# 'Stop Stealing Our Stories': The Ethics of Research with Vulnerable Groups

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## Abstract

The article discusses the challenges and opportunities faced when integrating participatory methods into human rights-based research. It describes the development of a participatory action research approach designed to fulfil the aim of undertaking advocacy-focused research grounded in human rights and community participation. It reflects the principles of anti-oppressive social work and the ethics of undertaking research with vulnerable populations. In line with other contributions to this special issue, the article explores questions such as: 'Where does knowledge about the story come from and how is it passed on?'; 'What spurs ethical thinking at an individual and organizational level?'; and 'How can ethical sensitivity and strategic effectiveness be combined?'

*Keywords*: refugee research; reciprocal research; participation; ethics

*You know many of the organizations came to the refugee camp and they see the refugees in many ways as the monkeys . . . like a monkey in a cage . . . and then they thought that if we show this monkey to . . . the big countries of power like the EU [European Union], they will have a lot of money and it will benefit us [the non government organizations] . . . They documented things [stories] of the women that is oppressed, then when they get money they use some for the refugees but mostly they use for themselves.* (Discussion with a refugee men's group, Thai–Burma border, 2009)

## Introduction

Based on the work of authors Pittaway and Bartolomei with refugee groups in sites around the world, this article discusses some challenges and

opportunities facing those working to integrate participatory methods into human rights-based research. The article analyses incidents and discussions the authors have had with refugee research partners they have worked with over the past eight years, and explores how the authors have tried to address the challenges posed to them. It describes the development of a specific participatory action research approach designed to fulfil the aim of undertaking advocacy-focused research grounded in human rights and community participation. The approach they have developed is designed for working with communities and individuals experiencing multiple oppressions and persecution. It reflects the principles of anti-oppressive social work and the ethics of undertaking research with vulnerable populations.

As with other contributions to this volume, the article seeks to address the following questions relating to 'the responsibility to the story': 'Where does knowledge about the story come from and how is it passed on?'; 'What spurs ethical thinking at an individual and organizational level?'; and 'How can ethical sensitivity and strategic effectiveness be combined?'

### Background

In recent years there has been a sustained increase in the number of refugees and internally displaced persons (IDPs). Currently an estimated 35 million 'persons of concern' fall under the mandate of the United Nations (UN) High Commissioner for Refugees (UNHCR) (UNHCR, 2009). Forced migration results in disrupted community and social networks, contests over limited resources, multiple public health risks, and heightened instances of human rights abuses, including sexual and gender-based violence. These factors, and the associated vulnerability and marginalization of displaced populations, highlight the need for knowledge and understanding of refugee and IDP populations. This has led to a considerable rise in research on and among these groups, which is invariably undertaken in complex, difficult, and sometimes dangerous settings. This can place refugees at great risk of exploitative and damaging research practices (Allotey and Manderson, 2003), however unintended this might be. While the ethics of academic research involving human subjects has long been a concern for universities and researchers, it is now becoming recognized that the ethics of research with vulnerable communities needs to be readdressed in the light of the challenges posed by research among refugees and IDPs. The authors of this article believe that the ethical challenge is for researchers to add value to the lives of the people they are researching, recognizing them as subjects in the process and not simply as sources of data (Hugman, 2005, 2010).

### Ethical Challenges in Research with Refugee and IDP Communities

Recent academic literature identifies key concerns regarding the ethics of research with refugee, IDP, and other at-risk populations (Jacobsen and Landau, 2003; Mackenzie et al., 2007). These include the intersecting issues of

power and consent, confidentiality and trust, risks to researchers and potential harm to participants, as well as the broader cross-cutting issues of gender, culture, human rights and social justice. While there is growing evidence of these challenges, much of it is dispersed across a range of academic disciplines, is descriptive in nature, and offers little practical guidance to researchers working with refugee and IDP populations and those responsible for ethics oversight (Reed, 2002). In particular, a model of bioethics (Beauchamp and Childress, 2001) tends to dominate ethical frameworks in western research institutions. This model is well-founded, highly regarded, pluralist, and robust, in that it embraces principles of respect and dignity, justice and beneficence alongside that of non-maleficence (seeking to do no harm). However, the way in which it has been developed and applied in research contexts frequently lacks the capacity to address the complexity of working with vulnerable populations (Jacobsen and Landau, 2003; Mackenzie et al., 2007).

Power imbalances between researchers and participants raise complex ethical issues. Such issues are present in the biomedical and other western professional fields, but the mechanisms for dealing with these tend to assume that participants have access to courses of redress in cases of grievance. Even though such assumptions are often open to question in western health settings (for reasons of gender, socio-economic class, educational background and so on), they are completely untenable in research with refugees and IDPs, especially in oppressive environments, where autonomous decision-making is seriously limited, or where these vulnerable participants are involved in legal status determination and/or resettlement procedures. Researchers are often perceived as having power to effect change at both an individual and community level, and refugees are very cognizant of this fact. Refugees constantly approach researchers seeking assistance for themselves or their family, providing what is often compelling evidence of malpractice or neglect in the systems of protection that govern their lives. Sometimes refugees take considerable risk to raise these concerns, as in many camps authorities will punish refugees after the researchers have left for perceived breaches of confidence. In one site in Bangladesh, refugees who talked to researchers had very serious threats made against them by criminal elements operating in the camp, necessitating high-level intervention from those in authority (UNHCR, 2007). In another instance, following a visit by the authors, over 100 families at risk were resettled from a particular refugee camp in an African nation to countries in the West. While on the one hand this could be viewed as a good outcome, on the other hand it privileged those people who participated in the research over those who had not, despite there being no objective assessment of the comparative need of those who were resettled and the many other families at risk in the camp (reference withheld to ensure the security of those involved). This in itself is an ethical dilemma.

As discussed below, when working with populations at risk, there can be ethical issues involved in publishing research findings. Apart from the most obvious problem, that of researchers publishing data without due

consideration of the potential impacts on the communities involved, there are more complex issues. The desire of the refugees themselves to have their 'stories' told to the international community can outweigh consideration of the potential danger to themselves and their communities. Finally, the researcher sometimes has to make a judgement as to whether or not the refugee community, which may have been in an isolated camp for 15 years, can understand the implications of, for example, releasing a DVD to the media. We have personally experienced the reaction of refugees resettled to Australia when they have found that their images are widely used in books or on DVDs. While for the most part they are proud to be featured, at times they are shocked to find that their story is public knowledge. When giving 'informed consent' while still in the camp, they had little understanding of what this might mean at a later stage of their lives.

In refugee and IDP contexts, complex and contested issues of community representation are also often encountered. Community leaders and those familiar with the language, social systems, and culture in these settings may exert tight control through their ability to offer patronage to some researchers (Ebbs, 1996). This poses both practical and philosophical problems, in that researchers may be asked to compromise their methodology, or participants may not be giving genuinely voluntary consent. At the same time, however, without such patronage access may be impossible. This is often exacerbated by the non-governmental organization (NGO) gatekeepers, who control access to community leaders. These particular leaders have a vested interest in ensuring that the NGOs who validate their power are protected from negative research outcomes. While community leaders may be prepared to take risks disclosing information, community members might not share this view. Often this divide is gendered, with male leaders speaking on behalf of the entire community (Gujit and Shah, 1998). Despite a strong push by the UNHCR to include female representatives on all camp committees, these are often only token appointments. 'Yes. They made the men let us come to the committee, but they will not let us speak, and we do not have a vote' (Female refugee from Sudan in Ethiopia, 2005). At other times the female representatives are the wives and daughters of the male leaders. 'They just say what their husbands tell them to – otherwise there is trouble' (Female refugee from Burma, Thai–Burma border, 2004). Researchers who do not understand this complex network of relationships will only ever record an 'official' version of events. On the other hand, untangling the web of loyalties and benefits to record other versions of realities in camps and urban sites can be time-consuming and frustrating. How do researchers ever know that the version they have recorded is an accurate reflection of the refugee experience?

Pushing past these multiple gatekeepers and getting to the grass roots community is a further ethical challenge for many researchers. It speaks to the question of where the story comes from, and confronts the rhetoric of community participation, which implies that all community members have equal

access to participate in research. It challenges the researchers to develop strategies to reach out to the broader community members whilst still respecting and acknowledging the status of the gatekeepers.

Confidentiality is important for protecting both the identities of and information provided by research participants. In refugee and IDP contexts confidentiality may be especially difficult to maintain and the hazards of broken confidences may be extreme (Karen Women's Organization, 2004; Leaning, 2001). It appears that researchers in refugee and IDP settings have often forgotten the capacity that their work might have to cause unintended harm to participants through inappropriate disclosure of identities or other personal information that to the researchers may have appeared innocuous. For example, stories or photographs identifying individuals in documents may become known in the original context, despite being published in another country or another language (Beauchamp and Childress, 2001; Mackenzie et al., 2007). This can call into question the values or rigour of the 'ethics of consent' and confidentiality (Pittaway and Bartolomei, 2009b). In all of these situations, achieving a mutual understanding of voluntary and informed consent is a considerable challenge (FMRS, 2003; Hyndman, 2000).

> When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce... What does 'informed consent' mean in an isolated refugee camp with security problems and no proper interpreters? (Personal comment Linda Bartolomei, 2004)

In contrast, the principle of reciprocity suggests that the risks and costs associated with participation in research can be offset by the delivery of direct, tangible benefits to those who participate. To achieve this, researchers need to return to the community something of real value, in forms determined by participants themselves. However, there is little guidance for researchers on how to negotiate benefits with participants, and current funding arrangements usually provide neither time nor resources to effectively do so. In the case study which was the springboard for this work, the reciprocal benefits the women's groups wanted were training and programme support. These items have continued to be the major 'goods' exchanged for research data in all refugee sites. The research team has now undertaken over 30 research and training-based consultations in eight different countries, and in every case training was seen as a major benefit by the displaced community.

Conversely, ethically unsound research practices can exploit and disempower refugees and IDPs, promote distrust or rejection of the solutions emerging from the research, and may lead to emotional or material harm. For example, research may raise expectations for participants that cannot be

fulfilled and introduce dangers of 'retraumatization' if sensitive issues are handled inappropriately.

Researchers themselves also face considerable risks working in some refugee and IDP settings. These include moral and ethical dilemmas of researching with those engaged in or affected by illegal activities (including rape, sexual exploitation, trafficking, and the use of child soldiers), and the risk of traumatization through exposure to stories of torture or abuse, grief and loss, and crimes against humanity (Jacobsen and Landau, 2003). Research institutions have a duty of care to ensure that researchers are not in undue danger, and this includes access to counselling support when it is known to be likely that they have spent time interviewing people about torture and extremely traumatic stories. This is seldom taken into account in research funding or institutional research support structures.

At other times, lack of action by a researcher can result in serious harm to, or even the death of, a refugee or IDP. Intervention in the lives of research participants may be ethically required, such as the intervention described by Pittaway and Bartolomei (2003) who intervened in the case of a nine-year-old girl who had been raped and badly injured and who was not receiving adequate treatment and support. We would argue that when a human being is in such need and the researcher is in a position to respond appropriately, non-intervention in the name of 'objective' research is ethically untenable.

### Negotiating an Ethical Research Framework with Refugee and IDP Communities

However, ethical issues and challenges detailed in this article came not from academic pursuit, or peer review, but were raised by the refugee communities with whom authors Pittaway and Bartolomei worked. They challenged us to consider both our own ethical research practice and the value of the organizational ethical arrangements which informed our work. More importantly, they challenged us to examine if we actually applied the principles of human rights and community participation, which we so proudly espouse in theory, to our work on the ground.

It began when the authors received funding from the Australian Research Council from 2002–2005 to focus on the situation of refugee women and girls at risk, who experienced systematized forms of rape and sexual abuse. It was decided to compare the experience of populations of refugees from Burma living in Thailand, and refugees from the Horn of Africa in Kenya. The population in Thailand were invited to be partners in the research project because Pittaway had been providing training to the groups since 1993, working with them to prepare advocacy materials for the UN Commission on the Status of Women, various UN World Conferences, and the [then] Human Rights Commission. She had established a sound working relationship with the groups, and knew of their need for change, and their

desire to tell their stories and to advocate at the UN. The initial reaction of the women to the news of the research funding was disappointment that someone they had trusted as a trainer should suggest that they now work with her as research subjects. Although the women had expressed the desire to have their stories told and their issues addressed at an international level, their deep fear of exploitation by researchers made them wary of the researcher. The concerns they raised centred around:

- exploitation by previous researchers and journalists, including unauthorized publication of names and photos, leading at times to situations of danger for those participating in the research;
- false expectations of assistance from researchers;
- lack of feedback from research, including promised reports and photos, after giving time for interviews and disclosing personal stories;
- fear of backlash from government authorities and military leaders within camps;
- mistrust of white researchers; class and ethnic distrust of local workers and researchers;
- distrust of research done by researchers who 'fly in and fly out' of camps and conflict zones without considering the local social, economic and political consequences;
- lack of consultation about recommendations and strategies;
- the inability of many researchers to cope with the absolute horror of the experiences of research participants;
- the potential for retraumatization, without any follow up support.

The women discussed their fear about the unintended consequences of participating in research, often learned from hard experience. Women, who had invariably overcome deeply ingrained distrust of white and westernized or higher class local researchers and service providers, found that too often their initial fear of disclosure was well-founded.

> They asked us to lead them to women who had been raped so they could record their stories. 'Tell us what happened – how did you feel?' Women were so upset after the interviews, we did not know what to do. We never heard from them [the researchers] again – we decided then that we would never work with researchers again. They stole our stories. We can gather the stories ourselves from our own people – you can help [with training]. (Women's Group, Thailand, 2003)

We would argue that in many cases these incidents constitute a violation of human rights. It firmly places refugees as 'objects' of research and denies their agency and capacity to respond to the serious issues affecting their communities. The concerns of the women add an additional dimension to the question of where does the story come from and how is it passed on. They speak to 'ownership' of the story once it has been told, and how much

control research participants have over these once they are taken away from them. They directly address the harm that can be done by the unethical misuse of data. They table the value of stories and the benefits that could be expected from sharing them and the benefits gained by the researcher who collects the stories. They bring into question the notion that research data, once collected, belongs to the researcher and their institution.

In an attempt to resolve the concerns of the group on the Thai–Burma border, a lengthy negotiation was undertaken. The women consented to participate if the researchers provided them with training and project support in return for research data. The women also required that a very strong ethics agreement be put in place which gave them control of the materials collected. The researchers could only use these in reports, articles, multimedia production and so on, following sign-off by the refugee groups. This entails sending all materials back to the researched community or their designated representatives for approval before release. This of course has significant time, resource, and capacity implications for the researchers who undertake this research methodology.

This particular group had a very clear agenda they wanted to pursue. Refugee communities on the Thai–Burma border come from a number of distinct ethnic groups. One group, the Shan Women's Action Network (SWAN), had recently released a publication titled *Licence to Rape* in which they recorded the systematic and brutal rape of Shan Women by the Burmese military (SWAN, 2002). It is a very powerful book and received significant international attention. The women were using it as an advocacy tool and hoped to achieve enhanced international protection for the Shan women through its wide dissemination. Other women's groups from Burma had similar stories and they also expressed an interest in documenting these and using similar advocacy strategies to bring about change in their circumstances. Following discussion, the women decided that what they needed most of all was training to prepare their evidence in a format suitable for presentation at a series of NGO and UN meetings to lobby for political change and to advocate for badly needed services for their communities. An agreement was reached between the researchers and the groups for the training, which would incorporate gathering data about and analysis of human rights abuses. Once the refugee groups had launched their own reports, the researchers would have access to all the research data. In addition, all data collected as part of the training and incorporated into reports by the researchers could be used once signed off by the refugee groups concerned. Strict ethical agreements, over and above the University of New South Wales (UNSW) Ethics Committee requirements, and on a letterhead decided by the groups themselves, were drawn up with the groups to enforce these principles. The new training involved human rights documentation techniques and formal report presentation. The refugees were assisted by a team of Masters students from the Centre for Refugee Research, and subsequently produced three major reports which were launched at UN fora including the Human Rights Council in Geneva.

This process spurred the building of a methodology which uses a human rights framework and participatory action research principles to work with refugee groups in a way which is respectful of their autonomy, agency and capacity, and seeks to address the issues detailed above. The knowledge and the stories stay in the possession of the groups with whom we work. The outputs are most often determined by the participants. This can cause yet more challenges to the researchers. On one occasion, political tensions were so high in one refugee site that the refugees requested that we withhold our report, releasing it only to UNHCR. This was done, with good research impact, including increased service provision for the groups concerned, but we have not been able to publish more widely about the work that we undertook. On another occasion when we went to a site with an understanding that the focus of the consultation would be on the occurrence of domestic violence, the groups decided that they needed to focus on livelihoods. After a speedy reorganization of training materials, a very successful consultation was undertaken. One outcome was the design of a number of livelihoods programmes and funding applications submitted. These examples demonstrate that it is possible to be ethically sensitive and strategically effective, but that this can come at a cost to the researchers' expected outputs.

We have named the method 'reciprocal research', and it has proved successful in gathering verifiable data and evidence of human rights abuses in many countries, and in enabling refugee groups to be active participants in the process of seeking redress and service provision.

*I have not drawn these people like this because I cannot draw – I have drawn them like this because there is not enough food any more – we are all getting thinner and thinner, like sticks.* (Refugee woman from Sudan, Ethiopia, 2005)

The development of the methodology has been an iterative process and it continues to evolve as we respond to different needs and deepen our analysis of the process (Mackenzie et al., 2007; Pittaway and Bartolomei, 2009b). It also began an exceptionally successful and ongoing collaboration between the UNSW Centre for Refugee Research (the Centre) and these (refugee) groups. Through word of mouth, information about the
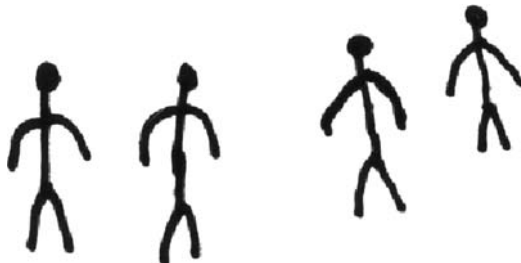
consultations and the research impacts have spread through the community of refugees from Burma, and the Centre regularly conducts training and research at the invitation of refugee groups in Thailand and India. The methodology has also been used with refugees in African countries, in Bangladesh, and in three states in Australia. Following the 2004 Asian tsunami, we were requested to work in Sri Lanka using the methodology to work with displaced women and children who were experiencing sexual abuse (Pittaway et al., 2007).

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**Reciprocal Research through Community Consultation and Training**

Reciprocal research is a 'step-by-step' process that starts with the provision of human rights training. It takes a minimum of four days working with communities and with the ideal duration of six days. The process involves using a human rights framework to set a context for discussion and to identify human rights abuses experienced by the participants. Next, the concept of 'stories as evidence' is introduced using a technique called 'story circles' in which participants are invited to share stories of particular issues positioned within the human rights framework. The stories yield a large amount of rich data on the type of problems being experienced and the impact of these on individuals, families, and communities.

Situational analysis and response mechanisms are developed by the participants through the use of 'storyboards'. Participants produce a series of drawings to conduct situational analysis including proposals for action, response and interventions. The storyboard technique allows participants to name problems and issues within their communities in a positive and empowering context. The technique recognizes the skills, knowledge and experience that participants bring to situations, and provides a human rights framework which acknowledges their rights to a secure life and social support. Interviews can be undertaken to further explore themes which emerge from the analysis of the documentation.

The final stage of the methodology is strategic planning. This step seeks to address at least some of the issues involved, and plan a programme of advocacy for action. Whenever possible, all key stakeholders are involved in this final stage. Critical to the entire process is an ethical 'confidentiality agreement', in which the researchers ensure that all the materials collected remain the property of the participants and can only be used with the participants' permission. An ethical framework based on, but often expanding, the UNSW Ethics Agreement is negotiated with participants (Pittaway and Bartolomei, 2009a, 2009b; http://www.crr.unsw.edu.au).

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In every instance, the Centre has a greater demand for participants to take part than we have the capacity to respond to. The opportunity to participate in training sessions and in problem solving has proved to be an attractive proposition for refugees. We are often told that this is the first time that they feel that researchers have really 'listened' to them, and have asked for their ideas about solutions as well as documenting the problems. NGOs and UN agencies have commissioned training in the methodology. Initial fears that refugees from professional backgrounds and with university degrees would not wish to participate in activities which employed techniques such as drawing were soon dispelled. For example, a group of professional Iraqi men who have been resettled in Melbourne participated in a four-day long consultation in 2009. The session started with a discussion about whether there was a saying in Arabic similar to the English expression 'a picture is worth a thousand words'. Once the purpose of the technique was explained, the men wholeheartedly endorsed it and their invaluable input can be seen in the report of the consultations, which has triggered significant change in service provision (Doney et al., 2009).

The fact that the field trips combine training and consultation/research removes the focus from the traditional gatekeepers who are seen as 'guardians of community knowledge' and broadens the pool of people who participate. Women are allowed to participate in training on gender issues and counselling where they may be excluded from other forms of research processes. This is not to suggest that the consultation is done covertly. The proposed process is shared with the community including the leaders, usually by the showing of DVDs of previous consultations. They then decide if they want to participate or not. In one site where we had accepted an invitation from a community-based organization to work with 40 participants over a week, on the first day 122 people turned up, some having walked eight hours over a mountain from a neighbouring camp. The training consultation took place with all participants and yielded excellent results. There were significant changes in camp service provision after the recommendations from the refugee groups were presented to the NGOs and UNHCR. Once the process is understood by the communities, people self-select to participate. While originally designed for working with women and girls, it was at the request of male community leaders that we began to use the methodology with mixed groups and with men and boys.

## Theoretical Foundations for an Ethical Research Framework

The challenges of working with refugees, IDPs, and other vulnerable populations are multi-faceted and cannot simply be addressed by the development of a research methodology. The particular challenge posed to the researchers was to develop an ethical framework for research undertaken with vulnerable groups. Their concerns mirrored the focus of this special edition, and

became a driver for all of the research which they subsequently undertook. The work we have undertaken in developing a methodology for working with these populations aimed to explore and address some of the many ethical dilemmas for researchers, such as those outlined above. It also focused our thinking about the theoretical and ideological frameworks in which we situate our work and challenged us to examine our own practice. In a current three-year project, authors Pittaway and Bartolomei, with Rebecca Eckert, are conducting research with refugee women resettled in Australia while author Hugman is monitoring the process to evaluate the way in which the ethical framework is applied. This process involves examining and at times challenging the organizational ethics procedure to ensure that it is adequate to the needs of very vulnerable groups and non-traditional research methodologies. Similar work has been done by researchers working with indigenous communities in Australia (Gorman and Toombs, 2009).

It was apparent from concerns voiced by the refugee groups that resolving ethical dilemmas has the potential to enhance the work of a range of academic disciplines in the social sciences, health and legal fields, as well as to aid service providers, social policy makers, and social development and other applied and professional disciplines. In order to do this it was necessary to engage with and reflect the perceptions of three key stakeholder groups: the 'researched' communities, researchers in the relevant fields, and the academic and professional bodies that have ethical oversight of such research practice. The aims of our ongoing work are to:

- establish a detailed theoretical analysis of the values and principles that are used to guide research in complex cross-cultural refugee and IDP contexts;
- identify and refine practical and innovative methodological solutions, involving reciprocal benefit for refugee and IDP communities as well as supporting rigour in research practice;
- develop and evaluate an ethical approach for research with refugees and IDPs that can guide and support good research practice, including methods for ensuring that researchers are better equipped to engage ethically with these vulnerable communities.

These aims are informed by the work of Hugman in applied ethics (2003, 2005, 2008), which explores the implications of new approaches in ethical theory for the practices of social work and service delivery, including social development and the health professions. This work is relevant also to the practice of social policy. It emphasizes that ethics is not simply a matter of following rules and procedures, as is often the focus of research ethics, but should inform all aspects of the discursive interactions between people. The significance for research with refugee and IDP communities is that ethics cannot be limited to fulfilling the formal requirements of sponsoring institutions. Nor can it be confined to notions of 'do no harm'. Ethics should be

extended to promoting the interests and well-being of extremely vulnerable research subjects, in ways that make sense for the research subjects, as well as for researchers and their academic institutions and professional bodies. Thus it promotes an ethical understanding of subjects as *participants* in and *beneficiaries* of such research.

It cannot be assumed that research participants necessarily share a common understanding of the purpose of research, the role of the academic and the academy, notions of consent, forms of engagement (and recruitment), or communication and perceptions of risks (Pittaway and Bartolomei, 2005). Notions of moral obligations, in this case between the researcher and researched, differ markedly from culture to culture (Hugman, 2008) and are further mediated in the context of asylum seeking, legal procedures and the migration experience (Reed, 2002). Cross-cultural communication on matters of ethics is difficult and makes additional demands on researchers. Language-use and the ability to communicate ethical information about the research process and outcomes are vitally important (Tesch, 1990). Researchers should, therefore, be familiar with the ethical frameworks relevant to their work and understand how these may be similar to or different from those of participants, so that they are capable of working cross-culturally with extremely vulnerable communities in ways that make sense in terms of participants' own values. At the same time, researchers also have a responsibility to their institutions, to respect their normative ethical standards and to comply with their procedures where these are reasonable and constructive.

Cultural sensitivity in the research process does not equate with ethical relativism, in which any attempt at finding common moral ground is seen as pointless, but rather it leads us to an understanding of the plurality of values in which dialogue is possible (Hinman, 2003; Beauchamp and Childress, 2001). What is required, and is provided by an ethical pluralist approach, is a framework for being able to make use of the common connections of human values, such as honesty, respect, privacy and so on, so that the researcher is able to negotiate processes and outcomes that both protect and promote the interests of participants and ensure that methodological rigour can be maintained. It is respect for these fundamental human values which facilitate cross-cultural dialogue. A more ethically pluralist and discursive approach has the potential to encourage researchers and their sponsoring institutions to consider research practice in a much broader cross-cultural way, emphasizing reciprocity in relationships. This is precisely because such an approach seeks to recognize the commonalities and differences of interest and values between researchers and participants/subjects, and to find ways of responding to these in the research process. In turn, this points to an expanded view of research ethics, in which concepts such as 'do no harm' must be accompanied by a more positive value of seeking to identify and pursue good outcomes for participants.

### A Participatory Approach – Integrating Human Rights and Social Work Practice

> The proposed [human rights-based] approach, in line with this would transform beggars into claimants. Claimants have their dignity and strength derived from these entitlements. They have a position from which to negotiate. (Frankovits, 1996: 123–128)

The human rights framework is core to the work of the research team. Components of this framework are understood to include justice, recognition, self-determination, voice and agency in addressing all forms of oppression. This is articulated by Ife (2008) as 'human rights from below', in which the notion of rights is not just regarded as a legal framework but a moral framework which must underpin community development practice. Participation in research has a strong community development component. It has the potential to empower refugees and IDPs and build capacity, resilience and agency through enhancing the skill base of some participants, providing access to services, offering new contacts and facilitating their voices being heard (Reason and Bradbury, 2006). While participation is fundamental to a rights-based approach, a number of recent critiques by key development actors point more to the rhetoric of participation than its reality (Cornwall and Brock, 2005; Slim, 2001). For this reason, in the development and implementation of a genuinely rights-based practice, the form that participation takes is key. If the affected communities are not actively participating in identifying rights violations and solutions, then it is not a rights-based approach.

In the course of our work with refugee communities and as lecturers in a Masters course on International Social Development, the authors are frequently challenged about the value of teaching human rights to refugees who live in abject poverty, often with only marginal access to their most basic needs. They are often not legally registered in the countries which host them and have no security of tenure. We have been accused of raising false expectations and setting unreachable goals by introducing these concepts. It has been said that the discourse is too difficult for pre-literate people to fully understand. It is sometimes argued that because human rights is a contested discourse, with many host states neither respecting nor ratifying either the Refugee Convention or other human rights conventions, this can lead to misunderstandings and conflict. While being fully cognizant of the risks, we argue that it is a lack of information and misinformation about rights which causes greater risk.

Sally Engle Merry (2001: 94) has argued that 'In many ways human rights represents a discourse available for framing problems rather than a system of law for preventing them'. Human rights provide an 'agenda setting framework', not just for binding international law but for policy and social norms

(Risse and Sikkink, 1999). Many writers have suggested that a key challenge for the human rights community is to develop a culturally resonant approach to the articulation of human rights (An-N'aim, 1999; Dominelli, 2002a). Lena Dominelli (2007: 24) states that 'it is useful to envisage the [Universal Declaration of Human Rights] provisions as contingent on context, as the social environment and the people involved in any interaction create its meaning'.

We have to make the human rights framework relevant and accessible to the communities with whom we work. The answer is not to withhold 'rights knowledge' from refugees, but to ensure that we discuss both the advantages *and* the limitations of the approach and framework with the communities. Effective training and consultation provide sufficient information to enable refugees to make informed choices about what they wish to do and acknowledge their agency and ability to do this responsibly. For both the affected populations and as advocates, it is more effective to lobby from an informed position as legal and moral claimants, than as supplicants. The result of over 30 consultations has made us increasingly confident that this is the case.

In 2007 the authors were commissioned by UNHCR Geneva to conduct community consultations with refugees from Burma residing in Bangladesh, in what has been described as one of the worst refugee camps in the world. Child prostitution was sponsored in the camp by a local crime ring, women and girls were trafficked to local towns, rations were stolen, malnutrition was rife, and men who tried to protect their families were beaten and imprisoned in horrific circumstances on false charges. UNHCR staff had come from Geneva, Dhaka and the local UNHCR office to observe and participate in the process (UNHCR, 2007). The consultations began with human rights training, which included the making of a 'human rights necklace', in which different coloured beads represent different groups of rights. The necklace is used to symbolize the indivisibility, inalienability and the universality of human rights.

At the end of the consultations, representatives from the groups were selected by the community to present their storyboards and analysis to UNHCR staff and local NGOs. An older, pre-literate woman was elected by one group to make their presentation, and she had agreed with the group about which storyboards she would use and what she would say in her allocated time. On the morning of the presentation, she stood before the senior and local UNHCR staff in her torn and dusty burka. Instead of starting with the storyboards as expected, she pointed out that over her burka she was in fact wearing a necklace, as were all of the other women seated on the low bench around her. Talking with great dignity, this is what she said to the assembled UNHCR staff, NGOs, and service providers:

*Do you see my necklace? It is a human rights necklace. Every bead represents the rights that we have as human beings. Many years ago in Burma, we all wore these necklaces, men and women, and we were proud of them. We lived happy lives and enjoyed our human rights. Then we were persecuted by the SPDC [the State Peace and Development Council, the military regime in Burma], we lost everything; we were forced to flee for our lives. We came here and the abuses continued. We are starving, and beaten, the children are in danger. This is what has happened.*

At this point she stopped talking and took hold of her necklace and pulled it so hard that the beads fell and scattered all over the floor. She continued:

*Our necklaces were broken, our rights were scattered, and we lost them all. Now UNHCR, we ask you to help us to pick up all of those beads. We want our rights. We want our necklaces back. Once again, we want to wear them with pride.*

The woman then waited for a moment and proceeded to present the storyboards and analysis as planned.

The impact was immense, the meaning unmistakable. The human rights framework does indeed turn beggars into claimants. There have been other stories since then, but this is the most simple and most powerful endorsement of using the human rights framework we have. It empowers people to claim their rights, provides a framework for analysis and for the identification and implementation of strategies to address some of the worst abuses endured by refugee communities. Following the consultation UNHCR made the two camps involved priority areas for assistance. They worked with the government of Bangladesh to begin to address the corruption in the camp. The Australian government paid for the construction of new accommodation and the EU paid for lighting in the camp to improve safety for the refugees visiting latrines at night. Five nations opened programmes of resettlement from the camps, targeting the most vulnerable refugees, and livelihood programmes were introduced. Children were allowed to attend secondary school and food rations improved. While there are still significant problems in the camps, major steps were taken following the research project and at least some of the human rights abuses were addressed.

In sum, the philosophical notions of universality, indivisibility and inalienability of human rights enshrined in the Universal Declaration of Human Rights (UN, 1948) forms the epistemological umbrella for the reciprocal research methodology. We understand and work with human rights as broad principles of empowerment, rather than legal standards for enforcement.

Social work ethics offer some important insights to the research process in such circumstances. The international statement on social work ethics includes human rights and social justice as primary values (IFSW/IASSW, 2004). Discussions of ethics in social work research (for example, see Butler,

2002) make strong connections between these values and methodologies that recognize and respond to the autonomy and agency of those who participate in research. In turn, this often finds its most concrete expression in an approach that creates opportunities for participatory research practice, in which participants are genuinely *subjects* beyond the giving of informed consent (Hugman, 2010). This approach allows for the identification of universal structural oppressions, including those on the grounds of race, gender, and social and economic status, while considering the impacts of individual circumstances and identities. It provides a theoretical framework which supports an investigation of the manner in which structural oppressions and individuals' identities intersect to either increase or decrease the impacts of human rights abuses and oppressions. It enables a critique which combines a critical/structural analysis of the root causes of oppression with individual circumstances (Bartolomei, 2010).

This approach is informed by the principles articulated in anti-oppressive, decolonizing and antiracist approaches to social work and community development practice (Dominelli, 1998, 2002a, 2002b; Ife and Tesoriero, 2006; Quinn, 2003). These urge a reflexive approach to social work practice involving a constant revaluation of the workers' own power and perspectives, knowledge, and skills, to challenge racism, nurture emancipation and to work with cultural and linguistic difference (Dominelli, 2002a, 2002b; Quinn, 2003). Approaches to individual and community empowerment are underpinned by understandings that this is not something 'done to' individuals or communities, but that instead the role of the social worker is to work with communities to create the environmental and social conditions that build community capacities and enable self-determination to grow and flourish (Ife and Tesoriero, 2006; Kenny, 2006; Westoby, 2008).

Critical theorists working in this tradition stress the importance of agency, the capacity of people to actively engage in challenging social structures in order to bring about emancipation and social change (Pease et al., 2003; Ngwenyama in Boudreau, 1997). Critical approaches have been employed by a range of social theorists concerned with understanding, exploring and challenging the impacts of oppressive social, political and ideological structures on people's lives. In this case we would argue that some forms of research constitute an additional layer of oppression.

This critical social work approach is further enriched by Lena Dominelli's body of work on anti-oppressive social work practice (1998, 2002a, 2002b) and Jim Ife's (2001, 2008) and Elizabeth Reichert's (2001, 2003, 2007) work on human rights and social work. It is an approach directly informed by both human rights and anti-oppressive social work to expose 'unjust polices and practices', to 'promote institutional and organizational change' and to advocate for 'non-oppressive alternatives' (Dominelli, 2002a: 35).

Based on these principles, the focus of the method we have developed is the collection of information from often vulnerable populations in a way

that is empowering, not harmful or exploitative, and which has the potential for bringing about social change. It is ideal for use with marginalized and disadvantaged groups who have valid and historically based reasons for distrusting people in authority, including researchers, academics, and representatives of governments and other institutions. This might include people who experience discrimination on the basis of class, race, gender, and disability and refugee status. The reciprocal nature of the method transforms people from subjects of research to participants in research, moves from 'harm minimization' as an ethical base to reciprocal benefit, and from researcher directed projects and outcomes to participant and community directed outcomes (Pittaway and Bartolomei, 2009b).

## Conclusion

Poorly designed and implemented research produces bad policy and practice with inadequate protection outcomes for refugees and IDPs. There are many problems, including mismatches of expectations, misleading processes for gaining consent, risks posed by the use of information and the treatment of human subjects as data rather than as moral agents. While it is entirely plausible that much of this is unintended, in practical terms ethical inadequacies lead to the ill-treatment of extremely vulnerable individuals and groups as a means to achieve research ends, which breaches the basic principles of accepted research ethics (Hugman, 2005; Reed, 2002; Beauchamp and Childress, 2001). Thus, guidance is needed in a range of areas, including the roles and responsibilities of researchers and sponsoring institutions, the complexities of achieving meaningful informed consent, the representativeness of 'community leaders' facilitating research on behalf of refugee and IDP populations, and finally, ethical issues that arise in the publication or dissemination of research findings.

The ethical issues raised by refugee and IDP research are of crucial importance to three distinct but interdependent groups: refugee and IDP communities who participate in research; researchers and the agencies that commission research; and institutional ethics committees. More often than not, these groups work theoretically and conceptually independently from each other and have different interests in the research process. Refugees and IDPs are seldom consulted about the methods of research or about the impact of research on individuals and communities. Researchers are seldom given an opportunity to discuss the relationship between ethical issues and the practical challenges that they face in the field. Sponsoring institutions may be regarded as taking a policing and organizational risk management role rather than a supportive role in enabling researchers to address the ethical issues arising from their work.

To address these issues, we suggest that we need a new theoretical framework for research with refugee and IDP populations that draws on both human rights and social work. This new framework would be based on a

detailed theoretical analysis of the values and principles that should guide ethical research in complex cross-cultural contexts, and be informed by the relevant literatures in theoretical and applied ethics, human rights, social work and community development. The new framework will draw on relational approaches to autonomy and agency (Hugman, 2005; Mackenzie et al., 2007). It will propose a shift in approaches to research ethics with refugee and IDP populations, moving beyond the dominant principles of harm minimization to an emphasis on negotiated reciprocal benefit that challenges researchers to justify their projects with reference to the benefits delivered to the vulnerable groups themselves. Such a framework would enable refugee and IDP studies to progress beyond its current discussion of ethical challenges to develop practical solutions.

While we have suggested one model of working to achieve these aims, we propose that additional ethical research models for use with refugee and IDP populations which are both academically rigorous and incorporate a reciprocal benefit for the population involved could be developed by scholars in the field and shared with colleagues.

## Acknowledgements

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