

**Contested identities:
Qualitative research and the
politics of injecting drug use**

**Betwiste identiteiten:
Kwalitatief onderzoek en
de politiek van injecterend
drugsgebruik (met een
samenvatting in het Nederlands)**

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CHAPTER 1

Introduction

Despite the celebrated pluralism and diversity of liberal Western societies, people who inject drugs remain beyond the bounds of the socially acceptable (Nettleton, Neale, & Pickering, 2012). The “uniquely stigmatised position” (Fraser & valentine, 2008, p. 1) which injecting drug use occupies in contemporary society is well documented in the scholarly literature (e.g., Fraser et al., 2017; Room, 2005) and the demonisation of ‘the junkie’ remains a commonplace trope in popular discourse (e.g., Manderson, 2005; Radcliffe & Stevens, 2008). For many people who inject drugs, their drug use assumes a “master status” (Lloyd, 2013) in the social imaginary, crowding out or obscuring alternative identities, and rendering those identified as such “intimately alive” (Goffman, 1973/1963, p. 17) to the feelings of abjection and censure frequently incited in others (Lloyd, 2013).

This thesis is about the *politics* of the social practice we know as ‘injecting drug use’ and those we identify as ‘people who inject drugs’: a politics less concerned with institutionalised governmental processes and more with the contest over forms of knowledge, identity and representation. It is a thesis about the innovative potential of qualitative research to recover and reconstitute the voices, the lived experiences, of some of society’s most socially excluded and disadvantaged citizens, in Australia and elsewhere. Drawing on these qualitative accounts, this thesis challenges the narrow nor-

maturity and discredited identities that dominate representations of injecting drug use(rs) in contemporary discursive settings, mapping the contexts and conditions under which new and alternative understandings and possibilities are realised.

This introduction is organised into three sections. In the opening section, I briefly establish the context of Australian drug policy and practice; in the second, I review the key conceptual and theoretical tools which underpin my analysis; and in the final section, I briefly discuss my research methods before providing a comprehensive overview of the chapters to come, including a detailed exposition of how each chapter and each analysis align to form a coherent whole.

1. CONTEXT, PRACTICE AND POLICY

Injecting drug use and hepatitis C

In Australia, an estimated 300,000 people have reported injecting illicit drugs in their lifetime, with 60,000 reporting doing so in the last year (AIHW, 2014). According to national survey data (Memedovic, Iversen, Geddes, & Maher, 2017)¹, methamphetamine has become the most commonly injected drug since surpassing heroin and pharmaceutical opioids (including morphine and oxycodone) in 2015. People who inject drugs experience high rates of imprisonment, with roughly 15% of Australia's current injecting population incarcerated at any given time (Butler, Callandar, & Simpson, 2015). Around half of the prison population report ever injecting drugs, while 70% of inmates are incarcerated for drug-related crimes (Butler et al., 2015).

For many people who inject drugs, the contraction of the hepatitis C virus reflects and reinforces the experience of social stigma and exclusion associated with their drug use. Symbolically associated with human immunodeficiency virus (HIV) (Fraser & Seear, 2011, p. 1), and transmitted predominantly via contaminated injecting equipment, the sense of abjection experienced by many living with hepatitis C has been well documented (Fraser & Seear, 2011; Harris, 2009; Treloar & Rhodes, 2009)². In Australia, the prevalence of chronic hepatitis C among people who inject drugs is 50% (Larney et al., 2015), with more than 230,000 (or over 1% of the general population) estimated to be living with the virus (The Kirby Institute, 2016). Ninety percent of all new incidents of hepatitis C are among people who inject drugs (The Kirby Institute, 2015), with 75% of all acute infections leading to chronic conditions. Over the next decade, hepatitis C-related

1 The Australian Needle and Syringe Program Survey provides serial point prevalence estimates of HIV and hepatitis C virus antibody prevalence and sexual and injecting risk behaviour among people who inject drugs in Australia. Conducted annually over a one-to-two week period in October, all clients attending participating Needle and Syringe Program (NSP) services are invited to complete a brief, anonymous questionnaire and to provide a capillary blood sample for HIV and hepatitis C antibody testing (Memedovic, Iversen, Geddes, & Maher, 2017).

2 For a detailed, theoretically informed account of the 'making' of hepatitis C, see Fraser & Seear (2011); for a history of disease concepts, including hepatitis C, see Duffin (2005).

costs are projected to be more than A\$2.5 billion (Sievert et al., 2014). Advanced liver disease has doubled in the past decade (Sievert et al., 2014), with rates of hepatitis C-related mortality now surpassing those of HIV/AIDS (The Kirby Institute, 2016).

Gender and Indigeneity have complex effects on practices of injecting drug use and rates of hepatitis C infection³ in Australia. A report prepared on behalf of the Reference Group to the United Nations on HIV and Injecting Drug Use (Roberts, Mathers, & Degenhardt, 2010, p. 7) concluded that, "Women who inject drugs have substantially different needs and face higher risks of disease and violence than do men who inject drugs." In Australia, women make up around one-third of people who inject drugs (Memedovic et al., 2017) and share similar rates of hepatitis C infection to men. Nonetheless, within the context of heterosexual relationships, women are exposed to patterns of injecting that put them at considerably greater risk than their male partners. Women are more likely to have a male sexual partner who also injects drugs (e.g., Choi, Wah Cheung, & Chen, 2006); to be introduced to injecting by a male sexual partner (e.g., Bryant, Brener, Hull, & Treloar, 2010); to be injected by a male sexual partner (e.g., Maher & Hudson, 2007); and to go "second on the needle" when sharing with a male sexual partner (e.g., Grund et al., 1996).

As in other post-colonial nation states, Australian Aboriginal and Torres Strait Islander people who inject drugs experience a disproportionate burden of disease. Rates of hepatitis C 'notification' (indicating new diagnoses) are *four* times greater among the Indigenous injecting population than the non-Indigenous (The Kirby Institute, 2016). Significantly, while rates have stabilised among the under twenty-five aged non-Indigenous population, they are steadily *increasing* among the same-aged Indigenous cohort (The Kirby Institute, 2016). Finally, while HIV prevalence among non-Indigenous people who inject drugs is just 1.7%, among Aboriginal and Torres Strait Islander people who inject it is 16% (The Kirby Institute, 2016).

Injecting drug use and hepatitis C occupy symbolically and politically fraught and contested terrain. Not surprisingly, their respective medical treatments have been freighted with much of the same complexity. I will return to briefly review both areas of treatment at the conclusion of the following section.

Australian National Drug Strategy and harm reduction

Following the advent of HIV/AIDS in the early 1980s, a partnership formed between Australian federal and state/territory governments, social researchers, clinicians and those either living with or most at risk from HIV, including gay men, sex workers and people who inject drugs. In 1985, the first National Drug Strategy (formerly known as the 'National Campaign Against Drug

3 For examples of qualitative research that attempt to address the particular risks and complexities facing women who inject drugs, see Bourgois, Prince, & Moss (2004); MacRae (2000); Malins, Fitzgerald, & Threadgold (2006); similarly, for qualitative work concerning Indigenous people who inject drugs and/or are living with hepatitis C, see Bryant et al. (2016); Treloar et al. (2016).

Abuse') introduced the overarching framework that remains Australia's official response to addressing licit and illicit drug use (AIHW, 2016)⁴. This Strategy is guided by the principle of 'harm minimisation', encompassing three components or 'pillars': demand reduction, supply reduction and harm reduction (Ministerial Council on Drug Strategy, 2011). While 'recognising' illicit drug use as a health and social issue, the Strategy also 'acknowledges' the role of law enforcement in detecting and deterring drug-related crime (Ministerial Council on Drug Strategy, 2011). Legislative and regulatory provisions relating to illicit drugs, precursor chemicals and proceeds of crime exist at the national level (for example, border protection and compliance), but most action (including expenditure) in relation to illicit drugs rests with the states and territories (Ritter, McLeod, & Shanahan, 2013). Australian governments spent approximately A\$1.7 billion in 2009–10 on illicit drug programs, of which an estimated 64% was spent on law enforcement, 22% on treatment, 9.7% on prevention and 2.2% on harm reduction (Ritter et al., 2013).

The essence of harm reduction is perhaps best described as simply those policies and programs designed to reduce the adverse consequences of psychotropic substances without necessarily reducing their consumption (Wodak, 1995, p. 340). While 'harm reduction' is now listed as one of the three officially sanctioned 'pillars' of Australian harm minimisation, its origins in Australia lie with the grassroots activism and allegiances of people who inject drugs, sex workers and gay men working alongside federal and state/territory governments, researchers, public health advocates and healthcare providers (Hopwood & Treloar, 2013; Madden & Wodak, 2014; Smith, 2012)⁵. This broad coalition remains the cornerstone of Australia's response to HIV and the basis of blood-borne virus prevention today (Madden & Wodak, 2014; Ministerial Council on Drug Strategy, 2011). While debate continues in Australia regarding what some critics argue is the increasingly depoliticised and technocratic nature of harm reduction — its institutionalisation within the machinery of public health (e.g., Keane, 2003; Miller, 2001; Roe, 2005)⁶ — this lies outside the scope of this introduction. My intention here is simply to note the success of the original national HIV response in Australia and briefly outline the ongoing implementation or application of its principles in practice.

For nearly three decades, Australia has maintained one of the world's lowest rates of HIV among people who inject drugs (Madden & Wodak, 2014) — as noted earlier, a prevalence of just 1.7% (or less than 0.5% if men with a history of male-to-male sex are excluded) (The Kirby

4 Australia has signed and ratified the three major international drug treaties (1961, 1971, 1988) which serve as the basis of the global drug prohibition system, and like many other countries, as the foundation for Australia's drug policy (Wodak, Symonds, & Richmond, 2003). However, as Alex Wodak and colleagues (2003) note, although these coexisting policies are viewed as consistent, there has always been an uneasy tension between them. Since 1985, Australia's increasing emphasis on harm reduction has pulled drug policy in "somewhat different directions" (p. 611).

5 Hopwood and Treloar (2013) trace the beginnings of contemporary harm reduction to activism among Dutch health professionals, social and political activists, and policy makers in the 1960s, leading to the Dutch Parliament's promotion of a 'balance-of-harms' approach in the 1970s. The movement continued with the formation of 'junkiebonden' in Rotterdam in the early 1980s, with other European cities, such as Liverpool in the UK, following suit with the advent of HIV/AIDS.

6 See Smith (2012) for a critique of current harm reduction practice in North America.

Institute, 2016). In 2015, just 3% of new HIV diagnoses were attributed to people who inject drugs (The Kirby Institute, 2016). One of the key reasons Australia's harm reduction response has been so successful was the timely introduction of the Needle Syringe Programs (NSPs). NSPs have been a core component of consecutive national drug frameworks since the emergence of the HIV pandemic in the late 1980s (Treloar & Fraser, 2007). In 2002, an independent report commissioned by the Federal Government estimated that from between their introduction in 1988 to the year 2000, NSPs had prevented 25,000 HIV and 21,000 hepatitis C infections. The report estimated that over the period 1991 to 2000 this amounted to a saving of A\$2.4 to A\$7.7 billion, based on an investment of A\$130 million over the same timeframe (Health Outcomes International Pty Ltd, National Centre in HIV Epidemiology and Clinical Research, & Drummond, 2002). In Australia, the majority of needles and syringes used by people who inject drugs are distributed via government-funded NSPs⁷ (The Kirby Institute, 2016). Given the sensitivity of rates of infection to variations in the availability of sterile injecting equipment (Treloar & Fraser, 2007), people who inject drugs are identified as a priority population for prevention in both the national hepatitis C and HIV strategies (Australian Government Department of Health, 2014a, 2014b). The opening of the Sydney Medically Supervised Injecting Centre in May 2001 represented a triumph for Australian harm reduction advocates and people who inject drugs over a culture of prohibition (van Beek, 2004). In public health discourse, the introduction of Sydney's injecting centre was framed as a logical extension of the harm reduction continuum. Nonetheless, despite its seemingly conservative, clinical model (van Beek, 2003), and the demonstrable success of safer injecting facilities elsewhere (Maher & Salmon, 2007), Sydney's injecting centre operated under a 'trial' licence for nearly a decade before legislation enacted by New South Wales Parliament in 2010 secured its permanency. While the Sydney centre remains the only safer injecting facility in Australia, there has been determined and persistent advocacy for others to be established, most notably in Melbourne (Australia's second largest city).

Treating hepatitis C and opioid dependence

Until recently hepatitis C treatment was interferon-based and characterised by consistently low uptake rates (1%–2% per year). Alongside biomedical explanations, notably debilitating side effects and suboptimal therapeutic efficacy (Hopwood & Treloar, 2007), these low uptake rates need to be

7 While the primary function of NSPs is the provision of sterile injecting and ancillary equipment (alcohol swabs, sterile water etc.), along with a means of safe disposal, they also provide safe sex information and products, such as condoms, to help prevent the sexual transmission of blood-borne viruses and other sexually transmitted infections (Health Outcomes International Pty Ltd et al., 2002). Standalone or 'primary' NSPs, along with secondary outlets (located within hospital emergency departments or community health centres) also provide information on safer injecting and referrals to other services (The Kirby Institute, 2013). Automatic dispensing machines dispense needles, syringes and ancillary equipment, providing additional coverage during the hours staffed outlets are unavailable, while community pharmacies may also provide equipment for sale or for free on exchange of used equipment (Bryant et al., 2010; Islam, Wodak, & Conigrave, 2008).

contextualised within a range of social structural factors (e.g., Fraser & Seear, 2011; Rhodes, Harris, & Martin, 2013), including the systemic stigma and discrimination frequently experienced by people with histories of injecting drug use attending mainstream healthcare settings (Paterson, Backmund, Hirsch, & Yim, 2007). Nonetheless, with the recent advent of a new generation of highly effective direct acting antivirals (or DAAs), the treatment landscape is being dramatically reshaped. Following the Federal Government's decision in May 2016 to cover the full cost of these otherwise prohibitively expensive new treatments, over 25,000 people initiated DAA-based treatment through Australia's public healthcare system in the first six months alone, a substantial increase over the previous 2000-3000 people treated annually (The Kirby Institute, 2017). The comparative ease, shorter duration and substantially reduced side effects of the new treatment regimens have enabled innovative initiatives to decentralise the care of hepatitis C, away from tertiary hospitals and into community-based settings, such as opioid substitution therapy clinics and primary care settings. Nonetheless, while the language of 'treatment as prevention' and 'viral elimination' has now taken centre stage, mathematical modelling has been quick to emphasise the imperative of high, ongoing needle-syringe and opioid substitution coverage if prevention efforts are to be ensured (Grebely, Matthews, Lloyd, & Dore, 2013; Martin, Hickman, Hutchinson, Goldberg, & Vickerman, 2013).

Lifetime engagement with treatment for illicit drug dependence remains "high" among people who inject drugs, according to national survey data (Memedovic et al., 2017). Nearly three-quarters of all 2016 respondents to a nationwide survey of NSP attendees reported previous or current engagement with the various pharmacotherapies (i.e., methadone, buprenorphine and buprenorphine-naloxone) comprising opioid substitution therapy. In Australia, methadone maintenance treatment has been available since the early 1970s, with buprenorphine-based treatments registered for use in opioid substitution therapy since 2000 (Day & Haber, 2009). While 34,000 individuals received opioid substitution therapy in 2016 (a significant decline from the previous year when over 48,000 people received treatment), the overall proportion of treatment recipients receiving methadone remained constant at approximately two-thirds. Arrangements for the provision of opioid substitution therapy vary across state jurisdictions in Australia: typically via large public or private clinics (with an estimated median of 150 people per service; Fraser & valentine, 2008) or community-based pharmacies⁸.

While opioid substitution therapy is a medical response to drug dependence, one with well-documented clinical, social and public health benefits (Marsch, 1998; Ward, Mattick, & Hall, 1998), a small but important body of critical literature also attests to the ambivalent place it can occupy in both the lived experience of those on treatment, and contemporary drug research and debate (e.g., Bourgois, 2000; Radcliffe & Stevens, 2008; Smith, 2010). In this thesis, I am aligned with this critical view which posits that rather than understanding substitution therapy as *just*

8 In the Australian context a 'public' client is one whose prescribing doctor is a state employee and who may be dosed at either a public (government-funded) clinic or a community pharmacy; the latter requiring a service fee. A 'private' client is one connected with a private (for profit) clinic and/or private prescriber, where s/he pays a fee to the prescriber and a dosing fee to the clinic or pharmacy.

another medical treatment, it is more robustly conceptualised as one “freighted with many of the criminal and political meanings attached to drugs and addicts” (Fraser & valentine, 2008, p. 117). While substitution therapy provides a pragmatic and sometimes compassionate response to opioid dependence, under the existing sociopolitical and legal conditions of the liberal West, it also plays an active role in the (re)production and perpetuation of socially stigmatised identities and related experiences of social disadvantage and exclusion (Fraser & valentine, 2008; Radcliffe & Stevens, 2008; Smith, 2011). Treatment recipients find themselves “situated between the ideologies of medicalisation and criminalisation” (Harris & McElrath, 2012, p. 819), embroiled in a system more concerned with controlling their behaviour than treating their drug dependence. Here the discredited identity of ‘the drug user’ is reproduced and reinforced by the very treatment program purportedly aiding its relinquishment. This treatment paradox has serious policy and practice implications. The (re)creation of ‘non-addict’ identities is crucial for individuals seeking to move on from drug dependence, yet “when individuals are devalued by the treatment process itself, how then can recovery be achieved?” (Harris & McElrath, 2012, p. 819).

2. CONCEPTUAL FRAMEWORK

Stigmatisation and the ‘drug-using subject’

People who inject drugs represent some of the most socially disadvantaged and excluded members of liberal Western societies (Bourgois & Schonberg, 2009; Fraser & valentine, 2008; Lloyd, 2013). As Room (2005, p. 144) suggests, while there is no necessary or inevitable relationship between drug use and stigma, aspects of drug use (such as dependence and treatment) appear to attract “near-universal stigma and marginalisation”. Posited as the “Other” of Western liberal democracy (Fraser & valentine, 2008), the figure of the ‘drug user’ aptly underscores Babcock’s observation that what is “socially peripheral is often symbolically central” (1978, p. 32). As Manderson (2005, p. 48) puts it, “The standard portrayal of the drug addict, stultified and immured in incapacity, reassures us of their absolute otherness”. For people who inject drugs, the identity of the ‘junkie’ serves as a metonym, a totalising identity (Harris, 2009), “one that encompasses all the dirtiness, disease, deviance, dangerousness, laziness, and absence of will that are so commonly associated with injecting drug use” (Malins, Fitzgerald, & Threadgold, 2006, p. 519). They are, in a sense, *failures by identity*.

Foucault’s (1979, 1982; see also Hirst, 2004) notion of “subjectification” is instructive in conceptualising the relationship between stigma and identity, particularly in the creation of so-called ‘spoiled’ or ‘damaged’ identities. Foucault was concerned with the regimes of power embedded in particular knowledge systems, in the inevitable nexus between power and knowledge. He was particularly interested in the processes of “subjectification” that take place through this nexus, with “the different modes by which, in our culture, human beings are made subjects” (Foucault,

1982, p. 777). As Bell (2006, p. 215) has observed, "In Foucault's power/knowledge regimes, the knowledge is taken in, folded into the subject's very being". Importantly, such constructions of subjects are not viewed as being essentially and universally so, but rather are always historically and contextually contingent (Ramazanoglu, 1993). Foucault (2003) conceived of a form of power that acts through 'normalising judgement' to fashion and manufacture human subjects which reproduce the constructed and cherished norms of contemporary culture. While Foucault is seemingly unconcerned with the notion of stigma in and of itself, Parker and Aggleton (2003, p. 17) propose that reading his work on power alongside Goffman's (1973/1963) classic work on stigma offers a "compelling case for the role of culturally constituted stigmatisation ... as central to the establishment and maintenance of the social order". Here stigmatisation is understood as an *ongoing social process* not simply linked to the production of negatively valued social difference (as stigma), but part of the "political economy of social exclusion" (Parker & Aggleton, 2003, p. 19) and, as such, inseparable from broader notions of power and social inequality.

Butler's (1993) work is similarly concerned with processes of normalisation. Describing the "exclusionary matrix" by which subjects are formed, Butler posits that this process requires the simultaneous production of a domain of 'abject beings', of non-subjects, which form "the constitutive outside to the domain of the subject" (1993, p. 3). In their investigation of "addiction stigma", Fraser et al. (2017) draw on Butler's insights into the political production of abjection to propose a reconceptualisation of stigma as a "performative biopolitical technology of power" (p. 4). Here stigma is understood as a systemic and normalising process which simultaneously constitutes legitimacy and abjection, belonging and exclusion; a *contingent* and *performative* process rather than a 'stable marker' of some form of anterior difference (Fraser et al., 2017, p. 2).

Despite its seemingly endemic and enduring nature, understanding stigma as a process which is contingent and political, rather than fixed and stable, suggests the possibility that things could be otherwise. In this thesis, I am particularly interested in investigating participant accounts which speak of experiences *other to*, or disrupting of, stigma's 'taint'. In this endeavour I am aligned with Foucault's recognition that concomitant with the process of subjectification is the potential for resistance. That is, within any power relation, there is necessarily, and always, the possibility of resistance (Armstrong & Murphy, 2012; Pickett, 1996). In collecting and analysing the narratives of people who inject drugs, this thesis seeks to move beyond a reductive or 'bottom-line' account of identity to explore what, following Deleuze (1995), we might call 'lines of flight'. Deleuze conceptualised power relations diagrammatically in terms of 'lines of power'. His diagrams of lines of power included "places of mutation" (1995, p. 85) where people "bend" or resist lines of power, seeking out lines of flight to somewhere else. According to Winslade (2009, p. 338)⁹, Deleuze conceptualised lines of flight as opportunities for identity transformation, giving rise to "new possibilities for living ... directions rather than destinations".

9 Scholar and clinician John Winslade (2009) cleverly elucidates the relevance of Deleuzian concepts for 'narrative therapy', a form of therapeutic practice strongly influenced by post-structural notions of identity and self.

Discourse, 'social space' and identity

Derrida (1993) argued that drugs do not exist in nature as such, but rather as a concept, a social and political category. In sympathy with this proposition, I see my thesis as engaged with the *idea* of drugs, or more precisely, the *politics* of that idea. This politics can be usefully elucidated by drawing on Foucault's (1972) notion of 'discourse' as a socially produced, rule-governed body of knowledge which is immersed in and constituted through relations of power (see also Bacchi & Goodwin, 2016; McHoul & Grace, 1993). Discourse provides "a language for talking about — a way of representing the knowledge about — a particular topic at a particular historical moment" (Hall 1992, p. 291). Put more simply, discourse is "what it is possible to speak of at a given moment" (Ramazanoglu, 1993, p. 19). Discourses circumscribe what it is possible to think, write or speak about a given social object or practice (Bacchi & Goodwin, 2016; McHoul & Grace, 1993). And as Foucault reminds us, discourse is "not simply that which translates struggles or systems of domination, but is the thing for which and by which there is struggle, discourse is the power which is to be seized" (1981, pp. 52–53).

Importantly, discourses are not to be understood as free products of an autonomous mind but instead require what Foucault (1972) referred to as "surfaces of emergence": particular institutional-organisational conditions of articulation (see also, Hirst 2004, p. 383). As such, discourses, and the social practices which surround them, are necessarily connected to particular social and institutional contexts, or *spaces*, and forms of power (Hirst, 2004; McHoul & Grace, 1993). While the concept of 'social space' has been the subject of a substantial, sophisticated and multidisciplinary body of literature (Soja, 1989; Twigg, 2006), its influence in qualitative research in the illicit drugs and addictions field has been significant over the past decade (see also, Duff, 2007). The concept has been taken up in innovative and instructive ways to explore, for example, how the spatial dimensions of opioid substitution clinics actively participate in the (re)production of stigmatised and discredited identities (Fraser, 2006; Smith, 2011), or how the "sensation" of the syringe shapes the "affective space" of a New York shooting gallery (Vitellone, 2010). What unites this otherwise diverse and eclectic body of work is a conceptualisation of 'space' or 'social space' as "a necessarily constitutive element of interaction, something active" (Thrift, 1996, p. 3). The term 'space' or 'social space' connotes a social context, place or setting which is conceptualised less as a passive vessel or container for action and more as a means of "making sense of the world" (Duff, 2007, p. 509); of organising social relations and cultural practices.

In Foucault's work (1991, p. 252), "space is elemental to any exercise of power"; it is where discourses of power and knowledge are translated into actual relations of power (Wright & Rab-inow, 1992, p. 14). Much of Foucault's work on the 'making' of subjects focuses on the local, the specific, and the *spatial*: the asylum, the clinic, the prison. Here processes of subjectification do not simply 'occur' in social and institutional sites serving as mere stages or vehicles for power, but are in and of themselves spatial practices (e.g., Foucault, 1979). The process of stigmatisation,

allied more broadly to processes of social classification (of excluding and 'othering'), can similarly be understood in spatial terms, as having spatial effects and relations. Takahashi's (1997) notion of "socio-spatial stigmatization", for example, usefully describes the spatial aspects of stigma, whereby physical places, such as drug treatment clinics, are associated with the stigma, the 'taint', of its service users, and, in return, influence how people become stigmatised through their association with particular places.

In this thesis, I am interested in exploring the relationship between *social* and *discursive* spaces and their role in the co-production of identities. Drawing on post-structural insights regarding space, language and subjectivity (e.g., Duff, 2007; Moore & Fraser, 2006; Winslade, 2005, 2009; Vitellone, 2010), the underlying conceptualisation of 'self' or 'identity' which informs this thesis emphasises the importance of context, of social *and* discursive location. Rather than emerging from an essential 'core', contained in an individual body, the post-structural conception of self I draw upon is understood to be "inevitably fragmented"; "contradictory"; "dynamic and contextual rather than static" (Lupton, 1997, p. 106; see also, Wolgemuth, 2014). Caught up in a process of continual creation (Winslade, 2005), identity is understood to be situated and 'constituted' within discourse, shaped by the 'folding' (Deleuze, 1988) of exteriority into interiority. Such an approach emphasises the role of the outside, the external world, in the construction of the interior experience of the subject. Despite its contingent and emergent nature, its *performativity*, there is nonetheless nothing free-floating in this conception of identity (Somers, 1994). Power and force inevitably constrain and pattern our choices (Winslade, 2009, p. 336); our identities are neither readily available nor freely chosen.

Nonetheless, subject positions, locations within discourse in which a subject can appear in, are not fixed (Rose, 1996; Winslade, 2005)¹⁰. Regardless of their seeming inviolability, bodies of power/knowledge (discourses) are never totally closed systems; rather they are open to contestation and contradiction, and thus the opportunity to take up new subject positions and construct counter-discourses (Lupton, 1995; Moore & Fraser, 2006). In my thesis, I actively emphasise the role qualitative research can play in enabling new subject positions for marginalised, discredited and often silenced participants from which to speak, to explain themselves, to *make themselves heard*. In so doing, I hope to demonstrate, drawing on both conceptual and empirical logics, the contribution qualitative research can make to the documentation of new understandings of identity-making and knowledge production.

10 Some scholars (e.g., Winslade, 2005) use the term 'discursive position' instead of 'subject position'; they denote the same concept.

3. THESIS OVERVIEW

Methods

Qualitative research has proven well suited to respond to the methodological challenges posed by working with people experiencing significant social isolation and stigmatisation (e.g., Fraser & Moore, 2011; Rhodes, Stimson, Moore, & Bourgois, 2010). Ever since research on illicit drug use began occurring regularly in the 1920s, qualitative approaches have proven invaluable in accessing often 'hidden or hard-to-reach' populations, allowing researchers to build trusting relationships with participants in order to facilitate discussion regarding sensitive and intimate information (Neale, Allen, & Coombes, 2005). By establishing mutual respect and acknowledging participants' specific expertise, researchers have been able to effectively gather the rich and contextualised details of participants' lived experience.

Extending this rich tradition of qualitative drugs research, this thesis comprises detailed analyses of seven qualitative datasets, each of which I was actively involved in collating and analysing. Material for chapter two was gathered from nine 'client comment books' filled out by service users visiting the Sydney Medically Supervised Injecting Centre during the first four years of its operation. The subsequent six chapters draw on six distinctive sets of semi-structured, in-depth interviews (263 in total), most of which were conducted face-to-face ($n=228$), with the remainder conducted by telephone ($n=35$). The majority of participants identified as people who inject drugs ($n=198$), including three participants who were interviewed on the basis of their role as peer support workers. The remaining participants comprised a mix of health professionals: doctors, nurses, pharmacists, health education officers, clinical managers and administrators ($n=65$).

Recruitment sites varied across projects and datasets. The focus was on people who inject drugs and associated health professionals, and demographic diversity was sought by including a range of geographic locations, from community centres in large rural towns to inner-city needle-syringe programs. Although the majority of recruitment took place either in Sydney or across New South Wales (Australia's largest city and most populous state, respectively), other parts of Australia were also represented, especially Melbourne (Australia's second largest city). Considerable efforts were made to capture those voices who remain 'outside' the public health net, that remain marginalised even from those services set up specifically to work with them. Whenever possible, participants were interviewed in locations where they could feel comfortable; in their regular 'dosing' (substitution therapy) clinic, for example, or a neighbourhood park or the library of the local, peer-run advocacy service. All studies received the relevant ethics approval. All interviews were audio-recorded following participant consent, professionally transcribed, de-identified and anonymised.

CHAPTER TWO: **Accidental intimacy**

On May 6th 2001, the doors of the first, legally sanctioned, yet demonstrably controversial (e.g., van Beek, 2004), safer injecting facility in the English-speaking world were opened. Located in the Sydney suburb of Kings Cross, long recognised as the epicentre of Australian drug dealing and using, the Sydney Medically Supervised Injecting Centre (MSIC) was conceived as a balanced response to both public health and public order concerns surrounding street-based injecting drug use. In many respects, this service remains the apotheosis of Australia's harm reduction program.

This chapter of the thesis explores an aspect of safer injecting facilities previously overlooked in the scholarly literature: the relationships forged between staff and service users in harm reduction settings. In doing so, it introduces many of the key themes of my thesis. In addition to confirming the intense stigma and shame experienced by people identified as 'injecting drug users,' this analysis also provides an opportunity to explore the potential for particular discursive, social and structural contexts to challenge and transform these experiences through the creation of alternative possibilities. By analysing entries made in the MSIC's 'client comment books,' this chapter underscores the unique potential of qualitative approaches to recover or reconstitute the voices of some of Australia's most socially stigmatised and disadvantaged citizens. In drawing on this unorthodox data source, I was able to not only gain access to voices which were hitherto marginalised in safer injecting facilities research, but to also underscore the methodological potential of post-structural theory to challenge positivist claims of what constitutes 'proper,' objectively verifiable research.

Using Ahmed's (2004) work on the sociality of emotions, this chapter examines the centrality of emotional connection in participants' accounts of their experience of the service. I argue that the everyday contact between staff and clients, including the 'accidental intimacy' that develops when clients inject in the presence of staff, can be seen to counter or transform the sensations of stigma and shame identified by many in the comment books, creating new forms of social relations and new performative possibilities (of self and identity, belonging and citizenship) among users of this service. In doing so, this analysis underscores the complex, mutable relationships between place, identity and language (as discourse). I argue that without an ongoing commitment to creative, innovative methods and data sources within the fields of harm reduction and addictions research generally, there is a danger that such perspectives will remain as marginalised within the scholarly literature as they are beyond research in the broader social world.

CHAPTER THREE: **The politics of place(ment)**

Prior to the recent surge in hepatitis C treatment uptake ushered in by the 'new era' of direct-acting antivirals (or DAAs), Australian public health efforts were focused on improving low treat-

ment uptake rates by expanding access away from the tertiary-hospital-based liver clinics and into community settings. This chapter examines the original proposal to integrate hepatitis C treatment in opioid substitution therapy clinics, a setting where historically the prevalence of the virus has been high.

In this third chapter, I introduce Foucault's deployment of social space alongside the more familiar themes of his work. For Foucault (1991, p. 252), "space is fundamental in any exercise of power"; it is where discourses of power and knowledge are translated into actual relations of power. In this chapter, I examine how the intersections between place, identity and discourse introduced in the previous chapter play out in the context of healthcare responses to hepatitis C. Drawing on two empirical datasets comprising interviews with opioid substitution health professionals and service users, my analysis examines the critical but often overlooked question of how staff organisational culture and power shape the practices, interactions and treatment identities enacted in substitution therapy settings.

Introducing Fricker's (2007) work on "epistemic injustice" and expanding on Foucault's (see for example, 1991) notion of discourse (as spatially situated), I examine the discrediting effect of stigma on service users' speech, their "credibility deficit" (Fricker, 2007). Utilising Fricker and Foucault's work alongside Parker and Aggleton's (2003) work on the stigmatisation process and Takahashi's (1997) notion of "socio-spatial stigmatization", I continue my examination of the relationship between stigma, identity, discourse and place begun in the previous chapter. However, while that chapter focused on the possibility of *transforming* identity, this chapter describes the *consolidation* of identity. I argue that the specific context of substitution therapy clinics not merely reflects but actively contributes to the political economy of social exclusion through which the socio-spatial segregation and stigmatisation of the service user as 'drug user' is enacted. Integrating Foucauldian concepts with Parker and Aggleton's (2003) work on the contextual specificities of stigmatisation, this chapter develops a novel way of thinking about not only the spatial dimensions of drug treatment but also the spatial relations of power more generally.

CHAPTER FOUR: "Not just Methadone Tracy"

The Enhancing Treatment of Hepatitis C in Opioid Substitution Settings (ETHOS) study was a prospective observational cohort designed to trial the proposed integration of hepatitis C care and treatment in opioid substitution therapy clinics, which was discussed in the previous chapter. As the next step in examining key conceptual and empirical issues associated with the proposed integration, this chapter examines an important counterpoint perspective to the one developed in the previous chapter. In the study reported in the previous chapter, participants had been effectively asked to comment on an idea, a proposed integration. This chapter is based on interviews conducted with participants from four Australian trial sites with *actual experience* of the new model.

In contrast to chapter three, this chapter identified unanticipated accounts of identity transformation among participants following the trial introduction of hepatitis C care and treatment at the four sites. The negative, stigmatising stereotypes characteristic of opioid substitution therapy settings documented in the previous chapter — of limited, routinised clinical exchanges and minimal social-care interaction — are unsettled in these accounts by the change in the form of care provided, opening up the possibility of new relations between staff and service users. The shift in the dynamic of the clinical encounter to addressing issues of health and wellbeing *in addition to dependence* appears to have catalysed transformative possibilities not only for the therapeutic alliance but also for service-user understandings of self and identity.

In this chapter, concepts of stigma, identity and place are explored in the light of new empirical data. While in some ways echoing chapter two's theme of the facilitation of identity transformation via the enactment of staff-service-user relations (of accidental intimacy and so forth) — this analysis represents another pivotal point in the development of my research on this subject. Here, the empirical data supports the introduction of the theme of 'care' as enabling this transformation. Initially emerging as a data-driven hypothesis, the notion of transformation *via* relations of care was then developed with the support of Fox's (1995) conceptually driven work on the "postmodern politics of care" and Mol's (2008) ethnographically informed "logic of care". This chapter offers critical insights, not only into the transformative possibilities of care for people living with stigmatised identities, but for institutional contexts and cultures of care more broadly.

CHAPTER FIVE: "We are people too"

The benefits and practice of 'consumer participation' have been championed for a number of decades across a range of social fields, including those of physical and mental health (Tritter & McCallum, 2006). The belated recognition of the benefits of 'user' or 'peer' involvement in drug treatment settings has meant very little social research has documented the actual implementation of such initiatives. My fifth chapter investigates just such an initiative as it was introduced in three Australian drug treatment services.

Drawing on interviews with service users and staff participating in a consumer participation project, themes of transformation and changing relations of care are explored, with a focus on understanding what they reveal about the political dimensions of representing marginalised people's perspectives in institutional contexts. Participants' accounts of transformation concern the changes they observed in the relationship between service users and staff, in the 'therapeutic alliance'. It appears that enhanced opportunities for interaction enabled by user involvement fostered a sense of service users and providers coming to know one another beyond the usual constraints and limitations of their formal, clinical relationship. Both sets of participants described a diminution of adversarial relations, an unsettling of the 'them and us' treatment

divide. Participants noted 'seeing' one another, *the other*, differently, as people rather than simply an identity category.

This chapter draws in more depth on the concept of "epistemic injustice", developed by Fricker (2007) and introduced in chapter three, alongside Fox's (1995) work on the politics of care, introduced in chapter four. The study reported in the latter chapter centred on transformations in service user identity and the 'therapeutic alliance' realised through the introduction of a new modality of care (hepatitis C treatment) in a context of stigmatisation and over-regulation (opioid substitution therapy). The study reported in the current chapter is concerned with transformation in the opioid substitution therapeutic alliance realised through the introduction of consumer participation initiatives in which service user participants are accorded 'a voice.' Here we are reminded of Foucault's (1981) dictum that discourse is the object of struggle rather than simply the means of its communication. Here too, as in chapters two and four, Deleuze's (1995, p. 85) notion of "places of mutation" is pertinent: the bending of lines of power creates new possibilities for living; new directions, if not destinations. While the empirical focus of this chapter is on a trial introduction of a consumer participation initiative in drug treatment settings, it contributes to a broader understanding of the centrality of being heard to our sense of self, our sense of humanness.

CHAPTER SIX: Practices of partnership

Chapter six signals a return to the subject of hepatitis C via an exploration of how 'viral risk' is negotiated in the partnerships and practices of people who inject drugs. Despite the serious implications for public health, scant research has focused on sexual partnerships as a key site of hepatitis C prevention and transmission. My analysis draws on a large, qualitative dataset collected as part of the Couples Who Inject Drugs (CUPID) project, a three-year qualitative study exploring the understanding and prevention of hepatitis C transmission among couples who inject drugs living in the inner city of Australia's two largest cities, Sydney and Melbourne.

Introducing the language of 'situated rationalities' and 'embodied knowledges', this chapter maintains my commitment to privileging the voices of participants. How do these particular couples engage with hepatitis C health promotion and prevention and incorporate it into their everyday lives and practices? Health promotion discourses and conventional epidemiology have tended to interpret the practice of 'sharing' injecting equipment (like the absence of condom use) in terms of 'noncompliance' relative to the normative behavioural expectations of public health. This chapter, however, is interested in participants' socially and relationally situated accounts or 'rationalities.' Employing the concept of "negotiated safety", a term originally coined to describe the creative risk-reduction practices which some gay men developed in the context of the HIV epidemic (Kippax & Race, 2003), I explore participants' injecting practices in relation to multiple

and alternative framings of risk and safety. By focusing on their accounts of lived partnership, I endeavour to understand notions of risk and safety as the couples themselves do, grounded in the lived reality of partnerships that are both reasoned and embodied.

Unlike in previous chapters, here stigma and identity are (re)configured in the context of intimate partnerships. Yet even here, such so-called 'private' spaces are never entirely outside the meaning making processes of the social world. For most participants, their partnerships constituted a form of social protection against an otherwise hostile and stigmatising world. Here, the situated and embodied knowledges of participants resist or contest mainstream epidemiological and health promotion understandings of risk, acting as a form of counter-discourse to the authority of 'expert' knowledges. I argue that our positioning of participants' partnerships as the primary unit of analysis represents not only an innovative way of thinking about hepatitis C virus transmission and prevention, but a powerful rejoinder to prevailing identity-based presumptions regarding the capacity of such couples to forge 'proper,' loving and caring partnerships.

CHAPTER SEVEN: **"Don't think I'm going to leave you over it"**

This chapter continues my investigation of the couples' dataset from the CUPID project. Here I argue that while the health-related benefits of intimate partnership are well documented, little attention has been paid to couples exposed to high levels of social stigma and exclusion, such as those who inject drugs. This chapter focuses specifically on the accounts of participants who reported a change in their hepatitis C status ('sero-change') during the course of their relationship. I wanted to explore what these narratives of sero-change reveal about the meaning of hepatitis C for these couples.

While some couples sought greater biomedical understanding of hepatitis C prevention and treatment as a means of coming to terms with sero-change, others drew on the alternative logics or rationalities (privileging notions of kinship, for example) which I noted in the previous chapter. Regardless of which explanatory framework they drew on, participants invariably prioritised the security of their relationship over the dangers of viral infection, thus privileging the maintenance of intimacy over the clinical definitions of health for the individuals involved. Such findings make sense in the context of the social stigma and isolation routinely reported by participants. Alongside chapter six, this chapter reveals the forms of counter-discourse which participants constitute in the face of 'expert knowledge' regarding risk and safety. I argue that engaging couples in hepatitis C prevention and care, or indeed other forms of injecting-related education, requires attention to the competing priorities and complex realities of such couples, beyond the identification of viral and drug-related risks.

Positioning the couple as the primary unit of analysis, as in chapters six and seven, affords a novel means by which to address the central theme of this thesis: the contested identities of

people who inject drugs. This novel methodological approach challenges the commonplace tendency in both popular and scholarly portrayals to overlook couples who inject drugs or to discount them as dysfunctional. It offers a way of thinking about couples that has clear implications (and applications) for policy and practice, not only in the harm reduction, drug treatment and hepatitis C care sectors, but in broader social and health policy fields as well.

CHAPTER EIGHT: “Why am I the way I am?”

Increasingly, social scientists acknowledge that ‘self’ and ‘identity’ are narratively constructed, or *storied*. Narratives and narration are understood as a means of human sense-making, the means by which we constitute past experience, claim identities and construct lives. This chapter signals another distinctive methodological contribution made in my thesis. Here I adopt a narrative analysis approach, taking as my object of investigation the life history account of a single participant preserved in its entirety, a distinct departure from the analyses of aggregated sets of data which are common to thematic analysis and other approaches to qualitative data analysis.

While a critical lens and qualitative method inform all chapters of my thesis, this chapter focuses on the unique challenges facing research participants who are asked to tell their personal or life stories in the context of issues or practices which are ascribed with significant social stigma, such as experienced by people who inject drugs. In this chapter I explore the particular advantages of adopting a narrative approach to understanding these complexities through a detailed, in-depth examination of a single case study, across two life-history interviews, with ‘Jimmy’, a young man with a history of social disadvantage, incarceration and heroin dependence. Drawing on the work of Fricker (2007), the notion of “hermeneutical injustice” is taken up to consider the effects of stigmatisation on the sociocultural practice of storytelling. I note the way Jimmy appears both constrained and released through the telling of his story, how he conforms to but also resists the master narrative of the ‘drug user’. Narrative analysis, I conclude, honours the complex challenges of the accounting work evident in interviews such as Jimmy’s. Accounting, Dingwall (1997) suggests, is talk that shapes a world such that others will recognise it and hold us to it; it is “how we build a stable order in social encounters and in society” (p. 9). I argue that a narrative analysis of Jimmy’s accounting practices provides a valuable counterpoint to the other forms of qualitative inquiry represented in my thesis and the illicit drugs and addictions field more broadly.

While this final empirical chapter returns to an explicit examination of the central themes of stigma, identity and discourse in this thesis, it does so via a methodological and theoretical framework which poses new and challenging questions regarding the politics of (self-)representation. Drawing once again on the critical insights of post-structural theory, alongside those of Fricker, this chapter raises critical conceptual and empirical concerns pertinent to those working with, or affected by, experiences of significant social stigma.

CHAPTER NINE: **Conclusion**

In my final chapter I reflect on the politics of knowledge production in the illicit drugs and addictions field. Recognising the ineluctable nexus between knowledge and power, I argue that the peripheral place qualitative research methods occupy relative to the longstanding dominance of positivist approaches is not simply an issue confined to the world of scholarly research, but one with direct implications for the broader social world. How drug use is understood or *constructed* within different knowledges has real-world ramifications for the people who use them. I question the effect on knowledge production and identity formation within the illicit drugs and addictions field when certain ways of knowing and certain kinds of ('rational' and 'objective') voices are valorised to the exclusion of others. Nonetheless, I also note the flourishing of innovative, social-theory-driven qualitative scholarship over recent decades which has sought to challenge and unsettle the ways in which we make sense of the empirical. I briefly review the contribution my thesis has made within this tradition. I conclude by positing the critical contribution qualitative methods can make in shaping political, policy and programmatic responses to the issues affecting those who inject drugs.

CHAPTER 2

Accidental intimacy

Transformative emotion and the Sydney Medically Supervised Injecting Centre

How do emotions work to secure collectivities through the way in which they read the bodies of others?

—Ahmed, 2004, p. 25

... when I'm here I do not feel judged or like a low life.

— 'Paulo', September 2001

This chapter widens the debate surrounding supervised injecting facilities (SIFs) by identifying and exploring an aspect of SIFs yet to be examined in the scholarly literature: the relationships forged between staff and clients within these settings. By analysing entries made in the Sydney Medically Supervised Injecting Centre's (MSIC) client comment books and reading these through the work of Sara Ahmed on the social productivity of emotions, the chapter explores the centrality of emotional connection to clients' experiences of the service, their perspectives on themselves, and their drug use trajectories and practices. It argues that the everyday contact between staff and clients — including what we in the chapter call the 'accidental intimacy' that develops

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when clients inject in the presence of staff — counters or transforms the sensations of shame identified by many in the comment books, creating new connections and relations, and new performative possibilities for the production of self, belonging, and citizenship for clients of the service. Theorised as thoroughly social, the emotions (here those of ‘shame’ and ‘acceptance’) are understood in this formulation to emerge from the space between individuals rather than from within individuals moving outwards, or from outside individuals moving inward. In this respect, the Sydney MSIC offers a very specific and unique opportunity to engage with clients at the level of emotions, transforming, for some, social relations conventionally predicated on shame to those predicated on acceptance. In the process, as Ahmed might argue, new collectivities are generated, which trouble normative and stigmatising binaries such as inside and outside, belonging and exclusion, and respectable and marginal.

Assessing supervised injecting facilities

To date, little or no research has been published on the social aspects of supervised injecting facilities (for a notable exception, see Malowanec & Rowe, 2003). While the geographic history of SIFs means that much of the early literature was originally published in German and Dutch (Hedrich, 2004), English-language scholarly literature has grown considerably since 2000. Both the *Journal of Drug Issues* (33:3, 2003) and the *International Journal of Drug Policy* (18:1, 2007) have, for example, devoted special issues to the subject. According to Kimber, Dolan, van Beek, Hedrich and Zurhold (2003) much of this literature can be broadly divided into:

commentary on the history of DCRs [drug consumption rooms], their actual and potential role in different jurisdictions, descriptions of service provision and different models of service delivery models and guidelines on the operation and use of DCRs.

(p. 228)

The available evidence from different jurisdictions has been collected in a number of reviews, including Dolan et al. (2000), Kimber et al. (2003), Hedrich (2004) and the *International Journal of Drug Policy* (18:1, 2007). More recently, editorials in two prominent international journals (Maher & Salmon, 2007; Strathdee & Pollini, 2007) and a comment in another (Kerr, Montaner, & Wood, 2008), argue strongly that it is a lack of political will rather than a lack of rigorous, supportive data that is hindering the consolidation and expansion of “these life-saving services” (Strathdee & Pollini, 2007, p. 848). Broadly put, the evidence suggests that SIFs have proven to be “highly effective interventions” (Maher & Salmon, 2007, p. 351) in reducing the harms associated with injecting drug use (MSIC Evaluation Committee, 2003; Kimber et al., 2003; Hedrich, 2004; Wood

et al., 2004; Freeman et al., 2005; Kerr, Tyndall, Li, Montaner, & Wood, 2005; Wood, Tyndall, Calvin, Montaner & Kerr, 2006; Lloyd & Hunt, 2007; NCHECR, 2007a; NCHECR, 2007b; Kimber et al., 2008; Wood, Tyndall, Zhang, Montaner, & Kerr, 2007; Salmon, Thein, Kimber, Kaldor, & Maher, 2007). Indeed, as Maher and Salmon (2007) argue:

enough international evidence now exists to suggest that the main questions, in terms of the impact of SIFs on needle and syringe sharing, overdose, public injecting, uptake of drug treatment and public amenity have been answered unequivocally.

(p. 352)

The number and rigour of SIF impact evaluations has grown in recent years. Indeed, in 2007 Strathdee and Pollini pointed to no fewer than 28 “methodologically rigorous studies” in peer-reviewed medical journals. While surveys of clients (see, for example, Fry, 2002; Petrar et al., 2007), staff focus groups and other qualitative approaches have formed a part of these evaluations (Hedrich, 2004, pp. 28–29), quantitative approaches and methodological debates have predominated. The risk here, as Fry, Cvetkovski, and Cameron (2006) argue, is that:

By focusing too narrowly on evidential questions about SIF impact, we miss an opportunity to engage with the ethical issues and value questions that are also important in public policy.

(p. 465)

In focusing on quantitative methods and on evaluations of the efficacy of SIFs from the point of view of their most directly stated goals, research is yet to explore a range of other important issues. Our view is that, while a substantial body of data now exists on the most visible principles and functions of SIFs, important aspects of their processes and outcomes will remain invisible unless more innovative questions and methods are brought to bear on them. While there is a substantial body of social welfare literature addressing the notion of engagement and the importance of relationships between staff and clients (Schorr, 2003; Watson, 2005; Wisdom, Hoffman, Rechberger, Seim, & Owens, 2009), this is largely absent from the burgeoning body of SIF-related literature. More specifically, the contribution of these relationships to the operations of SIFs has thus far remained outside the purview of scholarly investigation. As we argue, the role of emotion as both a product of, and productive of, the social — in this context, the sociality of staff/client relations — warrants serious consideration.

On May 6th 2001 the doors opened on the first, legally sanctioned safer injecting facility in the English-speaking world. Located in the Sydney suburb of Kings Cross, the MSIC was conceived as a balanced response to both the public health and public order concerns surrounding street-

based injecting drug use. Following a lengthy period of independent evaluation, the MSIC has recently had its trial status removed by NSW Parliament and continues to operate under the auspices of UnitingCare (the community service arm of the Uniting Church). Over the first six years of operation, 9778 clients made 391,170 visits to the MSIC; 2,106 overdose-related events were successfully managed on-site; and 6243 referrals were made to other services (NCHECR, 2007b).

The history of the MSIC has been thoroughly documented elsewhere (see, for example, van Beek, 2004; Haemmig & van Beek, 2005). We will not revisit this history again here, except to note that political opposition to the establishment of the service was intense. John Howard, the Australian Prime Minister at the time, the United Nations International Narcotics Control Board, state-based political parties, and the Kings Cross Chamber of Commerce were all vociferous in their opposition to the MSIC (van Beek 2003, p. 628). What this tumultuous history highlights is the extent to which injecting drug use and measures designed to reduce the harm associated with it (rather than to eradicate it) are stigmatised. The intensity and persistence of the opposition to the MSIC serves as a reminder of the stigma routinely experienced by those who inject drugs and the marginalisation of their lives and stories. In this chapter, we will argue that the MSIC intervenes in individual lives and alters perceptions of stigma in subtle but important ways. The chapter engages with the stories and statements of affected people, as captured in the client comment books, thankyou letters, and satisfaction survey.

METHOD

Approaching the comment books

In total, nearly nine A4-sized comment books were completed by MSIC clients between May 2001 and May 2005. The books were located in stage three of the service, the after-care or 'chill out' room. This is the most relaxed, least clinical, of the three service stages: a large room with comfortable chairs and small tables; an adjoining telephone room; a bathroom; and free tea, coffee and newspapers. The area affords a range of seating options, enabling clients to use the comment books as they wish: lingering over them privately; fussing over them publicly as part of a group effort; or merely noting something down as they passed through. Typically, the current comment book would be left lying unobtrusively on one of the tables, only a small label attached to its cover announcing its purpose. If the pen was missing, clients would just ask for another. As distinct from the cajoling from staff that necessarily accompanies formal client surveys, there was no sense of pressure or obligation attached to the use of the books. As the MSIC's founding medical director, Ingrid van Beek, recalls,¹ the books were instituted at the request of clients who insisted on having their say about this long-awaited service:

¹ Personal communication, August 16, 2007.

[clients] were all so moved by the MSIC at the outset — wanting to say a lot about it all, asking for pens and bits of paper to write on etc. all the time, so having a book where they could express their thoughts became more practical.

The books came to represent a plethora of purposes, styles and voices. From admonishments to peers: “Hi Guys Stop Shooting Up Pills It’s Fucked” (Anonymous, January 2002); to good wishes for friends: To M-C² “Hope your wedding plans go well — all the best — love ya’s” Pete xx (June 2002); to complaints about the snacks provided:

Piss off the Jats!!! [Jatz brand savoury cracker biscuits] We want [chocolate] Timtams, Kingstons or Choc Teady [Teddy] Bears, no dried shit, unless we have nice cheese, or pate!!!
(Jimmy, December 2002)³

Such comments are sometimes accompanied by rejoining remarks. In the case of the biscuit complaint, for example, another client replies unsympathetically: “Go to afganistan [Afghanistan] poor hard luck baby” (Anonymous, December 2002).

Underpinning the diversity of content runs a strong and consistent theme of client ownership and expressive entitlement. In this sense, the books offer a unique opportunity to explore the views and thoughts of clients unprompted or shaped by conventional research processes. Likewise, although they are written expressions, they are not shaped by the conventions of public address associated with more usual means of accessing attitudes and views through text (such as those found, for example, in newspaper and magazine letters pages). This is not to say the comments are not written for a public audience. Many are. Indeed, the comments address an intriguingly wide array of audiences (a far broader range than most other forms of expression); some are written solely for other individual clients, some for clients as a group, some for individual staff, some for staff as a group, some for both staff and clients and some, even, for society as a whole. In a range of ways, then, the books provide a valuable data source on what is often termed a ‘hard-to-reach population’ (Haemmig & van Beek, 2005, p. 160).

There is no doubt that this method is unconventional in some respects. This is perhaps its greatest strength. As feminists have argued for many years, recovering or reconstituting the voices of the marginalised often requires innovative methods and the willingness to go beyond assumptions about how research can and should be done. One of the main contributions of feminist epistemology has been its thoroughgoing critique of the positivist method, perhaps most significantly, its demonstration of the ways in which the values and assumptions implicit

2 All clients quoted in this chapter were assigned a pseudonym to preserve anonymity.

3 The only copy editing of client quotes has been the insertion of square brackets clarifying misspelt words and/or proper names.

in positivism shape the kinds of research conducted and even the outcomes produced (see for example, Nochlin, 1989; Harding, 1986). The feminist insight that traditional, supposedly objective research merely masks its biases has led, along with the critical impulses of post-structuralist theory, to a far more skeptical relationship within the social sciences to ambitions toward bias-free research. This skepticism, along with the recognition that conventional approaches to 'proper' sources of data and data collection techniques have tended to privilege male, middle-class perspectives, has led to the acceptance of the need to think creatively about data sources and collection techniques if more rigorous research is to be achieved (Fine, 1992; Lorde, 1983; Ramazanoglu and Holland, 2002). Drawing on this literature, this chapter consciously appropriates an unorthodox data source in order to access in novel ways marginalised voices: those of some of Australia's most disadvantaged injecting drug users.

The comment books were read in full several times by the first author and extracts indicative of emerging themes then selected. This selection process was then reviewed independently by both authors and a shortlist compiled and agreed upon. In addition to analysing the client comment books, we have also drawn (sparingly) upon client thankyou letters and a client satisfaction survey conducted in 2005. As with the client comment books, letters from clients offer an unorthodox but useful source of data. The survey affords us an additional opportunity to include qualitative material gathered from clients anonymously but via a more conventional format. There are a number of inclusions from the 2005 survey, taken primarily from material collected under the subheading, 'Main reasons clients use MSIC'. Together the three sources of data help us track an emotional trajectory otherwise ignored in the literature associated with SIFs.

As noted earlier, the comment books were freely available to anyone passing through the after-care area, the only temporary constraint being their use by other clients. Clearly, contributors were able to look over past comments, and were potentially influenced by them. While it is important to recognise this, it would not make sense to suggest that such exposure to the words and thoughts of others is unique to this context. The comments were made in a public setting, and were subject to the possibilities and limitations of available discourse. In this they differ little from other utterances. As is now well established in the critical literature influenced by post-structuralist understandings of language and subjectivity, all discourses embody rules and constraints about what can and cannot be said. Statements are not free products of an autonomous mind but have 'surfaces of emergence' — that is, institutional-organisational conditions of articulation (Hirst, 2004, p. 383; Foucault, 1980). Appreciating that the books functioned as a form of discursive practice rather than as a collection of isolated comments allows us to acknowledge the context of their formation: that forces were brought to bear on them just as they are on any public expression or utterance. It does not, *ipso facto*, diminish their worth, or render them more partial than others regularly analysed in qualitative and quantitative research.

It is important to note that while we argue that emotions are relational and social, the available data have inevitably directed our focus towards the clients, rather than the staff, of the Sydney

MSIC. We have framed this chapter around the available data and the concepts of transformative emotion they suggest. In making our argument, we do not claim that every comment posted in the books or given in the survey is unequivocally positive about the service. Our purpose is not to paint an unrealistically rosy view of day-to-day events. We do, however, wish to draw attention to a specific way in which particular relationships and emotions generated in the encounter between clients and service manage to ameliorate stigma. Nothing in the comments, letters, or survey, even where criticisms are made, contradicts this trend.

This chapter employs an innovative methodological and theoretical approach to draw attention to a social dimension of SIFs otherwise overlooked in the scholarly literature. In exploring the role of emotions in the operation of the MSIC we also aim to highlight the political, policy, and clinical value of qualitative forms of inquiry for the harm reduction field. According to Philippe Bourgois (2002), “[q]uantitative and qualitative researchers concerned with the social suffering of street-based drug users have a great deal to offer one another” (p. 259). This would-be collaboration has been largely absent in the short history of research investigating SIFs since the first was established in Berne, Switzerland in 1986 (Hedrich, 2004, p. 15). Qualitative social approaches, especially those drawing on the “dramatic theoretical advances” (Rhodes, Samson, Moore, & Bourgois, 2010) evident within the humanities and qualitative social sciences during this period, have been almost entirely absent from published accounts of SIFs.

Conceptualising the comments

The MSIC differs from all other health services in Australia in actively hosting the injection of illicit (and licit) drugs. The controversy that marked the MSIC’s (pre)history gives testimony to the significance this held — and continues to hold — not only for various sections of the general community but for those who became clients of the service. The act of injecting, which, for many clients, operates as a symbolic moment of internalised shame and social marginalisation, is performed within the MSIC in the immediate presence of staff. Physically the space is organised as follows. The injecting booths and the clients seated at them face away from staff, who are positioned behind an elongated desk. While the physical space is thus roughly demarcated into client and staff areas, there is considerable mobility between these spaces, and an ease and fluidity of movement and interaction. In part due to this absence of strict boundaries, a form of client–staff intimacy is generated during the injecting process as staff interact with clients. This creates a space shared by both client and practitioners within which staff acceptance and client trust — as well as physical safety — take priority. There is a sense in which this proximity grounds the client–practitioner relationship, creating what we will call ‘accidental intimacy’. Importantly, we describe this intimacy as accidental insofar as it falls outside the formal aims of the MSIC. It is, we argue, an unintended but highly productive effect of the very particular service the MSIC

provides. Without wishing to overdefine this somewhat intangible phenomenon or ascribe to it some magical, redemptive power, we nevertheless argue that its potential is currently poorly recognised and understood within harm reduction. Indeed, while the phenomenon we are describing is undoubtedly intangible, it also finds very concrete expression in the pages of the MSIC client comment books.

In attempting to do justice to the social processes described by service users in their comments, it is necessary to adopt a theoretical framework able to recognise emotions as intrinsically and primarily social. Why social? It is worth beginning with a detailed example taken from a thankyou card sent by client 'Sarah' to MSIC staff. It demonstrates the centrality of social relationships and feelings of acceptance to the service's effectiveness:

During the lowest point in my life you provided the only stability I knew. [It was a] time [in] which I didn't know where I'd be sleeping from night to night, where the next meal was coming from or whether I was going to live or die (by choice or otherwise). Having a safe place to go with people I felt I could trust was a life-line. I am forever grateful to you all, as a team, for having such a positive effect on my life. I'd like you to know that the greatest quality you all showed was the ability to make me feel that I was not being judged. Pretty amazing considering the "state" I was in ... I'm sure you guys are a large part of the reason I'm still alive.

This extract captures many of the themes expressed by clients in the comment books. Crucially, it places emotions related to trust and acceptance directly at the centre of Sarah's understanding of her own survival, and makes clear that for her, the MSIC was not only a physical facility, but a social context in which she could feel herself supported.

How might we understand the social-emotional processes at work in this example? Sara Ahmed's writing on the politics of emotion provides a valuable entry point. In her 2004 article, "Collective feelings", Ahmed concentrates on the role of emotions in creating and securing collectivities. Her interest is in a set of issues rather distant from those canvassed here: the role of nationalist fervour and the emotion of hatred in generating national collectivities and the national boundaries on which they rely. She argues against formulations of emotion that understand it either as located in subjects and moving outwards to society, or in society and moving inwards into subjects. Both models, she suggests, reify emotion. Instead, Ahmed argues that emotion emerges between subjects, and between subjects and society: that it is in the space between these that emotions occur and have their effect. Indeed, in her view, it is emotions that work to define the boundaries of subjects, and of collectivities, and she uses the example of nationalist extremism and race hate to illustrate the ways in which the perception of shared emotion create defined collectivities such as nations:

The ordinary white subject is a fantasy that comes into being through the mobilisation of hate, as a passionate attachment tied closely to love ... hate works to create the very outline of different figures, which aligns those figures together, and constitutes them as a common threat.
(p. 26)

The idea that hate constitutes categories of persons by which some are included and some excluded, some valued and some denigrated, resonates strongly with the conditions under which injecting drug users must operate in society. 'Hate' is clearly a strong word, but it does not overstate the emotion that produces the 'ordinary non-injecting' or 'clean' subject of Western discourse against the despised injecting subject or 'junkie' (Manderson, 2005). As the protracted lead-up to the opening of the MSIC — along with the many political challenges described above — indicates, injecting drug use occurs amid intense political and social controversy.

Ahmed's theory is particularly evocative in the context of this chapter in that her emphasis is on boundaries — including bodily boundaries such as that presented by the skin — and of processes of movement across boundaries, and the (re)creation of these boundaries through attempts at movement, as defining subjects and collectivities. Thus, hate outlines the contours of a nationalist collectivity by constructing the inside and the outside of this collectivity. By virtue of their race or colour, some subjects belong 'inside' the national collectivity, others belong 'outside' it. She asks, "How do emotions work to align some subjects with some others and against other others?" (p. 25). While Ahmed focuses here on the negative emotion of hate and the formation of racist collectivities, it is worth considering how her argument could apply to the positive account given in Sarah's postcard quoted above, and to the client comments presented below. Certainly, we can begin by considering the emotion of shame as generated in the space between injecting subjects and others — indeed, it plays a key role in delineating these categories — and likewise the emotions of belonging and acceptance. Ahmed describes emotions as establishing the very subjects and objects understood to generate them. From this point of view, it is possible to understand emotions as creating subjects rather than expressing them. It is this insight that we can apply in the first instance to the MSIC, to feelings of shame and acceptance, and to the transformations described in client comments.

Also important in taking up Ahmed's insights is avoiding the assumption that the collectivities generated by emotions must be based on likeness. To put this another way, perceptions of likeness are created in the process of sharing feeling and of creating collectivities, rather than being ontologically anterior to them, or instigating them. Thus, as with the White supremacist collectivities Ahmed describes, the collectivity we might posit as a product of the emotions at work at the MSIC is one in which likeness or shared feeling is the product of contact rather than its precursor. As Ahmed puts it, "It is through the intensification of feeling that bodies and worlds materialise and take shape, or that the effect of boundary, fixity and surface is produced" (p. 29). Our starting

point is that, as a heavily stigmatised practice, injecting constitutes an 'intensification of feeling', in the daily contact intrinsic to the MSIC's primary functions. And, as Ahmed points out, if feelings act to make surfaces, borders and collectivities, they can also unmake them. As will become clear, this is precisely how we read the client comment books we analyse for this chapter.

Injecting drug use and shame

The stigmatisation of injecting drug use is well established in the literature (see for example, Rhodes et al., 2010; Radcliffe & Stevens, 2008; Smith, 2010). The MSIC client comment books reflect this stigmatisation in the many references that are made to the situation of injecting drug users and the perception that mainstream society holds them in contempt. Indeed, many entries offer the view that beyond the MSIC, they are regarded as little more than refuse:

[We are] the supposed "dregs of society".
(Sara-Jane, November 2001)

[We are] treated like lower class citizens.
(Rachel, December 2001)

[T]he rest of the world think we should be left to die or shot dead. ...
(Philippa, August 2002)

As many entries also make clear, these negative judgements on the part of mainstream society shape injecting drug users' understandings of themselves, so that the line between the contempt held by others and negative judgements about the self is blurred:

[P]eople look down on you. You feel like you are just a low life junkie. ...
(Anonymous, January 2001)

You have made us feel like citizens rather than scummy junkies. ...
(Petra and Philip, April 2002)

This last quotation encapsulates especially neatly the effect to which this chapter is attempting to draw attention. In a few words it references several highly complex phenomena: first, the stigmatising effects of mainstream society with respect to views on addiction and injecting drug use; second, the negative judgements injecting drug users make about themselves; third, the ability of the MSIC to interrupt or alter these judgements; and finally, the role of notions of the

state and citizenship in this shift for many. In the process, it makes use of figures of spatiality that find echoes in Ahmed's theory.

The primary examples of spatial metaphors found in the client comment books can be characterised along the lines of the binaries inside/outside and high/low. Other spatial metaphors invoke other relationships, but all are explicitly aware of social hierarchy and the exiling of injecting drug users outside the norm. For this reason we have included "dregs" and "scum" as examples of spatial (and spatialising) metaphors which nonetheless function atypically compared to the others discussed below. As the extracts indicate, the MSIC is able to disrupt the clients' ordinary perceptions of these spatial relationships, creating new locations and collectivities via emotional engagements and the mutual generation of feelings:

High/low:

When I'm here I do not feel judged or like a low life.

(Paulo, September 2001)

We don't need a return to syringes in the gutter, or people lying there either.

(Anonymous, June 2003)

Inside/outside:

Great place. It feels safe and the staff is so kind and understanding. They and this environment make drug users feel less like social outcasts. Thanks.

(Anonymous, November 2001)

I find the service that you offer is undeniably fantastic. ... You have taken a service, outside society's normal parameters, and made it accessible to us, the normal everyday using addict.

(Anonymous, October 2001)

'Dregs' and 'scum':

Its good to see that people do care about us — the supposed 'dregs of society'. We are real people too — with mothers and fathers and people that love us. Your lack of judgement is also appreciated. Thanks guys.

(Sarah-Jane, November 2001)

... general atmosphere of care and non-judgmental makes me feel more human & less like scum.

(2005 client satisfaction survey)

All these examples indicate perceptions of social position, or a sense of (not) belonging. Clearly to be *outcast* is to be excluded, to not belong. Marginalisation, as in being on the margins, is obviously a variation on this theme. In spatial terms, high/low can be read as the vertical variation on the second set of metaphors: the horizontal inside/outside. Being in the 'gutter' (literally a low position), being looked 'down' upon and so on are also ways of expressing a 'fall' (in a Christian narrative, from grace; but also 'falling' out of favour). The third set of spatial metaphors noted in these extracts — top/bottom — differ from the others in that both the top and the bottom positions represent the abject (that is, 'dregs' as leftover sediment on the bottom; 'scum' as waste matter floating on the top). Nonetheless, taken as statements of spatial positioning both dregs and scum are located on the periphery as opposed to the centre; they are not part of the liquid/substance but apart from it — that which is excess, polluting, and must be removed.

In all these examples, we can see how the engagements made possible between staff and clients by the MSIC generate new emotions, the possibility of movement across boundaries into spaces of belonging and collectivity, and new definitions of collectivity. By bringing their marginal, stigmatised practice to the MSIC and enacting it in the presence of those otherwise (perceived to be) located at the normative centre, these clients experience a shift. In Ahmed's terms, this shift can be said to generate new subjects: legitimised subjects able to imagine, sometimes for the first time in years, a legitimate place in society.

The client comment books also exhibit a strong theme of displacement, mainly based on the idea of being 'lost', and frequent reference is made to the place of the MSIC in undoing this lost status. We can be lost in many ways: geographically, socially, psychologically. To be lost is to be 'misplaced'. If we think about power being, in part, about the correct order — or placement — of things, then being lost is about being out of place, out of order ... *disempowered*. Being lost or rejected is of course the flipside of belonging:

Thanks for all your hard work and dedication. This gallery is crucial for this area and has surely [surely] saved and will save many lives however lost or rejected by society they are.

(Reg, December 2001)

And I am really grateful [grateful] to all of you guys that honestly, genuinely want to help those so called Junkies that other people perceive to be a lost cause.

(Pippa, June 2004)

As in the previous section, the emotions generated between the MSIC clients and the staff serve to constitute new relations, locations and collectivities. Those once lost now feel less so. Some-

thing in their engagement creates a new feeling, one that simultaneously makes a new spatial location: that of being found or properly placed.

Citizenship, rights and collectivity

How is this sense of a proper place in society constructed in the client comment books? Our analysis found numerous references to the social, that is, to society, citizenship, and civilisation, and by implication, enfranchisement in that it by definition accompanies the status of the citizen (being enfranchised comprises inclusion plus a set of rights):

[I]t is a great idea as we are closer to acceptance in society. The staff are very professional ... nonjudgemental and understanding.

(2005 client satisfaction survey)

Dear Staff, to me you have been such a god-send. Our sanctuary — smiling faces, polite conversation and always helpful. You have made us feel like citizens rather than scummy junkies + you have given us a safe, clean place, instead of sneaking around the alleyways in unclean surroundings. Bless you all.

(Petra and Philip, April 2002)

The way that clients were helped with genuine concern, no sense of condescension safe, friendly — other services and information available but not pushed. This is a benchmark of civilised society.

(Anonymous, June 2003)

In these examples, the comments point to emotions that constitute formal notions of belonging as well as the informal notions cited earlier. Engagements between clients and staff at the MSIC produce new emotions that reposition or remake clients as having some kind of stake in the formal structures of society, and in turn, some claim to the rights enshrined in conventional understandings of society. As above, these shifts are generated not simply by the provision of a set of services but also by the processes and tone of engagement between the individuals involved. In other words, the extracts indicate the role of subtle, interpersonal dynamics that serve to generate emotions and related shifts in subjectivity and collectivity. As Ahmed argues, emotions create the very subjects said to express them. This is an iterative process which allows for change and intervention. In these examples, emotions create new formations of citizenship as belonging, and the nascent sense of a collectivity of injectors with the potential to claim full citizenship rights.

Good 'treatment'

Another metaphor evident in the comment books can be read off the multiple uses of the term 'treatment'. Here the (ubiquitous) rhetoric of treatment — of being in treatment — is not so much inverted as expanded to include the very quality (effect and affect) of interaction; to *treat* someone (humanely, compassionately, respectfully, and so on):

Nice to be treated like a human being in here instead of a scummy addict i.e. with respect and dignity. Keep up the good job.

(Bev, July 2002)

Bloody brilliant idea. If you treat people like humans they behave like humans.

(Ben, September 2002)

The worst thing about being a user is the way people look down on you, you feel like you are just a low life junkie but the workers here treat you like you are someone and not like the scum of the earth. People aren't judgemental and we can take time out from the Cross.

(Anonymous, January 2001)

The substance of our argument is in some ways located in the overlap between formal treatment and interpersonal treatment evident in these examples. As we have argued throughout this analysis, much happens on the level of affect, of emotion, that cannot be measured by conventional research methods and can therefore go unnoticed in the evaluations and other assessments of this service and potentially others like it. Assessments of this service place a great deal of emphasis on measuring the number of referrals of clients — into formal treatment such as opioid pharmacotherapy treatment, detox and so on (Kimber et al., 2008). As we have noted, this means that the qualitative dimensions in the MSIC's effects may be missed.

In drawing together the observations made possible in examining the data presented here, it is useful to return briefly to the MSIC's founding public health aims outlined earlier. The successful achievement of the MSIC's primary aims — of reducing the harms associated with overdoses and blood-borne viruses, of establishing earlier engagement with the target population, and increasing the effectiveness of referrals into treatment and appropriate social welfare services — all necessitate the establishment of an environment which both attracts and retains those at risk. It is this that allows the preconditions for change where appropriate and desired. As the client comments books indicate, the MSIC manages to create an environment of this kind for many clients, partly because its central task entails accepting — witnessing and supporting —

the unacceptable: the intrinsically transgressive act of illicit drug consumption via the crossing of the corporeal boundary of the skin.

Here we have been concerned to explore the emotional ground on which measurable effects are produced: the space of possibility and transformation that is opened up through the changing narratives of space, self, and other among those who use the MSIC. Our aim has been to point to the way the feelings created in the encounters between staff and clients have the potential to enhance the service's effectiveness. We do not argue that the comments made by clients prove that trusting relationships do engender change, instead we point to the need to listen to the voices of those who testify that they do.

CONCLUSION

In an editorial published in the *International Journal of Drug Policy*, Rhodes et al. (2010) pose the following (rhetorical) question about the place of qualitative research in addiction studies: "[s]urely, addiction journals wish to encourage rather than marginalise qualitative research that engages with current developments in social and cultural theory and methodology?" This chapter is in many ways just the kind of work to which this question responds. It has employed an unconventional approach to an unorthodox data source to illuminate the words of marginalised people and the complex effects of a marginalised service. It is indeed ironic and frustrating to find that the critical tools often best suited to accessing and ameliorating marginalisation are themselves marginalised such that their power to effect this amelioration is diminished. It is our view that without an ongoing commitment to creative, innovative methods and data sources within the fields of harm reduction and addiction research generally, there is a danger that such perspectives will remain as marginalised within the scholarly literature as they are beyond research in the broader social world.

The marginalisation to which we refer matters in more than one way. Not only is it ethically indefensible when it shapes lived experience, it also endangers our ability to understand and act effectively on social problems. This chapter has attempted to draw attention to and better understand an otherwise overlooked dimension of one response to a social problem: SIFs. In particular, it has examined the role of emotions in the provision of a legal, supervised injecting space. Looked at more broadly in terms of the literature on harm-reduction services and drug treatment, we can see that clients' and service providers' feelings are at times recognised as part of the nature and impact of these services (see, for example, Ashton & Witton, 2004). Our chapter builds on these occasional moments of recognition. It differs, however, from this literature in explicitly positioning emotions as performative of subjects — not as essential attributes within subjects. As we have seen in the comments presented above, in the generation of emotions in the spaces between clients, staff and the material environment of the clinic, between moments of shame and stigma and across the boundaries of skin as entailed by injecting, new moments

of subjectivity are created. The comments show powerfully how significant these are to clients. Indeed, in recognition of the importance of these constructions of emotion, one contributor to the comment books says of the staff:

I think their emotional minds are fit, strong & powerful as Anthony Mandine's muscles [Anthony Mundine is a popular Australian boxer].
(Anonymous, March 2003)

In keeping with Ahmed's argument and ours, this quote emphasises the active nature of making emotions — the fitness and power of a good emotional mind. Amid the many different ways the MSIC and other services like it are assessed, evaluated and tracked, there must be space to document, analyse and draw on — for the benefit of other programs and services — the more elusive processes of feeling, of the creation of accidental intimacy, that introduce and support transformation for people who inject drugs.

CHAPTER 3

The politics of place(ment)

Problematising the provision of hepatitis C treatment within opiate substitution clinics

BASED ON:

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Conception, analysis and writing by J.R.; data collection by J.N. M.H. and C.T. contributed to the initial coding frame and provided critical feedback throughout.

The hepatitis C (HCV) epidemic is a significant public health challenge in Australia and the burden of disease is increasing (Dore & Jauncey, 2009). With chronic HCV affecting an estimated 217,000 people, national health policy currently targets a doubling of treatment uptake to ameliorate the looming healthcare burden of end-stage liver disease and transplantation. In Australia, as elsewhere in the developed world, the primary risk factor for contracting HCV is injecting drug use. Estimates suggest 80% of all chronic HCV infections in Australia are due to injecting drug use and close to 90% of the 9700 incident infections recorded in 2005 were transmitted via this route (Hellard, Sacks-Davis, & Gold, 2009).

Australian initiatives to expand HCV treatment provision beyond the specialised clinics of tertiary hospitals have focused on opiate substitution therapy settings where HCV prevalence among the client population is high (Hellard et al., 2009). Of the over 46,000 people (AIHW, 2010) currently receiving OST Australia-wide, it is estimated that more than 27,000 have HCV

antibodies and more than 21,000 live with chronic HCV infection (Day & Haber, 2009), yet less than 5% have commenced treatment (Dore & Jauncey, 2009). In 2007 the ETHOS (Enhancing Treatment of Hepatitis C in Opiate Substitution Settings) initiative was funded by the Australian Government and New South Wales Health Department to undertake HCV education and training of healthcare workers in OST settings, as well as qualitative and quantitative research around HCV treatment willingness and barriers. Additionally several pilot HCV treatment services were established within the NSW Opioid Treatment Program, which were still underway at the time of publication.

This chapter argues that the successful introduction of HCV treatment within the OST sector is not a given. We are concerned that particular areas of tension, if not explicit contradiction, have been overlooked in the research and debates which inform the provision of HCV treatment in OST. Research seeking to document reasons for the low uptake of HCV treatment among OST clients has focused primarily on questions of clinical appropriateness (Grebely et al., 2008; McNally, Temple-Smith, Sievert, & Pitts, 2006). Other research has examined levels of knowledge and willingness to engage with HCV treatment among OST clients in terms of both clinical and demographic variables (Doab, Treloar, & Dore, 2005; Grebely et al., 2007). Discussions of OST clients' suitability for HCV treatment have frequently been dominated by issues related to illicit drug dependence (of homelessness, poverty, court cases and so on). Clearly there needs to be recognition of the multiple disadvantages and complex life factors that regularly confront those on OST. Nonetheless, we are concerned that a focus on individual-level variables as the object of inquiry has rendered less visible other factors operating within OST settings that are of critical importance to the successful introduction of HCV treatment. Only recently has the consideration of barriers been expanded to highlight the importance of the treatment site (Novick & Kreek, 2008) and the structure of the clinic (Hellard et al., 2009).

This chapter builds upon and extends earlier work that called for a more critical consideration of the culture and context of OST and the implications it held for the introduction of HCV treatment delivery (Treloar & Fraser, 2009). Our previous work cited perceptions of convenience among clients and clinicians inherent in a 'one-stop' treatment model (Treloar, Newland, Rance, & Hopwood, 2010). It also cautioned against the hasty and ad hoc amalgamation of one treatment system with another. This chapter engages with the narratives of individual clients and clinicians within a framework that emphasises the importance of social structural factors operating outside, and organisational factors operating inside, OST clinics.

BACKGROUND

Treating hepatitis C and opiate dependence in Australia

The available treatment for HCV infection has been described as “long and arduous” (Hopwood & Treloar, 2007, p. 253). The toxicity of the antiviral drugs (interferon and ribavirin) and the duration of treatment — either 24 or 48 weeks depending on factors such as viral genotype — present substantial challenges for patients. Studies indicate significant impairment in physical and mental functioning during interferon-based treatments (Fried, 2002) due to physical and psychiatric side effects (Cornberg, Wedemyer, & Manns, 2002). Dose reduction and discontinuation of treatment are reported to occur in between 10% and 50% of clinical trial patients because side effects become dangerous or intolerable (for example, Potgieter, Hickey, Matthews, & Dore, 2005). Patients in trials who discontinue treatment usually do so because of psychiatric impacts, which include depression, anxiety, amotivation, suicidal ideation, anorexia and paranoia (Majer et al., 2008). More than 30% of people receiving treatment experience depression, anorexia, weight loss, irritability, hair loss, joint pain, nausea and insomnia and more than 50% of people experience chronic fatigue, headache and muscle aches (Fried, 2002). Even among well-resourced patients with strong family and social support systems in place, adherence to hepatitis C treatments is often adversely affected by these side effects (Hopwood & Treloar, 2008).

HCV treatment has typically been provided by a hospital-based specialist within a dedicated multidisciplinary team (including nurses, social workers or psychologists) who assist the person with HCV to prepare for and cope with treatment. However, current low rates of HCV treatment uptake (Grebely et al., 2007; Mehta et al., 2008) have led to a growing interest worldwide in the provision of care and treatment for HCV infection within opiate substitution treatment programs (Astone, Strauss, Hagan, & Des Jarlais, 2004; Litwin et al., 2007; Winstock, Anderson, & Sheridan, 2006). In Australia, only 4% of people who inject drugs have entered treatment despite reported high rates of willingness to undertake treatment among this population — many of whom would also be receiving OST (Doab et al., 2005; Grebely et al., 2008). Estimates suggest that among Australian OST clients, HCV prevalence ranges from 67%–87%, with available evidence suggesting prevalence has remained at this level since the mid-70s (Day & Haber, 2009).

In Australia, barriers to HCV treatment have been relaxed considerably over the past decade, with active injecting drug use as an exclusion criteria removed in 2001 and the requirement for a liver biopsy prior to treatment removed in 2006. While some research suggests that the biggest barrier for physicians in prescribing HCV treatment to current users remains a perception that this population will not adhere to treatment (Hopwood & Treloar, 2007), this perception is contradicted by a growing body of clinical data and opinion (Hellard et al., 2009; Novick & Kreek, 2008; Sylvestre & Zweben, 2007). Early clinical trials using interferon/ribavirin combination therapy among methadone maintenance treatment clients concluded that this population “should be

considered good candidates for referral and HCV treatment" (Sylvestre, 2002, p. 117). Further, there is mounting clinical evidence that OST clients achieve acceptable rates of adherence to antiviral treatment and sustained virological responses (Novick & Kreek, 2008).

In Australia, methadone maintenance treatment (MMT) has been available since the early 1970s, with buprenorphine registered for use in opiate substitution therapy since 2000 and now accounting for approximately 15% of all OST (Day & Haber, 2009). Given MMT and buprenorphine are delivered in the same clinics and subject to essentially the same socio-spatial regimes we will treat both under the general rubric of OST. Arrangements for the provision of OST vary across state jurisdictions within Australia: for many clients it is via large clinics — both public and private — with an estimated median of 150 clients per service (Fraser & valentine, 2008), but also via community pharmacies. Our focus is the clinic as the intended site for the introduction of HCV treatment.

It is important to note that while this chapter may take a critical stance towards the organisational culture within the Australian OST program, it is not our intention to undermine the value of this program. The benefits of the Australian OST program are well documented (Ward, Mattick, & Hall, 1998). OST remains a critical, pragmatic and often compassionate response to the manifest problems associated with opiate dependence under existing sociopolitical and legal conditions. While we do not want to flatten out the differences that exist across OST operational cultures and between the philosophical approaches of individual workers — and the enormous impact both have on clients' experience (Fraser & valentine, 2008) — we do want to focus here on some of the shared, troubling aspects of OST culture and practice. In addition, while individual client–clinician relationships within the OST sector may be characterised by a complexity evident across all areas of organised medical treatment, we do not believe that OST is just another medical treatment. Instead, we contend that as an organised, institutionalised 'treatment,' OST contributes to the structural and discursive frameworks within which the stigmatisation of illicit drug use is produced and this should be recognised within the debates around introducing HCV treatment into these settings.

APPROACH

Foucault, social space and the 'stigmatised' subject

Our approach draws on the work of French post-structuralist, Michel Foucault. Foucault has been credited with "opening our eyes to processes and relationships of central importance to health and social care" (Twigg, 2006, p. 12) and with providing "an analysis of power [that] has proved particularly useful in understanding the functions of the medical profession and the clinic" (Turner, 2004, p. 60). Foucault's exposition of the nexus between power and knowledge, and their role in the discursive production of subjectivity (or 'subjectification') within particular institutional sites,

holds particular import for our consideration of the proposed placement of HCV treatment within OST settings. As Foucault (1979, p. 27) explains,

Power and knowledge directly imply one another. There is no power relation without the correlative constitution of a field of knowledge, nor any knowledge that does not presuppose and constitute at the same time power relations.

The concept of social space has been the subject of a substantial, sophisticated and multidisciplinary body of literature, ranging from geography to cultural studies (Twigg, 2006); a thorough account of social theory's 'spatial turn,' including the spatial themes of Foucault's work, can be found in Soja, 1989. The utility of this concept has been recognised and taken up in recent work exploring illicit drug use, treatment clinics and the urban landscape (see for example, Fraser, 2006; Keane, 2009; Smith, 2010, 2011). In general, however, the implications of Foucault's conceptual deployment of social space have been largely overlooked in contemporary social research, including the field of illicit drug use.

Much of Foucault's work focuses on the local, the specific, and the spatial: the asylum, the clinic, the prison. Foucault refuses to isolate discourses from their institutional non-discursive sites, networks and supports, and in this sense his analysis of power is also the analysis of spaces. Foucault (1982) was concerned with "the different modes by which, in our culture, human beings are made subjects" (p. 777). 'Subjectification' can be understood as the ways in which social agents are constituted as persons with certain attributes and capacities within particular institutions or settings (Foucault, 1982; Hirst, 2004). While the question of the subject constituted the 'general theme' (1982, p. 778) of Foucault's research, it can only be properly understood by considering its imbrications within power relations (McHoul & Grace, 1993, p. 57) and by extension, social spaces. It is within power relations, within 'discourse,' that human beings are produced as social selves, as subjects — not as essentially so but as historically variable (Ramazanoglu, 1993, p. 24).

Aspects of OST services resemble the surveillant and regulatory nature of the criminal justice system more than they do a form of medical provision for some of society's most disadvantaged and vulnerable (Bourgois, 2000; Fraser & valentine, 2008). The presence of automated doors (requiring staff activation), protective plastic shielding and/or bars from behind which staff 'dose' clients through small windows (akin to bank tellers), plastic chairs in run-down institutional 'waiting rooms,' the highly regimented movement of clients through the clinic (sometimes requiring separate entrance and exit points), the privileging of staff protection with little regard for the personal safety of clients, the routine requests for urine samples to detect 'unauthorised' drug use, the withholding of methadone in cases of unpaid accounts ... these are just some of the experiences and practices readily reported by clients (Fraser, 2006; Fraser & valentine, 2008; Smith, 2011). As Fraser and valentine (2008) put it, "MMT operates in ways unthinkable in other treat-

ment formats" (p. 86). Embedded in the everyday institutional practice and culture of OST such disciplinary mechanisms as those described above not only reflect the social marginalisation of the client population but also enact it. As Smith (2011, p. 300) suggests, "the spatial dimensions of MMT treatment practice contribute to the experience of stigma".

Parker and Aggleton (2003) suggest that reading Foucault's work on the production of cultural difference in the service of power, alongside Goffman's (1968) on stigma, can combine to "offer a compelling case for the role of culturally constituted stigmatisation as central to the establishment and maintenance of the social order" (p. 17). They argue that stigma and stigmatisation function, "quite literally, at the point of intersection between *culture, power and difference*"; as social processes intimately linked not only to the reproduction of social difference but inseparable from broader notions of power, domination and social inequality (pp. 16–17). Understanding stigma and stigmatisation as "part of the political economy of social exclusion" (p. 19) as always taking shape in a "specific context of culture and power" (p. 17) allows us to incorporate the seminal work of Takahashi (1997) on the spatial relations of stigma. For Takahashi (1997), "socio-spatial stigmatization" is a "mutually constitutive process, whereby places inherit the stigma of persons, but persons also become stigmatized through their interaction with places" (p. 910). For our purposes, we see the physical space of treatment, the OST clinic, as coming to carry the 'taint' of drug use(rs) through "the projection of 'social pathologies' on to physical places" (Smith, 2010, p. 860; 2011). The socio-spatial stigmatisation of OST clients and clinics is central to our concerns about such spaces serving as sites for the proposed provision of additional (HCV) treatments. This chapter understands the specificities of OST organisational culture and space as not merely vehicles for the manifestation of socially prevalent, pathologising accounts of drug use but as active participants in the stigmatising process. Through the narratives of individual service users and clinicians this chapter explores the stigmatising process as taking shape in a "specific context of culture and power" (Parker & Aggleton, 2003, p. 17): the Australian OST clinic.

METHOD

The study was approved by the Human Research Ethics Committee of The University of New South Wales. Informed consent, either written (for face-to-face interviews) or audio recorded (for telephone interviews), was obtained from all participants.

SAMPLING AND RECRUITMENT

Data was collected from two samples during 2008/9: OST clients living in New South Wales (NSW), Australia and health professionals working Australia-wide in OST settings. OST client

participants were recruited from a larger sample of people living with HCV participating in a cross-sectional survey-based study of HCV treatment decisions (Grebely et al., 2011; Treloar et al., 2011). The survey participants were recruited from needle and syringe programs, OST clinics and community pharmacies dispensing OST across NSW and from the mailing list of the community organisation, Hepatitis NSW. Of the total 445 survey participants, 206 volunteered for a follow-up interview and provided contact details. Nineteen people were randomly selected and could be contacted. An additional sample of eight OST client participants was recruited directly from NSW Users and AIDS Association (NUAA), a state-based illicit drug user organisation through flyers distributed to clients (see Treloar et al., 2010, for full details).

Delegates of the 2008 Australasian Professional Society on Alcohol and other Drugs (APSAD) Conference (approximately 630) were invited to participate in a focus group discussion held during the conference or to provide contact details for a post-conference telephone interview. A further recruitment strategy involved an email invitation to all APSAD members (approximately 350) seeking their participation in a telephone interview.

DATA COLLECTION

In total, 27 interviews were conducted with current OST clients; 19 by phone and 8 face-to-face. Of the client group, 22 were men (82%), 15 had left school at 16 years or younger (68%), 22 were recipients of social welfare benefits (82%), and 18 were parents (67%). One focus group (of 6) and 16 telephone interviews were conducted with health professionals. Of the health professionals, 13 were medical practitioners, 5 were nurses, 2 pharmacists and 2 clinical managers; the majority (19) worked in public clinics, 2 in both public and private settings, and 1 in private only. In the Australian context a 'public' client is one whose prescribing doctor is a state employee and who may be dosed at either a public (government funded) clinic or a community pharmacy; the latter requiring a service fee. A 'private' client is one connected with a private (for profit) clinic and/or private prescriber, where s/he pays a fee to the prescriber and a dosing fee to the clinic or pharmacy.

Semi-structured interview guides were organised around a core set of issues. OST client interviews included a brief biographical snapshot (including OST and HCV experiences), knowledge and expectations about HCV treatment (including concerns, advice provided by clinicians, relationship to illicit drug use and to OST treatment), factors shaping OST clients' decisions regarding uptake of HCV treatment (including barriers, motivators, social supports and perceived impacts of treatment), experience of OST and interaction with HCV treatment, preferences for HCV treatment, experiences or fears of stigma related to HCV or HCV treatment, general health and wellbeing and demographic information.

The core set of issues raised with clinician participants included their initial thoughts on providing HCV treatment in OST clinics, influences on their decision to include HCV treatment in

their OST clinic (including personal issues, client issues, organisational issues and broader social structural issues), and their perceptions of the primary barrier and motivator to providing HCV treatment in OST clinics.

Each interview took between 20 and 60 minutes. In accordance with convention, OST client and clinician participants were reimbursed with a A\$20 and A\$60 voucher respectively for their time and/or travel expenses.

DATA ANALYSIS

Digitally recorded interviews were transcribed verbatim. The transcripts were then 'cleaned' to remove any identifying details and ensure participants' anonymity before being entered into NVivo 8. The transcripts were read repeatedly to identify OST client and health professional participants' descriptions of barriers and incentives to the delivery and uptake of HCV treatment within OST settings. The authors independently constructed coding frames, compared coding decisions, and discussed any differences until consensus was reached. The data was then analysed with particular attention to articulations of power manifest within, and productive of, the practice and culture of OST. Specific consideration was then given to the implications these held for the proposed introduction of HCV treatment into this context.

Foucault uses the term 'discourse' to mean "a group of statements which provide a language for talking about — a way of representing the knowledge about — a particular topic at a particular historical moment" (Hall, 1992, p. 291); or put simply, "what it is possible to speak of at a given moment" (Ramazanoglu, 1993, p. 19). Discourses embody rules and constraints governing what can and cannot be said, to 'make sense' or to be 'true' (Foucault, 1980). Discourses and the social practices which surround them are connected with particular spaces — institutions, organisations, locations — and forms of power; they are part of the way power circulates and is contested. Within OST clinics — operating alongside, and in dialogue with, the 'formal' discourse of OST with its network of clinical policies and procedures — a coalition of 'informal' staff knowledges (attitudes and opinions) combine as expressions of a workplace culture. Reading such expressions as elements of a workplace culture allows us to apprehend their collective coherence, their enmeshment within systems of power and the institutional-organisational conditions of their articulation.

RESULTS AND DISCUSSION

This section considers the question of an integrated treatment model via discussion of four themes identified in the data: OST's 'core business'; OST governance and client tenure; OST treatment identities; and the question of methadone 'takeaways'.

Defining OST: a discourse of 'core business'

Data from health professionals reveal valuable insights into OST culture, troubling the notion of a readily integrated treatment model. There was disagreement amongst health professionals regarding a place for HCV treatment within OST programs. For some the provision of HCV treatment represented a professional duty of care, while for others, considerable barriers were perceived to exist at the organisational level. Irrespective of the differing attitudes held by clinicians towards the introduction of HCV treatment they shared a broad consensus regarding the prevalence of a workplace culture that polices and reinforces the (limited) formal functions of the OST clinic.

A thing that's always astounded me ... has been the fact that ... there's some understanding from the staff and unfortunately the clients as well within those [OST] services that treatment is generally around their methadone and buprenorphine prescribing and dosing. And it doesn't seem to have much of a greater vision than that. And that's pretty sad, pretty tragic, really.

(Doctor, public)

I think the biggest barrier for me [in the provision of HCV treatment in OST] would be possibly the organisation. I think a lot of the workers would say, 'We're too busy doing other things to do this. And that's not our core business anyway. Can't you send them to the hospital?'

(Doctor, public)

The health professionals' comments reveal the presence of an organisational culture that functions as a dominant discourse to both constrain and enable speaking and thinking about what constitutes 'proper' OST knowledges: defining what is core business. The effects of this discourse are, in part, spatialising: regulating OST discursive space (limiting 'vision', for example) and physical space (sending HCV clients 'to hospital' and so forth).

While the rhetoric of 'core business' reveals a set of shared (if not unchallenged) values and beliefs regarding the appropriate role of OST, it is clearly not a term unique to health workers within opiate substitution therapy programs. Its commonplace usage within managerial discourse is in itself noteworthy, reflecting the wider socio-economic context and pressures within which OST must currently operate. The language of 'core business' is entirely consistent with the increasing 'corporatisation' of both government and non-government sectors over the last few decades; invoking notions of competitiveness, acumen, efficiency and so forth (Connell, Fawcett, & Meagher, 2009). Critics such as Miller (2001) and Mugford (1993) argue that the 'bottom line' of economic rationalism has come to explicitly influence the rhetoric and practice of harm mini-

misation. Miller (2001, p. 175) maintains that the notion of harm reduction “as being based on the idea of a cost-benefit analysis” is entirely congruent with the philosophy of economic rationalism, wherein the benefit is ultimately evaluated in dollar terms.

OST is frequently promoted as an opportunity for clients to access additional social support services whilst also receiving treatment for drug dependence (Fraser & valentine, 2008). Despite the rhetoric, chronic under-resourcing as a result of the broad macro-economic, deregulating ‘reforms’ Australia has experienced alongside other industrial nations since the 1980s, and the subsequent retreat of the state from health and welfare provision, means such ancillary services are frequently unavailable. The stark reality is that for most clients the OST clinic serves as little more than a single-purpose dispensary — a ‘juice bar’ (Smith, 2011) — and their care as part of an ‘at risk’ population is supplanted by ever increasing forms of surveillance and other technologies of governance (Fraser & valentine, 2008).

The reduction of OST to little more than a highly regulated dispensary intensifies the production of socio-spatial stigmatisation. As Smith (2011, p. 306) puts it:

Without a comprehensive service model, the ‘juice bar’ can be seen as the literal application of the hegemonic paradigm for understanding addiction, positing pharmacological substitution as a panacea ...

The implications for the successful introduction of an additional ‘treatment’ into such a context, particularly one as arduous and lengthy as the combination therapy required for HCV, are serious if not self-evident. Leading HCV clinicians engaging with the provision of HCV treatment for those concurrently receiving OST explicitly advocate due consideration to the importance of clinical context and structure (Sylvestre & Zweben, 2007). As Novick and Kreek (2008), in their comprehensive review, conclude: “High quality medical care for all aspects of HCV infection can be provided to methadone maintenance patients. The literature supports the effectiveness of such services, but the reality is that most patients do not receive them” (p. 1).

The OST client: questions of identity

The meanings attached to OST clients — their treatment identities — are produced within the specific social and clinical spaces of OST. These identities both reflect and participate in the limited and limiting repertoire of socially available and invariably stigmatising interpretations of the ‘drug user’. Keane (2009), in a review of recent publications critically examining OST, makes the comment that “the drug-using subject after Foucault does not exist outside of the clinics, programs and other disciplinary regimes which produce it” (p. 452). Fraser and valentine (2008) argue that OST clients are not viewed as merely ‘consumers’ of services — or customers — but also as “inherently

dishonest drug users" (2009, p. 251). Similarly, Radcliffe and Stevens (2008) examine the stigmatised figure of 'the junkie,' arguing that its association with treatment services has in turn stigmatised the treatment regime itself: "the routine of supervised consumption of methadone was itself seen by some as stigmatising" (p. 1065) and "may also have the effect of further fixing drug users' discredited identities, rather than creating opportunities for them to live different lives" (p. 1067).

The production of the OST client as 'inherently dishonest' raises serious concerns when considering the integrated treatment model of HCV within OST clinics. How will the hegemony of this ascription be effectively negotiated by both clients and staff of OST clinics during the protracted administration of HCV treatment? Will the testimony of OST clients receiving HCV antiviral treatment — regarding the crucial issue of side effects, for example — be believed by clinicians? If we understand the 'legitimacy' or otherwise of the social subject to be, in part, a question of location, whereby people act and speak according to expectations which are, in part, spatially distributed and determined (Cresswell, 1992), then what of the client-as-speaker, located within the compromised space of the OST clinic?

Philosopher Miranda Fricker (2007) uses the term 'epistemic insult' to describe the special sort of injustice that takes place when social prejudice undermines the level of credibility given to certain speakers — the process by which people are undermined specifically in their capacity to know, their capacity as a 'knower.' Fricker argues that to insult someone as a knower holds particular significance given that our capacity to pass on knowledge is so intimately tied up with our very status as rational beings. To be insulted in one's capacity as a knower is to be seen as a lesser rational being and ultimately, therefore, a lesser human being. Here the relevance of Fricker's argument for our own is quite explicit. If discourse includes and excludes, frames and makes possible what one can think and ask (and by implication, hear), how then can the levels of nurture, care and trust necessary for successful HCV treatment outcomes be achieved within the power-knowledge nexus that currently holds sway within OST clinics? A comment from one of the health professionals further illustrates our argument:

I mean my background's in, in general practice. And so, you know, I sort of have this uneasy ride all the way through this [working in OST] ... but having said that, you know, I mean treating people with hep C is quite a, quite a nice professional, professionally different. Because you actually, you know, you're back in, despite the rhetoric, you're actually back in partnership with patients, generally.

(Doctor, public)

The clinician draws a clear distinction between the different treatment modalities he has experienced. Framing treatment modalities as discourses — "as practices that systematically form the objects of which they speak" (Foucault cited in Eribon, 2004, p. 290) — allows us to conceive of

the modality itself as implicated in constructing both the 'object' of treatment (the recipient as client or patient) and the qualities of the professional relationship. Different treatment modalities inevitably produce different subject positions for patients-clients and clinicians. The interviewee describes his experience of working in opiate substitution as an "uneasy ride". Relative to his previous work in general practice, his uneasiness indicates a professionally problematic experience of OST; one where the clinician is no longer 'in partnership with', but rather expected to take up a position where he is in control over, the client and their treatment. As Paterson, Backmund, Hirsch, and Yim (2007) suggest, "blaming the individual practitioner for discriminatory behaviour often functions as a substitute for sustained organisational attention to the stigmatisation that is embedded in everyday institutional practices" (p. 371). The role particular modalities play in shaping the experience and identity(s) of both clinician and client cannot be simply overcome by attitudinal change and nowhere is this more evident than within OST.

OST governance: a fragile tenure

Entwined with the problematic identities of OST and embedded within its organisational culture is a particular understanding of drug treatment which underpins the client's legitimacy within the clinic. This understanding reflects a socially widespread, moralising discourse that posits illicit drug use as a matter of individual choice. 'Problematic' or dependent drug use is consequently understood to be a result of personal weakness not social problems (Radcliffe & Stevens, 2008) and is therefore undeserving of treatment, unlike 'genuine' medical conditions. The effect of this interpretation within OST staff discourse is insidious and renders the clients' place within treatment as precarious by constructing treatment as a privilege:

I've got a huge concern that I think the reality is a lot of staff ... perceive opiate substitution treatment to be a privilege not a right. And have a long history of ... without much thought or process at all, deciding on the people they want to remove that right [from] ...

(Doctor, public)

The fragility of tenure for clients of OST programs needs to be acknowledged and addressed within any discussion of an integrated HCV treatment model. There is a prevalence of client treatment exclusion unique to OST when considered within the broad domain of clinical treatment provision. The belief within OST organisational discourse that clients' access to treatment is a 'privilege' is not only troubling but antithetical to the established, organising principals of clinical practice, and further, harm reduction. As Fraser and valentine (2008) concur, the treatment status of methadone recipients is indeed extraordinary:

while any treatment or service relationship is bound by explicit or implicit rules of conduct, the [OST] client's position in treatment is especially precarious, and felt to be so ... [T]he fragility of that access, its felt instability and the constant danger of its being lost, is unlike either customer service or other kinds of treatment.

(pp. 127–128)

The distribution of methadone, officially classified as a restricted 'drug of addiction,' is inevitably and understandably subject to various policy, administrative and clinical regulations. Nonetheless, we argue that the routine use of treatment practices such as urine testing have little to do with its 'therapeutic' deployment and simply serve to contribute to the punitive and disciplinary experience of OST recipients, evident in both our data and other investigations into opiate substitution programs (Smith, 2011, 2010; see also Bourgois, 2000; Fraser, 2006; Fraser & valentine, 2008; Keane, 2009). While we do not negate the positive accounts of treatment reported by some OST recipients in our data (and elsewhere), we agree with Fraser and valentine (2008) when they suggest that within this context, "dependence on enlightened service providers starts to seem very much like paternalism, or benign authoritarianism" (p. 88). We question what place there is for the treatment of HCV within the existing 'political economy of human dignity' that Bourgois (2000, p. 189) suggests currently defines the biopolitics of methadone provision. The likelihood that OST clients' clinical presentations will be further complicated and additionally challenging with the introduction of HCV treatment medications (with potentially adverse psychological side effects) needs to seriously be considered. This eventuality is particularly concerning in light of OST clinicians' power to make seemingly arbitrary decisions about clients' tenure:

And given the sorts of things that can happen, you know, pertinent issues with people's mood and behaviour, just on opiate substitution treatment let alone when you add [HCV treatment medication] into the picture, that's, that's a potentially, you know, pretty challenging situation.

(Doctor, public)

there is so much poor practice in I guess [opiate] substitution treatment ... there's just too much of a risk of things going wrong. And you know, when you're talking about nearly \$30,000 worth of [HCV] treatment that the government will fund as a once off then some sort of arbitrary decision about a behavioural incident for a person is just, is just too critical. I mean I, I hope that's not gonna happen but I've just, I've seen too much to think that, to believe that it is possible ...

(Doctor, public)

The notion that OST is just another medical treatment is erroneous and misleading. As Fraser and valentine (2008) point out, while OST is a medical response to drug dependence it is one “freighted with many of the criminal and political meanings attached to drugs and addicts” (p. 117). In this context the term ‘liquid handcuffs’ (Fraser & valentine, 2008, p. 9) — commonly used by OST recipients to describe their sense of being imprisoned and chained to their treatment and its regimes — seems particularly apt. For clients of OST, the mutually constitutive relationship between social space and subjectivity manifest within the specific context of OST organisational power and culture enacts the productive interplay of social stigma. The effects of this process of association and transference are mutually reinforcing and somewhat paradoxical: stigmatising both the subjects and spaces of OST while at the same time casting treatment as a privilege.

The outcome is, however, uniform: the rendering of clients’ tenure as precarious. Individual staff may play a prominent and vocal role as advocates of this position, as discursive ‘gatekeepers’: “If we hadn’t had a couple of significant changes in staff that we have had in the last 12 months then I wouldn’t embark on it [the introduction of HCV treatment]” (Doctor, public). Nonetheless, the effects of this discursive regime endure despite the removal of particular spokespeople:

There are also, you know, deeper cultural issues that [OST] clinics exhibit. And we’ve been trying to work on this. And they can be very, very hard to shift. And even though you have almost all the staff turnover in a clinic, yet the, the kind of certain ethos still prevails.

(Doctor, public)

Methadone ‘takeaways’: a case in point

Access to takeaway doses of methadone is highly valued among OST clients, not least for the simple respite ‘takeaways’ provide from the daily rigmarole of attending clinic. As this MMT client explains:

it’s just a waste of half a day ... I get up at 8.30 every morning, go have a shower ... get dressed and walk [to the inner-city clinic] every day and then walk home. It’s like 7 k’s [kilometres] there, 7 k’s back. The chemist is only a hundred metres from my house but it costs a hundred [dollars] a fortnight ... I can’t afford it so I got to go to the free clinic.

(Male, 45 years)

Our interest in methadone takeaways concerns the politics of their provision and how such a politics is further illustrative of our argument. While the specific rules and regulations governing methadone takeaways in Australia vary across state jurisdictions, what is germane to our argument is

the experience of their seemingly arbitrary interpretation reported universally by OST clients. (A detailed elaboration and discussion of the clinical guidelines governing methadone takeaways can be found in Treloar, Fraser, & valentine, 2007).

Flexibility of HCV treatment delivery was identified in OST client data as a major factor in their considerations of treatment. 'Flexibility' in the context of HCV treatment delivery was interpreted by participants in relation to the willingness of OST clinics to provide (and if necessary, deliver) takeaway doses of methadone. Takeaways were identified by OST client and health professional participants as a necessary feature of HCV treatment because of concerns that the side effects of HCV treatment could interfere with clients' capacity to present in person for their methadone, particularly during the early stages of treatment:

that's the sort of thing I'm scared about ... getting sick on my methadone but can't get up 'cause I'm [too] sick on [HCV treatment].

(Male, 27 years)

the first month [of HCV treatment] when you're really sick. That would be the only problem, where you don't want to go out anywhere ... Until you can get better and then you can start going in to get [methadone] yourself ...

(Male, 47 years)

For OST clients already experiencing both a precarious sense of treatment tenure and concerns about being judged unreliable or non-compliant, the fear of jeopardising access to their OST due to the debilitating side effects of HCV treatment and the absence of reliable, transparent takeaway provisions is both real and understandable. Confounded by their experience of the controlling, opaque, and seemingly intractable practices governing the provision of methadone takeaways, OST client interviewees hypothesised about the conditions under which they might receive their HCV treatment:

My methadone clinic is stuffing me around over my takeaways, and they have the right to give me seven days worth of takeaways. I am only asking for four days. They are not saying they won't do it, but they are saying they want to put it to review. They are wanting to talk amongst the doctors and all that stuff, and it just seems a bit of a fuck around. I go in every day, I don't desert, I follow all their rules, and it seems like it is a bit of a catch 22, and a bit of hypocrisy ... How would they go about giving me my [HCV treatment] pills and my injections?

(Male, 21 years)

The politics of takeaway provision are not merely instrumental, however. Alongside the explicit, practical benefits of receiving takeaway doses — commonly cited by clients as ones of convenience, less travel, lower costs, and so on — are those less tangible benefits registered at the level of affect (Treloar & Fraser, 2007). Feelings of ‘normality’, flexibility, greater control over life, and ‘feeling trusted’, are all cited by methadone clients as benefits of being granted access to takeaways (Treloar & Fraser, 2007). Takeaways are often experienced by clients as a ‘reward’ for ‘good’ behaviour or evidence of progress in treatment (Treloar & Fraser, 2007; pp. 66–67). The converse, however, is also evident, leaving clients not granted access to takeaways feeling a sense of personal failing or even punishment (Treloar & Fraser, 2007).

Foucault understood power to be a relationship that was localised and dispersed throughout the social system, operating at the micro level through specific practices (Turner, 2004). We believe the politics of methadone takeaway provision serve as a microcosm of the governance of OST in broad terms, as well as the specific complexities, frustrations and inequities that too often characterise the relationship between OST staff and clients. The effects of this power relationship are not merely instrumental but actively work to produce the client as a deserving or undeserving subject, regulating bodies through pharmacotherapy and subjectivities via its administration.

How then, as the client cited above wonders, will those on OST be treated should they commence HCV treatment through their clinic? What will happen when someone is too sick with the side effects of HCV treatment to attend the clinic for their dose of methadone? Will the concerns and requests (including those for takeaways) of clients undertaking HCV treatment be heard, or will their discourse be rendered the object of clinical suspicion? As Fraser and Valentine (2008) point out, because clients on methadone maintenance treatment are seen as not just customers, their complaints can be more readily dovetailed into interpretations of ‘chaotic use’ or suspicious ‘drug seeking behaviour’ (p. 123). Furthermore, in the context of such suspicion, what of the confusion that may arise when OST clients undertaking HCV treatment present for their OST seemingly drug affected, thus jeopardising their ‘dose’ if judged to be ‘intoxicated’?

CONCLUSION

For Foucault (1991), “space is fundamental in any exercise of power” (p. 252); it is where discourses of power and knowledge are translated into actual relations of power (Wright & Rabino, 1992, p. 14). This chapter takes up Foucault’s deployment of social space alongside the more familiar themes of his work. In recognising the mutually constitutive relationship between social space and subjectivity — for our purposes, the spatial relations of stigma — we posit that HCV treatment is potentially misplaced, out of place, within the existing institutional, clinical and social parameters of the OST clinic. We argue that the existing regime too often works against the care of marginalised people, particularly those potentially affected by medications with

serious negative physical and psychiatric side effects, such as those involved in the treatment of HCV. The widespread failure within OST to address the clear need for comprehensive ancillary care (Fraser & valentine, 2008) is arguably one factor in the poor retention of clients where the median in Australian settings is only four to six months (Day & Haber, 2009). Not only is this of concern for the successful treatment of opiate dependence — where retention is the main predictor of successful OST treatment (Day & Haber, 2009) — it further underlines our concerns about the appropriate co-location of HCV treatment, where a minimum of 6 to 12 months is required to achieve a successful treatment outcome.

Treloar and Fraser (2009) argue that expanding the provision of HCV treatment into drug treatment services is “not just a matter of generalising speciality services to other contexts” (p. 439); that indeed, “if such an approach is taken, there is a strong risk that success rates will be disappointing, and that stereotyped ideas about injecting drug users, their priorities and their attitudes towards their own health will be reinforced” (p. 439). The clinical literature citing successful HCV treatment outcomes for people concurrently undergoing opiate substitution therapy emphasises the necessity for comprehensive medical, psychiatric and psychosocial care (Sylvestre, Litwin, Clements, & Gourevitch, 2005; Sylvestre & Zweben, 2007; Norman et al., 2009; see also reviews by Hellard et al., 2009, and Novick & Kreek, 2008). Social researchers in the drugs field have similarly emphasised the primary importance of ‘engagement’ in staff–client relationships — of the “social interactional process” — in the successful delivery of OST (Lilly, Quirk, Rhodes, & Stimson, 2000).

There are existing treatment models that do provide comprehensive care for people seeking assistance for both illicit drug use and HCV, and do so within the one integrated setting (Norman et al., 2009; Sylvestre et al., 2005; Sylvestre & Zweben, 2007). These models emphasise a philosophy and practice of care conspicuously absent in the reductive, single-purpose, pharmacologically focused treatment model common to much existing Australian OST. Crucial to the successful structure of these models has been the integration of a ‘peer-based approach’ and the active inclusion of clients in decision making.

This chapter has consistently cautioned against the likely success of a hasty and ad hoc addition of HCV treatment and care to a model of OST that currently contributes to the socio-spatial stigmatisation of people who inject drugs. The ‘junkie’ is a commonplace and despised figure in Western discourse (Rance & Fraser, 2011). Understanding the process of stigmatisation as central to the constitution of the social order (Parker & Aggleton, 2003) serves to further underline the obstacles faced by those concerned with challenging the stigma associated with injecting drug use. It is thus all the more crucial that the systemic shortcomings currently and specifically characterising much OST, including those identified in this chapter, be comprehensively reviewed and solutions sought. Sustained attention needs to be paid to the stigmatisation embedded in the everyday institutional practices and culture of OST in order to create a drug dependence treatment system that can appropriately support those engaged in the vulnerable and arduous process of hepatitis C treatment.

CHAPTER 4

**“Not just
Methadone Tracy”****Transformations in service user
identity following the introduction
of hepatitis C treatment into
Australian opiate substitution
settings**

BASED ON:

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Worldwide, there is growing interest in the provision of care and treatment for hepatitis C virus (HCV) infection beyond the specialised clinics of tertiary hospitals (Bruggmann, 2012; Grebely & Tyndall, 2011). In Australia, efforts to decentralise HCV care and treatment are focused on the opiate substitution therapy (OST) program, where HCV prevalence among the service user population is high (Hellard, 2009). For many clients, the provision of OST is via large, single-purpose clinics, with a median of roughly 150 clients per service. It is estimated that greater than half of the more than 46,000 people currently receiving OST Australia-wide are living with chronic HCV infection (Day & Haber, 2009), yet fewer than 5% have entered treatment (Dore & Jauncey, 2009). With more than 1% of the general population infected, mortality due to hepatitis C now surpasses HIV/AIDS in

Australia and the burden of liver disease is growing (The Kirby Institute, 2012).

Despite the apparent logic of introducing treatment into settings where the need is greatest, the attempt to merge two distinct health systems into the one delivery site raises a number of potential complexities and contradictions. Alongside the operational and clinical challenges are issues of treatment setting and culture. A body of critical literature attests to the ambivalent place that OST occupies, within both the lived experience of those on treatment and contemporary drug research and debate. On one hand, the clinical, social and public health benefits of OST are well documented (Marsch, 1998; Ward, Mattick & Hall, 1998); OST continues to provide a pragmatic and sometimes compassionate response to opiate dependence under the existing sociopolitical and legal conditions of the liberal West. On the other hand, much of the critical literature argues for the active role OST settings play in the (re)production and perpetuation of socially stigmatised identities and attendant social disadvantage and exclusion (Fraser, 2006; Radcliffe & Stevens, 2008; Smith, 2010). Hence, the discredited identity of 'the drug user' is reproduced and reinforced by the very treatment program purportedly aiding its relinquishment.

In line with this critique, we challenge as "erroneous and misleading" (Rance, Newland, Hopwood, & Treloar, 2012, p. 250) the notion that OST is just another medical treatment. While OST is a medical response to drug dependence it is one "freighted with many of the criminal and political meanings attached to drugs and addicts" (Fraser & valentine, 2008, p. 117). Here recipients of OST find themselves "situated between the ideologies of medicalisation and criminalisation" (Harris & McElrath, 2012, p. 819), embroiled in a treatment system more concerned with controlling their behaviour than treating their drug dependence. One principal effect of such a treatment regimen is the risk of "further fixing drug users' discredited identities, rather than creating opportunities for them to live different lives" (Radcliffe & Stevens, 2008, p. 1071).

This treatment paradox has serious policy and practice implications. The (re)creation of 'non-addict' identities is crucial for individuals seeking to move on from drug dependence (McIntosh & McKeganey, 2000), yet "when individuals are devalued by the treatment process itself, how then can recovery be achieved?" (Harris & McElrath, 2012, p. 819). The meanings available and attached to OST service users — their treatment identities — are negotiated within the OST clinic, within the treatment regimen and its attendant practices of care. These identities both reflect and participate in the limited and limiting repertoire of socially available and stigmatising interpretations of 'the drug user' (Rance, Newland, Hopwood, & Treloar, 2012). Nonetheless, we are drawn to the possibility that the introduction of a new treatment — a new and different form of care — has the potential to challenge, even change, service users' sense of identity. We have argued elsewhere that different treatment modalities produce different subject positions for service users (Rance, Newland, Hopwood, & Treloar, 2012); this re-positioning, in turn, creating the possibility of re-negotiating relationships and identity conclusions (Winslade, 2005). This chapter takes up the critical question of treatment identity by examining what happens under an integrated treatment model when a new and different treatment modality and form of care is introduced into the OST setting.

The Australian ETHOS (Enhancing Treatment for Hepatitis C in Opiate Substitution Settings) Study was established to examine the feasibility of introducing care and treatment for HCV into the OST setting. Perhaps the most remarkable, if unanticipated, data emerging from the pilot sites concern the theme of 'transformation.' In exploring this theme, we ask: has the introduction of HCV care and treatment created new, alternative possibilities for the identities of OST service users?

METHOD

The ETHOS study was a prospective observational cohort, designed to evaluate an innovative model for the provision of HCV assessment and treatment among people with a history of injecting drug use in New South Wales (NSW), Australia (Alavi, Grebely, Micallef, Dunlop, Balcomb, Day et al., 2013). The aim of the study was to evaluate HCV specialist assessment, treatment uptake and associated factors among people with chronic HCV infection and a history of injecting drug use assessed for HCV infection by a nurse (Alavi, Grebely, Micallef, Dunlop, Balcomb, Day et al., 2013). Recruitment took place between 2009 and 2012 across a network of nine clinics in NSW, Australia.

Our chapter draws on findings from a substudy of the larger ETHOS project: a qualitative evaluation of the service user and provider experience of care, assessment and treatment for HCV infection in opiate substitution settings. Our qualitative substudy recruited a specific sample of people enrolled into or eligible for the larger ETHOS cohort: individuals attending selected sites with a history of injecting drug use who reported living with chronic HCV infection (service users were not required to be current OST recipients). We were interested in understanding the attitudes, experiences and motivations of these service users: both those who were assessed for HCV treatment and those who were not. Even if participants did not move onto HCV treatment, their engagement with the assessment process was significant in terms of the opportunities it afforded for care and support.

Recruitment and interviewing took place across four ETHOS sites in NSW: three within OST clinics (inner-city private clinic, outer metropolitan public clinic, regional city public clinic) and one within a NSW community health centre (large rural town) operating a public OST clinic. Most participating clinics had limited prior experience in the provision of HCV care, did not provide on-site pathology services and were reliant upon referrals for off-site HCV care. Core features of the ETHOS model included the provision of on-site HCV nursing and physician assessment and treatment. Peer-support programs — employed and supported by the NSW Users and AIDS Association (NUAA), a state-based drug user organisation established in 1989 with ongoing funding from the NSW Ministry of Health — were introduced at two sites to complement and extend the services offered by the clinical care team.

A total of 76 in-depth interviews were completed. Face-to-face, semi-structured interviews were conducted with 57 service users, ranging in age from 25 to 58 years. Of the service user

sample, 17 had declined HCV assessment, 21 had an initial HCV assessment only and 19 were engaged in care, were awaiting or had initiated HCV treatment; approximately half were men ($n = 32$), nearly all were social security recipients ($n = 52$), with 7 in either full-time or part-time employment (two participants reported being both employed and receiving social security), and 20% identified as Aboriginal and Torres Strait Islander ($n = 11$).

Interviews were also conducted with a range of clinic staff and peer-support workers involved in the ETHOS study to ascertain their views on the response of service users to the initiative, the barriers and incentives to HCV treatment reported by service users, the general effect of the initiative on the clinic and any organisational factors affecting the delivery of services. Of the 16 staff participants, 9 were nurses, 4 were clinical managers, 2 were administrators and 1 was a medical practitioner. Three peer-support workers were interviewed. While analysis of the role and impact of the peer-support program is not included here, a full discussion can be found in the work by Crawford & Bath (2013).

The study was approved by the Human Research Ethics Committees of The University of New South Wales (NSW) and the NSW Ministry of Health. Informed consent, either written or audio-recorded, was obtained from all participants. In accordance with convention, service user participants were reimbursed A\$20 for their time and expertise.

The analysis of interview material was shaped by our knowledge of the data, the existing literature and by themes that had emerged in previous, ETHOS-related work undertaken by the research team. In this sense our analytical approach could be described as “adaptive coding” (Radcliffe & Stevens, 2008). Digitally recorded interviews were transcribed verbatim and identifying details removed. Each transcript was given an identifying clinic number, a pseudonym and a code designating ‘service user’, ‘staff’ or ‘peer support worker’. Transcripts were then entered into a qualitative software program (NVivo version 8).

The authors collaborated on the construction of coding frames for the three categories of interview participants (service user, staff and peer-support worker), discussing and negotiating differences until consensus was achieved. An additional coding frame was subsequently constructed to capture and organise data under more concept-driven categories that had been identified in the interviews and which reflected our emerging hypotheses (Glaser & Strauss, 1967). The data were then analysed with specific consideration given to the theme of ‘transformation’.

RESULTS

The OST setting: systemic neglect and discredited identities

Our argument, that a culture of minimal engagement and limited care is commonplace under the single-purpose, pharmacological focus of the OST treatment model, was evident in the ETHOS data. Some staff participants were highly critical of the social and clinical shortcomings

of OST, at times identifying the absence of care as a form of systemic neglect:

When it comes to methadone service users they're the end of the food chain. ... They're not seen as important ... We [in OST] do not offer the greatest service ... It's just, you know, dosing people, dosing people and getting them out ...

(Remi, staff)

As far as the actual dosing sites, I think it's pretty appalling. It's like you're a cow going into slaughter. You've got this line in the morning. There's no cover if it's raining. Winter it's freezing here. There's winds. There's no protection ... [T]he actual atmosphere is very punitive ... it wouldn't be tolerated for any other illness.

(Bea, staff)

Service user participants were also acutely aware of the highly regulated but limited nature of the OST treatment model and its potentially deleterious effect on therapeutic relationships:

I can't talk to her [methadone prescriber] about nothin' ... I find that methadone doctors don't really care. They only care about the [takeaway doses] ... I'm not gonna sit down there and tell her my problems ... I like to sit down and talk to somebody who cares, who wants to listen and ... maybe do somethin' about me problems.

(Dave)

Here too, the discredited identity of the 'drug user' was either evident or implied in the accounts of several OST service users. These individuals felt trapped — fixed — in an undesirable, stigmatising identity by their place of treatment:

I just find it really depressing this place. It just really gets me down ... you just wanna get on with the future ... you don't wanna be in that box [as a 'drug user'] ... I mean I haven't used drugs for 20-something years.

(Maryla)

I mean if I had my way, I'd pick up six take-aways and not come here at all. I like to pick mine up, my 'done [methadone] up, and then pretend I'm just a normal person in my head.

(Sarah)

The ETHOS initiative: service user and provider responses

Interestingly, despite Sarah's reservations regarding her OST clinic, she nonetheless undertook the initial HCV assessment offered under the ETHOS initiative; Maryla, however, declined. Criticism more generally among service users regarding the new treatment model was restricted largely to issues of privacy and confidentiality. Some participants expressed reservations that the social and physical structure of their OST clinic meant it would be difficult for them to access HCV care without drawing unwanted attention regarding their serostatus. A potential complication concerning confidentiality between clinical teams (HCV and OST) was also raised. For those on HCV treatment, could sharing information with their treatment team about the use of illicit drugs potentially jeopardise their access to OST if subsequently disclosed to the substitution team?

When I started here, I made it clear to [staff] that ETHOS is a separate part of the clinic ... that whatever ETHOS does, [it does] not go over to the [OST] part. It wouldn't work. As soon as [OST] confidentiality in there and ETHOS is broken, no-one's gonna trust, trust it to be the way it should be.

(Hannah, peer worker)

While this potential conflict of interest was noted by both staff and service users, no actual incidents had been reported.

Largely, however, service user participants across the four ETHOS sites welcomed the introduction of HCV treatment as a practical, clinical intervention that also intimated a more comprehensive, holistic form of care. The co-location of HCV and OST treatment, coupled with the high visibility and ready accessibility of the newly introduced HCV treatment regimens, received critical approval from many service users:

It's [HCV care] in your face so it's available to you. You don't have to go somewhere else ... You don't have to go here or [there] or wherever they wanna send you. It's one building and they can talk to you about it there. We come here anyway ...

(Ruby)

I wouldn't have been able to do [HCV treatment] if it wasn't accessible through this clinic here and now ... and it's great. It's great. I'm probably one of the people that need it the most.

(Paul)

Staff shared this sense that integrating HCV and OST treatments was a laudable and logical move. The opportunity for staff to actively and effectively promote the care and treatment of HCV resonated with their professional duty of care while also highlighting the frustrations they typically experienced under the standard OST model. Staff recognised that the ETHOS initiative provided the opportunity for them to properly engage with and respond to the needs of the service-using population:

There was always an understanding ... a feeling or a belief from the clients that there was a lot of hep C issues out there and people with hep-C that needed and wanted treatment ... And while [HCV care] was really, really important, one of the most important things we do, we couldn't kind of do it ... because of the manpower and the hours we just didn't have [in OST] ... And then, of course, when [the ETHOS nurse] started, the talk amongst the clients really escalated ... [was] really positive because they felt that someone was actually listening to their needs.

(Lenny, staff)

The growth of therapeutic alliances

Such accounts from staff and service user participants start to unsettle the negative clinical stereotypes — of limited, routinised clinical exchanges and minimal social-care interaction — characteristic of OST settings. The ETHOS initiative appeared to open up the possibility of new connections and relations between staff and service users, and a growth in the establishment of therapeutic relationships:

I think ... some of the service users respect us a bit more 'cause they see us actually being interested in their overall health and welfare; we're not just there to dose them ... I think that changed a lot of perceptions of us as these strange, cold people that sit behind the counter and dole out methadone ... They actually see us now as involved in their health.

(Jane, staff)

So ... when someone comes in and pays them that bit of attention, it's like, 'Well hang on, I am worth this. I am worthwhile. My health is important and it doesn't matter how I contracted hep C or why I've got it. But hey, someone's given a damn about, you know, me and my health.'

... It's not that stigma of 'You're on methadone so you're not worth it, it's 'you are worth this.'
(Remi, staff)

The ETHOS initiative appeared to catalyse a general shift in the ethic of engagement, disrupting the widespread understanding — and experience — among service users that the OST setting affords little more than one's scheduled 'dose.' Crucially, those who declined HCV-related interventions were nonetheless able to benefit from this new and inclusive ethos of care:

I hadn't realised ... how transforming it can be for some people ... even for those who don't go on [HCV] treatment and have been worked-up... [Y]ou can often have a great help to their lives by just, you know, having someone keep an eye on them, get their teeth done, offer them services ... give them some hope ... I've been surprised by the expectation and the need, and how ... effective we've been ...
(Bea, staff)

'Good care' and the transformation of identity

Staff participants also recognised the opportunities these enhanced forms of care and engagement afforded service users to counter, even transform, their discredited identities, positing instead more expansive and legitimising possibilities:

Looking at [service users] as a whole rather than ... 'you're an opiate addict' or, you know, 'you're heroin, you're on oxycontin and you're on morphine' ... [N]o, hang on, you know, 'this is Rebecca and, you know, she has hep C' ... She's a mother, a friend and a lover ... it's looking at them as a whole but also that you are worth this.
(Remi, staff)

[A] lot of it is just being treated as a ... normal person. Just the way you're talking to them ... there isn't the judgement and they ... pick that up pretty early ... They almost wait for the judgement when you're talking about, you know, 'Have you ever used?' And ... taking a care in the whole of their body, you know. It's like what else is going on in life ...
(Bea, staff)

For service users, the experience of being listened to, of having the details of their particular stories attended to, featured prominently in their accounts of 'good care.' For Saul, the experience of his initial appointment with the HCV clinician was a catalyst to commencing treatment:

The doctor that's runnin' the show ... he treats me like a friend, not a doctor/patient ... He's never steered me wrong ... everything he's done for me ... 'Cause some people need to be listened to and, you know, talk. Not about his disease or how, you know, but just to listen. 'Cause I come in here like that. I hadn't slept for days and he just listened. By the end of it, it was like, 'Let's go! Let's get on with it [HCV treatment]!' But I come through that door determined to tell him to punch it up his arse.

(Saul)

While, for Will, the quality of the therapeutic interaction was equally noteworthy, if somewhat more clinically orientated:

Like I say, she [the ETHOS nurse] helps me, tells me nothing but the truth about it [HCV] and I do everything she says ... she's probably saved my life mate. You know what I mean? Explained it to me properly why I should take it [HCV medication], you know. Why I should keep taking it. Nobody in the gaol told me that.

(Will)

What such accounts suggest is a form of care that attends to the particularities and complexities of the individual. For service users familiar with the limited and limiting nature of OST, the experience of being recognised beyond the immediate and instrumental needs of their daily 'dose' opened up other, more expansive narratives about the self, creating new and enabling possibilities for identity formation. While other service users typically implied or inferred such possibilities, Tracy was explicit:

It was nice to know that somebody actually looked out for Tracy, not just 'Methadone Tracy' ... they took the time out to realise that there was something more than me just coming to get methadone. I had other issues. And it [HCV] was something I didn't wanna address. And she [the ETHOS clinician] helped me address it ...

In this account Tracy is treated, in her words, as 'not just a druggo.' For Tracy, "it felt good to have somebody actually care about me ... to worry about me". Here Tracy, like others, was able to

re-position and re-negotiate her 'self', experiencing an alternative identity through the generosity of the clinical encounter and the discursive possibilities it opened up.

DISCUSSION

This chapter explores some of the important, if unanticipated, consequences arising from the co-location of two distinct health systems within the one clinical setting. In particular we have focused on the theme of individual 'transformation' evident in the data. While drawing upon Australian material, this study offers conceptual insights potentially relevant to other contexts governed by a harm reduction approach wherein OST functions as the primary treatment modality for opiate dependence.

Nonetheless, this is a qualitative study grounded in the empirical particularities of the Australian OST system. While qualitative methods are especially helpful when applied to new and under-developed areas of research (Patton, 2002) — such as the introduction of HCV treatment and care into OST — they necessarily sacrifice the generalisability of the findings for the depth and richness of contextualised data. In interpreting our findings we do not want to posit an unrealistically rosy picture of wholesale individual change among OST service users. Indeed, our findings are noteworthy precisely because of the possibilities they indicate and the hope they engender despite the systemic shortcomings that characterise OST systems. While staff accounts refer explicitly to the changes evident in the lives of individual service users resulting from the introduction of HCV care and treatment, references to transformation within service user narratives are typically less explicit — embedded in accounts of 'life-saving' treatment, enriched experiences of care, enhanced therapeutic relationships and so forth. Nonetheless, a qualitative approach facilitates the capture of subtle shifts in interpersonal dynamics and expressions of subjectivity found in the narratives of service users. Finally, we note the influence of self-selection: OST clinics volunteered to participate in the ETHOS trial and as such were willing to accommodate the organisational and cultural changes documented here.

Despite the apparent advantages of integrated on-site care, barriers to HCV treatment persist. It is important, however, to distinguish here between the reasons service users provided for refusing the offer of HCV care and treatment and more general reservations regarding the integrated treatment model: declining an HCV assessment did not equate with criticism of the ETHOS initiative in this study. Also noteworthy was the widespread support for the introduction of HCV services among OST staff. In a previous paper exploring perceptions of the proposed integrated treatment model we cited evidence of staff resistance: concerns that HCV care did not constitute OST 'core business' (Rance, Newland, Hopwood, & Treloar, 2012). Such reluctance was not reflected in our ETHOS data.

In Australia, while OST is promoted widely as an opportunity for service users to also receive psychosocial support, in actuality such ancillary care is frequently unavailable (Rance, Newland,

Hopwood, & Treloar, 2012). Increasingly, 'care' in such settings has come to be replaced by ever more sophisticated forms of surveillance and other technologies of governance (Fraser & Valentine, 2008). Under this single-purpose treatment model OST is cast as "the technocratic magic bullet that can resolve social, economic, and human existential quandaries by intervening almost surgically at the level of the brain synapses" (Bourgois, 2000, p. 173). In contrast, research within the drugs field has underscored the benefits of psychosocial services (Ward, Mattick & Hall, 1998; Bourgois, 2000) and the importance of the "social interactional process" (Lilly, Quirk, Rhodes, & Stimson, 2000) in the successful delivery of OST.

In her work on the "logic of care," Annemarie Mol similarly emphasises the imperative of interaction; care is not a limited product but "an interactive, open-ended process" (Mol, 2008). In approaching the question of what constitutes good care, Mol proposes we begin by asking what it is that people need — something, she suggests, that contrasts with neglect: "In the logic of care, the crucial question to ask about a category is whether or not it takes good care of you" (2008, p. 66). Mol goes on to suggest that "[g]ood communication is a crucial precondition for good care. It is also care in and of itself. It improves people's daily lives" (Mol, 2008, p. 76). Part of good communication, Mol argues, is attending to the particularities of patients' stories; stories, she notes, are not merely ways of representing reality but also have therapeutic effects. Our argument is that the form — the category — of care typically provided within OST is inadequate to the needs of its treatment population; that, in crucial respects, it fails to take 'good care' of its service users. In contrast, the ETHOS data contain consistent, at times compelling, references to the substantive improvements in communication and interaction between staff and service users made possible with the introduction of HCV care and treatment.

Here Nick Fox's (1995) work on the 'politics of care' is instructive when considering the potentially transformative effects of introducing a new treatment modality into a clinical setting — particularly one as defined by its limitations as OST. Fox suggests that "care is paradoxical", functioning on one hand as a technology of surveillance, and on the other hand as a relationship of generosity: 'care-as-vigil' versus 'care-as-gift'. Within this formulation, care-as-vigil functions as "the discursive fabrication of a subjectivity upon the person who is cared-for", while care-as-gift becomes a "positive and enabling investment" (Fox, 1995, p. 117). It is one's experience of the latter, of care-as-gift as a positive and enabling investment, which allows the recipient of the gift to "become other, to establish a new subjectivity" (Fox, 1995, p. 117). Transformation is enabled through a shift in the form of care enacted: from the vigil as a "relationship of possession" to the gift as a "relationship of generosity".

Fox's work has significant implications when conceptualising our ETHOS data. The introduction of HCV treatment facilitated new forms and experiences of care, engagement and relationship that challenged and subverted the minimal social-care interaction typical of OST. The opportunity to depart from the strictly controlled, routinised exchanges practised within OST — following Fox, what we might characterise as 'relationships of possession' — was largely embraced by staff and

service users. Both sets of participants spoke enthusiastically about establishing what, following Fox once again, we might call 'relationships of generosity.' Service users emphasised the psychosocial benefits of receiving committed, holistic care while staff referred to a greater level of service user participation and the establishment of trust; both spoke of a diminishing sense of 'us and them' and a concomitant growth in therapeutic partnerships. For some OST service users the experience of such relationships of generosity were indeed 'positive and enabling,' functioning as a "resource with which to challenge her/his subjectivity" (Fox, 1995, p. 117). For these service users, this resource was one with which to challenge the dominance of 'the drug user' identity, allowing them to 'become other,' to establish new identities beyond its hegemony.

CONCLUSION

This chapter explored what happened to the service users of OST when an additional treatment modality and form of care was introduced for those concurrently living with HCV infection. The shift in the dynamic of the clinical encounter to address health in addition to dependence appeared to catalyse transformative possibilities not only for the therapeutic alliance but also for service user understandings of self and identity. It seems that the integration of HCV care and treatment within selected OST clinics not only provided some service users living with hepatitis C increased access to treatment, but also facilitated alternative, 'non-addict' identities to emerge from a clinical setting where the stigmatising figure of 'the drug user' has traditionally prevailed.

CHAPTER 5

“We are people too”**Consumer participation and
the potential transformation
of therapeutic relations within
drug treatment**

INTRODUCTION

The rise of ‘consumer participation’

Over the past three decades, Western liberal democracies have witnessed the widespread emergence of ‘consumer participation’: the notion of service user involvement in public policy-making and service delivery (Crawford et al., 2002; Ti, Tzemis, & Buxton, 2012; Tritter & McCallum, 2006). The language of user involvement, empowerment and participation has become “ubiquitous in healthcare discourse” (Patterson et al., 2008, p. 54). In Australia too, consumer participation has become a key principle in the delivery of health and social welfare services (Hinton, 2010, p. 9; see also Nathan, 2004). Here national health policy broadly defines consumer participation as, “the process of involving health consumers in decision-making about health service planning, policy development, setting priorities and quality issues in the delivery

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of health services" (Commonwealth Department of Health and Aged Care, 1998). The Australian Commission on Safety and Quality in Healthcare currently lists "partnering with consumers" as number 2 on its checklist of 10 key principles or 'standards' (Australian Commission on Safety and Quality in Health Care, 2011, p. 22).

Nonetheless, despite its commonplace occurrence in areas of healthcare such as mental health, disability and cancer treatment (Hinton, 2010, p. 9), the introduction of consumer participation within the Australian drug treatment field has lagged conspicuously behind (Hinton, 2010; Treloar, Rance, Madden, & Liebelt, 2011). While the current National Drug Strategy (Ministerial Council on Drug Strategy, 2011) advocates "consumer participation in governance" (p. 3) as part of its broad commitment to harm minimisation (alongside promoting a national approach to user involvement that includes quality frameworks and reporting requirements) there remains "virtually no evidence of policy frameworks specifically developed to support consumer participation in the drug user treatment context" (Treloar et al., 2011, p. 2). Recent studies by Australian research teams (Bryant, Saxton, Madden, Bath, & Robinson, 2008; Bryant, Saxton, Madden, Bath, & Robinson, 2008) found that while consumer participation activities in drug treatment settings were not uncommon — in fact were widely endorsed 'in-principle' by both consumers and providers — they were primarily restricted to low-level involvement (suggestion boxes and so forth); were largely ineffectual due to "poor communication between providers and consumers" (Bryant et al., 2008a, p. 130); and that "a significant shortcoming exists with respect to turning this in-principle commitment into practice" (p. 136).

OUR APPROACH

The drug treatment setting

Appreciating the unique complexities of consumer participation within drug treatment is hampered by a dearth of Australian and international research (Hinton, 2010; Neale, 2006; Ti et al., 2012; Treloar et al., 2011). While there has been growing recognition of the benefits of user involvement, there is scant literature documenting the actual implementation of such initiatives (Fischer & Neale, 2008; Neale, 2006; Ti et al., 2012). Nonetheless, the extant research has been remarkably consistent in not only underscoring the actual and/or potential benefits of consumer participation in drug treatment but in identifying the very particular challenges it faces. The deleterious impact of stigma, discrimination and unequal service user–staff relations has been highlighted repeatedly (Fischer & Neale, 2008; Hinton, 2010; Patterson et al., 2008, 2009; Patterson, Weaver, & Crawford, 2010; Ti et al., 2012; Treloar et al., 2011). Patterson et al. (2008) describe the drug treatment setting as a "complex cultural context imbued with stigma" (p. 60); one where power imbalances and prejudices are "invidious" and "a pervasive influence" on user involvement (p. 59). Many service staff

continues to hold “deep stereotypes” (Zibbell, 2004, p. 62) about people who inject drugs, leading to discriminatory practices in service provision. Underpinning this stereotype is what Treloar and Holt (2006) describe as a “deficit model”: “The perception of a person seeking drug treatment ... as deficient, defective or lacking” (p. 377). Or, as Crawford (2013) puts it from the perspective of consumers: “[r]egardless of whether we are seen as immoral or sick we are understood as a problem to be solved” (p. e15). The potential of the therapeutic alliance is all-too-frequently reduced to an ‘us and them’ scenario, characterised by “mutual antagonism” (McDermott, 2002, p. 18) and exacerbated by the structural inequalities underpinning the relationship between users and services (Patterson et al., 2008; Treloar et al., 2011; Zibbell, 2004).

This chapter takes up the question of the ‘therapeutic alliance’ via an investigation of a consumer participation initiative — the CHANGE Project — introduced within three Australian drug treatment settings. Our intention here is not to produce a comprehensive nor ‘balanced’ review of the project. Rather, by analysing interviews with service users and staff and capturing the shifts in interpersonal dynamics between the two we hope to elucidate the conditions under which something new was produced. While our focus is on those aspects of the intervention that ‘worked’ — that effected change — we do not want to present an unrealistically rosy picture of wholesale transformation. In important respects our findings are noteworthy precisely because of considerable barriers that militate against the successful introduction of consumer participation within drug treatment. As noted above, one of the chief barriers consistently cited in the literature is the relationship between service users and staff. Hence our focus on evidence of change within that dynamic — evidence found within accounts from both service user and staff participants of the CHANGE Project. What made such transformation possible?

The drug-using subject and the notion of ‘epistemic injustice’

Elsewhere we have argued that the meanings attached to drug treatment service users — their treatment identities — “both reflect and participate in the limited and limiting repertoire of socially available and invariably stigmatising interpretations of the ‘drug user’” (Rance, Newland, Hopwood, & Treloar, 2012, p. 249). Central to these ‘stigmatising interpretations’ is the disregard and disqualification with which the drug-using subject is routinely treated. Within opioid substitution therapy (OST), for instance — the most popular and populous of Australian drug treatment modalities — service users are commonly viewed as not merely consumers, or customers, but as “inherently dishonest drug users” (Fraser & valentine, 2008, p. 123). Or, as Crawford puts it: “[w]e pay money like a customer but are generally treated like a naughty patient’ (2013, p. e15).

The suspicion and disregard with which they are treated — their “credibility deficit” (Fricker, 2007) — has profound implications for service users. What is at issue is the questioning, the doubting, of drug users’ capacity to reason and make decisions (Wolfe, 2007), to be fully rational

subjects (Seear et al., 2012) and ultimately, by extension, their very membership of the human community (Moore & Fraser, 2006). What Manderson (2011) refers to as their “absolute otherness” (p. 230). Here the work of philosopher Miranda Fricker (2007) is particularly illuminating. Fricker uses the term ‘epistemic injustice’ to describe a form of injustice that takes place when social prejudice undermines the level of credibility ascribed to certain speakers: a process by which particular social subjects are undermined specifically in their capacity to know and share knowledge. Fricker argues that our capacity to pass on knowledge is not only intimately bound up with our status as rational beings, but ultimately, as human beings. Thus, she argues, to be undermined in one’s capacity as a ‘knower’ is to be ‘wronged in a capacity essential to human value (p. 44). Epistemic injustice then, according to Fricker, is not only about being degraded as a knower but about the meaning of being treated like that. It carries a symbolic power that adds its own layer of harm: “a social meaning to the effect that the subject is less than fully human ... a dehumanising meaning” (p. 44).

METHOD

In 2012, the NSW Users and AIDS Association (NUAA), a state-based drug user organisation, was contracted by the New South Wales (NSW) Ministry of Health to undertake consumer participation projects in three drug treatment facilities across the state: two publicly funded opiate substitution therapy (OST) services and one non-government residential rehabilitation service. The Centre for Social Research in Health (CSRH) was employed by NUAA to evaluate what became known as ‘The CHANGE Project’. The initiative introduced a range of activities or ‘objectives’ across the different sites: a ‘welcome diary’ for new residents, a service users’ newsletter, a policy review committee, tea and information stalls, etc. The choice of activities at each location was determined by service users in collaboration with the NUAA project worker. In addition, NUAA coordinated a three-day workshop (the Consumer Participation Training package) at each clinic; service users and staff attending one day each before uniting for the final day.

Over the six months following the workshop, service users from each of the three clinics worked in collaboration with the NUAA project coordinator to initiate a series of consumer participation activities. Visits by the NUAA worker were widely advertised and all service users, already alerted to the CHANGE Project via the three-day workshop, were actively encouraged to participate. All service staff were also invited to participate in relevant activities, if or when required. Service management similarly contributed to the Project’s promotion: in one instance, by organising an off-site lunchtime picnic for all staff and service users. While the NUAA worker attended each site on a rotational basis to provide ongoing support, including the administration of a modest project budget, a strong commitment to the principle of consumer ownership and control was retained. To this end the activities established at each of the three clinics reflected choices made by con-

sumers themselves with regard to the particularities and dictates of each service. Service users from the residential rehabilitation service, for example, crafted the aforementioned 'welcome diary' along with a revamped job description for their 'peer buddy' system, while consumers from the regional pharmacotherapy service initiated CPR and naloxone training sessions — in part, a response to the recent fatal overdose of one of its service users. Similarly, consumers from the metropolitan service began attending local community 'law and order' forums (as clinic representatives) organised by the local shopping precinct. Through the day-to-day awareness of, involvement in and exposure to, such initiatives — owned and orchestrated by consumers and supported by the NUAA worker and service staff — the possibilities for change were created.

Approximately 10 participants from each of the three services were recruited and semi-structured interviews were conducted at baseline and six months later at evaluation. To enable the inclusion of a range of staff and consumer perspectives and experiences, the research team actively targeted four groups within each site: key staff, key consumers, general staff and general consumers. The first group included team leaders and management, along with those staff members who had completed the consumer participation training workshops provided by NUAA and remained directly involved in consumer participation activities ($n = 1-2$ per site); the second group comprised service users who had completed the NUAA training and were directly involved in consumer participation activities, e.g. consumer representatives ($n = 1-2$ per site); the latter two groups were made up of staff ($n = 3-5$ per site) and service users ($n = 3-5$ per site), respectively, who had not necessarily been directly involved in consumer participation.

Participation in the evaluation process was voluntary. Key and general staff participants were invited via letter. Consumer representatives were approached by key staff, while general consumers were made aware of the project via key staff and consumer representatives. The majority of interviews were conducted at the services. Several telephone interviews were conducted with participants, including one consumer from the regional site. Key and general consumers were paid A\$20 for their time and/or travel expenses.

A total of 57 interviews were conducted. Of these, 30 were with consumers: 17 'general' and 13 'key'; and 27 were with staff: 15 'general' and 12 'key'. The mean age of participants was 45 (range 25–69). Participation in both rounds was not a prerequisite for inclusion in the study. Anticipating changes among staff and consumers during the life of the project, and recognising that not all staff or consumers necessarily had the time or inclination to participate in both rounds, recruitment was conducted separately at baseline and at evaluation. Of the 15 key individuals (staff and consumers) who participated overall, 10 were interviewed in both rounds. The five participants who were interviewed only once were all service users (key consumers), reflecting the turnover of consumers within the services.

Digitally recorded interviews were transcribed verbatim and identifying details removed. Transcripts were read closely by members of the research team and a number of key areas identified as germane to the evaluation report. A coding frame was developed and the interview material

entered into a qualitative data management program, NVivo 9. Each of the individual codes (or 'nodes') was then reviewed and summarised, along with supporting quotes (identified as staff or key staff, consumer or key consumer). Following completion of the evaluation, the coded data was then reviewed and re-analysed for the purposes of this chapter. Particular attention was paid to participant accounts documenting the changing nature of relationships between service user and staff. Analysis was shaped by our knowledge of the data, the existing consumer participation literature, and the insights generated within contemporary social commentary (see for example, Fox, 1995; Fricker, 2007). In this sense our analytical approach could be described as 'adaptive coding' (Radcliffe & Stevens, 2008).

The study was approved by the Human Research Ethics Committee of The University of New South Wales and the relevant human research ethics committees in each site. Informed consent, either written (for face-to-face interviews) or audio recorded (for telephone interviews), was obtained from all participants.

RESULTS

"No-one's gonna ever listen to us": disenfranchisement in drug treatment

Our argument that experiences of powerlessness, marginalisation and discrimination are commonplace among drug treatment service users was evident in baseline data from the CHANGE Project.

It's hard to get an even, fair treatment ... They [staff] don't know us! I've just suffered a little bit more 'cause I will speak up.

(Susan, general consumer)

[I]t is a hierarchy and ... you have to do as you're told ... [W]e're in a facility that is just saying, "We're here to teach you how to basically just live, get up, wash, eat."

(David, key consumer)

I would defy anyone to say working in a methadone clinic can be an equal in power. There's a power differential, no two ways about it! Because of the regulation, because of the set-up.

(Lara, general staff)

Both service user and staff participants reported noting a sense of disenfranchisement and disengagement among consumers. This sense of disengagement was particularly evident during

initial discussions about the project and the early stages of its implementation. For some service users their sense of disengagement appeared to be exacerbated by feelings of being misunderstood or not being 'seen' by staff: "they don't know us!" More generally, however, this lack of engagement was interpreted by both service user and staff participants as a reflection or 'symptom' of drug users' broader social marginality and exclusion, including their diminished credibility within the broader discursive economy.

I get the feeling that people just think, "It's never gonna happen. No-one's gonna ever listen to us," you know. And then you're also fighting the idea that, basically, what we do is against the law ... [I]f that's sitting in the back of your mind, which I think it would for most of us, you sorta go, "There's no fuckin' point," sort of thing. Other people were sort of, "No, there is a point and there is something ..."

(David, key consumer)

So I think that they're confused ... they don't really know what it [consumer participation] really means. And I also think that the ones that do know what it means are, don't really trust that there'll be much of an outcome from it because they are so disenfranchised and not really able to, well have never really had much of a say in their treatment.

(Ashley, general staff)

"We've never had a voice before": an opportunity to be heard

What was also evident in the data, however, was the clear sense of enthusiasm and novelty with which the notion of consumer participation was received by some participants. For some service users, the opportunity to 'speak' was synonymous with having their 'humanness' recognised and acknowledged; it represented a person's basic (human) right. For others, it seemed to take on a more collective, overtly political, purpose.

I think it is important that users have a voice 'cause we are people too ...

(Lucy, general consumer)

[W]e've never had a voice before. And this is the first time we've actually been asked how do we feel, you know. Yeah. So it's been a long time comin'.

(Robyn, key consumer)

I think that the more the staff hears of our problems, like the little everyday problems of coming here, I think the more ... they can see that you know, you are a human.

(Jason, general consumer)

[I]t's [consumer participation] having a say in, in our health, our health services ... making the general public more aware of what issues are affecting people that have drug addiction ... being a, a group that stands together and can start to, you know, have our voices heard.

(David, key consumer)

The response from many staff participants similarly revealed marked enthusiasm for the introduction of the consumer participation project. Implicit within these responses from staff was a critique of existing modes of service user–staff interaction — particularly those characterised by an absence of ‘real’ or ‘genuine’ communication. The CHANGE Project promoted opportunities for engagement and interaction beyond the routinised and quotidian communication commonplace within institutionalised treatment settings. As one staff member noted, the initiative provided a way of “really knowing how the clients are feeling ... what’s really happening for them”; or, as one consumer remarked: “to step outside that little box sometimes is great!” By enabling a more idiosyncratic, personalised dimension to enter the otherwise relatively predictable discursive terrain, the project seemed to open up possibilities for individual participants to “speak-to-be-heard”:

[T]o know the real stories about them. Yeah, the true worries instead of just asking the routine questions and answering our questions. Yeah, that's, that's different than the normal way of communicating between us.

(Gerri, general staff)

I think that it [consumer participation] definitely helps between clients and staff — definitely — cos you can talk to them on a personal level, not through the [dosing] window sort of thing.

(Yasmine, key staff)

I've had clients say to me, look they feel more comfortable with us now. They're the ones saying look they feel like the culture has changed and they feel like they can ... talk to us about anything whereas before they were unsure about that.

(Sheryl, general staff)

I mean often in the waiting room there's a great chat going on and it's so noisy the receptionist nearly goes mad. Everybody's chatting away ... I think it's improved the whole, you know, communication ... [T]here's a good feel about the place.

(Georgia, key staff)

"Everyone's working together": towards a more collaborative ethos

In response to the discursive possibilities opened up by the CHANGE Project, some participants reported substantive changes taking place within service user–staff relations. The separation of users and staff — noted earlier as commonplace within an 'us and them' treatment culture — was challenged by the emergence of a more collaborative ethos of 'working together.' As one participant explained, their shared intention was to create "a place where everyone is heard." Participants noted staff were now experienced as more approachable, more 'available.' These enhanced opportunities for interaction — entailing new and different styles of communication — in turn fostered a sense of service users and staff getting to know one another beyond the usual constraints and limitations of their relationship. Participants noted 'seeing' one another — the other — differently; as people rather than simply an identity category.

The best thing that I have noticed is our relationship with some of the clients, I feel like they look at us a little bit differently and probably the same for us: we look at them a little bit differently.

(Elle, key staff)

Staff have been pretty positive. And they're pretty open ... It's like everybody's working towards one thing ... It's good to know instead of, you know, seeing the staff as staff, you know, that they are people ...

(Robyn, key consumer)

I have just found it has been a positive experience even with clients that are coming into the clinic now ... [P]eople who have been with us for years, they just say that the relationship is so much better ... [T]hey feel like they can talk to us, that they know we're available and the culture has changed more than anything for them.

(Sheryl, general staff)

Everyone's working together actually. It's been good ... They never used to interact with us as much. You know what I mean? And we never got our questions answered. We always got told, "Just sit down, be quiet. We're busy," you know type thing.
(Lucy, general consumer)

Central to participants' accounts of a changing service user–staff dynamic were references to 'level playing fields' and feeling 'equal' — to notions of equality. The unsettling of institutionalised identities fits with participant reports of a growing sense of equality, for such labels function as more than merely descriptive categories: they are part of how power is organised, how it circulates, and how it is contested.

[T]here used to tend to be us against them, us against them. Now we're on the same playing field and we're all a team ...
(Craig, key consumer)

[I]t was quite nice to sort of sit in the room, you know, as equals and have discussions ... I was most surprised about how much of an interest they were taking.
(Elle, key staff)

It's developed into a relationship where I feel like I am talking to colleagues, not as a dozer and a staff, and that makes a huge difference.
(Susan, key consumer)

I think it has just created a level-playing field, that's what it's done ... [I]t successfully gives people a little bit of power, pride even — that being able to speak, to not be running against brick walls all the time: that someone listens to you openly and freely.
(Susan, key consumer)

"A place to say something": discursive space, social place

Although our analysis is principally concerned with the discursive realm, we nonetheless recognise the productive interplay between discursive space and social place. During the CHANGE Project both were implicated in recasting existing consumer–provider dynamics. The spatial context and organisation of treatment clinics not only reflect social power relations but also

actively refashion these relations (Duff, 2007; Smith, 2011). While one clinic organised several all-inclusive, off-site picnics as part of the project, the interactional possibilities of social place were generally restricted to creating opportunities within the existing confines of the clinic.

I mean just quite a little corner [of the clinic] for them [service users] ... a little bit like they're home. They feel more comfortable to stay here.

(Gerri, general staff)

[O]ur clinic area waiting room ... That is a client area. ... We very rarely go in there. So it was really nice to see everyone in there at once ... It's crossing the border because we don't go in there ... and here it is being used for a whole other purpose ... It was quite a marker, really.

(Lara, general staff)

It's funny that over the years we've encouraged the clients to come in, get your dose and go. Now we're encouraging them to come in and sit around, and chat ... [W]e are giving out two mixed messages: come in, have your dose, go; come in, have a cup of tea and put your feet up.

(Pippa, key staff)

[T]hey [service users] are part of their program. They are not just a customer: come and go, come and go. And [now] they have a place to say something.

(Gerri, general staff)

While modest in scope, the adaptations to place introduced as part of the CHANGE Project — the creation of information stalls, the commingling of service users and staff in a waiting room, even the removal of security guards at one location — were important both practically and symbolically. As staff member Lara (cited above) suggests, they signified crossing the border. Seemingly small cultural shifts — such as the invitation for service users to have a cup of tea and put your feet up (i.e. remain on site following their 'dose') — become noteworthy when considered within the context of the Australian OST system, where professional care has been increasingly displaced by ever-tightening regimes of governance and control (Fraser & valentine, 2008). The simple recalibration of treatment spaces and routines signified something considerably more meaningful than merely the opportunity to have a cup of tea: they started to challenge the established order of things. Such innovations not only represented but realised the sense of transformative possibility evoked by participants: in some instances quite literally providing a place to say something.

DISCUSSION

Participants consistently recounted positive experiences of change as a result of the consumer participation initiative, particularly with regards to relations between service users and staff. Both sets of participants described a diminution of adversarial relations: an unsettling of the 'them and us' treatment divide. This transformation was facilitated by increased opportunities for engagement and interaction outside the conventional discursive routines of drug treatment; opportunities for both users and staff to come to know and 'see' one another better. For service users, the introduction of consumer participation — the opportunity to have a voice, to speak-to-be-heard — began to disrupt the routine objectification or dehumanisation that consistently, if inadvertently or unintentionally, characterise the treatment experience. References to 'being human' or to 'being people too' were commonplace among participants.

Our analysis focuses on participants' accounts of the changing nature of relations between service users and staff. We have not canvassed the various organisational-level barriers encountered during the course of the project: the chronic under-resourcing of the Australian drug treatment sector (affecting staffing levels etc.), the high turnover of service users (most notably in the residential rehabilitation), nor indeed the skepticism among some staff — and service users — regarding the capacity of service users to contribute meaningfully to the project (an extended discussion of staff and consumer attitudes toward consumer participation can be found in Bryant et al., 2008b). Rather, by capturing the shifts in interpersonal dynamics between service users and staff we hope to elucidate the conditions under which something new was produced. For as Lupton (1995) reminds us: '[i]f it is acknowledged that discourse formations and subject positions are not bounded systems, but are open to dispersal, contradiction, contestation and opposition, then the opportunity to construct alternative discourses and subject positions is facilitated' (p. 161). Although the data analysed in this chapter reflects the findings from one Australian consumer participation project, our discussion is potentially relevant to treatment settings more broadly. For as long as the demonisation of drug treatment service users continues, so too will the challenges facing user involvement.

The consumer participation literature highlights the often desultory, inadequate quality of communication between service users and staff, emphasising the implications this holds for the introduction of meaningful user involvement within the drug treatment sector (see for example, Fischer & Neale, 2008; McDermott, 2002; Ti et al., 2012). Reminding us that the importance of good communication in medical and social care has long been established, Fischer and Neale (2008) recommend prioritising improvements in consumer-provider communication as a strategy to reinvigorate consumer participation initiatives. Annmarie Mol (2008), in her work on the 'logic of care', similarly emphasises the imperative of 'interaction' and 'good communication'. "Good communication is," Mol suggests, "a crucial precondition for good care. It is also care in and of itself. It improves people's daily lives" (p. 76). For Mol, peoples' stories, their accounts of

themselves, are central to this endeavour: stories are not just ways of representing reality, they have therapeutic effects.

Here Nick Fox's (1995) work on the "politics of care" helps elucidate our discussion. Care, according to Fox, is "paradoxical". On one hand it operates within "relationships of possession", as a "technology of surveillance": care-as-vigil. On the other hand, it also operates within what Fox suggests are "relationships of generosity": care-as-gift. Within the latter, care functions as a "positive, enabling investment": it "enables and empowers" (p. 117). Thus change within the therapeutic dynamic is enabled through a shift in the form of care enacted: from care-as-vigil to care-as-gift, from a relationship of "possession" to one of "generosity".

Fox's insights are instructive when considering our data. Fox argues that the "labelling ... as clients or patients creates a subjectivity for the cared-for which is then played out in the gaze of the vigil" (p. 114). As we contended earlier, for drug treatment service users this process of subjectification is particularly problematic, often producing subjects considered deficient or undesirable. Within drug treatment, as our participants noted, the rigid separation and policing of identity categories — of 'client' and 'staff, 'us and them' — are routinely enforced; where "what passes for addiction treatment is little more than a regime of disciplinary scrutiny" (McDermott, 2002, p. 20). Here care functions, in Fox's terms, as a "technology of surveillance": a "relationships of possession". Yet, as Fox suggests, while the vigil's disciplinary power is situated in the everyday practice of care — in the relationship between 'the carer' and the 'cared-for' — it is also within these relationships that alternative possibilities exist. These possibilities are manifest when the dynamic of care shifts to a "relationship of generosity".

Several participants described the CHANGE Project as creating "a conversation" between service users and staff — or, as one participant put it, "a doorway". The introduction of consumer participation enhanced opportunities for communication and generated alternative forms of interaction and engagement, creating new subject positions for both service user and staff participants. It facilitated new and different styles of interaction, and allowed the ethos of care to move beyond the regular constraints and limitations of service user–staff relationships to produce more 'real' and 'authentic' communication. Both sets of participants largely, it seems, embraced what Fox calls, "relationships of generosity". For some service user participants, such relationships appeared to function as what Fox refers to as "positive, enabling investments", as a resource which "enables and empowers". For these participants, the shift in their relationships with staff challenged the sense of powerlessness commonplace among service users of drug treatment. Here both sets of participants noted 'seeing' one another — the other — differently: "as people too", rather than simply an identity category.

For Miranda Fricker (2007), the experience of epistemic injustice — the undermining of one's capacity to know and to share knowledge — signifies a diminution of the affected subject's human worth. It bears a "dehumanising meaning" (p. 44). Epistemic injustice is invariably associated with broader patterns of social injustice. Within the drug treatment setting such testimonial

injustice is part of the broader subjectification process, aligned with other forms of disqualification or diminishment: with other constructions of subjectivity that render service users as (humanly) lesser. In contrast, accounts from service user participants in the CHANGE Project contained frequent references to being treated as 'a human', feeling acknowledged as 'being human', or (as cited above) being recognised 'as people too'. Consumer participation appeared to offer a place — a subjectivity — from which service users could speak-to-be-heard. This subjectivity included the recognition of one's underlying humanity: with being human. For some service user participants, the opportunity to speak and be heard — to have 'a voice' — began to redress their disenfranchisement not only from the discursive economy of the treatment setting but their membership of the human community.

CONCLUSION

This paper explored interview accounts from service users and staff engaged in a consumer participation project introduced across three Australian drug treatment settings. Our analysis has focused on the transformative effects the intervention had on relationships between service users and staff: on the therapeutic alliance. While consumer participation is typically implemented at one or more of three levels — the individual, the organisational, and the policy or strategic — the CHANGE Project aimed to involve service users at the organisational level of service planning and delivery. Generally, consumer participation aims to improve service quality and health outcomes by reflecting consumer issues within policy and the delivery of services: an instrumental relationship between consumer feedback and service change. However, when examining participant narratives it became clear that in some important respects the process of implementation itself may have contributed to improved service quality and health outcomes. The effect of service users having 'a voice' may, in and of itself, have enhanced the services' effectiveness.

We cannot, of course, 'prove' our argument: the project evaluation did not quantify health outcomes nor include any other measurable performance indicators. We can, however, point to the voices cited throughout this paper that consistently testify to the positive changes within the therapeutic alliance resulting from the intervention. We can also point to the substantial body of social welfare and health-related literature that document the vital role that service user engagement and service user–staff relations play in the effective operation of services (see for example, Rance & Fraser, 2011; Schorr, 2003; Watson, 2005; Wisdom, Hoffman, Rechberger, Seim, & Owens, 2009). Our paper has explored the qualitative ground on which 'measurable outcomes' are produced: the space of possibility and transformation opened up via consumer participation. By documenting the transformative effects arising from one particular intervention we hope to highlight the therapeutic potential of user involvement for drug treatment services more broadly.

CHAPTER 6

Practices of partnership

Negotiated safety among couples who inject drugs

BASED ON:

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AUTHOR CONTRIBUTIONS:

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Sexual relationships frequently incorporate a high degree of intimacy, collaboration and sharing: this is as much the case for partnerships between people who inject drugs (PWID) as for other partnerships. Yet, the intimate partnerships of PWID have been largely overlooked as not only crucial sources of care, support and stability but as influential sources of practice, including those negotiated around injecting drug use (El-Bassel et al., 2014; Fraser, 2013; Fraser et al., 2014; Rhodes & Quirk, 1998; Seear et al., 2012; Simmons & Singer, 2006; Stevenson & Neale, 2012). Prevailing biomedical and psychological models of illicit drug use and dependence have tended to privilege atomistic explanations of human behaviour while neglecting the social and cultural influences that shape human relations and experiences (Seear et al., 2012; Simmons & Singer, 2006). Similarly, most HIV and hepatitis C virus (HCV)–related prevention and education efforts targeting PWID have focused on individual-level behaviour and responsibility, effectively eliding not only the influence of broader structural factors, such as social isolation and mar-

ginalisation, but the everyday exigencies of intimacy and partnership (Dwyer et al., 2011; Fraser, 2004; Fraser et al., 2014).

An epidemiology of risk has largely focused on the proximal 'risk factors' linked to viral safety, concentrating on the obstacles PWID face in practising safer injection (De et al., 2009; Sherman et al., 2001; Unger et al., 2006). While mapping the distribution of viral risks and their possible 'determinants', including in relation to factors such as gender, ethnicity, age, duration of drug injecting and geographic environment (Bryant et al., 2010; Morris et al., 2014; Strathdee et al., 2010), these studies reveal little about the complex interpersonal and social dynamics characterising risk relationships, including intimate and sexual partnerships (Fraser, 2013; Seear et al., 2012). The intimate partnership may be viewed as an important site of everyday risk management, shaping how viral and other risks are given particular meaning, and framing how risk-related practices unfold (Simmons & Singer, 2006). The experience of injecting together, for example, may function as a powerful and meaningful form of co-created intimacy (Davies et al., 1996; Rhodes & Quirk, 1998; Syvertsen et al., 2013). Similarly, practices of viral risk, such as unprotected sex or syringe sharing, may be situated as symbols of relationship intimacy and security, thus pointing to risk management as a product of negotiation and emotion and not merely risk calculus (Rhodes & Cusick, 2000).

Here, we attempt to redress the 'individualising tendency' of risk-factor-oriented research (Fraser et al., 2015) by adopting a methodology that positions partnerships rather than individuals as a primary unit of analysis (Eisikovits & Koren, 2010; Simmons & Singer, 2006). Drawing on interviews with heterosexual couples who inject drugs, we explore accounts of the sharing of needle-syringes between intimate partners. While health promotion discourses and conventional epidemiology have tended to interpret the practice of 'sharing' (like the absence of condom use) in terms of 'noncompliance' (Race, 2008; Rhodes & Cusick, 2000; Rhodes & Quirk, 1998), we are interested in participants' socially and relationally situated accounts or 'rationalities'. Focusing on participants' lived experiences of partnerships, and what we identify as protective agencies, we endeavour to make sense of risk and safety as participants themselves do. How do PWID engage with, appropriate and, at times, transform medical knowledge around HCV infection and its transmission? And how have our participants taken up this knowledge and, while not 100% risk-free, incorporated it into their everyday lives and practices in ways that are both pragmatic and sustainable (Kippax & Race, 2003)?

Entertaining a 'situated' rationality of risk shaped by its particular social relations lends emphasis to understanding risk as a product of competing interpretation, social interaction, and crucially, negotiation. We therefore also draw on the notion of 'negotiated safety'. Emerging during the early 1990s, at a stage in the HIV epidemic when all unprotected anal intercourse between men tended towards a singular framing in relation to risk regardless of social or relationship context, 'negotiated safety' was coined by social scientists in recognition of deliberate sexual risk and prevention strategies practised between partners in gay communities (Holt, 2014; Kippax & Race, 2003). While

the term was initially used in the literature to describe the negotiated practice of unprotected anal intercourse within regular partnerships between men of HIV-concordant serostatus, much of the subsequent work tended to focus on negative concordant partners (Kippax et al., 1993, 1997). A combination of factors was identified in the early literature: partners' knowledge of their respective serostatus; the presence of an agreement; honesty and trust (Kippax et al., 1997). Importantly, what it suggested was that gay men were drawing on their knowledge HIV status and transmission routes to generate protective strategies in addition to condom use (Holt, 2014). Despite the persistence of its detractors, negotiated safety was taken up and promoted by Australian AIDS Councils in 1994, before becoming more widespread in various prevention and education efforts internationally (Holt, 2014). Today, alongside other community-based strategies such as 'serosorting' and 'strategic positioning,' negotiated safety remains part of the HIV prevention and education lexicon (Holt, 2014).

The concept of negotiated safety enables the exploration of risk and safety practices in relation to multiple and alternative framings, including those which resist or challenge mainstream epidemiological or health promotion positions (Rhodes & Cusick, 2000). Understanding risk and safety as 'fluid' and in 'negotiation,' rather than as 'fixed' and 'determined,' also encourages critical reflection on individuals' practices of agency and accounting in light of their surrounding situations and contexts (Kippax & Race, 2003).

METHODS

Purposive sampling was used to recruit heterosexual couples in which both partners identified as PWID. Recruitment took place across four inner-city harm reduction services within Australia's two most populous states: a needle-syringe program (NSP) and harm reduction service in Sydney, New South Wales (NSW), and two primary healthcare centres in Melbourne, Victoria. All four were chosen as recruitment sites because they serve as the main needle-syringe outlets for their area. Each is part of a network of publicly funded primary healthcare, NSP and peer-led services established across both NSW and Victoria specifically for PWID.¹ While both Victorian services offer on-site HCV testing as part of their integrated primary care model, the two Sydney sites provide referrals to local primary healthcare clinics for HCV testing.²

1 Data from the annual Australian needle-syringe program (NSP) Survey (Iversen & Maher, 2015) indicate that among participants heroin was the most commonly injected drug in both states until 2014, when in New South Wales (NSW) it was exceeded by methamphetamine. In our study, heroin was cited as the 'drug of choice' by a clear majority of participants from both states, followed by stimulant-type substances, including methamphetamine.

2 In Australia, over 230,000 people are estimated to be living with chronic hepatitis C virus infections. People who inject drugs remain disproportionately affected, with approximately 90% of newly acquired infections due to the sharing of contaminated injecting equipment (The Kirby Institute, 2015). In 2014, the prevalence of HIV among NSW and Victorian participants in the annual Australian NSP Survey was 2.5% and 1.7%, respectively, while for HCV it was 55% and 67% (Iversen & Maher, 2015). Rates of HCV testing in NSW were 51% for the previous year (with 85% ever tested) and 60% in Victoria for the previous year (with 90% ever tested) (Iversen & Maher, 2015).

Staff from each site directed service users to flyers promoting the study and (with consent) facilitated contact with the research team. Eligibility for the study was then discussed with both members of the couple before arrangements were made to meet at one of the participating sites. Interviews were conducted in private areas set aside within three of the sites (the Sydney NSP and the two Melbourne services). Recruitment focused on generating a sample of couples representing a range of ages and a balance of HCV serostatus (negative concordant, positive concordant and serodiscordant). The majority of participants comprised couples where both partners agreed to be interviewed. However, in order to ensure a balance of younger participants, a number of 'sole' participants were later included on the basis of their current or prior relationship experience involving injecting drug use.

A diversity of approaches to dyadic-focused research is canvassed in the literature (see, for example, Caldwell, 2013; Eisikovits & Koren, 2010; Hertz, 1995; valentine, 1999). Our decision to interview partners separately was, we believed, the most likely to facilitate the emergence of sensitive intra-relationship talk (Eisikovits & Koren, 2010), including negotiations around injecting-related risk and safety. All Sydney interviews were conducted by the first author (J.R.); the Melbourne interviews initially by the third author (S.F.) and then by a research assistant (C.H.). The importance of anonymity and confidentiality was reiterated to all participants, including specific assurances that no information would be disclosed to partners.

Semi-structured interview schedules were organised around the core themes of injecting drug use, HCV and intimate partnership. Participants were asked to describe the nature of their current relationship (including other sexual partners), their knowledge of HCV and its relevance to the relationship, their experiences injecting with partner/s and with friends, and their experience accessing harm reduction services. Interviews took between 30 and 60 minutes. Each participant was reimbursed A\$20 for their time and travel expenses. The study was approved by the Human Research Ethics Committee of The University of New South Wales. Written, informed consent was obtained from all participants.

Interviews were digitally recorded, transcribed verbatim and de-identified to ensure participants' anonymity. Each participant was given a pseudonym to preserve anonymity. The authors collaborated on the construction of a coding frame, guided by a previous partnership-related pilot study (Seear et al., 2012) and by the existing literature. Transcripts were then entered into a qualitative data management program, NVivo 9. Consistent with positioning 'the partnership' as the basic unit of our analysis, all transcripts were organised within NVivo as couples. This meant that any narrative detail subsequently extracted for analysis was immediately identifiable as belonging to a broader story of partnership as much as an individual account. Summaries of each theme file or 'node' were subsequently produced by one researcher (J.R.) and then reviewed by all authors to further assist identifying concepts and support emerging hypotheses. This chapter focuses on the node that collated all data concerned with needle-syringe sharing within partnerships, analysed with particular attention to participants' accounts or rationalities

of sharing consonant with a 'negotiated safety' framework. Extracts cited are identified by participant pseudonym, age and HCV serostatus, along with their partner's corresponding details.

FINDINGS

The dataset comprised 34 couples and 12 'sole' participants, with equal numbers of men and women (n = 40) ranging in age from 19 to 61 years. Duration of relationships varied from 2 months to 20 years. Nine participants were in part or full-time employment, with nearly all receiving some form of social welfare (n = 71). Over half the participants identified as 'Anglo-Australian' and nearly one-quarter as Aboriginal or Torres Strait Islander (n = 17). In this chapter, we have focused our analysis on the 34 couples for whom we have both individual partner accounts of their shared partnership. Of these, 26 or approximately 75% reported sharing within their partnership. Only one participant reported sharing with someone other than their partner, while eight couples reported never sharing. Of the 26 couples who reported sharing needle-syringes, 20 believed they were HCV concordant (8 HCV negative and 12 HCV positive) and 14 discordant (8 HCV-positive men and 6 HCV-positive women). Serostatus was determined by self-report and in several cases partners offered conflicting accounts. There were also cases where participants reported that their serostatus had changed during the course of the relationship — through treatment, spontaneous clearance or seroconversion. Hence, we have classified participants by serostatus as reported at the time of interview.

The following analysis mobilises the concept of 'negotiated safety' (Kippax et al., 1993) in relation to needle-syringe sharing within intimate partnerships. It does so via the discussion of three key themes identified within participant accounts: the importance of 'trust' in enacting intimate partnerships; the sharing of 'intimate knowledge' with regard to partners' negotiations and decision-making around safety; and, the question of 'unevenness' in negotiating practice.

'Trust' and the practice of partnership

For most participants, 'trust' was the recurring trope of their relationship narrative. Often characterised as the absence of secrets, trust played a crucial role not only in the maintenance of intimacy generally but in negotiations around injecting practices and viral management specifically. For couples such as Patrick and Pam, trust reflected and enacted the ethical substance of their partnership:

I've always just found that honesty is the best policy ... It's my life: I look after myself and I look after my loved ones. And if people don't like the way I live my life that's their problem, not mine ... [K]nowledge is power

isn't it? I like to know what's going on ... [Pam] and I are both very open and honest people ... I don't understand couples that like skulk around behind each other's back doing things. Lying and cheating ... it just doesn't work. Either you want to be with your partner or you don't.
(Patrick 52 pos. (Pam 50 neg.))

For many participants, trust — and by extension, safety and security — was the distinguishing feature of shared drug use with their intimate partners. Here, safety and security meant more than simply the avoidance of viral danger. The presence of a trusted partner functioned as a form of emotional (as well as risk) management: reducing uncertainty and anxiety, and heightening a sense of security. For these participants, trust functioned as a form of relational boundary: socially, emotionally and virologically inoculating the partnership from the perceived risks posed by those outside the partnership. Its presence served to distinguish intimate partnerships from other forms of social relationships:

Interviewer: What do you think it is: being able to share with your partner but not with other people?

Christine: Because I know Craig. I know that there are no more secrets behind the hep C ... If he's sick and I'm sick, the one thing I understand is that we both have the same problem: if we shared strains, then we've both got the same shared strain. It's unfortunate we got to that point, but as long as no one else comes into the mix I feel safe.

(Christine 26 pos.(Craig 29 pos.))

Nearly all participants described rules or codes of conduct they had negotiated with their partner around injecting drugs with others. Following these 'rules' was integral to the maintenance of trust and intimacy within the relationship. Most participants explained that their preference to inject only with their partner was underpinned by a sense of safety. Here, 'safety' appeared to be synonymous with 'trust': it was participants' trust in their partners that allowed them to feel safe. Safety was also about the absence of the potential trouble of 'owing' others (drugs or money), negotiating the division of drugs, dealing with accidental overdoses and so on. Injecting with others required vigilance, so for many participants it was preferable to do so with a partner where things followed a predictable, familiar and comforting routine.

For couples like Fred and Fran, the decision not to inject with others was part of their on-going negotiation and maintenance of a shared ethos and practice of partnership. For others, such as Craig and Christine, occasionally injecting with others required the strict enforcement of injecting and disposal procedures. Such decisions not only established the practical limits of

these participants' partnerships with regard to injecting drug use, it also served as a meaningful, co-created sign of their mutual trust, commitment and exclusivity:

[I]t's not only my life I got to worry about. Once I inject with them [others], I'm going to be bringing it on to her [Fran], so I have to take care of her too.

(Fred 29 pos. (Fran 29 pos.))

Craig: [Sharing] happens sometimes when we haven't got fits. [However], we have a strict policy: if someone else uses and they want to dispose of it in our bin, then they've got to scratch off a number, the number has to be removed, so then I know and [Christine] knows that that's not ours.

(Craig 29 pos. (Christine 26 pos.))

'Intimate knowledge' and the negotiation of safety

Many couples, both serodiscordant and seroconcordant, practised forms of 'negotiated safety' in a strict biomedical enactment of the term: as the reduction of risk based on a shared knowledge of each partner's HCV serostatus or even genotype. Almost without exception, participants insisted that while they had shared needles with their partner they would not contemplate doing so with anyone else. For couples like Pam and Patrick, negotiating serodiscordance was both a meaningful expression and co-created practice of partnership that reproduced their sense of togetherness, their 'we-ness':

Pam: Every now and then when we have been stuck and we've only got one fit between us ... [Patrick] will make sure that I use it ... then he'll rinse it and use it ... Because he has [HCV] and I don't ... And he wants to keep it like that.

Interviewer: It sounds like on those occasions you've been very aware of Patrick's hep C status and so you've gone first?

Pam: Yeah ... he just wouldn't have it any other way. [Negotiating serostatus] isn't really an issue for people like us that are partners and are faithful, and are loyal and stuff; I just think there'd be a lot of people out there that keep secrets.

(Pam 50 neg. (Patrick 52 pos.))

The negotiation of safety within intimate partnerships can be reasonably explained as simply an expression of the familiarity and trust that comes with intimacy, sometimes also depicted as an 'equivalent' to unprotected sexual intimacy (Harris & Rhodes, 2013; Lenton et al., 2011; Seear et al., 2012). What was noteworthy among our participants, however, was the enabling role played by the particular types of knowledge participants had about their partners' injecting practices, viral serostatus and medical check-ups. In some instances, attaining access to such knowledge appeared to act as a catalyst for the establishment of intimacy and trust. As Suzie 46 pos. (Seth 34 pos.) explained, "when we got together we both went and got blood tests done, looked at each other's blood tests, knew exactly what each other had". In other circumstances, access to intimate knowledge was a consequence or reflection of the emotional closeness of the partnership. As Fran 29 pos. (Fred 29 pos.) puts it,

I know [Fred], I love him, it's different. We've been together for so long, we know so much about each other and we're just so close. Whereas other people, I don't trust, I don't know their life. I know his life.

Participants trusted their partners, at least in part, because they were witness to the intimate practices of each other's daily lives. Being continually physically proximate as well as emotionally close facilitated the co-creation of intimate interpersonal knowledge, in turn enabling the establishment and maintenance of mutual trust and collaborative forms of viral risk management:

Interviewer: *If you weren't in a relationship, would you share?*

Belinda: *[If] we were just best friends and we didn't have a sexual relationship, no I wouldn't ... We use always 100% together, all the time for the last 10 years ... so I see his practices. With friends and associates, I don't know what they're doing, they could pick them up in the gutter.*
(Belinda 36 pos. (Bob 46 pos.))

Interviewer: *So why would it be that you don't share with them [people other than partner]?*

Cath: *Because I don't know what they've got I suppose, but with [Colin] I'm sort of with him every day, all day: I know what he does. I know he wouldn't share with other people.*
(Cath 33 neg. (Colin 29 neg.))

Here, participants incorporated elements of biomedical knowledge into their intimate knowl-

edge of each other and their trust relations. Biomedical 'evidence' enabled trust relations to be applied: practised. In order to negotiate the minimisation of risk around sharing (and despite both being HCV-positive), Seth (34 pos.) and Suzie (46 pos.) drew on scientific knowledge current at the time of interview regarding interferon-based treatments of HCV according to genotype. Their decision for Suzie to inject first was based on their mutual understanding that interferon-based treatment for her genotype 3 was of shorter duration and more effective than Seth's genotype 1A: better to risk transmission from Suzie to Seth than vice versa. Couples such as Fred and Fran, and Ava and Alan, similarly drew on their awareness of HCV genotypes or 'strains' to inform their decision-making around drug and equipment use. This is not to reduce participants' knowledge of one another to a biomedical risk calculus but rather to illustrate the ways in which the 'biomedical' was both accommodated within, but also in turn enacted in, participants' trust relations:

Fran: [W]e found out we've both got the same strain, and we know we both don't have anything else. We always have blood tests ... he's the only person I'll share with.

(Fran 29 pos. (Fred 29 pos.))

[W]e are pretty vigilant about the practice [of injecting]. Because there's different strains of hep C. [Ava] might have hep C and I might have hep C, but different strains. If she gets my strain it might ... you know, make it worse.

(Alan 48 pos. (Ava 33 pos.))

Just as we need to appreciate trust's emotional, relational and social dimensions, so too do we need to recognise its historicity: remade over time through the lived experiences of the partners involved, in the context of historical shifts in biomedical and other knowledges (Rhodes & Cusick, 2000). For couples such as Seth and Suzie, and Jenn and Jim (below), their perceptions of risk changed in accordance with the emotional dynamic of their partnerships: reconfigured within the safety and security of a growing intimacy:

Interviewer: And so you guys didn't, you didn't try and distinguish your fits from [your partner's] fits sort of thing?

Seth: There were times earlier on in the piece, like if we just had one fit each, we're going to reuse them later. We'd wash them out, and one of us might burn an end or something, but as time wore on and we sort of realised that we were going to be spending quite a lengthy period

of time together, not just a fling kind of thing, it'd develop more into something like 'ours.'

(Seth 34 pos.(Suzie 46 pos.))

Interviewer: *So would it have been different in the past [sharing]?*

Jim: *At the start it was, because we weren't aware of what we had. But only since we both found out we had the same hep C it was like, well my blood is your blood and we're going to marry ... So for now [we're] happy to share ... we're two partners become one.*

(Jim 32 pos. (Jenn 31 pos.))

While negotiations and decision-making around viral safety were, at least in part, emotionally constituted — in Seth and Suzie's case, mirroring their emerging commitment to one another — they were not necessarily indifferent to or outside biomedical reasoning. For couples such as Jim and Jenn, and Fred and Fran, their change or 'relaxation' of attitude towards sharing equipment involved the integration of serology results within the private landscape of their partnership. This integration of the biomedical within the intimate was enacted in different ways within and across partnerships. Jenn, for example, emphasised the biomedical, "I found out we both had it [HCV] and we had the same genotype ... I know this is bad but if we have to share I'm not as worried now." Jim, on the other hand, referenced biomedical knowledge alongside a Western trope of romantic partnership: of 'two partners become one.' Fred, too, accommodated his knowledge of HCV and the 'strain' he shared with his partner Fran within a romantic ideal: "we've checked out each other's bloods ... so we are aware of exactly what we've got ... And because we're soul mates for life, it doesn't really matter". For both couples, negotiating safety was materialised through the coming together of biomedical knowledge and intimacy: an integration of biomedical and social knowledges embodied in practice.

For these couples, what counted over time in the process of negotiating safety was not simply the growth of emotional closeness coupled with the accumulation of intimate, interpersonal knowledge, but their exposure to biomedicine. Here, negotiations around safety did not follow a predictable or linear path over the course of couples' relationships; greater trust and commitment did not inevitably lead to a 'relaxation' of attitudes and practices around sharing. As Suzie, for example, learnt more about viral genotypes and began considering the possibility of treatment, her own and Seth's approach to viral-risk management returned, once more, to being — as Seth put it — "a lot more vigilant". Similarly, Shelly and Steve explained that going through treatment expanded their biomedical knowledge, prompting them to rethink their previous practice of sharing equipment:

Suzie: *I was one of those people that [said] 'yeah I've got hep C too ... it's [sharing] fine' ... But now that I have been more educated on hep C, I'm a lot more wary. I will not share his even [Seth's equipment] any more ... I won't risk getting another genotype ... No way!*

(Suzie 46 pos. (Seth 34 pos.))

Shelly: *In the past when we both were hep C positive and we both had the same strand, and we knew that, we weren't too concerned ... If we didn't have clean syringes we would just use our old ones and I'm sure I used his and he used mine ... but we don't do that now [that Steve has completed HCV treatment].*

(Shelly 34 pos. (Steve 33 neg., following treatment))

The 'unevenness' of negotiations

Participants' negotiations around safety, along with their implementation in practice, were necessarily enacted within relational and social environments that were themselves continually shifting and evolving. Even within the same relationship, the meaning of 'safety' was fluid, shifting over time and across place. For some couples, their negotiations around sharing, including who would go *first on the needle*, appeared to prioritise the risk of overdose. For others, the injecting process became organised, at least in part, around the dilemma of diminishing venous access (the less-used the needle, the sharper it is, the greater the likelihood of successfully finding a vein). For Seth and Suzie, the process of negotiating safety around genotype (discussed earlier) was further complicated by a number of additional factors: from a difference in injecting skills to fears around public and police detection:

I always went [injected] first I suppose ... [I]f the gear was too strong, or something like that, I would be the one to overdose first ... If Cath goes first, I don't want anything to happen to her.

(Colin 29 neg. (Cath 33 neg.))

[N]early all my veins are destroyed so I inject in my neck now and my groin ... [T]hat's why I usually get to inject first, that's why [Bob] usually helps me because it's so hard for me to get [myself].

(Belinda 36 pos. (Bob 46 pos.))

Interviewer: *And so how do you work out who's going to go first?*

Suzie: *Because he's got Genotype 1, I'd always like go first because I've got Genotype 3 ... I'm quicker too ... He takes too long ... [W]e're doing this stuff outdoors, so you've got to be constantly looking for police or other people ... we have to be quick and fast.*

(Suzie 46 pos. (Seth 34 pos.))

We are not proposing here that these couples were necessarily indifferent to viral risk but rather drawing attention to the 'unevenness' of negotiations: to the presence of other 'risks' being of greater immediate priority than viral risk and the shaping or disrupting of negotiations by other things. Negotiated safety is an uneven and evolving process according to context, which in turn has a bearing on the internal dynamic of relationships and communications within them. Participants' partnerships were regularly forced to contend with a myriad of competing factors and 'risks' — emotional, physical, viral, structural — in their negotiations around safety. While negotiated safety was a fluid and dynamic process for all of our couples, inevitably differentiated, at times, by the relational politics of power and gender, only two female participants provided accounts of the sort of gendered iniquities or abuses cited in the literature (Bourgois et al., 2004; MacRae & Aalto, 2000; Wright et al., 2007). Both Mandy and Rachel reported a grossly curtailed capacity to influence the injecting process due to their partners' dominant and controlling conduct. Both reported distress at not only their partners' insistence on injecting in public, but by the risk (viral and otherwise) that accompanied these episodes. Mandy's account was most striking in the admission — the only one reported among all our participants — that she would rather inject with friends: "my friends, they'll stop and listen to me and they'll take more time to be clean if I ask them to, rather than my partner". For Mandy, and arguably Rachel too, the negotiation process was confounded by what appeared to be an explicit disparity in power, not only with regard decisions around drug use, but the relationship more generally:

Interviewer: *Do you share injecting equipment with your partner?*

Mandy: *Sometimes, all the time actually ... it's pretty scary sometimes what I see, because [Mike] does the mixing of the dope ... we never go home and have it, whereas I, if I had it my way, we'd be taking the drugs home, and it would be a whole lot cleaner ... [I]t's got the point where I've just given up. It's like I think: 'Well I've got hepatitis C now'... [I]f I say something you know, I get shot down in flames ...*

(Mandy 45 pos. (Mike 37 pos.))

Interviewer: *Do you inject together?*

Rachel: *[H]e can't wait to go home and have it. We'll stop in a laneway or whatever and have it. I get really paranoid but he loads mine up and I have it anyway ... He asks me to get everything out and he'll just do it ... It's just always been that way, even if when I'm buying it he takes over.*
(Rachel 41 pos. (Robert 42 pos.))

DISCUSSION

Without exception, intimate partnerships played a central role in the lives of our participants. Despite the ambivalence, disappointment — even disaffection — reported by some, partnerships invariably represented participants' primary source of material and emotional comfort, support and security. For many, their intimate partnerships functioned as an 'emotional refuge' (Syvertsen et al., 2013) and form of 'social protection' in an often hostile world (Rhodes, Rance, Fraser & Treloar, 2017). Partnerships were also instrumental in shaping how participants thought about, negotiated and practised blood-borne virus prevention. Negotiating safety was a complex and at times contradictory process, involving the balancing or prioritising of multifarious, often competing, risks. While we recognise the critical role played by broader forms of social structural vulnerability and marginalisation in shaping and constraining participants' 'private' lives and relationships, our analysis here has been principally concerned with participants' accounts of what they do *within* partnerships.

Rather than recognised as a unit of analysis in its own right, the partnerships of PWID have tended to be either overlooked by the literature or discounted as dysfunctional and drug-driven (Fraser, 2013; Keane, 2004; Seear et al., 2012; Simmons & Singer, 2006). Notable exceptions have, however, underscored the need to take seriously their affective dimensions and emotional dynamics (see, for example, Rhodes & Cusick, 2000; Rhodes & Quirk, 1998; Seear et al., 2012; Syvertsen et al., 2013). The management of risk and the negotiation of safety among such couples, they argue, need to be understood not just as exercises in rational calculation but as an integral part of how couples actively 'do' or *enact* intimacy — as caring, secure and trustworthy. In stark contrast to the routine "dehumanization and distortion" (Simmons & Singer, 2006) characterising popular representations of couples who inject drugs, many of our participants emphasised notions of love, trust and commitment in their accounts of partnership.

This chapter is based on a study designed in a way that potentially affected the data in unintended but important ways. Recruitment involved self-selection and voluntary participation from both partners, and as such necessitated a level of mutual decision-making and cooperation. This may have reduced the likelihood of making contact with couples whose relationships were affected by issues of inter-partner violence and abuse. We note that while only two female participants provided explicit accounts of diminished power and agency in regard to negotiating safety

with their partner, we cannot be sure that such experiences were not more widespread among participants. Although qualitative methods are well suited to capturing contextual and relational complexities beyond gender norms and stereotypes (Fraser, 2013) — including decision-making around drug use — we acknowledge the limits to our claims-making regarding the apparent absence more broadly of gendered inequity within our dataset.

Our analysis has revisited and refashioned the term 'negotiated safety' from its origins in HIV-prevention practice and sought to extend its explanatory efficacy to couples who inject drugs. We too have considered how our participants engaged with and transformed medical knowledge in an attempt to fashion their own prevention strategies in ways that reflect both the possibilities and the constraints of their situation. Our participants consistently reiterated the importance of trust, honesty ('the absence of secrets') and the presence of an agreement or 'rules.' For both gay men and couples who inject drugs, negotiated safety as a form of viral risk reduction relies on the coming together of the biomedical and the intimate: on sharing and incorporating knowledge of each other's serostatus within a relational context of honesty and trust.

While there are viral specificities which differentiate the practice of negotiated safety among gay men compared with couples who inject drugs — the presence of HCV genotypes, for example — we do not want to reduce such negotiations to simply a question of biomedical acumen or risk calculus. Divorcing the role of people's emotional lives from their decision-making processes — including choices made around drug and equipment use — risks constructing accounts in which lived, embodied intimacy is missing (Rhodes & Cusick, 2000). 'Negotiated safety' is a negotiation in the sense of couples coming to a (seeming) consensus to enact a risk-reduction decision or action, as well as in the sense of being produced through the relational effects of biomedical knowledge merging with embodied knowledge about the sense and meaning of relationship. Negotiated safety is at once a coming together of different forms of knowledge — of reasoned action and the embodied or emotional.

For our participants, negotiating safety required balancing the emotional dimensions of the partnership alongside its pragmatic functions (Rhodes, Rance, Fraser & Treloar, 2017). Selective sharing with one's partner was framed by many participants as a means of keeping their partnership safe (including virologically) from 'irresponsible others' (Fraser, 2004): a means of keeping *us* literally and symbolically distinct — safe — from *them*. For gay men, on the other hand, the practice of negotiating safety has typically been in the context of open relationships where the focus has been on how to *include* others safely within the (sexual) dynamic of their relationship. For our couples, the trust invested in their relationship was intimately bound up with the intimate knowledge they had of each other; others could not be 'known' — and therefore trusted in the same way. For serodiscordant couples in particular, while this would appear to contradict normative understandings of viral risk which suggest that danger actually lies *within* the relationship, it does not — unlike for HIV-serodiscordant gay partnerships — preclude the practice of negotiated safety. For nearly all our participants, risk (both viral and otherwise) was invariably reconfigured

and relocated: as coming from *others* and from the *outside* (the partnership, the home and so forth). Selectively sharing with one's partner, albeit as a 'last resort', was nonetheless still about prioritising and enacting the value of intimate partnership and the protective effects of relationship: something participants reported not countenancing with anyone else.

CONCLUSION

While the concept of 'negotiated safety' has been well utilised within the HIV literature on men who have sex with men, it has rarely been explored within the field of illicit drug use and HCV. Similarly, our positioning of participants' partnerships as the primary unit of analysis represents a novel and instructive way of thinking about not only HCV transmission and prevention, but the complexities and contradictions of risk production and its negotiation more broadly. Within liberal Western contexts, drug users' capacity to reason and make decisions (Wolfe, 2007), be fully rational subjects (Seear et al., 2012) even their inclusion as members of the human community (Moore & Fraser, 2006) are all routinely subjected to doubt (Rance & Treloar, 2015). Hence, it is all the more important to not only acknowledge the integrity of intimate partnerships between PWID, but to recognise that such partnerships are both 'reasoned' *and* 'embodied' (Rhodes & Quirk, 1998): capable of not only enacting their own form of 'prevention ethics' (Race, 2008) but made up of lived emotion and affective experience.

We argue that at a service, programmatic and policy level, failing to acknowledge and work with the strengths, knowledges and practices of partnership among PWID will continue to limit the impact of HCV prevention and health promotion programs. Such an acknowledgment, we maintain, needs to be contextualised within a redistribution of responsibility for HCV prevention beyond simply those injecting to include social structures and institutions. It needs to be accompanied by a determination to address the shortcomings that have tended to characterise HCV testing: of poor diagnosis experiences; confusion regarding the meaning of different tests; inadequate counselling and follow-up (see, for example, Seear et al., 2012; Treloar et al., 2010). The individualising tendency of existing models of needle-syringe distribution similarly needs to be challenged, requiring a redesign of equipment packaging and presentation to reflect not only the sociality of injecting but the diversity of meanings needle-syringes carry for many of their users (of care, fidelity and so forth) (Fraser, 2013; Fraser et al., 2015).

Our findings echo calls within HIV prevention to move beyond narrow, individual level, cognitive-based models of health behaviour (El-Bassel et al., 2014; Jiwatram-Negron & El-Bassel, 2014; Montgomery et al., 2012). Recent interventions in the field have emphasised a conceptual and motivational shift from a 'self-care' orientation to a 'relationship' orientation: from independence to interdependence and 'communal coping' (Lewis et al., 2006; Montgomery et al., 2012). While our analysis has been principally concerned with participants' accounts of what they do

within partnerships, we recognise that for many couples, chronic structural vulnerability, hostile social environments, and the multiplicity of competing demands associated — directly or indirectly — with drug use and dependency, all form part of both the production of risk and attempts at negotiating safety (Fraser & Seear, 2011). In our continued efforts to understand and prevent the transmission of HCV, as well as address the dynamics of social exclusion, we need to better acknowledge and work with the sources of intimate knowledge, trust and negotiated safety created and enacted within the partnerships of those who inject drugs, as well as identifying the viral risks. We need to better recognise not only the reasoned relationships of couples who inject drugs but the disciplinary effects of their social contexts wherein structural forces shape not only what is 'reasonable' but what is possible.

CHAPTER 7

“Don’t think I’m going to leave you over it”**Accounts of changing hepatitis C status among couples who inject drugs**

BASED ON:

Rance, J., Treloar, C., Fraser, S., Bryant, J., & Rhodes, T. (2017). “Don’t think I’m going to leave you over it”: Accounts of changing hepatitis C status among couples who inject drugs. *Drug and Alcohol Dependence*, 173, 78–84.

AUTHOR CONTRIBUTIONS:

Conception, analysis and writing by J.R; data collection conducted and/or overseen by J.R. C.T., S.F., J.B. and T.R. all contributed to the initial coding framework and provided critical feedback throughout.

While the health-related benefits of intimate partnership are well documented (Kiecolt-Glaser & Newton, 2001; Lewis et al., 2006), little attention has been paid to couples experiencing high levels of social stigma and exclusion, such as those who inject drugs and are affected by the hepatitis C virus (HCV) (Treloar et al., 2015). In Australia, approximately 90% of newly acquired HCV infections are due to the sharing of contaminated injecting equipment (The Kirby Institute, 2015). Australia’s primary public health response to HCV is focused on the distribution of sterile equipment (along with safer injecting advice) via government-funded needle-syringe programs (Treloar & Fraser, 2007).

Integral to the prevention response has been the long-held understanding that avoiding transmission is a matter of individual responsibility (Dwyer et al., 2011; Fraser, 2004; Fraser et al., 2014). This is reflected and reinforced not only through the prevention education and health promotion materials produced for people who inject drugs (PWID) (Dwyer

et al., 2011; Fraser, 2013), but the practical measures designed to enable the fulfilment of this responsibility, such as the ways in which sterile injecting equipment is distributed (Fraser et al., 2014). Despite epidemiological and surveillance data consistently showing that the majority of equipment sharing occurs between sexual partners, this onus on individual responsibility has effectively elided the importance of the intimate partnership as a key site of hepatitis C prevention and transmission (El-Bassel et al., 2014a,b; Fraser, 2013; Rhodes & Quirk, 1998; Seear et al., 2012; Simmons & Singer, 2006). Recent survey data, for example, indicate that more than 50% of participants who reported sharing injecting equipment did so with their regular sexual partner (Iversen & Maher, 2015), with similar patterns found in earlier studies (Roux et al., 2014; Bryant et al., 2010; Cao & Treloar, 2006).

This “individualising tendency” (Fraser et al., 2015) has important implications for efforts to understand and prevent the transmission of hepatitis C, particularly within couples where arguably the risk is greatest. In this chapter we address this tendency by adopting a methodology that positions partnerships rather than individuals as the primary unit of analysis (Eisikovits & Koren, 2010; Simmons & Singer, 2006). Drawing on qualitative interviews with couples who inject drugs, we focus on those couples that reported changes in HCV status (or “sero-change”). We explore how these participants responded to sero-changes within the lived contexts of their intimate partnerships and how such changes affected their perceptions of transmission risk.

Framing participants’ partnerships as the primary unit of analysis represents a novel and instructive way of thinking about HCV transmission and prevention. Rarely have the intimate partnerships of PWID been conceptualised as units of analysis in their own right, tending to be either overlooked or discounted as dysfunctional and drug-driven (Fraser, 2013; Keane, 2004; Seear et al., 2012; Simmons & Singer, 2006). Recently there has been an emergence of HIV-related research focusing on the “micro-social contexts” of heterosexual couples who inject drugs (El-Bassel et al., 2014a, 2014b; Montgomery et al., 2012). This work emphasises the need to move beyond individual-level, cognitive-based models of health behaviour, underscoring instead the importance of a conceptual, motivational and “ideological shift from focusing on the individual to the dyad” (Jiwatram-Negron & El-Bassel, 2014, p. 1885) from an orientation of “self-care” and “independence” to one prioritising “relationship”, “interdependence” and “communal coping” (Montgomery et al., 2012). In this chapter we build on these broad conceptual concerns via new empirical territory: an exploration of the particularities of acquiring and living with HCV among couples who inject drugs. Here a qualitative approach is not only well suited to capturing the richness and subtleties of contextualised, interpersonal dynamics, it is also particularly effective when exploring new and underdeveloped areas of research such as people’s accounts of sero-change (Patton, 2002).

MATERIALS AND METHODS

Recruitment and data collection

This project used purposive sampling to recruit heterosexual couples in which both partners identified as PWID. Recruitment took place across four harm-reduction, inner-city services within two Australian states, New South Wales and Victoria. Couples were included on the basis that both partners agreed to be interviewed. Each partner was interviewed separately by the same researcher, with assurances of confidentiality emphasised. Interviewing partners separately, it was felt, would best facilitate the emergence of sensitive intra-relationship talk (Eisikovits & Koren, 2010): the attribution of responsibility (or 'blame') for HCV transmission within couples, for example. Semi-structured interview schedules were organised around the core themes of injecting drug use, HCV, and intimate partnership. Interviews took between 30 and 60 minutes. Each participant was reimbursed A\$30 to cover time and travel expenses.

Data management

The total dataset comprised 80 qualitative, in-depth interviews.¹ All interviews were digitally recorded, transcribed verbatim, de-identified and anonymised with the use of pseudonyms. A coding frame was developed collaboratively by the authors, drawing on the data itself, the interview schedule, and our knowledge of the literature. Consistent with positioning 'the partnership' as the basic unit of analysis, transcripts were entered as couples within a qualitative data management program, NVivo 9. Consequently, any narrative detail extracted for analysis was readily identifiable as part of a broader story of partnership rather than simply an individual account. Individual theme files or 'nodes' were reviewed by all authors to assist with identifying and consolidating key themes and concepts. The data analysed in this chapter comprised 28 of the total 80 interviews, collected from the 14 couples that reported changes in HCV status during the course of their relationship. Our focus was on the node that collated all data concerned with couples' accounts of sero-change.

ANALYSIS

Our analysis was conducted using a mix of inductive (data-driven) and deductive (analyst-driven) approaches (Braun & Clarke, 2006). Induction enabled key themes to be identified in the relevant node and subsequently corroborated against the original transcripts. These emergent themes plus

¹ The 80 respondents comprised 34 couples, plus 12 'sole' participants included on the basis of having had relationship experience (prior or current) involving injecting drug use.

indicative quotes were discussed among all authors. During this stage, summary accounts of each couples' sero-change story were also mapped out (see Table 1). Accounts from some participants included recollections of confusion or 'misinformation' regarding their status; others described being uncertain, even perplexed, regarding the circumstances of transmission. Within couples, too, partners sometimes made contradictory statements about the other's status. A deductive analytical approach enabled us to begin to make sense of this apparent confusion or "mess." The extant literature, including our own earlier analyses of the dataset (see for example, Rance et al., 2016; Treloar et al., 2015), provided an analytical framework through which to interpret couples' often complex accounts of sero-change. Our final analysis, including the three themes under which our results are organised, reflect these elements of grounded analysis (Glaser & Strauss, 1967) coupled with analyst-driven deduction. Throughout the writing process, each subsequent iteration incorporated suggestions from all authors, with differences negotiated until agreement was reached.

The study was approved by the Human Research Ethics Committee of The University of New South Wales (reference HC12430). Written, informed consent was obtained from all participants. All extracts cited here are identified by the participant's pseudonym, age and self-reported HCV status² (at time of interview), followed by their partner's corresponding details, and the duration of their relationship.

2 Our use of terms in this chapter refers to HCV status as it relates to the potential for transmission. 'HCV-positive' refers to chronic infection (antibody-positive and RNA-positive); such a person is infectious to others. 'HCV-negative' refers to people without chronic infection (that is, antibody-negative and RNA-negative, or antibody-positive and RNA-negative); such a person is not infectious to others. 'Exposure' refers to an exposure to HCV which did not result in chronic infection (antibody-positive and RNA-negative). 'Seroconversion' refers to exposure to HCV which did result in HCV chronic infection (antibody-positive and RNA-positive). We use the term "sero-change" as a catchall to describe any change in HCV status reported by participants.

Table 1: Participant accounts of sero-change

*Seth34pos/Suzie46pos (2 yrs.) 1 seroconversion	<i>Initially positive seroconcordant (i.e. at relationship outset). Seth reported subsequently contracting an additional genotype (1a) via Suzie.</i>
Janine48neg/Jim61pos (15 yrs.) 1 seroconversion + post-pregnancy clearance	<i>Initially serodiscordant. Janine reported subsequent seroconversion following accidentally sharing a needle-syringe with Jim. She reported clearing the virus following the birth of their child three years later.</i>
Fran29pos/Fred29pos (8 yrs.) 1 seroconversion or "clinical mistake" 1 seroconversion	<i>Initially negative seroconcordant. Fred reported a previous HCV-positive diagnosis but a "negative" result at the start of the relationship. Believed his HCV had subsequently either "come back" or that the clinician had been mistaken regarding his earlier "negative" result. Fran reported contracting HCV after the relationship commenced, via Fred.</i>
Debbie33pos/Dan33pos (14 yrs.) 1 seroconversion	<i>Initially serodiscordant. Debbie reported subsequently contracting HCV via Dan and remaining HCV-positive. Dan agreed he "gave it" to Debbie but believed she had subsequently cleared her infection.</i>
Keith40pos/Karen32neg (8 yrs.) 2 exposures + spontaneous clearance 1 seroconversion	<i>Initially positive seroconcordant. Both claimed to have been HCV-positive twice. Karen: "I had hep C and then it went away and come back and now it's gone"; Keith: "I've got rid of it and got it again ... I feel stupid". Although unclear, it seems Keith's latest infection was acquired during his relationship with Karen but not via her. Karen reported she had been exposed to the virus twice during the relationship (at least once via Keith) but is now HCV-negative. Keith, however, believes they are both still HCV-positive. Accounts suggest Karen began injecting drug use after the relationship began.</i>
Terry37neg/Tegan38pos (6 yrs.) 1 seroconversion	<i>Initially negative seroconcordant. Tegan reported subsequently contracting HCV via Terry except he reports always being HCV-negative.</i>
Jenn31pos/Jimmy32pos (6 yrs.) 1 seroconversion or "clinical mistake" 1 seroconversion	<i>Initially negative seroconcordant. Both reported being diagnosed HCV-positive after beginning relationship: Jenn for the first time; Jimmy for the second. Jimmy reported receiving a "positive" diagnosis years earlier before later being told by a clinician that he had cleared the infection. Suggested he then "got it again" after he started injecting with Jenn. Jenn, however, believed Jimmy's doctor had made a mistake and that Jimmy had not cleared his initial infection. Jenn reported contracting HCV since meeting Jimmy but was unclear about source of transmission.</i>
Ava33neg/Alan48pos (1 yr.) 1 exposure + spontaneous clearance	<i>Initially serodiscordant. Ava reported acute HCV symptoms after relationship began but subsequently cleared infection. She recalled sharing spoons/filters with Alan but suspected transmission had been via "this couple I used to share it with ... a lot of times." Alan reported he had been HCV-positive for 20 years; believed Ava was still HCV-positive.</i>
Les55pos/Libby26neg (1 yr.) 1 seroconversion	<i>Initially negative seroconcordant. Les reported commencing injecting drug use two years previously; shocked by HCV-positive diagnosis.</i>
Charlie34neg/Crissy30neg (10 yrs.) 1 exposure + spontaneous clearance	<i>Initially negative seroconcordant. Crissy reported subsequently contracting HCV before spontaneously clearing; perplexed by circumstances of exposure.</i>
Tanya23pos/Tim39neg (9 yrs.) 1 seroconversion 2 exposures + spontaneous clearance	<i>Initially negative seroconcordant. Tanya reported subsequently contracting HCV while pregnant via a non-drug related blood exposure. Tim reported two HCV exposures and spontaneous clearance; vague about timeframes and details for both but did not link either directly to Tanya.</i>
Shelly34pos/Steve33neg (8 yrs.) 2 seroconversions 1 clearance following treatment	<i>Initially negative seroconcordant. Shelley introduced Steve to injecting drug use. Both reported HCV-negative results following tests at start of the relationship. Shelley refused to show Steve her results but insisted it was "negative." Both reported subsequently seroconverting; speculation from about transmission source included: contaminated "street deal" and ex-partners. Steve later successfully completed treatment.</i>
Mindy39pos/Mac35neg (10 mths.) 1 clearance following treatment	<i>Initially positive seroconcordant. Mac reported successfully completing treatment during the relationship.</i>
Cameron39neg/Camila39neg (9 yrs.) 1 spontaneous clearance	<i>Initially serodiscordant. Camila diagnosed HCV-positive prior to relationship. Although later tests indicated Camila had cleared it, both she and Cameron believed her to be "positive" (i.e. infectious) at the start of the relationship.</i>

* Couples identified by participant pseudonym; age; HCV status (by self-report at time of interview); and length of relationship.

RESULTS

The 28 participants ranged in age from 23 to 61 years; their relationships varied in duration from 10 months to 15 years. Twelve participants identified as 'Anglo-Australian' or 'Anglo-New Zealander', nine as Aboriginal and Torres Strait Islander, and the remainder as Australian-Armenian (n = 2), Greek-Italian (n = 2), Hungarian (n = 1), Scandinavian (n = 1) and Indian (n = 1). Three-quarters of participants (n = 21) received some form of social welfare, five worked full-time (n = 3) or part-time (n = 2), one was dependent on his partner's income and one declined to answer. Based on self-reported status at the time of interview, two couples identified themselves as HCV-negative, four couples as HCV-positive, and the remaining eight as serodiscordant. The couples reported a total of 13 seroconversions (including 2 instances alternatively described as "clinical mistakes"), 8 exposures-plus-spontaneous-clearances and 2 successful treatment outcomes.

This section explores participants' accounts of sero-change via three themes identified in the data: negotiating new diagnoses and accommodating chronic infections; status confusion; and the prioritisation of partnership.

Sero-change: new diagnoses and chronic infections

While participants' accounts of negotiating a new diagnosis within the context of intimate partnership varied markedly according to the relational, social and viral specificities of their situation — including stated beliefs regarding the source of transmission — they invariably shared an overarching concern for the effect it might have on their relationship.

It's almost like having to tell your partner you're pregnant or something, it's really fucking scary ... it tests your relationship, it really does.

I hate it, I was so ashamed, and I didn't tell [partner Dan] that I had caught it off him for, say, like 13 months ...

I didn't contract genotype 3 until a lot later in life. I was only diagnosed with that in the last 18 months ... It's most probable that I got it from [Suzie] ... I'm very happy and lucky in the sense that I'm glad that she hasn't got my genotype 1, which seems to be a bit more problematic at times for people.

Crissy recalled feeling bewildered by her diagnosis, stating she had "never shared or used someone else's needles." Nonetheless, these feelings were ultimately secondary to her fear of trans-

mitting the virus to her partner in the period before her spontaneous clearance was identified: “the guilt would just kill me.” For Debbie, her reluctance to tell her partner Dan was bound up with feelings of shame but also her desire to protect him from similarly uncomfortable emotions: “I didn’t want him to blame himself and feel bad, because it wasn’t his fault that he got it either.” However, for Seth (already living with genotype 1), “It was kinda just like acceptance. I was more concerned when the results were coming back that ‘please don’t let [Suzie] get what I’ve got.’”

Participants reported a range of emotional, discursive, and practical concerns and accommodations to living with long-term sero-change within their partnerships. Beyond a shared expression of concern among parenting participants about preventing household transmission to children, these accounts were diverse. For Fran, who reported seroconverting via her partner Fred and initially feeling “devastated”, living with HCV “actually hasn’t been like a big thing”. Fred reported that his one concern was “that I don’t want her to feel angry if she feels I gave it to her”. Partners Debbie and Dan adopted a strategy of relative “sero-silence” (Persson, 2008) in what appeared to be a mutual (if unspoken) effort to normalise their relationship in the face of internalised stigma and shame. For Jenn and Jimmy, who both reported seroconverting whilst together but expressed uncertainty about the source of transmission, their confusion emerged from time to time in moments of tension within their relationship.

*It’s a hard thing to talk about ... you try and keep it as low as possible.
We’ve had a few talks about it, but not as much as we should.*

*A little bit of ‘who gave it to who?’ ... The occasional ‘well you gave me
hep C!’ And it can be used against you, and when you don’t know where
it comes from that doesn’t help either, because you don’t want either
party to have it.*

Status confusion

Also commonplace (and evidenced in participants’ excerpts above) was uncertainty and confusion regarding HCV status and/or the circumstances of transmission. Both Camila and Crissy, for example, were perplexed by their diagnoses. For Crissy and her partner Charlie, the distress caused by both the diagnosis itself, and the uncertainty of the circumstances surrounding transmission, seemed to be unnecessarily compounded by a delay Crissy experienced in receiving a follow-up PCR³ test. “They said it was a blood-borne thing, but I was so careful ...

³ A PCR test can detect infectious agents directly, as opposed to antibodies which are produced in response to infection (Dore, 2009). Approximately 25% of people exposed to HCV do not go on to develop chronic infections but will nonetheless remain ‘antibody-positive’. A PCR test should therefore be included as part of a complete virological assessment in order to avoid confusion.

like I never used anybody's [injecting equipment], so how did their blood connect to my blood?"

It's something that I've really thought about because, like I said, I've never shared a needle ... Charlie hasn't got it and I haven't used his needles. So, it was a real mystery to me ... Something I really, really ponder and pondered with Charlie as well ... My doctor was more of a sports doctor ... I hassled him and hassled him and hassled him for a year and a half to do the PCR test. Turned out I cleared it myself, so for a year and a half ... That was a really horrible part of my life.

A number of participants reported that clinical "mistakes" or "misunderstandings" were the source of their confusion about status. For others, understanding the circumstances of transmission, or simply their current status, was complicated by a complex chronology of events: of previous relationships ending and new ones beginning, HCV testing window periods and so on.

At the start [of our relationship] I went and got blood tests, and the doctor did a mistake: he told me I was clean and then I went back a couple of months later and said, 'are you sure?' And when he checked I had hep C ...

When I met him [partner Jimmy], he thought he didn't have it.

... The doctor actually made a mistake ... I think he did actually have it [and] the doctor got it mixed up.

I don't know if [HCV] was from my old partner ... I had a test done [at the beginning of current relationship] and it was clear, but then sometimes they say it can take up to 6 months to show up in the test.

In addition to HCV-related confusion and uncertainty among participants, there were several sets of partners whose respective accounts of status appeared to be in clear contradiction. Debbie believed she was still living with a chronic infection, while her partner Dan expressed the conviction that she had cleared it. Karen and Keith both reported seroconverting twice, yet Karen also reported clearing her infections on both occasions; Keith, however, believed that she, like himself, was still HCV-positive. Tegan and Terry's accounts provided another permutation: while Tegan was adamant she had contracted HCV via Terry, Terry himself reported never having been HCV-positive. While Tegan agreed that Terry was no longer HCV-positive, she argued that he had either "secretly" undergone treatment in prison or had spontaneously cleared it.

Prioritising partnership

Accompanying participants' diverse, sometimes contradictory, accounts of negotiating HCV within their relationships was an important series of statements in which the centrality of the partnership, and its priority over HCV-related concerns, was articulated. Libby's response to her partner's diagnosis (from an unknown source) captures the essence of this commitment: "Well, I just said to him, 'don't think I'm going to leave you over it or anything like that,' because I didn't want him to worry" (Libby26neg.; Les55pos., 1 year). Similarly, Debbie reported insisting to her partner that, despite his responsibility for her contracting HCV, "I'm always going to be with you, so don't worry!" For Janine, the "good responsibility" her partner Jim had consistently demonstrated around the management of his HCV helped consolidate their relationship, making her feel cared for and "valued" (Janine48neg. following spontaneous clearance; Jim61pos., 15 years). Her suggestion that HCV-positive partners can demonstrate their love and support by making sure that they "deal with it" was reiterated by a number of participants. As Libby (cited above) went on to explain: while she did not want Les to worry, "I wanted him to learn about [HCV]." This complex interplay of intimacy, partnership and status is insightfully captured by Janine in an observation about serodiscordant relationships: "Sometimes you [the 'negative partner'] can show your love by showing them that it's not important, but they [the 'positive partner'] show their love by saying that it is important." In addition to these observations, a number of participants framed their experiences of sero-change within broader narratives of personal and relational transformation: HCV came to mean something different to them over time. For Jimmy, attending to his and his partner's HCV had become a priority:

Once we've lost [HCV], I would not do it again to a person and I would not like to get it back. Because it was clumsiness from the addiction — you don't care about it — but now we're down this stage of the track, it is the first thing on the mind.

While for Suzie, her relationship with Seth catalysed a change in her knowledge and attitude towards HCV:

[Seth] actually educated me on it ... About the genotypes and the interferon and everything. He's very knowledgeable in that area; more so than me ... Now I've got to do 6 months of interferon to correct my carelessness in the past.

While some participants acquired or sought greater biomedical understanding as a means of coming to terms with sero-change, others employed explanatory frameworks that sat firmly out-

side conventional biomedical discourse. Drawing on a number of alternative logics or “rationalities”, these participants were primarily concerned with limiting the potential social and relational damage associated with contracting HCV. The virus itself meant something different when transmitted within the partnership rather than outside it. Jenn, for example, explained the difference between Jimmy’s experience of contracting HCV via a friend’s “betrayal” and, years later, their experience together when she seroconverted. Fred too, accommodated (“rationalised”) Fran’s seroconversion within a narrative of romantic intimacy.

He’s just never gotten over it, of course not ... Whereas what happened with us [seroconversion] was an accident ... It’s very different from a friendship to a relationship ... in a relationship, you love each other, you don’t want to harm each other. That’s the way I look at it.

Most likely I gave [HCV] to [Fran], because we share utensils but ... it’s only with one partner, it’s not like I share it with everyone. And because we’re soul mates for life, it doesn’t really matter ...

Tim and Karen similarly articulated socially and relationally situated rationalities, constructing a hierarchy of equipment sharing based on a logic of social rather than sero status. While Tim, like Jenn and Fred, referenced Western tropes of romantic love in order to differentiate between sharing equipment with a friend and a partner, Karen drew on notions of kinship to extend the intimacy, and thus the acceptability, of sharing to include family members.

I usually let her [inject] first, even though she’s the one who’s got hep C ... To me she’s still my lady and she goes first no matter what ... We’ve both got each other’s best interests at heart. Now my mate, we could be mates for years [but] the main thing in his head though is not going to be ‘Oh fuck, I hope he doesn’t get sick or anything’, you see where I’m going? So there’s that emotional connection with [a partner] as well as just the fact we’re friends or we use together.

I don’t really use [injecting equipment] after anyone. Only like my partner or my sister or my real close cousin. Because they’re family. Like with my sister, we got the same blood.

DISCUSSION

In this chapter we have focused on participants' accounts of changing HCV status within the context of their intimate partnerships. While some couples sought greater biomedical understanding as a means of coming to terms with sero-change, others drew on alternative rationalities that sat firmly outside conventional biomedical discourse. Regardless of which explanatory framework they drew on, participants ultimately prioritised the security of their relationship over the dangers of viral infection. The intimate partnerships of PWID may function as forms of social care and protection in relation to typically hostile social environments and structural vulnerability (Seear et al., 2012). As Rhodes and Cusick (2000) suggest, "efforts to protect intimacy and relationships from risk may be particularly important in lives perceived to be particularly insecure or continually under threat" (p. 4). Among people who are socially excluded, including many who inject drugs, meaningful intimate relationships may provide one of the few forms of social capital available to them (Stevenson & Neale, 2012). We need to recognise then, that within such partnerships the negotiation of risk is as much an enactment of emotional intimacy as of reasoned action: that ensuring the ongoing maintenance of the relationship is itself a form of risk management (Rhodes & Quirk, 1998). As our findings suggest, participants frequently prioritised the security — the 'emotional refuge' (Syvertsen et al., 2013) — of intimate partnership over competing concerns, including those of viral safety.

Enacting effective prevention and care, we argue, requires moving beyond the employment of narrowly defined, individual-level psychological models of behaviour — beyond simple injunctions to take "individual responsibility" (Fraser, 2004) — to acknowledge the often complex interpersonal, social and structural imperatives governing intimate (and other) relationships among PWID. We need to better acknowledge and work with the competing priorities and complex realities of such partnerships beyond simply the identification of viral risk. We need to recognise that, as Hepworth and Krug (1999) argue, "While medical and psychological knowledge are necessary and relevant in the case of HCV, they are not the sole basis, nor necessarily the primary basis, on which individuals act" (p. 245).

We recognise that this study was designed in ways that could affect the findings. We have drawn on couples that reported changes in HCV status whilst remaining together. Consequently there was less likelihood of attracting accounts from couples for whom the pressure of status change contributed to the end of their relationship. More broadly, recruitment required self-selection and participation from both partners. This too may have shaped the dataset and the kinds of partnerships studied; it could have, for example, reduced the likelihood of making contact with couples affected by inter-partner violence and abuse. While we noted a general absence of gendered inequity within our dataset (only two female participants provided explicit accounts of diminished power and agency within their relationship) we cannot be sure that such experiences were not more widespread.

Participants were adept at accommodating changes to status within the lived contexts of their private lives and relationships. For our participants, the meaning of risk and safety was multiple, socially and relationally situated, rather than singular, fixed and predetermined. Even serodiscordance itself was perceived in diverse and unexpected ways, encompassing a range of meanings and practices among participants (Persson, 2013). This is perhaps not surprising, given that, as others have argued (Fraser & Seear, 2011; Hepworth & Krug, 1999), the meanings of diagnosis and living HCV are “embedded” within the social and cultural dimensions of everyday life and relationships. Participant accounts of status confusion and contradiction, of doctor’s mistakes and lay (mis)understandings, need to be balanced against the limitations of conventional biomedical approaches to HCV education and care. Social researchers have consistently described the disconnection reported between people’s lived experience of HCV and biomedical concerns focused solely on the physical body (Harris, 2005; Krug, 1995; Sutton & Treloar, 2007). As Rhodes and Treloar (2008) argue, biomedical responses can be “at extreme odds with the situated and competing priorities of people who inject drugs” (p. 1330). Nonetheless, our results do suggest the need to continually engage those who inject drugs, in both HCV testing and in improving the systems by which these tests and resultant information are provided. With the “new era” of direct acting antiviral treatments promising to profoundly change what it means to acquire and live with HCV, opportunities will arise to learn to integrate biomedical information within more socially sophisticated, relationally aware approaches.

CHAPTER 8

“Why am I the way I am?”

Narrative work in the context of stigmatised identities

The social exclusion and stigmatisation frequently experienced by people who inject drugs pose critical challenges not only for those directly involved but also for those concerned with understanding and documenting the experience. The analytical focus in qualitative research on the rich and contextualised details of lived experience has proven well equipped to respond to these methodological and theoretical challenges (e.g., Fraser & Moore, 2011; Rhodes, Stimson, Moore, & Bourgois, 2010). In the field of “addictions,” qualitative studies have been occurring regularly since the 1920s (Neale, Allen, & Coombes, 2005). Qualitative methods have been invaluable in accessing “hidden or hard-to-reach” populations (Neale et al., 2005, p. 1587), allowing researchers to build trusting relationships with participants by establishing mutual respect and acknowledging participants’ specific expertise to facilitate discussion regarding sensitive and intimate information (Neale et al., 2005). Indeed, as Rhodes et al. (2010) maintain, the field of drug use and addiction “has an established tradition in generating ground-breaking qual-

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itative and ethnographic research that has crossed over into wider fields to inform social science methods and theories" (p. 441).

In this chapter, we explore some of the distinct advantages of narrative analysis as a valuable counterpoint to the other forms of qualitative inquiry commonplace in the addictions field. A narrative approach, we argue, is well suited to capturing the particular complexities faced by those attempting to tell their stories amid significant social stigma and hostility. "How can we," as Andrews (2004) asks, "make sense of ourselves, and our lives, if the shape of our life story looks deviant compared to the regular lines of the dominant stories?" (p. 1). We ground our argument in a case study: two life-history interviews with 'Jimmy,' a young man with a history of social disadvantage, incarceration and heroin dependence. We propose that Jimmy's story exemplifies the kinds of complexities and contradictions — the "paradoxical accounts" (Wolgemuth, 2014) — well served by a narrative approach.

BACKGROUND

Revisiting the Staying Safe study

Jimmy was originally a participant in the Sydney arm of an international, social research project titled 'Staying Safe: Injectors Who Avoid Hepatitis C.' M. Harris, Treloar, and Maher (2012) provide a detailed account of the Sydney study and a background to the broader study.

The Sydney team (of which the first author was a member) employed life-history interviews and computer-generated timelines to explore how some long-term injectors had avoided contracting the hepatitis C virus. Individuals were encouraged to locate their personal accounts within social, economic and historical contexts, recalling the critical dimensions and circumstances of their lives both before and after their drug use had commenced. In line with all participants, Jimmy was interviewed twice by the Sydney team. His initial interview entailed an in-depth investigation of his life history, with open-ended questions from the interviewer prompting discussion of multiple, diverse aspects of his life: from memories of his early home life, changing family circumstances, and educational experiences, to his initial and subsequent drug use, engagement with legal and drug-treatment authorities, and changing social, sexual, and employment landscapes. Discussions ranged from the retelling of memorable or traumatic events to recalling seemingly quotidian details. Jimmy's follow-up interview was intended to focus more explicitly on exploring the details of his drug use and injecting practices, particularly his recollections and understandings of risk and its amelioration; it also provided an opportunity to revisit and clarify details from the first interview.

By examining these life-history narratives, the Staying Safe team hoped to identify some of the protective strategies, practices and circumstances of those participants who had remained

virus-free. Approaching the data inductively, the team collated hundreds of pages of interview transcripts into categories or themes that cut across individual participant accounts (M. Harris et al., 2012). Thematic analysis is arguably the foundational method (Braun & Clarke, 2006) of qualitative research: a rigorous, reliable and productive approach to working with large volumes of data. As social researchers working in the field of hepatitis C and illicit drug use, constructing 'coding frames' and organising participant transcripts into thematic fragments or 'nodes' enables effective and efficient analyses across often large and complex sets of qualitative data.

Nonetheless, regardless of methodological approach, every study necessarily delimits its field of inquiry simply by virtue of the questions it asks; all interpretations are provisional and analyses are always incomplete (Rosaldo, 1989). In undertaking a secondary analysis of the original Sydney Staying Safe dataset, we wanted to shift our focus from a thematic to a narrative approach: from investigating aggregations of data to exploring an individual case study, an extended account preserved and treated analytically as a unit. In doing so, we were curious as to the different story that might emerge, offering us a new understanding of the data that would complement (rather than supplant) earlier analyses.

Some 18 months after recruitment for the original Sydney Staying Safe study had been completed, the first author returned to the dataset, reviewing hundreds of pages of participant transcripts before deciding to focus on Jimmy's case. Jimmy's narrative, we believed, exemplified the kinds of contradictions and tensions readily incorporated into and accounted for within a narrative approach, but overlooked within a typical thematic analysis. Following the selection of Jimmy's case, the first and second authors independently read his two transcripts a number of times, exploring his narrative, noting recurring themes, and identifying emerging contradictions and tensions. The writing process was led by the first author, but some analysis was drafted by the second author, and the third author provided critical feedback on the evolving iterations. While we had chosen to explore the value of a narrative approach to retain the 'integrity' of Jimmy's narrative, we are nonetheless aware that our own analytic decisions also shaped this process. Which particular elements of Jimmy's story to include and how to interpret them, what to overlook, what to emphasise, were all questions that ultimately required our editorial intervention. While such decisions were negotiated at length between the first two authors, including the third author when necessary, it is nonetheless important that we acknowledge the role our own subjectivities played in the production of this chapter. We therefore view this chapter as an opportunity to not only interpret research data from another vantage point but to critically reflect on the process — our process.

ETHICAL CONSIDERATIONS

Approval for the Sydney Staying Safe study was obtained from the University of New South Wales (UNSW) Sydney Human Research Ethics Committee. Participants provided written in-

formed consent and were remunerated A\$50 for the first interview and A\$60 for the second. Ethics approval and participant consent covered the use of interview material for all subsequent analyses and reports, as long as confidentiality and anonymity were maintained. Interviews were audio-recorded with participants' consent, transcribed verbatim, and de-identified. Pseudonyms were used for all participants, including Jimmy. Given that a narrative analysis typically includes a larger number of distinctive data points, particular efforts have been made to de-identify Jimmy's transcripts. We note that while it would have been preferable to have worked with Jimmy himself on the production of this chapter, this possibility was precluded by the terms of our ethics agreement. Permission to contact participants following the completion of their second interview was not included within the ethics process.

APPROACH

Narrative, the 'drug-using subject' and the notion of hermeneutic injustice

Increasingly, social scientists are acknowledging that 'self' and 'identity' are narratively constructed, storied (e.g., Bishop & Shepherd, 2011; Ezzy, 2002; Hurwitz, Greenhalgh, & Skultans, 2004b; Riessman, 1993, 2008; Somers, 1994; Tamboukou, 2008; White, 2002).

Narrative is a means of human sense-making; the means by which we constitute past experience, claim identities and construct lives. Nonetheless, Lawler argues, narratives do not originate with the individual but are social products that circulate to provide a (contextually circumscribed) repertoire from which people can produce their own stories (as cited in Nettleton, Neale, & Pickering, 2012, p. 242). Narratives are not, Lawler continues, transparent carriers of experience but "interpretive devices" by which people (re)present themselves, both to themselves and to others. As McIntyre puts it, "We are never more (and sometimes less) than the co-authors of our own narratives" (as cited in Hurwitz, Greenhalgh, & Skultans, 2004a, p. 11).

Storytelling is thus an intrinsically social process; so-called 'personal' stories necessarily reflect and incorporate wider social meanings, drawing on specific historical moments and sociocultural contexts. This, we contend, holds particular implications for those whose lived experience and identities are intimately bound up with a stigmatised social practice. As Riessman (2008) explains, "transforming lived experiences into language and constructing a story about it is not straightforward, but invariably mediated and regulated by controlling vocabularies" (p. 3). We argue that aspects of drug use in contemporary society (such as dependence and treatment) attract "near universal stigma and discrimination" (Room, 2005, p. 144), with those involved often "intimately alive" to what others may see as their moral failing (Goffman, 1963/1973, p. 17). We suggest that when research participants such as Jimmy, with extensive histories of injecting drug use, drug treatment and incarceration, are recruited on the basis of that history, the process of

life-story telling presents particular challenges. Prefigured in such a manner, participants like Jimmy are effectively required to negotiate the stigma that has been invited to take centre stage in the research. Struggles over narration therefore become struggles over identity (Somers, 1994).

Here the work of philosopher Miranda Fricker (2007) is illuminating. Fricker develops the notion of what she terms “epistemic injustice”: a wrong done to someone specifically in their capacity as a knower. Fricker posits two forms of epistemic injustice: “testimonial injustice” and “hermeneutic injustice.” The former describes a form of injustice that takes place when social prejudice undermines the level of credibility ascribed to certain speakers; the latter occurs at a prior stage, when a gap in collective interpretive resources puts someone at an unfair advantage when it comes to making sense of their social experience. Given the value we accord our capacity to know and to share knowledge — as integral not only to our status as rational beings but as human beings — epistemic injustice has clear implications for our understanding of social injustice more broadly. As Fricker explains, it carries a symbolic power that adds its own layer of harm, a social meaning to the effect that the subject is less than fully human: a dehumanising meaning. Elsewhere we have taken up Fricker’s notion of epistemic injustice to illustrate the damaging and dehumanising effects testimonial injustice can have for clients of drug-treatment services (Rance, Newland, Hopwood, & Treloar, 2012; Rance & Treloar, 2015). Here, we are particularly interested in Fricker’s notion of hermeneutic injustice.

Unequal relations of power, Fricker (2007) posits, tend to skew our collective hermeneutical resources, such that the “powerful tend to have appropriate understandings of their experiences ready to draw on” (p. 148). On the contrary, “the powerless are more likely to find themselves having some social experiences through a glass darkly, with at best ill-fitting meanings to draw on in the effort to render them intelligible” (p. 148). Fricker uses the term “hermeneutically marginalised” to describe those who are disadvantaged by their unequal participation in the social practices through which meanings are generated. It is the presence of hermeneutical marginalisation that serves as the background condition for what Fricker calls hermeneutical injustice: “the injustice of having some significant area of one’s social experience obscured from collective understanding owing to hermeneutic marginalisation” (p. 158). Fundamentally, Fricker argues, hermeneutical injustice is a kind of “structural discrimination” founded on social-identity prejudice: “a lacuna generated by a structural identity prejudice in the hermeneutical repertoire” (p. 168). Hermeneutical injustice occurs when “a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (p. 1). Not only are such experiences left “inadequately conceptualised and so ill-understood, perhaps even by the subjects themselves” (p. 6) but so too are the hermeneutically marginalised further disadvantaged by their resulting exclusion from participating in the public spread of knowledge (p. 162).

Before turning to our analysis, we wanted to provide some context for Jimmy’s story, drawing on both his own words and a brief biography constructed from his interview narrative. Consequently, we begin the next section with an extract taken from early in Jimmy’s first interview,

where he reflects upon the violence and the unhappiness characterising his childhood experiences of family and school. Following this extract is a brief biography. It is important to note that the details we have included in this biography reflect what we as a writing team believe to be important to the reader, rather than what Jimmy himself may have chosen to emphasise.

CONTEXT

Jimmy's first interview: an extract

Interviewer (I): *Okay, and do you want to tell me a bit about your childhood years and anything that stands out for you?*

Jimmy (J): *[Pause] I used to get bashed a lot but that was about it, that's the only thing that really, like I don't seem to remember anything that was happy. I just remember being hit a lot.*

I: *Oh okay so*

J: *You know for little things, either smoking a cigarette or pinching \$2 or the normal things that a child does sort of thing. But yeah the worst thing was playing video games, my mum hated video games and I was pinching money to always go play the video games, and yeah so that was the main thing ... that was the main thing I got hit for was playing video games.*

I: *And when, how old were you about then?*

J: *About 10 I think, I'm not sure.*

I: *So [pause] so from how old do you remember getting, getting hit by your parents?*

J: *Dad wasn't ever, dad wasn't there. [Pause] There was a little yellow spelling book, that's what it start ... yeah, I don't think I ever got hit until this spelling book come up because I can't read and write properly, and I remember mum having little yellow spelling book and I used to get 'an', 'a', 'n' and 'and' wrong all the time, same with 'day', 'daye' and all them*

words wrong, and I used to get belted like no tomorrow. The school sent me home one day, yeah S Public School sent me home one day. I remember that, I remember going home from school 'cause I couldn't sit down. So I was sent home.

I: Because you, you couldn't sit down because you'd been belted so badly? And did the school do nothing too?

J: I didn't say anything to them, I don't remember saying, I might have I ... I'm not sure. I don't know, I was in the sick bay for like nearly the whole day or something until they sent me home, until mum got home from work, I mean she picked me up and took me home so yeah, I was laying on my belly the whole time, I remember that too.

I: So how old were you about then, with the spelling book do you reckon?

J: I think that was in Year 6 I think that that happened, I would have been 11 'cause I know I was 12, hang on [pause] I was 14 in Year 10. I was the youngest in Year 10, so I, I might have been, I'm not sure, Year 9 [pause] so four years, 10, yeah I was 10 years old.

I: So your parents were separated?

J: From ... I don't

I: Were they?

J: I can't remember when they separated, like I just know that they were separated since I can remember.

Jimmy's story: a brief biography

Thirty-two years old at the time of the interviews, Jimmy grew up in a working-class suburb of Sydney. Jimmy's parents separated during his early childhood and he was raised in public housing by a mother who "belted [him] around a lot" — so badly on one occasion he was sent home from school because he was unable to sit down. Jimmy recalled "always being in trouble" and

was suspended from school on multiple occasions. At 13, he was “kicked out” of home by his mother and placed on a “restraining order” at her request. Jimmy reported being taken in by a group of Indigenous, street-based, inner-city residents — including an older woman he came to identify as a mother figure. Jimmy credits her with motivating him to continue his schooling despite living on the streets. Following his return home, Jimmy was expelled from school just prior to his 15th birthday and began working in a supermarket. At this point in the interview, Jimmy noted, “I [still] can’t read or write properly.”

By 15, Jimmy was regularly committing crime (“break and enters”), “smoking pot,” and “doing acid.” During a “sweet and peaceful” two-year spell interstate — “about the only time I wasn’t doing any crime” — Jimmy worked cleaning boats. He returned to Sydney after being “wrongly accused” by local police and instructed to leave the state. Not long after his return to Sydney, Jimmy was charged with a number of offences and incarcerated for several years. Just prior to his release, he smoked heroin for the first time. Over the next decade, Jimmy moved from smoking to injecting heroin, was sentenced to another lengthy period of incarceration, and had extended periods on methadone maintenance treatment.

Jimmy also recounted periods of respite from both Sydney and regular heroin use, during which he lived in regional townships and worked as a manual laborer. On one occasion, he reconciled and lived briefly with his estranged father and stepmother. Jimmy recounted three significant relationships with women but maintained that each had ultimately involved betrayal. He noted, “[I] don’t trust anybody.” Jimmy also disclosed three suicide attempts. At the time of the interview, Jimmy reported being on a “good behaviour bond” — a result of old legal charges catching up with him. He reported that in the year prior to interview, he had been involved in a motor vehicle accident and suffers some minor cognitive impairment as a result. In the absence of a professional carer, Jimmy was once again living with his mother, a nurse. He noted, “she still hits me every now and again but usually I deserve it.” No longer using heroin but on methadone maintenance treatment, Jimmy intended “full-heartedly” to get “stable” on his methadone before coming off treatment altogether. Only then, he believed, could he “start to get the actual normal life.”

FINDINGS AND DISCUSSION

The situated nature of risk

The research interview sets story parameters and asks informants to respond within these parameters (Presser, 2004). Jimmy was recruited on the basis of his history of injecting drug use. It was this aspect of his lived experience that prompted his recruitment and ultimately framed his engagement with the researcher. Driving the research project was a concern with notions of “risk” and “safety” conceived largely in epidemiological terms: with contracting or avoiding

the hepatitis C virus. What Jimmy's account evinces, however, is a determination to resist a risk-factor-orientated approach to prioritise talk about areas of his life he considers more meaningful, particularly those involving his relationships. Despite gentle and repeated attempts by the researcher to re-establish the parameters of the interview, Jimmy consistently pushes back, redirecting the conversation toward events that involved the significant people in his life. Jimmy's account of his childhood and early adolescence, for instance, is dominated by stories of family violence and parental abandonment. The physical abuse he describes receiving at the hands of his mother is troubling: "I used to get bashed a lot but that was about it ... I don't seem to remember anything that was happy. I just remember being hit a lot ... Dad wasn't there." He recounts being homeless and without resources at the age of 13.

Risk is embedded throughout Jimmy's narrative, even if it is not named as such. For Jimmy, however, risk concerns the social rather than the medical: it is situated outside the epidemiological framework underpinning the research. In Jimmy's account, risk is emotionally and socially constituted. The significant risks in his life have involved experiences of intimacy: the feelings of abandonment and betrayal associated with the people he has loved. Nonetheless, it is also intimacy that has, at other moments in his life, provided Jimmy with his most abiding experiences of safety, emotional and otherwise. His depictions of romantic partnership attest to this ambiguity. On one occasion, Jimmy describes a previous girlfriend: "At first she was a nice, sweet, innocent girl and then I found out the real truth ... she was the devil in bloody disguise." While on another, he gives voice to his fears about failing to attract a future life partner: "If I continue [using drugs] I'm going to lose my [looks]. I'll never have a chance of getting a girlfriend ... of being in love ... of emotional contact."

Jimmy's narrative is punctuated with calls for a "good woman in his life". Such a woman, he maintains, would provide a stabilising and positive influence in his life: "Behind every good man there's a good woman ... no matter what happens to him, she'll pick him up." Here again, Jimmy's account, with its emphasis on intimacy and human connection as potential emotional refuge, confounds a risk-factor-orientated approach. Despite his wish for a stabilising intimacy, Jimmy acknowledges that not only is his drug using "more intense" when in sexual relationships but that he never practises safe sex. His repeated desire to connect with lovers is prioritised above his adoption of safer injecting or safe sex practices. While in conventional epidemiological terms Jimmy's sexual partnerships would appear to be infused with drug and virus-related risk, for Jimmy, the need for human connection and the fear of living without it are prioritised.

After being "kicked out" of home by his mother, Jimmy experienced an extended period of homelessness. During this time, he developed a relationship with a woman he came to treat as an adopted or "street" mother. Mamma provided stability and routine for Jimmy and other young people in her informal care: "She made me go to school and all that." Jimmy felt nurtured and supported by Mamma: "She looked after me well, like you know, for somebody that's injecting." Here again intimacy enacts different and competing forms of risk and safety. Jimmy is recruited

into assisting Mamma to inject (a common practice among people with compromised venous access), putting him at risk of an accidental needle-stick injury and potential blood-borne virus infection. Yet, when framed within its social context, Jimmy's decision to forgo safer injecting practices for the sake of his protective bond with Mamma "makes sense" socially and emotionally. The affective or embodied knowledge of 13-year-old Jimmy constitutes a form of socially situated "rationality" that exceeds the limitations of biomedical and epidemiological knowledge. What could be characterised as a highly risky point in Jimmy's history — involving parental abandonment, homelessness and regular exposure to injecting-related risk — was also a time of emotional comfort, security and educational continuity.

Adolescence and adulthood posed multifarious risks for Jimmy: of potential trauma relating to family violence, of parental abandonment, a lack of safe and stable housing, irregular employment, imprisonment, exposure to unsafe drug injecting practices, and blood-borne viruses. Such a list highlights not only the layering of risk for Jimmy and many other vulnerable young people but the tensions which frequently exist between public health priorities and the experiences of marginalised, disadvantaged youth (Panter-Brick, 2002; Rickwood, 2011). While here such differences are primarily manifest between interviewer and respondent, they nonetheless represent broader discursive positions and agendas: of researcher and subject, of epidemiology and the drug user, and so forth. The complex network of forces, influences and priorities present in Jimmy's story challenges mainstream public health understandings of vulnerable young people, which all too often reduce complex individual lives into aggregations of atomised risk factors, leaving 'at-risk' young people to be potentially overlooked by a service matrix overly concerned with specialisation.

Retaining Jimmy's story in its entirety facilitates a better apprehension of the social context that serves to both enable and constrain his sense of agency, including his accounting of decisions made regarding risk and safety. A narrative approach allows us to capture not just the different, competing forms of risk in Jimmy's life but the shifting, sometimes contradictory positions he takes in relation to risk itself. Here, for example, Jimmy describes a decision to smoke heroin rather than risk contracting hepatitis C by injecting with unclean equipment: "It's too much to lose, just for that one fix ... Like that's your life"; yet later, he describes his reluctance to accept "Narcan," the opioid antagonist used to reverse heroin overdoses: "If you're on the drugs, well obviously you don't want to be saved ... I would tell them [paramedics], 'just let me die.'"

The meanings of mother

Jimmy's account of his relationship with his mother is a story in progress: emotionally fraught, often paradoxical and, in many senses, unresolved. The power of Jimmy's story lies less in its ability to be read as objective and verifiable accounts of actual events but rather, as Singer, Scott,

Wilson, Easton, and Weeks (2001) suggest, in its effectiveness in giving a meaningful voice to heartfelt and troubling sentiments and concerns. Even as Jimmy acknowledges his mother's violent and abusive behaviour — "Mum just had a lot of temper issues, so I used to get belted around a lot" — he attempts to normalise it, claiming that her violent abuse was "the only part that wasn't normal with my childhood ... [until] I was kicked out of home at 13." Even at the time of interview, Jimmy rationalises, "She still hits me ... but usually I deserve it when she does." Yet, Jimmy also attributes "keeping safe" from drug-related harm to his mother and her knowledge as a nurse: "A lot, a lot, a hell of a lot." He expresses distress as he remembers how his mother had cried "when she found out about the injecting drug use, but [nonetheless] taught me how to inject safely." He reflects upon the complexity of his relationship with a mother who beat him but is "probably responsible" for his HCV (and HIV)-negative serostatus: for "staying safe".

Jimmy explains in his first interview:

I used to take the drugs just to forget. Forget that I was ... a part of that family. I used to think that I was adopted. I thought there was no way I could have a mother that was like that.

Yet he also attributes his tendency to cry both before and after injecting to his mother: "I cry more because I feel like I'm hurting my mum as well ... that seems to be the one thing that seems to hurt me more than anything." Despite the violence and abandonment experienced in their relationship, Jimmy has maintained contact with his mother and was living with her at the time of his interviews. In his second interview, he describes the simultaneously positive and negative impact of their relationship on his sense of self and his history. Seemingly unable to disentangle himself from his deep affection for his mother, Jimmy expresses distress that "she didn't even know where I was living"; that she "can't talk about his lifestyle"; and, as noted above, that she still "hits me".

A tension around belonging and longing to belong plays out consistently throughout Jimmy's narrative. His desire to belong to "normality", to lead a "normal life," is a recurring and persistent theme: "I know I want a normal life ... the wife, the kids ... a family, the house, everything. I'd love to have it all." And yet he tells the interviewer: "Now look at me, 32 and I've got nothing ... I thought I had a better purpose than this." At times, Jimmy acknowledges his difficulties in accounting for his life — the challenges he faces in "getting the story out". At one point, Jimmy expresses dismay that he has "lost himself" — a "grown man living with his mother," unable to attract a "good woman". At another, he simply asks, "Why? Why am I the way I am?" Such moments of despair remind us of the way agency is forestalled as well as facilitated in the process of accounting — that suffering stretches human sense-making capacities beyond most other experiences (Gabriel, 2004). The poignancy of Jimmy's struggle to tell his story, to find himself in the telling, is captured here in a way that would risk being obscured by an aggregating methodology.

Jimmy's narrative suggests a life increasingly enmeshed with his mother's. He describes their respective "habits": "I don't use needles any more, I don't use any other drugs, I don't drink alcohol, or smoke cigarettes. My mum plays the poker machines, I smoke pot, I don't play the poker machines anymore, so." At times, Jimmy hints at the challenges he faces in managing a sense of self despite a profound lack of approval by his mother: "Her son was coming good again. I do remember her saying that to me once, before the [car] accident happened: *that I finally got my son back*". Jimmy also describes occasions when he has protested her violence, such as when he "hocked" (sold) some of his mother's jewellery:

I remember begging her not to hit me ... I wanted to teach her a lesson basically. Like help your son out for a change instead of fucking making him do the wrong things. Like, you've got the money.

As Jimmy wrestles to make sense of it, his account of his mother and their relationship is inconsistent, equivocal, sometimes paradoxical. In a narrative sense, she embodies precisely the counterpoising forms of risk and its management we have been discussing: her nursing 'know-how' has kept Jimmy safe in a virological sense, yet her physical and emotional violence has presented Jimmy with a multitude of risks, from educational disruption to homelessness. On only one occasion does Jimmy ask, "Why is mum the way she is?"

Identity work

An interview is a point at which order is deliberately put under stress (Dingwall, 1997). In soliciting life histories from participants, we, as researchers, are enjoining them to account for their lives and themselves, to find, shape and re-present themselves. In this sense, the interview can be understood as a practice of self-formation, a moment in identity work wherein personal narratives present, perform and negotiate a self or an identity in relation to a situated context of meaning (Rhodes, Bernays, & Houmoller, 2010). Indeed, Jimmy's transcript is punctuated with unprompted and unsolicited identity claims: "I'm not a normal criminal"; "I'm a petty criminal"; "I'm a trustworthy bloke"; "I'm a good worker"; "I have a gut instinct about people"; "I'm nearly forty ... I want what everyone wants"; and "I'm an Aquarian, like nothing seems to faze me."

Nonetheless, Jimmy's inclusion in the research study ultimately rested on his identification as someone who injects drugs — as someone "at risk" of a blood-borne virus, not, for example, "a survivor" of family violence. Thus far, we have argued that Jimmy negotiates, even resists, this potentially shaming frame by presenting his life in ways that prioritise *his* concerns, typically those encompassing his social rather than his injecting history. We have identified the socially and relationally situated accounts or 'rationalities' that have informed the ways in which Jimmy

has made sense of and managed 'risk', noting in turn how little viral infection has appeared to matter relative to other more fundamental or pressing concerns, such as housing, social connection, intimacy and maternal approval. While we have posited that Jimmy creates storylines out of those areas of his life he finds most meaningful, we also need to recognise that at times (and for various reasons) Jimmy may simply have found these storylines more accessible or more available to him. Either way, we note that at the beginning of the second transcript, there is a postscript from the interviewer noting that the interview had gone "way off track" as Jimmy was "keen to talk about other things".

Inevitably, however, there are times during Jimmy's interviews when his identity as a "drug user" is foregrounded; when he is discursively positioned as such. It is on these occasions when Jimmy is required to speak from such a position that his stigmatised identity as a drug user takes centre stage, assuming what Lloyd (2013) refers to as a "master status." Elsewhere, we have written about the limited and limiting repertoire of socially available and invariably stigmatising interpretations of the "drug user" (Rance et al., 2012, p. 249). Here too Jimmy's master status as a drug user threatens to crowd out or discredit alternative, potentially legitimating storylines and identity conclusions, obscuring the possibility that other meanings can even exist (Winslade, 2005). At such times, Jimmy finds himself "hermeneutically marginalised", unable to interpret or make sense of his life, other than, as Fricker suggests, "through a glass darkly." He is left with gaps or *lacunas* in his interpretive resources, or at best, "ill-fitting meanings to draw on in the effort to render [his experience] intelligible" (Fricker, 2007, p. 148). During such moments, the nuance and complexity found elsewhere in Jimmy's account are obscured, flattened out.

At the beginning of the second interview, a particularly poignant exchange takes place. During the first interview, Jimmy and the researcher had worked together on constructing a timeline of the Jimmy's life, with the researcher subsequently creating a computer-generated, graphic representation of these details. In line with Staying Safe methodology, the second interview began with the researcher sharing the timeline with Jimmy. In response, Jimmy expressed considerable distress. It made him feel, he explained, "Like a piece of shit ... It hurts to see it ... you realise you've made a lot more than one bloody mistake." When asked by the researcher, "What are the mistakes that you can see? What do you think?" Jimmy simply replies, "The drugs. The drugs are where everything went wrong early." Here, Jimmy is confronted, overwhelmed even, with the timeline's stark, visual rendering of his life and how it might have departed from what he had wanted for it. While ultimately we can only speculate, it is possible that in this moment Jimmy sees himself as he believes others do: as falling short of who he really ought to be. And in this atmosphere of heightened affect (of shame and personal failure), he struggles to find words that might tell another, less punitive story. For if, as we have posited, narratives are social products, *interpretive devices*, that circulate culturally to provide a repertoire from which people can make sense of and narrate their own lives, then Jimmy's narrative is, at this moment, profoundly constrained by the limited range of potential storylines. Here the metonym of 'the junkie' serves a hegemonic function by which

“other meanings, and by elaboration, identity positions, are thus systematically excluded by processes of social legitimation and authorisation” (Winslade, 2005, p. 354).

For Jimmy, part of the shame and the self-loathing of this moment concerns the extended time he has spent on methadone treatment. Again, the gap in our “collective interpretive resources” leaves Jimmy at an unfair disadvantage when it comes to making sense of this aspect of his social experience. The pervasive, stigmatising figure of ‘the junkie’ has, by association, come to taint the treatment regime itself: “further fixing”, as Radcliffe and Stevens (2008) put it, “drug users’ discredited identities, rather than creating opportunities for them to live different lives” (p. 1067). Thus, for Jimmy, the identity-spoiling reputation of methadone treatment obscures the possibility of alternative accounts or “counter-stories” (Lindemann Nelson, 2001) — one which might, for example, celebrate his considerable achievement in successfully negotiating the highly regulated, and at times punitive, nature of methadone treatment (Fraser & valentine, 2008; J. Harris & McElrath, 2012). Rather than providing Jimmy with the interpretive resources which might enable him to *story* methadone as part of a longstanding determination to move away from injecting drug use and the crime associated with it — to understand methadone as part of a story of survival — Jimmy’s identity, his discursive position, as a *drug user*, a *junkie*, obscures these other meanings. Instead, Jimmy insists, methadone treatment has been a “pansy’s way out”.

This exchange involving Jimmy’s timeline highlights the essentially collaborative, co-constructed nature of the research interview: its “joint accomplishment” (Dingwall, 1997). As none of the authors were present during Jimmy’s interview, we can only speculate on the nature of the encounter. Nonetheless, we do know that the researcher involved had extensive experience and expertise in conducting qualitative interviews, and indeed verbal cues from Jimmy suggest a considerable level of trust and rapport had been established. We also know that Staying Safe interviews were conducted in a local park or in a quiet section of the nearby library; both sites likely to be well known to participants and as such to contribute to a relaxed atmosphere. Nonetheless, Jimmy was a participant in a study that necessarily kept drawing him into discussions where, as Goffman (1963/1973) puts it, shame remained a “central possibility” (p. 18). Jimmy’s identity as a drug user was graphically captured in his timeline, foregrounded in a way that, as Jimmy himself puts, “it hurts to see it”. His distress — in response to what was doubtless intended as a benign request to check the accuracy of his timeline — reminds us of the complex ethical responsibilities, and the unintended consequences, which can confront the researchers, and the researched, while engaging in work on life-course narratives (Harris, 2015). The research interview can be, as Bourdieu (in McKendy, 2006) recognised, an exceptional opportunity for the most disadvantaged to testify, to make themselves be heard. Indeed, as we have noted with Jimmy, “It even happens that, far from being simple instruments in the hands of the investigator, the respondents take over the interview themselves” (Bourdieu in McKendy, 2006, p. 497). Yet precisely because of its potency — the power of both telling *and* listening — the qualitative research interview also holds the potential to unsettle, to challenge, even to shame, both respondent and researcher.

CONCLUSION

In this chapter, we have argued that while 'personal' storytelling is indeed a valuable form of knowledge production (Lau & van Niekerk, 2011), it is nevertheless a sociocultural practice that can never completely escape the broader politics of meaning-making. We have argued that for those whose lived experience and identities are intimately bound up with a socially stigmatised practice, such as injecting drug use, the telling — the *making* — of one's story presents additional complications. Miranda Fricker's work on epistemic injustice similarly underscores the critical value of people accounting for themselves, particularly those with histories of social disadvantage and exclusion. Importantly, however, it also elucidates the particular challenges inherent in such an undertaking.

Here our argument is illuminated by reading Fricker alongside some of the critical insights regarding language and subjectivity posited by post-structuralist theory (e.g., Lupton, 1997; Ramazanoglu, 1993) and taken up in recent narrative-based work (e.g., Winslade, 2005; Wolgemuth, 2014). In this conceptualisation, human identity is located and "produced" in discourse, as multiple, relational, and contextual, rather than static, stable and immanent. In this conception, the self is inevitably fragmented, contradictory and often fraught with ambivalence, irrationality and conflict (Lupton, 1997). This understanding of identity, of the self, as always in a process of creation (Winslade, 2005), enables us to conceive that during the course of a conversation (or an interview), a speaker might occupy a number of different subject or discursive positions. Different positions which can, in turn, permit greater or lesser discursive possibilities: a process of social constraint as well as production. Consequently, we can now appreciate how a person's access to interpretive resources might differ not only, as Fricker argues, from one social context to another depending upon which aspect of their identity is to the fore but also from one discursive position to another within the one interview. For Jimmy, resisting his identity as a drug user required taking up, or being invited to take up, alternative discursive positions — as confused son, aggrieved lover, hard worker and so forth — which in turn fostered alternative interpretive resources and storylines.

McKendy (2006) proposes, "Developing new understandings of past actions depends upon the person being afforded new positionings in the here-and-now, ones that give him a chance to stray beyond 'the same old story,' to overhear himself saying some surprising things" (p. 498). For Jimmy, the research experience was an ambiguous one. The life-history interviews afforded him a rare and valuable opportunity to be heard — to be listened to patiently by someone in an open-ended and considerate fashion. It is perhaps not surprising that Jimmy found an epidemiological framing of his existence an othering and objectifying one. It also makes equally good sense that social risk would be far more likely to resonate with Jimmy's lived experience, thus making this frame more coherent for him. Here, we might interpret Jimmy's attempts to resist a public health framing by moving the interview toward more meaningful or available discursive territory as symbolising a more general movement from reduction to wholeness: from a dehumanising to a humanising discourse.

The interviews presented Jimmy with the possibility of *re*-storying his life and *re*-negotiating his relationship with himself and others — precious moments of identity work. Nonetheless, in enjoining Jimmy to account for himself as someone with a history of injecting drug use, the research agenda required him to engage with a potentially shaming frame, to speak from the position of “drug user”. It was during the latter that we noted evidence of gaps or lacunas in Jimmy’s hermeneutic resources as he struggled with the master status of ‘drug user’, its hegemony threatening to crowd out or discredit alternative, potentially legitimating storylines and identity conclusions. Yet, we also witnessed moments in Jimmy’s narrative when he took up more resistive forms of subjectivity (Wolgemuth, 2014), often when emphasising his *social* rather than his *drug-using* history. We speculated that Jimmy resisted a risk-factor-orientated approach to prioritise talk about those areas of his life he considered either more meaningful or simply more available, particularly those involving his relationships.

Jimmy’s contribution would undoubtedly have been invaluable in the writing of this chapter. His absence from our process — along with our absence from his interview — has made for a different sort of analysis. We have, for instance, been unable to comment at any length about the embodied or affective aspects of the interview process (Ezzy, 2010; M. Harris, 2015). Instead, beyond some speculation in this area, we have kept to the spoken word of the transcript. In drawing attention to the important phenomena of discursive disadvantage in the context of social stigma — which, following Fricker, we have referred to as hermeneutic injustice — we run the risk of being accused of speaking for others and thereby potentially reproducing the very sort of injustice we have set out to critique. This has clearly not been our intention.

In this chapter, we have highlighted forms of discursive inequity we believe deserve our collective attention alongside other, perhaps more obvious, forms of social injustice. Narrative analysis, we have argued, attempts to honor the challenges and the complexities of the accounting work evident in interviews such as Jimmy’s, providing a valuable counterpoint to other qualitative approaches. Not only does such an approach foreground the shifting, non-unitary nature of the self in ways too easily overlooked or disregarded when working with aggregated sets of data, but it does so in ways well suited to helping us better understand the complexity of the lives we work with, especially in the context of stigma and disadvantage.

For health researchers such as ourselves who regularly work with marginalised and stigmatised populations, our argument underscores the ethics or “duties” of intersubjectivity (Charon, 2004). It reminds us not only of the power of telling and listening but also of the complexities, the challenges and the potential injustices involved in the process. In the face of the vulnerability and trust so often granted us by participants, we need to recognise not only our role in the making of people’s stories but our responsibility in the interpreting of them.

CHAPTER 9

Conclusion

The genesis for this work lies in the years I spent as the senior drug and alcohol counsellor for the Medically Supervised Injecting Centre (MSIC), in Sydney's Kings Cross. As the symbolic face and epidemiological epicentre of Australian drug dealing and using, Kings Cross had been the logical site for a trial of the nation's first and only safer injecting facility (van Beek, 2004). Following its controversial inception in May 2001, the MSIC was subject to a comprehensive, decade-long evaluation process that ranged from independent surveys assessing levels of community and business support, to systematic reviews of crime rates in the local area, to assessments of public health impact, including epidemiological and economic cost-benefit analyses (MSIC Evaluation Committee, 2003; NCHECR, 2007a, 2007b). What was almost completely absent throughout this entire process, however, were the voices, the subjectivities, of those whose attendance lay at the very heart of the service: the service users themselves¹. And yet it was the collective experience of service users which constituted the qualitative ground upon which the metrics of success or failure were realised. The achievement of the MSIC's primary public health aims — of injecting 'episodes' supervised, overdoses managed, refer-

1 As noted in chapter two, despite the inclusion of some service-user surveys and staff focus groups, quantitative approaches and methodological debates have consistently dominated the literature regarding safer injecting facilities worldwide, including the Sydney MSIC.

rals to drug treatment enacted and so forth — was only possible in the context of a service culture able to both attract and retain those considered ‘at risk.’

Nonetheless, what concerned me most regarding the epistemological limitations of the evaluation process was its inability to comprehend, to see, the remarkable stories of unanticipated transformation unfolding among service users and often given expression to in the pages of the client comment books. What was for me the defining phenomenon of the service — that which I came to refer to as “accidental intimacy” (Rance & Fraser, 2011) — was rendered paradigmatically invisible within the positivist methodology of the evaluation process. And along with that invisibility, any recognition of the MSIC’s potential to challenge, ameliorate, even transform, the experiences of stigma and shame felt so deeply by so many who used the service. Ironically, despite the all-too-public nature of the MSIC and its obvious symbolic potency in the public imaginary, those who used the service remained to all intents and purposes a “marginalised and silenced population” (Mosack, Abbott, Singer, Weeks, & Rohena, 2005, p. 603). And while the MSIC may be unique in the context of Australian public health provision and the lives of those who attend the service, the routine marginalisation of the voices of people who inject drugs — and of qualitative research approaches — is a familiar one.

In this final chapter I reflect on the politics of knowledge production in the illicit drugs and addictions field. Recognising the inevitable nexus between knowledge and power, I argue that the peripheral place qualitative research methods occupy relative to the longstanding dominance of positivist approaches is not a simply an issue confined to the world of scholarly research, but one with direct implications for the broader social world. How drug use is understood or *constructed* within different knowledges has real-world ramifications for the people who use them. While my approach is a critical one, my intention is not to dispute the veracity or otherwise of particular scientific discourses, nor to diminish some of the invaluable contributions disciplines such as epidemiology have made to the field of illicit drug use. Rather, I question the effect on knowledge production and identity formation within the illicit drugs and addictions field when certain ways of knowing and certain kinds of (‘rational’ and ‘objective’) voices are valorised to the exclusion of others, and power becomes entrenched within particular epistemological frameworks². For as Foucault puts it: “What types of knowledge are you trying to disqualify when you say that you are a science? What speaking subject ... what subject of experience and knowledge are you trying to minorize ...?” (2003, p. 10; see also, Lancaster, Seear, Treloar, & Ritter, 2017)

It is, of course, as I noted in chapter two, both ironic and deeply frustrating that the critical tools of qualitative research often best suited to accessing and potentially ameliorating experiences of marginalisation are themselves chronically marginalised. In an editorial published in the *International Journal of Drug Policy*, Rhodes et al. (2010) reconfirmed earlier findings by conducting a ‘snapshot’ survey that starkly revealed the minority status of qualitative publications within the

2 As social anthropologist Bourgois (2002, p. 267) posits, “In the field of public health, epidemiologists hold the institutional power and set the agenda.”

illicit drugs and addictions field. The authors found that of all the publications appearing in the top-eight ranked social science 'addictions' journals of 2009, just 7% had employed qualitative methods. Addictions research, the authors conclude, is dominated by biomedical and psychological approaches. Despite its rich heritage, the social science of addiction, and qualitative research in particular, remains a "*peripheral voice*" in addictions publishing (Rhodes et al., 2010, p. 443). Not simply contained within the output of academic publications, this marginalisation has particular "*effects in the real*" (Foucault cited in Bacchi, 2012, p. 150) for those people whose identities have been accounted for and frequently subordinated by the prevailing hierarchy of knowledge.

Epidemiology, for example, the cornerstone of public health, has played a key role in actively shaping how 'affected' and 'at-risk' populations have come to be *known* and *acted upon* within the prevention and education efforts of public health (e.g., Bourgois, 1999; 2002; Maher, 2002; Moore, 2004; Persson, 2013; Rhodes, 1997; Schiller, 1992)³. While concerned with mapping 'risk' at a population level⁴, epidemiology's "narrative of risk" (Kippax & Race, 2003) has functioned to individually *responsibilise* members of 'at risk' categories (such as people who inject drugs). Public health promotion and prevention efforts invariably represent risk-related decision making as a matter of individual agency and responsibility (e.g., Fraser, Rance, & Treloar, 2015; Fraser, Treloar, Bryant, & Rhodes, 2014)⁵. More broadly, the hegemony of biomedical and psychological models of illicit drug use and dependence have similarly tended to privilege individualistic explanations of human behaviour while neglecting the social, cultural and structural influences that shape human relations and experiences (Fraser, 2013; Seear et al., 2012; Simmons & Singer, 2006). As Bryant et al. (2017) argue:

[B]ecause public health research often uses positivist methods, and because it tends ultimately to rely on biomedically-informed concepts of human behaviour or action, public health studies typically reproduce individualised and often pathologising understandings of drug use.

(para. 14)

Despite the longstanding pre-eminence of positivist approaches within illicit drugs and addictions research (Fraser & Moore, 2011; Rhodes et al., 2010), qualitative studies have been making valuable contributions to the field since the 1920s (Neale, Allen, & Coombes, 2005). The last few decades in particular have witnessed a flourishing of innovative scholarship that has sought to

3 In relation to the role played by epidemiology in early HIV/AIDS education and prevention efforts, social anthropologist Schiller (1992) provides a powerful critique of the hegemonic processes by which 'at risk' populations were constructed for epidemiological analysis. She highlights the unhelpful and stigmatising tendency of epidemiologically orientated researchers to equate injecting drug use with minority populations and the construction of "Hispanic" as a population "at risk for AIDS".

4 Such as the distribution and possible determinants of viral risks (e.g. Morris et al., 2014; Strathdee et al., 2010) and the broad patterns of injecting-related risk practice (e.g. De et al., 2009; Unger et al., 2006).

5 Fraser and colleagues (2015) refer to this as the "individualising tendency" of risk-factor-oriented epidemiology.

make sense of the empirical via often complex and challenging social theory. Notwithstanding some important conceptual differences, much of this work has shared a broadly 'social constructionist' approach to understanding illicit drug use and addiction, including addiction science. Broadly characterised by its "commitment to illuminating how power, context and objectification shape knowledge", social constructionism emphasises the historical, contextual and discursively contingent nature of reality (Rhodes et al., 2010, p. 442). Foucauldian scholarship in particular, alongside post-structuralist approaches more broadly, have been enduring influences in illicit drugs and addictions scholarship since the late twentieth century (e.g., Keane, 2002, 2009). Influenced by Foucault, the conceptual insights of scholars such as Judith Butler and Nikolas Rose, particularly with regards power relations and subject formation, have in turn inspired valuable contributions from critical drugs researchers (e.g., Fraser & Seear, 2011; Race, 2011).

More recently, the field has witnessed an exciting, burgeoning body of work that has been variously characterised as the "ontological" and the "new materialist" turn (Deleuze & Guattari, 1987; Dennis & Farrugia, 2017; Latour, 2005). While sharing many key conceptual tenets with social constructionism, this latest body of critical scholarship also heralds some distinct epistemological and methodological departures⁶. Here social realities are continually made and remade — *enacted* — within relations or networks of agents or "actants", both human *and* non-human (Latour, 2005). Here too, much emphasis is given to the role research methods play in not simply describing social realities but actively creating or enacting them (Law, 2004). Key influences within this 'turn' include Science and Technology Studies scholars Bruno Latour (e.g. Gomart, 2004), Annemarie Mol and John Law (e.g. Fraser & Seear, 2011); feminist technoscientist Karen Barad (e.g. Fraser & valentine, 2008); and French philosopher and psychoanalyst team Gilles Deleuze and Felix Guattari (e.g. Duff, 2014; Malins, 2017).

Whether inspired by the work of Foucault or Mol, what underpins this eclectic, conceptually driven body of critical drugs and addictions scholarship has been (and continues to be) a commitment to producing qualitative work that constructs (or indeed, enacts) new ways of understanding and seeing the social world in all its complexity. Throughout my thesis I too have drawn on social theory to elucidate the possibilities and the potential of my empirical material. In my opening empirical chapter (two), I argued for the analytical inclusion of the MSIC client comment books by drawing on the methodological potential of post-structural theory to challenge positivist claims of what constitutes 'proper', objectively verifiable research. I employed Ahmed's (2004) work on the sociality of emotions, alongside my own notion of accidental intimacy, to elucidate and substantiate the experiences of transformation documented by clients in the comment books.

6 While attempting to explain these complex differences lies outside the purview of my conclusion, it is important to note that such differences are by no means settled nor self-evident. While, for example, the new materialists (as their name suggests) claim to be "retrieving materiality" (Fraser & Moore, 2011) from social constructionism's over-emphasis on the role of discourse, Bacchi's Foucauldian-inspired post-structuralism makes a strong case for a thoroughly materialist understanding of the notion of discourse (see for example, Bacchi & Goodwin, 2016).

In the following chapter I drew on Foucault's (1991) work on "social space", Parker and Aggleton (2003) on the "political economy of stigmatisation", Takahashi (1997) on "socio-spatial stigmatization", and Fricker (2007) on "epistemic injustice", to develop the concepts of stigmatisation, social space, identity and discourse I introduced in the previous chapter. This time, however, my empirical focus was interviews with staff and service users of opioid substitution therapy clinics. It became clear to me that, just as discredited or tainted identities could be transformed through a shift in the play of relations between stigma, place, identity and discourse, so too could they be *consolidated*. The following two chapters (four and five) again explored the empirical and conceptual nuances and possibilities manifest within this set of relations. Drawing on Fox's (1995) notion of "care as gift" and Mol's (2008) on the "logic of care", both chapters examined accounts of identity and relational transformation noted in participant interviews. In both instances, the introduction of new forms of engagement and interaction (as either treatment modality or consumer participation initiative) created new relations of care, and in turn, new experiences of staff and service-user relations and (among service users) new experiences of self and identity.

Chapters six and seven were grounded in the accounts of couples who inject drugs. Here the concepts of 'negotiated safety' and 'alternative rationalities' were introduced via the intimate and social spaces of lived partnership. I endeavoured to make sense of couples' injecting practices and accounts of risk and safety (viral and otherwise) as participants themselves did, typically framed within a social context of isolation, stigma and hostility. Counterpoised against the 'expert knowledges' of epidemiology and health promotion, the couples' situated 'rationalities' invariably privileged the maintenance of their relationship over concerns regarding viral risk. In my final empirical chapter (eight), I returned to Fricker (2007) and to an examination of her notion of "hermeneutic injustice". I wanted to reflect on the practice of the research interview itself. Throughout my thesis I had always been fundamentally guided by what participants said, not by what *might* have been said. However, my final empirical chapter signalled a methodological departure. By problematising the interview process itself, by framing storytelling as a sociocultural practice necessarily affected by its relationship to stigma, I took the risk of being accused of speaking for others: of committing the very injustice I had set out to critique. What I hope, however, is that my final empirical chapter evinced the sort of empirical and theoretical synthesis I had been working to achieve throughout my thesis: one of participant testimony illuminated via conceptual exposition.

Despite the critical tenor of this chapter, this thesis has not been about comparing qualitative methods with quantitative, or indeed championing the superiority of one over the other. While I have focused on demonstrating and exploring the possibilities of qualitative research within the field of illicit drugs and addictions, I have also endeavoured to consistently reflect on the limitations of its methods. Within particular chapters I have noted those instances when study design or approach may have had unintended but important consequences. With regards to couples who inject drugs (chapters six and seven), for example, the voluntary and self-selected nature of recruitment necessitated a level of mutual decision-making and cooperation which may have

reduced the likelihood of making contact with couples whose relationships were affected by issues of inter-partner violence and abuse.

More broadly, qualitative research tends to sacrifice the generalisability of its findings for the depth and richness of contextualised data; an approach typically grounded in empirical particularities (Ezzy, 2002; Patton, 2002). While, for example, in-depth interviewing may be well suited to capturing the subtle shifts in interpersonal dynamics and expressions of subjectivity found in the narratives of service users (and providers) within opioid substitution clinics (chapters three, four and five), it will not help us situate such findings within a nationwide snapshot of opioid substitution recipients (indicating average treatment duration, hepatitis C prevalence and so forth). Or, to use the couples study for another example: while a qualitative approach may enable us to identify some of the contextual and relational complexities beyond the gender norms and stereotypes reproduced (at times) within epidemiological studies (Fraser, 2013), such an approach offers us little regarding the broader patterns of gendered injecting risk (such as the greater likelihood of women using a needle-syringe *after* their male partner when injecting equipment is shared, or of being introduced to injecting by a male partner)⁷.

Given its centrality to my work, I now want to briefly reflect on how we might best understand or characterise the forms of participant knowledge realised in this thesis. Here I turn to a concept that has been taken up productively in recent health and drug-related scholarship: that of the 'counterpublic.' The concept of "subaltern counterpublics" was first coined by Fraser (1990) to describe the alternative spheres or 'publics' of subordinated social groups, such as women, peoples of colour, and workers. Fraser employed the term to underscore the relationship and background of marginalisation and disadvantage relative to the public sphere. The term counterpublic has since developed "to characterise responses to the marginalisation of contributions by members of subordinated groups, both in everyday contexts and in official public spheres" (Bell & Aggleton, 2012, p. 386). While publics and counterpublics are both arenas of discursive circulation in which subjectivities are formed, in the case of a counterpublic, the members maintain some awareness of their subordinate status (Race, 2009, p. 159). Warner's (2002) influential, post-structuralist adaptation of the term examines how publics (their audiences and normative characteristics), rather than simply being addressed, are actually *made* and *remade* through public discourse. Warner's argument has subsequently been adopted by critical drugs scholars (e.g., Duff & Moore, 2015; Fraser, valentine, & Seear, 2016) to contend that public health discourse

7 While a more detailed discussion lies outside the focus of this conclusion, the merits of strategic collaborations between qualitative and quantitative research are clear. While remaining outspoken regarding what he perceives to be the epistemological shortcomings of epidemiology, social anthropologist Philippe Bourgois (2002) has, among others, argued cogently for "the great deal" both approaches have to offer one another. Citing his own involvement in a mixed-methods study concerning gender power relations and hepatitis C seroconversion in San Francisco, Bourgois (2002, p. 265) notes that while "gendered power dynamics are too complicated to reduce to discrete linear variables," it was nonetheless through his collaboration with an epidemiological research team that they were able to demonstrate a two-fold increase in hepatitis C seroincidence among the (young) female participants in their cohort study relative to their male counterparts. In other words, while the historically and socioculturally embedded complexities of gendered power relations were best explored via qualitative approaches, the stark manifestation of such relations in blood-borne virus terms were laid bare through epidemiological means.

enacts a public rather than responds to the needs of an existing population. Here the notion of counterpublic health acknowledges, rather than disregards or stigmatises, the everyday health needs and aspirations of socially subordinated citizens whose norms of embodied practice (such as injecting drug use) contradict the normative assumptions governing public health principles (Bell & Aggleton, 2012). As Duff and Moore (2015, pp. 61–62) explain, “Far from according closely with normative ideals, counterpublic health is forever sensitive to the ways health is lived or realised in the context of endemic social, economic and personal disadvantage”.

Importantly, the concept of counterpublic health is not counter ‘public health’ as such (Race, 2009), but rather counter the notion that experiences of social disadvantage necessarily mean the absence or rejection of health (Duff & Moore, 2015). Counterpublic health acknowledges the real differences that public health discourses and services make in the lives of (counterpublic) communities, whilst also creating space for the recognition and inclusion of lay knowledges and experiences of health (Duff & Moore, 2015). It endeavours to make sense of notions such as ‘risk’ and ‘safety’ in ways that those directly affected do, and thus to take seriously the alternative or situated ‘rationalities’ that account for practices that appear ‘non-compliant’ in the face of normative public health expectations. From its very conception (Fraser, 1990) counterpublics recognised the complexities, the discursive inequities and epistemic injustices (Fricker, 2007) frequently faced by members of subordinated groups; the recognition that sometimes those who are marginalised may struggle to find the right voice or the right words, and that even when they do, they still face the risk of not being heard (Fraser, 1990).

Palestinian American academic and activist Edward Said (2002, p. 153) once suggested that we “must remember more seriously what Foucault himself teaches ... [that] it is sometimes of paramount importance not so much *what* is said, but *who* speaks”. This seems particularly apposite when, as qualitative researchers, we routinely work with people whose lives have been characterised not only by experiences of social marginality and exclusion, but more prosaically, by an enduring sense of a world that is indifferent. If, as this thesis has consistently argued, to be heard is central to our sense of humanness, our sense of self, then we should not underestimate the possibilities and the meaning the research interview holds for such participants. As Bourdieu (1996) observed:

... certain respondents, especially the most disadvantaged, seem to grasp this situation [the interview] as an exceptional opportunity offered to them to testify, to make themselves heard, to carry their experience over from the private to the public sphere; an opportunity also to explain themselves in the fullest sense of the term, that is, to construct their own point of view both about themselves and about the world and to bring into the open the point within this world from which they see themselves and the world, become comprehensible, and justified, not least for themselves.

(p. 615)

Although, as I argued in the last chapter, the telling of one's story is a complicated matter, the testimony of participants must nonetheless remain central to the practice and ethos of the qualitative approach. We must ensure that the voices of people who inject drugs continue to be heard and their stories told. Not so that such accounts can be naively valorised nor taken as transparent renderings of experience, but because it is only through critically engaging with such knowledges that the identities and the politics of injecting drug use can continue to be challenged, contested and remade.

At a service, programmatic and policy level, failing to acknowledge and work with the accounts, knowledges and practices of people who inject drugs will continue to limit the scope and impact of public health interventions, including blood-borne virus prevention and education. Such an acknowledgment needs to include a reconceptualisation and redistribution of questions of responsibility regarding the health of those who inject drugs: *away from* our current focus on 'the individual' and *towards* the inclusion of social structures and public institutions. The ongoing emphasis on individual choice and behaviour within biomedical and psychological models of illicit drug use not only elides questions of social inequity and obscures the range of interpersonal and institutional imperatives governing the lives of people who inject drugs, but also works (albeit inadvertently) to disproportionately burden already vulnerable individuals with the onus of responsibility and blame (e.g., Fraser, 2004). Qualitative research creates the opportunity for people with lived experience of injecting drug use to narrate their *own accounts* of drug use — to, as Bourdieu (1996, p. 615) notes above, *explain themselves* in the fullest sense of the term — thus providing alternative narratives to those of academics, policymakers, treatment professionals, family and friends. By facilitating the means by which such 'other' voices can be heard, qualitative research is not only creating space for the recognition and inclusion of lay knowledges and experiences of health but engendering the means by which they can potentially contribute to the production of public knowledge and practice.

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Summary

Despite the celebrated pluralism and diversity of liberal Western societies, people who inject drugs remain beyond the bounds of the socially acceptable. They occupy a uniquely stigmatised position. This thesis is about the politics of the social practice we know as 'injecting drug use' and those we identify as 'people who inject drugs': a politics less concerned with institutionalised governmental processes and more with the contest over forms of knowledge, identity and representation. It is about the innovative potential of qualitative research to recover and reconstitute the voices, the lived experiences, of some of society's most socially excluded and disadvantaged citizens, both in Australia and elsewhere. Drawing primarily on qualitative interview accounts, this thesis challenges the narrow normativity and discredited identities that dominate representations of injecting drug use(rs) in contemporary social, treatment and research settings. And in so doing, maps the contexts and conditions under which new and alternative understandings and possibilities are realised.

My thesis extends the rich tradition of qualitative drugs research which first begun occurring regularly in the 1920s, its methods proving well suited to respond to the challenges posed by working with often 'hidden or hard-to-reach' populations experiencing significant social isolation and stigmatisation. The thesis includes seven empirical chapters, each of which features a detailed analysis of a distinct qualitative dataset. Material for my first empirical chapter was gathered from nine 'client comment books' filled out by service users visiting the Sydney Medically Supervised Injecting Centre during the first four years of its operation. The subsequent six chapters draw on six distinct sets of semi-structured, in-depth interviews (263 in total), most of which were conducted face-to-face (n=228), with the remainder by telephone (n=35). The majority of participants identified as people who inject drugs (n=198); the remaining comprising a mix of health professionals: doctors, nurses, pharmacists, health education officers, clinical managers and administrators (n=65).

My seven empirical analyses are accompanied by comprehensive introductory and concluding chapters. My Introduction is organised into three sections. In the opening section, I briefly establish the context of Australian drug policy and practice; in the second, I review the key conceptual and theoretical tools which underpin my analysis; and in the final section, I briefly discuss my research methods before providing a thorough overview of the chapters to come, including a detailed exposition of how each chapter and each analysis align to form a coherent whole. My Conclusion reflects on the politics of knowledge production in the illicit drugs and addictions field. Recognising the ineluctable nexus between knowledge and power, I argue that the peripheral place qualitative research methods occupy relative to the longstanding dominance of

positivist approaches is not simply an issue confined to the world of scholarly research, but one with direct implications for the broader social world. How drug use is understood or constructed within different knowledges has real-world ramifications for the people who use them. I question the effect on knowledge production and identity formation within the illicit drugs and addictions field when certain ways of knowing and certain kinds of ('rational' and 'objective') voices are valorised to the exclusion of others. Nonetheless, I also note the flourishing over recent decades of innovative, social-theory-driven qualitative scholarship which has sought to challenge and unsettle the ways in which we make sense of the empirical. I briefly review the contribution my thesis has made within this tradition. I conclude by positing the critical contribution qualitative methods can make in shaping political, policy and programmatic responses to the issues affecting those who inject drugs.

Samenvatting

Ondanks het gevierde pluralisme en de diversiteit van liberale westerse samenlevingen, blijven mensen die drugs injecteren buiten de grenzen van het maatschappelijk aanvaardbare. Ze bezetten een uniek gestigmatiseerde positie. Dit proefschrift gaat over de politiek van de sociale praktijk die we kennen als 'injecterend drugsgebruik' en degenen die we identificeren als 'mensen die drugs injecteren': een politiek die minder bezig is met geïnstitutionaliseerde overheidsprocessen en meer met de strijd over vormen van kennis, identiteit en vertegenwoordiging. Het gaat over het innovatieve potentieel van kwalitatief onderzoek om de inbreng, de geleefde ervaringen, van enkele van de meest sociaal uitgesloten en benadeelde burgers van de samenleving te hervinden en reconstrueren, zowel in Australië als elders. Dit proefschrift is gebaseerd op kwalitatieve interviews en daagt de beperkte normativiteit en afgewezen identiteiten uit die representaties van injecterend drugsgebruik (rs) domineren in moderne sociale, behandelings- en onderzoekssituaties. En brengt hiermee de contexten en omstandigheden in kaart waarmee nieuwe en alternatieve inzichten en mogelijkheden worden gerealiseerd.

Mijn proefschrift breidt de rijke traditie van kwalitatief geneesmiddelenonderzoek uit, die vanaf de jaren twintig opgeld deed, en waarvan de methoden uitermate geschikt zijn om te reageren op de uitdagingen van het werken met vaak 'verborgen of moeilijk bereikbare' groepen die groot sociaal isolement en stigmatisering ervaren. Het proefschrift bevat zeven empirische hoofdstukken, elk met een gedetailleerde analyse van een afzonderlijke kwalitatieve dataset. Materiaal voor mijn eerste empirische hoofdstuk is verzameld uit negen cahiers met opmerkingen van gebruikers die een bezoek brachten aan het Sydney Medically Supervised Injecting Centre, in de eerste vier jaar na oprichting hiervan. De daaropvolgende zes hoofdstukken zijn gebaseerd op zes verschillende sets van semi-gestructureerde, diepte-interviews (263 in totaal), waarvan de meeste face-to-face werden uitgevoerd ($n = 228$) en de overige telefonisch ($n = 35$). De meerderheid van de deelnemers waren mensen die zichzelf identificeerden als iemand die drugs injecteerde ($n = 198$); de overigen omvatten een mix van gezondheidswerkers: artsen, verpleegkundigen, apothekers, gezondheidsvoorlichters, managers en ondersteuners ($n = 65$).

Mijn zeven empirische analyses gaan vergezeld van uitgebreide inleidende en afsluitende hoofdstukken. Mijn introductie is georganiseerd in drie secties. In de openingssectie leg ik in het kort de context vast van het Australische drugsbeleid en de praktijk; in het tweede deel bespreek ik de belangrijkste conceptuele en theoretische perspectieven die ten grondslag liggen aan mijn analyse; en in het laatste deel bespreek ik kort mijn onderzoeksmethoden voordat ik een overzicht geef van de hoofdstukken die volgen, inclusief een gedetailleerde uiteenzetting van hoe de hoofdstukken en analyses op elkaar aansluiten en een samenhangend geheel vormen. Mijn con-

clusie weerspiegelt de politiek van kennisproductie op het gebied van illegale drugs en verslavingen. De verwevenheid tussen kennis en macht erkennend, betoog ik dat de perifere positie van kwalitatieve onderzoeksmethoden ten opzichte van de voortdurende dominantie van positivistische benaderingen niet alleen beperkt is tot de wereld van wetenschappelijk onderzoek, maar directe implicaties heeft voor de bredere sociale wereld. Hoe drugsgebruik binnen verschillende typen van kennis wordt begrepen of geconstrueerd, heeft praktische gevolgen voor de mensen die deze kennis gebruiken. Ik stel het effect op kennisproductie en identiteitsvorming aan de orde binnen het gebied van illegale drugs en verslavingen waarin bepaalde manieren van weten en bepaalde soorten ('rationele' en 'objectieve') stemmen worden gewaardeerd, met uitsluiting van andere. Niettemin zie ik ook de bloei van innovatieve, sociaalwetenschappelijke vormen van kennis in de afgelopen decennia die trachten om de manieren waarop we het empirische interpreteren, uit te dagen en op te schudden. Ik bespreek kort de bijdrage die mijn proefschrift heeft geleverd binnen deze traditie. Ik besluit met het vaststellen van de kritische bijdrage die kwalitatieve methoden kunnen leveren aan het vormgeven van politieke, beleidsmatige en programmatische antwoorden op de problemen van mensen die drugs injecteren.

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My subsequent years with the Centre for Social Research in Health (CSRH) have been similarly inspirational. I have been surrounded by smart, committed, generous and unfailingly supportive colleagues: Loren Brener, Joanne Bryant, Kerryn Drysdale, Martin Holt, and Limin Mao. Max Hopwood has been a veritable one-man cheer squad!

When I joined the CSRH it was under the leadership of Professor John de Wit, followed then by Professor Carla Treloar. I have had the great fortune of their supervision. Long before my PhD formally became 'a thing,' they were staunch advocates of my work and its potential adaptation into a doctoral thesis. After leaving CSRH for Utrecht University in The Netherlands, John set about facilitating the submission of my thesis to his new institution. I am profoundly grateful for his unstinting generosity and support. Carla was one of the principal reasons I joined the Centre and without doubt has been one of the principal reasons I have stayed! For many years Carla was the person I worked most closely with across various projects. She has been a mentor, a colleague, a co-author and a friend. She has made this thesis possible.

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Curriculum Vitae

Jake is a Research Fellow with the Centre for Social Research in Health (CSRH), UNSW Sydney, Australia. Jake has a disciplinary background in social anthropology, politics, philosophy and cultural studies, and graduated from The University of Sydney with a Bachelor of Arts (Hons) Class 1 in 1991. Since joining the CSRH in late 2008 (initially in a casual capacity and then part-time from 2011) Jake has published 26 peer-reviewed publications in the social sciences and addictions field. This includes seven first-authored articles which have been published in very high-quality and high-impact journals, a number featuring within quartile 1 journals in the fields of Medicine, Health Social Science and Health Policy (from the 2016 Scimago Journal Rankings). He has presented extensively, from international conferences to invited guest lectures, community fora and research symposia. Jake is an editorial board member of the *International Journal of Drug Policy* and reviews regularly for other key journals in the field, including *Social Science & Medicine* and *Addiction*. He is actively involved in a number of community and university-based advisory and service roles.

Prior to joining the CSRH, Jake worked in several harm reduction services in Sydney's Kings Cross, including five years as the Drug and Alcohol Counselling Unit Manager of the Sydney Medically Supervised Injecting Centre (MSIC). There his role involved the leadership, education, support and supervision of staff, alongside the management of critical incidents and the clinical care of service users. Jake's role also entailed regularly representing the MSIC to diverse audiences across an array of different fora, including international conferences and, on several occasions, national radio and television. Jake was interviewed annually between 2002–2005 as a 'key Informant' for the Australian National Drug and Alcohol Research Centre's Illicit Drug Reporting Scheme.

Jake is currently working on a new program of research at the CSRH focusing on using social science methods and theories to develop a critical social science of implementation science. The program aims to investigate both how to optimise the translation and implementation of health interventions, and to reflect critically on the practices of evidence-making in the implementation sciences. Jake is also involved in the qualitative component of the world's first real-world trial of hepatitis C 'treatment as prevention' in prison: Australia's Surveillance and Treatment of Prisoners with Hepatitis C (SToP-C) study.