



Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health



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ABSTRACT

Advocacy for people using health and social care services is widely promoted but its theoretical foundation is under-developed and its impact poorly conceptualised. This paper explores the liberatory potential of independent advocacy, using Fricker's concept of 'epistemic injustice' as a framework. People experiencing mental distress are particularly vulnerable to epistemic injustices as a consequence of deeply embedded social stigma resulting in *a priori* assumptions of irrationality and unreliability such that their knowledge is often discounted or downgraded. The mental health service user/survivor movement is at the forefront of validating personal experience and narrative to secure a different ontological and epistemological basis for mental distress. A foundational strand of this is advocacy to enable people to give voice to their experience.

The case of independent mental health advocacy (IMHA) services under mental health legislation in England, provides an opportunity to critically examine whether advocacy can promote epistemic justice as a result of the legally sanctioned encounter between clinical assessment and subjective experience, pivoting on judgements about risk. This paper draws on empirical data from a national evaluation of IMHA services, which included 90 individual interviews with people subject to detention and three focus groups with mental health service users. Fricker's concept of epistemic injustice is used as a lens to investigate how this type of advocacy might mitigate forms of epistemic injustice, and thereby promote greater social justice in mental health.

The concept of epistemic injustice provides a valuable theoretical basis for understanding the worth of advocacy in addressing testimonial injustice as well as its relative weakness in overcoming hermeneutical injustice. The challenge of independent advocacy to the dominant discourse within mental health is considered and questions raised about the place of advocacy in modern democratic mental health systems.

1. Introduction

In mental health services, power asymmetries are particularly stark with the existence of legislation permitting involuntary hospitalisation and treatment. Because of this, people experiencing mental distress can find their encounter with mental health professionals profoundly disabling: muting their experience, compounding isolation and exclusion, and perpetuating stigma and social disadvantage. Sharing experience, survivor activism, and advocacy to promote different understandings of mental distress have been central to mobilising against psychiatric hegemony (United Nations Human Rights Council, 2017).

In this paper we focus on independent advocacy, which is often framed as a liberatory practice. Advocacy aims to enable people to have a voice, to express their needs and wishes and protect their rights

(Henderson and Pochin, 2001; World Health Organization (WHO), 2005). It creates a space for different forms of knowledge within an unequal power dynamic that privileges professionals' authority over that of lived experience (Code, 2006; Molas, 2016). Although appreciated for contributing to greater democratic sensibility in mental health, the theoretical foundations for individual advocacy are under-developed and how to evaluate its impact poorly conceptualised. The aim of this paper is to investigate advocacy in theorising around epistemic justice. Fricker's concept of epistemic injustice (2006) is used to analyse people's direct accounts of independent mental health advocacy (IMHA) in England. IMHA provides a critical case of advocacy, a type of statutory advocacy introduced for people subject to compulsion under mental health legislation, and where the power asymmetries are particularly glaring.

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2. Background

2.1. Power asymmetries in mental health

For centuries, the social position of and care and support for people experiencing mental distress has been found wanting, often attributed to stigma and the resulting low priority afforded to mental health. Globally, this is often framed as inadequate resourcing of mental health care (Becker and Kleinman, 2013) resulting in a reliance on outdated and institutionalised models of care, even in well-resourced countries, and social marginalisation exemplified by prison occupancy and homelessness (Care Quality Commission, 2017; Insert United Nations before (UN), 2017). The UN identifies three reasons for the lack of progress: (1) the dominance of the biomedical model and the ‘arbitrary assumption that biomedical interventions are more effective than psychosocial approaches (UN, 2017: 6); (2) power asymmetries between mental health professionals - notably psychiatrists - and service users, reinforcing paternalism and patriarchy; and (3) a biomedical bias in the use of evidence in mental health reflecting the power asymmetries. At the heart of this critique are epistemic questions about what knowledge counts and whose knowledge matters.

2.2. Epistemic injustice

In theorising about the relationship between social power and our understandings of social experiences, Fricker (2006) describes how epistemic injustice prevents some groups from contesting distorted understandings of their social experiences (Fricker, 2006). In Fricker's terms, epistemic injustice occurs when a person is “*wronged specifically in her capacity as a knower*” (2007: 18). Epistemic injustice is foundational to other forms of social injustice because the capacity as a giver of knowledge is intrinsic to human value (Fricker, 2007; Medina, 2013).

Fricker distinguishes two forms of epistemic injustice: testimonial and hermeneutical. Testimonial injustices arise when an individual's word is afforded less credibility or invalidated through discounting or diminishing their account, creating a credibility deficit. Fricker contends that this reflects prejudice based on negative stereotypes associated with a particular social identity, and thus identity-prejudicial credibility deficit becomes the paradigm case for testimonial injustice (Faulkner, 2012; LeBlanc and Kinsella, 2016). Thus, the person is wronged not only for the testimonial injustice but because it diminishes them as a person: the ‘*core epistemic insult*’ (Fricker, 2007: 44). Hermeneutical injustice refers to the cognitive disadvantage when trying to make sense of social experience as a consequence of gaps in our collective understanding (Fricker, 2006). This arises when there is a lack of conceptual resources for understanding experience (Hookway, 2010), influenced by dominant social norms and values privileging particular types of knowledge.

Epistemic injustices also arise when people are denied the opportunity to participate as epistemic agents because they are treated as a ‘*non-knower*’ (Hookway, 2010). Silencing, or ‘*epistemic violence*’, is predicated on communication as reciprocal exchanges and occurs when the hearer fails to recognise the vulnerabilities of the speaker (Dotson, 2011). This failure is profoundly influenced by structural barriers and social norms impeding participation or ignorance impeding recognition of epistemic agency.

Whilst people who are ill are vulnerable to epistemic injustice (Carel and Kidd, 2014), those experiencing mental distress are particularly so. This is a consequence of social inequalities; historic marginalisation and social stigma associating forms of mental distress with possession by the devil or spirits, moral infirmity and moral depravity (Crichton et al., 2016). The culturally embedded relationship between madness and non-reason allied with an assumption of moral failure (Porter, 1987; Scull, 1979) persists in concepts of incomprehensibility, personal responsibility and deviancy. Over the centuries, this has served to sanction paternalism, exclusion from decision-making and enforce

agential limitations increasingly fostered by socially sanctioned professional power (Foucault, 2006).

The mental health survivor movement has long identified the assaults on the credibility and validity of their experience as a consequence of psychiatric power (Plumb, 1993). ‘Sanism’, i.e. the irrational stereotyping and prejudice associated with mental ill-health (Perlin, 2013) has been identified as more deleterious than the conditions themselves (Thornicroft et al., 2016). Common stereotypes foster negative perceptions that people experiencing mental distress are “*delusional, emotionally unstable, unpredictable, untruthful, untrustworthy, lacking all capacity for ‘rational’ thought and invariably dangerous to oneself or others*” (LeBlanc and Kinsella, 2016: 64). At an individual level, the encounter between people experiencing mental distress and mental health services relies almost exclusively on narrative and the interpretation of subjective knowledge (Sanati and Kyratsous, 2015). A priori assumptions of irrationality and cognitive deficits are often made, particularly for people experiencing psychotic symptoms, thus rendering assessments liable to grave epistemic errors (Sanati and Kyratsous, 2015; Molas, 2016).

The testimony of people experiencing mental distress is, therefore, at high risk of being viewed as irrelevant or unreliable and, therefore, ignored, downgraded, or rejected. Thus, justifying their exclusion from decision-making about their lives and increasing the likelihood of compulsion (Crichton et al., 2016; Sanati and Kyratsous, 2015; Scrutton, 2017). The survivor literature provides extensive examples of the consequential harms of epistemic injustices including isolation, threats to personal identity, alienation and the perpetuation of stigma (Lee, 2013). This includes exclusion as epistemic agents, and epistemic violence when:

Different forms of madness are constructed in particular ways and then used to diminish and deny the legitimacy of the knower—that renders that person out of existence, unable to be heard and to have their interests count.

Lieghgio:124).

The egregious impact of epistemic injustice in mental health is particularly stark in relation to mental health legislation (Sanati and Kyratsous, 2015). This also impacts adversely on the life chances of people diagnosed with a mental illness in relation to increased mortality (Thornicroft, 2011) and barriers to employment, housing, and relationships. The dominance of a biopsychosocial model privileges objectivity and third person accounts (Molas, 2016; Scrutton, 2017) and locates mental distress in the individual rather than the product of social relationships and context, described by LeBlanc and Kinsella (2016) as pre-emptive silencing.

2.3. Addressing epistemic injustice

Potential remedies proposed to address epistemic injustice take two forms. First are those from philosophy and medicine, which focus on increasing epistemic humility and the capacity of the listener to hear in order to develop greater awareness of potential epistemic injustice in the care professional and service user relationship. Carel and Kidd (2014) describe a phenomenological toolkit and with Crichton et al. (2016), promote ‘Schwartz Rounds’ in medical training and clinical practice designed to raise awareness of the existential, ethical and personal aspects of individual circumstances of service users. Second are those from the perspective of epistemically marginalised groups, which target empowerment and increasing the agency of people experiencing mental distress. These focus on strengthening voice, resisting the dominant discourse and neo-liberal politics of individualism, and seeking to develop alternative understandings of the diverse experiences of distress and strategies for support (LeBlanc and Kinsella, 2016). Mad Studies, emerging from survivor activism, foregrounds political participation, peer support, a focus on recovery and various forms of advocacy, and validates personal experience and narrative as a

foundation for a different ontological and epistemological basis for mental distress (LeFrançois et al., 2013; Beresford and Russo, 2016).

2.4. The rise of advocacy to address power asymmetries

Advocacy as a movement gathered momentum in the UK in the mid-1980s as a consequence of survivor activism promoting individual and collective advocacy to situate and validate personal experience, and to counter discrimination, coercion and rights infringements (Newbigging et al., 2015a). Advocacy is fundamentally concerned with seeing the world from the perspective of marginalised individuals and representing their voice (Henderson and Pochin, 2001). It serves to address power asymmetries, protect rights and promote social justice through greater empowerment and democratic participation of voices that might otherwise be silenced (WHO, 2005; Code, 2006).

Advocacy is provided independently from the health and social care sector and there are different types of advocacy (Newbigging et al., 2015a). In England, advocacy is typically provided by not-for-profit or community organisations. The introduction of IMHA in 2007, a statutory form of advocacy, resulted from lobbying by the Mental Health Alliance in the course of the prolonged and conflictual reform of the 1983 Mental Health (MH) Act (Newbigging et al., 2015a). The existence of mental health legislation is highly contested and argued to constitute a breach of human rights (Minkowitz, 2006; UN Human Rights Council, 2017) and exemplify sanism (Perlin, 2013). In England, people are subject to detention under the 1983 MH Act if they are assessed as ‘suffering’ from a mental illness and it is necessary for their own health and safety or the protection of other people (Mental Health Act, 1983). The rates of compulsion continue to rise: people from Black, Asian and Minority Ethnic communities (BAME) are over-represented and there are enduring concerns about rights infringements not only in England (CQC, 2018) but also across Europe (WHO, 2018). The purpose of IMHA, therefore, is to protect the rights of people detained under the 1983 Mental Health Act and to enable people to exercise those rights by having a voice and supporting participation in decision-making. The operation of advocacy in the context of compulsion provides a critical exemplar of the epistemic encounter between clinical assessment and subjective experience, pivoting on judgements about potential risk.

3. Study context

The data presented is drawn from a large-scale study of the implementation and quality of IMHA services in England, using a mixed methods design. Quantitative methods enabled examination of IMHA provision and access, while qualitative methods supported investigation of experiences of IMHA services from different perspectives and the factors influencing its quality (Newbigging et al., 2012, 2015b). The study was in two stages, with the first identifying dimensions and benchmarks of quality and generating a framework of quality indicators for IMHA, which were then explored empirically in eight sites at the second stage. A case study approach was adopted to enable real-time exploration of complex and dynamic phenomena (Yin, 2009). The case study sites were purposively selected to reflect variations in delivery contexts with regard to demography, organisational arrangements and approaches to the provision of IMHA services. The sites covered inner city, urban, rural, and coastal areas and included seven Mental Health NHS Trusts, covering the full range of mental health services from community services to high secure services, and one independent provider of low and medium secure services. The sites were located across England: two in the North West, and one each in the North East, Midlands, East of England, South West, South East, and London. In each site, data were collected to explore the operation and experience of IMHA services, including interviews with 214 participants (qualifying patients, mental health professionals, and advocacy staff).

4. Methodology

4.1. Study design

The element of the study concerned with the themes of this paper was qualitative. It involved three focus groups with mental health service users, including a specific BAME focus group in stage one, and semi-structured qualitative interviews with 90 service users eligible for IMHA services (i.e. ‘qualifying patients’) in stage two. Both methods were used to maximise participation and ensure the richness of data so that the analysis was grounded in complexity and detail (Emmel, 2013).

4.2. Research team

The research team involved a partnership between four academic researchers, including the authors, and nine specifically recruited co-researchers who were people with lived experience of mental distress, including detention in acute inpatient settings and secure services. One of the four academics also had recent experience of being detained under the MH Act, two had a professional background in mental health and across the team there was experience of commissioning and/or providing different forms of advocacy services as well as evaluation expertise. Involvement of service users including recruitment, training and support was consistent with national good practice (National Institute for Health Research, 2009) and, apart from the initial study design, co-researchers were involved in all aspects of the research process and dissemination of the findings. A Service User Reference Group, consisting of six people acted as a critical friend to the project and also contributed to the design of the research tools and interpretation of the findings. These two elements of involvement of people with lived experience were critical to exploring the theme of epistemic justice and ensuring the validity of the research through accessing multiple interpretations, which reflected the different values, experiences, and social contexts of the team. This required us to reflect on how power was shared between the academics and the researchers to move towards a greater democratic sensibility in the research process.

4.3. Recruitment and sampling

Information about the research and the focus groups was promoted on key service user websites and via local networks, with three community-based advocacy organisations also facilitating the recruitment of service users, who had experience of detention under the 1983 Mental Health Act.

The criteria for inclusion in the interviews was qualifying for support from IMHA services, as defined by the 2007 Mental Health (Amendment) Act, and having the capacity to consent. Three methods were used to recruit qualifying patients with the aim of ensuring diversity of participant characteristics across the sites, with more than one method being used in three sites:

- (a) Purposeful stratified sample (Sandelowski, 2000) of mental health provider data of anonymised detentions of people qualifying for IMHA services in the previous 12 months (five sites); and
- (b) Via service user or BAME organisations (two sites)
- (c) Via IMHA provider organisations (three sites)

Approximately 175 qualifying patients received information about the study either by post or in person from a mental health or advocacy service. Informal feedback indicates that those that declined to participate either considered that they were not well enough or were no longer detained and did not wish to revisit the experience. Ninety-two people were recruited, with two people excluded because they were lacking the capacity to consent to participate.

- Understanding of independent mental health advocacy (IMHA) services.
- Experience of using advocacy services.
- Access to IMHA services.
- Experience of using IMHA services.
- Views of local IMHA services, including how well the service met advocacy needs/protected rights and the quality of the service offered.
- IMHAs role in relation to Advance Directives, where they existed.
- Views on what would make a quality IMHA service.
- Outcomes from using IMHA services.
- Recommendations for IMHA services locally

Fig. 1. Lines of inquiry for the qualitative interviews.

4.4. Data collection methods

Focus groups with service users explored perceptions of, and personal experiences of IMHA services, as well as views on the dimensions of quality for IMHA services. Face-to-face semi-structured qualitative interviews used the lines of inquiry summarised in Fig. 1. In each site between 8 and 15 qualifying patients were interviewed (mean = 11) in a variety of settings including acute inpatient (AIP) and secure facilities, community-based mental health services and individuals' homes and this included a small number of people on Community Treatment Orders (CTOs). Interviews lasted 45 minutes to 2 hours and were conducted in English, via interpreters where necessary, and were recorded with participants' permission. All participants were invited to complete a brief questionnaire gathering information on demographic variables and information about detention under the MH Act. Co-researchers co-facilitated the focus groups and either led or were partnered with an academic for the face to face interviews. The co-researchers often disclosed their service user identity and the questionnaire asked for views on being interviewed by a service user. The responses to this method were positive and in general facilitated rich accounts.

4.5. Ethical approval

Ethical approval for the study was granted by the Cambridgeshire 3 NHS Research Ethics Committee and the University of Central Lancashire International School for Communities, Rights and Inclusion Ethics Committee. Research governance approvals were obtained for each study site from NHS Mental Health Trusts.

4.6. Analysis

The focus group and interview data were transcribed and imported into NVivo 10 for data management and to enable coding and comparisons between different respondent types. The analytic process was iterative and inclusive, designed to explore differences in interpretation. The development of the coding framework was initially driven by the research objectives, beginning with the identification of key themes and patterns and open coding (Bazeley, 2013; Saldana, 2012). A two-day workshop was held with all members of the team to refine the coding frame through engaging with the original data, review the emergent themes, identify additional themes, and analyse the relationships between the themes. The workshop started with reflecting

on individual personal experience and how this might influence us to privilege particular accounts; throughout the workshop, team members were challenged to justify their analysis with reference to the data. The subsequent coding of transcripts involved seven team members, including four co-researchers and a subsample of transcripts were coded by an additional member of the research team for inter-rater reliability.

Having a voice emerged as a central finding, and this led to the discovery in the literature of inter-related concepts concerned with epistemic agency and epistemic injustice (i.e. testimonial injustice, hermeneutic injustice; pre-emptive silencing and prejudicial-credibility deficits). These have been used by the current authors as sensitising concepts (Blumer, 1954) to interrogate the impact of advocacy in promoting epistemic justice. Sensitizing concepts serve as “points of departure from which to organize, interpret, and extend previous research findings” (Charmaz, 2000: 515) and link the particular with the universal to facilitate the development of theoretical linkages and new insights (Van den Hoonaard, 1997).

5. Findings

Fifteen mental health service users participated in three focus groups, including five people from BAME backgrounds; three people unable to attend the focus groups were interviewed by telephone. A further 90 people were interviewed across the case study sites, all of whom had qualified to access IMHA services. The demographic questionnaire was completed by 91% of the interview sample and the results demonstrating the variability in the characteristics illustrated in Table 1.

The interview sample included 61 people who had used IMHA services (IMHA partners) and 29 who qualified to use IMHA services but had not used the service (qualifying patients), two thirds of whom were unaware of the existence of IMHA services or uncertain whether they had used them.

The findings are presented under three major domains: epistemic agency; experiences of epistemic injustice; and the impact of advocacy in promoting epistemic agency and addressing epistemic injustices. Verbatim quotes have been selected purposefully with participant attribution referring to IMHA use/non-use, and the participant's location.

5.1. Epistemic agency

The difficulties of finding one's voice in the midst of acute distress,

Table 1
Key variables of the sample of qualifying patients interviewed.

Variable	Description
Gender	47 men: 43 women
Age	Age range = 15–75 years Mean age = 39 years
Ethnicity	White British: 70% BAME: 28.5% Other: 1.5%
Sexual orientation	Asylum seekers and refugees; 8% Heterosexual: 90% LGBT: 7.5% Other: 2.5%
Disability	A: 'mental health condition' (including diagnoses of bipolar, schizophrenia, depression, and eating disorders or poor mental health associated with anxiety or a pervasive lack of confidence): 35% Physical or sensory disability: 10.1% Learning disability: 8% Autistic spectrum condition: 5% Multiple mental health and physical health problems: 2% Not relevant: 22%
Length of contact with mental health services	Less than 3 months: 2.8% 3–6 months: 3.5% 6–12 months: 2.8% 1–3 years: 22.5% 3–5 years: 10% More than 5 years: 57.5% No response: 1.3%
Number of times sectioned	Never: 1.3% Once: 25% Twice: 17.5% Three times or more: 50% No response: 5%
Access to IMHA Service location	68% had accessed IMHA services In in-patient wards mainly acute inpatient adult wards (AIP): 53% Ssecure (including learning disability forensic services and child and adolescent forensic mental health services (CAMHS)): 40% Compulsory Treatment Order (CTO) and using community mental health services: 7%.

and personal confusion regarding the process of detention, often in unfamiliar surroundings, were evident. Participants reported feeling fear, panic, anger, aggression, paranoia, worry, vulnerable and alone, and for some detention amplified past experiences of compulsion and limited epistemic agency. This was exemplified by a woman who described ongoing abuse and coercive control by her husband leading her to make a serious suicide attempt triggering a police intervention, where she was handcuffed and detained in a cell:

“It’s a very traumatic experience on its own and I think that was more of a trauma ... in the end it actually displaced everything my husband actually did to me”.

Qualifying patient (AIP)

Although a minority described the feeling of security that being detained provided, the majority described it as disempowering, frightening and stigmatising, engendering a sense of criminality rather than care and support:

“I felt like I was being punished, I felt like I’m ill, I’m trying to kill myself, nobody else, and now I’m being punished, that’s how it felt to me. It still does actually.”

IMHA partner (Psychiatric Intensive Care (PICU) (Newbigging et al., 2012)

Mental distress, the context for admission, and the experience of compulsion impacted on epistemic agency and the capacity to process information and the confidence for self-expression. This was also influenced by perceived social differences between participants and

professionals in relation to class and ethnic background.

The process and relational aspects of compulsion served to further limit epistemic agency and impede the motivation to exercise their rights. For some participants, this was as basic as not having access to an interpreter and for others it was the cursory approach to providing relevant information:

“I was just left with these bits of paper with names and addresses of solicitors on and didn’t know what to do with them, but at that point I was too unwell to realise or to be able to speak up and say ‘I’m not happy with this’. I just kind of gave up at that point, I thought ‘right well I’m sectioned, I might as well just sit it’ out’ and I didn’t go for my appeal.”

IMHA partner, (AIP)

Participants described how professional power operated in ward meetings with large numbers of professionals present there was a sense that there was a hidden agenda and little scope to challenge the assumptions that were being made about them. Observations were also made about ward regimes, which limited opportunities for contact with staff:

“You might be banging your head off a brick wall. I’d say ‘I want to see the manager I’m not happy about this’, ‘The manager will see you in ten minutes’, the manager’s too busy to see you, he’ll see you tomorrow, or he’ll see you the next day..’ so that’s how it would go on, and on and on.”

BAME qualifying patient (AIP)

Incidents of abuse, coercion, and physical and pharmacological restraint were frequently referenced, often experienced as punishment and clearly serving as a restraint on voice. This included dehumanising practices, epitomised by a woman who described being assessed by two psychiatrists whilst she was in the bath. Regimes and staff behaviours were interpreted by participants as expressions of professionals’ power, reinforcing feelings of passivity and anger and undermining capacity and confidence to speak up.

5.2. Epistemic injustices

Accounts of testimonial injustice were common and participants described how their experience, and by implication how they, had been dismissed as irrelevant:

“I think a person should be able to speak for themselves ... but the Doctor doesn’t always want to listen to you when you are on the mental health section, they want to poo poo you out of the room.”

Qualifying patient (AIP)

In particular, pressing concerns pertaining to an individual’s daily life were ignored despite being relevant to the circumstances of admission. Concerns about housing, physical health, care and treatment under the Mental Health Act, including incidents of abuse and complaints also went unheeded:

“Getting shouted at, getting called a retard, getting, called a bastard by staff here. And nothing’s ever done about it. Management just says ‘oh away you go, you know, you’re imagining things’ but we’re not stupid. We may have mental health problems but we’re definitely not stupid.”

IMHA partner (rehabilitation hostel)

Participants powerfully illustrated the prejudicial-credibility deficit described by Fricker:

“Well the doctors, they tend to think ‘oh she’s mental, she’s this, she’s that, she’s queer, she’s crackers’ and they want to pass you over and shove me out of the room”

Qualifying patient (AIP)

“I feel like I’m howling at the moon no matter how coherent, how rational you know how considered my arguments and my explanations for events are, that assumed level of incompetence undermines it because you’re given sub-status”.

IMHA partner (AIP)

Instances of clinicians actively silencing participants and contra-vening their rights were also referred to:

“I applied for a tribunal with the solicitors, he [the psychiatrist] called me into his office and said to me 'don't go ahead with the tribunal'. When I told him I was going to tribunal they only had about three or four days and I think they were panicking so somehow they convinced me not to go through the tribunal and I'm still kicking myself for that.”

BAME IMHA partner (AIP)

It was evident that the dominant service discourse related to illness, diagnosis, and compliance with the section and medication regimes:

“I'm not mentally ill, they keep changing the diagnosis, one minute they say I'm personality disorder, then I'm schizophrenic, then I'm paranoid. They keep changing the label now and then because I keep proving them wrong.”

IMHA partner (medium secure unit)

Participants felt reduced to a diagnosis or a risk assessment. A sense of their personhood, an understanding of the context of their lives and an alternative framing of their preferences and experience was often absent.

5.3. Advocacy's contribution to addressing epistemic justice

Giving testimony to experience was seen as central to retaining a sense of personhood and restoring hope. *“The one thing that makes a difference is knowing that your voice is being heard”*. Whether or not qualifying patients had accessed IMHA, there was an appreciation of the role in enabling voice and mitigating the limitations on agency.

The difference having an IMHA made was described in terms of having more of a voice and the experience of being listened to; that someone understood their situation, what mattered to them, and recognised the troubling nature of detention. All of this helped restore a sense of personhood and greater control:

“I've got more of a voice through having an IMHA and because they know all the rules and regulations, I can confront the mental health team and say I know things, and the IMHA service will back me up.”

IMHA partner (AIP)

The presence of an advocate served to legitimise the participant's voice and their presence altered the communicative exchange so that health professionals were more respectful and listened more keenly, increasing the likelihood that service users' views, preferences, and choices would be heard.

Having an ally, particularly in the context of formal meetings, created a sense of solidarity: *‘someone there to sit in and be on my side’*:

“... if your advocate is there for you she's going to fight for you. She came in that day and she was speaking up for me and that was cool. I've got learning difficulties but when I try to talk I always get frustrated about words because I've only been in England for seven years. I speak English really good but when it comes to hard questions I always sweat and I just walk away.”

BAME IMHA partner (CAMHS)

Advocacy facilitated participants' voices through three modes of action: preparatory work, presence and positive action. Preparatory meetings between the IMHA and their partner focussed on the key issues the partner wanted to raise and the outcomes s/he was aiming for, which were typically leave arrangements, changes to care and treatment, returning home and wider concerns relating to housing, finances and family relationships. Advocates regularly sourced information about rights under the MH Act, medication and alternative treatments or diagnosis resulting in participants feeling more empowered to participate in discussions about their care and treatment. The presence of

the advocate in meetings with professionals served to enable the person to feel more confident to be able to speak for themselves (self-advocate), and to ensure that concerns that mattered to them were raised and acted upon:

“They provide help to people who need support to be able to speak up for themselves, get their views across, get their wishes and feelings out and shared with the professionals so that the person isn't just left to be dragged along by the system. You feel as if you have no rights and no control over anything that's going on in your life and the advocate can make sure that you're not being forgotten or abused or denied your rights.”

IMHA partner (AIP)

Advocates also represented people if they felt unable to have a voice including those that were generally able to advocate for themselves. In some instances, participants used the advocate tactically to manage the communicative exchange with care professionals, including situations where they wanted to challenge staff but feared the consequences of doing so directly. Participants valued the independent and confidential nature of the advocacy relationship, and appreciated the approachable and non-judgemental approach of advocates as being ‘alongside’ them, all critical to ensuring they had a voice:

“It gave me a voice, it gave me a platform in life. I don't have no family or relatives or anything so the [IMHA] is there to get in touch with when I need him, I call him and he offers support.”

IMHA partner (AIP)

Trust in the advocate, often referred to as ‘good and honest’ people, was related to the authentic representation of voice:

“ He [IMHA's name] was good at talking to the doctor, the way he worded things and he'd always say what I wanted to say for me and he'd always say it how I wanted it said, he'd never write it in his own way or anything.”

IMHA partner (AIP) (Newbigging et al., 2012)

It was also evident that the advocate's presence influenced the power dynamic through exposing the communicative exchange and professional practice to scrutiny:

“It (IMHA) opens it up, makes things transparent, changes the dynamic. There is so much secrecy around mental health, around wards and it's bullshit that staff give off, staff are the ones that enforce it and protect it more than anybody else. The more they (IMHAs) are in here, rummaging around and opening this place up, the more that light that comes on it and the more open and transparent it becomes.”

IMHA partner (AIP) (Newbigging et al., 2012)

Advocates acting as a ‘witness’ to communicative exchanges with health professionals served to strengthen participants confidence in their personal interpretations of experience and could prevent rights transgressions:

“I'm under, the Doctor, CPNs and the social workers from the Assertive Outreach Team, and they have kind of built up a brick wall between me and them, they're unhelpful, they're nasty, and they can be as awkward as they possibly can be. So, it's nice to have the advocate to be there as a witness to it all and see what they get up to, and put a stop to certain events that they could get up to”

BAME IMHA partner (CTO)

In promoting the voice of service users, participants highlighted how IMHAs were, in some instances, treated poorly suggesting that advocates' epistemic authority was also constrained by the service context:

“She supports me in every way but the hospital haven't gone along with her, they haven't been open with her, they haven't told her the truth, they haven't told her when my reviews are, she's rung up and she hasn't been

able to get through and they've made it really hard for her."

IMHA partner (AIP)

Some participants, while positive about the outcome of advocacy, felt that contrary to enhancing their voice, the IMHA could serve to reinforce the sense that they were not a credible witness to their own experience:

"It just made me feel like I was considered unworthy, not worthwhile enough and that you know obviously they would listen to her [IMHA] but not to me and why would they listen to her and not to me when we were both asking for exactly the same thing? But when she did get me the leave, when she did help me to not be detained for a further six months I did start to heal."

IMHA partner (AIP)

Advocacy served to create a space for different understandings and some participants referred to an appreciation of their social and relational context by mental health professionals as a consequence. There was less evidence that advocates were shifting professionals' conception of mental distress or that they had facilitated access to alternative conceptual frameworks, for example, survivor literature and service user groups, or that they were challenging assumptions on the basis of race, gender or sexuality.

"I don't think she's [the advocate] there to challenge the decisions of the hospital, she's there to support me which she did. I was literally trying to kill myself but she's not there to do that, she's not there to be judgemental or anything like that, she was just asking me what my problems were and could she help me."

IMHA partner (AIP)

Different conceptual frameworks for mental distress were raised by BAME participants in particular and in both the service user focus groups and interviews there was a call for more peer advocacy:

"Peer support, peer support, peer advocacy because as service users you do know there are things we will not tell anybody except say amongst ourselves, you know because if you do say they will lock you up and won't let you out."

BAME service user (focus group)

This raises questions of trust in statutory advocates and the sense that some conversations are off-limits except with peers, notably perspectives that run counter to the prevailing discourse.

6. Discussion

In this article we explore a new approach to theorising advocacy based on Fricker's evolving concept of epistemic injustice by grounding it in empirical data. The service user accounts demonstrate how professional behaviours, and structural and institutional barriers underpinned by legislative frameworks can conspire to negate epistemic agency – the epistemic violence that Liegghio (2013) describes so powerfully. Transactional forms of testimonial injustice were described when the behaviour of an individual clinician was described as dismissive. Reference was also made to identity prejudice and the role of the advocate as a witness to this, serving to vindicate the service user's perspective, prevent rights transgressions, and above all maintain their sense of personhood. Institutional and structural forms of epistemic injustice were evident in the institutional regimes, particularly the construction of ward rounds. Furthermore, the very essence of mental health legislation, in privileging a biomedical discourse, negated the social context and realities of people's lives, and in some instances further compounded their difficulties.

Our findings indicate that advocacy can serve both to increase recognition and legitimisation of people detained under mental health law as 'epistemic agents' and go some way to promoting testimonial justice through strengthening voice and addressing prejudicial-credibility

deficits. They also indicate that the advocacy role extends to acting as an epistemic witness and ensure that epistemic agency is protected. However, our findings suggest that advocacy is having little impact on hermeneutical injustice in enabling people to reclaim or develop a different understanding of their experience. Two immediate reasons are likely. First, the context of compulsion and experience of fearfulness and disempowerment (Newbigging et al., 2015a; Stomski et al., 2017) mean that advocates focus on securing rights and the immediate issues rather than broader hermeneutic and ontological concerns. This potentially engenders compliance with the dominant paradigm of mental distress resulting in epistemic objectification (LeBlanc and Kinsella, 2016) and a disconnection from their experience, which is likely to impact negatively on recovery and future prospects. Second, the purpose of IMHAs is prescribed in legislation and potentially limits their scope, with some participants questioning how much IMHAs could really achieve given the problematic nature of compulsion.

Alongside this, the introduction of statutory advocacy has increased the professionalisation of advocacy through adversely impacting on other forms of advocacy, which have strong connections with grassroots activism (Newbigging et al., 2012, 2013; 2015a). Severing advocacy from its foundations in lived experience, could explain why IMHA can go some way to promoting testimonial justice but may fail to address the more profound question of hermeneutical justice. For hermeneutical justice, advocacy needs to enable people to access conceptual resources to understand and frame their experience: for example in relation to the contribution of trauma, and the relational and social context for their current distress. This represents a fundamental challenge to the dominant biomedical discourse and has more far-reaching implications than ensuring voice and representation, important as that is. However, it is evident that detention and coercion under mental health legislation has far reaching social and existential impacts justifying a more penetrating understanding of experience of distress (Norvoll and Pedersen, 2016) and exploration of alternative framings of the experience. Indeed, questions of hermeneutical injustice are particularly pressing for those that are most marginalised by the mental health system, notably people from BAME communities, with contrasting interpretations of the experience of mental distress and preferences regarding support and advocacy models (Robinson et al., 2011; Foley and Platzer, 2007; Newbigging et al., 2013; Newbigging et al., 2012; 2015a).

Theorising advocacy in terms of epistemic injustice provides a foundation for advocacy as a liberatory act and Code's (2006) distinction of it as voice-driven and knowledge-driven resonates with Fricker's work. This conceptualisation not only provides a theoretical framework for individual advocacy but also a basis for evaluating its impact. Effective voice-driven advocacy enables marginalised voices to be heard and increases the propensity for self-advocacy. Effective knowledge-driven advocacy enables people to access different conceptual resources, particularly through peer relationships and connections with user-led organisations, to make sense of their experience. A good example of this is the Hearing Voices Network, which has reframed hearing voices from illness to expressions of distress.

Adopting this theoretical framework of epistemic injustice raises questions about the authenticity of voice, the impact of acute mental distress on personal agency, and the appropriateness of advocacy interventions in not only promoting epistemic justice for people experiencing mental distress but also in addressing the epistemic disadvantage of mental health professionals who do not have access to lived experience and knowledge (Scrutton, 2017). This framework also provides a way forward for evaluating advocacy and the identified difficulties of disentangling the process of advocacy from its impact (Ridley et al., 2018) to be clearly sighted on the type of impact.

It also raises fundamental questions about the purpose and future of advocacy. Its sheer existence serves to mitigate the excesses of professional behaviours and institutional regimes in the context of mental health legislation and access to IMHA needs to be widened (Newbigging

et al., 2012, 2015b). It makes a significant contribution to addressing testimonial injustices, but its disconnection from its activist foundations potentially mutes its impact in relation to hermeneutical injustice. Thus, the future development of advocacy needs to pay heed to both functions: realising voice and experiential knowledge.

The power disparities in mental health are clearly ingrained and evidenced by an impasse in addressing the use of compulsion, contravention of human rights and poor quality care in mental health. The response to the UN call for an ‘international revolution’ in mental health needs to foreground epistemic justice and methods for achieving this, including advocacy, to progress a greater democratic sensibility and social justice in mental health.

7. Limitations

The focus of the study was the quality of IMHA services in the UK (Newbigging et al., 2012; 2015a), and other methods may have been better suited to specific investigation of epistemic injustices in the context of communicative exchange between service users, advocates, and care professionals. Direct observation (Denzin, 2007) and conversation analysis (Drew et al., 2001) in particular are promising methods to garner a rich and nuanced understanding of how epistemic injustices play out in practice. Participants’ negative experiences may have influenced their motivation to access IMHA and to participate in this study, although the sampling method and attention to counterfactual data was designed to mitigate this.

Article aim

To explore a new approach to theorising advocacy based on Fricker’s evolving concept of epistemic injustice and grounded in empirical data from mental health service user accounts of statutory advocacy.

To identify the implications for promoting rights under mental health legislation and achieving greater democracy in mental health services.

Declarations of interest

None.

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Appendix A. Supplementary data

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