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Should case documentations be used for research?

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We would like to present the ethical dilemmas we face in our current work at Dilaasa, a public hospital-based crisis centre providing social and psychological support to women facing domestic violence. Started in 2000, it is a joint initiative with the Municipal Corporation of Mumbai. It attempts to sensitise the public health system to domestic violence through counselling services and training of staff.

In 2003 we wanted to conduct research to understand the impact of counselling on women's lives. The centre documents each counselling session. The counsellor's notes include the woman's socio-demographic details, details about past and ongoing violence, her health history, a safety assessment and details of the counselling process. But this information was not adequate to understand the impact of counselling? On the other hand, interviewing survivors would force them to relive the trauma. They would also be spending time which they could otherwise use in work, or in dealing with the crisis in their lives.

Still, we felt the need to understand the impact of counselling from their perceptions and did not wish to rely merely on case documentations. We proposed to minimise the risk to women by setting up a mechanism. The interview would not seek any information from women that was available in case records.

The next question arose when our protocols and the consent form were reviewed by our institutional ethics committee. We were asked whether we were taking consent from the woman for the use of her case records. We had taken for granted that the woman's consent to participate in the research study, and be interviewed, included her consent to the use of information that she may have revealed during counselling that has taken place earlier. Thus we perhaps missed a serious ethical issue, especially since when women come to the centre, we assure them confidentiality. On reporting to the centre, the woman is given information about the services, and counselling begins only after she consents to avail of these services. She is promised that whatever she shares will not be disclosed to anyone; only counsellors would have access to information about her. Effectively, the woman shares her private oppression with the centre staff. Using this information without her consent could mean a serious breach of trust, as well as a violation of norms.

Separately, for an impact study, we sought separate consent for the use of case records from women who participated in the study. This discussion, too, raised several issues which remained unresolved at the time of ethics review and IEC members expressed the need to have a larger debate on them.

The central question is whether information shared in a counselling session can be used for research purposes. When we offer the women complete confidentiality, should we use what she has shared for public analysis? Would this not violate her trust? After all, she shares with us her personal agony and her innermost feelings, on the understanding that it is kept private.

On the other hand, while we are certainly bound by confidentiality, we also have an ethical responsibility towards changing the oppressive social structures which support and perpetuate domestic violence. Every woman who steps into the centre is in some way questioning patriarchy. Our role is to support her in her struggle, to help her resist violence at an individual level. These individual struggles must be systematically fed into the larger society; we must increase awareness about this issue, and change attitudes. This will give individual women more options to stop abuse. It will also make social agencies – the police, health professionals, the legal system, families, neighbours, schools -- more responsive to victims. Finally, it will create an intolerance to violence against women.

For this, we must constantly examine trends and analyse available information. For example we started a dialogue with the police who are often insensitive to women reporting domestic

violence. We were backed by information from women's experiences. Most importantly, we are in a hospital setting. To create an understanding amongst health care providers of their role in responding to violence, we need to use the information that we have at the centre. We need to analyse the types of domestic violence, the profile of women facing it, and its health consequences.

Domestic violence is a sensitive issue. Research on it is both difficult and ethically challenging. So it is all the more necessary that the data generated at the centre are systematically analysed. (Of course it also raises the question of how such notes should be used in other settings.) But is it unethical to compile this information in the form of a report, as long as one ensures that the reports contain no identifiable information? If confidentiality and anonymity are maintained, why should this information not be used for systematic analysis? Though the centre was not opened with the purpose of doing research, is it not our ethical responsibility to use the information on hand in order to both inform and change the systems within which we work, and society at large? We believe there is not enough evidence on violence and health. Conducting research on domestic violence is difficult, and we feel it is essential that we use this information.

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