Setting the Stage: Creating Study Sites That Promote the Safety and Dignity of Research Participants

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The U.S. Department of Health and Human Services' (HHS) Code of Federal Regulations regarding Protection of Human Subjects (45 C.F.R. part 46) provides guidance to social science researchers on how to minimize risks to research study participants. In most academic contexts, institutional review boards use these regulations to assess and monitor research protocols to limit participants' exposure to physical and psychological risk. Although these guidelines provide rigorous oversight of research activities (for example, recruitment, consent processes, instruments, and protocols), they do not offer direction on how to set up data collection sites (that is, the specific places where interviews or surveys are conducted). Lack of discussion about this critical piece of the project development process ignores the central role of place in constructing human interactions and may put both research subjects and staff at risk. This research note seeks to address this gap in knowledge by drawing attention to the issue and sharing five recommendations for creating a safe study space. Specifically, we discuss the development of a freestanding study site for community-based social science research where data is collected outside the physical space of a university or agency.

The need to create community-based study sites that can effectively minimize risks borne by research participants, as well as staff, during data collection is particularly salient to social work researchers. The NASW *Code of Ethics* section 5.02, "Evaluation and Research," subsection (e), articulates a research ethics mandate that extends beyond the federal HHS requirements. The *Code of Ethics* calls for members of the profession to conduct research "with due regard for participants' well-being, privacy, and dignity" (NASW, 2008, p. 25). Developing a study site that will promote participants' well-being and

dignity is no small charge. BSW and MSW professionals who are employed as research assistants and project managers, and the social work faculty who train students in research methods, may benefit from more deliberate discussion about the logistical and planning issues related to research space.

Existing literature discusses tasks that can be "undertaken prior to data collection to ensure that data are of the highest possible quality at the time they are collected" (Whitney, Lind, & Wahl, 1998, p. 72). Suggestions focus on research design issues (for example, framing research questions, developing instruments, engaging stakeholders, recruiting and retaining participants) relevant to multisite studies (Knatterud et al., 1998; Rahbar, Wyatt, Sikorskii, Victorson, & Ardjomand-Hessabi, 2011; Yeatts et al., 2012), interventions research (Naleppa & Cagle, 2010), longitudinal studies (Dennis, Perl, Huebner, & McLellan, 2000; Whitney et al., 1998), and university-community collaborations (Begun, Berger, Otto-Salaj, & Rose, 2010; Secret, Abell, & Berlin, 2011). Practical suggestions about site selection and development are generally not included in this literature. There is a small body of literature about research staff safety that describes the necessity of acknowledging that risks exist "in the field" and introduces safeguards to reduce the ambient and situational dangers that can arise during the course of data collection (Bloor, Fincham, & Sampson, 2007; Craig, Corden, & Thornton, 2000; Dickson-Swift, James, Kippen, & Liamputtong, 2008; Lee, 1995).

We would like to contribute to this existing literature on project organization and mediation of risk by providing five recommendations about how to design, create, and operate a research study office derived from our experience conducting the Structures, Health and Risk among Re-entrants,

Probationers and Partners (SHARRPP) study. This research about the impact of criminal justice systems on HIV risk was funded by the National Institute on Drug Abuse and included two mixed-methods projects: a cross-sectional pilot study (principal investigator [PI]: K. M. Blankenship, 5R21DA019186) and a larger longitudinal study (PI: K. M. Blankenship, 1R01DA025021) that, together, spanned a period of eight years. During this time, the study was located in three different study sites, each with its own set of distinct challenges in terms of preserving participant confidentiality, dignity, and well-being. This research note shares the knowledge we learned from and inside these different spaces.

The SHARRPP research protocols involved collecting interview and survey data from over 400 formerly incarcerated men and women in New Haven, Connecticut. Particular care and attention to human subjects protections were required because of the participants' varied and intersecting vulnerabilities produced by criminal justice identities, substance use histories, race, socioeconomic backgrounds, housing insecurity, physical and mental health disability, sexual orientation, and gender. Although SHARRPP's sample may have been especially vulnerable, engaging with marginalized communities is part of social science research, and social work research in particular, so this discussion about the promotion of safety and dignity has broad relevance.

Taken together, our recommendations aim to expand researchers' capacity to conduct ethical research by providing strategies for creating a study space that is safe for both research participants and staff. The recommendations may also promote project efficiency and the reliability and validity of study data by minimizing the potential for lapses in security that could result in lost data, participant attrition, and staff turnover. Many dimensions of our experience with SHARRPP were site-specific and cannot be generalized, yet the core lessons related to office space are germane to all freestanding data collection sites regardless of the study's aims and design. Our five recommendations are presented next, followed by a discussion about the implications of our experiences and suggestions for future research.

1: FIND A SPACE THAT REVEALS LITTLE ABOUT THE STUDY

Recommendation Details

Locating the office in a space where participants feel comfortable and confident that their privacy will be

maintained is critical for study recruitment and retention. Efforts should be made to secure space in generic buildings with nondescript labels. Further, when conducting research about stigmatized populations or conditions (for example, formerly incarcerated people, drug use, HIV/AIDS), it is important to obscure the study topic when interacting with the building's front desk staff or door attendant, if any, and people working in adjoining offices. Response to friendly inquiries about the nature of your work may later become problematic if assumptions are made about visitors to the study office. Staff should resist sharing their work with people in the building who are not directly involved in the project.

Our Experience

In the first phase of the pilot project, we conducted qualitative interviews in a generic downtown office building. Because the building was used by a range of small businesses (lawyers, accountants, and so on), the space was completely anonymous. We used the space infrequently and had no interaction with other tenants. However, a very curious front desk guard did present some challenges to preserving the participants' privacy. His direct inquiries about what we were doing in our office and who was coming to visit required staff to creatively deflect questions. Our attempts to skirt the issue seemed to only increase his interest. Eventually, his questions subsided. What we do not know is whether he also interrogated participants, pressuring them to reveal information about their backgrounds and the study's eligibility criteria. In retrospect, we might have asked the building manager to provide training about confidentiality and professional boundaries for their staff.

A second site, where survey data were collected during the pilot phase, was a university office that had the word "AIDS" in its title. We were concerned that this name could represent a barrier to participation for potential study subjects but did not have resources to locate the study in another space. Ultimately, because the office was referred to by its acronym, rendering the word "AIDS" largely invisible, the name was not problematic. Also, the building was sparsely populated and had no front door staff, so participants came to and from the office with little to no interaction with nonstudy personnel.

Subsequently, when the larger grant was awarded, we consolidated all of our research activities in a single office suite in a large medical building. This space was ideal because the front desk staff were

extremely professional and never inquired about the purpose of our work or the population who visited the office. The staff were consistently courteous and attentive, without being intrusive. Given that the majority of the building's tenants were medical offices, it was possible that training for the front desk position included attention to privacy considerations. When speaking with the landlord, building staff, and neighboring tenants about our work, we found that truthful yet vague responses describing SHARRPP as a "health study" sufficed.

2: PROVIDE A WAITING ROOM

Recommendation Details

Given the transportation insecurity of vulnerable populations, it is not uncommon for participants to arrive early, or late, for appointments. Therefore, having a place where participants can comfortably wait for their appointments is a key feature for all study sites. A safe and comfortable space may also lend dignity to the experience of study participation. To limit traffic and preserve confidentiality, ideally, only study participants should be permitted to wait in the office. Nearby space outside of the office can be identified as waiting places for people who accompany participants to the study.

Our Experience

During the pilot phase, our study spaces did not have adequate waiting areas. There was no waiting room in the downtown office building. This forced participants to wait in the building's reception area, near the front desk, which may explain some of the guard's curiosity about the study. In the university space, where survey data were collected, the small, shared waiting room was quickly filled to capacity by participants and their companions, creating noise and activity that was disruptive to the colleagues with whom we shared space. Both of these scenarios posed challenges for maintaining participants' confidentiality and dignity.

When we moved to the medical building for the larger study, we deliberately created an adequate waiting area within the office suite. A single research assistant (RA) was charged with overseeing the flow of the office, which could include up to three participants at a time. (There was always at least one other staff person present, but she was often conducting qualitative interviews and was not readily available.) The waiting area, which had seating for up to three people, allowed the RA to focus on survey participants and incoming phone calls by minimizing the

number of extraneous people in the office. The small, simple reception area allowed enough space for participants to wait comfortably, without providing any incentive for people to do so.

In spite of our experiences during the pilot, we had no clear policy on nonparticipant guests when we first began the larger study. We continued to find that it was common for study participants to come to the office with a friend or family member who was not enrolled in the study. In many cases, the companion had given the participant a ride and was waiting to drive him or her back home. Some participants were in residential treatment programs that required them to travel with another person. Other participants, especially women, chose not to travel alone for safety reasons. The project's lack of "guest policy" quickly became problematic as we found ourselves in the awkward position of having to ask people to leave the office. We remedied this situation by making it clear during the informed consent process that participants' companions could not be accommodated in the study office, due to space constraints and to guard the confidentiality of other participants. We identified local coffee shops where people could wait. We also tried to be flexible with this policy, allowing companions to stay in the waiting area when the office was not busy and no other participants were present. After being advised ahead of time about these policies, participants cooperated fully.

3: SECURE A PROJECT-SPECIFIC BATHROOM

Recommendation Details

Securing a bathroom for participant use is essential in studies like SHARRPP where the surveys and interviews can take over an hour to complete. In addition, for studies that involve vulnerable people who are unstably housed and spending long periods of time in public spaces while looking for work and attending service appointments, access to a clean, safe bathroom can be a benefit of participation that helps with recruitment and retention. Providing clean and accessible bathrooms also reflects social work's commitment to participant well-being and dignity. Ideally, the facilities should be either reserved for study participants and staff or open to a diverse public so that participants are not made to feel as if they are intruding on a private space.

Our Experience

In the professional office building used during the pilot, there were large bathrooms located in the

hallway. Because the building housed multiple offices that were open to the public, the study participants' use of the facilities was not remarkable in any way. In contrast, at the university site where participants had access to employee bathrooms in the hallway, their presence was more conspicuous. The use of these bathrooms by study participants disrupted "business as usual" for the university employees who worked in the building and were required to share "their" facilities. Although no acute incidents arose from the bathroom encounters between these two populations, participants may have felt out of place and some employees expressed resentment about having their private space open to the public. Our final space, in the medical building, was an all-inclusive suite with four offices and a single bathroom. We created protocols to ensure the safety of this bathroom space, including keeping a key to the bathroom available should someone be unable to exit after locking themselves in, and a sharps kit, including gloves and a hazardous material container, in the event that hazardous materials (such as syringes) were found in the facilities.

4: REDUCE THEFT OPPORTUNITIES

Recommendation Details

Failure to protect personal belongings and valuable study equipment and supplies puts study data, staff, and participants at risk. Every effort should be made to secure the office and reduce opportunities for theft. It is difficult for laptops secured by safety cables to "walk away." Staff cell phones, purses, and other personal items should be kept in locked cabinets. Cash required for participant payments should be stored off-site or in a safe and withdrawn when there are no study subjects in the office. Only the amount of cash needed for the day's data collection should be kept on hand. Should resources permit, the installation of an alarm system, to monitor the office space after hours, is ideal.

Our Experience

These precautions should be in place regardless of the population participating in the study. The inclination to take advantage of an opportunity to steal something of value reflects a combination of individual and situational factors that spans all socio-demographic groups (see, for example, [Cupchik, 2013](#); [Gino, Ayal, & Ariely, 2009](#); [Greenberg, 2002](#)). SHARRPP's policies about theft prevention were instituted not because we assumed the formerly

incarcerated people coming to the office were different from the general population, but because we assumed they were the same. Nonetheless, we recognized that because SHARRPP specifically recruited people who had been recently released from prison or placed on parole and probation, the implications for them if they were to become entwined in a theft incident were enormous. By being sloppy with valuable items in the study space, study staff might inadvertently facilitate opportunities for theft that could return a SHARRPP participant to prison. Without diminishing the central importance of personal responsibility, we understood the task of creating a secure space as a human subjects protection issue.

To create a safe space that could safeguard participant confidentiality and study property, we made efforts to monitor the number of people in the study office. Keeping the front door of our office suite locked at all times allowed staff to stay apprised of who was inside the study space. We installed an inexpensive remote doorbell that participants used to request entry. At the same time, we discussed the fact that keeping the door locked could prevent or slow access to the suite in the case of an emergency. Offices with interior doors that locked were identified as places where staff could find refuge and call for help, if a dangerous situation arose and the suite door was inaccessible.

5: PLAN FOR BAD WEATHER

Recommendation Details

The zeal to reach recruitment and data collection goals should never be placed ahead of a study's commitment to participant and staff safety. Plan to close the office if the public schools in the jurisdiction where the study office is located are closed. Aligning severe weather policy with the school district prevents confusion about whether or not the office is open and prevents participants and staff from placing themselves in harm's way to make a study appointment. This is a relatively small issue but one that should not be overlooked, especially because it is so easy to resolve.

Our Experience

Severe winter storms forced the study office to close on several occasions during the data collection period. Because the roads were treacherous and participants had been advised during the consent process that the office would close with the public

schools, staff was fairly confident that participants would not attempt to come in for their appointments. Still, staff called participants to confirm that the office was closed. Because not all participants could be reached by phone during the storm, having a clear closure policy was important.

SUMMARY AND CONCLUSION

Federal and social work research guidelines stipulate that the privacy, dignity, and well-being of human subjects must be protected. Success in achieving these goals hinges not only on the research design (that is, the ways in which we recruit and enroll subjects and the information and activities that are required from them), but also on the configuration and design of the space where research activities take place. Failure to carefully explore safety and space design issues may result in situations that cause harm to participants or staff, upset recruitment and retention efforts, and compromise data collection. However, human subjects research regulations are largely silent on this issue of place, leaving researcher teams without formal guidance when it comes to setting up freestanding study sites. Missteps related to space are rarely shared (unless they produce adverse events related to participants that must be reported to an institutional review board), making them largely invisible and limiting the ability of future projects to learn from these mistakes. Similarly, clever innovation goes untapped unless staff has the good fortune to overhear implementation tips in the lunchroom or at professional networking venues. Our goal with this research note is to promote deliberate discussion and documentation of these issues by providing specific recommendations from our own research experience and encouraging other researchers to do the same.

Although funding deadlines and the desire to get a study “up and running” may push investigators to accelerate the logistical planning process, we encourage teams to be thoughtful and deliberate about decisions related to space. Academia’s commitment to building knowledge, understanding psychosocial problems, and informing social services should include dissemination of field knowledge about study site development and safety by encouraging journal publications, conference discussion, and undergraduate and graduate education on this critical research issue. **SWR**

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