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research article

'Should we even have questions?' From survey to exhibition – co-producing research about 'mental health' with carers and adults with learning disabilities

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Carers' mental health is often the focus of policy and research in Global North contexts. Research exploring carers' views often uses survey methods to collect information about their experiences and views of services and support. However, the experiences of adult carers of adults with learning disabilities have often been marginalised within these domains. Here, we report on how, working together with family carers, we disrupted survey methods and generated new insights into what matters to family carers when sharing their experiences of care, mental health, services and support, as well as the crucial role of co-production in this research.

Keywords family carers • mental health • surveys • co-production

Introduction

Carers' mental health is often the focus of public policy and academic research in the Global North, yet the experiences of family carers of adults with learning disabilities are often sidelined, as the focus remains on the lives of carers of older people (Smith et al, forthcoming). We are working together with family carers of adults with learning disabilities to understand carers' experiences of mental health, services and support as part of an ongoing research project based in England: 'Tired of spinning plates: an exploration of the mental health experiences of adults and/or older carers of

adults with learning disabilities'.[1] The research explores how family carers of adults with learning disabilities conceptualise and experience mental health throughout different stages of life. We are exploring family carers' views of the quality, accessibility and effectiveness of support for carers' mental health and their perspectives on the effectiveness of interventions, including respite, medication, social prescribing, passport schemes, employment support, and alternative and complementary therapies. The research is driven by principles of co-production and has been developed and carried out together with family carers and people with learning disabilities. In this article, we describe the power of working in co-production to disrupt habits of researching care and mental health in order to generate new insights into family carers' experiences and (re)consider how these insights can inform and disrupt research, policy and practice.

We begin by locating the study in terms of its disciplinary, theoretical and methodological influences. We then turn our attention to consider the proliferation of the use of surveys in the lives of people who use mental health services, including family carers of adults with learning disabilities. We describe a series of meetings and workshops with family carers and people with learning disabilities in which we planned to co-design an online survey about family carers' experiences of care and mental health. We reflect on what these workshops reveal about how family carers understand mental health, their experiences of services and support, and how they disrupt our understanding and expose the limitations of survey methods. We share how these revelations opened the research up unexpectedly to the possibilities for co-creating alternative online approaches for sharing family carers' perspectives and experiences. These online spaces are co-created spaces that value belonging and sharing what matters, not what is imposed by researchers or policy. We conclude by discussing how learning from this generative and disruptive co-production process can be embedded more widely in research practices with family carers to co-productively inform policy and practice.

Theoretical perspectives

Our approach to this study is critical and political. We make no apology for our scholar-activist orientation and for believing that we have a role to play in working for social justice (Farnum, 2016). This critical approach means that we are committed to troubling the ongoing ontological assumptions that shape the lives of carers of adults with learning disabilities (Haraway, 2016). We are interested in the ways in which 'mental health', 'care' and 'learning disability' are entangled in public policy discourse and the consequences of the uses and abuses of these terms in people's lives (Runswick-Cole et al, 2024). We draw on a number of intersecting critical-theoretical perspectives that we understand as being united by their attempts to reveal, critique and challenge power structures (Bohman, 2021). These resources include critical disability studies (Goodley, 2014), critical approaches to the study of care and disability (Hughes et al, 2005; Herring, 2014; Lai, 2020; Drotbohm, 2022), and critical approaches to mental health, drawing on perspectives from feminist (Harper et al, 2021; Marecek and LaFrance, 2021) and critical psychology (Parker, 2002), critical race scholarship (Craps, 2013; Andermahr, 2015), and 'Mad Studies' (Spandler and Poursanidou, 2019).

Crucial to disability studies scholarship is the rejection of the often taken-for-granted perception of disability as an individual flaw or lack (Smith et al, forthcoming). Instead, we embrace the potential of disability to trouble the current order (Goodley and Lawthom, 2019). We recognise the persistent marginalisation and abuse of disabled

people in contexts of care (Kelly, 2011) and seek to expose and challenge models of deficit and lack that construct the lives of disabled people (Oliver, 1990). We welcome the way that care has been problematised as a site where gendered, classed, raced, economic and social inequalities are reproduced (Drotbohm, 2022), but we know that the experiences of disabled people and family carers are often marginalised within these debates and that theorisations of ableism and sanism are marginalised in conceptualisations of care (Runswick-Cole et al, 2024).

We write from a Global North context in which discussions of disability, care and mental health continue to be underpinned by the assumptions and discourses of the 'psy' disciplines, including psychology, psychiatry, psychoanalysis and psychotherapies, as well as developmental, educational and occupational psychologies (McAvoy, 2014). 'Psy' discourses have permeated the fabric of everyday life, dominating the ways in which many people make sense of themselves and their relationships with others (Rose, 1998). The 'psy' disciplines story mental health as something that has enormous power in people's lives and that constructs the interiority of a person and the nature of biomedical disease as the primary focus of concern and intervention (Marecek and LaFrance, 2021). The representational language of illness, healing, symptom, syndrome, trauma and relapse constructs this biomedical narrative (Marecek and LaFrance, 2021) and is based on the persistent assumption that caring is carried out in a dyadic and unidirectional relationship between a caregiver and a care receiver. Disabled people are usually constructed in these relationships as a 'burden' on and a potential threat to the mental health of the caregiver (Marks et al, 2002). In this dominant narrative, the social, material and interpersonal contexts of both the caregiver's and care receiver's lives – such as social inequality, poverty, housing, identity-based violence and inequality – are sidelined (Marecek and LaFrance, 2021), and the support that disabled people provide their carers is ignored (Smith et al, forthcoming). In response to an earlier draft of this article, family carers reminded us to include health inequalities in this list of sidelined matters.

Critical approaches to mental health have long been adopted by feminist scholars who have sought to foreground the social, material and interpersonal context to tell different stories of mental distress (Masters, 2023). They have exposed and challenged the ways in which women are made particularly vulnerable to the workings of the 'psy' professions and the profiteering of the 'psy' industries (Masters, 2023). Critical psychologists (Parker, 2002) have increasingly called for alternatives to a biomedical approach.

We know that there are concerns when white, cis-gender, middle-class academics draw on the politics and theory of postcolonial writing (Ali, 2007). Yet, we want to learn from postcolonial writers' powerful critiques of the biomedical model of mental health (Craps, 2013; Andermahr, 2015). Andermahr (2015) describes how trauma theory marginalises and ignores the experiences of non-Western and/or minoritised groups by persistently narrating trauma as the result of 'a single, extraordinary, catastrophic event' (Craps, 2013). Experiences of racism are not one-off events. Racism continues to damage people in the present and the experience of distress that follows is not disordered; rather, it is an understandable response to discrimination (Andermahr, 2015). Craps (2013: 5) argues that 'we need to take account of the specific and historical contexts in which trauma narratives are produced and received and to be open and attentive to the diverse strategies of representation and resistance that these contexts invite or necessitate'. This critique of trauma theory is crucial to understanding the specific and historical contexts in which carers of adults with learning disabilities talk

about their mental health; in neoliberal ableist times, disabled people are devalued and dehumanised and the care provided by family carers is economically and socially devalued (Goodley et al, 2014; Drotbohm, 2022).

Our engagement with 'Mad Studies' entangles with our ongoing critical scholar-activism, which seeks to foreground the experiences and knowledge of mental health service users/survivors with the aim of generating new understandings of mental health that value and centralise the lived experiences and living knowledge of Mad-identified people (Daley et al, 2019) and the 'allies, social critics, revolutionary theorists, and radical professionals who have sought to distance themselves from the essentializing biological determinism of psychiatry' (LeFrancois et al, 2013: 2). We are drawn to the attempts by Mad Studies scholars and activists to trouble the assumptions that underpin traditional approaches to mental health, but we agree with Spandler and Poursanidou (2019: 19) that we need to be wary of the potential exclusions that are produced by 'unhelpful binary oppositions, such as mind/body; physical/mental; social/medical model; and pro/anti-psychiatry'. As LeFrançois (2016) explains, this exclusion is produced by binary thinking, which leads to the privileging of Mad activist scholarship over other forms of scholarship.

Mental health surveys and social issues

Public policy discourse continues to warn of a 'tsunami of mental health ill health' accelerated by the COVID-19 pandemic (Shevlin et al, 2023). However, pre-pandemic, austerity had already exacerbated and prolonged mental health risks (Stuckler et al, 2017).

A plethora of research from the perspective of a biomedical model of mental health argues strongly for the validity and efficiency of mental health screening tools (Spitzer et al, 2006; Blevins et al, 2015), though inconsistency has been identified between tools (Newson et al, 2020). Some research exploring the emotional impacts of mental health service users using the tools reports little evidence that filling in a questionnaire causes further distress and finds that people accept surveys and may find them useful (Willebrand et al, 2004; Yeater et al, 2012). Nevertheless, practitioners and researchers are encouraged to pay attention to the potential affective impacts on participants who take part in surveys (Jorm et al, 1994; Sollis et al, 2020).

Yet, other research finds that filling in standardised clinical outcome measures in therapeutic sessions is seen as taking away from what is regarded as precious therapeutic time (Rizq, 2012: 8). Clinicians acknowledge the limited value of outcome measures for them and their service users and the potential detrimental effects on care (Rizq, 2012: 8). For Rizq (2012: 9), outcome measures can result in 'a perversion of care, exemplifying the way in which NHS [National Health Service] services appear to be turning away from the realities of suffering, dependence and vulnerability and from the complexity of managing this'.

Carers organisations in the UK and globally regularly disseminate mental-health-related surveys to family carers (see, for example, Embracing Carers, 2020; Carers UK, 2022). Academic research focused on mental health and caring also frequently draws on a survey design to report on well-being and quality of life (see, for example, Chou et al, 2009; Joseph et al, 2012). Given the prevalence of the use of surveys in the lives of carers and our commitment to co-production, our original aim was to work with carers to co-design a survey with them. As we developed the project, we anticipated

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that we would draw from family carers' expertise to work together to identify topic areas and questions that mattered to them. We imagined that the questions that would matter in the co-designed survey may differ from those questions that have been made to matter in pre-existing surveys. However, we came to see surveys about family carers' mental health as potentially problematic rather than a part of a solution for understanding what matters in their lives.

Co-production in research

As we describe in the following, it was only through a process of co-production that we came to understand the surveys as part of the 'problem' rather than as a useful mechanism for understanding carers' experiences. Despite, or perhaps because of, the ubiquity of the term 'production', it is not always clear how the term is understood, what it means in practice and what exactly it is that is being 'co-produced' (Filipe et al, 2017). In health and social care research, 'co-production' has taken many forms, including the 'co-design', 'co-evaluation' and 'co-implementation' of services all carried out by patients and/or service users, clinicians, carers, and managers (Filipe et al, 2017). However, the use of the term 'co-production' usually suggests that there has been some blurring of the boundaries between researchers and members of the public, and 'co-production' is underpinned by an asset-based model, where the partners in research are believed to have something to offer in the process of knowledge production (Boyle and Harris, 2013).

Beresford and Croft (2012: 8) describe the contributions of disability activism to the emergence of an emancipatory research paradigm, citing Oliver's (1990: 111) description of the emancipatory research agenda as follows:

> The issue then for the emancipatory research paradigm is not how to empower people but, once people have decided to empower themselves, precisely what research can then be done to facilitate this process. This does not mean that the social relations of research production do have to be fundamentally changed; researchers have to learn how to put their knowledge and skills at the disposal of their research subjects, for them to use in whatever ways they choose.

This article includes the story of our attempts to put our 'knowledge and skills' at the disposal of our research partners in 'whatever way' they chose. We hope that this experience makes a useful contribution to the wider project of co-produced participatory research (Kemmis and McTaggart, 2008).

Method

The original project plan had six research phases: (1) the formation of the Tea and Cake Group, a public involvement group made up of family carers and adults with learning disabilities and university-based researchers, with the group meeting regularly and flexibly to guide the research; (2) a rapid scoping review of the literature; (3) a series of workshops to co-design a carer mental health survey ($n = 6$), with a plan to then disseminate the co-designed survey ($n = 300$); (4) interviews with family carers, including parents and siblings ($n = 24$); (5) online digital storytelling workshops to create short films ($n = 24$) that explore caring and mental health; and (6) the development of

learning and teaching resources to support family carers and inform the development and delivery of high-quality mental health services to meet their specific support needs.

The proposal was developed with partners, including family carers and people with learning disabilities. We recognise that the promise of co-production has not always been delivered in academic research or service design, and the term is part of an ever-changing vocabulary (Boyle and Harris, 2009; Rose and Kalathil, 2019). Even in what seem to be successful examples of partnership working, power relations persist, based on status and knowledge possession (Rose and Kalathil, 2019). From the beginning, we understood that co-production is a process and that plans would change and develop over time. Yet, we had not anticipated the degree of discomfort that would be felt by the university researchers when the promise of co-production collided with the pressure to deliver the project on time and on budget. Following the workshop, there was a huge amount of unanticipated work as protocol changes and ethical amendments were made in response to the expert guidance of family carers and adults with learning disabilities. The importance of each member of the research team sharing a scholar-activist orientation became evident through this process, as the team embraced the generative and disruptive changes that emerged through this co-productive working together with family carers and adults with learning disabilities (Farnum, 2016).

Thus, we report here from the first and third phases of the research project, drawing on discussions from the Tea and Cake Group (Phase 1) and from the survey co-design workshops (Phase 3) with family carers. We took extensive notes during the meetings and workshops. Our original plan was to hold two in-person workshops with family carers of people with learning disabilities to design an online survey that explored family carers' experiences and understandings of care, mental health, services and support. We planned for two in-person meetings, remunerating participants for their time and expertise, covering travel and replacement care costs, and providing refreshments. We anticipated that these plans would need to be responsive and flexible to meet the requirements of family carers. Participants all opted for online meetings, and we held two sets of survey workshops with a total of six participants (five parent carers and one sibling) (see Table 1). In the first workshop, we opened the discussion by explaining the idea of co-designing a survey about mental health and the lives of carers of adults with learning disabilities and shared examples of existing surveys. As we describe in the following, family carers quickly decided that a survey was not the best approach, and through careful discussion, the idea of an online exhibition was suggested. After each round of workshops, we took the discussions back to the Tea and Cake Group (see Table 2). Reflections from both groups are included in the following analysis.

Table 1: Survey workshop participants

Name	Carer
Deanna	Parent
Tamsin	Parent
Caitlin	Parent
Florence	Parent
Amir	Sibling

Table 2: Tea and Cake Group participant table

Name	Carer/person with learning disability
Bea	Parent
Matthew	Sibling
Julie	Parent
Emma	Person with a learning disability
Elspeth	Parent
Grace	Sibling
Carrie	Parent
Devi	Person with a learning disability
Daniel	A person with a learning disability

Analysis

As researchers and activists, we are response-able for what is made to matter through our research and writing (Barad, 2007; Smith, 2021). We engage with a concept of mattering to not only draw attention to that which matters deeply and demands collective response-ability but also position our approach to theoretical engagement in research. Theorising what matters is not an attempt to simply describe or represent a fixed idea about what matters and what is excluded from mattering; rather, it is a way of staying with possibilities for reconfiguring what matters (Barad and Gandorfer, 2021). Thus, we engage with an agential realist approach to theorising and researching that undoes habitual practices of describing the world as if we are not a part of its ongoingness. Toppled from our academic pedestals, we roll up our sleeves and attune to the troubles of the world we are a part of (Haraway, 2016). Research and theorising in this context is an inextricable part of an indeterminate world, and we are acutely aware of our response-ability for the part we play in each remaking of the world (Haraway, 2016; Barad and Gandorfer, 2021). Theory becomes a tool for our activism and for staying with the troubles and re-matterings while opening up to the possibilities of kinder worlds (Barad, 2007; Haraway, 2016).

Too often, the lives of family carers and people with learning disabilities are excluded from mattering. As one of the sibling carers in the Tea and Cake Group, Matthew, told us in a meeting: 'We are never really listened to … but you guys are listening to me.' These lives are often sidelined in research and made not to matter in policy and public debates (Barad, 2007; Smith et al, forthcoming). We intersect our agential realist framework with traditional approaches to thematic and narrative analysis (Braun and Clarke, 2022). The first stage of this approach involves reading and rereading notes from the meetings and thinking about what makes itself matter through the data, that is, through our lives, readings and conversations. We are guided, not constrained, by procedural approaches to coding and thematising what has made itself matter through the entanglement of data and lives shared with us. We remain vigilant to the unexpected and disruptive possibilities for re-mattering in the lives of adults with disabilities and their family carers. In practice, this involves paying attention to 'not just the story of individual people, but the stories of matter – stuff, objects, spaces – *every thing*' (Brown et al, 2020: 226, emphasis in original). We take nothing for granted, and that includes the habitual assumptions of boundaries between human and non-human agents that constitute the world (Barad and Gandorfer, 2021).

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We shared the analysis as both an easy-read summary of findings, the subsequent online and face-to-face discussion guide and later a draft of this article for email comment with both workshop members and the Tea and Cake Group. The Tea and Cake Group members reviewed the workshop suggestions, and their responses, for the most part, echoed the views of workshop participants; however, as we see later, they also reflected on different experiences, particularly in relation to how they understood mental health. The reflections and comments from these discussions and their disruptions to the ways in which we understand family carer mental health and researching carer mental health are shared throughout the following explorations of what mattered to family carers, adults with learning disabilities and us as researching allies.

Thematic matterings

We discuss four themes in the following: mental health matters; trauma matters (past, present and future harms); paperwork matters; and co-production matters, from survey to exhibition. These are offered not as contained representational themes but as provocations for staying with what matters, what has come to matter through our co-researching and what is normatively excluded from mattering.

Mental health matters

Family carers are acutely aware of the power of mental health discourse in their lives, and their engagements with the term 'mental health' echoed wider debates about the nature and causes of mental distress (Masters, 2023). In the first survey workshop, Tamsin began the discussion by directly challenging the dominant narrative which assumes that family carers have mental health difficulties (Marks et al, 2002): 'I just want to say that there is an assumption to start with that there may be mental health challenges. I have never been on antidepressants, never been through therapy.' Tamsin offered a powerful counter-narrative to the dominant discourse that care is associated with 'burnout' and 'burden'. She exposed and rejected the conflation of the categories of 'family carer' and 'person with mental health difficulties' and, crucially, she challenged the idea that caring for her daughter poses a threat to her mental health (Marks et al, 2002). Rather, she explained that she 'spends time with my daughter' when she finds life difficult because it is 'joyful'. Tamsin troubles the binary of caregiver and care receiver and acknowledges the support her daughter gives her in their relationship of care (Marks et al, 2002).

Family carers repeatedly referred to the social, material and interpersonal contexts of their lives in which their mental health came to matter (Marks et al, 2002). Caitlin was clear that the cause of her distress was located in the constant battle for services and support:

> A label of depression is unhelpful, as [mental distress] is being done to me [by services]. [It is caused by] having to be on the roundabout [of fighting for services and support] all the time. Sometimes, you just have to stay on the roundabout for hours. Always on the roundabout…. I've never taken antidepressants … I know that the way I feel isn't how *I* feel, it's because it's done to me.

Caitlin is clear that she experiences distress because of what services *do to her*, as she resists interpretations of her life that position the 'problem' within her and within her son. However, family carers are not a homogeneous group, and Bea was surprised by the idea that mental health was something 'done to you':

> I'd need time to think about that [the idea that mental health is something done to you]. It just shows that we all think differently, we are all unique…. I do have a mental health issue, which I have to manage separately [from caring], although it is worsened sometimes by my caring responsibilities.

There are differences between family carers in the ways that 'mental health' comes to matter in their lives. It is important to make space and become response-able with and for these differences and to resist the lure of binary thinking and the temptation to code their responses into 'mind/body; physical/mental; social/medical model; and pro/anti-psychiatry' (Spandler and Poursanidou, 2019: 3). Instead, we see the importance of engaging with a multiplicity of perspectives on mental health rather than drawing on problematic assumptions that attempt to fix a static meaning of 'mental health' as something to be captured. We engage with the ongoingness of mental health and the ways in which it re-matters beyond the confines of stagnant representation and embrace the idea that '[t]he world and its possibilities for becoming are re-made with each moment' (Barad, 2007: 396).

Crucially, we suggest that those who support family carers can also learn from this more uncertain and indeterminate approach. We encourage them to explore how mental health comes to matter to the family carers they support and to resist the temptation to impose their own ontological assumptions and understandings on family carers' lives.

Trauma matters

The past, present and future are entangled within family carers' accounts of how trauma comes to matter in their lives (Craps, 2013; Andermahr, 2015). Caitlin describes being 're-traumatised every single day' in her interaction with services, as she fights the British government's Department for Work and Pensions (DWP) for access to benefits and with her son's social worker to access social care. Caitlin described the ways in which she was judged in and by services, being blamed by them, and how she started to blame and doubt herself, questioning whether she even deserved support for her mental health, 'though you know you do'. Mental health labels mattered when they were 'used against her' when she asked for support for her son. She described having been labelled as 'hypervigilant, assertive, aggressive', though she believed that 'being hypervigilant' was what was keeping her son 'safe' in the context of inadequate health and social care services. She described 'services and state systems' as using 'psychological tools on purpose' to harm her, saying: 'They use systems that are in place to actively ignore you, to gaslight you into making you feel that what you are asking for is impossible. This needs to be said.' Labelling mothers as 'unstable' and 'unreasonable' has been documented elsewhere as a technique of control in service systems that are designed to make sure that family carers, and women in particular, know their place and comply with practitioners' judgements and

expectations (Ryan, 2021; Douglas et al, 2021; Runswick-Cole et al, forthcoming). The ways in which mental health labels could be taken up deterred family carers from seeking support for their mental health, as they worried that being seen 'as unable to cope' would trigger safeguarding concerns.

Tamsin describes the way in which the temporalities of care operate in her life, as anxiety about the future impacts on present well-being: 'Mental health challenges can be around the future, not about the here and now, but what *might* happen. Things might be ok in the now, but there is still the overwhelming anxiety about the future.' What mattered to Bea was that:

> Support for planning for the future is not there. A lack of decision making is causing me stress. There is never time to think about it and talk it through. I would like someone to sit down with me, [my son] and his sister – no one in social services could.

The future also mattered to Matthew, who said: 'The reason we're sitting here today is in the best interests of our loved ones. What will happen to my son, daughter when I die, to my grandchildren when I die? Many people don't have to face that question. We do. It's a constant fear.'

Family carers' experiences reveal the dangers of attempts to impose assumptions of a hyper-normative unilinear life course on family carers' lives, which result in discrimination in mental health services and a lack of support for future planning (Smith, 2021). Policymakers and service providers need to pay attention to matters of trauma and the ways in which past and future harms construct the present rather than attempting to deny these entanglements using techniques of control to disregard family carers' experiences.

Paperwork matters

Discussions with family carers returned again and again to the matter of paperwork, that is, its materiality and its meaning in their lives (Barad, 2007). Family carers described the mountains of paperwork records that took up physical space in their homes. The stuff of paperwork was described as 'toxic' and as 'a fire hazard', with 'a forced longevity' for fear that they might need the documentation again one day to 'prove' something about the person they care for or about themselves as a family carer. Many carers felt that they could not throw it away, as it could be key to accessing future services and support. While Caitlin threw away all the paperwork when her daughter turned 18, other parents felt they needed to keep it: 'You can't throw anything away; you never know when you'll need it again' (Florence).

Paperwork matters through physical and emotional spaces, (re)producing both labour and fear: 'The fear and worry of not doing something right – not documenting properly, not keeping records properly, not sure how to use direct payments. You're never told really what to do and fear you will be punished, alongside the person you care for, if you do [the paperwork] wrong' (Florence). Turning away from 'the realities of suffering, dependence and vulnerability' means that the matter of paperwork in carers' lives is marginalised or ignored (Rizq, 2012: 9).

Co-production and community matters: from survey to exhibition

We recognise that co-production has not always mattered in academic research or service design (Rose and Kalathil, 2019). The pressures of delivering projects on time and on budget often come to matter more than promises of co-production in the context of funded research. However, resisting these pressures and staying with the principles of co-production opened up different ways of knowing what mattered to family carers.

Family carers told us of the material affects/effects of the piles of paperwork that clutter their homes and their thinking. For them, the idea that more paperwork, in the form of a survey method, could be used to capture their experiences of mental health and care was roundly rejected as 'death by survey'.

A survey was seen as an ineffective way of learning about what mattered in family carers' lives. Caitlin told us: 'You can't put 25 years of experience into tick boxes. You just can't. That has to come in a different format.' What mattered to family carers was that in the process of seeking their views, we should 'not re-traumatise' family carers through more paperwork (Florence), which challenges the proliferation of the use of surveys by mental health services, the third sector and charities and in research (Rizq, 2012).

With the idea of a survey firmly rejected, an alternative emerged through discussion: we should create a space 'for experiences conveyed in any way carers want – pictures, photos, anything really' (Florence). An ethic of care, which values context, emotion and experience (Hamington, 2018), mattered to family carers as they discussed the creation of an online exhibition. Deanna suggested: '[Contributing to the survey] couldn't be done all at once; it would need to be doable over time. I don't feel the same all the time. Can we capture the ups and downs? We have to think about the future, not just the past.'

Family carers were acutely aware of the risks involved in asking people to participate in an online exhibition. Florence stressed, 'We need a safety net around people – ask people, think: "Do you want to do this on your own or with a friend? What will you do afterwards to keep yourself safe?"', while Caitlin wanted 'a cooling off period to let people know that until you press "submit", it isn't going anywhere'. Florence was conscious of the risks of digital exclusion and suggested the option to send things in by post.

What mattered to family carers was that the exhibition could create a space to feel that 'I belong and that other people get it' (Caitlin), a space to share experiences and ideas and to create a sense of belonging. However, at the same time, they wanted to make their lives and experiences matter to other people so that they could send a message to the 'social workers, support workers and bus drivers' because 'everyone has responsibility for supporting one another's mental health'. This was echoed by Emma, one of the self-advocates in our Tea and Cake Group, who told us about the caring she does for her housemates and her feelings of responsibility to support the paid carers who work with them all.

As we continue to develop the online platform, we are ensuring that we are responding to carers' ideas. The information about the survey will be shared via social media and will be made available in English, Welsh, Polish, Romanian, Punjabi and Urdu. Participants will be able to contribute to the exhibition via the online platform Qualtrics or by email or post. Family carers will be asked to read an online

information sheet and fill in a consent form. Crucially, family carers will also be able to decide whether they wish each item they deposit to be private to the research team or whether they are happy for it to be shared via the online exhibition. Family carers will have multiple opportunities to add items for up to 12 months. If people contribute items to be shared publicly and then change their minds, they will be able to ask for their contributions to be removed from the project website at any point until the end of the exhibition. We are also grateful to the Manchester Metropolitan University Ethics Committee for its support in helping us to think through the ethical principles and practicalities of this work and for their ethical approval.

We expect that contributions will include audio recordings, video recordings, images, artwork, texts and music. Data analysis will be carried out by the research team with the Tea and Cake Group. Data will be analysed using rhetorical analysis (Leach, 2000) to interrogate the meaning of the text, images and sounds. We continue to work with family carers to develop the online exhibition, updates will be posted on the project website (see: https://sites.google.com/sheffield.ac.uk/tiredofspinningplates/home) and the project's X account, which can be found via the handle @SpinPlatesCare.

Conclusion

Mental health matters in the lives of family carers. Whether or not family carers identify as experiencing mental distress, and regardless of what they understand about the nature and origins of mental distress, their lives are often understood by others through the lens of the biomedical model of mental health and the language of 'burden' and 'burnout' (Marks et al, 2002). Worse still, they feel that mental health labels are used against them to destabilise them and negate their views (Runswick-Cole et al, 2024). Family carers reflected on a multiplicity of perspectives on mental health, sitting with them and taking time to think about the perspectives others had shared. Those who seek to offer support to family carers need to understand these diverse perspectives and recognise that family carers are each unique in their experiences and understandings. Would-be allies (including researchers) must resist the temptation to impose their own assumptions and understandings of 'mental health' and 'care' on family carers' lives.

Trauma matters in the lives of family carers. A systemic failure to attend to the ways in which past and future harms construct the present results in repeated trauma for family carers and contributes to discrimination in service models that fail to recognise past, present and future harms (Smith, 2021). Services and service providers need to pay attention to matters of trauma across time rather than denying family carers' views by using techniques of control to disregard experiences of the past and present and fears for the future. Family carers need timely support to lessen past and present traumas and to prevent worries about the future.

Paperwork matters as stuff that takes up physical and emotional space in family carers' lives. Family carers explained that the everyday stuff of life matters to them, impacting on experience and engendering fear and labour, which is enduring and inescapable. Stories of stuff, objects, spaces and things matter (Brown et al, 2020: 226). Their impacts should not be ignored or diminished in service systems.

Co-production matters in the lives of family carers. Co-production opens up different ways of understanding. Ideas matter, and so does experience (Hamington, 2018). Co-production opened up the potential for a space for belonging and for

sharing experiences that can educate and enlighten others. Crucially, co-production makes it possible for an ethic of care, which centres family carers' knowledge and expertise, to matter and reduces the risk of (unintended) harms, both in research and in practice, as well as in family carers' lives. We are aware of the argument that carers' knowledge is situated and relational (Popay and Williams, 1996; Haraway, 2016) and 'that it should be identified as a particular *epistème* (form of knowledge)' distinct from professional knowledge (Malm et al, 2023). We argue that all knowledge is situated and relational, and we struggle to imagine how or why we might begin to construct family carers' knowledge as a different, and implicitly lesser, 'form' of knowledge than academic and professional knowledge. The process has been challenging, insightful and generative, and so we conclude with the hope that 'This [exhibition] could be a really good way of supporting people's mental health because we're not very good at talking about the difficult things or the things that could help support our well-being or mental health. [These] could be some really poignant ways of supporting people's mental health' (Amir).

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