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Conducting Sensitive Research With Disabled Women Who Experience Domestic Abuse During Pregnancy: Lessons From a Qualitative Study

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Published Articles

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Bradbury-Jones, C., Breckenridge, J. P., Kroll, T., Lazenbatt, A., Devaney, J., & Taylor, J. (2015a). Disabled women's experiences of accessing and utilizing maternity services when they are affected by domestic abuse: A critical incident technique study. *BMC Pregnancy & Childbirth, 15*, 181-192.

Breckenridge, J., Kroll, T., Lazenbatt, A., Devaney, J., Taylor, J., & Bradbury-Jones, C. (2014). Access and utilisation of maternity care for disabled women who experience domestic abuse: A systematic review. *BMC Pregnancy & Childbirth, 14*, 234-247.

Abstract

This research-methods case study shares some practical and methodological reflections on doing sensitive research with participants who are typically underrepresented. We focus specifically on the challenges researchers facing during recruitment and data collection. We reflect on the opportunities and challenges created by engaging with gatekeepers to access "hard to reach groups," particularly within the context of sensitive research. We also offer practical examples and solutions to help ensure that research interviews are conducted in an accessible and inclusive way. These challenges and solutions are illustrated by examples from a recently completed research project on how domestic abuse affects disabled women's access to maternity care. Disabled women (women with a long-term health condition or impairment) are at significantly higher risk of experiencing domestic abuse (physical, emotional, sexual, or financial abuse from

an intimate partner) than nondisabled women. Pregnancy is a particularly vulnerable period for all women experiencing domestic abuse, but internationally, very few studies have explored how domestic abuse affects disabled mothers. Both disability and domestic abuse are associated with late or poor access to maternity services, and the aim of our study was to understand the particular barriers and facilitators to accessing care when disability and domestic abuse coexist. The study took place during 2012-2014 and involved three phases: a systematic review, interviews with women, and focus groups with maternity care practitioners. The learning from our study is relevant and useful to anyone planning and doing sensitive research with underrepresented populations.

Learning Outcomes

By the end of this case study, students should be able to

• Explain the terms "sensitive research" and "hard to reach" participants

• Understand the opportunities and challenges of working with gatekeepers and how to prevent and/or overcome difficulties

• Know how to plan accessible interviews that take account of issues relating to either disability or domestic abuse or both

Project Overview

Between 2012 and 2014, the research team carried out a three-phase study to find out about the relationship between disability, domestic abuse, and access to maternity care. The study began with a systematic review, followed by individual interviews with women and then a series of focus groups with health professionals working in maternity care services. Each phase of the

study directly informed the next, and we combined these different perspectives to develop a comprehensive understanding of how domestic abuse affects disabled women's access to care, especially maternity care. A study by Sumilo, Kurinczul, Redshaw, and Gray (2012) found that nearly 10% of women giving birth in the United Kingdom each year are disabled, and up to half of these women are affected by domestic abuse. Despite these stark findings, our systematic review of the international literature found just 11 studies that looked specifically at the barriers preventing these women from getting good and timely maternity care. The findings from our review showed that mental health problems, poor relationships with health professionals, and environmental barriers make it particularly difficult for women to access maternity services. None of these studies came from within a UK context, and they were of varying methodological quality; so, this provided a sound rationale for the importance of undertaking our study (see Breckenridge et al., 2014).

To build on the findings from our review, we then conducted individual interviews with five disabled women affected by domestic abuse who had recent experience of using maternity services. We used critical incident technique (CIT), a research methodology developed by Flanagan (1954). The purpose of CIT is to identify the antecedents, motivators, and consequences behind participants' behavior in order to help solve practical problems. We interviewed women about the specific encounters they had with health services during their pregnancies and asked them to tell us about how and when they accessed services and the specific barriers and facilitators they experienced. Collectively, the women reported 45 critical incidents relating to accessing and utilizing maternity services, and we analyzed the data using Andersen's (1995) model of health-care use as our theoretical framework. We learned from the interviews that positive staff attitudes and women's perceived control over their own health care

influenced their decisions about when and how they used maternity services. If women had negative experiences of maternity care in the past, they were less likely to use services again in the future, and therefore, staff attitudes were really important (for more information, see Bradbury-Jones et al., 2015a).

In the final phase of the study, the team held seven focus groups with 45 health professionals working in maternity services or supporting women during pregnancy. We shared examples of women's stories in the focus groups and asked the professionals to consider and respond to the issues the women had raised. We collected and analyzed both qualitative and quantitative data about health professionals' perceptions on the barriers and strategies to improving maternity care (for the full paper, see Bradbury-Jones et al., 2015b).

The Focus of This Research-Methods Case Study

This case study focuses on the second phase of our project: individual interviews with disabled women. In particular, we will explore, in detail, the nuances of recruiting and interviewing "hard to reach" participants (disabled women experiencing domestic abuse) about a "sensitive" topic (domestic abuse). These were the challenging aspects of our study, and we hope that sharing lessons from our own project will help other researchers considering complex, sensitive topics like ours.

Sensitive Research

There are many definitions of "sensitive" research. In their book, Dickson-Smith, James, and Liamputtong (2008) suggest that research is "sensitive" when it has the potential to negatively

affect any of the people who are involved in it. This might be because the topic is "taboo," highly emotive, deeply personal, or has the potential to result in disclosures with legal or ethical implications. Of course, any research topic has the potential to be "sensitive," and it is impossible to predict what information participants will share and how they will respond emotionally during the research process. However, certain topics are inherently sensitive, for example, research on domestic violence, rape, abortion, child abuse, substance misuse, death, HIV/AIDS, and so on. These topics are sensitive on both a societal level and an individual level; the topics are not only socially sensitive because they are associated with social stigma but also personally sensitive because the empathic connection between researcher and participant may involve difficult emotions. This case study explores two particular challenges in disability and domestic abuse research: specifically, recruitment and data collection. Although challenging, it would be wrong for researchers to be "put off" by sensitive research topics. Researchers have a social responsibility to advocate on behalf of research participants; to ensure their voices are heard and to generate a better understanding of so-called taboo issues. It is only by bringing stories to the fore through sensitive research that we can begin to break down stigmatizing and discriminatory opinions. For some wider reading around doing sensitive research, researchers are directed to the work of McCosker, Barnard, and Gerber (2001); Kidd and Finlayson (2006); and Watts (2008).

"Hard to Reach" Populations

Sydor (2013) has defined hard to reach populations as people "who are difficult for researchers to access" (p. 34). Other terms that are frequently used interchangeably in the research literature include "vulnerable groups," "marginalized groups," "hidden" or "forgotten populations," and

"underrepresented," "underserved," or "disadvantaged populations." Within the research literature, "hard to reach" groups tend to include, for example, refugees, sex workers, homeless people, people with HIV/AIDS, and so on. However, although many of the terms listed above are used interchangeably, it is important to recognize that they are not all synonymous. For example, not all so-called hard to reach groups are socially disadvantaged or vulnerable. Research participants from "elite" groups—company chief executives, prominent politicians, millionaires, or world-leading academics, for instance—can be hard to reach because of their time constraints, geographical location, competing priorities, or a perceived power imbalance between researcher and interviewee. Similarly, it is important to draw a clear distinction between populations who are hard to access, perhaps because of societal barriers, and populations who are "hidden." As Sydor (2013) explains, hidden populations are people who are largely unrepresented in research, to the extent that we cannot be sure how many people there are or where they might be located.

In the case of our project, disabled women experiencing domestic abuse are both hard to reach and hidden. Domestic abuse, as well as being a sensitive topic which can be a barrier to finding participants, is also notoriously underreported, and current estimates of the prevalence of domestic abuse are wide-ranging. Women's reluctance to come forward and use services because they fear retribution from their partner or their children being taken into care makes them harder to identify. Moreover, disabled people have typically been excluded from much mainstream research because of social or physical barriers and the presence of an impairment which makes research participation more difficult (for further reading, see Kroll, 2011). These difficulties were compounded in our study, and indeed, although our original recruitment aim was 10-12 participants, we only recruited half of this number.

Flanagan and Hancock (2010) remind us to use the term "hard to reach" with caution. Although it is commonly used, the term is highly contested, and it is problematic for several reasons. First, the so-called hard to reach groups are not homogeneous, and in relation to disabled people, for example, individuals with a visual impairment may face different barriers to people with a mental health issue. Second, groups are not divided by neat lines, and it is important to think in an intersectional way. People's lives fit into multiple, cross-cutting categories. So, for example, one of the women who took part in our study had a physical impairment, a long-term mental health issue, and a history of domestic abuse. She was also a mother, a pregnant woman, an employee, a family member, a volunteer, a service user, and so on. Finally, and perhaps most importantly, the problem with the term "hard to reach group" is that it implies that the blame lies with the people themselves, rather than it being a failing on the part of researchers, existing recruitment strategies, and traditional methods to access and include people in research. Researchers should be challenged to reframe the problem; rather than participants being hidden or hard to reach, perhaps researchers are failing to engage with participants because they are not using appropriate engagement methods. This reflects a broader shift within health and social care provision, where services have typically categorized individuals as "hard to reach" rather than their services as being "hard to access" (Daniel, Taylor, & Scott., 2010). As our experience shows, recruitment can be very difficult. However, to ensure that research is more inclusive, we must reflect on what went well, and what did not go so well, in order to generate useful learning for the future. The next section explores some of the recruitment difficulties we faced in more detail, focusing particularly on recruitment strategies and accessible methods to facilitate greater participation.

Reflecting on Recruitment Challenges: Working With Gatekeepers

According to Abrams (2010), researchers typically use either snowball sampling or recruitment via gatekeeper organizations to reach hidden or hard to reach populations. In our study, we recruited women through a range of different gatekeeper organizations across the United Kingdom. We worked predominantly with Women's Aid by asking support workers to identify potential participants and share study information with them. We also sought to work with a range of other organizations and found it helpful to map all of our potential gatekeepers at the start of the study. We wanted to work with a range of organizations with remits that came under the following categories: (1) domestic abuse organizations, (2) disability organizations, and (3) parenting organizations. We made contact with these organizations via email, phone, and social media. We found Facebook and Twitter to be particularly helpful when engaging with third-sector organizations. To try and reach women who did not already engage with existing services, we also advertised the study in mainstream media. After a press release about our study and subsequent newspaper and radio interviews, we were contacted by three women who wanted to take part. It is often assumed that a press release comes at the end of a study as a form of dissemination; however, our experience highlights how useful a press release can be in also facilitating recruitment.

Working with gatekeeper organizations can be highly beneficial to researchers. As Abrams (2010) suggests, organizations have established links with pools of potential participants and can provide advice on effective stakeholder engagement. Overt support from well-known and trusted organizations can help to enhance the perceived credibility and trustworthiness of

research activity, meaning that potential participants are more likely to engage with the researcher. Organizations can also provide safe and familiar meeting places; we interviewed one participant in a Women's Aid office. Recruitment via gatekeepers, however, is also inherently challenging. Recruiting through gatekeepers can skew the representativeness of the sample by excluding the important voices of women who do not have existing support services in place; they remain hidden. Moreover, although organizations can lend credibility to research, it is important that genuine informed consent is upheld, and potential participants are not coerced, either directly or indirectly, to take part (Abrams, 2010). Researchers also have an ethical responsibility to work with gatekeeper organizations in a way that is sensitive to the financial pressures they face, particularly organizations within the charity sector. Researchers should work to minimize the demands placed on gatekeeper organizations and may wish to consider financial recompense for gatekeepers as part of the research planning process. We will now explore in more detail some of the particular challenges arising in our study, using our own experience to offer insights into addressing some of these challenges in practice.

Dealing With Different Interpretations

Gatekeepers may interpret the recruitment inclusion and exclusion criteria quite differently to the researchers' original intentions. For example, our inclusion criteria were based on a very wide definition of "disability": we wanted to speak to women with any health condition or impairment that affected her ability to participate in daily life. This definition covered any range of physical, sensory, and intellectual impairments and mental health conditions. It also included long-term conditions such as asthma or epilepsy. However, it became clear to us very early on in the study that gatekeepers envisioned "disability" as referring only to physical disability. This potentially

narrowed our pool of potential participants, and although we made every effort to reiterate our wide definition within study documentation, this continued to pose a challenge throughout the project. It is possible that our lack of specific criteria was more of a hindrance than a help, and perhaps, it is easier for gatekeepers to have quite clear and narrow criteria to remember and operationalize. However, one way to engender shared understanding with gatekeepers is to ensure that they are fully engaged and committed to the research, as discussed next.

Increasing the Perceived Value of the Research

In general, we found that the more gatekeepers saw the value in the research project, the more likely they were to engage in assisting us access to potential participants. Recruitment for research presents additional work for gatekeepers who are ordinarily busy with their existing workload, and so, it is essential that they perceive the research project to be worth their time and effort. It is helpful to recognize too that gatekeepers may perceive "research" in different ways. For example, one gatekeeper said to one of our research team, "no offence, but I just couldn't do your job, it sounds so boring." On further, tactful exploration, it transpired that the gatekeeper had a negative, preconceived notion about the research process; she thought that a research interview was about going through a highly structured, tick-box questionnaire. Once she understood that the "interview" was an unstructured, informal conversation to capture what was important to women she was much more engaged in the process. This is an important lesson, because as researchers we cannot assume that others place the same value—or have the same understanding—of research as we do. It is also important to meet with gatekeepers face to face, rather than in formal email communications. Sharing the researcher's personality and connecting on a personal level with gatekeepers "humanizes" the research process. In areas where we met

face to face with gatekeepers, we were much more likely to get their continued engagement and follow through to finding participants. In practical terms, this means that researchers need to include time and budget for traveling to meet with gatekeepers within their research plan.

Counterbalancing Protectionism

Gatekeepers are bound by a duty of care toward their service users and may be worried that engaging with the research will negatively affect participants, particularly if the research involves a sensitive topic or potentially vulnerable participants. According to Atkinson (2007), however, it is important that the desire to protect potential participation does not deny them the opportunity to have a voice in the research process. In our study, for example, one disability organization we contacted was reluctant to help us with recruitment because, in its view, "disabled people don't like to talk about sensitive issues." While there is a place for protecting vulnerable people, "protective" views such as this become problematic if they are based on stigma or generalizations. Excluding disabled people from research contributes to their continued marginalization in society, and it is important that people are offered an opportunity to talk about the social issues that affect their lives. As Haines and Devaney (2004) argue,

> it would be a perverse consequence if, in trying to protect the rights of vulnerable individuals, that their lived experiences were lost, and those responsible for formulating policy and delivering services knew less, rather than more, about the needs and views of the marginalized in society. (p. 329)

Moreover, it is critical to remember that "vulnerability" is highly context dependent and is not determined by personal characteristics alone. Again, we found that meeting face to face, or, at least, over the telephone, with gatekeepers was essential in building gatekeeper trust. When

gatekeepers trusted us and were reassured that we could interact with their service users in an ethical, sensitive, and inclusive way, they appeared to feel more comfortable in promoting the project to potential participants and putting us in touch directly with women to talk about their decision to participate. Ultimately, it is important that people themselves make an informed decision about whether or not to participate in research, and a positive working relationship with gatekeepers can facilitate this.

Another strategy we used to make sure that potential participants got information directly from the research team rather than exclusively through gatekeepers was to develop a Facebook page for the study (see www.facebook.com/maternitystudy). We recorded and uploaded videos of the researchers talking about the project in an informal way. Providing that gatekeepers passed on our study leaflets to potential participants, they would be able to go online and "hear" directly from the research team about what the study involved. We also hoped that this would humanize the research process for research participants. To someone who does not know about academic research, the terminology of participant information sheets can be confusing and, at worst, intimidating. People may have anxieties or negative preconceptions about what university research is, what researchers are like, and what happens during a research interview. By modeling the informal style and showing some of the researcher's personality, we hoped that the videos would encourage people to talk to us about potentially taking part. The Facebook page also provided a good means of dissemination, and it continues to be used and accessed long after the study officially came to an end.

Practicalities of Data Collection

Accessible Interviews

When doing research with disabled people, researchers need to plan data collection carefully. As Kroll (2011) demonstrates, researchers need to accommodate for people with different types and levels of impairment. Individuals who have sensory, physical, cognitive, and communication impairments may experience different barriers to engaging in research. For instance, our study included five women with a variety of impairments, including anxiety and depression, congenital physical impairment, communication impairment, acquired physical impairment, and learning disability. Moreover, many people live with multiple impairments, and the women in our study experienced a combination of the impairments listed above. When planning our grant application, we ensured that we sought enough funding to support additional considerations such as accessible venues, accessible transport, carer assistance, and producing easy read materials. We also made adaptations to the research process. For example, when working with one woman who had a learning disability, we used a longer process of informed consent. One of the researchers met with her on several occasions with her Women's Aid support worker to talk about the research and what this would involve. Seeing this participant on several occasions ensured that she had time to fully understand the research process before taking part. Similarly, during the interview itself, the researcher made sure to adapt her interview style so as not to include jargon or overly complicated sentence structure. We offered different interview formats, for example, a woman with a communication impairment preferred to do her interview via email. This presented some methodological challenges; email is asynchronous and may not elicit such rich data as other methods. However, we felt it was more important to be flexible and accommodate women's needs and preferences.

A Foundation of Trust

There is some debate within the methodological literature on sensitive research about the ideal depth of relationship between researcher and participant; while some authors believe that a one-off encounter is best (participants are more likely to disclose personal stories to an objective stranger who they will never see again), others believe that the key to successful interviewing in sensitive research is to build a relationship with participants over time. Hill (2004), for instance, suggests that researchers should be willing and able to provide support to participants before, during, and after their participation in the study where appropriate. In the context of our study, relationship building was crucial to ensuring that the women felt comfortable, and we were able to gather good quality data. We engaged in a process of trust building before doing the interview, and indeed, the interview was never the first and only encounter between researcher and participant. The researcher visited women in hospital several times and chatted over the phone, email, or text to develop rapport. This social "getting to know you" process developed a familiarity between researcher and participant that provided a supportive context for talking about sensitive, personal experiences. This was particularly helpful for women living with anxiety disorder as it helped to put them at ease. After the interview, we offered women the opportunity to keep in touch to hear about how the study progressed. By giving women this choice, they were able to continue the relationship or not, depending on their individual needs and preferences.

Fitting Around Family Life

Research participants' lives amount to much more than the narrow focus of any research study. This is true for all research participants and is worth always bearing in mind. All the women who took part in our study were mothers; they each had between two and six children and so, to

ensure they could take part, data collection needed to fit around their family lives. We asked participants to choose the location for their interview. Some chose to have the interview at homes, while others were interviewed at their Women's Aid offices where child care might be available for a short time. We carried out interviews to fit around school or nursery hours. Fitting around family life means that the researcher must fit into the participants' environment where there may be other children around, the television might be on, the phone might ring, there might be a visit from a health visitor, another family member, and so on. We interviewed women between bottle-feeding schedules, and interviews often took place in whispered voices as women held their sleeping babies in their arms. Of course, research textbooks about qualitative interviewing rarely warn researchers about how to prepare for this!

Some Words on Safety

Domestic abuse research carries specific ethical and practical risks for researchers and participants. Much has been written about this elsewhere, and the reader is directed to Downes, Kelly, and Westmarland (2014) and World Health Organization (WHO, 2001) for further advice on planning ethically sound domestic abuse research. Working with gatekeepers can facilitate safer data collection. One of the benefits of working with gatekeepers such as Women's Aid was that we could draw on their expertise and could interview women within a safe location where support was at hand, for both researcher and participant. Recruiting women who had support in place already was useful because it meant that we could encourage women to talk to their existing support worker if they wanted to debrief following the interview or if they were at risk. For women recruited via other means (e.g., disability organizations or via social/mainstream

media), we also ensured that we had domestic abuse helpline numbers available and had a process in place if participants or their children were at immediate risk.

While we said earlier that it is important to fit around women's family lives and to offer a choice of meeting location, visiting women at home is not without risk. This is the case for lone researchers in any context but is particularly heightened when visiting a woman known to have an abusive partner. Before arranging interviews, it is important to risk assess the situation and have a process in place for ensuring researcher safety. For example, in our study, the researcher contacted the principal investigator (PI) via telephone before and after each interview and ensured that the PI had details of the interview location and expected finish time. Advances in technology will change the landscape of fieldwork, for example, there are now several varieties of lone worker global positioning system (GPS) tracking devices that could enhance the safety of researchers in the field. Of course, researchers not only face physical risks but must also plan for their emotional safety. Domestic abuse research involves collecting and analyzing potentially distressing data which can affect researchers emotionally. We cannot emphasize enough how important it is that researchers make full use of supervision available to them from PhD supervisors or line managers. To consolidate and further the reader's learning, we recommend further texts which explore reflexivity, reflection, and researcher well-being within the context of sensitive research, for example, McCosker et al. (2001); Dickson-Smith, James, Kippen, & Liamputtong (2007); Watts (2008); and Taylor, Bradbury-Jones, Breckenridge, Jones, and Herber (in press).

A Final Note on Recruitment

This research-methods case has described our difficulties with recruitment. While we were only able to fulfill half of our recruitment target, it is important to state that we did identify a further nine women who met our inclusion criteria. For different reasons, such as immediate personal safety, current physical or mental health state, child-care arrangements, housing status, or simply being too anxious about the research process, these potential participants were not willing or able to take part. These reasons were typically relayed to us via gatekeepers and as a result, we were not always sure whether these reasons were identified by women themselves or were assessed by gatekeepers as barriers to engaging in the research. Had we been able to speak to potential participants directly, using many of the strategies discussed earlier, we may have been able to allay some of their anxieties and assure them that we could be flexible and sensitive to their circumstances. However, it is also important to acknowledge that even when a variety of mechanisms are in place to support research participation, there are elements of recruitment that are outside the control of the research team. Researchers must respect informed *non*-consent and ensure that potential participants' decision making is supported in a way that meets their individual needs. This has implications for planning sensitive research with hard to reach, hidden populations, and extra time should be allowed in order to maximize opportunities for people to take part. For instance, it might be possible to return to participants who were initially too unwell to take part at a later date if money and time allows within the research process. Ultimately, as researchers, we are privileged when people agree to take part in our studies, and we must be mindful that research participation does not cause undue stress, worry, or harm to participants and that participants see value in the research process.

Conclusion

Although sensitive research is challenging, it is crucial that researchers raise awareness about difficult issues and start to address the stigma surrounding so-called taboo subjects. Sensitive research often also involves hidden or hard to reach populations, which can compound the challenges researchers facing as they plan and implement research projects. Our research-methods case study has highlighted some of the difficulties we faced in doing research with disabled women who experience domestic abuse during pregnancy. We have shared some hints and tips for working with gatekeepers and collecting data in a way that is accessible, inclusive, and fits within the greater context of participants' lives.

Exercises and Discussion Questions

1. Define and explain the difference between "hard to reach" and "hidden" populations. Can you think of specific examples to illustrate this?

2. In relation to your own study, spend some time mapping out potential gatekeepers. What strategies will you use to engage them fully in your research?

3. What could we have done differently in our study to maximize recruitment?

4. When planning qualitative interviews, what would you need to consider if your participants had (1) a physical impairment, (2) a visual impairment, (3) a learning disability, and (4) a mental health condition?*

5. What extra considerations must researchers think about when doing research with women experiencing domestic abuse?*

* The "Further Reading" section below will help you to answer these questions more fully.

Further Reading

Sydor, A. (2013). Conducting research into hidden or hard-to-reach populations. *Nurse Researcher, 20*(3), 33-37.

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Web Resources

www.facebook.com/maternitystudy

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