

Ethical dimensions of using individual case history studies in campaigning, fundraising and publicity work

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I. Introduction

For many non-governmental/charitable organisations the globalised world offers many opportunities, but it also raises some serious challenges. In an increasingly competitive environment, many organisations are seeking new donors and to influence the agendas of governments. To do this effectively they must remain relevant and visible to the wider public. As The International Rehabilitation Council for Torture Victims (IRCT) comes of age, and the torture rehabilitation movement continues to grow, these issues are becoming increasingly important for survival, being as they are dependent on exterior funding from international and national institutions, foundations and private donations. The focus of this article is to evaluate how the torture rehabilitation movement can ethically use the individual case histories of torture survivors (with their consent), to raise awareness, mobilise financial support and seek justice for victims of torture. The dilemma posed by the use of these cases in such work is that neither the work of centres nor the interests of the

victims should be put at risk, a point that forms the crux of the debate in this article.

II. Protection of clients and informed consent

It is clear that patients are protected adequately by ethical codes at the medical/treatment stage of the rehabilitation process; a fundamental principle is the duty of confidentiality. The confidentiality of the individual torture victim must always be respected to preserve the inherent dignity of the individual. However the multi-disciplinary working practices of many centres and programmes leave a question mark over the ethical protection surrounding the relationship between the patient/client and organisation in a social research context. Raising awareness of the issue of torture is a critical factor in both the protection (through rehabilitation) of survivors of torture and the prevention of torture, through increased public awareness of the issue. This dichotomy highlights a potential conflict between the needs of the victim to assimilate normally back into society and the needs of the organisation to make public the work it does in assisting such individuals to recover

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their lives. The balance of interests therefore lies between the collective interests of the rehabilitation movement and the vulnerability of the individual survivor of torture who views the organisation as “protector”. It is the imbalance of power in this relationship, which should be addressed.

To a greater extent, the issue revolves around informed consent between the organisation and the individual in the non-therapeutic relationship context. As a cornerstone of ethical practice the organization requires the individual’s full consent. However, it also has to make an assessment of the capacity of the individual to cope with public disclosure. Because all necessary measures must be taken to prevent adverse effects of disclosure for the torture survivor or their family, other questions arise about how informed consent is gained in the non-therapeutic relationship. Informed consent is defined as valid only when an appropriately informed person, who has the capacity to consent to the envisaged request in question, who furthermore must “comprehend and retain information material to the decision”¹, gives it voluntarily. Informed consent therefore focuses on the content and process of consent. To what extent does the individual, or the organisation, understand about what informed consent means and its possible consequences? Informed consent to do what exactly, and for how long and on what basis? If an individual’s identity is used in a case history, can it really be disguised so they are truly unidentifiable? Those organisations working in the field may be exposing themselves and their clients to danger as governments, who may themselves be currently complicit in human rights abuse, sometimes take direct or indirect action to attack centres or individuals willing to speak out publicly against torture. Social science academics and practitioners are increas-

ingly grappling with these ethical dilemmas as events move quickly in the faced-paced, globalised media, because outcomes are not easy to predict, and the makes *really* informed consent a thorny issue.

Institutions such as the World Health Organisation (WHO), London School of Hygiene and Tropical Medicine, UK Crown Prosecution Services and the British Medical Association have made valuable contributions in the form of ethical guidelines, particularly for interviewing vulnerable groups such as trafficked women and also children/unaccompanied minors. Increasingly, non-governmental organisations, particularly those heavily involved in campaigning/research or fieldwork, are realising that their methodologies may not be as ethical as they could, or need to be, and they are dedicating themselves to review these issues. Organisations such as Medicines Sans Frontiers (MSF) and Amnesty International are in the vanguard of this work and they have been carefully examining their own guidelines of how to collate and disseminate information taken from testimonies given by victims of human rights abuse in the course of their fieldwork. Whilst the aim of these organisations is to “do no harm” to the victim of human rights abuse, precisely how *best* to protect them ethically is debatable and it is still a steep learning curve for many of these organisations.

Within social research methodologies, Humphries and Martin argue in their critical study that orthodox statements of ethics “show their limitations and the ways they support the interests of dominant groups”.²

1) IRCT, Draft policy position paper, 2006.

2) Research in Social Care and Social Welfare, ed. B. Humphries, 2000, Ch. 6: Disrupting Ethic in Social Research. Jessica Kingsley Publications.

The balance of power between the institution and the individual poses challenges in drawing up social research methodologies, principally because the institutions have a vested interest in offering the researched information for public consumption as previously noted. The individual, who's case study may be used as an example, conversely may be grateful, beholden or have unrealistic expectations of the outcome they can expect from the organisation, thus consenting to any process too readily. There may also be cultural differences in the understanding of the nature of consent. Following her research with indigenous peoples Tuhuiwai Smith posits that indigenous cultures have a different approach to the issue of consent "Consent indicates trust and the assumption is that the trust will not only be reciprocated but constantly negotiated – a dynamic relationship rather than a static decision"³ which denotes a distinct need for the individual to be part of the methodological process from an indigenous cultural perspective. Benhabib summarises the aim of ethical research as "a reversing of perspectives and a willingness to reason from the other's (Other's) point of view, does not guarantee consent; it demonstrates the will and the readiness to seek understanding with the other and to seek some reasonable agreement in an open-ended moral conversation".⁴ In this brief snapshot of the issue of consent, it is clear that it is a complex process in the social science context, requiring flexibility and negotiation. The onus however, is on the organisation to monitor its role carefully in

3) Decolonising Methodologies: research and indigenous peoples, Tuhuiwai Smith, L 1999 (and reprints) Zed Books.

4) Situating the Self: Gender, Community and Postmodernism in Contemporary Ethics. Benhabib. S (1992), Cambridge Polity Press.

the negotiation as the balance of power tilts heavily in its favour.

With particular regard to the media, the use of case stories can enhance the amount of media coverage and thus the general visibility of the organisation. The general rule in journalism is that the more details told of a personal story, the more effective the message and its impact. Likewise the opposite is true; fewer details are less effective. Therefore, the objective of communicating effectively must be taken into consideration. One approach is to find torture survivors who are "already public" meaning that they have already presented their case to the media and thereby to the public, and don't run the risk of suffering negative effects from their revelations. A preferred approach may be to mix a number of anonymous statements up into a collection of personal stories made up of various elements, but this is not considered an effective communication, as it is often regarded as "too general" and "too de-personalized" by the media. The external influence of the media is therefore driving the need for detailed, sensitive and sensational stories. Likewise, similar arguments enhancing the importance of case story coverage for the media can be used in lobbying campaigns aimed at donors or politicians, who also respond positively to a personal story rather than general points. In a competitive environment it is necessary to "play the game" but there again there is a limit that must be decided upon by the organisation itself as to how far it will comply with this and at what point does it feel that sensationalism has taken over from the basic aim of communicating. It can be particularly harmful to an organisation's reputation if this matter is not handled sensibly and sensitively.

The Medical Foundation for the Victims of Torture, a torture rehabilitation centre in the UK, has substantial experience of

publicising its work using individual case histories of victims of torture. According to Press Officer Andrew Hogg, the Medical Foundation has certain procedures that it adheres to, particularly when patients/clients talk to the press. In all instances the clinician has to give their professional opinion about the individual's capacity to speak to the media, and where appropriate (i.e. if it is an asylum case) the individual's lawyer is consulted too. If their approval is given and the individual agrees and wishes to tell their story, the Press Officer then interviews the individual to assess their capacity to handle a media interview. Once they are satisfied that the person can be interviewed by the media without being re-traumatised, the individual is informed about what the implications of consent are. For example the person has to be aware that their case may remain on the Internet for perpetuity, something that has caused a great deal of concern in child pornography cases. They are asked to define the level of confidentiality they wish to agree to, such as do they allow their real name and details to be used or will they allow themselves to be photographed. They are also asked to sign a release form, so the contract between the organisation and the individual is binding and transparent for both. Finally, in any interview with the media there is always a representative of the Medical Foundation Press Office present to ensure support and bear witness. Interestingly, in recent consultation interviews with victims of torture, it emerged that some patients/clients actually want to tell their stories, something that Hogg points out is "often not recognised". As the Medical Foundation demonstrates, the patient's/client's and the organisation's needs can both be met through strong communication, clear procedures, good political judgement, professional expertise and constant negotiation

and consultation both internally within the organisation and externally with the patients/clients, clinicians and lawyers.

III. Conclusions

In the multi-disciplinary working practices of torture rehabilitation centres, as well as in the torture rehabilitation movement I will be more general and not directed exclusively to the IRCT. At the end of the day you are an employee, the debate needs to begin about how best to enter (from an organisational perspective) into negotiated and informed consent with individuals willing to have their case histories used for awareness raising purposes. There is a need to establish parameters about how the relationship between the collective and individual should be handled. In particular, it is clear that the organisations bear the responsibility to establish some procedures or codes of conduct in order to manage the conflict of interests, which it sets up itself in wanting individuals to talk about their experiences. Debates can be had about the efficacy of using individual case histories in the media, to seek justice in the courts, mobilise political support or fundraise, and each of these areas in turn open up further debates about how the best way to do it. However, at the same time it is important to ensure that the victims of torture themselves are included in these debates, to allow them to have a part in the process and understand better, and thus be more informed, about matters that affect them directly.

Human rights organisations and organisation dealing with traumatised survivors of torture should explore these issues and there are three key areas that require defining: a code of conduct; security guidelines for centres; and a standardised informed consent procedure. Whilst this may be a time-consuming and/or complex process, the reputation and image of the organisation, from

its base to its peer's, ultimately hinges on its own ethical behaviour. Leaving these issues unresolved until a problem forces attention on it could be a highly counter-productive strategy for all concerned. It is hoped that the debates will commence within the reha-

bilitation movement about these issues to help inform the investigations. Above all it is important to ensure that any procedures, informed consent, or security measures adhere to fundamental ethical standards, which is in everyone's best interests.

Errata

In the letter to the editor "Children and Torture", published in *Torture* 2006;16:136-7 the numbers 1-4 in paragraph 2 should be in a parenthesis, as it refers to the references in general. The numbers 1, 2, 3, 4 in the following four paragraphs should be omitted.

The letter has two authors:

Jørgen Cohn, Professor Emeritus of pediatrics, health and human rights, Ærøskøbing, Denmark and

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Neither Pusjka Helene Cohn as co-author to the letter nor Jørgen Cohn are connected with the IRCT.

Margriet Blaauw, answering the letter, has, however, references to the IRCT.