


“Three in the Room”: Embodiment, Disclosure, and Vulnerability in Qualitative Research

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Abstract

The researcher’s body in qualitative research is often absented, an absence that can render deceptively tidy research accounts. In this article, I reflect on the interplay of embodiment and disclosure in the interview dynamic and the way in which my body became an object of inquiry in the research process. Three qualitative studies inform the article: the first exploring the experiences of 40 people living with hepatitis C in New Zealand and Australia, the second comprising life-history interviews with 38 people who inject drugs in London, and the third following 27 people through hepatitis C treatment in London. Bodily and verbal disclosures of my history, as someone with/without hepatitis C and a former heroin user, affected the energy of the interview dynamic, also embodied understandings of illness and drug use. Disclosure can enhance researcher vulnerability and I close with reflection on the ethical implications of “enhanced rapport” in the research situation.

Keywords

addiction / substance use; autoethnography; boundaries; disclosure; embodiment / bodily experiences; ethics / moral experiences; hepatitis C; reflexivity

Over the past decade conducting qualitative health and harm reduction research, I have felt torn between the worlds of the researcher and the participant—while fully belonging in neither. In this article, I reflect on this ambivalence and the impact of embodiment and disclosure in interview interactions with people who inject drugs and/or who live with hepatitis C. On both of these fronts, there is a point of connection—for the first 3 years of this research, I also had hepatitis C, and my drug-using past was never far from the surface when interviewing current and former heroin users. A commitment to a reciprocal and reflexive methodology, informed by feminist and interpretive epistemologies (Denzin, 2001; Oakley, 1981), led me to disclose my hepatitis C and/or drug-using history, often in response to queries by participants. On occasion, my body disclosed my past—a decade of injecting excesses writ large on the arms. These disclosures, embodied and verbal, affected the energy of the interview dynamic and, in turn, my embodied understandings of illness and drug use.

The nature of the relationship between researcher and researched, and the place of biographical disclosure in this dynamic, remains a focal point of epistemological contention (Carter & Little, 2007). Although researcher self-disclosure—both to participants and in publication—is more common and accepted in a disciplinary tradition

drawing on ethnographic, phenomenological, and feminist approaches (e.g., Ellingson, 2006; Finlay, 2006; Wheatley, 2005), this does not preclude anxieties about, and experiences of, intra-disciplinary critique (Bishop & Shepherd, 2011; Mykhalovskiy, 1997). For example, DeVault (1997) expresses concern that her intertwining of the personal and empirical is “not quite sociology” (p. 217), echoing Mykhalovskiy’s (1997) experience of having his reflexive publication (and, by extension, himself) deemed “self-indulgent” and his related doctoral application rejected (p. 134).¹ Anxieties can be particularly acute in relation to disclosure of stigmatized practices such as illicit drug use (S. Blackman, 2007; Moore & Measham, 2006) or bodily vulnerabilities such as anorexia (Chatham-Carpenter, 2010)—both undoing idealized notions of the “normative” self-contained and immutable body (Shildrick, 2002).

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Reflexive writing can evoke emotion, affect, and bodily attunement: the messy intricacies of the inter- and intra-subjective research process (Probyn, 2011). This “messiness,” and the related embodiment of the researcher, is typically cordoned off in reports and publications, rendering “deceptively tidy” accounts of research (Ellingson, 2006). The absencing of the inquirer’s body from research accounts and analysis can solidify existing power differentials in the research relationship, particularly when the object of inquiry is the materiality of the participants’ body. This said, there is a burgeoning empirical literature, often referencing a feminist epistemology, in which the inquirer’s emotion, affect, and embodiment are not rendered inconsequential. A point of biographical connection with the research topic can generate powerful emotion and personal reflection, as articulated in scholarship addressing illness (Ellingson, 2006; Wheatley, 2005), disability (Toombs, 2001; Wendell, 1996), eating disorders (Chatham-Carpenter, 2010; Probyn, 2011), dance club drug scenes (Moore & Measham, 2006), sexualities (Ettorre, 2010; Race, in press), HIV risk (Maher, 2002), and trauma (Culbertson, 1995)—all deeply “embodied” subjects. There has, however, been scant reflexive scholarship in regard to the personal experience of injecting drug use—perhaps reflecting the particular vulnerabilities that disclosure of this not only illicit but socially “abject” practice connotes (Harris, 2009b).

Qualitative interview practice incorporates “somatic modes of attention,” described by Csordas (1993) as “culturally elaborated ways of attending to and with one’s body in surroundings that include the embodied presence of others” (p. 138). This is an active rather than an object body, embodied perception formed through the intertwining of the social and the corporeal (Merleau-Ponty, 1962). In studies where embodiment is a focus, priority is generally given to the embodiment of the participants rather than the inquirer (Sharma, Reimer-Kirkham, & Cochrane, 2009). The disclosures of my history meant that my body also became available as an object of inquiry in the research process. Scrutiny was paid, both by participants and myself, to the embodiment of hepatitis C and injecting, whether manifest in fatigue or in the tracks of needles on arms. Questions were asked on both sides about lived experience, leading in the first research project to a refiguring of what it personally meant to live with, and be treated for, hepatitis C. The second project evoked embodied memory of heroin use: in dreams, in the energy of the interview encounter, in the scrutiny of the skin. In the third project, as a “redeemed body” (not injecting, “cured” of hepatitis C), I find myself operating as a vector of hope for some participants, who—considering or just about to embark on treatment—are eager to hear of my return to “normalcy.”

These research projects have, therefore, entailed a movement in connection with participants: from the nebulous and intangible (fatigue, the unseen liver) to the visceral and tangible (gut-churning recollection, scars delineating veins), to again something more nebulous—the memory and imagining of a treatment experience. In this article, I reflect on this movement and the impact of embodiment and emotion on the research process to provide, in Wacquant’s (2005) words, a sociology not *of* the body but *from* the body, an account “recognising and taking full epistemic advantage of the visceral nature of social life” (p. 446). Personal disclosure in empirical research accounts can enhance vulnerability—vulnerability to perceptions of “biased,” “unscientific,” and “self-indulgent” scholarship (Maher, 2002; Mykhalovskiy, 1997)—and, in the field, vulnerabilities to the vicissitudes of embodied memory and unstable research boundaries. It is with reflection on the ethical implications of these vulnerable disclosures that I close the article.

The Research

The research I draw on in this article consists of three qualitative studies: (a) a doctoral research project (2005–2008), exploring the experiences of 40 New Zealanders and Australians living with hepatitis C; (b) the London Staying Safe project (2009–2012), comprising life-history and follow-up interviews with 37 people who injected illicit drugs; and (c) an ongoing postdoctoral research project (2012–2016), following the hepatitis C treatment journey of 27 people from specialist referral to a year post treatment. Data collection for the latter study involves up to five interviews with each participant, single interviews with 18 health care providers and stakeholders, and 100 hours of hepatitis C clinic observations. The methods and aims of the first two projects are outlined elsewhere (Harris, 2009b; Harris & Rhodes, 2012). All projects received Research Ethics Committee approvals. Participants were provided with project information leaflets and the opportunity to ask questions before agreeing to participate. Written consent was obtained before each interview commenced. All participant names referred to, including in field notes (identified by FN), are pseudonyms. In this article, I use interview and field note extracts from the studies, not to present research findings *per se*, but to facilitate methodological and theoretical reflections.

Hepatitis C: An Avenue Through Silence

My doctoral research was partly motivated by personal curiosity: How do others with hepatitis C negotiate the dilemmas of living with this stigmatized illness? Who do

they tell, and what are their perspectives on hepatitis C treatment—a lengthy and possibly debilitating regime that I had been advised to undergo but had serious reservations about. Hepatitis C is known as the “silent epidemic,” primarily in regard to the long latency period of the illness (Steedman & Zobair, 2000). This is an appropriate moniker. More than 170 million people are estimated to live with chronic hepatitis C (World Health Organization, 2014), yet until recently (with the advent of new drug developments), the virus has received little policy, media, or public attention (Harris, 2010). This silence has been associated with the lack of transmission threat to the “general population” with 90% of all new diagnoses in developed countries attributable to unsterile illicit injecting practices (Shepard, Finelli, & Alter, 2005). An early mantra of the HIV/AIDS activist movement was “silence equals death” (Gamson, 1989). The silencing of hepatitis C and other issues affecting people who inject drugs perpetuates stigma, marginalization, and political inaction. A very small act against this silence is to be open about my status (Harris, 2009a, 2012).

In the research context, my personal disclosure relates to the facilitation of a “reflexive dyadic” interview process, where the inquirer is open to responding to questions and, if appropriate, sharing relevant experiences (Ellis & Berger, 2001). The recruitment notice for my doctoral project stated that I was a research student living with hepatitis C; it elicited a plethora of responses. No remuneration was offered to participants. The majority were not in touch with drug and alcohol services, had not participated in previous research studies, and had not talked at any length about their hepatitis C status before. It appeared that my disclosure might have influenced their interest in the study. Claire, for example, said that this was the reason she responded to the advertisement, adding, “Not that there’s any prejudice there but you know what I’ve been going through and I know what you’ve gone through, even though we have different, totally different lives. We’re still connected by, by that virus.”

For many participants, the process of coming to terms with hepatitis C involved a gradual piecing together of biomedical, experiential, and peer-based information. This collating of information was evident in interviews where participants asked about my experiences of the virus: Did I get nausea, fatigue, or food intolerances? Did I use herbs or other alternative treatments? Did I drink alcohol, and were those track marks (injecting scars) on my arms? In answering these questions, I was made more conscious of my body—as a site of interest, inquiry, and also of comparison for participants. Necessary in these interactions was an attention to the waxing and waning of fatigue (both participants and my own), a primary hepatitis C symptom. Attention to the

participants’ embodiment, including manifest and subtle indications of fatigue, impacted on the way I conducted the interviews but also on my own understandings of what it was to live with hepatitis C.

I recognized my own bodily experiences in participants’ narratives, experiences I had never before attributed to the virus. Zoe commented, “Having hepatitis C causes depression there is no doubt in my mind. I knew as the disease took over more and more and the sicker I got, the worse I got mentally . . . It affects everything.” Klara noted, “That’s what people see me as, as very irritable, a lot of the time,” and Elisabeth commented, “I was so tired. I was just so tired that when I went home at night I would cry, weeping with fatigue.” Prior to starting the study, I related fatigue to hepatitis C but conceptualized my frequent irritability and dislike of social situations as character flaws. On hearing other participants speaking at length about these issues, I came to perceive them as hepatitis C–related. In this way, my self-identification as a person who was “bad-natured” shifted to an understanding of myself as “ill.” This shift in understanding allowed me to reconceptualize my fatigued body as expending energy in keeping the virus in check, meaning, as a consequence, that I was less able to meet the energy demands of sustained interaction with others.

My shift in identity from bad-natured to ill only eventuated through listening to others talk of their bodily experiences, and whether “correct” or not, this reframing illuminates the contextual nature of understandings of hepatitis C and what it is to be symptomatic.² This new awareness was then challenged by Jack, a Sydney participant who was practically housebound because of complications related to end-stage liver disease. Despite frequent hospitalizations and medication side effects, he announced, “Apart from these varices, I don’t really feel sick at all.” This was followed by, “So, you feel sick, do you?” My mobility and apparent good health contrasted starkly with Jack’s shaking hands and unsteady gait—confronting my “illness” identity. Here any claim I might lay to “sickness” felt uncalled-for and self-indulgent. Jack’s claim not to “feel sick” can be read in a number of lights. It might have been an expression of autonomy in constrained circumstances, an expression of stoicism, the result of becoming used to debility, and/or simply that Jack did not actually “feel” sick. In this way, Jack’s and others’ narratives coupled with my own bodily refiguring helped me think about “health” and “illness” as contextual and contingent states, not necessarily determined by the presence of symptoms or lack thereof.

The fraught subject of hepatitis C treatment was another arena of bodily scrutiny and reflection, both for participants and myself. Nearly every participant I interviewed asked about my intentions regarding treatment, with a few proffering advice or encouraging me to “give

it a go.” Indeed, I was acutely aware of how participants’ treatment experiences affected my decision-making process, as illustrated by my field notes:

Been feeling scared about treatment again—now don’t think I want to do it. Too many people talk about debilitation and cognitive dysfunction on the treatment and then long periods of recovery afterwards. What to do? (FN. Sydney, March 2006)

She [research participant] was interested and encouraged me to do treatment and after talking to her and hearing her positive experiences I feel more inclined to think about the possibility of doing it. Interesting how I fluctuate on that one! (FN. Sydney, May 2006)

I made the decision to commence hepatitis C treatment at the end of the doctoral data collection process. This decision involved a temporal realignment: a reconceptualization of treatment from six long months of fearful side effects, to providing the possibility of feeling better for the long term (Harris, 2010). It is hard to say how much this shift was influenced by the interviews I had conducted. There is no doubt, however, that the participants’ narratives of treatment and of living with hepatitis C played a part in informing my decision, just as my disclosure is likely to have informed the way participants approached the interview situation and framed their narratives.

Heroin, Be the Death of Me

In some doctoral interviews, my heroin-using past facilitated a sense of trust or comradeship with participants who had a similar history. The effect of this amity could, however, be confronting, awakening embodied memories of drug use and that old anticipatory sickness in the pit of the stomach. An urge, a memory, reflected in my dreams. An excerpt from my field notes at the time is presented below:

I had a dream about using last night, very visceral. My vein was large, bulbous, like a pipeline under the skin. The needle-pick sharp—the drawing back of blood—but of course it was not enough. And Jesus—the mix was murky and of uncertain constitution. (FN. Sydney, April 2006)

This dream partly illustrates why I did not act on occasional injecting urges. It contains elements of desire (the bulging vein, the sharp needle, the drawing back of blood) but also disappointment (it was not enough) and disgust (the murky mixture). I was aware when beginning the doctorate of the potential triggers and risks that talking to people who injected drugs could entail. How would I feel interviewing participants who might talk at length about

their injecting practices? It eventuated that the majority of the participants were no longer injecting. I also knew that my way of thinking about drug use had changed from the early days of abstinence where the sensuous pleasure of the rush dominated my thoughts. Heroin memories had become tempered with the murky reality of that time, and having become adept at observing thoughts of using without putting them into action, I felt at little risk. As time has progressed, these thoughts and feelings remain, a background/foreground play of embodied memory, a tension between repulsion and desire that pops up in and around my interview practice, which I observe with varying levels of dispassion or disquiet.

This play of embodied memory has become particularly apparent in more recent years, while I have been working on the Sydney and London Staying Safe projects. These projects, aiming to explore the social/structural facilitators of hepatitis C avoidance among long-term injectors, led me to conduct repeat in-depth life-history interviews with 13 people who injected illicit drugs in Sydney in 2009 (Harris, Treloar, & Maher, 2012) and 38 in London from 2010 to 2011. The difference between interviewing former (the doctoral research) and current drug users (the Staying Safe project) was marked. The embodied scrutiny and energy generation shifted—moved up a gear. Although my veins, in particular my track marks, had been remarked on approvingly by one doctoral participant: “a lot of heroin must have gone in those arms” (Jack), the primary focus in this study had been on my and their bodies in relation to hepatitis C—encompassing a shared recognition of fatigue and questioning/comparing of symptoms. In the Staying Safe project, however, the veins were center stage. As one participant said, “Oh look: you’ve got a massive vein there! Bloody hell!” (Max).

Venous Envy

In my field notes for the London Staying Safe project, reflections on veins predominate. The principal investigator on viewing these notes commented on my “reification of the vein.” This is perhaps emblematic of my past. As an ex-intravenous drug user, I know the central importance this bodily porthole holds, and my dreams of using are always centered on this make or break of the injecting experience. From my field notes of the time:

Before I went to interview Andy I read through his first interview transcript and it triggered a remembrance from the night before: “Dreamt about trying to get a vein. Awful. The desperation growing with each attempt, smeared blood and bruised, too-thin recalcitrant veins. I was with others—their ease at injecting exacerbating my desperation and despair.” I think this dream was triggered by interviewing Baxter

yesterday—his hands displaying evidence of many unsuccessful attempts; desperation writ large on the flesh. The dream had slipped my mind until reading Andy's interview transcript this morning before going to interview him—he talks about the same thing, up to two hour attempts to inject. (FN. London, September 2010)

My past is reflected in my interview practice. I, perhaps more than other researchers, ask participants about their ability to find a vein and am apt to empathize with the desperation occasioned by lengthy and painful injecting episodes. This often results in participants showing me their scarred and abscessed limbs, and even stripping to point out injection holes in the groin, with the question “am I going in the right place” (Cath). Again, from this time:

Half way through the interview Colin showed me his arms—pitted with abscess holes and scars, red raised lumps and then his legs—motley of scars, discolorations, lumps and bumps. The skin on his lower legs was grey and crinkly, two huge abscess scars on one calf—comprising a thin membrane of skin stretched red tight. At times during the interview I felt like retching—my stomach turning over in embodied recall. He noticed at one point and said “I'm not, you know?” meaning triggering me, upsetting me. (FN. London, June 2010)

Colin's concern was in relation to his knowledge of my past—and an understanding that, no matter how long ago, a return to the needle is never out of the question. In moments such as these, the interview process became one of mutual consideration—for the outcome and effects of these verbal, emotional, and embodied explorations on both of us. Colin's comment halfway through the interview was also notable: “You don't have to pull your arm. You don't have to pull that [sleeve] down.” I replied, “No, no, I was just getting a bit cold.”

Earlier in the interview, Colin had commented on my track marks, old injecting-related scars tracing portions of the cephalic and brachial veins in my right arm. As the interview progressed and the room chilled, I pulled down my sleeve—thus eliciting his response above. Although the meaning of Colin's exclamation is not self-evident, I knew exactly to what he referred. Our exchange strikes me with its poignancy. Informed by a shared experience of stigma, a reality where track marks are best covered, it was I who at this point was on the receiving end of a protective impetus. In turn, my response was informed by a desire to let Colin know that in front of him, I was not embarrassed and, of my scars, I was not ashamed. It is easier, of course, to take this stance, when your track marks are no longer red and raw, bruised and pock-marked with the signs of current injecting.

In these interviews, as Manderson (1995) writes, the body can be seen as an object to be understood in relation to the needle and the drug: “the culture of the needle, the culture of the vein” (p. 809). Venous envy: an eyeing up of each other's veins. This became more acute during the fieldwork:

Will I ever stop eyeing up my own veins? Caught—at the gym—in an uncomfortable reverie entranced with my veins, the way those on the hands move under the skin and the delicate blue bulge of those on the wrist. Nervous about what this gaze potentiates—forcing myself to look away, not think of the needle sliding in. Noticing, as I shave, the veins on my legs. Never having to access these sites, I had little thought of them, but am now aware in regard to the participants' tales. (FN. London, February 2011)

As with the interviews focused around hepatitis C, these interviews precipitated a new awareness of my body. The possibilities enacted by the veins on my legs, suddenly brought to attention as never before. In respect to Manderson's comment, however, this body with its injecting potentialities is not merely an object, the mutual attention to venous structure and damage not necessarily objectification. Indeed, this mutual attention can be experienced as facilitating recognition of a shared visceral relation to drugs, stigma, and the body, provoking an intensity that can churn the gut, quicken the senses.

This shared intensity was evident in many of these interviews. Facilitated by the presence of track marks and our stories, heroin became a third presence in the room, informing the shift and flow of energy, of embodied recall and recognition between myself and the participant:

Jake had been talking about the pleasure associated with using and even the anticipation of using, describing “almost swooning” with pleasure at the anticipatory/preparation stage. I could feel it also, especially when he talked about the pleasure of injecting alone, how he wanted to “savour” the hit. A gut feeling/recall/desire—I could picture in my mind's eye preparing a taste in my little flat and that feeling when the rush hits, the sinking back. The energy in the room had heightened, Jake said “I've got to stop talking about it cause I want a fix now,” to which I replied: “I know, I know what you mean.” (FN. London, September 2010)

The drugs enact a presence, a material effect felt even in their absence. Indeed, the memory, the desire, the potentiality of these psychoactive substances created a powerful energy in the interview situation. This third presence was spoken of by another participant, in reference to his relationship with his partner:

Do you know what I mean when two people in a relationship, there's not two, there's three of you, there's three people in a

relationship and it don't work . . . The drugs. It's the third thing innit? And what comes between us is drugs. (Will)

Heroin as the absent presence—desired or reviled, its impact felt in the energy flow between myself and Jake. For Will and his partner, the energy of heroin embodied a threat as tangible as another lover.

Pushing the Boundaries

My position as an ex-injector and disclosure in the interview situation—whether preemptive or elicited—facilitated a certain kind of interview dynamic, which was often conducive to the development of rapport with participants, eliciting comments akin to Claire's above:

The good thing about it [the interview] is because you're an ex-user so you know how it feels, do you know what I mean? Like if you had been a normal person it would have been harder for me to break out and tell you how I felt. (Kyle)

This included a searing indictment of non-injecting researchers who worked in the field:

These "textbook junkies" I call them, they just know what they read in a book. Have they ever felt a rattle? Have they ever felt them shivers and them cramps? No, the fuck, I've still got disco legs now and they've never felt that, so I'd like to give them a taste of it and then, and then try and judge a drug addict once you've tried it. (Abby)

The embodied experience of heroin withdrawal is not one that can be learnt from a book. However, Abby's vehemence in regard to "text-book junkie" researchers took me aback, particularly as it was directed at an experienced and compassionate colleague who had conducted the first and second interviews with her, and to whom she had disclosed other vulnerable experiences—such as domestic violence and child removal. In this third interview, she disclosed needle and syringe sharing practices, previously denied. The disjunction between her interview narratives was explained as such: "I knew he wasn't a drug user and I thought 'no, he's not judging me for something I've done, no.'"

Although under no illusion about any claims of social research to uncover a "truth" in regard to people's practices, Abby's divergent interviews provided a vivid example of the performativity of narrative, and the co-constitutive and contingent nature of interview data (Riessman, 1993). This is not to say that my background as an ex-injector, or a person living with hepatitis C, meant that I received a privileged version of events from research participants. Indeed, in one case in particular, my position made it very difficult to elicit any information. I conducted my interview with Ben in a park. He had

already been informed by the study field worker that I was an ex-injector, perhaps to encourage him to attend. This knowledge was, however, not exactly conducive to a productive interview situation:

Ben: What are you up to doing in your spare time, what do you do for kicks? You obviously don't take drugs.

Magdalena Harris: No I don't take drugs.

B: Off the record.

MH: Yeah, I don't take drugs.

B: Any?

MH: No.

B: So if I got some decent crack, you don't do gear anymore?

MH: No.

B: I got some decent crack.

MH: No.

B: You'd be up for having a party?

MH: No I wouldn't.

B: What do you like?

MH: I think we should get back to you.

B: I think if you're doing a survey about people who have got problems with these drugs, yeah, just a reminder little lick, yeah, just so you know how powerful it can be and what it does to your endorphins and your . . .

MH: Yeah, Ben, I know, okay, I'm not going to fuck up my life by having a reminder.

B: You don't have to fuck up your life.

MH: Yeah but it would, that's the reason I don't use drugs anymore because I had a problem with them, right.

I was shaken at the end of this interview, as Ben was continually attempting to fight against its format, and get me to use crack with him. He was charming yet relentless and it became a battle of the wills, with Ben pushing the boundaries at every angle: "Can I give you a little kiss on the cheek?" and "Just show me how to fucking bang up in my groin." Although, in my experience, this relentless boundary pushing is uncommon, it spoke to my sense of the nebulous ground on which I stood—no longer a drug user, nor a "traditional" academic, but somewhere in-between.

Closing the Circle? Hepatitis C Treatment and Hope

There have always been bodies that create ontological anxiety in their failure to conform (Douglas, 1966; Kristeva, 1982; Shildrick, 2002). The drug-dependent or virally infected body is one of these. My body is now, in a way, socially conforming; it is no longer dependent on illicit drugs, and, since completing interferon and ribavirin treatment in 2007, I no longer have hepatitis C. My embodiment and biography inform the way I conduct interviews and in turn, participants' perceptions of what it is that I embody. This has been notable in my current study,

following 27 people (to date) from before commencing hepatitis C treatment up to a year after completion. Participants have a mix of histories, some currently inject, some did so formerly, others contracted hepatitis C through unsterile medical practices in their country of origin or through blood transfusions before blood was screened in the United Kingdom. As with the doctoral study, I disclosed my “personal experience of living with hepatitis C and going through hepatitis C treatment” in the participant information sheet. However, unlike my doctoral study, this disclosure was about a past state—hepatitis C and treatment as experienced rather than experiencing.

This past state was picked up on by participants, eager to hear the outcome of my treatment and how it was experienced. Ibrahim’s questioning is illustrative (sans responses):

So you said you were on exactly the same treatment, that was six months and then when do you find out that you are absolutely clear? . . . But then what if it’s hidden somewhere? . . . So what things did you actually personally do on treatment? . . . What exactly your routine was? . . . How did exactly you find it after the injection? When did it actually affect you? . . . And the tablets you was taking every day? . . . Oh you had the Paracetamol before the injection?

This last question was in response to my previous answer, where I mentioned taking paracetamol before each interferon injection. In the following interviews, Ibrahim recalled this point, stating, “on your advice I’ve been taking Paracetamol, I always have them in my car, two Paracetamol in the morning.”

Hepatitis C treatment, particularly the new direct-acting antiviral formulations, can be seen as a “technology of hope” (L. Blackman, 2007). This technology of hope promises a narrative of restitution in which the infected individual undergoes treatment and, by eradicating hepatitis C, is able to return to a state of normality and functionality (Frank, 1995). In eliminating hepatitis C, the treatment can also offer so much more. For some participants, hepatitis C represented a stigma or an unwelcome reminder of their past, and despite uncertainty regarding its outcome or effects, treatment was framed as enabling a new start, a way for them to feel “clean” and redeem their place in the social body (cf. Rhodes, Harris, & Martin, 2013). My experience of coming through both injecting drug use and hepatitis C embodied this hope for many. Ezra, for example, initially wanted to know the outcome of my treatment (“Did you clear it? [*Yes*]. Oh you know what a relief it is to talk to you now”), and then moved onto the topic of injecting:

Ezra: Oh my god, and how long have you been clean [not injecting] now?

MH: About 12 years.

E: Oh I’m so proud of you doing that man, well done man, ah that’s what I want to get to. All this like, you’re a professional now and you know it’s amazing man.

MH: So anything is possible.

E: Yeah, how old are you if you don’t mind me asking?

MH: No, I’m nearly 40.

E: Yeah, ’cos I’m 34 and yeah. They say never too late, no. Yeah, no, that’s amazing man, that’s good to know that man.

This positioning—as a promise of hope—was an uneasy one, an ideal which neither the treatment, myself, nor potentially the participants could live up to. For some participants, their treatment was unsuccessful, some continued to feel unwell/unhappy/“unhomelike”³ after a successful treatment or transition from injecting—and for myself—this transition did not feel especially real or praise worthy. This is perhaps a strange admission after the visceral remembrances disclosed in the previous sections, but it is because these memories are so often absent, especially in that form, that their embodied occasioning through the research process was noteworthy. Roberta Culberton (1995) writes of the “paradox of distance from ones experience” encapsulated in embodied memory. This paradox is of “a known and felt truth that unfortunately obeys the logic of dreams” (p. 170), which in the relating can feel flat, unreal, as if telling the tale of another. Such memories “absent and yet entirely too present” are of the body, and can provide a valuable insight into the somatic modes of attention co-constituting the research process—as well as the particular vulnerabilities that can arise for researchers in the field.

As in the other studies, I experienced a blurring of the boundaries—in this case less a researcher than a peer educator or a counselor. This boundary blurring operated also in the hospital clinic where I conducted observations in the first year of the research—the nurses discussing cases with me as if I were a medical colleague and referring patients my way who they thought might “need some extra support.” In another site, a drug and alcohol service, a participant spoke of the potential benefits of having a peer ensconced in service provision:

It would be really good to have someone sit down with you and talk to you, just in a peer mentoring way, that would be great for anyone . . . it could be someone like, whose been through the treatment themselves, who can connect on a different level. (Alec)

These research interactions highlighted the potential benefits of enhanced peer involvement in service provision, not in a token fashion (as is generally the case in the United Kingdom), but in a more meaningful (trained and paid) capacity—as implemented to good effect in other locations (Norman et al., 2008). There is also a

need for peer involvement in the design and implementation of research, as in community-based participatory research models. Stewart, Wright, Sims, Tyner, and Montgomery (2012) describe the benefits of incorporating former drug users as key full-time staff in their research team and their vital role as “translators,” who are able to “speak the language” of both the target community and the research team. The challenges of this position are acknowledged, albeit briefly, in terms of triggers to relapse that a given situation or setting might potentiate. Cognizance of these issues (not only for those working in the drugs field, but other sensitive areas such as domestic violence; see S. Blackman, 2007) and ethical reflection on strategies for participants and researchers in such situations can only help strengthen research design and practice.

Ethical Reflections

People living with hepatitis C and/or drug dependencies are generally able, in Erving Goffman’s (1963) terms, to “pass” as “normal” if they so desire. Concealing one’s viral status or drug-using practices can be seen as a form of control, of one’s body and social identity (Maynard, 2006). This control can come at a cost, limiting the ability to access support or talk openly with friends and family. The interview situation, with its promises of anonymity, is a place where participants can either maintain or relax the control of their social narrative. My disclosure might have helped facilitate a different interview dynamic, one more akin to a conversation between peers than more traditional interviewer/interviewee interactions. This dynamic, while potentially productive, could also be pushed to discomfort—as in the interview with Ben.

These encounters have led me to reflect on the “ethical and emotional implications of enhanced rapport” in the interview situation (Davidson, 2004, p. 381). While researchers need to be aware of potential harms to participants arising from the research process, less attention is traditionally paid to potential adverse effects on the researcher. Davidson recommends the use of a detailed personal journal to minimize researcher distress, akin to my field note process where I recorded my thoughts and feelings after each interview. Yet, what is the place of those field notes? They appear to operate in the vicinity of “corridor talk” (Yow, 1997) where the messy intricacies of interview practice and resultant emotions can be expressed “around the water-cooler” but are less suitable for academic publication. This view is changing, with increased calls to attend to researcher emotion and affect in social research (S. Blackman, 2007), yet vulnerability to academic opprobrium still permeates such disclosures.

Research accounts of interactions where boundaries are pushed beyond comfort are comparatively rare and

might not sit easily with an image of the “legitimate competent reflexive researcher” (Bishop & Shepherd, 2011, p. 1286). Such accounts can challenge assumptions of an inevitable power imbalance in the interview dynamic (or shed light on other—potentially gendered—power imbalances) and provide an insight into the messy reality of qualitative research. They also highlight the potential need for additional supports for researchers, beyond the keeping of personal diaries. Qualitative research, especially involving sensitive subjects and vulnerable populations, can often give rise to unanticipated stories of trauma, rape, childhood abuse, and other sufferings. A participant might unexpectedly, tragically die in-between interviews, as was the case in the London Staying Safe study. Research supervision might be time limited, focused primarily on the nuts and bolts of research practice and/or research “competency.” In these cases, it might be appropriate for researchers to have recourse to professional counseling support, as is provided for professionals working in the field of mental health (Spence, Wilson, Kavanagh, Strong, & Worrall, 2001). However, this support is rarely provided or written in research budgets. Although vital, attention to the “welfare, rights and integrity of the researched” should not be taken to imply that researchers have “raised ourselves above such vulnerabilities” (Davidson, 2004, p. 390).

Concluding Thoughts: Embodiment and Vulnerability

My body speaks to me in the research process. At times, my muscles tense in reaction to the sight of a participant’s bruised and scarred arm or my gut will clench upon hearing or revisiting a certain story. A particular participant’s energy, something about the way they move or speak, can awaken bodily memories of my drug-using years, which might sit with me for a time after the interview concludes. In this way, the interview process and even that of writing can be said to occur in the intermundane space between bodies, where energies circulate and boundary distinctions are unclear (L. Blackman, 2008; Crossley, 1995). These “somatic modes of attention” (Csordas, 1993), these ways of attending to and with our bodies to the bodies of others, speak to debates about whether it is more accurate to view the body as material or as inscribed. As Connell (2001) writes, these concepts are not exclusive:

Joy is here, it is not just an interpretation; horror is here, it is not just the effect of a discourse. The materiality of bodies matters . . . Bodies are labelled and drilled, we acknowledge, but they also wriggle out of categories and march out of step. (p. 17)

Like Connell, I believe that the “materiality of bodies matters” and that while bodies are “labelled and drilled” by social institutions and normative discourses, this is not a purely passive inscription. Bodies can be socially influenced, but they can also be seen to actively negotiate, adopt, or resist normalizing discourses. This is a process in flux, in which lived experiential bodies can “wriggle out of categories and march out of step” (Connell, 2001, p. 17). Lived bodies are, however, more than simply reactive. They are agential and productive, with a life of their own, which neither discourse nor consciousness can fully grasp (Leder, 1990). Joy/horror, desire/desperation, responsibility/abandonment, sickness/pleasure, shame/transgression—all are socially mediated but also profoundly corporeal and embodied experiences. In regard to the injecting of heroin, my body remembers—a particular interview can bring back feelings of the sweet anticipatory sickness, the envelopment of the hit, the rush and the release—even though this was last experienced a decade ago. Certainly, this is a culturally/consciously mediated experience, but when conducting interviews with current users my gut is very good at making its presence felt.

My understanding of embodiment is that of the body as a lived experiencing agent, located in a substantive web of connections, whereby history, culture, corporeality, and sociality inform and mediate one another. It is a conception of the body as neither essential nor purely inscribed. Embodied narrative arises from this intersection of corporeality and discourse. It follows that narrative is not understood as a gateway to the “truth” of the participants’ experiences but as an often purposeful practice, which individuals might engage to present a certain version of the self, as can be seen from Sally’s disjunctive interview accounts.

It is through this intertwining of the corporeal and the social that participants offered their reflections on what it was to live with drug dependencies and/or hepatitis C. Participants’ narratives exemplified the contextual and fluid nature of what it was to be “ill” or “healthy.” These understandings do not necessarily depend on biomedical diagnostic categorizations, or on the presence or absence of symptoms, but are informed by an array of embodied socio-cultural meanings and motivations. The meanings and motivations participants brought to the interview situation, and my role as an interviewer, also resulted in a particular telling: The co-constructed nature of the interview process informed not only the participants’ narratives but also my sense of self in relation to questions of health, illness, treatment, and hope.

During these interviews, the presence of heroin or hepatitis C was apt to join myself and the participant in the room—a third energy—waxing and waning with the

flow of the narrative. This co-created energy was at times heightened by participant descriptions of heroin use and my attendant embodied recall, at others by the mutual attention to veins or the fatigue of hepatitis C. This heightened energy and my related disclosures can potentially create a situation of vulnerability. A vulnerability to thoughts of drug use as a result of the interview situation, to boundary blurring in interactions with participants, and in relation to publications such as this—vulnerability to perceptions of indulgence and flaky professional integrity. This is, however, just one version of the interview experience, a presentation of the self and the participants in a particular way, and as such can only be a partial story. Participants are invariably vulnerable to our readings/misinterpretations of their data—the taking of a quote out of context, the theoretical extrapolation/impoverishment of a narrative, and so on. By including that which is generally only relegated to “corridor talk,” in the form of personal reflections and field notes, I invite a reflection on the ethical implications of such “enhanced rapport” and of the play of embodiment, narrative, and disclosure in the interview situation.

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Notes

1. While these are not recent texts, they reflect current concerns (Bishop & Shepherd, 2011)—particularly in social sciences such as sociology, not traditionally aligned with (auto)ethnographic methodologies.
2. See also Carrier, Laplante, and Bruneau (2005) for how hepatitis C-related biomedical discourses recreated/resisted in light of peer understandings and experiences.
3. See Heidegger’s (1996) conception of existential anxiety as “unheimlich”—meaning both “uncanny” and “not at home” or “unhomelike” (not being at home in the world).

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