

Advocacy as a Means to an End: Assisting Refugee Women to Take Control of Their Reproductive Health Needs

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SUMMARY. Negotiating reproductive rights is particularly complex for resettling migrant women from refugee backgrounds. In our ongoing work with women who have fled from countries in Africa and the Middle East, and have resettled in Australia and New Zealand, subtleties of discrimination and perceptions of human rights discriminations were revealed through the complex interplay between research and advocacy. Community Based Participatory Research (CBPR) has therefore been critical in assisting women to identify their needs and negotiate acceptable solutions with health services. This paper presents qualitative and quantitative findings of research with women from refugee backgrounds in Australia (n = 255) and New Zealand (n = 64). The research questions were a combination of community-driven and researcher initiated issues and the projects developed through a continuous iterative process involving feedback from women in the community. We highlight the essential role of advocacy in CBPR and how that can enhance research quality. We argue for the justification of this approach as not only valid and credible but essential in research with these and other communities. doi:10.1300/J013v43n04_02 [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2006 by The Haworth Press, Inc. All rights reserved.]

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The events that lead to displacement, such as complex humanitarian emergencies, result in the loss of stability and cultural and social infrastructure. Displaced persons often deal with corrupt bureaucracies, have difficulties in securing the basic needs of food, shelter and health care and experience fear and anxiety over uncertainties about the future. Many of these experiences result in the erosion of trust, particularly of those in authority (Daniel & Knusden, 1995).

The early 1980s saw an increasing awareness of the gendered nature of the refugee experience (Barnett, 2002; Callamard, 1999). The safety of many refugee women and girls was difficult to ensure against violence, rape and other forms of exploitation, particularly in the absence of the traditional support and protection of male family members. The women-at-risk program was created to give priority to the resettlement of refugee women in this category who have been identified by the United Nations High Commissioner for Refugees (UNHCR). The governments of Australia and New Zealand set a quota of 10% of refugee

intake for women-at-risk (Manderson, Kelaher, Markovic, & McManus, 1998; NZIS, 2004). However, resettlement, particularly of refugees from low-income countries in Africa, Asia and the Middle East (and to a lesser extent, Eastern Europe), presents challenges due to a wider cultural chasm that impedes successful integration. Lack of language proficiency has been identified as the primary barrier (Beiser & Feng, 2001). Other studies have identified difficulties in understanding the health, education and welfare systems (Manderson & Allotey, 2003a, 2003b) as well as technologies and environmental conditions often taken for granted by the host populations (Guerin, Guerin, Diiriye, & Abdi, 2004; Guerin, Diiriye, Corrigan, & Guerin, 2003).

Of the 9.7 million refugees worldwide at the end of 2003, less than 60,000 were resettled in 10 high-income countries, including 11,860 to Australia and 650 to New Zealand (UNHCR, 2005). Their countries of origin included Afghanistan, Sudan, Burundi, the Democratic Republic of Congo, Palestine, Somalia, Iraq, Viet Nam, Liberia and Angola. In accepting these humanitarian settlers, host countries took on the obligation to assist in their resettlement and integration into their new home.

This paper focuses on the experiences of resettling refugee women from Horn of African and Middle Eastern countries in Australia and New Zealand. Concerns were raised by resettlement support services in health, welfare and education of the needs of these “new and emerging” communities because of their considerable cultural and linguistic diversity. Within the health services, one of the main concerns was the cultural practice of female genital cutting (FGC)¹ prevalent in some of the countries of origin in these communities. As a result, much of the research on women from these communities has focused on reproductive complications associated with FGC (Allotey, Manderson, & Grover, 2001; Knight, Hotchin, Bayly, & Grover, 1999). However, in the course of conducting research with the communities, refugee women² became proactive partners in the research process, identifying areas that presented priorities for them. They worked with researchers to highlight relevant research questions for which they required advocacy. This process was critical particularly in the light of previous experiences of betrayed trust relationships (Verdirame, Harrell-Bond, Lomo, & Garry, 2005).

This paper provides a critical examination of how two independent groups of social scientists, committed to the philosophy of advocacy, researched the experiences of resettling refugee women from Horn of African and Middle Eastern countries in Australia and New Zealand. New data are presented from both research projects and discussed in the

light of Community-Based Participatory Research (CBPR) and advocacy issues in a manner that refines current understandings of this research methodology. The aim of the Australian study was to enhance the understanding of the immigration experience on the reproductive health of women from Horn of African and Middle Eastern countries resident in Victoria³ (Allotey, Manderson, Baho, & Demian, 2004). The aim of the New Zealand study was to provide a safe means by which Somali women could express their views about FGC (Guerin & Elmi, 2004, 2005). Our analysis of these two CBPR projects shows that the negotiation and prioritization of research topics informs our understanding of the process of CBPR and advocacy.

STUDY 1: AUSTRALIA

The wave of refugee arrivals in the mid-1990s from countries where FGC is practiced gave impetus to the development of a national program for the elimination of FGC within the target communities. The program prioritized the obstetric and gynecological management of women who had undergone various forms of FGC.

Methods

An ethnographic cohort design was employed with predominantly qualitative methods, using in-depth, open-ended and unstructured interviews, focus group discussions and participant observation. The study was approved by the Human Research Ethics Committee of the University of Melbourne, and informed consent was obtained from all the participants in the study.

Sample. It was difficult to obtain an estimate of the size of the population of refugee women from countries that practice FGC. This was due in part to the mobility of these communities both between states and within Melbourne. Based on available census data the combined estimates of the target population (women between the ages of 20-44 years from Horn of African and Middle Eastern countries) was approximately 2,000 (Victorian Office of Multicultural Affairs, 2003). Recruitment of the sample was initially through a range of community and social groups, formal ethnic organizations and projects funded by various government and non-government organizations. The sample snowballed from these initial contacts to a total of 255 participants. Given the lack of an existing sampling frame, the recruitment strategy was appro-

priate for research with refugee communities. A community advisory group (CAG) was constituted with representation from the relevant ethnic community groups, service providers such as women's hospitals and community health and migrant resource centers and government agencies responsible for ethnic health policy formation. The role of the CAG was to assist in the recruitment of the sample; provide a mechanism for feedback and dissemination to and from their communities and agencies; and identify relevant priority issues within the local contexts. The CAG met four times a year but individual members were consulted as required.

The African women in the sample ($n = 141$) were from Somalia, Ethiopia, Eritrea, Sudan and Nigeria⁴ and had been in Australia an average of five years, having emigrated mostly from refugee camps under the women-at-risk program or family reunion programs. The Middle Eastern women ($n = 114$) also arrived under the humanitarian program mostly for reasons of family reunion and marriage migration and were from Egypt, Lebanon, Iraq, Jordan, Saudi Arabia and Syria with a longer duration of residence—an average of 13 years. In general, the women who participated in the study were between the ages of 19 and 50 years. More than half were married (53%). None of those who were working had been able to find employment that took advantage of their prior qualifications, and their employment was restricted largely to subordinate positions in domestic and other service related industries. This is not atypical for new immigrants to Australia (Markovic & Manderson, 2000). However, it was uniformly perceived as race-related, demonstrated for instance by comments that had been made about their 'obvious' presentation (veils, scarves, *hijab*), "impenetrable accents" and desire to remain different from the host population by continuing to engage with cultural and religious practices. A majority of the women (70%) had 'health care cards' indicative of low income, and a dependency on welfare benefits and state subsidized concessions. Over a third of the women lived in low cost, state subsidized accommodation.

Although they were a widely diverse group in terms of ethnicity, education and other socio-economic indicators, they shared some similarities in cultural backgrounds and family life experience and common experiences of the migration process and in accessing health care services in Australia.

CBPR in data collection. Discussions with women during recruitment found that the women were uncomfortable with the focus on FGC. The national and international profile given to the FGC eradication program had resulted in women from affected communities feeling resent-

ful of being perceived and identified solely as “infibulated women.” A practice that traditionally characterized their modesty had been publicized to the extent that they were defined by the structural integrity of their “private parts” (Allotey et al., 2001). While most agreed that reproductive health issues were a major concern, they were more inclined to participate in a research program that was also open to investigating the broader issues that affected their resettlement and broader health and well-being. For instance, in early focus groups to set up the study, many women characterized their experience of and treatment by the health and social services as inherently marginalizing; unless they appeared to be destitute, they could not obtain assistance. They described this as “benevolent racism” and “demeaning.” As a result, the level of wariness of the “advocacy industry” was distinct. Similar findings have been reported in other studies of refugee resettlement (Peisker & Tilbury, 2003).

Consequently, while data collection proceeded on the original proposal, the research relationship was negotiated to include a range of other projects initiated by the women. These included a study on parenting difficulties, a joint project with emergency services to identify their needs in relation to domestic and racially motivated violence and safety (Baho & Allotey, 2004) and a review of the work conditions for bicultural workers (Baho, 2005). These became an integral part of a larger research program with the goal of investigating and enabling the health and well-being of resettling refugee women. We describe the development of one of these projects following a summary of the results.

Data analysis. Interviews and focus group discussions were tape recorded and transcribed. Thematic analysis was the main approach to analysis. Data were coded based on themes related to reproductive health. Coding was revised as other themes emerged from ongoing discussions with women in the community. The research team disseminated results to the women predominantly through the CAG, but also through interaction at social gatherings and through annual newsletters targeted at service providers and community groups. The qualitative data were analysed with QSR NUD*IST Software. Coding was done mainly by one of the principal investigators (PA) and discussed in research team meetings.

Results and Discussion

We present a brief summary of the findings as they pertained to FGC to give some context to the concern the women had about research ques-

tions that were not a priority for them. Other results of the study are reported elsewhere (Allotey & Manderson, 2003; Allotey et al., 2004; Allotey et al., 2001; Manderson & Allotey, 2003a, 2003b).

Women from the target communities had a high level of understanding and to a large extent, acceptance of the legislation against FGC. They required some clarification about a number of related issues, such as the potential for the clitoris and labia to continue to grow in women who were not excised. The issue of agency was raised in the context of women who had requested re-infibulation following childbirth—a procedure that is illegal under the current FGC legislation. Women perceived this as racist because non-African women are able to undergo procedures such as hymen and labial reconstruction for cosmetic reasons (Allotey et al., 2001). In general, women who had undergone FGC did not perceive themselves as being at higher risk for gynaecological complications. Most of the discussion on complications returned to the definitions of ‘normal.’ They reported that when reproductive health histories were taken for antenatal care, they were asked questions about painful menstruation and difficulties in passing urine. With their own bodies as their only reference point, most found that these questions either did not make sense or were difficult to answer. Recent mothers of young daughters also described their apprehension about cleaning the genitalia of their infants because of lack of familiarity with unaltered genitals. Indeed, one reported being reprimanded by a maternal health nurse during a six-month postnatal assessment for failing to maintain the hygiene of her daughter adequately.

More significantly for the women, however, was a strong sense of needing to put the discussion of FGC into perspective. For many, perceptions of reproductive health were tempered by previous sexual and reproductive health experiences. Some who had come through refugee camps had to trade sexual favors for food or medicines for themselves and their families as a matter of basic survival. Current priorities in their lives were more important: maintaining constant supplies of basic resources for resettlement of their families, the continued racial and social problems faced by their children as visible minorities, issues of inter-generational family conflict, and concerns about family remaining in conflict areas. The FGC procedure, which had occurred for them when they were very young, was therefore not the most pressing issue. One woman reported “what has happened has happened, it is in the past, why do we have to keep going on about it.” While CBPR is founded on the premise of researching what is most important to community members,

the Australia data showed that the researchers and the women in the community had different priorities and different long-term goals.

Supporting a mother with an intrauterine death: CBPR in action. This case was chosen because it typifies the range of issues that were of concern to the community and illustrates the importance of advocacy and research approaches that enable prompt intervention.

Mrs. A (gravida 1, para 0) from Eritrea reported to the antenatal clinic of a women's hospital for a routine antenatal check at approximately the 25th week of her pregnancy. She had missed her last appointment by a week because of a death in her community. The bicultural worker, who also acted as an interpreter, accompanied her into the obstetrician's consulting room. During her examination, the obstetrician was unable to hear a fetal heart beat, and Mrs. A could not remember precisely when she had last felt any fetal movements. She was sent to have an ultrasound, a procedure that she had consistently refused prior to that because of her concern that it might harm the fetus. Through translation of the obstetrician's advice, the bicultural worker explained the importance of the ultrasound to determine fetal problems. Mrs. A finally consented and an intrauterine death was confirmed. However, Mrs. A was then told that no beds were available and she would need to return the next day for a termination of her pregnancy.

Distressed, Mrs. A could not understand why, despite her position in the hospital, the bicultural worker did not react against a client being sent home with a "dead baby inside her." She returned the next day for an induction of labor. She was again accompanied by the bicultural worker who explained that she had to be de-infibulated⁵ prior to the delivery as was the normal procedure for infibulated women (RACOG, 1997). The bicultural worker was then called away to another client. Following the birth, Mrs. A was presented with the dead fetus and left alone with it; again this was then normal hospital procedure to enable a healthy grieving process (Hughes & Riches, 2003; Hughes, Turton, Hopper, & Evans, 2002; Leon, 1992). Only after about 10 minutes of distressed calls was she finally able to communicate to the staff that she wanted the dead fetus to be removed from the room. When the bicultural worker returned to visit, Mrs. A expressed her disappointment that the bicultural worker had not explained the inappropriateness of leaving her with a corpse to the hospital staff. In reporting the events, Mrs. A described the whole experience as one of the worst in her life, surpassing anything she had experienced as a displaced person.

For Mrs. A, the experience highlighted her powerlessness within a system that she did not understand. She had been given no support to

deal with the still birth and had not understood the purpose of being “abandoned with a dead fetus.” Most importantly for her, however, was the sense that the one person she could have relied on, the bicultural worker, was not available and had let this happen to her.

This and other supporting cases resulted in the researchers taking a strong advocacy role and working with the women to make presentations to various agencies regarding their needs and to initiate a number of further research projects (Allotey & Manderson, 2003). One of these was an exploration of the position of bicultural workers. Under the Australian policy of multiculturalism, agencies were encouraged and often funded to employ staff from ethnic minority backgrounds to deal with the issues that affect clients from those ethnic backgrounds (Commonwealth of Australia, 1998). Within the implementation of the Family and Reproductive Rights Education Program (FARREP, the Victorian State strategy for the National FGM program), the FARREP workers were critical to ensuring that the needs of infibulated women were met within clinical and other health related settings. The FARREP workers were attached to hospitals and community health centers around Melbourne that had significant clientele from the target communities. In hospitals, FARREP workers were expected to support women in all areas of their clinical encounter, both as interpreters and cultural brokers.

However, focus group discussions with bicultural workers revealed that their roles within the work place were unclear and lacked organizational support with no prospects for career advancement. Their skills levels were variable ranging from medical practitioners unable to get their qualifications recognized to those with no formal qualifications. The main essential “skills” in the job description were their ethnicity (loosely defined as country of birth) and language proficiencies. As a result of the lack of preparation for their role, they often found themselves in situations in which they felt uncomfortable proposing interventions to clients that could create “cultural discomfort.” They found that women from their communities would accept their translation of physician explanations as an implicit recommendation from the bicultural worker. In spite of an expectation that bicultural workers would be advocates for their communities, the workers usually felt unable to question the authority of their employers in order to represent the needs of the clients. Similar observations have been made in research in the United States and the United Kingdom in the development of community health worker models of primary care delivery (Corkery et al., 1997; Musser-Granski & Carrillo, 1997; Tribe, 1999). However, in spite of ongoing funding for bicultural workers in Australia, the effi-

cacy of their roles remains poorly investigated and evaluated as an intervention. The research presented here was critical in facilitating a review of bicultural workers in general (ongoing) and of the conditions for FARREP workers in particular (Baho, 2005). In addition, a group of FARREP workers, supported by the research team and women from their communities, have initiated a series of workshops for assertiveness and leadership training.

STUDY 2: NEW ZEALAND

Similar to Australia, in the early 1990s refugee women from countries where FGC is practiced began arriving in New Zealand, drawing attention to this previously unheard-of practice. Within only a few years, FGC was criminalized with an amendment to the Crimes Act (1996). It was not until 1998 that a one time only education program was implemented in New Zealand for health professionals. Education programs for affected communities (unevaluated) have appeared sporadically but have generally been based in one city in New Zealand, while the women live in four main cities and do not have access to these programs. Compared with Australia, New Zealand has minimal, if any, cultural support for refugee women in the health care system and this varies widely between cities in New Zealand.

Methods

The New Zealand study⁶ was initiated by a group of well-regarded, elder women leaders from the Somali community who approached the research team (which includes both Somali and non-Somali members) and requested research that would represent their views on FGC. They wanted the voices of the women to be documented in safe and appropriate ways. The project received ethical approval from the University of Waikato Psychology Department Ethics Committee. Informed consent was obtained from all participants in accordance with the approved protocol.

Sample. Data were collected in two phases. In this paper, we will focus on the findings from Phase 2 as they more directly related to the theme of advocacy. Details of Phase 1 and results can be found elsewhere (Guerin & Elmi, 2004, 2005). Briefly, the first phase of the project was larger and more comprehensive, with both quantitative and qualitative data collected using semi-structured interviews between De-

ember 2003 and January 2004. A total of 54 women from a wide range of age groups (16-50 + years) from four different cities in New Zealand were recruited initially through community networks and then through snowball sampling. A convenience sample of ten women participated in either small focus groups or were individually interviewed during Phase 2. These were conducted between September 2004 and January 2005. These women were not necessarily participants in Phase 1 and they ranged in age from 27 to 48 years and were from two cities in New Zealand. This phase focused on presenting women with the results of the Phase 1 and gaining their feedback about the project and their impressions of the accuracy of the data from Phase 1. All participants were provided with \$10.00 grocery vouchers after the interviews or focus groups. A number of years of research and consultation with the women in this community found that some form of compensation or gift for participation in research was appropriate and expected.

Data collection. Interviews and focus groups were conducted almost exclusively in the homes of the participant. Interviews were conducted independently by one of two female, multi-lingual interviewers in the language preferred by the participant (usually Somali or English). Because FGC is illegal in New Zealand, no interviews were audio-taped, and no questions were asked that could potentially reveal illegal activity. Data collected during Phase 1 included demographic information about the participant, ancestry, knowledge about the practice of FGC, knowledge and views about media and publicity relating to FGC, views about medicalization of FGC, personal experience, ideas or experience in relation to continuing FGC with their daughters, views and knowledge about educational programs and the laws. While interviewers generally followed a semi-structured interview guide, they were encouraged to allow participants to have relaxed conversations about the general topic of FGC.

Data analysis. Interviewers took diligent notes, with word-for-word quotes when possible. These were later typed into an Excel spreadsheet and were analyzed for general themes and frequency of occurrence where appropriate. The two main researchers (PG & FE) hand coded and discussed the results and interpretation at length from these Excel spreadsheets. When necessary, interviewers re-contacted participants if any comments were unclear. We present a brief summary of results from Phase 1 with a focus on the comments from Phase 2.

Results and Discussion

In contrast to Australia, the topic of FGC in New Zealand was generally either biased against the practice or 'silent' (i.e., not discussed at all), but an issue that Somali women wanted prioritized, as they felt that they were not involved in important decisions that affected them and their Somali identity. Overall, we found that the prevalence of Type I circumcision, or *Sunna* was higher in the younger population with one third reporting having had Type I in the 16-35 year age group but none with Type I in the older age groups. All the others reported Type III circumcisions. The majority of women reported positive experiences with only two women reporting negative experiences. The two women who reported negative effects reported having Type III and none of the women who had Type I reported any negative effects. For the two women who reported negative effects of their circumcision, one was supportive of Type I circumcision and the other replied, "I don't know. Not for me, but maybe for others."

Most women had never attended a FGC-related education program in New Zealand or overseas. About half thought the programs were necessary and most suggested that education programs should target health professionals about FGC and the Somali culture. The majority of women reported knowing about the laws, but that they had never been formally provided with this information, and most felt that these laws were unfair and harsh. Nearly all of the women wanted FGC to be legalized in New Zealand, but only Type I.

Participants in Phase 2 agreed with the results of Phase 1. Of interest for this paper, were a few of the general discussion comments and the implications of these for advocacy and future programs in New Zealand. For example, one woman said:

Women should have the right to practice their culture without running away from New Zealand and they should have someone they trust to discuss and talk to about cutting and what possibilities are there for their issue to be discussed in legal terms, without fear of being watched or spied on if ever you go out of the country?

Another woman felt very differently, saying,

Women should be told and educated on how circumcision has not done any of the things that they think it was performed for in the

first place and that if they don't do it to their girls, they will not be affected at all. I think it's the women who worry more than the young girls.

The comments documented in Phase 2 revealed the subtleties of discrimination and the feelings of marginalization in their new country. For example, this woman said:

. . . Western countries take children and women [refugees] more because they can brainwash them with their wrong ideas on circumcision. They will do anything to make Somalis follow Western practices but at the same time, because they cannot change how you look, they will still call you names like 'black' and 'go home you fucking black.' When people say you can't practice your culture anymore, simply, they are telling you to go away indirectly: they don't want your culture and they don't want you.

Another woman's comments reflected the distrust of authorities and the complicated nature of working through the issues of identity.

I had Sunna and if I have daughters and if they are not cut it will not be a problem unless it starts affecting their identity or they become outcasts. See, my mother had Type III; I had Sunna. I will want Sunna for my daughters if it's acceptable here, but if not, then I will not bother like those women who are saving up to take their daughters out of the country in the future. They don't know they are being spied on and whatever they do and wherever they go they will be caught because the kids will tell the teacher about their holiday and what happened. New Zealand teachers are government spies and they ask the children all the information.

Participants in Phase 2 indicated concern about the mothers of daughters who were not yet circumcised and how they were going to negotiate solutions to what they saw as a very serious problem in a hostile climate.

We should be able to cut our girls without fear of being jailed. We should be able to talk freely about our feelings without fear. Now we worry if you discuss this, your name will be recorded and even if you go out of New Zealand we fear that our daughters will be investigated whether they had been circumcised.

GENERAL DISCUSSION

In broad terms, the content of these studies address similar issues about the reproductive health of refugee women from countries where FGC is practiced. The voyeurism and arguably, the cultural imperialism raised by interest in FGC (Bridgeman & Millns, 1995; Kluge, 1996; Obermeyer, 1999; Parker, 1995; Sheldon & Wilkinson, 1998) remains a cause for the reaction of communities against programs that address the health and underlying gender inequalities assumed to be associated with FGC. However, the context of distrust experienced by many refugee women and disempowerment faced by ethnic minority groups within a dominant health and welfare sector, underscore the need for approaches that value genuine community participation.

Participatory action research combines participatory research, the goal of which is community led structural transformation, with action research, which involves an iterative process of acting on, evaluating research findings and revising research aims, thus creating a dynamic research process. The approach lends itself to working across cultural groups and particularly with disadvantaged communities to ensure that the research is ethical and non-exploitative (Khanlou & Peter, 2005; Minkler, 2004). As was evident in both studies presented here, the involvement of communities is critical in defining the research.

In the New Zealand study, CBPR enabled women in the resettling communities with the support of researcher advocates to initiate the building of an evidence base documenting their views on FGC. The New Zealand researchers have presented the work to government, agencies, community groups, as well as academics, both nationally and internationally, but are finding that influencing the quickly implemented legislation and policy, and corresponding misconceptions, is a more difficult task.

The FARREP program in Australia was developed on the basis of community consultation (Baho, 2005), but the implementation through FARREP workers found that the bicultural worker model did not take account of the ability of the workers to advocate on behalf of the clients on culturally sensitive and emotive issues. Again the CBPR approach has been critical in enabling these subtle but important issues to be identified.

Research limitations. The issue of representative sampling in hard to reach communities continues to remain a challenge in the generalizability of research findings. This is important to consider in CBPR because even at the community level, the voices represented through

advocacy are the ones that are able to obtain access to researchers and the research process. The importance of relationship building in this type of research, the use of known community members as researchers (Guerin, Abdi, & Guerin, 2003; Guerin & Elmi, 2004) and the multiple roles played by researchers also have implications for the “objectivity” of data generated (Allotey & Manderson, 2003) and these issues need to be further explored in CBPR as this area of research gains increased currency. Another limitation is the potential that women will provide socially acceptable responses. Guerin and Elmi (2004) describe the complex multiple influences that bear on the telling of personal stories or interview responses, including cultural, social and legal histories and present contexts. They also discuss how responses can be interpreted or mis-interpreted from the same influences on interviewers and researchers.

Advocacy. The researcher-as-advocate potentially plays a dual role in the CBPR method—as advocates at an individual level within communities and as contributors to addressing policy concerns (Johnston & Allotey, 2003). Advocacy on the personal level during research projects serves a number of functions, both for the researcher and for those receiving the advocacy. For the researcher, participating with women in the community as an advocate is a good way to understand the subtleties of discrimination, the pressures and hassles of day-to-day life for many refugee women, and is a way of developing trust with the women in the community. For the refugee woman, having the researcher-as-advocate helps on a practical level, but also, less obviously, it can provide a learning opportunity of how to do things in a ‘Western way.’

Advocacy at a policy level is a final way of ‘completing the process,’ in that the issues revealed through personal advocacy and research results can potentially be corrected. It is this step in the process that is often missed out by researchers, although it may not always be necessary. However, for marginalized and vulnerable women, this is a critical step in closing the loop. Tiilikainen (2002) explores this issue in her work with Somali women in Finland stressing the need for research to have a purpose and usefulness, especially for groups such as these.

Implementing CBPR research with refugee women also requires considerations in terms of ethics, funding and dissemination that often extends beyond what is required in Western-based research. Both studies described here showed how the researcher-as-advocate became an essential role when working with people who have unmet needs and issues that the researcher can, minimally, facilitate. But this researcher-as-advocate role also requires a re-thinking of the professional bound-

aries often surrounding research, such as being a neutral observer documenting information. The obligation of the researcher to assist where there is a need is often a reality in research with groups such as these (Lammers, 2005). Finally, dissemination of research results can require a greater amount of creativity, time and cost for the researcher. Some refugee women who do not read or write, even in their own language, require oral dissemination of results and those who do not read English require translated reports. For the research to have an empowering aim for the communities involved, they will need to have the results provided in appropriate ways, but may also need assistance with the next steps in ensuring that the research has positive outcomes, such as contributing to the development of programs, interventions, and policy.

NOTES

1. Female genital cutting is used here to refer to the range of cultural practices that involve varying degrees of excision and infibulation of parts of the female genitalia. 'Cutting' is used in preference to the previously used 'mutilation' to avoid an implicit value judgement. This had been a significant issue with women who participated in our study (see for instance Allotey, Manderson, & Grover, 2001). The WHO classifies four types, (Type I, II, III, and IV), but only Type I and Type III were relevant in this study. Type I is generally the most "mild" ("excision of the prepuce with or without excision of part or all of the clitoris") and is sometimes called *Sunna*, which means "tradition," in some practicing communities. Type III is perhaps the most "severe" with "excision of part or all of the external genitalia and stitching/narrowing of the vaginal opening" and is also called *infibulation* or *Pharaonic* circumcision (Guerin & Elmi, 2004).

2. 'Refugee women' is used for brevity. 'Women from refugee backgrounds' would more accurately describe the participants with whom we worked.

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4. Nigeria is obviously not in the Horn, but the women in sample were closely associated with the target community and had also undergone FGC.

5. Women who have been infibulated are often de-infibulated prior to marriage (to facilitate first intercourse) or prior to childbirth. Some women prefer to be re-sutured or re-infibulated following childbirth (Allotey, Manderson & Grover, 2001).

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