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Beyond 'Do No Harm': The Challenge of Constructing Ethical Relationships in Refugee Research

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This paper highlights some of the central ethical challenges involved in undertaking social science research with refugees in conflict and crisis situations. It focuses on two main sets of challenges: first, the difficulties of constructing an ethical consent process and obtaining genuinely informed consent; and second, taking fully into account and responding to refugee participants' capacities for autonomy. The authors also discuss the challenges involved in applying the central normative principles governing ethics review processes—the principles of beneficence, integrity, respect for persons, autonomy and justice—to the context of refugee research. It is argued that researchers should seek ways to move beyond harm minimization as a standard for ethical research and recognize an obligation to design and conduct research projects that aim to bring about reciprocal benefits for refugee participants and/or communities. Some of the methodological issues raised by this analysis are discussed in the conclusion.

Keywords: ethics, consent, autonomy, relational autonomy, power, confidentiality

Introduction

Qualitative and quantitative social science research involving refugees and Internally Displaced Persons (IDPs) is often undertaken in politically complex, difficult and sometimes dangerous settings and with participants who may be traumatized and vulnerable. The ethical complexities raised by research in such contexts have recently begun to be identified and discussed in the academic literature in refugee studies (e.g. Allotey and Manderson 2003; CPOP 2002; Hynes 2003; Jacobsen and Landau 2003; Landau and

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Jacobsen 2004; Leaning 2001; Zwi *et al.* 2006). However, circumstantial evidence is now emerging of unethical and potentially exploitative research being undertaken among refugee and other displaced groups by researchers who may not have fully considered the ethical complexities of their research or are not fully supported by the current research ethics frameworks and processes (McDowell *et al.* 2004; Pittaway and Bartolomei 2002).

The bodies charged with the ethical review of academic research, such as institutional ethics committees (IECs), are often ill equipped to provide proper ethical oversight of research involving refugees and IDPs. The guidelines to which these committees refer in their deliberations focus primarily on quantitative biomedical research—such as clinical drug trials, epidemiological research or hospital-based studies—or on quantitative psychological research that uses test measures developed in Western countries, primarily the US. Further, since committee members are often researchers drawn from these fields, they may have little understanding and experience of qualitative research in the social sciences, particularly when undertaken in developing countries, let alone with refugees. In reviewing research protocols they therefore find it difficult to assess how the normative principles guiding the review process should be interpreted in such settings and which research methods and practices best promote ethical research.

One of the aims of this paper is to highlight some of the central ethical challenges involved in undertaking social science research with displaced populations in conflict and crisis situations. These challenges are myriad and arise from a range of intersecting issues including those of power, consent and community representation; confidentiality; trust and mistrust; harms, risks and benefits; autonomy and agency; cultural difference; gender; human rights and social justice; and in the worst cases, oppression and exploitation. We will concentrate on two related areas that pose particular practical, ethical and methodological challenges for researchers undertaking refugee research. First are the difficulties of constructing an ethical consent process and obtaining genuinely informed consent. And second is the issue of how to be attentive and respond to the effects of forced displacement, encampment, and dependence on humanitarian assistance on refugee participants' capacities for autonomy, while also recognizing and respecting their resilience and agency.

A further aim of the paper is to highlight some of the challenges involved in applying the central normative principles governing the ethics review process—the principles of beneficence, integrity, respect for persons, autonomy and justice—to the context of refugee research.[1] While we do not question the importance of these principles, their articulation in research ethics guidelines is often highly abstract and as such they provide insufficient concrete guidance for both researchers and ethics committees.

We will propose an interpretation of the principles of beneficence, autonomy, justice, and respect for persons in the context of refugee and IDP research that makes quite stringent demands on researchers. We will argue that researchers need to move beyond harm minimization as a standard

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for ethical research and recognize an obligation to design and conduct research projects that aim to bring about reciprocal benefits for refugee participants and/or communities. The notion of reciprocity involves negotiating a research relationship with participants that not only respects, but also promotes their autonomous agency and helps re-build capacity. It is argued that the principle of respect for persons entails a responsibility on the part of researchers to try to understand and engage with the different perspectives and life experiences of research participants and to construct research relationships that are responsive to their needs and values.

Much of the empirical research referred to in this paper was done by Pittaway and Bartolomei in Kenya, Thailand and Sri Lanka between 2002 and 2005. In that time they made 21 visits to refugee camps, interviewed 238 refugees and service providers and conducted 12 fully documented consultations/training sessions (average duration five days per session) involving over 300 additional refugees.

The Complexities of Consent

The principles of *respect for persons* and *beneficence* underpin the importance accorded to informed consent in medical, legal and research contexts and consent is a central concern of institutional review procedures. The minimum requirements for informed consent are that participants are fully and adequately informed about the purposes, methods, risks and benefits of the research and that agreement to participate is fully voluntary. In medical research in Western countries, the usual method for satisfying these requirements is to provide research subjects with a detailed written information statement outlining the aims and methods of the research and disclosing potential risks, including potential side-effects of treatments, drugs or other interventions. Research subjects or their legal guardians must also sign a consent form acknowledging their understanding of the information that has been provided to them, including risks.

These procedures are intended to safeguard participants from harm, coercion and exploitation. However, even with such procedures in place, ensuring that both the information and voluntariness conditions are met in biomedical contexts can sometimes be fraught. For example, patients who are ill or whose capacities are to some degree impaired may have difficulty fully comprehending the medical information provided to them or distinguishing research from treatment. The voluntariness condition may also be compromised. False expectations on the part of the desperately ill that participation in a clinical trial will provide a cure for their condition, financial or other incentives provided by pharmaceutical companies, or recruitment procedures that involve the potentially coercive enlistment of hospital patients by their doctors, may all compromise voluntariness.

These difficulties point to an underlying problem with standard interpretations of informed consent: that consent provides protection on the

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assumption that participants are autonomous, understand the implications of giving consent and are in relatively equal positions of power with researchers. These assumptions are unjustified in many research contexts in which research participants are vulnerable, but particularly in the context of refugee research in situations of crisis and conflict. In this section we show why issues of vulnerability, compromised autonomy, mistrust and the complexities of community representation make the issue of informed consent in refugee settings so complex.[2] In the following section, we propose an iterative model of consent as a way of addressing some of these complexities for qualitative social science research. We do not address the question of whether or not such an approach to consent is feasible for quantitative psychological or medical research in such settings, although we believe it could be adapted for use in such contexts.

Vulnerability, Compromised Autonomy and Mistrust

The vulnerability of refugee and other displaced participants is one of the main reasons why refugee research is ethically fraught and the reasons for this vulnerability are many and varied. Those who have been displaced or forced to migrate have often suffered serious physical, psychological and emotional trauma. For example, they may have been subject to political or ethnic persecution or violence; they may have been tortured, raped or beaten or witnessed such acts inflicted on others; they may have lost children, parents, spouses or other family members through conflict; and they may have lost their homes, livelihoods and possessions. If they are in camps, women and children in particular may still be subject to ethnic and/or sexual violence, be living in cramped and often squalid conditions with the majority having little prospect of returning to their homes or of being re-settled elsewhere.

Compounding the effects of past, and sometimes, present trauma, many refugees are in situations where they are in the main unable to exercise political or socio-economic power and are in many respects at the mercy of others. This may be the case in a camp situation where refugees and IDPs become dependent and reliant upon humanitarian relief agencies providing assistance; or in conflict where rebel or government forces are responsible for their persecution. Spending protracted periods in camps may compromise refugees' capacities for autonomous agency. Autonomy refers to both a capacity and a right (Feinberg 1989). Understood as a capacity, autonomy involves determining the direction of one's life, making considered choices among one's options, and acting in accordance with one's own beliefs and values. Having a right to autonomy entitles persons to the social, political and economic protections that enable them to exercise these capacities for self-determination. In some refugee settings such protections will be absent and refugees' rights to autonomy severely curtailed. Furthermore, since many aspects of refugees' lives are under the control of others, their scope for exercising self-determination is seriously limited. But the impacts on

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autonomy may go much deeper than this. Protracted displacement situations can undermine people's sense of their own identity, their sense of self-worth, as well as their trust in themselves, thereby impairing, at least to some degree, their capacities for self-determination.

Such situations are likely also to undermine refugees' sense of trust in others, giving rise to a generalized mistrust or a particular mistrust of officials such as agency workers, translators or local community representatives who may be engaged to provide advice to international agencies (Hynes 2003). As a result, some refugees may mistrust the motives and independence of researchers as well as the information provided to them about the research, and may therefore be very wary about how any information they provide will be used. Alternatively, some participants may have unrealistic expectations of the benefits of the research, believing that researchers may have the power to influence legal or resettlement processes. Finding ways to construct the consent process in order to mitigate these effects, and in doing so to build relationships of trust between researchers and refugee participants, is challenging but essential for ethical research.

Power Relations within Refugee Settings and the Complexities of Community Representation

Within biomedical contexts, consent is typically understood in individualistic terms. Both the ESRC Framework and the Australian *National Statement* recognize that in some cultural contexts consent is not just a matter of securing agreement between the researcher and individual research participants but may also involve negotiating an agreement with community bodies or representatives (NHMRC 1999: 12). As such, these ethics frameworks acknowledge the need for culturally appropriate consent procedures. However in many cross-cultural contexts, and particularly in the context of research in refugee settings or conflict zones, community representation is complex and contested and researchers would be unlikely to take claims to representation at face value (Goodhand 2000).

The problem of gaining consent through genuinely representative bodies is particularly acute in protracted refugee settings. Refugee and IDP camps are often dangerous places where conflicts continue to be played out and where local populations may resent the refugee population. The maintenance of pre-displacement family and community life is virtually impossible, food may be in short supply and education and health services are often minimal. The resources, infrastructure, and legal authority necessary to establish a representative community are usually absent (Crisp 2000; Harrell-Bond 2005; Hyndman 2000; Pittaway and Bartolomei 2003, 2004, 2005).

Power structures evolve in refugee settings, particularly camps, where 'community leaders', who may not have played a leadership role in the previous location, are identified and often given formal roles by UNHCR and NGOs managing the camps. Hyndman, quoted in Rackley (2000) argues

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> that the UNHCR and NGOs, by subscribing to a naïve myth of 'unity in diversity' (i.e., that despite our many differences we are all one), become blind to the hierarchies of domination and oppression endemic to refugee camps.

Simplistic assumptions of cultural homogeneity, knowledge and adherence to what are loosely called 'justice systems' often bestow power on rival factions and people who may not be equipped to undertake the roles in a democratic and just manner (Hyndman 2000; Crisp 2000).

This makes the acceptance of research populations nominated by 'community leaders' highly problematic. This situation is not unique to refugee camps but in those camps positions of authority and contact with outsiders, such as researchers, may bestow additional privileges and enhance the political standing of an individual, or group of individuals. Furthermore, this ability to control the research process by controlling access to interviewees and the timing and location of contacts has implications for the quality of research. Many refugees from very different regions have complained about this process, saying such things as 'They come in and just talk to the leaders and their wives—they never hear what it is really like in the camps' (Thailand); 'We get no justice from the leaders, but they are the ones that UNHCR listen to' (Kenya) (Pittaway and Bartolomei 2003, 2004). Researchers who depend on nominated representatives for access to the refugees may therefore end up negotiating agreements that silence the voices of those most in need of being heard, namely those who are already disempowered. In some situations, the presence of the researcher, involvement in the research and resources made available by the research (for example, material compensation for participation, access to transport) may function to legitimate or enhance the power, or further the cause, of one party to a conflict. Furthermore, in situations like these, where some parties have power over entire groups, the voluntariness of individual participation may be highly doubtful.

Reliance on translators can also be ethically problematic. Poor translation can hamper the kind of mutual understanding required for ethical research, as well as potentially undermining the validity of the research (Inghilleri 2004). Temple and Edwards (2002) remind us that interpreters are active in the production of research accounts. Interpreters may bring to the research relationships a complex mix of power based on ethnicity, class and race, incurring the risk of 'transgressing political, social or economic fault-lines of which the researcher may not be aware' (Jacobsen and Landau 2003: 103). In worst cases translators may breach confidentiality or may be hostile to the views and interests of research participants. Being employed as interpreters in situations where there are few means of earning an income can also be seen to bestow privilege.

Confidentiality, Trust and Safety

The complexities of community representation, and the potential for community representatives, local research assistants and translators to be

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antagonistic towards the interests of particular individuals or groups makes confidentiality absolutely essential for ethical qualitative research, even though it may be difficult to achieve in some contexts. In designing and conducting research with refugees, careful attention therefore needs to be paid to translation arrangements, to research methodologies (such as assessing whether focus group interviews on sensitive issues are appropriate) and to the settings in which the research is conducted. Careless disclosure by researchers, or malicious disclosure by others, of information provided during the research process, or other forms of unethical research practice may increase the vulnerability of participants or seriously compromise their safety.

A refugee on the Thai–Burma border who was also a human rights activist, reported that a researcher had interviewed her and taken her photograph, promising that the photograph was just for her personal collection and that the interview was part of research data. The refugee did not receive either a transcript of the interview or a copy of the research report or the photograph. Eighteen months later, she reported, someone came to the camp with an international magazine, which contained her story and photograph. This was printed entirely without her permission and put her in potentially extreme danger, as it disclosed her political activity and illegal movements across the border into Burma to investigate human rights abuses (Pittaway and Bartolomei 2002).

In a different piece of research in Kakuma Camp in Kenya, Pittaway and Bartolomei heard from women leaders who expressed reluctance to grant or organize interviews with their peers, because researchers had previously disclosed the identity of women who had been raped and this caused 'shaming' within the community. In the same camp, refugees talked of their fear of researchers disclosing their identity, their location and details of their political activities and allegiance. There was concern that knowledge of their personal circumstances would follow them to countries of resettlement and prejudice the host community, or affect relationships within the resettled community.

In both Thailand and Kenya refugees revealed their anger and resentment about sharing their very personal stories with researchers, allowing their photos to be taken and not receiving either the report or a copy of the photos, as is evident in the following sample of comments, recorded by Pittaway and Bartolomei during their field research in Thailand and Kenya in 2002 and 2003: 'They come and get their PhDs and write their books at our expense—we should get something back'; 'They get their PhDs and funding from our stories and they cannot even be bothered to send us a report and a thank you letter'; 'Do they think that because we cannot read English we do not care?'; 'We give up our time and share our pain and they cannot give the time to write us a letter'; 'We put ourselves in danger for them, and they don't even seem to understand'; 'They think that because we have to accept their [charity] they have the right to ask us anything they want to'; 'They say it is to help us—how does it help us?' Similar concerns were

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raised by the head of a community-based organization: 'In the past year I have spoken to eleven people who are doing their PhD and not one of them has even sent me a report'.

This kind of behaviour is seen by refugee research participants as an extreme breach of trust and exploitation of privilege. It also manifests disrespect on the part of researchers who are in effect using refugees and other displaced people to further their own careers. The principle of respect therefore entails a responsibility on the part of researchers to be very mindful of the trust that is being placed in them by refugees and to reflect carefully on ways to build and sustain that trust. One way to build trust is to include agreements relating to confidentiality in the consent process. Such agreements could allow participants to make informed decisions about what they want to share in research reports, what stays 'off the record' and how any data collected is to be used. Building and sustaining trust also requires, where this is feasible, ongoing contact after the research, including opportunities for de-briefing and the consideration of issues that might arise and remain after the research is concluded. Where ongoing contact is not feasible then it is important to establish mechanisms to feed back to the community information arising from the research.

Iterative Consent and Relational Autonomy

Given the complex ethical issues concerning consent discussed above, it is evident that the kinds of consent procedures that are standard practice in many research contexts are inadequate or inappropriate for research in most refugee settings. For example, it is perhaps naïve to assume that in extreme refugee settings informed consent can be obtained through the one-off provision of written or verbal information statements, or by asking participants to sign a consent form. Not only are such procedures often culturally inappropriate, in refugee settings they may expose participants to increased risk, arouse mistrust and suspicion of researchers, and undermine the possibilities for negotiating genuine ethical engagement with participants.

In this section we propose that an iterative model of the consent process developed by some researchers conducting research with Aboriginal and Torres Strait Islander communities in Australia may be usefully adapted for many forms of research with refugees, and is relevant to non-emergency and non-camp situations (National Health and Medical Research Council 2003). We also link iterative models of consent with a relational understanding of autonomy and argue that re-thinking consent is not just a matter of devising alternative consent procedures. It requires a fundamental re-conceptualization of the nature and aims of the research relationship.

Iterative Consent

The aim of iterative models of consent is to develop consent processes that enable the establishment of ethical relationships between researchers and

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participants that are responsive to the needs, concerns and values of participants. Iterative models of consent start from the assumption that ethical agreements can best be secured through a process of negotiation, which aims to develop a shared understanding of what is involved at all stages of the research process. This process must be thought of as ongoing throughout the duration of the project, and so requires the researcher and all other parties involved to refine and re-negotiate the terms of the project, and their respective roles and obligations within it, as the project evolves. The parties to this process of negotiation might include, where appropriate, community leaders or representative bodies, NGOs, as well as researchers, local research assistants and translators, and refugee participants, and needs to be initiated before any formal research activities commence. The initial stages of negotiation might involve drafting a formal research agreement. However in many contexts, for example, in contexts where written agreements and consent forms are inappropriate, a verbal agreement may be more appropriate. In such situations, it is the responsibility of the researchers to document both the process and whatever agreements have been made about recruitment procedures, research methodologies, reciprocal benefits, confidentiality, withdrawal and feedback provisions, and so on. Inevitably the initial agreement will not be able to take account of all contingencies that may arise during the period of research. Further, research directions can change once data collection is underway; as new problems and research questions emerge, initial research hypotheses need to be refined or discarded, and so on. The initial research agreement may therefore have to be re-negotiated at various points during the research.

From the point of view of some researchers it might seem as though this kind of procedure is time-consuming, cumbersome and undermines their academic autonomy. However, we would argue that its value, especially in qualitative research, is that it establishes the research as a partnership, enabling refugee participants and communities to play a more active role in setting the research agenda so that it answers better to their needs and respects their concerns and values. In doing so, it helps to build trust and to avert misunderstanding. From an ethical point of view such a process gives real content to the principle of *respect for persons*. From a pragmatic point of view, it makes it more likely that problems and misunderstandings will be ironed out before or in the initial stages of the research rather than once it is well underway. Furthermore, if changes to the initial agreement are required, these are more likely to be agreed upon if all parties are aware of the reasons for the changes and have been consulted about them. This approach to consent is therefore likely to enhance the confidence of both researchers and participants in the legitimacy of the project as well as in its capacity to demonstrate respect for refugee participants and lead to genuine improvements at the level of policy and/or intervention.

Another advantage of iterative consent procedures is that they better reflect the realities of data collection on the ground. In research among refugee and

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IDP populations, and with professionals involved in refugee protection and assistance, a good deal of data and information is collected in research contexts where formal and even informal consent is not, and cannot be given. It is not always possible to predict who will talk to whom or about what from the outset, and sources of information are varied. Information received through informal rather than formal channels, overheard, or told in passing may be quite crucial to the research and possibly more reliable than information obtained through formal channels or through formal processes of consent. Since these informal, 'back stage' channels may provide more useful insights into the true situation faced by individuals or communities in vulnerable positions than 'front stage' information given through formal channels, researchers need to be confident that they can incorporate the information obtained through them into the research.

For example, in formal interviews conducted in one camp, researchers from the University of New South Wales, Australia were informed by several UN and INGO staff that women made up stories of rape in order to try to gain resettlement in a developed country. Later, talking informally in the compounds where staff were under curfew at night the same people discussed the fact that one of the hardest things to cope with was the high rate of rape and sexual abuse of women and their inability to address this. When questioned about the incongruity in their accounts they referred to 'the official line'. Several people also said 'tell the truth, but don't ever quote me'. A senior administrator in another camp made the comment 'I will give you a prize if you can find a woman in this camp who has not been raped'. This comment was not made in the context of a formal interview, but it is invaluable information in both revealing the extent of rape in the camp and the attitude of those in power about the issue. It was later supported by interviews with refugees and staff working on the ground.

In reviewing applications for ethical clearance where an iterative process of obtaining consent from the community and individual is required, institutional ethics committees would need to recognize that researchers may not be able to specify in advance all aspects of recruitment and consent procedures, community consultation processes and methodology. This would place a responsibility on the committee to negotiate with researchers an ethical framework that ensures researchers are accountable to both the researched population and the institution, but that gives researchers the flexibility needed to respond to the challenges presented by the research situation as they arise, particularly in field work contexts.

In some cases the research that ends up being undertaken may be significantly different, in terms of its focus and methodology, from the project for which approval was originally granted. For example, in a recent mission to an African refugee camp, ethical permission had been granted by an Australian university for the researchers to investigate the implementation of a certain piece of refugee policy. However, their consultations with groups in the camps uncovered large scale fraud and malpractice which was having

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extremely detrimental effects on the health and wellbeing of the refugee populations. The researchers did not have institutional approval to investigate the issue, and nor were they likely to obtain approval from local bodies with the authority to grant it. The researchers were faced with a difficult ethical dilemma. If they collected and recorded the data they would be doing so without prior institutional ethical approval. However they judged that it would be grossly unethical not to record and act on information about practices that were causing great harm to a large population of vulnerable people. In our view, the ethical obligation to record data obtained in situations like this, or through backstage channels, significantly outweighs the obligation to comply with the original conditions of approval. Institutional ethics approval processes therefore need to be sufficiently flexible to enable researchers to respond to situations of this kind. Whenever possible researchers should expect to revert to their IEC and as part of the flexible, iterative arrangements, be able to seek *ad hoc* approval from the field. If, because of time constraints or communication difficulties, this cannot occur, processes need to be in place which allow the material to be recorded, but only included in the research findings once approval has been obtained from the IEC.

Relational Autonomy

Recognizing that capacities for self-determination among some refugee populations may be compromised gives rise to a very serious ethical challenge for researchers working in these settings. On the one hand, researchers need to respect refugee participants' capacities for self-determination and their agency and resilience and avoid paternalism. On the other hand, it is imperative that researchers recognize the ways in which the ongoing effects of displacement and trauma may be affecting refugee participants' capacities for autonomy and hence for genuinely informed consent. We propose that a relational understanding of autonomy can help meet this challenge (Friedman 2003; Mackenzie and Stoljar 2000; Meyers 1989).

Relational models start from the assumption that self-determination is an important value for all people and crucial for a flourishing life. However, relational models differ in a number of important respects from the individualistic models of autonomy and consent that tend to inform much bioethics and research ethics (Mackenzie and Stoljar 2000a). First, relational theories start from the premise that persons are fundamentally social and relational beings. They therefore aim to develop a conception of autonomy that upholds the value of self-determination while acknowledging the importance of relationships of care and dependency and of family and community bonds. Second, they argue that autonomy is a social capacity, for it is in and through social relationships that persons develop the skills and competences necessary for self-determination. Third, they pay particular

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attention to the relational, social and political conditions necessary for autonomy. Because autonomy is a socially acquired capacity, its development can be thwarted or stunted by oppressive or abusive relationships and by oppressive social institutions, norms and practices. For relational theorists there is a close connection between autonomy and social justice. Individuals can only flourish, and determine the shape and direction of their lives, in supportive and just relationships and communities, in which their basic rights are protected and in which they have a reasonable range of educational and other opportunities.[3]

Relational theories do not regard autonomy as an all or nothing affair. Autonomy is a complex cluster of capacities, some of which may be more developed than others, and that can be exercised or thwarted in a range of different ways (Meyers 1989). It is wrong to think that the experience of being displaced, living under external protection, lacking day-to-day security, experiencing uncertainty about the future, concern about family and friends, poor health, lack of reliable information about home, all of which are common to the refugee experience, undermine autonomous agency altogether. Persons who are subject to oppression or abuse, or whose social and political environments are highly restrictive, may nevertheless be able to express their autonomous agency in some aspects of their lives.

In our view, relational approaches to autonomy give rise to both negative and positive obligations on the part of researchers. The negative obligation is to ensure that participation in research does not compromise or further erode participants' capacities for self-determination or their scope for exercising these capacities. By constructing consent as a process of ongoing negotiation, iterative models of consent help fulfil this negative obligation by aiming to ensure that participants are able to exercise some degree of control over the research process and the conditions of their involvement in it. The positive obligation is that, wherever possible, social researchers should aim to develop research projects that not only identify the problems experienced by refugees and their causes, but that help to promote their autonomy and re-build capacity (Dyregrov *et al.* 2000). Built into medical research is an expectation that researchers will both identify the causes of illness and seek to find cures. So too, we would argue, social research involves an obligation to assist in redressing social problems, wherever possible. Thus, Turton argues, for example, that research into the suffering of others can only be justified if alleviating that suffering is an explicit objective of the research (Turton 1996, cited in Zwi *et al.* 2006).

We acknowledge the limitations of the role that researchers can play in this regard, given the complex social, political, economic, environmental and other factors that shape the refugee context. However, in our view, it is unethical for researchers merely to document the difficulties of refugees and their causes without, whenever possible, offering in return some kind of reciprocal benefit that may assist them in dealing with these difficulties and, where possible, in working towards solutions.

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Zwi *et al*. argue that 'reciprocity implies that the risks and costs associated with involvement in research are offset by tangible benefits to participants' (2006: 267). Some researchers might argue that negotiating reciprocal benefits with research participants could undermine the objectivity or impartiality of the research, raise unrealistic expectations of the research or function as an inducement that compromises voluntary participation. We acknowledge that these risks are real and that the process of negotiating reciprocity can be fraught with difficulty. We would argue, however, that the best way of minimizing these risks is to negotiate reciprocal benefit in the context of an iterative consent process in which participants' expectations of the research and the research project, their motivations for participating, and their needs, concerns and values, are openly declared at the outset. Researchers are then in a better position to make it clear what the research can and cannot deliver and so to avert the kind of misunderstanding that may later lead participants to feel that researchers have broken their promises. We also acknowledge that the kinds of benefits researchers are able to deliver, and the way in which these can be delivered, vary considerably. For example, researchers may not be in a position to follow up after the research, perhaps because of ongoing conflict or instability or because research participants have moved elsewhere. In such cases, researchers may need to find ways of providing some immediate benefit or feedback rather than negotiating benefits that may follow some time after the research has been conducted (*ibid*.).

The above discussion of the positive obligations of researchers towards research participants focuses on reciprocal benefits to researched individuals or communities. We acknowledge, however, that in some research situations the benefits of the research might not accrue directly to the research participants but to others. Referring back to the case of medical research mentioned above, it would be unrealistic to expect or require that medical research can only be justified if it provides direct therapeutic benefits to research participants. In many if not most cases, the benefits of medical research will accrue rather to future individuals or populations. Similarly, in research with refugee and IDP populations, the groups that participate in the research may not be its main beneficiaries. In such cases, a sufficient justification for research into the suffering of others is if it reduces future suffering of other populations, for example by generating lessons about how to minimize similar suffering in the future.[4]

Iterative models of consent and relational approaches to autonomy involve a series of fundamental conceptual shifts in research ethics: from subjects *of* research to participants *in* research; from harm minimization to reciprocal benefit; from informed consent to the promotion of autonomy; from researcher-directed to participant and community-negotiated. While we acknowledge that this kind of approach may not be suitable for all types of research, our view is that in qualitative social research the research relationship should be conceptualized along these lines as much as possible.

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In the following case study we provide an example of how constructing research that is attentive to women's articulated concerns can also promote autonomy, rebuild capacity and bring about social change in an ethical and culturally sensitive manner.

Case Study

Iterative models of consent aim to try to redress or at least to even out power differentials between researchers and participants, and to promote autonomy and re-build capacity among participants. They are thus consistent with the methodology of participant action research, arguably an overtly political methodology, grounded in critical theory that aims to effect social change and address issues of social justice. Miller (2004), and Jansen and Davis (1998) use this methodology in their work with refugee populations with the explicit aim of building trust and giving voice to the views of the powerless and voiceless. An action research methodology was also employed in a four-year research project with women refugees on the Thai–Burma border, and in subsequent research with women refugees in five other countries, including Kenya and Ethiopia. Because of the complexity of the social and political issues involved, this methodology enabled the researchers to uncover findings that would have remained hidden if a more conventional methodology had been employed.

Pittaway had worked with representatives from several of the refugee groups over a period of five years, in connection with advocacy at the United Nations. She had thus developed a level of trust with the groups and was aware of their felt need for change and their desire to tell their stories as survivors of systematized rape by soldiers and other military personnel. It was on the basis of this prior relationship that she first approached one network of women to ask whether they would be interested in participating in an action research project investigating the rape and sexual abuse of refugee women and the effectiveness of international protection. The prior relationship enabled the refugee women involved to openly discuss their reservations about the research at the beginning of the project. They discussed their concerns about the unintended consequences of involvement in research projects, often learned from hard experience. 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 very wary. For example, one participant who had worked closely with the researcher on other projects said: 'Oh no—not you too—we trusted you because you are not a researcher—you will not steal our stories'. Despite the fact that the leaders of these groups knew the researcher, they were reluctant to agree to the research until there had been a meeting of their own very active network.

A process of negotiation was established, which took several months. After discussion with their broader community at their council meeting, the women

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agreed that they did want to participate and would do so because of their trust in the researcher. They stated quite clearly that they did not want to be formally interviewed and have their stories 'taken from them', stolen and used by other people without their permission and in ways which they did not originally intend. The women were asked how they would like to work with the researcher, and what sort of reciprocal arrangement could be reached which served the purpose of both parties. After several meetings, they requested that the researcher provide them with Human Rights Documentation Training and Advocacy Training so that they could then conduct their own interviews and collect their own stories for use in their advocacy work. It was agreed that following the provision of the training the women would conduct interviews with their own communities, using the documentation techniques (including strict confidentiality agreements) learned in the training sessions. The training involved the use of focus groups and all the women involved also shared their own experience of flight and trauma.

Attending training was a risky enterprise for the refugee women. Participants were therefore nervous and needed to be sure that the trainers would understand their situation and ensure confidentiality. Further negotiation took place about who would be allowed to deliver the training, in addition to the principal researcher. A research associate was accepted on condition that the principal researcher would vouch for her ethical use of the materials and confidentiality, and because she was also known by some of the women. Problems arose when the researchers requested permission to involve two additional facilitators in training sessions, to allow for a smaller participant-to-trainer ratio. The women at first refused outright to have trainers whom they did not know.

Written consent forms on university letterhead were signed by all participants in the training, as well as consent forms drawn up with the women on the letterhead of their community-based organization. The researchers also signed a written guarantee stating that they would send back reports and audio-visual materials to the camps as well as copies of all reports produced. Materials would not be used without the permission of participants. The groups agreed to allow the researchers to use interviews which they undertook as secondary data, again only once written permission was given by those who had collected the data. Some of the participants also agreed to be individually interviewed for the project. Verbatim reports were made of all sessions, interviews and focus groups. The key points from these were identified while the researchers were on site and discussed with the refugees through interpreters and amended as required. As part of the confidentiality and ethical approach safeguards used in this methodology, agreement was then gained for these to be used by the researchers in their final reports, once these had been submitted back to the groups concerned. This process was extremely successful. A similar process was also used for individual interviews.

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This four year long process proved to be an invaluable experience both for the research team and the women concerned. The women from Burma have produced three books, which have been tabled in various fora at the United Nations and which are a key plank for their advocacy work. The researchers have undertaken similar research in other settings, using the methodology and model of dual confidentiality agreements developed with these women. The outcomes from the interviews and focus groups conducted in all sites have contributed to the tabling of a new UNHCR Conclusion (soft law which informs the interpretation and implementation of the Refugee Convention and Protocol), and Guidelines on the protection of refugee women and girls. Significant changes have been made in the level and types of service provision for refugees in the camps where the research has taken place. There is a conventional wisdom that 'women do not talk about sexual abuse'. However, in camps and urban settings in five countries the researchers have found that by using this methodology, once trust is established and they have been involved in negotiating the process, the women are desperate to tell their stories and to share their experience if there is a chance that something might be done to address the problems they are facing.

We acknowledge that this intensive form of research is neither easy nor quick. Jansen and Davis (1998) report spending nine months developing relationships with the research population before beginning formal interviews. Continual staff turnover in refugee camps and other sites is a major problem, as these staff are the conduit to refugees and without them it is often difficult to get photos, reports and other materials back to refugees for permission to use them. Difficulties gaining access to interpreters can also pose problems. In other cases, staff who are either antagonistic to researchers or who do not respect refugees can act as 'gate-keepers' and refuse to hand on material for permission. For these reasons, the kind of 'fly in, fly out' research, where researchers spend a short amount of time in camps, conduct a number of interviews arranged by those in charge of the camps, and perhaps conduct a couple of focus groups, may seem much more manageable to researchers. However, we would argue that while this kind of approach may sometimes yield useful data, its value is questionable if it leaves refugees feeling exploited, or if it presents a partial and skewed picture and does not enable the concerns of the more vulnerable and powerless to be voiced.

Conclusion: Methodological Implications

The analysis of research ethics developed in this article raises a number of complex methodological issues. We conclude by briefly canvassing some of these.

There is an ongoing debate in the academic literature about both the quality and appropriateness of methods for research among refugees and other forced migrants. On the one hand, Jacobsen and Landau (2003), Landau and Jacobsen (2004) seek to embed general research standards in the

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relatively young 'field' of refugee studies. Their concern is in part about the policy orientation of much forced migration research and the selectivity of the data produced. They argue that to be useful data must be transparent and comparative, both intellectually across disciplines and across different refugee settings, and must yield analysis that contributes to theory-building. Much current qualitative participatory research, they argue, is too localized and limited to allow for the identification of global patterns (Landau and Jacobsen 2004: 4) or to provide evidence that is sufficiently robust to either critique or support policy (*ibid*.: 5).

Rodgers (2004) on the other hand, defends and seeks to reassert the 'continued relevance and importance of small-scale qualitative approaches, generated largely through intensive, informal and interpersonal interactions between researchers and the forced migrants' (*ibid*.: 48). He calls this participatory approach to generating information 'hanging out' and argues that such techniques are indispensable for research conducted in the 'chaotic' worlds that refugees inhabit, where making sense cannot be achieved through precise tools of surveys and 'crude quantitative research'. In addition to permitting the 'simultaneous presence of multiple and contradictory experiences and perspective', hanging out, Rodgers believes, enables a 'humanism' in research that can inform 'ethical', reflective and accountable policy-making. He argues for an ethical imperative to conduct such research over more positivist methodologies. Rodgers criticizes Jacobsen and Landau for advocating an ethical justification of positivist research that 'unwittingly serve(s) a highly polarizing social agenda' by effectively severing the link between knowledge and power, and thus silencing the voice of the displaced.

Our use of the case study described above and our argument in the previous section for a fundamental conceptual shift in research ethics to a model of community negotiated research that provides reciprocal benefit to refugee populations, may seem to have placed us firmly in Rodgers' camp. To clarify our position on this issue, while we agree with Rodgers about the value and importance of participatory, small-scale research, we also think Jacobsen and Landau are right to emphasize the importance of standards in research, whether the research is primarily quantitative or qualitative in nature. Qualitative research is not intrinsically more ethical or of better quality; an interview can be as unethical and poorly conceived as a bad questionnaire. Conversely, good survey research can yield important quantitative data while also upholding strict ethical standards. For example, Jacobsen and Landau correctly cite Scudder and Colson's long term survey work among the Gwembe Tonga, who are not refugees, but development displacees, as an example of excellent and sound 'positivist' research. Although our main focus in this paper has been on qualitative research, we think the kinds of ethical difficulties arising in refugee settings and discussed earlier in the paper must be taken into account by both qualitative and quantitative researchers. We also think the processes of negotiating consent

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discussed above could, and should, be adapted for use in quantitative research.

Jacobsen and Landau also raise concerns about an issue to which we have referred, but not discussed in detail, the issue of researchers intervening in the lives of research participants, or taking sides in conflicts. Our view is that researchers need to be very attentive to the risks of intervention or of openly declaring their political sympathies. Such risks include exposing themselves or participants to potential harm, being used by one or other of the parties to the conflict, producing biased or unbalanced data or reaching unreliable conclusions, and so on. However, intervention or declarations of sympathy need not compromise ethical or research standards. In some cases, it may be necessary if the research is to be conducted at all. For example, in some conflict situations researchers will not be able to develop trusting relationships with research participants unless they make their political sympathies known. Miller (2004) notes that his own research with refugee populations has required him to declare his political opinions in order to gain trust and that researchers in South Africa have recorded the necessity of declaring their opposition to apartheid in order to conduct research in that country. In other cases, intervention in the lives of research participants may be ethically required, such as that 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. In such cases, we would argue that when a human being is in need and the researcher is in a position to respond to that need, non-intervention in the name of 'objective' research is unethical. Similarly, as in the case study example discussed above, it would be unethical for researchers to fail to take a strong moral stand against the systematized use of rape by military and paramilitary forces in any country or conflict situation. Further, it could be argued that if researchers are in a position to assist refugees to advocate on their own behalf or on behalf of others who have been subjected to these kinds of abuses, then it is morally incumbent on them to do so. As we have indicated, however, such involvement must be at the request of, or willingly agreed by, the refugees concerned.

Some researchers might protest that the kind of engagement with participants for which we have argued would make research in refugee contexts too difficult. We agree that our approach places real demands on researchers, in terms of the time and resources required to negotiate an ethical research relationship. We also acknowledge that funding bodies and research institutions place demands on researchers for the timely completion of projects that are often in tension with this approach. However we agree with the view that research with refugees can only be justified if it is seen to entail an obligation to ensure that the research provides reciprocal benefits for those concerned, whether in the form of developing skills and capacities, improving health outcomes, improving the quality of humanitarian intervention, guiding policy, influencing governments or changing social attitudes

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(Hynes 2003; Jacobsen and Landau 2003; Zwi *et al*. 2006). Unethical research, even if it is conducted with the intention of benefiting refugees, may exploit, disempower and endanger those whom it is intended to assist.

1. For statements of these principles and their application to research ethics, see for example, the Belmont Report (1978) and the Australian *National Statement on Ethical Conduct in Research Involving Humans* (1999). The *National Statement* defines respect as respect for individual autonomy, protection of persons with diminished autonomy and 'regard for the welfare, rights, beliefs, perceptions, customs and cultural heritage, both individual and collective, of persons involved in research' (p. 11). Beneficence involves 'an obligation to maximize possible benefits and minimize possible harms', where harm is construed broadly to include not only physical but also 'psychological or emotional distress, discomfort and economic or social disadvantage' (p. 4). The principle of justice refers to fairness in the distribution of the benefits and burdens of research, and inclusion and exclusion conditions that do not discriminate on the basis of 'race, age, sex, disability or religious or spiritual beliefs' except where this is required for the purposes of the research (p. 11). Other principles, for example, concerning confidentiality, informed consent, and disclosure of conflicts of interest, are derived from these central principles. In the UK, the Research Ethics Framework developed by the Economic and Social Research Council (ESRC) identifies the main ethical principles of ethical research as informed and voluntary participation, confidentiality, harm minimization and disclosure of conflicts of interest.
2. A further issue, which we do not discuss here, concerns difficulties arising from inequalities between researchers and refugee participants, for example, with respect to power, socio-political representation and economic status, education, and resources. This issue is discussed in ESRC (2004).
3. The connection between autonomy and social justice is also central to the 'capabilities' approach to autonomy, developed by Sen and Nussbaum (Sen 1992, 1993; Nussbaum 2000).
4. The authors are grateful to the anonymous reviewer who helped clarify this strand of our argument.

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