Chapter 20. Research from a social justice perspective: concepts and practice

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Abstract

This chapter will set out the case for making social justice and related ethical and moral issues central to the research process. In order to do this, it will locate the research enterprise in the context of human rights and justice, with reference to the United Nations Declaration on Human Rights. Next, the philosophical concepts ontology and epistemology will be introduced and some of the ways in which these concepts can be used to further disadvantage marginalised and less-powerful groups will be presented. It will then describe how evidence generated by certain approaches is more valued than that obtained in other ways. The consequences of the resulting hierarchy of evidence will be discussed in relation to concepts such as epistemic injustice and epistemic violence. The chapter will then go on to explore how the manner in which questions are framed, methods are selected to address them and the resulting data analysed and interpreted can reflect and embody pre-existing values and biases. This will be followed by important considerations relating to global health research, particularly the ethics of informed consent and the intended beneficiaries of the research. In this context, epistemological imperialism and the lasting impact of colonialism will be discussed. Finally, the chapter will map out key areas and questions for researchers to engage with when designing and developing a research project.

Keywords: research, power, privilege, minoritized, marginalised, epistemic injustice, epistemic violence, discrimination, colonialism, global.

Introduction

Before exploring approaches to conducting research from a social justice perspective it is important that we address the reasons for thinking about research in this way.

Many people, including scientists and researchers as well as members of the public, view research as an enterprise that sits outside those social processes and practices that need to be thought about in relation to social justice. It is relatively easy to grasp that education, the law and politics, for example, are areas in which personal values, biases and frank prejudice might operate and in which issues of equality and justice are therefore relevant. Science and the conduct of research within the scientific frame of reference are typically positioned as being governed by and carried out within an approach informed by the enlightenment values of rationality and objectivity. Scientific practice is therefore positioned as being unclouded by the sorts of emotions, values, personal preferences and biases that may deform practice and outcomes in other areas of human activity.

The scientific enterprise has come under sustained attack from populists of different political hues in recent years and many well-intentioned defenders of science have responded by re-iterating the importance of recognising that there are such things as facts, truth and expertise. We respect the motivations of those mounting this defence, but in this chapter, we want to outline a more nuanced argument. We argue that the goals of any given programme of scientific research, the methods employed in that programme and the ways in which the resulting data are analysed and interpreted are all subject to values and taken-for-granted assumptions grounded in particular historical, cultural and intellectual frameworks that can marginalise and discriminate against particular individuals and groups.

Our focus here will primarily be on the social and behavioural sciences as they apply to mental health, though much of the content will be equally applicable to the biomedical sciences and physical health.

Justice and human rights

The Preamble to the United Nations Universal Declaration of Human Rights (UDHR; United Nations, 1948) positions rights and justice as inextricably linked. It states that "… *recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world*". More specifically, knowledge, information and the means of accessing and communicating them are explicitly included in the UDHR. Article 19 states that "*Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers*". Vadi (2008) has argued that "*access to knowledge is a fundamental human right and a key instrument to development*". In these statements an outline of the nature and importance of an approach to research that explicitly attends to and incorporates a social justice perspective begins to emerge. The Information Society Project at Yale Law School makes a direct link to the research enterprise, stating that knowledge is "*the right to participate in the creation, distribution, and acquisition of raw information, secondary analyses of data, and knowledge-embedded tools and services*".

John Rawls is one of the most influential thinkers in relation to the concept of justice, its nature and application. In "A Theory of Justice" (1971) and "Justice as Fairness: Political not metaphysical" (1985) Rawls set out important principles underpinning access to and sharing of social and material resources. An important principle in the work of Rawls is distributive justice, which is framed in terms of equality or equity of access in relation to opportunity and material resources. In A Theory of Justice (Revised) Rawls (1999) identified a category of primary goods that individuals are likely to prefer, defining them as "*rights, liberties, opportunities, income and wealth".*

In the social domain a great deal of attention has, understandably, been given to goods of the kind identified by Rawls. However, focusing solely on material resources can result in neglecting non-material contributions to justice; knowledge and information are also important. The concept of liberty is central to Rawls' work, but arguably liberty is impossible without knowledge and information. Freedom is dependent on knowledge of one's state, of the constraints operating on it and of ways of challenging and ameliorating those constraints. Foucault (1980) wrote of "subjugated knowledge" and Spivak (1998, 1988), together with the Subaltern Studies Group in India, elaborated this insight into a critique of the imperial agenda and the way in which elite power enabled the construction of a partisan narrative of history. Spivak also developed the concept of epistemic violence to refer to the way in which members of marginalised groups are silenced and their knowledge dismissed in favour of that possessed by more powerful, privileged groups. Fricker (2007) coined the term "epistemic injustice" to characterise the ways in which individuals can suffer injustice in their capacity as a "knower". Testimonial Injustice occurs when less credibility is granted to particular individuals or groups because of prejudiced attitudes towards them. Hermeneutic injustice occurs when people's experiences are not understood by themselves or others because the necessary conceptual tools are not available. Both types of injustice reflect the operation of power, in that some individuals and groups receive preferential credibility and also control access to the means of producing and disseminating knowledge. Historically, many categories of person, including women, racialised and sexual minorities, people living in poverty and socially marginalised and colonised peoples have not had such access.

Exercise 1: Think of examples of testimonial and hermeneutic injustice in research you are familiar with. Can you recall instances of epistemic injustice in your personal or working life?

Knowledge and information alone are insufficient to ensure justice and deliver on the promises of the UDHR if they are produced by elite groups and do not address, or indeed completely ignore, the issues and concerns of the less-privileged. Understanding and control of the means required to generate, curate and evaluate knowledge and information are, therefore, crucial to ensuring full human rights and justice.

The scientific approach, research and justice

As noted above, it is widely taken for granted that science is a value-free undertaking and that the application of suitable methodological approaches, such as randomised controlled trials (RCTs), in conjunction with appropriate analytic tools will produce knowledge uncontaminated by human hopes, values or expectations. Furthermore, this knowledge is generally assumed to apply universally. This approach implicitly positions issues of culture, history, society and power differentials between the researcher(s) and the researched as largely irrelevant. However, feminist scholars have long been critical of the idea that research can be a value-free enterprise and in June 2022 Nature published an editorial (Nobles, Womack, Wonkam & Wathuti, 2022) stating that "*Apartheid, colonization, forced labour, imperialism and slavery have left an indelible mark on science*".

An awareness that science is not a value-free enterprise, along with sensitivity to its unstated values and assumptions, enables us to think critically about the ways in which researchers parse the social world when identifying the "subjects" (in both senses of the word) of their research. For example, research in the social and biomedical sciences often proceeds on the basis of studies of binary categories. Examples include:

- sick/diseased *vs*. healthy individuals
- members of racial, ethnic and sexual minorities compared with normative concepts of whiteness, straightness etc.
- gender-based research that frequently incorporates assumptions of masculine norms

None of these are naturally-occurring categories and all reflect historically, culturally and ideologically determined ways of structuring the social world and the people in it. Ontology is the branch of philosophy that is concerned with the sorts of objects and entities that exist in the world and the ways in which these objects interact with each other. While few scientists or researchers explicitly engage with the concept of ontology most implicitly subscribe to some form of scientific realism. Under this view the world can be decomposed into more basic entities that are discoverable by following scientific procedures and which interact under the influence of a relatively small number of "laws". These entities can be observed and measured and are generally assumed to be independent of time and place. The categories that become the focus of research reflect a particular way of segmenting reality and their nature is often unquestioned. For example, most research in the social sciences takes the individual human being as the basic component and research then focuses either on processes within that individual, such as memory or decision-making, or on interactions between individuals and between groups of individuals. Because the category "person" is often assumed to be largely unvarying studies of, for example, university undergraduates, are presented as providing information that is applicable to many other classes of person.

Some research seeks to examine differences between defined groups of people, for example those with and those without a particular diagnosis, medical or psychiatric. The comparative approach serves to construct a category of other and these "others" are then defined and compared in relation to a norm that is at times explicit and at others implicit. For example, psychological, biological and physiological parameters of those with a diagnosis (physical or mental) might be compared to those without. Moreover, the categories employed in such research are frequently poorly defined and subject to variability across studies. They are also generally determined by those carrying out the research and may not reflect the ways in which the "subjects" of the research think about or understand themselves and their lives. A particularly egregious instance of this practice occurs when diverse racialised groups are classified under a single, geographically-determined, label. Examples of this practice are the labels "Black" and "South Asian" to represent groups from very different cultures and with different histories of, for example, racial oppression and colonialization. Hence, American descendants of African slaves, UK residents from African-Caribbean backgrounds and natives of Africa are regarded as broadly equivalent with a consequent flattening of their complex identities.

Exercise 2: Can you identify examples of this kind of flattening in research that you are familiar with? Can you identify examples of good practice?

The issues identified above reflect imbalances of power whereby one group is able to define the nature of other groups in ways that operate to the benefit of the more powerful group but may well disadvantage the less powerful group.

Science, research, facts and methods

While it is tempting to think of research as a dispassionate search for an abstract truth, in reality it is typically carried out for specific, proximal reasons. It might be about developing and elaborating a particular theoretical framework, such as quantum physics, it might be about pursuing a particular goal, such as a treatment for cancer, or it might be driven by policy or commercial priorities. This means that the topics of research are determined by particular groups of people, reflect predetermined priorities and are informed by specific conceptual frameworks. In many instances, such as seeking treatments for cancer, the goal will be valued by the great majority of people, including those outside the decision-making loop, but this is not necessarily always the case. For example, a desire to reduce the number of teenage pregnancies may be far from a universal priority. The point here is that certain programmes of research, particularly those in the behavioural sciences, healthcare and policy, frequently reflect value judgements that are grounded in a particular world view and moral framework. Those outcomes are determined by individuals at higher levels in a hierarchy of power. They are not necessarily chosen to reflect the concerns or preferences of those targeted by the policy or intervention and the outcomes provide information that is most useful to the more powerful individuals or groups.

The process of identifying and prioritising particular issues for research necessarily results in the active neglect, and consequent ignorance of, other issues. The philosopher Charles Mills (2007) developed the concept of "Epistemologies of Ignorance" to describe the ways in which social and political structures can serve to occlude the reality of racism while denying the lived experience of black and other racialised minority peoples. This concept has been employed by feminist activists and scholars to help illuminate the manner in which women, their bodies and their health have been excluded from research, often on the basis of an implicit commitment to the male as a standard model. For example, women are sometimes excluded from drug trials because their menstrual cycle might complicate trial design and data analysis and the standard treatments for heart attacks are based on what is appropriate for men (e.g., McGregor, 2021). In each case the resultant ignorance about what works for women has resulted in harm to women, and indeed trans men.

Carel and Kidd (2014) have described how healthcare practitioners are epistemically privileged with respect to those they care for, resulting in neglect or denial of their lived experiences. A key source of this epistemic privilege is Evidence Based Medicine (EBM). EBM has become hugely influential and has been broadened to cover all areas in which research evidence can be used to inform practice (Evidence Based Practice – EBP). The concept of a hierarchy of evidence is central to both EBM and EBP. It is based on the premise that knowledge generated through some methodologies is more objective, reliable and provides a firmer basis for generalisation than that produced by means of others. Typically, RCTs and meta-analyses sit at the top of the hierarchy while case studies and qualitative methodologies sit at the bottom. This hierarchy can contribute to and exacerbate ignorance. RCTs and meta-analyses are helpful for those commissioning and funding treatments, but less so for individual patients or healthcare professionals because they provide information about average effects at a population, not individual level. Greenhalgh et al. (2015) identified a number of “biases” against both patients and carers in EBM. These include the absence of patient voices in research, the devaluing of patient and carer experience and the existence of power imbalances. Other concerns include the stringent inclusion/exclusion criteria required for RCTs, which mean that whole groups of individuals, are not represented. Rogers (2004) argued that, with its biomedical and individualised focus, EBM results in ignoring the social and cultural factors that influence health, precisely those things that have the greatest impact on marginalised and disadvantaged groups.

Additionally, many RCTs are under-powered for detecting harmful side-effects. This, together with the downgrading of individual reports in terms of their evidential value, can result in denial of problems experienced by those receiving a treatment. For example, many people reported withdrawal symptoms when attempting to stop using anti-depressant medication, but these reports were ignored by medical bodies who claimed that such effects did not occur and suggested that the issue was a re-emergence of depressive symptomatology (Davies & Read, 2019). Something similar occurred in the case of vaginal mesh and the drugs primidos and valproate when the accounts of women of painful and deeply distressing side-effects were dismissed and ignored for many years (Independent Medicines and Medical Devices Safety Review, 2020).

Both of the above examples link epistemic ignorance to Fricker’s concept of epistemic injustice, in particular testimonial injustice. In each case the testimonies of less epistemically privileged groups of people, women and those with a mental health condition, were ignored with devastating consequences for both groups.

The categories employed in selecting individuals to participate in clinical research also reflect a privileging of particular ontological and epistemological positions. The use of sex-based categories, such as male and female, gender-based categories such as man and woman and racialised categories, such as white, black and South Asian, serve both to constrict broad spectra of identity along which people might choose to position themselves and neglect intersections of identity across the categories. This has resulted in a situation in which the needs of, for example, black women and trans people, have not been considered in research and clinical practice. In a similar way, the diagnostic categories employed in mental healthcare and research reflect particular normative assumptions concerning what constitutes mental health and the manner in which departures from those norms should be characterised and classified. The diagnostic categories for mental health problems developed by the American Psychiatric Association and set out in its Diagnostic and Statistical Manual (DSM) have been heavily criticised over the years for the way in which they pathologise normal variations in human behaviour (homosexuality was regarded as a mental health disorder at one point) and reduce complex and often socially situated patterns of distress to a single diagnostic label. There are also concerns that the categories employed represent a particular, largely Western, understanding of health, human behaviour and normative social and cultural expectations. In addition, the ways in which mental and physical healthcare are separated can result in neglect of physical problems in those with a mental health diagnosis or *vice versa*. For example, adults with a "*serious mental illness*" have been found to have a significantly reduced life-expectancy compared to adults without such a diagnosis (Chang et al., 2023). The fact that DSM diagnostic categories and measures of mental health difficulty based on diagnoses are routinely used in research studies is therefore cause for concern.

A global perspective

As healthcare research and the practice of EBM and EBP have become increasingly globalised there is a growing awareness of the importance of the issues identified above in addressing inequalities in health care at an international level. There are two key, though interlinked, ways in which these inequalities are particularly apparent. The first concerns the ethics of research in developing countries, particularly in relation to collaborative research. One aspect of this relates to issues of consent, particularly when ensuring that potential participants fully understand what is being asked of them and that they feel empowered to decline to participate given the very significant power differentials that prevail in such contexts. There are also questions as to whether research participants in developing countries will have access to the same levels of care and support as participants in similar studies in more developed countries. The second aspect of concern is the interests served by the research in question. There is a growing trend for pharmaceutical companies to conduct trials in less developed countries, but frequently the beneficiaries of these trials are those living in more developed countries. It is not always obvious that trials address healthcare priorities in the less developed country and, even when they do, such countries may not have easy access to the treatment being developed. Benatar (2002) has made a strong case for the importance of addressing these issues and set out a number of recommendations for developing best practice guidelines.

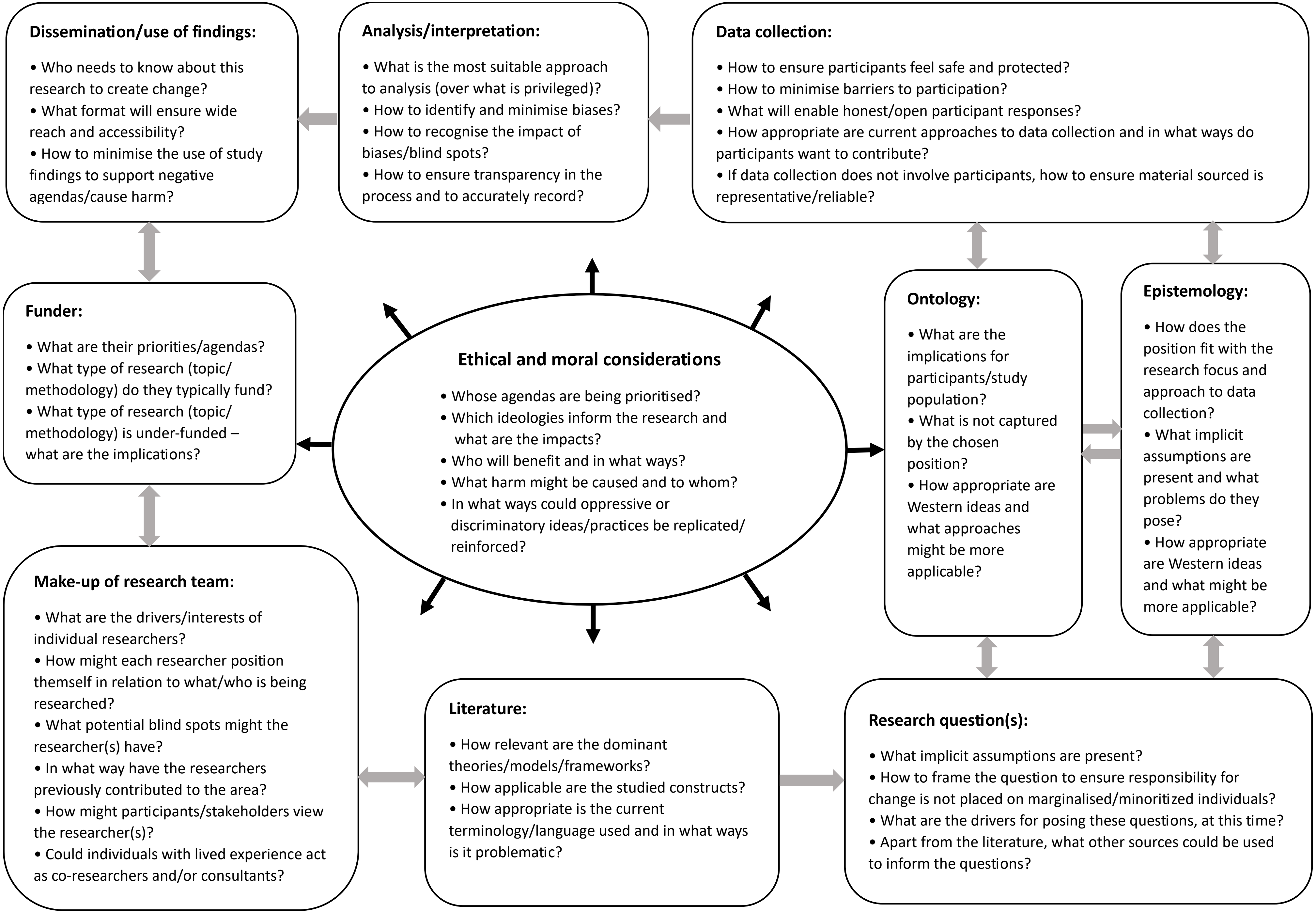
Critics of global health initiatives have drawn on critiques of the epistemological imperialism of EBM and its inherent social and cultural biases to call for efforts to decolonialise global health. Herrick and Bell (2022) state that "*the decolonisation movement forces us to question how global health works, for whom, where it is located, its funding practices, power asymmetries, cultures of collaboration and publication*" (Abstract). These issues became even more crucial in the context of the Covid-19 pandemic. Fofana (2021) locates modern global health in a historical context of colonialism and shows how this inheritance has contributed to hindering attempts to address the pandemic in Africa.

In 2015, the Hastings Centre produced a briefing paper on Research in Resource Poor Countries (Chuan & Schaefer, 2015). It noted that researchers and sponsors from high-income countries may opt to conduct research in low-and middle-income countries for reasons such as fewer regulatory constraints and access to large numbers of potential participants. It argued that such research raises significant ethical concerns relating to informed consent, standards of care and exploitation. Additionally, the benefits of the research may not be equitably shared with the host countries.

Lorde's (2017) statement that "*The master's tools will never dismantle the master's house*" is particularly apposite in the context of global health research. The tools (RCTs etc.) and their outcomes reflect the values of privileged groups. The information they provide might be of little or no value to those studied and be of little help in challenging the legacies of colonialism.

Carrying out research from a social justice position

This is a complex issue and there are no simple or straightforward recipes that can be offered. There is no single approach that can be adopted and no short-cuts. Some argue that quantitative research is inherently problematic and that qualitative approaches enable participants to tell their own stories. While there is some truth in this, the fact is that qualitative methods can be as saturated with ontological and epistemological assumptions concerning the nature of the issue to be studied, the people that experience it and how to interpret what interviewees tell the researcher as the most reductive quantitative research. Because there is no royal road to conducting social justice research, it is important not to allow the best to become the enemy of the good; it would be unproductive, and possibly a source of injustice, if important topics were unaddressed because of the challenges inherent in researching them in a particular way. We suggest a broadly pragmatic approach based on a thoughtful consideration of the nature of the topic to be researched, the questions it raises, the nature of the people that will be invited to participate in the research, the approach to data analysis and the ways in which the data from the study and the findings of the researchers will be disseminated to and shared with others. We have set out the key points that need to be considered as well as the relationships between them in Figure 1. The labels on the boxes (data collection, analysis etc.) will be familiar, but we have tried to identify important considerations in framing these in a manner that reflects a commitment to social justice. The importance of attending to ethical and moral considerations is reflected in its positioning at the centre of the figure.



Ethical and moral considerations

- Whose agendas are being prioritised?
- Which ideologies inform the research and what are the impacts?
- Who will benefit and in what ways?
- What harm might be caused and to whom?
- In what ways could oppressive or discriminatory ideas/practices be replicated/reinforced?

Dissemination/use of findings:

- Who needs to know about this research to create change?
- What format will ensure wide reach and accessibility?
- How to minimise the use of study findings to support negative agendas/cause harm?

Analysis/interpretation:

- What is the most suitable approach to analysis (over what is privileged)?
- How to identify and minimise biases?
- How to recognise the impact of biases/blind spots?
- How to ensure transparency in the process and to accurately record?

Data collection:

- How to ensure participants feel safe and protected?
- How to minimise barriers to participation?
- What will enable honest/open participant responses?
- How appropriate are current approaches to data collection and in what ways do participants want to contribute?
- If data collection does not involve participants, how to ensure material sourced is representative/reliable?

Funder:

- What are their priorities/agendas?
- What type of research (topic/ methodology) do they typically fund?
- What type of research (topic/ methodology) is under-funded – what are the implications?

Ontology:

- What are the implications for participants/study population?
- What is not captured by the chosen position?
- How appropriate are Western ideas and what approaches might be more applicable?

Epistemology:

- How does the position fit with the research focus and approach to data collection?
- What implicit assumptions are present and what problems do they pose?
- How appropriate are Western ideas and what might be more applicable?

Make-up of research team:

- What are the drivers/interests of individual researchers?
- How might each researcher position themself in relation to what/who is being researched?
- What potential blind spots might the researcher(s) have?
- In what way have the researchers previously contributed to the area?
- How might participants/stakeholders view the researcher(s)?
- Could individuals with lived experience act as co-researchers and/or consultants?

Literature:

- How relevant are the dominant theories/models/frameworks?
- How applicable are the studied constructs?
- How appropriate is the current terminology/language used and in what ways is it problematic?

Research question(s):

- What implicit assumptions are present?
- How to frame the question to ensure responsibility for change is not placed on marginalised/minoritized individuals?
- What are the drivers for posing these questions, at this time?
- Apart from the literature, what other sources could be used to inform the questions?

Figure 1: Social justice in the research process

Table 1 illustrates stages in the development of a research study from a social justice position, showing a progression from a relatively weak position to something stronger. There is no Platonic ideal of what “socially just” research should be, and any study is likely to be deficient in some respects.

Table 1: Considerations in the development of a research project

Quality in terms of social justice positioning	Research question	Participants	Methods and measures	Comments
Weak	What is the frequency, severity and impact of physical domestic violence (DV) among married women in the UK?	Population sample of married women in the UK.	Standardised measures of violence capturing type and severity. Standardised measures of depression and anxiety.	The question and study design regards "women" as a single, homogeneous group and takes no account of intersecting identities relating to class, race, culture, religious affiliations etc. It implicitly assumes that DV occurs solely in the context of heterosexual relationships. The framing in terms of physical harm neglects other, potentially equally harmful forms, which are often omitted from standardised measures of DV. Unless the measures have been translated, only English speakers will be able to participate. The use of psychiatric categories of distress imposes a medical lens on participants and risks missing serious harms.
Stronger	What are the experiences and psychological impacts of DV among South Asian English-speaking women in the UK?	Women recruited via various community resources, including religious groups, libraries etc.	Individual interviews structured to explore issues of depression, anxiety, post-traumatic stress disorder etc.	The use of diagnostic categories narrows a range of issues that can be explored and imposes a medicalised ontology and epistemology. The label "South Asian" arbitrarily groups people with very different cultural, religious and historical backgrounds.
Stronger still	How is shame experienced and expressed by first-generation Tamil women survivors of DV in the UK?	Purposive sample of women recruited via a community support group.	Individual interviews employing questions developed following extensive consultation with professionals and in partnership with the support group and ex-group users. Interpreter used to ensure that the questions and responses are clear.	The question specifies the population of interest precisely. The question and interview schedule were developed in consultation with mental health professionals from the community and in partnership with the support group and ex-group users. The use of interpreters enables women with little or no English to participate. However, "shame" is a complex, socially determined concept, largely developed and elaborated in Western psychology. It might have a different meaning and resonance in non-Western cultures.

Exercise 3: Design a study to *explore barriers to accessing professional support by gay men following domestic violence*. Use Figure 1 and Table 1 to inform different stages of the research process. What challenges arose and how might you overcome them?

Tips to get you started:

(a) Relevance of dominant frameworks for understanding DV for men in same sex-relationships?
(b) Appropriateness of the term "gay men"? What might be some of the problems with only recruiting participants who identify as a gay man?
(c) What type of professional support will you focus on and why?
(d) How might you frame a question to explore service-level barriers?

Conclusion

Research from a social justice perspective is not merely about the topic area, methodological approach or involvement of individuals and/or carers with lived experienced in the research process. It requires interrogation of agendas and likely beneficiaries at all levels of the system, with careful consideration of the conceptual, philosophical and ethical underpinnings that can disadvantage marginalised and less-powerful groups. The manner in which researchers frame questions, select and employ particular methods and analyses, as well as interpret and disseminate the data will implicitly reflect and embody pre-existing values, attitudes and biases. It is important to acknowledge that despite a commitment to social justice and the positive intention of researchers, blind spots will be inevitable and study findings may be used by others to support negative agendas (e.g., further problematise, discriminate and oppress minoritized and marginalised groups). We recommend researchers attend to how they can minimise and safeguard against potential harm.

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