time when several members of his family received HIV diagnoses). These items are counted separately and included in the column totals, where I document the percentage of HIV references out of total textual and image items. When determining how the men and women compared to one another, the average in each category is used and not the raw score because the number of participants was not the same in each workshop.

The Enumerated Findings: A Gendered Analysis

On their maps, women use twice as many textual items compared to images, which is true for non-HIV and the HIV-related items. The most textual images appear on the Support figure, followed by On Map, and On Body. The difference between the number of items on Support and On Map is slim, but the On Body items are fraction of the others in this category. For the Images, the most items appear On Map, followed by On Body and On Support. The numbers in the three image categories are equally distal from one another, which is different than the spread across the Text categories. Among the men, their use of textual and image items was very similar, which is different than the women who had far more textual items than images. In the textual category the men scored highest in the On Support category, followed closely by On Body, and On Map. The distribution across the three textual categories is more even than among the women. In the Image categories, men scored highest in the On Map layer, followed very closely by On Body and then On Support. Compared to the women’s spread across the image categories, the men’s is a bit more evenly distributed.

In general, the men used more images than women did, not by a large margin but the difference is discernible. They scored higher than women in the two image categories of On Body and On Support. However, men also scored significantly higher than the women in one of the textual categories, that of On Body. The women scored higher than the men in two of the Text categories: On Map and On Support, and they had almost twice the total average of textual items than the men. Among the starkest difference between the men and women’s scores was in the Text Category—with women scoring over two times as many Text on Map items as the men and the men scoring over twice as many Text on Body items as the women. Interestingly, the women and men had the same average number of Images on Map ($n = 12$) and were fairly close in their average in the other two Image categories.

Among both groups, the textual and image items related to HIV/AIDS constitute a small fraction of the map items. This makes sense because of the approximately 20 questions in the workshops, only about six are specifically about HIV/AIDS. For both groups, the length of time living with HIV/AIDS is not correlated with the number of HIV-related textual or image items. As with the general trend women scored significantly higher than men for the number of textual items, with the exception of the On Body category, where the men scored higher. For the image items, women and men scored highest for the Images on Map category and lowest for Images on Support.

Content Analysis

Along with the numerical distribution of textual and image entries across the layers of each map, I wanted to analyse what the participants are communicating about and how they are doing this. My aim was to thematically code the contents of the Map, the Body, and the Support layers, using the visual and textual entries as the basis for the interpretation of what the participants are communicating about and how they express their various ideas, feelings, and experiences. Table 3.2 captures the dominant themes within and across the maps, which are organized by gender and by map layer, and Table 3.3 provides a succinct summary of the body mapping contents and communicative patterns across the sample.

Table 3.2 Content analysis of primary textual and symbolic items on maps

	Women	Men
On map	HIV Healing Addictions and other health conditions Identity Affirmative statements/slogans Journeys Supports Travel	HIV Goals Identity Journey Travel Supports Addictions Affirmative statements
On body	Biological representations of internal body Other health conditions HIV Marks Resilience statements/symbols	HIV Addictions Sexuality/sex Healing and recovery Marks Other health issues Cultural identity Travel
On support figure	Healing Various people/supports Nature Love/heart	Places Various people/supports Love/heart

Table 3.3 Overview of primary body mapping data and communication patterns

Gender	Primary mode of expression	Dominant issues	Life issues featured	Emotive engagement	Data consistency
Women	Textual	Culture, addictions, HIV/AIDS, health, healing, relationships	Comprehensive, contextual	Emotionally reflexive	Coherence in terms of what they say and how
Men	Symbolic	Addictions, HIV/AIDS, sexuality, mental health, self-acceptance	Comprehensive and select issues, sense of immediacy/ongoing struggle	Some are detached, some very introspective	Diversity in terms of what they say and how

On Map

Women and men feature similar themes on this layer of their maps, including HIV, identity, addictions, affirmative statements, future goals, and meaningful people, places, and animals. A unique feature of the women's themes on this map layer is a focus on healing and other health conditions, which are not seen on this layer of the men's maps. However, the men's maps feature more prominent expressions related to life goals that could be connected with healing and change, and they are concrete examples of future desires (e.g., getting married, going back to school, buying a house, travel, making restorative connections). The women's maps contain more expressions of connectivity and the relationships between different aspects of their healing journeys than the men's. The way the men and women express their experiences with HIV is also very different. The women provide more in-depth accounts of their lived experiences prior to diagnosis, life with HIV, and examples of positive outcomes/transformations associated with HIV, while the men focus more on learning their status, treatment, and stigma.

Many experiences that are specific to being Indigenous are featured on this layer of the women's maps, including symbols related to healing/medicine wheels, connections with family, and being involved in Indigenous-specific HIV/AIDS agencies and programs. More painful aspects of colonization also surface, including Georgia's reference to a residential school (Kuper Island),[3] Tarah's white footprints across her map that symbolize being raised in a white family, and Isabel's depictions of the different state institutions she and her family have experienced (i.e., residential schools, incarceration, foster system) that run along the bottom of her map.

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[3] Which was referred to as 'Alcatraz' by those who were forced to go there.

On Body

Both groups of participants feature experiences related to HIV, marks or scars, other health conditions, and resilience/self-care on this map layer. Regarding HIV/AIDS, all of the women mark this experience by highlighting the outlines and boundaries of their body, which have been ruptured by the virus, along with their internal bloodlines, and many document the bodily effects of HIV (e.g., memory loss, kidney failure). Among the men, three out of five signify HIV as being present on/in their bodies and include issues like their diagnosis date/conditions, medications, and infection journeys. A unique feature of this layer of the women's maps is their inclusion of biological representations of their internal bodies, including organs, which is only seen in one of the men's maps. Many of the health conditions identified by the women illuminate the connections between gender and health, such as HPV (human papillomavirus) and menopause, versus conditions like COPD (Chronic Obstructive Pulmonary Disease) or OCD (Obsessive Compulsive Disorder) on the men's maps; which are not tied as strongly to gender. This layer of the men's maps features more items than the women's, including several unique issues related to sex, sexuality, and being gay, and it is clear that the men tell the strongest stories through their bodies.

On Support Figure

Most of the items marked on the women and men's support figures refer to family and friends as well as HIV-related providers and agencies. Animals and nature are also featured on both sets of maps, as are indications of love, most often symbolized by whole or broken hearts. While the men include more references to spaces/places, namely friends and community-based agencies, the references on the women's maps relate more strongly to healing and along with the names of family often include the names of certain HIV physicians.

Interpretive Insights of the Participants

Women

Our participants had interesting insights about how the body maps could or should be interpreted, which for the women posed certain challenges because the process is complex and the meaning of the items featured are not always discernable. As Georgia said, "It's hard to describe! Gosh, I'd have to sit down for 10 min and try to explain it to them. I guess it's just your life on a map. You know…From birth to now!" Although very enthusiastic about the mapping process, Isabel also found it difficult to describe:

> I've been trying to describe it and I usually just say: 'It's to do with your past… and what's making you take your meds and what's making you want to take your meds!!! It's… looking at'…. I don't know, I can't explain it!…You've just got to look at it and you just got to do it yourself…You know, it's interesting. It's the thrill of doing something different…Plus, I think it's good to get away for four days and just be involved in yourself.

Abby also found it tough to define the maps, but like Isabel she said that with a visual example she could explain it more easily: "I had a hard time with the explaining! But I said, 'When I get the picture I will show you!'" Tarah said she is enjoying telling people about it, however, the links between HIV and body mapping may be something she shares only with people who are already knowledgeable about these issues:

> I'm having fun explaining it to people!.. 'You have to start off with – you draw yourself with a picture, an outline of your body on a six- foot poster'. I explained it all to my mom– she's more receptive about [it]… and how it relates to HIV or taking meds.

When discussing these issues with the women we asked them if including the one-page stories they crafted,[4] which summarize what the body mapping experience was like for them and what they hope the viewers 'see' in their maps, would make interpreting the maps easier. Rayna indicated that this might be helpful and drew parallels between this and the way art is displayed in galleries: "Maybe for other people have…you know, something to explain it. But to me, myself, I can see. I can see so much without explaining…I've been to Art Gallery. They always have a little introduction or something about the painting". Georgia concurred and drew attention to the sociomoral work that the stories could perform, namely reducing the stigma associated with HIV and people living with the virus:

> I think that's a good idea….I don't think they'd understand, you know, just looking at that…Then maybe you might have a chance, you know? But if somebody is still closed-minded around HIV and all, they probably wouldn't understand nothing.

Sue oscillates between appreciating the 'magic' of an unmediated presentation of the maps and being uncertain about having an outsider interpret her work lest it collide with her intentions:

> I really don't know how people interpret it… I think that that's the whole magic of it, you know? They might see a part of themselves in there. It may help them. It could be interpreted in a whole different way and so sometimes it would be good to hear… I don't know if I really want to hear what they have to say. Because if it isn't what I really meant, but it could be really helpful!

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[4] Which were part of the follow-up interviews and designed to summarize, in their own words, what their mapping experience was like and what they hope those who view their maps 'see'.

Men

Most of the men did not talk about trying to define or summarize body mapping and their discussions related to interpretation focused on the positive outcomes of the mapping experience. Ted was an exception in this regard and he indicated that without some kind of explanation or the one-page stories those viewing the maps could be confused or unable to make full sense of them. To address this, he suggested taking people on a 'tour' of the maps, which is something he regularly does when people ask about his map (which is stored in a visible space at his workplace) and what it means:

> It would be cool if somebody else could read it and know what it all means. But that just won't happen…You actually need to be taken on a tour of somebody's body map…I think it's important to have some sort of a description or an explanation…So people will know what they're looking at.

The other men provided moving accounts about the transformative effects of the methodology and how it contributed to their healing journeys. Here, Nolan draws attention to the special power of art to reveal different sides of ourselves to each other:

> Body mapping was a way to take a good look at myself and to face some of my fears…It helped me…. because I didn't do it alone…. I was able to learn from other people and see sides to them….That sometimes we're afraid to show. And I think it's easier to show other sides of ourselves through art…I think it's a way for the soul…. It's a way to bring the different parts of ourselves together and to sort of vocalize it. But without saying it.

Andrew expressed a deep affinity for the process, which he identified as supportive and unique in making room for considerations of the complex impact of time on lived experience:

> It's about getting into yourself in a real, physical space…I would say it's about taking an inventory. A personal inventory over time. It's not a point in time – it spans over time, both past and into also future, in terms of what your goals and aspirations or what your intentions are for your life… So each process was about a time and sometimes, parts of the process link time. And I really love that. I think the process was a brilliant one that facilitated taking that inventory…And…it didn't leave you hanging.

Evan also discussed body mapping in relation to what he was able to receive from the workshop, which emerged as a shining moment in his sometimes difficult life:

> The body mapping experience was exceptional, emotional, not-so-time-consuming, fun and an opportunity to meet other people …For me, HIV is not just a mind-fuck, but a cluster fuck. [But] with the support of my doctors, I know that I have a bright 'glittering' future ahead of me.

Key Study Themes: HIV and HIV Medications

I do not have the space to include all of our findings related to HIV and HAART (highly active antiretroviral therapy), however, this section includes some of the most salient themes related to these important issues that emerged in the interviews and my fieldnotes.[5] Along with the axial embodiment analysis of the body maps discussed above, these data add considerable richness to our already layered understandings of how the virus and HAART configure, shape, and complicate the everyday lives of our study participants.

HIV/AIDS

Women

> When Tricia went through the steps for today [day three of the workshop]and said that HIV is the focus, there was an immediate change in the women's mood. Sue turned her chair around so that her back was to the group, looked down, looked sad mixed with anxiety and resolve, and I think she may have shed a few tears. The first exercise was to put what it was like when the women received their positive HIV test results. They all paused for some time on their chairs before beginning and a couple of them commented about this being hard, and that they didn't know what to put down or how to put down what was in their heads. As Tricia noted, the air felt sort of tense today. She also said that the women didn't talk too much about why it was tense (Fieldnotes, May 5, 2012).

Living with HIV is a life-changing process that is realized within a shifting set of experiences and realities that change over time according to the unique contours of people's lives. While most of the women have been HIV positive for many years, even decades, they spoke about this aspect of life in very charged ways that resurrected the trauma associated with their status, the conditions surrounding their infection, and the lingering moral stain that is cast upon those with HIV. As Rayna said:

> Your life it's attached to a lot of things, like how you get HIV… It's so bloody…Like on the street, it's so bloody. You're working on the street…It took me six, seven years to basically accept that I'm a HIV Positive. Didn't even tell my family until I got in hospital last year. Not even my mom and dad.

Isabel described a host of competing and interwoven feelings related to learning her HIV status, including anger, self-pity, and using it to repel people:

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[5] Which come primarily from our interactions with the women participants who we were, as discussed in Chap. 2, able to maintain a longer and more extensive connections with compared to the men.

> I used to feel really, really sorry for myself. Like, 'poor me, I have this disease…'cause you go through that when you find out that you have HIV…I wanted to be sick and I wanted to be angry! It was just really bizarre! It was just, you know, wanting to attack people. I told everybody, 'I don't give a shit who you are! Yeah, I've got HIV!'

Abby focused less on the visceral outcomes of her HIV positive status and more about how it is linked with feelings of owning her status and knowing who she is: "I see it as, this is how I live with HIV. Not any woman in particular, but me, just me." Another woman, Georgia, reflected on how the body maps illustrate the temporal journey people travel when living with the virus, including how they contracted it, its effects, and using this information to further people's knowledge of HIV:

> You get to see how people got the virus, and how they coped with it, and how they're dealing with it. And you get to put that on statistics, whatever, and you know, for the future. I think it's a good idea, to see what went on with the time going by as, you know, age with the Virus, the HIV and how it affects somebody."

Sue's insights reflect her biological knowledge about HIV, which has been demonstrated to 'live' for long periods of time in spinal fluid and what could be termed folk understandings of the virus's behaviour- referring to how it 'hides' in certain parts of the body.[6] Speaking about the large splotches of paint in the upper portions of her body on the map, she said: "The HIV Virus, the heart and in the head, because I think that's where it's hitting me more. They say it lives in the spinal fluid, so that's why it's chunky up there 'cause that's where I think it's really hiding."

Men

The men's discussions of HIV focused less on traumatic experiences and more on coming to terms with being positive and finding ways to resist dominant discourses and testing practices related to HIV. When talking about disclosure Andrew drew attention to its multiplicity, and how it includes the ways that he tells others about his HIV status as well as the processes through which he is learning to self-identify as being HIV positive. In the following excerpt he engages with these issues reflexively and asks questions of himself, HIV, and his body map, each of which is integral to his evolving journey:

> This [his map] is a disclosure to myself. It brings up issues around disclosure and these are things that I face at work….The reason HIV is a connection… How does this live, now that I have this Map in my possession? …It's something that I own?…It goes back to my… that I am HIV Positive. I see disclosure as a process. As a journey, it's not a destination. So this is part of the journey and I'm glad I have it.

Disrupting certain symbols and terms used in mainstream HIV discourse are important in Ted's personal life and work in the field of HIV/AIDS service

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[6] Which brings to mind Sontag's discussion, early on in the AIDS epidemic (as it was called), of how the virus was often described as "lurking" in certain parts of the body (2001: 107–108).

provision. The traditional looped "red ribbon" that denotes HIV/AIDS appears on his map as a straggly, undone cord laid atop the phrase "STIGMA SUX", which was done purposively: "I entitled my Map: 'Stigma Sucks' because…My son lives with a great amount of stigma. You know, internalized stigma. So to me, that's why stigma sucks". He also critiques a keystone phrase developed in the late 1990s that was intended to foster greater inclusiveness of HIV positive peoples in research and activism, that of "living with HIV". He explains why he does not like this term and placed the following statement on his map instead, "I don't live with HIV. HIV lives with me. I am the boss. I am the landlord of my own body":

> Many years ago, when I was first diagnosed I learned the term "Living with HIV." I've never liked that term…. I was here first and if I live with something, then I live under their rule, whereas if they live with me they live under my rule. That's why if I was ever to get married, we would get a house together rather than have that person live with me, or have me live with that person…That way, 'It's our house.' But in this case, this is my body!…I have more control.

Evan shared interesting insights that reflect how biomedical knowledge of HIV and symbols of popular culture come together in his ideas about the virus. The Pac-man symbol in the middle of his map represents his spleen and is described in the following way: "The Pac Man…They go around and they munch up viruses. I chose this symbol because when I was first tested for HIV and then found out that I was positive, I envisioned many Pac-men chasing the virus throughout my body". The belief that the spleen can play a role in mitigating HIV spread has some medical validity because of this organ's ability (along with other lymphatic tissues) to absorb or slow aspects of the viral replication process (Li et al. 2014). However, Evan may have also selected this symbol because it captures the time of his diagnosis—the early 1990s—when this video game about a little yellow figure eating pellets and avoiding ghosts to save his own life was popular.

HIV Medications

Women

> One of the exercises was for the women to draw how they take care of themselves, including their medications. I overheard Tarah, as she stood in front of all the paints, saying "I see all the pills in all the colours." She seemed confused or uncertain as to the colours and kinds of her pills. At one point she poured out the pills she'd brought into her hand and painted those on her map. Most of the women drew the individual pills they take, and several also drew pot leaves because the majority of them smoke weed for pain. Tricia made an interesting point, that the women seem to have limited knowledge about what kinds of medications they are on and maybe also what they do in the body. I wondered how important it was for them to know the complete pharmacology of their medicines. Maybe they know "just enough", as has been demonstrated in other studies, they have their own way of internalizing and using prescribed medical information, or they 'simply' don't know (Fieldnotes, May 4, 2012).

This fieldnote excerpt reveals the women's uncertainty about and incomplete knowledge of their medications, including their effects on the body. Some indicated that although they do not know very much about their medications, they just follow their doctor's prescriptive advice: "I don't know all the side effects from the medications …and what the medication even does to me. I'm just taking it…'cause the doctor says so! Maybe if I did my own research, I'd think different" (Georgia). Tarah discussed feeling like an experimental subject, referring specifically to the side effects women experience from HIV medications[7]: "We're usually the ones that end up being the guinea pigs and finding out the hard way or watching other people do it the hard way, and then saying, 'you know, maybe I shouldn't do that!'" The women were very interested in taking part in an additional workshop that focused specifically on their medications, which was held a few months after the mapping workshop. Sue, who experiences significant medical problems related to menopause and her HIV treatment, was particularly enthusiastic about this:

> I would like that [a treatment workshop] because a lot of times we don't know what we're finding out about ourselves. I've been learning so much more about Menopause now… So why don't we get together and do something about it?!.. Or somebody that will even listen to our symptoms. I had heart palpitations and didn't know that was part of Menopause! I was scared to death, I thought I was having a heart attack…I talked to a few people and Googled heart palpitations and who do I get but Oprah Winfrey!

The women also expressed conflicting feelings about their medications, which help keep them healthy but also make them sick in debilitating, sometimes traumatic ways that bely the temporary discomfort connoted by the term "side effects". Georgia talked about the negative health outcomes associated with her medications and feeling caught between wanting to live and being scared by the medications that help her survive:

> I'm only taking five per day…..I'm starting to get side effects from, I don't know which one of them, but it's tingling in the feet, and neuropathy. In the mornings, most of the time I have a burning sensation in my stomach…It's affecting my memory big time. Sometimes I can't even remember what I did yesterday…It's just terrifying… I guess if I want to live, I gotta take these medications. Yeah. It's a catch 22.

Sue used the metaphor of a battle to describe the embodied and psychosocial conflict she feels because of the medications which, like Georgia, involve reflections on life and death:

> The memory loss. The dreams. That's all pill-activated…What's going on in your body? I really have a battle, like all these chemicals going in my body…Do I really want to continue that? Do I want to go on natural stuff? It's a real conflict…I don't want to risk dying…I stay on the pills because I want to live for [her family]…I'm alive and happy, so let's leave it at that.

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[7] Which have, as discussed in Chap. 2, been developed to respond to the [White] male body/physiology.

Isabel also situated taking medications within the realm of living or dying and juxtaposed being sick from HIV meds with being sick from addictions, revealing another layer of complicated feelings associations with HAART: “You know, the meds are hard to do…But what’s a little pain or a little discomfort for half a day, or a day, or I mean you got diarrhea for a few days? It’s better than being dope-sick or hung over… or sick in the hospital and dying”. Rayna drew attention to the importance that people place on pills and how much they know about them, along with the role that emotions, fears, and addictions have in shaping whether or not medications are taken:

> One of the things really important is not only how do we feel about the pills; how important we think the pill is… A lot of people don’t really care!…They don’t want to talk about it… They’re so nervous. They tell their friends, you know their friends gonna run away… They’re too busy doing drugs. They don’t have time to go to the clinic to pick up the pills or forgetting all together.

Men

Three of the five men in our study are on HIV medications, some for short periods and others for longer stretches of time. Ted has been on HAART and many other medications in the years that HIV has lived with him, as reflected in the approximately fifty individual pills scattered throughout the centre of his body map. Being regularly compliant with his treatment regime is not central to the management of his HIV and he chose to represent medications as a basic lived reality, nothing more: “Those are all my meds. I’ve been on many meds over the years. So I just had to acknowledge them. There’s no rhyme or reason to them, because I’ve never been very compliant!”

The other two participants discussed medication in terms of taking care of themselves and as part of their identities as HIV positive men. As Nolan said, “Something that is important in my self-care routine is taking my medication, seeing my doctors and discussing with my counsellors how I honestly feel about being HIV positive.” Medications figure prominently on Andrew’s map, within a triangular symbol that has information about CD4 counts, Viral Loads, their pharmacological contents, and a huge silver ‘check mark’ in the centre. His relationship with these medications is thick with competing, powerful meanings and, like learning to live with HIV, he has transitioned through different stages as he gets used to taking them. Here he describes his initial fears and how they were assuaged by the trusting relationship he developed with his doctor:

> I had lots of preconceived notions of meds and what they do….Without sounding horrible, but terms I heard, like ‘The AIDS look’… The wizened… atrophying of the muscles and then the fat distortions…I would see people like that I would think…Like, not ‘Eeeuw’, but ‘I don’t want that’… Luckily I have a really good Physician….I chose to stay with her because when I met her I disclosed my addiction and said: ‘I want you to keep track of this with me …I’m becoming accountable to you.’

In this next excerpt Andrew takes us through, in intimate and emotive detail, what it was like to take his first round of HIV medications—a touchstone moment when many feelings and new realities collided:

> I remember the first day I took meds…Rationally, I could get the prescription. I could pick it up and I could put it on the table… but to take that first…. I cried! It wasn't because of the fear, it was the whole recognition of where I am today and I have to do this for life. Part of it might have been a pity party. It was painful. Today, I take my meds… I'm not perfect at it but I always come back to – it's part of taking care of myself.

Discussion

I developed the axial embodiment approach at the heart of this chapter to document the wealth of information contained in our participants' maps and make sense of them in a way that goes deeper than the analyses featured in most body mapping studies, which focus on macro level themes like HIV, medications, health, family, personal journeys, and future aspirations. This approach allowed me to identify the array of issues/events that matter in the participants' lives, where and when within their layered lives they occurred and acquired significance, and also how their modes of communicating are shaped by gender. To operationalize this quasi-mixed methods approach, I looked very closely at what the maps are made of in terms of their symbolic and textual references and then proceeded to: (1) Enumerate these items by type and mapping layer (i.e., background, support figure, body layer); (2) Organize them visually (i.e., Maps 1.2, 1.3, and 1.4) to illuminate the unique characteristics and content of each layer; (3) Conduct a content analysis of the different map layers, based on their symbolic and textual content; and (4) Employ a gendered lens throughout this process.

The two sets of maps reveal similar kinds of information on the support figure/layer: people and places, love/heart, and for the women nature is also important, while for the men particular agencies emerge as important. However, the background and personal body layers reveal differences in the number of textual and symbolic references and their content. For the women, the background layer features far more items than the body layer, whereas for the men the number of items are distributed more equally. In terms of content, for the women issues related to the body, health, life before their HIV diagnosis figure prominently on the background layer and HIV is present but not immediately front and centre. Whereas among the men, their body layer contains emotive references to struggles with addictions, sexuality, cultural identity, and HIV is prominent; represented by specific references (i.e., diagnosis dates, infection journeys, stigma). Interestingly, the issues the men marked on their body layer align very closely with those that the women mapped onto the background layer, which may signal that among the men these difficult issues are more immediate and are having a particularly significant impact on their bodies—as the chosen layer/embodied medium through which they are expressed. These 'enumerated' findings correspond to patterns in the interview data, namely how the men discuss addictions and mental health issues more often than the women, as facets of life they are more directly engaged in. In contrast, most women do not raise these issues as often as immediate or pressing life issues, likely due to the fact that most are no longer using drugs and are engaged in therapeutic counselling and Indigenous health practices as part of their healing journeys.

The difference in communication patterns between the participants, namely that women use textual references twice as often as men and men use symbolic references far more often, is another unique finding. Determining what this might mean is challenging given the small sample size and the fact that examples of how gender shapes non-verbal forms of communication are nonexistent in the arts-based literature. However, one could infer that the use of text is a specific or precise mode of expression, whereas the use of symbols may be a less exacting or more indirect form of communication. That women use more textual items may signal their desire for more accurate or specific messaging. Men's use of symbols could be connected with their attempts to capture different experiences that are still raw or not yet dealt with. This corresponds with insights in the content analysis and interview data, which demonstrate that for the men certain issues (i.e., addictions, sexual identity, HIV) are more immediate and troubling compared to the women. What is particularly compelling about these findings is that they are diametrically opposed to those featured in gender communication studies, where men are framed as using textual references, which are thought to convey precision and agential power, far more often than women (Kimbrough et al. 2013; Siegman and Feldstein 2009). Further exploration of how gender structures communication patterns in projects that rely on enacted creativity, versus strictly verbal or textual approaches, could confirm (or contest) these study findings and represents an exciting area of research.

Another strength of the axial embodiment approach is that it is firmly rooted in participants' lived experience. By this, I mean that counting and organizing of the mapping contents relies on no external model, quantitative, text-based, or qualitative for that matter, and is quite strictly a counting of what the maps 'say'. The same is true of the content analysis of these data, which is also guided by what the maps 'say'. That I was present during the creation of the maps increases the likelihood that my interpretation of what the symbols and textual references mean are correct. These aspects of the approach can go a long way to reduce researcher-driven interpretations and strengthen data validity and credibility, issues that are often deemed to be lacking in arts-based research and one of the reasons it is assigned labels like 'non-scientific' (Conquergood 2002; Liamputtong and Rumbold 2008; McNiff 2013). Including the participants' perspectives about the ways in which body mapping can be explained or interpreted, and the kinds of experiences it can produce or enables individuals to experience, are additional participant-generated insights that are unique within the body mapping and arts-based literature.

Analysis is one aspect of arts-based research that is open to endless possibilities because of the diverse nature of this field and the lack of systematic analysis, an exception being Photovoice. I found the process of developing the axial embodiment approach challenging, but also very exciting because it enabled me to get more out of the maps—something that one of the participants, Luke, commented on when describing how body mapping is unique compared to other research approaches: “I think this has more facets to it…I mean it has more, you guys are trying to get more of us out of it”. This was a particularly important part of the overall project, which hopefully helps to refine the method and fully account for the tremendous work and life experiences the women and men put into their maps. Suggestions by others in the arts-based field may also be helpful for practitioners or arts-based enthusiasts who wish to enhance the analysis of their art data. Issues to consider, particularly during the planning stage, include determining the role that art can and should play in the research: “What is it we want it to do?” (Viega 2016: 34); “Are we searching for what is symbolic through the visual or what is intersubjective in relation to its social action?” (McIntosh 2010: 167). These decisions need not constrain or standardize the uniquely expressive, beautiful nature of arts-based research, which remains open to a great deal of interpretation. However, further exploration is important so that we can follow and understand the patterns in the images, rather than just viewing them in the hope that something will emerge (McIntosh 2010: 168).

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Chapter 4
To Change and Be Changed: Transformative Research Experiences

Art is the concrete representation of our most subtle feelings.
Agnes Martin (1996: 12)
Vulnerability is the shared condition of becoming.
Schildrick (2002: 133)

Exploring the Embodied, Political, and Aesthetic Dimensions of Transformative Research

During my twenty years of community-based ethnographic research I have worked with diverse groups of people in Canadian Indigenous reserve communities, women in sex work in rural south India, and men and women living in poor urban neighbourhoods, and each of these experiences has been deeply meaningful personally and professionally. During the present project I was struck by how transformative the research experience seemed to be for the participants, and myself. The meanings the women and men attributed to the body maps are rich and multi-layered, and it was as though they were re-fashioning themselves through their creation. I observed them taking emotional and creative control over the bumpy terrains of time, space, and the embodied contours of their lives as they confronted their pasts, made certain events explode with colour, and charted future goals. During the follow-up interviews they discussed how taking part in the workshops set in motion the participation in new kinds of employment, volunteer and research opportunities, and how it reminded them of their self-importance as well as the need to take care of themselves. Thus, the body maps emerged as embodied compasses and socio-emotional and material records of their lives, and by using them and the overall research experience to reformulate their relationship with themselves they are interactive tools of transformation.

The theme of transformation emerged strongly across both sets of participants and it captures the profound impact this project had on me personally and as a researcher. This chapter explores these issues, with a focus on the participants' insights about the therapeutic nature of the body mapping process and how the research experience sparked changes in them individually and socially, as a shared

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experience that bound them together and restructured particular relationships. I also discuss how this project was cathartic in my life, which is not meant to be an indulgent self-confessional exercise (Bowtell et al. 2013; Pillow 2003) but a celebration of the meaningful human connections that can be fostered during research that is life-changing (See also Hodgins 2014; Learmonth and Huckvale 2012; Levine 2011). To contextualize these data, I begin by tracing some of the constituent methodological and experiential factors that make arts-based work, including that which relates to HIV/AIDS activism, uniquely transformative.

One of the most significant aspects of arts-based research is its empowering and emancipatory potential. This stems in part from the transfer of creative license and power from researchers to participants, whose work not only captures their lived experiences but is considered of equal value alongside other kinds of data (Barone and Eisner 2011; Leavy 2009; Packard 2008; Pink 2001). Given the special power of art to both generate and assuage certain experiences this kind of work allows people to channel events and memories, including those that have been silenced due to trauma or structural oppression, and release them in ways that are therapeutic and constructive (Bagnoli 2009; Barone and Eisner 2011; Chilton 2013; Crawford 2010; Huss 2007; Lu and Yuen 2012). Although this is sometimes referred to as ‘giving voice’ to participants (Guillemin and Drew 2010: 177; Mand 2012), this term is somewhat problematic because it implies that participants possess agential power and the ability to express themselves only when these things are given to them or directed by researchers. Against this idea are studies that explore how encouraging participants to tell their own stories through photography, drawing, or body mapping is an empowering experience, as exemplified in the South African Long Life Project (Morgan 2003) and Gastaldo et al. (2012) study with Latin American undocumented workers in Canada.

Additional examples of the transformative nature of arts-based research are found in work that combines the arts with on-going sociopolitical struggles and therapeutic practice. As discussed in the Introduction, the HIV-specific model of body mapping emerged as a tool of collective healing, of memorializing, and a way to make visible the experiences of people whose lives were devastated by the epidemic. Women were using their own bodies and those created through body mapping to speak out politically for better health care services, access to HIV medications, and for the healing of their communities, families, and their own selves (Devine 2008; MacGregor 2009). This politicization through the arts did not occur in a bubble, however, and without the dedicated community therapists, artists and researchers who guided the women through this process it might not have been as powerful an experience. Indeed, many arts-based researchers note that the inter-subjective nature of these methodologies, which induce deep personal connections as well as vulnerability for participants and researchers, is part of their transformative power (Hogan and Pink 2010; Levine 2011; Potash 2013). As art critic and historian Amelia Jones (1998: 34) says about the link between environment and the actualization of the body-subject, the body is not self-contained in its meaningfulness and the ways it is received plays a critical role in the transformation from body into subject.

Activism is another vital context that contributes to subject and meaning-making in the world of art, and it is one of the most important tools used by those living with HIV and their allies to fight for sociopolitical and legislative change and human rights. The AIDS Memorial Quilt, which is the world's largest community art project, is one of the most evocative and politically important examples. Recognizing the need to publicly document and remember the gay men and others who were dying early in the epidemic, often alone in shame and fear, American LGBT activist Cleve Jones began making quilt panels[1] with the names, photos, and symbolic elements reflective of those lost (Jones and Dawson 2000; Shilts 1987). In 1987 he founded the NAMES Project Foundation[2] and organized one of the landmark rallies and showings of the quilt in the Washington Mall, near the Lincoln Memorial and within close proximity to both the White House and the Vietnam Veterans Memorial (Hawkins 1993). As a collective shroud, community fabric, and shared cry in the face of the national tragedy of AIDS and political apathy shown to its victims, on that day the quilt and its creators made history.

A tremendous amount has been written about the complex role of the quilt[3] and other memorial arts projects within the HIV/AIDS movement, as tools of consciousness-building, as ways to raise private funds in times of austerity and sociopolitical 'fatigue' with the epidemic, and as contested symbols that mark the transition from more radical forms of protest to those governed through mainstream or corporatized interests (Blair and Michel 2007; Catungal and McCann 2010; Capozzola 2002; Carocci 2010; Morris 2011). However, the quilt and other forms of arts-based production (Francis and Hemson 2012; Nabulime and McEwan 2010), including the tremendously important Visual AIDS foundation,[4] continue to be mediums through which to address the sociopolitical challenges facing those with HIV/AIDS. Securing support for HIV/AIDS-related artistic work is among those challenges given its 'third rail' status within funding and gallery/space showing contexts (Pence 2015), thus reminding us of how intertwined art is within the on-going struggles for that which not only reflects life but is an integral part of it (Watney 1987: 4).

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[1] Which, rather chillingly, measure "the size of a grave" or six feet by three feet (Hawkins 1993: 757). These remain the measurements that those wishing to contribute panels to the quilt must adhere to.

[2] The organizational home of the quilt, which was initially called the "NAMES Project quilt." Over time it came to be known as the "AIDS memorial quilt".

[3] Which at the time of writing (August 2016) contains over 49,000 individual panels remembering almost 100,000 names, and it weighs over 54.5 tons. Over the past 5–10 years, the Names Project/Memorial Quilt organizers receive an average of one new panel every day of the year (Williams 2016).

[4] Whose mission is to utilize "art to fight AIDS by provoking dialogue, supporting HIV + artists, and preserving a legacy, because AIDS is not over" (https://www.visualaids.org/).

Ethnographic Insights: Transformation Through the Eyes of Our Participants

The body mapping literature contains many powerful stories about living with HIV/AIDS and how these experiences are expressed in embodied form, alongside issues of health, relationships, and violence. Comparatively less has been written about how the body mapping methodology itself is perceived by participants and how the socio-emotional and transformative experiences gained from doing this kind of research can help support aspirations related to self-care, healing, and set in motion future or life goals. The data presented here is unique in its focus on the therapeutic, individual, and social changes our participants associated with the body mapping method and their participation in the project. Each of these themes is discussed below and is broken down by gender, beginning with the women.

Therapeutic

Women

When discussing the effects of the body mapping experience the women often highlighted how it opened up opportunities to reflect on their lives, good things and bad, and reconnect with their personal histories in ways that were healing or restorative. As Sue said: “The women are really, like…. It’s a great thing to help with their healing process and to acknowledge what’s going on inside themselves.” Several used visual metaphors to describe how the mapping enabled them to ‘see’ their lives in a different way or ‘opened their eyes’ to different interpretations of life events, as Tarah does:

> It forced me to see what I could remember from when I was really zoned out…When I hadn’t done anything for myself…. I was happy being unhappy, I guess!…It forced me to use my brain ‘cause I know current things are what’s keeping me together, but it’s all about what happened over the years that made me want to get better, so yeah, it was a good way to reminisce and remember.

Isabel talked about being woken up and having her eyes opened when reflecting on how the mapping impacted the way she views her body: “A lot of stuff came up for me…. I guess thinking back to how my life was before and how I wasn’t paying attention to my body…. So I kind of woke up a little bit, because my body is important…. It looks at the inside…. That really opened up my eyes.” Georgia also used a visual reference when discussing how looking at her map ushered in new realizations about her life and HIV/AIDS journey: “It helped me realize how I went through life and the reason I’m still here, you know? What I did and am doing. I just look at it and different things come to my mind as I see it again and—it makes you think. It’s one person’s journey from 24 years… being Positive.”

For several women the materialization of their lived experiences, embodied in the act of getting them ‘down’ on paper, helped ameliorate the pain associated with certain events or times in their lives. Isabel shares these insights when she discusses her initial embarrassment about recording ‘dirty’ parts of her life on her map and how she came to own them as part of her story:

> You see all the city and the hotels and all that kind of stuff? That really is a dirty part of my life…It was all about the drugs and about not taking care of myself, not caring if I died of HIV…I never thought I would really share that with anybody…But, you know, I have to. It’s my story. I can’t hide that…It’s embarrassing, but you know, I overcame it.

Sue also talked about the healing effects of letting some of life’s hardships go by putting them ‘down’ on her map, which involved taking a visual stock of her life:

> It’s my journey. It comes from my heart, it comes from my soul. Sometimes it’s hard to bear, to put it out there, but it’s the only way you can actually heal. When you stand back and look at it, it’s like that is my life, some of it…It’s like the hurt isn’t there anymore… I’ve taken it from here and put it there. A lot…of the negativity is gone.

Rayna echoes these sentiments, saying: “It’s an emotional release, you know? You walk out of the room, you know, you don’t take it home. Like, leave the work on the paper. They say you can’t take your work home.” Similarly, Abby mentions how helpful it was to be able to express and share her experiences on paper, versus ‘just’ talking about them or keeping them inside:

> When I go to things like this, it’s like ‘don’t talk about it’…It just stays, everything stays in…I was so honored to be able to take this. I know I got a lot out of it. You open up and then you’ve got to be able to share it by, like, putting everything down on the paper, rather than talking about it, right?

Men

“If people look closer, they’ll see… someone who dreams of becoming.” This moving account from Nolan captures his desire to transform, which was partially realized through the mapping workshop when he had the chance to document and dream about what this might look like. He went on to describe the heart he painted on his body map, which is a record of suffering and a symbol of the love and change he wants for himself:

> When I did the heart in the centre, originally I did it as a broken heart. But then I thought about it. What I’m trying to do with my life today is to mend my heart and to heal my heart, you know? And like, allowing others to love me …I’m learning to love myself and accept who I am.

These aspirations were shared by other participants who made connections between the mapping experience and taking care of themselves, including Andrew:

> One of the most powerful things for me…. Where I talked about, 'What does it look like today, in terms of taking care of yourself?' That's a positive thing and it has brought some positives in my life in terms of my lifestyle and how I take care of myself.

Evan shared similar perspectives and identified the workshop as a turning point that helped him identify and come to terms with some of his most pressing life challenges, while generating hope about overcoming these issues in a supported way:

> The body mapping made me realize. It made me realise that I'm at a cross roads…It was so overwhelming. I felt like I really had no future, I was stuck. The mapping made me feel like I do have a future…And I'm getting help and with the help I'll be able to overcome a lot of this.

For Ted the therapeutic outcomes associated with the mapping workshop are linked to the ways that it enabled him to take stock of his life and reaffirmed where he is at, along with where he wants to go:

> It really made me feel better… Not that I felt bad about myself, but it put things in perspective. It made me think that I'm on a good trajectory forward, you know? It made me kind of look at where I've been, where I am and where I'm going, and for me that was all good.

Luke talked about how the mapping workshop helped him organize and cope with some of his most painful experiences, by marking them physically on his map and in the process feeling as though he can be done with them: "So it's sort of like saying 'Move On', like 'This happened', 'The drugs happened, 'The HIV happened.' All this shit happened and now…. Move on! Next! Sounds kind of bitchy! 'Next!!'"

Self-transformative

Women

The body mapping experience generated a multitude of self-transformative outcomes among the women, which were framed in terms of enabling them to learn about themselves and feel good about who they are. As Georgia said, primarily in reference to living with HIV: "It's like an eternity. It doesn't seem real, I mean, I've lived this long with this disease and how I got through it. You know, I amaze myself." Abby's newfound confidence allowed her to open up more in relation to her own thoughts and feelings and with different people:

> I think a lot. I keep a lot within myself… But it was like, ever since I did this I'm starting to talk more about things, like with other people and other women too…I can't explain it. Just knowing that makes me feel better about myself, because I learned more about myself through a Body Map.

Rayna also learned about herself, including her thought processes, new coping strategies, and finding a way to come to terms with relationships that have been jeopardized because of difficulties associated with her past:

> It's tell me a lot about myself too, you know, a lot of things that I don't really realize. It sort of gives me an idea what it is going on in my head. What I have been going through…How I deal with it, you know? How am I finding a better way to deal with it…What can I do with the people that I love that I can't even talk to because of a lot of reasons, because of you know, like, my past.

She went on to describe her map as a kind of record that can be read to tell her things about herself and her life, which was unique among the women. Here Rayna ascribes additional attributes to her map, which emerges as not only a reminder but also a reflection of herself that she envisions interacting with as she seeks to take care of herself:

> Just like the hand – it's almost like: 'I'm gonna grab you!'… It's so powerful, to me, to look at it. It's almost like, I can jump out of it anytime for a fight or something!…It's almost, like, it's tell me what is wrong with me. You know what I mean? It tells me which part of me need work done because they always, like, tied to the other.

For some the mapping workshop was less about opening up new sides of themselves and more about providing a chance to reconnect with who they are, as Sue shared:

> Personal growth. Just reflecting on this stuff and this [body mapping] has got me through it…And my roots. I'm doing a lot of smudging, a lot of natural medicines…I'm getting back to being me and I'm really enjoying it.

Several women discussed their self-transformative experiences in relation to healing, remembrance, and the sense of achievement they felt upon completing the workshop. Here Sue introduces the multivalent symbol of the butterfly, which is used figuratively to describe her healing journey and it may become marked on her body as a permanent testament to these changes and the exciting new direction she is heading in:

> That is emerging from where I've been, coming out of the cocoon of where I was and really letting myself be me…The butterfly has been my symbol. It's in all my work… And I'm getting the tattoo done of that too. Yeah, that's my emergence…Not to where I ever was, but to my new direction and just going there. Continue to fly!

With introspective reflection Tarah talked about how some of the negative events recorded on her map have 'changed positive' and that she is no longer in the sex trade, two pivotal experiences that she frames through reference to looking out the window and its protective curtain:

> I look out my window…I'm not trying to advertise myself as I was looking for things before. It helps to have my curtain on my window because it allows me to remember that I don't want to be out there…A lot of things are negative on here that changed positive. It helps to know what I was doing then to what I'm doing now, or what I translate as being what's important to me or not.

Isabel talked a great deal about the positive outcomes stemming from the completion of the workshop, which include overcoming obstacles, doing new and inspiring things, and entering into meaningful relationships with the team members and other participants:

> I get inspired by what I'm doing right now. It's taking my life to a different level. I've never done this before…I can see how far I've come and that other stuff…the obstacles. They were just obstacles…Thank you so much for allowing me to do it and for allowing me to come into your guys' life and you guys coming into my life.

Men

The men in our study identified various personal changes associated with the mapping workshop, however, for Luke they are only touched upon briefly: "It did help me learn some things about me." Like Luke, Evan did not go into detail about self-transformative outcomes linked with the workshop but the message he hopes that his map conveys evokes a sense of profound, even cosmic, change: "I guess it talks about the Circle of Life and the human journey…. From birth to death, and I'm somewhere in between!" One of the most important aspects of the experience for Ted was the cultural currency and power associated with the maps, specifically the role he anticipated them playing in the context of his HIV-specific workplace:

> I was really excited about being able to show them…Like having them at the Annual General Meeting and having them at the Vigil[5] and having the guys be okay with that. Which is, you know, that's huge. I'm really looking forward to that. And sharing that with my bosses and having them be excited about it.

Nolan went into more depth when talking about the socio-emotional changes generated by the workshop, including helping to believe in and care about himself:

> One thing that I've sort of taken away from it, which I still struggle with is, self-acceptance…When I did the evaluations and I filled out mine, you know, one thing that stood out to me is that it's beautiful…It was like…'Okay, you know what? You're a beautiful person.' And it did sort of help me to see that.

Equally moving is how he described the lasting effect of Tricia's supportive feedback on his body map during the informal art show at the end of the mapping activities, which surfaced as a flicker of hope in the darkness of his drug relapse that followed the workshop:

> That struck a chord with me because even when I did relapse, it was almost like her spirit was saying to me 'Nolan, stick with this!'…It really spoke to something inside of me that said this person sees something…'This is something that is really good for you, Nolan! Stick with it!'"

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[5] Which is part of the celebration, awareness, and education activities that take place during International HIV/AIDS Day, held annually on December first.

The workshop was also transformative for Andrew, who talked about growing up feeling "terminally unique" or very alone and as though he never fit in. The body mapping experience brought him out of those lonely shadows and into the energy, belonging, and confidence that he is beginning to feel about himself and his life:

> It should have all been grays and muted blacks…I think that, in part, is how I see my life… But I'm beginning to see that and as I'm more genuine…There's lots of positive action – there is life and there is energy!…Holy shit, there is a lot of fucking colour on this! And it is real – when I look at it, I actually identify with it. I don't think, 'Oh my God, I want to change that!'"

Andrew also spoke about the importance of balance- of restoring it, of having it returning to his life, and how it is connected to his shaping of the future. On his map he chose to represent these issues via an electro cardiology machine, which is a diagnostic test that measures the electrical activity of the heart:

> I chose a heart-beat, like, the EKG machines to transverse me from there [reference to past] …to there [reference to the present]…To this point where I'm holding my future in balance and I'm shaping it…That's what those hands and that yellow, glowing ball is!…I sit in balance with those things in my life…The balance came back.

Socially Transformative

Women

The women formed strong connections with one another during the mapping and although many of them were familiar with each other prior to the workshop, the bonds they formed as part of that shared experience are very meaningful. As Abby, with typical good humour, described: "We all know a lot about each other now and that's nice. Because it's weird, after that first day, right?" Speaking about the prospect of staying in touch with each other Rayna said: "You know, just once in a while get together with a group who do it together, have light meals. With the same women, whoever can show up, you know, just a little get together thing. It would be very nice!" Sue talked about how authentic their connections are and used examples of how the closeness fostered during the workshop carried over into her relationships with other participants after the body mapping activities were over:

> Through this I've made such a connection. One of them, she wanted me to go with her when she went into surgery…I see her quite often and it just seems we're more comfortable with each other now…I think knowing that I had those days together made a big difference. And you know, one of the other women is in one of my support groups right now and it's just… It's a real connection.

Tarah used the visceral image of a scar/wound when explaining the care that needs to be taken when attending to such close relationships and heavy issues that emerged during the workshop:

> Yeah, for sure! I think that would be good for them! [to meet after the workshop]…'cause you don't open up a scar or a wound and not expect it not to be an open scar after all that time. You have to tend to it, sort of thing, or it keeps opening up. And it's like, who's going to take care of that?!"

This account from Isabel illuminates how the relationships among the participants constitute, from her perspective, a supportive community of women that she hopes will never cease being an important part of her life:

> Making us six women get closer, like… I need to hear other women's stories. And they need to hear ours… because they're kind of the same thing, but just in a different way. It's a community. I have a community of us women in the group. And I'll probably never lose touch with each other. Ever. And that's my story! I love you guys. Thank you!

Men

While the men did not assign as much meaning to the connections made during the workshops as the women, they enjoyed getting to know each other better, as Nolan shared: "I connected with some of the other men there, and you know…. It was good." Similarly, Andrew said:

> It was interesting…. When went out for a break or whatever and as it went on in time, it was: 'Oh, my opinion of you has changed. You're not as much of a bitch as I thought you were!'…On the last day… It was like, 'Oh, you guys are so familiar now.'

Evan shared similar insights, "It was nice to meet new people…. It was just nice to meet all the guys, now I feel like I know him [another participant] a little bit better." For Luke, the importance of the relationships he formed was linked with their shared vulnerability, which made him feel more at ease: "I got to meet them in a different way, and it was a good way for the most part…. It's nice to be able to see them, you know, in a vulnerable state. It makes it more comfortable for me."

Transforming Therapeutic Relationships and the Politics of HIV/AIDS Research

Towards the end of the workshops many participants discussed wanting to share the mapping experiences with their HIV physicians, other care providers, and community agencies they access regularly for various services. These people/places are marked in prominent spots on their 'Support Figure' and are described as being extremely important, often life-sustaining. That our participants wanted to bring the mapping experience into these relationships is further evidence of how important the workshop activities are to them, and that they envision the maps as having the potential to transform or infuse particular relationships with new meanings. Many discussed having copies of their maps in the therapeutic, supportive, and work-related spaces they frequent, specifically those related to HIV/AIDS. This was described as helping to illustrate what body mapping is and the vitality, creativity, and hope in the lives of people living with the virus, representations that are rarely featured in clinical and service-related settings. Having the maps in these special spaces is also part of paying respect to the people who have played the most important roles in their HIV journeys, as Sue shared in her follow-up interview:

> Those are the people I associate with first, and like anything, you want your friends to see it first. If we were to say, do it at the Shoe Store,[6] and then Dr. Roze walked in and… I could see where the staff, who have gone through all this with you, would say 'Why are the public seeing this before I do? I've been there since the beginning?…We're the ones that were there when you cried, when, you had this', you know? To me it's just respect.

For Sue, the body mapping experience also provided an opportunity to contest or reshape a different set of relationships, those related to the divisions between 'researchers' and 'participants' within the realm of HIV/AIDS research. While these data could be considered "minor" because reflect the experiences of one participant, they are included because they illustrate the tensions related to the experiences of those with HIV, whose insights about and roles within the stratified power relations in the realm of research are rarely explored.

Early on the workshop Sue seemed incensed when one of the student-researchers expressed a desire to lead a body mapping workshop, asking her "What do you know about this?"—referring to being HIV-positive. This complex question evokes the thorny ethical issues within HIV and other collaborative research fields, in which funders often mandate the participation of people with lived experience but provide little substantive discussion of what that should look like (Aldridge 2014; Carter et al. 2015; Persson et al. 2003). It also aligns with claims made about participatory visual methods being more 'equitable' or emancipatory, which may not always be the case (Packard 2008). Many HIV-positive people, like Sue, want to be more meaningfully involved with research beyond the token positions offered to those with 'lived experience' (i.e., members of community advisory boards). However, within the hierarchically structured arena of HIV research the more substantial roles are usually allotted to those with formal research training and education, which can make those living with HIV feel used and as though their 'glass ceiling' within the HIV research world is quite low. The notes below illuminate some of these tensions, including the fact that Sue knows she plays an essential role within research, yet possesses somewhat limited power to make a place for herself at the table:

> At some point Julie said she wants to learn how to lead a body mapping workshop. Sue retorted, saying something like "what do you know about this [HIV/AIDS]?" It's so complicated when and how meaningful participation of people living with HIV/AIDS is

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[6] Initial ideas about a venue to display the maps included a trendy shoe store that has a beautiful shop layout and with whom one of the team members is associated. This option was not popular among all of the participants, who were more interested in the art show-dinner event we ended up organizing.

> taken up by real people, not researchers who have no idea what it's like. Sue's somewhat forceful insistence upon inclusion reflects the experiences of "HIV work" of a whole generation of researchers and researchees, of which she sees herself a part. I'm speaking of the time when people realized they can't just use these people's disease and farm out their experiences in the form of $, drugs, and publications but actually have to involve them. The critique of the inclusion of "peers" that stems from this period (c. early 2000s) often focuses on how the experiential partners' lack of knowledge about research means that they're doomed to be no more than token representatives. Obviously things have shifted since this time and Sue is reminding us that the fact that I don't know what it's like to be HIV positive means something, and it can be harnessed by "them" to try and ensure that research is more equitable. Just like the 1000s of people without HIV or AIDS who have HIV and AIDS to "thank" for their careers, people like Sue can claim a certain slice of the HIV empire/business/work/industry (Fieldnotes May 5, 2012).

Since completing the workshop Sue has gone on to be a major player within the HIV research field in Vancouver and nationally, and as a 'peer researcher' and 'research associate' she has presented at various national and international conferences and is an author on several academic publications. She has also received training in how to facilitate body mapping, a desire that she expressed during the project.

Transformation Through the Eyes of the Researcher

In the years between the workshops and the writing of this book, I found myself pouring over our participants' maps[7] and recalling certain words and phrases from the transcripts. *'Remember when Sue asked us to paint our hands on her map?'*; *'I cry every time I read Nolan saying that he is learning to love himself'*; *'The seemingly smallest things can mean so much, like when Isabel said going to a 'cool' restaurant boosted her self-confidence and made her feel 'normal.'* Research, particularly that which is collaborative and participant driven, is about more than collecting facts; it is fundamentally about connection and striving to make a difference in people's lives. This is especially true when working with people who are socio-economically, sexually, and racially marginalized and for whom opportunities to connect, without strings and in supportive ways, are infrequent (Stein and Mankowski 2004). While my feelings as a researcher are secondary to the success of the project they emerged during interactions with our participants, not in a placid or detached analytical space, and as such they are social facts (Kelly 2008) and relational ways of knowing (Spencer 2010) that form part of the fabric of the overall research experience. Writing about these things may encourage other researchers to reflect upon their own work in different ways, including how to make sense of

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[7] See also Futch and Fine's (2014: 55) discussion of how mapping/visual data allow the participants to enter researchers' minds/memory during analysis in ways that are unique compared to text-based data.

arts-based and visual research that describes human experience and directly manifests it (Briggs 2013; Franklin 2012: 90).

One of the most powerful aspects of this study was being able to witness the changes that participating in this project had in the lives of our participants. When I took Evan out for lunch a few weeks after the men's workshop wrapped up he brought some photos of himself and his dogs, who figured prominently on his map, and a gift for me—a pendant that matched some earrings I wore on one day of the workshop. He and I share the experience of having lived in Vancouver, loving animals and the decorative arts, and knowing many people who survived the early years of the HIV/AIDS epidemic. These things bound us together in a meaningful way. Evan also shared with me (and Tricia) his on-going struggles with alcohol and PTSD, his loneliness, and how much being a part of the workshop meant to him. He discussed these things over lunch, which he thanked me for several times. While this may seem like a 'small' example it stands out in my mind because it reflects Evan's courage, kindness, and desire to connect, and mine too, which is the beating heart of research/human experience that is transformative.

As with other rather discrediting things,[8] researchers' accounts of their personal struggles with addictions rarely find their way into academic projects or writing. However, sharing these experiences with the women and men in our study felt safe, perhaps because they were also engaged in healing journeys and felt like trusted members of a 'therapeutic community' (McNiff 2011). While I did not divulge this aspect of my life to gain 'street credibility', it generated bonds between myself and certain participants that may not have formed as quickly or strongly had I not shared this with them. It also signalled my vulnerability and opened up meaningful, potentially 'power-leveling' (Packard 2008: 63), interactions between us. The following fieldnote excerpt captures some of these issues, including my initial worries about spending time with Rayna during the art show because she had been drinking and how our embodied interactions through tattoos (and the sharing of a cigarette) dissipated these concerns and made me feel comfortable to share where I was at in my sobriety. Her insight about 'the holiday' was especially touching:

> Rayna asked if she had shown me her new tattoos and she pulled up the sleeves of her hoody to show me: "believe" in nice script on the inside of her right forearm and a skull with a melting candle on her left arm. I said that I have a new one and we scuttled off into a corner of the café and I showed her my emerging Frida piece. Tattoos are a medium though which she and I communicate. It's something that not only she and I share (the others have them too), but we seem to feel quite similarly about them. We went outside for a smoke together and had a good chat, and I forgot she might be drunk and forgot my earlier concerns about interacting with her. I mentioned that I'm nine months clean and she congratulated me, but said the holidays are coming, implying that it's a hard time to be sober (Fieldnotes December 18, 2012).

My third example relates to leaving the field, which is always difficult because it means leaving people I care about. Saying goodbye to the women, in particular, left

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[8] See Warden (2012) for a similar discussion of PTSD and emotional trauma in ethnographic research.

an indelible mark on me because our last meeting with them (the art show) coincided with the release of the inquiry into the police mishandling of the Robert Pickton case.[9] Given the powerful impact the case had on the city of Vancouver and the issue of murdered and missing women internationally, all forms of media were flooded with stories about the case, the women's family members, and agencies involved in the fight for judicial reform and healing. Being in Vancouver at that moment, working with women whose lives are similar to those who fell prey to Pickton, and knowing I had to leave after making powerful connections with them was a heavy swirl of feelings to navigate. Reflecting on this cluster of issues in my fieldnotes after the art show was a way of trying to ground myself, as was marking these transformative events more permanently:

> I tell myself that writing these notes are a book-end to the body mapping project, a way to wrap up data collection. In reality, they are being written to contain, savour, and keep sacred all that has happened over the past five days and the 200 days in between the time I first met the women and had the first workshop. Talk about "revolution" Rayna, that's what this has been. A jarring, unexpectedly transformative series of pages and chapters of change in the lives of the six women, in my life, and in Trish's life. I had to turn the radio off because I can't hear any more about yesterday, when the report was finally released, all 1,450 pages…I can't handle it any more right now…I got a tattoo yesterday to commemorate the day and the place. It had to be done yesterday and it had to be done in Vancouver. I got the words: "FOR ALL THE WOMEN" in capital letters and 'old school' script beside the Mariner's Cross- a multivalent symbol of being anchored in the world, the loss of human moorings, and the ever-present, complicated role of hope, salvation, freedom in our lives (Fieldnotes December 18, 2012).

I include Tricia's insights as well because she also found the experience transformative and is in an excellent position to reflect on these issues given her expertise with body mapping.[10] In our discussions about how special this project has been, she often talked about the psycho-social challenges of being a facilitator and her relationship with one woman in particular, Tarah. These notes are from an email:

> It is not easy to be everything to everyone in a workshop, and leading a Body Mapping workshop demands stamina, self-love, and focus. For a facilitator, there is always the reminder that the workshop is for and about the others in the room and not the opportunity for you to tell your story or to let your emotions rise to the surface. It is a fine balance to be present, empathetic, and to provide an environment that fosters creativity and emotional, physical and psychological safety.
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> I remember first meeting Tarah and recall appreciating, but being slightly intimidated by, her candour and honesty. I remember thinking that I might need to spend a bit more time explaining the exercises to her, as it seemed her ability to focus and sit quietly was often

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[9] Who murdered forty-nine women from the Downtown Eastside neighbourhood in the late 1980s–1990s, most of whom were poor women struggling with addictions, racism, and various forms of socio-economic, sexual, and historical trauma (Cameron 2010). I lived in Vancouver during the Pickton trial of 2007, which was a deeply disturbing experience that can only be described as emotionally surreal (See Baldwin and Orchard 2009).

[10] She has led over twenty-five body mapping workshops all over the world.

> interrupted by her knee-jerk responses to the artistic prompts. Her quick responses and somewhat antagonistic retorts to some of the exercises led me to worry that she would not enjoy the experience as much as the others or that she would not return on day two. But Tarah showed up every day and with each passing day became more engaged, more sociable and more enthusiastic. I watched her map take shape, with light brush strokes that revealed her beautiful, cherished cat, a grand piano; suggesting that she had lived a life I never expected to learn about. She was a so many things- an accomplished classical pianist, an animal lover, a sister, a former sex worker, an Indigenous woman “raised white.”
>
> After the art show, Tarah invited us to her home, to see her pictures from a recent family vacation. I ‘oohed’ over her pictures, met her beautiful cat, and a friend of hers (Geoff) who offered to work with me to create website for the maps. One day after the project wrapped up, I received an email from Geoff saying; “It shouldn’t take long to get the site running… No fees for this project. It’s an opportunity to spread awareness about what I call, “The Russian Roulette of Disease”(You really don’t know [what] you’re actually going to die from). Information like this may prevent another victim. Will say hi to Tarah for you.” Geoff’s email reminded me of the power of this work – how it often does not start and stop with the participant. For those who know and love individuals living with HIV, there’s a desire to learn more about HIV, to save others from its pain, and to spread the word about the disease and the body mapping process itself.
>
> Just before leaving Tarah’s home, she handed me a Christmas card. The white envelope was a bit crinkly around the edges, as if it had been carried in a bag for some time. Alone in my hotel room, I opened the card to see that it read: “Thanks for helping me with my life. Merry Christmas. Love, Tarah.” This card sits in a special place in my home today. I have kept it because I do not “do” the Body Mapping work in search of accolades or appreciation. I do it because it means something to me and I hope it means something to those I have the privilege of sharing the experience with. I could not have asked for a more precious gift from Tarah. I treasure my memories of her and every once in a while, when I am looking through my keepsakes, I take out the little Santa Claus card and read it over again.

Discussion

The arts-based research literature is replete with examples of the unique, deeply moving findings associated with approaches like Photovoice, drawings, performance-based studies, and body mapping. However, less attention has been paid to the ways in which these approaches and attendant research experiences, in and of themselves, can generate personally and socially relevant outcomes for those taking part. This chapter illustrates how our participants were regenerating, across time and the embodied spaces on their maps, their accumulated life experiences and making room for future or imagined desires and ways of being. This re-charting of how they inhabit the world and the spaces within themselves illustrates how body mapping can offer participants opportunities to cope with past events and open new doors of pride, self-discovery, and knowing that are empowering. These insights about the connection between body mapping and the production of multiple embodied subjectivities (Braidotti 2011) are a unique contribution to the arts-based literature, and they align with studies that demonstrate how participant-generated forms of art and reflexivity can improve people's lives and their ability to create a place for themselves in the world (Biehl 2005: 23; Garber 2004).

The women discussed how the body mapping experience enabled them to reflect upon their lives and reconnect with difficult times or events in ways that were restorative. They often used visual metaphors like "it opened my eyes" (Isabel), "it forced me to see" (Tarah), and "as I see it again" (Georgia) to capture the reformulation of their lives that unfolded during the body mapping and the importance of seeing or visually witnessing these processes. Some of the men employed similar metaphors, including Nolan who highlights the visual for others to see that he is a person worth looking at and as a therapeutic talisman for himself:

> It really just helped me to take a good look at myself…It helped me look at myself in a different way…. I'm definitely going to put this up on my wall because I need to remind myself that, you know, I am a beautiful person…If people look closer, they'll see that there is someone who has been through some stuff, and struggled with some things, and someone who is embracing a sense of community with being HIV Positive.

The ability to get difficult or deeply buried experiences 'out' and 'down' on the map was raised by several participants, particularly the women, as helping them heal from these experiences. Several men also discussed the mapping workshop as a turning point in their lives, which served to remind them to take care of themselves (or to keep on doing this) and allowed them to take stock of their lives. As Evan said: "The body mapping made me realize I'm at a crossroads in my life, suffering from PTSD-it was so overwhelming…. I felt like I really had no future, I was stuck. And the body mapping made me feel like I do have a future."

Along with the therapeutic outcomes our participants identified personal transformations that occurred as a result of doing the body mapping, many of which continued to shape their lives after the workshops were over. The women frequently talked about learning who they are and feeling good about themselves, and Abby discussed being able to open up more to people after the workshop: "Ever since I did this I'm starting to talk more about things, like with other people and other women too…. I can't explain it. Just knowing that makes me feel better about myself." Isabel said that the workshop enabled a new way of living for her, which includes knowing that she can overcome life's hurdles: "It's taking my life to a different level. I've never done this before…. I can see how far I've come and that other stuff… the obstacles. They were just obstacles." The men identified individual changes less often, however Nolan's insights about how this experience helped him accept himself and showed him that others care about him (especially during his relapse following the workshop) are deeply moving. For Andrew the body mapping was also transformative, helping him restore balance in his life and realize that he—and not only his map—is full of vibrant, complex colour: "And it is real. When I look at it, I actually identify with it."

Socially transformative outcomes connected with the workshop were also identified, mainly by the women who cherished the bonds fostered between each other. As Sue said, "Through this I've made such a connection…. It's a real connection." Isabel drew attention to way in which sharing each other's experiences transformed them into a special community of six women: “Making us six women get closer…. I need to hear other women’s stories. And they need to hear ours…. I have a community of us women in the group.” Tarah highlighted the care and work that such special relationships need to be maintained, likening it to a wound that needs tending to: “You have to tend to it, sort of thing, or it keeps opening up.” Another instance of how the body maps functioned to sustain social relationships emerged when participants discussed where they wanted their maps to be placed following the workshop. They identified HIV-specific spaces and health care contexts where they have developed strong relationships with particular providers, and where others living with HIV might see the maps. In this way, the maps were envisioned as symbols of health-related accomplishments and functioned as powerful, therapeutic testaments to the beauty and vitality in the lives of those living with HIV/AIDS. The final ethnographic example in this chapter involved Sue, whose questioning of a team member who wanted to lead a body mapping workshop revealed some of the ethical and political tensions that shape the field of HIV/AIDS research. In particular, the differential power assigned to people with ‘lived experience’, who sometimes feel used in research that depends upon their participation but offers little in the way of substantial contributions or long-term employment opportunities.

This chapter also featured insights about how the project impacted me as a researcher and women deeply engaged in this transformative experience alongside the participants. This work does not happen in an objective bubble removed from experiential meaning for us as researchers (Berger 2013), and it was through deep human connection, the creative power of art, and the special people I was able to meet during this project that made a difference in my life.

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Chapter 5
Between a Method and a Hard Place: Cultural Appropriation and Body Mapping

> *Cultural appropriation can be defined when one person from one* culture *takes culturally distinct items, the aesthetics or spiritual practices from another culture and mimics it. They adopt it as their own without consent, permission or any cultural relationship to the object or practice, in order to make money or just because they think it's cool*
>
> Janet Rogers (2016)

Cultural Appropriation in Body Mapping Research

Recognized for its potential to generate rich, artful data while providing enriching experiences for participants, researchers and practitioners from around the world use body mapping to explore the social and embodied determinants of health among various populations, primarily marginalized women. These studies rely heavily on the South African approach developed by Solomon (2007) and Morgan and The Bambanani Women's Group (2003), specifically the 'Living with X' guideline that lays out the daily exercises and how to respond to questions or emotionally challenging situations that may arise. However, when applied in research projects, particularly those in the Global North that do not explore HIV/AIDS, the therapeutic process[1] is often excluded or significantly downplayed. Discussions about how researchers have adapted the South African methodology to align with the cultural context or aims of their projects are also rarely featured. The adoption of some tenets of the method and disregard for others raises important ethical questions about the cross-cultural use of research methods. Is it permissible to selectively borrow aspects of the method for use in settings that are different politically, culturally, and materially from those in which body mapping was cre-

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[1] Referring to considerations of time (i.e. a four-day process), check-in and check-out activities (which enable participants share their experiences and be supported in an on-going way), ensuring that a trained facilitator leads the process and that additional support staff/helpers are on hand, and having well thought out ways of responding to any triggering experiences participants and others involved may have.

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ated? What are the implications of these borrowing practices, for the integrity of the methodology and experience of participants? How might cultural appropriation in this context be resisted or ameliorated? This chapter explores these questions and situates different examples of the cultural appropriation of body mapping within broader debates about global flows of power and knowledge.

While cultural appropriation is sometimes conceived of as a historical practice involving the theft of Indigenous cultural items and their placement in imperial palaces and state museums, it is very much alive today. Indeed, it is discussed in relation to an array of issues, including clothing and sport (Forsyth 2016), knowledge and natural resources (Batiste 2016; Pert et al. 2015), legislation (Riley and Carpenter 2015), literature (Madsen 2016), design (Tunstall 2013), as well as sexuality and gender (Acoose 1995; Pickles and Rutherdale 2005). Although a research methodology is a less 'tangible' example of cultural appropriation compared to stealing a cultural artifact or co-opting ceremonial practices, the case can be made. First, the body mapping approach constitutes an indigenous form of knowledge and aesthetic as well as healing practice that originated within a culturally distinct place and time-that of South Africa, during the early part of the HIV/AIDS epidemic, when women and others were being denied access to life-saving medications. Second, it is being used throughout the world in divergent ways that do not always align with the intentions of the original creators. All body mapping projects need not be about women and/or HIV/AIDS, nor do they have to follow the South African approach in its entirety. My critique here is about the lack of attention, if any, paid to the use of therapeutic principles and practices and the insufficient recognition of the cultural context in which the method originated.

These issues are of significant concern to the creators of the method and those working in the body mapping field,[2] who have witnessed the dangers of the careless adaptation of the methodology. Shortly after the 'Living with X' facilitator's guide was created and shared among non-profit agencies and practitioners in South Africa, there was tremendous interest in body mapping. In response to this, the facilitators guide was made available online, so that others could learn about and from this special work. However, almost immediately Solomon and others began hearing of individuals and organizations who were using aspects of the guide/methodology but not following through with the therapeutic practices. The South African agency Solomon and others worked with was even called into mediate and work with participants in a regional study, who were traumatized when their facilitator left them mid-way through the workshop because he/she was not equipped to handle the difficult experiences being shared. Reflecting upon this situation and learning of other similarly troubling examples, the facilitators guide was removed from the Internet. Those in key body mapping circles were very

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[2] These insights were provided by teammate Tricia Smith, who was trained in the body mapping methodology by Solomon and Morgan. She remains in close contact with them and uses their approach in the mapping workshops that she leads all over the world, including the two for our project.

concerned about any harms they may have inadvertently caused by making the guidelines freely available and deeply saddened by the misuse of their methodology.

The situation surrounding an invitation I received to take part in a body mapping study reveals another set of issues at play in the cultural appropriation of the body mapping methodology. In the introductory email the team lead, who I had never met, indicated that my experience with body mapping would strengthen the application. While I was cautiously optimistic, these feelings gave way to frustration and dismay during our meeting, which consisted of her sitting across from me—pen poised—wanting to record what I knew about the methodology. She did not seem to have a clear sense of how body mapping works, evidenced by her suggestion that participants have one or two mapping sessions, not even full days and nowhere near the four days recommended. She was also unable to respond to my inquiries about practical issues (i.e. space, materials, number of participants/mapping group, hiring a trained facilitator) and had not given much thought to therapeutic principles and/or practices. The impression I had is that she wanted to try out this new method and needed someone on board who could or would ‘do this part of the project’. Although this happens all the time in university and community settings, that she had not taken the time to explore the literature or think carefully about how this method fit with her study aims, and would impact the experiences of prospective participants, made me very uncomfortable. I went through with the submission process out a sense of obligation to the integrity of the method and to infuse a modicum of expertise into the application, and was relieved that it did not get funded.

These examples illuminate some of the troubling practices at work in the cultural appropriation of the body mapping methodology, which remains very popular in various research, clinical, and community circles settings. These instances of cultural appropriation matter because they can harm participants and fuel projects designed with methodological innovation in mind at the expense of methodological integrity. They have also left those who designed the approach feeling as though their ideas and what they helped create was being taken and represented, but not fully valued: “The experience of everywhere being seen but never being heard” (Coombe 1997: 88). But why has it become so popular? Understanding this can shed light on the deeper issues at play in its appropriation, which did not ‘just happen’ and is connected to broader processes within the disjunctive, overlapping, multiple, and mobile flows that make up our global cultural economy (Appadurai 1990).

One issue is access to information, specifically the Internet where the ‘Living with X’ guideline and subsequent body mapping studies have been made available. Between 2007[3] and 2016 rates of global Internet usage more than doubled (20.6–43.1%),[4] which has made information about body mapping more readily available

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[3] The year the ‘Living with X’ guideline was created and released online.

[4] Source: http://www.internetlivestats.com/internet-users/.

to greater numbers of researchers and community agencies around the world. A second issue is the rising interest in 'alternative' approaches to data collection, particularly among qualitative researchers seeking to explore sensitive issues with marginalized populations using social justice or action-oriented frameworks. As discussed in Chapter One, this is one of the reasons for the explosion of interest in arts-based studies in general, of which body mapping is a key example. The third issue is the body itself which has, over the past twenty years, been 'everywhere' (Rosser 2001) and studied in relation to risk (Lupton 1995), gendered performance (Butler 1990), embodiment (Csordas 1994) and more recently subjectivity (Braidotti 2011) and cultivations of the self-as becoming (Schildrick 2015). Despite these different theoretical treatments, its signification of flexibility (Martin 1994) and anxiety in our modern cultural time is perhaps most enduring, and this may explain the interest in body mapping as a technique through which the body is used to express multiple, competing, and shifting subjectivities across stretches of time and embodied space. I also think that the alienation many people feel as a result of 'device addiction' (i.e. inability to separate from cellular phones/technology), disengagement from traditional modes of production, and the increasingly unfathomable gaps between the rich and everyone else may be fueling a desire to return the body as our first and last site of human connectivity and self-actualization.

Resisting and redressing the cultural appropriation of body mapping begins, as others writing about this issue more broadly have demonstrated, with the respectful acknowledgement of the setting in which it was created. A commitment to mindful, respectful therapeutic principles and practices is also essential, along with an indication of how/if the method will be adapted to meet the study objectives/participants' experiences. Ultimately, it is about context: "Context, particularly as it relates to power relationships, is a key factor in distinguishing borrowing from exploitative cultural appropriation" (Arewa 2016) and 'knowledge democracy'—the recognition of all forms of knowledge or ways of knowing (Openjuru et al. 2015). Additional considerations from the field of art therapy may be helpful to practitioners/researchers who wish to use body mapping, including reflecting on whether arts-based/body mapping approaches are well suited to the project at hand and populations involved (Kapitan 2015), adopting empathetic 'spectatorship' practices (Oliver 2010), and giving careful thought to the role of cross-cultural difference throughout the creative process; including what collaboration 'looks like', artistic ability, and the relationship between participants and Western/Eurocentric powers (Betts 2013).

Ethnographic Insights: Staying Close to the Source

I grappled with these issues during the planning stages of the project and wondered if or how the methodology should be adapted within the context of our study. Ultimately I decided to adhere to the South African model because it was created with the experiences of people living with HIV/AIDS in mind, and is structured in a way that supports participants throughout the intense psycho-social and embodied body mapping experience. The therapeutic principles and practices are the heart of the methodology and what ensures that participants—irrespective of their life experiences or cultural identities—feel welcome, respected for who they are, and most importantly: safe. This is not to say that the methodology cannot be adapted to focus on a particular population or set of issues that diverge from the original focus, it can and has been (see Gastaldo et al. 2012[5] and Lu and Yuen 2012). The point is that without the therapeutic pieces the transformative, radical, and critical consciousness potential of body mapping is significantly diminished and the cultural context in which the method was created must be acknowledged.

In our project, discussions about the cultural origins and uses of the methodology opened each workshop, and it was made clear to participants that their diverse lived experiences, pleasant and difficult, male and female, straight and gay, were respected and open for creative expression in the maps as they wished. Setting the stage mindfully and with respect helped the participants feel comfortable to share their life experiences and challenges, including those related to *cultural identity*, *sexuality*, *addictions*, and trauma. Although these issues are not featured in the 'Living with X' guide, nor are they explored in any depth in the current body mapping literature, they are keystone issues in the lives of our participants and making room for them within the story of this project is important. Following a discussion of these issues, I explore six 'real' or on-the-ground issues to consider when doing body mapping research, which may be of value to researchers and community groups who want to integrate the methodology into their work with similarly vulnerable and complex populations.

Culture

The cultural diversity of our participants is striking for a relatively small group of eleven people, with five women identifying as Indigenous, one woman as Chinese, one man as Black, one man as mixed race, and three men as White. Culture is represented in complex ways on the maps and for a number of participants, it is something they struggle with because they were not encouraged to embrace being unique or 'different' from an early age:

> The one part that was kind of revealing for me, which I still sort of struggle with…being mixed race. Choosing that dark brown… was me embracing the fact that I am mixed race… My mother taught me and my sisters from a young age, which has caused some mental anguish and emotional damage, that having darker skin was a bad thing… So it can be a real struggle to push through that (Nolan).

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[5] While this is one of the best adaptations of the South African methodology, this team does not cite Solomon (2007), Morgan and The Bambanani Women's Group (2003) work or mention anything about the cultural context in which the approach originated.

The women represented issues related to culture more overtly and more often than the men, especially the Indigenous participants for whom reconnecting with their traditional knowledge, healing practices are integral aspects of life. This is reflected in Sue's description of the symbols on her map, which are intimately connected with the healing journey she is on in partnership with various people and natural forces:

> Those hands represent the ocean, the forest and the brown of Mother Earth….The four colours of the Medicine Wheel. So that is my medicine. I couldn't have got anywhere without the help of everyone else, so that's why I want everybody on my Map, because a journey is never taken alone. And that's why I wanted different handprints of everybody. This is the Ocean. Mother Earth. The Forest. The Sky. And the Medicine Wheel.

Several of the cultural references that surfaced during the mapping process were subtle and would not be easily identified without sufficient knowledge of the colonial process. An example of this is the white feet that stretch across Tarah's map that signify her experiences as part of the '60s Scoop', when some sixteen thousand Indigenous children were taken from their families and placed in White foster homes. Similarly, the white splatters of paint on sections of Isabel's map reflect her understanding of HIV/AIDS as a disease associated with colonial contact; a 'white man's disease'. Some of the women's historical experiences and on-going traumas related to the colonial process were not featured on their maps[6] and emerged during informal discussions in the workshop. This is revealed in an exchange between Sue and Tarah that I recorded in my fieldnotes, which illuminates some of the hidden stories related to the colonization of the body:

> Tarah and Sue were talking about their scars from various surgeries and births, and Tarah (who never again or before mentioned anything about children) said that she had a son before she had her tubes tied at the age of nineteen. I wondered about that and thought of one of the horrible legacies relating to the colonization of Indigenous women's bodies, the widespread forced or highly coercive practice of sterilization that took place until far more recently than most of us think.[7] Why did Tarah have her tubes tied at the age of nineteen? If she was born in the late 60s that would have been in the late 1980s—two decades after the 60s scoop (Fieldnotes, May 3, 2012).

This next fieldnotes excerpt captures the powerful ways that cultural identity and practices were brought into the body mapping process to aid in healing processes between the participants:

> It was cool to see Sue bring her sacred container today, which had different kinds of sage (including buffalo sage, which is for women because it's stronger), sweetgrass, and her smudging shell and stand. I inquired yesterday if it was ok for us to smudge because some of them had asked about it. The folks at [the location of the workshop] said it was ok and

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[6] Which may be because of the belief that it is inappropriate to associate harmful/negative behaviours with Indigenous symbols, knowledge, and practices. Tarah shared an example of this when she said that she did not want to put up any Indigenous art in her apartment when she was doing 'bad' things (i.e. drug use) because it is disrespectful.

[7] See Stote (2015).

> although Sue brought these items with her, we didn't smudge and there wasn't really any discussion about doing it. Around lunch time I saw her show Georgia how to tear off a chunk of the braided sweetgrass, which she then put in a small square of red fabric with some other things, tied it up, and presented it to her. I didn't see her do that with anyone else and I wondered, given how close Georgia's struggles are and how often she sheds tears, if Sue sees that too and is giving her some good medicines (Fieldnotes, May 6, 2012).

Sexuality

Sexuality is something that emerged primarily among the men and was connected to issues that inform who they are as gay men and learning to accept themselves. Nolan shared distressing early life experiences with religion and homophobia and how he is learning to find a new belief system that more closely aligns with who he is:

> I had a religious upbringing and I was taught that being gay is wrong, that you're a bad person if you're gay…I was always very conflicted and not really knowing…I was told I was a bad person because I didn't really want to do what other boys were doing… Narcotics Anonymous has been teaching me that I can come up with a new Higher Power, one that loves me and accepts me for me…You know?

Andrew discussed how sexuality was linked with addictions and his search to find validating meaning in life, a painful process that he documented with courage and explosive colour:

> The joining parts are the crotch, the heart, which is the "feel" part…I remember going to the first meeting and thinking: 'What the fuck! How do I stop?"…I needed to make a journey from my head, down to my heart. And that's where I'm living now. Mitigating that journey… That crotch! Where there's all that colour and I spent so much time trying to connect that to feeling…I needed to address it and to give it the weight it deserved!

He went on to talk about attending his first Gay Pride celebration and referred to the large red ribbon that he placed in a prime spot on his map, which symbolizes who he is: "I'm going this year for the 1st time…start small!… The red ribbon is not just about my HIV diagnosis. It's about my homosexuality, my lifestyle… it's about saying: 'This is who I am', whatever that might be." Evan made reference to his sexuality and identity as a gay man, also featured in a prominent place on his map, describing the symbols he selected in the following way, "On my head is … the Gay Rainbow…He's a Circle of Life."

Addictions

All of our participants have struggled with addiction issues and while most are getting support or have been in treatment, some still use hard drugs and/or alcohol. Addictions are often understood in the biomedical context as a disease rooted in family history or as the product of individual behaviours and decisions (Pauly et al. 2015; Reinarman 2005). Developing a deep need for drugs occurs within diverse socio-economic, racial, sexual, and gendered contexts, some of which are similar across marginalized groups and some of which are unique to each individual's life. Bringing this situated understanding of addictions into our workshop (i.e. at the outset when discussing issues related to emotional safety) let our participants know that we did not, *in any way*, judge them because of their past or present experiences with substances and including these life events/periods (or not) on their maps was entirely up to them.

Generally speaking, the men were closer to their addictions, referring to active drug use or having recently gone through drug treatment programs, than the women and that may explain why they discussed this issue more often. Several men spoke about using drugs to deal with traumatic life events and situations beyond their control, and for Nolan thinking about how to represent his addictions was challenging:

> My drug addiction… It's been a hard one for me to give up…. It's what I knew and it was my source of comfort and familiarity, you know, for something unknown…I didn't have any tools for dealing with life…I didn't even colour in all the stuff in the corner because it is very one-dimensional. You know? My using.

Luke also talked about using drugs as a way to organize and cope with life, a strategy that sometimes generated its own hardships: "The drugs and the bad things that happened when I was on it… and the stress from it…I became very good at putting the problems out of my head…I could somehow shut it off for the time being." Andrew debated about including addictions on his body map but ultimately decided to because of the important, albeit painful, role they have played in his life and healing journey: "I did hesitate putting that needle in there….But, it's my truth. It's my reality. And it's something that I can't be ashamed of, nor can I forget. It is part of my journey and it's part of what gets me to where I am today."

Some of the women in our study also discussed addictions experiences, which seemed to bring up feelings of regret as well as shame or embarrassment. As Georgia said when talking about some of the more difficult aspects of the body mapping experience, "Our addictions and I guess the scar on the body. That was pretty hard for me." Tarah also identified her past drug use, specifically the marks left on her body from using intravenous needles, as a very challenging aspect of the mapping:

> Tarah said to Tricia that she couldn't put drugs on her map, maybe because that was too negative or because she felt that the maps should look only pretty and nice. She chose instead to do a rainbow, but one that was sideways. She explained that she drew it like this not because there wasn't room to do it the "right" way, but because it captured her feelings of being a bit off centered with respect to all the complexities [of her life], which she said are represented in the layers of colours in her rainbow. She repeated that she is complex and the colours represent that (Fieldnotes, May 5, 2012).

During the course of the workshop she was able to move beyond feeling embarrassed, a powerful transition to make: "I was very embarrassed about my skin and how I was going to fill up those marks and stuff like that…I got a chance to get off needles… I'm pretty self-conscious about my body, but not so much anymore because I don't have a reason to be."

Trauma

Trauma is a complex phenomenon that can stem from a singular tragic event or a series of on-going life conditions characterized by neglect, betrayal, and violence at the interpersonal, social, and systemic levels. The ways it is expressed are equally varied and some survivors go through profound memory loss and block experiences out, while others are triggered and pulled back into different disturbing events on a regular basis. This often happens when the initial experiences are not treated and similarly negative or violent events are experienced repeatedly (Freyd 1996). Going through trauma can lead to various outcomes and coping mechanisms, including addictions, homelessness, unemployment, self-doubt, and deep-seated mistrust of people and 'the system'. These issues are present in the lives of the women and men in our study, however, the ways they were represented and expressed are unique. The women talked about trauma regularly and in specific ways, often using the word 'trauma' itself and actively reflecting upon their pasts, whereas the men tended to discuss traumatic issues in a less overt way and often with reference to the different contexts in which it occurred (i.e. addictions, sexuality, culture) versus the events themselves.

Some women drew attention to how the maps reveal and made them revisit their difficult histories, including Tarah who questioned how present she was at certain points: "There's a lot of history in it… I've sort of put the history away as being …. It's like, 'I know where I come from! I'm the one that was there!' But really, was I? I wasn't really there." Rayna focused on the therapeutic value of revisiting these experiences: "After I did this, like a lot of things come back up, you know? I realize a lot of consequences, a lot of things that we deal with the decision you make… That's how I learn from this….This taught me so much." Others discussed trauma in relation to the body mapping process itself, including Sue who appreciated the supports built into the process: "I liked how the tough one [when HIV is introduced] was the third day in. Because, if we'd done it the first or second day, I think it would have been too traumatic. You didn't have the foundation good enough." Isabel also discussed how difficult the body mapping can be, and stressed the importance of having facilitators that generate trusting relationships with participants: "To allow somebody like myself to do stuff that's really personal and really damaging … It's really personal…You don't just trust…And if I didn't like you guys, I wouldn't have been there…You guys are very good."

When discussing their experiences with trauma the men, like Evan, mentioned dealing with things like post-traumatic stress disorder and seeking an escape from life's hardships. Referring to the image of the airplane on his map, he said: "Just away… Yeah, it just signifies, I guess, an escape." Andrew provided a richly detailed account of the life factors that caused him much pain and made him question himself and the familial hand dealt to him:

> I think my life was lived in a lot of questioning 'why me'? Basically… why was I born into this Black family? …Why would God do this to me? …Why don't people behave the way I want them to?…There's a lot of questions around religion, around emotion. I was putting them out there and I wasn't getting an answer back.

'Real' Time and Space: Insights to Consider When Doing Body Mapping Work

Being a part of the two workshops taught me a great deal about the key issues that informed the project (i.e. HIV, addictions, health, gender, the body), the complex and unique life experiences of the women and men in the study, and how the different groups responded to body mapping. In many ways, these data could be considered a companion piece to the 'Living with X' document developed by Solomon (2007), as it also features insights that span the experiential arc of the methodological process. Although these insights directly relate to our participants' lives and how they went through the process, they may be of significant value to others who wish to incorporate body mapping into their research or community programs.

Preparatory Considerations

When organizing a workshop, one of the most important things to consider is the comfort level of the participants. While it is not possible to anticipate all of the interpersonal and individual factors that impact the experiences of each participant, knowing as much as possible about each person and existing relationships participants may have with one another is helpful. Both sets of participants indicated that knowing some of the other people in the workshop helped considerably, especially when deciding whether or not to take part, and that their familiarity provided support during the process. As Tarah said: "I only went there because Sue thought it was a good idea, and I knew Sue from the Community Class we go to. So I figured, she's very valuable with her resourcing, information and her experience, and she might know what she's talking about."

The inclusion of at least one support staff from an agency with whom participants are familiar is also integral to providing a supportive experience: "Someone who was removed from what we were doing and who was there to just be a support. That was really helpful for me" (Nolan). Having more than one facilitator is also useful, given that each participant may not know or gel with the main facilitator leading the process: "If there is only one person facilitating and right away you don’t have a rapport, or you don’t like them, who do you go to?” (Sue). The women indicated that they would have liked to know more about body mapping before they arrived at the workshop, as several were a little confused and daunted because it was an arts-based activity. Knowing that preliminary information about the body mapping process could be helpful, on Day One of the men’s workshop I showed them the brochures we made of the women’s maps. In retrospect, I would not do this again because the men who saw these images compared them to their own maps, which may have unduly influenced their own artistic creation and workshop experience. Discerning how to provide participants with sufficient information prior to the workshops is ultimately up to each researcher/community team, however, from our experiences describing the process versus providing ‘actual’ examples may be useful.

In Situ Considerations

Many emotional issues can arise for participants during the workshops, including feeling anxious, having difficulties expressing complex or traumatic experiences artistically and, for those with HIV/AIDS, being at different places in their HIV journeys. Given the strong connections between trauma and the body, the potential for body mapping to reanimate certain kinds of painful experiences is important to consider. There is no ‘magic’ way to address these issues, but acknowledging them before the workshops and in an on-going way reflects a sense of mindfulness and reassures participants that it is ‘OK’ to get upset. In addition, discussing different decompression or break activities (i.e. taking a time out, going for a walk with participants, talking things out in a safe space away from the workshop), and having on-hand information about crisis services or supports is critical.

Sometimes participants experience anxiety or trauma related to their fears of spending time with a group of people and being accepted by them, as Nolan said: “It was tough for me at times…Being in a closed space with a bunch of people, like my anxiety tends to go up and I get really fearful… I’m always afraid that people won’t accept me.” Tarah, who was unused to socializing with women, expressed concerns about being able to complete the workshop: “I’m not used to being around women. I didn’t know if I would pull through it because … I’ve always been around men”. Participants who are not confident about using art to express themselves can feel insecure and compare their work to others’:

> I’m not an artist, I refuse to say that I am!… As soon as you go into an art situation, it’s like I can’t draw because I know there’s people that know how to draw better…I can figure it out…However, there will be something silly in-between that makes me uncomfortable (Tarah).

Other participants struggled with using art to express themselves because the complexity of certain experiences are difficult to represent visually, which can cause them to simplify what ends up on their maps. As Luke said, “I’m not an artist. So there's a lot of things… I don't know how to paint…So I stuck with mainly things I could draw…..I didn't put every detail because … I don't want to look at it." Georgia share similar thoughts, "Memories and bringing up the past and regrets…If I wanted to put that down on the Body Map I wouldn't know how to do it."

Where participants are at in their HIV journey is another very important issue that can significantly impact the kinds of experiences participants have and what they include on their maps. For those who are newly diagnosed, just being in a room with other people with HIV can be overwhelming and they may be less connected in terms of support systems and health or social services. It is important to know these things before beginning a workshop, to ensure that the right kinds of support are provided during the process for each person taking part.

Compassionate, Patient Facilitators Who Work Well Together

Having facilitators and other support people on hand who know the logistics of body mapping and have experience working with marginalized populations and/or sensitive issues is critically important. The use of humour can also go a long way to helping people feel comfortable, and it is something the participants appreciated: "They were just outstanding! The help and the encouragement, and their positive influence… They used a lot of humour and they were so compassionate" (Sue). Having facilitators who work well together or complement one another was also raised as a positive aspect of the experience: "I think it's nice… I think you two [myself and Tricia] worked really well together. Because you balance each other out in different ways" (Nolan). Knowing when and how to intervene during workshops is unique to each participant group, team of facilitators, and the issues being explored. From my experience, it is a fine balance between letting participants work and in some cases struggle a bit on their own and being there for them in ways that are respectful of their individual experiences/needs. This nuanced approach is something that Andrew observed as being helpful for him and the other participants:

> I close my eyes and I smile, because I think, in terms of facilitation…It was beautiful, yeah? Like, what you guys brought to it was, you gave people space. When I came out of my bubble, I noticed that you were all very aware of each individual, and where they were and what their bubble looked like… And accepting that different people were at different places…I think it was really positive.

Recognizing How Much It Takes for Participants to Show up and to Finish

Completing the workshops is not something highlighted in other body mapping studies, however, it surfaced repeatedly among our participants as something they were proud of. The women and men in our study have had life experiences that predispose them to being and feeling vulnerable because of addictions, HIV stigma, early and on-going trauma, and marginalized sexual identities. Add to these experiences the emotional difficulties associated with body mapping, and it makes sense that our participants cited the completion of the workshops as something very significant: “I’ve accomplished this!…This is something that I accomplished. Something that I did! And I’m proud of myself for that” (Nolan). For some, the sense of accomplishment is couched in temporal terms and folded into their reflections on how far they have come: “If you’d asked me that maybe two years ago, I probably wouldn’t have come, because I was afraid to…I didn’t know if I was going to be accepted” (Sue).

Others were proud of themselves because they realized that they can succeed in something new: “I’m just really proud of what I did… I mean, you know, just doing it. I got asked to come and do it, and I said ‘Sure, no problem’…and just got in there… Just, raise the bar a little bit!” (Isabel). The fact that doing the body mapping, including the everyday logistics of getting up in the morning, is hard was also acknowledged: “For me, just to finish it, just to finish it got me going so far already….. It was deep. It was hard” (Rayna); “Getting up in the morning was really strange for me…How hard it was!” (Luke). Finding ways to celebrate their courage and commitment during the process is important.

Follow the Therapeutic Format

Morgan and The Bambanani Women’s Group (2003) and Solomon’s (2007) approach was developed as a tool for community mobilization and healing, and built into the process are several key therapeutic practices, including establishing safety and stability amongst the participants and facilitators, ensuring that each day is not overly full with activities, and that there is ample space allotted for breaks if people need to stop and/or return to a specific set of exercises. As discussed in Chapter One, the workshops take place over four days, each day opens and ends with a ‘check-in’, the exercises unfold from more general to more specific, the HIV-specific questions emerge on Day Three, and there is an informal art show that concludes the workshop. During the art show, the facilitators hang the maps on a wall and participants sit in front of their map and are provided feedback from the others taking part, which are recorded on pieces of paper that each participant is given to take home. I also purchased small gifts and cards for each participant that reflected their unique characteristics or interests (i.e. favourite animals, colours, sayings), which was greatly appreciated. While adhering to all of these practices may not be possible, for financial or time reasons, staying as close as possible to them is something to aim for because they create a supportive and respectful experience for participants, facilitators, and others involved.

Four days can be a long time to remain engaged in and enthusiastic about body mapping, and some participants questioned the duration of the workshop: “At first I thought you guys were crazy because, I thought, how much can you do in four days?! But from beginning to end, it needed to be done. Like, it was a good process" (Sue). For many participants this amount of time is needed to foster trust among themselves and with the facilitators: "I was guarded the first day, second day too. Third and fourth… no" (Isabel). The daily check-ins were also valued by participants: "I found it like closure…We got to talk about it, and you know, people cried. The support was there…It was 'Okay, we're finished with it this day…We started as a group, you have to finish as a circle, too (Sue). Sticking to the format of the workshop was identified as helpful to keep them on track, as Isabel shared: "It was very well explained…I can't work without structure, I need structure in my life…I love when it's '1, 2, 3, 4, 5, 6'….'cause you know what you're doing!"

At certain points in the workshops, the final 'product' is not always clear and many participants expressed doubt about their work and some questioned the different exercises. One of the ways our team instilled confidence and trust in the process is by using the phrase 'Trust the Process', which Andrew identified found very reassuring:

> I think just being really honest, and saying why it is, and what it relates to for me… when I went to Rehab, one of the signs is… it said "Trust the Process." It was a massive painting… If I hadn't gone through that, this would have been different… If somebody says: 'Trust the Process' I get it. It's built on an experience. It's built on something.

The informal art show was described by participants as one of the most enjoyable aspects of the body mapping experience,[8] and all of the women and most of the men saved the pieces of paper with our comments on their work that were given to them during the event. The meanings attached to and symbolized by these pieces of paper are significant and many participants kept them in important places: "I still have them on my dresser. I look at them every once in a while" (Georgia); "Yeah! I have that on my table still. That was cool!…That was a nice compliment. It was a compliment to everybody" (Tarah). Abby's friend was going to buy a picture frame for her to put them in: "Lloyd is putting them in a frame for me!" When discussing why they saved these souvenirs of the workshop several participants remarked that they were useful to reflect on when they were feeling down, thus revealing their lasting therapeutic effects:

> All those pieces of paper, I take them out and read them whenever I'm feeling, like, down, or whenever things just aren't going right, I just pull those out, and I like that. It's because it's somebody else's perspective of you. A lot of time we don't praise ourselves or thank ourselves for things, and that way you can sort of do that by reading them (Sue).

Two of the men expressed similar sentiments about the healing quality of these pieces of paper: "I put them in a place where I can go…when I'm having a rough day, I can pull them out and you know…. 'Okay, this is what other people see in

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[8] Although it can be a little nerve wracking for some because they are not used to being the centre of attention or receiving feedback in this way, which is why Ted referred to it as the 'hot seat!'.

me'" (Nolan); "I read them over the phone to [friend] and she thought they were really great and she said, 'If you're ever feeling down or whatever' I should read them!" (Evan).

Innovative Approaches to Knowledge Translation

Determining how to disseminate the body mapping findings can be a challenge given their large size (6 ft. x 4 ft.), deeply personal content, and because arts-based research is not always commensurate with traditional ideas about knowledge translation as a set of practices designed to influence decision-making or policy development (Lafrenière et al. 2012). We approached knowledge translation as part of the process and our participants often started these conversations with questions like: "Where is this going to go?" and "What is this for, again?" During both workshops we indicated that where, when, and how (if at all) the study findings will be shared are decisions that we should make together. When discussing dissemination options, we began with suggesting more formal academic dissemination practices like conference presentations and journal articles, which did not raise any red flags or terribly interesting discussions. Ultimately, our decisions about what to 'do' with these findings emerged many months after the workshops were completed, during which time we let our ideas percolate and kept in touch with many of the participants and agency/project staff involved.

Our knowledge translation activities with the women were enhanced by the treatment workshop they requested during the body mapping, which helped them learn more about the HIV medications they were taking. This gave us additional opportunities to discuss dissemination ideas over a longer period of time than was the case with the men. Along with telephone calls and emails, we arranged lunches and other informal events to meet with them. The following quotation from Isabel captures how powerful something as 'small' as a lunch in a cool spot, versus a soup kitchen or low budget restaurant she may be used to, is to fostering connections between the women as well as her confidence and pride in herself:

> You know, going to these little luncheons and all this with them, seeing them – it's really good for us. For me, it does something for my insecurities, you know? As a woman? Like, we all can go to a fancy ball.... A restaurant that's cool! Like it's in the paper! ...And talk like we're doing a business meeting. It's awesome!

Additional strategies with the women included an art show and dinner in the Downtown Eastside area of Vancouver (where many participants live, access services, and spend time), which was attended by most of the women and their family and friends. This was a special way to wrap up the project and we had t-shirts, brochures featuring the maps and one-page stories, and postcards made for the event. We also continued to gather their insights about where they might like the data to go, which led to the installation of smaller copies of their maps at the host restaurant (for a week after the wrap-up event), a women's only pharmacy, and a clinic where many of the women access health care services. While they supported these dissemination approaches, the prospect of having their experiences out there for all to see also made them a little nervous; which is something facilitators need to be mindful of. As Rayna said, it is about "Letting other people know our lives."

The men talked about different places or events to showcase their maps, however, they seemed somewhat less enthusiastic about these discussions than the women. Two or three of the participants were really interested in seeing the maps displayed in their work environment, which focuses on HIV and community-based treatment and advocacy. Along with making brochures like the ones we put together for the women, the men's maps were displayed at a local HIV organization's Annual General Meeting and an event commemorating International AIDS Day. Two of the participants, including Andrew, have their maps hanging in their offices at work he begins his training exercises with a discussion about his map and the transformative mapping experience.

Discussion

This chapter explored the issue of cultural appropriation in relation to the South African methodological approach created by Solomon and Morgan, which is the framework used most often by researchers, practitioners, and community agencies in body mapping research. I began by demonstrating the key processes through which appropriation works in this instance, namely the selective borrowing of certain tenets of the method and the lack of acknowledgement of the cultural context in which the method originated. The tendency for many researchers to disregard or downplay the therapeutic principles and practices, in particular, was identified as problematic because they are integral to the method and ensuring participants' safety during body mapping. As demonstrated in the Southern Africa example, ignoring these practices can have devastating consequences for participants[9] who may be re-traumatized as a result. Reflecting on this situation and others in which researchers and community groups were taking what they wanted from the methodology, Solomon and others removed the 'Living with X' guideline from the Internet to avoid further appropriation of their method and prevent harm to prospective participants stemming from this misuse. These events were disturbing for the method's creators, whose culturally distinctive knowledge and aesthetic healing practices were markedly transformed through their consumption and

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[9] As well as the facilitator, who was not adequately trained to know what kinds of issues to expect or how to cope with them.

objectification in the global cultural economy, all of which are hallmarks of cultural appropriation (Hahn 2008; Haig-Brown 2010; Root 1996; Ziff and Rao 1997).

Another example of the appropriation of body mapping was discussed in relation to a project I was invited to participate in that was designed, ostensibly, with the approach in mind. However, the study lead seemed to have limited knowledge of or interest in the cultural context of body mapping and the attendant therapeutic principles or practices. My role was that of conveyer of condensed or commodified knowledge, as I was called upon to "do that part of the project" and freely give my insights to a person who seemed to have limited knowledge about it. This experience was unsettling because of the disregard for the cultural context and therapeutic principles inherent to the original method, but also because I felt as though I was being co-opted in the selective consumption and misuse of the methodology.

Taken together, these examples reveal the complex and multi-directional flows of knowledge and power that undergird the appropriation process relative to body mapping, which travel not only from 'South' to 'North' but within and across different global regions. These flows are directed by many factors, including increased access to information about body mapping via the Internet, the push for methodological innovation in many research and community settings, and the enduring role of the body as signifier of our uncertain cultural times. Along with understanding how these processes have emerged, it is important to think about how they might be resisted. The key factor in this regard is attentiveness to context, as Ziff and Rao (1997: 13) clearly state: 'Context counts'. This does not mean that each body mapping project need be about HIV and involve women, or that all studies need to follow the 'Living with X' guidelines word-for-word. It means that the setting in which the method originated must be acknowledged, along with how the approach is adapted to meet the study aims and ensure the well-being of the participants and others involved. These principles align with what Openjuru et al. (2015) call 'knowledge democracy', referring to the equitable evaluation and consideration of indigenous knowledge and practices that are taken up 'locally' and internationally through different research, funding, and development agendas.

The second part of this chapter featured an in-depth discussion of four issues that emerged as central to our participants' lives and their body mapping experience itself, those of culture, sexuality, addictions, trauma. Although these issues are not featured in the South African methodology, per se, I chose to explore them it honours the totality of our participants' lived experience; and these insights may be valuable for others who wish to use body mapping with similarly complex populations. I also discussed the most important 'on-the-ground' issues to consider when doing body mapping, which span the experiential arc of the process from the pre-workshop stage through to knowledge translation activities. These sections are threaded with insights that reflect a deep commitment to mindful and therapeutic practice which are, as reflected in the words and creative expressions of the women and men in this study, the most important aspects of the body mapping praxis. To be safe, cared for, and given the time to 'just be' with one's life is among the most powerful gift and experience to share.

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