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Ethical Challenges of Research on and Care for Victims of Intimate Partner Violence

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INTRODUCTION

The purpose of this article is to discuss the ethical challenges faced by researchers who study and practitioners who assess and intervene in cases of intimate partner violence (IPV) — in higher income countries such as the U.S., U.K., and Canada, and also in low and middle income settings — as well as to provide recommendations for research and practice. After a brief overview of the global impact of IPV, the article describes ethical guidelines relevant to research on IPV and the provision of healthcare services, and then discusses ethical challenges related to both research on IPV and the provision of healthcare services. The article concludes with a discussion of recommendations for improving IPV-related research and practice.

IPV, one of the most common forms of violence against women (VAW), is now recognized as a significant, global violation of human rights and a serious public health problem.¹ IPV is defined by the Centers for Disease Control and Prevention (CDC) as "actual or threatened physical, sexual, psychological, or stalking violence by current or former intimate partners (whether of the same or opposite sex.)"² The overwhelming burden of abuse by a partner is endured by women at the hands of men, and, for the purposes of this article, we will focus on aspects of IPV in which a male harms a female.

The precise magnitude of IPV is unknown, although there is increasing evidence on prevalence from many different countries. Findings from the National Violence Against Women Survey (NVAWS) suggest that in the U.S. 22.1 percent of women have experienced IPV.³ From an international perspective, the World Health Organization (WHO) Multi-country Study on Women's Health and Domestic Violence against Women measured the extent of IPV in 10 low and middle income countries.⁴ Estimates of physical violence by partners ranged from 13 percent in cities in Japan to 61 percent in provinces in Peru, with African countries such as Namibia and Tanzania reporting estimates of 31 percent and 47 percent, respectively. A broad range

of immediate and long-term adverse consequences for women's physical, mental, sexual, and reproductive health related to IPV have been documented around the world.⁵

The need for research and healthcare services specific to IPV is clearly warranted by the global magnitude of the problem. Nonetheless, work in IPV has challenges, including an array of ethical dilemmas. Although researchers and practitioners are guided by norms for safe and ethical conduct of violence-related investigation as well as the provision of care, ethical codes, policies, and principles do not cover every situation that may arise in research or clinical practice in diverse rural and urban settings. Ethical principles often conflict and require significant interpretation on the part of a researcher or practitioner that must be subjective.

ETHICAL GUIDELINES FOR IPV RESEARCH AND PRACTICE

There is no doubt that scientific and clinical research has benefited society. However, even when research has been well designed and the intent of researchers has been to improve the health and welfare of society, research has caused harm to participants. Research in the late 1940s through 1960, such as the Nuremberg war crimes (1947), the Tuskegee Syphilis study (1950s), and the Thalidomide trials (1960s), used unethical methods and caused significant harm to the research participants. As a response, "The Belmont Report"⁶ set forth three major research ethics principles: respect for persons, beneficence, and justice. Three foundational documents that followed "The Belmont Report" provide ethical guidelines for conducting research on IPV with human subjects, including: the Council for International Organizations of Medical Sciences (CIOMS) *International Ethical Guidelines for Biomedical Research Involving Human Subjects*,⁷ the WHO *Putting Women First: Ethical and Safety Recommendations for Research on Domestic Violence against Women*,⁸ and the WHO *Ethical and Safety Recommendations for Researching, Documenting and Monitoring Sexual Violence in Emergencies*.⁹

Clinical care is also guided by ethical codes of conduct, based on human dignity, informed choices, and the protection of individuals, families, and communities from unsafe care and practitioners. The "World Medical Association International Code of Medical Ethics" was first adopted in 1949 and reaffirmed in 2006.¹⁰ "The ICN Code of Ethics for Nurses" was first adopted by the International Council of Nurses in 1953 and was newly revised and reaffirmed in 2005.¹¹ Measures to protect victims of IPV who disclose violence in the clinical or community setting as patients need to be based on guidelines developed by experienced practitioners, such as those developed and set forth by several national and international professional organizations, such as the American Medical Association,¹² the American Nurses Association,¹³ as well as the Nursing Research Consortium on Violence and Abuse,¹⁴ the International Research Network on Violence Against Women,¹⁵ and the WHO.¹⁶

ETHICAL CHALLENGES ENCOUNTERED BY IPV RESEARCHERS AND PRACTITIONERS

Despite the aforementioned guidelines regarding IPV research and practice, research and healthcare professionals continue to encounter a broad range of ethical, moral, cultural, and social dilemmas that are not easily solved by referring to such codes, standards, or policies. This section discusses a range of these dilemmas. Although some are mentioned in the existing literature, discussion about the context in which they occur, as well as their implications, is limited. This portion of the article is divided into six sections: (1) Methodological Constraints, (2) Safety Planning, (3) Resource-Poor Settings and Reduced Capacity, (4) Requirements to Report Cases and Perpetrators, (5) Therapeutic Misconception, and (6) Culture and Context: Balancing the *Emic* Versus the *Etic* View.

Methodological Constraints

Conducting research on or asking clients about IPV is complex, in that the topic is potentially traumatic for the participant/client and can threaten both the safety of the woman disclosing and the person asking

about the abuse.¹⁷ Recent research, particularly from higher income countries, has dispelled common misconceptions about the harms of asking research participants about IPV and has further established that it is unethical to fail to ask about IPV.¹⁸ Studies provide evidence that women who participate in research as well as women who visit their health practitioners want to discuss IPV if they perceive that the investigators/clinicians will be non-judgmental and supportive.¹⁹ Most prominent are studies that report low to no distress by respondents, and even relief, after answering questions about IPV.²⁰ Despite the growing body of literature on the ethical challenges faced by IPV researchers, many instances of IPV have yet to be addressed or require further attention in this important area of public health inquiry. Some of the most prominent situations are discussed below.

As discussed by Ellsberg and Heise,²¹ one of the most important methodological challenges in research on IPV is to increase reporting of the abuse. This applies to practice as well. Under reporting leads to biased information about the magnitude of the problem. When women will not admit there is abuse, a practitioner cannot offer assistance. Nonetheless, increasing disclosure of IPV is difficult, for a variety of reasons. In research there are measurement challenges, such as when violence-related items on a questionnaire are used in new cultural settings (beyond the samples with which they were initially tested). In such cases, the meaning of terminology can be lost in translation or, even when terms are translated accurately, they may lose cultural salience. Thus, unadapted survey questions may generate data that inadequately measure violence or disallow comparison. For example, researchers who conducted survey research in rural Uganda asked married female respondents if their husbands had ever "forced" them to have sex. Translated into the vernacular, this question asked respondents if they had ever been raped by their husband. Marital rape is not recognized by Ugandan law, and thus was nonsensical for many respondents. When the research question was retranslated using a modified and culturally adapted version of the Conflict Tactics Scale, rates of disclosure of perpetrated "forced sex" by respondents' partner increased dramatically.²² Disclosure of IPV is also challenged because IPV is often perceived as taboo, or off-limits for discussion (in the research as well as the healthcare setting). Many practitioners fear asking about abuse, and many women find it difficult to disclose their experience of violence due to feelings of shame or fear.

Another constraint in many research settings is ensuring that results of research are applied to benefit the groups investigated, in terms of effective sharing of information, informing political and other influential leaders to incorporate research findings into revised policies and guiding principles. Ideally, researchers should collaborate with local activists to ensure that their voices are heard in a way that accounts for issues related to IPV and gender. This is difficult, however, in settings where gender inequity is normalized and the rules are developed and enforced by men. In low and middle income settings, the conduct of ethical research is further challenged by insufficient financial and technical resources to implement study methods that will produce results that are beneficial to study participants.

Researchers can also be restricted and/or unduly influenced by the priorities of their funding organizations. Although IPV research has been gaining interest on the international scale, many studies on violence are nested into larger investigations of other health outcomes, such as HIV/AIDS. The conduct of safe and ethical IPV research may be accorded low priority, behind pressing needs to follow other scientific regulations and meet other funding requirements. Challenges arise when research teams are minimally trained on how to conduct ethical IPV research, and/or are trained to do IPV research as a second priority, and/or are rushed through the research process so as to produce results according to the rapid time lines. It becomes difficult to follow protocols for ethical conduct and to produce valid data and/or use findings to the benefit of study populations in these contexts.

Safety Planning

Researchers and practitioners are ethically responsible for ensuring the safety of respondents and clients who disclose violence and may be in danger. Together the researcher/practitioner and the woman experiencing violence can create a safety plan that identifies action steps to increase her safety and prepare her for the possibility of further violence. Another effective response to disclosed violence is referral to a skilled advo-

cate who is associated with the study team or a larger (established) violence prevention support network. At the minimum, a passive referral can be offered, in which phone numbers or directions to various agencies dealing with IPV can be given at the end of the interview.

Safety planning challenges are often encountered by professionals working in low and middle income countries where violence-related support services are nonexistent and/or it is not culturally appropriate or normative to seek assistance, particularly of the psychosocial nature, from community sources outside the immediate or extended family. Providing information on referral resources will either not be an option or may not be useful. The WHO guidelines recommend creating short-term support mechanisms when few resources exist.²³ However, when considering the traditional taboo placed on talking with outsiders about family matters, and difficulties discussing IPV when it is first disclosed, provision of immediate counseling services and/or safety planning by the interviewer (or other research staff) may be of limited assistance to a study participant. Furthermore, financial limitations and existing responsibilities might make it impossible for study teams or healthcare staff to take time from their routine work to offer support to victims of violence.

Resource-Poor Settings and Reduced Capacity

In many lesser developed countries, as well as working class populations in more developed settings, professionals in various sectors are extremely underpaid, underfacilitated, and overloaded with work. Consequently, it is not uncommon for practitioners, as well as other service providers and researchers in these settings, to "make ends meet" by extortion. A challenge to the fields of IPV research and practice is presented when women who disclose violence are asked for some kind of payment in exchange for assistance. This is of particular relevance in settings where women are economically dependent upon their husband and do not have the resources necessary to pay for services, regardless of whether fees are legitimate or corrupt.

Another challenge is that many investigative staff and healthcare practitioners are not trained to ask about IPV. It is clear that researcher-respondent and patient-provider encounters have the potential to assist IPV victims in finding support, understanding the options for living without violence, and learning how to reduce exposure to IPV. In fact, the majority of women in the WHO Multi-country Study said that they might find healthcare providers a good source of help if they were sure that the providers had been trained to offer assistance.²⁴ Nonetheless, the reality is that many healthcare practitioners (and researchers) have not been trained to ask about IPV effectively nor have they been informed about what to do if and when a woman discloses.

Although researchers, doctors, nurses, and other healthcare providers are in a unique position to help victims of IPV, they can do very little if they do not know how to assess and intervene. Groups such as the Family Violence Prevention Fund in the U.S. have worked for more than 10 years on projects such as the National Health Initiative on Domestic Violence, aimed at improving the healthcare response to IPV through public policy reform, health education, and prevention efforts.²⁵ Nonetheless, many health professionals in the U.S. do not routinely ask their patients if they experience IPV. Reasons for this lack of inquiry range from practitioners' perceptions that such questioning is invasive, out of the realm of routine medical practice, and/or a cause of unusual distress and discomfort for patients. Other providers said they avoid asking about IPV because it is time consuming and difficult, and because they deal with heavy work loads.²⁶ Another type of ethical challenge is presented when practitioners are reluctant to assess, intervene, and follow up on cases of IPV because they consider IPV to be an acceptable, normal part of life, not a problem.²⁷

Requirements to Report Cases and Perpetrators

Mandatory reporting laws in some settings have created challenges for health researchers and healthcare practitioners who work with victims of IPV. In the U.S., for instance, all 50 states currently mandate that practitioners and researchers report child abuse to state authorities.²⁸ Proponents of IPV reporting laws argue that mandatory reporting catalyzes prosecution of perpetrators, protects potential victims from harm, and promotes the identification of IPV in clinical and research settings.²⁹ The ethical dilemma caused by attempts

to protect victims from harm, by reporting their abuse and abuser, is that disclosure to a third-party conflicts with the ethical duties to preserve patients' confidentiality and to "do no harm." Researchers and practitioners have found that, in some cases, mandatory reporting may increase violence by perpetrators, diminish the autonomy of those who report the violence, and compromise patient-clinician and respondent-researcher confidentiality.³⁰ For reasons already discussed here, women who experience violence are often hesitant to confide in others. Researchers and healthcare practitioners must work to establish rapport and gain an abused woman's trust. This trust can be negated should a researcher or practitioner breach confidentiality by reporting to a third party. Thus, researchers and practitioners who are forced to breach confidentiality by mandatory reporting laws are faced with a severe ethical dilemma.

Many scientific investigators and healthcare providers report that they feel mandatory reporting laws violate medical and research ethics.³¹ As a result, many report that they refrain from asking victims of IPV questions related to their or their child's exposure to violence. Many professionals perceive that the risk of "asking" is larger than any benefit might be. As such, many professionals refrain from soliciting disclosure altogether. As discussed previously, when victims do not disclose because they are not asked, the potential to assist is ended before it can start.

"Duty to warn" is another challenging aspect of requirements to report abuse.³² According to the California Supreme Court *Tarasoff* decision of 1976, careproviders have a duty to warn when a patient is deemed to be a serious danger of violence to another. In such cases, careproviders must attempt to protect the potential victim by warning the third party directly or by notifying criminal justice authorities.³³ Although *Tarasoff* involved a psychologist-patient relationship, the ruling is seen as generally applying to those in a professional relationship (for example, nurses, physicians, social workers) with a potentially violent individual. Clinicians of all disciplines need to be aware of the potential for violence in their patients and clients, and to appropriately warn anyone who is overtly threatened. In IPV, this is particularly salient to those who work with batterers in batterer intervention programs or in substance abuse or mental health settings. This is also relevant to those who work primarily with victims of IPV, who may express intent to harm an abuser. In this realm, it is important to recognize that 75 percent of women who kill an intimate partner were abused by their partner.³⁴ Another important aspect is the possibility that patients will exhibit signs of potential harm to themselves. Clinicians have the duty to report when they work with abusive partners as well as victims.

Therapeutic Misconception

Therapeutic misconception relates to the distinction between research and a care intervention. It has been defined as "a mistaken belief of study participants that therapy and research are governed by the same primary goal: to advance the individual patient's interests."³⁵ The two goals may become blurred when a clinician-researcher discusses the benefits of participation in a research study with a patient who has come to the clinician to seek care. It is common for clinical investigators to encounter misunderstanding in patients participating in research — and in many referring practitioners.³⁶ Participants may not fully understand the experimental nature of the study, the chance they may not be enrolled in the intervention, that there may be risks associated with the intervention, and the intervention may not result in a cure. Therapeutic misconception is of particular concern in the case of IPV, since the services provided (for example, referrals, professional care), self-disclosure to research staff, and the risk of the partner finding out about a patient's involvement may put her at additional risk for re-victimization. In the informed consent process, researchers have the responsibility to ensure that participants are able to understand the standard of care, the nature of research, and any potential risk of the research related to enrollment in the study. This is particularly important when working with women who may have low rates of literacy and a poor understanding of the research process.

Culture and Context: Balancing the *Emic* Versus the *Etic* View

As noted earlier in this article, definitions of IPV have been established (such as that from the CDC).³⁷ The United Nations "Declaration on the Elimination of Violence Against Women" defines violence against

women as "any act of gender-based violence that results in, or is likely to result in, physical, sexual or psychological harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life."³⁸ This definition was adopted by the U.N. General Assembly as well as by the WHO. The use of consistent definitions in research allows the generation of comparable data that can contribute to the international literature on the magnitude of IPV. However, some researchers are concerned about this *etic* approach (the description of a behavior by an externally developed, "universal" standard, that can be applied to other cultures; that is, an *etic* account is culturally neutral) to investigate IPV, and instead recommend using an *emic* framework (a culturally specific description of behavior or a belief, in terms of how it is perceived or defined within the research population). It is argued that an *emic* approach meaningfully evaluates IPV and associated ethical responses within their sociocultural context.³⁹

Several international research studies have generated findings suggesting that, from an *emic* perspective, partner abuse is not consistently defined and is widely perceived to be acceptable by some populations.⁴⁰ The use of an *etic* approach in this type of setting will yield data that erroneously measures the occurrences of violence (in that the researcher measures what he/she has defined as violence, as opposed to what the respondents define as violence). By investigating IPV from an *emic* approach, researchers are able to understand how violence is defined in the population, and they are therefore able to more accurately measure its occurrence.

DISCUSSION

It is important to note that the goal for most practitioners and researchers who deal with IPV is to "do no harm" (nonmaleficence) and do what is in the best interest of the victim of violence (beneficence). As illustrated in this article, applying these two values, as well as the other guiding principles of safe and ethical research and clinical practice, cannot be simple, because IPV is not simple. To the contrary, it is a complex public health problem caused by an interplay of individual, relational, communal, and societal dynamics.⁴¹ Due to the imprecise and multifaceted nature of IPV, the way in which it is perceived varies across cultures, social groups, and individuals, including professionals in similar fields. A challenge herein is that the concepts of "good" and "harm" are unquestionably influenced by an individual's or society's belief system pertaining to what is normative (and acceptable) versus what is aberrant (and unacceptable) behavior.

It is the responsibility of researchers and practitioners to do everything possible to ensure a woman's safety, particularly when the reason for her disclosure or "opening Pandora's Box" was initiated for the benefit of research. After a research or clinic-based encounter with an IPV victim, professionals are challenged with maintaining confidentiality by not speaking with others about her disclosure and ensuring that her confidential written documentation is handled and stored safely and privately. Some of the largest challenges in maintaining confidentiality are associated with the requirements of mandatory reporting in some settings. Laws requiring researchers and clinicians to report cases of violence are highly controversial and disagreed upon. It is essential that best practices for mandatory reporting be established.

Implications for Research, Practice, and Policy

Overcoming methodological constraints. Methodological challenges to obtaining valid data, such as prevalence of IPV, can often be overcome via the implementation of rigorous, scientifically sound research techniques. Specific to violence investigation, the WHO guidelines recommend that prevalence studies "build upon current research experience about how to minimize the under-reporting of violence."⁴² Thus, research questions should be based, to the extent possible, on items that demonstrate validity. Research instruments for investigation of IPV must be revised or developed initially via formative research and pre-testing in the actual research setting, and preliminary factor analysis should be conducted on the responses to (and estimated comprehension of) these items prior to formal use. Scientific monitoring is needed to ensure the consistency of the techniques used.

Reducing under reporting. With respect to the barriers to disclosure of IPV, many could be overcome by increasing practitioners' and researchers' collective knowledge about the magnitude of IPV, the link between abuse and the negative physical and mental health consequences, the cycle of abuse and why victims and perpetrators often try to hide it, and how victims of violence would prefer to be screened and responded to during and after disclosure. Professionals should learn to measure how victims define and rank their own safety priorities and those of their children and other immediate family members. These issues could be addressed in capacity-building training programs that educate clinicians and investigators and offer instruction on (1) how to ask questions about abuse, (2) how to recognize and overcome language barriers between providers/researchers and victims, (3) how to ascertain information about a person's or family's history of abuse and how chronic the abuse is in the current relationship; and (4) how to develop safety plans with victims. Finally, healthcare providers and investigators should receive brief, clear resources to share with victims: referral networks, local IPV services, and hotline numbers.

Managing mandatory reporting. To develop best practices related to mandatory reporting, it is critical to understand IPV victims' support or opposition to mandatory reporting laws. In at least three large studies, abused women said they preferred to have the final say about whether the police were called by healthcare professionals in IPV cases.⁴³ We agree with Ellsberg and Heise and the vast majority of advocates who believe that the preservation of confidentiality and a woman's right to make autonomous life choices must be paramount concerns in these situations.⁴⁴ However, some state legislatures, healthcare practitioners, and researchers disagree; for example, Fontes recommends that researchers communicate with their institutional review board about the importance of mandatory reporting, inform participants about the researchers' duty to report cases of IPV to local authorities, and develop a plan for reporting cases when such situations arise.⁴⁵ To address these conflicting recommendations, as with child abuse reporting, research teams are now working collaboratively with local community experts to develop reporting protocols and train research team members in these protocols in states where mandated reporting for IPV is applicable, as well as to test if whether the risks of mandatory reporting outweigh the benefits.⁴⁶

Although there is a debate on best practices for responding to mandatory reporting laws, we believe that ethical principles require that study participants and patients be provided with information on mandatory reporting laws prior to being asked specific questions about child abuse and IPV, and that women's decision-making autonomy, consent, and safety should be a priority when developing protocols for reporting IPV to authorities. Participants must be informed that if they report that a child has witnessed or experienced violence, the researcher is required to stop the study and ask specific questions to determine if a report of child abuse must be made. If a report is necessary, the study protocol must focus on the safety of the child and engage the participant in making the report. This allows the participant to take control of the situation and be supported by research staff, to learn what can be expected once a report is made. The protocol should include information for the participant on local counseling and other referral resources for children.

Accounting for the human side of research and practice. Healthcare practitioners and investigators are in positions of power that command respect and trust within the community and, specifically, from patients and respondents. It may be easy to lose sight of the fact that before people are doctors, nurses, or researchers, they are human beings who have their own experiences and established belief systems. Thus, although practitioners and investigators are in a unique position to intervene in the lives of women who experience IPV, the professionals' experiences and attitudes about IPV may affect their ability to handle situations of abuse effectively. Practitioners and researchers who have been (or who are) victims of IPV may find it particularly upsetting and/or difficult to treat women who have been harmed or to collect data regarding their accounts of violence. Both strengths (for example, increased empathy) and weaknesses (for example, personal breakdown or inability to cope) may come from personal experience with abuse. It is recommended, however, that regardless of past history, systems should be established to address the emotional needs of researchers and clinicians who deal with IPV, as the absence of such support may lead to burnout or inability to work effectively.⁴⁷ Conversely, providers/researchers who are themselves perpetrators of violence might find little reason or motivation to help clients/respondents who are victims; they may even condone the

behavior of other abusers. Without addressing these possibilities, the dynamics of the clinician-patient/researcher-respondent relationship can actually lead to exacerbated abuse, insensitive or derogatory responses to an abused woman, blaming the victim, or delivery of substandard care — none of which honor the ethical principles of beneficence and nonmaleficence.

Policy-level recommendations. Professionals should advocate for the continued use or adoption of strategies and guidelines to promote gender equity that reflect the health and social needs of women in abusive relationships, as well as the rights of all women to equal treatment in each sector of society. Health and research policies should be evidenced-based, drawing on research findings that highlight the link between IPV and adverse outcomes. Prevention efforts should be evidence-based, and focus on the needs of women in violent relationships. Finally, funding agencies should be monitored to assure they promote and back the conduct of scientifically sound research and practice that generates data and care of high quality.

CONCLUSION

Given the urgency of addressing the global problem of IPV and the range of ethical dilemmas commonly encountered in the process of doing so, there is need to focus on the ethical design, implementation, and evaluation of violence-related research and practice. Failing to address the ethical challenges of work with IPV victims may yield substandard healthcare service, as well as substandard research data.

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