
Care and Concern: An Ethical Journey in Participatory Action Research

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Abstract

The four basic principles of an ethical research framework, as outlined by the *Code of Ethical Conduct for Research Involving Humans* (1998), are reviewed in light of the requirements of a participatory action research approach. Literature on the ethics of participatory research is summarized as the backdrop for a discussion about the ethical principle of care and concern within a participatory action research paradigm. It is argued that the ethics of morality and justice are appropriate, but insufficient, for participatory action research. The ethic of care obligates us to create improved conditions in the lives of those we join with in the research journey.

Résumé

Les auteurs examinent, dans le contexte d'une approche participative, les quatre principes fondamentaux d'un cadre déontologique pour la recherche, tels qu'énoncés dans le *Code d'éthique de la recherche avec des êtres humains 1998*. La documentation sur les aspects déontologiques de la recherche participative est passée en revue afin de préparer le terrain à une discussion sur le principe de diligence et sa place dans un paradigme de recherche-action participative. On reconnaît le bien-fondé des préceptes moraux et juridiques, mais on maintient qu'ils ne sont pas suffisants dans le cas de la recherche-action participative. Le principe de diligence nous oblige à travailler à améliorer le sort de ceux avec qui nous nous unissons dans l'aventure de la recherche.

This paper explores the ethical dilemmas involved in Participatory Action Research (PAR), an adventurous research process that creates meaningful change in the lives of those who are engaged in the research. Action research is a relatively new research paradigm, having first emerged with the work of Kurt Lewin's Centre for Group Dynamics in the United States and the Tavistock Institute of Human Relations in Great Britain between 1945 and 1965 (Cunningham, 1993). It has been furthered more recently by Carr and Kemmis, (1986) and Reason and Rowan, (1981). They emphasize rigour, reflective interpretation, the active participation of the those being studied in the research process, and the inclusion of some practical outcome related to the work or lives of the participants (Stringer, 1996).

According to Stringer (1996), practitioners have found that the theoretical knowledge of the academic world has limited relevance to their work. This can be attributed, in part, to the fact that most traditional research is based on a positivist scientific paradigm, which requires distance and objectivity to control for bias and extraneous effects. While such controlled situations make it possible to draw firm conclusions about specific effects, they bear little resemblance to the multifaceted,

uncontrolled encounters between practitioners and clients. For research to be relevant to practitioners, its design must be sensitive to the demands of practice. Participatory action research, therefore, is a response to the pressure to make research more relevant to the ongoing work of practitioners and to apply the processes of change in a way that directly benefits the participants and involves them in guiding the research project. A fundamental premise is that the research begins with an interest in the problems of a group of people and assists them to understand, and thus resolve, the problems before them. If an action research project does not make a difference in the lives of the people involved, it has not been successful.

The involvement of the research participants in the design and implementation of the research has the potential to raise ethical dilemmas that are not adequately addressed by the current codes of conduct for research with humans. Universities, hospitals, school districts, government, and many professional associations, have ethical codes of conduct, which address the conduct of research. Larger institutions have research ethics boards (REB) which approve and monitor the ethical implementation of research projects. Prior to 1997, the major granting councils for research in Canada, the Medical Research Council (MRC), the National Science and Environment Research Council (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) each offered their own set of guidelines to researchers in their respective disciplines. They have now collaborated to develop the *Code of Ethical Conduct for Research Involving Humans* (1998). The code articulates a common set of principles with enough flexibility to accommodate a variety of disciplines, and the Councils expect the code to be used by REB's and researchers in academic institutions that receive funding. They also suggest that it is relevant for other organisations.

Codes of ethical conduct for research involving humans determine what is the "right way" to conduct research without bringing harm to those that help us in the research adventure. The ethical principles that underlie these codes are necessary for the protection of participants, but they are insufficient within the participatory action research framework, which cares about the people and is committed to creating tangible change in the lives of those who participate in the research. In this paper I briefly review the PAR paradigm and the principles of the *Code of Ethical Conduct for Research Involving Humans* (1998). I use the metaphor of a journey to develop the framework for reviewing ethical issues because, like research, a journey may be undertaken to seek clarity and understanding about a particular phenomenon. Journeys often involve guidebooks and research follows methodological and ethical procedures, agreed to and charted by previous researchers. Meaningful discoveries, however, often come from mistakes or wrong turns. When I discovered

that the ethical codes provided insufficient guidelines for the projects in which I was engaged, I turned to the literature on the ethics of participatory research. I summarize this literature here as the background to the principle of care and concern, which I believe is essential to "right and caring" approach to participatory action research.

APPROACHING THE ADVENTURE

Preparing for a PAR adventure is confusing. My training as a researcher introduced me to methods drawn from traditional research paradigms: positivistic, interpretative, social constructivist. These paradigms "emphasize the separation of knowledge, or theory, from action" (Kerruish, 1995, p. 134). A brief review will provide a contrast to the discussion of PAR that follows. Positivistic approaches emphasize objectivity and rigour in their methods in order to present conclusions about the cause or effects of a particular phenomenon. Interpretative approaches emphasize the outside perspective of a researcher studying a phenomenon among a specific group and conveying an understanding of that phenomenon to others. The goal is analytic insight (Price, 1996). In both the foregoing paradigms, the people in the study were traditionally referred to as subjects, participants who are acted upon by the researcher. Social constructivist approaches emphasize a partnership between researcher and participant, often referring to the participant as a co-researcher. The findings explain a phenomenon from the jointly constructed understandings of both the researcher and the participant. The findings are credible if they are representative of the experience of the participant. While social constructivist approaches are participatory, they do not necessarily involve purposeful action for change.

PAR projects use a wide variety of types of data and methodologies for analysis. What differs in an action research paradigm is the commitment to social change. The researcher and study participants have a vested interest in the knowledge produced by the research. PAR is a collaborative effort involving the integration of research, participation, and political action such that the knowledge produces tangible social change for participants (Flynn, Ray, & Rider, 1994; Kerruish, 1995; Stringer, 1996). These elements were present in a collaborative project I undertook with a local children's mental health centre. We were interested in understanding the parenting experience for parents of children with emotional and behavioural disorders. Our hope was to change the nature of services provided to these parents to help them better manage the stress of parenting. We also hoped that the parents who participated might begin to advocate for themselves and others like them in a more active and systematic manner. These elements were built into the research design.

There can be many vested interests in such collaborative efforts and they may at times conflict. Conflicting agendas emerged when the par-

ents expressed a desire to produce a video about their experiences with their children and the social service/mental health system in order to communicate to practitioners the importance of listening to and advocating for the parents' needs. Some of the practitioners involved in the project felt that this approach to public dissemination of information was an inaccurate representation of the issues because it only presented the parents' experience and not that of the practitioners or the children.

This conflict raised a crucial issue for us in both the social constructivist paradigm and the action research paradigm. In both participatory paradigms, there is an obligation to render an account that is true to the participants (Bar-On, 1996; Kerruish, 1995). In the action research paradigm, the obligation goes further than just rendering an accurate account, to an ethical obligation to create change (Kerruish, 1995; Rosenwald, 1996). Despite the clarity of the mandate to include participants in decision making and to foster change, the research method does not offer guidance for resolving disagreements between researchers and participants. The vested interests of the parties led to a conflict about what constituted an accurate account and how best to facilitate change. When we identified this dilemma, we realized that existing ethical codes for research also failed to provide any guidelines that would help us with to make the right decision and respect the rights of the participants while creating social change.

As background for understanding the limitations of the current ethical codes for PAR projects, the following section describes the principles underlying ethical decision making and the guidelines contained in *Code of Ethical Conduct for Research Involving Humans*, (1998). This code is the most recent and universally accepted guidebook for ethical decisions on research in Canada.

FOLLOWING THE RIGHT PATH

"Today many scholars are convinced that no research topic involving humans is purely biomedical, humanistic, scientific or social. Many of the ethical questions raised in research involving humans are common across all disciplines" (*Code of Ethical Conduct for Research Involving Humans*, 1998). The Code is intended to be a guide for ethical decisions in the research adventure, to be combined with the guidelines provided by the paradigm of the research methodology. The principles outlined in the document are consistent with an approach to ethics known as ethical objectivism which is centred on moral facts and principles that are posited to exist independently of individual beliefs and situations (Kluge, 1997). The rationale approach dictates that these basic principles must be considered in a total and balanced manner; that is, one principle does not supersede another, rather they are considered as a whole. Thus, a process for resolving conflict between principles should

be established by REB's and researchers. The four principles and the implications that they have for research ethics are outlined below.

Respect for Persons

Respect for persons requires that we treat others as individuals with the right to autonomous decision making. For those who have diminished capacity or impaired autonomy, respect for persons implies protection against abuse. This principle is evident in the requirements for informed consent in research projects. Withholding information is only allowed when it is essential to the research study and will not cause harm to the participants. Corrective action to inform the participants must be taken as soon as possible following the completion of the study (Canadian Guidance and Counselling Association [CGCA], 1989; *Code of Ethical Conduct for Research Involving Humans*, 1998). Informed consent is typically accomplished through the provision of detailed information for participants, prior to their participation in the research, about the purpose, procedures, and outcomes of the study. Participants sign a form or give verbal consent stating that they understand the information and the procedures that will be undertaken to ensure confidentiality and anonymity.

In PAR, respect for persons requires more than informed consent. The research paradigm implies that the participants will be involved in determining some of the questions, procedures, and the outcomes of the study. It is difficult to inform them prior to the study of what will be done since that would violate one of the basic tenants of the paradigm, that of their participation in the process. Instead, respect must be demonstrated through a process of continual communication between the designated researcher and the participants. The researcher is obligated to negotiate research procedures and provide information about the consequences of the various procedural choices for the rigour of the research as well as the potential implications for the participants. Informed consent prior to participation is not only impossible, it could be considered unethical since it violates the principle of participant inclusion in the research that is required by the PAR paradigm.

Non-Malificence

"Do no harm to others" embodies the principle of non-malificence. Key to this principle is the concept of a threshold for normally acceptable risk. "When the possible harms (e.g. physical, psychological, social, and economic) implied by participation in the research are within the range encountered by the participant in everyday life, then the research should be taken to fall within the range of normally acceptable risk" (*Code of Ethical Conduct for Research Involving Humans*, 1998, Part I, A). If normally

acceptable risks are exceeded, then greater attention must be paid to mitigating the effects of harm.

It is noteworthy that, in PAR projects, which often target social action issues, the day-to-day life of the participants may contain significant risk and discomfort. Merton (1990), for example, describes a community-based research project that collaborated with an AIDS advocacy association to research new drugs for treating AIDS patients. Kerruish (1995) describes a PAR project involving housing people with mental illness. In both these populations, it could be argued that the threshold for acceptable risk based on participants' daily lives is very different from the threshold for acceptable risk within the lives of the general population. The risk of physical, psychological, social and economic harm is a part of daily life for these marginalized members of society. Within the PAR paradigm, the obligation to mitigate the effects of harm for such groups would be discharged by creating change in participants' daily lives.

In our children's mental health centre project, the obligation to reduce harm was initially implemented through informed consent and the provision of various needed support services to individual parents during their participation in the research. During the data collection it became apparent that parents faced the risk of harm from the children's unpredictable behaviour, which could escalate to aggressive physical attacks on siblings, property, and/or themselves. As parents struggled to access appropriate services to help the children with their emotional and behavioural difficulties, the children faced increased difficulties in social acceptance and success in school. We became convinced that we had an obligation to further reduce the threshold for normally acceptable risk for the population represented by the participants. The parents believed that, by producing a video of their experiences, they would have a powerful advocacy tool with which they believed they could create change in their lives, and in the lives of similar families, by increasing the awareness of community service providers about this risk of harm. The video was to be produced from hours of focus group videotapes that formed the data in the project. Since the parents' faces would be visible they would no longer be completely anonymous, even though their names were not attached to their faces. We were faced with a dilemma involving the balance of risk in protecting the anonymity of the parents and children, as compared to giving them this tool for personal and systemic change.

Beneficence

The principle of beneficence is based on a duty to advance the good of others (Kluge, 1997). Benefits may be for the participants, for society, or for the advancement of knowledge. The principle of beneficence is the hallmark of the PAR approach to research. The *Code of Ethical Conduct for*

Research Involving Humans however, does not place the same interpretation on the principles of beneficence. "In most research, the primary benefits produced are for society and for the advancement of knowledge rather than for the participants themselves" (1998, Part I, B). The obligation for social action in PAR requires that the primary benefits of the research accrue to the participants in the project.

The *Code of Ethical Conduct for Research Involving Humans*, (1998) deals primarily with the concept of equity under the principle of beneficence. It notes that the benefits of participation in a research project have historically been denied to those under-represented in research agendas (e.g. women, infants, non-mainstream ethnic groups, and the disabled). The principle of beneficence implies that such benefits should no longer be denied to these groups. In fact, researchers and members of these under-represented groups initiate most PAR projects.

The guidelines also state that benefits of participation should not be denied because of an inability to provide informed consent (*Code of Ethical Conduct for Research Involving Humans*, 1998). While this guideline applies specifically to those who are judged incapable of giving consent (under the first principle), it might also be interpreted as relevant to participants who are involved in PAR projects. The benefits of participation should not be denied simply because informed consent in a PAR project must be a process rather than a consent form listing predetermined procedures.

Justice

The principle of justice assumes that all persons are equal, and should be treated in a manner that guarantees the equitable distribution of both benefits and burdens (*Code of Ethical Conduct for Research Involving Humans*, 1998). It is most relevant for individuals and groups that are vulnerable and open to exploitation, including those that are marginalized. It is embodied in guidelines that require the inclusion of those from marginalized groups and prohibits discrimination against prospective or actual research participants. The principle of justice strongly supports the PAR paradigm because many projects deal with marginalized groups.

Shortcomings of the Ethical Objectivism Approach

The principled approach to ethical decision making is based on the view of people as rational beings (Kluge, 1997). This view is fundamental to a research paradigm based on objectivity; however, it is not the only approach to ethical decision making (see Kluge, 1997, and Kvale, 1996, for a discussion of other approaches). While the *Code of Ethical Conduct for Research Involving Humans* briefly describes different approaches, it maintains an objective and rationale approach to its ethical guidelines. While

the principles of ethical objectivism contained in the Code can be interpreted differently, (as identified in the previous discussion), additional principles essential to a PAR approach are necessary to guide ethical PAR projects. Unfortunately, according to the current code, the research journey ends when “the active involvement of the research participants has been completed” (*Code of Ethical Conduct for Research Involving Humans*, 1998, Part 1, E), the publication and dissemination of results has occurred and the effects of the research on the participants is debriefed. Since social action is not part of the paradigm upon which traditional research approaches are based, and the Code was designed within traditional research paradigms, it is unable to offer specific guidance regarding some aspects of ethical decision making in the PAR paradigm. The next section reviews the thoughts of those involved in participatory research about ethical practice. Following this, I use the principled approach and suggest an additional principle that is essential to ethical decisions in PAR.

LISTENING TO FELLOW ADVENTURERS

Codes of ethical conduct for research laid out by REBs have been criticised for their basis in a legalistic perspective. They are designed to protect the researcher and the institution from lawsuits and are rule based. “‘Genuine ethics’ . . . are at risk of giving way completely to meeting the letter of the countless regulations promulgated by institutional review boards” (Wolcott, 1994, p. 403). For example, in jurisdictions where reporting child abuse or AIDS is mandated for all individuals who are aware of such circumstances, a researcher interviewing deviant populations may have the study rejected by the REB because he/she would be required to break the confidentiality and anonymity of a research participant who disclosed such events (DeKaraai & Sales, 1991; Price, 1996). This breach of confidentiality could be required to improve the lives of children experiencing abuse and individuals with AIDs.

In part, REBs serve the purpose of placing limitations on the power and authority of the researcher. In participatory research, one must equalize power consciously between the researcher and the participant since the researcher already holds power in the perception of others (Kerruish, 1995).

Authority rooted in specialised training and expertise does not extend to authority over the life and death decisions affecting the lives of patients and those dear to them. Dialogue can take place only when participants acknowledge one another's status as equal partners in the dialogue. (Attig, 1995, p. 17.)

In participatory research, the researcher must not just be cautious about the use of power, but must actively work to redistribute power and create both dialogue and equality in decision making. For example, as noted previously, informed consent, typically used as a tool for limiting the

researcher's power to harm participants, is insufficient in the PAR approach since following the leads and directions of the participants is essential. A description of pre-defined procedures limits the participants' ability to dialogue and implies that the researcher holds the power of decision making. It would be unethical not to discuss roles, relationships and decision-making authority and to come to consensus on these. It would also be unethical not to revisit the discussion as necessary. In this model, decisions about what constitutes an ethical course of action are shared, mutually agreed upon and, often, constructed by the researcher and participant(s) together.

In participatory research, the distinction between intervention and research begins to blur. "When we take a closer look at interviewing . . . it seems less like a formal research set of a priori rules and more like an intervention without the clear boundaries or a contract that clinical intervention contains as a given" (Bar-On, 1996, p. 9). A research interview can easily metamorphose into a therapeutic interview as the researcher and participants co-construct meaning about the phenomenon being researched. The participant develops new insights and acts on insights developed in the interview (Kvale, 1996). In medical research with a PAR approach, results would be immediately available to individual participants to inform their decisions about the course of their own illness (Merton, 1990).

According to Rosenwald (1996), method and ethics are closely linked and the methodological paradigm behind the REB process holds objectivity as important. Objectivity requires the careful analysis of constituent parts to understand their relationship to each other. In the realm of human subjects studies, the subjective, reflective experience of the whole person is forgotten, except to say that the person must not be harmed. Unfortunately, REBs do not take any stance on the need to consider that the whole person could have a right to benefit from the research and to become "more whole."

Does the interviewer own the meanings constructed in and on an interview, interpreting it within his or her selected contexts? Or should the original authors of the interview statements have their say in the interpretation and communication of their stories? This is not only an issue of validity of interpretation, but of ethics and power, to the right and the power to attribute meaning to the statements of others. (Kvale, 1996, p. 227)

Jointly constructed meaning can occur in several ways. Researchers can present texts to participants for review, correction, and discussion so that the final interpretation is genuinely a joint text (Mihesuah, 1993). This raises additional questions about joint authorship and anonymity on the part of participants. Some participants may choose to use their names and/or be co-authors of the text (Bar-On, 1996; Mihesuah, 1993). At the very least, "writing on the research should not be elitist, but written

by, and available to participants and researchers alike” (Kerruish, 1995, p. 137).

Change is a fluid process and research interviews capture the moment. The mainstream perspective holds that research should be generalizable. Thus, the results of a human subjects study are expected to fit the traditional paradigm where the results are disseminated through publication. Publications are necessarily static documents and thus, due to the change process inherent in the PAR approach, are immediately out of date and may, in fact, cause harm to participants by portraying a condition that doesn't currently exist, subjecting them to stereotypes or prejudice.

As I listen to the ideas and dialogue of others that are travelling the PAR journey, there are many thoughts about what constitutes ethical practice, each based on the unique circumstances of the project. What seems to be needed is an additional set of principles from which I can develop guidelines for each PAR journey. These principles would ensure that I might “feel right” about the research and act on the care and concern that I have for fellow research participants. The *Code of Ethical Conduct for Research Involving Humans* (1998), acknowledges that an ethic of care, involving “an empathetic understanding of the hopes and fears of prospective research participants . . . [with] candour, compassion, prudence, fairness and courage” (1998, Part I) is another approach to the ethics of research involving humans. Building on the principles of respect for persons and beneficence, I suggest in the following section the principle of care and concern as fundamental for ethical practice in PAR.

Cartography: Mapping the Area

The *Code of Ethical Conduct for Research Involving Humans*, (1998) is based on the view that humans are rational beings. An ethic of care, on the other hand, is based on the view that humans are relational beings. Being relational means that, at the forefront of decisions about what is right, are caring relationships with others. Gilligan, (1987) proposed that this way of looking at the world was common to the morality of girls and women. While morality based on an ethic of care is not exclusive to the female gender, it is a fundamentally different way of viewing the world than that underlying the theories of moral development generated in the 1950s by male researchers. Theories of moral development are based on the principles of justice rather than the principles of care and seem to form the basis for the current code(s) of ethical conduct. While others may disagree, I do not believe that the view of humans as rational beings is incompatible with the view of humans as relational beings. I do believe, though, that these views are tied to research methodology. Principles based on an ethic of care are fundamental to the PAR paradigm.

I suggest that the principle of care and concern, in conjunction with the principles identified in the *Code of Ethical Conduct for Research Involving Humans* (1998), is essential for ethical decision making in any PAR project. As noted in the Code, principles do not exist in isolation from each other. There is the potential for conflict between principles, and an awareness of the potential for this conflict should lead to the development of strategies to minimize the conflicts. While its application may differ or be less apparent in more traditional research projects, the principle of care and concern must be explicit and apparent in the methods of PAR projects. This principle is further elucidated here through three corollaries that lend specificity to its use.

Care and Concern

Fundamental to the ethic of care is the principle of care and concern. This principle holds that as a researcher, I offer, through my relationship with participants, an empathetic understanding of their hopes and fears as well as active support for change in their circumstances in relation to those hopes and fears. In this principle, relationships with participants are held as a high priority. Feelings and emotions form the basis for considering what action to take. Relationships occur with participants, either as unique individuals or as members of the collective they represent, but they *are* present and they guide ethical actions on the part of the researcher. This principle goes beyond the notion of collective rights which is used as a basis for the guidelines on research involving collectives and their members outlined in the *Code of Ethical Conduct for Research Involving Humans*, (1998). The Code outlines "good practices" such as conceptualising the research as a partnership between the researcher and the collective and "examining the possibility that their research could be shaped in a manner that addresses matters relevant to the collectivity" (*Code of Ethical Conduct for Research Involving Humans*, 1998, Part 2, VII). When the principle of care and concern is operating, ethical research requires that the research be shaped in this manner, with the intent to create change in those matters relevant to the participants.

Research on First Nations people has often exploited these groups in the name of academic freedom or the advancement of knowledge by exposing traditional cultural and spiritual practices (Mihesuah, 1993). PAR is an ideal model for research with First Nations people because it involves the community of participants in the process. Basic ethical procedures suggested by Mihesuah include: approval of the proposal by the communities spiritual and political leaders after extensive consultation; fair and appropriate return to participants; and review of the results by political and spiritual leaders. These procedures are a necessary part of the PAR journey. The PAR researcher engages in these procedures because of deep convictions and caring about the disempowerment of

First Nation's people. The principle of care and concern is thus operating to guide the ethical researcher.

Corollary One: Obligation to Improve Participant's Lives

Extending oneself to assist others to overcome difficult circumstances is fundamental to an obligation to improve participant's lives. This goes beyond beneficence to a requirement for *active* intervention to improve the circumstances of individuals and collectives participating in the research. Improvement in quality of life goes beyond advancing knowledge about the conditions(s) of a collective or the production of benefits for society; it is specific to the participants in the study.

I was asked by a mother, who was participating in the aforementioned study with the parents of children with emotional and behavioural disorders, to write a letter on her behalf to a local practitioner who had recently assessed her son. A report that blamed the mother and termed her overprotective and overinvolved in the life of her son was disturbing to her. I was torn, based on my traditional research training, because I had not seen the report and there could be an element of truth to that interpretation of the family dynamic. The mother understood that I could not speak to specifics other than what she had told me and in fact was not requesting that I do so. What she wanted was a letter which spoke to the research we were doing on the conditions of parenting a child with emotional and behavioural disorders; in particular, the difficulty that parents have with finding appropriate and sensitive service options. She felt that such a letter might be of assistance in helping the practitioner to understand the bigger perspective. This I could do; in fact, I felt ethically obligated to do so, since it might well improve the conditions of her life, as well as the lives of other parents like her if the practitioner could understand this perspective.

Corollary Two: Collective Representation of Meaning

The meaning of an individual's experience is uniquely his or hers, until a researcher joins that person to explore the experience and change it. The meaning will be changed through the process of exploration. The final capturing of meaning from which decisions for action are made must be a joint representation of researcher and participant experience. Collective representation of meaning recognizes the importance of that process and its fundamental connection to change on the part of the participants in the project. It is based upon the humanistic notion that understanding is required for change and that people must be ready in order to take steps toward change. This is in contrast to the notion of rational and objective research reflected in the *Code of Ethical Conduct for Research Involving Humans* that states:

There are many situations where collectivities may wish to react to the findings, especially when shortcomings are perceived. It is usually inappropriate for the collectivity to seek (or to be given) a veto on the reporting findings. At the same time, it is inappropriate for researchers to dismiss matters of disagreement with the collectivity without giving them due consideration. (1998, Part 2, VII)

The Code suggests that compromise with the representatives of a collective is ideal. At a minimum, the opportunity for response and accurate reporting of disagreement must be provided. In PAR, if collective representation is to be achieved, compromise is more than just ideal and the power to make the final decision does not rest with the researcher.

Conflicting priorities for representing the results of a PAR research project can easily emerge based on the differing interests of the researcher and participants. In a project for the development of a 30- to 40-minute video, with parents of children with emotional and behaviour disorders, I was fascinated with two themes that emerged from the analysis. "Looks Normal but it's Not" captured the grief of parents as they began to define their child as someone who needed help and "Parenting is a Science" outlined the exacting requirements for parenting these children. As the researcher, I was most interested in the parenting process. The parents, on the other hand, were interested in communicating to friends and practitioners what it was like to live in their families because they constantly felt misunderstood and unheard. They wanted to portray two other themes; "Family Chaos," which described the constantly changing nature of their child's behaviour and its impact on family members and "Strength and Hope vs. Numbed out," which described the feelings and actions that helped parents keep life in perspective and enabled them to continue to provide care for their child. All of these interests could not be portrayed. We decided to represent the last two themes in the video because they would create the most impact on practitioners and communicated support and understanding to other parents in similar situations. This focus seemed most likely to create change in the service delivery system. My interest in the loss experience of the parents and the exacting requirements of parenting was summarized into a brief introduction describing the life story of being a parent of a child with an emotional or behavioural disorder.

Corollary Three: Timeliness

Timeliness requires that decision making for change occur within a timeframe that maximizes the impact of the results and minimizes the risk that the analysis will be rushed and thus lack credibility because an important component has been missed. In PAR, decisions for change occur based on information and understanding generated by the data collection, analysis and interpretation. Since both the processes of data collection and interpretation can follow several cycles, the findings may change with each new round of data collection, or analysis and inter-

pretation of the collected data. Stability of the results is important for informed change to occur; however, change due to the research process can lead to results that appear unstable but are really an indication of change in the circumstances of the participants. These two considerations must be held in a careful balance in a PAR project. The process must occur within a time frame that is developed and managed with the participants in the project.

We initiated a PAR project in response to a request by health and social service practitioners to help them better understand the source of suicidal behaviours exhibited by youth. They also needed to identify youth that were potentially at risk. A research team was formed with local school counsellors. Timely presentation of the results was managed in several ways. A questionnaire administered over time to groups of youth was scored and individual results returned within one week allowing us to identify and assess further those youth at risk for suicide behaviours. The assessment was accompanied by a follow-up interview with the aim of coming to a fuller understanding of the factors surrounding suicidal risk. As the questionnaire was administered, the statistical analysis of the related risk factors could occur. Initial results on the questionnaire were presented at the mid point in data collection, with a caveat that these were preliminary. Within one month of completing data collection, the statistical results were reviewed with the research team. Qualitative analysis of the interviews proceeded more slowly; however, preliminary themes were shared verbally, adding more meaning and depth to the statistical analysis. At all points the practitioners helped the research team to interpret the findings and make recommendations for additional programming. Towards the end of the research phase, the youth were involved in responding to the results and presenting their own interpretation. The recommendations of youth and practitioners were included in the final report.

Suggestions for Specific Guidelines

Funding and ethical approval for PAR may require two stages; the first stage would allow the researcher and the group of interest to develop a solid understanding of each other's roles and responsibilities in the research project and to develop a specific plan of action. Ethical approval for stage one would be based upon the participants understanding of roles and responsibilities and require that the proposed research indicate that a relationship has been developed with the leaders of the population to be studied, or the specific participants. Ethical approval for stage two would incorporate the existing REB requirements interpreted through the principle of care and concern. When the principle of care and concern is used in conjunction with the four principles forming

the basis of the REB guidelines, guidelines for ethical decisions in PAR projects might include such specifics as:

1. The proposed research must detail the process by which relationships with participants will be maintained and how these relationships will impact on the decision making that occurs within the project. Leaders within the participant population would be co-signatories to the proposed research.
2. REB's would include representatives of the population to be studied. Their perspective must be included in determining the ethical suitability of the project.
3. Informed consent procedures must describe the ongoing communication process used to shape the project and identify the roles and responsibilities of all involved parties. A process for conflict resolution must be identified that respects all parties.
4. The second stage review of a PAR project would require the designated researcher(s) to describe the "normally acceptable risks" for the participant population and describe the process by which change might occur within the participant's lives.
5. Publications and presentations of the research should be credible for participants and for the designated researcher, with a priority placed on the participant's experience. Until agreement on content is achieved, public presentation of the results should not occur.
6. Preliminary reports and working papers should be disseminated and discussed among the leadership of the participants as early as possible. Interpretation of the meaning and potential actions resulting from the findings should be undertaken as early as feasible in the research process.
7. Members of the participating collective should be actively sought and used as researchers, on an ongoing basis, within the project. Their role in data collection, analysis and interpretation should be identified in the research plan.

CREATING AN INTERACTIVE GUIDE: DOING THE RIGHT THING AND CARING

It is the beginning of a "new world" in academic research, as granting bodies recognize the importance of participant input into the research process. In order for researchers to undertake ethical journeys in this new world, the development of additional ethical guidelines is essential. Codes of ethical conduct, as they stand now, represent standards defining more and more tightly what is right and proper behaviour on the part of researchers. The codes are beginning to recognize the importance of including in ethical decisions the very humans that are the objects of such decisions. Unfortunately, they continue to do so based only on principles of rational and just treatment. Milligram's famous experiments in the 1950s took us on a journey to create guidelines that limit the harm we do to others, assuming that we are under no obligation to create improved conditions (Price, 1996). I believe that we are under an obligation to incorporate an ethic of care in research that operates from a PAR paradigm. This obligation goes beyond just the creation of good or improved conditions through the dissemination of knowledge and ne-

cessitates active intervention in people's lives based on the principles of care and concern for collective social conditions. Traditional research done in the pursuit of knowledge for the benefit of society is admirable and current codes of ethical conduct offer appropriate guidelines for such adventures. PAR researchers, however, are obligated to use their power for the direct advantage of individual participants and to incorporate the principles of an ethic of care into the guidelines that they follow for an ethical research journey.

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About the Author

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