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ABSTRACT

This article explores the emotional labour of involvement and co-production in mental health research as experienced by service user/survivor researchers and research managers. It is based on a consultation aiming to explore some of the emotional implications raised by bringing lived experience into mental health research, through interviewing people with experience on all sides of the challenges raised. The aim was to develop a research proposal on the basis of the issues raised. Our analysis identified themes describing the negotiation of identity, the emotional work of using and embodying lived experience, and aspects of the working environment. This consultation highlights the intersectional complexities of identity and alienation experienced by people who bring their lived experience of mental distress or using services into unprepared workplaces. It also sheds light on the structural factors that mitigate against the successful integration of lived experience into mental health research.

Points of interest

- In this article, we explore the emotional implications of being known to have experience of mental distress within the workplace and being expected/expecting to use this experience in your role as researcher.
- The following themes were identified from interviews: the need to negotiate a 'mental illness' identity alongside an identity as researcher; the emotional work needed to use lived experience in research; the emotional implications of being known to have experience of mental distress and of being expected to use that experience as part of your role as researcher; the implications of competitive working environments; and strategies for managing these complex experiences.

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- We highlight the additional challenges affecting people from Black and minority ethnic communities working in predominantly white workplaces.
- We highlight the hierarchical and competitive features of academic institutions that prohibit the successful integration of lived experience into mental health research.

Introduction

Policy guidance in England and in other parts of the UK encourages the involvement of service users and carers also termed 'members of the public' as active collaborators in the research process (DH 2010; NIHR 2015). The rationale for this is that it will improve the relevance and appropriateness of the research (Staley 2009; NIHR 2015; Brett et al. 2014), although many service user and survivor researchers have greater aspirations for the transformation of knowledge (Rose 2014; Rose, Carr, and Beresford 2018). Many authors reference the ethical imperative to involve people in research: that those for whom the research is intended should have a stake in how it is undertaken (Rose 2013). However, the notion that people with direct experience of the service or condition in question could improve the quality and relevance of the research, provide the missing piece of the research jigsaw (Davies 2009) goes much wider than this.

Mental health service users and survivors have been arguing for a greater role in the production of knowledge for many years (Beresford and Wallcraft 1997; Wallcraft 2009; Rose 2004, 2009; Russo 2012; Sweeney 2013), building on the legacy of the Disabled People's Movement which established the principle 'nothing about us without us'. Survivor research has assumed an identity of its own (Sweeney 2013; Faulkner 2017; Rose, 2015) and in between the notion of involvement in research and survivor research there are many different ways in which service users and survivors, people with lived experience have sought to bring experiential knowledge to bear on mental health research (Faulkner 2017; Rose 2013; Sweeney 2013). People with experience of mental distress can offer insight into what it feels like to experience different types of distress, to be diagnosed, to use (or not use) mental health and social care services, to live with stigma and discrimination and to find ways of recovering or managing with mental distress on an ongoing basis. They can also offer their expertise to influence research methods and have the potential to create a body of knowledge that could transform mental health services and treatments but also, crucially, the nature of our understandings (Rose 2013; Rose, Carr, and Beresford 2018; Faulkner 2017; Beresford 2010; Jones et al. 2014; Sweeney, 2016).

Survivor research and involvement or co-production are not without their challenges, as has been acknowledged by a number of authors (Rose 2003a; Brett et al. 2014; Carr 2019; Staley 2009; Patterson et al. 2014; Oliver et al. 2019; PARTNERS2 writing collective 2020). However, few have addressed directly the emotional implications of bringing their experience and perspectives into the research and workplace, whether from the point of view of those speaking from lived experience or those managing the process from a non-service user perspective (Pollard and Evans 2013; Faulkner 2004b; Carr 2019). Carr (2019) identifies the 'psychological and emotional energy' that can impact on service user researchers, and can become a serious risk to mental health. She identifies the notion of 'emotional labour' as potentially helpful for service users and survivor researchers in understanding and managing the additional stress experienced when engaged in work that directly calls upon personal experience.

There is a wider body of literature regarding the emotional labour of service user involvement in health and social care services and of peer support (Lewis 2012; Carr 2007; Barnes 2002; Mancini and Lawson 2009; Watson 2017). Lewis (2012) suggests that the emotional work of involvement in mental health services operates at three levels. Firstly, services themselves are concerned with the management or suppression of distress, interpolated by the culture of fear and domination resulting from the threat of legal compulsion. Secondly, she proposes a level of emotion management that takes place within involvement spaces by professionals wary of emotional expression, resulting in the exclusion of the emotional aspects of lived experience from those spaces (Barnes 2002; Carr 2007). Lewis contends that a third level of emotional work arises from this, in which the emotional context of user involvement '*becomes amplified as a result of its apparent ineffectiveness in managing to meaningfully accommodate service users' experiences or achieve any actual, observable change*' (p. 279).

Whilst these levels are conceived of as operating in a service rather than a research context, they can be assumed to inflect the research space through the individuals who carry these same experiences and emotions with them. It is easy to see how a parallel appeal to rational debate within research spaces can seek to exclude or contain the emotional expression of mental distress (Rose 2003b; Carr 2019).

Literature concerning the emotional labour of peer support in mental health highlights the pressures of role and culture conflicts in the workplace (Watson 2017; Mancini and Lawson 2009; Voronka 2017). Watson prefers the term 'love labour', to describe the '*deliberate and skilled work that PSWs undertake to build relationships founded on mutuality, emotional honesty, love, reciprocity and authenticity*' (p. 9). For her, this love labour is an essential part of the work, although the negative effects of peer support work can be seen in relation to poorly supported 'love labour': where demand is too

high, there is little understanding of the peer support role, or the working environment is not supportive.

Faulkner (2004b) explored the clash of cultures in a research team where there was a lack of understanding of the challenges embodied by people with little or no experience of work, of ongoing distress, or of simply not fitting into the social norms of the academic workplace. Rose (2003a) talks of the dual identity that can at times cause an advisory group meeting to feel like a ward round. People are being involved in research *because* of their direct experience of mental distress, but when this distress manifests itself in the workplace, they can be experienced as too emotional or challenging: an emotionality that can be interpreted within the context of previous mental illness diagnoses and pathology, which is not always appropriate or helpful (Rose 2003a; Lewis 2012; Carr 2019).

It is important to note that the entire context of Patient and Public Involvement (PPI) and user/survivor research has been a predominantly white endeavour, with survivor researchers from racialised communities involved sometimes as an afterthought and often as participants in the research rather than as equal partners in knowledge production (Kalathil 2013). Kalathil and Jones (2016) note that when researchers from racialised communities are mentioned, it is often as part of an attempt to accommodate 'diversity' in a context where addressing diversity falls to the people who embody difference. This highlights the need to understand the intersectional experiences of researchers from racialised and other marginalised communities who are likely to have additional layers of emotional labour to contend with.

Alongside these issues, there is some indication that mainstream researchers managing the process may feel inadequate to the task of managing the emotionality of working with service user researchers (Faulkner 2004b; Pollard and Evans 2013). Pollard and Evans write of the emotional work involved for researchers in running a project that involves mental health service users: from negotiating between service users' individual needs and the inflexible institutional policies and procedures, through dealing with episodic illness, to managing meetings and dealing with disappointments and dissatisfactions.

Oliver et al. (2019), in writing of the 'dark side of co-production', highlight the personal and professional costs to researchers of co-producing research. In calling for a cautious approach to co-production, they fail to highlight the pressures and priorities inherent in academia that create some of the pre-conditions for these costs. Williams et al. (2020), in responding to Oliver et al. suggest that the authors are seeing '*only the dark side rather than what is casting the shadows*' (p. 8). They call for greater scrutiny of the structural factors that obstruct the potential of co-produced research. It is our intention here to shed some light into

those shadows and to scrutinise the structural factors responsible for casting them.

Language and definitions

The landscape of which we speak and write is complex. Terms such as peer research, user-led research, co-production, survivor research, user involvement in research and user-focused research are used across different organisations in different ways without clear definitions. Whilst NIHR holds there to be a clear distinction between involvement, participation and engagement (with involvement being the most active form), there are other fields of enquiry where, for example, participatory action research is held to be a distinct approach to undertaking research. More recently, the term PPI has come to be understood as a somewhat diluted and sometimes tokenistic form of involvement (Rose 2014; Rose, Carr, and Beresford 2018). Peer research has been described as research where people with lived experience of the issues being studied take part in directing and conducting the research (Lushey 2017). Meanwhile, survivor research tends to be defined by the significance of empowerment and experiential knowledge throughout the whole research process (Russo 2012; Faulkner 2017). Russo highlights the challenge that survivor research presents to the bio-medical model of mental illness as a key identifier.

   The distinctions between these various terms are difficult to establish, and indeed gave rise to debate in the writing of this paper. Consequently, the landscape for this paper is complicated both by the different ways in which people might be bringing their lived experience into research and research workplaces but also by the different understandings surrounding the terminology (Rose 2014; Rose, Carr, and Beresford 2018). For the purposes of this paper, we often use the generic term 'involvement'. However, we acknowledge that this term masks many different modes of action and power. Our interest is in the emotional implications for anyone who is involved or employed in research because of the experiential knowledge that they bring.

Aims of the study

This small study was established as a pilot to explore some of the emotional implications raised by bringing lived experience into mental health research, through interviewing people with different perspectives on the issues raised. The purpose of the project was to explore:

- The benefits and challenges for service user/peer researchers of working on research that involves the personal engagement of their lived experience;

- The benefits and challenges for researchers managing the process of involvement in research;
- Issues of identity and self-definition in relation to research roles and work;
- What strategies have worked and what strategies have not worked in the endeavour to support people and value lived experience within research;
- Intersectional experiences of power and privilege, class and education, white privilege and racism and ableism throughout the research environment.

Methods

This was a qualitative interview study based on the use of a topic guide (see Figure 1). We approached a purposive sample, with the aim of including people with a range of backgrounds and experiences in order to understand the intersectional issues of power and privilege related to involvement. We aimed to interview people from racialised communities, people with and without experience of higher education; people with physical disabilities; people who identified as having lived experience (or as mental health service users/survivors); and people managing people involved in research. We aimed to include people employed as survivor or peer researchers as well as people 'involved' in research on a consultancy or occasional basis.

We want to understand more about both the barriers people experience and the things that have worked well in helping people with lived experience to bring their lived experience to the research table, to work well in research environments, and to contribute to research on an equal basis. We understand that there is an emotional cost on both sides when things do not go well. Even when they do go well, the experience can bring emotional issues to the surface and support may be needed along the way. Both people with lived experience and their managers and supervisors (and people who wear more than one hat!) have important experience to share in this endeavour.

- Introductory questions: experience, current role
- Self-definition: how you define yourself and why
- Experience of involvement in research/peer research/survivor research (and/or managing involvement): benefits, challenges
- 'Emotional work' involved in your role
- The working environment: challenges, supports, other issues
- Research projects: challenges, supports
- Discrimination, stigma, power - experiences or views
- Supporting the involvement of lived experience in research: what helpful, what would like.
- Anything else you would like to say

Figure 1. Topic guide summary.

The two study researchers interviewed each other, in order to scope the language, perspectives and experience they brought to the study and to inform the development of the topic guide. The aim of the interviews was to remain open to the issues raised by participants, whilst guided by the items in the topic guide. All interviews were recorded and transcribed. Both researchers first analysed each interview separately on a case-by-case basis, recording themes and issues arising and constructing an analysis sheet for each interview, in an adapted form of Framework Analysis (Ritchie and Spencer 2002; Srivastava and Thomson 2009). The two authors then compared their analysis sheets in order to identify common themes and engage in further discussion to resolve points of difference. The lead author then constructed a single analysis sheet per interview and resolved the final list of themes, in consultation with the second author. The writing of an initial report summarising the themes formed a final step in the analysis, providing a space for both researchers to reflect on the themes, drawing together key elements of each from the interview data.

Ethical issues

As this was a pilot study developed within a voluntary sector organisation with a view to developing a research proposal, we did not seek formal ethics approval. The study was conducted in accordance with ethical guidelines as described in Faulkner (2004a). Full informed consent was obtained from interviewees and this report was checked back with them for amendments and for them to check their own anonymity. Both researchers maintained safe password-protected storage of interviews and transcripts.

The study gave rise to sensitive ethical issues that required particular care with regard to confidentiality and anonymity from the start. Although the field of service user/survivor research in mental health has been increasing over the years, many people know each other. Two people declined to be interviewed because we would know people they were talking about and/or they did not want to be identified. For this reason, we have approached the analysis of these interviews and the writing of this report in a particular way. We have focused on themes and issues raised, and avoided attributing quotes or demographic characteristics to individual voices. This paper was checked back with participants in order that they can determine whether or not they feel themselves to be identifiable in a way they would prefer not to be.

An additional ethical concern is that, in surfacing the emotional challenges represented by bringing lived experience into research, we are potentially problematising the entire involvement 'project' with the risk of discouraging people from embarking on it. With this in mind, we asked people about the strategies and supports they had found helpful or thought would be helpful to them.

Findings

Participants

The purposive sample of 10 interviewees included people who identified as managers or supporters of people employed or involved for their lived experience; people who identified as survivor or peer researchers; and people who held both roles. Eight people were white, two South Asian, one had a physical disability, and four were male. The people with lived experience we interviewed included people a different stages in their careers, people with lived experience employed on studies led by non-peer researchers; people employed on studies led by survivor researchers; PhD students; freelance survivor researchers; two PPI leads, one in an NHS Trust and one in a University department. These last had responsibility for the involvement and/or management support of other people with lived experience. The two managers without lived experience either employed or involved people with lived experience in their research studies. Geographically, the ten interviewees were drawn from London, the South East and the East and West Midlands.

For reasons of maintaining anonymity within a relatively small community, we have avoided more specific identification of people's demographic characteristics. For the same reason, we do not assign quotations to individuals.

Themes

Our analysis identified the following themes: Negotiating identity; Emotional work: using lived experience; Emotional work: embodiment and alienation; Working environment: productivity and bureaucracy; plus Strategies for managing emotional labour: personal, collective, organisational and systemic.

Negotiating identity

The participants with experience of mental distress used a variety of terms to describe themselves: service user researcher, mad identified survivor researcher, peer researcher, survivor researcher, queer academic, broken academic, lived experience researcher, disabled researcher.

Participants talked of the complexities of assuming a research identity founded upon their lived experience. This affected people in different ways, depending on their route into research and their route into distress or mental health services, as well as the nature of their current role. A few interviewees, on discovering peer or survivor research roles, had initially experienced a sense of fit: the feeling 'this is for me'. Struggles with their studies in mainstream psychology and/or use of services had already sown seeds of discontent with mainstream ideas about mental illness: finding a position in which that discontent could be voiced brought a sense of 'fit'.

> I heard a particular survivor researcher give a presentation and it was a boom moment, I was like, 'this is for me, this fits' and that's what drew me to it, I think.

For some people, the identity or role had functional use: for interviewees with a research or academic career behind them, adopting (or publicly declaring) the identity or experience of mental distress opened up new opportunities for employment.

> And then I got really intrigued about research, peer research and how [organisation] works and how that lived experience is brought into it. And I just thought, this is my way into something that I feel I'm really passionate about and it's not necessarily my background but I feel like I could give a lot too.

Identifying or naming oneself in particular ways could also be contextual; there might be spaces in which some terms would hold less meaning or be interpreted as political statements, leading to choices being made.

> So in a way, I identify the work as survivor research but I'm not so comfortable with the identity location of survivor researcher.

Many participants expressed ambivalence about sustaining a dual identity as both researcher and service user/survivor, for example, feeling that they were holding a 'transgressive identity' or occupying a liminal space between researcher and service user. This ambivalence was associated with the status of lived experience in an academic context, as it had the potential to compromise the credibility of the individual—and their research—for the future, a matter of particular concern to early career researchers. The liminal space had complex implications for the authenticity and credibility of its occupants. Several participants talked of feeling 'fake': of being neither an authentic service user nor a proper researcher, and of 'getting flack from both sides'. They found themselves criticised for being too academic to be an authentic service user as well as being too 'mad' or biased to be an authentic researcher.

Some felt 'fixed' by the service user or lived experience identity, finding that everything they did in the workplace could be seen through this lens, with the result that they were not expected or required to contribute in a broader way to the research.

> It's a double-edged sword. Maybe this is my only identity, like, is that all people see you as? The fact that you do a lot of things that don't require lived experience on the day to day….

People described a negotiation with power and identity: once they had assumed more power as a researcher, this could be interpreted as losing the power of the authentic user voice. Being or becoming knowledgeable as a researcher was interpreted as losing authenticity as a service user/survivor by some people, whilst being a service user/survivor invalidated expertise or experience as a researcher for others.

> One of my co-researchers said, "You are going over to the dark side." Because in my research role, even though I was saying this is co-produced and all that, I had all the knowledge about narrative, I was running the focus group, you know, he was right in that sense.

Participants from racialised communities talked of the importance of understanding the complexities of intersectional identities, both in the research space and within the context of 'lived experience'. They were not alone in suggesting that lived experience itself is broader and more complex than is often allowed or assumed, but they also sought to challenge (white UK based) assumptions of what it means to share a 'service user' or survivor identity. Different cultures and different countries have different histories around mental health and mental health services, which affect the experiences that individuals will bring. Foregrounding the mental health/distress identity without addressing the diversity of experience that can be subsumed within it can obscure other identities, particularly those associated with race and culture, that might be more significant in this space to the individual.

> it feels like in this role, […] race and lived experience are both visible for me in this role whereas in life, race is always visible to me but lived experience isn't necessarily because I don't have to talk about lived experience in everything that I do whereas in work, it probably, it's something that's there all the time.

Emotional work: using lived experience

Most participants accepted the inevitability of some degree of emotional distress within this research context: that it could be 'harrowing' to be faced with aspects of your experience in your work. Staying connected to something that was traumatic could be a huge challenge.

> I guess for me, the question was how can I use that knowledge, the experiential survivor knowledge, in a way that is constructive and I'm not constantly overwhelmed by terror, because that's how I felt when I was detained, or rage because there were things that made me so angry on the wards that I was observing, or a sense of grief, a sense of what I've lost.

Some participants talked with passion about their role in bringing lived experience to the research table: not just their own, but the lived experience of their peers, co-workers or research participants.

> that's why I'm here doing the work that I do, is that people can start owning their issues and people can start sharing their issues and to find a safe place to share these difficult things and hold these difficult cases.

It was framed at times as a responsibility and a vocation, sometimes also a burden. It could be both rewarding and challenging, and had the potential to enable the individual to learn and develop their own sense of themselves and their narrative.

By contrast, two participants talked of the additional resilience they brought to the research endeavour as a result of being through difficult experiences. They found they were less shocked by environments or experiences described to them in interviews, and one found themselves more prepared for engaging in debate and criticism:

> I didn't realise, because I've been through so much in my life. I'm quite resilient in the sense that I've had horrific things told to me, like in my life by other people, and people can't actually handle criticism.

One of the research managers articulated the need to acknowledge and support, but not pathologise, the emotional distress experienced by survivor researchers. They were aware of the potential for other members of staff to overreact to the distress of a survivor researcher.

> So, it's part of the rationale for doing this work is that people will have a personal connection with the thing we're doing research about, the questions we're asking or the people we're talking to, the kind of the asset, the value of that is also challenging.

There was a particular intensity when the research topic concerned issues of direct personal relevance. One person talked of working on a project that explored experiences of coercion and detention:

> Violence is not just an academic intellectual issue. It has a very strong affective element, emotional element because of … my lived experience.

She described the emotional work involved in maintaining this position as finding a balance between '*trying to use your knowledge and managing your emotions so you can stay afloat*', but also described the experience as having been '*reparative*' in enabling her to return to the wards in a different, more powerful, role than when she had been an inpatient.

Managing peer researchers brought different challenges; one person talked of managing younger peer researchers who had high expectations about using their lived experience in the research. It was not enough simply to be there: they wanted to feel that they were using their lived experience actively and could claim their experiences as a valid source of expertise alongside other research team members. This could lead to frustration:

> […] it's only the numbers that count and then we were told we would use our lived experience to help shape the project, and there's no time for that.

Emotional work: embodiment and alienation

Many of our interviewees described the significant emotional labour required of them in *embodying* mental distress, madness or disability within a

sometimes alienating workplace, particularly, but not exclusively, in academic spaces. People described feeling or being too emotional for their colleagues, overstepping boundaries and not understanding the rules of behaviour. This could lead to a sense of alienation:

> I don't have anyone to have a coffee with, nobody wants to have a coffee with me.

To express emotion in this research environment was to invite pathologisation. When one survivor researcher described doing so, she said that (non-survivor) researchers expressed doubt that she was sufficiently robust to continue with the work.

Two participants used the metaphor of the 'performing monkey' in relation to their presence in the academic space. On the one hand, they found that they were expected to perform as the service user when required to do so, but then also expected to perform as effectively as any other researcher.

> when it suited, I was a traditional researcher that should do it all. I mean, you can't have it both ways.

Connected to this was the pressure of being required to perform or behave in accordance with what has been referred to as 'sanestream' culture (Fabris 2016): the sense of feeling pressure to behave in a certain way, to disguise or hide distress in an effort to not challenge the prevailing culture. Similarly, researchers supporting service users felt a pressure to involve people who would fit into the prevailing culture, to contribute but not to challenge:

> We are under pressure from researchers to actually have perfect LEAP [Lived Experience Advisory Panel] members.

For the participants from racialised communities, there was the more significant challenge of embodying the 'other' in a predominantly white organisation, dealing with racist micro-aggressions on a regular basis. Power influenced who could express themselves in the space: not just hierarchical power but intersectional, in that white people struggling with racism could be given more space than their non-white colleagues.

> I am having to console and support a white person through their struggles of dealing with their whiteness … if I had to just pick one most difficult experience, that's been it.

A couple of interviewees highlighted the tick-box approach to diversity and involvement adopted by organisations, and several talked of the expectation that they represent diversity for the organisation. Organisations used images of people of colour to display diversity in their publicity materials, but did not support those same people in the workplace. Issues of whiteness and race were obfuscated and poorly understood with nowhere to go for

support or redress. People found it difficult to have their views or perceptions taken seriously. One interviewee expressed this potential for epistemic injustice with passion:

> Don't let anyone else convince you that something that they've never ever experienced is not happening.

Working environment: productivity and bureaucracy

Several aspects of the academic environment were identified by participants as being not just antithetical to the involvement and employment of people with lived experience, but as sources of distress in their own right. The pressure to be productive in academic terms affected both people employed as service user researchers and researchers managing the involvement or employment of service users in research. The productivity imperative presented service user researchers with a dilemma, in that they wanted to be both equal to their non-service user colleagues and yet also valued for their difference.

> … you have to be a service user but you have to show that when it comes to it, you can deliver just as well as everyone else.

The pressures fell in a particular way on people with physical disabilities, for whom circumventing physical barriers of access could at times be seen as their personal responsibility and extraneous to the requirements of the work:

> When you tell people about it, they go 'yes that's terrible but you've still got to get your work in' and it's like, no, what I'm saying to you is, these barriers or these issues, sometimes have a debilitating effect on my self-esteem and self-confidence, in order for me to perform the role of an academic or a researcher or whatever.

There was a parallel pressure on research managers to run large scale research studies and trials to attract funding to the detriment of smaller scale studies where the involvement of people with lived experience could be more meaningful. Valued outcomes, including research funding and publications in high impact journals, were less likely to be achievable through these smaller studies.

The academic system was seen to be failing to reward researchers for involving or employing people with lived experience in their research. Indeed, the pressures and incentives of academia were seen to preclude some of the primary adjustments required to facilitate involvement. There was a sense that funders and the academic hierarchy were failing to understand the work involved in supporting involvement, co-production and service-user led research.

> We had thought about doing some work to try to, again, uncover this emotional labour, the work that needs to be done to help and support people that's not recognised by anyone, least of all by our funders, […] because again, they'll provide

support to the service users and patients themselves in terms of costs. They'll even appoint patient and public involvement leads, but there's no recognition of what that job should entail and the support and work that goes into it.

The bureaucracy was seen to have increased in recent years, leading to challenges in engaging with Human Resources and Occupational Health over the involvement or employment of service users. This could have implications for the timely payment of fees and expenses. Research managers felt the emotional work they undertook in support of involving or employing people with lived experience in research went unrecognised and unsupported by senior members of staff in the academic hierarchy. This was a particular concern in relation to service users who were 'involved' rather than employed, as there was no structure in place to ensure their support.

I think again, it's really interesting about how we might treat these service users, who are doing work for us, as lesser employees. On one hand, treat them like they're not really employees but then on the other hand have expectations like they're employed by us. I find that quite challenging. I feel like it's very unfair. Often, again, the onus falls on the individual to be able to organise and try to ask for things rather than us, as people, who support them to be able to know what we should be offering them.

Precarious employment status was another issue raised, with the sense that there was no obvious career path from this role. This connects with the earlier concerns about assuming a fixed identity as 'service user researcher' within an academic context. Younger researchers and those planning an academic career had more concerns about this than older or more experienced survivor researchers who had sought or discovered this identity later in their lives or careers. Without substantive support or systemic incentives, the presence of service users and survivor research within the academy was experienced as potentially precarious or transient.

Strategies for managing the emotional work

We asked participants about the strategies or supports they had found or thought would be helpful. The strongest message was the need for external support or supervision, outside of the line management hierarchy and possibly also independent of the organisation. One of the main purposes of such support was find a space in which to talk about the emotional distress and labour without having to simultaneously worry about work delivery or deadlines. The potential conflicts of interest involved where support was not separated from line management were articulated by several people. A few had found their own sources of support outside of the workplace, such as therapy and friends, but nevertheless found the idea of independent support valuable. Beyond this overarching theme, the support strategies mentioned

by participants fell into the following categories: personal, collective, workplace and systemic strategies.

Personal strategies

Personal strategies included writing and keeping a journal, therapy, talking to friends and family, participating in social media groups, and reading and researching issues such as race and white privilege as a form of seeking external validation. These were strategies that people found helpful, but did not necessarily substitute for support at an organisational or structural level.

> I think having the therapy that I had anyway was very helpful, particularly for the ethnography. Interestingly enough, that wasn't part of the original plan of their job description. They hadn't thought that the service user researcher that they would throw into wards for fifteen months or so would need to be supported.

Collective strategies

A few people talked about the value of peer support or peer mentoring within the workplace (*'someone who gets it'*), or of collective strategies such as engaging with the Union for a wider approach linking mental wellbeing to employment structures. One idea was to engage across a University or across a number of Universities to create a peer network of researchers. One isolated peer researcher expressed the need to explore how to create a 'critical mass' of mad people in the academy, a strategy for connecting with others for shared understanding and validation:

> … they've let the mad people in, but it's kind of like how the mad people start leading projects and I think it maybe it's building it and get to a critical mass of people who are working in this environment.

Workplace strategies

Suggested workplace strategies included: optional mental health days and flexible working practices, reflective practice groups, identifying and budgeting for support roles within the team, training and buddying/mentoring. Some had found flexible working hours and the option to work from home helpful in managing mental distress, but these could not necessarily be applied to experiencing racism in the workplace. People with lived experience in senior positions were valued for their understanding of the mental health issues. However, it was felt important that people in positions of power speak out when necessary and make it clear that racist, sexist or transphobic behaviour (etc.) is not acceptable. The presence of people of colour in senior positions was something that the two participants of colour identified as potentially of value (although unlikely in practice).

> … because just like it's easier to speak to somebody with a shared experience of mental distress or mental health services about a particular thing related to that, it's easier to speak to a person who shares those experiences of racism.

A significant issue raised was the need for space(s) to discuss issues of lived experience, power and privilege in an open and transparent way. This point was made in relation to the creation of survivor research spaces and the largely unexamined assumptions underlying them, alongside the need to talk about other issues associated with their identity and experience

> … it would be helpful if we talked about how [survivor research] may not be better for everybody, how it may be difficult, basically just opening up space to ask questions and have those questions be discussed, not even answered.

In a similar way, one of the research managers raised the issue of needing more time within research contracts and the time and space to talk about the issues raised for everyone by working with lived experience in research.

> it's just time to talk about everything and to understand what's expected and when and why and how and it's time to talk about the stuff that's difficult and that can be distressing, not in any remedial sense of, "God, you need some support now."

Systemic strategies

People made suggestions for systemic or structural changes that might support involvement in research, but without a great deal of hope or expectation. They felt the emotional support implications of involvement need to be formally recognised within organisational structures; and researchers explicitly rewarded for involvement work, through the Research Excellence Framework (for example). In general terms, interviewees had observed the pressures of academic life worsening in recent years along with the bureaucracy surrounding employment and involvement.

Managers of research and involvement suggested that service users being involved (as against employed) need to have similar rights to employees, with access to support, contracts and resources. People talked of the need to work with University HR departments to enable a greater understanding of the need to involve and employ people with lived experience.

Practical issues such as more time and flexibility in research contracts were raised, including the time to enable the support strategies to be implemented alongside the research. Many talked of the need to change the culture, not just to accommodate people with experience of mental distress but also, crucially, to raise awareness across the academic hierarchy of race and white privilege. Training and resources might make (some) people more aware, but might not really change the situation in a predominantly white organisation.

But I don't think it's right that we bring people with lived experience and the complexities of race and lived experience into these places because we don't have the right systems in place to support them when things happen.

A couple of people talked about integrating race/whiteness and mad culture into University curricula. This would, they felt, have a greater prospect of bringing about cultural change over time, through introducing different knowledges to student populations.

Discussion

This small study has helped to shed light on different aspects of the 'emotional labour' involved for people working across the various ways in which they bring lived experience into research and research workplaces. Issues of identity, power and alienation struggled alongside organisational culture and intersectional understandings, making safe spaces hard to find. Interviewees talked at least as much about the challenges represented by the organisational context and culture as they did about the challenges of using their lived experience in their work, suggesting that in order to achieve the latter, it is essential to work on the former.

There are at least two paradoxes that arise from this work. One of these relates to the complexities of identity. Whilst many of our participants appreciated the positive connection or 'fit' with the service user or peer researcher role and work, almost affirming their sense of identity as both service user and researcher, many were also conflicted about its potential to fix them within this identity and perpetuate the 'othering' that takes place within a 'sanestream' culture (Fabris 2016). In explicitly bringing lived experience into the workplace, people are being asked to embody mental distress within a potentially pathologising environment: to, effectively, carry this identity in an environment that does not ultimately value it (Lewis 2009; Hutchinson and Lovell, 2013).

Many of our interviewees found themselves attempting to bestride the two domains of research and lived experience, with conflicts of culture, loyalty and belonging. Carr (2019) talks of straddling two identities: of being made 'other' both by powerful and by oppressed people, finding her occupying an uncertain and challenging space.

But, despite my challenges and experiences of distress and service use, from the outside I am seen as part of the elite; betraying a set of fundamental values by working in a neoliberal university system that commodifies and monetises experiential and first-hand knowledge and colludes with the psychiatric establishment. (p. 9)

A recent report by SCIE (Faulkner et al., unpublished) also found identity to be a significant issue for disabled people and service users involved in social care research. In that study, several people talked of being assigned

a label or identity through their involvement in research. Both studies high-light a lack of understanding in research teams about the complexities of identity struggles for those with lived experience, and how exposing it can feel to bring a 'lived experience' identity into the workplace.

Aspects of identity were differently reflected in the intersectional experi-ences of the study participants from racialised communities; they found that their experience of being othered within a white organisation was at least as powerful as their experience of being identified as having lived experience of mental distress—if not more so. Jones and Kelly (2015) remind us of the 'inconvenient complications' of identity; they highlight, the significant dif-ferences in background and experiences between different individuals who identify as 'mad', and the ways in which we can mask these differences to the detriment of our knowledge and understanding. People do not and cannot separate aspects of their identity for the purposes of involvement in research (or other activities) but are influenced by the context in which they take place (Kalathil 2013).

The second paradox arising from this study relates to the emotional expression of involvement. Organisations employing or involving people with lived experience of mental distress tend to suppress or deny the emotional expression of this distress, requiring people to conform and perform accord-ing to the dominant rational culture (Carr 2019). Carr (2007) suggests that a degree of conflict is inevitable given the power relations inherent in involvement. She suggests that the direct experience of service users may be expressed in ways that are too distressing or disturbing to be acknowl-edged through 'rational' involvement strategies. She recommends flexible and creative spaces for inclusive dialogue, similar to those suggested in this study, allowing for the expression of some passion or emotion with the time to discuss their implications:

> Any such strategies should be both robust and flexible enough to create a safe environment in which both staff and service user stakeholders can express them-selves honestly, in a language most natural to them and be listened to respect-fully…. (p. 273)

Whilst this is about involvement in services rather than research, the principle of dialogue remains, and was reflected in the views of many of our participants. Pollard and Evans (2013), in focusing on the researchers' perspective on the emotional work of involvement, also highlight the value of dialogue. They finish their chapter with a plea for '*academic, clinical and service user researchers to create space for reflection on, and honest dialogue about, these 'wicked issues"* (p. 48).

As in this study, Carr (2019) highlights the fact that service users do not get much help with the emotional and psychological aspects of the work, which can sometimes damage mental health. Defining emotional labour

with reference to Matinez-Inego et al. (2007) as being where '*employees regulate their emotions in exchange for a wage*', she suggests that the concept could help service user and survivor researchers in understanding the nature of the work they are engaged in. However, only if it is acknowledged at an organisational and structural level will it be offered the support it merits. The message about emotional labour needs to reach not just the University hierarchy but the research funders, whose demands are often used by academics to excuse poor support or process.

Service user/survivor researchers have been highlighting the need for support for people involved in researched at least as far back as 2004 (Faulkner 2004a). This small study finds that the situation remains largely unchanged. Where non-service user researchers seek to implement meaningful involvement, it is largely left to them to navigate the bureaucratic procedures of their University systems as well as to support people through sometimes challenging work. People with lived experience of mental distress may or may not find their own ways of supporting themselves and each other, but there are few examples of solid support offered within research organisations. Our participants recommended a range of personal, collective and workplace strategies, with one overarching message: that support outside of the line management hierarchy is essential.

Carr (2019) recommends strategies aimed at fostering collectivity and connection between academia and service user communities, building bridges between academia and service user/survivor communities, through dispersing power and resources and sharing knowledge. Most of the other authors to have touched on this theme identify the value of building in spaces for open dialogue to take place, where people with lived experience have the time and space to reflect on the impact of this work and their identity.

Interpreting these findings requires an understanding of the wider academic culture within which research and involvement in research takes place in this country. Government funded research is dominated by the consumerist/managerialist notions of public involvement conferring an ethos of research led by clinical academics inviting members of the public into a pre-existing study, whether through employment or involvement. Consequently, not only do those who embody mental illness within this space remain subject to pathologisation but the status of service user/survivor knowledge in academia remains marginalised (Russo and Beresford 2015; Jones and Brown 2013; Rose 2003b).

Perhaps as a result of this context, the barriers to more meaningful involvement or something approaching co-production remain largely unchallenged and unchanged (Rose, Carr, and Beresford 2018). Faulkner et al. (unpublished) found similar structural barriers to the involvement of service users and disabled people in social care research in academia. They noted financial

bureaucracy, precarious employment status and the disabling effects of academic incentives. The individualised and competitive nature of academic incentives (publications in peer-reviewed journals, research grants) undermines both the potential for employing service users and disabled people, and the efforts of researchers who want to work in a collaborative way. As one of our participants said: '*You've got to want to do it*'.

The present study highlights the need for both research organisations and survivor research/peer research spaces to address the intersectional experiences of people from racialised communities alongside the lived experience of mental distress (Shilliam, 2014). The experiences and the knowledge of people who are marginalised by the whiteness of organisations are disregarded, within critiques of a culture that tends to foreground rationality and objectivity to the exclusion of madness and distress (Kalathil and Jones 2016). As one participant said, '*the acceptable face of madness in the academy is white, articulate, productive*'. One way of addressing this is for these strands of knowledge and discourse to be integrated throughout the mental health/psychiatric curricula, as suggested by a couple of our participants. This might have the effect of ensuring that both students and staff are exposed to different ways of making sense of the world challenging the dominance of Western biomedical theory (Kalathil and Jones 2016).

Conclusions

The emotional labour of working with, and integrating, lived experience in research is worthy of serious consideration, from the perspectives of people doing it, supporting it and managing it. It is vital that we work out how to do this well, because the emotional authenticity of experiential knowledge is essential to understanding our research and our world better. Experiential knowledge has the capacity to disrupt the illusion of rationality in mental health research and to transform our understandings (Faulkner 2017; Beresford 2010).

This small study highlights the complexities of identity and alienation experienced by people who bring their lived experience of mental distress or using services into unprepared, even stigmatising, workplaces. There are personal, interpersonal, organisational and systemic issues concerning the production of research that need addressing for this to work well. The strategies indicated by this study operate at all of these levels and could enable people with to work with their lived experience in positive and mutually beneficial ways if they wish to do so.

However, it is also clear from this study that reward and recognition for involving or employing people with lived experience in research need to be structurally embedded in academic research, perhaps through the Research Excellence Framework as well as through commissioning and contracts. The

issues raised, in relation to reward and recognition, time and flexibility in research, are not easily integrated within the pressurised environment of academic research (Wellcome 2020). It is essential that they are integrated if we are to maximise the potential contribution of experiential knowledge in mental health research and diminish the factors casting dark shadows over co-production (Williams et al. 2020).

Authors' contributions

AF led on the analysis and report writing. RT carried out five of the interviews and participated in the analysis. The pilot consultation was undertaken with the support of Dr Vanessa Pinfold at the McPin Foundation with a view to preparing a proposal for a larger research study.

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