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Participatory research in a pandemic: The impact of Covid-19 on co-designing research with autistic people

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Abstract

Social work research should adopt a critical approach to research methodology, opposing oppression that is reproduced through epistemological assumptions or research methods and processes. However, traditional approaches to autism research have often problematised and pathologized autistic¹ individuals, reinforcing autistic people's positions as passive subjects. This has resulted in autistic people being largely excluded from the production of knowledge about autism, and about the needs of autistic people. Participatory approaches promote collaborative approaches to enquiry and posit autistic people as active co-constructors of knowledge, a stance that is congruent with social work values of social justice and liberation. However, Covid-19 is not only altering our everyday life but also upending social research. This paper discusses the challenges faced by a participatory study involving autistic people during the Covid-19 pandemic. This paper examines how Covid-19 increased the individual vulnerability of autistic participants and changed their research priorities, increased the researcher's decision-making power, and placed greater emphasis on barriers created by inaccessible methods. Covid-19 did not present novel challenges, but rather exacerbated existing tensions and inevitable challenges that are inherent in adopting an approach that aims to oppose oppression.

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Keywords

Participatory research, autistic people, practical and ethical issues, Covid-19, anti-oppressive research

Introduction

Covid-19 is significantly affecting the way social research is conducted. Many empirical research projects have been suspended or have been redesigned to consider social distancing measures. Covid-19 is leading social researchers to utilise remote modes of data collection to conduct research safely. Participatory approaches, which aim to include the people who are being studied as active partners in the construction of knowledge, are difficult to redesign because it is not only data collection that needs to be considered but all aspects of the research process. Involvement in all aspects of the research process, including research design, has been recognised as empowering for marginalised people who would otherwise be positioned as only passive subjects of research. Autistic people have called for a more participatory approach to autism research (see Chown et al., 2017; Crane et al., 2021; Fletcher-Watson et al., 2019; Stahmer et al., 2017) that aims to fully reflect autistic people's research priorities, including research into services for autistic people (Pellicano et al., 2014). Nevertheless, few studies relating to services for autistic people have adopted a participatory approach (Bradshaw et al., 2020), leading to the provision of services that are constructed on assumptions by non-autistic researchers and professionals about the needs of autistic people. This study aimed to explore services and support for autistic parents using participatory visual methods. Traditionally, participatory research is conducted face-to-face, where researchers and participants follow a process of defining research questions, collecting data, analysing and co-editing materials, and deciding on dissemination strategies together (Kindon et al., 2007). However, responses to Covid-19 included national travel restrictions and constraints on physical contact, making face-to-face research almost impossible. In light of Covid-19, the university implemented severe restrictions on any research involving face-to-face interaction with participants. Continuing with the planned study meant it was necessary to re-design the research project to include collecting and analysing data using remote technology, changing the original plan that had been co-designed with autistic participants and relied on face-to-face contact. At the same time, strict 'lockdown' measures had interrupted daily life for the autistic participants, impacting on access to support and necessities. Under this context, the study faced unexpected ethical and practical dilemmas relating to attempting to co-design the research with autistic participants. In this paper, we reflect on the challenges of adopting a participatory approach to autism research during Covid-19 pandemic.

Participatory approaches in social work research

Participatory approaches to research are grounded in the idea that people should be actively involved in the construction of knowledge through sharing power and decision-making in research processes (Cornwall and Jewkes, 1995). Participatory approaches position the knowledge derived from lived experience as valid, in opposition to the assumption in traditional research that the academic researcher is the ‘expert’. Participatory approaches assume that working collaboratively to combine academic experience and insight from experience will lead to the most valid knowledge. As pointed out by Beresford (2005), only service users have direct experience of using services.

Participatory research is particularly important for social work, due to its emphasis on systemic social change, the liberation of marginalised groups, and examination of systems of power and knowledge. Participatory approaches reflect the values of the ‘anti-oppressive’ approach that is so prominent in social work education and practice. Social work’s role in opposing oppression has been well-established. Dominelli (2002) refers to promoting social justice in an unequal world as the “raison d’être” of social work (p4). The principles are included in the global definition of social work:

“Social work is a practice-based profession and an academic discipline that promotes social change and development, social cohesion, and the empowerment and liberation of people. Principles of social justice, human rights, collective responsibility and respect for diversities are central to social work...” (International Federation of Social Workers (IFSW, 2014)

This definition emphasises the theoretical underpinnings of social work, and the importance of engaging with structural sources of oppression to achieve social change (Ornellas et al. 2018). Strier (2007) points to the emphasis on ‘anti-oppression’ in social work education and practice, but notes its absence in social work research. Strier argues that uncritically adopting traditional research approaches without considering how these might reproduce oppression is inconsistent with the ‘mission’ of the social work profession to oppose oppression. Strier argues that participatory approaches are more consistent with an anti-oppressive approach to social work research (Stier, 2007).

Participatory autism research

Qualitative autism research traditionally focuses on the views of non-autistic parents, carers or professionals, rather than the views of autistic people (Lam et al., 2020), because assumptions about autism as an individual deficit have constructed autistic people as unable to meaningfully participate in autism discourse (Milton and Bracher, 2013). Services for autistic people are therefore constructed predominantly on the assumptions of non-autistic professionals, policy makers and researchers about what autistic people need, rather than on autistic people’s self-articulated needs. Traditional qualitative research often relies on verbal

interaction between a researcher and research subject, with the aim of gaining insight into the unique perspectives of individuals. Traditional methods therefore often rely on writing, speech, and interacting with a non-autistic researcher, problematising individuals who cannot easily engage with these methods, rather than understanding the methods as discriminatory (Aldridge, 2007). The dominant deficit-focused discourse posits autistic participants as vulnerable, hard-to-reach, or lacking insight into autism. Donna Williams, an autistic self-advocate, once remarked,

‘right from the start, from the very time someone came up with the word “autism”, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced’ (1996: 14)

Most autism research is led by non-autistic researchers, focusing on the views of non-autistic professionals or carers, and this knowledge is considered valid even when in opposition to the views of autistic people (Lam et al., 2020), reinforcing autistic people’s position as passive subjects who rely on non-autistic professionals and carers to express their views, and non-autistic researchers to interpret these views. This is epistemologically problematic in that the dominant discourses about autism are reproduced by non-autistic people who commence research with the a priori assumption that autism is a deficit (Milton and Bracher, 2013). This process reinforces the ‘taken-for-grantedness’ of a ‘medical model’ understanding of autism, disguising processes of ‘medicalisation’ (Oliver, 1990) and ‘othering’ (Dominelli, 2002); processes which actively construct autistic behaviour as pathological and inferior. This process of pathologizing problematises autistic individuals and therefore legitimises the exercising of power over autistic people by professionals such as social workers. This oppression can be reinforced and reproduced through research processes that exclude autistic people through discriminatory methods, and then rely on taken-for-granted assumptions of individual deficit to explain this exclusion. Using more inclusive methods might remove some barriers to research participation for some autistic people, but only changing methods while leaving epistemological assumptions intact is unlikely to address oppression that arises from a pathology paradigm.

Inclusion in all aspects of the research process allows autistic people to articulate their own needs and provides opportunities to challenge oppressive discourses and taken-for-granted assumptions. Autistic people have expressed that participatory research about services is needed (Pellicano et al., 2014). However, research about social care services for autistic people rarely adopts a participatory approach (Bradshaw et al., 2020).

Designing the study

Autistic people have expressed that research should focus on service provision as a priority (Pellicano et al., 2014), and this study aimed to explore services for autistic parents. We aimed to take a participatory approach to the study through inviting autistic people as consultants (hereafter ‘participants’) to become involved from

the earliest practical stage of research design, and through using methods that would promote autistic-led dialogue, facilitated by an autistic researcher. We planned to do this face-to-face, following discussions about research design with autistic participants. However, strict measures to contain Covid-19 were implemented, including national or local lockdowns and constraints on physical proximal contact, making it difficult to conduct face-to-face participatory research. Although there are examples of participatory autism research being conducted online (Nicolaidis et al., 2011), moving this study online was likely to mean over-riding decisions already made by autistic participants to conduct the study face-to-face, and would create further barriers to participation for some autistic people.

Changing priorities of the autistic participants

Autistic people need different forms and levels of support at different points in their lives. Research shows that an increase in environmental stressors and/or barriers to accessing support often results in a loss of functional skills and a greater need for support (Raymaker et al., 2020). The pandemic and its subsequent restrictive measures have disrupted daily routines, causing even greater disruption for autistic people (Moran et al., 2020) and the National Autistic Society in the UK reports that autistic people are experiencing increased psychological distress, discrimination, and barriers to accessing services (National Autistic Society, 2020). When the restrictions were implemented, participants requested that research skills were utilised to research which local services could help address immediate needs for food, medicine, and emotional support. In some ways, this reflects the emancipatory research ideal, in which a community successfully takes ownership of activities and utilises the skills of the researcher as they see fit. In reality, this shift placed the researcher into a role of ‘helper’, rather than co-researcher. Far from feeling ‘emancipatory’, this change in participants’ positions emphasised increased vulnerability and power relations that had become more unequal. Cornwall and Jewkes (1995) also identified difficult circumstances as a barrier to participation in early discussions about participatory research. It is likely that the autistic participants experienced the situation in this way, because they expressed that they would like to continue the research, but an immediate need for accessing support and necessities simply took priority.

Considering ‘expertise’ in the context of ethics

The Covid-19 pandemic and associated restrictions created practical difficulties for the study, resulting in a need to consider whether the study should continue. Many face-to-face research activities became impossible under the UK government restrictions. There were considerations about the validity of the data and relevance of the study, including considering the importance of collecting contemporaneous data, and how retrospective data might differ if we decided to carry out the study at a later date. There were also practical considerations about being able to access

participants; the original recruitment strategy had emphasised recruiting people face-to-face, and through self-advocacy organisations that had changed operation due to Covid-19. The practical difficulties meant that a participatory approach, which generally requires substantial time and resources, might be less feasible during the Covid-19 pandemic. When adopting a participatory approach, a researcher makes an epistemological and moral commitment to involve people in the production of knowledge, believing that validity is achieved through actively challenging oppressive research practices that privilege dominant discourses: 'nothing about us without us'. After some reflection, we decided to honour this commitment. This was both a methodological and personal decision, most strongly advocated by the researcher who is also a member of the autistic community. However, maintaining a commitment to a participatory approach raised some ethical dilemmas. At the time the restrictions were implemented, we had already invested significant time into co-designing the study. We had also spent time getting to know each other, negotiating how to share decision-making processes and who would take ownership of the project. The changed circumstances of the Covid-19 restrictions meant that the researcher had a responsibility to consider the continued ethics of the project and, if significant risks are identified, the researcher had a responsibility to halt or change the study, possibly overriding decisions by participants to accept these risks, and possibly overriding previous decisions participants had previously made about research design or implementation.

With little precedent, it is difficult to predict the risk of harm for autistic people taking part in research during a pandemic. This situation appears to reflect a participatory opportunity for collaboration, one in which the researcher brings experience in relation to research ethics, and participants share autistic 'expertise' (Fletcher-Watson et al., 2019). However, this was difficult in practice. Participants said they wanted to continue the study, but that they were also unable to access necessities such as food and medicine, and practical and emotional support. They described the project as a welcome 'distraction', but from significant isolation and increasingly poor mental health. Research shows that autistic people are at increased risk of experiencing poor mental health (Hollocks et al., 2019), leading to an increased risk of suicidality (Cassidy et al., 2018). A study conducted by National Autistic Society (2020) showed that 9 out of 10 autistic people worried about their mental health during Covid-19 lockdown, and that autistic people were often cut off from services and support due to the pandemic (National Autistic Society, 2020). Lack of support is a risk marker for suicidality in autistic people (Cassidy et al., 2018).

While traditional ethical approaches to qualitative research often ascribe the researcher a role of 'protector' when working with so-called 'vulnerable' individual participants (Iacono, 2006), participatory approaches often posit the researcher as someone who can somehow support the self-emancipation of communities that are 'vulnerable' due to their disadvantaged social position by providing access to academic processes and discourses from which they are usually excluded. This created

a dilemma: the ‘researcher-as-protector’ of vulnerable individuals might decide it would be in the participants’ best interests to halt research participation, while the ‘researcher-as-emancipator’ might prioritise participants’ desire to continue with the project, either because of a belief that research inclusion leads to emancipation and this should be of paramount consideration, or because participants’ wishes and decisions should be respected, whatever these might be. To pause the project might undermine the autonomy of the participants, while continuing the project might expose autistic people to further vulnerability. While this has obvious ethical implications, there are also methodological implications because if participants do not truly share power in decision-making processes, it cannot be considered ‘participatory’ research. Despite best intentions, it was the researcher who made decisions about how to define ‘vulnerability’ in relation to autistic participants.

Accessibility and remote participation

It is important to consider accessibility when conducting participatory autism research (Cascio et al., 2020; Fletcher-Watson et al., 2019; Nicolaidis et al., 2019) with the social model of disability “at the heart of the project ethos” (Chown et al., 2017: 727), aiming to address barriers to participation. Working with autistic consultants, we adapted a version of photovoice (Wang and Burris, 1997) to use as a data collection method for this study. We had aimed to include autistic people with an intellectual disability in our study, and studies using visual methods such as photovoice have been recognised as accessible to people who, for example, do not use written or spoken words (Aldridge, 2007). The inclusion of nonspeaking autistic people and autistic people with an intellectual disability continues to be a challenge for participatory autism research (Elsabbagh et al., 2014; Fletcher-Watson et al., 2019), but flexibility in methods can facilitate inclusion of autistic people with varying accessibility needs (Crane et al., 2021; Nicolaidis et al., 2019). The ability and willingness to adopt a plurality of methods to reduce barriers to participation is an important element of conducting research with the aim of addressing the oppression of disabled people (Stone and Priestley, 1996). However, Covid-19 restrictions made it impossible to use these methods as intended. Universities encouraged academic researchers to change the mode of their research to remote and online research. It is difficult to replicate these methods using remote technology. While there are some suggestions that moving to online research during the pandemic might benefit some autistic people (Kapp, 2020 in Cassidy et al., 2020), other autistic people might face challenges such as technology access (Onaiwu, 2020 in Cassidy et al., 2020), managing sensory sensitivities, and following conversation (Zolyomi et al., 2019). Especially, people with an intellectual disability often face digital exclusion, and people living in institutional settings are less likely to take part in online research during the pandemic (Inclusion London, 2020). Moving online was not easily achieved for this project. Nicolaidis et al. (2019) warn against the tendency to

pathologise autistic participants when understanding barriers to collaboration. It is our experience that barriers resulted primarily from inequality in technology, and not from autistic individuals. For example, one participant in this study uses a 'pay-as-you-go' mobile internet data contract, meaning there is an unreasonable cost implication. Another participant in this study often loses speech and written communication, and so cannot reliably communicate using the technology currently available to the researcher. Moving online might mean that some autistic people find research participation more accessible, but it might also mean that other autistic people find it less so.

A difference in emphasis

This study adopted a participatory approach with the aim of including autistic people as equal partners, considering the knowledge of autistic people as valid, and addressing barriers to participation through ensuring accessibility in methods and discussions. The original, and co-designed, research planned to use an adapted version of photovoice as its methodology, but most autistic people who took part chose to do so by means of a more 'traditional' interview, often because this was a more familiar method that did not require extensive time commitments or the ability to access complicated technology to undertake any training in the methodology or methods. However, such decisions about methods were made through discussions with autistic participants. The crisis meant that the priorities of autistic participants changed as access to necessities became more important than abstract discussions relating to structural oppression. The crisis also increased the researcher's responsibility to safeguard so-labelled 'vulnerable' participants, making shared decision-making difficult in relation to participant safety and continuation of the study. Restrictions on physical proximity and the inability to use face-to-face methods created further barriers to participation for some participants, after considerable time had been dedicated to addressing such barriers prior to the initiation of the Covid-19 restrictions. Although the Covid-19 pandemic is a novel situation, those issues are not new. A focus on the unequal distribution of power and the barriers to active participation, in pursuit of social justice, is at the heart of participatory and anti-oppressive approaches. Researchers cannot 'emancipate' people, and so adopting particular methods will not achieve this, and there is no way to predict emancipation as a result when beginning the research process (Oliver, 1997). Social work researchers can only adopt a commitment to an awareness of the potential for research and its processes to reproduce oppression (Strier, 2007), and work to promote social justice. The challenges arising from Covid-19 meant that this study "regardless of the benevolent and progressive nature of its goals and intentions, may [have replicated] the structural conditions that generate oppression" (Strier, 2007: 859), despite committing to a participatory approach. However, until oppression is addressed in wider society, there will always be the risk that research will reproduce and reinforce this oppression (Zarb, 1992), and researchers will inevitably face challenges when committing

to a participatory approach. Struggle is an inevitable part of challenging oppressive structures and processes and should be considered characteristic of participatory approaches.

Conclusion

This paper explored some of the practical and ethical challenges of conducting participatory research with autistic participants during the Covid-19 pandemic. The unique context of Covid-19 created unique difficulties, leading to a need to re-examine and redesign a participatory study that had been co-designed to be carried out face-to-face. Changing the mode of research and moving online had implications for the overall participatory ethos. While Covid-19 is novel, the increased vulnerability of the participants, decreased power in decision-making, and issues relating to accessibility, are characteristic of oppression, disadvantage, and exclusion. Participatory research with marginalised people is about addressing the reproduction of oppression through research processes, and so it is crucial that researchers view such practical and ethical challenges as an intrinsic part of adopting a participatory ethos. In this study, addressing these challenges provided an opportunity to gain important new insights into participatory research with autistic people. This study provides a greater understanding of how the collaborative nature of participatory approaches can be maintained under unprecedented circumstances.

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Note

1. This paper uses 'identity-first' language (i.e. "autistic person") rather than person-first language (i.e. "person with autism"). Research (Kenny et al., 2016) shows that identity-first language is often preferred by autistic people.

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