

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

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; Florida 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; Nicastrì 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 men¹ 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).

¹Which 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

²Pursuing 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

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

⁴The 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

⁵She 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 Indigenous⁶ 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

⁶Which 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.

⁷See 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 feminine⁸ 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.

⁸Given 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.

References

- Acoose, S. 2015. *An arrow in my heart: A first Nation Woman's account of survival from the streets to the height of academia*. Vernon: JCharlton Publishing Ltd.
- Bangsberg, D., S. Perry, E. Charlebois, M. Robertson, and A. Zolopa. 2001. Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *AIDS* 15(9): 1181–1183.
- Barone, T., and E. Eisner. 2011. *Arts based research*. Thousand Oaks, California: SAGE.
- Biehl, J. 2005. *VITA: Life in a zone of social abandonment*. Berkeley: University of California Press.
- Binford, M., S. Kahana, and F. Altice. 2012. A systematic review of antiretroviral adherence interventions for HIV-infected people who use drugs. *Current HIV/AIDS Reports* 9: 287–312.
- Bourgois, P., and J. Schonberg. 2009. *Righteous dopestfiend*. Berkeley: University of California Press.
- Bresalier, M., G. Loralee, C. McClure, L. McCoy, E. Mykhalovskiy, D. Taylor, and M. Webber. 2002. *Making care visible. Antiretroviral therapy and the health work of people living with HIV/AIDS*. Toronto: Making Care Visible Working Group.
- Browne, A., C. Varcoe, S. Wong, V. Smye, J. Lavoie, D. Littlejohn, D. Tu, O. Godwin, M. Krause, K. Khan, A. Fridkin, P. Rodney, J. O'Neil, and S. Lennox. 2012. Closing the health equity gap: Evidence-based strategies for primary health care organizations. *International Journal for Health Equity* 11: 59. doi:[10.1186/1475-9276-11-59](https://doi.org/10.1186/1475-9276-11-59).
- Broyles, L., A. Colbert, and J. Erlen. 2005. Medication practice and feminist thought: A theoretical and ethical response to adherence in HIV/AIDS. *Bioethics* 19(4): 362–378.
- Conrad, P. 1985. The meaning of medications: Another look at compliance. *Social Science and Medicine* 20: 29–37.
- Conrad, D., and G. Campbell. 2008. Participatory research—An empowering methodology with marginalized populations. In *Knowing differently: Arts-based and collaborative research methods*, ed. L. Liamputtong, and J. Rumbold, 247–263. New York: Nova Science Publishers.
- Cran, B., and G. Jerome. 2008. *Hope in shadows: Stories and photographs of Vancouver's downtown eastside*. Vancouver: Arsenal Pulp Press.
- Di Matteo, M., K. Haskard-Zolnierrek, and L. Martin. 2012. Improving patient adherence: A three-factor model to guide practice. *Health Psychology Review* 6(1): 74–91.
- Florida, M., M. Guiliano, L. Palmisano, and S. Vella. 2008. Gender differences in the treatment of HIV infection. *Pharmacological Research* 58: 173–182.
- Harrigan, P.R., R. Hogg, W. Dong, B. Yip, B. Wynhoven, J. Woodward, C. Brumme, Z. Brumme, T. Mo, C. Alexander, and J. Montaner. 2005. Predictors of HIV drug-resistance mutations in a large antiretroviral-naïve cohort initiating triple antiretroviral therapy. *The Journal of Infectious Diseases* 191: 339–347.
- Hooks, B. 1995. *Art on my mind: Visual politics*. New York: The New Press.
- Huss, E. 2007. Symbolic spaces: Marginalized Bedouin women's art as self-expression. *Journal of Humanistic Psychology* 47(3): 306–319.

- Huss, E. 2011. A social-critical reading of indigenous women's art: The use of visual data to "show" rather than "tell" of the intersection of different layers of oppression. In *Art in action: Expressive arts therapy and social change*, ed. E. Levine, and S. Levine, 95–103. London: Jessica Kingsley Publishers.
- Johnson, J., L. Greaves, and R. Repta. 2007. *Better sciences with sex and gender: A primer for health research*. Vancouver: Women's Health Research Network.
- Kelm, M. 1998. *Colonizing bodies: Aboriginal health and healing in British Columbia, 1900-1950*. Vancouver: University of British Columbia Press.
- Knight, K. 2015. *Addicted. pregnant. poor*. Durham: Duke University Press.
- Lambers, F., I. Stolte, C. van den Berg, R. Coutinho, and M. Prins. 2011. Harm reduction intensity —Its role in HAART adherence amongst drug users in Amsterdam. *International Journal of Drug Policy* 22: 210–218.
- Liamputtong, P., and J. Rumbold. 2008. Knowing differently: Setting the scene. In *Knowing differently: Arts-based and collaborative research methods*, ed. L. Liamputtong, and J. Rumbold, 1–23. New York: Nova Science Publishers.
- Lima, V.D., R. Harrigan, R. Hogg, R. Gross, and B. Yip. 2009. The combined effect of modern highly active antiretroviral therapy regimens and adherence on mortality over time. *Journal of Acquired Immune Deficiency Syndrome* 22(1): 75–82.
- Martin, E. 2006. The pharmaceutical person. *BioSocieties* 1: 273–287.
- Mrus, J., P. Williams, J. Tsevat, S. Cohn, and A. Wu. 2005. Gender differences in health-related quality of life in patients with HIV/AIDS. *Quality of Life Research* 14: 479–491.
- Mykhalovskiy, E., L. McCoy, and M. Bresalier. 2004. Compliance/Adherence, HIV, and the critique of medical power. *Social Theory & Health* 2(4): 315–340.
- Napravnik, S., C. Poole, J. Thomas, and J. Eron. 2002. Gender difference in HIV RNA levels: A meta-analysis of published studies. *Journal of Acquired Immune Deficiency Syndromes* 31: 1119.
- Nicastrì, E., C. Angeletti, L. Palmisano, L. Sarmati, A. Chiesi, A. Geraci, M. Andreoni, S. Vella, and The Italian Antiretroviral Treatment Group. 2005. Gender differences in clinical progression of HIV-1-infected individuals during long-term highly active antiretroviral therapy. *AIDS* 19: 577–583.
- Orchard, T., K. Salters, A. Palmer, W. Michelow, K. Lepik, and R. Hogg. 2015a. Vets, denialists, and rememberers: Health care providers perspectives about adherence and non-adherence to HAART among poly-substance users. *AIDS Care* 27(6): 758–761.
- Orchard, T., T. Smith, and W. Michelow. 2014. Imagining adherence: Body mapping research with HIV-positive men and women in Canada. *AIDS Research and Human Retroviruses* 30(4): 337–338.
- Orchard, T., K. Salters, W. Michelow, K. Lepik, A. Palmer, and R. Hogg. 2015b. "My job is to deal with what I can": HIV care providers' perspectives on adherence to HAART, addictions, and comprehensive care delivery in Vancouver. *British Columbia, Canada, Critical Public Health* 26(5): 542–553.
- Osterberg, L., and T. Blaschke. 2005. Adherence to medication. *New England Journal of Medicine* 353: 487–497.
- Penn, C., J. Watermeyer, and M. Evans. 2011. Why don't patients take their drugs? The role of communication, context and culture in patient adherence and the work of the pharmacist in HIV/AIDS. *Patient Education and Counseling* 83: 310–318.
- Pinn, V. 2003. Sex and gender factors in medical studies: Implications for health and clinical practice. *Journal of the American Medical Association* 289(4): 397–400.
- Puskas, C., J. Forrest, S. Parashar, K. Salters, A. Cescon, A. Kaida, C. Miller, D. Bangsberg, and R. Hogg. 2011. Women and vulnerability to HAART non-adherence: A literature review of treatment adherence by gender from 2000 to 2011. *Current HIV/AIDS Reports* <http://link.springer.com/article/10.1007/s11904-011-0098-0>.
- Sandelowski, M. 1995. Sample size in qualitative research. *Research in Nursing & Health* 18(2): 179–183.
- Shiavo, R. 2013. *Health communication: From theory to practice*. San Francisco: Jossey-Bass.

- Smith, L. 2012. *Decolonizing methodologies: Research and indigenous peoples*, 2nd ed. London: Zed Books.
- Solomon, J. 2007. *“Living with X”: A body mapping journey in the time of AIDS*. Johannesburg: REPSSI.
- Sterk, C. 2000. *Tricking and tripping. Prostitution in the era of AIDS*. Putnam Valley: Social Change Press.
- Truth and Reconciliation Commission of Canada. 2015. *Honouring the truth, reconciling for the future: Summary of the final report of the truth and reconciliation commission of Canada*. Ottawa, Ontario.
- Wood, E., R. Hogg, B. Yip, R. Harrigan, M. O’Shaughnessy, and J. Montaner. 2004. The impact of adherence on CD4 cell count responses among HIV-infected patients. *Journal of Acquired Immune Deficiency Syndrome* 35(3): 261–268.

Remembering the Body

Ethical Issues in Body Mapping Research

Orchard, T.

2017, XIX, 105 p. 2 illus., 1 illus. in color., Softcover

ISBN: 978-3-319-49860-7