

# Discovering Voice: A Participatory Action Research Study with Nurses in Uganda

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**Abstract:** *In this article the authors present findings from a qualitative research study carried out with Ugandan nurses from September 2003 until June 2004. They highlight the process and philosophical basis of participatory action research (PAR) by reflecting on the challenges, opportunities, outcomes, and ethical issues encountered during the conduct of the research. In this study PAR fostered a climate in which nurses could engage in collective reflection on their practice, make sense of their experiences, and thereby change their understanding of their work.*

**Keywords:** *Uganda, nurses, participatory action research, international research, HIV, AIDS, photovoice*

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## Authors' note

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Participatory action research (PAR), referred to as “the enlightenment and awakening of common peoples” (Fals-Borda & Rahman, 1991, p. vi), is often associated with the Southern approach. This approach to research grew out of a concern for inequalities in class, race, age, and gender in Asia, Africa, and Latin America. Rather than merely recording observable facts, researchers using PAR have the explicit intention of collectively investigating reality to transform it (Kemmis & McTaggart, 2000). Feminist, critical, and emancipatory theories buttress the Southern tradition. Common tenets associated with the Southern PAR approach are enlightenment, empowerment, and emancipation. We will describe a PAR project that involved use of the method of photovoice to highlight the many challenges and opportunities of 6 Ugandan nurses during the provision of care to AIDS patients. The article will also give voice to the changes that emerged both professionally and personally for the nurses and Fournier. In addition, we will link the methodological rationale to PAR theorists (Kemmis & McTaggart, 2000; Reason 1994; Reason & Bradbury, 2001), emancipatory theory (Freire, 1970), and critical traditions (Habermas, 1971). The study was part of the first author’s master’s thesis conducted from September 2003 until June 2004 in Kampala, Uganda (Fournier, 2004).

### Background

Historically women in Uganda have suffered from low status within their social structure. Before colonialism the Ugandan social structure was based on a hierarchy of authority-wielding kings, chiefs, and clan heads, all of whom were, by tradition, men. Under this system power relations marginalized women and rarely allowed them rights over productive resources such as land (Nuwagaba, 2002). Ugandan women continue to experience oppression due to the social structure in their country. As most nurses are women, nurses are similarly oppressed. As Kaseje (1995) contended, “The nurse is the mirror in which is reflected the position of women throughout the ages” (p. 212).

Nursing in Uganda is not a highly valued profession; consequently, nurses experience a decreased sense of self-worth as they work within a hierarchical structure that respects higher education and experts such as physicians. Nurses spend 3 years in school and on completion receive a diploma in nursing. In addition, nurses’ opinions are not often sought by authority, and their voices remain silenced. As a result, little is known about Ugandan nurses’ experience and their role in the care of persons with AIDS (PWAs), which

further conceals the visibility of nursing in Uganda. Many researchers (Adelekan & Jolayemi, 1995; Kohi & Horrocks, 1994; Mbanya et al., 2001; Walusimbi & Okonsky, 2004) have identified the deficiencies of nurses and nursing, such as negative attitudes and lack of knowledge of nurses who care for individuals with HIV and AIDS. These studies have failed to recognize the contribution nurses are making. Although these studies are important, they further marginalize nurses’ voices by focusing on deficiencies in nurses and nursing and excluding nurses from finding solutions to these issues.

### Methodology

An essential feature of PAR is collective reflection by participants on their efforts to change the ways they work, which are often shaped by discourse, organization, power relations, and practice (McTaggart, 1992). One of the aims of PAR is to include all of the participants in the process of planning, acting, observing, and reflecting to achieve change (Grundy, 1982). PAR attends to issues directly experienced and explicitly recognized as problems by local people. Researchers go beyond proposing changes based on the findings to incorporating methods for translating the knowledge gained directly into practical decisions and/or practical courses of action.

Discovering voice is central in PAR. Reason (2004) has pointed out that “sometimes in action research what is most important is how we can help articulate voices that have been silenced” (p. 16). PAR has been defined by Reason and Bradbury (2001) as “a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes” (p. 1). According to Reason (2001), there are two objectives of PAR: to produce knowledge and action directly useful to a group of people and to empower people at a deeper level through the process of constructing and using their knowledge. In conducting research with oppressed groups, researchers using PAR set out to facilitate the empowerment of the participants through the creation of knowledge and the taking of action that leads to change on a personal and structural level (Maguire, 1996). The emphasis on the formation of partnerships in PAR and the acknowledgment that research is influenced by values are advantageous when conducting research in another culture (Mill & Ogilvie, 2003). Furthermore, PAR embraces a variety of research methods to explore local knowledge and can be used in a diverse range of settings (Cornwall & Jewkes, 1995).

## Theoretical underpinnings

The study was guided by Freire's (1970) emancipatory approach to critical education and a participatory approach to documentary photography called photovoice (Wang & Burris, 1997). Because nurses' voices have been obscured within the health care system, Freire's (1973) model of emancipatory education served as way to work with nurses to give them voice. Freire's approach involves four elements: (a) listening, (b) participatory dialogue, (c) envisioning action and change, and (d) acting (reflecting on action and action again with new insights [praxis]). This model stresses the importance of people speaking from their own experience, identifying a common theme among their individual situations, creating an analytical perspective from which to relate their situation to root causes, and developing solutions and strategies for change (Freire, 1970; Wallerstein, 1992; Wallerstein & Bernstein, 1988). By engaging in critical and liberating dialogues, individuals uncover the hidden distortions within themselves that help to maintain their oppression.

## Method

PAR is an approach that guides the research process but does not prescribe the methods; therefore, a range of methods can be used in pursuit of its transformatory aims (Seng, 1998). Some of these can be nontraditional; for instance, storytelling, sociodrama, plays and skits, puppetry, song, drawing, and painting (Reason, 1994). This diversity of data-gathering methods is one of PAR's strengths when working in international settings. Group discussions, photovoice, and interviews were the data collection methods chosen for the study. The findings from the interviews are discussed elsewhere (Fournier, in press); in this manuscript, we highlight findings from photovoice and the group discussions to highlight the PAR process.

### Photovoice

Freire (1970) noted that one means of enabling people to think critically about their community and to begin discussing the everyday social and political forces that influence their lives is the visual image. The process of creating visual images is often a source of empowerment, as are group dialogues that affirm individuals' collective struggles and insights (Wallerstein & Bernstein, 1988). In Africa it is said that the most important thing to do is to listen to people's stories because many African cultures are rooted in oral cultures and traditions. Storytelling in the current study was fa-

ilitated by an approach to documentary photograph called photovoice.

In photovoice cameras are entrusted to the hands of people to enable them to act as researchers of their communities. The method known currently as photovoice is one way of giving voice to people's experiences by recording their life conditions as they see them, which then becomes the central point for critical dialogue. By taking photographs, individuals become researchers of their lives and their communities.

### Group discussions

Meetings with the nurses served as a means for group discussion using a participatory approach. The first author and the 6 Ugandan nurses were guided by Freire's (1973) three-stage process of participatory analysis, which are described as selecting (choosing those photographs that most accurately reflected the nurses' concerns), contextualizing (telling stories about what the photographs mean), and codifying (identifying the issues, themes or theories that emerge). In the first stage, the nurses chose the photographs and, by doing so, defined the course of discussion. The second stage occurred during group discussion. A framework for telling stories (Wallerstein, 1987) was used. The acronym **SHOWeD**—What do you **See** here? What's really **Happening** here? How does this relate to **Our** lives? **Why** does this problem or strength exist? What can we **Do** about this?—was used to guide the discussion. The purpose of this "root cause" questioning was to identify the problem or the asset, critically discuss the roots of the situation, and develop strategies for changing the situation (Wang & Burris, 1997). The third stage was framed by the understanding that the participatory approach might generate many different meanings for a single image.

## The study

Nurses working in resource-poor countries face many challenges in the care they provide to individuals with HIV and AIDS. Research indicates that these challenges include stigma, lack of resources, fear of contagion, and perceived stress (Kaimenyi & Ndung'u, 1994; Mbanya et al., 1998, as cited in Mbanya et al., 2001; Mbanya et al., 2001; Mill, 2003; Simmoff, Erlen, & Lidz, 1991; Uwakwe, 2000). The main purpose of the current study was to explore the experience of Ugandan nurses in caring for individuals with HIV and AIDS and, at the same time, to include nurses in a participatory approach that would enable them to de-

fine their issues, find solutions, take action, and then reflect on the process and outcome (praxis). The aims of the study were (a) to improve the understanding of the practice of nursing by nurses, (b) to improve nurses' practice, and (c) to improve the situation in which the practice takes place. The study was carried out over a 10-month time frame and involved two trips to Uganda by Fournier. Ethical approval was obtained from the University of Alberta, Makerere University, and the Ugandan Institute for Science and Technology. We will now turn to the process whereby a small group of Ugandan nurses found their voice.

#### Sampling and recruiting

Six nurses participated in 11 group discussions that took place between September 2003 and June 2004. The first author was part of the group for the first 4 months and for the final month of the study. Participants were native Ugandans who spoke fluent English as a second language, and therefore each discussion was conducted in English. The nurses worked in pediatric, medical, cancer, and tuberculosis units in a large government hospital situated in Kampala, the capital of Uganda. Recruitment was done at a nurse manager meeting, where managers nominated individuals that fit the eligibility criteria. The criteria included being able to speak English, caring for PWAs on a regular basis (at least one patient every shift or every day), over the age of 18 years, and working in a hospital setting. Student nurses, visiting nurses from other hospitals, and nurses working in nonclinical areas were not considered. Hospital administration fully supported the study and approved nurses' time off during their working day to attend the discussion group. The study was explained, an opportunity for questions was provided, and oral and written informed consent was obtained from each participant during the first meeting. A room at a nearby guesthouse was used for each discussion group. Following each group discussion, nurses were given an honorarium to compensate them for their time.

#### Implementing photovoice

The first meeting began with introductions, which allowed the participants to become familiar with each other and the first author. Next, the goals, methods, and consent for the study were discussed, and questions were answered. The study aimed to involve the participants at every level of the study, and during the initial meeting it was emphasized that by participating in the study, nurses were co-researchers who would be in-

involved in planning and implementing the project, and analyzing the data. Fournier's intent was to build the nurses' research capacity. In an effort to enhance decision making during the first meeting, Fournier introduced the concept of photovoice and advised the group that the research process was negotiable. The nurses' first task together was to decide if using the photovoice technique was culturally appropriate and would be of value to them. Other group decisions made on the first day included length, timing, and dates of each meeting. Group norms were developed, which included values such as trust, respect, and confidentiality. Engaging the group immediately in the decision-making process allowed for ownership of the project to take root. Although Fournier came to Uganda with cameras and film, being flexible and encouraging the group to make important decisions enhanced the overall impact of the study. The nonnegotiable part of the study was the initial focus on the experience of nurses in caring for individuals with HIV and AIDS. Ideally, the topic of inquiry should come from the people concerned; however, as Baylis and Bujra (1995) have pointed out, this is rarely achieved in practice. A truly participatory process cannot be generated spontaneously, given the power relations at all levels and the deep-rooted dependency relationships of the people (Burkey, 1993). During the second half of the first meeting, the nurses decided to use the cameras and the photovoice technique.

Training in the photovoice technique included exploring ways to approach people to take their pictures. Each participant received a 35mm Polaroid camera with one roll of 24-exposure color film and batteries. The nurses loaded film and took several practice photographs during the training session. It has been recommended when using photovoice that it might be advantageous to provide a theme for what people photograph (Wang, Yi, Tao, & Carovano, 1998). Therefore, Fournier suggested that the initial theme for taking pictures would be nurses' work. The nurses were encouraged to refine or redevelop the theme. However, they decided that the theme was valuable and commented that it was too difficult to create a theme on their own so early in the research process. The inquiry started with the nurses' working knowledge of their everyday activities. The number of pictures taken and the photographs they shared were left up to each individual nurse. Developed photographs were delivered to each nurse 2 to 3 days in advance of the next group meeting to allow the nurses to choose the pictures they wished to share and begin making meaning using the storytelling process.



### Photovoice meetings

The entire photovoice process lasted 4 months, which included two photovoice meetings and four research process meetings, for a total of six meetings. After the initial meeting the participants spent the next 3 weeks photographing their responses to the initial theme. During that time, the group met once to discuss issues related to picture taking and camera usage. Many of these issues involved the mechanics of the camera, reactions from patients and colleagues, consent, and logistics of film pickup, drop-off and development. By discussing these issues, the group members assisted each other in solving problems related to the cameras and the research process in general.

During the photovoice meetings the nurses told stories about their pictures using the framework outlined by Freire (1970) and Wang and Burris (1997). As a result of taking pictures about their work and thinking about the story behind each picture, the nurses began to realize how challenging it is to be a nurse. Viewing their nursing practice from behind the camera allowed the nurses to see that they were not living up to the expectations of being a nurse. This confession sparked a discussion about the challenges of being a nurse in Uganda, and their critical consciousness began to develop. The nurses revealed that their opinions were not sought by hospital administration, which created feelings of powerlessness. As we talked further about what they could do about their challenges, participants continued to feel powerless. They felt "there's nothing we can do."

Poverty was often discussed as the reason why many of their challenges existed. As the group talked about poverty, issues related to power and money emerged. The nurses began to wonder how change could ever happen on a political level when their country was plagued by corruption. The nurses commented that if an individual was wealthy, he or she could buy anything, including laws. When looking at the big picture, the group all began to feel that many of the nurses' issues were insurmountable. Fournier recognized the feelings of powerlessness and suggested to the group that change needed to occur in small steps. She directed them to think about their nursing practice. The group analyzed each issue to find a solution that was realistic and practical. Sometimes they were unable to find a solution; nonetheless, this did not deter the nurses from suggesting changes that needed to occur within their institution.

After each photovoice meeting the nurses filled out an evaluation form that asked them to respond to four statements about what they liked/disliked about the

meeting, what they learned, and if they needed clarification about any particular part of the study. These self-reported comments served as a way to evaluate the change that was occurring with each participant. As the research study progressed, it was evident that the nurses were not only gaining research skills but were also teaching each other what they understood research to be. As well, the nurses began to teach each other informally about certain diseases and nursing interventions. In essence, the nurses were learning about research and being researchers as well as about their nursing practice.

After 4 months in Uganda, Fournier returned to Canada. The nurses continued to meet once a month on their own for the next 5 months. A leader was chosen from the group through a democratic voting process. Fournier provided telephone support to the group once a month from Canada. As well, the field supervisor, Walusimbi, was available to the groups for guidance and support. During these meetings the nurses discussed how they could take action to improve the care they provided to individuals with HIV and AIDS and to evaluate the process. The research study was designed in this manner with the aim of raising feelings of autonomy and a sense of control over the research process. It was hoped that ownership of the project would grow, which would enhance the sustainability of the group.

### Data analysis

The photovoice method provided participants with a way to critically analyze their stories. Therefore, this informal type of data analysis was ongoing. The nurses also analyzed data in the more traditional way. Fournier gave a brief discussion about the research process, including how to analyze data, at the third group meeting. The group was encouraged to be flexible and adapt the analysis plan as needed. One meeting was spent analyzing the data from the nurses' stories. The nurses were asked to review all of the stories on their own, write down common themes, and come back to the entire group with their analysis. They nominated a group leader to facilitate their discussion. The categories were recorded on sticky notes and organized into broader themes as the group progressed through the data analysis process. Many Ugandan nurses believed that only highly educated people can do research. However, working through this process, the group was able to demystify the research process. Data analysis also continued when Fournier returned to Canada. An additional 2 months was spent by the first three authors analyzing the data using techniques described by Miles and Huberman (1994).

### Rigor

Summaries were written immediately after each discussion group and were reviewed with the participants for validation, which often included correction and comment. The process of ensuring that the interpretation and meaning were accurately acknowledged and validated local beliefs, thereby enhancing rigor (Mill & Ogilvie, 2003). Cycles of reflection and action with participants mean that validation of the research process and its findings are representative of rigor. Field notes were also taken after each meeting to record the researcher's thoughts and feelings about the process as well as to document the process of creating an audit trail. McNiff (1994) believes that rigor in action research is concerned with personal and interpersonal issues. A discussion of Fournier's personal and interpersonal issues that arose during the study is outlined in the next section.

### Reflections

In the remainder of this article Fournier will highlight the challenges, opportunities, outcomes, and ethical issues that became apparent during the conduct of international research using PAR. As well, reflections on future research will be explored.

### Cultural adaptation

Conducting international health research poses many challenges, especially when in unfamiliar settings. Mill and Ogilvie (2003) have suggested that acknowledgment of one's own inadequacies in new and culturally different environments is needed to conduct culturally competent scholarship. This phenomenon is referred to as cultural adaptation, which describes the experience of individuals when they become immersed in a culture that is different from their own (Oberg, 1958). Cultural adaptation has four phases: honeymoon, crisis (culture shock), recovery, and adjustment. The ideal situation occurs when a person moves through these phases, fully adapts, and becomes well adjusted in the other culture.

Fournier entered the crisis phase soon after arriving in Uganda. The initial crisis occurred when Fournier discovered that her key contact would be out of the country for 2 weeks. Therefore, gaining entry was slow, and it took longer than anticipated to establish the nurses' group. As well, it was a slow process to obtain ethical permission at the national, university, and the hospital levels. As the research project progressed and Fournier moved through the phases of cultural adaptation, she was exposed to the extreme poverty and

suffering of the Ugandan people. Fournier did not anticipate how deeply she would be drawn into the nurses' stories of patient suffering and death. A reflective diary illuminated the sadness she felt hearing the stories from the nurses. On returning to Canada, Fournier discovered that she was experiencing compassion fatigue, which is the consequence of caring about and for people who have experienced extremely stressful events (Figley, 1995). Fournier was at elevated risk of developing compassion fatigue because her sense of control over her life had been stripped away by living and working in another culture.

### Power issues

Challenges also emerged related to conducting a PAR study. A researcher facilitating a PAR study must be flexible, willing to give up the idea of control and adapt the approach as needed. If PAR is to evolve as it should, power and control should remain with participants. Therefore, a dilemma can potentially occur when the researcher is held accountable for producing a product such as a thesis at the end of the study. Expectations of time, funding, and producing immediate and practical research findings might result in the researcher's controlling the research process with a predetermined agenda. Consequently, true collaboration cannot be obtained, and the interests of the powerful (the researcher) might take precedence over those of the participants. Therefore, Fournier needed to be cautious about the types of expectations from all involved in the research.

In the current study tension surfaced for her regarding the disparate, yet valid, reasons for carrying out the research: for academic qualification or for altruistic ends. Fournier began to question her role as a researcher. Questions such as What did I really hope to accomplish? and Who was I to think that by using this method and acting as a change agent that I would influence these nurses to begin to make changes at either an individual, organizational, community or government level? began to surface for Fournier. Reflecting on these questions and issues while in Uganda heightened Fournier's awareness and sensitivity to potential power issues between her and the participants. In a sense, she began a conscientization process. Freire (1996) stated,

A person who has reached conscientization has a different understanding of history and of his or her role in it. He or she will refuse to become stagnant, but will move and mobilize to change the world. He or she knows that it is possible to change the world, but impossible without the

mobilization of the dominated. He or she knows very well that victory over misery and hunger is a political struggle for the deep transformation of society's structures. (p. 106)

During the study Fournier also became aware of many other challenges. Being an "outsider" proved to be a challenge. Understanding of the local setting and issues developed slowly as the study unfolded. As a result, Fournier often felt ineffective when facilitating discussions. She was also conscious of the decisions she made in isolation and how they influenced the direction of the study. Because the time with the nurses was relatively short for a PAR study, Fournier made a decision to focus discussions on their nursing practice rather than the larger power structures that influenced their lives. Evaluating the impact of the study after only 10 months is neither feasible nor appropriate. Blacker (1998) warned that "one who aspires to articulate emancipation must acquire a certain theoretical modesty" (p. 357). As a result of time and theoretical modesty, Fournier was cautious about claiming any significant effect of the study.

#### Saying goodbye

Fournier had difficulty saying farewell to the nurses in the discussion group. There comes a time in a PAR study when researchers are faced with saying goodbye. How does one say goodbye to a group when so much time was spent sharing lives with one another? More attention needs to be placed on the process of saying goodbye to allow psychological preparation for this exit. In this study Fournier was compelled to leave Uganda because of academic constraints. When should the academic exit? How does one determine the "end" of a project? When the funding runs out? When the goals have been achieved? Never? Furthermore, if the study is truly collaborative with emancipatory aims, does the researcher have an obligation to ensure that sustainability is built into the project? Should sustainability be a goal in itself? Researchers using PAR need to examine their deeply and often hidden beliefs about the goals of their project before the project begins. An outside facilitator might not be able to facilitate true emancipation of any group to which they do not culturally belong. Therefore, in this study sustainability was built into the project to provide the opportunity for emancipation to be nurtured and grow.

#### Opportunities

Many opportunities emerged that facilitated change in the study and had implications for its success. The op-

portunity to include decision makers with power was a positive side effect of the research study. The local supervisor, Walusimbi, was a key person who positively influenced the project and acted as an internal change agent. As a principal nursing officer at the study site she was in a key position to facilitate sustainable change at an organizational level. In 2001 Walusimbi carried out a survey in Uganda for her master of nursing thesis. She worked with nurses and midwives at her own hospital to determine their knowledge and attitudes toward the care of patients with HIV and AIDS. Walusimbi found significant knowledge gaps in relation to transmission, agent, and immunology. Walusimbi's research provided her with insider information and a deep understanding of the local issues related to nurses and HIV. She attended two of the group discussions with the nurses, which served two purposes. First she was able to help the group think about practical solutions that would improve their practice, and second, she was able to provide encouragement and show the group members they were fully supported by hospital administrators to make change. During the final phase of the study Walusimbi was promoted to the most senior position in the hospital, assistant commissioner of nursing. Walusimbi's promotion is yet another opportunity that will ensure that change will occur and be sustained within the hospital.

#### Ethical issues

Mill and Ogilvie (2002) have argued that researchers in international settings must ensure that their work is ethically sound by meeting international standards for protection of human participants while continuing to examine cross-cultural ethical issues. The researcher must be willing to discuss difficult ethical issues. Obtaining local ethical approval became a potential dilemma. National and institutional (study site) approval had been granted; however, once in Uganda, Fournier discovered that approval was also needed from Makerere University. After many visits to the appropriate faculty she discovered that the process could take up to 3 months. With this information in hand Fournier spoke with one of her local contacts and was advised to continue on with the research as planned. This direction went against everything she knew and understood about ethics. How to proceed? Fournier began to ask all of her local contacts about this dilemma. Each person stated that the university approval was not needed immediately, but the institutional approval was required to begin. Fournier used this culturally relevant advice to carry on with the study while waiting for ethical approval from the university.

During one of the group discussions the nurses raised an issue regarding informed consent with patients. The nurse was to explain the study to the patient by reading the consent form and then have the patient sign it if he or she agreed to have his or her picture taken. However, the consent form stated that they would be involved in a study about HIV. As many patients do not know their status or do not want to know their status, having HIV on the consent form deterred some from participating. The nurses began to improvise, and some would conceal the word *HIV* with their thumb when asking the patient to sign or would leave out the part about being in an HIV study, as many patients were illiterate. When the nurses reported at the second discussion group how they were improvising, a discussion began and the group decided that the word HIV needed to be changed to *immunosuppression*, a word that did not have stigma associated with it. The group members commented that they felt more comfortable explaining to their patients that it was a study about immunosuppression rather than about HIV. One group member stated,

We can't tell patients it's an HIV study because they will wonder why we want to take their picture. If they don't know their status they will begin to think they have HIV. Many patients do not want to know.

In addition to the stigma surrounding the diagnosis of HIV, another issue surfaced related to informed consent. Written consent when people are illiterate and consent with disempowered people who are either literate or illiterate can be challenging. How does the process of obtaining informed consent differ with illiterate, disempowered individuals?

Informed consent became an issue again when the nurses mentioned that patients would not agree to have their picture taken if their neighbor had refused, but if their neighbor had agreed, they would also agree. This need to behave in a socially acceptable manner affects the patient's understanding of the research study. This phenomenon is known as social desirability and occurs when patients intentionally or unintentionally modify their behavior to conform to expected behavior (Hays & Ware, 1986). Social desirability can occur between individuals and their peer groups or between the researcher and participants (Hays & Ware, 1986). In the group this issue was discussed, but action was not taken to minimize the risk of social desirability.

### Individual, practice, and institutional changes

The study generated many changes at the individual and institutional levels. Specifically, the changes that occurred within each study participant, within their nursing practice, and within their work setting will be illustrated. As well, the action taken collectively by the group to solve a practice issue, that is, nurses' lack of knowledge about antiretrovirals (ARVs), will be discussed. Finally, the change that occurred within the first author will be highlighted.

The first step in action research turns out to be central: the formation of a communicative space . . . and to create this space in a way that will permit people to achieve mutual understanding and consensus about what to do, in the knowledge that the legitimacy of any conclusions and decisions reached by participants will be proportional to the degree of authentic engagement of those concerned. (Kemmis, 2001, p. 100)

Reason (2004) has argued that this formation of communicative space is in itself a form of action.

It may well be that the most important thing we can try to do in certain situations is to open, develop, maintain, and encourage new and better forms of communication and dialogue. (p. 20)

In the current study a group of strangers converged and shared their experiences and understandings through storytelling. They discovered that they shared many similar issues. The research process enabled these six strangers to develop a relationship with one another that deepened their sense of social support and propelled them into action to improve their nursing practice and the setting in which their practice took place. The group work permitted the nurses to support each other in exploring their views within their own "framework for understanding the world" (Kitzinger, 1994, p. 108). They discovered that they shared many similar issues, concerns, and hopes. Over time the group of nurses became more willing to share their lives with one another. A community of trust was built through shared experiences, and the nurses gained confidence in their nursing knowledge and skills. Participation in the research had more meaning for the group members because their lives were now intertwined



with one another. The nurses involved in this project found the experience of participating in the research process empowering.

#### Individual change

Fournier compiled the nurses' self reported comments, which were collected throughout the research process. The following is their account of their experience in participating in the PAR study. Pseudonyms have not been used as the nurses felt it was important to liberate their voice from the silence.

*Emoit.* During the last 10 months, I have learned that I can influence others to make change, especially within my institution and the community at large. However, it is difficult because you have to involve many people and it is time consuming. I have gained more confidence in my nursing practice, and I also recognized my weak areas, such as counseling skills. My attitude has changed towards individuals with HIV and AIDS, as I no longer stigmatize people. I have also gained knowledge about HIV and TB illness.

*Josephine.* I used to fear to touch HIV and AIDS patients, but now the fear has gone. Stigmatizing is not there, and I now see them as any other patient in the ward. I am freer with individuals with HIV and AIDS and listen to their problems and advise them accordingly. I did not know how to solve our challenges before the study; however, now I feel more confident to solve our issues. The study was an "eye opener" in helping me realize the gap in the care of these patients. I am now empowered with the knowledge of problem solving, new knowledge of HIV, communication skills, confidence, and how to do research. I hope we continue with more.

*Flavia.* The storytelling process increased my awareness about patients with HIV. Working together as a group made me learn more about my colleagues and the challenges they encounter on their wards. We were able to solve some of the challenges, which have changed my role as a nurse. Working on the research proposal has been eye opening, though time consuming but rewarding in the long run. I am more patient with patients with AIDS as they have a lot of psychological torture. I feel more devoted to nursing.

*Sarah.* Photovoice is a good method of data collection since it gives what is on the ground and not just in someone's imagination. As a group we shared our experiences and were exposed to different opinions. We

respected our differences, and maximum cooperation was the outcome. I have been able to recognize my strengths and weaknesses and increased my confidence as a nurse by expressing my views about caring for patients with HIV. My knowledge of HIV and TB has increased. I realized that making change is not an easy process as it may meet resistance but can be rewarding. We as a group can influence change. I learned practical skills of how to conduct research and to write a proposal.

*Aisha.* I learned how to care for patients with AIDS in the research group. I am more sympathetic and empathic towards these patients than I was before the study. I realized that I need further training and education about ARVs and counseling skills. However, my knowledge has increased about many diseases such as HIV and TB. I learned practical nursing skills such as how to give TB medications using the DOTS system.

*Janet.* During the study I realized the problems of nurses and patients, is that HIV and AIDS is a disease of stigma. I have learned that it is good for nurses to discuss their nursing experiences in a group as it helps to solve problems. By contributing to the research study I have gained confidence and skills in proposal writing and the research process. I have realized that the process of making change is time consuming but rewarding because the nurse gains confidence and the patients are satisfied with the services. I have more interest to study so that I can acquire further knowledge and skills as how to care well for patients. I have decided to go back to school to obtain my degree in nursing.

Presenting research findings also opened up a new communicative space where one did not exist. This process gave nurses a voice. PAR projects can open space for communication and dialogue, creating space for muted and silenced voices (McArdle, 2002) or where there are no forums for democratic dialogue (Gustavsen, 2001). After hearing the findings presentation, a nurse in the audience stated, "I feel like I have just awoken from a deep sleep as a nurse at our hospital." This awareness demonstrated a consciousness-raising moment for this particular nurse. Another nurse commented, "On a daily basis we keep reducing ourselves, devaluing ourselves and because of this nurses do not believe in themselves. So that is one reason why nurses voices are invisible." Central to PAR is the concept of hegemony (Hagey, 1997). Hagey believes that it is through awareness that individuals contribute to their own oppression that an empowerment

process can begin. Following a subsequent presentation, a discussion group participant stated,

We have taken for granted these challenges and have continued to work by improvising. You helped us to see these things we always do in a new light. We can refuse to use IV tubing and then they will have to supply us with the proper oxygen tubing.

During the dissemination of the findings with nurses at Mulago Hospital, Walusimbi took the opportunity to introduce her new position as the assistant commissioner of nursing and to advise the nurses in the audience that change based on the findings would occur. This discussion encouraged the nurses in the audience to speak freely about other challenges they were experiencing. Walusimbi was responsive to the issues raised and suggested that she would personally look into these challenges. A positive energy was felt in the room during this discussion. The energy was manifested by the realization that change was possible. This, in turn, fostered a sense of empowerment among the 50 nurses who attended the presentation. Reason (1994) believes that there exists potential for the empowerment of people through the reflective processes of constructing and reconstructing meaning through retelling of participants' experiences and knowledge. Through the presentation of the findings, empowerment stretched beyond the participants and touched the audience.

#### Nursing practice change

While Fournier was in Canada, the nurses took action on their identified challenge of not having enough knowledge about ARVs. It is interesting that they decided to solve this issue by developing a research proposal. This can be seen as an indicator that research capacity had been built. The nurses were very resourceful and used a proposal from a nongovernment organization as a guide to develop their own proposal. The nurses in the group had never been involved in writing a research proposal. They met once a month, bringing together their ideas and drafts of the proposal. At the final meeting their proposal was complete and given to Walusimbi for her comments and corrections. Drafting a proposal was fully supported by Walusimbi.

#### Institutional change

There was also evidence of change within the hospital as a direct result of group discussions and nurses taking on a leadership role to address an ethical dilemma.

During the group meetings it became evident that the nurses were facing many ethical issues that had remained hidden until the nurses began to discuss their practice issues in the group. For instance, Emoito commented to the group that on his ward patients' files were kept at the bedside. A lively discussion broke out about how patient confidentiality could not be maintained with this practice. Emoito had already addressed this issue with his supervisor but had been told that it was the doctors who insisted that this was the way it had always been done and would continue this way for doctors' convenience. He asked, "I know it's wrong but what can I do when my manager tells me it's a doctor's order?"

Once Emoito related this practice, the nurses began to share with him how they kept the files on their nursing units. Fournier facilitated the discussion by asking the nurses about the ethical code for nurses in Uganda. She asked if they viewed this as an ethical issue. The ethical code for nurses and doctors was discussed. In the end, Emoito decided to approach the next person in authority to explain this issue. Two meetings later, Emoito shared with the group the outcome of his action. The files were moved and were now being kept at the nursing station. On hearing this positive feedback, the nurses broke out into applause. It was truly an empowering experience for all the participants in the group.

#### Collective action

In PAR knowledge is created through participatory processes in the context of human relationships (Maguire, 1987). Knowledge that is constructed with participants reflects their own experiences, encouraging them to use their own language and hear their own voices in understanding what is happening to them and around them. This obtained knowledge becomes a source of power and builds group ownership of information as people move from being objects to acting as subjects of their own research process (Maguire, 1987). Taking ownership of the project was evident in group members, who initiated the research agenda and subsequent action. As co-researchers the nurses were involved in all phases of the research process, which helped to develop a sense of ownership, with the aim of raising feelings of autonomy and a sense of control. Carr and Kemmis (1986) have argued that these feelings of autonomy and control in the long term could improve the position of collectives of individuals in society and therefore enhance their lives. Ownership of the project occurs if each participant feels that he or she has an equal share of the power base (Stringer, 1996). The participants made decisions about which issues were important to them and facilitated their participa-

tion and empowerment. Authority, control, and responsibility for the study were spread across all participants. Most of the practical applications of the research framework were directed by the nurses. This authority established their power within the research context. Consensus was evident by the participants' discussing decisions and ensuring that everyone was heard and at the same time being willing and able to challenge their colleagues.

#### Researcher conscientization

What about the change that occurred within Fournier? In a PAR study, the researcher is also influenced by the research process and changes as a result of being part of this type of study. Fournier learned many things about Ugandan nurses and Ugandan culture and about herself. She learned how to conduct a PAR study in an international setting and became aware that issues at the local level are often a reflection of broader issues at the global level. Fournier gained a deep appreciation for the many structural challenges that nurses face in their daily care of individuals with HIV and AIDS. With this greater appreciation came a motivation to take action at the global level. Throughout this study Fournier's passion to make a difference underpinned her motives and actions. This intense emotional drive enabled her to continue her work amidst the many personal challenges faced conducting research in an international setting. Fournier's connection to the research deepened through her own conscientization process, which was more likely to occur in a PAR study. This conscientization process caused what Lincoln (1997) referred to as "yearning" or a "a powerful, heartfelt driving impulse toward some world which is only dimly glimpsed, but profoundly desired" (p. 21). The desire to live in a world where everything is possible has created energy for Fournier that drives all of her actions. She has gained critical knowledge and skills during this research study that will equip her with the basics she needs to advance democratic principles based on social justice and equity.

Weiler (1988) believes that changing people's consciousness is not enough: Real relationships and forms of power must be changed. As Freire (1970) pointed out, it is not enough for the oppressed to recognize their own oppression. Although it is true that awareness and consideration of new possibilities is not complete transformation or emancipation, it is the place where consciousness raising must begin. The nurses who participated in the study have become aware of influences and constraints that affect their nursing practice. Knowledge has been generated in relation to the roles of nurses in caring for individuals with HIV and AIDS.

Evidence from the current study suggests that group members, by reflecting on their experiences as nurses and as participants in the study, were able to change their current understanding of their practice and to make sense of their experiences, collectively, as nurses. This new understanding created a deeper self-awareness, which also was empowering. Fournier also felt empowered in conducting PAR and successfully facilitating change.

#### Reflections on future research

Working from an emancipatory perspective while experiencing culture shock, compassion fatigue, and conscientization was challenging for the first author. In emancipatory action research the focus is clearly broad, and the responsibility for the process lies with the group. As Carr and Kemmis (1986) have pointed out, emancipatory action research leads the group involved to "take responsibility for its own emancipation from the dictates of irrationality, injustice, alienation and unfulfillment" (p. 30). The group looks at the policies and practices typical of the institution in which it works, and the groups own responsibility in maintaining these. The group investigates whether the culture in which it works is just and equitable, and tries to determine how to improve the culture if deficiencies are noted. In the spirit of emancipatory research these goals were not explicitly achieved. Perhaps this could be the next phase of the PAR process with the participants. Continuing the empowerment process might have required the nurses to be more involved in changing policy at a government level. This would require training regarding policy change. Also, the original group of nurses could invite others to join their group so that research capacity and professional practice would be an ongoing process thereby enhancing the empowerment potential of each nurse and the group. In discussing ways of making change with individuals and communities, McTaggart (1995) suggested that "it is possible (and sensible) to start small, because social life is manifold—not complex or made up of separate bits—to change one aspect inevitably means changing others" (p. 35). In retrospect, Fournier could have spent more time encouraging the nurses to share their views and experiences of doing research to help them feel more relaxed with the idea of research.

#### Conclusion

In this study we used photovoice to explore the experience of nurses in caring for individuals with HIV and AIDS. Through the opening of a space for new conversations to take place about their experiences as nurses,



enlightenment took root. This enabled empowerment to grow and the idea of emancipation to be nurtured by the group. Fournier's role in this process resembles the work of a gardener. She nurtured already existent sprouting thoughts and dreams and at the same time facilitated others to find their green thumb to continue the process of growth, regeneration, and transformation. It might be some years before this PAR process reaches full maturity. As Fournier's thesis came nearer to completion, the nurses were transforming into a new group. The purpose of the group might change, what is important to the group may change, and the relationships of the participants may change. PAR as a continuous process does not end with the completion of one project. When successful, it lives on in each individual (Park, 1989). Street (1995) has proposed that actions create changes for more people than the participants because PAR is life altering for all concerned. The idea of having voice and of giving voice is central to enlightenment, empowerment, and emancipation.

Fournier's passion to make a difference comes from a place where people's voices have value and should be heard. Our role as researchers is to ensure that people speak and are heard by their peers and policy makers. Pearpoint (1989) suggested,

We all have the power to listen to "voices" that are seldom heard. If we choose to make the time, to learn, to listen and to struggle with the pain and frustration that disempowered people feel, we will see new visions, feel new energy and find hope in our future. (p. 503)

According to Canadian political and cultural theorist Kingwell (2000), "The world we want always lies beyond our grasp but we can not give up wanting it" (p. xxii). PAR is a way to move toward a world based on justice. As researchers living the philosophy of PAR we become the change we want to see in the world. Living this philosophy has the potential to make the world a better place to live.

### Note

1. The Southern tradition refers to the Southern hemisphere and focuses on empowering marginalized groups. The Northern approach, referring to the Northern hemisphere, uses a problem-solving approach in organizational change (Brown, 1993).

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