Research Relationships and Responsibilities: 'Doing' research with 'vulnerable' participants: Introduction to the Special Edition

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Introduction

For some decades now, human geography has sought to engage with the narratives of those whose voices have been absent from research accounts and policy discourse. This interest in the experiences of those who have been side-lined from social, cultural, economic and political agendas has been part of move towards an increasingly inclusive approach to the social sciences and a means of using the academy as a tool for social justice. This approach is illustrated through geography texts since the 1990s, a new wave of 'critical geography' encompassing the burgeoning sub-disciplines of social and cultural geography. With roots in both a Marxist and a Feminist approach (Gibson-Graham, 1996; Massey, 1994; McDowell, 1999, Valentine, 2001), geographical engagement with the lived experiences of socio-culturally, politically and economically marginalised groups of people, is no longer a new endeavour. What is new, however, is the rapidity in the growth of interest of researchers seeking to engage with these populations, and the variety of the toolkit of methods, for research and analysis, available to support this engagement. Whilst this special edition seeks to draw out and explore a range of novel approaches to research methods and practice, the particularly unique contribution presented by this publication is a candid exploration of the ethical challenges of engaging with populations identified as 'vulnerable' as expressed through the discussion of first-hand fieldwork experience.

The increased interest in research with people considered to be vulnerable mirrors a recent rapid development in interest and practice in social and cultural geography, and associated sub-disciplines such as children's geographies, the geography of education and geographies of disability (van Blerk and Kesby 2009). What is clear from this body of work is that vulnerability is socially-constructed and dependent on the way in which power relations are created between marginalised people, be they children, elderly, sick, disabled, or otherwise marginalised, and non-marginalised adults at a structural level across society (Pells, 2012; Tisdall and Punch, 2012). This special issue seeks to demonstrate the relational nature of vulnerability (see particularly Baillie Smith and Jenkins; and Eggleton, Kearns and Neuwelt, this issue).A relational approach demonstrates that vulnerability is context-dependent, with groups being more or less vulnerable to exploitation (in the widest sense of the word) based on the particular circumstances of an encounter. Therefore, research methodologies that are power-laden and unequal in their presentation and outcomes will position marginalised people as 'vulnerable'. At the heart of the methodological and ethical challenges to researching with groups who may be positioned to some degree as vulnerable, is the need to transform research from a 'top-down' researcher-led encounter to a 'bottom-up' participant-led encounter (Aldridge, 2014).

 Qualitative approaches have been favoured for reflecting on the potentially unethical practices of some methods that may objectify marginalised groups, and geographers have increasingly sought to find new ways to engage in research relationships on a more equal footing (Williams et al., 2016; Parr and Stevenson, 2014; Hall and McGarrol, 2013; Moran, 2013). Participation has been increasingly valued as part of a qualitative approach where participant empowerment is viewed by researchers as a necessary, and beneficial, part of the research process (e.g. Kindon, 2003; Cahill, 2007; Askins and Pain, 2011). There is now a large literature that has employed qualitative and participatory research to highlight the experiences of diverse groups including those who may be considered vulnerable in a research encounter due to their age, status, education, disabilities and other factors, (Kesby et al., 2005; Pain, 2004; Pain and Francis, 2003). Within this literature research that involves participants as decision

makers, and even researchers themselves, is widely understood to be the gold standard. Rigorous discussion and detailed explanation addresses all stages of conducting participatory research with marginalised people, from recruitment to research methods to analysis and dissemination.

Whilst there is no doubt that there exists a wealth of published discussion on the topic, this has not translated into straightforward practice in research with vulnerable groups throughout the academy. Despite a generalised willingness to do research alongside, rather than 'to', populations who have suffered discrimination or whose voices are less –well represented, human geographers are consistently faced with challenges to this endeavour. These challenges are explored in detail, in a variety of forms, within the papers contained in this special edition. Distinct from other special issues dealing with marginalised or vulnerable groups and research methodology, the papers here address a wide variety of different groups, in geographically diverse locations. However, the methodological and ethical challenges are unifying. These papers starkly indicate that the perception of inherent vulnerability, on the part of the people and the institutions that care for or contain them, the research institutions and the researchers themselves, puts strain on the research relationship, forcing researchers to compromise principles of 'bottom-up' working in order to work within limits imposed by institutions. Focused on a wide variety of international locations and contexts, this collection of papers shares an over-arching narrative: that research with people who experience vulnerability, or are perceived to be vulnerable, is complicated by issues concerning researcher-participant relations, and the responsibilities of the researcher, which are less fraught, and less contested, when researching our socio-economic peers.

This special edition acknowledges that conducting research with people who are considered vulnerable involves a more complex network of actors than is often the case in other research situations. Specifically, researchers intending to involve 'vulnerable' people as participants will need to engage with processes that may not allow for the specific tailored needs of the group being researched. For example, university ethics committees, who have power to permit or prevent research, are likely to put particular requirements on research practices (Dyer and Demeritt, 2009; Baillie Smith and Jenkins, this issue). Sometimes their procedures can be restrictive of the development of new ways of researching ethically with groups who do not fit the traditional model of research participants, or new ways of viewing participants as more than research subjects (Blake, 2007). Once permission is gained, most researchers will be confronted with other gatekeepers, usually in the form of host institutions, who may also put parameters on the practice of the research in order to ensure the protection of participants. Finally, researchers may be able to access the participants themselves, who may or may not be in a position to offer their own informed consent.

Through exploring the complexity of the research process we highlight how procedural issues of access and ethics in research with groups perceived to be vulnerable, elucidates further vulnerabilities. These vulnerability may, in turn interrupt or distort the way research is able to be carried out. Below we draw out three key foci that repeatedly emerge in this special issue and warrant further reflection from researchers: participant vulnerability; institutional vulnerability and researcher vulnerability. We discuss each of these in turn before exploring how the papers in this special issue bring these areas together in a call for more critical engagement in the research process and ethics. This critical engagement must be one that considers carefully the research relationships and responsibilities of all agential parties in the research process. As notions of vulnerability translate into risk, the perception of research with vulnerable people as a risky endeavour can signifcicantly impact research.

Exploring 'vulnerability' in social and cultural geography research

Participant vulnerability

By-in-large minority, marginalised, and excluded populations are considered in social, political and economic terms as vulnerable. The notion of vulnerability reflects a socially-constructed perception, and sometimes a reality, of a

lack of social, political and economic capital held by such groups when compared to the societal norm. The groups explored in this volume: prisoners (Mitchelson), refugees and asylum seekers (Maillet, Mountz and Williams), indigenous peoples (Eggleton, Kearns and Neuwalt) disabled children (von Benzon) , the homeless (Lancione),and drug addicts (Williams), share a common experience, where the societies in which they live perceive them to have reduced social and economic capital, which is seen to impede their capacity to act independently. Baillie Smith and Jenkins' participant group, of NGO activists in South India, presents an interesting contrast. In this case, the participant activists are not typically considered vulnerable people in their community context, but are relationally vulnerable in the convext of government and intergovernmental development discourse and planning and their labour relations within this framework. Indeed, Baillie Smith and Jenkins' acknowledge that their participants included those who were wealthy and 'less vulnerable' by South Indian standards, but highly vulnerable when their labour situation was compared to that of a UK employee in a similar organization. This underlines a key theme of this Special Issue, that vulnerability is not only material, but also relational.

Research already carried out with marginalised participant groups demonstrates that despite economic hardships or reduced social networks, new ways of developing social and economic capital emerge. For example, in discussing prisoners' experiences Moran (2013) highlights how the prison visiting room becomes a space where social networks from the outside can be re-engaged. Similarly, Johnsen et al (2008) discuss how auto-photography with homeless people facilitated an understanding of their everyday lives as similar to societal norms, in terms of activities carried out and social networks engaged with, albeit in different settings. Yet, the perceived lack of independence renders marginalised groups as reliant on others; whether they be carers, family members, adults, social workers, volunteers, health professionals or guards. This reliance on others, despite being a form of social capital in itself, creates the perception of vulnerability, and indeed materially generates socio-economic frailty, as individuals do not have control over their own assets, independent social networks, or relevant training and skills. This results in an institutional or policy perception of decreased social capital, and therefore decreased power, on the part of the 'vulnerable' adult or child.

This can be seen in everyday contexts in the UK, for example, through legislation such as that preventing children engaging in activities perceived as 'dangerous' that are permissible to adults, such as drinking or smoking, or the ability of medical professionals to incarcerate the mentally ill, or the 'rules' imposed on hospital wards that don't apply outside (see for example, Williams, this issue). This paternalism is well discussed and debated within disability studies, and to a lesser extent, geography of disability, where it is argued to be an unreasonable justification for the oppression of disabled people, and limitations to their rights. The argument is made eloquently in Wolpert's seminal paper 'The Dignity of Risk' where he argues that a paternalistic approach to disabled people, that prioritizes safeguarding over the rights of individuals to independent decision making, is a limitation to personal freedom (Wolpert, 1980, see also work such as Tregaskis, 2004).

 The same paternalistic desire to protect vulnerable people often extends to institutional policies that inhibit interaction between vulnerable clients and researchers (Carter, 2009). Mitchelson (this volume) discusses the way in which historic abuses of prisoners through bio-medical and psychological experimentation have led to a widespread culture of institutional resistance to research participation from prisons. Mitchelson suggests that little distinction is made between the motivations of psycho-medical research and social science research, with institutions often on the offensive, presuming participants will be reduced to objectified subjects in academic discourse. von Benzon (this volume) in her research with learning disabled children, discusses similar frustrations illustrated through an exceedingly low response rate from families and from schools, apparently reticent to engage with any research process, prior even to having any knowledge of what the research might entail. Where institutions or individuals prevent researchers from accessing marginalised people, as a means of protecting the marginalised from harm, they prevent those in their care from contributing to a research agenda. In turn, this silences the voices of those who lack the independence to engage without 'permission' from gatekeepers. This lack of engagement limits the capacity of

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marginalised people to have either a direct or indirect influence on academic, and subsequently socio-political, understanding of their lived experience (Kramer-Roy, 2015).

This approach is completely at odds with a 'right-based' approach, or the concern of much of a new, critical approach in geography and the broader social sciences (see for example, the new sociology of childhood), that provides an argument for the necessity for marginalised people to be supported in decision making about their own lives, rather than to have decisions made for them by others (Cope, 2008). Indeed, ideas such as 'Gillick Competence', applied in medicine, might provide a useful blueprint for determining whether people perceived as vulnerable should be given the opportunity to participate, and provide their own informed consent, in research projects. The concept of Gillick Competence, relates to the ability of children to consent to medical treatment independently of their parents once a child is able to show sufficient understanding and intelligence on the matter. This approach prioritises a relational understanding of intellectual maturity over an essentialist definition of age. Assessing individual capacity as a criteria for participation could be applied to many research contexts in which access to marginalised populations is frustrated by the actions of gatekeepers, due to the label of vulnerability placed on a potential participant, rather than any demonstrable inability (see for e.g. Parsons et al., 2015).

Institutional vulnerability

Alongside a perception of marginalised people as 'vulnerable', care institutions are increasingly aware of their own vulnerability. We arguably live in a panoptic society, where the actions of protective and caring services, be they state owned, private companies, or within families, can be constantly monitored (Wrenall, 2010) . Even private and domestic spaces are subject to surveillance through requirements to document, and the potential for whistle blowing. Such perpetual, or at least, potential, monitoring and interference, often leads those with a duty of care to marginalised people to be wary of increasing the number of 'visitors' and inviting potential whistle blowers inside. In turn, ethical challenges can be faced by researchers who do grapple with concerns of wrongdoing occurring within institutions in which they are working for fear of speaking up and undermining a research relationship and subsequently limiting the ability of individuals to participate (Maillet, Mountz and Williams, this issue; Williams, this issue).

Meanwhile Western society grows increasingly litigious, with service providers held accountable for wrongdoing (Cooper, 2005). In an increasingly risk averse society, institutions and families alike are bound to foreground a need to reduce the potential of harm to their charges, prioritising this over potential benefits of engagement in research. Gill (2007) particularly attributes restrictions on children's free play to a wide-spread social risk aversion. Whilst host institutions, acting as gate keepers to marginalised people, may be the most obviously vulnerable institution in the research relationship, universities, as the institutions responsible for both the actions and the welfare of researchers, may also consider themselves vulnerable and act to minimize risk to themselves (Parsons, 2005). Within this research relationship research institutions are at risk of litigation both from participants, or participating host institutions, and from the researchers themselves. Whilst participant vulnerability might manifest as an inability to act, perceived potential institutional vulnerability, underpinned by significant agency, will result in action to mitigate risk to both the potential research population, and perceived potential researcher vulnerability (Haggerty, 2004). A clear example of this in the Special Issue is Baillie Smith and Jenkins discussion of the use of consent forms in their research. These forms were insisted upon by the researchers' institution as a way of proving informed consent, but were protested against by participants who were reticent to sign a form that might be used to identify them.

Researcher vulnerability

A further vulnerability exists in the way in which researchers themselves are viewed as being at risk of harm from participants. Researchers may be viewed as particularly vulnerable when working with marginalised people due to a perceived increased risk of erratic or irrational behaviour on the part of the participant or indeed, more often, that they will be exposed to emotional encounters that are upsetting and difficult to deal with. As Anderson and Smith

(2001) highlight, emotions were, for a long time, ignored in the research process and only in the last decade or so have Geographers sought to explore this in more detail with Punch (2012:86) noting that 'guilt, apprehension, fears and worries are legitimate, common and even useful experiences of fieldwork'. Bondi (2013) highlights the emotional benefits that can arise from engaging in research, not least for those who stories are more often ignored or hidden but often researchers are less well equipped to deal with difficult and traumatic experiences rasied through research (see for example, Mitchelson, this issue). For example, Briggs (2013) raises the emotional consequences of leaving the field when conducting visual ethnography with street drug users in London, emotions that are reflected in Williams' account (this issue).

Further vulnerability may also be due to the fact that the participants are viewed as vulnerable, and unable to protect themselves, and therefore an 'easy target'. As such, a researcher could easily be perceived to have 'overstepped a mark' or acted inappropriately when behaving in a manner that would not have been labelled as such had the other person been considered a socio-economic peer, or superior. This is particularly a concern of ethics committees that seek to protect members of staff from harm through limiting their interaction with populations viewed as potentially harmful. This experience is discussed candidly in von Benzon's paper (this issue), in which the author discusses the university ethics committee's requirement that two adults be present on research trips involving learning disabled child participants. Von Benzon reflects that this requirement on one hand, potentially provided another adult 'witness' when an incident did occur. On the other hand, she suggests, this incident might not have occurred, had the established, positive, one-to-one research relationship built up in the participant's home, been allowed to continue on the research visit.

This highlights the competing demands and expectations (Williams, this issue) that researchers are grappling with when in the field, which can further increase their emotional vulnerability, as they seek to develop relational research encounters with participants at the same time as they adhere to the institutional (university and host) requirements placed on them. As such, the researcher will enter the field with divergent responsibilities, or as Williams (this issue) puts it, 'mixed loyalties'. By contrast, other researchers have embraced their own vulnerability in the field, drawing on the potential epistemological benefits of presenting their own vulnerability to participants and as such seeking to diminish relational vulnerability. For Eggleton, Kearns and Neuwalt (this issue), this is through a process of sharing the researcher's own drawing with the participants during the research process.

The final section of this paper seeks to explore some of the ways in which mixed loyalties may be competing through the lifecourse of research projects. It is hoped that by bringing these issues to the fore, the questions raised through the papers in the special edition may speak beyond the pages of this volume, as methods and ethics approaches are developed through research institutions and third sector organisations. Many of the papers in this special issue are highly personal accounts that candidly discuss the experiences of researchers in the field. At times these papers may be 'raw',drawing on the emotional encounters that researchers experienced and captured in their fieldwork diaries, which as Punch (2012) suggests are legitimate and revealing parts of the process. Voicing these struggles is something that is necessary for developing understanding, challenging current practice and shifting debates. This special issue intends to demonstrate the importance of honesty in methodological discussions, particularly regarding the specific challenges of doing research with people who are perceived as vulnerable (Horton, 2008). It is our hope, that through openness, and constructive self-criticism, not only will we as individual researchers learn from our mistakes, but others may be able to as well (Pyer, 2008).

Research relationships and responsibilities in fieldwork with vulnerable people

The papers in this special edition suggest that perceived participant vulnerability impacts on research projects from the earliest stages of conception and planning, through to the dissemination of research ideas (for example, Lancione, this issue). In particular these papers draw out the theme of research relationships, emphasising the complex mix of responsibilities navigated by geographers engaging with vulnerable people. In all of the papers in this special issue, authors engage with the notion of divided loyalties and competing responsibilities. Foremost in the

researchers' interests remains the need to engage not only empathetically, but also positively, in the lives of the research participants. However, each paper alludes to the difficulties of meeting what researchers see as an ethical imperative, a responsibility or an obligation, whilst maintaining a positive and professional working relationship with or within a gatekeeper (institution) and/or their own university.

A number of the marginalised people who participated in the studies detailed in the special edition have little or no independence, due to institutionalization (Williams, this issue; von Benzon, this issue) and incarceration (Maillet, Mountz and Williams,this issue) or heightened surveillance (Mitchelson, this issue). One key theme arising in the research is the issue of lack of privacy in research engagements when undertaking research with vulnerable people. This lack of privacy is largely a product of the institutionalization of vulnerable people and/or the need to access these populations through institutional gatekeepers. This is particularly stark in Maillet et al.'s paper (this issue) where they discuss multiple instances of being forced to undertake interviews with incarcerated refugees and asylum seekers in the presence of guards. In this situation the capacity of the participant to take part in the research process was significantly limited through direct prohibitions on discussion topics enforced by guards, and/or through fear of reprisals if contributions were interpreted as complaints. Von Benzon (this issue) similarly discusses the problem of outside interference in the research process, but in contrast finds this reduces the opportunities for participants to remove themselves from research interactions due to institutional pressure to conform to their alternate role as 'pupil'. Lack of privacy may also reflect a choice made by the researcher and the participants. In the case of Mitchelson (this issue) a cafe was used as a meeting place that might be considered safe space for both parties. However, the contrast in these research experiences suggests that it is not the possibility of being overheard that is risky to the production of research data per se, but rather the potential of interference from those in positions of power over the participant.

Lancione's paper (this issue) focuses on the broader duty of researchers engaging with vulnerable people to intervene in socially unjust situations through facilitating direct public engagement with the research outcomes. Lancione explains that for him, simply publishing his work in academic outlets wasn't sufficient. Society moves at a faster pace than academia, and Lancione's paper demonstrates the need to engage with non-traditional and non-academic means of dissemination, if research with marginalised people is to having any chance of having a positive impact on the lives of the vulnerable people who contributed. For Maillet, Mountz and Williams (this issue) one means of facilitating broad dissemination will be through the use of a publicly-accessible website, allowing access to research data and analysis to those outside academia. Disseminating research widely and effectively, for maximum impact as well as academic scholarship, is just one way in which researchers are able to attempt to ensure a positive outcome from research participation

Concluding remarks

This special edition seeks to bring together seven stories of doing geographical research alongside individuals, or groups, deemed 'vulnerable'. The papers explore the process of striving to be a responsible, or ethical, researcher, discussing candidly the challenges to this endeavour presented when the research participants are considered by others, and even themselves, to be vulnerable. Moreover we draw out the vulnerability experienced by the researcher, and perceived by the sponsoring universities, that is distinctive to working with marginalised social groups.

As academics we recognise the burgeoning sub-disciplines within which many of the social and cultural geographers who've published in this special edition work. We value the creative and supportive communities within our subdisciplines, and the space these academic foci offer for the development of expert knowledge and networks. Whilst many of us may work within broad teams of human geographers within our institutions, we are often drawn to these specific communities for inter-institutional discourse such as conferences and workshops. This special issue seeks to draw out the similarities of research experience with very different participant groups, due to their shared

identity as 'vulnerable'. As such, this special edition highlights the utility of broadening conversations beyond sub-disciplinary boundaries for knowledge sharing and potential discourse for change.

It is our hope that this special edition generates further reflection and honest discussion around the conflict that exists between the responsibility that institutions, whether academic or care-giving have to cause least harm, and the obligation felt by many social and cultural geographers to do more-than-least-harm. This is the recognition that 'doing' geography well may be a risky endeavour, and we need to do more as a discipline to convince our universities, and our potential host institutions that this is a risk worth taking. Where we take the easy way out and acquiesce to ethics committee requirements that we feel undermine our research aims, or allow gatekeepers to influence our method or practice, in fact we put much more at stake. In these circumstances we risk both our academic integrity, and finding a meaningful and ethical way of allowing marginalised people to 'do' geography alongside us.

Acknowledgements

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