Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Queer Solidarities: New Activisms Erupting at the Intersection of Structural Precarity and Radical Misrecognition

Michelle Fine*[a], María Elena Torre[a], David M. Frost[b], Allison L. Cabana[a]

[a] Public Science Project and Department of Critical Social/Personality Psychology, The Graduate Center, City University of New York, New York, NY, USA. [b] Department of Social Psychology, University College London, London, United Kingdom.

Abstract

This article investigates the relationship between exposure to structural injustice, experiences of social discrimination, psychological well being, physical health, and engagement in activist solidarities for a large, racially diverse and inclusive sample of 5,860 LGBTQ/Gender Expansive youth in the United States. Through a participatory action research design and a national survey created by an intergenerational research collective, the "What's Your Issue?" survey data are used to explore the relationships between injustice, discrimination and activism; to develop an analysis of how race and gender affect young people's vulnerabilities to State violence (in housing, schools and by the police), and their trajectories to activism, and to amplify a range of "intimate activisms" engaged by LGBTQ/GE youth with powerful adults outside their community, and with often marginalized peers within. The essay ends with a theoretical appreciation of misrecognition as structural violence; activism as a racialized and gendered response to injustice, and an elaborated archive of "intimate activisms" engaged with dominant actors and within community, by LGBTQ/GE youth who have been exiled from home, school, state protection and/or community and embody, nevertheless, "willful subjectivities".

Keywords: participatory action research, LGBTQ, identities, activism, youth, solidarity, health, discrimination

Alex couldn't attend the last participatory analysis session for *What's Your Issue?,* a national participatory survey of/by LGBTQ and gender expansive youth. They sent a photo instead, and apologized: "I am 7 months pregnant and my gynecologist said I couldn't fly." An organizer at Gender Justice in Los Angeles and a transman now in their third tri-semester, Alex sent their photo (see Figure 1) not so much as an expression of "identity politics" as a radical insistence on recognition and reproductive justice; or what Sara Ahmed (2014) has called "willful subjectivity." While primarily engaged in having a baby at the moment, Alex has been and continues to be an important colleague in our research, a persistent voice queering categories, pluralizing identities and contesting binaries.

Alex embodies and organizes, at the intersection of an array of movements for racial, gender, sexual and reproductive justice.

Figure 1. Alex, Organizer and What's Your Issue? Researcher.

Like Alex, and the editors of this volume, we find ourselves bewildered and enraged by the current political circumstances, a dangerous cocktail of rising inequalities, spiking hate crimes, emboldened White nationalisms, a shrinking middle class, attacks on gender/sexual/reproductive rights, criminalization of communities of color and poverty, rising xenophobia and Islamophobia, and a deepening climate crisis. Just to name a few of the current threats to our collective well-being. And yet we find ourselves, at the same time, encouraged by increasingly vibrant solidarity movements and bold courage of young people, joined across struggles and identities, demanding a justice of redistribution, recognition and radical participation, and we learn that many of these movements are led by queer, trans, or gender expansive youth of color, at least in the U.S. In this context, at the Public Science Project of the Graduate Center, CUNY we have positioned ourselves among those critical scholars engaged with movements for justice, and engaged in movements for epistemic justice, that is the democratization of knowledge production.

We write this article to understand what we are calling "queer solidarities," a new form of activism in which demands for recognition and belonging sit beside demands for redistribution and participation. We write this article with contributions from our co-researchers Shéár Avory, Jai' Celestial Shavers, and Kat Williams. We enter and contest the false debate between "identity" based vs. "structural" political struggles, and empirically unpack how LGBTQ/GE young people, particularly those in the working class and those of color, are joining these commitments in their new activisms, and how activism seems to be good for their health.

Precarity and Misrecognition: A Politics Rooted in Redistribution and Recognition

The debates around identity, or identitarian politics, have inflamed of late. Political theorist Nancy Fraser (2000) has argued that movements for recognition (gender, sexual, racial, religious) have frequently "displaced" movements for structural transformation and redistribution; reified and "essentialized" identities and have reproduced false "binaries" activating feuds between and within marginalized communities and ultimately strengthening forms of domination by elites. In 2000, Fraser argued, "Today's struggles for recognition often assume the guise of identity

politics. Aimed at countering demeaning cultural representations of subordinated groups they abstract misrecognition from its institutional matrix and sever its links with political economy" (Fraser, 2000, p. 9). In 2017, Fraser complicates her earlier position further troubling the binary, when she argues:

> Especially troubling is the resurgence of an old tendency on the left to pit race against class...Both views are problematic to the extent that they treat attention to class and race [and we would add gender and sexuality] as inherently antithetical, a zero sum game. In reality, both of those axes of injustice can be attacked in tandem, as indeed they must be. Neither can be overcome while the other flourishes (p. 10).

We would agree that movements, and critical scholarship, must be rooted in an intersectional politic, interrogating race and class, and we would add gender and sexuality focused on the transformation of economic and political systems. For this essay, we introduce the epistemologies and methodologies of *What's Your Issue?* as an example of critical participatory inquiry, and we explore a slice of the results to understand how structural precarity and misrecognition live in the bodies of LGBTQ/GE youth in the U.S., and how oppression is metabolized into activism – on the streets, in the courts, online and at home. We also unpack how we have taken up an intergenerational participatory project, anchored in queer justice movements, across the U.S., and designed to interrogate questions of theory, social movements, methods, ethics and democratic knowledge production.

The evidence we gather draws from the 5,860 responses to the What's Your Issue? survey – designed/analyzed/produced by an explicitly intergenerational research collective including a range of LGBTQGE (Gender Expansive) youth, most of whom are young people of color, trans and/or gender expansive (identifying as nonbinary or gender nonconforming). This research project is committed to an intersectional analysis (Cole, 2009; Crenshaw, 1989) and our evidence attends to structural conditions. Our results, elaborated in previous essays (Fine, Torre, Frost, & Cabana, 2017; Frost, Fine, Torre, & Cabana, 2017; Torre et al., 2018) demonstrate that *being denied one's identity*, whether at home, in school, at church, by the police, in juvenile facilities, at work or in the law, unleashes an avalanche of adverse material, social, psychological and physical health consequences. This is particularly true for youth of color and trans and gender expansive youth who report the most substantial financial troubles, educational struggles, exposure to aggressive policing, housing instability and vulnerability to violence and exploitation. These experiences make clear that the structural politics of (mis)recognition are entangled with political economy. And we find significantly that racial and homophobic experiences of discrimination are positively associated with levels of activism, which are positively associated with mental health. This finding seems striking for the community under study, but also wonderfully suggestive about the politics of marginalized youth in revolt globally.

As a critical participatory action research project (Torre, Fine, Stoudt, & Fox, 2012), our work is conducted with and for LGBTQ and gender expansive youth in the U.S. This article lifts up a number of concerns that are of course particular to this group, living at a time of both heightened human rights and hate crimes. But it is also true that our evidence speaks to a broader swath of youth at the margins. That is, these young people may be distinct from their peers, by virtue of the ways they carry and express gender and sexuality, but largely they are young people, late adolescents and young adults, living at a time of rising inequality gaps, spiking rates of housing insecurity, and police violence. They have been deeply betrayed by the state, the economy and sometimes intimates, and they are deeply engaged with a range of solidarity activist social movements.

Structural Precarity and Youth Activism at the
Radical Margins

Lauren Berlant (2007) writes that precarity, living in conditions both traumatizing and unpredictable, is the fuse to slow death. Our research with marginalized youth over 20 years, living at multiple margins and intersections, suggests that precarity is multi-scalar; it occurs at the macro, meso and micro levels (see Fine, 2017; Torre, Stoudt, Manoff, & Fine, 2017). In the U.S. and globally, precarity derives from a structural realignment of global capital and a rise of White nationalisms, entangled with immigration, gender and sexuality politics. Under conditions of neoliberalism and concentrated wealth, we witness economic dynamics and transnational policies that undermine and target those at the margins. These conditions undermine economic opportunities, threaten living and learning settings and heighten police surveillance and violence. Marginalized youth are left more vulnerable to the unnerving predictability of impending disaster. Within the United States, the pooling and coagulation of precarity-inducing policies can be found most viscerally and viciously in communities of color, struggling with poverty, dealing with issues related to immigration, as well as those marginalized by their gender and sexual identities.

It is well documented that structural dispossession – what we are calling precarity – leads to adverse economic and social conditions as well as psychological distress and physical health problems (Bullock & Reppond, 2016; Fine & Burns, 2003; Fine, Burns, Payne, & Torre, 2004; Fine & Weis, 1998; Frost et al., 2017; Lott & Bullock, 2006; Meyer, 2003). There is, however, also a rich literature on "radical marginality," in which critical psychologists have demonstrated the mobilization of activist, critical consciousness rising in the margins. Clara Mayo (1982), Rhoda Unger (2000), and later Ruth Hall and Michelle Fine (2005) have published on the critical consciousness and radical commitments marinating in the margins of social hierarchies. More recently Anjali Dutt and Shelley Grabe (2014) have written on positive marginality, critical consciousness and social identities as core precursors to activist identity. Even as we interrogate in this essay, the devastating consequences of structural injustice on LGBTQ/GE youth on health, we also seek to document the creative and strategic forms of resistance, activism and political solidarities engaged by those exiled to the radical margins.

Indeed – this rising of activism from the ashes of discrimination – was part of our funding mandate. When we started this project, we were called by funders who asked us, plainly: "Have you ever noticed that the leaders of major youth organizing movements – Dreamers, Prison Abolition, Black Lives Matter, Fight for $15, Muslim justice work, Environmental Racism, Educational Justice, UndocuQueer…. are disproportionately queer and trans youth of color?" (Youth organizing funder, personal communication, March 23, 2014)

Well, we had.

So with this question as part of our genesis story, we committed to unpacking relationships between discrimination, health and activism, informed by research on adult collective action (Drury & Reicher, 2005; Dutt & Grabe, 2014; Hammack, 2010; Hammack & Pilecki, 2012; Reicher, 2004) as well as youth activism (Conner & Rosen, 2016; Su, 2009).

Provoked by the notion that alongside experiences of hardship, harm and discrimination one might find a reservoir of activist subjectivities, we turned to Sara Ahmed's (2014) writings on "willful subjects", Cathy Cohen's (1997) work on the politics of deviance, and José Esteban Muñoz's (1999) writings on "disidentification" and the perfor-

mance of politics among queers of color. These writers contest psychological arguments about stigma, shame and depression as the primary psychological footprints of oppression. Ahmed argues that queer lives embody "willful subjectivities," that do not shrink at misrecognition but unapologetically "refuse to straighten." Cathy Cohen extends this line of analysis, recognizing that queer young women of color are not only willful but increasingly emergent as leaders of collective movements for queer justice, but also education, prison abolition, immigration justice:

> There have always been radical black women or radical women engaged in mobilization, organizing, and leadership: we know that is not new….

> …I do think what's new is the ways in which, at this moment in the Black Lives Matter movement, young, black, often queer women are not just doing the work but are part of a collective leadership. (Cohen & Jackson, 2015, para. 16-17).

And José Esteban Muñoz (1999) moves us beyond politics of social movements, onto the stage of the politics of performance, amplifying what he calls disidentification as a

> …mode of performance whereby a toxic identity is remade and infiltrated by subjects who have been hailed by such identity categories but have not been able to own such a label… This management is a critical negotiation in which a subject who has been hailed by injurious speech, a name, a label, reterritorializes that speech act and the marking that such speech produces. (p. 185)

While traditional psychological research has focused primarily upon the relationship of oppression and internalization of stigma, in contrast, queer theory, critical race theory and performance studies join radical marginality studies to suggest that oppression accumulating in the margins may indeed affect health, educational and social outcomes adversely but may also be metabolized into critique, performance, contestation and collective action with beneficial effects on health. This discrimination-health-activism paradox is one that we explore in this article.

Empirical warning: our data are of course cross sectional. Arguments that suggest causality cannot be advanced. And yet, as you will see, the recurring patterns of association, both statistical and narrative, between precarity, health and activism are intriguing and worthy of far more critical analysis/exploration, particularly at a moment in history in which both State repression for "suspect" identities and collective protest by those who embody "suspect" identities are cresting.

What's Your Issue? Critical Participatory Action Research With LGBTQGE Youth

What's Your Issue? (WYI) is a national, intergenerational participatory action research (PAR) project, developed out of the Public Science Project at the Graduate Center, CUNY created with, by, for, and about LGBTQ and gender expansive youth, ages 14-24. For the purpose of this essay, we will use the language "queer," as our research collective has determined, to encompass the wide range of young people who identify as lesbian, gay, bisexual, transgender, queer, questioning, intersex, asexual and gender non-conforming or, as we prefer, gender expansive. WYI was designed by a diverse intergenerational team of activists and researchers, all dedicated to the production of knowledge by young people too often left out, specifically to over-recruit queer youth and espe-

cially youth of color, youth living at the intersecting margins of race/ethnicity and economic, gender, and sexuality struggles who have been absent from most national surveys of LGBTQ young people.

As a critical PAR project, it is important to understand that our research collective included the authors of this essay (diverse by age/sexuality/gender/race ethnicity), and close to 40 youth co-researchers from 10 cities around the country, all of whom identify as queer, most of color, and activist/engaged in youth social movements in their local communities. This large collective gathered in person, at the Graduate Center, at the City University of New York (CUNY), for three in-depth research retreats, to design the survey, analyze the data and generate products, and across two years sustained contact over email, video conference calls, telephone calls and meetings around the country.

Together, over the course of six months, we drafted and edited, piloted and refined, varied versions of what would become the national survey, with structured input from more than 400 youth across the United States, recruited from 40 youth organizations around the country (GSAs, immigration justice, YMCAs, spoken word organizations, homeless youth groups, foster care advocacy, racial justice organizations and listservs and word of mouth). Across these many conversations there were "difficult" conversations, and as is the case with critical PAR, we dove into these generative conflicts. We had to decide, for instance, with young people across the country, on what language to use in the survey (queer? Gay? Trans? Cis?); we had to try to come to consensus on whether we would include traditional indicators of bullying, suicidality, mental health distress (we did); we worked hard to craft language that would ask about housing insecurity as we were aware that most "homeless" youth don't consider themselves "homeless"; we had to manage the sampling demographics, particularly the influx of white respondents, as we sought the over-representation of African American, Latinx, Asian American, mixed race respondents, as well as trans and gender non-conforming/gender expansive; we worked with social media specialists across the country to be sure to reach rural respondents, those in the South, and multiply marginalized young people. When it came time for analysis, we had to negotiate, with difficulty, how we might aggregate the data so that we could statistically analyse by race (white vs. respondents of color), by gender (cis – that is, self identification is consistent with sex assigned at birth – vs. trans or gender non-conforming/expansive – that is, self identification is at variance with sex assigned at birth). We have written expansively about these debates (with much dissension) among our full research collective (see Fine, Torre, Frost, Cabana, & Avory, 2018; Torre et al., 2018), we have produced a video laying out the arguments against categories (www.whatsyourissue.org) and we invite you to consider not simply how we *resolved* these impossible epistemological/political tangles, but more importantly how we *struggled* – together – to appreciate our widely diverse conceptualizations of identities and refusal of binaries even as we were rooted in the statistical policy imperative to document serious disparities by race and gender in a world rife with injustice. In the end of the lengthy survey production process, we landed on a set of research questions elaborated below.

Research Questions

Drawing on quantitative and qualitative data from a large-scale national survey (*N* = 5,860), within a broader participatory action research project, in this paper we explore five questions:

1. What are the material and psychological correlates of structural injustice for queer youth in the U.S., by race/ethnicity and by gender?

2. What is the relationship between exposure to structural injustice and psychological well-being?

3. How does structural injustice shape activism?

4. What forms of activism do WYI queer youth engage, for gender justice and beyond?

5. What is the association between engagement in activism and psychological well-being?

Sample

Over 6,000 young people across the U.S. took the survey and answered 80% of the questions; some identify as "straight" (heterosexual) and "cis" (they self-identify with the sex assigned at birth). In this paper we will discuss the data from a substantial subgroup, those who identify as LGBTQGE (*N* = 5,860). Ranging in age from 14 – 24, participants were from all US states, Guam and Puerto Rico, and reflected a balanced representation of the 4 primary geographic regions of the US. The research held a commitment to represent experiences missing in the existing national data about LGBTQGE youth; purposive sampling strategies were used to achieve a high representation of youth of color (39%) as well transgender/non-binary/gender non-conforming/gender expansive youth (58%), youth with disabilities (39%) and youth under 18 (46%) – populations under represented and often absent from the literature. We adopted various internet and community based sampling strategies to reach youth of color and trans and gender expansive youth (Meyer & Wilson, 2009) including a team of youth outreach workers who posted survey advertisements on Facebook, Tumblr, Twitter, and Instagram, directing interested youth to the project website, which contained an explanation of the project, video narratives from the CPAR collective, and a link to take part in the survey. Outreach was made to community organizations serving LGBTQGE youth in cities and towns across the US, as well as music, theatre, sports, spoken word, activist organizations which were provided incentives to host "survey making parties" and "survey taking parties" whereby youth were able to complete the survey in person, with assurance of confidentiality, anonymity and privacy.

A word on our sample: Our sample was gathered to be inclusive: a range of gender and sexualities, an over representation of youth of color, gender expansive youth and young people who had experienced negative interactions with police, schools and housing instability; young people from urban, rural and suburban communities, and from every state in the country. We wanted a sample that included young people attached to/engaged with community-based organizations (30%), but also those who are not involved with community based organizations (70%).

Epistemological and Methodological Muddles

We realize the critical PAR may be a novel design to many readers, and so in this section we lay out some principles/strategies/commitments of our practice.

To questions of ethics and IRB: In WYI, as in other critical PAR projects, we followed traditional mandates of IRB and we developed more expansive commitments to ethics. The survey was submitted to and approved by the CUNY IRB; allowing young people aged 14 – 24 to take the survey with nothing more than their consent, and we provided "resources" and "supports" at the conclusion of the survey. The survey was anonymous and largely taken online. In settings where young people took the survey on computers in the same room we tried to assure confidentiality and privacy. In a rural YMCA in Missouri, at the Creating Change conference in Phoenix, at a homeless shelter in Detroit, we spent time with advocates speaking through questions of anonymity, confidentiality and privacy.

The Survey: We ultimately crafted an online survey, using Qualtrics. The survey was made available by following a link that we posted on the *What's Your Issue?* website (www.whatsyourissue.org) and shared widely though

listservs, word of mouth, and a variety of social media outlets. At the conclusion of the survey, respondents were given the opportunity to enter a raffle for a gift card. With content determined by the core research collective, and iterative drafts passed back and forth with over 400 youth across the nation, the final survey included questions about identities, struggles, activisms and relationships with public institutions and intimates; there were traditional items about school belonging, relationships with family and police and educators; items borrowed from Black Youth Project (Cohen, 2010; Cohen, Celestine-Michener, Holmes, Mersth, & Ralph, 2007) about civic engagement, and open ended questions about "what do you do in your free time?" "what does community mean to you?" "what would you like to tell the next President of the U.S." "what it your vision of your future?" "if you were to create a banner about yourself, what would it say?".

Creating qualitative and quantitative databases: We have a vast quantitative and qualitative database, managed through SPSS. Demographic (for gender/race/sexuality) were created through a meticulous analysis of the entire data set for each demographic question, including all write-ins that was heavily informed by the insights of youth researchers. The qualitative data to date has been analysed by sub-samples.

To questions of generalizability: We make no claims about our sample being "representative," but we do about its inclusiveness. We present few overall descriptive statistics, but offer statistical evidence of associations between, for instance, housing insecurity and psychological troubles; rates of discrimination and activism; having "out" teachers and queer-friendly curriculum and overall positive academic outcomes. That is, we sought (1) to recruit an inclusive sample, representing the wide swath of LGBTQ and gender expansive youth who had been severely underrepresented in prior surveys of the LGBTQ/GE population; (2) to analyse where racial and gender disparities amplify within the LGBTQ/gender expansive community, and where race/gender do not seem to demarcate large differences, and; (3) we have sought out evidence of distressing statistical associations between precarity and negative outcomes but also promising associations between dignity, respect, and agency with positive outcomes.

A note on statistical categories: As you might imagine, our research collective spent weeks battling out the question of "categories." As a group firmly resistant to the "straight jackets" of gender/race/sexuality categories, a number of the youth co-researchers were initially distressed that the adult co-researchers were interested in "collapsing the data" so that we could "trace" statistically where race and gender matter. And so we discussed different ways of cutting the data and decided – in a nation in which trans women of color are murdered at outrageous rates; where youth of color are assaulted and killed by police in shocking disproportionality; where queer youth of color are significantly over-represented in foster care, homeless shelters and juvenile justice facilities (especially youth of color who identify as lesbian, bisexual, or trans) – we committed to a to create combined categories for statistical comparisons, and to simultaneously find ways to honor the rich and complex self identifications of the respondents in all data presentations. With these dual ethical principles, as you read the text below you will hopefully see, our "jazzy" commitments to both rich self-descriptions and to statistical disparity analyses so that we might reveal, at once, the profound complexity of subjectivity and the oppressive blades of race/gender injustice. In addition, we have produced a video, available online, to explore how/why we reject categories for self-definitions, see whatsyourissue.org.

A note on sustained muddles and disappointments: This question of statistical comparisons remains unresolved. Our research collective asked, and debated: If gender and sexuality are fluid, how can we construct binaries? If race is a social construction, how can we re-inscribe these racial distinctions? And even more complex – if I identify as a trans-woman does that mean I am not a real "woman" on the gender choices? If a person of color

passes as white, should they be included in the "of color" category (say, if we are analysing their treatment by police)? If someone is "mixed race" does including them in the "of color" category erase their white heritage? Don't we need to look at skin color rather than race?

Long hard discussions were held and our "resolutions" were not entirely satisfying but ultimately we decided "good enough". To ease the our decisions we collectively committed to supplement the research "results," we have committed to producing videos about "Categorical Refusal"; policy documents that reveal how much "whiteness" protects young people in contentious relations with police and in schools; to present our findings as an amalgam of rich self-descriptors alongside any qualitative material, and to generate evidence of statistical disparities only in terms of issues of public policy (aggressive policing, school suspension, access to public housing). We were disappointed our final sample didn't include, immigrant or undocumented respondents but we understand the deeply embodied fears in the queer undocumented community, in the U.S., even to respond to an anonymous survey; we were discomforted by the high rates of psychological distress reported by respondents and unsure how to "make sense" of these findings; we have held "sub sample parties" with under-represented groups included young intersex folks, queer Muslims, and are planning gatherings with queer Mormons, disabled trans folks to help "unpack" what these subsamples are teaching us. For these discussions, WYI data are a platform for conversations long over-due, and much deserved.

A note on names: In this text, we use "real names" for the youth and adult researchers and pseudonyms for participants in our survey making parties. Our data is anonymous. When we present qualitative material from respondents, we display their self-curated gender/race/sexuality descriptors.

Cumulative Misrecognition Incites Dispossession

As the writer Junot Díaz (quoted in Stetler, 2009) has argued[i], recognition matters:

> You know how vampires have no reflections in the mirror? If you want to make a human being a monster, deny them, at the cultural level, any reflection of themselves. [G]rowing up, I felt like a monster in some ways. I didn't see myself reflected at all. I was like, 'Yo, is something wrong with me?' That the whole society seems to think that people like me don't exist? And part of what inspired me was this deep desire, that before I died, I would make a couple of mirrors. That I would make some mirrors, so that kids like me might see themselves reflected back and might not feel so monstrous for it.

In this project we collectively, sought to design a survey, with traditional quantitative items as well as open-ended qualitative questions, that could feel like a mirror, reflecting back the often difficult biographies and rich complexity of lives.

Jai' Celestial, one of the What's Your Issue youth co-researchers and an organizer at BreakOUT! in New Orleans argues, queer youth – particularly those of color – insist on challenging dominant categories and exploding binaries. "LGBTQ youth of color reject the binaries and identities that have been placed on us. We have a range of identities and refuse to squeeze ourselves into categories you can understand."

More over as, Shéár Avory, another youth co-researcher and national social justice youth activist who identifies as trans, Black, Indigenous, and from Los Angeles, argues identity categories have been used to oppress and

contain, with devastating consequences for the "cradle to prison" pipeline encountered by queer youth of color. Sharing from their own life, they illustrate how this can unfold:

> From age 5 to 10 my father had me in conversion therapy. When that didn't work I was placed in foster care, at 10. I never finished high school because I was traumatically bullied in elementary, middle and high school. At 17 I left LA for NYC. I wasn't able to find stable housing and was finally thrown out of a youth shelter because they wouldn't let me stay with my partner. We were on the streets, went to a small home in rural Pennsylvania, to stay with relatives, and then there was family violence – it's Trump country. We ended up in jail – I was assigned to the men's facility and experienced relentless transphobia – me at 18, being lectured by a captain about chromosomes, X and Y.

We learned much at our survey making parties, where young people would explain that they reject categories for self-descriptions, but that adults in positions of authority – police, social workers, teachers, politicians – deploy these identity categories as weapons of misrecognition and then unleash terror on youth who dare to transgress hegemonic binaries. At one of our survey making parties, we were trying to finalize questions to ask about young people's interactions with police when Sam whose uses the pronoun, they, raised a hand, and from under a baseball cap sitting atop a full Afro, soft brown skin, welcoming smile, grey eyes, spoke, "Every time the police stop and frisk me, you know in parks or at the piers or even in my neighborhood, when they feel my breasts they get angry and beat me up. Can we put that on the survey?" And at another gathering discussing both policing and school suspensions, Angelique, a 17 year old Puerto Rican woman who identified as a lesbian explained, "When I walk down the street alone, the police cat call me; when I am walking hand in hand with my girlfriend, they say 'can I fuck both of you?'" To which affirming finger snapping sounds filled the room.

No surprise – these incidents were not reported to the police.

We define misrecognition – far too soft a language for capturing the range of violent provocations we have archived – as a range of experiences in which LGBTQGE youth are denied full expression of self, shoved into boxes by authorities, parents/caregivers, peers and strangers, and/or are punished physically, verbally, psychologically for transgressing gender/sexual norms. Banal and severe, everyday and spectacular, "didn't bother me" and traumatizing, cumulative and episodic, predictable and not, misrecognition permeates bodies, communities and institutions. We draw from critical race theorists including Fanon (1967) who marks the sharp wound of being denied humanity, as well as Taylor (1992) who argues that recognition is considered a "vital human need" (p. 26). Honneth (2003, 2007) writes on the harms produced when ideological belief systems depict some as non- or sub-human, and when networks of love and care withhold reciprocity to those deemed Other. We also appreciate the writings of Young (1990) who recognizes justice as a combination of access to opportunities and resources, as well as respect and "standing" in the eyes of one's peers. And we take seriously by Yuval-Davis' writings on the need for "belonging" (Yuval-Davis, 2012) in conversation with Honneth's sense that recognition flourishes inside love and friendships, relations of loving care.

Misrecognition, then, can be devastating – whether from strangers or ideological systems, laws or policies, peers or those whom we love. For queer youth we learn that misrecognition often takes the form of structural and intimate betrayal (e.g. by families, schools, community leaders), neglect (e.g. by educators, religious leaders, social workers) and abuse (e.g. by police, shelter staff, juvenile facility staff, foster families, peers). When a family member, police officer, teacher or social worker is disturbed, irritated, outraged, or aroused by their own affective response to a gender nonconforming, or same sex loving young person, the unleashed responses are poured

onto, and pummelled into, the body and psyche of the young person, ranging from disrespect to violence (see Fine et al., 2017; Torre et al., 2018).

Evidence from WYI suggests that LGBTQGE young people carry painful amounts of contested misrecognition and resistance. For some the wounds are deep and widespread; for others, the wounds are hidden. We consider below structural sites of exposure to state violence – housing, police and schooling – as sites of misrecognition, discrimination and negative experiences, asking how often, for whom and under what conditions does precarity cascade into cumulative dispossession? And, we ask, what else emerges from these experiences? What is, for example the relationship of discrimination to activism? We consider housing insecurity, a well documented struggle for young people who identify as LGBTQ or gender expansive.

Disproportionality Along Key Vectors of Structural Precarity: Housing Insecurity, Bullying/Harassment and Police Aggression

Across these three vectors of precarity, we know from national surveys, queer youth suffer disproportionately when compared to their "straight" peers. On each metric, queer youth report higher than average rates of housing insecurity, bullying and harassment and police aggression. WYI data allow us to explore variations within, so we learn that youth of color and trans/gender expansive youth are most vulnerable. We report in the following section, data from the national What's Your Issue survey with a total *N* = 5,860 LGBTQGE youth. It is important to note that missing data varied from question to question and thus, the analytic sample may shift from one analysis to the next.

Across the sample, our respondents report housing insecurity rates of 40%, in line with national estimates (Choi, Wilson, Shelton, & Gates, 2015; Keuroghlian, Shtasel, & Bassuk, 2014; "True Colors Fund" at https://truecolors-fund.org/our-issue). Cautioned by youth researchers experienced in housing precarity, on the survey we defined housing insecurity broadly to include young people living in a public or not for profit shelter, in another family member's home or a friend's apartment, in foster care, inpatient institution, on the street, or feeling unsafe where they are sleeping, at least once in the last year. For housing insecurity, participants reported their housing/living situations over the past 12 months and indicated "How often have you faced not having a safe place to spend the night in the past 12 months?" on a scale of 5 = never to 1 = always. Participants were considered to have experienced housing insecurity if (a) they reported being homeless, living anywhere other than in a home they personally rent/own or the home of a parent/guardian and/or (b) reported any experience of not having a safe place to spend the night during the past 12 months. For a sample aged 14 – 24, the rates of "not having a safe place to sleep" are alarming. And then variations by race and gender are exponentially disturbing: youth of color are consistently more likely to experience housing insecurity than white youth, and trans and gender expansive youth substantially more likely than youth who are cisgender. Trans and gender expansive youth of color are almost twice as likely as white cisgender youth to report housing insecurity. The following tables (see Table 1, 2, and 3) reflect the percentage within each group by race/ethnicity and gender to report each experience.

Table 1

Percent of Youth Living With Housing Precarity: Race/Ethnicity and Gender

Gender	Youth of Color	White Youth
Cisgender (gender identity matches sex assigned at birth)	37% (*n* = 369 of 994)	28% (*n* = 395 of 1423)
Trans/Gender Expansive	54% (*n* = 676 of 1256)	42% (*n* = 860 of 2057)

We assessed experiences of bullying borrowing two items from the Youth Risk Behavior Surveillance System (Kann et al., 2018) asking: Have you ever been bullied?" and "Have you ever been electronically bullied?" (count being bullied through texting, Instagram, Facebook or other social media). We also asked young people if they were harassed in the last 12 months. In the last 12 months:

Table 2

Percent of Youth Bullied or Harassed: Race/Ethnicity and Gender

Gender	Youth of Color	White Youth
Cisgender (gender identity matches sex at birth)	87% (*n* = 812 of 936)	88% (*n* = 1174 of 1339)
Trans/Gender Expansive	91% (*n* = 1088 of 1194)	92% (*n* = 1825 of 1982)

And we have documented the race/gender distribution for young people who report negative interactions with police. We defined negative police contact as being stopped, frisked, or arrested:

Table 3

Percent who Report Negative Contact with Police

Gender	Youth of Color	White Youth
Cis gender (gender identity matches sex at birth)	27% (*n* = 273 of 1002)	15% (*n* = 213 of 1425)
Trans/Gender Expansive	36% (*n* = 444 of 1249)	18% (*n* = 365 of 2051)

Across these three matrices of structural injustice, we find that race matters dramatically in housing precarity and exposure to aggressive policing; gender matters on all three measures, and trans and gender expansive people of color endure the most systematic forms of oppression across various sectors of public life.

From Discrimination to Activism

We analysed the relationship between discrimination, economic, social and psychological outcomes, and also with activism. Specifically, we examined the associations between structural inequality (e.g., economic hardship, over-policing), interpersonal injustice (e.g., racism, homophobia, transphobia) and well-being (measured using

standardized indicators of psychological distress, physical health, and suicidal ideation). These associations are perhaps best articulated as a life story by Kat, an author and co-researcher from Detroit Represent!:

When asked, "Why do you think that being discriminated against makes young people more activist?" Kat connected the dots:

> My experiences 'in the system' encouraged me to become the change I needed when I was younger. I was in the system since I was 13; ran away, lived on the streets, in shelters, juvenile facilities, back into sleeping in an abandoned building. Then I met Lance who offered me a place to stay, and I learned the importance of activism and giving back. So now, as an activist and an organizer, I work on campaigns for housing, against domestic violence and for the human rights of young people living on the streets of Detroit.

Kat's experiences mirrors our empirical models, confirming the relationship of precarity and discrimination with activism; the buffering impact of activism on mental health, physical health and suicidal ideation, and the range and forms of activist solidarities WYI youth pursue.

Levels and forms of activism: As seen in Figure 2, queer and trans youth in the WYI sample are highly involved in activism. We assessed "civic engagement" building on a series of measures borrowed from Cohen and the Black Youth Project (Cohen et al., 2007). We asked youth to indicate whether they participated in any of 14 possible activities (e.g. "signed a paper or email petition," "been active in or joined a political or justice focused group" "worked with people in the neighbourhood on a problem or issue"… in past 12 months; we also assessed forms of activism by asking participants "Are you presently involved or participating in activist organizing work" in 11 different areas including LGBTQ issues, racial justice, gender justice, and environmental justice. Additionally, we asked participants were asked whether they participated in a community based organization.
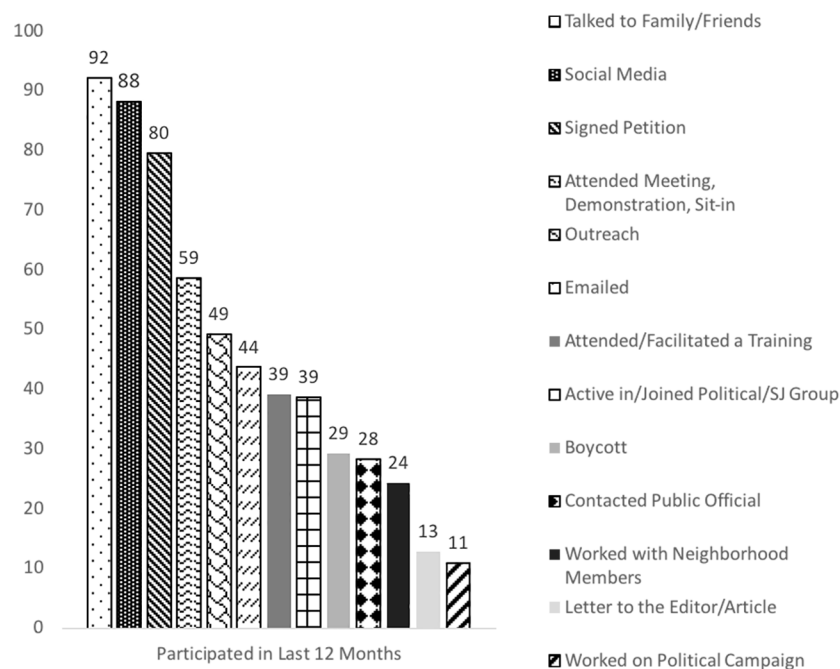

Figure 2. Percent of youth involved in activist activities.

It is important to note that the high level of civic engagement cannot be explained only by respondents' participation in community based organizations. In fact, only 30% of the respondents report that they are involved in a community based/youth leadership organization. Queer and trans young people across the country seem to be generally primed to activism, on the streets, through organizations, on line, and with family/friends.

Cutting a little more deeply into the database, Table 4 reveals two particularly interesting associations between discrimination and activism. Discrimination was measured by the Everyday Discrimination Scale (Williams, Yu, Jackson, & Anderson, 1997) of 9 items in which participants indicated how often they experienced forms of discrimination (based on race, ethnicity, gender, gender expression, sexual orientation, religion) on a scale of 6 = never to 1 = almost every day. Items included: How often: "You are treated with less courtesy than other people" and "People act as if they are afraid of you."

Table 4

Correlations Between Discrimination and Activism

Group	Activism Indicators	
	# of Activist Behaviors	# of Activist Areas
TGE & POC	.23	.24
TGE & White	.18	.22
Cis & POC	.21	.21
Cis & White	.15	.12
Total Sample	.22	.23

Note. All correlations are statistically significant at *p* < .001.

Interestingly, for the WYI sample, the more discrimination reported, the more activist behaviors engaged. That is, we find a robust relationship between experiencing injustice and fighting back. As important, however, the relationship is stronger for transgender and gender expansive youth and youth of color and relatively weaker among cisgender white youth. A buried resource within the LGBTQ/GE community, trans and gender expansive youth of color seem to be most adept at converting structural pain into political action. Particularly for queer youth of color and transgender, non-binary and gender non-conforming youth, activism may be a positive resistance response to discrimination among those who are most marginalized.

Of course, reverse causal explanations are also possible: activist youth may be more likely to explain their circumstances in terms of discrimination than non-activist youth, and queer youth of color and trans/gender expansive youth may be most adept at such "bottom up" analyses of resistance. Either way, we want to signal that this dynamic of discrimination metabolized into activism is a crucial generational dynamic worth further inquiry.

But What About Health? The Curious Relationship of Discrimination, Activism and Health Outcomes

In response to calls for more systematic inquiries into health inequalities faced by queer and trans youth (see Frost, 2017 for a review), we examine how experiences of discrimination and bullying—along with potential responses in the form of activism behaviour—were associated with indicators of health. Specifically, following the minority stress model (Meyer, 2003), we hypothesized that discrimination and stigma faced by LGBTQGE youth (i.e., the forms of discrimination and bullying discussed above) would be associated with poorer health outcomes.

Additionally, following critical and feminist analyses of positive marginality (e.g., Unger, 2000), we hypothesized that engagement in activism behaviors would be associated with better health (Klar & Kasser, 2009).

As can be seen in Table 5, both discrimination and bullying were indeed both associated with three indices of poorer health: higher levels of psychological distress and suicidal ideation along with poorer levels of self-rated health. And yet activism was positively associated with all three indicators of health. Even though the magnitude of this association was small, it is important to note that this association persists controlling for exposure to discrimination and bullying, which are known robust correlates of negative health (see Table 5).

Table 5

Multivariate Regression Models Testing Associations Between Discrimination, Bullying, Activism and Health Outcomes

Variables	K6				Suicidal Ideation				Self-Rated Health			
	B	Lower CI	Upper CI	Beta	*B*	Lower CI	Upper CI	Beta	*B*	Lower CI	Upper CI	Beta
Intercept	14.33***	13.35	15.32		1.68***	1.46	1.91		2.59***	2.40	2.78	
Person of Color	-0.26	-0.55	0.02	-0.02	0	-0.07	0.06	0	-0.01	-0.07	0.04	-0.01
Cisgender	-1.95***	-2.23	-1.66	-0.17	-0.41***	-0.47	-0.34	-0.16	-0.37***	-0.42	-0.31	-0.18
Age	-0.21***	-0.26	-0.16	-0.11	-0.05***	-0.07	-0.04	-0.13	0	-0.01	0.01	0.01
Discrimination	2.15***	1.99	2.31	0.39	0.35***	0.31	0.38	0.29	0.23***	0.20	0.26	0.24
Bullied	0.70***	0.38	1.01	0.06	0.14***	0.07	0.21	0.06	0.06*	0	0.12	0.03
Activism Behavior	-0.17***	-0.22	-0.12	-0.09	-0.02***	-0.03	-0.01	-0.05	-0.01*	-0.02	0	-0.03

*$p < .05$. **$p < .01$. ***$p < .001$.

To summarize the data to this point: First, queer and trans youth – at least those represented in WYI – are highly engaged in a range of social movements and activist strategies. Second, there appears to be a modest relationship between discrimination and activism, particularly for youth of color who are trans and/or gender expansive. Third, activism also seems to demonstrate a positive association with health, one that persists even when controlling for the well-demonstrated negative effects of discrimination and bullying. Fourth, we can see in Figure 3 that queer youth and young adults are engaged broadly in intersectional social movements, not only in LGBTQ movements but in a *wide range* of social movements.
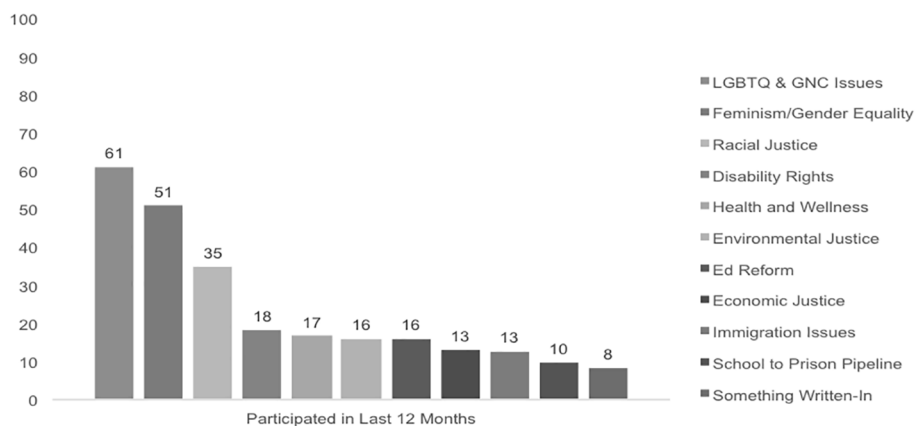

Figure 3. LGBTQGE youth involvement in social issues.

Insisting upon what Fraser (2000) calls a *Justice of Recognition*, and enacting what Ahmed (2014) calls *Willful Subjectivities*, young queer people live "unapologetically" at varied intersections, voicing commitments to and engaging broadly with a wide range of political solidarities (e.g. Black Lives Matter, Muslim American youth, young people with disabilities, prison abolition). Their activisms seem to demand recognition and transformation, not assimilation and inclusion; they voice a critique of structural/State/social violence and commit to feminism and gender justice, anti-racist organizing, disability rights, environmental justice and immigration justice. And as much as they engage these "normative" political strategies, they also take up a range of what we are calling "intimate activisms" with family and friends, for themselves, other queer youth and those coming up behind them.

Intimate Activisms

While our quantitative dataset reveals the intensity and range of activist commitments pursued by LGBTQGE youth, the qualitative material reveals a rich range of what we are calling *intimate activisms*. We take seriously what we now consider the *intimate politics* of queer activism – the hidden and bold, relational and solitary, everyday enactments of interruption, care and solidarity, evident in delicate challenges to family, friends, teachers, and strangers who vocalize discriminatory attitudes, enacted in deep *generosity/care work* with/for "others," and marked in the hilarious, if biting humor – that we call "*radical wit*" that jumps off the survey pages.

Inspired by Muñoz (1999), we want to end with some reflections on the wide range and forms of intimate activisms expressed by and among LGBTQGE youth. Beyond the substantial evidence of political solidarities, deep commitments to protest on the streets, posting and tweeting online, talking to family and friends, writing letters and showing up at public meetings, there are other forms of "intimate activism" animated throughout the survey – care work, speaking up/intimate interruptions and radical wit. We will briefly touch on these activist strategies. We draw largely from a cursory thematic analysis of narratives gathered across responses to the open ended question "What is your proudest moment?, as we did not anticipate these intimate activisms adequately when designing the quantitative items for WYI.

Deliberate and Delicate Interruptions

One of the ways in which LGBTQGE youth are advocating for themselves and for peers is by interrupting and initiating difficult conversations with family, peers, educators and strangers. Throughout the survey, there are many instances of these moments of deliberate and delicate interruptions. As one survey participant (who self-identifies as White, agender girl) recounts in response to a question about their "proudest or happiest moment":

> My proudest moment was two weeks ago, when I came out as gay to one of my teachers. Three years ago he had said some very homophobic things in my history class, and it stuck with me for basically the entire time between then and now – I became suicidal, depressed, and I went into denial about my identity. After talking to one of my friends (a straight ally) about what was up, and I got up the courage to confront him about it. I was pretty much terrified about the outcome (I thought that he wouldn't care about what he had done, would deny he had done anything wrong, etc.) but she convinced me to stick it out even after I tried to back out. I came out as gay to him, and told him about how what he said had affected me for so long; it was the first time I had actually told anyone that I was suicidal, and it was a huge relief to finally say it. He ended up being really supporting and took everything I said to heart. Even though I kind of regret telling him and my friend as much as I did, it feels good to say things which I hadn't been able to before. Now, I feel a lot more at ease with the fact that there are people who change and learn, and who care about me and my well being.

PsychOpen GOLD

A recurring theme shared by youth making these stands is the simultaneous feeling of strength and the discomfort when they challenge everyday heteronormativity and racism. As one participant describes, sometimes the conversations are on a large scale (what they call "Big Activism") and sometimes the conversations are on an interpersonal scale ("little activism")- and yet both are important. The young person (who describes themselves as queer, fluid, and bi-racial) shares:

> To me there is Big Activism and little activism. Big activism is protesting in the streets, is going to rallies and creating petitions, it is driving people to polls to make sure they can vote because you know that they aren't the people that those in positions of power want voting. Big Activism is actions that you take publically on a larger scale than yourself. little activism is just as important and I only call it little because of the way it seems smaller in proportion, not because of its relative importance. little activism is all of the things you do everyday to make the lives of those discriminated against better, it could be asking for preferred pronouns, setting up a safe space in your office, it could be tweeting about #BlackLivesMatter or making sure that people #StayWoke. It is a hundred little things that begins the death of a thousand cuts for the status quo.

And at other moments the tension is intimate, rising in the most important relationships. This participant identifies as a lesbian, cis female, Chinese American:

> When I was 21 I came out to my parents and while it was definitely not my happiest moment, looking back now I would have to say it's my proudest. I had to work hard and overcome a lot of things internally to be who I am today. We were in a hotel room for my sister's volleyball tournament and I handed them a manila folder with a letter I had been writing for the past six months. Coming out to first generation immigrant, Christian parents is not an easy feat. I broke their hearts when I told them who I was and while we are still in the process of figuring out how to love and understand each other, I'm glad I can die unapologetic about who I am or what I stand for.

As reflected in these responses, young people are taking up the intimate labor of interrupting the very banal offensive speech that is too common. In these moments they advocate for themselves and others. They risk rupturing tender, sometimes vital relationships, so they – and others – might be seen and recognized.

Care Work

Queer and trans youth are engaging in deliberate and delicate interruptions that challenge, and at the same time, they are also building *care worlds* and community. We hear in their words a stitched together "we", with a rich sense of generosity, a commitment to others, a knowledge of surviving in the cracks, and a wisdom mastered too young. That is, we hear much about what critical childhood studies scholar Wendy Luttrell (2013) calls *care work*.

While our findings suggest more research should be done in this area, we do have some suggestive quantitative evidence of care work: 23% report missing 1 or more days of school in the past 30 days to "take care of family responsibility"; 69% indicate they "make a difference in someone else's life" at least once a month, which seems as prevalent as a reported 70% of youth who to "achieve a personal goal" at least once a month or more, and 83% report spending days "helping a friend with depression."

We also grew attuned to care work as we reviewed questions, penned at the end of the survey, when participants were given the chance to "If you could ask three questions of other young people, what would you ask?" While

most asked questions like "how old were you when you came out?" or "do you daydream?", quite a few turned the focus back on others, asking how might "I" help you.

They explicitly make the connections between themselves and the imagined youth they are talking to, asking questions about what "we" might do or need. For instance:

How are you? (straight, female, Dominican American)

How can I help to make your life better? (bisexual, woman, White)

Can I give you a hug?, how are you feeling today?, do you want a cookie? (gray-asexual-pansexual, agender, White)

How can I make today a better day for you? (demisexual, trans male, African American)

Is there anything I can do to make a change in your life for the better? (pansexual, non-binary, White)

How can I help you? (queer, heavily leaning towards lesbian, ???, Black American)

What are we going to do to make this place better? (queer, nonbinary Black girl, Black)

These commitments to care were voiced over and over at our research collective meetings. At the participatory data analysis session, Kwan Moonlite, a co-researcher and colleague/ youth organizer at BreakOUT! in New Orleans, responded to the question, so What's YOUR issue?

When I think about my issue, I think about something that's in my mind all the time – the next time we get a flood in New Orleans, the next time the dams break, for QTPOC without family, who is going to protect us, even as we will try to protect ourselves and each other?

Denied the public and private assurances of protection and care, that too many of us who are relatively privileged may take for granted, for LGBTQ/GE young people questions of protection, care and responsibility sit on the very surface of their skin, and deep in their souls.

Radical Wit

Finally we have come to be interested in yet another form of intimate activism, what we are calling "radical wit." We have just begun to analyse these narratives, and so only offer this as a still forming/"forthcoming" thought. There is a long, and sometimes quite stinging legacy of humor from the shadows – Jews, Blacks, Irish, now Muslim women – and LGBTQ/GE comedians. Radical wit appears to be a discursive opportunity to parody the normative, expose the ugly, refuse the silences, critique the everyday thorns of oppression. Comics at the margins refuse to respect the proper silences that accompany oppression.

Radical wit was most apparent to us when we reviewed the range of responses to an item tucked away early on in the survey, where we asked the respondents: "If you could design a banner for yourself, what would it say?"

I was born gay, were you born an asshole? (natural, queer, woman, White**)**

We were all born naked and the rest is drag. (goldstar, platinum, double mile gay, male with some drag queer influences, sombrero AF, Latino, Native)

I am #tamirrice I am #sandrabland I am #john crawford (Straight?, nonbinary, two spirit, GNC, Peruvian)

Radical by necessity not choice (gay as hell, queer, pansexual, fluid, female, Korean, Asia)

Yellow Peril supports Black Power (lesbian, cis, biracial, Japanese/White)

Mexican, dyke, disability, woman… how much more powerful can I be in this country? (dykeness, cis gender, Mexican to the core, Maya/Aztec)

Disability is about a system of oppression, not about me being broken (straight, transman, White)

Flexing my complexion over white supremacy (Gay, boy, multiracial, Brazilian, Latino, Asian, Black)

My PGP is prison abolition (Queer, GNC, butch, White)

Hug a Gay Mormon: We Exist!! (I am a boy who is attracted to other boys for emotional and physical reasons, I am Caucasian and my family stems from Europe… I am LDS but have Jewish heritage and practice both Jewish and Christian holidays, White)

Reflections

We close by reflecting on the contributions this project makes to social and political psychology, justice studies, and activism research. We begin by asserting *misrecognition* as a social psychological and political experience that results in dispossession, health problems and also activism. Like African American scholar and activist W.E.B. DuBois who reflected on a question he was asked, "how does it feel to be a problem?" the young respondents to What's Your Issue refuse to be a problem: they will not be misrecognized, they reject their erasure, challenge the categories and violence that support harmful hierarchies, and they insist on being known in their full complexity. With a full embodied sense of Ahmed's "willful subjectivity," they refuse boxes and generate a rich palette of identities, fluidities and hybridities to narrate their subjectivities.

We also feel the need to comment on critical PAR in times of ideological assault on young people of color, queer youth and marginalized youth, and assert our commitment to "no research about us, with out us." This project was deeply participatory: in ways both profound and hysterically funny, enacted with great joy and pain, seamless and bumpy. To understand both oppression and resistance from and with those who have endured the most substantial violence from the State and from intimates, and remain radically generous and witty, is an epistemological gift. In this project we learn from/with young people that experiences of discrimination seem to accumulate in the body, and just as they are associated with material and psychological outcomes of dispossession, they also may metabolize into resistance – enacted as a range of activisms, both the traditional sort of protests and campaigns, and also the intimate sort including care work, social interruptions and radical wit. We witness, today, LGBTQGE youth organizing for gender/sexuality justice *and also* deep and expansive engagement with intersectional solidarities. We confirm, as our funders, and later youth colleagues anticipated, that LGBTQ/GNC youth of color are indeed disproportionately leading various social movements for gender, economic, immigrant/refugee and criminal justice.

We close indebted to our nearly six thousand respondents, and all those they represent, who carry the affective burden of misrecognition and yet teach us to transform pain into the passions of solidarity.

Notes

i) We acknowledge the controversy surrounding Junot Díaz brought from within the #metoo movement. Before any accusations were made public, we used this quote to provoke writing as part of our analysis process and found its call for "mirrors" useful for describing aspects of our research purpose.

References

Ahmed, S. (2014). *Willful subjects*. Durham, NC, USA: Duke University Press.

Berlant, L. (2007). Slow death (Sovereignty, obesity, lateral agency). *Critical Inquiry, 33*(4), 754-780. doi:10.1086/521568

Bullock, H., & Reppond, H. (2016). Of "takers" and "makers": A social psychological analysis of class and classism. In P. Hammack (Ed.), *The Oxford handbook of social psychology and social justice* (Oxford Handbooks Online). doi:10.1093/oxfordhb/9780199938735.001.0001

Choi, S. K., Wilson, B. D., Shelton, J., & Gates, G. J. (2015). *Serving our youth 2015: The needs and experiences of lesbian, gay, bisexual, transgender, and questioning youth experiencing homelessness* (Report). Retrieved from The Williams Institute website: http://escholarship.org/uc/item/1pd9886n

Cohen, C. J. (1997). Punks, Bulldaggers, and Welfare Queens: The radical potential of queer politics? *GLQ, 3*, 437-465. doi:10.1215/10642684-3-4-437

Cohen, C. J. (2010). *Democracy remixed: Black youth and the future of American politics.* New York, NY, USA: Oxford University Press.

Cohen, C. J., Celestine-Michener, J., Holmes, C., Mersth, J. L., & Ralph, L. (2007). *Black Youth Project: The attitudes and behavior of young Black Americans: Research summary* (Report). Retrieved from Black Youth Project Website: http://www-news.uchicago.edu/releases/07/pdf/070201.cohen-byp.pdf

Cohen, C. J., & Jackson, S. (2015). Ask a feminist: A conversation with Cathy Cohen on Black Lives Matter, feminism, and contemporary activism. *Signs.* Retrieved from http://signsjournal.org/ask-a-feminist-cohen-jackson

PsychOpen GOLD

Cole, E. R. (2009). Intersectionality and research in psychology. *American Psychologist, 64*(3), 170-180. doi:10.1037/a0014564

Conner, J., & Rosen, S. M. (Eds.). (2016). *Contemporary youth activism*. Santa Barbara, CA, USA: Praeger.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A Black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum, 1989*, 139-167.

Drury, J., & Reicher, S. (2005). Explaining enduring empowerment: A comparative study of collective action and psychological outcomes. *European Journal of Social Psychology, 35*, 35-58. doi:10.1002/ejsp.231

Dutt, A., & Grabe, S. (2014). Lifetime activism, marginality and psychology: Narratives of lifelong feminist activists committed to social change. *Qualitative Psychology, 1*(2), 107-122. doi:10.1037/qup0000010

Fanon, F. (1967). *Black skin, White masks*. New York, NY, USA: Grove Press.

Fine, M. (2017). *Just research in contentious times: Widening the methodological imagination.* New York, NY, USA: Teachers College Press.

Fine, M., & Burns, A. (2003). Class notes: Toward a critical psychology of class and schooling. *Journal of Social Issues, 59*(4), 841-860. doi:10.1046/j.0022-4537.2003.00093.x

Fine, M., Burns, A., Payne, Y. A., & Torre, M. E. (2004). Civics lessons: The color and class of betrayal. *Teachers College Record, 106*(11), 2193-2223. doi:10.1111/j.1467-9620.2004.00433.x

Fine, M., Torre, M. E., Frost, D., & Cabana, A. (2017). 'Speaking words of wisdom': Metabolizing oppression into intersectional activism, radical wit, and care work. In M. Fine (Ed.), *Just research in contentious times: Widening the methodological imagination* (pp. 97-112). New York, NY, USA: Teachers College Press.

Fine, M., Torre, M. E., Frost, D., Cabana, A., & Avory, S. (2018). Refusing to check the box: Participatory in(queer)y at the radical rim. In K. Gallagher (Ed.), *The methodological dilemma revisited: Creative, critical and collaborative approaches to qualitative research for a new era* (pp. 11-31). London, United Kingdom: Routledge.

Fine, M., & Weis, L. (1998). *The unknown city: Lives of poor and working-class young adults*. Boston, MA, USA: Beacon Press.

Fraser, N. (2000, May-June). Rethinking recognition. *New Left Review, 3*. Retrieved from https://newleftreview.org/II/3/nancy-fraser-rethinking-recognition.

Fraser, N. (2017, Winter). From progressive neoliberalism to Trump – and beyond. *American Affairs, 1*(4). Retrieved from https://americanaffairsjournal.org/2017/11/progressive-neoliberalism

Frost, D. M. (2017). The benefits and challenges of health disparities and social stress frameworks for research on sexual and gender minority health. *The Journal of Social Issues, 73*, 462-476. doi:10.1111/josi.12226

Frost, D. M., Fine, M., Torre, M. E., & Cabana, A. (2017, August). *Precarity and activism in the face of economic hardship: Results from a national participatory action survey of LGBTQ & GNC youth*. Paper presented at the European Conference on Developmental Psychology, Utrecht, The Netherlands.

Grabe, S., Dutt, A., & Dworkin, S. (2014). Women's community mobilization and well- being: Local resistance to gendered social inequities in Nicaragua and Tanzania. *Journal of Community Psychology, 42*(4), 379-397. doi:10.1002/jcop.21616

Hall, R. L., & Fine, M. (2005). The stories we tell: The lives and friendship of two older Black lesbians. *Psychology of Women Quarterly, 29*(2), 177-187. doi:10.1111/j.1471-6402.2005.00180.x

Hammack, P. L. (2010). Identity as burden or benefit? Youth, historical narrative, and the legacy of political conflict. *Human Development, 53*, 173-201. doi:10.1159/000320045

PsychOpen GOLD

Hammack, P. L., & Pilecki, A. (2012). Narrative as root metaphor for political psychology. *Political Psychology, 33*(1), 75-103. doi:10.1111/j.1467-9221.2011.00859.x

Honneth, A. (2003). Redistribution as recognition: A response to Nancy Fraser. In N. Fraser & A. Honneth (Eds.), *Redistribution or recognition? A political-philosophical exchange* (pp. 110-197). New York, NY, USA: Verso.

Honneth, A. (2007). Recognition as ideology. In B. van den Brink & D. Owen (Eds.), *Recognition and power: Axel Honneth and the tradition of critical social theory* (pp. 323-347). Cambridge, United Kingdom: Cambridge University Press.

Kann, L., McManus, T., Harris, W. A., Shanklin, S. L., Flint, K. H., Queen, B., . . . Ethier, K. A. (2018). Youth Risk Behavior Surveillance – United States, 2017 [Morbidity and Mortality Weekly Report]. *Surveillance Summaries, 67*(8), 1-114. doi:10.15585/mmwr.ss6708a1

Keuroghlian, A. S., Shtasel, D., & Bassuk, E. L. (2014). Out on the street: A public health and policy agenda for lesbian, gay, bisexual, and transgender youth who are homeless. *The American Journal of Orthopsychiatry, 84*(1), 66-72. doi:10.1037/h0098852

Klar, M., & Kasser, T. (2009). Some benefits of being an activist: Measuring activism and its role in psychological well-being. *Political Psychology, 30*(5), 755-777. doi:10.1111/j.1467-9221.2009.00724.x

Lott, B., & Bullock, H. E. (2006). *Psychology and economic injustice: Personal, professional, and political intersections.* Washington, DC, USA: American Psychological Association.

Luttrell, W. (2013). Children's counter-narratives of care: Towards educational justice. *Children & Society, 27*(4), 295-308. doi:10.1111/chso.12033

Mayo, C. (1982). Training for positive marginality. In C. L. Bickman (Ed.), *Applied social psychology annual* (pp. 57–73). Beverly Hills, CA, USA: SAGE.

Meyer, I. H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: Conceptual issues and research evidence. *Psychological Bulletin, 129*(5), 674-697. doi:10.1037/0033-2909.129.5.674

Meyer, I. H., & Wilson, P. A. (2009). Sampling lesbian, gay, and bisexual populations. *Journal of Counseling Psychology, 56*(1), 23-31. doi:10.1037/a0014587

Muñoz, J. E. (1999). *Disidentifications: Queers of color and the performance of politics*. Minneapolis, MN, USA: University of Minnesota Press.

Reicher, S. (2004). The context of social identity: Domination, resistance, and change. *Political Psychology, 25*(6), 921-945. Retrieved from https://www.jstor.org/stable/3792283 doi:10.1111/j.1467-9221.2004.00403.x

Stetler, C. (2009, October 26). Junot Díaz: Man in the mirror. *NJ Star Ledger*. Retrieved from https://www.nj.com/entertainment/arts/index.ssf/2009/10/junot_diaz_man_in_the_mirror.html

Su, C. (2009). *Streetwise for book smarts: Grassroots organizing and education reform in the Bronx*. Ithaca, NY, USA: Cornell University Press.

Taylor, C. (1992). The politics of recognition. In A. Gutman (Ed.), *Multiculturalism: Examining the politics of recognition* (pp. 25-73). Princeton, NJ, USA: Princeton University Press.

Torre, M. E., Fine, M., Cabana, A., Frost, D., Avory, S., Fowler-Chapman, T., & the What's Your Issue? Youth Research Collective. (2018). Radical wills (and won'ts): Critical participatory inqueery. In S. Talburt (Ed.), *Youth sexualities: Public feelings and contemporary cultural politics* (Vol. 2, pp. 169-191). Westport, CT, USA: Praeger.

PsychOpen GOLD

Torre, M., Fine, M., Stoudt, B., & Fox, M. (2012). Critical participatory action research as public science. In P. Camic & H. Cooper (Eds.), *The handbook of qualitative research in psychology: Expanding perspectives in methodology and design* (2nd ed., pp. 171-184). Washington, DC, USA: American Psychological Association.

Torre, M., Stoudt, B., Manoff, E., & Fine, M. (2017). Critical participatory action research on state violence: Bearing wit(h)ness across fault lines of power, privilege, and dispossession. In N. Denzin & Y. Lincoln (Eds.), *The SAGE handbook of qualitative research* (pp. 492-516). Beverly Hills, CA, USA: SAGE.

Unger, R. K. (2000). Outsiders inside: Positive marginality and social change. *The Journal of Social Issues, 56*(1), 163-179. doi:10.1111/0022-4537.00158

Williams, D. R., Yu, Y., Jackson, J. S., & Anderson, N. B. (1997). Racial differences in physical and mental health: Socio-economic status, stress and discrimination. *Journal of Health Psychology, 2*(3), 335-351. doi:10.1177/135910539700200305

Young, I. M. (1990), *Justice and the politics of difference*. Princeton, NJ, USA: Princeton University Press.

Yuval-Davis, N. (2012) *The politics of belonging: intersectional contestations*. London, United Kingdom: Sage.

Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Can Digital Health Save Democracy? Meeting the Cosmopolitical Challenge of Digital Worlds

Elena Gonzalez-Polledo*[a]

[a] Department of Anthropology, Goldsmiths, University of London, London, United Kingdom.

Abstract

This article explores the challenges and opportunities of social media health activisms to shape public participation in the digital future of healthcare. As health becomes ever more entangled with digital technologies, a growing ecology of digital health services promise greater individual autonomy to learn about and managing medical conditions, as well as accessing health services and engaging in forms of self-care. Cautioning against optimist visions of digital health and their promise of empowerment and autonomy, the article explores how health activisms on social media are reclaiming visions of healthcare that move beyond individual and depoliticised models of health technologies. The notion of cosmopolitics is employed to conceptualise relations between technology and health that implicate human and non-human interests in entanglements between health, morality and technology.

Keywords: health, digital health, surveillance, politics, social media, healthcare futures

The potential of social media platforms and digital health technologies to improve healthcare has been widely discussed in medical literature, public health and popular media in recent years. The rapid adoption of digital health technologies and artificial intelligence in medical research and clinical practice is making possible new organisational approaches to healthcare provision (Martínez-Pérez et al., 2013), where the aggregation of large databases yields new forms of value (Parry & Greenhough, 2018). These technologies have come hand in hand with new capacities for observation, tracking and prediction, underwritten by promises of greater autonomy and better health for users, and of growth for service providers and new enterprises linked to the endless analytic possibilities of health-related data (Milne, 2018)[i]. These technologies enact socio-technical interactions where patient identities, clinical roles and illness worlds are transformed by technological mediation. In making new kinds of communication possible within and across groups, digital technologies enable access to health services, and

become drivers of systemic transformations of the kinds and quality of healthcare services, while they also pose new challenges of access and integration for health services.

Data-centrism in general medical practice and public health is generally understood as inevitable. However, despite a promise of endless progress derived from the analysis of information aggregates, research shows that the reality of data driven healthcare is also riddled with risk and frictions. As Prainsack (2017) has noted, data driven processes pose new challenges to clinicians, patients, health authorities and enterprises, who struggle to turn unprecedented amounts of data into meaningful and actionable analyses. As health becomes ever more entangled with digital technologies, the growth of medical services increasingly also necessitates a new model of healthcare delivery where active patients are willing to be involved as participants in producing and interpreting data, as well as using digital technologies to learn about and manage their conditions (Lupton, 2013). In this context, data that was previously understood not to be relevant to healthcare, such as user produced lifestyle data stored in apps and social media, is now understood as a resource to complete medical histories and power personalised treatments. The increasing complexity of digital health ecosystems poses new interoperability challenges to work across multiple infrastructures and data sets, and users have less control of how their data travels in 'seamless' models of data driven healthcare (Wadmann & Hoeyer, 2018). Although research points to ways in which medical technologies are routinely appropriated by users and clinical professionals to creatively pursue their own ends, for example in terms of reproduction, education and health optimisation, data driven processes pose new risks for individuals and populations as automated decision-making and decisions by data can harbour old and new forms of social violence and inequality (Eubanks, 2017; Noble, 2018; O'Neil, 2016).

As data worlds demand governmentality challenges of renewal to respond to the challenges of information societies (Floridi, 2014), digital politics are increasingly understood as a response to calls for accountability, transparency and access that are now central to defining how collaborations between public and private sector organisations need to be regulated (see, for instance, Sorell, 2017; Draper & Sorell, 2013). However, it is still far from clear how a public interest in embedding ethical practice in data driven healthcare can shape the commercial interests of health corporations and venture platforms. Questions about how ethics should underpin data-centric healthcare have taken central stage as new actors and processes threaten to erode public models of healthcare in favour of integrating an array of diverse actors and third party services, which pose new difficulties to health authorities in terms of quality standards and regulation. Powell et al. (2016) have argued that public rights in relation to digital health empower users through a new model of digital citizenship – one that could come with new rights and obligations over data, as well as yet to be established responsibilities for organisations. These new forms of digital citizenship situate data as a key currency of epistemic value that comes with new and changing sets of rights and responsibilities attached[ii]. As networks-in-formation, data worlds assemble users and organisations through information pathways and solidarity networks, social media is becoming ever more central to finding information and articulating patient concerns than any other source (Vicari & Cappai, 2016, p. 1665). In this context, the effective use of social media can become key to shaping the role of patient voices in the future transformation of healthcare. For example, in the United Kingdom, the Patient Voices network[iii] situates digital storytelling at the core of attempts to involve patient voices in the transformation of healthcare (Hardy & Sumner, 2018). Weighting the 'evidence of experience' against mainstream evidence-based healthcare agendas, this network uses digital stories as devices to improve healthcare delivery by effectively engaging patient concerns, generating dialogue, with the aim to transform organisations and healthcare delivery.

However, despite the promise of digital storytelling in clinical contexts, the capacity of patient organisations to effect change, as Rabeharisoa (2006) notes, grows around biosocial entanglements that can mobilize patient identities, knowledge and political action. Beyond weak individual interactions, traditional patient organisations facilitate effective forms of participation, visibility and direct action. As collective actors, patient organisations are shaped by public and scientific knowledge as they link knowledge, citizenship and action spaces. Rabeharisoa et al. (2013) suggest that the expertise and effectiveness of patient organisations 'lies in their capacity to articulate various knowledges, so much so that what constitutes evidence for patients may also count as such for scientific and health professionals' (p. 11). Their role is to translate medical knowledge and help concerned parties develop background knowledge to back statements and claims that can support them pursuing a diagnosis and care. Digital worlds, by contrast, don't simply mirror or coexist with healthcare frameworks, but, rather, become as an affordance of information infrastructures, testament of their world-making capacities. Media platforms generate new imaginaries of citizenship no longer tied to emplaced identities but assembled in the coming together of people, issues, and infrastructures demanding rights through data (Isin & Ruppert, 2015; Marres, 2006). Social media platforms make possible forms of cooperation and collective thinking that shape how issues matter, contributing to 'counter-emplot' (see Dumit, 2006) illness narratives and health experiences in continuities between life, media and technologies (Kember & Zylinska, 2012). While multiple interests shape how digital platforms collect and use data, people often use social media platforms to make public the experience of living with illness, and to create public spaces that reframe what should count as expert health knowledge (Page, 2012). Digital environments make visible ways of knowing, and living, otherwise, link health practices to everyday social worlds, and provide a background for experimental definitions of both health and politics (Ginsburg & Rapp, 2013; Goggin & Newell, 2003).

Yet the contrast between organised patient associations and digital activisms is not merely between reformist and confrontational approaches to advancing healthcare users' agendas. While ethical questions regarding the integration of digital technologies in healthcare often presume the inevitability of their adoption, highlighting the need for public voice in overarching themes of consent, fairness and rights, Lupton (2017) has shown that users' own maps of the promises and potential of digital health highlight the need to think more critically about ethical and social issues, and pay particular attention to the distinctions that emerge in contextual technological adoption. In Lupton's study, participants felt that overarching discussions of ethics did not adequately capture the multi-sided effects of self-management for patient identities, or the forms of exclusion generated due insufficient infrastructures, socioeconomic disadvantage, health status, or because of inadequate framing of the health needs of particular populations.

The following sections explore some ways in which digital health practices in social media environments can challenge universal logics of progress associated with discourses about the central role of technology in healthcare futures. By pointing to subversive or excessive uses of technology as central to definitions of health, digital activisms make a significant contribution toward reshaping the core issues emerging from living in a digital age, changing conversations about what should matter in health debates. Problematising distinctions between 'life-nurturing and life-negating habitation', these activisms challenge premises and promises of data centric healthcare by becoming a public domain where claims about health can be made without necessarily seeking health reform. In this sense, these activisms allow us to frame the politics of technology beyond formal distinctions between personal and algorithmic agency, and crucially without recourse to distinctions that pit data ethics against politics. Rather, I propose to propend the prefix cosmo- to digital health politics to recuperate technological politics as multiple, situated, processual and unfinished, politics implicated in multiple processes, and which not concern only a priori ethical

principles or universal notions of progress. For Isabelle Stengers (2011), the question about cosmopolitics demands taking seriously the limitations of universal logics to accommodate resolution to political relations. Stengers' demonstration of cosmopolitics in the context of physics illustrates how, against a priori teleologies of scientific practice based on a universal rationality, the space of science demands that the conditions of politics be invented (Stengers, 2011, pp. 354-355). For Stengers, 'the prefix [cosmo] makes present, helps resonate, the unknown affecting our questions that our political tradition is at significant risk of disqualifying' (2011, p. 355). Cosmopolitics is a speculative concept that relies on alterity and context to avoid identifying with a progress story to define politics beyond slogans and disparities between absolute concepts, not least, as Stengers notes, disparities between 'ourselves' and 'others' (2011, p. 356). The anthropologist Marisol de la Cadena, for example, conceptualises cosmopolitics in relation to indigenous political worlds that emerge from the need to reconceptualise politics beyond colonial narratives of progress. De La Cadena's (2010) engagement with cosmopolitics renders politics newly relevant to postcolonial and neoliberal crises. Importantly, cosmopolitics encompass arrangements of human and non-human beings, representing a need to 'slow down reason' to locate more than human practices that may allow new interpretations and responses (p. 337). Indeed, for Latour, cosmopolitics can prevent both the premature closure of politics by resisting meanings of cosmos that mean a final list of entities to be included in politics, while it also sets politics against a premature closure of the notion of cosmos, for example, around idioms that link politics to human sets of human relations (see Latour, 2004, pp. 454-455).

While the application of a cosmopolitical framework may not necessarily be new in the context of scientific practice, I argue that it is particularly relevant to sedimented media histories. As neoliberal policies exacerbate the fragility and uncertainty of care, cosmopolitics open up the temporalities of the political to new objects, agencies and processes, and can lead to recognising value in a slow, 'idiotic' approach to politics. While the debate about digital health development has often focused on the agenda of large service providers and corporations, bringing to the foreground localised digital activisms around health extend definitions of the political to critical and utopian thinking through media practices. Cosmopolitics, in this sense, can be described as an experimental concept of political relations concerned both with the affirmation of life at the margins and, as Farias suggests, 'an opening toward the unknown, toward alternative definitions of the common world' (Farías, 2017, p. 36). Digital worlds afford new contexts in which new kinds of health politics come to matter, demanding recognition of forms of living which do not neatly fit neatly mainstream biomedical models. Rather, these uses of technology evince how technological mediations re-situate health experience in pre-digital inequalities, as well as new data centric logics, to pursue health agendas that are not pre-given, but emerge as a result of sociotechnical interactions, making possible to demand health rights through data, and participation in changing conversations about healthcare futures.

Technical Objects, Interfaces and Disaggregation

Let me briefly conceptualise the ways in which digital data adds value to health systems. As digital data have become ever more ingrained in everyday life, their purchase in redefining health comes hand in hand with the reliance of venture services on user data in order to improve clinical outcomes within and across user groups (Lupton, 2014). Clinical professionals and patient groups use social media to share medical knowledge with wider communities, to gain new knowledge about health, and to provide information, patient education, and advertising goods and services. Digital data makes possible modes of extra-clinical observation which allows clinicians to form more complete medical histories, bringing life activities and behaviours which may not have been considered

relevant to healthcare provision to bear on diagnostic and treatment outcomes (Sosnowy, 2014). Multiple devices, platforms and fora offer interfaces to control users' health practices through a range of affective, haptic, and functional atmospheres (Ash et al 2018; Tucker & Goodings, 2017). Through design and usability aspects, they become 'sites of desire and recipients of affect' (Shah, 2015, p. 2) shaping everyday health practices, and revealing, through design and usability features, semiotic patterns at play in how institutions work and think.

Digital models of patient participation encourage patient activation by engaging users with their personal data – encouraging active responses to accessing records, information and advice online. In this context, new questions emerge around the transformation of personal data as a driver of healthcare. First, as Aicardi et al. show, the personal and the individual are no longer synonymous in the digital age. As technological objects reshape patient identities implicating technicity in the process of managing illness (Mackenzie, 2002, pp. 16-19), digital health raises new fundamental questions about the interdependency of digital and political worlds. The materiality of information now 'operate(s) as a site of analysis which is simultaneously technical and cultural' (Aicardi et al., 2016, p. 58). Technical objects expose cultural fictions that bound together people and technologies and evince how technical and cultural realms are bound together (Schwennesen, 2017; Seaver 2017) producing continuities and spatial proximities between people, devices and infrastructures. But while digital interfaces shed light on how institutions produce health as a capacity newly reimagined though informational materialities[iv], healthcare is no longer about whole human persons, but rather, the digitised fragments, samples and data that interfaces can work with. Data processing, particularly machine learning, poses new ethical challenges as algorithms 'hover high above the flow of data, attempting to force fit the snippets of information in to patterns that represent its target' (McQuillan 2018a, p. 5).

In this sense, human-technology interactions are no longer located at the centre of technological politics as non-human agencies gain centrality as recipients of information flows. The new imaginary that derives from these data worlds, as Shah suggests, reverts the social to an ontology of interactions: data circulation does not primarily derive its value from being interpretable by human readers, but is aimed at mechanic processors which can make sense of information flows. Third parties providing digital healthcare services rely on software and agile working to undertake digital transformations in health services. These technological 'solutions' are developed by external supply-side vendors who effectively develop and market technology (Lidell et al., 2008). This operating model is underpinned by economic interests realised through commercial partnerships, where health data becomes part of large scale aggregates analysed and re-analysed through speculative processes of algorithmic learning, leading to health data not simply being collected but emerging over time as datasets are cleaned, re-analysed and linked to other data sets.

In this context, ethical issues surround the production, collection and use of health related data, and yet the assessment of the social implications of technology have only partially included public voices[v]. The becoming of digital worlds brings together multiple agendas, involving people, organisations and infrastructures in defining and pursuing healthcare futures. However, these futures may not be easily accommodated under single definitions of the public good. Promises of venture platforms such as PatientsLikeMe's much debated campaign 'Data for Good', which aimed to encourage data sharing to help data make medical science 'advance faster' while promising 'a better future to someone like you', are now shown not to have delivered on their promise of democratisation[vi]. Tempini and Del Savio's (2018) empirical research paints a bleaker picture of the platform as a business model for medical research: while driven by the exceptional medical knowledge accrued by patients with chronic conditions, the platform has done little to advance their medical agenda, often voiding the promise of return to patients who

drive the platform by donating their data (Prainsack, 2017). While the platform seeks to involve patients in their own self-management, and improving their autonomy from biomedical knowledge and services, in practice the model entails that the labour and investment of patients goes unrecognized. Indeed, in this model, people are not passive objects who receive the expert knowledges at the end of a data cycle, but become the primary human resource to shape not only biomedical research, but unknown technological futures predicated on future values of their data.

For Aicardi et al., an important consequence of the data shift in biomedicine is that it raises new questions about the possibility of replicating benchmarks of privacy and confidentiality that subjected the collection and use of personal data in ethical research. Aicardi et al. note the difficulties in providing informed consent, a mainstay of ethical research. Furthermore, they note that in an age of aggregation and data science

> The challenge ahead is not so much that of extending existing ethical principles and reflecting on how they play out in a changing landscape of data collection and use. Instead, along with methodological changes, the management of health databases and biobanks is accompanied by changes in the social, economic, and moral order, which require a new language in which we frame and address the ethical challenges arising (Aicardi et al., 2016, p. 211).

More importantly, digital interfaces provide a new scale to think through the coming into existence, the erasure and transformation of health as an experience. As global health databases expand to include and aggregate multiple types of health data, users are also turning to social media in order to claim new rights around data, including rights to access services and to shape discussions about the future of healthcare. Isin and Ruppert (2015) note that the process of becoming citizens in digital worlds not only comprises processes of shaping internet regulation, but how technologies are embedded in socio-technical arrangements that create new ways of subjectivity and citizenship -as users and producers of digital technologies- (2015, p. 6). Citizenship, in digital societies, is a changing notion shaped by internet participation, which, among other processes, may lead to imaginative ways of engaging with government practices. In this context, digital infrastructures become a condition of citizenship. Yet, rather than adopting the existing figure of the citizen gaining rights through internet participation, Isin and Ruppert (2015) think of the digital citizen as 'an embodied subject of experience who acts through the Internet for making rights claims' (p. 11) What is important regarding the act of defining digital citizens, they argue, is to account for a transversing political subject who becomes global by engaging multiple struggles, a cosmopolitical citizen defined through digital practices. The political subjectivity that digital technologies afford, in their view, requires theorising digital life and political life in non-deterministic ways, as subjects are enacted through struggles across multiple domains. Indeed, for Isin and Ruppert there is a critical dimension of digital citizenship that emerges clearly though how people use internet practices to disrupt politics as usual.

Health, Experience and Mediation

Digital citizenship can enliven debates around digital health by providing new relevance of the distinction posed by Foucault and Deleuze between politics and the political (see Foucault & Deleuze, 1977). For Foucault and Deleuze, politics may refer to the continuity of institutions and the management of populations (potestas), while the political emerges as a capacity for subversion linked to the disruptive capacities of critical events (potentia). Although these two dimensions have separately been deployed to analyse how commercial technological appli-

cations make bodies and persons more amenable to surveillance, it also applies to how social media's affective atmospheres shape the experience of politics (Papacharissi, 2014). Digital health activisms, particularly on social media, appropriate technology to experiment with alternative definitions of health, and explore the potential of these interventions to address health inequalities experiments in thinking critically, while at the same time leading to ruptures in both. Ethnographic studies of social media use among healthcare users point out the capacities of social networks to generate communities of trust, highlighting the everyday significance of media worlds to make or break sociality. For example, Miller's (2017) study of social media use among terminal patients explores how social media 'solved' communication problems for many cancer patients, who used digital technologies to communicate about their illness, were empowered by choices regarding when and how they could communicate about their illness, sometimes posting information preceeding offline encounters, or choosing the amount of information given to acquaintances. Miller understands social media as an extension of local cultural scripts that dictate how people socialise and communicate in the public domain. However, while social media may afford intimacy despite geographical distance, their potential to make or break relations was not equally evident to all participants in Miller's ethnography. Rather, Miller contends that platforms are part of ecologies or polymedia that allow users control over social situations, making some social relations possible or inviable, promoting participation or forcing distance, and providing a background for social lives to cohere. Not only do they provide proximities between people living with illness and health professionals, but, more importantly, they call into being social ways of feeling by making public issues that may otherwise be obscured by forms of structural prejudice at the level of public discourse.

In this context, digital citizenship is becoming a fundamental right to enable individuals to participate in the governance of health services, which remains particularly challenging for vulnerable and marginalised groups (Groleau, 2011). Social media generates social worlds that shift the location of health from inside the body to distributed environments, in which technical objects, infrastructures, stories and allegories mark what becomes relevant to health as an experience, contrasting ways of living with the acuteness of diagnostic interventions (Dumit, 2006; Manderson & Smith-Morris, 2010). While the biomedical model of health recognises the importance of translations between physical, psychosocial and social domains, and it has consistently relied on technologies to assess, diagnose and make sense, social media and the internet of things relocate users' experiences of illness in multiple interfaces and algorithmic logics, encouraging users to move between platforms, social media, websites, wearables and apps. As such, these systems are best understood as relational ecologies that organise the present. Indeed, part of the contradiction that social media holds for health activisms is condensed in the politics behind its 'realtimeness'. For Weltevrede, Helmond, and Gerlitz (2014), social media real time is not a flat universal, but rather a distributive fabrication (p. 5) which articulates experience by organising content in relation to multiple temporal frameworks. Not only does this process affect the construction of patient identities (Koteyko & Hunt, 2016), but belonging in multiple and changing units of participation produces experimental forms of thinking and feeling linked to multiple claims to health rights through data. For instance, social movements can make visible conditions and illness experiences while advocating for the right to disengage from media applications for practical, ideological or technical reasons, and demanding public participation in the shaping of healthcare services.

Consider chronic illness activisms. People living with chronic illnesses are widely regarded as the most active patient groups online, bringing together multiple health experiences across platforms to re-frame expert health knowledge by demanding inclusive definitions of illness no longer tied to biomedical diagnostic categories. These activisms use social networks to challenge systemic prejudice against the validity of patient testimonies. These epistemic boundaries have been well documented: Kidd and Carel (2017) report that value distinctions between

patient testimonies and those of clinical professionals is the most often reported barrier to inclusion. Epistemic injustice associated with chronic illness not only leads to unequal relations that affect individuals, but can, over time, lead to undermining social confidence and sustaining forms of social injustice. For Kidd and Carel, the routine undermining of existential ways of knowing illness 'others' patients by linking the assumed lack of reliability of patient testimonies with the structural position of an ill person as 'impaired' by their illness. Patient complaints centres denounce the often reported lack of 'testimonial sensibilities' they encounter in clinical relations, the failure of clinicians to connect with patient narratives, and their being perceived by patients as cold, impersonal, and dismissive (p. 7). In contrast, digital health activisms seek to counter epistemic prejudice through solidarity networks that empower people to make associations and enact resistances through criticism and direct action. For instance, London's Chronic Illness inclusion Project, which spreads across a number of platforms and defines the experience of chronic illness as a self-reported condition based on perceived capacities to cope with the weight of everyday activities. Social media users linked to this project advocate for changes to traditional definitions of what counts as chronic illness, and the expansion of diagnostic categories by including forms of self-reporting[vii]. Jennifer Brea's documentary film *Unrest* documents the journey of learning to see differently where biomedical models could not see a complete picture. Social media became a resource in the filmmaker's elusive search for information regarding ME/CFS (Myalgic encephalomyelitis / Chronic Fatigue Syndrome), but the role of social networks in leading to public awareness, organised protest and eventual recognition of the physical symptomatology of the CFS syndrome. Community design projects and Human Computer Interaction practitioners facilitate participation by addressing structural differences and involving communities in defining the impact of issues such as race, income, power and equity that work against populations. As Parker (2013) notes, social involvement in the shaping of technological futures continues to be important in making communities around participation, as well as designing spaces that foster the involvement of public voices in the transformation of health services.

Indeed, these critical stances are all but new. Patient associations have long been involved in in intervening expert definitions of health problematics, and seeking to make medical systems accountable. Although digital health ecologies have been linked to a modernist logic of medicalisation that tends to individualise and depoliticise illness, while maximising the creation of value out of users' data, social media activisms evince how people's use of these technologies transform health experience in public environments where claims about health futures can be made public and negotiated. Social media offers a democratic potential to mobilise dissenting experiences to reframe what is at stake, opening up spaces where knowledge itself is the target of activism, but where, rather than being pre-set at the outset, the goal emerges over time. These processes enable people to invent and contest conventional meanings of health, situating experience across forming and shifting collectives, infrastructures, health and information systems, and mediation. These evidence-based activisms, as Rabeharisoa et al. (2013) have shown, achieve epistemic shifts by foregrounding the experiential knowledge of patient groups and health professionals in healthcare reform. Challenging ableist definitions of health by highlighting the social basis of illness, these activisms contest dominant models of active patienthood predicated on the involvement of individual users in producing and analysing their own health related data. Digital worlds evince the significance of relations, both human and non-human, and change public conversations by making a difference in public debates.

Conclusion: Cosmotechnical Futures

The wide presence of digital technologies in debates about the future of healthcare demands thinking through politics as presupposing multiple logics and rhythms. Rather than uncritically accepting digital technologies as conduits to equity, the essential multiplicity of these technologies demands a critical situated understanding of the relations that produce health. This article has argued that multiple health activisms enabled by digital technologies open up the way in which diverse experiences may inform digital healthcare in the future. Thinking *with* interfaces, digital futures must be open to account for multiple data politics, and for the uncertain. In this sense, their speculative potential must be recognised. As Shotwell has argued, these futures are never pre-given but, rather, 'grounded in the experience of interdependence, politically organized around the idea of identifying into a world that we create starting from the speculation that it could be otherwise than it is' (Shotwell, 2016, p. 193). As speculative health practices become part of this these complex futures necessitates concerted efforts to democratise technology, and to assess their purchase and potential for changing public debates.

Digital worlds afford multiple political agencies as they are constituted differently in particular contexts. Hence, the analysis of their purchase must also take seriously the challenge of their situatedness, as well as grapple with technology as a universalizing force (Dourish & Bell, 2011). Hui has argued that the reconciliation between the general and the particular characterises technologies as a form of cosmotechnics – which reflect the intrinsically multiple status of technologies. Hui (2017) defines cosmotechnics as the 'unification of the cosmos and the moral through technical activities', a definition which needs to attend to historical particularity as much as universal processes of technological acceleration and globalization. Indeed, digital technologies transform not only individual experiences of illness, but social environments, norms and logics of practice. By intervening politics as usual, digital worlds decentre relations and open a space to revalue the politics of experience. Digital health activisms evince the importance of technological mediation to reverse conventional cultural narratives about health experience and social justice activism, as technology provides ways of overcoming barriers of access to knowledge, intervening how and in what contexts issues and publics come to make a difference[viii].

Importantly, social media health activisms health activisms invite us to abandon naïve claims of machinic Neoplatonism, to borrow McQuillan's (2018b) description of the philosophies behind data science. As digital health becomes pervasive, there is an increasingly pressing need to open up democratic participation to address health inequalities through digital technologies, and to diversify the voices and experiences that shape healthcare. Lest health practices be 'fitted' to a digital model where metrics override qualities of health experience, digital health activisms point towards how avoiding a view from nowhere might entail recuperating standpoints from which to refocus healthcare futures. This investigation of data and its real-timeness has the potential to reconfigure what is thinkable by developing sensibilities and new forms of attentiveness to the tensions between surveillance and justice.

Notes

i) See, for example, Scotland's Digital Health Institute's ambitious plan to integrate health and social care at
https://dhi-scotland.com/about-dhi/scotlands-opportunity

ii) A concept that does for data what Heath, Rapp and Taussig (2004) dubbed genetic citizenship for genetics, p. 152.

iii) See http://www.patientvoices.org.uk

PsychOpen GOLD

iv) See, as an exception, Wakeford's (2002) model of Citizen's Juries. A number of recent studies have addressed scandals surrounding automated decision-making in welfare. See for example the Robo-Debt debacle in Australia, or the social implications of aggregators determining insurance and welfare claims in O'Neil (2016) and Eubanks (2017).

v) See digital.nhs.uk

vi) See http://news.patientslikeme.com/press-release/patientslikeme-launches-data-good-campaign-encourage-health-data-sharing-advance-medic, accessed January 2018.

vii) See http://inclusionproject.org.uk/about

viii) For instance, see debates around the forum Health Talk Online (http://www.healthtalk.org), which offers a space for people seeking health information and support to share information and participate in research.

Funding

Competing Interests

The authors have declared that no competing interests exist.

Acknowledgments

References

Aicardi, C., Del Savio, L., Dove, E. S., Lucivero, F., Tempini, N., & Prainsack, B. (2016). Emerging ethical issues regarding digital health data: On the World Medical Association Draft Declaration on Ethical Considerations Regarding Health Databases and Biobanks. *Croatian Medical Journal, 57*(2), 207-213. doi:10.3325/cmj.2016.57.207

Ash, J., Anderson, B., Gordon, R., & Langley, P. (2018). Unit, vibration, tone: A post-phenomenological method for researching digital interfaces. *Cultural Geographies, 25*(1), 165-181. doi:10.1177/1474474017726556

De La Cadena, M. (2010). Indigenous cosmopolitics in the Andes: Conceptual reflections beyond "politics". *Cultural Anthropology, 25*(2), 334-370. doi:10.1111/j.1548-1360.2010.01061.x

Dourish, P., & Bell, G. (2011). *Divining a digital future: Mess and mythology in ubiquitous computing.* Cambridge, MA, USA: MIT Press.

Draper, H., & Sorell, T. O. M. (2013). Telecare, remote monitoring and care. *Bioethics, 27*(7), 365-372. doi:10.1111/j.1467-8519.2012.01961.x

Dumit, J. (2006). Illnesses you have to fight to get: Facts as forces in uncertain, emergent illnesses. *Social Science & Medicine, 62*(3), 577-590. doi:10.1016/j.socscimed.2005.06.018

Eubanks, V. (2017). *Automating inequality: How high-tech tools profile, police, and punish the poor.* New York, NY, USA: St. Martin's Press.

Farías, I. (2017). An idiotic catalyst: Accelerating the slowing down of thinking and action. *Cultural Anthropology, 32*(1), 35-41. doi:10.14506/ca32.1.05

PsychOpen GOLD

Floridi, L. (2014). *The 4th revolution: How the infosphere is reshaping human reality*. Oxford, United Kingdom: Oxford University Press.

Foucault, M., & Deleuze, G. (1977). Intellectuals and power. In D. F. Bouchard (Ed.), *Language, counter-memory, practice: Selected essays and interviews*. Ithaca, NY, USA: Cornell University Press

Ginsburg, F., & Rapp, R. (2013). Disability worlds. *Annual Review of Anthropology, 42*(1), 53-68. doi:10.1146/annurev-anthro-092412-155502

Goggin, G., & Newell, C. (2003). *Digital disability: The social construction of disability.* Lanham, MD, USA: Rowman & Littlefield.

Groleau, D. (2011). Embodying 'health citizenship' in health knowledge to fight health inequalities. *Revista Brasileira de Enfermagem, 64*(5), 811-816. doi:10.1590/S0034-71672011000500002

Hardy, P., & Sumner, T. (2018): *Cultivating compassion: How digital storytelling is transforming healthcare*. Basingstoke, United Kingdom: Palgrave Macmillan.

Heath, D., Rapp, R., & Taussig, K.-S. (2004). Genetic citizenship. In D. Nugent & J. Vincent (Eds.), *A companion to the anthropology of politics* (pp. 152-167). Hoboken, NJ, USA: Blackwell.

Hui, Y. (2017). Cosmotechnics as cosmopolitics. *e-flux, #86*. Retrieved from https://www.e-flux.com/journal/86/161887/cosmotechnics-as-cosmopolitics

Isin, E. F., & Ruppert, E. S. (2015). *Being digital citizens*. Lanham, MD, USA: Rowman & Littlefield.

Kember, S., & Zylinska, J. (2012). *Life after new media: Mediation as a vital process*. Cambridge, MA, USA: MIT Press.

Kidd, I. J., & Carel, H. (2017). Epistemic injustice and illness. *Journal of Applied Philosophy, 34*(2), 172-190. doi:10.1111/japp.12172

Koteyko, N., & Hunt, D. (2016). Performing health identities on social media: An online observation of Facebook profiles. *Discourse, Context & Media, 12*, 59-67. doi:10.1016/j.dcm.2015.11.003

Latour, B. (2004). Whose cosmos, which cosmopolitics? *Common Knowledge, 10*(3), 450-462. doi:10.1215/0961754X-10-3-450

Lidell, A., Adshead, S., & Burgess, E. (2008): *Technology in the NHS: Transforming the patient's experience of care*. London, United Kingdom: The Kings Fund.

Lupton, D. (2013). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health, 11*(3), 256-270. doi:10.1057/sth.2013.10

Lupton, D. (2014). Apps as artefacts: Towards a critical perspective on mobile health and medical apps. *Societies, 4*, 606-622. doi:10.3390/soc4040606

Lupton, D. (2017). Digital health now and in the future: Findings from a participatory design stakeholder workshop. *Digital Health, 3*, Article 2055207617740018. doi:10.1177/2055207617740018

Mackenzie, A. (2002). *Transductions: Bodies and machines at speed.* London, United Kingdom: Continuum.

Manderson, L., & Smith-Morris, C. (2010). *Chronic conditions, fluid states: Chronicity and the anthropology of illness*. New Brunswick, NJ, USA: Rutgers University Press.

Marres, N. (2006). Net-work is format work: Issue networks and the sites of civil society politics. In J. Dean, J. Anderson, & G. Lovink (Eds.), *Reformatting politics: Information technology and global civil society* (pp. 3-18). New York, NY, USA: Routledge.

Martínez-Pérez, B., de la Torre-Díez, I., & López-Coronado, M. (2013). Mobile health applications for the most prevalent conditions by the World Health Organization: Review and analysis. *Journal of Medical Internet Research, 15*(6), Article e120. doi:10.2196/jmir.2600

McQuillan, D. (2018a). People's councils for ethical machine learning. *Social Media + Society, 4*(2), Article 2056305118768303. doi:10.1177/2056305118768303

McQuillan, D. (2018b). Data science as machinic neoplatonism. *Philosophy & Technology, 31*(2), 253-272. doi:10.1007/s13347-017-0273-3

Miller, D. (2017). *The comfort of people*. Cambridge, United Kingdom: Polity.

Milne, R. (2018). From people with dementia to people with data: Participation and value in Alzheimer's disease research. *BioSocieties, 13*(3), 623-639. doi:10.1057/s41292-017-0112-x

Noble, S. U. (2018). *Algorithms of oppression: How search engines reinforce racism*. New York, NY, USA: New York University Press.

O'Neil, C. (2016). *Weapons of math destruction: How big data increases inequality and threatens democracy*. New York, NY, USA: Crown.

Page, R. E. (2012). Blogging on the body: Gender and narrative. In R. E. Page & B. Thomas (Eds.), *New narratives: Stories and storytelling in the digital age*. Lincoln, NE, USA: University of Nebraska Press.

Papacharissi, Z. (2014). *Affective publics: Sentiment, technology, and politics*. Oxford, United Kingdom: Oxford University Press.

Parker, A. (2013). Designing for health activism. *interactions, 20*(2), 22-25. doi:10.1145/2427076.2427082

Parry, B., & Greenhough, B. (2018). *Bioinformation*. Oxford, United Kingdom: Polity.

Powell, J., Newhouse, N., Boylan, A.-M., & Williams, V. (2016). Digital health citizens and the future of the NHS. *Digital Health, 2*, Article 2055207616672033. doi:10.1177/2055207616672033

Prainsack, B. (2017). *Personalized medicine: Empowered patients in the 21st century*. New York, NY, USA: New York University Press.

Rabeharisoa, V. (2006). From representation to mediation: The shaping of collective mobilization on muscular dystrophy in France. *Social Science & Medicine, 62*(3), 564-576. doi:10.1016/j.socscimed.2005.06.036

Rabeharisoa, V., Moreira, T., & Akrich, M. (2013). *Evidence-based activism: Patients' organisations, users' and activist's groups in knowledge society* (CSI Working Papers Series, Working Paper No. 033). Paris, France: Centre de Sociologie de l'Innovation, Mines ParisTech.

Schwennesen, N. (2017). When self-tracking enters physical rehabilitation: From 'pushed' self-tracking to ongoing affective encounters in arrangements of care. *Digital Health, 3*, Article 2055207617725231. doi:10.1177/2055207617725231

Seaver, N. (2017). Algorithms as culture: Some tactics for the ethnography of algorithmic systems. *Big Data & Society, 4*(2), Article 2053951717738104. doi:10.1177/2053951717738104

Shah, N. (2015). When machines speak to each other: Unpacking the "social" in "social media". *Social Media + Society, 1*(1), Article 2056305115580338. doi:10.1177/2056305115580338

Shotwell, A. (2016). *Against purity: Living ethically in compromised times*. Minneapolis, MN, USA: University of Minnesota Press.

Sorell, T. (2017, March 17). Asimov's laws of robotics aren't the moral guidelines they appear to be. *The Conversation.* Retrieved from https://theconversation.com/asimovs-laws-of-robotics-arent-the-moral-guidelines-they-appear-to-be-74634

Sosnowy, C. (2014). Practicing patienthood online: Social media, chronic illness, and lay expertise. *Societies, 4*, 316-329. doi:10.3390/soc4020316

Stengers, I. (2011). *Cosmopolitics II*. Minneapolis, MN, USA: University of Minnesota Press.

Tempini, N., & Del Savio, L. (2018). Digital orphans: Data closure and openness in patient-powered networks. *BioSocieties*. Advance online publication. doi:10.1057/s41292-018-0125-0

Tucker, I. M., & Goodings, L. (2017). Digital atmospheres: Affective practices of care in Elefriends. *Sociology of Health & Illness, 39*(4), 629-642. doi:10.1111/1467-9566.12545

Vicari, S., & Cappai, F. (2016). Health activism and the logic of connective action: A case study of rare disease patient organisations. *Information Communication & Society, 19*(11), 1653-1671. doi:10.1080/1369118X.2016.1154587

Wadmann, S., & Hoeyer, K. (2018). Dangers of the digital fit: Rethinking seamlessness and social sustainability in data-intensive healthcare. *Big Data & Society, 5*(1), Article 2053951717752964. doi:10.1177/2053951717752964

Wakeford, T. (2002). Citizens Juries: A radical alternative for social research. *Social Research Update, 37*. Retrieved from http://sru.soc.surrey.ac.uk/SRU37.html.

Weltevrede, E., Helmond, A., & Gerlitz, C. (2014). The politics of real-time: A device perspective on social media platforms and search engines. *Theory, Culture & Society, 31*(6), 125-150. doi:10.1177/0263276414537318

PsychOpen GOLD

Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

"Do You Want to Help or Go to War?": Ethical Challenges of Critical Research in Immigration Detention in Canada

Rachel Kronick*[abc], Janet Cleveland[ac], Cécile Rousseau[ac]

[a] Division of Social and Transcultural Psychiatry, McGill University, Montreal, QC, Canada. [b] Lady Davis Institute, Jewish General Hospital, Montreal, QC, Canada. [c] Sherpa Research Institute, CIUSSS du Centre-Ouest-de-l'Île-de-Montréal, QC, Canada.

Abstract

In a time of mass displacement, countries across the globe are seeking to protect borders through coercive methods of deterrence such as immigration detention. In Canada, migrants—including children—may be detained in penal facilities having neither been charged nor convicted of crimes. In this paper we examine how we dealt with the series of ethical dilemmas that emerged while doing research in immigration detention centres in Canada. Using a critical ethnographic approach, we examine the process of our research in the field, seeking to understand what our emotional responses and those of the staff could tell us about detention itself, but also about what is at stake when researchers are faced with the suffering of participants in these spaces of confinement. The findings suggest that field work in immigration detention centres is an emotionally demanding process and that there were several pivotal moments in which our sense of moral and clinical obligations toward distressed detainees, especially children, were in conflict with our role as researchers. We also grapple with how the disciplinary gaze of the detention centre affects researchers entering the space. Given these tensions, we argue, spaces of critical reflection that can consider and contain the strongly evoked emotions are crucial, both for researchers, and perhaps more challengingly, for detention centre employees and gatekeepers as well.

Keywords: migrants, immigration detention, asylum seekers, children, ethics, critical ethnography, emotions

Research *is* reform, or it can be.

(Liebling, 2014, p. 485)

> The emotion of caring is inextricable from the act of caring for someone or something; the former compels the latter. . . There are so many ways to really not care, and we've seen most of them exercised energetically these last couple of years and really throughout American history. They are narrative strategies and most of them are also fundamentally dishonest.

(Solnit, 2018)

Around the world, States are deploying increasingly stringent measures to implement what they view as their sovereign right to determine who may enter and remain on their territory. Since the late 20th century, administrative detention of non-citizens has been used more and more systematically as one of a panoply of coercive state mechanisms of migratory control, along with deportation, interdiction and similar measures (Nethery & Silverman, 2015). Migrants are usually incarcerated in prison-like conditions, although generally neither charged nor convicted of any crime, and very rarely even suspected of posing a potential threat to public safety. Targeting arriving migrants—including refugee claimants—and non-citizens who have lost status, immigration detention serves primarily to keep migrants under state control pending the outcome of often lengthy administrative procedures, designed to verify identity documents and mitigate flight risk concerns pending deportation (Bosworth, 2014).

Research Questions

In 2010-2011, we conducted a Canadian study on the impact of detention on adult asylum seekers' mental health (Cleveland & Rousseau, 2013), and to understand the lived experiences of children and families imprisoned in immigration detention centres (Kronick, Rousseau, & Cleveland, 2015). In this paper we examine how we dealt with the series of ethical dilemmas that were part and parcel of doing this research with migrants, especially children, held in immigration detention centres. We try to understand what the process of conducting research can tell us about the practice of detaining migrants, and also about the ethical and practical challenges of mobilizing change and taking humanitarian action as researchers. We ask three specific questions: 1) What were our emotional responses when faced with a population suffering in a carceral context and how do these feelings shape research decisions? 2) How does one maintain a position as an impartial participant-observer? And 3) What might our affective experience and individual reactions tell us about the larger structural issues at stake?

Any understanding of research on immigration detention must be foregrounded by the global and local context of migrant incarceration, and so we begin there.

Global Trends in the Context of Border Control

Although always coercive, immigration detention may be more or less punitive. In many countries detention conditions conform to minimum standards and certain basic procedural guarantees are respected (e.g., time limits, access to review, protection for vulnerable individuals). Detention serves primarily as a mechanism of bureaucratic control. In others, immigration detention is viewed as an instrument of deterrence, with harsher conditions cited as proof of willingness to be tough on 'illegal' migrants.

In Australia, for example, most governments have, since 1992, celebrated the use of mandatory detention of 'boat arrivals' in often extreme conditions as a necessary tool to stem the flow of 'illegals' (Sampson, 2015). Australia's use of offshore facilities as a means to circumvent international and domestic obligations regarding the human

rights of migrants is increasingly cited by other governments around the world as a model to combat irregular migration.

Rising numbers of irregular migrants entering Europe in recent years, particularly in 2015-2016, have led a number of countries to enact more stringent border controls, including detention. Hungary, for example, now systematically detains asylum seekers in prison camps at the border, including families with children, for the duration of the refugee claim proceedings (European Council on Refugees and Exiles, 2017).

In 2017, the EU concluded a deal with Libya designed to strengthen Libya's capacity to intercept migrants heading for Europe, including the use of detention—ignoring reports from the Office of the UN High Commissioner for Human Rights and other organizations detailing massive human rights abuses against migrants in Libya. Shortly after the deal was concluded, the High Commissioner denounced Libyan detention centres as 'an outrage to the conscience of humanity' where 'thousands of emaciated and traumatized men, women and children piled on top of each other, locked up in hangars with no access to the most basic necessities, and stripped of their human dignity' are routinely subjected to beating, rape and other forms of violence (Agence France-Presse in Geneva, 2017). Yet, in June 2018, the EU once again confirmed its resolve to reinforce externalization of border control to North Africa—notably Libya—and Turkey, including detention and offshore processing in hotspots. Support for these measures, far from being limited to right-wing populists, is now expressed by most mainstream EU governments (Dos Santos, Smith-Spark, & Frater, 2018).

In 2017, the United States government decided to systematically bring criminal charges against migrants who enter 'illegally' (including asylum seekers), using this as an excuse to forcibly separate children from their detained parents. Faced with an outcry against the separation policy, the US then sought to instead hold children with their parents in immigration detention facilities for the duration of their asylum proceedings, which may last years. A similar policy implemented by the Obama administration in 2014 was struck down by the courts, which decreed that children (whether unaccompanied or accompanied) could not be held longer than 20 days. After a court blocked the Trump administration's attempt to impose long-term detention of entire families, the administration now says that it will offer parents the 'choice' of remaining detained indefinitely with their children or of 'consenting' to their children's release while the parents remain detained (Parker & Satija, 2018).

While there is a dominant trend toward more stringent measures and widespread use of immigration detention, there is also resistance. There are calls for greater protection of vulnerable groups, particularly children, as well as limiting recourse to detention and promoting the use of non-custodial alternatives. For example, Belgium (in 2009) and the UK (in 2010) announced that they were putting an end to detention of children, including families with children. However, the UK still detains families in certain cases, while Belgium has announced plans to resume family detention in 2018 (Opening Doors, 2018).

Detention in Canada

Detention centres in Canada are modelled on medium-security prisons. They are surrounded by razor wire fencing; movement and all activities of detainees are rigidly controlled; observation by guards is constant; detainees' personal effects are confiscated and anyone entering the detention centre is searched (Cleveland, 2015). Although the average length of detention is around a month, there is no maximum time limit; in one extreme case, a non-citizen was on immigration hold for 11 years. At the time of our research, children were routinely detained in Canadian Immigration Holding Centres (IHCs). Mental health problems or other forms of vulnerability are gener-

ally not grounds for release. The detainee population therefore includes highly vulnerable migrants, such as children, pregnant women, and victims of trauma and torture. About a third of immigration detainees are held in maximum-security jails along with the criminal population, primarily due to lack of space in dedicated immigration detention centres. Our study pertains only to the latter type of detention in IHCs.

Compared to many other countries, conditions in Canadian immigration detention centres are relatively adequate and allegations of mistreatment or abuse very rare. Yet, IHCs are carceral, 'total' institutions in which inmates are subjected to pervasive, tight controls.

Immigration detention is one of the very rare situations in which children may be lawfully detained. Access to psychological or social services is often extremely limited or non-existent, such that researchers generally do not have the option of making an outside referral, as detainees are (literally) not free to consult other professionals (aside from the privately contracted IHC physician) or community services. Concerns about children's wellbeing may provoke referrals to child protection services.

In Canadian IHCs, as in other carceral institutions, management response to manifestations of distress is often increased control and surveillance. If detainees mention suicidal thoughts, standard policy is to place them in segregation under 24/7 individual surveillance, either in the detention centre (in Montreal) or via transfer to a maximum-security prison (in Toronto) (Gros & van Groll, 2015).

Symbolic Violence, Disempowerment and Mental Health

Our studies have shown that detention negatively impacts the mental health of both adults (Cleveland & Rousseau, 2013) and children (Kronick et al., 2015; Kronick, Rousseau, & Cleveland, 2016; Kronick, Rousseau, & Cleveland, 2018). These findings are consistent with studies conducted in multiple other countries (Bosworth, 2016). Although the negative impact is even greater when conditions are harsh and/or detention is prolonged, a number of studies (including ours) have shown that even relatively short detention in reasonably adequate conditions is harmful. This may be attributed to two main factors: symbolic violence and disempowerment (Cleveland, Kronick, Gros, & Rousseau, 2018).

Detention is experienced as a form of symbolic violence, through which migrants who have committed no crime are subjected to a series of measures signaling social degradation, including handcuffing, constant surveillance, searches and other severe restrictions on liberty and dignity. The symbolic violence is compounded by the fact that the vast majority of migrants are racialized, originate from historically oppressed countries, and are often poor, while the states imposing detention are often historic oppressors, largely white and wealthier.

Immigration detention is also consistently experienced as disempowering. Migrants are kept under coercive state control for indeterminate periods while awaiting the outcome of administrative decisions which are most often highly discretionary and based on opaque criteria. In countries such as Canada and the UK, where there is no maximum time limit on their detention, migrants' feelings of anxiety and uncertainty may be particularly intense. Being detained at the pleasure of the state for an unpredictable length of time may be seen as an enactment of power relations.

Methods

Our larger study on the impact of immigration detention on the mental health of adult asylum seekers, conducted by the second author (Janet) and two research assistants in the IHCs in Montreal and Toronto, started in July 2010. Early in 2011, we added a smaller study on the mental health of migrant families and children, conducted by the first author (Rachel). Both research protocols included elements of observation in the field.

This portion of the study—which takes the data about researcher experience in the field as its object of inquiry—is informed by a critical ethnographic stance. Ethnography focuses on generating understanding of everyday life in specific social settings, including institutions, through participant observation, field notes, and interviews. Both institutional and *critical* ethnography are preoccupied with "the institution and its effects, with a focus on mapping the daily lived 'relations of ruling,'" (Billo & Mountz, 2016) thereby revealing implicit tensions, contradictions and forms of power or oppression (Schwandt, 2007). As Timothy Mitchell suggests: "analysis of disciplinary power must occur at 'the level of detail', or the scale of the everyday" (Billo & Mountz, 2016). Critical ethnography also demands researcher reflexivity through the acknowledgement that the researcher is not a neutral subject outside of the field of study, but rather a participant who is shaped by the research itself as well as social forces and inequalities that are manifest in the field. Because in this study as we are looking at detention itself, as well as the experiences of researchers who are studying detention, a critical ethnographic stance was well-suited. As in autoethnography we are interested in the stories that were told in the field as well as the stories *we told ourselves* about being in the field (Ellis, Adams, & Bochner, 2011).

Driven by our research question, we were especially interested in understanding the emotions recorded in our field notes. As psychiatrists and psychologists we think that affective reactions can tell us about the object of examination as well as the clinician (here the researcher). In this paper a psychoanalytic stance is part of a larger "psychosocial" paradigm that views individual psychic experience as being constructed and formed by "outer worlds of social structural oppression" (Frost & Hoggett, 2008, p. 440). In this paradigm, emotions emerge in the context of social relations and structures and only then become "individualized and internalized – built in to subjectivity" (Frost & Hoggett, 2008, p. 442). In this study, we do not differentiate between notions of affect and emotion, as some philosophers have (Massumi, 2015). But like these thinkers we are interested in how being in the detention centre "is experienced in visceral, affective and embodied terms" (Frost & Hoggett, 2008, p. 443) because we believe it can tell us something about the research process and the social conditions of detention.

Data were collected in two detention centre settings, one in Montreal and the other in Toronto. While interviews and questionnaires with participants were the subject of previous papers, for this study our principal data were ethnographic field notes, and other texts that were produced during our research such as emails and administrative documents. We deliberately chose data sets for this study whose focus was on researcher experience as well as on the detention centre staff's reaction to our work.

During the studies each researcher in the field (Rachel, Janet and two research assistants) kept field notes after each trip to the detention centres. These documented experiences, conversations and observations took place during the visit or were related to the process of conducting the research. Over a 12-month period, Janet and two research assistants visited the Montreal IHC 35 times and the Toronto IHC 22 times, for half-day periods. Rachel was in the detention centre over a period of 6 months, spending approximately one half-day per week in the field. Ethics approval for our studies was granted by the McGill University Faculty of Medicine IRB.

Data were analyzed using both inductively and deductively generated codes, derived by the first author. The ethnographic data were contextualized using previously published data that included detainee interviews and questionnaires. Our analysis attempted to both identify content themes and also salient stories emerging from the research process, and thus our orientation was both thematic and narrative.

To protect the confidentiality of the detention centre staff and key informants who peopled our field notes, we refer to all as "staff" or "professionals" rather than identifying nurses, doctors, managers, and head guards. We use the labels of "gatekeepers" or "decision makers" to identify players who are in greater positions of power. While the elision of identities might limit some narrative detail and belie the power hierarchies at play in the centre, our hope is that the central themes and research processes remain intact. The challenge of preserving confidentiality fits into our larger dilemmas—discussed below—of conducting critical research without muting our findings, given that access to the centre was precarious and, in the case of detention centre staff, their own jobs might be endangered if we were to identify them.

Findings

Our data from the field are presented in three sections, each derived from the themes emerging in the analysis. First, we examine the emotional responses evident in our field notes. Second, we elaborate on the carceral space and its players and describe how the researchers negotiated with the institution. And third, we describe how our research turned toward *advocacy* or humanitarian action and elaborate on the conflictual loyalties and ethical imperatives that resulted.

Emotions in the Field

Like Bosworth and colleagues who speak cogently about feelings of self-doubt, guilt, anxiety, and sadness present during and after their research with adult detainees (Bosworth & Kellezi, 2017; Bosworth & Slade, 2014), we were confronted with our own distress as we bore witness to that of others. Often, we were torn between the desire to help and the obligation to stay in our researcher role.

After an interview with a rejected asylum-seeking couple who had been detained without their young (Canadian-born) children the first author wrote: "I cried at multiple points during the interview, especially telling them how powerless I felt, unable to help them. It's the most poignant interview I've done. The most loving couple, husband stroking her hair, her holding his hand" (Field notes, July 26). In another interview, following the 3-month detention of a mother, father and their two children, Rachel admits to being "overwhelmed" by emotions (as was the interpreter) as the mother spoke: "at points, I find myself speechless when they spoke of the exploitation they experience". (Field notes, May 26)

Our distress led us to try to comfort and care for the families and children. On a few occasions, Rachel went beyond the research protocol—which instructed giving participating children a box of crayons and parents a long-distance phone card—and gave children multiple gifts and art supplies, or an extra phone card to an especially worried parent. Similarly, Rachel's field notes showed she was frequently physically affectionate with families:

> When the family arrived . . . I stood up and hugged them both. The interpreter greeted them warmly. (Field notes, May 26, 2011)

The baby was moving constantly and wanted to grab everything to put in his mouth (lego, pens, my foot!) . . . I frequently had to walk around the room with the baby in my arms to prevent him from screaming and fussing. (Field notes, July 26)

Much as certain guards responded with physical affection to the children despite their role (Kronick et al., 2015), we too were moved by families' plights and children's vulnerability to breach the distance of researcher-subject.

Emotional Responses to Gatekeepers

Strong emotions were present not only in response to detainees, but also in reaction to staff of the detention centre. During visits to the detention centre, we were frequently angry at actions of the decision-makers, but worked actively to keep these emotions hidden. For example, on one detention centre visit Rachel met with a pregnant Afghani mother and her children—described as looking "very sick indeed . . . her lips were crusted and dry like a hospitalized patient" (Field notes, June 17). Rachel's frustration rose during the encounter when a staff person would not permit a Dari-speaking guard to interpret for the mother (no outside interpreters were allowed), and the mother was not permitted to lie down for an hour because the mother-child section was being cleaned. Rachel spoke with another detention centre staff after:

I made pleasant small talk with Mr X . . . I realize I was trying to say: 'look, we are the same, we work in the same way.' Perhaps this was my own reaction formation against my rage towards the institution. . . The only thing I could do other than scream was make pleasant, superficial small talk. (Field notes, July 17)

Rachel also expressed empathy with decision-making staff, even when feeling angered, telling them on one occasion, for example, that we understood "how difficult the situation [the detention of a child whose mental health was deteriorating] was with such limited resources". (Field notes, April 8)

The muting of our own emotional responses as researchers felt—or indeed was—obligatory. Given we had almost no power in the context of the institution, and no means to ensure that detention centre staff would take measures that were humanely indicated, we had to be agreeable and pleasant in hopes of influencing staff to take actions which would be right for detainees. Further, as we will describe below, we had to be "nice" to ensure that our research access was not revoked.

Emotional Responses to the Research

As researchers we were met not only with our own affective responses, but also the reactions of the detention centre staff to our presence. At times staff seemed anxious about our potentially critical research. Rachel was asked:

What is the research going to show? This is *me* asking [i.e. not the Canada Border Services Agency]. Because of course everyone hates detention. No one likes losing their freedom. (Field notes, March 22)

Another staff member half-questioned, half-stated: "I mean, it's not so bad here?" (Field notes, June 17). It seemed clear that staff were worried how the detention centre would be portrayed in the research and were hopeful that our finding would be "not so bad."

Staff also appeared nervous about children's wellbeing, and hoped we could provide support. However, there were also messages conveying—perhaps because of the anxiety about our potentially critical stance—that we

were subject to surveillance, and under the constraints of the centre ourselves. One staff told Rachel "when you went outside [in the courtyard with a family] it was written down." The staff communicated that there were careful records kept of all activity in the centre, but also that we were being closely monitored as researchers.

There were also moments when staff turned to the researchers, knowing we were clinicians, to relieve some of their worries. In response to an asylum-seeking child's deteriorating mental and physical health after two weeks in detention, a staff person spoke with Rachel:

> He asked—with much anxiety in his voice—if the IHC should consider involving "social services" (he did not mention, as I had heard from the NGO, that the IHC had offered to the mother that she give her children to youth protection). (Field notes, April 8)

Staff's anxieties about the presence of children in detention was evident even before the study began. For example, when Rachel was awaiting her security clearance, the detention centre management were concerned about the welfare of three young children who had been detained with their mother after guards had reported that the mother wasn't adequately parenting the children. There was no social worker or mental health professional on-site to assess the situation. Detention centre management are charged with making decisions involving children's welfare because the latter are in their custody. Because of the detention centre's limited repertoire of responses and resources to address detainee suffering and the understandable anxiety that provoked, it was agreed that Rachel would conduct a clinical assessment and submit a report to the detention centre physician. This was not a straightforward situation however, as we will discuss below: through intervening as clinician-advocates we blurred our roles as researchers and also experienced conflicts of loyalty.

In summary, in the field we encountered the anxieties of professionals in the detention centres, both about our potentially critical work, as well as regarding the children they were mandated to confine.

Institutional Dimensions

Close to a year of negotiation was required to get permission to carry out the research, followed by several months of processing of individual researchers' security clearance documents. Like all persons entering the detention centre, we were subject to multiple controls on each visit to the IHC. The normal procedure was to send a fax in advance; check in at the front desk, where staff verified that we had security clearance and had sent a fax; place all but a few authorized objects in a locker; undergo a metal-detection search; and put on a vest identifying us as a 'volunteer'. Like the detainees, we had to be accompanied by a guard when moving from one section to another. Doors could only be unlocked by the central control desk, at a guard's request.

At one level, these control mechanisms can be viewed as mere minor inconveniences. But cumulatively, they convey a strong message: should you fail to comply with each and every rule, there will be consequences. Eight months into the study, for example, a research assistant was denied access to the detention centre because her name had been (erroneously) left off the list of people with security clearance. Yet, all the guards recognized her, as she had been visiting weekly, and were aware that she in fact had clearance. After lengthy negotiations, the research assistant was allowed to access an office but not to enter the more heavily restricted area of the detainees' common room—although everyone knew she was authorized to do so, and had been doing so for eight months. Bosworth and Kellezi (2017) have described remarkably similar incidents during their study of immigration detention centres in the UK.

By contrast, the procedure was not as strictly applied to Rachel. For example, she was rarely subjected to the metal detector search. It seemed her profession and perhaps even age and gender identity conferred some special status at times. For example, even while expressing concerns about the research, a staff noted that the first author was not a problem, per se, given she was a "young, enthusiastic doctor."

Despite the discretion used to determine security procedures for each of us, we often felt frustrated by the staff's lack of flexibility as they followed the prescribed rules. While guards are not allowed to speak to detainees in languages other than English and French, Rachel asked them to help with a pregnant detainee who only spoke Dari. Her field notes suggest she hoped her status as researcher/physician would convince them to bend the rules:

> [The staff] emphasized a few more times that I should have brought an interpreter and that she couldn't help me. I asked if I could even have the [Dari-speaking] guard for three minutes. She said no. I could feel my own heat and anger rising with her dismissive attitude and rigidity. This was perhaps one small glimpse of how it feels to be a detainee. This woman did not know that I was "a doctor" or researcher. I was just a visitor—a *detainee's* visitor, making unreasonable demands. (Field notes, July 17)

The rigid rules often left us feeling powerless, while the unpredictable minor variations only reinforced our awareness that our access depended on cultivating a good relationship and complying with institutional rules. Despite frequent moments of frustration at the inflexible procedures and constant surveillance, we generally felt compelled to bow our heads and submit. The IHC sometimes left those of us who were obviously least vulnerable—compared with the detainees—feeling powerless and frustrated.

Conflicting Ethical Imperatives and Dual Identities: "Who Do You Represent?"

Just as the research itself was met by the IHC with some concern, our advocacy was received with significant objection. One child whom we encountered during our interviews appeared to deteriorate in detention, compelling us to advocate. The child, described elsewhere (Case 2, Kronick et al., 2015; Kronick et al., 2018), demonstrated signs of poor physical and mental health during her three-week detention. We agreed as a research team that we would provide a psychiatric assessment report for the lawyer who would represent the family at a detention review hearing, documenting the mental health problems likely caused by her imprisonment.

In the week after the detention review hearing (in which our report was not invoked and the decision-maker ruled that the family's detention be maintained) Rachel attempted to return to the detention centre to interview another family. A gatekeeper, who was involved in approving each of our visits, did not respond to the request and instead, a few days later, sent an email expressing concern about why "a client's lawyer is involved in your evaluations?"

The phone conversation with another gatekeeper following this email was summarized in Rachel's field notes:

> The staff person made clear that she did not understand what was going on. I had come in as a researcher and suddenly I was writing reports and "working for" the lawyer. She asked me multiple times "who do you represent?" I struggled (or felt I struggled) to explain that as a physician I did not "represent" anyone. I was acting as a physician. The closest I came to "representing" someone was to try to act in the best interests of the patient. [. . .] She kept returning to the point that this was "going beyond the research project." I tried to speak to the complexity of being a clinician-researcher. [. . .] By the end of the interview, I felt we had not come to any agreement, and that she felt threatened by what I had done. And indeed I am aware of the threat which her disapproval poses. She has the power to stop the study. (Field notes, April 8)

Another staff member who became aware of the situation asked Rachel "Do you want to help [the family] or to go to war?" The research team had heard rumours that, in the past, staff had lost their job after taking an advocacy stance for detainees. We had also been told that the detention centre physician never provided expert medical reports and that he had 'lasted' much longer than any of his predecessors. As mentioned in her field notes, all this led Rachel to feel that "if I advocated on behalf of detainees my access as a researcher would be under threat" (Field notes, April 8).

Following this incident, we renegotiated our access with gatekeepers. Because concerns were expressed regarding the blurring of our roles as researcher and clinicians, as well as our communication with lawyers, we agreed to cease providing assessment reports to detainees and their lawyers and to speak directly to the IHC health professionals if we had medical concerns. Thus in order to preserve our access to the centre as researchers we agreed outright to curtail any interventions that were "outside" of the research, specifically any actions that involved advocating for participants. Our work to advocate for individual detainees was silenced by the larger agenda of our research.

Surveillance in the Field

The incident not only changed our actions in the field, it also impacted our sense of our work. In her field notes, Rachel wrote about a sense of being watched when a staff asked to speak from his landline (rather than his cell phone):

> The thought occurred to me that the phone conversation might be recorded, bugged . . . I feel under surveillance. Unsure of who is watching, listening, keeping record. Unsure of how my words will be used. (Field notes, April 8)

Although we do not believe that any conversations were recorded, the entry reflects the emotional impact of our immersion in the detention centre environment. The sense of surveillance is experienced by the research team, as Rachel expresses in an email to co-authors about her anxieties emerging from the advocacy incident:

> I have been feeling such self-doubt about how things unfolded and have questioned if I made mistakes or acted inappropriately. In fact, I think that is probably an introjection of the surveillance and discipline of the institution. I am left with this feeling that I have not properly policed myself. (Email, April 10)

The feeling of paranoia is understood by Rachel in her field notes as a kind of panopticism (Foucault, 1977). As Judith Butler (1997) writes, for Foucault "the prisoner is subjected 'in a more fundamental way' than by the spatial captivity of the prison (1997, p. 85). The prisoner "becomes the principle of his own subjection" (Foucault, 1977, pp. 202-203, as cited in Butler, 1997, p. 85). As a researcher, Rachel feels disciplined by the institution, but like Foucault's prisoner, she takes inside herself this disciplinary gaze. The atmosphere of distrust that seems to underwrite the detention setting is internalized by the researcher.

The conflict over our advocacy for the child patient exposes the challenges of advocating for the protection of individual children in the context of conducting detention research. The institution's mandate to confine, and sometimes expel children and families appeared threatened by our attempts to advocate for release of one child, and in turn, the gatekeepers suggested that our access would be withheld. Potential activism was silenced. We were in relative positions of power and safety, compared to the detainees, and yet the institutional culture of the centre left us feeling precarious and expellable.

Discussion

In this paper we were addressing three interrelated questions. First, we wanted to understand the emotional effects of doing detention research. Secondly, we wondered how we managed our dual roles and obligations when faced with our own feelings and the suffering of detainees. And lastly, we asked what our own affective experience can tell us about how the detention centres work.

The results highlight two important challenges associated with conducting research in Canadian immigration detention centres. First, it was an emotionally turbulent process that provoked reactions in the researchers, *and* in the detention centre staff. As researchers, we both suppressed our negative emotions towards the institution and staff, while also sometimes crossing the boundaries of our researcher role in an attempt to alleviate the suffering we witnessed. The staff's response to our presence revealed their own sense of vulnerability, their wishes to avoid criticism, and also how the disciplinary practices of the centre—surveillance and control—were used to contain (and limit) the research. It also revealed how our gaze was destabilizing to a certain extent for them. Second, we were facing contradictory demands. During the field visits our own sense of ethical obligation to intervene when we felt the participants were not emotionally safe was in conflict with our contractual obligation to comply with the implicit terms of our access authorization: to withhold from intervening and conform to detention centre rules and practices. We argue that these two challenges are interrelated and part of a common dynamic, elicited by the unique context of detention systems, which follow a disciplinary logic (Butler, 1997).

The Unique Context of Detention

The basic facts of an immigration detention centre make it a place where strong emotions and ethical challenges are apt to appear. Functioning as "total institutions" (Goffman, 1957), immigration holding centres are spaces where "whole blocks of people" (p. 314) are restricted in their freedom, expected to follow rigid and strict rules overseen by an organizational hierarchy of authority over which detainees have no control. Entering such a space—where an often-arbitrary structure is designed to coercively control an innocent, non-criminal population—the researcher has good reason to experience strong emotions. As Bosworth and Kellezi (2017) write, "transforming human beings into bodies that can be expelled is not just a legal but also a symbolic and affective endeavour. Denial and rejection, inherently, are painful to endure and to witness" (p. 131). Detainees are of course the most impacted, but as we see in our findings researchers and detention centre staff are also touched by the "affective endeavour" of confinement.

Bosworth (2013) suggests that immigration detention is a sort of "'hybrid space' . . . in which the population is marked out and governed by their precariousness" (p. 162). "Lived insecurities" become a hallmark of life in detention—and the era of mass mobility—both for detainees and staff (Bosworth & Slade, 2014, p. 181). As researchers and participant observers, we were pulled into this experience of insecurity. Our sense of the insecurity of the research's status, knowing we could be expelled from the site if we deviated from the norms, put us in a position of "dual loyalty and role conflict" (Zion, Briskman, & Loff, 2012, p. 69) which we discuss further below.

Dual Loyalties

For health professionals, their patients' best interests outweigh all other considerations, always (Physicians for Human Rights, 2011), and "while the term "dual loyalty" may imply equivalence between a medical professional's loyalty to the patient and loyalty to third party interests, no such equivalence exists" (pp. 7-9). In the context of an

ethic of care, anyone who witnesses abuse or violence has a moral responsibility to try to stop or attenuate the harm: "To witness an abuse means to become responsible for taking some form of action in response" (Fleay & Briskman, 2013, p. 114). This responsibility would clearly extend to researchers—whether or not they are health professionals.

Medical professionals providing services in immigration detention centres may face a variety of pressures from immigration authorities, particularly if, in addition to providing individual care, they point out the need to modify conditions that are detrimental to detainees' physical and mental health. In Australia, for example, clinicians who spoke out against harm to detainees and policies of immigration detention usually had contracts terminated or not renewed (Brooker, Albert, Young, & Steel, 2016).

Research ethics recognize that priority should be given to participants' safety, particularly in the case of children. In child abuse and neglect research researchers have the obligation to put the child's best interests above their commitment to confidentiality, for example. But what if this happens in a study that is not about child abuse, but uncovers the inherent harms to children of a particular institutional setting, in this case immigration detention? Beyond physical signs of abuse, how does one determine that a child (or adult) is emotionally unsafe, and what constitutes potential maltreatment, particularly when it is perpetrated by the state? If we bear witness to the oppressive (and perhaps even abusive) system as researchers, are we not complicit if we do not intervene?

Empathy and Ethics

Emotions may be seen as tools that help us to feel the pain of the Other, playing a key role in supporting moral action (Hoffman, 2001). This is certainly the case in advocacy processes, which are not only rational but often driven by emotion. In the detention context, the strongly loaded emotional experience was a valuable source of information and suggested that all involved parties were, to some degree, *feeling* that something was not quite right. The compelling need to act to protect the subjects, rooted in this empathic stance, was, however, putting in danger the alliance with the detention centre staff, who felt criticized and betrayed.

Our results suggest that researchers have to navigate a fine line between becoming accomplices of an abusive system, and minimizing breaches of their research contract. They also underline that emotional interactions among all involved parties should be closely heeded, as they may (and should) inform action, but can also lead to splitting and self-justification.

In the field of refugee research, Mackenzie, McDowell, and Pittaway (2007) have stated that "researchers need to move beyond harm minimization as a standard for ethical research and recognize an obligation to design and conduct research projects that aim to bring about reciprocal benefits for refugee participants and/or communities". Mekki-Berrada and colleagues (2001) acknowledge that "for ethical reasons, interviewers [working with refugee families] cannot totally distance themselves from the expectations of the respondents, from the empathic nature of the relationship, or from the need to help provide appropriate psychosocial support" (p. 52). Further, the obligation to protect from harm must "override any wish to protect a project from accusations of bias or interference" (Mackenzie et al., 2007, p. 310).

During our research, our strong sense of moral obligation toward detainees—emerging not only from our professional obligations to attenuate harm, but also from our strong emotional reactions—directed our actions of subversion and advocacy, though they came at a cost. As Rousseau and Kirmayer note: "the question [. . .] shifts from "How

can we avoid complicity?" to "To what degree will we compromise and at what cost?" This shift entails mourning the limits of our benevolence and acknowledging with some lucidity the ways in which we harm, even while intending to help" (Rousseau & Kirmayer, 2010, p. 66).

While Canadian government officials have suggested to us that our study played a role in recent policy changes aiming to reduce the detention of children, we still ask: what if we had had less fear of the institution's disciplinary power and had resisted conforming to the research contract? Would completely subverting (and abandoning) the research in favour of an activist's stance have better served the detainees we encountered? This raises complex questions not only about ethical decisions within the research protocol but also about the uses of academic research itself, particularly when the aim, in addition to understanding, is social and political change. Was our research "useful" enough that it justified our actions?

We are also cognizant that bearing witness to detainees' distress without being able to help them often induces feelings of guilt, as other researchers in the field have pointed out (Bosworth & Kellezi, 2017). Although our interventions to protect children were, in our view, clinically and morally warranted, we can also ask how much they reflected a response to intolerable feelings of guilt and powerlessness.

Trustworthy Research in a Polarized Setting

The transgression of our researcher positions threatened our access but also imperiled our even-handed relationship with detention centre staff. What if we—even unconsciously—were dismissive of facts inconsistent with our empathic feelings towards detainees? Just as Bosworth notes that "nobody wants to admit to toning down their assessments" (Bosworth, 2014, p. 55) of detention settings to placate gatekeepers, neither should we ignore the risk that our strong empathic alliance with detainees might narrow our vision.

In a polarized setting such as an immigration detention centre, where our empathic responses are strong towards detained migrants, keeping open to multiple perspectives is essential for us to build a full and complex understanding of the institution (Liebling, 2001). In carceral settings, many researchers have been particularly concerned with appearing 'neutral' and 'objective', perhaps in part because their publications are likely to be read by government bureaucrats on whom their access to prisons depends (Drake & Harvey, 2014; Jewkes, 2012, 2014). Fine (2006) argues in favour of "*strong objectivity*—achieved when researchers work aggressively through their own positionality, values and predispositions, gathering as much evidence as possible, from many distinct vantage points, all in an effort *not* to be guided, unwittingly, by predispositions and the pull of biography" (Fine, 2006, p. 89). Quoting Lillian Comas-Dias, Fine continues: "The ethnopolitical approach requires psychologists to act as change agents, asking them to examine the political and social costs and benefits of their interventions . . . taking sides is not bias but an ethical choice . . ." (Fine, 2006, pp. 1322–1323). Much as we strove for even-handedness, such a stance is not straightforward when one is studying a disciplinary institution and hoping that the research will incite change.

Spaces for Critical Reflection

As others have suggested (Bosworth & Kellezi, 2017; Liebling, 2014) our findings support the notion that research with detained migrants should include forums for self-reflection. There is a need to "work through" traumatic material, acknowledging both the negative impact this might have and the potential for vicarious post-traumatic growth (Cohen & Collens, 2013). Through this self-reflection, researchers would record and analyze their relationships with the participants. This is not with the goal of divorcing themselves from those relationships personally, but of gaining a better understanding of how they fit into the context of the research and how they may be sources of

knowledge themselves. In other words by rendering the affective responses to the research and the carceral space more conscious, the aim is not to protect against bonds with participants but to ensure that such bonds are met with self-reflection. This will not resolve the profound challenges of conducting critical research in a "total institution," but can help make unconscious reactions, and power structures, conscious.

The strong emotional reactions of the detention centre staff also suggest that there is a need for critical spaces of reflection in the IHCs themselves, all the more so because staff—especially management—are faced with significant decisions impacting the wellbeing of detainees. Detention centre staff, like other government officials, may be left feeling "fearful of the consequences of acting humanely beyond (and sometimes within) the terms of their employment" (Gill, 2016, p. 137). As Crepeau and Nakache have suggested in the context of the refugee determination system in Canada, there is a need for the creation of "critical spaces . . . as spaces of debate, interaction and of decision" (p. 51) in IHCs. Others have highlighted the importance of training for CBSA and detention centre staff (Gros & Song, 2016). However, for such training to have impact we believe it would require *ongoing* spaces of self-reflection and debate. Creating such spaces would be complex and challenging given the emotional tensions, disciplinary culture and "affective" climate we have observed in the IHCs. A sense of emotional safety would likely be needed to foster reflection, and staff would need to feel held empathically before they could decenter themselves and reflect critically on their experiences and decision-making.

Conclusion

Research in an immigration detention setting is difficult. From securing access to the site, to facing the realities of its detainees, to grappling with the strong emotions that "live" in disciplinary institutions, researchers are faced with complex ethical challenges and often contradictory obligations. As Bosworth notes, "the relationship between understanding and reform is not a simple one" (Bosworth & Kellezi, 2017, p. 17). While academics may strive to produce trustworthy and nuanced accounts of detention settings they are faced simultaneously with the imperative to do what they can to protect detainees. Spaces of critical reflection are needed to consider and contain the strong emotions evoked in all parties, especially given that emotions inform action, and also because of the defensive bias they often introduce. Further, as political and critical researchers, we must ask questions about research's role in bringing about social change. This study suggests that, in our contemporary climate in which migration is frequently securitized and criminalized, researchers and activists will continue to be challenged by dual loyalties and the complexity of studying and resisting disciplinary institutions.

References

Agence France-Presse in Geneva. (2017, November 14). EU's policy of helping Libya intercept migrants is 'inhuman', says UN. *The Guardian.* Retrieved from https://www.theguardian.com/world/2017/nov/14/eu-libya-coastguard-detention-centres-migration-mediterranean-un-zeid-raad-al-hussein

Billo, E., & Mountz, A. (2016). For institutional ethnography: Geographical approaches to institutions and the everyday. *Progress in Human Geography, 40*(2), 199-220. doi:10.1177/0309132515572269

Bosworth, M. (2013). Can immigration detention centres be legitimate? Understanding confinement in a global world. In K. Franko & M. Bosworth (Eds.), *The borders of punishment: Migration, citizenship, and social exclusion* (pp. 149-165). Oxford, United Kingdom: Oxford University Press.

Bosworth, M. (2014). *Inside immigration detention*. Oxford, United Kingdom: Oxford University Press.

Bosworth, M. (2016). *The impact of immigration detention on mental health: A literature review* (Criminal Justice, Borders and Citizenship Research Paper No. 2732892). Retrieved from https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2732892

Bosworth, M., & Kellezi, B. (2017). Doing research in immigration removal centres: Ethics, emotions and impact. *Criminology & Criminal Justice, 17*(2), 121-137. doi:10.1177/1748895816646151

Bosworth, M., & Slade, G. (2014). In search of recognition: Gender and staff–detainee relations in a British immigration removal centre. *Punishment & Society, 16*(2), 169-186. doi:10.1177/1462474513517017

Brooker, S., Albert, S., Young, P., & Steel, Z. (2016). *Challenges to providing mental health care in immigration detention*. Geneva, Switzerland: Global Detention Project.

Butler, J. (1997). Subjection, resistence, resignification: Between Freud and Foucault. In *The psychic life of power: Theories in subjection* (pp. 83-105). Palo Alto, CA, USA: Standford University Press.

Cleveland, J. (2015). Not so short and sweet: Immigration detention in Canada. In A. Nethery & S. J. Silverman (Eds.), *Immigration detention* (pp. 93-101). London, United Kingdom: Routledge.

Cleveland, J., Kronick, R., Gros, H., & Rousseau, C. (2018). Symbolic violence and disempowerment as factors in the adverse impact of immigration detention on adult asylum seekers' mental health. *International Journal of Public Health, 63*(8), 1001-1008. doi:10.1007/s00038-018-1121-7

Cleveland, J., & Rousseau, C. (2013). Psychiatric symptoms associated with brief detention of adult asylum seekers in Canada. *Canadian Journal of Psychiatry, 58*(7), 409-416. doi:10.1177/070674371305800706

Cohen, K., & Collens, P. (2013). The impact of trauma work on trauma workers: A metasynthesis on vicarious trauma and vicarious posttraumatic growth. *Psychological Trauma: Theory, Research, Practice, and Policy, 5*(6), 570-580. doi:10.1037/a0030388

Dos Santos, N., Smith-Spark, L., & Frater, J. (2018, June 29). EU summit deal reached after Italy demanded action on migrant crisis. *CNN.* Retrieved from https://www.cnn.com/2018/06/28/europe/italy-eu-summit-migrant-crisis/index.html

Drake, D. H., & Harvey, J. (2014). Performing the role of ethnographer: Processing and managing the emotional dimensions of prison research. *International Journal of Social Research Methodology, 17*(5), 489-501. doi:10.1080/13645579.2013.769702

Ellis, C., Adams, T. E., & Bochner, A. P. (2011). Autoethnography: An overview. *Forum Qualitative Social Research, 12*(1). Retrieved from http://www.qualitative-research.net/index.php/fqs/article/view/1589/3095

European Council on Refugees and Exiles. (2017, March 17). *Hungary approves controversial law allowing automatic detention of asylum seekers.* Retrieved from https://www.ecre.org/hungary-approves-controversial-law-allowing-automatic-detention-of-asylum-seekers/

Fine, M. (2006). Bearing witness: Methods for researching oppression and resistance—A textbook for critical research. *Social Justice Research, 19*(1), 83-108.

Fleay, C., & Briskman, L. (2013). Hidden men: Bearing witness to mandatory detention in Australia. *Refugee Survey Quarterly, 32*(3), 112-129. doi:10.1093/rsq/hdt010

Foucault, M. (1977). *Discipline and punish: The birth of the prison* (A. Sheridan, Trans.). New York, NY, USA: Pantheon.

Frost, L., & Hoggett, P. (2008). Human agency and social suffering. *Critical Social Policy, 28*(4), 438-460. doi:10.1177/0261018308095279

Gill, N. (2016). *Nothing personal? Geographies of governing and activism in the British asylum system*. Chichester, United Kingdom: John Wiley & Sons.

Goffman, E. (1957). *The characteristics of total institutions.* Paper presented at the Symposium on Preventive and Social Psychiatry, Walter Reed Army Institute of Research, Washington, DC, USA.

Gros, H., & Song, Y. (2016). *"No life for a child": A roadmap to end immigration detention of children and family separation*. Retrieved from https://tspace.library.utoronto.ca/handle/1807/80115

Gros, H., & van Groll, P. (2015). *"We have no rights": Arbitrary imprisonment and cruel treatment of migrants with mental health issues in Canada* (Report; International Human Rights Program in the Faculty of Law at the University of Toronto). Retrieved from http://ihrp.law.utoronto.ca/utfl_file/count/PUBLICATIONS/IHRP We Have No Rights Report web 170615.pdf

Hoffman, M. L. (2001). *Empathy and moral development: Implications for caring and justice*. Cambridge, United Kingdom: Cambridge University Press.

Jewkes, Y. (2012). Autoethnography and emotion as intellectual resources: Doing prison research differently. *Qualitative Inquiry, 18*(1), 63-75. doi:10.1177/1077800411428942

Jewkes, Y. (2014). *An introduction to "doing prison research differently"*. Los Angeles, CA, USA: SAGE.

Kronick, R., Rousseau, C., & Cleveland, J. (2015). Asylum-seeking children's experiences of detention in Canada: A qualitative study. *The American Journal of Orthopsychiatry, 85*(3), 287-294. doi:10.1037/ort0000061

Kronick, R., Rousseau, C., & Cleveland, J. (2016). "They cut your wings over here . . . you can't do nothing": Voices of children and parents held in immigration detention in Canada. In R. Furman, D. Epps, & G. Lamphear (Eds.), *Detaining the immigrant other: Global and transnational issues* (pp. 195-207). Oxford, United Kingdom: Oxford University Press.

Kronick, R., Rousseau, C., & Cleveland, J. (2018). Refugee children's sandplay narratives in immigration detention in Canada. *European Child & Adolescent Psychiatry, 27*(4), 423-437. doi:10.1007/s00787-017-1012-0

Liebling, A. (2001). Whose side are we on? Theory, practice and allegiances in prisons research. *British Journal of Criminology, 41*(3), 472-484. doi:10.1093/bjc/41.3.472

Liebling, A. (2014). Postscript: Integrity and emotion in prisons research. *Qualitative Inquiry, 20*(4), 481-486. doi:10.1177/1077800413516273

Mackenzie, C., McDowell, C., & Pittaway, E. (2007). Beyond 'do no harm': The challenge of constructing ethical relationships in refugee research. *Journal of Refugee Studies, 20*(2), 299-319. doi:10.1093/jrs/fem008

Massumi, B. (2015). *Politics of affect.* Cambridge, United Kingdom: Polity Press.

Mekki-Berrada, A., Rousseau, C., & Bertot, J. (2001). Research on refugees: Means of transmitting suffering and forming social bonds. *International Journal of Mental Health, 30*(2), 41-57. doi:10.1080/00207411.2001.11449518

Nethery, A., & Silverman, S. J. (2015). *Immigration detention: The migration of a policy and its human impact.* London, United Kingdom: Routledge.

Opening Doors. (2018). *Belgium plans to resume child detention in 2018.* Retrieved from http://www.openingdoors.eu/belgium-plans-to-resume-child-detention-in-2018/

Parker, C., & Satija, N. (2018, July 11). Trump officials want to give migrant families two options: Stay detained together or agree to separation. *The Texas Tribune.* Retrieved from https://www.texastribune.org/2018/07/11/trump-border-separation-immigrant-families-choice/

Physicians for Human Rights. (2011). *Dual loyalties: The challenges of providing professional health care to immigration detainees.* Washington, DC, USA: Physicians for Human Rights Washington.

Rousseau, C., & Kirmayer, L. J. (2010). From complicity to advocacy: The necessity of refugee research. *The American Journal of Bioethics, 10*(2), 65-67. doi:10.1080/15265160903506418

Sampson, R. (2015). Mandatory, non-reviewable, indefinite: Immigration detention in Australia. In A. Nethery & S. J. Silverman (Eds.), *Immigration detention: The migration policy and its human impacts*. London, United Kingdom: Routledge.

Schwandt, T. A. (2007). *The Sage dictionary of qualitative inquiry* (3rd ed.). Thousand Oaks, CA, USA: Sage.

Solnit, R. (2018). Not caring is a political art form: On Melania Trump and the politics of disconnection. *Literary Hub.* Retrieved from https://lithub.com/rebecca-solnit-not-caring-is-a-political-art-form/

Zion, D., Briskman, L., & Loff, B. (2012). Psychiatric ethics and a politics of compassion. *Journal of Bioethical Inquiry, 9*(1), 67-75. doi:10.1007/s11673-011-9346-7

PsychOpen GOLD

PsychOpen GOLD

Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

'Are You a Radical Now?' Reflecting on the Situation of Social Research(ers) in the Context of Service-User Activism in Mental Health

Cristian R. Montenegro*[a]

[a] Department of Methodology, London School of Economics and Political Sciences, London, United Kingdom.

Abstract

The relationship between activism and social research constitutes a longstanding source of debate. In the mental health and disability fields, this tension has specific connotations: User-survivor activism is premised on the priority of first-hand experience over detached, 'objective' knowledge. Personal experience is the foundation for the specific and irreplaceable perspective that users and survivors bring upon issues of interest. Considering this, how do user/survivor activist groups relate and collaborate with academically oriented researchers who lack a first-person encounter with psychiatry? Drawing on my participant observer role in a user-led activist group in Chile and through three 'reflexive vignettes', in this paper, I retrospectively trace how my interests and presence were received, negotiated and contested by users and non-users in the field. The findings describe three episodes in which my own status - and that of others participating 'in the name of research' - was interrogated. Although the group was open to anyone, boundaries emerged in response to specific demands from external agents interested in participating. A sense of 'personal connection' with the aims and nature of the group was one of those boundaries. In parallel, professional members had their own way of signalling their legitimacy, usually through a self-critical, anti-professional and anti-academic attitude. Doubts about my commitment to the group emerged as fieldwork progressed. The vignettes map the tensions that I experienced, the efforts I made to navigate them and the way they affected my disposition towards the group. The article argues that researcher's reflexivity towards their own situation constitutes a primary source of information in the context of emergent, user-led advocacy efforts. Attention to how these groups accept and/or resist academic agendas provide insights into the solidarities and affinities that shape activist efforts. More than a pre-defined, 'ethico-political' disposition what's required from researchers interested in this field is reflexivity to navigate the interface between academia and activism, honesty about the limits of academia and openness towards the contingent outcomes of an encounter with activism.

Keywords: mental health, service-users, activism, reflexivity, research vignette, mad studies, Chile

Discussions around the continuity or discontinuity between 'activism' and 'academia' have been part of the social sciences since their inception. This tension has specific characteristics in the context of mental health service-

user activism, where priority is given to first-hand experience over detached, 'objective' or 'expert' knowledge (Noorani, 2013). First-hand experience is usually a marker of membership across activist groups and the foundation for the specific and irreplaceable perspective that users and survivors bring upon issues of interest. How, in this context, do service-user groups relate and interact with academic researchers who do not have a direct experience with psychiatric services? What are the boundaries that link and differentiate activism and academia in this context and how are they negotiated in concrete situations?

Over the last eight years, I have worked in mental health settings and conducted research into different social aspects of the Chilean mental health field (Mascayano & Montenegro, 2017; Montenegro, 2011; Montenegro & Cornish, 2015, 2017). In 2015, I spent three months participating in the activities of Agrupación Libre Mente (ALM), a user-led activist organisation, with the aim of understanding their main concerns and forms of collective action. This exploration resulted in a published paper that describes how ALM actively rejected the parameters of 'civil society engagement' defined by the mental health system, demonstrating, through conversations and decisions, a will for self-differentiation in response to expectations about their role (Montenegro, 2018).

The reflexive dimension of this research process - my own engagement with the group and what I perceived to be their perceptions about me - remained somehow marginal in that account. But over time I came to realise that my presence was an opportunity for the group to play out its own boundaries, this time in relation to social research and, more importantly, social researchers. I also realised that the contingent nature of this relationship differed from similar attempts and reflexions in the literature (Cresswell & Spandler, 2013).

In this article, I want to retrospectively unpack how my interests and presence were received, negotiated and contested by a service-user group engaged in activism. Using the model of the 'reflexive vignette' (Langer, 2016), I present three fieldwork episodes in which my status - and that of other participants who identified as social researchers - was interrogated, and the efforts I made to articulate the legitimacy of my goals and to secure the continuity of my participation. The discussion articulates the lessons contained in each vignette with respect to the relationship between activism and academia in this field. In the conclusions I reflect on what can be learned from my experience in order to engage in the sociological study of activist practices in mental health, responding to current debates about the interface between social research and service-user activism (Cresswell & Spandler, 2013; Rose, 2008a; Russo, 2012; Russo & Beresford, 2015). Rather than providing a comprehensive overview of the findings of the fieldwork, my aim with the vignettes is to illustrate the argument of the article.

Activism and the Chilean Mental Health Field

While the autonomous organisation of mental health service users and survivor groups is a stable feature in different countries of the Global North, in Latin America this is a recent and under-researched phenomenon. Available studies and policy documents usually place the actions and concerns of users alongside those of professionals, caregivers and other allies, under a common horizon of advocacy, usually oriented towards the expansion of mental health services (Ceriani, Obiols, & Stolkiner, 2010; Zaldúa et al., 2012). However, over recent years, an intense politics of dealgnment is taking place: between users and families, between users and advocators, and between different user groups with opposing political orientations (Montenegro, 2018).

The first expressions of service-user collective organisation in Chile started in the late 90s with the creation of the National Association of Users of Mental Health Services (ANUSSAM). ANUSSAM was the outcome of the efforts of users working in high profile family organisations, born in the context of deinstitutionalisation (Montenegro &

Cornish, 2017). For this process to consolidate the definition of mechanisms to legitimise coercive measures in the community was indispensable. The 'Commission for the Protection of the Rights of Persons with Mental Illnesses' was thus born, requiring the representation of a service-user organisation alongside other professional groups (MINSAL, 2000). The match between this legal demand and the prior organising efforts of users within family organisations gave birth to ANUSSAM (Montenegro & Cornish, 2017).

Since its inception in 2001, ANUSSAM has been the main user-led advocacy organisation in the country. Its role is to represent users vis-a-vis different government agents, including the Ministry of Health and the National Disability Service. However, over recent years alternative expressions of activism have emerged at the margins, under the influence of two relatively distinct processes. On the one hand, the disability rights movement has seen a growth in support over the last few decades, particularly after different Latin American states signed the Convention for the Rights of Persons with Disabilities (CRPD) (Angel-Cabo, 2015; Figueroa, 2017b). Several efforts have been made to harmonise national legal frameworks and the Convention, with a parallel articulation of advocacy actions across the country. In Latin America mental health issues are usually framed as psychosocial disabilities and, through this lens, the vocabulary and political horizon of the CRPD have penetrated debates about mental health services and the right of self-determination, self-expression and the autonomy of users (Figueroa, 2017a; Minoletti et al., 2015; Observatorio de Derechos Humanos de las Personas con Disacapacidad Mental, 2014).

On the other hand, a burgeoning 'anti-psy' scene has emerged in the country, particularly within academic psychology, partly influenced by the work of Chilean philosopher Carlos Pérez-Soto (2012) and the critical community psychology of Domingo Asún and others (Domínguez, Kornblit, Rovira, & Asún, 2002). Their work has mobilised a sense of exasperation with the role of psychological knowledge and techniques in the production of 'neoliberal subjects' adapted to post-dictatorship Chile, in the school and at work (Pavón-Cuéllar, 2017). Simultaneously, these ideas have resonated with the political values of a generation of students who participated in the waves of protest sweeping the country over the last few decades (Cabalin, 2012).

Both scenes help to explain the political and organisational style of Agrupación Libre-Mente and its view of institutions and professionals, aspects that are developed in subsequent sections. Prior to this, key elements in the literature on service-user activism are discussed, in order to situate the study.

Tensions Between Academia and Activism

The relationship between academia and activism has been debated since the origins of the social sciences. Whilst, for Marx and Engels', dialectical materialism was simultaneously a science of society and a tool of its transformation (Engels, 2012; Marx, 1990), Weber (2008) claimed that science and politics responded to different and irreducible *calls* linked to differentiated spheres of action in modernity. Recent calls for activist scholarship have questioned these boundaries (Maxey, 1999) through integrative epistemological and methodological frameworks (Croteau, Hoynes, & Ryan, 2005; Hale, 2008; Smith, 1990).

Activism itself is a very wide concept that includes different goals, strategies and scales. While in many cases a shared vision of social transformation allows for the integration and hybridization of academic and activist orientations, in other cases knowledge and expertise themselves are key objects of contention, such as in the mental health service-user and survivor movement (Coleman, 2008; Everett, 2000).

User-produced knowledge and 'lived-experience' (Rose, 2008b) are key aspects of the autonomous service-user activism developed in different English-speaking countries over several decades (Campbell, 1996; Crossley, 2006; Hughes, 2006). For Faulkner (2010), engaging in knowledge production 'has the potential to empower people, in that it gives us the opportunity to, as it were, reverse the "research gaze" and to use research for our own purposes' (p. 37). While overlapping with the so-called 'era of the patient' in medicine (Reiser, 1993), in the context of psychiatry lived-experience, not only enriches a clinical approach but it becomes a fundamental ground to dispute the authority of psychiatric knowledge and the very notion of 'the patient' (Lester & Tritter, 2005; Noorani, 2013).

The specific perspective that service-users bring to matters of shared concern is based on their direct experiences of use - and abuse - at the hands of service providers and broader institutional frameworks. The centrality of lived-experience complicates the simple crossing of activist and academic boundaries. This has prompted the creation of hybrid platforms such as Mad Studies, defined as 'a project of inquiry, knowledge production, and political action devoted to the critique and transcendence of psy-centred ways of thinking, behaving, relating, and being' (Menzies, LeFrançois, & Reaume, 2013, p. 13). Taking distance from anti-psychiatry and other academic polemics, Mad Studies 'takes as its principal source, inspiration, and raison d'être the subjectivities, embodiments, words, experiences, and aspirations of those among us whose lives have collided with the powers of institutional psychiatry' (Ibis).

Although Mad Studies exemplifies a way of understanding the relationship between political and academic commitments in the field, it is still a very localised enterprise mostly situated in English-speaking countries. Moreover, the relationship between 'experience' and expertise has been debated (McKevitt, 2013; Meriluoto, 2018). Experience is a heterogeneous category whose form and validity are associated with other markers such as class and gender (Kelly, 2017). The position from which an experience is conveyed is not unitary, receiving modulation by the practical situations taking place to an individual or a group (Jones & Kelly, 2015). As stated by Schrader et al. (2013), the 'mad' identity that some of these movements claim is not an intrinsic, defining feature but an 'active and thoughtful positioning of the self with respect to dynamic social narratives regarding mental difference and diversity' (p. 62).

Across the Global South, experiences of service-user activism are emerging, responding to local concerns, drawing on different forms of solidarity and developing unique trajectories of self-differentiation that reconfigure the links between experience and membership. What is the situation of social research(ers) in these processes? How do these groups deal with the concrete presence and the interests of academics? What does this say about the way the relationship between activism and academia has been conceptualised in western countries?

Rather than a systematic answer to these questions, in this paper, I reflect on my academically oriented engagement with a group of service-user and non-user activists in Chile. Considering my experience and the interactions between other researchers and the group I aim to unravel some of the concrete ways in which the boundaries between activism and social research are negotiated in this specific field. Deeply testimonial in nature, the findings are modelled around the 'reflexive vignette' (Langer, 2016), a methodological and analytical tool for the retrospective reconstruction of the experiences of researchers in the field. This tool is described in the next section.

The Function of Reflexivity and the Research Vignette

Although reflexivity has long been part of the toolbox of qualitative social research, recently there have been attempts to problematise its scope. Especially in health, the notion has been formalised as a way to reduce bias and

recognise the influence of the researcher in the field, a version that Kuehner et al. (2016) describe as 'weak re-flexivity'. In contrary, as stated by Hervik (1994) reflexivity is not an 'internal' feature of the researcher but forms part of the "intersubjective context of fieldwork' (p. 60).

According to Hammersley and Atkinson (2007), during fieldwork, the researcher 'will be channelled in line with existing networks of friendship and enmity, territory and equivalent "boundaries" (p. 59). This is relevant in the context of emergent activisms, where political affinities are in the making and the roles of academia and 'research' are disputed. A careful consideration of the dynamics of encounter, insiderness, and outsiderness *experienced* researchers are, therefore, not a supplement to the description of practices (Labaree, 2002) but rather a window into the boundaries defining activist spaces (Casas-Cortés, Osterweil, & Powell, 2008; Lichterman, 2017).

Langer's (2016) 'Research Vignette' is an attempt to operationalise this stronger form of reflexivity. In its most basic form, the vignette is the description of specific episodes experienced while conducting research. It is grounded in an understanding of interviews and other methods as instances of situated and shared construction of meaning, exposing the experience of the researcher as the basis for a more accurate description of the field.

This retrospective analysis is not developed from a fixed position. For Langer (2016), 'reflexivity does not refer to a solid researcher-subject but has to take into account that this particular subject is constituted performatively in the interview interaction with the interviewee' (p. 745) or, as in my case, in the process of participant observation and the complex interactions it entails. The unsettledness of the research-position becomes a source of information about the field. For Devereux, whose work directly inspires this call for stronger reflexivity, a primary source of data for the social scientist is 'the behavior of the observer: His anxieties, his defensive maneuvers, his research strategies, his 'decisions' (= his attribution of meaning to his observations)' (Devereux, 1967, p. XIX). Following this, the following vignettes want to allow the reader to understand

a. how my presence was received, negotiated and contested by members of ALM and

b. how, in response, I tried to articulate the legitimacy of my goals and to secure the continuity of my engagement in the group.

In each vignette I highlight (i) the ways in which me and other members participating 'in the name of research' (Clough, 2004) were received by a very diverse group, (ii) the issues they brought to bear on their interrogation of the researcher's position, (iii) the way in which I sought to respond and (iv) the outcome of this particular inter-action in the context of my evolving relationship with the group. But in order to understand the context of these situations, I will first describe how I approached the group and what were its characteristics during the time I spent with them.

Approaching the Group

First Contact

Between July and September of 2015, and in the context of a larger project about the emergent forms of collective action by service-users in Chile, I conducted participant observation with a group named Agrupación Libre Mente (ALM). I knew them through their Facebook page where they shared different activities.

I first contacted ALM through Ramon, an ex-user and disability rights activist whom I had met a year before in the context of my participation in a study evaluating the quality of care and the respect of the human rights of users. I explained my research project to him and, after consulting with the group, they allowed me to attend their meetings. I flew back to Santiago at the end of July 2015 and three days later I participated in my first meeting.

I participated in 17 meetings with the group including nine regular weekly meetings, two extraordinary meetings (focused on specific projects) and six other events and activities involving specific members of the group. This amounted to 70 hours. I interviewed five of its members (service-users). Through field notes I recorded conversations and other aspects of the meetings, focusing on how the group described itself. In parallel, I followed the groups' social media activity, before and after fieldwork.

The Group

ALM was the result of a transformation of a prior group composed of psychologists and other professionals engaged in the growing 'anti-psy' scene in the country (Montenegro, 2018). Ramon was the first member with a direct experience with psychiatry. He wanted to transform the group into a user-led and user-oriented initiative, but ALM was open to anyone interested.

The number of participants in ALM's meetings fluctuated between 7 and 15. Participants who did not describe themselves as users or ex-users worked in mental health or related fields, in different levels and locations, and some were involved in other forms of activism. In terms of age, gender and background, the group was very diverse.

Those who described themselves as users and ex-users in the group shared stories of neglect, abuse and manipulation by mental health professionals. All of them were working to regain control over their lives. Still, their perspectives on psychiatry were diverse, with no set of agreed-upon principles. Above any other goal, they wanted to work together.

In one of our first conversations, Ramon emphasised how the meetings provided a space of authentic encounter that transcended clinical definitions, and how that was the foundation for empowerment and collective agency. Several months after concluding my fieldwork, and while walking together in London for a meeting with local activists, he expressed concerns about the sudden increase of researchers and other 'non-users' in ALM's meetings. Long-term user-members felt increasingly alienated and wanted their own, exclusive space. My engagement with the group broadly coincided with this growing concern, a process that the following vignettes aim to reveal.

Findings: Three Vignettes From the Field

Vignette 1: 'We Only Accept Participants, not Observers'

During fieldwork, ALM met every Monday at an anarchist bookstore in central Santiago. The meetings lasted around 2 hours. While there was no predefined structure, they started with a round of lengthy introductions that provided themes for further conversation. Whether old or new, each participant received the same level of attention. The composition of the meetings, involving users, ex-users, non-users and guests, produced lively conversations (Montenegro, 2018).

Two psychology students came to one of the meetings to conduct research on the group. A social psychology assignment required them to investigate an 'active minority' and, they thought, ALM was a perfect example. Ramon explained that the group needed to decide upon their participation. The students kept asking 'research' questions and Ramon, finally, advised them to submit those questions via email because 'the meeting had a different purpose'.

After the interruption the conversation moved to the organisation of the Mad Pride Parade, the first such event in the country, organised by ALM. A discussion ensued about using the word 'mad'. Some members felt that this could be offensive and alienating for other service users. The conversation revealed deep differences of opinion on fundamental matters, drawing the attention of the students.

> **Student 1:** *After hearing all of you I noticed that everybody has a very specific perspective. How do you manage to have a shared view of social or other problems?*
>
> **Valeria [psychologist and long-term ally]:** *You mean how do we reach a consensus?*
>
> **Raul [psychologist and long-term ally]:** *We just know each other for a long time and, slowly, we have developed certain ideas together.*
>
> **Student 1:** *Yes, I understand, the meetings are important and that you know each other and all that, but where do your ideas come from, do you take lessons somewhere?*
>
> **Raul:** *Look, here the craziest teach the least crazy, and that's it.*

The students' questions and concerns contrasted with the flow of the conversation. Other participants began to talk simultaneously - something that rarely happened. The students directed their questions to the members they thought were most fit to respond: Raúl, a psychologist and ally, and Ramon. They wanted to define the group through its aims, tracing the group back to a shared position on different issues.

However, as the quote reveals, the group resisted. The conversation moved back to the parade and the risk of appropriation of service-users voices, considering that the event was open to everybody and that the aim was to gather people and support. The students wanted to be there, to which Claudio, a user, responded, partly joking: 'but in the Parade, we only accept participants, not observers'.

I could understand and somehow share annoyance of the group faced with these untimely observers. Their approach lacked skill and sensitivity, there was no attempt to participate and it felt like an empty attempt to get their homework done. But I could also see the similarities between my situation and theirs. In what sense was I different?

After a while, Mariela, a professional, asked the students if they were only interested in the group because of their assignment or if they had a personal connection with mental health. In response, they highlighted how 'critical' their academic training was. Mariela replied 'in any case, you should be involved with the group beyond that assignment of yours… that could actually make you better psychologists'.

This episode revealed the discontinuity between the questions and requirements of these observers and the way the group understood itself. Being 'critical' - within the confines of psychology - was not enough. While not a precondition for participating in the meetings, a 'personal connection', emerged as a relevant boundary, a way to differentiate 'observers' from 'participants'. While I was not directly implicated in the situation, and while I had a relatively secure position collaborating with the coffee shop project, the episode revealed the fragile situation of those participating 'in the name of research' (Clough, 2004), anticipating some of the issues that I faced afterwards.

Vignette 2: 'An Exception to the Rule'

In the meetings, professionals were usually dealt with through the function they accomplished for the group. Earlier on, somebody brought a formally dressed lawyer to advise the group around the legalities of the coffee shop. Several attempts to incite a more 'human' side to him failed, including jokes about the need to upgrade the dress code for the meetings. A personal connection was not required in this case: he knew things the group did not, things the group needed to know and, on that basis, he had a place in the meeting,

It was different for psychologists and other mental health professionals. Their lack of a direct experience with psychiatry meant that they needed to legitimize their position. In several occasions a self-critical stance emerged as a mechanism of legitimation, but there was diversity in this. Some expressed a desire to learn about real people in order to overcome the limitations of academic psychology. Others denounced the psy-disciplines as aides of neoliberalism and framed their own role as collaborating with the 'revolution of the mad'. But through diplomatic or critical distance, a professional background was still useful to position themselves within the group.

A new participant came to a meeting, and the group had a very specific reaction, one that involved me directly. She was around 30 years old and, although she had suffered a mental breakdown at an early age, she did not consider herself a service-user. She had studied sociology but never saw herself as one. At the moment, she was exploring the healing powers of plants. Most of the members shared a clear disdain for medicine. The idea of finding cures for personal ailments without relying on what they called 'pharmafia' produced an intense conversation.

Renata, a user and former biology professor, who usually insisted on her love for science, asked her if she had ever worked as a sociologist. Constanza replied:

> **Constanza:** *I studied sociology but please don't think that I believe myself to be a sociologist. I finished my studies and now I do other things.*
>
> **Ramon:** *That's great!*
>
> **Natalia:** *Do you feel disappointed about sociology?*
>
> **Constanza:** *Yes… unfortunately, sociology is not practical. It's like… you want to do things and you clash against a wall. The stuff about how modern society works is so abstract, it's just palaver, it's useless for me.*
>
> **Claudio:** *But I suppose the knowledge helps you somehow.*
>
> **Constanza:** *I mean there's people that believe in sociology, people that think that sociology is the solution for everything… I'm not saying that people shouldn't study this, it's just that… my friends who moved into sociology-related positions are just so far away now, they have no contact with real people anymore.*
>
> **Claudio (pointing at me):** *Well, here we have an exception to the rule.*
>
> **Me:** *I hope so.*
>
> **Ramon:** *That's what we all expect.*
>
> *[Laughs]*

In the first episode I remained an observer, but here I was implicated, not only by Claudio but indirectly by Constanza and her explicit disdain for the professional identity that I had espoused from the beginning. Her attitude

was explicitly endorsed by Ramon, and it was common amongst the professionals in the group. An anti-professional stance and a general rejection of the role of 'experts' lined itself very well with the 'anti-psy' spirit of the group.

After this episode, something became clear to me. The group saw me as an exception to the vision of the sociologist as a distant bureaucrat. More importantly, I was the subject of the groups' interpretations and expectations and, while obvious, that realisation shaped my ensuing interaction with them, adding to my prior interrogation: 'What am I for this group at this point and how is that relevant for my project?'

In the first vignette, a 'personal connection' with madness and/or psychiatry emerged as a boundary, delimiting observers from participants. The second vignette shows how a disdain for professions allowed professionals to add legitimacy to their participation in the group. This complicated the production of boundaries by the group. Furthermore, the expectations some members had about me and the fact that, for them, I was not the 'standard' sociologist made me particularly aware of further expressions of disdain and/or support towards academia, as revealed by the following vignette.

Vignette 3: 'Are You a Radical now?'

During the final period of fieldwork, I began to think about the end of my participation in the group. I had only four more meetings with them and I was planning to hold some kind of feedback exercise. Simultaneously my relationship with Jaime - a mental health professional and one of the founders of the initial group - was getting very tense. He never came to the meetings that I attended but we talked at different events and had some communication through social media (especially Facebook). Initially, he was supportive of my project but, as my fieldwork progressed, he seemed increasingly doubtful and hostile. In more or less explicit ways he let me know that I had no reason to participate in the group. My agreement and collaboration with Ramon and others did not convince him. I talked this over with Ramon, he dismissed Jaime's attitude but the tension continued and I feared that this could affect my relationship with the group and my fieldwork plan.

Although without explicit membership criteria, the group clearly privileged the presence of users. Non-users were welcomed, and, in several meetings, they were the majority, but permanent efforts were made to invite more users and to give those who were already part of the group more responsibilities and opportunities to lead different actions. This created specific dynamics of interaction and worth inside the group.

Besides Constanza, across the meetings, it was common to hear professionals and students expressing disdain towards professions and universities. They despised the training they had just received, taking pride in decidedly pursuing a completely different path in life. Universities were elitist, distant and ultimately useless.

However, the constant repetition of such views resembled a ritual of purification they needed to perform in order to feel at home. I immediately detected and reacted to this, on one level because it was interesting but, more importantly, due to a personal sensitivity towards everything anti-academic, given my own role in the group.

On the 5th of September, I went to the regular Monday meeting. I reminded the group that I was leaving by the end of the month, mentioning my intention to hold some sort of final session with them. I suggested two options. The first was to have a session centred around the social sciences, aimed at giving them resources to better engage with students and people conducting research. This seemed relevant, as Ramon had already mentioned the need to address the growing influx of students in the meetings. As an alternative, I proposed the idea of building

flowcharts. Just as health services guide their interactions with users through flowcharts, users might also draw on their own experiences to build decision frameworks for dealing more effectively with service-providers. I hoped such a tool could assist them in visualising the widest possible range of responses in the face of arbitrary institutional decisions.

While explaining these options I felt that my textbook idea of a final feedback session was not appealing to most members. I had already talked with Ramon about concrete possibilities of collaboration from the UK, and my intentions to stay in touch with them were clear but it seemed like the group wanted something different. In one public Facebook interaction, Jaime had already told me that I was supposed to 'bring money back from Europe', that being my only role in the group and, at that precise moment I thought that maybe this expectation was shared.

Ramon broke the silence, saying: 'Beside those options, it would be good to hear about what happened to you during this time'. I replied by discussing the impact of the group upon my broader research project and the way the meetings had become a lens to understand the limitations of the mental health system and the potential of users working together. Natalia, an anthropology student and ally, interrupted me, asking 'Are you a radical now?'. It took me by surprise, and I asked her to explain the question. 'I mean you surely don't see things the way you did before?' I replied that I had always experienced a deep dissatisfaction with the precarious and unequal public health system in the country and that my research was moved by a concern for the rights and experiences of users. She interrupted me again, saying 'But I suppose that your ideas have changed a lot, haven't they?'

Two parallel processes contextualise my position at that specific point during fieldwork. On the one hand, I was clearly enthusiastic about the group, its message and its value. I felt welcomed and confident, proposing ideas and taking part in debates and conversations. I wanted to help them in the terms they had set for me. But at the same time the episode with the students, the anti-professional attitude of the professionals and Jaime's constant and unfounded doubts about me had made me more sensitive about the fragility of my role and defensive against those doubts.

Natalia was herself a social scientist, she had no direct experience of psychiatric treatment, was very vocal against professionals and was Jaime's partner. Her demand for a proof of transformation and radicality inevitably felt like a deliberate attempt to demonstrate precisely the contrary, my lack of commitment and radicality. I could have said 'yes, my ideas have changed deeply after this', I could have drawn on my honest enthusiasm. But the question and its context precluded this option. I did not want to fit within the norms of (self) legitimacy defined by the professionals in the group.

Somehow, in that situation, my defensive side clashed with and prevailed over my enthusiasm and sense of connection. In response, I embraced more explicitly the identity of a sociologist. They all knew who I was and why I was there but still, being *more* sociologist was a way to respond to this dichotomous demand for commitment. A way to move out of the game of self-critique that professionals constantly played in the group.

This vignette shows that the anti-professional attitude discussed earlier was accompanied by more or less explicit expressions of doubt and disdain against newcomers who were not users. In an attempt to give themselves legitimacy as members, professionals created their own filters – or boundaries - for the group. Demands for demonstrations of commitment need to be situated within these dynamics, that are themselves linked to the composition of the group and the fact that it was still transitioning from being a student-led critical psychology effort to becoming a user-led advocacy platform.

That day, as usual, the conversation moved into other topics and activities. During the final part of the meeting, several members showed their interest in my proposal for a final feedback session. The attitudes towards my project were as diverse as the group itself and I could draw on the support of users to take my project forward, establishing a longstanding relationship with some of them. These vignettes are, in this sense, an attempt to throw some light into the contingent experience of conducting sociologically-oriented research with service-user activists and their allies.

Discussion

Following the call for 'strong reflexivity' (Kuehner et al., 2016) the previous vignettes described my engagement as a social researcher with a group of mental health service-user and professional activists in Chile. While the reflexive vignette was originally used as a richly described, personal account of a single moment in research (2016), here, they map a process. This process and the broader lessons that can be drawn are articulated in this section.

The first vignette showed the discontinuity between those trying to study the group and the group itself. The group resisted these observers not by excluding them or rejecting their questions but by questioning them in return. In particular, several members demanded the demonstration of a personal connection with madness and psychiatry beyond mere curiosity, a connection that was not only a condition of possibility for access but the foundation of a better way of being professionals – in this case, psychologists. As argued before, the notion of a personal connection should be seen as forming part of the emergent boundary that the group created to deal with those participating out of curiosity or with a 'scientific' goal. Research, in an on itself, was not reason enough to be there.

Several professionals without a direct experience of mental health services participated, since the beginning. This diversity was valued, but the group prioritised the presence and leadership of users. In this context psychologists and other professionals found ways to demonstrate and negotiate their legitimacy in the group, and, as revealed in vignette two, this involved expressions of disdain towards professions in general and other professionals in particular, as shown in vignette two and three. If a 'personal connection' acted as a boundary between the group and the universe of potential participants, this anti-professional stance acted as a secondary boundary by which professionals assessed each other's validity to participate in the group.

As my planned departure from the field was near, tensions with other professionals emerged. The fact that I was there conducting research was accepted from the beginning but, as fieldwork progressed, some professionals expressed doubts about my role and intentions. I tried to manage such tensions in order to sustain my place in the group, but they inevitably shaped my own disposition, something revealed by vignette three. These tensions can be linked to the conflict between a strong presence of professionals and the ideals of user-control that defined the group. It is in this context where the experience of social researchers interested in these groups needs to be situated and where the possibilities of intimate qualitative engagement find its limits. Non-user researchers interested in service-user activism should intensely reflect on their own experiences of engagement, as they can illuminate the dynamics of membership and identity involved in emergent service-user activist initiatives.

Conclusion

Much remains to be learned about the shifting interface between research and activism and the many forms it takes. In this paper, based on a case study in Chile, I have developed an idea of reflexivity aimed at enriching the study of this interface, in the specific case of service-user activism. Avoiding a solipsistic self-examination, the aim was to use my experience in approaching a service-user organisation as a window into how these groups define their own boundaries and expectations vis-a-vis social research. In line with this understanding of reflexivity, this paper has sought to illustrate my interactions with the group, and the unfinished production of a mutually agreed, legitimate interaction.

On the basis of this effort, it is possible to problematize how we understand the relationship between professionalism and activism in the mental health field. Although user-led initiatives embody a rejection of professional authority and domination, in the case at hand they also redefine what counts as 'good' or 'bad' ways of being a professional. While the main producers of these values are professionals themselves, they shape the emergent boundaries of activism in the field understood as the explicit and implicit terms defining who gets to have a place.

Since I participated in the group with the intention of conducting research, I was directly confronted by these shifting dynamics of membership. The threshold of legitimacy and acceptability that kept me in the group was very dynamic; it shifted over time, responding to my assertions and expressions of commitment. As stated by Lichterman (1998) 'we will understand more not only about social movements but volunteer groups (…) if we attend closely to what it means to be a member' (p. 403).

The experience of fieldwork was marked by a tension between an effort to take a closer look at the actions of the group while negotiating the expectations attached to this proximity. This tension shaped what I could observe, but in ways that were not completely transparent *during* the process. Reflexive vignettes are a way to make sense, through writing, of these tensions and use them productively to enrich the description of the phenomena under study (Langer, 2016).

Finally, I would like to return to a fundamental question that sits at the heart of this paper: What justifies the participation of social researchers as observers of the activism of users? On a more abstract level, what justifies observation when there is already self-observation? In general, sociologists and other social scientists have immunised themselves against the problem, striving for a position of neutrality. However, the emergence of hybrid activist-academic communities such as Mad Studies, where users and survivors themselves produce research and create political platforms in academia (Menzies et al., 2013) poses new challenges to the legitimacy of *external* academic observation. The question still lurks in the back: what justifies external observation when activists are already engaged in the production of knowledge about themselves?

Making a critical contribution to this discussion, Cresswell and Spandler (2013) have defended an ideal of committed engagement beyond the boundaries of academia and its imperative of neutrality. Through 'reflexive auto-critique' they consider the limits of the academic gaze in relation to the user/survivor movement. On this basis and following the work of Barker and Cox (2002), they propose the need for 'an effective politico-ethical stance' (Cresswell & Spandler, 2013, p. 142), different to a traditional academic 'interest'. They set out to evaluate the work of scholars interested in user/survivor activism on the basis of the depth of their engagement with the 'lived contradictions' involved in such research.

PsychOpen GOLD

Because of the nature of my project, these and similar calls are particularly relevant and challenging. However, my own 'lived contradictions' differ from these ideals. More than a politico-ethical stance, I can only try to offer a *retrospective-analytical* stance: one that looks backwards and recognises the accidental nature of encounters and dis-encounters across qualitative, field-based research projects. Such stance does not present itself as right or wrong but as a contingent outcome of the situations experienced in the field and, to an important degree, as an outcome of the encounter itself, of the unsettled negotiation of roles between researchers and activists.

In this sense, what Cresswell and Spandler define as 'depth of engagement' needs to be examined. In a context of emergence and self-differentiation, visions of transformation and horizons of action are *in the making*. Aligning one's own stance with that of the research participants - or with an abstractly adequate politico-ethical stance - can prevent researchers from perceiving often diverse and even self-contradictory spectrum of political and ethical orientations that take part in activist spaces.

Furthermore, if 'engagement' is a condition of possibility of valid observation, then one could ask about the conditions of possibility of engagement itself. In my view, that which makes engagement valid is a contingent outcome of engagement. Legitimacy, in this sense, is not achievable *before contact*. Everything starts with contact. Sometimes a process of intense political alliance and connection between researchers and activists will begin. Other times, a series of tensions, miscommunications and doubts will ensue. Yet other times, an oscillation between connection and tension, commitments and doubts will take place. In this sense, researchers in this field should not blackbox their complicated engagement with users. Stories of tension and unmet expectations shouldn't be hidden away. Activism and social research co-inhabit the world and open themselves up to each other in many different ways, beyond any preconceived notion of commitment and alliance.

References

Angel-Cabo, N. (2015). Human rights legal clinics in Latin America: Tackling the implementation of disability rights. In M. H. Rioux, P. C. Pinto, & G. Parekh (Eds.), *Disability, rights monitoring, and social change: Building power out of evidence* (pp. 97–112). Toronto, Canada: Canadian Scholars' Press.

Barker, C., & Cox, L. (2002). *'What have the Romans ever done for us?' Academic and activist forms of movement theorizing.* Paper presented at the 'Alternative Futures and Popular Protest' 8th annual conference, Manchester Metropolitan University, Manchester, United Kingdom. Retrieved from http://www.iol.ie/~mazzoldi/toolsforchange/afpp/afpp8.html

Cabalin, C. (2012). Neoliberal education and student movements in Chile: Inequalities and malaise. *Policy Futures in Education, 10*(2), 219-228. doi:10.2304/pfie.2012.10.2.219

Campbell, P. (1996). The history of the user movement in the United Kingdom. In T. Heller, J. Reynolds, R. Gomm, R. Muston, & S. Pattison (Eds.), *Mental health matters: A reader* (pp. 218–225). London, United Kingdom: Macmillan Education UK.

Casas-Cortés, M. I., Osterweil, M., & Powell, D. E. (2008). Blurring boundaries: Recognizing knowledge-practices in the study of social movements. *Anthropological Quarterly, 81*(1), 17-58. doi:10.1353/anq.2008.0006

Ceriani, L., Obiols, J., & Stolkiner, A. (2010). Potencialidades y obstáculos en la construcción de un nuevo actor social: Las organizaciones de usuarios. In *II Congreso Internacional de Investigación y Práctica Profesional en Psicología XVII Jornadas de Investigación Sexto Encuentro de Investigadores en Psicología del MERCOSUR*. Buenos Aires, Argentinia: Facultad de Psicología-Universidad de Buenos Aires. Retrieved from http://www.aacademica.org/000-031/579

Clough, P. (2004). Theft and ethics in life portrayal: Lolly—The final story. *International Journal of Qualitative Studies in Education, 17*(3), 371-382. doi:10.1080/0951839042000204642

Coleman, E. G. (2008). The politics of rationality: Psychiatric survivor's challenge to psychiatry. In B. da Costa & K. Philip (Eds.), *Tactical biopolitics art, activism, and technoscience* (pp. 341-363). Cambridge, MA, USA: The MIT Press.

Cresswell, M., & Spandler, H. (2013). The engaged academic: Academic intellectuals and the psychiatric survivor movement. *Social Movement Studies, 12*(2), 138-154. doi:10.1080/14742837.2012.696821

Crossley, N. (2006). *Contesting psychiatry social movements in mental health*. Abingdon, United Kingdom: Routledge.

Croteau, D., Hoynes, W., & Ryan, C. (Eds.). (2005). *Rhyming hope and history: Activists, academics, and social movement scholarship*. Minneapolis, MN, USA: University of Minnesota Press.

Devereux, G. (1967). *From anxiety to method in the behavioral sciences*. The Hague, The Netherlands: Mouton & Co.

Domínguez, J. F. M., Kornblit, A., Rovira, D. P., & Asún, D. (2002). *Psicología social*. Madrid, Spain: Pearson Educación.

Engels, F. (2012). *Dialectics of nature.* London, United Kingdom: Wellred Publications. (Original work published 1925)

Everett, B. (2000). *A fragile revolution: Consumers and psychiatric survivors confront the power of the mental health system*. Waterloo, ON, Canada: Wilfrid Laurier University Press.

Faulkner, A. (2010). Measuring the marigolds. In T. Basset & T. Stickley (Eds.), *Voices of experience: Narratives of mental health survivors* (pp. 33–43). Chichester, United Kingdom: Wiley-Blackwell.

Figueroa, F. (2017a). Internamientos involuntarios y tratamientos forzados en psiquiatría: Autonomía y no discriminación como estándar de derechos humanos. *Anuario de Derechos Humanos, 13*, 111-121. doi:10.5354/0718-2279.2017.46893

Figueroa, F. (2017b). Voces de usuarios y sobrevivientes de la psiquiatría contenidas en la convención sobre los derechos de las personas con discapacidad: Un nuevo paradigma abre camino en Chile. *Revista Latinoamericana en Discapacidad, Sociedad y Derechos Humanos, 1*(1). Retrieved from http://redcdpd.net/revista/index.php/revista/article/view/37

Hale, C. R. (Ed.). (2008). *Engaging contradictions: Theory, politics, and methods of activist scholarship*. Berkeley, CA, USA: University of California Press.

Hammersley, M., & Atkinson, P. (2007). *Ethnography principles in practice* (3rd ed.). Hoboken, NJ, USA: Taylor & Francis.

PsychOpen GOLD

Hervik, P. (1994). Shared reasoning in the field: Reflexivity beyond the author. In K. Hastrup & P. Hervik (Eds.), *Social experience and anthropological knowledge* (pp. 59-75). Abingdon, United Kingdom: Routledge.

Hughes, J. (2006). Movements in the 1970s. Retrieved from http://studymore.org.uk/mpu.htm#Hughes1970s

Jones, N., & Kelly, T. (2015). Inconvenient complications: On the heterogeneities of madness and their relationship to disability. In H. Spandler, J. Anderson, & B. Sapey (Eds.), *Madness, distress, and the politics of disablement* (pp. 43-56). Bristol, United Kingdom: Policy Press.

Kelly, T. (2017). Heterogeneities of experience, positionality, and method in user/survivor research. *Philosophy, Psychiatry, & Psychology, 23*(3), 229-232. doi:10.1353/ppp.2016.0022

Kuehner, A., Ploder, A., & Langer, P. C. (2016). Introduction to the special issue: European contributions to strong reflexivity. *Qualitative Inquiry, 22*(9), 699-704. doi:10.1177/1077800416658069

Labaree, R. V. (2002). The risk of 'going observationalist': Negotiating the hidden dilemmas of being an insider participant observer. *Qualitative Research, 2*(1), 97-122. doi:10.1177/1468794102002001641

Langer, P. C. (2016). The research vignette: Reflexive writing as interpretative representation of qualitative inquiry — A methodological proposition. *Qualitative Inquiry, 22*(9), 735-744. doi:10.1177/1077800416658066

Lester, H., & Tritter, J. Q. (2005). 'Listen to my madness': Understanding the experiences of people with serious mental illness. *Sociology of Health & Illness, 27*(5), 649-669. doi:10.1111/j.1467-9566.2005.00460.x

Lichterman, P. (1998). What do movements mean? The value of participant-observation. *Qualitative Sociology, 21*(4), 401-418. doi:10.1023/A:1023380326563

Lichterman, P. (2017). Interpretive reflexivity in ethnography. *Ethnography, 18*(1), 35-45. doi:10.1177/1466138115592418

Marx, K. (1990). *Capital: Critique of political economy* (Vol. 1, new ed., B. Fowkes, Trans.). Harmondsworth, United Kingdom: Penguin Classics. (Original work published 1867)

Mascayano, F., & Montenegro, C. R. (2017). El 'modelo de la recuperación' y la reforma de la atención en salud mental. *VERTEX: Revista Argentina de Psiquiatría, XXVIII*, 460-467.

Maxey, I. (1999). Beyond boundaries? Activism, academia, reflexivity and research. *Area, 31*(3), 199-208. doi:10.1111/j.1475-4762.1999.tb00084.x

McKevitt, C. (2013). Experience, knowledge and evidence: A comparison of research relations in health and anthropology. *Evidence & Policy: A Journal of Research, Debate and Practice, 9*(1), 113-130. doi:10.1332/174426413X663751

Menzies, R., LeFrançois, B. A., & Reaume, G. (2013). Introducing mad studies. In B. A. LeFrançois, R. Menzies, & G. Reaume (Eds.), *Mad matters: A critical reader in Canadian Mad Studies* (pp. 1-22). Toronto, Canada: Canadian Scholars' Press.

Meriluoto, T. (2018). Turning experience into expertise: Technologies of the self in Finnish participatory social policy. *Critical Policy Studies, 12*, 294-313. doi:10.1080/19460171.2017.1310051

Minoletti, A., Toro, O., Alvarado, R., Carniglia, C., Guajardo, A., & Rayo, X. (2015). Respeto de los derechos de las personas que se atienden en servicios de psiquiatría ambulatoria en Chile. *Revista Medica de Chile, 143*(12), 1585-1592. doi:10.4067/S0034-98872015001200012

MINSAL. Decreto 633 - Crea comisión nacional de protección de las personas afectadas por enfermedades mentales, 633 § (2000). Retrieved from https://legislacion-oficial.vlex.cl/vid/proteccion-afectadas-enfermedades-mentales-243330870

PsychOpen GOLD

Montenegro, C. R. (2011). *La idea de comunidad en la salud mental comunitaria: Observaciones y Propuestas desde la Sociología.* Paper presented at the VI Congreso Chileno de Sociología, Grupo de Trabajo 15: Salud y Seguridad Social, Valparaiso, Chile.

Montenegro, C. R. (2018). Beyond participation: Politics, incommensurability and the emergence of mental health service users' activism in Chile. *Culture, Medicine and Psychiatry, 42*(3), 605-626. doi:10.1007/s11013-018-9576-9

Montenegro, C. R., & Cornish, F. (2015). 'It is not the State's fault that we have a person like this': Relations, institutions and the meaning of 'rights' to carers of people with psychosocial disabilities in Chile. *Global Mental Health, 2*, Article E22. doi:10.1017/gmh.2015.20

Montenegro, C. R., & Cornish, F. (2017). Historicising involvement: The visibility of user groups in the modernisation of the Chilean mental health system. *Critical Public Health*. Advance online publication. doi:10.1080/09581596.2017.1400659

Noorani, T. (2013). Service user involvement, authority and the 'expert-by-experience' in mental health. *Journal of Political Power, 6*(1), 49-68. doi:10.1080/2158379X.2013.774979

Observatorio de Derechos Humanos de las Personas con Disacapacidad Mental. (2014). *Derechos humanos de las personas con discapacidad mental: Diagnóstico de la situación en Chile*. Retrieved from http://www.observatoriosaludmental.cl/wp-content/uploads/2014/05/informe-ODDHHPDM-final.pdf

Pavón-Cuéllar, D. (2017). *Capitalismo y psicología crítica en Latinoamerica: Del sometimiento neocolonial a la emancipación de subjetividades emergentes.* Ciudad de México, Mexico: Kanankil Editorial.

Pérez Soto, C. (2012). *Una nueva antipsiquiatría: Crítica y conocimiento de las técnicas de control psquiátrico*. Santiago, Chile: LOM Ediciones.

Reiser, S. J. (1993). The era of the patient: Using the experience of illness in shaping the missions of health care. *Journal of the American Medical Association, 269*(8), 1012-1017. doi:10.1001/jama.1993.03500080060033

Rose, D. (2008a). Madness strikes back. *Journal of Community & Applied Social Psychology, 18*(6), 638-644. doi:10.1002/casp.981

Rose, D. (2008b). Service user produced knowledge. *Journal of Mental Health, 17*(5), 447-451. doi:10.1080/09638230802453682

Russo, J. (2012). Survivor-controlled research: A new foundation for thinking about psychiatry and mental health. *Forum: Qualitative Sozialforschung / Forum: Qualitative Social Research, 13*(1), Article 8. doi:10.17169/fqs-13.1.1790

Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: Seeking a place for mad people's knowledge in academia. *Disability & Society, 30*(1), 153-157. doi:10.1080/09687599.2014.957925

Schrader, S., Jones, N., & Shattell, M. (2013). Mad pride: Reflections on sociopolitical identity and mental diversity in the context of culturally competent psychiatric care. *Issues in Mental Health Nursing, 34*(1), 62-64. doi:10.3109/01612840.2012.740769

Smith, G. W. (1990). Political activist as ethnographer. *Social Problems, 37*(4), 629-648. doi:10.2307/800586

Weber, M. (2008). *Max Weber's complete writings on academic and political vocations* (J. Dreijmanis, Trans.). New York, NY, USA: Algora Pub.

Zaldúa, G., Bottinelli, M., Sopransi, M. B., Longo, R., Nabergoi, M., & Tisera, A., … Freire, M. (2012). A un año de la Ley Nacional de Salud Mental: Nuevos desafíos para las políticas públicas, los dispositivos y las prácticas. Paper presented at the Congreso Regional de la Sociedad Interamericana de Psicología.

PsychOpen GOLD

Special Thematic Section on "Rethinking Health and Social Justice Activism in Changing Times"

Struggle Against Outsourcing of Diagnostic Services in Government Facilities: Strategies and Lessons From a Campaign Led by Jan Swasthya Abhiyan (People's Health Movement) in Chhattisgarh, India

Sulakshana Nandi*[a]

[a] Jan Swasthya Abhiyan (People's Health Movement India), Raipur, India.

Abstract

Since 1991, India, like many countries, has undergone a process of 'liberalisation' which has entailed an increase in outsourcing of public services through Public Private Partnerships. In December 2012, Chhattisgarh state started the process of outsourcing diagnostics and radiology services in 379 government health facilities. Jan Swasthya Abhiyan (People's Health Movement) Chhattisgarh mounted a (so far) successful campaign against this move. Drawing on secondary data and the personal experiences and observations of the author, this paper documents Jan Swasthya Abhiyan's struggle, describing the strategies that were used, their efficacy, the facilitators and challenges. It uses this experience as a basis to reflectively suggest lessons for health activism and the theoretical implications. Jan Swasthya Abhiyan founded its resistance on a detailed evidence-based critique of the proposal that was disseminated, along with demands. The campaign then used multiple strategies, from petitioning the government, to street action, to advocacy with media and bureaucrats. Alliances were built with trade unions and groups working on social justice issues. Privatisation and neo-liberal policies provided a rallying point and framing the issue as a moral argument and in terms of larger concerns for social justice helped build wider solidarity. This experience suggests that the use of evidence and multiple strategies, effective framing of the issue, forging broader alliances, and a sustained campaign can all be important strategies for health activism. It also highlights the need for health activism to continue beyond a single campaign. Staying vigilant, monitoring, evidence building, mobilizing people and continuing to build alliances on such issues are critical tasks for social movements and networks like the People's Health Movement.

Keywords: outsourcing, People's Health Movement, health services, diagnostics, public services, public private partnerships, privatisation, India

Background

As part of a global process of 'liberalisation' over the last three decades, there has been continual pressure to privatise public services globally and in India. These reforms were driven by the World Bank and the IMF that

supported commercialisation, privatisation and competition (Birn, Pillay, & Holtz, 2009). Globalisation and Structural Adjustment Programme (SAPs) led to a retreat of the state from many sectors, with sectors like health bearing the brunt (Baum, 2001). After 1991, in order to adhere to IMF structural adjustment loan conditions, India was forced to cut down public expenditure. As a result, government health expenditure went from 1.4 per cent of GDP in the mid-eighties to 0.9 per cent in 2002 (Rao, 2009). The public health scenario that emerged at the time was grim. Government hospitals had to impose user fees, most states were unable to hire health staff, free drugs and diagnostics were no longer being provided, and more beds could not be added in government hospitals (Public Health Resource Network [PHRN], 2013). A decline in routine immunisation coverage as shown in 2002 government figures illustrates the grave consequences of the resource shortages in general health services at the time (Priya, 2005). While starving the public sector of funds, the government promoted the growth of the private sector. However, during this period, the growth of the private sector was skewed towards urban areas and supply driven services (Public Health Resource Network [PHRN], 2013). Surveys of the time show that the expenditure on treatment was the second most common cause for rural indebtedness among the poor (Banerji, 2001). This thrust on greater privatisation has not only been seen in health services, but in all public services like education, electricity, roads and infrastructure, both in India and globally (Birn et al., 2009; Labonté & Schrecker, 2009). Women and vulnerable groups often faced the brunt of such 'reforms' (Shiva, 2013).

By the early 2000s, the disastrous impact of the Structural Adjustment Programmes (SAPs) was clearly visible (Birn et al., 2009). The new Indian coalition government (United Progressive Alliance) which came into power in 2004 attempted to reverse these trends, the National Rural Health Mission being one of the universal programmes introduced at the time. However, though the Indian Government increased its health budget, its thrust on the growth of the private sector remained. It increased subsidies to the private sector and engaged in Private Public Partnerships and outsourcing of public services, catering more to international demands rather than local needs (Rao, 2009).

Navarro (2000), in his assessment of the 2000 World Health Report asserts that the World Health Organisation (WHO) too seemed to have decided that publicly funded and provided healthcare systems are outdated. He criticises the WHO for propagating market-demand based, rather than need based planning (Navarro, 2000). The understanding was that governments should not 'provide' or 'make' health services, but instead 'purchase' or 'buy'. Such an understanding sees healthcare as a commodity, rather than as a public good or a social good and patients as clients. The claims made by the World Bank and others in favour of privatisation of health services have been that the private sector market would make for more efficient, effective and equitable management of health services and despite evidence that this strategy has led to decreased healthcare access, especially for the marginalised, World Bank and others have continued to promote it (Birn et al., 2009; Marriott, 2009). In more recent years, under the paradigm of "Universal Health Coverage' (UHC), private sector involvement in providing publicly funded healthcare is being promoted and expanded (Sengupta, 2013).

The People's Health Movement (PHM) is a global network of civil society organisations, grassroots health activists, and academic institutions, mainly from low and middle income countries (LMICs). PHM strives towards achieving health equity and health for all, with a strong focus on the social, structural and political determinants and people's participation. PHM has been a strong critic of the impact of neo-liberal policies and SAPs and believes that for people's health to improve, governments, and not markets, need to intervene, and that public health governance needs to improve along with active participation and advocacy from people's movements and public health professionals (Baum, 2001).

Jan Swasthya Abhiyan (JSA) is the India circle of PHM. JSA has a national coordination committee that consists of other networks, organisations, individuals and state representatives. Each state has its own JSA chapter, facilitated by conveners. This paper describes the campaign by Jan Swasthya Abhiyan (JSA) Chhattisgarh against the proposal for outsourcing of diagnostic services in government facilities. It aims to describe the strategies that were used, the efficacy of those strategies, the facilitators and challenges in the struggle and on the basis of that experience, to suggest lessons for health activism in current times.

Outsourcing of Government Health Services in India

A direct impact of the above policies has been the increase in outsourcing of public services, including for healthcare, under the umbrella of 'Public Private Partnerships' (PPPs). PPPs are varied, ranging from outsourcing of primary health services, to global PPPs (Kapilashrami, 2010). The National Rural Health Mission (subsequently re-named as National Health Mission) talks about Public Private Partnerships as supplementing government services (Jan Swasthya Abhiyan, 2006; National Health Systems Resource Centre, 2012). The recent National Health Policy of 2017 makes a case for private sector involvement and talks about government engaging in 'strategic purchasing' of health services (Ministry of Health and Family Welfare, 2017).

In India, like in many other LMICs, low budgetary allocations and inadequacies in government health services, along with the expectation that 'purchasing' from a private provider will be more 'efficient' and also bring in private investment, are often used as the rationale for engaging in PPPs (Roy, 2017). However, in India, it mainly translates into outsourcing certain public health services or facilities to the private sector that are expected to provide these services using government funds and/or user fees (Baru & Nundy, 2008). The other rationale given for engaging in PPPs is that of 'reaching the unreached', i.e. reaching the 'underserved' areas, which are mainly the remote, rural, tribal areas of the country (Ministry of Health and Family Welfare, 2017). There is however increasing evidence of failure of outsourcing health services. Though many attribute this to the failure of governmental regulation, the failure of such projects are mainly a result of the inherent nature of public services to be provided (Kotecha, 2017), the incongruence between market logic and social logic (Leys, 2018) and the inability of the market to play a social role (Deppe, 2009). In India, recent studies led by the author show that though certain PPPs may have led to an increase in or provision of health services in the short run, it often fails to strengthen the overall health system and may end up exacerbating existing problems (Public Health Resource Network [PHRN], JSA, & Oxfam, 2017a, 2017b, 2017c, 2017d).

Introduction to Chhattisgarh State

Chhattisgarh is a new state, formed in 2000 (Government of Chhattisgarh, n.d.). It has a population of about 25 million of which 77% live in rural areas (Office of the Registrar General & Census Commissioner, India, 2011). It is seen as a 'tribal' state with 32% of the population belonging to tribal or indigenous communities, with the districts situated at the northern and southern parts of the state having highest tribal populations (Office of the Registrar General & Census Commissioner, India, 2011). These 'tribal' districts are hilly and forested while the central plains have more urban centers with mainly non-tribal population (Government of Chhattisgarh, n.d.).

As a new state, Chhattisgarh started many new reforms focused on strengthening the government health system, starting from the primary healthcare levels, including initiatives like the Mitanin Community Health Worker programme (Sundararaman, 2007) and a three year medical course to prepare health workers for rural and remote areas (Rao et al., 2013). The National Rural Health Mission that was launched in 2005, supported these reforms for government health system strengthening. However, the state continued to face challenges in providing health

services in the rural and remote areas, some of the reasons being the historical neglect of the area leading to lack of higher educational institutions and therefore lack of qualified human resource, and issues in implementation and governance.

In 2012, through the initiative of a technical assistance agency and certain bureaucrats in the health department, a state policy on 'Strengthening health services in Chhattisgarh state through Public Private Partnerships' was developed and notified by the government (Department of Health and Family Welfare, 2012). This was followed by a number of Request for Proposals (RFPs) for such partnerships that were advertised, which included proposals for outsourcing of Mobile Medical Units, Primary Health Centers, Referral transport, school health programme and so on. The proposal for outsourcing of diagnostic services that is discussed in this paper, was part of this group of outsourcing initiatives. Most of these proposals either got stalled at the bidding stage or had to be shut down after some time (Public Health Resource Network [PHRN] et al., 2017b; Times News Network, 2014).

This paper aims to describe the struggle by JSA Chhattisgarh against Chhattisgarh government's proposal for outsourcing diagnostic services in government facilities. The paper will present strategies that were used and their efficacy, the facilitators and challenges in the struggle and finally, the lessons for health activism in current times.

Methods

This paper draws on secondary data and the personal experiences and observations of the author, who, being the Convener for JSA in Chhattisgarh, herself was involved in the struggle. The secondary sources of information include the notes, critiques, petitions, memorandums and emails circulated during the campaign. It also draws from the official documents related to the outsourcing, media articles and subsequent studies on PPPs. In analysing the implications of this campaign for health activism in current times, the author has subsequently also drawn on theories of social movements and social activism.

As a participant in the struggle, the author was involved in planning the campaign and developing the resource materials. The author's potential biases as a researcher-activist may have affected the analysis, and therefore rigour has been attempted through reflexivity (Malterud, 2001). The positionality of the author regarding the context and what is to be investigated and the motivation for undertaking this research have been made explicit. Being part of the struggle has helped the author in bringing out unique evidence and practical insights. Methodologically, this study hopes to contribute to the literature on solidarity research and work with respect to social movements (Brem-Wilson, 2014; Mishler & Steinitz, 2001).

In what follows, the nature and strategies of the anti-privatisation campaign are first presented, following which I reflect on lessons learned with potential applicability to other contemporary social movements.

The Proposal, the Critique and the Campaign

The Proposal for Outsourcing Diagnostic Services in Government Facilities

The Request for Proposal (RFP) was advertised in December 2012 (Directorate of Health Services Chhattisgarh, 2012). It was put up on the health department's website and bids were elicited from companies and organisations. The RFP was amended in January 2013 after incorporating concerns of the private agencies at the pre-bid meeting (Directorate of Health Services Chhattisgarh, 2013a). The amended RFP also included certain points emerging out of JSA's critique, for instance, the revised RFP had more details on who will pay for the services. The salient features of the proposal are given in Table 1.

Table 1

Salient Features of the Request for Proposal for Outsourcing Diagnostic Services

Number of facilities where outsourcing was to be done	Outsourcing of radiology and lab services in 379 government facilities was to be done. This included: • All 149 Community Health Centres (CHCs) in the state • 22 out of the 27 District Hospitals • Eight out of 17 Civil Hospitals • 200 of the better functioning Primary Health Centers (PHCs) The facilities were categorized into three levels (A, B, C), according to their level of functioning and requirement. The list was to be subsequently expanded to include medical colleges and other facilities.
Geographical coverage	The initial RFP divided the state into four Divisions or lots- Bastar, Raipur, Bilaspur and Sarguja. However, in the first round of bids, organisations applied only for the two divisions situated in the central, non-tribal, relatively more urban belt (Bilaspur and Raipur) and there were no applications for the tribal and remote regions of the state (Bastar and Sarguja). The government then re-defined the lots and combine one tribal region with a non-tribal region (Sarguja along with Bilaspur and Bastar along with Raipur), thereby forcing the bidder to take up the tribal areas if they wanted to bid for the non-tribal divisions (Directorate of Health Services Chhattisgarh, 2013b).
Services to be provided	The services to be provided included radiology and laboratory services. Three lists of tests were prepared, according to level of facility. Upto 25% of the lower facilities were allowed to function as 'collection centres'.
Project period	Agreement for 10 years with annual renewal
Eligibility and operating procedures	Both private profit and not-for profit organisations could apply, with defined minimum experience and annual turnover. Accreditation under the National Accreditation Board for Testing and Calibration Laboratories was not necessary, and could be done within 2 years and that too only for higher facilities. They were free to appoint own staff or could further contract it out to a 'concessionaire'. The agency or Concessionaire had to comply with standards under the state's Clinical Establishment Act. Each center was to be maintained as a 'business centre'. Concessions given by Government included space and electricity. They would have the 'freedom' to serve 'external' customers.
Rates and payment mechanisms	The payments were to be done per procedure or tests on the basis of government rates. For patients being treated under the state funded health insurance scheme for hospitalisation and for Below Poverty Line patients undergoing ambulatory or out-patient care, the payment would be made by the Hospital Management Committees. The rest of the patients were to pay for the services themselves, out of pocket.
Monitoring	Monitoring was to be done by a third party and performance based incentives were designed.

Source: Prepared by the author on the basis of the revised RFP document (Directorate of Health Services Chhattisgarh, 2013a).

Campaign by JSA Chhattisgarh Against the Outsourcing

Analyzing and Critiquing the Proposal

The JSA Chhattisgarh members got to know about this move of the government very soon after the RFP was put up on the website. They accessed the RFP as it was in the public domain and started to analyse it. It became clear to them that this move of the government had the potential to harm and undermine the existing public services and therefore JSA activists developed its critique. The critique argued out some of the common assumptions and rationale for such a move, and also tried to show the impact that this move will have on the existing diagnostic services in these facilities (Jan Swasthya Abhiyan Chhattisgarh, 2013). The critique was substantiated by evidence from within and outside the state. Some of the main points were as follows:

Questioning the rationale that the outsourcing was meant for — This proposal was attempting to outsource diagnostic services in bulk of the hospitals in the state. This included even the non-remote areas, where lab services could be provided within the government system as human resource and accessibility were not a problem. Moreover, it was suspect whether the private agencies would be willing to go to remote areas as they won't find it 'profitable' enough. This suspicion came true when in the first round of bidding, no one applied for the 'tribal' and remote divisions (Directorate of Health Services Chhattisgarh, 2013b; Pandey, 2015b). Subsequently when the government combined two divisions (one remote and one non-remote) together, there was the danger that the private agencies could demand extra incentives and funds to go to the remote districts, thereby increasing the costs for government.

Questioning the evidence on which this proposal was based — A reading of the proposal showed that it had ignored the fact that certain diagnostics services were currently available in most of these facilities. The hospitals and tests seemed to be listed en bloc and not based on any situational analysis or study (Jan Swasthya Abhiyan Chhattisgarh, 2013). There was the question of what would happen to the existing human resource (HR) and the lab set-up and equipment in the facilities once outsourcing was complete. Moreover, the RFP had also been revised to allow collection centers in 25% of the less functioning centers and it was feared that this would hinder timely access to services. The government's own evaluation of diagnostics outsourcing in states like Bihar had found that it had led to redundancy of existing human resource, the in-house facilities had become dysfunctional and the services that were previously being provided were stopped (Ministry of Health and Family Welfare, 2012). Moreover, the evaluation also found that having collection centres had led to delayed turn-around time

Concerns regarding replacing existing diagnostics services — It was evident from the proposal that the existing services were not being improved or expanded, rather the existing diagnostics services would practically be replaced by services being provided by private agencies, something that had already proven disastrous for the government health services in Bihar.

Concerns regarding cost to patient and their entitlements — The proposal mentioned that the state funded health insurance scheme would cover costs of patients, but that meant that costs only in the case of hospitalisations were to be covered and not ambulatory care. Moreover, instances of unethical healthcare and provider-induced demand had been documented under this scheme within the state and outside and there was the danger of this happening in the case of diagnostics too (Mazumdar, 2013).

With regards to ambulatory or out-patient care, the proposal mentioned that the hospital management committees would pay for the BPL (Below Poverty Line) patients while the rest of the patients would have to pay out of pocket.

This meant that only 1.9 million households listed as BPL in the state would be covered under this and the rest would have to pay for the services. The Chhattisgarh government had separately identified and was already providing food support to nearly four million poor families (80% of the families in the state) (Puri, 2012). JSA questioned the government as to how they expected more than half of these families who they themselves had deemed requiring subsidised food grain, to pay for diagnostic services out of pocket.

Furthermore, it was not clear as to how a private centre would be made to provide tests that are already free under various Government (disease control and maternal and child health) programmes.

Concerns regarding the concession to serve 'external' patients — The proposal allowed the labs to serve external patients, i.e. private paying patients. JSA expressed concern that if the private laboratory that was located within the government hospital premises became entitled to take payment from some patients, they might make others pay too (Jan Swasthya Abhiyan Chhattisgarh, 2013). This went against the principles of providing free healthcare services and financial protection.

Mismatch between proposed diagnostic services and availability of specialists and doctors — JSA undertook a detailed analysis on the existing human resource available at the facilities and the corresponding diagnostic services being outsourced and found that in the proposal there were inconsistencies. For instance, in certain CHCs (e.g. Manendragarh) and new District Hospitals (e.g. Dantewada), there were hardly any specialists posted and most tests that were prescribed by the doctors posted, were being done. Therefore, providing higher diagnostic services through outsourcing in these facilities, without providing for doctors, would not lead to any meaningful improvement and additionally, the currently functioning labs would be rendered redundant.

Lack of monitoring and grievance redressal systems — The RFP spoke of a 3rd party monitoring mechanism. The selection of the 3rd party would have to be done through a bidding process. This meant making things more complicated as rather than dealing just with a set of one's own staff, the health department would then have to deal with two private agencies; one running the units and another one monitoring them. The performance parameters were also not articulated in the RFP. There was no mention of patient's rights, grievance redressal systems, community monitoring or any other systems of accountability that are important elements of governance and people's participation.

Experiences of other states ignored — Outsourcing of diagnostic services had been tried out in few states, Bihar being the largest model. The government's own criticism of diagnostic outsourcing in Bihar has been mentioned above (Ministry of Health and Family Welfare, 2012). Among other things, the evaluation report notes that while one hand the outsourced lab services were not functioning properly, there was high turn-around time, access to services had reduced, quality had reduced and costs increased, on the other hand, the in-house services (those being provided from before through government labs) were under-utilised, had become dysfunctional and the government lab technicians and radiographers had become redundant. It further recommended that the government should re-start its own facilities and that "out-sourced services should supplement the existing structure and public services, not become its substitute" (Ministry of Health and Family Welfare, 2012, pp. 72–73).

In terms of best practices, Tamil Nadu state offered an example in contrast where, without any outsourcing the public health facilities, even the Primary Health Centres had been able to provide well-functioning diagnostic services (Pandey, 2015c).

However, in floating the RFP, Chhattisgarh government did not seem to have taken into account either the best practices or the negative experiences of outsourcing of diagnostics elsewhere.

Therefore, JSA raised the question that if this had been tried before in other states and had failed, then why was Chhattisgarh trying to repeat it, and that too at such a large scale (Jan Swasthya Abhiyan Chhattisgarh, 2013). The experiences in other states showed that instead of improving and expanding the services already being provided by the government facilities, this initiative will completely destroy the existing services and replace them with privately and more expensively provided services and collection centers. Moreover, this was clearly not an 'interim' arrangement as the Agreement was to be done for ten years. Hence JSA contended that as the evidence clearly showed that there was hardly any rationale to outsource lab facilities at any level in Chhattisgarh in the present situation, this proposal had to be scrapped.

Getting the Message out

Equipped with the critique, an urgent state meeting was called on 11th January 2013, of the civil society organisations (CSOs) who were involved with the JSA network. The next steps for the campaign were discussed and demands prepared. There was a consensus that this issue had to be taken up head on. JSA made the following demands to the government:

- Outsourcing of diagnostic services in public hospitals had to be stopped.

- Posts of lab technicians and radiographers needed to be filled as there were trained unemployed people available in the state.

- A twenty-five old recruitment rule that restricted recruitment of health workers needed to be modified.

- For the long term, local youth from marginalized communities and underserved areas needed to be trained and recruited as lab technicians and radiographers.

- Multiskilling training was needed for existing lab technicians so that they could undertake a variety of lab tests.

- Every health facility needed to be equipped with adequate human resource, equipment and supplies

- Public health services needed to be strengthened and not privatised. They needed to be made more responsive and accountable to people

The critique and the demands were translated into the local vernacular Hindi, and also simplified so that everyone could understand what was at stake. Subsequently, the critique and JSA's demands were circulated to the media, both to the state (mainly Hindi) media and the national media. The submissions to media went with the message that JSA will resist this move of the government and was getting ready to unleash a state wide campaign against it. Within a few weeks, state and national media had covered the issue widely, along with JSA's critique and call to action against this proposal (Das, 2013; Pandey, 2015a). Meanwhile, the national JSA group was also informed of this proposal and support was garnered from them. Some suggestions on how to move forward came from them.

Petitioning and Submitting Memorandums to the Governor

In the meeting on 11th January, it was also decided that JSA members from different districts would send petitions against this proposal to the Governor, the highest Constitutional post in the state. This was also a way to give

government a chance to review their decision, before any explicit public action. JSA network organisations and activists from districts thus met the Collectors (district administrative head) and handed them the memorandums to be sent to the Governor.

Further Evidence Building

Meanwhile, a group of people within JSA kept collecting evidence on the availability of diagnostic services in the facilities that were listed in the proposal. A rapid survey of facilities was undertaken by an existing network of public health professionals who had access to government facilities. They were requested to send in information about availability of services in their facilities and the data was collated. An application under the Right to Information (RTI) law was submitted to the health department asking them on what basis had they made the plan, and to share any feasibility study that may have been undertaken before preparing the proposal for outsourcing. In responding to the RTI application, the technical agency stated that they had not be asked to prepare any feasibility study or value for money analysis by the government (SHRC Chhattisgarh, 2013).

Building Alliances With Trade Unions and Other Groups Working on Social Justice Issues

As JSA proceeded with the campaign, it built alliances with trade unions and organisations working on social justice, and not necessarily only on health. JSA members reached out to these groups. These groups were of two kinds- one were the unions of government health workers, lab technicians themselves, whose jobs were on line. The other were organisations that were engaged in struggles against forced displacement due to mining and industries, farming crisis and so on, which were an outcome of the same market-based policies of the government. These groups seemed to find a common ground in this struggle against outsourcing of health services. Though the health worker trade unions were politically divergent and the one aligned with the ruling party did not want to be seen as actively opposing the government, they spoke up against the outsourcing in various fora, including in media.

State Level Rally and Press Conference

Realizing that visibility at the state level was required for the campaign, and that there was need to keep up the pressure, a rally cum public meeting and press conference was organized in state capital Raipur on 31st January. Civil Society Organisations (CSOs) mobilised people from the districts that they were working in. There was no funding specifically for this event and organisations and individuals used whatever funds they had, for this. Hundreds of people came from across the state. The police were in touch with JSA members throughout the day. The rally started from the railway station (where everyone had gathered) to the meeting venue at the heart of the city. Activists, community leaders and health workers came up to the dais and spoke about their concerns regarding the outsourcing. Slogans raised and written on placards reflected the mood of the assembly.

A memorandum, with a critique of the outsourcing proposal and demands on behalf of everyone assembled was given to a representative of the Governor who came to receive it at the meeting venue.

Simultaneously, few JSA Chhattisgarh members, that included well-respected activists and doctors, did a press conference at the Press Club. The events of the day were very well covered by all (Hindi and English) newspapers of the state, national media and international journal (Hitavada, 2013; Kay, 2013; Patrika, 2013a; Times News Network, 2013a).

District Level Events and Signature Campaign

At the public meeting it was discussed that the campaign needed to be taken back to the villages and districts. The members assembled decided to hold district level events and undertake further dissemination of the outsourcing proposal, critique and demands. Activists visited health facilities and spoke to doctors and health workers, they stood at bus stands and market places and spoke to people about government's plan to outsource diagnostic services. They distributed pamphlets outlining the issue and the demands, written in a simplified manner and in the local language Hindi. A signature campaign was carried out against the outsourcing in villages and towns. Then by April, when the government did not budge, sit-ins were organized at district headquarters. This time round the memorandums and petitions were addressed to the Chief Minister, the head of the government. These district events were covered widely by the local media in every district. These efforts resulted in further dissemination of information & solidarity building.

State Level Silent March

By May, there were no signs of government relenting. The bidding process too faced problems and was going slow. JSA decided that people had spoken enough and now it was the turn of the government to just listen. Therefore a silent march was organised in the state capital Raipur on 19th May 2013. Activists once again came from all over the state. They tied black bands over their mouths and marched carrying sheets of cloth with 1000s of signatures denouncing the outsourcing plans. It was visually very striking and the media covered the event, publishing photographs and JSA's demands (Naidunia, 2013; Patrika, 2013b; Times News Network, 2013b).

Representations to Sympathetic Bureaucrats in State and National Government

During the period of struggle, JSA activists made representations to bureaucrats who seemed sympathetic to the cause. An article criticizing the government's move was written by an ex-Health Secretary in a leading national newspaper (Rao, 2013). The governing board of the technical agency that was helping the government in developing the PPPs consisted of few people who were part of larger health rights and social justice movements. They pursued evidence-based critique of the proposal within the organisation. As a result the governing board registered displeasure at the agency and its leadership's role in promoting PPPs. They advised the agency to instead support the government to strengthen public services and subsequently changed the leadership. More recently, the technical agency has undertaken capacity building of lab technicians and provided other support in order to improve diagnostic services in the government facilities of Chhattisgarh, which has led to an increase in the number and type of tests being provided at government facilities (Tripathi & Garg, 2018).

JSA activists also approached certain politicians who were seen to be progressive. However, even though politicians and elected representatives may have been influenced by the media coverage and advocacy and played some role in reversing the government's decision, their role was not explicitly visible to the campaigners.

Others, who were in critical decision-making positions, especially regarding approving funds for this project, like bureaucrats in the finance department and the National Health Mission, were also sent representations. One of the outcomes of this was that the Government of India sent a team to study the proposal and make an assessment of the need for outsourcing diagnostics. The study team concluded that the proposal was flawed and was not based on the needs of the people of the state and that it may in fact do more harm than good (Pandey, 2015d).

Diagnostics Outsourcing Proposal Gets Stalled by Government

Under pressure from all directions and after failing to get financial approval either from the state finance department or the central government, in June the government announced that it was stalling the project (Bagchi, 2013c; Jaiswal, 2013). With this, the move towards outsourcing diagnostic services was halted for the time being.

Recent Developments

The Chhattisgarh government has once again, in August 2018, issued a Request For Proposal for outsourcing diagnostic services at various government facilities. Following previous processes, JSA has undertaken evidence-based critique of the RfP and tried to get the message out through writing in media (Nandi & Joshi, 2018) and issuing press statements (Jan Swasthya Abhiyan Chhattisgarh, 2018).

Lessons for Health Activism

The following section presents some reflections on the nature and efficacy of the strategies used and the lessons it has for health activism elsewhere:

Evidence-Based Critique

First step for the campaign was to analyse the proposal and provide a point-by-point critique along with evidence. As it became clearer that the proposal itself had been prepared without any evidence base, JSA's arguments became stronger. The campaign made use of the network of CSOs and public health practitioners to collect and submit information about the availability of diagnostic services in the state. The network's base among organisations working in tribal areas, helped to bring forth the issues and data from areas that were being showcased as the main beneficiaries of the outsourcing proposal. JSA also brought in data from other states like Bihar where such projects were failing and used that to further critique the proposal (Jan Swasthya Abhiyan Chhattisgarh, 2013; Ministry of Health and Family Welfare, 2012). Moreover, the critique also tried to refute the larger rationale used for promoting privatisation of services and market-based policies, such as higher efficiency, equity and effectiveness, with evidence. The government tried to refute JSA's arguments through statements in media (Bagchi, 2013b). However the government's arguments had a much weaker evidence base than the campaign's arguments and demands. It also helped that in the course of the bidding process, many of the arguments made by the campaign got proven (Bagchi, 2013a). For instance, when the private agencies did not apply for the more remote areas, the government's claim that outsourcing will bring these services to 'underserved' areas, was proven wrong.

Information as Power

Developing the detailed critique was possible only because the JSA activists could access the RfP. Though the RfP was posted on the health department's website, it was not easily searchable. Only those who were aware of the pathways to the site could access it. Once JSA activists accessed it, they converted it into simpler terms, so that everyone, and not only people with health or formal technical knowledge, could understand the issue. This was kept in mind even when drafting the critique and the demands. Once the documents were ready, they were then distributed. They were send to villages via the CSOs, and to media and bureaucrats. Throughout the campaign, JSA activists diligently circulated all the information and materials that was created as a result of the campaign. For instance, media reports were circulated far and wide as soon as they appeared. Even though during that time

the network did not make use of any digital social media, the use of emails, two-pagers explaining the issue, personal interaction and media coverage helped to further spread the word. Accessing and disseminating the information was a very critical step in the struggle as often governments or the ruling dispensation don't 'allow' information about their plans to be known to people. As Foucault (1980) maintained, knowledge and power reinforce each other. However, disseminating the information was just one step, though a crucial one, which to lead to further collectivisation and action (Fox, 2015).

Use of Multiple Strategies, in Degrees and a Sustained Campaign

The action led by JSA was akin to what Tilly (2004, pp. 3–4) describes as a social movement that includes a combination of concerted and sustained campaign, multiple strategies and types of political action and public displays of "worthiness, unity, numbers and commitment (WUNC)". The campaign used multiple strategies, from petitioning to street action, to advocacy with media and bureaucrats. However these strategies were not used all at once. It was done step by step, starting from relatively 'milder' action like petitioning, and then going on to more 'aggressive' action, like street demonstration and subsequently the silent march. At every step there was stock-taking of what had been achieved and what had not, and then the next level of action was strategized, planned and undertaken. Different tactics were tried and different types of people and groups were approached for support. There was no funding for this campaign and organisations involved in the network picked up costs as and when they could per their funds availability. The campaign went on for nearly six months, during which time the group of activists leading JSA Chhattisgarh at that time relentlessly followed up on each and every action and reaction that took for the government to finally back down. This highlights the importance of at least one group of people or organisation taking the leadership and persisting with the struggle. In this case, JSA Chhattisgarh was the group that led the struggle and others rallied around it. Though the core group was small, having this group constantly 'on the job' was critical. All of these activists were volunteers, doing this work in addition to their full-time jobs, which were mainly in related public health work. The government tried to discredit the campaigners saying that these were ideologically motivated 'left wing campaigns' (Bagchi, 2013a).

Privatisation and Neo-Liberal Policies as a Rallying Point

The issue of privatisation emerged as a common concern and a rallying point that brought together different kinds of people and groups. Tarrow (2011, p. 235) writes about 'global framing' which he describes as "the framing of domestic issues in broader terms than their original claims would seem to dictate". In the campaign too, the issue at hand, i.e. the outsourcing of diagnostic services, was thus framed. The broader alliances that were built over this campaign seemed to emerge from a concern regarding neo-liberal policies, its societal impact and the way it had negatively affected public provisioning of services (education, transport etc.), community's ownership over natural resources, labour rights and other dimensions of people's lives. As a result, trade unions and a number of organisations, such as those of indigenous people working on land and forest rights, who were not involved in direct health work, joined the campaign. So while these organisations may have considered healthcare as an important and relevant issue to intervene in, the concerns around marketisation and commercialisation of public goods provided the overarching solidarity. This was also reflected within the bureaucracy. Many within the bureaucracy believed that the government should be providing these services rather than outsourcing and this greatly strengthened the campaign's cause within the government. One lesson for activism from this is that the issue at hand is usually always related to larger, structural issues and issues of social justice that could be framed and articulated in order to form solidarity and broader alliances with groups working on those issues. This strengthened the campaign.

Posing the Issue in Terms of a Moral Argument

Another aspect closely related to the above point is that in addition to the evidence-based and technical critique against outsourcing of diagnostic services, the issue was also articulated as a moral issue. It posed the question as 'right' versus 'wrong' using the discourse of social justice and rights and the role of the state in protecting them. This lent legitimacy to the campaign and helped mobilise people in large numbers. Posing the issue in this way also made it simpler for people to respond and react and lent "cultural resonance" to its framing (Benford & Snow, 2000, p. 622).

Active Role of the Media

Through the months of struggle, the media was mobilized and it played a big role in bringing the concerns of the campaign into public gaze and discourse. Both the national and the state media took up the issue repeatedly. In retrospection, the overwhelming support to the campaign from the local media seems to have been due to the strength of the campaign in being able to mobilise a large number of people and organisations on this issue and the larger concerns over privatisation, social welfare and social justice. Personal interactions with media persons at that time revealed that they were overwhelmed at the extent of mobilisation and campaigning and felt compelled to cover the issue. They further contributed to posing the issue in terms of vocabularies like 'privatisation' and 'selling of hospitals' which caught the public imagination.

Theoretical Implications

The fact that the government finally had to reverse its decision points to the success of the campaign. The strategies and processes of the campaign are concordant with the frameworks and theories of social movements and social activism.

The framing of the issue was undertaken by JSA, collectively with state and national units. Benford and Snow (2000, p. 615) write about the three core framing tasks, i.e. "diagnostic framing", "prognostic framing," and "motivational framing". For JSA, the goal of the campaign was very clear and uncomplicated, even in an operational sense, which was that the move for outsourcing diagnostic services had to be reversed. The problems with the proposed move, along with proposals for alternative steps that the government could take, were articulated with evidence. The strategies for action were planned and the persons or institutions that had to be approached were identified, both for making submissions and for building solidarity. The issue was raised as a moral issue and as indicative of other larger socio-economic policies, that had already negatively affected many of those who were involved in the struggle. The credibility of the framing was upheld throughout the campaign as it had consistency, was empirically sound and undertaken by a group of people who themselves had credibility (Benford & Snow, 2000). The issue of privatisation resonated among most who got involved, including bureaucrats. The 'global framing' of the issue that helped in this process has been similarly used by transnational campaigns against neoliberalism and globalisation (Tarrow, 2011).

The interactions with bureaucrats revealed that there are people within the government or the agencies that one is opposing, who may believe in the principles that the campaign is fighting for. Such people need to be identified and approached though they may be part of the very institution that the campaign is opposing, they often have the power to take decisions that could go in favour of the campaign demands. Klugman (2011) specifically writes

of the need to influence bureaucrats and politicians as part of such advocacy. The campaign facilitated both collective action from below, influencing policy makers, leading to cohesive action towards the goal. Such action has been described in different frameworks as the 'sandwich strategy' (Fox, 2015) and 'nut cracker' effect (Baum, 2007).

Klugman (2011) presents a model for strategising and evaluating advocacy process and social justice outcomes. She argues that strengthened organisational capacity, support base and alliances that "draw on increased data and analysis from a social justice perspective" form the basis for effective advocacy (Klugman, 2011, p. 148). Advocacy could be done within the 'corridors of power' or through peoples mobilisation, public action and media engagement (Klugman, 2011). This should lead to consensus building in a common definition of the problem and possible solutions that would further facilitate participation in advocacy and policy processes and also increase visibility of these views and issues (Klugman, 2011).

This paper narrates the story of a specific campaign against outsourcing of diagnostics in the state of Chhattisgarh. But the campaign and the issue are embedded within the larger policy environment and political economy that defines social and public goods like health as a commodity and goods and services produced for sale (Deppe, 2009). Outsourcing of public services is being promoted as a desirable norm. The contestation remains between the ideas of 'providing' and 'purchasing', between the neoliberal and social justice approaches to health (Birn et al., 2009). However, the implications of market-based policies are becoming more and more visible and such policies are being resisted both globally and in India (Kishimoto & Petitjean, 2017). One set of (long term) outcomes that Klugman (2011) mentions is that of a shift in social norms through increased support for the views and positive change at the population level with respect to the issue under advocacy. As is evident from the recent developments in Chhattisgarh, this is where the work of PHM and other movements remain critical and relevant. The experience in Chhattisgarh shows that a campaign may be successful, but there is always the danger of reversal of the gain. Sustained campaigns, joint participatory and visible action, effective communication, knowledge building and co-production through interaction between varied groups of people, developing common values and principles and building networks and broader alliances around issues of social justice are critical for health activism (People's Health Movement [PHM] & Third World Health Aid [TWHA], 2017).

Conclusion

In Chhattisgarh, JSA was able to stall the privatisation of government diagnostic services and continues to try to do so. The success of the campaign has multiple lessons for health activism. Evidence based critique, effective framing of the issue, collective action from below and from policy makers from above, dissemination of information, use of multiple strategies, forging broader alliances and persistence were key elements for its success. It also highlights the need for health activism to continue beyond a single campaign. Staying vigilant, monitoring, evidence building, mobilizing people and continuing to build alliances on such issues are critical tasks for social movements and networks like the People's Health Movement.

Funding

PsychOpen GOLD

Competing Interests

The author has declared that no competing interests exist.

Acknowledgments

References

Bagchi, S. (2013a, February 2). Bid submission of Chhattisgarh's health privatisation postponed again. *The Hindu*. Retrieved from http://www.thehindu.com/todays-paper/tp-national/bid-submission-of-chhattisgarhs-health-privatisation-postponed-again/article4370927.ece

Bagchi, S. (2013b, February 26). Private test for Chhattisgarh's public health care. *The Hindu*. Retrieved from http://www.thehindu.com/opinion/interview/private-test-for-chhattisgarhs-public-health-care/article4439563.ece

Bagchi, S. (2013c, June 20). Chhattisgarh diagnostic project on hold. *The Hindu*. Retrieved from http://www.thehindu.com/todays-paper/tp-national/chhattisgarh-diagnostic-project-on-hold/article4831965.ece

Banerji, D. (2001). Landmarks in the development of health services in India. In I. Qadeer, K. Sen, & K. R. Nayar (Eds.), *Public health and the poverty of reforms: The South Asian predicament* (pp. 39-50). London, United Kingdom: SAGE.

Baru, R. V., & Nundy, M. (2008). Blurring of boundaries: Public-private partnerships in health services in India. *Economic and Political Weekly, 43*(4), 62-71. Retrieved from https://www.epw.in/journal/2008/04/special-articles/blurring-boundaries-public-private-partnerships-health-services

Baum, F. (2001). Health, equity, justice and globalisation: Some lessons from the People's Health Assembly. *Journal of Epidemiology and Community Health, 55*, 613-616. doi:10.1136/jech.55.9.613

Baum, F. (2007). Cracking the nut of health equity: Top down and bottom up pressure for action on the social determinants of health. *Promotion & Education, 14*(2), 90-132. doi:10.1177/10253823070140022002

Benford, R. D., & Snow, D. A. (2000). Framing processes and social movements: An overview and assessment. *Annual Review of Sociology, 26*, 611-639. doi:10.1146/annurev.soc.26.1.611

Birn, A., Pillay, Y., & Holtz, T. H. (2009). *Textbook of international health: Global health in a dynamic world* (3rd ed.). New York, NY, USA: Oxford University Press.

Brem-Wilson, J. (2014). From 'here' to 'there': Social movements, the academy and solidarity research. *Social Studies, 10*(1), 111-132.

Das, R. (2013, January 25). State proposes "outsourcing" of health services. *Raipur City Line, Hitavada*, p. 1.

Department of Health & Family Welfare. (2012). *Public-private partnership policy for strengthening health care service in Chhattisgarh.* Raipur, India: Government of Chhattisgarh.

Deppe, H.-U. (2009). The nature of health care: Commodification versus solidarity. In *Socialist Register 2010: Morbid Symptoms* (pp. 29-38, Vol. 46). London, United Kingdom: Merlin Press. Retrieved from https://socialistregister.com/index.php/srv/article/view/6762

Directorate of Health Services Chhattisgarh. (2012). *Request for Proposal for establishing diagnostic centres in public hospitals / health facilities in the state of Chhattisgarh.* Raipur, India: Government of Chhattisgarh.

Directorate of Health Services Chhattisgarh. (2013a). *Request for Proposal for establishing diagnostic centres in public hospitals / health facilities in the State of Chhattisqarh* [As amended after pre-bid meeting held on 19th January, 2013]. Raipur, India: Government of Chhattisgarh. Retrieved from http://cghealth.nic.in/ehealth/2013/advertisement/shrc/establishingdiagnostic.pdf

Directorate of Health Services Chhattisgarh. (2013b). *RfP for organizing diagnostic services-Amendment of Lots.* Raipur, India: Government of Chhattisgarh. Retrieved from http://cghealth.nic.in/ehealth/2013/Advertisement/SHRC/OrganizingDiagnosticServicesAmendmentOfLots.pdf

Foucault, M. (1980). *Power/knowledge: Selected interviews and other writings 1972-1977* (C. Gordon, Ed.). New York, NY, USA: Pantheon Books. Retrieved from https://monoskop.org/images/5/5d/Foucault_Michel_Power_Knowledge_Selected_Interviews_and_Other_Writings_1972-1977.pdf

Fox, J. A. (2015). Social accountability: What does the evidence really say? *World Development, 72*, 346-361. doi:10.1016/j.worlddev.2015.03.011

Government of Chhattisgarh. (n.d.). *Chhattisgarh: A profile.* Retrieved June 20, 2018, from http://www.im4change.org/docs/chhat_Chhattisgarh_AProfile.pdf

Hitavada. (2013, February 1). JSA flays state government over outsourcing of diagnostic services. *Raipur City Line, Hitavada*, p. 3.

Jaiswal, A. (2013, June 21). State govt shelves plans for diagnostic lab privatisation. *The Times of India*. Retrieved from https://timesofindia.indiatimes.com/city/raipur/State-govt-shelves-plans-for-diagnostic-lab-privatisation/articleshow/20695416.cms

Jan Swasthya Abhiyan. (2006). *Health system in India: Crisis and alternatives* [National Coordination Committee, JSA]. Retrieved from http://communityhealth.in/~commun26/wiki/images/8/85/JSA_Health_system_in_India.pdf

Jan Swasthya Abhiyan Chhattisgarh. (2013). Outsourcing of diagnostic services in public health facilities in Chhattisgarh: A critique. Retrieved from https://archive1.phmovement.org/sites/archive1.phmovement.org/files/PHM%20India%20_%20Final_Critique_privatisation_diagnostics_chhattisgarh.pdf

Jan Swasthya Abhiyan Chhattisgarh. (2018). *Note on Chhattisgarh's Health Budget: Chhattisgarh's Health Budget deals a further blow to the government health system.* Raipur, India: Jan Swasthya Abhiyan.

Kapilashrami, A. (2010). *Understanding public private partnerships: The discourse, the practice, and the system wide effects of the global fund to fight AIDS, tuberculosis, and malaria* (Doctoral dissertation, Queen Margaret University, Musselburgh, United Kingdom). Retrieved from https://eresearch.qmu.ac.uk/handle/20.500.12289/7473

Kay, M. (2013). Chhattisgarh's proposal to outsource diagnostic services draws criticism. *British Medical Journal, 346*, Article f691. doi:10.1136/bmj.f691

Kishimoto, S., & Petitjean, O. (Eds.). (2017). *Reclaiming public services: How cities and citizens are turning back privatisation*. Amsterdam, The Netherlands: Transnational Institute (TNI) et al. Retrieved from https://www.tni.org/files/publication-downloads/reclaiming_public_services.pdf

Klugman, B. (2011). Effective social justice advocacy: A theory-of-change framework for assessing progress. *Reproductive Health Matters, 19*(38), 146-162. doi:10.1016/S0968-8080(11)38582-5

Kotecha, V. (2017, February). Outsourcing will not be the panacea for the NHS funding crisis. *National Health Executive*. Retrieved from
http://www.nationalhealthexecutive.com/Comment/outsourcing-will-not-be-the-panacea-for-the-nhs-funding-crisis

Labonté, R., & Schrecker, T. (2009). Introduction: Globalization's challenges to people's health. In R. Labonté, T. Schrecker, C. Packer, & V. Runnels (Eds.), *Globalization and health: Pathways, evidence and policy* (pp. 1–33). New York, NY, USA: Routledge.

Leys, C. (2018, January 24). Carillion shows the urgent need to democratise social services. *Red Pepper.* Retrieved from
https://www.redpepper.org.uk/carillion-shows-the-urgent-need-to-democratise-social-services/

Malterud, K. (2001). Qualitative research: Standards, challenges, and guidelines. *Lancet, 358*(9280), 483-488. doi:10.1016/S0140-6736(01)05627-6

Marriott, A. (2009). *Blind optimism: Challenging the myths about private health care in poor countries* (Oxfam Briefing Paper 125). Retrieved from
https://policy-practice.oxfam.org.uk/publications/blind-optimism-challenging-the-myths-about-private-health-care-in-poor-countries-114093

Mazumdar, S. (2013). *Forced hysterectomies, unscrupulous doctors.* Retrieved June 20, 2018, from
http://southasia.oneworld.net/news/forced-hysterectomies-unscrupulous-doctors

Ministry of Health and Family Welfare. (2012). *Report of the Sixth Common Review Mission – Bihar*. New Delhi, India: Missing Steering Group.

Ministry of Health and Family Welfare. (2017). *National Health Policy 2017*. New Delhi, India: Government of India. Retrieved from http://164.100.158.44/showfile.php?lid=4275

Mishler, E. G., & Steinitz, V. (2001). *Solidarity work: Researchers in the struggle for social.* Paper presented at the Annual Qualitative Interest Group Conference on Interdisciplinary Qualitative Studies, Athens, GA, January 12-14, 2001. Retrieved from ERIC database (ED457206): https://files.eric.ed.gov/fulltext/ED457206.pdf

Naidunia. (2013, May 21). Muh par kaali patti bandhkar jataya nijikaran ka kada virodh. *Naidunia*, p. 3.

Nandi, S., & Joshi, D. (2018, August 28). Chhattisgarh is outsourcing diagnostic services to the private sector despite having adequate staff. *Scroll.In*. Retrieved from
https://scroll.in/pulse/891907/chhattisgarh-is-outsourcing-diagnostic-services-to-the-private-sector-despite-having-adequate-staff

National Health Systems Resource Centre. (2012). *NRHM in the Eleventh Five Year Plan (2007-2012): Strengthening Public Health Systems*. New Delhi, India: National Rural Health Mission. Retrieved from http://nhsrcindia.org/sites/default/files/NRHM in 11th five year plan.pdf

Navarro, V. (2000). Assessment of the World Health Report 2000. *Lancet, 356*, 1598-1601. doi:10.1016/S0140-6736(00)03139-1

Office of the Registrar General & Census Commissioner, India. (2011). *2011 Census Data.* Retrieved from Census of India Website: http://censusindia.gov.in/2011-Common/CensusData2011.html

Pandey, K. (2015a, July 4). Chhattisgarh to outsource diagnostic services in government hospitals. *Down To Earth*. Retrieved from http://www.downtoearth.org.in/news/chhattisgarh-to-outsource-diagnostic-services-in-government-hospitals-40127

Pandey, K. (2015b, July 4). Private firms show no interest in Chhattigarh's invite to set up diagnostic facilities in tribal and remote areas. *Down To Earth*. Retrieved from http://www.downtoearth.org.in/news/private-firms-show-no-interest-in-chhattigarhs-invite-to-set-up-diagnostic-facilities-in-tribal-and-remote-areas-40427

Pandey, K. (2015c, June 28). Public's private peeve. *Down To Earth*. Retrieved from http://www.downtoearth.org.in/coverage/publics-private-peeve-40326

Pandey, K. (2015d, July). "Chhattisgarh's PPP model for diagnostic services flawed." *Down To Earth*. Retrieved from http://www.downtoearth.org.in/news/chhattisgarhs-ppp-model-for-diagnostic-services-flawed--41160

Patrika. (2013a, February 1). Aspatal bechne ka virodh (Protest against selling hospital). *Patrika*, p. 5.

Patrika. (2013b, May 21). Nahi bechne denge aspataal (We will not let the hospital be sold). *Patrika*, p. 3.

People's Health Movement & Third World Health Aid. (2017). *Building a movement for health*. Retrieved from https://twha.be/PHM-manual

Public Health Resource Network. (2013, May). *Health care under fiscal consolidation.* Retrieved from http://phrsindia.org/wp-content/uploads/2015/03/Health_care_under_fiscal_consolidation.pdf

Public Health Resource Network, Jan Swasthya Abhiyan, & Oxfam. (2017a). *Public private partnerships in healthcare*: *Outsourcing of haemodialysis services in Delhi: A case study*. Retrieved from https://www.oxfamindia.org/sites/default/files/Delhi_Dialysis_PPP Study Report.pdf

Public Health Resource Network, Jan Swasthya Abhiyan, & Oxfam. (2017b). *Public private partnerships in healthcare*: *Outsourcing of mobile medical units in Chhattisgarh: A case study*. Retrieved from https://www.oxfamindia.org/sites/default/files/CH_MMU_PPP Study Report.pdf

Public Health Resource Network, Jan Swasthya Abhiyan, & Oxfam. (2017c). *Public private partnerships in healthcare: Outsourcing of radiology services in Bihar: A case study.* Retrieved from https://www.oxfamindia.org/sites/default/files/Bihar_Radiology_PPP Study Report.pdf

Public Health Resource Network, Jan Swasthya Abhiyan, & Oxfam. (2017d). *Public private partnerships in healthcare: Outsourcing of recruitment and management of human resources for remote and conflict areas in Chhattisgarh: A case study.* Retrieved from https://www.oxfamindia.org/sites/default/files/CH_HR_PPP Study Report.pdf

Priya, R. (2005). Public health services in India: A historical perspective. In L. V. Gangolli, R. Duggal, & A. Shukla (Eds.), *Review of healthcare in India* (pp. 41–74). Mumbai, India: Cehat. Retrieved from http://www.cehat.org/cehat/uploads/files/rhci.pdf

Puri, R. (2012). Reforming the public distribution system: Lessons from Chhattisgarh. *Economic and Political Weekly, 47*(5), 21-23.

Rao, K. D., Sundararaman, T., Bhatnagar, A., Gupta, G., Kokho, P., & Jain, K. (2013). Which doctor for primary health care? Quality of care and non-physician clinicians in India. *Social Science & Medicine, 84*, 30-34. doi:10.1016/j.socscimed.2013.02.018

Rao, M. (2009). "Health for All" and neoliberal globalisation: An Indian rope trick. In L. Panitch & C. Leys (Eds.), *Socialist Register 2010: Morbid symptoms* (Vol. 46, pp. 262–278). London, United Kingdom: Merlin Press. Retrieved from https://socialistregister.com/index.php/srv/article/view/6774

Rao, S. K. (2013, January 29). No sweetening this bitter pill [Opinion / Lead]. *The Hindu*. Retrieved from http://www.thehindu.com/opinion/lead/no-sweetening-this-bitter-pill/article4354414.ece

PsychOpen GOLD

Roy, B. (2017). *How reforms are reorienting public sector hospitals in India.* Paper presented at the 3rd International Conference on Public Policy. Singapore, Singapore: International Public Policy Association. Retrieved from http://www.ippapublicpolicy.org/file/paper/593bbc3046ba8.pdf

Sengupta, A. (2013). *Universal health coverage: Beyond rhetoric* (MSP Occasional Paper No. 20). Retrieved from https://www.municipalservicesproject.org/sites/municipalservicesproject.org/files/publications/OccasionalPaper20 _Sengupta_Universal_Health_Coverage_Beyond_Rhetoric_Nov2013_0.pdf

Shiva, V. (2013, January 1). Violent economic "reforms" and the growing violence against women. *Aljazeera*. Retrieved from https://www.aljazeera.com/indepth/opinion/2013/01/20131192034265193.html

SHRC Chhattisgarh. (2013). Response to RTI application no. 088/2013.

Sundararaman, T. (2007). Community health-workers: Scaling up programmes. *Lancet, 369*(9579), 2058-2059. doi:10.1016/S0140-6736(07)60326-2

Tarrow, S. G. (2011). *Power in movement: Social movements and contentious politics* (3rd ed.). New York, NY, USA: Cambridge University Press.

Tilly, C. (2004). *Social movements, 1768-2004*. Boulder, CO, USA: Paradigm Publishers.

Times News Network. (2013a, February 1). NGO campaigns against outsourcing of diagnostic centres. *The Times of India*. Retrieved from https://timesofindia.indiatimes.com/city/raipur/NGO-campaigns-against-outsourcing-of-diagnostic-centres/articleshow/ 18281422.cms?referral=PM

Times News Network. (2013b, May 21). Silent march against privatization of diagnostic centres at Chhattisgarh hospitals. *The Times of India*. Retrieved from https://timesofindia.indiatimes.com/city/raipur/Silent-march-against-privatization-of-diagnostic-centres-at-Chhattisgarh-hospitals/ articleshow/20163377.cms

Times News Network. (2014, February 5). Privatization of Primary Health Centres across Chhattisgarh put on hold. *The Times of India*. Retrieved from https://timesofindia.indiatimes.com/city/raipur/Privatization-of-Primary-Health-Centres-across-Chhattisgarh-put-on-hold/ articleshow/29877844.cms

Tripathi, N., & Garg, S. (2018). *Strengthening essential laboratory services in public health facilities in Chhattisgarh state: A case study.* Paper presented at the National Consultation on Universal Access to Affordable Diagnostics Under the National Health Mission, 4th-5th May 2018 at Tata Institute of Social Sciences. Mumbai, India: TISS & NHSRC.

PsychOpen GOLD