



Research paper

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

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ABSTRACT

Background: While there is growing recognition of the benefits of user involvement within drug treatment there is scant literature documenting the actual implementation of such initiatives. Nonetheless, the extant research is remarkably consistent in identifying poor relationships between service users and staff as a principal barrier to the successful implementation of consumer participation. Focussing on participants' accounts of change within the 'therapeutic alliance', this paper investigates a consumer participation initiative introduced within three Australian drug treatment services.

Methods: In 2012, the New South Wales Users and AIDS Association (NUAA), a state-based drug user organisation, introduced a consumer participation initiative within three treatment facilities across the state. This paper draws on 57 semi-structured interviews with staff and service-user project participants. Approximately ten participants from each site were recruited and interviewed at baseline and six months later at evaluation.

Results: The enhanced opportunities for interaction enabled by the consumer participation initiative fostered a sense of service users and staff coming to know one another beyond the usual constraints and limitations of their relationship. Both sets of participants described a diminution of adversarial relations: an unsettling of the 'them and us' treatment divide. The routine separation of users and staff was challenged by the emergence of a more collaborative ethos of 'working together'. Participants noted 'seeing' one another – *the other* – differently; as people rather than simply an identity category.

Conclusion: For service users, the opportunity to have 'a voice' began to disrupt the routine objectification or dehumanisation that consistently, if unintentionally, characterise the treatment experience. Having a voice, it seemed, was synonymous with *being human*, with having ones' 'humanness' recognised. We contend that not only did the introduction of consumer participation appear to empower service users and enhance the therapeutic alliance, it may have also improved service quality and health outcomes.

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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 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 two on its checklist of ten 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

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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 paper 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 dehumanizing 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 offsite 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 consumers 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 ten 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 ($n = 1\text{--}2$ 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 ($n = 1\text{--}2$ per site); the latter two groups were made up of staff ($n = 3\text{--}5$ per site) and service users ($n = 3\text{--}5$ 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 AUD \$20.00 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 paper. 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 routinized 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 doser 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 re-fashion 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 co-mingling 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 onsite 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 scepticism 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 paper reflects the findings from one Australian consumer participation project, our discussion is potentially relevant to treatment settings more broadly. For as long as the demonization 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 focussed 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.

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Conflict of interest statement

The authors have no conflict of interest to declare.

References

- Australian Commission on Safety and Quality in Health Care (ACSQHC) (September 2011). National Safety and Quality Health Service Standards. ACSQHC, Sydney.
- Bryant, J., Saxton, M., Madden, A., Bath, N., & Robinson, S. (2008a). Consumer participation in the planning and delivery treatment services: The current arrangements. *Drug and Alcohol Review*, 27(2), 130–137. <http://dx.doi.org/10.1080/09595230701829397>
- Bryant, J., Saxton, M., Madden, A., Bath, N., & Robinson, S. (2008b). Consumers’ and providers’ perspectives about consumer participation in drug treatment services: Is there support to do more? What are the obstacles? *Drug and Alcohol Review*, 27(2), 138–144. <http://dx.doi.org/10.1080/09595230701829405>
- Commonwealth Department of Health and Aged Care. (1998). *Consumer focus collaboration*. Canberra, Australia: Commonwealth of Australia.
- Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., et al. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*, 325, 1263. <http://dx.doi.org/10.1136/bmj.325.7375.1263>
- Crawford, S. (2013). Shouting through bullet-proof glass: Some reflections on pharmacotherapy provision in one Australian clinic. *International Journal of Drug Policy*, 24(6), e14–e17. <http://dx.doi.org/10.1016/j.drugpo.2013.07.004>
- Duff, C. (2007). Towards a theory of drug use contexts: Space, embodiment and practice. *Addiction Research and Theory*, 15(5), 503–519. <http://dx.doi.org/10.1080/16066350601165448>
- Fischer, J., & Neale, J. (2008). Involving drug users in treatment decisions: An exploration of potential problems. *Drugs: Education, Prevention, and Policy*, 15(2), 161–175. <http://dx.doi.org/10.1080/09687630701391604>
- Fox, N. (1995). Postmodern perspectives on care: The vigil and the gift. *Critical Social Policy*, 15(44–45), 107–125. <http://dx.doi.org/10.1177/026101839501504407>
- Fraser, S., & Valentine, K. (2008). *Substance and substitution: Methadone subjects in liberal societies*. Basingstoke: Palgrave Macmillan. <http://dx.doi.org/10.1057/9780230582569>
- Fricker, M. (2007). *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press.
- Hinton, T. (2010). *Voices on choices: Working towards consumer-led alcohol and drug treatment*. Hobart, Australia: The Social Action and Research Centre, Anglicare Tasmania.

- Lupton, D. (1995). *The imperative of health: Public health and the regulated body*. London: Sage.
- Manderson, D. (2011). Possessed: The unconscious law of drugs. In S. Fraser, & D. Moore (Eds.), *The drug effect: Health, crime and society* (pp. 225–239). Port Melbourne, Australia: Cambridge University Press. <http://dx.doi.org/10.1017/CBO9781139162142.017>
- McDermott, P. (2002). Flavour of the month: Users in service provision. *Druglink*, 17(1), 18–21.
- Ministerial Council on Drug Strategy. (2011). *National Drug Strategy 2010–2015*. Canberra ACT, Australia: Commonwealth of Australia.
- Mol, A. (2008). *The Logic of Care: Health and the problem of patient choice*. London: Routledge.
- Moore, D., & Fraser, S. (2006). Putting at risk what we know: Reflecting on the drug-using subject in harm reduction and its political implications. *Social Science and Medicine*, 62(12), 3035–3047. <http://dx.doi.org/10.1016/j.socscimed.2005.11.067>
- Nathan, S. (2004). Consumer participation: The challenges to achieving influence and equity. *Australian Journal of Primary Health*, 10(3), 15–20. <http://dx.doi.org/10.1071/PY04042>
- Neale, J. (2006). Feel good factor. *Druglink*, 21(1), 20–21.
- Patterson, S., Weaver, T., Agath, K., Albert, E., Rhodes, T., Rutter, D., et al. (2008). 'They can't solve the problem without us': A qualitative study of stakeholder perspectives on user involvement in drug treatment services in England. *Health and Social Care in the Community*, 17(1), 54–62. <http://dx.doi.org/10.1111/j.1365-2524.2008.00797.x>
- Patterson, S., Weaver, T., Agath, K., Rutter, D., Albert, E., & Crawford, M. (2009). User involvement in efforts to improve the quality of drug misuse services in England: A national survey. *Drugs: Education, Prevention and Policy*, 16(4), 364–377. <http://dx.doi.org/10.1080/09687630802061544>
- Patterson, S., Weaver, T., & Crawford, M. (2010). Drug service user groups: Only a partial solution to the problem of developing user involvement. *Drugs: Education, Prevention, and Policy*, 17(1), 84–97. <http://dx.doi.org/10.3109/09687630802225495>
- Radcliffe, P., & Stevens, A. (2008). Are drug treatment services only for 'thieving junkie scumbags'? Drug users and the management of stigmatised identities. *Social Science and Medicine*, 67(7), 1065–1073. <http://dx.doi.org/10.1016/j.socscimed.2008.06.004>
- Rance, J., & Fraser, S. (2011). Accidental intimacy: Emotional transformation and the Sydney Medically Supervised Injecting Centre. *Contemporary Drug Problems*, 38(Spring), 121–145.
- Rance, J., Newland, J., Hopwood, M., & Treloar, C. (2012). The politics of place(ment): Problematising the provision of hepatitis C treatment within opiate substitution clinics. *Social Science and Medicine*, 74(2), 245–253. <http://dx.doi.org/10.1016/j.socscimed.2011.10.003>
- Schorr, L. (2003). *Determining "what works" in social programs and social policies: Toward a more inclusive knowledge base*. Cambridge, MA: Harvard University.
- Seear, K., Gray, R., Fraser, S., Treloar, C., Bryant, J., & Brenner, L. (2012). Rethinking safety and fidelity: The role of love and intimacy in hepatitis C transmission and prevention. *Health Sociology Review*, 21(3), 272–286. <http://dx.doi.org/10.5172/hesr.2012.21.3.272>
- Smith, C. B. R. (2011). A users' guide to 'Juice Bars' and 'Liquid Handcuffs': Fluid negotiations of subjectivity, space and the substance of methadone treatment. *Space and Culture*, 14(3), 291–309. <http://dx.doi.org/10.1177/1206331211412238>
- Ti, L., Tzemis, D., & Buxton, J. (2012). Engaging people who use drugs in policy and program development: A review of the literature. *Substance Abuse Treatment, Prevention, and Policy*, 7(1), 47. <http://dx.doi.org/10.1186/1747-597X-7-47>
- Treloar, Rance, J., Madden, A., & Liebelt, L. (2011). Evaluation of consumer participation demonstration projects in five Australian drug user treatment facilities: The impact of individual versus organizational stability in determining project progress. *Substance Use and Misuse*, 46(8), 969–979. <http://dx.doi.org/10.3109/10826084.2010.540289>
- Treloar, C., & Holt, M. (2006). Deficit models and divergent philosophies: Service providers' perspectives on barriers and incentives to drug treatment. *Drugs: Education, Prevention and Policy*, 13(4), 367–382. <http://dx.doi.org/10.1080/09687630600761444>
- Tritter, J., & McCallum, A. (2006). The snakes and ladders of user involvement: Moving beyond Arnstein. *Health Policy*, 76(2), 156–168. <http://dx.doi.org/10.1016/j.healthpol.2005.05.008>
- Watson, J. (2005). *Active engagement: Strategies to increase service participation by vulnerable families*. Sydney, Australia: NSW Centre for Parenting and Research, Department of Community Services [Discussion Paper].
- Wisdom, J., Hoffman, K., Rechberger, E., Seim, K., & Owens, B. (2009). Women-focused treatment agencies and process improvement: Strategies to increase client engagement. *Women and Therapy*, 32(1), 69–87. <http://dx.doi.org/10.1080/02703140802384693>
- Wolfe, D. (2007). Paradoxes in antiretroviral treatment for injecting drug users: Access, adherence and structural barriers in Asia and the former Soviet Union. *International Journal of Drug Policy*, 18(4), 246–254. <http://dx.doi.org/10.1016/j.drugpo.2007.01.012>
- Zibbell, J. E. (2004). Can the lunatics actually take over the asylum? Reconfiguring subjectivity and neo-liberal governance in contemporary British drug treatment policy. *International Journal of Drug Policy*, 15(1), 56–65. <http://dx.doi.org/10.1016/j.drugpo.2003.08.004>