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Structural Influences on Consent Decisions in Participatory Health Research in Eswatini

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Abstract

Recognition that structural factors influence participation decisions and have potential to coerce participation, emerged relatively recently in research ethics literature. Empirical evidence to elucidate the nature of "structural" coercion and influence is needed to optimise respect for autonomy through voluntary informed consent. We present findings from ethnographic data about community co-researchers' experiences designing and implementing demographic and health survey consent procedures in participatory health research in Eswatini. Informed by Bourdieu's sociological theory of multiple types of capital/power, our findings detail structural influences on research participation decisions, highlight the inherently power-laden dynamics of consent interactions, and suggest that to be optimally ethical, research ethics principles and practices should consider and account for structural power dynamics.

Keywords

power, participatory health research, structural coercion, Eswatini, sociology

Background

The ethical principle of respect for autonomy addresses people's right to decide if they want to participate in research. Voluntary informed consent, which may be provided verbally or in writing, is the typical procedure for respecting autonomy (Fisher, 2013). To be valid, consent must be provided by a cognitively competent person who has been informed of the risks, benefits and procedures research participation may entail, and of their right to decline or refuse participation (informed). Consent must also be voluntary, that is, given by a person whose decision to participate is not coerced (compelled by threats) or unduly influenced (compelled by incentives) by a researcher (Hoeyer & Hogle, 2014).

Voluntary informed consent as a standardised, procedural approach to respecting autonomy, situates coercion and undue influence as arising exclusively within the researcher-participant dyad. The procedure reflects Emmanuel Kant's philosophical conceptualisation of autonomy as the ability to deliberate, rationalise, and decide to pursue goals that surpass immediate, individual desires (Campbell, 2017). Grounded in Kant's conceptualisation of autonomy, voluntary informed consent procedures imply that potential participants consider only study information provided by the researcher when deliberating and rationalising their decision to participate (Campbell, 2017). Because research usually involves risks for individual participants that are justified by the expected scientific benefits to society, deciding autonomously to take on the burden of research participation implies an altruistic motivation (Fisher, 2013).

The Kantian-based notion that research participation should be altruistically motivated is reinforced by sanctioning incentives for research participation (Largent & Lynch, 2017). Providing incentives from which research participants will personally benefit (e.g., payments, free health care) is often considered by research ethics committees unethical, and a potential source of undue influence or coercion, despite evidence to the contrary (Largent & Lynch, 2017). The notion that providing individuals with material incentives that benefit them personally is unethical implies altruism is the most (only) legitimate motivation for research participation (Campbell, 2017). However, empirical evidence from structurally marginalised settings demonstrates that non-altruistic motivations, including a desire to access resources such as money and healthcare to alleviate suffering underpinned by structural power inequalities (i.e., structural violence), influence participation decisions (Authors, 2021; Fisher, 2013; Kalabuanga et al., 2016; Lairumbi, Parker, Fitzpatrick, & English, 2012). This is

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perhaps self-evident. However, it is not reflected in research ethics guidelines (e.g., CIOMS, 2016), in which benefits are defined as positive scientific and therapeutic outcomes of the research.

Third-party coercion and structural coercion are important new theoretical concepts for understanding the nature of power-laden influences on autonomy in research participation decisions. "Third-party coercion" (Millum, 2014, p. 113) is a relatively new concept from moral philosophy, which has great relevance to research ethics. It refers to coercive effects exerted intentionally, by a person who will not directly benefit from the practices they have compelled (Millum, 2014). In research, third parties are people outside the research team. Empirical ethics studies show that third party coercion or undue influence to participate in research may be exerted by a range of individuals in positions of relative social power, including parents, spouses (Appiah, 2021), health professionals (Nyirenda et al., 2020), government stakeholders (Nyirenda et al., 2020), teachers (Nyirenda et al., 2020) and/or authoritarian community leaders (Appiah, 2021; Graboyes, 2010; Nyirenda et al., 2020). It is again self-evident that individuals' decisions about participation in research are influenced by people other than researchers. However, this reality is not reflected in research ethics guidelines and practices, which continue to situate coercion within the researcher-participant dyad (Campbell, 2017).

"Structural coercion" (Fisher, 2013, p. 355) is a concept that first appeared in the research ethics literature in an article presenting empirical examples from biomedical research in North America. It draws attention to social, economic and political contexts that may exert a coercive or undue influence (Fisher, 2013). Coercion (i.e., persuasion involving violence or threats) is structural when it emanates from the basic structures of society, especially major social institutions and dominant economic and social arrangements that influence individual prospects (Wong, 2020). For example, economic and social arrangements profoundly affect the types of biomedical services different types of people can access (Fisher, 2013). Inability to access essential (e.g., health) services manifests as "structural violence" (Farmer, 1996, p. 261), that is, actual or threatened harm or suffering underpinned by social structures, rather than a discernible individual's intentional action.

Structural coercion highlights the ways in which social structures influence individuals' agency to make autonomous decisions about participation in research (Fisher, 2013). It suggests that participation in research may, at least sometimes, be driven by a desire to reduce or avoid, actual or threatened suffering or harm emanating from unequal social structures (Bourdieu & Wacquant, 1992; Farmer, 1996). The ways in which economic structures might compel participation in biomedical research involving free clinical services or cash payments to healthy volunteers was the focus in Fisher's (2013) seminal account of structural coercion. The concept was later utilised to model structural coercion in community-engaged biomedical research in Malawi, southern Africa (Nyirenda et al., 2020). Nyirenda et al.'s (2020) model of structural coercion, highlighted how poverty compelled some people to participate in research to access clinical services. It also highlighted the influence on research participation decisions, of social power inequalities that enable third parties to exert coercive effects. For example, Nyirenda et al.'s findings demonstrated the influence of power differentials in relations between research participants and authoritarian community leaders (traditional chiefs), community researchers, collaborators (e.g., government agencies) and researchers with advanced formal education. These types of social power inequalities have also been conceptualised as third-party coercion, which may be overt or covert.

Social norms, the socially structured and sanctioned expectations of how different types of people should act, also influence decisions about if and how people participate in research. Women tend to respond "don't know" (i.e., decline to offer an opinion) to survey questions about politics at a far higher rate than men (Bourdieu, 1984). Although coercion does not feature in it, this example demonstrates how gendered social norms, which have historically excluded women from cultural activities such as holding or sharing political opinions, tacitly influence women's decisions about *how* they participate in research (Bourdieu, 1984). Where gendered social norms dictate women should obey men, women may not consent to participate in research without permission from a husband or male community leader, or feel compelled to participate because a man grants permission (Appiah, 2021; Tindana, Kass, & Akweongo, 2006). Social norms which require women's obedience and sanction male violence to control women, could be considered coercive because they exert their influence via the implicit threat of physical, emotional and/or economic violence to women who disobey. These examples highlight how socially structured relations of power may influence women's decisions about if and how they participate in research, in the absence of an explicit threat.

Aims

Structured relations of unequal cultural, social and economic power influence research participation decisions. An emerging body of literature conceptualises the influence of these relations in terms of "structural" or "third party" coercion/influence. However, these concepts remain underdeveloped, partly because their development has not yet been informed by a comprehensive theory of power. Against this backdrop, our aim is to build on empirical (Fisher, 2013) and theoretical (Nyirenda et al., 2020) work on the concept of structural coercion by analysing ethnographic data, detailing community co-researchers reports and the first author, MB's direct observations of consent

interactions, informed by a sociological theory of power (Bourdieu, 1990).

Study Design

The data were collected through a project ethnography of the process and outcomes of participatory health research (PHR). The project ethnography was conducted in Eswatini (formerly Swaziland), a lower-middle income country in southern Africa. It was approved by the Name University Human Research Ethics Committee (CF12/2637–2012001422), the Swaziland Scientific and Ethics Committee (MH599C) and the community's traditional governance authority, the *umphakatsi* (described below).

Setting

The study community was situated in a rural area governed by *tinkhundla*, a political system of chiefly governance unique to Eswatini and described further below. It was selected purposively because the MB had been working in partnership with women from the community for over five years, to establish services, including a preschool, to support families caring for children affected by acquired immune deficiency syndrome (AIDS). She had thus developed the relationships and trust considered prerequisites for ethical PHR.

The Kingdom of Eswatini is Africa's last absolute monarchy and the country with the highest recorded prevalence of human immunodeficiency virus (HIV) globally. The King's absolute power (i.e., control of the legislature, judiciary and military) is inseparable from the quasi-feudal *tinkhundla* system, which is one arm of Eswatini's dual system of governance. The other is a quasi-Westminster political system in which the King appoints the majority of senators while citizens elect most members of parliament. There are 55 *tinkhundla* in the country. Each *inkhundla* consists of a *bucopho* (community representative elected for a five-year term) and numerous *imiphakatsi* (singular *umphakatsi*), which are local districts governed by chiefs who are selected by the king and/or according to birth right, for indefinite terms. Chiefs wield extensive power over their constituencies, including to: tenure plots of Swazi National Land (land held in trust for the nation by the King) to married men who pledge allegiance to the King; administer unwritten Swazi Law and Custom in community-based courts; and fine residents of the chiefdom who transgress (Debly, 2014).

Eswatini's 2005 constitution includes provisions for gender equality. Conversely Swazi Law and Custom, which is administered by chiefs in rural areas such as the study community, is gender discriminatory (Mavundla, Strode, & Dlamini, 2020). For example, according to Swazi Law and Custom, women, unlike men, cannot marry multiple spouses, access Swazi National Land once married or open a bank account (Mavundla et al., 2020). Women are considered the property of their fathers until they become the possession of a man who has paid *lobola* (bride price, usually paid in cattle) for their hand in marriage (Daly, 2001). They are expected to submit to their husbands' demands (Russell, 1993) and do 'women's work' such as cooking, bearing children and caring for the young and sick (Brear et al. 2019; Russell, 1993; Shabangu and Brear 2017), roles that confine them to the domestic sphere and limit their public participation. Anecdotally, power in rural Eswatini is also unevenly distributed based on education, age, economic and social status.

Participants and Methods

Participants in the project ethnography were co-researchers in the PHR. One was a PhD student (MB) and 10 (including PS) were members of a rural community governed by *tinkhundla*. The community co-researchers were six women and four men aged 18–40 years at the commencement of the study, who were residents of the community and responded to local advertisements, and were selected purposively for age and sex diversity. One female and one male co-researcher were married and one woman was widowed. The other seven were unmarried. Each co-researcher provided written voluntary informed consent for MB to collect unstructured participant observations (PO), interview (INT) and focus group discussion (FGD) data about their participation in all aspects of the 14-month PHR process, the process and outcomes of which were the focus of the ethnography.

The co-researchers' participation included attending 76 participatory workshops through which co-learning for, co-design of, and reflection on practice in the PHR study were facilitated. In preparation for workshops the co-researchers often individually completed short readings or activities. Each workshop was facilitated by MB and included several participatory activities (e.g., debates, role plays and group discussions) through which the co-researchers shared their experiences, ideas and opinions and made decisions about research design and implementation. MB recorded handwritten PO notes in the workshops and transcribed the PO data within 24 h.

MB also conducted, audio-recorded and transcribed 21 FGDs and 22 individual interviews with the community co-researcher participants. Focus group discussions and interviews were conducted periodically, using questions that were developed iteratively and designed to encourage the community co-researchers' to narrate their opinions, experiences in the PHR and interpretations of them. Each focus group had 4–8 participants. Each co-researcher participated in an average of 3 in-depth interviews which occurred near the beginning, middle and end of the PHR process. Interviews were conducted by MB and enquired about the participants' experiences being co-researchers in the PHR.

The ethnography was one component of a multiple-methods research project [i.e., a project involving two distinct but related component studies, each of which can be presented in its own right (Morse, 2016)]. The sequential mixed-method PHR (i.e., study involving two or more methods which produce data about the same phenomena and are implemented sequentially) (Morse, 2016) that was the focus of the project ethnography was a second component. The PHR was focused on structural determinants of health in a community caring for children affected by AIDS. It engaged community members as respondents in a demographic and health survey (DHS) implemented as a census of all (N = 126) homesteads (domestic social groups potentially including multiple households) in the community and FGDs with a randomly selected sample of community members enumerated through the DHS. The DHS was co-designed and implemented face-to-face by community co-researchers in the local language siSwati. It is described in detail in Brear et al. (2022). Results of the DHS and FGDs conducted within the PHR are not reported in this article. Hence, we do not describe the PHR research instruments or analysis of the data collected in the PHR.

Data Analysis

Structural coercion was determined as the focus of the analysis by MB and PS, through reflective discussions about 'ethically important moments' (Guillemin & Gillam, 2004, p. 261) in their research practice. The analysis considered project ethnography data relevant to the design and implementation of consent procedures.

DHS informed consent processes and outcomes documented through the ethnographic study were the focus of the analysis presented herein. Ethnographic data tagged to 'research ethics' and/or 'social power relations' codes during MB's primary thematic analysis formed the ethnographic dataset for analysis. These data were primarily collected during workshop activities focused on: co-learning about research ethics and community power relations; designing consent procedures for the PHR; and/or reflecting on PHR data collection field work. For specific results and quotations, references to PO (PO-DD/MM/YYY), FGD (FGDNN- where N is the sequential number on the series 21 of FGDs) and interview (INTNN) data are included in the results narrative. MB conducted interpretive, abductive (inductive-deductive) analysis of these data using NVivo V12. Inductively the analysis was informed by the data and reflective discussions between MB who initiated the PHR as a PhD student, and PS who led the PHR data collection field work as a community co-researcher. In addition to co-designing the PHR in workshops, PS's role in the PHR process included enumerating approximately one-third of the homestead and household DHSs, checking DHS data collected by other co-researchers, facilitating debriefing sessions with the community co-researcher group at the end of each day's field work and providing daily updates to MB. Deductively the analysis was informed by the research ethics literature on third party and structural coercion and Bourdieu's sociological theories of structure, agency and power.

Theoretical Framing

Bourdieu developed his theories the "logic of practice" (Bourdieu, 1990) and "different types of capital (or power, which amounts to the same thing)" (Bourdieu, 1986/2011, p. 82) to elucidate the simultaneous influence of structure and agency on all individual practices (including thoughts and behaviours). These theories highlight the importance of, and provide the rationale for, understanding autonomy as *inherently* structured by unequal relations of economic, social and cultural power.

Bourdieu conceptualised the social world as made up of objective relations between agents (individuals, whose practices are always simultaneously structured and chosen). All agents interact from different positions of power in numerous **social fields** (social networks of unequal power relations) (Bourdieu & Wacquant, 1992). Each agent's position in each social field is determined by the different types of **capital/power** that they possess, the capitals' value in the field, and the agent's embodied historical experiences (referred to theoretically as **"habitus"**) of interacting amidst structural power inequalities. Habitus, a source of practical logic that tacitly informs decision making, is structured by and in turn structures, agents' practices (Bourdieu, 1990).

Bourdieu conceptualised capital as synonymous with power and taking multiple forms, economic/material, social and cultural/knowledge (Bourdieu, 1986/2011). He emphasised that the three types of capital were exchangeable and might be possessed in actual/material or symbolic forms (Bourdieu, 1986/2011). For example, money, a key material form of economic capital, can be exchanged for both cultural/knowledge capital (e.g., a recognised education, symbolised through a qualification) and social capital (e.g., friends in 'high' places). The opposite is also true; knowing the right people or having a university degree can be 'converted' into a well-paying job or symbolic title such as Professor (Bourdieu & Wacquant, 1992). Although different forms of capital/power are inherently exchangeable, the intrinsic and exchange value of each type is specific to the social field (Bourdieu & Wacquant, 1992). For example, a university degree may have a higher value in the social field of a university, compared to that of a business.

Knowledge and experiences of one's place in the hierarchy of multiple social fields are embodied as habitus. Habitus is a source of practical logic, which tacitly predisposes individuals to choose practices that provide the greatest likelihood of accumulating social, cultural and/or

economic capital, considering their objective position of power. Practices are always chosen autonomously by agents, but also simultaneously structured by constraints imposed by social power structures and embodied practical knowledge. For example, a woman's position of power in the social field of the family may predispose her to submit to her husband's demands while also expecting her children to submit to her demands.

Defining social fields through empirical study was a key aspect of Bourdieu's reflexive sociology, a methodology developed alongside his theoretical tools. It involves empirically studying the objective structure of social relations that characterise a field and the habitus of different agents within the field. Bourdieu's theories and method provide a robust framework for detailing and interpreting the meaning of empirically observed practices in our research consent processes, in relation to individual agents' positions of unequal power.

Findings

Following the Bourdieusian approach, we first present our findings about the economic/material, social and cultural/knowledge power dynamics in the PHR field. We then detail how these relations of power were considered during, and influenced, the design of consent procedures. Finally, we describe how these relations manifested in power-laden consent interactions, in the PHR.

Power Relations

Power dynamics in the community were characterized by inequality and limit. The community, and households and people within it, lacked the power needed to achieve "health capability" (the ability to be healthy) (Venkatapuram, 2012) and were thus subjected to structural violence underpinned by poverty. For example, in Brear et al. (2018) we report widespread "health capability deprivations" such as food insecurity and lack of transport infrastructure, clean water, soap, health services, schools, employment, livelihood opportunities, and money. Although married men in the community could acquire Swazi National Land use rights with relatively little economic capital, typically by giving a cow and making a symbolic pledge of allegiance to the Swati King, their land could not be owned or sold. Swazi National Land's economic exchange value was limited to the extent to which it could be used to support livelihoods, for example through subsistence or commercial farming endeavors. Community members' cultural/knowledge capital, although abundant in particular forms (e.g., as knowledge of child rearing and subsistence farming), typically had limited economic exchange value. Exchanging one's knowledge for money usually required moving to an urban area to take-up "unskilled" and poorly paid jobs (PO06–05–2013). Despite having relatively large extended family and other (e.g., church groups and football clubs) social networks, community members typically did not have powerful friends or relatives, for example who could loan them money or help them find a job (Brear et al., 2018).

Amidst the overall lack of valuable capital/power, community members gained relative power by having a job, owning valuable assets (especially livestock and cars), being (more) formally educated, married, old(er), male, White, and/or a member of the *umphakatsi*. The community co-researchers reported "whatever piece of information you [MB] give us, we believe that information is true" (FDG11) and that they expected other community members to trust MB and do what she asked, partly because she had played a leading role in developing a preschool in the community. Several community co-researchers indicated that they felt pride and gained social power in the community because they were "working with [Michelle], the white person" (FGD16).

Social power also had age and gender dimensions. Children were not given opportunities to express their opinions and told to "listen to your father" (FGD08) and other adults. Adults' power over young people was constituted partly by physical performances of power such as parents or teachers, "beat[ing] you… teach[ing] respect with a stick" (PO06/05/12/12), but also ideologically, for example through teaching children that the "bible says you have to respect your parents" (INT-02). Amongst children "boys [were] freer than girls because they herd[ed] cattle" (PO-04/02/2013), away from the home, whereas girls were expected to stay home and help with domestic work.

Gender power inequalities amongst adults also involved men and women occupying different physical spaces. For example, at community meetings men and women sat in different places and only men were allowed to sit on chairs. Women, who sat on mats or the ground, were expected to kneel when they spoke (unlike men who stood) (PO45–19/07/2013). Many families in the community were separated because men migrated to towns to work, leaving their women to maintain their rural homesteads (PO06/05/2013). Men gained power through marriage and siring children (PO14/01/2013). The co-researchers reported that married men in the community believed that "no one [especially no other man] can talk to my wife without my honour" (PO-06/05/2013). Women who did not respect (often absent) husband's control were perceived to risk the men withholding money, being physically violent and/or reporting them to their parents, who had received a bride price for their hand in marriage (PO-08/07/2013).

Members of the *umphakatsi* also derived power from the traditional land tenure system, which vested in them authority to allocate land use-rights to married men and accept other forms of economic capital such as cattle in exchange. They also had the power to evict or fine male landholders for

their own or family members' misdemeanors. These people potentially included "women who wear pants" (PO-30/11/2012), those who refused to make financial contributions to or do unpaid work on community development projects (FGD08) and men who perpetrated gender-based violence. However, MB heard of several women being beaten by husbands who were not punished. This was perhaps because women's rights, such as the right to refuse to have sex with their husband or insist on using a condom:

> "come from [non-governmental] organisations like SWAAGA [the Swaziland Action Group Against Abuse) [but] there is still the family courts [that a man could report his wife to] and the family [especially her biological parents who had received a bride price] will talk to her and tell her that she is the wife and she is supposed to have sex when he wants to (co-researchers' comments in workshop discussion detailed in PO42–08–07–13).

Historic experiences of interacting amidst the economic, cultural and social power inequalities of the community field, according to our theoretical framing, were embodied by community members. They provided a tacit source of practical logic which predisposed them to certain practices in the newly established PHR field.

Research Practices in co-Design

The PHR, including voluntary informed consent procedures, was designed by eight of the community co-researchers and MB, with input from her academic supervisors. They engaged in deliberations about power relations that informed the design of consent procedures that were intended to be culturally respectful and academically robust. Three considerations, respecting men's power and women's autonomy, encouraging and appreciating participation, and disrupting perceptions of research as development, were prominent in the data about designing the PHR consent processes.

Respecting Men's Power and Women's Autonomy. To enable women to decide about research participation for themselves, but also respect the norm of men controlling who spoke to their wives, the PHR group designed a two-stage, homestead-household consent process and DHS. The DHS consent process they decided upon involved first consenting, and completing the homestead component of the DHS with, the homestead head (the man who tenured the homestead's land from the *umphakatsi*) or a representative in his absence. The homestead DHS asked about the number of households in the homestead and the age and sex of the "head cooker" (head of domestic work, assumed to be a woman) in each. It asked for the respondent's consent to invite each head cooker to participate in a household DHS (Supplementary File 1). Identifying households through the heads of registered homesteads was a way of respecting men's power but also necessary to identify the population for the household DHS, which was administered as a census. The *umphakatsi* had a list of all homesteads in the community, but no record of the population of households within them (PO29–23/04/2013).

If consent was provided by the homestead DHS respondent, the head cooker in each homestead would be invited, and given an opportunity to consent to or decline, participation in a household DHS. The household DHS consent clause (Supplementary File 1) did not mention that the homestead respondent had given permission. Both homestead and household DHS consent clauses stated that individuals did not have to participate even though the study had been approved by the *umphakatsi* at community meetings. Household DHS respondents who consented would be asked to provide demographic information about each resident and non-resident household member and to consent to resident household members being included in the sampling frame from which potential FGD participants would be selected.

Including a separate consent process for the household DHS was intended to enable (female) household DHS respondents' autonomy to decide for themselves about participation in the research. It was also intended to uphold the research ethics norms, which MB had shared her knowledge of with the co-researcher during the workshops (FGD09). The risk of harms for women who participated in the DHS without their husbands' permission were not discussed by the PHR group, nor was the possibility that asking male homestead heads for permission to invite head cookers might be a source of coercion or undue influence. For example, a group discussion of a role play created by two community co-researchers, in which a man acting as a DHS participant told his wife to answer the questions (PO-06–05–2013) on his behalf, focused on the sensitivity of the questions and if the wife would feel comfortable answering them in front of her husband and/or other household members. The PHR group decided to minimise the number of sensitive and personal questions that they asked, conscious that they had insufficient power to prevent husbands and other household members from listening to the DHS interview if they wanted to.

The possibility that being "told" made the woman feel forced to answer, was not discussed, seemingly because the group had come to accept the research ethics assumption, that people would be able to decline the invitation to participate, because they would be told by researchers that it was their right (FGD09). The gender-transformative potential of asking women to consent on behalf of the household or speaking to (privileging) women and valuing their typically under-valued domestic knowledge, was not deliberated. Neither the PHR group nor the two ethics committees that approved the study raised any concerns about men's permission, or their presence during the consent

procedures, coercing or unduly influencing women's participation.

Encouraging and Appreciating Without Unduly Influencing. Another prominent topic of deliberation in the PHR group was how best to encourage community members to participate, and appreciate the efforts of those who did, without unduly influencing them. The community co-researchers considered giving "things like soap or food, just to appreciate" (FGD10) research participants' time and knowledge, appropriate. However, they thought that giving needed to be carefully managed to avoid unduly influencing participation decisions:

> **MB**- [What if someone] didn't really want to be involved… but they're like, 'hey, I really want that soap?' [laughter…] Do you think it can happen? Or how can you make sure this doesn't happen?
>
> **Community co-researcher-01**- I think that the better [way is] … not to mention the token of appreciation [until after the participant has completed the DHS].
>
> **Community co-researcher-02**- I think when they see the soap, some they can lose themselves… they can say, 'yes, I'll participate because of the soap, I don't have a soap in my house.' (FGD10)

The group decided, as suggested, to give bars of soap upon completion of the DHS. In addition to giving soap to appreciate, they agreed that an unspecified degree of verbal encouragement to participate was ethical and positive, in a context where, "because they are living in poverty [some potential participants will think] they [have] nothing to offer. But they will just say they don't want to participate" (PO-06/05/13). One of the two ethics committees expressed concerns about giving soap. However, the concerns were related to "setting a precedent that other researchers might be expected to follow" (Letter from Ethics Committee), not to undue influence to participate in the DHS.

Attempting to Disrupt Perceptions of Research as Development. The possibility that community members would be (unduly) influenced to participate in the study because they conflated research with, or assumed it would result in, development/humanitarian assistance, was also discussed. For example, in a role play activity, co-researchers acted-out a potential participant commenting on a DHS enumerator's 'papers' (survey forms) and saying that he thought the researcher was coming with money or help because of the papers (PO/06/05/2013). The community co-researchers made comments such as, "Swazis… think that they [researchers] conduct a research because there is something that they will give us" (FGD05).

Conceptualising research as assistance was influenced by past experience. For example, the group discussed how the community's HIV support group provided agricultural inputs only to those who had reported that they were living with or otherwise affected by HIV (FGD18). One community co-researcher, in her role at the preschool, compiled a list of children who were orphaned or vulnerable, because the list was required to access humanitarian assistance in the form of food for the soup kitchen (PO18/12/2012). However, the group assumed that informing community members that there were no direct community development benefits of participating in the research, would mitigate perceptions of research as development assistance and related coercion/influence (FGD05).

Practices in DHS Fieldwork

Unequal and existing relations of power within and beyond the community, manifested as structural influences on consent during DHS fieldwork. Specifically, many community members' consent to participate appeared to be influenced by excitement about receiving the token of appreciation (soap), which they constructed as a personal benefit and/or assumptions about research leading to development assistance from which they would personally benefit. Community members made their consent decisions drawing on information from their own sources, in addition to that provided by the co-researchers during consent interactions. The consent processes appeared to reinforce some, and disrupt other (gendered) social norms.

Wanting to Participate. The co-researchers reported, and MB observed, many participants consenting to and appearing to enjoy participating in the DHS. Only one of 126 invitees declined participation in the homestead DHS (PO-31/10/2013). All invitees consented to participate in the household DHS. In some households, family members and/or neighbours and friends sat and listened to the entire DHS interview. Desire to participate was also apparent in members of neighbouring communities requesting to participate in the DHS (PO03/09/2013) and community members requesting the co-researchers come to survey their house, sometimes adding that they were waiting for their bar of soap (FGD18).

After the first couple of days of DHS fieldwork, knowledge that soap was being given to DHS respondents as a token of appreciation became widespread in the community. For example, one community co-researcher reported that when she walked past a homestead that was not on the list she had been asked to survey, people called out, "hey, when are you going to come back? I am ready for you, I want a bar soap" (FGD18). The co-researchers perceived that community members also obtained information about the DHS questions from their neighbours, before they consented to participate (FGD18). Some community members

appeared to have decided to participate before the co-researchers read them the DHS consent clause. For example, MB observed one community co-researcher telling a potential participant that she was there "to do the [DHS] interview and he agreed and then she asked if she could read the consent clause before he agreed and he said yes but interrupted her halfway through to say that he agreed again" (PO-13/09/13).

Community members' decisions to participate also seemed to be influenced by perceptions that the research would lead to development assistance. For example, one co-researcher believed that an elderly DHS respondent thought she "was coming with the food so continuing asking those [DHS] questions, she became tired. She refused to continue with the DHS" (FGD18). The same co-researcher reported another DHS respondent saying, "you must tell your *mlungu* [literally White person, colloquially boss/employer, a reference to MB] that we need water here" (FGD19), which the co-researcher interpreted to mean that the respondent thought MB would be able to organize development assistance to resolve issues such as lack of clean water.

Reinforcing and Disrupting Perceived Norms. The practice of giving soap as tokens of appreciation was popular, at least partly because it was novel, in a community where people (and especially women) were often expected to participate in community development efforts and get nothing in return (FGD08). Seeking out women to respond to the household DHS disrupted what the co-researchers perceived to be their community's gendered social norms. In addition to valuing the knowledge of women as "the one who normally leads… who is always, always there and she normally knows… [about] everyone in the household" (FGD09), seeking out female DHS respondents gave us an opportunity to include in the dataset (in an open-ended comments variable) information they offered spontaneously. Numerous women contributed gendered data that was not elicited but important to them, for example about gender-based violence and the burdens of child rearing [as reported in Brear et al 2021].

Data showing that most women decided to participate without consulting men is paradoxical given that the DHS consent procedures the PHR group designed were intended to reinforce men's gendered power to control. Although all male homestead DHS respondents consented for the co-researchers to invite women in their homestead to complete a household DHS, men's desire to control what women said was sometimes apparent. For example, the community co-researchers made comments such as, "in all the homesteads that I went to, where there was the husband and the wife, the husband… will not go away… he will sit until I finish the interview because he wants to listen to all the questions" (FGD17). There were several reports of husbands changing or influencing their wives' answers.

The PHR group were surprised that analysis of the DHS data performed by MB (and reported separately in Brear et al. 2022) showed that two-thirds of homestead DHS respondents were actually women. These women disrupted social norms by nominating, and consenting for themselves as homestead DHS respondents, either because they were widowed (one-third) or their husbands lived away most of the time (one-third) (Brear et al. 2022). Women who responded to the homestead DHS because their husbands lived away (typically as migrant workers) nonetheless nominated the absent men with who the land was registered at the *umphakatsi* as the homestead heads. Widowed women nominated themselves heads of homesteads, although officially their homestead would have been registered with the *umphakatsi* in the name of a male relative. There was no indication that any of these women felt they needed to, or actually, involved the absent male heads of their homesteads in the participation decision (e.g., phoned them to ask for permission). The only potential participant that declined to participate in the homestead DHS was a woman. Although not required to provide a reason, she told the co-researcher who invited her that she declined because she had not heard about the DHS on the radio. In practice, male control of women's speech, which was perceived to be a norm, was only apparent in a one-third minority of homesteads.

Discussion

Our findings highlight structural factors exerting influence over research participation decisions in community-based PHR in Eswatini. They extend earlier empirical evidence regarding "structural coercion", which has focused primarily on economic factors that influence research participation decisions in biomedical research, with limited theoretical framing. Our theoretically informed analysis of data detailing consent decisions in health social science research, demonstrates the broad potential for structural and third-party coercion or influence in research conducted in marginalised populations, where the threat of structural violence is pervasive and defining a line between influence and coercion is challenging. Our findings suggest that third parties' capacity to influence is a function of socially structured power inequalities and thus a type of structural coercion. Despite structural factors influencing their participation decisions, potential participants in our study, most of whom were women, exerted considerable agency to seek information from third parties to inform their participation decisions and push researchers to invite them to participate. This finding extends the growing body of literature highlighting the limitations of standardised voluntary informed consent procedures which assume participants make decisions considering only study information and the conceptualisations

of autonomy on which these are based. The unique insights and implications of our findings from Eswatini, must be considered with cognisance of the strengths and limitations of the study.

Strengths and Limitations

The analysis was informed by long term reflective discussions between academic and community co-researchers, as well as a comprehensive sociological theory of power. The data, collected over a 14-month period, captured community co-researchers' reports about community norms and observed practices in a PHR process. We did not specifically enquire about autonomy or coercion. We consider these features strengths, given that according to our theoretical framing the practices documented were norms, taken for granted so much that people did not consciously think about them and were unlikely to report them in response to direct enquiries. The findings would have differed if we had enquired directly (e.g., asked DHS respondents if they had felt influenced). Accordingly, the results must be interpreted as one of many possible representations of the nature of structural coercion. However, our use of sociological theory to interpret and abstract our findings, should ensure that they provide insights regarding autonomy and coercion in other settings characterised by social, cultural and economic power inequalities.

Social, Cultural and Economic Forms of Structural Influence

Our findings about community members being influenced to participate by knowledge of material benefits, concur with previous findings that accessing individual economic/material goods is an important motivation for people with limited economic power to participate in research (Kalabuanga et al., 2016; Molyneux, Mulupi, Mbaabu, & Marsh, 2012). Accessing a material token of appreciation influenced potential participants' decisions in this community, where many households periodically ran out of soap (Brear et al., 2018). The expectation of long-term community development initiatives, which would have required considerable economic investment (e.g., potable water reticulation systems), also appeared to exert an influence, despite the co-researchers explicitly informing respondents that no such benefits would result from the research. Ethics guidelines and committees define benefits exclusively as knowledge or therapeutic derivatives of the research itself and exclude material goods provided to participants or their communities from their assessment of research risks and benefits (CIOMS, 2016). Conversely, participants in our study framed material tokens and hoped-for development as personal benefits. They desired these benefits in a context where not being able to access them implied the threat of structural violence, for example harms that might arise from living with insufficient sanitation and the increased risk of illness or death that comes with that. These motivations seem reasonable, and our attempts to address and respect them ethical, in a community with widespread health capability deprivations (Brear et al., 2018). While giving tokens of appreciation influenced participation decisions, there is no evidence that it did so unduly, because the study involved minimal risk and people likely would have participated anyway. This is partly because the research had been endorsed by the *umphakatsi* which held considerable symbolic power. The *umphakatsi's* approval of the research, and the power it vested in co-researchers, may have influenced homestead DHS respondents to consent to participation.

Our findings extend evidence of potential for third party coercion in research (Nyirenda et al., 2020), by documenting how it is underpinned by socially structured gendered and other power inequalities. Although typically manifesting in interactions between individual men and women (or other individuals from power-unequal groups), gendered (and other forms of) power is socially structured. In this community it was structured by laws that relegated women to positions of material/economic dependence on men, whose relatively powerful position as heads of homesteads was inseparable from their exclusive land access rights. Recognising that men's (and other third parties') power to coerce is socially structured, indicates that third party coercion should be conceptualised as a type of structural coercion. This concurs with Nyirenda *et al*.'s (2020) conceptualisation of social power inequalities between research participants and researchers and their collaborators, as an aspect of structural coercion. It extends their model by highlighting the need to consider and address power inequalities between potential research participants and third parties who do not collaborate in the research, including husbands and neighbours.

Relations of power in the community were known to and considered by the co-researchers who co-designed the study, from their position as community members (Bourdieu & Wacquant, 1992). However, failure to recognise the structured and embodied nature of these relations of power, influenced by learnings about Kantian-based conceptualisations of autonomy from research ethics, meant that these relations of power were not adequately addressed in the consent procedures design. Our assumption that women would be able to decline participation because we told them it was their right according to research ethics guidelines, neglected the ways in which women's historic experiences of interacting in the power unequal community field, would have predisposed them to submit to and tacitly accept the *umphakatsi's* and their husbands' gendered power and the PHR group's cultural/knowledge power, even in the absence of a direct influence (i.e., a man or co-researcher threatening or incentivising a female

respondent). This has implications for the interpretation of our findings. For example, although we did not find any evidence that particular men directly influenced their wives to participate, women's decisions would have, according to our theoretical framing, been structured by what (they thought) their husbands wanted them to do. Women may have decided to consent without appearing to object, even if they did not want to, or wanted to only to the extent that it would please their husbands, the PHR group and/or the umphakatsi which had approved the study. Their decisions were structured by practical logic and experiential knowledge of the objectively possible decisions (consent or decline) and related outcomes (e.g., receive or not receive soap, please or displease a husband/co-researcher/umphakatsi representative). Even though they were predisposed to socially expected practices, women still exerted agency to make their own decision about participation, albeit not necessarily motivated by the promise of socially useful knowledge, which is situated as the "right" motivation for participation in research ethics guidance. In doing so they disrupted social practices and created space for imagining new possibilities (Bourdieu, 1990).

Acknowledging Individual Agency of Vulnerable Individuals, Amidst Structural Influences

This sociological conceptualisation of people's agency to act autonomously as intrinsic but always structured (constrained or enabled) by objective relations of power has important implications for understanding influence and coercion in voluntary informed consent procedures. It highlights the importance of recognising the ability to coerce/influence as a function of power, whether held by a researcher whose authority is determined by their accumulated cultural/knowledge capital (as MB, who was always believed because she had been to university) or a third party whose authority may be underpinned by any combination of social, cultural and/or economic capital. In this study men's power to control their wives was derived from their social status as homestead heads, which was inseparable from their power to access a key form of material capital, land. While the relations of power we have described are specific to a rural Swati community, they exist in one form or another in every research setting. Our findings build on previous studies of structural coercion (Fisher, 2013; Nyirenda et al., 2020), by highlighting the subtle but pervasive ways in which unequal social, cultural and economic power dynamics might influence research participation decisions.

While acknowledging and addressing vulnerability to structural coercion and influence is important, it must not overshadow the agency vulnerable people exercise in making consent decisions. In our study people, especially women, exerted agency by actively pursuing researchers to invite them to participate, seeking-out study information from third parties and/or making decisions about participation, albeit possibly to please the PHR group, their husbands or the *umphakatsi*. The nature of the information potential participants in our PHR sought and their assumptions, for example about the DHS questions, tokens of appreciation and potential for future community development projects, suggests that their motivations for participating went beyond, and may not have even included, an altruistic desire to contribute to knowledge creation, the motivation implied to be most legitimate in research ethics guidelines, drawing on Kantian philosophy (Campbell, 2017).

Bourdieu's sociological theory provides a comprehensive system for understanding the simultaneous influence of power unequal structures and individual agency to exercise autonomy on practices, including research participation decisions. In doing so it demonstrates that the conceptualisation of autonomy prominent in research ethics- deciding for oneself based exclusively on study information- is impossible in practice. Individual agents bring into consent interactions, and utilise as a source of practical logic, their entire embodied experience of unequal power relations (Bourdieu, 1990). People's motivations for participating in research are influenced by substantive conditions, for example if they have soap in their house or a controlling gatekeeper physically or symbolically present. These motivations are logical and chosen with agency, albeit tacitly, by the potential participants whose autonomy research ethics aims to respect.

The need to provide "fair benefits" to research participants in low- and middle- income countries is receiving increasing attention. It has led to guidelines mandating economic/material reimbursements and/or tokens of appreciate for research participants in several African countries (El Setouhy *et al*., 2002; Hébert et al., 2015; Kalabuanga et al., 2016; Lairumbi et al., 2012; NHREC, 2012). Within this work, material goods have been reconceptualised, in contrast to in dominant research ethics guidance, as benefits. The reasons for providing material tokens have been related to the research ethics principle of beneficence, and ensuring fairness in benefit. We are not aware of any studies that discuss the provision of material benefits in relation to respecting autonomy by legitimising different motivations for research participation, nor in relation to the limitations of the neo-Kantian conceptualisations of autonomy upon which the research ethics principle of respect is based that imply material motivations to participate are unacceptable. Our sociological framing, although not intended to allow us to make moral judgments (e.g., about whether or not the actions of women participants who disrupted gender norms was positive or negative), suggests that any comprehensive attempt to respect autonomy must be grounded in respect for individual's autonomously determined motivations to participate. Expecting people to be motivated by what researchers or philosophers uphold

as the ideal reason for participation in research, is inconsistent with the principle of respect.

Best Practices

Our findings indicate that in structurally marginalised communities informed consent practices will be optimally ethical if researchers:

- Consider and account for researchers' and third parties' structural power to influence potential research participants' decisions.
- Recognise that informing potential participants about what participation involves and their right to decline is important and potentially transformative, but insufficient to enable autonomous decision making.
- Respect participants' actual motivations and where appropriate provide, material tokens of appreciation that represent fair benefits for time and knowledge contributed to research.
- Design research and report findings in ways that consider and account for unequal relations of power which structure individual agency.

Research Agenda

More empirical research about how social structures exert coercive effects on research participation decisions in a range of settings, will advance knowledge to inform research ethics guidelines and practice. Ideally this research will be informed by a variety of theories, including sociological and other theories of power. Such research is needed to elucidate a broader range of structural influences on research participation decisions and motivations to participate in research. Conducting this research is an important way to contribute to scientific knowledge, and in doing so legitimise, the motivations to participate in research that are chosen (autonomously) by structurally marginalised people.

Educational Implications

Research ethics education could be enhanced by introducing the concept of "structural coercion", especially to students and researchers who are likely to work in structurally marginalised contexts. It could also be enhanced by introducing sociological conceptualisations of autonomy as inherently structured, to augment Kantian-based philosophical conceptualisations of autonomy.

Conclusion

Potential participants' decision-making practices may be influenced by information from third parties and motivated by desires other than creating socially useful knowledge. These include accessing personal material benefits and choosing what they think researchers and others in positions of relative power want them to. Although potential participants always decide for themselves, their decisions are intrinsically and tacitly influenced by their position in a power-unequal social hierarchy, and related social norms which predispose them to act in accordance with their position of power (e.g., do what they think more powerful others want them to, to avoid a threat or access an incentive). Voluntary informed consent procedures in research ethics uphold a conceptualisation of autonomy that (at least sometimes) does not match reality and disregards the importance of respecting individuals' autonomy to choose their own motivations for research participation. To optimise respect for autonomy, participants' actual motivations and the structural factors that constrain and enable their agency to decide autonomously must be acknowledged and legitimised. Although participant motivations and structural influences will differ from study to study, the notion that participants should be able to decide for themselves what benefits they will derive from research and why they want to participate, and research ethics should respect participant constructions, has universal relevance.

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