

Research with Vulnerable Groups: Collaboration as an Ethical Response

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Journal of Social Work Values and Ethics, Volume 7, Number 2 (2010)
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Abstract

This paper explores the journey of a collaborative research project that was guided by the knowledge, skills, and values of social work training. The learning resulting from this multidisciplinary collaboration emphasizes the importance of the core principle of having a client-centered approach to all aspects of the research process. As the purpose of research in the social science fields is to glean knowledge that can be used to build a more evidenced-based practice model, the authors contend that multidisciplinary alliance and the meaningful involvement of clients in the process can greatly inform and assist the practice of the clinicians involved in research.

Key Words: Research, ethics, vulnerable population, late disclosure of pregnancy, social work, collaboration.

“Without adequate training and supervision, the neophyte researcher can unwittingly

become an unguided projectile bringing turbulence to the field, fostering personal traumas (for the researcher and the researched), and even causing damage to the discipline.” Punch (1994, p. 83)

1. Introduction

“Our capacity to do research with an individual is a privilege extended to us by the research subject,” according to Cournoyer & Klein (2000). Research is an activity that, in itself, is fraught with ethical and moral decisions at every stage of the process. The idea of research as a privilege is often lost in the power relations and the practical obligations that characterize much of contemporary research. The search for knowledge has a clear value base in decisions taken over which questions need to be answered and the desire to prove and disprove hypotheses. In social work and psychology, the need to understand the complexities of day-to-day life and human coping is a key part of any interaction and intervention. Indeed,

the very purpose of research in the social services field is to provide evidence that can be used to inform policy and practice and enhance the well being of vulnerable groups (Munroe, Holmes, & Ward, 2005, p. 1024). Striving toward evidence-based practice is a contemporary development and one that has engendered much debate (Smith, 2004).

This paper evolved from a collaborative research project that considered the phenomenon of late disclosure of pregnancy. Prior research had focused on the negative medical outcomes for both mother and child following this phenomenon, and a dearth of research exists in this area. Furthermore, no research had explored the meaning of late disclosure of pregnancy from the “insider” perspective—namely that of the women who experience it. This paper outlines how principles of good practice informed the research team, with the end result being a piece of research that was accomplished ethically and sensitively.

In addition, the journey of the research team is outlined, and the ethical considerations that needed to be teased through before the various steps of the research could proceed are explored. The research team included two medical social workers and a third medical social worker in clinical psychology training. The genuine desire to explore this phenomenon “from the inside” and to honor the women’s experience played a central role in molding how this study was designed and completed. A brief exploration of the nature of research ethics within the health and social services fields is presented, and an introduction to the development of the ethical basis to the qualitative research methodology is provided. There follows a discussion of the nature of researcher/practitioner co-operation in a multidisciplinary context. As different

professions have varying perspectives, the possibility to create a synergy that provides for mutual understanding is described. A detailed discussion of the aspects of the challenges involved in research with vulnerable groups is provided with a discussion of the research project in question outlined as an illustrative example. The main ethical issues involved throughout the process of this project are highlighted to provide a sense of the significance of ethical consciousness at all stages of the research process. The paper concludes providing a reflective analysis of the project and suggests some key issues for consideration in the practice of research with vulnerable groups based on the experiences, challenges, and outcomes of this piece of work.

2. Ethics and Research

“Ethics concerns the morality of human conduct. In relation to social research, it refers to moral deliberation, choice and accountability on the part of researcher throughout the research process” according to Edwards & Mauthner (2002, p. 14). The origins of the concern about ethics in research lie within the medical sciences when the abuses in research in Nazi Germany were highlighted in the Nuremberg Trials. This led to the beginning of governance at an international level of the ethical conduct in research with people with the development in 1946 of the Nuremberg Code. This code highlighted a number of key steps to be undertaken in the research processes including: informed voluntary consent, unnecessary suffering to be avoided, steps to be taken to protect participants from harm, and that suitably qualified people would conduct the research (Meltzoff, 2005). The Helsinki Protocols (1964) drew out these steps further

and introduced the idea of research proposals to go before ethics committees to ensure greater accountability and shared responsibility.

These protocols, revised in 2000, have provided clear frameworks for research in biomedicine and in the social sciences. The World Health Organization and UNESCO, who provided the frameworks for ethical research, defined participation in research as obtaining informed consent and respecting the right to withdraw from the research at any time. There was little room for the interpretations of “participation” to mean participant involvement in research design, implementation, analysis, and dissemination (Domenelli & Holloway, 2008). Domenelli and Holloway identify the more contemporary challenges that face researchers today—issues of power, control of research processes, and what counts as research. With the huge sums of money involved in research, along with the growing role of commercial interests, the drive to reconsider ethics and research governance has become a key issue at government level (p. 4).

Shaw (2003) identifies the central questions facing contemporary social work research as social work research methodology, social work’s governance and research ethics, building research capacity, and establishing research quality. In a discussion on governance and ethics, he notes that the term governance has a somber tone and “helpfully emphasizes the need to take issues of standards and ethics seriously...” (p. 112). However, he goes on to consider the related risks that go with the preoccupation with governance and frameworks; in the dangers of over regulation and therefore less sensitivity to the particular ethical challenges of social care research, and in the confining of ethical

decisions to the areas of access, design and management. Thus one could reflect that research, which can incorporate enough flexibility in devising structures and protocols to allow for the diversity and complexity of human life, is indeed a balancing act.

Munro, Holmes, & Ward (2005) state, “Although researchers, policy makers and local authorities may all work to enhance the well-being of vulnerable groups, they may well have different perspectives which frequently affect and occasionally undermine the research process” (p. 1025). This is an important issue particularly in relation to the issue of gate keeping information related to the identification of research participants and the level of participation, which the agency or the professional deems to be adequate. Interpretations of the boundaries of confidentiality and indeed the willingness of agencies and the professionals within agencies to get involved in research and support the research process is also a key part of this potential for different perspectives to undermine research undertaken (Munro, Holmes, & Ward, 2005).

3. Researcher / Practitioner Co-operation: Collaboration

The desire and impetus to examine the area of late disclosure of pregnancy emerged from a learning need identified by two medical social work practitioners working in the maternity department of a general hospital. They wanted to know more about the phenomenon of late disclosure of pregnancy in which women experiencing a non-marital pregnancy present late for antenatal care. Many of the women are often undecided about whether they will parent their child post delivery. The practitioners wished to examine

their practice with this specific population. The researcher had previously worked with the practitioners, and thus, they had a trust in the researchers' ability to work in a respectful and sensitive manner. Therefore, the clinician's mistrust of researcher's motives noted by others (Sutton, Erlen, Glad, & Siminoff, 2003) was not an issue in this instance. This prior professional relationship was a linchpin in bringing this research to fruition. Ongoing collaboration was an essential part of the design and implementation of this research, and it took place throughout every aspect of the research process.

4. Researching Vulnerable Groups: Selection of Participants

Past research with vulnerable populations highlights that many of the participants considered participation in research as a positive experience and linked this with being able to tell their story (Richards & Schwartz, 2002; Sutton, Erlen, Glad, & Siminoff, 2003). Research has also highlighted that participants feel that by agreeing to take part in the research, their story may be of benefit to others. Many other vulnerable participants, however, experience distress when talking about their past painful experience (Cooper, 1999).

One of the key issues in planning this study was the balancing of the risk of participation with the potential benefits of the study both to society and the study participants. Reference was made to the Belmont Report (NCPHS, 1979). One of the basic human rights outlined in the Belmont Report is the right of participants to decide whether to participate in a study or not. However, this rule may be ethically difficult to apply to certain clinical populations. Thus, the

practitioners and the researcher carefully considered the likely benefits and risk to each potential participant. The practitioners involved were effectively gatekeepers to potential research participants (Sutton, Erlen, Glad, & Siminoff, 2003). This gate-keeping involved balancing the need to protect vulnerable clients with the client's right to choose to participate, thus running the risk of limiting access to potential research volunteers because of well-meaning protection (Beauchamp & Childress, 2001; Emanuel, Wendler, & Grady, 2000).

The research participants were drawn from the caseloads of social work practitioners who had several years' professional experience of working with women who have delayed the disclosure of a pregnancy. Following careful discussion, it was deemed inappropriate and/or unethical to contact potential participants who had experienced any of the following: a miscarriage, a stillbirth, a termination, a recent bereavement, a diagnosed chronic mental health difficulty, or ongoing intervention from community social work services. Furthermore, some potential participants were not approached in cases in which they were going through an adoption process, as it was felt that the research might potentially jeopardize this process.

A clinical decision was reached that it would be insensitive to contact women who had presented in the previous 12-month period, as the experience was considered to be too raw and thus potentially more distressing to talk about (Dyregrov, 2004). Although these women had a right to participate in this study, this right was at times forfeited in what practitioners considered to be the best interests of the client. The social workers' professional judgment was respected and accepted as valid and informed. The caveat that the welfare of

individuals is greater than any research question was the yardstick by which the sampling process proceeded. Consequently, the sample was not intended to be representative of the total population of women who present late in pregnancy, but provided an in-depth understanding of a number of people's individual experiences.

5. Ethical Issues in the Research Project

5.1. Pre-planning phase: Terminology

A lack of clarity exists in the literature regarding the terms "denied" and "concealed" pregnancy. Consequently, at the outset of this exploratory research process it was unclear which term would best describe a pregnancy that is disclosed late. Furthermore, it was unclear what terminology women who experience this phenomenon would find acceptable, i.e., a concealed pregnancy, a denied pregnancy, or something else entirely. The term "late disclosure of pregnancy" was preferred by the researcher as a more inclusive term that encapsulates the existing concepts of denial and concealment but with less pejorative connotations in describing both concepts. Furthermore, the term "late disclosure of pregnancy" does not assume knowledge of the processes involved in this experience. This phrase was used in communication with the participants in the consent form. The term was also used when interviewing women who had experienced this phenomenon, as it was seen as a more neutral means of exploring how they related their experience to terms used in the literature, such as "denial" and "concealment."

5.2. The need to research this subject area sensitively

"A considerable degree of stigma still adheres to non-marital pregnancy in Ireland" (Loughran & Richardson, 2005, p. 112), and a late disclosure of pregnancy is perceived in the literature to be a highly sensitive and private experience that a small number of women encounter (Maldonado-Duran, Lartigue, & Feintuch, 2000). The choices these women have regarding the resolution of the pregnancy, i.e., termination, adoption, or parenting also have a varying degree of stigma attached to them (Mahon, Conlon, & Dillon, 1998). Therefore, given the documented level of stigma attached to the area of non-marital pregnancies, a methodology was required that was flexible and not predetermined in advance.

Feminist models of qualitative research proposed by sociologists such as Olesen (1993) and Reinharz (1992) influenced how the researcher reviewed the psychological literature in this area. It was found that the voices of women who have experienced this phenomenon had not yet been heard. A major aim of this study was to give a voice to this group of women and respect the participants' involvement during the process.

Qualitative methods do not make claims about trends or distributions; rather, they aim to give a description or explanation of an event or experience. This was the main objective of the study. Willig (2001) describes qualitative methods of data collection and analysis as "ways of listening" (p. 150). Furthermore, qualitative research methodology had not been used to date to investigate this area. Therefore, by using a qualitative method, the researcher could allow the women involved to "lead" the research process and tell their own stories.

Thus, to facilitate the generation of novel insights and new understandings regarding delayed disclosure of pregnancy, a qualitative methodology was employed.

Mahon, Conlon, & Dillon (1998) have described survey questionnaires as being impersonal, lacking in sensitivity, and lacking flexibility, and hence, they were deemed inappropriate for the present study. An open interview was felt to be a more suitable approach. McCracken (1988) referred to the long interview as “one of the most powerful methods in the qualitative armory” (p. 9). He proposes that, “the long interview gives one the opportunity to step into the mind of another person, to see and experience the world as they do themselves” (p. 9). Thus, the researcher endeavored to explore this sensitive area by having the participants tell their own stories in their own words, and a semi-structured open-ended interview was employed with women who had delayed the disclosure of a pregnancy.

Interpretative Phenomenological Analysis (IPA) was the method used to analyze the data. IPA is a method stemming from phenomenology (Willig, 2001), and phenomenology is a philosophical approach focusing on the world as it is subjectively experienced by individuals, within their particular social, cultural, and historical context (Giorgi, 1994). IPA lends itself well to the notion of exploring an experience such as a delayed disclosure of pregnancy, which is complicated, complex, and diverse. Furthermore, IPA has been utilized by other researchers to explore sensitive and personal experiences, such as sexual identity, termination, and sexual practices (Walker, 2001; Robson, 2002; Flower, Hart, & Marriot, 1999).

5.3. Beginning phase: Establishing a working definition

One of the most important initial steps in designing this study was creating a workable definition of delayed disclosure of pregnancy. Given the complexity of the phenomenon, working definitions were difficult to create and only emerged after considerable discussion and constructive debate. Fox’s (2004) definition of concealed pregnancy was regarded as a useful starting point. Fox defined a concealed pregnancy as a situation in which (1) a woman presents for antenatal care past 20 weeks gestation (2) she has not availed of antenatal care elsewhere and (3) she has not disclosed the pregnancy to her social network. However, discussions with the social work practitioners indicated that not all relevant cases would be encompassed by this definition. The social work practitioners pointed out three cases where women had presented to the social work service prior to 20 weeks but had continued throughout their pregnancies to hide their pregnancies and who disclosed the pregnancy in a limited fashion only. By drawing strongly on the work of other researchers in this area (Fox, 2004; Wessel, Endrikat, & Buscher, 2003), and in consultation with the social work practitioners, a working definition was developed. Thus, the working definition of delayed disclosure used in this study was informed by both the existing definitions in the literature and clinical experience.

5.4. Intermediate Phase: Contacting participants

In the interest of confidentiality, it was decided that the social work practitioners would make initial contact with potential participants. For the researcher to “cold-call” a potential participant would breach

confidentiality from the onset. It was decided that it would be unethical to conduct home visits as a means of making initial contact with potential participants, as clients may feel unable to refuse the practitioners' face-to-face request (Cooper, 1999). By compromising potential participants in this way, some of the principles of informed consent would have been violated. Therefore, a telephone call from the practitioner to the former client was deemed the most appropriate way to initiate contact. A telephone protocol was developed by the researcher for the social work practitioners to use as a guide when outlining the research project to their former clients. If the participant verbally agreed to take part in the study, her name, telephone number, and contact details were given to the researcher.

5.5. Anonymity, respect, and confidentiality

Based on the work of other researchers who have worked with vulnerable populations, (Kvale, 1996; Regan-Kubinski & Sharts-Hopko, 1997) and general clinical practice principles, factors that were considered included: (1) meaningful informed consent, (2) providing anonymity, and (3) confidentiality. Consequently, the process by which the interview tapes would be stored, and transcripts anonymised, was outlined in both the consent form and on the day of the interview. A coding system was also devised to anonymise the demographic questionnaire. Access to safe storage space within the social work department was also negotiated and arranged prior to the commencing of the research. Furthermore, the procedure to be used in the study was outlined to and approved by the ethics committee in the hospital.

5.4. Completion Phase: Attempts to counterbalance the power differential

A component of centralizing participants in the research was related to the collaborative validation process. To enhance the validity of the findings, the women received a summary of the researcher's interpretation of the thematic findings, which had emerged from the interviews. It was hoped that by being asked for their comments and feedback, they would feel they had some influence over the research. It was felt that this process not only enhanced the validity and credibility of the findings, but it also made the research process more democratic (Smith, 1996). Again, due to the private nature of the final report, the participants' contact addresses were re-checked before the reports were posted.

5.6. Followup support

The topic of delayed disclosure of pregnancy is highly sensitive. The researcher was aware that the research interviews could potentially cause distress to the participants, prior to, during or after the process. Participants were assured that withdrawal from the study at any stage was an option open to them and that turning off the tape recorder during the interview was also an option. As an extra measure to manage potential distress of the participants, all were informed of the availability of the medical social worker to support them, if they so desired. Followup support for vulnerable participants has been suggested by other researchers (Dyregrov, 2004; Sutton, Erlen, Glad, & Siminoff, 2003). A follow-up phone call was made one week after the interview had taken place to check on the participant's experience of the interview. The medical social worker took responsibility for this task.

Participants' right to receive information about the findings and analysis of the research was also deemed to be important

not only as a means of validating the findings, but as a mark of respect for the participant's time and involvement (Richards & Schwartz, 2002). Participant feedback on the findings of the research was very powerful. The feedback from participants reaffirmed the belief in the value of carefully listening to the voices of this hidden population. It was encouraging that the women felt that the research had represented their experience accurately. One woman highlighted that by taking part in this research, she experienced some type of validation and comfort knowing that others have experienced a late disclosure of pregnancy. She wrote:

It helped to see it written down on paper, that other women have gone through the same thing. Before this report, I thought no one else went through it. It helps to know that I'm not the only person who felt these things when I was pregnant and they went through the same thing with family and their partners.

6. Key Lessons from the project

The researcher's clinical training and social work background was an important factor in securing the commencement and completion of this piece of research. As a mental health practitioner, the researcher was able to conduct the interviews in a sensitive and respectful way by assuring responsive empathic listening and by engagement with the participants (Dyregrov, 2004). The researcher's clinical experience facilitated an appropriate response to distressed reactions, if they arose.

Logistical issues experienced by the researcher worthy of comment here included, first, that the population of interest seemed to be a more mobile population, and concerns

were raised about the need to re-check contact details and ensure that their involvement in the study was kept confidential in that no messages could be left anywhere for participants. Difficulties experienced by the social workers in trying to contact participants in the identified sample were compounded if a life situation had deteriorated for someone, and the decision not to include them in the research was generally discussed by the research team, which ultimately reduced the sample size.

The researchers were also concerned about the personal cost of bringing attention to an area that is so hidden for people. The cost to the participants of being reminded of a hugely difficult time in their lives. Thus, the ethical dilemmas of carrying out the research were always a part of the design and implementation of the research. In fact, many participants spoke afterwards about the therapeutic element involved in being a participant in the research, the opportunity to revisit the situation some time later, and that this was in fact helpful for them.

Through discussion and debate, the need for adequate time to be given to all stages of the research process was deemed to be paramount. First, extra time to "tune in" to participants' concerns and "where they are at" within their own personal circumstances was a key consideration. Second, extra time to check back with participants, following the collection of data, to ensure that this data was valid and representative of their experience, was essential. This attempt to make the validation process democratic can be construed as not an add-on; it is instrumental in the entire process if there is to be any sense of collaboration with participants in the validation of data. In research, this is an area in which the significance of time being made

available can be underestimated in both the planning stages and in the philosophical essence that guides decision-making. This issue also extends to the time taken for dissemination of the research in that the participants shared their own motivation for taking part in the research. Participants felt that it may provide information to help others in similar situations in the future. To this end the need to disseminate the research findings to all staff in the maternity unit once completed was a further link to honor the participants' motivation and the underlying value base of this collaborative project.

In the collaborative work undertaken between the researcher and the social work practitioners, there was a need for trust and good clear communication. For example, in developing inclusion criteria, many debates arose regarding the manner in which a balance could be achieved between the integrity of the research and the overall welfare of the participants. Through clear communication and time for discussion, professional responsibility wasn't compromised, and through a shared understanding of the principles of good practice, the research was non-tokenistic. Healthy tension between the roles of researcher and practitioner was evident, but through the establishment of mutual aims of the research from the outset, and a shared understanding of the importance of respect of varying disciplines, the differences in the roles became a constructive aspect of the process. The backing of management in the maternity unit to free up time for the practitioners to engage in the research as well as offer follow-up support to participants where the original work was completed was also crucial to the process.

7. Conclusion

The experience of carrying out this piece of research is evidence that it is possible to design and implement a piece of research that is scientific but genuinely sensitive to the area under exploration. The concerns of vulnerable groups need to be investigated as a means of informing practice and research. The balancing of ethical concerns with the needs of a valid and reliable piece of research is demanding but possible. The key to sensitive research is being led by the principles of best practice. Such principles include a client-centered approach that involves the clients being truly involved in each step of the project design. Principles that value anonymity, respect, and meaningful participation by the participants with confidentiality guaranteed and practiced throughout in conjunction with a collaborative approach are essential. The value of the clinical skills of tuning in, empathic listening, and providing supportive follow-up were also highlighted by our experience with this vulnerable group. Whereas collaboration is time consuming and demands clear communication and respect for divergent standpoints, ultimately, with collaboration, a richer, more sensitive, and considered piece of research can be achieved.

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