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Engaging Vulnerable Youth in Community-Based Participatory Research: Opportunities and Challenges

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ABSTRACT

Drawing on a community-university (CU) partnership between a non-profit organization that serves teen families, a housing organization and a university, this paper discusses the opportunities and challenges that can arise when engaging vulnerable youth in research. Through this paper, we share reflections on promising practices and ethical considerations in the participant recruitment, data collection, data analysis, and dissemination stages of the research process. Conclusions are offered for those seeking to engage vulnerable youth in research.

Keywords: vulnerable youth, community engagement, collaboration, teen parents

The last decade has involved growing efforts to include youth as active research participants rather than passive subjects (Kennan, Fives, & Canavan, 2012). Vulnerable youth are characterized by involvement in social service systems, lack of personal and financial resources, and risk of experiencing poor outcomes as they transition to adulthood (Tanner, 2007). The term “vulnerable” is used in the current paper to describe young people who are made vulnerable by social and environmental factors. While recognizing that this is not a unitary population, we use the term “youth” to refer to individuals in the broad stages of late adolescence to early adulthood (i.e., age 16-24). Although particularly difficult to engage, there are benefits to engaging youth exposed to the greatest risks for poor educational, health, and social outcomes (e.g., due to trauma, mental health issues, exposure to adversity), and/or who have needs that exceed those that can be addressed by a single service provider (Kennan et al., 2012). Participatory research approaches with vulnerable youth, such as community-based participatory research, are linked to

enriched research processes and enhanced social action, but can involve significant costs in terms of an added, ongoing need for financial and human resources (Flicker, 2008). Thus, there is a need for researchers and community partners to critically reflect on the processes, including potential risks and benefits, of engaging vulnerable youth in research.

This paper provides a discussion of the opportunities and challenges that can arise when conducting research with vulnerable youth. We draw on our experiences in a community-university (CU) partnership project that aimed to examine the impacts of a supportive housing model for teen parents and their children. To provide context, this paper begins with an overview of our CU project. Next, our discussion of opportunities and challenges is structured according to three main areas of the research process: (1) participant recruitment, (2) data collection, and (3) data analysis and dissemination. Within each of these three areas, we share promising practices and ethical considerations in light of current literature and our experiences. Finally, we end with

conclusions that bring our learnings together. This paper does not aim to provide an in-depth description of our research methods or results. The purpose of this paper is to describe our reflections, processes, and lessons learned in an attempt to elevate awareness and offer considerations regarding the complexities in conducting research with vulnerable youth.

SUCCESSFUL FAMILIES PROGRAM

This CU project is an equitable partnership between two community organizations and researchers from the University of Alberta. The Terra Centre for Teen Parents (Terra) is a non-profit organization that has provided comprehensive support services to pregnant and parenting teens for over 45 years. Brentwood Community Development Group (Brentwood) was formed in 1977 with the vision of providing affordable family housing. Terra and Brentwood partnered in 2014 to offer safe, secure, and affordable housing to teen parents and their children with wraparound supports in a neighbourhood located in Edmonton, Alberta, Canada. The Successful Families (SF) program was initiated out of a recognition that teen parents and their children often struggle to attain safe, secure, and affordable housing, with significant implications for child-rearing and child development (Graham & McDermott, 2006).

With respect to the SF program, Brentwood provides subsidized townhouse units for teen families based on income, and acts as the landlord for families by, for example, collecting rent payments and conducting unit inspections. Brentwood also provides a residence (the SF House) that has been converted to office space for SF staff members, and space for group programming. The SF House is located across the street from participants' homes. Terra trains, employs, and supports a staff team comprising one full-time manager and three full-time housing staff. Housing staff conduct home visits and provide group programming to build participants' capacity for

success as tenants, parents, and contributing members of their community.

With the intent of investigating the impacts of the SF program on teen parents and their children, Terra and Brentwood contacted researchers at the University of Alberta to begin a collaborative research project. The project was guided by community-based participatory research principles (CBPR; Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2003). Community-based participatory research (CBPR) brings researchers and community partners together to develop mutually beneficial knowledge and meaningful social change by applying local knowledge and experience to data. Researchers and community partners from Terra and Brentwood formulated the research objectives as well as plans for participant recruitment, data collection, and dissemination together. At the time that this paper was written, the partnership between the researchers, Terra, and Brentwood was ongoing, and had been in place for three years.

To determine the impact of the SF program, we used photovoice (Wang & Burris, 1997), interviews, and focus groups with staff and participants. Additionally, a clinician conducted child development assessments (i.e., assessments of children's cognitive, language, motor, social-emotional, and adaptive skills), and parents completed self-report questionnaires regarding the program, self-esteem, parenting attitudes, resilience, and parent-child relationship quality. To measure changes in parent and child outcomes, we aimed to complete assessments and self-report questionnaires three times over one year (at move-in, six months, and 12 months). In this article, rather than presenting results, we offer reflections upon ethical considerations and promising practices for engaging vulnerable youth in research.

PARTICIPANT RECRUITMENT

Promising Practices

Community-university relationship building. Connecting with youth for research recruitment is arguably the most challenging stage of the research process, particularly when youth are in vulnerable circumstances (Zayas, Hausmann-Stabile, & Pilat, 2009). For this reason, the most vulnerable populations are often left out of research (Curtis, Roberts, Copperman, Downie, & Liabo, 2003), which can silence their unique perspectives. In our work, we have learned that relationships are critical to recruitment for research. These relationships are multi-directional between researchers and program staff, researchers and participants, and program staff and participants.

Importantly, the partnership between Terra, Brentwood, and the University of Alberta was first formed with agency Executive Directors. It was, therefore, critical for researchers to also establish relationships with front-line staff who had direct contact with families. This initially took place through the researchers attending two to three staff meetings per month. Some SF participants reported negative experiences with service providers and varying levels of trauma, and SF staff needed to spend time with the researchers to trust that appropriate interactions with participants would take place. The research team built trust by demonstrating a willingness to learn from staff, openness about their perspectives and biases, and transparency regarding the approaches that they had experienced as successful in engaging vulnerable youth in research.

Community events. As relationships between researchers and staff were built, staff began to invite the researchers to program events such as play groups at the park and community barbecues, which provided the opportunity for the research team to interact with staff and participants in more informal settings. At these events, the

research team began to approach participants to introduce themselves and the research project.

Research information sessions and program groups. To further enhance recruitment, a research information evening was held at the SF house where participants were invited to share a meal and learn about the project. In addition, one of the research team members began to attend weekly SF groups to meet participants and sign new participants up for the project, which was an effective recruitment method.

Front-line staff involvement. An additional recruitment method involved staff explaining the project to participants. A brief training session was held with staff members to describe how to explain the project and gather informed consent. Packages with instructions, consent forms, and self-report questionnaires were created for staff to distribute to new participants upon joining the SF program. We were able to recruit a small number of participants this way, but found that having the research team explain the project to potential participants in person was a more effective recruitment method due to staff time constraints.

Ethical Considerations

A number of ethical considerations arose when recruiting teen parents for research participation, some of which related to informed consent. We approached informed consent as a process requiring ongoing negotiation at all stages of the research to uphold participants' rights and autonomy, and disrupt unequal power relations between researchers and participants (Brear, 2018). In the context of research, youth are typically viewed as more vulnerable than adults, given their less advanced stages of cognitive and emotional development, legal capacity, level of autonomy, and reliance on family influence (Hall, Stevens, & Pletsch, 2001). Many research ethics boards make consent-related decisions consistent with a protectionist framework, where youth are positioned as inherently

vulnerable subjects who require representation from adults (Chakraborty, Nansen, Gibbs, & MacDougall, 2012). In the current project, even when under the age of majority, teen parents provided consent for their own children to participate in research (i.e., to have child development assessments completed with their child). It, therefore, followed that teen parents could provide consent for their own participation, and our ethics board allowed for this. Contemplating these issues served as a reminder to critically consider how we obtain informed consent with other vulnerable populations.

SF staff members' involvement in gathering consent was another recruitment issue that we considered. The literature highlights the need for caution when staff members are involved in research recruitment, citing examples where agency staff may persuade youth to participate in research in ways that constitute coercion (Curtis et al., 2003). In the case of this project, SF staff were committed to a service delivery approach that involved walking alongside participants and upholding their individual autonomy, rather than persuading them toward any decision. Even so, frequent check-ins between the research team and SF staff took place regarding the ethics and power dynamics involved in research recruitment, and the ethics training session with staff described above was important for ensuring staff members' ethical recruitment of participants. In all, SF staff involvement was critical for recruitment. Even where SF staff members were not directly recruiting participants, they could follow up with participants and answer questions.

DATA COLLECTION

Promising Practices

Trust and relationship building.

Facilitating trusting relationships between researchers and participants was not only important for recruitment, but was foundational for data collection. When participants trust researchers, they are more likely to

share information and engage meaningfully in data collection (Bryant, 2014). Researchers' main strategy for relationship building with participants was to be present at the SF house and to attend program events. A meal was also shared with participants at the beginning of photovoice focus groups, which provided a highly effective opportunity for relationship building. In addition, one of the research team members was pregnant for a portion of the project and later brought her newborn baby to groups, data collection points, and program events such as a field trip to a furniture store. This shifted power dynamics, as participants shared their knowledge about pregnancy and parenting with the researcher, thus expanding participants' trust. Although this is not a replicable strategy, researchers learned about the importance of participants experiencing researchers as "human." We will continue to build trust with participants by attending community events with them outside of the traditional office setting, as well as by sharing meals together and engaging in activities that are often not part of the typical research process, as appropriate. Increasing trust on the part of participants was demonstrated when participants began sharing sensitive information with researchers and asking researchers for their perspectives on their children's development.

In addition, building researcher-staff relationships was helpful for gaining participants' trust, and therefore enhancing data quality. Where the researchers and SF staff worked closely together through regular meetings, this opened spaces for conversations about how data was being collected in order to address challenges and make adjustments as the project unfolded.

Flexibility and accessibility. In line with a flexible approach, the research team collected data from participants at the SF house, across the street from participants' homes, which consisted of the self-report questionnaires and child development assessments described earlier. This not only enhanced accessibility, but resulted in a different dynamic than may have been

present if data had been collected in university-based spaces. Data collection spaces are important to consider in research with youth because their lives are variably influenced and controlled by adults (Harris, Jackson, Mayblin, Piekut, & Valentine, 2015). By collecting data in the SF house, the research team engaged participants in a space that represented participants' territory, disrupting the traditional researcher-participant hierarchy. As such, collecting data at the SF house was pivotal. This required a degree of humility on the part of the researchers in addition to flexibility and openness to learn from staff about effective ways to engage youth.

Also, it was imperative to keep flexible schedules when arranging appointments for data collection and to provide childcare on site from trusted staff during data collection. It was also necessary to recognize that having the time and motivation to participate in research is generally a "luxury" for many participants, and therefore misaligned with the realities of some participants' circumstances. As a result, making appointments with parents for data collection did not necessarily lead to participation, meaning that participants would frequently not attend scheduled appointments, and this slowed project timelines considerably. We continued dedicating resources to data collection in the interest of following through with partnership commitments.

Multi-pronged approach. We made continual adjustments to data collection methods through an improved understanding of what did and did not work for participants. We made individual appointments for data collection, gave the option of completing data collection during regularly scheduled groups, and held an event at the SF house where participants baked cookies with staff members while their children were assessed. Participants also received grocery gift cards for participation, and were provided with feedback reports from assessments. In short, a multi-pronged approach to data collection was necessary.

Similarly, using multiple methods over time was important to gain a complete understanding of participant experiences, which may have been difficult to access through reliance on a single method or time point.

Although these approaches resulted in collecting data from some participants, after continuous cancellations from participants for child development assessment appointments, the CU partnership needed to have difficult conversations about further resource and time investment in this form of data collection. This was difficult because we would not reach our goal of 20 assessments at three time points. Thus, rather than measuring change in child development over time, we began looking at other options for working with the data such as case studies and profile analyses. This was an important realization in terms of the need to be flexible in our research design. In addition, some of the same teen parents who failed to attend assessment appointments eagerly engaged in photovoice, and it was thus necessary to reflect on the measures we were using for assessments. Our CU partnership recognized that child development assessments inherently involve judgment, which limited interest from participants who, as teen parents, face judgment on a daily basis and who understandably may have a limited trust in clinicians. The photovoice groups, however, shifted power to the teen parents, who defined the topics and direction of discussions. The researchers were deliberately nondirective during the focus groups in an effort to create a setting in which the participants retained control.

Ethical Considerations

The research team recognized that, when gathering data from vulnerable youth through forming trusting relationships, it would be necessary to establish boundaries around their roles as researchers rather than friends or service providers (Taylor, 2009). Despite this recognition early on, the process of navigating roles was complex. In particular, two members of the research

team (BK, MT) facilitated bi-weekly photovoice focus groups with participants for six months. In distinguishing themselves from service providers, it was not within the researchers' role to strictly manage comments or dynamics within the groups. In the interest of maintaining rapport and gathering honest perspectives, groups were open and nondirective. For one researcher who was training to be a psychologist, this required conscious separation of the researcher and practitioner role since the topics discussed in the photovoice focus groups were often sensitive (e.g., stigma, trauma, unhealthy relationships). At the same time, part of the project involved conducting child development assessments and providing brief feedback reports to participants. In this way, this research team member did cross over into the practitioner realm by providing child development feedback and recommendations. Regarding this, Newbury and Hoskins (2008) take the position that research with youth should not simply inform practice; rather, research with youth is practice, and this assumption should form the foundation for participatory research. The researchers found this to be true in their experience with the SF program, and as a result, it was necessary to acknowledge that the research team became a part of the program intervention by entering into the practice realm. At times, the researchers also felt as though they assumed an advocacy role by sharing knowledge regarding program successes toward the program goal of establishing sustainable funding. Although the team set out to enact boundaries around researcher roles, traversing multiple roles was necessary.

Navigating multiple roles and accepting the personal aspect of the research project helped to enhance the meaningfulness of project participation. It is important to note that participatory approaches are not always genuine or ethical (Abebe, 2009). When using participatory methods such as photovoice, researchers must be cognizant of the potential to engage youth in activities and decisions that they are not prepared for,

as this can overburden them (Beazley & Ennew, 2006). In keeping with a flexible approach, we conceptualized research participation on a spectrum, with some young parents attending all bi-weekly photovoice focus groups and participating in every aspect of data collection and others with more limited participation. We left the level of participation open in order for participants to engage in ways that were feasible for their own circumstances, in turn allowing us to have confidence in meaningful participation.

DATA ANALYSIS AND DISSEMINATION

Promising Practices

Reflective processes. Recruiting and collecting data from teen parents were time and resource-intensive tasks; therefore, the prospect of holding formal data analysis sessions with participants was not feasible. However, through ongoing photovoice focus group sessions, participants were repeatedly invited to reflect on, summarize, and help the research team understand their experiences as well as the meanings they assigned to the data. We also engaged participants in dissemination of findings and used iterative processes of data analysis and dissemination to explain interpretations to participants for their reflection and response.

Participatory knowledge dissemination. Participants have the opportunity to discuss sensitive topics, encourage change in their communities, and actively participate in the creation of locally relevant knowledge when participatory approaches to knowledge dissemination are employed (Yonas, Burke, & Miller, 2013). With the SF program, participants provided photos that reflected their experiences as teen parents, and matched photos with quotes from transcribed focus groups that took place bi-weekly. Photos and quotes were used to create photo books. In addition, an open house was held to showcase the photos, and participants took part in a panel presenta-

tion at this event. Event attendees included community members, representatives from other agencies, researchers, and policymakers. After this event, the photo exhibit was featured at the municipal city hall, and local and national news stations interviewed participants, researchers, and program staff. Presentations also were delivered at academic and practice-based conferences, some of which involved teen parents as copresenters. Participants shared that taking part in knowledge dissemination was rewarding and inspiring. From a research perspective, youth participation in knowledge dissemination was valuable for engagement, and revealed information that participants did not think to share during data collection.

Ethical Considerations

In disseminating learnings from photovoice, we critically reflected on confidentiality concerns. In line with university ethics board requirements, youth provided informed consent for their photos to be shown in public and needed to critically consider the potential long-term impacts of this decision. In this way, there was tension between the need to respect young people as agents in their own right with the need to protect participants from harm and exploitation. It was important to clearly communicate the limits to confidentiality as well as potential risks while gathering informed consent. One participant spoke about the difficulty she experienced in making her story public, although she decided to do so because she perceived a greater societal benefit. Ultimately, all participants chose for their photos to be publicly disseminated.

Overall, engaging participants was a personal exercise. It was critical to intentionally use interpersonal skills such as empathy, positive regard, respect, and sensitivity to establish and maintain researcher-participant relationships. This resulted in the formation of strong, trusting connections, and the research team regularly reflected on how these relationships impacted their perspectives. On one hand, the re-

searchers were acutely aware that relationships were instrumental to recruitment and data collection, and felt that a participatory approach enhanced the quality of the data. However, the researchers also maintained awareness that building these relationships could hinder the ability to critique the SF program. Practicing reflexivity and consulting with colleagues was instrumental in navigating this terrain. We essentially recognized that it was not possible, nor desirable, to separate ourselves from the human element of research.

CONCLUSIONS

In the current paper, we used a community-university partnership project to describe promising practices and ethical considerations in conducting research with vulnerable youth. Overall, recruiting and collecting data required extensive time and resources. In addition, trusting relationships between researchers, SF participants, and staff were critical and necessitated time and strong interpersonal skills. It was also important to use a multi-pronged approach to recruitment and data collection, including the research team attending participant groups and program events, spending time at the SF house, facilitating staff recruitment of participants, taking measures to maximize accessibility, and providing compensation. In addition, methods were continually adjusted.

Throughout the project, we navigated emerging ethical challenges. Gathering informed consent necessitated critical awareness of power differentials. In forming relationships, the research team needed to reflect on their roles, consider their level of objectivity, and match participation levels to youths' circumstances. Although the research team maintained power in many ways, researchers worked together with staff and participants to contribute equitably to the project and to reflect on how we could use our relationships, trust, and humility to mitigate power differentials. We

also considered issues of confidentiality in the context of vulnerability.

Our participatory, relationship-based approach within the context of a CU partnership resulted in rich and meaningful learnings that can inform approaches to research with vulnerable youth moving forward. Researchers seeking to engage vulnerable youth must be prepared to explore beyond the traditional boundaries of research by thinking critically and creatively. Questioning and renegotiating the roles and participation of researchers, youth, and other stakeholders should be part of an ongoing process influenced by shifts in relationships and capacities. Our experiences highlight the critical importance of relationships in conducting research with vulnerable youth, as well as the need for flexible, innovative methods that allow for a full spectrum of participation, sensitivity to issues of power, and continual reflection.

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